



Archived at the Flinders Academic Commons:

<http://dspace.flinders.edu.au/dspace/>

This is the authors' editorially accepted manuscript of an article published in the *International Journal of Palliative Nursing*. The original publication is available by subscription at:

<http://www.magonlinelibrary.com/doi/10.12968/ijpn.2015.21.3.117>

doi:10.12968/ijpn.2015.21.3.117

Please cite this article as:

Devery, K., Rawlings, D., Tieman, J. and Damarell, R. (2015) Deathbed phenomena reported by patients in palliative care: clinical opportunities and responses. *International Journal of Palliative Nursing*, 21(3) pp. 24-32.

Copyright 2015 Mark Allen Healthcare . Author version of the paper reproduced here with permission from the publisher. **Please note** that any alterations made during the publishing process may not appear in this version.

Introduction

Over many decades and across many cultures and disciplines, the scientific literature reports unusual and hard to explain phenomena at the end of life. In the palliative care literature these reports are often anecdotal (Nelson, 2000), poorly understood or even treated just as hallucination (Morse 1994). In practice though, many health professionals have heard accounts from ill and dying patients of difficult to explain events (Pflaum and Kelley 1986, Wimbush and Hardie 2001, Mazzarino-Willett 2010) and while health professionals need also to recognise hallucinations arising from delirium, dementia or other neurologic or psychiatric disorders, underlying causality for these experiences may not be obvious or attributable.

We have adopted the term Death Bed Phenomena (DBP) described here by Brayne and colleagues (2006, Page 17): *“death may be heralded by deathbed phenomena such as visions that comfort the dying and prepare them spiritually for death”* although these unexplainable accounts range from seeing dead relatives, hearing or feeling “other worlds” (Fenwick and Brayne, 2012), a significant dream, or patients being aware of the time of their own death. Patients and carers can be reluctant to discuss or divulge these phenomena for fear of being labelled ‘mad’ (Barbato et al, 1999) and health professionals (professionally trained and primarily educated in biomedical, scientific or rational models and ways of thinking) can find this a perplexing issue leaving them unsure how to respond to their patients’ stories and accounts (Brayne et al, 2006). In a quest to understand the clinical potential around these phenomena, we undertook this systematic review of the literature, with a specific focus on the palliative care population for whom death is an expected and foreseeable event due to progressive illness.

While postulations on possible causes of these extraordinary end of life phenomena can be fascinating to read (Blanke, 2004), such phenomena are real for those who experience them. *“Assumptions about their origins and credibility can alienate”* patients and their families *“at a critical time in their mourning or dying”* (Barbato et al, 1999). Like others (Brayne et al 2006, Fenwick and Brayne 2011), Barbato and colleagues (1999) raise the potential within our professional role to normalise the experience and encourage the patient to find solace and emotional and spiritual wellbeing.

In an effort to understand more fully these phenomena and their impact, health professionals, sociologists, psychologists and others have explored patient accounts of difficult to explain events and occurrences. Studies describing deathbed phenomena (DBP) (Barrett 1926, Sartori 2010) and near death experiences (NDE) (Morse 1994, Alvarado 2006, Bell et al 2010) emphasise the supportive spiritual potential of DBP (Ethier 2005, Fenwick and Brayne 2011), suggest additional therapies to further interpret DBP (Lordache and MacLeod, 2011), and put forward specific approaches for children and adolescents who experience NDE (Bell et al, 2010). DBP has been distinguished from NDE with the latter usually describing an unusual event or experience preceding an unexpected or accidental near death, or reported after successful cardiopulmonary resuscitation.

While the nomenclature and definitions of DBP are developing in the literature, a comprehensive review about these occurrences reported by patients in a palliative care context is not available. DBP may be of especial significance in this population where cure is not possible and death at some point is a foreseeable event.

Objective

The purpose of this study was to assess the literature on DBP and provide clinicians with judicious suggestions for a clinical response to dying patients' recounts of DBP or hard to explain phenomena. The specific question addressed by this systematic review is "*What are the clinical responses and opportunities to reported deathbed phenomena of patients in a palliative care context?*" Given the possibility that there would not be sufficient material on the clinical perspectives alone, the review process also included data extraction on the nature and characteristics of deathbed phenomena reported in published studies.

