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End-of-life experiences in the dying process: scoping and mixed-methods systematic review

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ABSTRACT

Objectives To identify the current state of understanding about end-of-life experiences (ELEs) and examine evidence concerning prevalence, the impact on the process of dying and the perceptions/explanations of patients, relatives and healthcare professionals (HCPs) with regard to ELEs.

Methods Scoping review and mixed-methods systematic review (ScR and MMSR). Nine academic databases were searched for a screening of the available scientific literature (ScR). Articles reporting qualitative, quantitative or mixed-methods studies were selected (MMSR), the quality of which was assessed using the Joanna Briggs Institute (JBI) standardised critical appraisal tools. The quantitative data were synthesised in narrative form while a meta-aggregation approach was adopted for the qualitative results.

Results The ScR identified 115 reports, with 70.4% published after 2010, 55.6% from the USA and the most common terminology for ELE was deathbed visions (29%). The MMSR included 36 papers, describing 35 studies in various settings. The combination of quantitative and qualitative evidence indicated a greater prevalence of ELEs in samples of patients and HCPs compared with relatives. The most common ELEs were visions and dreams of the presence of deceased relatives/friends with references to making ready for a journey. The impact of ELEs was mainly positive, and there was a tendency to interpret them as spiritual experiences inherent to the process of dying.

Conclusions ELEs are often reported by patients, relatives and HCPs and have a significant, generally positive impact on the process of dying. Guidelines for the furtherance of studies and clinical applications are discussed.

INTRODUCTION

Given the increase in life expectancy and mortality from non-communicable

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Spiritual experiences are common in those close to death.
- ⇒ There have been few comprehensive systematic reviews of existing evidence.

WHAT THIS STUDY ADDS

- ⇒ There has been a steady growth in studies in the area, with a peak of publication in 2020.
- ⇒ End-of-life experiences (ELEs) are quite prevalent, mainly seen as transcendent in nature and as having a positive impact on the process of dying.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ Research: It is necessary to refine the definition of ELE and perform more robust studies evaluating the diverse clinical variables involved, seeking a better understanding of their impact on the process of dying.
- ⇒ Practice: Healthcare professionals should be trained with regard to the prevalence, forms and impacts of ELEs and on how to question patients and relatives about these experiences, offering a welcoming, empathetic ear and not pathologising the experience.

diseases, there has been an increasing concern about the quality of the process of dying. In this context, end-of-life experiences (ELEs) appear to have a significant impact on the quality of the process of dying for all those involved.^{1–7}

ELE is an umbrella term used to describe a wide range of experiences that are spiritual or transcendent in nature, which occur in and around the process of dying, experienced by patients, relatives and healthcare professionals (HCPs) involved in patient care. A few hours, days or weeks prior to death, the patients recount experiences such as having seen or dreamt

of departed relatives/friends or religious figures who send messages inviting them to make the transition to death, the so-called deathbed dreams and visions.⁵⁻⁷ Another thought-provoking ELE is terminal lucidity (TL)—‘the (re-)emergence of normal or unusually enhanced mental abilities in dull (sic), unconscious or mentally ill patients shortly before death, including considerable elevation of mood and spiritual affectation’, which enables them to say goodbye to their loved ones.⁸⁻¹¹ Relatives, HCPs or individuals emotionally close to the dying person also report having received a ‘visit’ from him/her at the moment of death or having ‘sensed’ that the person is having problems or may have died (deathbed coincidences) as well as experiencing changes in room temperature, clocks stopping simultaneously, lights, vapours, mist or shapes around the patient’s body at the moment of death.⁵⁻⁷

There have been reports in diverse cultures, throughout history and in the literature, of ELEs experienced by people of both sexes, of all ages, socioeconomic status, occupations, with different diseases, places of death and religious/spiritual beliefs.^{3 12 13} In the 19th and 20th centuries, a number of attempts were made to conduct more systematic studies into these ELEs by researchers like Gurney *et al*,¹⁴ James Hyslop (1907),¹⁵ Ernesto Bozzano (1923),¹⁶ Barrett,¹⁷ Osis and Haraldsson.¹⁸ However, it is only recently that the scientific study of these experiences has resurfaced.

Despite being a somewhat common phenomenon at the end of life, ELEs have still not been studied to the same degree as near-death experiences (NDEs).¹⁹ Both experiences are part of the universal, human phenomenon we know as death, characterised as structured and complex mental activity in a dying brain. However, unlike NDE, where the patient is close to death but recovers, ELE is experienced by people who do actually die.²⁰

For the most part, these experiences are described as profoundly comforting and soothing for people who are dying as well as for their grieving families, providing them with refuge, sensations of peace, joy and hope.^{4 21 22} There are also reports of these experiences being distressing, usually relating to reminiscences of past traumas and unfinished business.^{23 24} Despite the acknowledgement that ELEs are significant from an existential and psychological point of view, the scientific community, most notably the physicians and psychologists, has habitually neglected or belittled these experiences, dismissing them as hallucinations or delirium induced by medication or as a result of unstable clinical conditions.^{2 3 12} Nevertheless, the literature on the topic highlights significant differences between these two types of experience.^{4 25}

Despite the prevalence and relevance of ELEs, as it is a relatively recent field of study, there are very few studies concerning the phenomenology, transcultural (in)variants, prevalence, differential diagnosis and the impact/significance for all those involved. In order

to further the study of ELEs, it is very important to perform a systematic review of the state of existing evidence. Although there exist a variety of reviews regarding ELE, a preliminary search of the JBI Evidence Synthesis and PubMed/MEDLINE identified just two systematic reviews, with a small number of articles and with different or more limited objectives than ours. Therefore, to map out and synthesise the available evidence concerning ELE, we have conducted both a scoping review (ScR) and a mixed-methods systematic review (MMSR). The ScR sought to identify and comprehensively analyse the current state of understanding about ELE. The systematic review examined the available evidence concerning the prevalence of ELE, its impact on the process of dying and the perceptions and explanations of patients, relatives and professionals concerning ELE.

METHODS

The initial goal was to perform just a ScR of ELE, in accordance with the protocol registered in the Open Science Framework.²⁶ However, based on the preliminary results, we became aware of the importance of performing a synthesis of the evidence and an evaluation of the methodological quality of the primary studies, with a view to providing a more substantial contribution to the development of this field of study. Therefore, both an ScR and an MMSR were performed.

Both reviews were conducted in accordance with the JBI methodology for ScR²⁷ and for MMSR,²⁸ respectively, also observing the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 statement²⁹ and the PRISMA Extension for ScR (PRISMA-ScR).³⁰ The construction of the research question for quantitative studies was carried out using the PICO (Population, Intervention, Comparison and Outcomes) and, for the qualitative studies, the PICo (Population, Phenomenon of interest and Context). The ScR research question was ‘What scientific literature is available regarding ELE?’. The MMSR questions were: (1) What is the prevalence of the various types of ELE found in the literature?; (2) Is there any evidence available about the impact of the various forms of ELE on the process of dying? and (3) What are the perceptions of patients, relatives and professionals concerning ELE and the explanations thereof?.

Search strategy

In 2021, in the months of September and November, we performed a search of nine electronic databases: Scopus, Web of Science, PubMed/MEDLINE, PsycINFO, Scielo, Virtual Health Library Regional Portal (BVS), OpenGrey, DART-Europe and the Brazilian Digital Library of Theses and Dissertations. No language filters were applied. The keywords used in the search were as follows (online supplemental material I): (end of life phenomena) OR (end-of-life

experience) OR (end-of-life dreams and visions) OR (hallucinations near death) OR (deathbed*) OR (terminal lucidity) OR (paradoxical lucidity) OR (awareness near death). All the key terms were in English, with the exception of the Brazilian Digital Library of Theses and Dissertations database, where the Portuguese language was used.

Eligibility criteria

For the studies to be included in the ScR, they must have: (1) investigated ELEs of a religious, sacred or transcendent nature, experienced by people who actually died; (2) included people of any age or with any illness who are dying, in any setting, or relatives or HCPs who may have undergone and/or witnessed these

experiences. To satisfy the MMSR inclusion criteria, in addition to the inclusion criteria outlined above, the documents had to be: (3) available in English, Portuguese and Spanish and (4) primary research studies (qualitative, quantitative or mixed, of any design).

Identification and selection of studies

The study identification and selection process was carried out in four stages. Figure 1 presents the PRISMA flow diagram showing details of the study search, selection and inclusion process. Prior to commencing phase 1, a pilot test was carried out on the PubMed/MEDLINE by the review team in order to set the parameters for their understanding of the document inclusion criteria. The suitability of all the

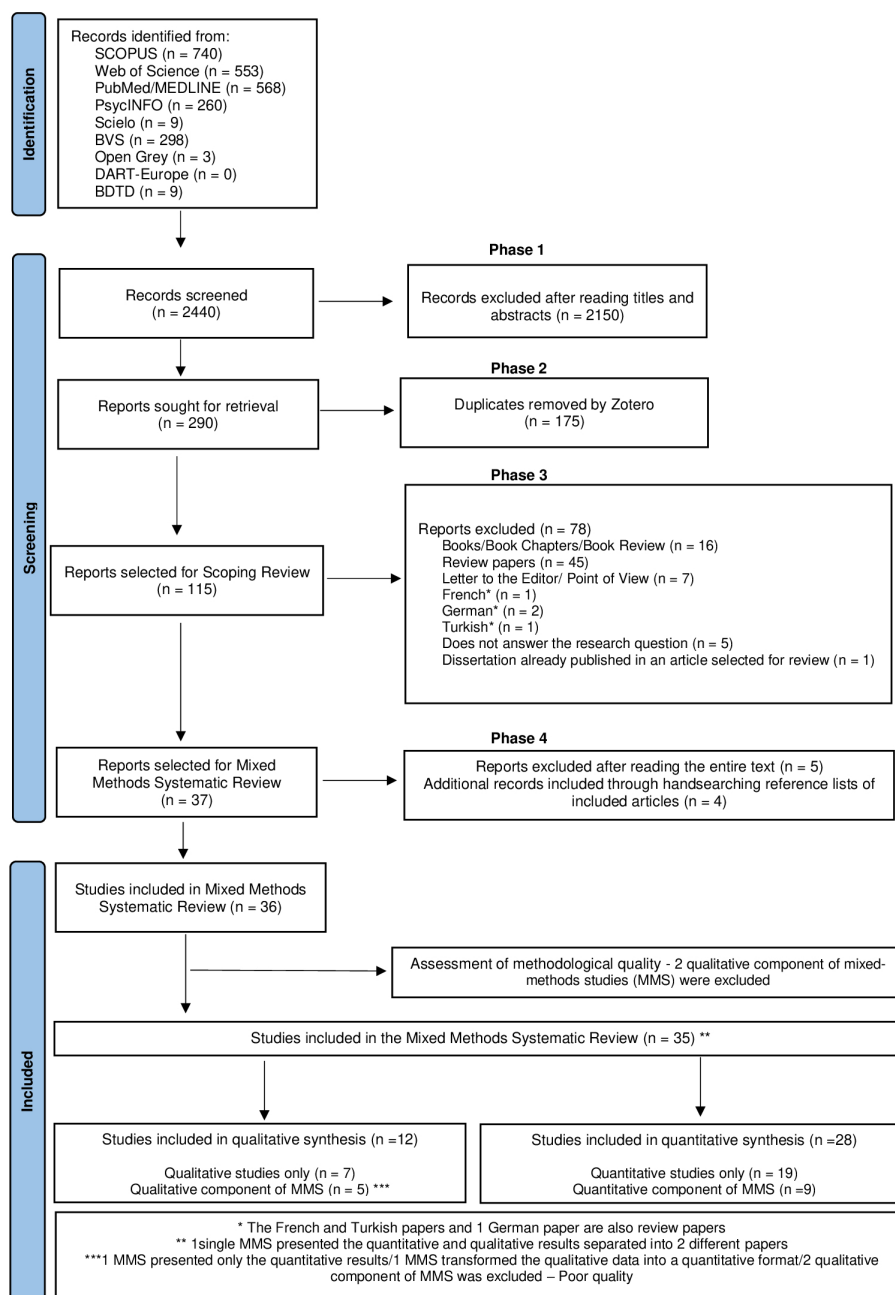


Figure 1 Flow diagram of study selection.

titles and abstracts resulting from the search of all the selected databases was evaluated by two independent reviewers (TOS and HGR), with any discrepancies being resolved by a third reviewer after discussion (AMA). Where the title or abstract did not provide sufficient information, the full text was acquired and analysed to determine eligibility.

