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Experiences at the End of Life In Nursing Homes

It has become the task of nurses and caregivers to make the end, the parting from the physical world of human beings, as pleasant as possible, for others as well as ourselves. During the last century, the manner of parting for old people has changed drastically.¹ Rather than being cared for within the family context, many elderly people now end their lives in nursing homes or hospitals. This institutionalization of the dying process means that medical staff have become the managers of how the elderly die² in a culture where death is often viewed as a mechanical process rather than a spiritually subjective journey.³ But end-of-life experiences are being reported by doctors and nurses.⁴⁻⁸ According to caregivers, these experiences are profoundly meaningful for the dying and help to ease the passage of death.

Existing reports of anomalous experiences by doctors and nurses⁴⁻⁸ consist of visions, “coincidences,” and other phenomena. Visions involve the appearance of dead relatives who have

come to help patients and residents through the dying process, providing comfort to them and their relatives. Coincidences are experienced by someone emotionally close to the dying person but physically distant who is somehow aware of their moment of death, or says the person “visited.”

These “visions” can occur in waking or dreaming states. Others describe seeing a light, associated with a feeling of compassion and love, surrounding the dying person. Both the imperative need to reconcile with one’s life and the sometimes sudden lucidity from coma or dementia sufficient to say goodbye are also regarded as significant experiences. Nevertheless, the experiences of elderly patients are often diagnosed as being caused by confusion, dementia, or drug-induced hallucinations. This is confirmed by an Open University study of spiritual support for the elderly. Other than in nursing homes with a religious affiliation, few managers explicitly acknowledged the existential pain of the elderly, although they recognized that



residents could be frightened of dying.⁹

The resounding message from many older people facing death is that they want to be treated as individual human beings, with emotions, feelings and spiritual needs, not as a machine that needs “fixing.” In this context, questions arise about whether anomalous experiences are not just the province of those who die “before their time,”^{4–8} but are also a profound part of the dying process irrespective of age or medical diagnosis.

In addition, “the sanitization of death,” as Dr. Sherwin Nuland calls it,¹⁰ has changed how relatives perceive the end of life. Rather than the traditional family wake in the front room where friends and family could gather around the body before burial, bodies are usually kept in funeral homes. From the deathbed to the grave, undertakers assume all the responsibility for handling the body. Society has therefore not only lost many traditional spiritually focused deathbed rituals and ceremonies, but relatives are often psychologically and emotionally removed from being receptive to the anomalous experiences of the dying or are afraid to speak about them for fear of being labeled “crazy.”¹⁰

The Interviews

Between 2014 and 2016, I conducted interviews with nurses and care assistants about the end-of life experiences of the elderly as a follow-up to a questionnaire survey I conducted. A total of 450 questionnaires were sent to the nurses of elderly residents in a Buenos Aires nursing home. The nurse participants were recruited with the cooperation of the Nursing Department of each (the Principal Nursing Officers). They gave me permission to administer the set of questionnaires.¹¹ Some care assistants were also recruited from courses and seminars through nursing schools and health centers seminars, where the questionnaires were completed in a classroom setting with the permission of their teachers and directors.

After they completed the questionnaire, those who agreed to an interview were invited to take part in a tape-recorded session that lasted between 1 and 1½ hours. The interviewees were encouraged to talk freely about their experiences with dying residents. These interviews were transcribed verbatim to enable examination of how anomalous experiences may have affected the interviewee personally and professionally and to explore further training needs in order to enhance best practice for end-of-life care. Potential interviewees were approached through the management team. Ten responded, five of whom were trained nurses, including the matron and the undermatron, and five were care assistants, including a care assistant supervisor.

Hallucinations or Anomalous Experience?

All the interviewees agreed that listening to the manner in which patients spoke provided valuable information. One interviewee believed that when residents reported strange things, it was a signal. “When they say that they’re seeing things, I feel they will go soon. So they need understanding and support.”

Three interviewees talked about the difficulties of distinguishing between anomalous experiences and drug-induced hallucinations, dementia, and confusion. Said one care assistant: “It’s hard to tell really because I don’t know if the medication may cause them to hallucinate or make them confused. I know some drugs may cause hallucinations.”

Another interviewee said that anomalous experiences and hallucinations might be the same thing. She cited an example of an elderly woman whose husband had died recently. The wife became ill, and after returning to the nursing home from hospital, she began calling out to her dead husband. “She was always saying her husband’s name, ‘Bob I am coming,’ whenever she talked about her husband. I think sometimes it’s because they have dementia, and that’s the reason they have hallucinations like that.”

