

End-of-life dreams and visions: a systematic integrative review.

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Manuscript pages (35) Figures (3 at end of manuscript) Tables (2 separate Excel files)

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ABSTRACT

Objectives

End-of-life dreams and visions (ELDVs) have been reported throughout history. We aimed to synthesise the research literature on ELDVs to determine: the proportions of patients, bereaved families, healthcare professionals and volunteers reporting ELDVs; ELDV content, timing and interpretation; and any evidence-based approaches to ELDV-related care.

Methods

A systematic review protocol was registered with PROSPERO (CRD4021282929). CINAHL, Medline, Embase, Emcare and APA PsycInfo were searched for peer-reviewed English-language articles reporting qualitative, quantitative or mixed methods studies that explored reports of ELDVs by patients, bereaved families, healthcare professionals or volunteers. Synthesis used both meta-analysis and a narrative approach.

Results

Of 2045 papers identified by searches, 22 were included, describing 18 studies in a variety of settings. Meta-analyses indicated that 77% (95% confidence intervals [CIs] 69-84%) of patients (n= 119) reported an ELDV compared with 32% (95% CIs 21-44%) of bereaved relatives (n=2444) and that 80% (95% CIs 59-94%) of healthcare professionals (n=171) reported either witnessing or being told of an ELDV in the preceding 5 years. Studies of volunteers reported 34% (95% CIs 20-48%) (n=45) either witnessing or being told of an ELDV over their entire period of service, with 49% of volunteers (95% CIs 33-64%) (n=39) reporting

events occurring in the preceding year. ELDVs reported by patients, bereaved families, healthcare professionals and volunteers were perceived as being a source of comfort. Healthcare professionals and volunteers expressed a need for further education on how to support patients experiencing ELDVs and their families.

Significance of Results

ELDVs are experienced by the majority of dying patients and need consideration in delivering holistic end-of-life care. Little if any research has been conducted in acute care facilities.

Keywords: End-of-life dreams and visions, Palliative Care, Terminal care, Hallucinations/delirium, systematic review.

INTRODUCTION

Palliative care goes beyond consideration of physical suffering, to also attend to the psychological, cultural, spiritual and social needs of persons with a life-limiting illness and their families (WHO, 2020; Lukovsky et al., 2021). These holistic needs include end-of-life phenomena considered to have emotional significance for the person who experiences them (Kerr et al., 2014), and which have variously been described as, ‘deathbed phenomena’(Corless, 2014), ‘death-related sensory experiences’(Ethier, 2005), ‘deathbed communications’ (Lawrence & Repede, 2012), ‘deathbed visions’ (Morita et al., 2016), ‘deathbed dreams’ (Wholihan, 2016), ‘near- death awareness’ (Pan et al., 2021), ‘deathbed escorts’ (Corless, 2014), ‘end-of-life experiences’ (Fenwick & Brayne, 2011), or ‘end-of-life dreams and visions’ (Kerr et al., 2014). This article will use the term ‘end-of-life dreams and visions (ELDVs)’, which has emerged as the most common in recent literature (Depner et al., 2020; Grant et al., 2020; Grant et al., 2021).

Devery et al. (2015) conducted a systematic review of studies published up to 2012 regarding the nature and content of ELDVs, as well as clinical responses to these phenomena. The authors identified eight studies and concluded that ELDVs are a “common but not well understood phenomenon” (p. 125) that are “both psychologically and spiritually” important for patients and their families. They also emphasise that ELDVs should be acknowledged as “real” for those who experience them, and suggested strategies to improve clinical practice. These strategies included raising awareness of ELDVs among healthcare professionals, conducting

comprehensive assessments to rule out organic or metabolic causes for patients' experiences, and, keeping an open mind as to the reasons why patients or families may be telling them about an ELDV. Most importantly, Devery et al. (2015) suggested that healthcare professionals should provide patients and families with reassurance and engage in conversations to explore what meaning or significance the ELDV may have for them. The review by Devery et al. (2015) did not include a meta-analysis of the occurrence of ELDVs nor examine the influence that setting, culture, race, or religion might have on ELDVs. Given the 10 years that have elapsed since Devery et al. (2015) conducted their searches, it is possible that new evidence has emerged regarding patient, family and health professionals' understandings of ELDVs, and optimal approaches to related care.

AIM AND RESEARCH QUESTIONS

The aim of this review was to explore empirical evidence to date on ELDVs as reported by patients, families and health professionals, or volunteers in any setting where end-of-life care has been provided, with a view to answering the following questions:

1. What proportions of patients, bereaved families, healthcare professionals and palliative care volunteers report ELDVs?
2. What is the content and timing of reported ELDVs?
3. How do patients, bereaved families, health professionals, and volunteers interpret ELDVs?
4. Are patterns in reporting and interpretation influenced by factors such as the group reporting (i.e., patient, family, healthcare professional, volunteers), setting, culture, and religion/spirituality?

5. What care is provided in relation to ELDVs, and what evidence is there for the best approach?

METHODS

Eligibility Criteria

Articles were eligible for inclusion if they were published in a peer-reviewed English-language journal and reported mixed methods, qualitative or quantitative studies exploring reports of ELDVs by patients, families, health professionals or volunteers in any setting where end-of-life care was provided published up to August 2021.

Articles were excluded if they were examining near-death experiences in a population not approaching end of life. Commentaries, reviews, personal reflections, single case studies and opinion pieces were also excluded from this review.

Information Sources

CINAHL, Medline, Embase, Emcare, APA PsycInfo electronic literature databases were searched with no date restrictions. Hand searches were conducted on reference lists of any relevant articles found.

Search Strategy

Databases were search with a combination of subject terms (e.g., ‘terminal care’ and ‘dream’) and keywords relating to ELDVs. Keywords were similar to those used by Devery et al. (2015)

but were expanded to include any new terms that were found to update the search strategy (Garner et al., 2016).

Two independent reviewers (AH and TL) reviewed titles and abstracts of the first 200 records and discussed any discrepancies. This process achieved 99% consensus, after which screening was conducted by one reviewer alone (AH).

Data collection process

Data were extracted and charted into a table detailing: author and year of publication, country and setting, sample characteristics, aims/question, methodology, any intervention, and main study findings.