Data extraction

All data were extracted from the included reports by two independent reviewers (TOS and HGR) using the data extraction instrument developed by the reviewers (online supplemental material II). The data extracted for the ScR included specific details about the authors, year, country, terminology and report types in the included reports. In the MMSR, for the quantitative studies and the quantitative component of the mixed-methods studies (MMS), the extracted data included specific details about the populations, geographical location, phenomena of interest, study methods and outcomes of significance to the review question. For the qualitative studies and the qualitative component of the MMS, extracted data included specific details about the population, setting, geographical location, study methods and the phenomenon of interest relevant to the review question. Additionally, some bibliometric characteristics of the included studies were accessed through the electronic database Scopus: (A) main authors; (B) author's h-index; (C) total number of author's publications; (D) total number of author's citations; (E) main journals and (F) CiteScores of main journals. Any disagreements arising between the reviewers were resolved through discussion (TOS, HGR and AMA).

Assessment of methodological quality of studies included in the MMSR

A quality assessment was used to check for bias and to confirm the integrity of the data collected from the studies selected for the MMSR. Quantitative papers and the quantitative component of MMS, plus the qualitative papers and the qualitative component of MMS selected for retrieval, were assessed by two independent reviewers (TOS and HGR) for methodological validity prior to inclusion in the review, using the JBI standardised critical appraisal tools.³¹ Any disagreements arising between the reviewers were resolved through discussion (TOS, HGR and AMA). For each JBI standardised critical appraisal tool, a score was arrived at based on the number of methodological characteristics in the study, for a classification of quality as good, fair or poor. Whenever a characteristic was not applicable to the study, this classification was reworked for the total number of remaining characteristics. Only studies evaluated as possessing good or fair quality were included in the MMSR.

Data synthesis of studies included in the MMSR

In accordance with the JBI methodology for MMSR,²⁸ a convergent segregated approach was employed in which the quantitative data and quantitative element of the MMS, and the qualitative data and qualitative element of the MMS were separately synthesised, with the subsequent merging of the results derived from each of the syntheses into a cohesive whole. The quantitative data were synthesised in narrative form, as the heterogeneity of the methods, samples and settings did not allow for meta-analysis.³² Qualitative research findings were pooled using a meta-aggregation approach, a process based on identifying the meaning of the findings from individual studies with different methodologies, which are organised into categories, and these were summarised as synthesised findings.³³

The synthesis of the qualitative data was limited to themes, metaphors and categories, selected only from the results section of the included studies. A single reviewer extracted and analysed the findings (TOS). These findings were classified into three levels of evidence: 'unequivocal' (experiencer transcripts in the paper supported the finding beyond reasonable doubt); 'credible' (experiencer transcripts that were open to challenge and interpretation) and 'unsupported' (findings with no supporting experiencer transcripts). Prior to the data aggregation and synthesis, TOS and HGR studied all quotations thoroughly. The findings were arranged into groups and rearranged into subgroups or vice versa until categories, based on similarity in meaning, became clear. Frequent reference to the articles was necessary to ensure that the original meaning of the texts was retained. Consensus with regard to categories was sought between the two reviewers, after which the data were synthesised. Synthesised findings were subsequently formulated from the aggregation and categorisation and presented as a set of statements.

RESULTS

Study inclusion

A total of 2440 potential articles were identified, with 290 publications remaining after a screening of titles and abstracts (figure 1). After removing duplicates (n=175), 115 proceeded to the ScR. For the MMSR, 78 reports were excluded, so 37 studies were selected for the MMSR, of which a further five were excluded after a reading of the full text (online supplemental material III). Six additional records were included through a manual search of reference lists of included articles, of which we were only able to access four.³⁴⁻³⁷ The total sample is composed of 36 papers that describe the results of 35 studies. Of these studies, 7 were qualitative, 19 were quantitative (case reports were classified as quantitative studies) and 9 were mixed. Of the MMS, one presented only the quantitative results³⁸ and another transformed the qualitative data into a quantitative format.³⁹

Types of reports	N (%)
Review papers	48 (42)
Original research	42 (36.5)
Books/book chapters/book reviews	16 (14)
Letter to the editor/point of view	7 (6)
Dissertations	2 (1.5)
Country of publication	
USA	64 (55.6)
UK	13 (11.3)
Germany	6 (5.2)
Canada	5 (4.3)
Brazil	4 (3.5)
India	4 (3.5)
Australia	3 (2.6)
Turkey	3 (2.6)
China	2 (1.7)
Japan	2 (1.7)
Republic of Korea	2 (1.7)
Switzerland, Sweden, France, Singapore, Argentina, South Africa, Republic of Moldova (one per country).	7 (6.1)
Terminology	
Deathbed visions	33 (29)
End-of-life experiences	18 (15.8)
Terminal lucidity/paradoxical lucidity	17 (14.8)
Deathbed phenomena/experiences/communications/observations/dreams and visions	16 (14)
End-of-life dreams and visions	14 (12.3)
Apparitions	6 (5.3)
Unusual end-of-life phenomena/unusual perceptions at the end of life	5 (4.4)
Awareness near death/near-death awareness/nearing death awareness	3 (2.6)
Shared death experiences/shared near-death experiences/shared dreams	3 (2.6)
Deathbed coincidences	2 (1.8)
Transcendent experiences of dying patients	1 (0.9)
Death-related sensory experiences	1 (0.9)

Methodological quality of studies included in the MMSR

The overall methodological quality of included studies was Fair. Of the seven qualitative studies, four were considered fair and three were good. Of the qualitative component of the MMS (n=7), five were considered fair and two were poor. The overall methodological quality of the quantitative studies and quantitative component of the MMS was Fair. Of the quantitative studies (n=19), 14 were fair and five were good. Of the quantitative component of the MMS (n=9), seven were fair and two were good (see online supplemental material IV).

Findings of the ScR

A total of 115 articles on ELE were identified, of which 42% were review papers and 36.5% were original research (table 1). The first publication found was 'deathbed visions' (DV), the seminal book by Barret

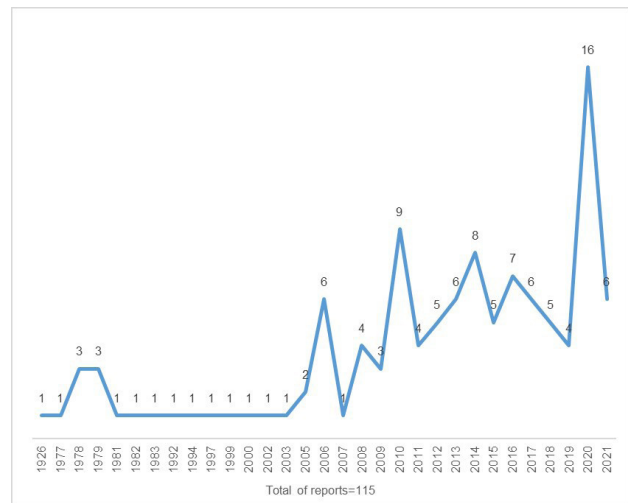


Figure 2 Distribution of publications by year.

from 1926.¹⁷ The second report was published 51 years later, in 1977, by Osis and Haraldsson,³⁹ a cross-cultural survey conducted in the USA and India. Only in 2006 can a more significant number of publications on the area be found (5.2%, n=6). After 2010 (7.8%, n=9), an increasing number of publications have been produced. The period between 2010 and October 2021 witnessed the majority of literature published on ELE (70.4%, n=81) (figure 2). The majority of reports published in 2020 and 2021 (n=22) were original research studies (77.3%, n=17), four were review papers and one was a letter to the editor (see online supplemental material V).

As far as the country of publication is concerned, the USA accounts for 55.6% (n=64) of publications, and 11.3% (n=13) were from the UK. Only four reports (3.5%) were published in a language other than English (two in German, one in French and one in Turkish).

A variety of terminology was found in the selected publications on ELE, often including more than one type of terminology within the same publication. The most frequent nomenclature encountered was DV—29%, ELE—15.8%, TL or paradoxical lucidity—14.8%, deathbed phenomena/experiences/communications/observations/dreams and visions—14% and end-of-life dreams and visions (ELDV)—12.3% (see table 1).

Characteristics of primary research studies included in the MMSR.

Country of research, year of publication, study design and data collection methods

Most of the primary research studies were published between 2011 and 2021 (80%) and 43% were conducted in the USA (see table 2).

As for the design of the quantitative studies (n=19), 4 were case reports,^{34 40–42} 4 were analytical cross-sectional studies,^{43–46} 10 were descriptive cross-sectional studies^{37 47–55} and 1 was a cohort study.⁵⁶ The main data collection method in these studies was the questionnaire (42%). Semistructured interviews were

Table 2 Characteristics of primary studies of end-of-life experiences (35 studies/36 articles)

Characteristics	No studies n (%)
Country	
USA	15 (43)
UK	5 (14.3)
India	3 (8.6)
Canada	3 (8.6)
Republic of Korea	2 (5.7)
Australia, Brazil, Japan, New Zealand, Republic of Moldova, Sweden, Switzerland (one per country).	7 (20)
Year	
Up to 1990	1 (2.9)
1991–2000	1 (2.9)
2001–2010	5 (14.3)
2011–2019	16 (45.7)
2020–2021	12 (34.3)
Method, data collection methods and setting	
Quantitative studies	19 (54.3)
Questionnaire	8 (42)
Case report	4 (21)
Analysis of medical records, chart audit+survey	2 (10.5)
Interview, instruments+interviews	2 (10.5)
Questionnaire+scales	1 (5.3)
Reports sent by email	1 (5.3)
Participant observation+questionnaire	1 (5.3)
Hospice, hospice+home, hospice unit within the hospital, hospice+palliative care settings	9 (47.4)
Hospital, hospitals/palliative care units/home	3 (15.8)
Nursing home, nursing home+hospital, nursing home+palliative care unit at hospital+cancer centre at hospital	3 (15.8)
Palliative care units at hospital, palliative care units/neurological clinics/hospices/dementia care locations	3 (15.8)
Home	1 (5.3)
Qualitative studies	7 (20)
Semi-structured interviews	6 (86)
Questionnaire+semistructured interview	1 (14)
Palliative care unit, palliative care settings+hospice	3 (43)
Home, home+hospice	2 (28.6)
Hospitals+clinics	1 (14.3)
Remote conference service	1 (14.3)
Mixed methods studies	9 (25.7)
Questionnaire+interview	4 (44.4)
Survey with open and closed questions, survey+focus group	2 (22.2)
Instrument+open-ended questions, instrument+questionnaire with open and closed questions	2 (22.2)
Semi-structured interviews with closed and open-ended questions	1 (11.1)
Hospice, hospice+nursing home, nursing home	6 (66.7)
Home	1 (11.1)
Hospital+mailed questionnaire	1 (11.1)
Nursing schools	1 (11.1)