Another nurse concluded that anomalous experiences were often a comfort to residents, commenting, “There’s no fear at all.” The interviewees explicitly cited examples where anomalous experiences provided great comfort to the dying in contrast to the anxiety caused by drug-induced hallucinations.

Seeing Children

Four interviewees reported residents seeing apparitions of children shortly before they died. One interviewee spoke about a resident who had been confined to bed because her condition was deteriorating. Apart from anti-inflammatory drugs for rheumatoid arthritis, the resident was not taking medication. “She was dying and she had brightened up considerably. She said she had seen children playing in her room, two or three of them. She didn’t say if they were male or female, she just said children . . . she was very clear about it.” The resident had not been frightened even though she had seen the children during the night. It was a comfort to her. She died a couple of days later.

One care assistant spoke of a resident seeing children going past the window of a room that was on the second floor of the nursing home; it was impossible for children to be outside the second floor. Again, the children appeared to provide comfort to the elderly person. The resident died a few weeks later.

Another care assistant described how a resident saw a group of children at the end of his bed. He could also hear old-fashioned playground music playing and was reassured by it. “I think he was seeing the children from when he was at school. It was in the war and [he told me] they had little black shorts on. He said, ‘They’re waiting for me. I can see them now, they are calling for me.’” At the time, even though the caregiver had participated in an end-of-life training program, she was concerned with how to deal with the situation. She wanted to go and fetch help but realized the resident did not want her to leave. She understood it was more important to stay with the resident, irrespective of feeling out of her depth

Another interviewee spoke of a female resident seeing a little girl dressed in a yellow cotton dress with flowers. The resident died a couple of days later. (Incidentally, this interviewee also said that her own mother and father-in-law both spoke of seeing children shortly before each died.)

Change of Room Temperature

Four interviewees spoke about experiencing a change in room temperature or atmosphere at the time of death, or shortly after. One said, “Sometimes the room is freezing. At other times it is really, really hot. Opening a window often helps. You feel a calm going out of the window.”

One care assistant spoke of a physical sensation after one resident died. “I went ever so warm [??] and it was nice.” Another interviewee experienced the same warmth, but described it as like a feeling when you give love to someone, there’s that kind of feeling of warmth and peace . . . I feel as though I am connected to it . . . Sometimes it’s there when you’re laying them out, there’s a feeling that you are doing something for them. When I go off to do other things and come back, it’s not there so therefore it may be momentary.”

Dreams

Eight of the nursing home’s interviewees also spoke about the power and impact that dreams can have to prepare for death. A nurse spoke of a resident whose dream, she believed, indicated his impending death. “He said he saw animals he had owned during his life that were obviously dead. He felt they were waiting for him.” Greatly comforted, the resident died within the week.

Another nurse spoke of a relative being awoken by a dream in the middle of the night telling that her mother was dying. The relative arrived at the nursing home at 4 o’clock in the morning and sat beside her mother until she died at 7 o’clock.

Without the dream, the relative would not have been present at her mother’s death.

It could be argued that dreams also act as a bridge between the care giver and the cared for. An example was given by one interviewee concerning a resident she had grown close to. “In the dream, he was sitting in a chair facing me. He asked me if I was coming to his funeral to give him flowers if he died.” The interviewee told a colleague about the dream and said she believed the resident would die shortly. But because it was a dream, the colleague did not believe her. Yet, the resident did indeed die the next week.

One nurse described a strange waking dream concerning a resident of whom she had grown very fond. The resident’s beloved husband had died a year previously. The resident’s health had subsequently deteriorated, and she was no longer able to walk. The nurse had gone home after tending to the resident during her dying process. While taking a bath, the nurse had an image of the resident standing with her dead husband holding his arm with a wonderful smile on her face, “She was saying to me, ‘I can walk now!’ It was odd, but very comforting.”

Animals anticipate death

A frequent experience reported by caregivers and nurses in nursing homes are the behaviors of some animals, such as birds and cats, in the vicinity of a dying patient. Animals seem to sense certain information before humans do. Rupert Sheldrake,¹² who analyzed 2,500 cases of unexplained behavior in animals, distinguishes three main types: telepathy, sense of direction (e.g., animals that can return home from places many miles away), and premonitions (e.g., animals that have anticipated a natural disaster and have fled the threatened area). I also found testimony from family members of hospitalized patients whose dogs barked and were very restless close to the moment of death of the resident.

