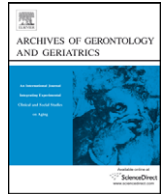




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Comfort for the dying: five year retrospective and one year prospective studies of end of life experiences

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ABSTRACT

Many cultures have reported end-of-life experiences (ELEs) as part of the dying process. However, few studies have examined the mental states of the dying in the weeks and days before death. Following an ELE pilot study with a palliative care team, 38 nurses, doctors and end-of-life carers from two hospices and a nursing home took part in a 5-year retrospective followed by a 1-year prospective ELE study. Interviewees' reports (first-hand and second-hand accounts from relatives, patients and residents) suggested that ELEs are not uncommon. ELEs included deathbed phenomena (DBP) such as visions, coincidences and the desire to reconcile with estranged family members. These experiences seemed to comfort both the dying and the bereaved. Interviewees described other phenomena such as clocks stopping synchronistically at the time of death, shapes leaving the body, light surrounding the body and strange animal behavior. Interviewees confirmed that ELEs differed from drug-induced hallucinations and occurred in clear consciousness. Most expressed concern about a lack of specialist ELE training and education and recommended that ELE modules be included in their training courses. ELEs provided comfort and hope for the dying and consolation for the bereaved. Further research is required to find the true prevalence and range of ELE phenomena.

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1. Introduction

The ELE in the form of deathbed-visions has been widely reported, and is found in biographies and literature from all ages and in many cultures, for example, the Tibetan Bardo (Sambhava, 1994), the Egyptian Pert Em Hru (Faulkner, 1973), and as wood-cut illustrations of the European mediaeval *Ars Moriendi*, The art of dying (Aries, 1974). Traditionally these end-of-life visions, such as those reported by Julian of Norwich in her major work, *Sixteen Revelations of Divine Love* (Norwich, Julian of c. 1342–1413), were associated with the spiritual preparation of the soul for death and the afterlife. More recent anecdotal accounts from nurses and doctors suggest that ELEs consist of a much wider range of phenomena than purely deathbed-visions (Barratt, 1926; Osis and Haraldsson, 1997). These phenomena include the ability to transit to and from other realities, usually involving love and light (Kubler Ross, 1971), coincidences around the time of death involving the dying person appearing to a relative or close friend who is not present at the time of death and a need to settle unfinished business such as reconciling with estranged family members, or putting affairs in order before death (Baumrucker, 1996).

The death of a patient and the grief of the relatives is part of general practice experience. In our survey we found that many people who had witnessed or experienced these end-of-life phenomena felt uncomfortable about discussing them with their doctor and that something which was intensely meaningful to them was often dismissed as insignificant.

Research conducted by O'Connor (2003) with end-of-life care nurses suggests that they find ELEs neither rare nor surprising. And yet our own research has found that even amongst palliative care professionals, ELE training is lacking and many palliative care nurses feel inadequate when dealing with such spiritual issues (Katz and Payne, 2003; Kellehear, 2003). Many people now die in hospital but unfortunately, nurses have neither the time nor the training to deal adequately with this very important aspect of the dying and grieving process.

2. Limited research into the mental state of the dying

Much has been written on the practicalities of providing end-of-life care. However, the *British Medical Journal* (Workman, 2007) considers that research into the dying process and the mental states of the dying is often overlooked. A recent study (Kendall et al., 2007) suggests that a physician's emotional response to death is often seen as a sign of weakness. The study also suggests that the lack of research into the dying process may be influenced by the continuing social taboos which surround death, and the

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tendency of doctors to concentrate on the survival of patients, rather than help them achieve a good death. Consequently, the prevailing scientific view is that ELEs, particularly deathbed visions, have no intrinsic value, and are either confusional or drug induced.

Imhof (1996) points out that since death is not taught as a medical subject, and 'dying right' is not part of medical studies, this special awareness of the dying process is often ignored by those who care for the dying. He considers that "Although all of us will die, hardly anyone is prepared, or is preparing to die right".

3. ELE research study

Our present research suggests that ELEs fall into two distinct categories: (i) transpersonal ELEs, and (ii) final meaning ELEs (Brayne and Fenwick, 2008).

3.1. Transpersonal ELEs

Transpersonal ELEs possess 'other-worldly' or transcendent qualities and cannot easily be explained by the pathological process of dying (Wallace, 2000). Transpersonal ELEs include:

Deathbed visions, e.g., of deceased family members, coming to 'take the dying person away' (take-aways), or powerful existential dreams involving deceased family members or pets that help the dying person to let go (Kubler Ross, 1971; Hallum et al., 1999).

The seeming ability to transit to and from other realities before death, often involving love and light, as a way of preparing to let go (Fenwick et al., 2007; Fenwick and Fenwick, 2008).