Methods and Information Sources

The search strategy sought to find both published and unpublished studies in English with no date restrictions¹. Databases searched include OvidSP Medline (1946-2012), Embase (1974-2012), PsycINFO (1806-2012), PubMed, CINAHL (1982-2012), ProQuest (Health subsets), and the Cochrane Library (1st quarter 2012). Database search strategies used a combination of database-specific subject headings (e.g. *Awareness, Hallucinations, Dreams, Sensation, Parapsychology, Death, Hospices, Terminal care, Hospice care, Palliative care, Terminally ill*) and textwords linked with proximity operators to increase search sensitivity, e.g. (*death\$ OR dying OR end of life*) adj2 (*phenomen\$ OR awareness OR sensory OR sensation\$ OR experience\$ OR apparition\$ OR vision\$ OR emanation\$ OR hallucinat\$ OR dream\$ OR encounter\$ OR visit\$*).

¹ *The authors are happy to be contacted for full details of the search strategy.*

Unpublished studies were sought using web search engines Google, Bing and Yahoo and the search phrases *deathbed phenomena*, *deathbed visions*, and *near death awareness*. Where possible, web searches were restricted to PDF documents available from educational and governmental sites (.edu, .ac, .gov). We also conducted a hand-search of two online palliative care journals: *BMC Palliative Care* and *BMJ Supportive & Palliative Care*, trawled the reference lists of any relevant articles found, and contacted relevant authors requesting information on other studies or investigations.

Eligibility Criteria

Considering the number of potentially impacting constructs, eligibility criteria were established. These criteria were generated by the researchers after preliminary scoping of the literature and the formulation of the research question. Each criterion was designed to help identify literature relevant to the intent of the review question, and needed to be rigorous and defensible, enabling the researchers to draw valid and reliable conclusions (Meline, 2006).

Inclusion criteria

Study characteristics

- The report must be a study published in a journal in English
- The report must be a patient report or a proxy report by a carer or health professional.

Study population

- The population must be defined as being in a 'palliative care' or 'end of life' context (i.e. having a diagnosis of a life-limiting illness) within a health care setting such as a palliative care service, aged care facility, or under a General Practitioner /Primary Care Physician.

Phenomena

- A significant dream or vision experienced either awake or in a dreaming state
- Seeing, hearing, or feeling something such as a bright or warm light, lovely music, or a beautiful place
- Seeing heavenly places or experiencing religious visions such as God, Jesus or Angels
- Travel analogues such as going on a journey or getting in a car
- The presence of a dead pet or a deceased relative
- Moments of lucidity following from states of unconsciousness.

Exclusion criteria

- Studies dealing with acute, unexpected, sudden death, or NDE
- Studies reporting on terminal restlessness, delirium or hallucinations
- Reports of deathbed 'coincidences' (e.g. a relative waking in the middle of the night knowing the death has occurred)
- Reports of experiences of the bereaved
- Commentaries and opinion pieces.

Quality Appraisal

To ensure a systematic and transparent process we were guided by the PRISMA guidelines for conducting systematic reviews (Moher et al 2009).

We developed a modified quality appraisal check list derived from the Critical Appraisal Skills Programme (CASP) Qualitative checklist. This covered the following 5 constructs: clear statement of aims, the appropriateness of methodology (ie, did the research seek to interpret the actions or subjective experiences of research participants), recruitment appropriate to aims of the study, rigour of analysis, clear statement of findings (CASP, 2013). This modified check list was applied to both the qualitative and mixed methodology papers. Studies were not excluded on the basis of quality assessment. The quality appraisal provided guidance as to the strength of the study. Cautions on quality issues are noted in the discussion as appropriate.

Data analysis

We took a narrative synthesis approach in analysing the results of relevant studies, which has been described as a way of “*bringing together evidence in a way that tells a convincing story of why something needs to be done*” (Popay et al 2006, pg 5). This approach is a key element of a systematic review (Popay et al 2006) and has enabled common themes to be elicited, not only from reading and re-reading the studies (an inductive approach) but also from the authors’ prior understanding of DBP (an a priori approach) (Ryan and Bernard, 2003).

Preliminary synthesis was achieved initially by describing each included study, and from the individual descriptions it was possible to compare and contrast findings across studies and identify common themes. Thematic analysis was used to identify, organise and summarise recurrent or main themes across the multiple studies, and can be useful for qualitative, quantitative and mixed methods studies (Popay et al, 2006). The generated themes are described in this paper. The study characteristics are found in Table 1.

Results

Study Selection

In total, 12,643 citations were identified through database searches and open web searching. Once duplicate citations were removed, 8,489 citations remained for preliminary assessment of titles and abstracts to ascertain relevance to the review question. This screening assessment eliminated 7,654 citations. Where a decision could not be made by title or abstract alone, full text articles were obtained and screened. In all, 835 full text articles were reviewed against the eligibility criteria.