Study risk of bias assessment

The risk of bias for each study was assessed independently by AH and TL who met to reach consensus. Studies of prevalence were assessed using the Johanna Briggs Institute (JBI) Checklist for Prevalence Studies (Munn et al., 2018); qualitative studies were assessed using the JBI Checklist for Qualitative Research (Lockwood et al., 2015); and studies utilising participant surveys were assessed using the checklist described by Kelley et al. (2003).

Synthesis methods

The proportions of people reporting ELDVs from each participant group (patients, bereaved families, healthcare professionals and volunteers) were summarised using meta-analyses in accordance with the Cochrane Handbook for Systematic Reviews (Higgins et al., 2019). A random effects model was used, and 95% confidence intervals were estimated. Heterogeneity between estimates was measured using I^2 statistics using recommended thresholds.

A narrative approach to synthesis was taken, following guidance by Popay et al. (2006). In the preliminary synthesis, study findings were grouped according to methodology (qualitative, quantitative, and mixed methods) and tabulated according to key characteristics of setting, population and findings relating to ELDVs. Study findings were then compared using textual summaries to identify patterns and explore heterogeneity in findings (Kelley et al., 2003; Popay et al., 2006; Devery et al., 2015).

RESULTS

Selection process

(Figure 1)

Study characteristics

From the database searches 2,045 articles were identified, 22 met inclusion criteria, reporting 18 distinct studies (Figure 1). Of the 18 studies, eight were quantitative (Barbato et al., 1999; Morita et al., 2006; Lawrence & Repede, 2012; Dam, 2016; Chang et al., 2017; Santos et al., 2017; Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020), 6 used mixed methods (Fenwick et al., 2010; Muthumana et al., 2010; Kellehear et al., 2011; Kerr et al., 2014; Grant et al., 2020; Grant et al., 2021), and 4 were qualitative (Brayne et al., 2006; McDonald et al., 2014; Depner et al., 2020; Nyblom et al., 2020). The pool of studies included all continents except for Africa and Antarctica (Table 1). Studies were conducted within community palliative care (n= 11), inpatient palliative care units (n=9), nursing homes (n=5), and acute hospital care (n=3). Participants included patients receiving end-of-life care, bereaved families, healthcare professionals and volunteers. In the overall sample of healthcare professionals, participation by nurses (n=191) (Brayne et al., 2006; Brayne et al., 2008; Fenwick et al., 2010; Lawrence & Repede, 2012; McDonald et al., 2014; Chang et al., 2017; Santos et al., 2017) and

nursing assistants (n=58) (Brayne et al., 2006; Santos et al., 2017), was greater than that of doctors (n= 53)(Brayne et al., 2006; Fenwick et al., 2010; Chang et al., 2017). Where reported, the number of female participants was greater than that of men (Table 1).

Risk of bias in studies

More recent studies tended to have a lower risk of bias, regardless of their methodology. For studies of frequency of reporting, sample size and sampling procedures were limited in two of the five studies (Brayne et al., 2008; Fenwick et al., 2010). Across the qualitative studies, there was insufficient reporting regarding the location of the researcher culturally or theoretically (Brayne et al., 2006; Brayne et al., 2008; Fenwick et al., 2010; Muthumana et al., 2010; Kellehear et al., 2011; McDonald et al., 2014; Nosek et al., 2015) and discussion of the influence of the researcher on the research (Brayne et al., 2006; Brayne et al., 2008; Fenwick et al., 2010; Kellehear et al., 2011; McDonald et al., 2014). Several studies utilising surveys to collect data were limited by lack of justification of methods being used (Fenwick et al., 2010; Lawrence & Repede, 2012; Dam, 2016), insufficient description of research tools (Fenwick et al., 2010; Lawrence & Repede, 2012; Dam, 2016; Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020) and lack of detail on methods and tests used for data analysis (Barbato et al., 1999; Fenwick et al., 2010; Lawrence & Repede, 2012; Dam, 2016; Santos et al., 2017; Claxton-Oldfield & Dunnett, 2018). Additionally, there was a lack of reporting on how consent was obtained (Lawrence & Repede, 2012; Dam, 2016; Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020), and discussion on how those who participated may have differed from those who did not (Fenwick et al., 2010; Lawrence & Repede, 2012; Dam, 2016; Santos et al., 2017; Claxton-Oldfield & Dunnett, 2018). Issues of quality will be noted in the discussion where appropriate. The results of individual study quality assessments are available as supplementary data.

Proportions of participants reporting ELDVs

Results from meta-analyses for estimates of the proportion of patients and families reporting ELDVs are provided in Figure 2. Variability in study settings and sample characteristics limited the opportunity for direct comparisons between patients and families with the exception of the community setting in India, where estimates from two separate studies identified a higher rate among patient reports (63.3%; 95% confidence intervals [CIs] 51%-75%) compared to bereaved families (30%, 95% CIs 21-39%) (Muthumana et al., 2010; Dam, 2016). Muthumana et al. (2010) suggested that fear of being embarrassed in front of ‘high status health care professionals’ might have led to under-reporting by bereaved family members. Morita et al. (2016) examined ELDVs reported by Japanese carers in the community and suggested that a lack of universal definition for ELDVs might have led to some perceiving the phenomena to be hallucinations or delirium. It is also noteworthy that bereaved family members were asked about their experiences immediately following the death in only one study (Muthumana et al., 2010), with others varying from one month to two years post-bereavement (Barbato et al., 1999; Kellehear et al., 2011). Authors of these latter studies have suggested that recall might have been a factor influencing estimates.