Coincidences which occur around the time of death, involving the appearance of the dying person to a close relative or friend who is not physically present (Kubler Ross, 1971; Fenwick and Fenwick, 2008).

Phenomena which occur around the time of death such as clocks stopping, strange animal behavior, or lights and equipment turning on and off (O'Connor, 2003; Betty, 2006).

3.2. Final meaning ELEs

In contrast, final meaning ELEs appear to have substantive qualities, firmly based in the here and now, often prompted by profound waking dreams, or dreams which help the person to process unresolved business so they can let go and die peacefully. They include a desire to put their affairs in order (Baumrucker, 1996) and to reconcile with estranged family members (Millison and Dudley, 1992). Sometimes a patient manages to hang onto life until a special relative arrives to say goodbye, or a previously confused or semi-conscious patient may have a brief moment of lucidity enabling them to say their farewells (Osiris and Haraldsson, 1997; Brayne et al., 2008).

3.3. Method

Over the past 4 years, we have conducted four ELE studies. These were a pilot study with the Camden Palliative Care Team (CPCT) already reported (Brayne et al., 2006), followed by three full-scale studies to explore ELE perceptions and occurrences with 38 nurses, doctors and carers from Phyllis Tuckwell Hospice, Farnham (PTH), Princess Alice Hospice, Esher (PAH) and Kingsley House Nursing Home, Gloucestershire (KHNH).

The three full-scale studies were divided into two parts. Part 1 was a 5-year retrospective study with 38 participants. Every participant admitted to the study was informed that at the conclusion of the study, they would be entered for the prospective study, which would run for 1 year, and they were asked to agree to this before being accepted into the Part 1 study.

Part 2 was a 1-year prospective study, taking place 12 months later with those 30 staff still employed at the three institutions. We felt this was necessary because we had learned from e-mails received after media discussion of the phenomena, that many of the experiences described had happened several years previously, but were vividly remembered because of their comforting nature and because in many cases they helped to abolish a fear of death. It was thus important to know whether, although the period of the retrospective study was limited to 5 years, many of the experiences reported by carers had in fact pre-dated that time and thus gave a falsely raised frequency for these phenomena. We hoped the prospective study would help us obtain a more accurate estimate of the prevalence of end-of-life events. Every interviewee in the retrospective study was therefore asked to keep a diary for the following year and to note all the ELEs told to them by either patients or relatives.

Comparison between the retrospective and prospective studies also enabled us to gauge whether there had been a shift in the attitude of the interviewee or the culture of the organization towards acceptance of ELEs.

The data collection consisted of a questionnaire and a tape-recorded interview, providing first-hand and second-hand accounts (recounting ELE stories from relatives). All the interviewees were assured of confidentiality, and gave their informed consent. Ethical approval for the study was granted by Southampton University and Camden Ethics Committee (LREC).

3.4. Quantitative data collection

The questionnaire had been piloted with the CPCT for validity and then modified for the three full-scale studies. The questionnaire was divided into three sections and involved 47 questions. Section 1 provided demographic information, including years working with the dying. Section 2 asked about the interviewees professional observations on ELES, including the effects of medication. Section 3 studied the impact that ELES may have had on the spiritual or religious beliefs of interviewees and on their training experiences and needs. Interviewees were invited to respond to each question by ticking boxes which scaled 1–5 from strongly agree to strongly disagree, or yes/no boxes. Statistical analysis was carried out using frequencies and the marginal homogeneity test, SPSS, to note significant differences between the retrospective and prospective data (SPSS, 15.0.1 for windows). The results of Sections 2 and 3 are shown in Table 1.

The tape-recorded interviews were semi-structured in style, and lasted approximately 1–1½ h, encouraging the interviewee to talk in more detail about their experiences. The interviews were transcribed verbatim. The interviewees were thus given an opportunity to speak freely about the topics covered by the questionnaire and helped us to confirm the questionnaire's reliability and validity. The transcripts also showed us how ELES may have impacted on interviewees personally and professionally, and helped us to explore further training needs for the provision of best spiritual practice in end-of-life care.

4. Results

In the Part 1 (retrospective) study, 38 carers were interviewed, 13 from PTH, 15 from PAH and 10 from KHNH. One year later, for the Part 2 (prospective) study we again interviewed those carers still employed, 9 from PTH, 12 from PAH, and 9 from KHNH. Although the prospective study was smaller, the relative numbers from each occupation in the two studies remained about the same: nursing staff 19 (Part 1) and 14 (Part 2); special palliative care nurses 5 and 4; pastoral carers (chaplains, etc.) 4 and 4; doctors, 2 and 1; other professionals 3 and 2; others 5 and 4.