One nurse told of a cat that was prowling in the hospital park and walking around the residents’ room windows: “Some patients fed him through the windows. One night, the cat was very insistent to enter the room of Mary, a tracheostomized patient, and although I threw it out, the cat insisted, again and again, to enter through the window. The next day, I found out that the patient had cardio-respiratory arrest and died . . . Even in some rooms, when the cat visited a room, you had to see where it was because it went right to the service where the most serious patients, some of them which are terminals. The cat had the habit of circling around some patient, and this indicated that someone was going to die. For example, Ruda, a patient who had had a car accident and had been in a vegetative state; the cat was hanging around the window of her room and the patient, a few minutes later, passed away.”

A nursing home nurse in Buenos Aires recalled: “It was summer and a beautiful, bright white dove perched on the bedside of an elderly patient. My companion and I watched in stupor as the dove remained for a long time asleep, next to the old woman, who closed her eyes, and minutes later passed away. This event surprised us a lot. Immediately afterwards, we





experienced a scent of roses, very intense, that disappeared in the same way as the strange and beautiful dove arrived.”

A more persuasive story concerned an account of a resident’s cat, which the interviewee found very significant. The cat had come into the nursing home with the resident and always slept on the resident’s bed. The interviewee was present when the cat came into the room at the moment the resident died. “Its hackles went up. It shrieked, and it just sped around the room a couple of times and then it shot out of the room as though it didn’t want to be there.” The interviewee is convinced the cat sensed the “spirits had finally come for the resident.” Of interest is a recent article published in *The New England Journal of Medicine*²⁷ that reports the antics of Oscar the cat. Dr. David Dosa, a geriatrician at Rhode Island Hospital, claimed that Oscar has an uncanny ability to predict when elderly residents were about to die.

Lucid Moments¹³

Seven interviewees reported residents who had dementia and confusion becoming lucid in the last few days of life. This is an experience that Karlis Osis and Erlendur Haraldsson drew attention to in their 1977 study.⁴ One nursing home interviewee explained: “It happens quite often... they just seem to lighten [awaken?] and are able to acknowledge who is with them and sometimes say things.” The interviewee continued with her own personal story: “It happened with my mother. She had dementia and didn’t really know any of us before the end. But for the last 24 hours she certainly did... just before she died she said to me ‘I love you.’”

Another nurse said, “Very often, before the person dies, they will rally round and can open their eyes and have a conversation which they haven’t been able to do for the past couple of days. It’s a little spooky sometimes if somebody has been practically unconscious. But then they will just open their eyes and say a few words and say hello to the person who is there. I wouldn’t say alert, but certainly peaceful.”

Other interviewees reported how residents who were physically incapacitated suddenly were able to pull themselves up and or do something that they normally would not have the strength to perform. Several of the interviewees told the remarkable story of a resident who had severe spinal fusion to the extent that the resident could only look at the floor. [That means she was face down?] “A couple of days before she died,” said one of the interviewees, “her head was up and she could look out of the window. She [the resident] said ‘Oh I can see the house over there.’” The nurses were so delighted, they wheeled her to the window so she could enjoy the view for the first time in years. She died shortly after. One of the interviewees described this phenomenon as a suddenly burst of energy, enabling the resident to communicate to those present for the last time.

Need for Reconciliation

Five interviewees found a resident’s need to right past wrongs as anomalous. One resident became increasingly agitated about her estrangement from her daughter. “She wanted to sort everything out with her daughter. She just wanted to get everything settled,” said an interviewee. The nursing staff arranged for the daughter to visit the resident. “They were fine, and then she passed away,” the interviewee concluded.

Another interviewee told a moving story about an elderly resident who had been abused as a child. The resident was a bitter woman who had never married, and her whole life had been colored by what had happened to her. “Only before she died did she tell one of the caregiver what had happened. Nobody had ever been there for her to resolve it. Once she told the caregiver, who she particularly liked, she was fine. Everything fell into place then why she’d been so bitter.” Commented an interviewee: “It’s mostly the people who have a fear that’s not resolved who don’t seem to have a good death. But you don’t often see people when they die look anxious or anything. Their faces relax and they almost look like they are smiling.”

Physical phenomena

All the interviewees also spoke about what might be described as paranormal incidents, such as lights going on and off in the room of a resident who had recently died. Others reported an episode involving a bell in the room of a resident who had died. This phenomenon was also reported by [First name?] O’Connor.⁸ The bell mysteriously continued to ring on the day of the resident’s funeral, even though no one else was in the room. “Well,” responded one interviewee to her colleagues at the time, “he’s saying goodbye then, isn’t he?”