Two studies examined the experience of healthcare professionals, both of which focused on recall over the previous 5 years (Fenwick et al., 2010; Santos et al., 2017), with one by Fenwick et al. (2010) also collecting data prospectively over one year. Results from a meta-analysis synthesising estimates from these studies are presented in Figure 3. Heterogeneity seems to have partly been explained by setting, given that health professionals from palliative care settings tended to have higher reporting rates than those in a nursing home or on an oncology ward, although this was complicated by a comparison that included health professionals from

both a PCU and nursing home, albeit a majority from the former. The study by Santos et al. (2017) comparing health professionals within different settings, reporting events from the previous 5 years, found that healthcare professionals in a PCU (94%, 95% CIs 81-99%) were more likely to have witnessed or been told of an ELDV than those in an oncology ward (63%, 95% CIs 48-77%) or nursing home (61%, 95% CIs 47-74%) (Figure 3). The rate reported over 5 years by Fenwick et al. (2010) (92%, 95% CIs 79-98%) was similar to that of the PCU group of Santos et al. (2017). The healthcare professionals in the Fenwick et al. (2010) study were predominantly from palliative care units (n=28) rather than nursing homes (n=10). Fenwick et al. (2010) found no significant difference ($p < 0.01$) between the reporting rates from the retrospective 5-year study and the prospective 1-year study.

The groups studied by Santos et al. (2017) had varying rates of exposure to ELDVs, with the estimated median of ELDVs observed or heard described over the 5 years being 15 (Q_{25-75%}, 4-62.5) for PCU, 3 (Q_{25-75%}, 0.0-6.5) for oncology, and 1 (Q_{25-75%}, 0.0-0.3) for nursing homes (Santos et al., 2017). In comparison, palliative care nurses responding to a survey asking about patients they had cared for, either at home or in a palliative care unit, during the previous 30 days, reported encountering a median of 4.8 patients (CIs not reported) per month experiencing ELDVs (Lawrence & Repede, 2012). Fenwick et al. (2010) report varying exposure rates for healthcare professionals within both their 5-year retrospective (84% reporting 1-50 ELDVs and 8% 50-100 ELDVs) and 1-year prospective studies (62% reporting 1-50 ELDVs and 0% 50-100 ELDVs) and suggest that an inequality of exposure to dying patients may lead to varying reporting rates by healthcare professionals.

Studies focusing on volunteers asked them to report either over the previous 12 months (Claxton-Oldfield & Dunnett, 2018) or the whole of their volunteering experience (Claxton-

Oldfield et al., 2020). Forty-nine percent (95% CIs 33-63%) of volunteers (n=39) reported either witnessing or being told of an end-of-life dream and vision in the preceding year and 34% (95% CIs 20-48%, n=45) of volunteers reported events occurring over their entire period of service. Volunteers reporting over the preceding year had an average volunteering experience of 9.6 years (SD = 8.3) (Claxton-Oldfield & Dunnett, 2018) whilst those reporting from their whole experience had an average of 12.1 years (SD = 9.2) (Claxton-Oldfield et al., 2020). The authors of the first study themselves highlighted their small sample size and low response rate as factors requiring caution when interpreting their results (Claxton-Oldfield & Dunnett, 2018).

Influence of sample characteristics on ELDV reporting

Patients, bereaved families, and healthcare professionals who participated in the studies were from a diverse range of religions and cultures (Table 2). Studies of volunteers were the exception in that both were conducted in Canada, however, few details were provided.

In discussing the effects of religion on patient reports of ELDVs, both Nyblom et al. (2020), who studied patients in a “highly secular country” (Sweden), and Dam (2016), who studied patients in a country with a “rich religious heritage” (India), remarked only on the lack of religious content of the ELDVs their patients reported. Muthumana et al. (2010), in their study of bereaved families in India, reported that 44% of Hindus experienced ELDVS compared to 21.2% of Muslims, and that the reason for this was unclear and required further investigation. In their report of a Japanese study, Morita et al. (2016) suggested that families with stronger religious beliefs were more likely to report ELDVs but did not investigate this further.

From their study conducted in Brazil, Santos et al. (2017), when comparing their results to studies conducted in the UK (Fenwick et al., 2010) and the US (Lawrence & Repede, 2012) suggested that “cultural factors” not otherwise specified were not associated with reporting of ELDVs by healthcare professionals. A study of whether healthcare professionals’ perceptions of ELDVs were influenced by personal spirituality using the Duke Religion Index (DUREL) (Koenig & Büssing, 2010), showed that there was no difference in reporting rates between those who had high rates of attendance at organised religious activities (48.4%) compared to those who had low rates of attendance (51.6% $p < 0.267$ Chi squared test) (Santos et al., 2017).

Volunteers expressed that their experience of talking to patients about ELDVs had a positive impact on their own spirituality and religious beliefs and lessened their own fears (Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020).

Content of experience

In two studies, ELDVs reported directly by dying patients were described as beginning while they were asleep (dreams) but having such intensity that they often continued as a waking reality (visions) (Kerr et al., 2014; Dam, 2016). In all studies, dying patients described in detail their ELDVs as being vivid and real (Kerr et al., 2014; Dam, 2016; Nyblom et al., 2020).

The majority of ELDVs were of deceased relatives and friends, including - in order of frequency - parents, siblings, and spouses (Muthumana et al., 2010; Fenwick & Brayne, 2011; Kellehear et al., 2011; Depner et al., 2020; Grant et al., 2020). Other less common phenomena included dreaming of going on a journey (Brayne et al., 2008; Fenwick et al., 2010; Kerr et al., 2014; Nosek et al., 2015; Dam, 2016; Claxton-Oldfield & Dunnett, 2018; Nyblom et al., 2020), seeing animals (Fenwick et al., 2010; Fenwick & Brayne, 2011; Kerr et al., 2014; Dam, 2016),

seeing religious figures (Muthumana et al., 2010; Fenwick & Brayne, 2011; Kerr et al., 2014), increased awareness of impending death (Brayne et al., 2008; Muthumana et al., 2010; Kellehear et al., 2011), seeing beautiful places or colours, and, hearing music (Claxton-Oldfield & Dunnett, 2018).

Timing of experience

The time period prior to death over which ELDVs were reported varied from 30 days prior to death up until the person was imminently dying, with the majority occurring in the last 48 hours of life (Barbato et al., 1999; Fenwick et al., 2010; Kellehear et al., 2011; Kerr et al., 2014).

Kerr et al. (2014) suggested that the changes in content and frequency of ELDVs in their study may have been prognostically significant, observing that ELDVs involving deceased relatives increased as death neared. Similarly, Brayne et al. (2006) reported healthcare professionals perceiving a change in the language used by patients to describe ELDVs, with those imminently dying talking about deceased relatives who had ‘visited’ and of needing to ‘leave ‘ suggesting that this may also be a prognostic indicator for nearing death .