Continued

Table 2 Continued

Characteristics	No studies n (%)
Participants	
Patients	11 (31.4)
Teenagers	1 (2.9)
Adults	10 (28.6)
Relatives	9 (25.7)
Family caregivers	6 (17.1)
Family and friends	1 (2.9)
Family and professional caregivers	1 (2.9)
Family, friends and/or caregivers	1 (2.9)
Healthcare professionals	15 (42.9)
Healthcare professionals	11 (31.4)
Healthcare professionals and caregivers	2 (5.7)
Volunteers	2 (5.7)
Sample size	
Patients	
1–6	4 (11.4)
25–80	6 (17.1)
338	1 (2.9)
Relatives	
47–107	5 (14.3)
159–500	3 (8.6)
2221	1 (2.9)
Healthcare professionals	
4–45	9 (25.7)
64–187	4 (11.4)
571–1708	2 (5.7)

used in 86% of qualitative studies.^{21 35 36 57–59} Of the quantitative component of the MMS (n=9), three were analytical cross-sectional studies,^{38 60 61} four were descriptive cross-sectional studies^{24 39 62 63} and two were cohort studies.^{7 64} Of these, 44.4% employed questionnaire+interview to collect the data (see online supplemental material VI).

The majority of the studies (71.4%, n=25) are descriptive and observational, level 4 (descriptive cross-sectional studies, case series and case reports), followed by analytical cross-sectional studies and cohort studies (level 3) (28.6%, n=10), with a low level of evidence of causality.³¹

Participants, data collection setting and sample size

Quantitative studies were conducted with a number of participants which comprised: patients (n=7), relatives (n=3) and a variety of HCPs (n=9)—nurses, doctors, volunteers, paid caregivers, etc. The principal data collection settings were hospices (47.4%). Qualitative studies were conducted with a number of participants and included: patients (n=2), relatives (n=2) and a variety of HCPs (n=3)—nurses, doctors, social worker, hypnotherapist, professional caregiver, etc of which 43% were collected in palliative care settings. MMS were conducted with a number of participants

and included: patients (n=2), relatives (n=3) and a variety of HCPs (n=4)—nurses, doctors, care assistant and end-of-life caregivers. The main data collection settings were hospices and nursing homes (66.7%) (table 2).

There is a large variation in sample size among the studies. In the studies involving patients, three studies report just one case,^{40–42} one describes a series of six cases.³⁴ In a further six studies, the sample size varies between 25 and 80 patients.^{24 43 56 57 64 65} The remaining study analysed the case records of 338 patients.⁴⁴ Studies with relatives (n=9) have the largest sample sizes, ranging from 47 to 2021.^{45 47 53 55 58–61 63} The majority of studies with HCPs have sample sizes ranging from 4 to 45 (n=9),^{7 21 35 36 49–52 62} from 64 to 187 (n=4)^{37 46 48 54} and 571 to 1708 (n=2)^{38 39} (see table 2).

Bibliometric characteristics of included studies

The principal authors were Kerr and Grant who, in collaboration with various colleagues, published six studies (seven articles) involving patients and relatives in the USA. Then come Fenwick (the highest h-index, h=36), with five publications including a sample of HCPs in the UK, of which four were written in conjunction with Brayne. Kellehear, with two publications involving relatives in India and the Republic of Moldova. Most of the papers were published in the *American Journal of Hospice and Palliative Care* (n=9, 25%), followed by the *Journal of Palliative Medicine* and the *Omega-Journal of Death and Dying*, both having a 13.9% share of publications on ELE (online supplemental material VII).

Findings of the MMSR

Quantitative evidence

Studies with patients

The prevalence of ELEs, in studies using a sample of patients, ranged from 50% to 90% (table 3), the most frequent experiences being visions and dreams that deceased relatives/friends are present and making ready for their final journey. Generally speaking, the participants reported that ELEs brought some benefit after assimilation of the experience as well as post-traumatic growth—‘the ability to overcome highly challenging, stressful or traumatic events, such as acknowledging one’s mortality and terminality, with positive psychological change’.^{43 56 57 64}

In a longitudinal study involving 59 patients,⁶⁴ 60.3% evaluated their dreams and visions as comforting or extremely comforting, and 18.8% as distressing or extremely distressing. Patients reported higher levels of comfort in dreams/visions about their deceased loved ones. On the other hand, in a study in India,²⁴ 84.2% of ELEs were considered distressing, but 94.7% felt more comfortable after discussing their experiences. In a study of 70 patients in the USA,⁴³ a significant, positive association was found between dreams/visions and

increased post-traumatic growth, particularly in terms of personal strength and spiritual change.

With regard to TL, a Korean study with 338 patients⁴⁴ indicated a prevalence of 4%, lasting up to 4 hours, and with survival up to 9 days. No significant differences were found between those who presented with TL and those who did not, and the phenomenon was not predictable based on patient characteristics. A study out of New Zealand³⁴ reported episodes of lightening up before death in a convenience sample of 6 cancer patients, of whom 50% were suffering from impairment of the central nervous system.

Studies with relatives

Between 21% and 49% of relatives reported ELE experienced by their loved ones (table 3), with a predominance of dreams and visions of deceased relatives being present. In a study with 228 North American families,⁶⁰ 58% of those whose loved ones shared dreams/visions reported a positive impact on the process of grieving, 49% said it helped to accept the reality of the loss, for 46% it helped to endure the pain of grieving, for 39% it helped to adapt to the new world without the deceased and, for 45%, it helped maintain a connection with the loved one. There was a significant correlation between comfort derived from dreams and a better bereavement process, accepting the reality of loss, adjusting to the new environment and continuing bonds. A recent study of 500 family members in North America⁶¹ found that the more the relatives felt their deceased loved one was comforted by dreams/visions, the more they found comfort themselves, or saw ELE as a natural part of dying, more easily accepting their loss and feeling a greater connection with their deceased loved one. Accepting the loss was increasingly difficult for relatives who viewed their loved ones’ ELE as negative. In a study involving 2221 Japanese family members,⁴⁵ ‘good death’ scores for the patients were not significantly different between the families who reported that the patients had experienced DVs and those who had not. Of these, 34% put the cause of the ELE down to organicity or medication, 38% associated ELE with natural/transpersonal phenomena and 80% of relatives felt it was very necessary for the physicians to share with the families the naturalness of this phenomenon.

A study evaluating parapsychological phenomena experienced by Australian relatives after the death of the patient observed a prevalence of 49%, the main sensation being the presence of the deceased (50%) and having occurred up to 7 days after the death in 55% of cases. A total of 82% of relatives who sensed the presence of the deceased felt anxious or threatened and 54% described the sensation as negative. There was a 40% increase in the belief in life after death, subsequent to ELEs.⁴⁷

In this regard, the impact of ELEs on relatives seems to be linked to a better acceptance of the loss and a

Table 3 Prevalence, typologies and impact of ELE in selected studies

	Authors (year)	Sample	ELE prevalence	ELE impacts	Perceptions/explanations
Studies with patients	Dam (2016) ²⁴	60	63.3% reported having experienced ELDV; 78.9% saw deceased relatives/friends/acquaintances; 21% making ready for a journey.	84.2% reported ELDV as distressing; 94.7% felt comfortable about discussing their ELDV.	
	Depner <i>et al</i> (2020) ⁵⁷	83	66% reported ELDV.		
	Kerr <i>et al</i> (2014) ⁶⁴	59	88.1% reported ELDV; 46% with deceased friends/relatives; 38.9% going or getting ready to go somewhere.	60.3% reported them as comforting/extremely comforting; 18.8% reported them as distressing or extremely distressing; the highest average comfort rating was associated with dreams/visions about the deceased.	
	Lewy <i>et al</i> (2020) ⁴³	70	35 patients with ELDV (50%) vs 35 patients without ELDV.	ELDV is positively associated with greater posttraumatic growth, with better performance in all Posttraumatic Growth Inventory (PTGI) subscales, and statistically relevant for personal strength.	
	Lim <i>et al</i> (2020) ⁴⁴	338	4% (6) presented with terminal lucidity; duration of terminal lucidity: between a few hours and 4 days; time until death: 1 day (1), 5 days (2), 8 days (1), 9 days (2).		The phenomenon was not predictable based on patient characteristics.
	Macleod (2009) ³⁴	6	100% (6) patients exhibited a lightening up before death; 100% (6) with cancer disease; 50% (3 had central nervous system involvement of disease; average length of episode: 12 hours.		
	Nosek <i>et al</i> (2014) ²³	63	82.5% reported at least 1 ELDV		
	Nyblom <i>et al</i> (2020) ⁶⁵	25	64% reported ELE; most common content: deceased loved ones and making ready for a journey	+impact for the majority	
	Renz <i>et al</i> (2018) ⁵⁶	80	90% underwent spiritual experiences; 31 visions/experiences of light and 21 visions of angels (among them some appearances of deceased relatives)	+ association between spiritual experiences and peace: 57.2%; + association between distress/pain/fear/denial and transformation of perception: 50%	

Continued

Table 3 Continued

Authors (Year)	Sample	ELE prevalence	ELE impacts	Perceptions/explanations
Barbato <i>et al.</i> (1999) ⁴⁷ (2011) ⁵³	47	49% reported a parapsychological phenomenon; 50% a sensation of the presence of the deceased; 33% auditory or olfactory hallucination; 11% tactile hallucination/5% visual hallucination	40% indicated that belief in life after death increased after the experience; 33% reported the experience as +; 29% reported the experience as -	
Fenwick and Brayne (2011) ⁵³	Accounts of 45 DV and 30 DC	DV: 70% visions of relatives or friends; DC: 67% occurred 30 min prior to death, 35% were awake, 38% were asleep and 26% were dreaming. 49% came to say goodbye and give assurance that everything would be ok; 32% messengers were dying or informing they were going to die.	DV: experience was comforting for 45% of those reporting and for 33% of the deceased; DC: 36% comforting impact, 36% discomfoting and subsequently comforting.	
Grant <i>et al.</i> (2020) ⁶⁰	228	27.2% reported ELDV; 29% occurred during wakefulness; 22% during sleep; 48% in sleep and wakefulness.	Of those who reported ELDV, 58% said it helped with their grief; 49% it helped to accept the reality of the loss; 46% it helped to go through the pain of grieving; 39% it helped to adapt to the new world without the deceased; and 45% it helped to maintain a connection with the loved one.	
Grant <i>et al.</i> (2021) ⁶¹	500	40% reported ELDV; 39.9% of ELDVs occurred during the patient's sleep and wakefulness.	+association between perceiving ELDV as a cause of comfort for the patient and relatives and understanding ELDV as a natural element of the process of dying. +impact on the grieving process; + association between perceiving ELDV as a cause of anxiety in the patient or the relative and a worse impact on the grieving process.	+association between not taking dreams seriously and believing that ELDV is a side effect of medication/ELDVs is not a natural part of the process of dying.
Kellehear <i>et al.</i> (2012) ⁵⁸	102	36% reported DV; 35% of visions of deceased mother; 2 deceased visitors/DV.		
Morita <i>et al.</i> (2016) ⁴⁵	2221	21% DV; 87% of DV with deceased individuals.	DV showed no association with a good death nor with comfort; DV caused fear in 19% of patients and 2.2% of relatives.	34% attribute DV to medication/organic causes; 38% to natural/transpersonal phenomena.
Muthumana <i>et al.</i> (2011) ⁵⁵	104	30% DV; 57% of DV with deceased mother; 30% of DV with deceased mother and father.		
Rivera (2013) ⁶³	59	40%/141 of respondents witnessed ELDV; 20.1% while awake or while asleep; Deceased parents 25.3% (n=23), deceased spouse 15.4% (n=14) and siblings 15.4% (n=14).	85.5%/62 perceived that ELDV enabled their deceased loved one to have a peaceful death. 2.3% perceived ELDV to be pleasant, 27.9% both pleasant and disturbing. Acceptance was the most frequently cited grief response (n=46) to be+affected by ELDV.	