All criteria had to be met for the study to be included in this review. If a question was raised regarding the eligibility of a particular study, consensus was reached by the team through discussion, negotiation and by reference to the research question.

Eight papers met eligibility criteria and were included for analysis (Osis and Haraldsson 1977, Barbato et al 1999, Fountain 2001, Brayne et al 2006, Brayne et al 2008, Muthumana et al 2010, Fenwick and Brayne 2011, Kellehear et al 2011). See Figure 1.

Findings

Interest has been shown in these phenomena by many disciplines and specialties including nursing, medicine (e.g., neurology, intensive care), parapsychology, and psychical and paranormal research. This has implications not only for how the relevant literature can be found, but also in terms of methodologies, differences in language used and the interpretation of findings. For example, the language used to describe these phenomena has varied by author or by their particular perspective and has included: deathbed apparitions, deathbed emanations, deathbed visions, pre-death visions, near death experiences, near death phenomena, nearing death awareness, end of life experiences, death related sensory experiences, visions of the dying, unusual experiences and behaviours, parapsychological phenomena and veridical hallucinations.

DBP reports are neither culturally nor geographically confined, nor can they be explained by religious beliefs. Studies have reported DBP in Eastern Europe (Kellehear et al 2011), North America and India (Osis and Haraldsson 1977, Muthumana et al 2010), United Kingdom (Fountain 2001, Brayne et al 2006, Brayne et al 2008, Fenwick and Brayne 2011) and Australia (Barbato et al 1999). Both males and females reported DBP.

Themes Emerging from the Review

The thematic process involved constant comparison and contrast of similarities and differences across the identified literature. Five themes are identified and discussed here: 1) the phenomenon as described by patients and proxies; 2) timing of the DBP;

3) patient and proxy responses to DBP; 4) professionals' responses; and 5) occurrences of DBP.

Phenomenon Described by Patients and Proxies

All included literature provided descriptions of DBP. Patients most commonly report seeing a deceased relative, often a mother or a sibling (Muthumana et al, 2010). Other visions described include God, Jesus, angels (Osis and Haraldsson 1977, Muthumana et al 2010), animals, children, and heavenly or beautiful places (Fountain 2001, Brayne et al 2008). Other phenomena described were highly significant dreams, or even dreams while awake (Brayne et al 2006, Brayne et al 2008, Kellehear et al 2011). Two observed phenomena common to several studies were sudden lucidity following on from altered conscious states prior to death (Brayne et al 2008, Fenwick and Brayne 2011), and foretelling the likelihood of death soon to occur (Brayne et al 2006, Kellehear et al 2011) (Table 1).

Timing

Responses to and timing of DBP were conceptually a substantial part of the results of the studies. DBP experiences are mostly reported in the last 24 hours before death. In the study by Barbato and colleagues (1999) just under half of DBP (45%) were experienced less than 24 hours before death, with 36% experienced more than a week before death. Similarly, Fenwick et al (2011) found the majority of DBP (54%) were within 12 hours of death with 26% within a week. Muthumana et al (2010) describe a median time for DBP as 2 days before death. Although some patients reported DBP up to a month before (Kellehear et al 2011), many of these authors recognise DBP as an important prognostic factor (Brayne et al 2006, Brayne et al 2008, Kellehear et al 2011).

Patient and Proxy Responses

The majority of studies report that DBP are deeply meaningful experiences that bring comfort, peace and reassurance to the dying person. Interestingly, noticeable emotions, even elation, are reported, as well as the idea that DBP prepare patients for death. Some studies report no frightening or threatening experiences (Muthumana et al 2010, Kellehear et al 2011) however Fenwick and Brayne (2011) reported that one person (of 45) found the phenomenon distressing. Likewise, Osis and Haraldsson (1977) reported that, after experiencing a DBP, 29% of patients (through proxy reports) 'didn't want to go or be taken away'. Some next of kin felt anxious at the patient's report of a DBP, however, in all patient reports in that particular study the experiences were described positively (Barbato et al, 1999).

Professional Responses

While patients and their families typically found the experience to be reassuring and comforting, several of the studies found that patients and/or carers were reluctant to disclose their experiences (Brayne et al, 2006). These same authors also attribute underreporting of DBP to poor management, revealing that staff might not be prepared to discuss this experience with the patients (Fountain 2001, Brayne et al 2006, Brayne et al 2008). This is supported in one study whereby nurses and caregivers in a nursing home described feelings of unease, fearful of upsetting residents by inappropriately bringing up the subject of their death (Brayne et al, 2008).