Interpretation of ELDVs

The overwhelming interpretation of ELDVs made by most studies was that ELDVs were comforting and provided personal or spiritual meaning, bringing a sense of peace to the patients involved (Morita et al., 2006; Fenwick et al., 2010; Kellehear et al., 2011; Lawrence & Repede, 2012; Kerr et al., 2014; Nosek et al., 2015; Chang et al., 2017; Santos et al., 2017; Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020; Depner et al., 2020; Grant et al., 2020; Nyblom et al., 2020). However, not all ELDVs were reported as comforting experiences, with a small proportion of patients bereaved families, healthcare professionals and volunteers

finding these experiences confusing or distressing, for either the patient or themselves (Barbato et al., 1999; Morita et al., 2006; Fenwick & Brayne, 2011; Kerr et al., 2014; Dam, 2016; Claxton-Oldfield et al., 2020; Depner et al., 2020).

Patients and bereaved families

The study by Nosek et al. (2015), using the same sample as Kerr et al. (2014), analysed patient responses to ELDVs and identified six categories of ELDVs – ‘comforting presence’, ‘preparing to go’, ‘watching or engaging with the dead’, ‘loved ones waiting’, ‘distressing experiences’ and ‘unfinished business’. “Distressing experiences” were those replaying traumatic life experiences such as previous war experiences, abusive childhoods, or difficult relationships and were described by patients as “reminiscent of negative past experiences” (p.271). “Unfinished business” referred to experiences of not being able to complete tasks in life that could potentially lead to “increased anxiety about family being left behind, or incomplete tasks” (p.272).

The study by Kellehear et al. (2011) identified six similar themes to describe the role ELDVs may have for dying patients, based on proxy reports by families. These included support for the dying person, comfort, companionship, reunion, prognosis, and choice and control. Bereaved families who had witnessed a dying person experiencing an ELDV considered them to be “natural and transpersonal phenomena” within the dying process (Morita et al., 2006). Bereaved families who provided care for the dying also found patients’ ELDVs to be comforting to themselves, and for some, a positive contribution to their grieving process (Barbato et al., 1999; Morita et al., 2006; Fenwick et al., 2010; Fenwick & Brayne, 2011; Lawrence & Repede, 2012; Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020; Grant et al., 2020).

Healthcare professionals and volunteers

Healthcare professionals described ELDVs as “transpersonal, spiritual experiences” for patients (Brayne et al., 2006; Brayne et al., 2008; Fenwick et al., 2010; Chang et al., 2017; Santos et al., 2017) and spoke of them as “having profound meaning for the patient” (Brayne et al., 2008; Fenwick et al., 2010). In several studies, healthcare professionals reported thinking that ELDVs contributed to a peaceful death and that they were an intrinsic part of the dying process, rather than a result of medications or fever (Lawrence & Repede, 2012; Chang et al., 2017).

Volunteers who visited dying patients stated a belief that patients who had ELDVs appeared to have a more peaceful death (Brayne et al., 2006; Fenwick et al., 2010; Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020). Volunteers also expressed that they believed ELDVs to be of a spiritual nature rather than a result of the physical deterioration associated with dying (Claxton-Oldfield & Dunnett, 2018).

In some studies healthcare professionals expressed the view that ELDVs may be hallucinations caused by delirium (Fenwick et al., 2010; McDonald et al., 2014; Santos et al., 2017). However, when asked, 69.3% of Brazilian healthcare professionals (95% CIs 62.3-76.3%) (Santos et al., 2017) and 67% of English healthcare professionals (95% CIs 52-87%,) (Fenwick et al., 2010) perceived themselves to be able to distinguish between experiences caused by delirium and ELDVs based on the ability of patients to report their experience with clarity and from the demeanour of the patient before, during and after the event (Brayne et al., 2006; Brayne et al., 2008; Fenwick et al., 2010; Santos et al., 2017). Nurses surveyed by Lawrence and Repede

(2012) reported that patients experiencing ELDVs required less medications, and, experienced less terminal agitation than those patients who did not experience ELDVs.

The emotional impact of ELDVs for healthcare professionals was said to be influenced by the emotional response of patients. Healthcare professionals who perceived ELDVs to help patients accept dying said this enabled them to better provide support to patients and families, and to experience a sense of personal and professional satisfaction (McDonald et al., 2014).

Care related to ELDVs

In the study by Santos et al. (2017) , examining healthcare professionals in a palliative care unit, nursing homes and an oncology ward, 36.8% of all healthcare professionals stated they were fearful of discussing ELDVs with patients for fear of causing distress, with no significant difference related to setting. This study also revealed a consensus across the settings that professionals felt they lacked training on how to respond to ELDVs. However, those who worked in the palliative care unit exhibited a greater openness and interest in undertaking further training and were more likely to discuss ELDVs with their supervisors and colleagues compared to healthcare professionals from the nursing homes or oncology ward (Santos et al., 2017). Respondents who wanted more training identified a specific interest in learning how to interpret and respond to the metaphorical language used by patients approaching death and how to start conversations about this aspect of the dying process. Respondents also expressed the opinion that information on ELDVs should be a part of end-of-life education (Brayne et al., 2006; Fenwick et al., 2010; Santos et al., 2017).

Two studies conducted with volunteers revealed that, like healthcare professionals, they were open to discussing ELDVs with patients but that they too had not received any formal training

in how to approach this. Volunteers specifically requested education on the nature of ELDVs and how best to converse with patients, families and other members of the health care team in a way that did not convey an adverse value judgment on the experience (Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020).

DISCUSSION

This systematic review identified a substantial empirical evidence base regarding the rates of reporting, content, timing and interpretation of ELDVs, synthesising an additional 16 studies further to those reviewed by Devery et al. (2015). Evidence to date suggests that ELDVs are prevalent throughout the dying process. However, whilst there have been several recommendations for care of patients experiencing ELDVs and their families (Barbato et al., 1999; Brayne et al., 2006; Sartori, 2010; McDonald et al., 2014; Devery et al., 2015; Wholihan, 2016), there have been no studies evaluating such care. Given the growing number of studies and mainstream journals in which more recent articles have been published, it appears that ELDVs are gaining recognition as a phenomenon of interest and are no longer considered “fringy” (Barbato et al., 1999). However, despite the growing number of studies on this phenomenon, there remains no consensus on the definition of an ELDV and what constitutes an ELDV.