Continued

Table 3 Continued

	Authors (year)	Sample	ELE prevalence	ELE impacts	Perceptions/explanations
Studies with Healthcare Professionals	Batthyány and Greyson (2021) ⁴⁸	187	72% of cases of lucidity in patients with dementia; 90% extremely impaired cognitively. Duration of episode of lucidity: 52% up to 1 hour, 27% a few hours, 10% approx. 1 day, 10% a few days. Proximity to death: 41% 2–24 hours, 23% 2 to 3 days, 15% 4–7 days, 15% less than 2 hours.		
	Brayne <i>et al</i> (2008) ⁶²	10	7 reports of terminal lucidity; 6 dreams and 2 visions of getting ready for death; 4 visions of groups of children before dying; 4 synchronicities with apparitions of animals/birds at the moment of death; 4 reported a change in room temperature; 2 reports of patient talking about transition to a new reality.		
	Chang <i>et al</i> (2017) ⁴⁹	31			> consensus: > of neurotransmitters in extreme circumstances/ change in basic cognitive function due to delirium in the final stages of life, spiritual experience of patient through a peaceful death; < consensus: evidence of somebody who is invisible welcoming the patient/vision due to nerve cell death.
	Claxton-Oldfield and Dunnet (2018) ⁵⁰	45	33% reports of ELE by patients or relatives; 47% visions of deceased relatives; 44% dreams of deceased relatives; 38% visions of lovely, colourful places or listening to wonderful music; 38% terminal lucidity; 33% deathbed coincidences; 31% change in a pet's behaviour; 25% patients making ready for a journey; 17% change in room temperature before or after death.	72% agree that ELEs are a source of comfort for the dying patient; 67% agree that ELEs are a source of comfort for the dying patient's relatives; 48% agree that patients who have ELEs have a peaceful death.	70% consider profound spiritual events; 64% transpersonal experience; 56% agree they are part of the process of dying; 21% consider the result of a dying or deteriorating brain; 14% consider hallucinations caused by painkillers or sedatives.
	Claxton-Oldfield <i>et al</i> (2020) ⁵¹	39	40.5% witnessed ELE; 36.8% received reports of ELE of patient/relatives.	77% agree that ELE is a source of comfort to the dying patient; 61.5% disagree that ELEs are distressing; 54% agree that ELE diminished the fear of dying.	56.8% agree that it may be part of the process of dying and influence it +; 41.2% agree that it may be a source of distress for patient and family
	Claxton-Oldfield and Richard (2020) ⁵²	22	59% reported having had ELE in their personal lives; 91% received reports of relatives of inpatients who were waiting for the arrival of a loved one or a specific event before dying; 64% paradoxical lucidity; 55% about dreams of deceased individuals or pets; 50% visions of deceased relatives/friends; 95% reported having witnessed an inpatient waiting for someone to arrive or for an important event to occur before dying.	77% agree that ELE is a source of comfort for the dying patient; 77% agree that it is a source of comfort for the patient's family; 82% disagree that ELE is emotionally distressing.	81% agree they are transpersonal experiences; 77% agree that it is part of the process of dying; 81% disagree that it is an invention of the imagination; 68% disagree that it is the result of a dying or deteriorating brain.

Continued

Table 3 Continued

Authors (year)	Sample	ELE prevalence	ELE impacts	Perceptions/explanations
Fenwick <i>et al.</i> (2010) ⁷	38	62% (48%) take-away apparitions or deathbed visions involving deceased relatives; 55% (48%) of interviewees reported secondhand accounts of deathbed coincidences; 25% (35%) secondhand accounts of the dying person surrounded by light at the time of death.	92% (82%) ELE offered spiritual comfort to the patient and 86% (79%) to the relatives; 70% (89%) ELE were intense subjective experiences which held profound personal meaning; 39% (50%) felt patients with ELE had a peaceful death.	76% (79%) did not attribute ELE to organic brain injuries; 68% (68%) that ELE were a spiritual event; 67% (65%) not associated with medication.
Lawrence and Repede (2013) ³⁴	75	8% DBC (stage 1); 25%–95% of patients presented with DBC in the last few weeks of life (stage 2).	89% of patients with DBC had a calm and peaceful death vs 40.5% of those who did not have DBC; 8% with DBC presented with terminal agitation vs 31% who did not; 44% DBC was pleasant; 84% DBC was neither negative nor distressing.	
Moore and Pate (2013) ³⁸	571	46% took care of a patient/relative who reported DV; 21% had personal experience of DV/relative who reported DV.		
Osis and Haraldsson (1977) ³⁹	1708	28% reports of DV of human figure by terminally ill patients: 47% deceased individual, 30% religious figure, 23% mother, 18% spouse, 13% brother, 13% son. Purpose of DV: 47% to take the patient with his/her consent; 18% to take the patient without his/her consent; 14% visit. Religious figures: 28% God or Jesus, 24% angels, 17% god of death or messengers, 12% Krishna, Shiva, Rama.	Emotional reactions: 29% negative, 21% elevated mood, 20% serenity, 30% no effect or relaxed.	DV is not affected by medical factors.
Santos <i>et al.</i> (2017) ⁴⁶	133	70.7% reported having observed/heard a report of ELE; 88.2% 'visions of deceased acquaintances' religious figures which appeared with the aim of taking the dying person away; 76.3% deathbed coincidences; 68.8% "waking dreams/visions in which the patient was comfortable/seemed to be ready for death; 60.2% paradoxical lucidity; 52.7% sensation of the patient coming from and going to another reality during the process of dying; 40.9% a symbolic apparition of an animal, bird, insect at the moment of death.	77.4% were a source of spiritual comfort to the dying patient; 60.2% believe that the patients who had ELEs died peacefully; 66% believe that the phenomenon may be a stressor, but helps the patient to resolve unfinished business.	78.5% believe that the ELE is a transpersonal experience; 69.5% that the ELE is a profound spiritual event; 69.3% that the ELE is different from a fever-induced or drug-induced hallucination.
Schreiber and Bennett (2014) ³⁷	64		Positive, memorable implications for the family; Expresses the final goodbyes and shows a wish to finish or perform an action or task; May create a false sensation of hope or a sensation of confusion for the family.	Premortem surge (PS) occurs between 24 and 48 hours before death and persists for between 6 and 24 hours. The individual frequently exhibits a resurgence of energy and improvement in mental acuity or clarity. Explained as a possible spiritual or psychological experience.
SCRI (2021) ³⁹	101	50.6% vision of the deceased; 25% apparition of transcendent light; 19.5% sensing energy; 18.9% time/space change; 15.8% encounter with nonhuman beings or entities; 14.6% vision of light or material that they believed to be the spirit leaving the body; 13.4% apparition or presence of deceased loved one; 12.1% otherworldly or heavenly realms; 20.7% reported remote sensation of death (mental impressions or acute physical symptoms).	69.1% report that these shared death experiences (SDE) helped to reconcile their grief; 52.3% in losing their fear of death; 42.9% brought renewal of purpose/meaning; 24.2% reported a greater perception of the maintenance of a bond with the deceased.	52.3% understand SDE to be a non-religious/spiritual phenomenon; 14.9% anxiety about the sacred/special nature of the experience being rejected or denigrated by others; 14.9% gave negative responses to the sharing of the experience.

DBC, Deathbed communications; DV, deathbed vision; ELDV, end-of-life dreams and visions; ELE, end-of-life experience.

greater connection with the deceased, when there is openness to the ELEs and a greater acceptance of these experiences as natural events in the process of dying.^{45 55 60 61}

Studies with HCPs

The prevalence of ELEs in studies with HCPs ranged from 28% to 95% (table 3), varying according to the phenomenon being studied and whether it is first-hand experience or one reported by patients/relatives. The main ELEs were visions or dreams of deceased relatives/friends/pets, awaiting an event/visitor before dying, and TL. A study with 38 HCPs in the UK which had a 5-year retrospective and a 1-year prospective data collection, found that 62% and 48%, respectively, of dying patients or their relatives had spoken about take-away apparitions or DVs involving deceased relatives, 55% and 48% of interviewees reported second-hand accounts of deathbed coincidences, 25% and 35% second-hand accounts of the dying person surrounded by light at the time of death, and 41% and 35% reported patients who had vivid dreams which helped them resolve unfinished business.⁷ In a multicentre study of 133 Brazilian HCPs,⁴⁶ 70.7% reported having observed ELE or heard reports of it, with significant differences in the prevalence of ELE recounted by professionals in palliative care, cancer care and nursing homes (PC 94.4%, ONCO 63%, NH 60.8%, $p=0.001$). The most commonly quoted ELE was 'visions of deceased acquaintances or religious figures who appeared with the aim of taking the dying individual away' (88.2%). A total of 78.5% of the HCPs believe that ELEs represent a transpersonal experience; 69.5% believe that they constitute a profound spiritual event; and 69.3% believe that they are different from a fever-induced or drug-induced hallucination. Individual religious beliefs had no influence on the perception of ELE.

A study involving 75 American HCPs identified deathbed communication with deceased friends or relatives in up to 95% of patients in the last stages of life, of whom 89% passed away peacefully and 8% experienced terminal agitation.⁵⁴ A transcultural study of 1708 American and Indian nurses and physicians identified 28% with visions, of which 62% took place on the last day of their lives. The main content of these experiences included a deceased person (USA) or religious figure (India) whose purpose was to take the person away with him/her.³⁹ In a Delphi study (a structured group communication method which permits various individuals to be consulted on a subject) with 31 Korean HCPs,⁴⁹ the explanation for the ELEs differed between physicians (who tended to attribute ELE to delirium or to a change in cognitive function) and non-physicians (for whom ELE was a spiritual/transpersonal event). However, there was consensus among these HCPs that ELEs are different from changes resulting from the use of medication, being natural to the process of dying.