Barbato et al (1999) recommend that professionals' normalise these experiences for patients and families, however we know that health professionals feel ill-equipped to respond to DBP. As staff are not surprised to hear patients speaking of DBP (Brayne et al, 2008) and DBP were interpreted by staff to be an intrinsic part of dying this has evoked the need for pastoral care, caregiver support, professional supervision, training and education on DBP and on the dying process. (Brayne et al, 2006). This is of particular relevance to nurses as Brayne and colleagues (2006), found that patients would prefer to discuss these issues with them rather than with doctors/medical staff.

Occurrence of the Phenomenon

All eight papers reported that DBP are common. The prevalence of this phenomenon in the community was stated by the authors in two studies (Muthamana et al 2010, Kellehear et al 2011) and could be estimated from data reported in a further three studies (Osis and Haraldsson 1977, Barbato et al 1999, Fountain 2001). Prevalence of those with DBP as a proportion of all respondents in the studies ranged from 24% - 51%, although this estimate is subject to multiple potential sources of sampling bias. However, the figure does confirm anecdotal evidence that DBP are not uncommon and therefore relevant to consideration of the implications for clinical practice.

In this review, most of the included studies (n=7) discussed the issue of DBP being distinct from hallucinations stemming from medical, neurological and psychiatric causes.

Discussion

When considering the occurrence of DBP as described earlier, it can be proposed that DBP are not uncommon in the health setting and they are important considerations in supporting appropriate care for patients and their families who may experience these phenomena. DBP can often be beneficial experiences for many patients and their families. Interestingly, DBP are independent of medical, geographical, psychological and cultural factors. As a result, health professionals need to consider the implications of DBP in care practices.

DBP or Hallucination?

From the acknowledgment of the difficulty of distinguishing DBP from hallucinations in the clinical setting (Brayne et al, 2008), to the delineation of DBP and hallucinations for the purposes of the estimation of prevalence (Kellehear et al, 2011), and the differentiating of DBP and hallucinations by case study (Muthumana et al, 2010), the literature reviewed highlights a complex clinical conundrum. Whether a patient's experience is clinically judged as a hallucination or a DBP may hinge on not only the patient's description of events but also the health care professional's knowledge, wisdom and educational opportunities, as well as the acceptance of the idea of DBP as real for those who experience them.

In a palliative care context there could be the need to consider the patient's experience of the DBP, as well as possible causes for the phenomena, so that appropriate strategies or interventions can be instigated (Ethier, 2005). DBP and hallucinations require very different approaches and management initiatives. Sometimes a patient will appear to 'see things' or perhaps 'talk to someone who isn't

there', which Teeple and colleagues (2009, pg 1) describe as hallucinations: "*the perception of an object or event (in any of the 5 senses) in the absence of an external stimulus*". When a patient is hallucinating, health professionals need to thoroughly assess the patient to identify any reversible causes. With complex pathophysiologic mechanisms, causation of hallucinations can be diverse and can include medications, psychosis, delirium, migraines, tumours or dementia (Teeple et al, 2009).

Delirium is also a common experience for many palliative care patients at the end of life, and often manifested in the form of perceptual disturbances such as hallucinations (O'Malley et al 2008). In a systematic review, Hosie and colleagues (2013) looked at the prevalence and incidence of delirium in specialist palliative care, finding it was as high as 88% in the hours before death. Non-veridical hallucinations have been described as those which are illusory or imagined, which may be experienced as part of delirium, often described as very frightening to those who have experienced or witnessed them; and frequently associated with agitation and involvement of imaginary insects or shadows (Mazzarino-Willett ,2010). It has been reported that patients will often know when they have had a non-veridical hallucination (Brayne et al, 2006) but, in the same way, others have also been clear that what they have experienced is not a hallucination at all (Betty, 2006). O'Malley and colleagues (2008), who studied the viewpoints of patients on their own hallucination, discuss the subjective perception of delirium as being negative and "*trapped in incomprehensible experiences*". The descriptions of hallucinations of organic causes seem very different to the subjective reports of DBP here.

Many palliative care nurses can describe the differences between DBP and hallucinations (Brayne et al 2006), however one study reported that aged care nurses couldn't always distinguish between the two (Brayne et al, 2008). There was also the conclusion that DBP often go unreported due to patient or family fear of being labelled 'mad' or 'crazy' (Brayne et al 2006, Kellehear et al 2011). They may also be mistaken for medication related hallucinations or simply missed by staff (Brayne et al, 2008).