Empirical studies have importantly revealed that rates of reporting for ELDVs appear to be highest for the group of respondents who experience them - patients. While estimates for healthcare professionals in 2 studies exceeded 90% (Fenwick et al., 2010; Santos et al., 2017), participants in this group were reporting on whether they had encountered one or more patient with ELDVs over 5 years. If the majority of patients experience ELDVs as suggested by the

patient studies, then *all* healthcare professionals who routinely care for people who are dying should have encountered at least one patient experiencing an ELDV. This raises the question of why healthcare professionals, as well as bereaved families and volunteers, have lower rates of reporting, for which there is a range of possible answers. First and foremost, rates of reporting by groups other than patients is likely to be affected by whether the patient recounted their experience. Without a universal definition of ELDVs, respondents in other groups may dismiss ELDVs as hallucinations secondary to medications or delirium, or, alternatively they may misconstrue what the patient is saying or doing (Callanan & Kelley, 1992; Kellehear, 2020). A universal definition of ELDVs is urgently needed as misinterpretation of ELDVs by healthcare professionals may lead to inappropriate administration of medical interventions which may inhibit the dying persons' ability to communicate meaning at the end of life resulting in an increased sense of isolation (Callanan & Kelley, 1992; Barbato, 2009; Doka, 2020; Kerr & Mardrossian, 2020)). That said, even with an agreed definition to assist clinicians to identify ELDVs, patients may not share their ELDVs due to fear of upsetting loved ones, fear of embarrassment or simply because they have not been asked (Barbato, 2009).

The studies of healthcare professionals suggest that setting and experience of those caring for the person dying are associated with increased reports of ELDVs, with those who work in palliative care settings being more likely to witness or have an ELDV reported to them compared to oncology and nursing homes (Lawrence & Repede, 2012; Santos et al., 2017). Unfortunately, there have been no studies examining the experience of healthcare professionals in acute care settings, where over 50% of deaths occur (Broad et al., 2013; Schwarz & Benson, 2018). Future research is needed to determine whether reports of ELDVS provided by acute care health professionals is lower than those from other settings because they are less aware of the phenomena and/or due to infrequent exposure to people who are dying.

Across all studies, nurses and nurses' aides reported being told of a greater number of ELDVs, when compared to medical staff (Brayne et al., 2006; Brayne et al., 2008; Lawrence & Repede, 2012; McDonald et al., 2014; Chang et al., 2017; Santos et al., 2017). This has been attributed to the possibility that patients and bereaved family members might be more willing to speak to nurses (Brayne et al., 2006), and that medical staff might be more likely to either dismiss a report of an ELDV as not being clinically important or diagnose it as delirium (Fenwick et al., 2007; Janssen, 2015; Chang et al., 2017; Kerr & Mardrossian, 2020; Pan et al., 2021). Additionally, nurses provide most of the care to the dying, and therefore have more opportunities to witness or be told of ELDVs (Sartori, 2010; Dong & Fu, 2014; Wholihan, 2016).

Interestingly, while a meta-analysis was not possible due to methodological differences between studies, the proportion of volunteers reporting ELDVs tended to be lower than that for healthcare professionals. This finding needs to be carefully considered given there were only two studies that examined prevalence in volunteers, each with a small sample size (Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020). Also, the likelihood of observing ELDVs will depend on the type of role that volunteers are engaged with, which was not explored in these studies.

The studies reviewed were conducted across much of the world and included people from a variety of cultural, religious, and social backgrounds. We found no evidence to support previous suggestions that informants' culture, religion, or social background might influence ELDV reporting and content (Alvarado, 2006; Mazzarino-Willett, 2010; Wholihan, 2016).

The content of ELDVs remains consistent throughout the studies reported and anecdotal reports (Callanan & Kelley, 1992; Barbato, 2009; Alvarado, 2014; Wallace, 2016; Heyen, 2019; Doka, 2020) with dreams and visions of deceased relatives, and dreams of travel being most often reported. Studies and anecdotal reports of timing indicate that ELDVs are not “one off” events and not necessarily confined to the “deathbed” but rather can occur over a period of time leading up to one’s death with the frequency of ELDVs increasing as death nears (Callanan & Kelley, 1992; Barbato, 2009; Kerr et al., 2014; Doka, 2020).

Present throughout all studies was the ongoing debate regarding the nature, cause and significance of ELDVs. Healthcare professionals, experienced in caring for the dying, consistently reported being able to distinguish between “hallucinations caused by fever, medications or delirium” and ELDVs (Brayne et al., 2006; Brayne et al., 2008; Fenwick et al., 2010; McDonald et al., 2014; Santos et al., 2017). However, the veracity of these claims is difficult to assess. Studies with patients have provided support for the idea that ELDVs differ from hallucinations, by the clear vivid accounts given by patients, their demeanour and the nature of the feelings evoked (Fenwick et al., 2010; Kerr et al., 2014; Nosek et al., 2015; Santos et al., 2017; Nyblom et al., 2020). In contrast, studies of patients experiencing delirium report that patients who remember the experience describe it as distressing and being fearful, anxious and threatened during the event (O'Malley et al., 2008; Grover et al., 2015). Kellehear (2020) p.243 suggests that the use of the term hallucination to describe ELDVs may be “unhelpful” in that it can be “stigmatising and alarming for patients and families”, and result in a lack of support.

Additionally, Nyblom et al. (2020) suggest that it is the patient’s ability to recall their dreams and the vivid nature of ELDVs that distinguish them from usual dreams, particularly for elderly

patients, as dream recall diminishes with ageing (Zanasi et al., 2005; Scarpelli et al., 2019). Analysis of ELDV content would suggest that their role is to provide comfort and closure to the dying (Depner et al., 2020).