Table 1

The questionnaire and the results obtained. Figures give percentage of carers who answered the questions in the 5 year and one year studies. The significance column shows the result of the marginal homogeneity test between the studies. (See Section 3.4 in text).

Questionnaire items	% 5-year	% 1-year	Signif.
1. Have you had DBP related to you by patients?	62	43	ns
2. Have you had DBP related to you by relatives	64	62	ns
3. DBP differ from drug or fever induced hallucinations	67	65	ns
4. Visions of dead relatives or religious figures who appear to have the express purpose of 'collecting' or 'taking away' the dying person	62	48	ns
5. Visions of dead relative sitting on, or near the patient's bed who provide emotional warmth and comfort	64	54	ns
6. Coincidences, usually reported by friends of family of the person who is dying, who say the dying person has visited them at the time of death	55	48	ns
7. Transiting to new realities. Patient reports a sense of going to and back from a different reality as part of their dying process	33	48	ns
8. Experiencing a radiant light that envelops the dying person, and may spread throughout the room and involve the carer	25	35	<0.01
9. Dying-dreams, dreams, or visions through which the patient seems to be comforted and prepared for death	62	50	ns
10. Vivid dreams or visions that hold a significant meaning for the patient which helps the patient come to an understanding of some unfinished business	41	35	<0.05
11. A sense of being 'called' or 'pulled' by something, or someone	56	57	ns
12. Seeing people/animals/birds out of the corner of the eye	29	40	<0.01
13. A sudden desire to write poetry or prose	22	35	<0.01
14. A sudden desire to sing or hum religious songs	16	35	<0.01
15. A symbolic appearance of an animal, bird or insect near or at the time of death	45	35	ns
16. At the time of death, synchronistic events happen, such as clocks stopping	33	33	ns
17. A patient who has been in a deep coma, suddenly becomes alert enough to coherently say goodbye to loved ones at the bedside	31	79	<0.01
18. A desire to mend family rifts	68	18	<0.05
19. Do you agree with this question: I consider DBP to be a transpersonal experience	70	89	ns
20. I consider DBP to be an altered state of consciousness	45	59	ns
21. I consider DBP to be a profound spiritual event	68	68	ns
22. I consider DBP to be a psychological construct, enabling patients to review their life	42	43	ns
23. I consider DBP to have little significance beyond a chemical change in the brain	34	31	ns
24. I consider DBP to be a manifestation of the imagination	5	10	ns
25. I consider DBP to be hallucinations induced by medication or fever	33	35	ns
26. I consider DBP to be an expression of psychological unrest or suffering	13	17	ns
27. DBP are often a source of spiritual comfort to the dying	92	82	ns
28. DBP are often a source of spiritual comfort to relatives	86	79	ns
29. Patients are reluctant to talk about DBP	28	32	ns
30. Patients who experience DBP have a peaceful death	39	50	ns
31. DBP can be distressing, but usually carry a significant meaning to help the patient come to terms with unresolved issues	28	14	ns
32. Most people experience DBP within the last month of their life	29	39	ns
33. DBP usually happens within the last 48–24 h of life	35	46	ns
34. Support and training over last year: I have received additional education/training regarding DBP	42	17	<0.001
35. I have had no specialist education/training this year, but I am able to talk with my team about issues related to DBP	X	84	X
36. Because of taking part in this survey, I feel more able talk about DBP with colleagues	X	79	X
37. Because of taking part in this survey, I feel more comfortable talking to patients and relatives about DBP	X	82	X
38. I have not discussed DBP with any of my colleagues this year	28	32	ns
39. I would like to see more widely available information for staff, patients and relatives regarding DBP	90	96	<0.001

Notes: The X for questions 35–37 means that this question was changed for the prospective study and so could not be compared.

In nearly every case interviewees answered all the questions. If, very rarely, an interviewee failed to answer a question, the percentages given are of the group who did answer the question. We felt this would give a truer picture of the responses of the group than counting the missing data as negative responses.

The 5-year retrospective data is presented first, followed in parentheses by data from the 1-year prospective study, if relevant. The marginal homogeneity paired sample test, two tailed significance, was calculated between the two sets of answers from the two studies for that question, not significant ns, $p < 0.05$, $p < 0.01$, $p < 0.001$.

4.1. Demographic results

Mean-age of interviewees was 48 ± 9.7 years (\pm S.D.). Years worked with the dying 13.7 ± 9.6 , and the number of dying cared for during this period was mean 173 ± 247 for the retrospective, and mean 194 for the prospective study.

In the retrospective study, carers were asked how many accounts of ELEs they had either witnessed themselves or been told about by relatives in the last 5 years; 84% of carers reported 1–50 ELEs and 8% 50–100 ELEs. In the 1-year prospective study the

respective figures for ELEs reported in the previous year were 62% (all 1–50 ($p < 0.01$) and 0% 50–100). 34% of carers had been given between 1 and 5 accounts of ELEs by patients in the previous year, 3% reported 5–10, and 6% 10–20 accounts. 59% of carers had been given between one and five accounts of ELEs by relatives and 3% had been given 10–20 such accounts.