Preparing for Death

Patients define DBP as intensely significant and most studies have described them as providing comfort and helping people to prepare for death (Osis and Haraldsson 1977, Brayne et al 2006, Brayne et al 2008, Fenwick and Brayne 2011). Here the vision or phenomenon is described as assisting the dying person in the final stages of life, and in this way, Kellehear and colleagues (2011) discuss the visions in terms of companionship and reunion. The study by Brayne et al (2006) alluded to look more broadly at what can be thought of as intensely personal experiences that are often described as spiritual and which can help patients connect and appreciate those most meaningful people in their lives. In many of these studies no correlation has been identified between religious belief or expectation, culture and social factors, suggesting that the experience is universal.

Health Professional Response

Health professionals, when faced with reports of DBP, often feel ill prepared to appropriately respond (Brayne and Fenwick 2008, Fenwick and Brayne 2011). It has been proposed that there is a lack of, or the need for, support, education and training

on DBP (Brayne et al 2006, Brayne et al 2008, Muthumana et al 2010). Other literature has supported this, highlighting the emotional or spiritual issues that may be raised following DBP, the impact of DBP, and that training and knowledge can help health professionals to support patients and/or families with issues that are not always understood, and with which clinicians are not always confident in responding to. (Barnett 1991, Serdahely et al 1988, Lawrence and Repede 2012).

Clinical Implications

Barbato and colleagues (1999) found that the issue of DBP disclosure was problematic, with none of the 10 subjects in the study sharing their experience with a health care professional. As these are common phenomena, it is imperative that guidance is available for those working with patients and families.

Recommendations have been suggested to alert all families (and maybe the dying person) to the possibility of DBP (Barbato et al, 1999). It has also been proposed that DBP can be a prognostic indicator, so there are implications for preparing the patient and family for what is happening and what these experiences may mean (Brayne et al 2006).

The literature supports the awareness of DBP as a common experience at the end of life. However, under-reporting is common by patients for fear of not being believed or perceived as mad (Brayne et al 2006, Fountain 2001) or even because they do not feel that their experiences are significant (Kellehear et al 2011). The fears of patients and, possibly, a professional and scientific community that may frown on the perceived 'fringy' (Barbato et al, 1999) character of these phenomena, add to the complexity of challenges and impede understanding as to the depth and breadth of these phenomena. Consequently, despite this being an important issue, there are

challenges to implementing practice recommendations regarding deathbed phenomena. Attitudes and beliefs of families, staff and possibly patients may challenge the reporting of these important experiences.

While recommendations include open discussion, not everyone is comfortable talking to patients or families about these extraordinary spiritual or existential issues, (Brayne et al, 2006). Health professionals are then required to have capacity in communicating these events which could, and should, be incorporated into formal and informal education programs as an integral part of caring for the dying person and his or her family (Fenwick and Brayne 2011, Brayne et al 200).

Strategies for Practice

At the heart of compassionate health care is a basic requirement to truly listen to the patient and carer. Rather than dismiss DBP as medication induced or merely the symptoms of the physiological effects of dying, these significant events can bring comfort to patients and carers. Disclosure of deathbed visions may be a point at which health care professionals can begin to support more spiritual and existential concerns of patients and carers, which have the potential to offer hope, meaning and connection.

Of the eight studies included in the review only two (Brayne et al 2006, Brayne et al, 2008) directly reported opportunities that have or could be instigated in response to DBP. These opportunities included strategies such as pastoral care, caregiver support, professional supervision, training and education on DBP and on the dying process (Brayne et al 2006, Brayne et al, 2008). As a result of what we have

identified as a gap in the literature we propose some strategies for clinical practice, developed from the themes that have emerged, namely: the phenomena experienced; the timing of DBP; patient and proxy responses, professional responses and occurrence. We propose that health professionals consider the following strategies, including education or dissemination strategies to inform all staff of these phenomena within their clinical practice:

Clinical Practice Improvement

- Be aware of the manifestations of DBP that can involve all the senses and include, visions, dreams, seeing or hearing dead relatives;
- Comprehensively assess the patient and exclude organic or metabolic causes. Do not assume that a hallucination is the result of medication or delirium. If the patient is lucid, it may be a DBP (Fountain, 2001);
- Ensure that you are comfortable with the conversation (Brayne et al, 2006). Keep an open mind and be aware of your own personal feelings. Some clinicians are cynical, especially as DBP has not been widely researched and discussed in end of life literature;
- Don't minimise the impact of a DBP, which can be tremendous for the patient or the family (Serdahely et al,1988)
- Think about why the patient or family member has told you about this phenomenon. It could be that they feel most comfortable to do so and are seeking your support/guidance/understanding.