It needs to be noted that not all ELDVs are comforting, with a small proportion of patients reporting ELDVs as distressing (Barbato, 2009; Fenwick et al., 2010; Santos et al., 2017; Depner et al., 2020). Negative experiences may be reminiscent of past trauma and should not be discounted as having no meaning (Shinar & Marks, 2015; Depner et al., 2020). At the same time, it is possible that groups other than patients may report ELDVs experienced by loved ones as distressing based on their own response to the event or lack of understanding of what they are witnessing or being told (Morita et al., 2006; Muthumana et al., 2010; Grant et al., 2020).

Healthcare professionals and volunteers experienced with caring for the dying reported a need to be able to support both patients and families when ELDVs occur (Fenwick et al., 2010; Santos et al., 2017) and requested formal education regarding ELDVs and how best to support patients and their families (Brayne et al., 2006; Brayne et al., 2008; Lawrence & Repede, 2012; McDonald et al., 2014; Chang et al., 2017). Healthcare professionals who provided support to patients and their families found the experience to be one of comfort to themselves and professionally rewarding (McDonald et al., 2014), and suggest that being able to discuss ELDVs in multidisciplinary meetings would be useful (Brayne et al., 2008; Fenwick et al., 2010; Santos et al., 2017). Recent studies of volunteers would also indicate that education concerning ELDVs continues to be lacking and suggests that ongoing training and mentoring for volunteers would be beneficial (Claxton-Oldfield & Dunnett, 2018; Claxton-Oldfield et al., 2020).

The current lack of formal recognition of ELDVs as part of the dying process has consequences for patients, their families and healthcare professionals. Despite the absence of evaluative studies, it has been recommended that healthcare professionals should see ELDVs as an opportunity to empower patients and families to find peace and closure, complete any unfinished business, and to attend to any rituals of significance (Fenwick et al., 2007; Barbato, 2009; Mazzarino-Willett, 2010; Broadhurst & Harrington, 2016; Doka, 2020). To this end, it has been suggested that healthcare professionals witnessing an ELDV engage, listen, and validate the patient's experience not only to normalise it but also to ensure that all concerned see it as a transcendent experience rather than a problem requiring medical attention (Callanan & Kelley, 1992; Barbato, 2009; Mazzarino-Willett, 2010; Wholihan, 2016). Future studies are urgently needed to evaluate care related to ELDVs to further inform clinical guidance as misunderstanding an ELDV can have negative consequences for the patient and their family and healthcare professionals (Barbato, 2009; Doka, 2020; Kerr & Mardrossian, 2020).

Limitations

The main limitation of our review is that the lack of a consistent definition for ELDVs means we cannot be sure that estimates of the proportions of participants reporting these phenomena were comparable between studies. There was also heterogeneity among settings and samples that made it difficult to compare directly between groups. Additionally, there is a lack of evidence as to the current state of knowledge of ELDVs within the acute care setting and the ability of health care professionals in acute care to respond appropriately to patients experiencing or sharing an ELDV.

Conclusion

ELDVs frequently occur and may be important accompaniment to the dying process that provide comfort, support and closure to those who are dying. Across all studies, ELDVs were consistent in their description of being of deceased relatives and of being a personally or spiritually transforming event, indicating that culture and religion appear to not influence the occurrence of ELDVs. Family members and healthcare professionals who witness or are told of ELDVs may also find comfort, but the lack of a universal definition for ELDVs means that these events may be missed.

Healthcare professionals and volunteers who are experienced in caring for the dying acknowledged that ELDVs are comforting to patients and families, whilst also expressing a need for education to enable them to provide appropriate support. There is increasing acknowledgement of ELDVs within palliative care and nursing home settings, however evidence is lacking for acute care settings.

Funding Statement

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Conflicts of Interest : None

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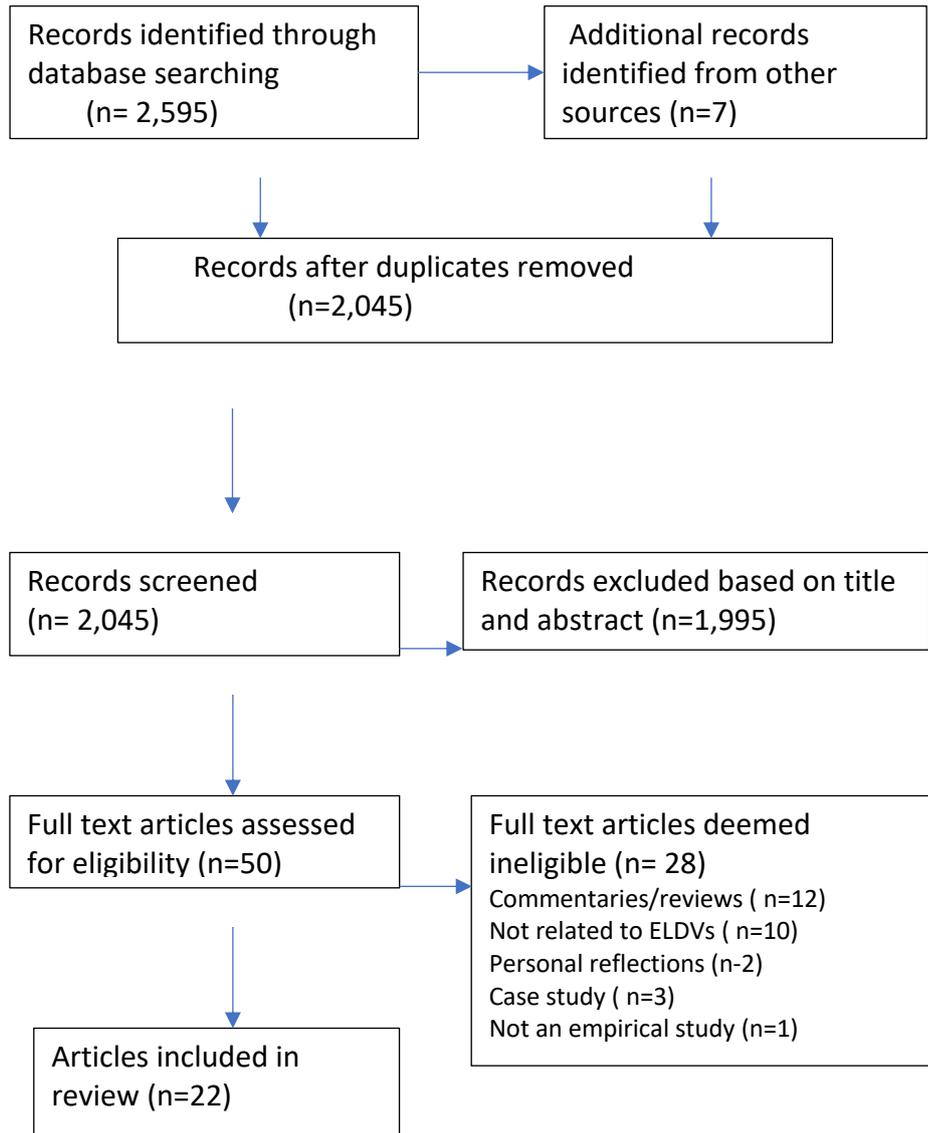