In another Delphi study, 64 North-American HCPs tended to see TL as having a positive impact for relatives and patient, a possible explanation for which is attributed to the spiritual or psychological experience.³⁷ One study with 187 HCPs/relatives and informal caregivers, described the findings of 124 patients with dementia (90% of whom suffered from very severe cognitive impairment) who had TL. The lucid episode lasted for up to 24 hours in 87% of cases, with 79% of patients experiencing ELEs providing clarity, coherence and preservation of verbal communication. As far as mortality is concerned, 66% of patients died within 2 days of the event of paradoxical lucidity and those patients who were lucid for longer than 24 hours survived for longer.⁴⁸

The impact of ELE was mostly understood by HCPs to be something positive, seen as an opportunity to resolve unfinished business, to construct a meaning to living, to get ready to die, influencing the belief about what happens after death. The need to provide HCPs with the tools to manage ELE and facilitate the approach in clinical practice was highlighted in the majority of the studies.^{7 46 50-52}

Qualitative evidence

Meta-aggregation of 12 qualitative studies included in the review generated four synthesised findings.^{7 21 23 35 36 57-62 65} These synthesised findings were derived from 100 study findings that were subsequently assigned to eight categories. The study findings are listed in online supplemental material VIII and the results of the meta-aggregation process are listed in online supplemental material IX.

The synthesised findings indicate that ELEs are an intrinsic, spiritual part of the dying process, that indicate the proximity of death with a mostly positive impact, that there are diverse types of experience besides deathbed dreams and visions, with references typical of making ready to go on a journey. They also reveal that, despite the difficulty of clinical definition, ELEs cannot be just attributed to biological and medication-related questions and that the patients and relatives are hesitant about talking of these experiences through fear, which shows the need for training for the proper clinical management of ELE. The list of synthesis topics, categories and findings are displayed in figure 3. Prevalence data provided by some qualitative studies are described in table 3.

Merging of quantitative and qualitative evidence

In this MMSR, the quantitative evidence was supported by qualitative findings. Several observations emerged from this fusion. First, ELEs were reported not only by patients and relatives but also by HCPs. These aspects appeared to be covered by quantitative studies which evidenced a greater prevalence of these experiences in samples of patients and HCPs than in those of relatives. The qualitative evidence

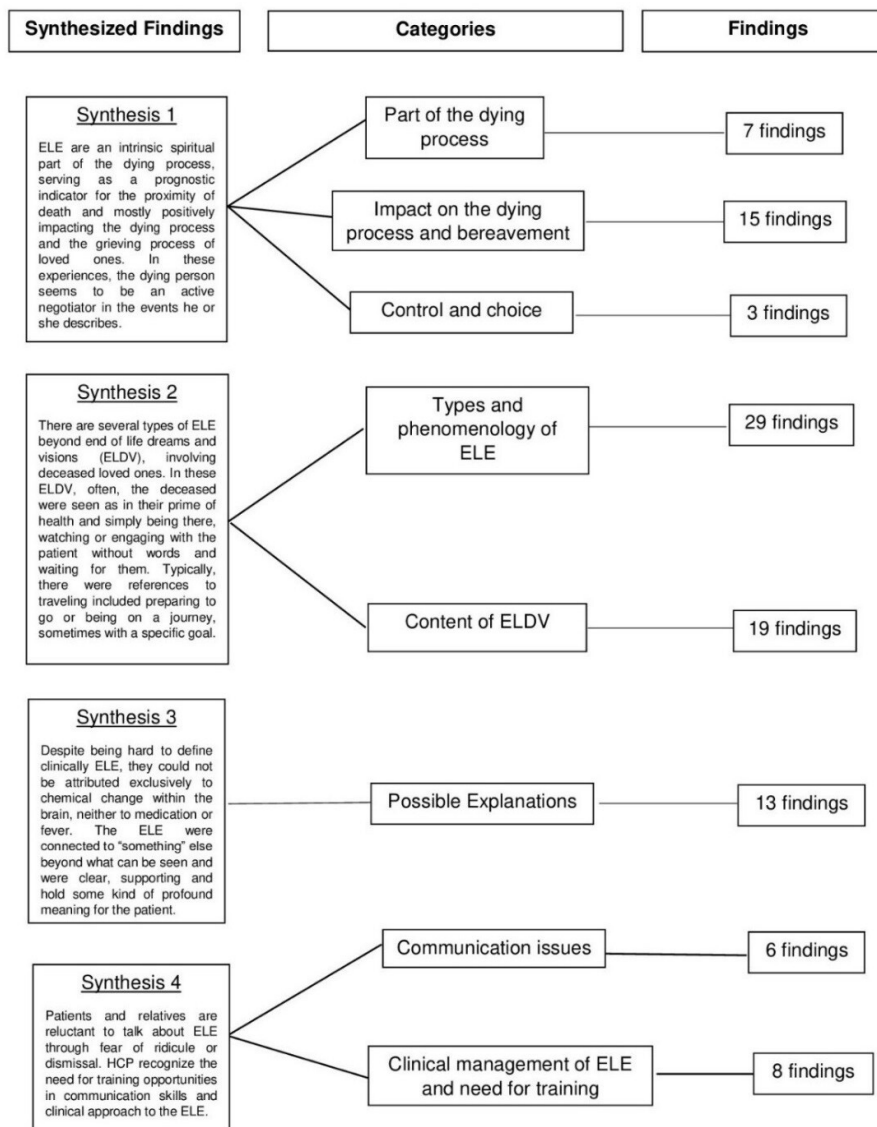


Figure 3 Synthesised findings, categories and findings. ELE, end-of-life experience; HCP, healthcare professional.

describes in detail diverse types of ELEs experienced by patients, as well as by the relatives and professionals, demonstrating the existence of a wide and complex range of experiences. In these experiences, the deceased loved ones were often seen as in the prime of health and simply being there, watching or engaging with the patient without speaking and waiting for them. Quantitative studies have shown that visions and dreams of the presence of deceased relatives/friends, with references to preparation for a journey, were the most predominant ELE. Second, qualitative and quantitative evidence indicates that, the closer to death, the more frequent these ELEs tend to be. The studies show that ELEs generally have a positive impact on patients' process of dying and the grieving of their relatives, however, there have been reports of distressing ELDV often related to traumatic life experiences and unresolved business. These results were corroborated by quantitative data,

as only two studies reported a distressing impact²⁴ or no significant differences in 'good death' scores or in comfort between the families who reported that the patients had experienced DVs and those who did not.⁴⁵ Third, patients, relatives and HCPs tended to interpret ELEs as experiences inherent to the process of dying, and not exclusively explained by biological processes or the effects of medication, there being a predominance of explanations that were spiritual in nature. These findings emerged from both the qualitative and the quantitative studies. Finally, patients and relatives addressed the challenges associated with the difficulty in talking about ELE for fear of social ridicule or rejection and their desire to have somewhere they can talk about these experiences. HCPs recognise the need for training opportunities in communications skills and their clinical approach to ELE.

DISCUSSION

The present review is the first to realise an ScR about the currently available scientific literature concerning ELE and MMSR, synthesising the prevalence of the various forms of ELE, analysing their impact on the quality of the process of dying, and exploring the perceptions and experiences of all those involved with regard to these phenomena, as well as the possible explanations.

The ScR revealed a continual growth in studies in the area, with a peak of publication in 2020. This trend had already been witnessed in a bibliometric analysis conducted in 2015, which found 56 articles, 42.8% of which were original articles and 37.5% were reviews.¹⁹ The present review located 115 documents, of which 42% were review papers and 36.5% original research. It should be stressed that, of these original studies, there was an increased number of studies involving patients (n=15), which had been a significant shortcoming in the area.⁶⁴

The vast majority of studies were conducted in North America and Europe, so there is a need for studies in other geographical and cultural contexts. Attention is drawn to the diverse terminology employed when referring to ELEs, which may result in confusion and conceptual inaccuracies. So there is clearly a need to finetune this construct and to develop a common terminology among researchers in the area, as well as to implement it in research studies, increasing the possibility of comparison between the different studies.

Fenwick *et al* proposed ELE terminology to describe this set of experiences of a spiritual/transcendent nature that occur in and around the process of dying, categorising them into two types: transpersonal and final meaning ELEs, which already represents an important step forward.⁷ In a more recent article,⁶⁶ the authors argue for a broadening of the ELE spectrum by incorporating the experiences of relatives with their deceased loved ones after their death, extended to a period of a year (direct postdeath communication, postdeath synchronicity, additional after-death communication, etc). We suggest using the definition of ELE proposed by Fenwick *et al*⁷ in this field of study, as it is comprehensive and specific, and it would contribute considerably to a better conceptualisation of these experiences, as well as the establishment of a panel of experts for the future construction of an ELE scale that will help with the standardisation of future studies regarding its mechanisms and effects.

The analysis of the quantitative and qualitative evidence (MMSR) suggests that ELEs are quite prevalent, mainly seen as transcendent in nature and as having a positive impact on the process of dying. Nonetheless, it will be necessary to better understand the predictive factors of the occurrence and impact of ELEs. It is known that these spiritual experiences may also be uncomfortable, particularly when the individual has no beliefs or does not belong to a social

group that accepts and helps to incorporate the experience in a more beneficial way.⁶⁷

There is a significant paucity of studies on how the approach to ELE should be incorporated into clinical practice. For example, investigating the impact on patients, relatives and professionals in palliative care to routinely challenge themselves regarding ELE, as well as to provide opportunities for psychoeducation about the experience (eg, they are frequent experiences and not indicative of pathologies or problems), and to enable them to express their perceptions thereof.

As far as the differential diagnosis between ELE and delirium is concerned, a predominance can be seen of specialist opinions that are not supported by empirical data. Thus, a tendency has been observed to consider egosyntonic experiences, experiences congruent with personal values and not accompanied by emotional suffering, as belonging to the group of spiritual or non-pathological phenomena, while those associated with psychomotor agitation, anxiety or fear are supposedly related to confusional or pathological conditions.

The emotional quality resulting from the spiritual experience does not seem to be a good criterion for this distinction since, as already stated, the experience of anxiety and fear is often not due to the experience in itself but rather to a lack of understanding and to beliefs that they could be indicators of problems or threats.⁶⁷

As for the physiopathology, aetiological heterogeneity and the diagnostic difficulties associated with delirium, as well as a possible overlap with ELE, particularly the distressing ELEs, it has become necessary to refine observational studies, using a 360° research approach, in which it would be evaluated in conjunction with laboratory data, biochemical markers, neuroimaging data or neuropsychological evaluation of patients and the prescription of drugs. Studies involving mental health, psychiatry and neurology professionals which are capable of combining the aforementioned variables with subjective, phenomenological findings, would provide greater reliability in the conceptual maturation and taxonomy of ELEs.⁶⁸

Strengths and limitations

To our knowledge, this is the first ScR and MMSR for ELEs. Unlike the few previous, systematic reviews, which have applied more restrictive search methods and inclusion criteria,^{22 69} our international search for ELEs was comprehensive, with a larger number of articles included and not limited by types of experience, publication status or language of publication.

This study has its limitations. The absence of a clear and consistent definition of ELE did not allow for more accurate comparisons between the prevalence of the various types of ELE reported by patients, family members and HCPs. The heterogeneity of the methods, samples and settings also did not allow for a meta-analysis of the quantitative data.