For Patient and Family

- The patient and family need reassurance that this is a common experience. Validate and normalise the experience and reassure them that they are not going mad (Barbato et al, 1999);
- Consider discussing with the family the prognostic factors associated with DBP, as they are usually experienced within the last few days or weeks of life;
- If the patient or family do talk about an experience, ask them to describe it and then listen without labelling or judging;
- Ask the patient what the phenomenon meant to him or her, and if they experienced anything like this before;
- What is the impact of this phenomenon for the patient and those close to him or her? There may be opportunities to further discuss spirituality or existential beliefs. The power of these experiences to heal and comfort both patients and their carers or families (Morse 1994, Muthumana et al 2010)

It is very likely that the patient and/or the family carer have positive, peaceful and highly comforting reactions to DBP. For some it may be a new but vastly spiritual experience. For others it may confirm spiritual beliefs and lifelong bonds and relationships. And we should remember that a small number of patients may find DBP insignificant, confusing or even negative (Osis and Haraldsson 1977, Barbato et al 1999, Fenwick and Brayne 2011). So while for most people this is a positive experience, a small minority of family members or patients are worried and unsettled by the report or experience of DBP. One way of working with them would be to listen and follow their lead. Some gentle questions about their feelings, fears or concerns could be supportive.

The potential for deep emotional, spiritual and pastoral healing and growth and the alleviation of distress following the experience of DBP is cited in the literature. The best way forward for any clinician sitting with a patient or carer is to follow the reactions of those retelling the story of deathbed phenomena and help them to find the meaning within. The most important thing we need to do is listen and be guided by the patient telling his or her story.

Implications for Future Research

Research to establish prevalence of these phenomena and of current clinical responses to reporting of DBP is urgently needed. Further research on the family experience of DBP could inform strategies for preparing families of the possibility of these phenomena occurring and support clinical understanding of the impact of these phenomena on patients and families. Confirming the value of the proposed strategies for clinical support through feedback or Delphi processes could be an important step. There is also the opportunity to explore how training and guidance in this area could enhance clinical care and enhance clinical responses.

Strengths and Limitations

The strengths of this review are in the comprehensive search strategy within bibliometric databases and searches for publications outside these databases. Also this is a topic not well published in the palliative care literature, and we focus on this area of clinical significance and offer clinical guidance. Identifying common themes and experiences and the sociocultural context of the studies offers a basis for considering relevance and transferability of the findings.

There are also some limitations to the study. Only published journal articles were included in this systematic review and so a potential bias may exist. Potentially relevant theses, conference papers and non-English language papers were not sought due to the unfunded nature of this review, although one relevant conference proceeding was pursued to see if it had resulted in a publication. Previous research (including our included studies) on DBP is limited with only a small number of published studies of variable study design and quality. Furthermore there is a risk of bias within some studies as not all papers are firsthand accounts from patients, but rather are from proxies, sometimes months afterwards. This secondary reporting can result in distorted recall or reinterpretation, as stories are re-told often with added layers of complexity from patient to carer to researcher (Kellehear et al 2011).

Conclusion

DBP appears to be a relatively common, but not well understood, phenomenon that has a significant impact on patients both psychologically and spiritually. It is an area of significance for family members who are told of these experiences but may not see them as a prognostic indicator of impending death. With a paucity of research in this area, we have provided some potential clinical responses for the clinicians providing care for patients who have experienced a DBP.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Author's contributions

[Removed] All authors wrote the manuscript. All authors read and approved the final manuscript.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

Acknowledgements

We thank Mikaela Lawrence for assisting with the design of the Endnote library.

References

- Alvarado C (2006) Neglected near-death phenomena. *Journal of Near Death Studies* 24(3):131-151.
- Barbato M, Blunden C, Reid K, Irwin H, Rodriguez P (1999) Parapsychological phenomena near the time of death. *Journal of Palliative Care* 15(2):30-37.
- Barnett L (1991) Hospice nurses' knowledge and attitudes toward the near-death experience. *Journal of Near Death Studies* 9(4):225-232.
- Barrett W (1926) *Death bed visions: Death bed visions* New York, NY, US: Methuen; US
- Bell K, Holden J, Bedwell J (2010) How school counselors can assist student near-death experiencers. *Professional School Counseling* 14(2):165-173.
- Betty L (2006) Are they hallucinations or are they real? The spirituality of deathbed and near-death visions. *Omega: Journal of Death & Dying* 53(1-2):37-49.
- Blanke O (2004) Out of body experiences and their neural basis. *BMJ* 329(7480):1414-1415.
- Brayne S, Farnham C, Fenwick P (2006) Deathbed phenomena and their effect on a palliative care team: a pilot study. *American Journal of Hospice & Palliative Medicine* 23(1):17-24.
- Brayne S, Fenwick P (2008) The case for training to deal with end-of-life experiences. *European Journal of Palliative Care* 15(3):118-120

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. *American Journal of Hospice & Palliative Medicine* 25(3):195-206.