Not all members of staff had an equal exposure to the dying patients, because of their professional roles, and not all were equally sympathetic to the occurrence of ELEs, thus a wide variation in numbers reported by the carers was to be expected.

4.2. Transpersonal ELE results

62% (48%, ns) of interviewees reported that dying patients or their relatives had spoken about take-away apparitions or deathbed visions involving deceased relatives. 64% (54%, ns) reported second-hand accounts from the relatives describing how the dying saw or felt the take-away apparition sitting on the bed.

Some examples: "... a Jamaican man who ... when he was dying ... was all the time talking about his auntie. His auntie was calling him, his auntie knew, we didn't need to tell her but when we talked to the family after he died, they said, Oh, she died a long

time ago.” “I had a patient recount to me, I think it was a week before he died, that he'd already lost his mother a few months before and lost his little boy who was only eight. He said they'd both come to him. We talked about it and he found it quite comforting and said that he felt that he'd be joining them quite soon.”

Although in most of the accounts we were given the 'visitors' were deceased relatives, religious figures were occasionally seen. “- one patient said she could see Jesus and I really wanted to see that, as well. I found myself looking. Equally, I was doing night duty, and this was all at the hospice where I am now, and one lady, about an hour before she died said, “they're all in the room; they're all in the room”. The room was full of people she knew and I can remember feeling quite spooked really and looking over my shoulder and not seeing a thing but she could definitely see the room full of people that she knew.”

Very rarely an interviewee reported seeing the 'visitor' too. Here, a pastoral care worker also sees an angel on the bed of a patient. “She looked a bit worried, she was really near the end, but not quite at the end, and she looked quite worried and this angel was sitting on the bed and I asked her if she was all right and she said, ‘Well I don't know’. I asked her what was the problem and she said, ‘I think I'm going mad’ so I said: ‘What makes you think you're going, you know (mad)?’ (She said, ‘Well, there's someone sitting on the bed beside me,’ and I said, ‘Well, I can see it too’ ‘Thank goodness for that,’ she said, ‘I thought I was going loopy.’ I said, ‘Well, maybe he's just come to keep you company.’ She was a lady who had no family, which is why I said I wonder if somehow we are supplied with what we really need. She had no one. So somebody turned up to be with (her).”

Accounts of moving to a different reality were less common, but were reported by 33% (48%, ns). “Sometimes people seem to oscillate between the two worlds for a bit, that can last for hours. They seem at some points to be in this world and at other points they're not. I think that for many people death is not just going through a doorway. You've sort of got a foot on the step and you stick your head in and you have a look, you know. I don't know what it's like but it feels (like that) from the way people are sometimes. I've had people open their eyes and say, ‘Oh, I'm still here then.’”

Surprisingly, more than 25% (35%, $p < 0.01$) reported second-hand accounts of the dying person surrounded by light at the time of death. One interviewee, asked if she had seen light round patients, replied: “A light often; especially my therapists often report on a light around patients and more towards when they die.” Another gave this account: “When her mother was dying this amazing light appeared in the room. She died in one of these places where nuns are, I don't think it was Mount Auvergne but one of these kinds of places; I don't know if it's still around because it was a while ago the woman died. The whole room was filled with this amazing light and her mother died.”

45% of interviewees (35%, ns) mentioned an animal that seemed to hold some significance for the dying person appearing at the time of death, ‘I've been in a room where somebody is dying and they've said that there is a bird in the room but ... the one lady in particular I'm thinking of, could never actually see it clearly. It was out the corner of her eye. ... there was something there. She asked me to open the window and I did and she said: ‘That bird will take my soul.’ A third of the interviewees gave accounts of clocks stopping synchronistically at the time of death. “One person told me her watch had stopped at the moment her husband died and she'd never got it repaired. I saw her six months later at the service and I said to her: ‘Have you still got the watch?’ and she laughed; she said: ‘Yes, I bought a new one. I'm not going to have it repaired. It hasn't gone since.’”

“A friend of mine, her twin sister died and they were just so close, I'm sure she could have told you far more but I do remember

about the clock stopping at the time of Maggie's death. This was the surviving sister, in her house, and they were living separately but only just round the corner from each other.”

55% (48%, ns) of interviewees reported second-hand accounts of deathbed coincidences. “I've had people who've said that they've woken in the night and just known that someone they love was gone and they've waited until the morning to ring and then – or before they could ring – they've been rung up and told they've gone. So yes, that has happened.”