CONCLUSIONS

Given the volume of data produced in studies conducted since the start of the 19th century, the presence of these ELEs and their importance to the patients, relatives and HCPs in coping with this complex life moment, that is death, is undeniable, all of which evidences a significant clinical and educational gap.

More methodologically rigorous, bold and creative studies are essential, particularly with regard to the mechanisms involved in the impact on the process of dying, as well as on the nature of these experiences, with a view to an accurate distinction from other experiences common to the end-of-life context, such as delirium and hallucination. An undertaking of this nature can contribute considerably to a better understanding of the human conscience.

Recommendations for practice

HCPs should be trained with regard to the prevalence, forms and impacts of ELEs and on how to question patients and relatives about these experiences, offering a welcoming, empathetic ear and not pathologising the experience. The training of communication and clinical skills, in psychopathology and neuropsychiatry, to manage in particular distressing ELEs, is seen to be of fundamental importance.

Recommendations for research

To establish a panel of experts, especially with professionals specialising in mental health, in order to refine the definition of ELE, with the subsequent development and validation of a scale, with a view to improving investigation and clinical quantification of these experiences. Moreover, it is necessary to perform more robust studies evaluating the diverse clinical variables involved, aiming towards a better understanding of their impact on the process of dying and distinguishing it from delirium and/or hallucination.

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SUPPLEMENTARY MATERIAL I - SEARCH STRATEGY

Table S1: Search Strategy

Database	Search Terms (Advanced Search)	Last Search
SCOPUS	TITLE-ABS-KEY ("end of life phenomena") OR TITLE-ABS-KEY ("end-of-life experience") OR TITLE-ABS-KEY ("end-of-life dreams and visions") OR TITLE-ABS-KEY ("hallucinations near death") OR TITLE-ABS-KEY (deathbed*) OR TITLE-ABS-KEY ("terminal lucidity") OR TITLE-ABS-KEY ("paradoxical lucidity") OR TITLE-ABS-KEY ("awareness near death")	09/13/2021
Web of Science	TS=("end of life phenomena") OR TS=("end-of-life experience") OR TS=("end-of-life dreams and visions") OR TS=("hallucinations near death") OR TS=(deathbed*) OR TS=("terminal lucidity") OR TS=("paradoxical lucidity") OR TS=("awareness near death") (TS = TOPIC - title, abstract, author's keywords and Keywords Plus), (ALL DATABASES)	09/13/2021
PubMed/MEDLINE	"end of life phenomena"[All Fields] OR "end-of-life experience"[All Fields] OR "end-of-life dreams and visions"[All Fields] OR ("hallucinations"[MeSH Terms] OR "hallucinations"[All Fields] OR "hallucinate"[All Fields] OR "hallucinated"[All Fields] OR "hallucinating"[All Fields] OR "hallucination"[All Fields] OR "hallucinative"[All Fields] OR "hallucinator"[All Fields] OR "hallucinators"[All Fields]) AND "near"[All Fields] AND ("death"[MeSH Terms] OR "death"[All Fields] OR "deaths"[All Fields]) OR "deathbed*"[All Fields] OR "terminal lucidity"[All Fields] OR "paradoxical lucidity"[All Fields] OR ("awareness"[MeSH Terms] OR "awareness"[All Fields] OR "aware"[All Fields] OR "awarenesses"[All Fields]) AND "near"[All Fields] AND ("death"[MeSH Terms] OR "death"[All Fields] OR "deaths"[All Fields])	11/02/2021
PsycINFO	"end of life phenomena" OR "end-of-life experience" OR "end-of-life dreams and visions" OR "hallucinations near death" OR deathbed* OR "terminal lucidity" OR "paradoxical lucidity" OR "awareness near death" (ANY FIELD)	09/13/2021
SciELO.ORG	"end of life phenomena" OR "end-of-life experience" OR "end-of-life dreams and visions" OR "hallucinations near death" OR deathbed* OR "terminal lucidity" OR "paradoxical lucidity" OR "awareness near death" (ALL INDEX)	10/15/2021
BVS	"end of life phenomena" OR "end-of-life experience" OR "end-of-life dreams and visions" OR "hallucinations near death" OR deathbed* OR "terminal lucidity" OR "paradoxical lucidity" OR "awareness near death" (TITLE, SUMMARY, SUBJECT)	10/15/2021
OpenGrey	"end of life phenomena" OR "end-of-life experience" OR "end-of-life dreams and visions" OR "hallucinations near death" OR deathbed* OR "terminal lucidity" OR "paradoxical lucidity" OR "awareness near death"	11/02/2021
DART-Europe	"end of life phenomena" OR "end-of-life experience" OR "end-of-life dreams and visions" OR "hallucinations near death" OR deathbed* OR "terminal lucidity" OR "paradoxical lucidity" OR "awareness near death"	11/02/2021
BDTD	"fenômenos do fim da vida" OU "experiência do fim da vida" OU "sonhos e visões do fim da vida" OU "alucinações perto da morte" OU leito de morte* OU "lucidez terminal" OU "lucidez paradoxal" OU "consciência perto da morte"	11/02/2021

SUPPLEMENTARY MATERIAL II - DATA EXTRACTION INSTRUMENT**Data Extraction Instrument**

STUDY/AUTHORS	NOMENCLATURE	YEAR	TERRITORY/COUNTRY	AIMS/PURPOSE	DESIGN	SAMPLE	METHODS	KEY FINDINGS (Prevalence of ELE/ Impact in the death process/ Possible explanations for the phenomena)

SUPPLEMENTARY MATERIAL III - SOURCES EXCLUDED AFTER FULL TEXT REVIEW

Sources Excluded	Reasons
Arnold, B. L., & Lloyd, L. S. (2014). Harnessing complex emergent metaphors for effective communication in palliative care: a multimodal perceptual analysis of hospice patients' reports of transcendence experiences. <i>The American journal of hospice & palliative care</i> , 31(3), 292–299.	The study does not answer the research questions. It tries to identify the prevalence and thematic properties of complex emerging metaphors that patients use to report these transcendent experiences in general, neither characterizing nor describing them, nor does it discuss their possible role in the dying process.
Grant, P., Wright, S., Depner, R., & Luczkiewicz, D. (2014). The significance of end-of-life dreams and visions. <i>Nursing times</i> , 110(28), 22–24.	This study is a summary of Kerr et al. (2014) - End-of-life dreams and visions: a longitudinal study of hospice patients' experiences. <i>Journal of Palliative Medicine</i> ; 17: 3, 1–8 – already selected for the systematic review.
Ney, D. B., Peterson, A., & Karlawish, J. (2021). The ethical implications of paradoxical lucidity in persons with dementia. <i>Journal of the American Geriatrics Society</i> , 10.1111/jgs.17484. Advance online publication.	The study does not meet the inclusion criteria 1. Despite describing a case that experienced unexpected lucidity, his death only happened one year later.
Parra, A. (2017). Factores de personalidad, perceptuales y cognitivas asociadas con las experiencias anómalo/paranormales en personal de enfermería. <i>Revista Cuidarte</i> , 8(3), 1733-1748.	The study does not answer research questions. Despite describing near-death spiritual experiences witnessed by nurses, the focus of the article is on the nurses' anomalous/paranormal experiences and their relationship with psychological variables.
Walsh, E. P., Flanagan, J. M., & Mathew, P. (2020). The Last Day Narratives: An Exploration of the End of Life for Patients with Cancer from a Caregivers' Perspective. <i>Journal of palliative medicine</i> , 23(9), 1172–1176.	The study does not answer research questions. Despite describing spiritual experiences near death, the focus of the paper is on the experience of the last day of life from the perspective of the surviving caregiver. In addition, the data were about spiritual experiences (spiritual visits) that mostly took place after the patient's death, and with caregivers, not being configured as an ELE, but as an After Death Communication (ADC).

SUPPLEMENTARY MATERIAL IV - CRITICAL APPRAISAL RESULTS FOR INCLUDED STUDIES IN MMSR

The analysis of the methodological quality of the qualitative studies included showed that in none of them, there were a statement locating the researcher culturally or theoretically nor the influence of the researcher on the research, and vice versa, were addressed. Furthermore, in most of it (n=11), the authors didn't state their philosophical perspective. The three studies that affirmed their philosophical perspective used the phenomenological approach(39), the hermeneutic approach(44), constructivism and post-positivism approach(45). In mixed studies, the same items were not addressed in their qualitative part. In fact, in them, the qualitative part generally had a lower methodological quality than the quantitative part (See below).

Critical appraisal results for included studies using the JBI Critical Appraisal Checklist for Qualitative Research

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score	Quality Rating
Brayne, Farnham & Fenwick, (2006)	N	Y	Y	U	N	N	N	Y	Y	Y	5/10	F
Curtis (2012)	N	Y	Y	U	Y	N	N	Y	Y	Y	6/10	F
Depner et al. (2020)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10	G
Kellehear et al. (2011)	N	Y	Y	U	Y	N	N	Y	Y	Y	6/10	F
Mcdonald, Murray & Atkin (2014)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10	G
Nyblom et al. (2021)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	8/10	G
Shared Crossing Research Initiative (SCRI) (2021)	N	Y	Y	U	Y	N	N	Y	N	Y	5/10	F
Qualitative component of mixed-methods papers												
Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Score	Quality Rating
Brayne, Lovelace & Fenwick (2008)	N	Y	Y	U	Y	N	N	Y	Y	Y	6/10	F
Dam (2016)	N	Y	Y	U	N	N	N	N	N	N	2/10	P

Fenwick, Lovelace & Brayne (2010)	N	Y	Y	U	Y	N	N	Y	Y	Y	6/10	F
Grant et al. (2020)	N	Y	Y	U	Y	N	N	Y	Y	Y	6/10	F
Grant et al. (2021)	N	Y	Y	U	Y	N	N	Y	Y	Y	6/10	F
Nosek et al. (2015)*	N	Y	Y	U	Y	N	N	Y	Y	Y	6/10	F
Rivera (2013)	N	Y	N	U	Y	N	N	Y	Y	U	4/10	P

* MMS – only qualitative results

Y - Yes, N - No, U - Unclear, N/A - not applicable

Quality Rating: G - Good, F - Fair, P - Poor

Quality was rated as Poor (0–4 out of 10 questions), as Fair (5–7 out of 10 questions), and as Good (8–10 out of 10 questions)

- Q 1. Is there congruity between the stated philosophical perspective and the research methodology?
- Q 2. Is there congruity between the research methodology and the research question or objectives?
- Q 3. Is there congruity between the research methodology and the methods used to collect data?
- Q 4. Is there congruity between the research methodology and the representation and analysis of data?
- Q 5. Is there congruity between the research methodology and the interpretation of results?
- Q 6. Is there a statement locating the researcher culturally or theoretically?
- Q 7. Is the influence of the researcher on the research, and vice-versa, addressed?
- Q 8. Are participants, and their voices, adequately represented?
- Q 9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?
- Q 10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?