One interviewee remarked she had been pushed on the shoulder after she had entered the room of a resident who had died. “I remember I thought I had tripped and it’s just like a sensation coming from my shoulder. A lot of things happen at night when residents are dying.” Another time, the same interviewee had sensed someone coming into the room while she was laying out a body and had heard footsteps in the corridor although no one was there.

One nurse spoke of seeing an apparition while she was working in another nursing home. She was having a tea break with colleagues around mid-afternoon and looked up at the doorway to see a lady walk past in a nightdress. The interviewee quickly got up to run after the lady because she thought the resident was going to get out the front door. But when she looked down the corridor, no one was there. “She was as real as you are,” she said to me.

Residents also reported seeing apparitions. One of the interviewees reported that “After a few days his former roommate saw him sitting there in his usual chair. He saw him and he told the nurses.” The second interviewee had gone to collect the dead resident’s clothes from his room. Again the roommate, who was not on any medication, told her the same thing. “You know that man came back! Yes, I know he is dead. Why is he still there sitting in the wheelchair?” The interviewee was scared.

Most of the interviewees appeared to be unfazed by these strange afterlife presences. One interviewee said, “Staff need to have an understanding that what the person is seeing is real to them, and so they then must be able to discuss it and not make the person feel that it’s not real.” Several interviewees also said they believed the residents are not frightened by what they see.

“It’s as if they are seeing real people. I didn’t believe in ghosts and things like that, but it’s always on my mind because a lot of residents have these experiences and tell me or ask me about them.” Other interviewees reported personal stories of seeing relatives after they had died.

Final Thoughts

In line with reports from the present study and from O’Connor’s investigation with palliative care nurses, the nursing home interviewees considered anomalous experiences to be neither rare nor surprising. The many new ideas revealed in this report will help us conduct a wider survey of other nursing homes in the future.

The anomalous phenomena reported to us seem to be powerful subjective experiences that hold profound personal meaning for those who experience them. It could therefore be argued that although the end-of-life for the elderly is becoming increasingly institutionalized in hospitals and residential homes,³ the dying process itself has not been affected by this institutionalization. In addition, the nursing home interviewees told us that unconscious residents often seem to possess the capacity to wait for the arrival of beloved relatives before they died.

The aim of these interviews, which followed the study I did with Paola Gimenez Amarilla on anomalous experiences related to nurses in a hospital,¹¹ was to determine the extent of occurrence of certain types of anomalous perceptual experiences and their relationship to the nurses’ job stress, the residents’ proneness to hallucination, and their psychological absorption. Those with hallucinations and a high level of psychological absorption tended to score higher for anomalous/paranormal experiences compared with those who did not report such experiences.

Generally speaking, the information that most people have about these experiences and their association with psychiatric disorders leads to prejudice and resistance to providing data. Thus, there are a number of drawbacks connected with this research in hospital settings as they are conservative institutions, unlikely to be open about their population and even more so with respect to providing information relating to the subject of this investigation. The nurses did reveal their personal and professional experiences and those of their patients, noting that they considered experiences of paranormal phenomena within a hospital setting not to be infrequent or unexpected. They were not frightened by their patients’ experiences, or their own, and exhibited a quiet confidence in the reality of the experiences for themselves and the dying person. Acceptance of these experiences, without interpretation or explanation, characterized their responses.

By reassuring them that the occurrence of paranormal phenomena was not only common but also a comfort to the dying person, we may assist nurses in normalizing a potentially misunderstood and frightening experience. The response of health professionals, specifically nurses, to anomalous experiences is an area not widely reported. Even palliative care literature is mostly silent on this topic.



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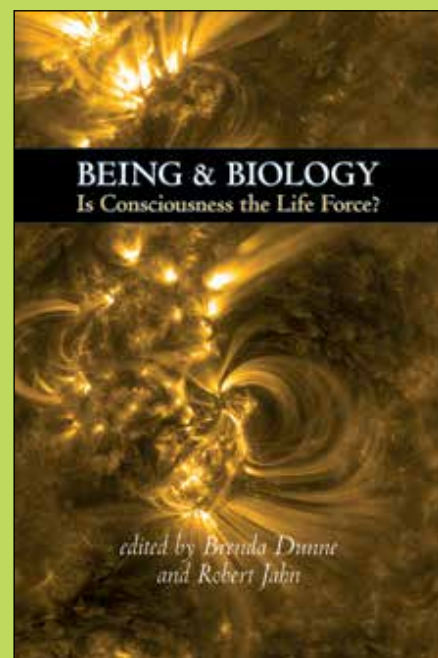
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