Critical Appraisal Skills Programme (CASP) 2013. *CASP Qualitative Checklists* (<http://www.casp-uk.net/#!/casp-tools-checklists/c18f8>) Oxford. CASP. Accessed 15/Sept/2014

Ethier A (2005) Death-related sensory experiences. *Journal of Pediatric Oncology Nursing* 22(2):104-111.

Fenwick P, Brayne S (2011) End-of-life experiences: reaching out for compassion, communication, and connection-meaning of deathbed visions and coincidences. *American Journal of Hospice & Palliative Medicine* 28(1):7-15.

Fountain A (2001) Visual hallucinations: a prevalence study among hospice inpatients. *Palliative Medicine* 2001, 15(1):19-25.

Hosie A, Davidson PM, Agar M, Sanderson CR, Phillips J (2013) Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: a systematic review. *Palliat Med* 27(6):486-498.

Lordache S, MacLeod R (2011) Do sleep dreams of palliative patients mean anything? *Home Healthcare Nurse* 29(5):291-297.

Kellehear A, Pogonet V, Mindruta-Stratan R, Gorelco V (2011) Deathbed visions from the Republic of Moldova: a content analysis of family observations. *Omega: Journal of Death & Dying* 64(4):303-317.

Lawrence M, Repede E (2013) The incidence of deathbed communications and their impact on the dying process. *Am J Hosp Palliat Care* 30(7):632-9

Mazzarino-Willett A (2010) Deathbed phenomena: its role in peaceful death and terminal restlessness. *American Journal of Hospice & Palliative Medicine* 27(2):127-133.

Meline T (2006) Selecting studies for systematic review: inclusion and exclusion criteria. *Contemporary issues in communication science and disorders* 2006, 33:21-27.

Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(6): e1000097. doi:10.1371/journal.pmed1000097

Morse M (1994) Near death experiences and death-related visions in children: implications for the clinician. *Current Problems in Pediatrics* 24(2):55-83.

Muthumana SP, Kumari M, Kellehear A, Kumar S, Moosa F (2010) Deathbed visions from India: a study of family observations in northern Kerala. *Omega - Journal of Death & Dying* 62(2):97-109.

Nelson H (2000) The near death experience: observations and reflections from a retired chaplain. *Journal of Pastoral Care* 54(2):159-166.

O'Malley G, Leonard M, Meagher D, O'Keeffe ST (2008) The delirium experience: a review. *J Psychosom Res* 65(3):223-228.

Osis K, Haraldsson E (1977) Deathbed observations by physicians and nurses: A cross-cultural survey. *Journal of the American Society for Psychical Research* 71(3):237-259.

Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M et al (2006) Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme Version 2006*, 1.

Pflaum M, Kelley P (1986) Understanding the final messages of the dying. *Nursing* 16(6):26-29.

Ryan G, Bernard H (2003) Techniques to identify themes. *Field methods* 15(1):85-109.

Sartori P (2010) Understanding the subjective experiences and needs of patients as they approach death. *Nursing Times* 106(37):14-16.

Serdahely W, Drenk A, Serdahely JJ (1988) What carers need to understand about the near-death experience. *Geriatric Nursing* 9(4):238-241.

Teeple R, Caplan J, Stern T (2009) Visual hallucinations: differential diagnosis and treatment. *Primary care companion to the Journal of clinical psychiatry* 11(1):26-32.

Wimbush F, Hardie T (2001) Supporting your patient after a near-death experience. *Nursing* 31(10 part 1):48-49.