Critical appraisal results for included studies using the JBI Critical Appraisal Checklist for Case Reports

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Score	Quality Rating
Levy, Grant & Kerr (2020)	Y	Y	N	N	Y	N/A	N/A	Y	4/6	F
Macleod (2009)	Y	Y	N	N	Y	N/A	N/A	Y	4/6	F
Pan, Thomson, Costa & Morris (2021)	Y	Y	N	N	Y	N/A	N/A	Y	4/6	F
Shinar & Marks (2015)	Y	Y	N	N	Y	N/A	N/A	Y	4/6	F

Y - Yes, N - No, U - Unclear, N/A - not applicable

Quality Rating: G - Good, F - Fair, P - Poor

Quality was rated as Poor (0–4 out of 8 questions), as Fair (5–6 out of 8 questions), and as Good (7–8 out of 8 questions)

- Q 1. Were patient's demographic characteristics clearly described?
- Q 2. Was the patient's history clearly described and presented as a timeline?

- Q 3. Was the current clinical condition of the patient on presentation clearly described?
- Q 4. Were diagnostic tests or assessment methods and the results clearly described?
- Q 5. Was the intervention(s) or treatment procedure(s) clearly described?
- Q 6. Was the post-intervention clinical condition clearly described?
- Q 7. Were adverse events (harms) or unanticipated events identified and described?
- Q 8. Does the case report provide takeaway lessons?

Critical appraisal results for included studies using the JBI Critical Appraisal Checklist for analytical cross-sectional studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Score	Quality Rating
Levy et al. (2020)	Y	Y	Y	Y	N	N	N	Y	5/8	F
Lim et al. (2020)	Y	Y	Y	N	N	N	Y	Y	5/8	F
Morita et al. (2016)	Y	Y	Y	Y	Y	Y	Y	Y	8/8	G
Santos et al. (2017)	Y	Y	Y	Y	N	N	Y	Y	6/8	F
Quantitative component of mixed-methods papers										
Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Score	Quality Rating
Grant et al. (2020)	Y	Y	Y	Y	Y	N	Y	Y	7/8	G
Grant et al. (2021)	Y	Y	Y	Y	N	N	Y	Y	6/8	F
Moore & Pate (2013)**	N	Y	N	Y	Y	Y	Y	Y	6/8	F

** MMS – only quantitative results

Y - Yes, N - No, U - Unclear, N/A - not applicable

Quality Rating: G - Good, F - Fair, P - Poor

Quality was rated as Poor (0–4 out of 8 questions), as Fair (5–6 out of 8 questions), and as Good (7–8 out of 8 questions)

- Q 1. Were the criteria for inclusion in the sample clearly defined?
- Q 2. Were the study subjects and the setting described in detail?
- Q 3. Was the exposure measured in a valid and reliable way?
- Q 4. Were objective, standard criteria used for measurement of the condition?
- Q 5. Were confounding factors identified?
- Q 6. Were strategies to deal with confounding factors stated?
- Q 7. Were the outcomes measured in a valid and reliable way?
- Q 8. Was appropriate statistical analysis used?

Critical appraisal results for included studies using the JBI Critical Appraisal Checklist for studies reporting prevalence data (descriptive cross-sectional studies)

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Score	Quality Rating
Barbato & Reid (1999)	Y	N	U	Y	Y	Y	N	Y	N	5/9	F
Batthyány & Greyson (2021)	Y	Y	Y	N	Y	Y	Y	Y	Y	8/9	G
Chang et al. (2017) ^{***}	Y	Y	U	Y	Y	Y	Y	Y	N	7/9	F
Claxton-Oldfield & Dunnett (2018)	Y	Y	Y	Y	Y	Y	Y	Y	N	8/9	G
Claxton-Oldfield & Richard (2020)	Y	Y	Y	Y	Y	Y	Y	Y	N	8/9	G
Claxton-Oldfield, Gallant, & Claxton-Oldfield (2020)	Y	Y	Y	Y	Y	Y	Y	Y	N	8/9	G
Fenwick & Brayne (2011) ^{****}	N/A	N/A	N/A	Y	Y	Y	N	N	N/A	3/5	F
Lawrence & Repede (2013)	Y	Y	Y	Y	Y	U	U	Y	Y	7/9	F
Muthumana et al. (2010) ^{****}	Y	Y	U	Y	U	Y	Y	Y	N/A	6/8	F
Schreiber & Bennett (2014) ^{***}	Y	Y	N	Y	Y	Y	Y	Y	N	7/9	F
Quantitative component of mixed-methods papers											
Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Score	Quality Rating
Brayne, Lovelace & Fenwick (2008)	Y	Y	N	Y	Y	Y	Y	Y	N	7/9	F
Dam (2016)	Y	Y	Y	N	Y	Y	Y	Y	N	7/9	F
Osis & Haraldsson ^{*****} (1977)	Y	Y	Y	Y	Y	Y	Y	Y	Y	9/9	G
Rivera (2013)	Y	Y	N	Y	N	Y	N	Y	N	5/9	F

^{***} Delphi studies /^{****} The qualitative data was transformed into a quantitative format/ ^{*****} MMS transformed the qualitative data into a quantitative format.

Y - Yes, N - No, U - Unclear, N/A - not applicable

Quality Rating: G - Good, F - Fair, P - Poor

Quality was rated as Poor (0–4 out of 9 questions), as Fair (5–7 out of 9 questions), and as Good (8–9 out of 9 questions)

- Q 1. Was the sample frame appropriate to address the target population?
- Q 2. Were study participants sampled in an appropriate way?
- Q 3. Was the sample size adequate?
- Q 4. Were the study subjects and the setting described in detail?
- Q 5. Was the data analysis conducted with sufficient coverage of the identified sample?
- Q 6. Were valid methods used for the identification of the condition?
- Q 7. Was the condition measured in a standard, reliable way for all participants?
- Q 8. Was there appropriate statistical analysis?
- Q 9. Was the response rate adequate, and if not, was the low response rate managed appropriately?

Critical appraisal results for included studies using the JBI Critical Appraisal Checklist for cohort studies

Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Score	Quality Rating
Renz et al. (2018)	Y	Y	Y	N	N	U	Y	Y	Y	N/A	Y	7/10	F
Quantitative component of mixed-methods papers													
Study	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Score	Quality Rating
Fenwick, Lovelace & Brayne (2010)	Y	Y	Y	N	N	N	Y	Y	Y	N/A	Y	7/10	F
Kerr et al. (2014)*****	Y	Y	Y	N	N	N	Y	Y	Y	N/A	Y	7/10	F

***** MMS – only quantitative results

Y - Yes, N - No, U - Unclear, N/A - not applicable

Quality Rating: G - Good, F - Fair, P - Poor

Quality was rated as Poor (0–5 out of 11 questions), as Fair (6–8 out of 11 questions), and as Good (9–11 out of 11 questions)

- Q 1. Were the two groups similar and recruited from the same population?
- Q 2. Were the exposures measured similarly to assign people to both exposed and unexposed groups?
- Q 3. Was the exposure measured in a valid and reliable way?
- Q 4. Were confounding factors identified?
- Q 5. Were strategies to deal with confounding factors stated?
- Q 6. Were the groups/participants free of the outcome at the start of the study (or at the moment of exposure)?
- Q 7. Were the outcomes measured in a valid and reliable way?
- Q 8. Was the follow up time reported and sufficient to be long enough for outcomes to occur?
- Q 9. Was follow up complete, and if not, were the reasons to loss to follow up described and explored?
- Q 10. Were strategies to address incomplete follow up utilized?
- Q 11. Was appropriate statistical analysis used?

SUPPLEMENTARY MATERIAL V - CHARACTERISTICS OF REPORTS INCLUDED IN SCOPING REVIEW

Author Year Country*	Terminology	Report Type
Alvarado 2005 USA	Deathbed visions Apparitions	Book review
Alvarado 2006a USA	Deathbed apparitions	Letter to the editor
Alvarado 2006b USA	Near-death phenomena	Review paper
Alvarado 2008 USA	Apparitions of the living seen shortly before their deaths	Letter to the editor
Alvarado 2010 USA	Death related phenomena Deathbed visions Apparitions	Review paper
Alvarado 2014 USA	Deathbed visions	Review paper
Arnold 2014 USA	End of life transcendence experiences	Original research
Barbato 1999 Australia	Parapsychological phenomena near the time of death	Original research
Barrett 1926 USA	Deathbed visions	Book
Batthyány 2020 USA/Europe	Paradoxical lucidity	Original research
Becker 1982 USA	Near-death experiences Deathbed visions	Review paper
Betty 2006 USA	Deathbed and near-death visions	Review paper
Betty 2008 UK	Deathbed visions	Book chapter
Bostanciklioğlu 2020 Turkey	Terminal lucidity	Review paper
Bostanciklioğlu 2021 Turkey	Terminal lucidity	Review paper
Branch 2006 USA	Spirituality in end of life experience	Original research

Brayne 2006 UK	Deathbed phenomena	Original research
Brayne (1) 2008 UK	End of life experiences	Original research
Brayne (2) 2008 UK	End-of-life experiences	Review paper
Broadhurst 2016 Australia	Transcendence experiences of dying patients	Review paper
Chang 2017 Republic of Korea	Deathbed visions	Original research
Claxton-Oldfield 2018 Canada	Unusual end-of-life phenomena	Original research
Claxton-Oldfield (1) 2020 Canada	Unusual end-of-life phenomena	Original research
Claxton-Oldfield (2) 2020 Canada	Unusual end-of-life phenomena	Original research
Claxton-Oldfield (3) 2020 Canada	Unusual end-of-life phenomena	Original research
Corless 2014 USA	End-of-life experiences Deathbed visions Deathbed phenomena Deathbed coincidences Nearing death awareness	Review paper
Daher 2017 Brazil	End-of-life experiences	Review paper
Dam 2016 India	End-of-life dreams and visions	Original research
Demirkol 2016 Turkey	Terminal lucidity	Review paper
Depner 2020 USA	End of life dreams and visions	Original research
Devery 2015 Australia	Deathbed phenomena	Review paper
Dong 2014 China	End of life dreams and visions	Review paper
Eldadah 2019 USA	Paradoxical lucidity	Review paper

Elsaesser-Valarino 2011 Germany	Awareness near death	Review paper
Ethier 2005 USA	Death-related sensory experience	Review paper
Fenwick 2007 UK	End of life experiences	Review paper
Fenwick (1) 2010 UK	End of life experiences	Original research
Fenwick (2) 2010 UK	Deathbed phenomena Deathbed visions	Review paper
Fenwick 2011 UK	End of life experiences Deathbed visions and coincidences	Original research
Fountain 2012 UK	Deathbed visions	Review paper
Gibbs 2010 USA	Deathbed visions	Review paper
Grant 2014 USA	End-of-life dreams and visions	Original research
Grant 2020 USA	End of life dreams and visions	Original research
Grant 2021 USA	End of life dreams and visions	Original research
Greyson 2009 USA	Deathbed visions	Book chapter
Greyson 2010 USA	Deathbed visions "Peak in Darien" experiences	Review paper
Grosso 1981 USA	Near-death experiences Deathbed visions	Review paper
Houran 1997 USA	Deathbed visions	Review paper
Houran 2000 USA	Deathbed visions	Review paper
Janssen 2015 USA	Deathbed phenomena	Point of view
Kellehear 2011 Republic of Moldova	Deathbed visions	Original research
Kellehear 2014 UK	Deathbed visions	Review paper