16% (35%, $p < 0.01$) of the carers reported patients who sang or hummed religious hymns around the time of death and 22% (35%, $p < 0.01$) reported the dying writing poetry which held significant meaning for them.

4.3. Final meaning ELE results

62% (50%, ns) of the carers reported the dying experiencing profound dreams which seemed to comfort and prepare them for death, and 41% (35%, $p < 0.05$) reported patients who had vivid dreams which helped them to resolve unfinished business. 68% (18%, $p < 0.05$) reported patients wanting to mend family rifts.

4.4. The nature of ELES

Profound: 70% (89%, ns) of the interviewees indicated that ELES were intense subjective experiences which held profound personal meaning for the dying person. 45% (59%, ns) thought ELES were an altered state of consciousness. 68% (68%, ns) felt ELES were spiritual events. What the great majority of carers 92% (82%, ns) agreed on was that ELES offered spiritual comfort to the patient and 86% (79%, ns) to the relatives. “In the week before she died she didn't become more religious but she became anxious that she wouldn't have to go through, as she saw it – this is her words not mine – the gateway to the other side on her own. I asked her how she would like to go and she said. ... ‘I want someone to come and get me and hold my hand.’ So we prayed about it. I got a phone call – it was in the night, actually – that she was going and her husband wanted me there. So I came in and as she was passing, the door opened and she put her hand out – she hadn't moved for probably a couple of days – and then her hand fell down and she died. Her husband is convinced to this day that someone came to collect her. I couldn't explain it any other way. She died with a smile on her face, which suggested to me that whatever had happened in her experience, it had been a good thing. She died peacefully and at ease and that was very powerful because the door was shut. It was absolutely firmly shut and it opened. That made me think.”

Organic or part of dying process: 76% (79%, ns) said that ELES could not just be attributed to chemical change within the brain. 67% (65%, ns) said ELES were not due to medication or fever. “.... I would surmise from my observations, and it's happened a few times, that there is something transitional going on with the spirit, the mind as well, that it isn't just the physical. Some people do just shut down and die; other people don't.”

Helpful or not: 42% (43%, ns) thought that ELES helped patients review and come to terms with their life. 39% (50%, ns) felt patients who experienced ELES had a peaceful death.

Impact of ELES: 25% (18%, ns) believed it was easy for the dying to talk about ELES. Asked whether ELES helped the dying to resolve unfinished business, 39% (36%, ns) agreed.

Predicting time of death: 39% (29%, ns) thought ELES occurred in the last month of life. 35% (46%, ns) felt ELES were common in the last 48 h before death.

Paranormal events: 56% (57%, ns) of interviewees reported first-hand, a sensation of being pulled or called by the dying person around the time of death. Although these was not included in the questionnaire, several carers reported in line with O'Connor (2003)

phenomena connected to someone who had just died, such as room-bells ringing, lights going on and off, and televisions malfunctioning.

4.5. Training and ELEs

58% (83%, $p < 0.001$) of interviewees said they had received no training in ELEs. Most, 90% (96%) strongly requested further training. The higher numbers in the second interview are because more carers understood the significance of ELEs and the need for education. However, they felt that lack of training did not compromise the care they were able to give. 80% (78%) of interviewees felt able to talk to the dying about ELEs and 70% felt they would not cause distress by doing so. We suggest this is because, as end-of-life carers, they are naturally empathetic. Because these three questions about training were worded slightly differently in the second questionnaire, significant changes were not calculated.

In the retrospective study, 72% said they felt able to talk to their supervisor about ELEs, and 84% were able to discuss them with their colleagues. 79% of interviewees who answered the prospective questionnaire noted that after taking part in the first survey they felt more able to talk to colleagues about ELEs and 82% felt more able to talk to relatives and the dying.

5. Discussion

Nuland (1994) comments, 'Death is not usually a time of wonderful experience. But is frequently a time for healing experiences.' Our research confirms that ELEs are such healing experiences, are commonly part of the dying process and may contribute to best practice in spiritual end-of-life care (Grant et al., 2004). We obtained a representative sample of carers from the hospices and nursing homes. Almost without exception the interviewees had heard about ELEs, and 91% of interviewees in the retrospective study and 68% in the prospective study had been given accounts of ELEs. This suggests that they are not uncommon. Most of the interviewees agreed that ELEs were not due to confusional states resulting from either medication or the toxic processes involved in dying (Betty, 2006). ELEs were considered to be profoundly subjective and meaningful events which usually occurred in clear consciousness (Osiris and Haraldsson, 1997; Betty, 2006) and often helped the individual to let go of life and lessened the fear of dying. They were seen as spiritual events with a meaning for the patient which took them beyond the distress of dying (Betty, 2006; Brayne and Fenwick, 2008).