Figure 1 – PRISMA flowchart of article selection process.

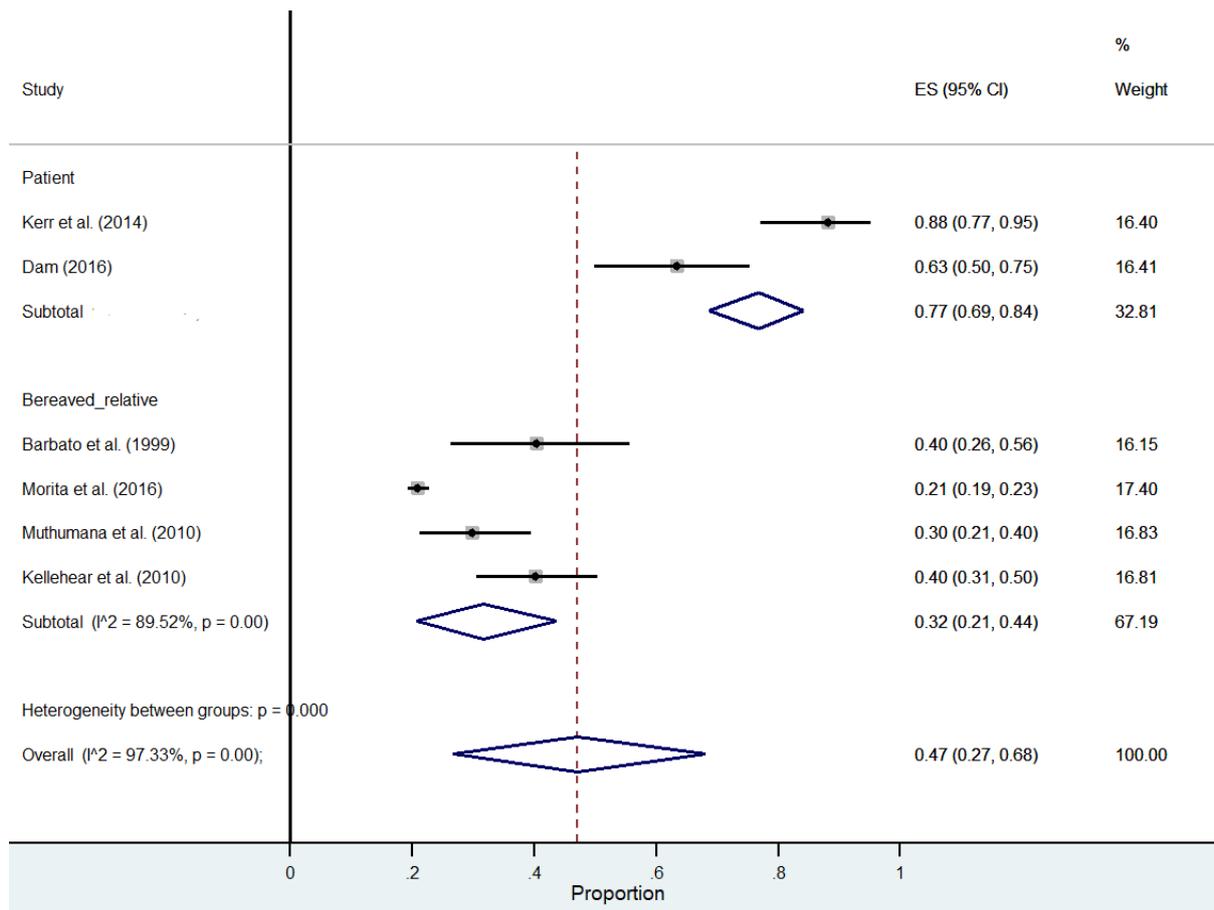


Figure 2 – Forest plot of the proportions of patients and bereaved families reporting ELDVs.

