

Palliative Care Workers' Experiences with and Beliefs Surrounding Deathbed Phenomena

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Abbreviated abstract:

Deathbed phenomena are unusual experiences reported by dying persons and those around them in the days and weeks prior to death. We administered an **online questionnaire** to **104 palliative care workers** about their experiences and beliefs surrounding deathbed phenomena. Overall, **97%** of palliative care clinical staff participants reported that they had encountered deathbed phenomena in the last 5 years. Further, most staff, regardless of their religious beliefs, interpreted these experiences as spiritual events which tend to provide comfort for dying persons and their families. Discussions to encourage openness surrounding these experiences with palliative workers may help staff in responding to patients and families who report deathbed phenomena.

Related References:

1. Fenwick P, Lovelace H, Brayne S. Comfort for the dying: five year retrospective and one year prospective studies of end of life experiences. Archives of Gerontology and Geriatrics. 2010;51(2):173-179.
2. Claxton-Oldfield S, Dunnett A. Hospice Palliative Care Volunteers' Experiences With Unusual End-of-Life Phenomena. OMEGA - Journal of Death and Dying. 2016;77(1):3-14.



Background & Methods

Deathbed phenomena are unusual experiences reported by dying persons and those around them in the days and weeks leading to death. For example:

- **deathbed visitors** (a dead relative appearing to dying person)
- **terminal lucidity** (a person with dementia having a period of lucidity and saying goodbye prior to death).
- **deathbed coincidence** (when someone who is emotionally close to a dying person has a sensation or feeling about the person at the exact time of their death)

The last study undertaken to our knowledge in the UK was in 2010 and involved a questionnaire and interviews with 38 healthcare workers in England. This found these experiences were not uncommon and were perceived to be of comfort.¹

Our study: a UK-wide **online questionnaire** of **clinical palliative care staff** involving multiple choice and free-text questions regarding experiences with and beliefs surrounding deathbed phenomena. **104** Marie Curie staff based in Scotland, NI and England responded.



Results

97% reported **at least 1 type of deathbed phenomena** (personally witnessed or relayed by relative/patient) in last 5 years, mean of **7.7 per respondent**.
(n=101/104)

76% agreed that deathbed phenomena are of a **spiritual nature** with **no significant difference** in response between those who identified with a **religion** and those who did not.
(n=78/102)

71% agreed that deathbed phenomena tend to be **positive experiences** for the patient and tend to **comfort the family**.
(n=73/103)

68% agreed that formal **training** in handling patients who experience deathbed phenomena would be useful.
(n= 70/103)

Deathbed Phenomena* (personally witnessed or relayed by patient/relative in last 5 years)	% Yes	Total Sample (x/n)
A patient seemingly timing their death – ie holding on in time for a loved one to get to the bedside	86.3	88/102
A vision of a deceased relative or friend who had appeared to the dying patient	74.8	77/103
Dreams of deceased relatives or friends during sleep	72.5	74/103
Dying person expressing a wish to 'go home' where home is unclear	70.6	72/102
A desire to mend family rifts	66.3	67/101
A dying patient who was unconscious, confused or suffering from dementia becoming suddenly lucid enough to coherently say goodbye to their loved ones at the bedside	56.3	58/103
Changes in pet or animal behaviour	55.3	57/103
Deathbed coincidences – this is when someone who is emotionally close to a dying person has a sensation or feeling about the person at the exact time of their death.	43.7	45/103

*18 types of deathbed phenomena were asked about in full survey.



Discussion and Conclusions

- Deathbed phenomena are frequently experienced in palliative care at the end of life
- Most staff, regardless of their religious beliefs, interpret these experiences as spiritual events
- Most staff believe that deathbed phenomena provide comfort for dying persons and their families.



Encouraging openness towards these experiences may help staff in responding to patients and families who report deathbed phenomena, improving spiritual care at the end of life.