There were differences in the KHNS sample as many residents suffered from dementia. Despite this, interviewees from all units reported first-hand accounts of previously confused residents suddenly becoming lucid enough in the last days of life to recognize and say farewell to relatives and carers. This return to lucidity just before death is certainly worthy of further study as it raises questions about changes in the cognitive processes of the dying and may have consequences for neuroscience concerning the functioning of memory in the terminal stages of life.

First-hand accounts suggested that during the last few weeks and days of life, some of the dying felt the need to become reconciled with estranged family members, although this was reported less often in the prospective study, and/or underwent profound life-reviews. These final meaning ELEs were viewed as an extremely important process which helped the dying resolve inner conflicts so they found release from restlessness and anxiety, and died in peace. This was a time when strong feelings of love and acceptance were recognized both by the dying and their relatives.

Transpersonal ELEs such as deathbed-visions were reported by up to two-thirds of the interviewees.

5.1. Community nurse specialist in palliative care

"But I do know of an incident that was reported to me on the ward where somebody saw their brother who had died in the war, just before death... and they'd had a conversation with their brother just before (her) dying... and she was shocked by it and also very relieved by it and somehow reassured by it that she'd been able to have that. My sense was that the relief was that she was about to meet him and that they would be reunited."

These visions were seen as comforting and supportive to the dying. Interviewees noted that 'Granny visiting' language signified the imminence of death, and that the dying seemed to be unafraid and hopeful at the prospect of being collected by deceased loved ones. Language used by the dying who experienced these events included such phrases as "I'm coming", "He/she is waiting for me". Often they underwent a change of mood from agitation and distress to peaceful acceptance. This supports other studies of deathbed visions (Houran and Lange, 1997; Barbato et al., 1999; Betty, 2006). It was interesting that in our sample nearly all the 'visitors' were dead family members: very few of the visions reported were of religious figures or icons. The few studies which have been carried out in North America and India, where religious figures appear far more frequently in deathbed visions, suggest a strong cultural element (Osiris and Haraldsson, 1997; Lerma, 2007).

Up to half of the interviewees provided second-hand accounts of deathbed coincidences. These were seen as comforting by the experiencer and if the 'message' was that the dying were 'OK' then the experience was both hopeful and reassuring to the relatives.

5.2. Carer hears deceased father's voice at mother's deathbed

'I took time off to nurse my mother at home and when she died, I was holding her in my arms and there was a brother there and a niece and I distinctly heard my father's voice calling her, just at the point of death. He had died some twenty-four years before and he certainly wasn't on my mind, as far as I'm aware. He may have been in my subconscious but I distinctly heard his voice call her name. That was amazing! It was lovely.'

Other examples are 'Patient in unconscious state dies just as relatives have left to take a break.' Or 'relatives phone hospice just as patient is deteriorating or slipping away.' And a 'Patient's dog at home howls at time of death'. In addition to reporting the serendipitous appearance or dreams of significant animals, birds or butterflies which held special meaning for the dying and often also for the relatives, interviewees provided second-hand accounts of paranormal events around the time of death such as clocks stopping synchronistically and first-hand accounts of lights going on and off, alarms ringing or TVs ceasing to work (O'Connor, 2003). These were usually interpreted as a final comforting message by the relatives and seemed to occur independently of prior belief or expectation. Those who described transiting to another reality gave further accounts of light, love and compassion and the meeting and greetings of dead relatives which are similar to descriptions of NDEs during cardiac arrest, when the patient is clinically dead (Parnia et al., 2001; Van Lommel et al., 2001; Schwaninger et al., 2002). Further studies should focus on first-hand anecdotal accounts of coincidences and deathbed visions, together with the wider phenomenology of dying (Fenwick and Fenwick, 2008).

5.3. Changing attitudes

Our retrospective survey indicated that although ELEs seemed to be relatively common, carers were reluctant to discuss them amongst themselves and in general meetings, and to accept the existence and spiritual significance of ELEs as an intrinsic part of

the dying process (Cobb, 2001; Brayne et al., 2006). One possibility was that they were thought to be of little significance, but the answers to questions #27 and #28 showed that the 82% of carers considered them important for the dying and 79% for their relatives. Education was certainly an important factor as only 17% of carers had had training concerning ELEs and their significance in the dying process. There was also a general feeling, although not all carers shared it, that ELEs were considered weird and those who talked about them openly might also be thought weird.

It seemed to us that the medical attitude which had filtered down to the carers in their earlier general palliative care training, was that death was simply a turning off and that the experiences of the dying were likely to be due to organic causes, and as such were unimportant. Although this view was not so strongly held by the medical staff in the hospices, it was still adhered to, to some extent by the carers, and was often repeated to us in the one to one retrospective interviews.