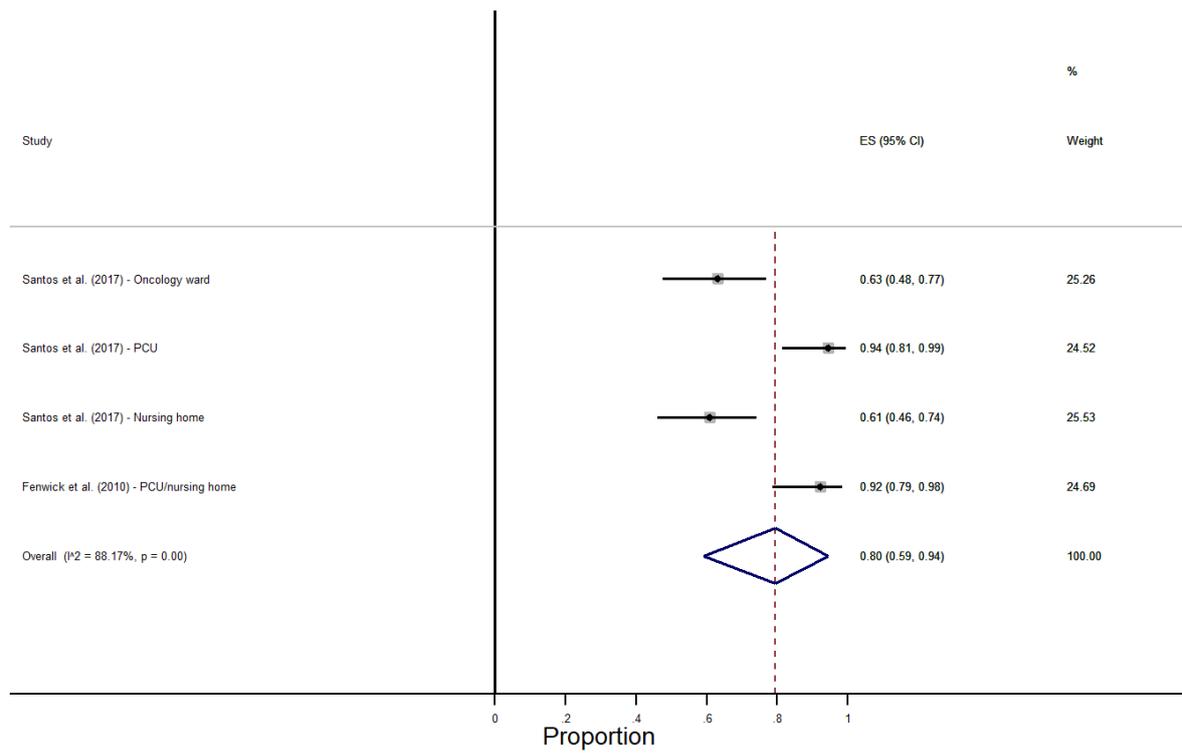


Figure 3. Forest plot of proportions of healthcare professionals reporting ELDVs based on care setting.

Participants	Sample size (n)	Males (n)	Females (n)	Setting(s)	Country	Authors
Patients	59	19	40	PCU	USA	^a Kerr et al.,(2014); ^a Grant et al., (2014)
	63	22	41	PCU	USA	^a Nosek et al., (2015)
	25	11	14	PCU	Sweden	Nyblom et al., (2020)
	60	26	34	Home	India	Dam,(2016)
	55	16	39	PCU	USA	Depner et al.,(2020)
Bereaved Relatives	47	11	36	Home	Australia	Barbato et al, (1999)
	45	NR	NR	Home	UK	Fenwick et al., (2010)
	2191	681	1510	Home	Japan	Morita et al.,(2016)
	104	NR	NR	Hone	India	Muthumana et al., (2010)
	102	NR	NR	Home	Moldova	Kellehear et al., (2010)
	500	135	365	Home	USA	Grant et al., (2021)
Health Care Professionals	213	61	152	Home	USA	Grant et al., (2020)
	31	NR	NR	Hospital and nursing home	Korea	Chang et al, (2017)
	133	28	105	PCU, Nursing home, oncology ward	Brazil	Santos et al., (2017)
	9	3	6	PCU	UK	^b Brayne, et al., (2006)
	9	0	9	Nursing home	UK	^b Brayne et al, (2008)
	38	NR	NR	PCU, Nursing home	UK	^b Fenwick, et al., (2010)
	8	0	8	Community Palliative Care team	USA	McDonald, et al.,(2014)
75	NR	NR	Hospice Care Agency nurses	USA	Lawrence & Repede, 2012	
Volunteers	45	9	36	Hospice Volunteers	Canada	Claxton-Oldfield & Dunnett (2018)
	39	6	33	Hospice Volunteers	Canada	Claxton-Oldfield et al.,(2020)

PCU = Palliative care unit

^aSame study group USA

^b Same study group UK

NR = not reported

Table 1 Samples and setting for studies of ELDVS included in the systematic review.

Author (Country)	Age (yrs) (mean+/-SD) or range	Cultural variable	Religion
Patients			
Kerr et al., (2014) (USA)	74.95+/-14.3	91.5% Caucasian, 3.4% African American, 1.7% Latino/Hispanic, 1.7% Asian/Pacific	not stated
Nosek et al., (2015) (USA)	75 +/- 14.28	90.4% Caucasian, 4.8% African American	not stated
Dam, (2016) (India)	55.16+/-17.30	not stated	81.5% religious, religion not specified
Nyblom et al.,(2020) (Sweden)	77.4	not stated	no stated
Depner et al., (2020) (USA)	61-101	97% White/European,3% African American	82%Christian, 13% Atheist, 4% Jewish, 1% other.
Bereaved Families			
Barbato et al.,(1999) (Australia)	59+/-14.0	not stated	39% regular religious attendance, not otherwise specified
Muthumana et al.,(2010) (India)	not stated	not stated	67% Hindu,30% Muslim, 3% Christian
Kellehaear et al., (2011) (Republic of Moldova)	not stated	not stated	Orthodox Christian
Morita et al., (2016) (Japan)	61.9 +/-12	not stated	Buddhist 56%, Christian 2%, none/other 42%
Grant et al., (2020) (USA)	64.5+/-12.9	95.1% White/Caucasion	Catholic 54%, Christian 34%, None/other 9%
Grant et al., (2021) (USA)	66.34 +/- 12.2	94.4% white/caucasion	83.5% Christian,2.3% Jewish, none/other 13.2%
Healthcare Professionals			
Brayne et al., (2006) (UK)	30-40	not stated	Christian, Buddhist, Humanist
Brayne, et al., (2008) (UK)	mean 4.0.1 (range 27-60)	Filipino 30%, Caucasion 70%	90% Christian, 10% Buddhist
Fenwick, et al., (2010) (USA)	48 +/-9.7	not stated	not stated

Chang et al., (2017) (Korean)	nurses 45.33 +/- 8.75 doctors 47.92 +/-10.39	not stated	not stated
Santos et al.,(2017) (Brazil)	41 +/-10	not stated	Catholic 56.5%, Evangelical 22.9%, other 20.6%
Volunteers			
Claxton-Oldfield and Dunnett., (2018) (Canada)	68.4 +/-7.3	not stated	94% religious, religion not specified
Claxton-Oldfield et al., (2020) (Canada)	68 +/-6.6	not stated	84% religious, religion not specified

Table 2 Age, Country Cultural Variable and Religion