Table 1 Study characteristics

Authors	Study setting Population	Study Design	Phenomenon	Study Findings
Osis and Haraldsson (1977)	USA and India n=877	Mixed Methods, (questionnaire / telephone interviews)	Terminal patients seeing human figures (67%), heavenly abodes (13%) with elevation of mood in 20%	Independent of medical, psychological and cultural factors. Help patients in transition to another world, to take away, to comfort.
Barbato et al (1999)	Australia n= 47	Quantitative (questionnaire)	49% reported some kind of phenomena. 7/11 seeing deceased relatives, other persons. 4/11 seemed to be looking at someone or something being unusually peaceful. All experiences were described positively.	Real for those who experience it. Frequently misunderstood. No correlation with religion, spiritual beliefs or culture.
Fountain (2001)	UK n= 100	Qualitative (Semi-structured interview)	47% had experienced visual hallucinations within the previous month. 43% - 25/58 perceptions of people (usually spouse or close relative). Complex scenes 14/58; animals and objects 6/58	Need to reassure patients they are not going mad. Talking about hallucinations allowed discussions about psychological or spiritual issues.
Brayne et al (2006)	UK n= 9	Mixed methods (a questionnaire and a tape recorded Interview)	Significant dreams and waking dreams, visions of dead relatives, a feeling around the bed of the patient, feeling of comfort.	Lack of education and training on DBP. Underreporting because of poor handling. DBP comforting and preparation for death. Are a prognostic indicator
Brayne et al (2008)	UK n=10	Mixed methods (a questionnaire	Dead relatives coming to help and comfort patients. Waking or dreaming states. Seeing	Staff can distinguish between hallucination and End of Life Experiences. Nurses and caregivers ill at ease in

		and a tape recorded Interview)	light associated with a feeling of compassion and love, bird and animals appearing and disappearing, sudden lucidity, seeing children.	discussing, fearful of upsetting residents. End Life of Experiences are a prognostic indicator.
Fenwick et al (2011)	General public emails. n=45	Qualitative (analysis of unsolicited emails)	70% saw dead relatives or friends, only 3% saw angels; most frequently siblings, followed by spouse, then parents. Almost all saw a single apparition. 14% experienced sudden lucidity before death.	DBV not dependent on religion. Terminal lucidity could be spiritual event, method of connectedness. DBV helped to calm and ready the person for death.
Muthumana et al (2010)	India. n=104	Qualitative (interviews)	3/30 saw religious figures (Two of God, one of an angel). 17/30 saw mother, 9/30 both parents.	Lack of social, cultural, medical factors that predict DBV. A greater number of relatives must be affected than realised. Further investigation for pastoral support reasons.
Kellehear et al (2011)	Republic of Moldova. n=102.	Qualitative (interviews)	Sightings of dead relatives and friends. Unusual dreams. Most common vision deceased mother.	Positive experiences that add to social wellbeing and psychological health. DBP support, comfort, companionship, reunion, prognosis, choice and control.

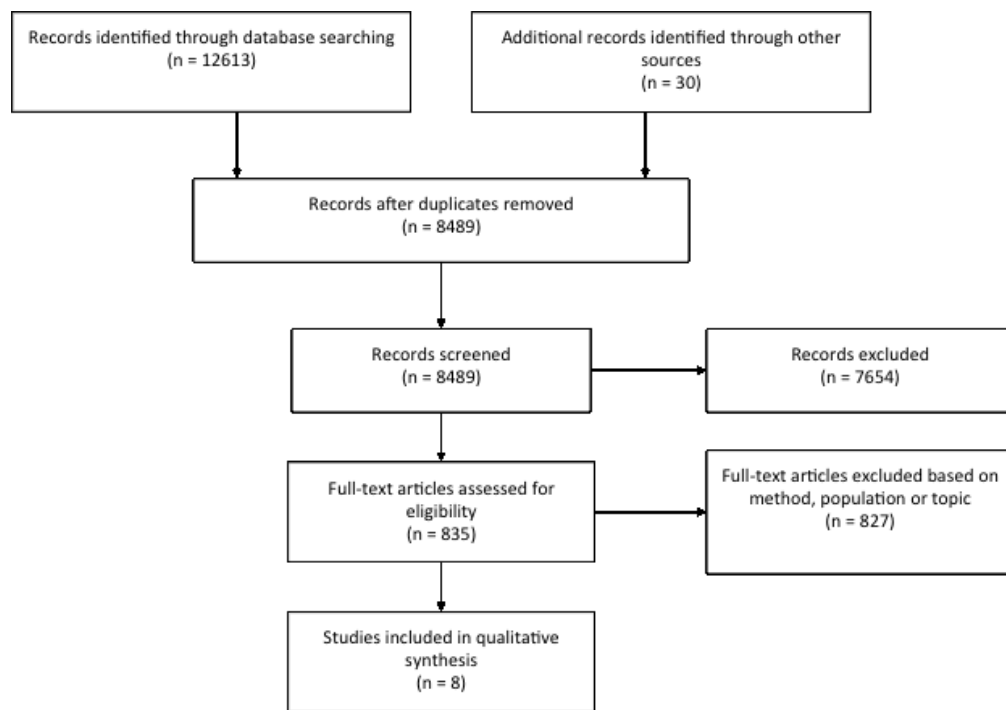


Figure 1 Flow Chart of Results