Because ELEs had not been explained in an academic framework, there was still considerable resistance at the start of the retrospective study to go beyond the medical model, and their spiritual nature and significance, both for the dying and their relatives, was seldom mentioned. Interviewees emphasised that ELEs were not discussed or valued as part of the dying process. Team leaders did not ask about ELEs and even if the carers believed that these experiences were important, because of their own need to be regarded as professional they were reluctant to discuss them even amongst themselves. However, we did find an interesting change in the prevailing institutional attitude when we re-interviewed the carers 1 year later, for the prospective study. The fact that the retrospective study had taken place was perceived as permission to start discussing some of the features of ELEs. We noticed that the longer the retrospective study continued, the easier it was for the staff to discuss these phenomena. In the private one to one interviews of the retrospective study, nearly all interviewees had been relieved to talk about these things, look more objectively at the phenomena and say what they thought. It was apparent that this was an institutional and not a personal change. From the interview data it was apparent that few doctors, nurses or carers said that hearing or witnessing ELEs had affected their own spiritual or religious views: their private attitudes, based on their own experiences with patients, remained the same. But they now felt that as the topic was a legitimate subject for medical research, it was no longer taboo and could be discussed more openly.

Nearly all interviewees expressed concern about the lack of ELE education and training and wanted ELE training modules to become part of standard teaching practice.

Hospice nurse on ELE's: "It's important, I think, if nurses are working in a specialty (palliative care), to be equipped to deal with these incidences because I feel they are more common than not and I think patients will want to share them. They will want to know that what they've just experienced isn't rubbish... is appreciated and that it has some sense of meaning in what is happening to them. And I think it saddens me that nurses might not be equipped to deal with 'conversations' like that. I absolutely believe that nurses don't (are not) and certainly not those new to this specialty. But I think if they don't have the skills, an attempt should be made to give them the skills." They believed that ELEs raised profound existential issues for which they were ill-prepared; some felt they were expected to be the new 'priest at the bedside' but were not trained for this role. Nevertheless, despite the lack of training many were able to talk to the dying about ELEs because they are naturally empathetic and caring.

For many relatives of the dying ELEs are often the 'elephant in the room' during discussions about death and grieving. The reports we have had suggest that when the dying or their relatives try to

talk about them they often feel their experiences are not validated or, especially if they are talking to non-medical friends or acquaintances, that people will think they are mad. Equally important is the thirst for information on the part of the carers (and indeed the relatives), and their need to discuss these events within their team: we feel that it is extremely important to open up discussion in this area. Thus the prospective study goes well beyond a simple validation of the retrospective study. It gives a much better picture both of the experiences that were gathered and the carers' own desperate desire for proper training in this area.

In conclusion here is a series of quotes which sum up the attitudes of the carers: "Dying is a process on all levels of being – not just an event." "ELEs play a role in the dying process and are not uncommon...". "ELEs range from fear and spiritual agony to serene acceptance, deep peace and joy". "Include deeply personal, comforting experiences of non-ordinary reality – seem distinct from drug-induced hallucination. Often generate a desire for resolution and healing of 'unfinished business' or involve spontaneous life review". "Can be informative and helpful for dying patients, grieving relatives and carers, seem to meet a need."

6. Conclusion

Our study suggests ELEs are not uncommon occurrences. It is also apparent that the mental state of the dying and the phenomena that occur at death need to be taken seriously and require further study to encourage best practice in spiritual end-of-life care. General practitioners, geriatricians as well as palliative care workers, are those most often involved in the care of the dying and the bereaved, and yet spiritual care of the dying and a knowledge of ELEs are not yet a standard part of the medical or palliative care curriculum.

Conflict of interest statement

None.

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References

- Aries, P., 1974. *Western Attitudes towards Death: From the Middle Ages to the Present*. Marion Boyars Ltd., London, p. 34.
- Barbato, M., Bluden, C., Reid, K., Irwin, H., Rodriguez, P., 1999. Parapsychological phenomena near the time of death. *J. Palliat. Care* 15, 30–37.
- Barratt, W.F., 1926. *Death-bed Visions: The Psychological Experience of the Dying*. Bantam, London, p. 10.
- Baumrucker, S.J., 1996. The therapeutic baptism: a case of missed cultural clues in a terminal setting. *Am. J. Hosp. Palliat. Care* 13, 36–37.
- Betty, S.L., 2006. Are they hallucinations or are they real? The spirituality of deathbed and near-death visions. *Omega* 53, 37–49 (Official Journal of the Assoc. of Death Education and Counselling) Pub. Baywood, USA.
- Brayne, S., Fenwick, P., 2008. The case for training to deal with end of life experiences. *Eur. J. Palliat. Care* 15, 118–120.
- Brayne, S., Farnham, C., Fenwick, P., 2006. Deathbed phenomena and its effect on a palliative care team. *Am. J. Hosp. Palliat. Care* 23, 17–24.
- Brayne, S., Lovelace, H., Fenwick, P., 2008. End-of-life experiences and the dying process in a Gloucestershire nursing home as reported by nurses and care assistants. *Am. J. Hosp. Palliat. Care* 25, 195–206.
- Cobb, M., 2001. *The Dying Soul: Spiritual Care at the End of Life*. Open University Press, Buckinghamshire, p. 15.

- Faulkner, R.O. (Ed.), 1973. *The Ancient Egyptian Coffin Text*. Avis and Phillips, Warminster, UK, p. 43.
- Fenwick, P., Fenwick, E., 2008. *The Art of Dying*. Continuum, London, pp. 37–76.
- Fenwick, P., Lovelace, H., Brayne, S., 2007. End of life experiences and implications for palliative care. *Int. J. Environ. Stud.* 64, 315–323.
- Grant, E., Murray Scott, A., Kendall, M., Boyd, K., Tilley, S., Ryan, D., 2004. Spiritual issues and needs: perspectives from patients with advanced cancer and non-malignant disease. A qualitative study. *Palliat. Support Care* 2, 371–378.
- Hallum, E., Hockey, J., Howarth, G., 1999. *Beyond the Body: Death and Social Identity*. Routledge, London.
- Houran, J., Lange, R., 1997. Hallucinations that comfort: contextual mediation of deathbed visions. *Percept. Mot. Skills* 84, 1491–1504.
- Imhof, A.E., 1996. *An Ars Moriendi for our time: to live a fulfilled life – to die a peaceful death*. In: Spiro, H., McCrea, C.M., Palmer, W.L. (Eds.), *Facing Death: Where Culture, Religion and Medicine Meet*. Part 2. Yale University Press.
- Katz, A., Payne, S., 2003. *End of Life in Care Homes*. Oxford University Press, Oxford.
- Kellehear, A., 2003. Spirituality and palliative care: a model of needs. *Palliat. Med.* 14, 149–155.
- Kendall, M., Harris, F., Boyd, K., Sheikh, A., Murray, S.A., Brown, D., Mallinson, I., Kearney, N., Worth, A., 2007. Key challenges and ways forward in researching the 'good death': qualitative in-depth interview and focus group study. *Br. Med. J.* 334, 521.
- Kubler Ross, E., 1971. What is it like to be dying. *Am. J. Nursing* 71, 54–62.
- Lehma, J., 2007. *Into the Light*. Career Press, Franklin Lakes, NJ, USA, pp. 21–45.
- Millison, M., Dudley, J.R., 1992. Providing spiritual support: a job for all hospice professionals. *Hosp. J.* 8, 49–66.
- Norwich, Julian of c. 1342–1413. *Sixteen Revelations of Divine Love*. Christian Class Etherial Library. February 2008 <<http://www.ccel.org/j/julian/revelations/>>.
- Nuland, S., 1994. *How We Die: Reflections of Life's Final Chapters*. Kopf, New York, p. 255.
- O'Connor, D., 2003. Palliative care nurses' experiences of paranormal phenomena and their influence on nursing practice. Presented at: 2nd Global Making Sense of Dying and Death Inter-Disciplinary Conference, November 21–23, 2003, Paris, France. Available at: <http://www.inter-disciplinary.net/mso/dd/dd2/s9.htm>. Retrieved: October 11, 2008.
- Osis, K., Haraldsson, E., 1997. *At the Hour of Death*. United Publishers Group, Hastings House, pp. 34–47, 62–81.
- Parnia, S., Waller, D., Yeates, R., Fenwick, P., 2001. A qualitative and quantitative study of the incidence, features and etiology of near death experiences in cardiac arrest survivors. *Resuscitation* 48, 149–156.
- Sambhava, P., 1994. *The Tibetan Book of the Dead* (translated by Robert A.F. Thurman). Bantam Books, New York, pp. 51–73.
- Schwanninger, J., Eisenberg, P.R., Schechtman, K.B., Weiss, A.N., 2002. A prospective analysis of near-death experiences in cardiac arrest patients. *J. Near-Death Stud.* 20, 215–232.
- SPSS 15.0 for Windows, 2007. Release 15.0.1.
- Van Lommel, P., Van Wees, R., Meyers, V., Elfferich, I., 2001. Near-death experience in survivors of cardiac arrest: a prospective study in the Netherlands. *Lancet* 358, 2039–2045.
- Wallace, B.A., 2000. *The Taboo of Subjectivity: Towards a New Science of Consciousness*. Oxford University Press, Oxford, pp. 97–120.
- Workman, S., 2007. Researching a good death. *Br. Med. J.* 334, 485–486.