Kellehear 2017 UK	Unusual perceptions at the end of life Deathbed visions	Review paper
Kelly 2015 USA	Deathbed visions	Book chapter
Kelly 2018 USA	Apparitions Deathbed experiences Deathbed visions Terminal lucidity	Book chapter
Kerr 2014 USA	End of life dreams and visions	Original research
Kheirbek 2019 USA	Terminal lucidity	Review paper
Kinsey 2012 USA	Deathbed visions	Book review
Klein 2018 Switzerland	End of life experiences	Original research
Kobayashi 2020 Japan	End of life dreams and visions	Letter to the editor
Lawrence 2012 USA	Distressing near death experiences	Book review
Lawrence 2013 USA	Deathbed Communications	Original research
Lawrence 2017 USA	Near-death and other transpersonal experiences	Review paper
Levy (1) 2020 USA	End of life dreams and visions	Original research
Levy (2) 2020 USA	End of life dreams and visions	Original research
Lim 2020 Republic of Korea	Terminal lucidity End-of-life experience	Original research
Mashour 2019 USA	Paradoxical lucidity	Review paper
Mazzarino-Willett 2010 USA	Deathbed Phenomena	Review paper
Moore 2013 USA	Deathbed visions Near-death experiences	Original research
Moreira-Almeida 2006 USA	Deathbed visions Apparitions	Book review

Moreira-Almeida 2013 Brazil	End of life and near death experiences	Review paper
Morita 2016 Japan	Deathbed visions	Original research
Morris 2020 Canada	Paradoxical lucidity	Review paper
Morse, ML 1994 USA	Death-related visions	Review paper
Morse, DR 2002 USA	Deathbed experiences	Book chapter
Muthumana India 2010	Deathbed visions	Original research
Mutis 2019 France	Terminal lucidity	Review paper
Nahm (1) 2009 Germany	Terminal lucidity	Review paper
Nahm (2) 2009 Germany	Terminal lucidity	Review paper
Nahm 2011 Germany	Near-death experiences (NDE) Deathbed visions Shared NDEs Shared dreams	Review paper
Nahm 2012 Germany	Terminal lucidity	Review paper
Nahm 2013 Germany	Terminal Lucidity	Review paper
Ney 2021 USA	Paradoxical lucidity	Original research
Nosek 2015 USA	End of life dreams and visions	Original research
Nyblom 2020 Sweden	End of life experiences	Original research
Osis 1977 USA and India	Deathbed observations Apparitions	Original research
Osis 1978 USA	Deathbed apparitions	Letter to the editor
Osis 1979 USA	Deathbed visions	Review paper

Palmer 1978 USA	Deathbed apparitions	Letter to the editor
Palmer 1979 USA	Deathbed apparitions	Letter to the editor
Pan 2021 USA	Near-death awareness	Original research
Parra 2017 Argentina	Deathbed visions Anomalous / Paranormal Experiences	Original research
Peterson 2021 USA	Paradoxical lucidity	Review paper
Playfair 2013 UK	Afterlife encounters	Book review
Punzak 2010 USA	End-of-life experience Pre-death experience	Book review
Ratshikana-Moloko 2020 South Africa	End-of-life experience	Original research
Reddy 2016 India	End of life experiences	Review paper
Renz 2018 Switzerland	Spiritual experiences in dying processes Deathbed visions	Original research
Rivera 2013 USA	End-of-life dream/visions Deathbed dreams/visions	Dissertation
Rogo 1978 USA	Deathbed experiences	Review paper
Santos 2012 USA	End of life experiences	Book chapter
Santos 2016 Brazil	Spiritual experiences in the end of life	Dissertation
Santos 2017 Brazil	End of life experiences Deathbed phenomena	Original research
Sartori 2010 UK	End of life experiences Shared death experience	Review paper
Schlieter 2018 Singapore	Deathbed visions	Book chapter
Serdahely 1992 USA	Deathbed visions	Original research

Shared Crossing Research Initiative (SCRI) 2021 USA	Shared death experiences End of life phenomena	Original research
Shinar 2015 USA	End-of-life dreams and visions Deathbed communications	Original research
Siegel 1983 USA	Deathbed visions	Review paper
Stevenson 1979 USA	Deathbed observations	Book review
Walsh 2020 USA	Spiritual visitations	Original research
Wholihan 2016 USA	End-of-Life Experiences Visions, energy surges and other death bed phenomena	Review paper
Wills-Brandon 2003 USA	Deathbed visions	Book
Woollacott 2020 USA	Spiritually transformative experience	Original research
Zhang 2014 China	End of life dreams and visions	Review paper

* Books, book chapters/reviews and letters to the editor: the country of publication was considered to be the country of the publisher or journal; Review papers: the country of publication was considered to be the country referred to in the main author's mailing address; Original papers: the country of publication was considered to be the country where the data were collected.

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SUPPLEMENTARY MATERIAL VI – SUMMARY OF INCLUDED STUDIES

Patients Studies (n=12)								
Study/ Authors	Terminology	Year/ Country	Aims	Design	Sample	Data Collection Setting	Data Collection Methods	Key Findings
Dam A. K. (2016) Significance of End-of-life Dreams and Visions Experienced by the Terminally Ill in Rural and Urban India. Indian journal of palliative care, 22(2), 130–134.	End-of-life dreams and visions	2016 India	To enquire into the nature of dreams experienced by the terminally ill in rural India; To determine any pattern of consistency in such dreams (when compared to other terminally ill); To determine the association of mortality, if any, with such dreams; To determine what effect ELDV had on the patients and their families.	MMS	60	Home	Questionnaire with closed/opened questions and semi-structured interviews	63.3% cases reported experiencing ELDV. 55.5% of the rural patients reported ELDV (10) while 66.6% of the urban patients did the same (28). 8 subjects (21%) reported seeing ELDV when they were asleep, 5 (13.1%) while awake, while the majority, 25 subjects (65.7%), reported seeing them in both states. 20 subjects (52.6%) reported that they saw ELDV at a particular time, usually night. 16 subjects (42.1%) reported having ELDV daily, 14 on a weekly basis (36.8%), and 8 on a monthly basis or less frequently (21%). 26 subjects (68.4%) reported that the dreams seemed real. 78.9% (30) of the subjects were able to recall the ELDV vividly and in detail, 13.1% (5) subjects were able to recall somewhat and 7.8% (3) subjects had trouble in recalling them. 84.2% (32) subjects reported the ELDV as 'distressing'. 30 subjects (78.9%) reported seeing 'deceased' people, be it relatives, friends or acquaintances. 12 (31.5%) saw living friends and relatives, 52.6% (20) saw people or forms that they did not recognize, 21% (8) visualized making preparations or going on a journey. About 31 (81.5%) of the subjects were religious and believed in God. 76.3% (29) patients had a symptom burden of >7 (on a VAS of 1-10), which corresponded to 'severe distress'. 94.7% (36) patients felt much better having discussed their ELDV with the team. ELDV are not uncommon in India and the incidence does not differ significantly between rural and urban population. Our subjects found them to be distressing initially, but felt better after discussing it with our team. There was a direct correlation between severity of symptoms and occurrence and frequency of ELDV. Another finding exclusive to our study was that the persons visualized in ELDV did not threaten or scare the patient and the known persons visualized were seen as they were in their prime of health.
Depner, R. M. et al., (2020) Expanding the Understanding of Content of End-of-Life Dreams and Visions: A Consensual Qualitative Research Analysis. Palliative medicine reports, 1(1), 103–110.	End-of-life dreams and visions	2020 USA	To evaluate the content of ELDV by using a rigorous qualitative approach	QUALS	83	Home	Semi-structured interviews	548 ELDV reports from 55 participants (66%). The following domains emerged: (1) <u>Interpersonal</u> , (2) <u>Affective Experience and Reflection</u> , (3) <u>Activities</u> , and (4) <u>Setting/Location</u> . <u>1) Interpersonal</u> : The interpersonal domain was operationalized as an ELDV description featuring people/animals, and information about interactions. Within this domain two primary categories emerged: <u>Characters and Relational Interactions</u> . <u>(2) Affective Experience and Reflection</u> : participants generally described their dreams with Feelings/Emotions. Traditionally positive emotions such as: peace/calm/comfort; nice/good/great; happiness/enjoyment/excitement/pleasure/fun; humor/silly/laughter; curiosity/wondering. Distressing emotions: uncertain/confused/puzzled; disturbing/distressing/scary/fearful/upset; mad/angry/frustrated/disappointed/irritated; worried/anxious/stressed/overwhelmed/concerned; surprised/startled/shocked; sadness/sorrow/blue. Reflection: Participants typically reflected on an element of Nostalgia, a longing to reconnect with a person, place, or experience from the past. <u>(3) Activities</u> : Typically, participants reported activities related to Traveling and Movement. Similarly, participants typically reported Verbal Communication and Observing and Watching as common. Interestingly, it was also typical for the ELDV to involve an Attempt to do something, including working toward a specific goal. <u>(4) Setting/location</u> : The final domain includes the setting and backdrop of ELDV. Individuals typically reported that the environment was Familiar/Known and involved the Natural Environment. Similarly, participants typically described settings related to Transportation and Travel. Typically, people reported ELDV set in their Home/Residence. It was typical for participants to describe settings or locations with cues related to Spatial Awareness and Directionality. Finally, it was typical for individuals to describe settings related to Institutions of Daily Life.

<p>Kerr, C. W. et al., (2014) End-of-life dreams and visions: a longitudinal study of hospice patients' experiences. <i>Journal of palliative medicine</i>, 17(3), 296–303.</p>	<p>End-of-life dreams and visions</p>	<p>2014 USA</p>	<p>To quantify the frequency of dreams/visions experienced by patients nearing the end of life, examine the content and subjective significance of the dreams/visions, and explore the relationship of these factors to time/proximity to death</p>	<p>PROSP MMS</p>	<p>59</p>	<p>Hospice</p>	<p>Semi-structured interviews with closed and open-ended questions</p>	<p>Frequency and prevalence of dreams: 52 (88.1%) reported experiencing at least one dream or vision. Almost half of the dreams/visions (45.3%) occurred while asleep, 15.7% occurred while awake, and 39.1% occurred while both asleep and awake. Nearly all ELDV events (267/269, 99%) were reported by patients to seem or “feel real.” Most daily reports included a single ELDV event (179, 81.4%) with two (13.2%), three (4.1%), and four events (1.4%) on other days. Content of dreams: Deceased friends or relatives (46%), living friends or relatives (17%), other people (10%), and deceased pets or animals, living pets or animals, religious figures, past meaningful experiences, and other content not listed (singly and in combinations, 35%). 38.9% of all dreams included a theme of going or preparing to go somewhere. Comfort and distress associated with dreams and visions: The mean comfort rating for all dreams and visions was 3.59 (SD= 1.21, 95% confidence interval [CI] = 3.44–3.73) with 60.3% rated as comforting or extremely comforting, 18.8% distressing or extremely distressing and 20.7% neither comforting nor distressing. The highest average comfort rating was associated with dreams/visions about the deceased (mean = 4.08, SD= 1.05), followed by deceased and living (mean = 3.61, SD= 0.78), living (mean = 3.22, SD= 1.15), and finally other people and experiences (mean = 2.86, SD= 1.19). Dream/vision content and comfort at daily report level: There was no significant linear or nonlinear relationship between days before death and comfort. The overall dream/vision content effect on comfort was significant; $F(3, 246.95) = 17.429, p < 0.001$. Significant effects were observed for seeing the deceased ($b = 1.16, t = 6.88, p < 0.001$) and both the deceased and living together ($b = 0.66, t = 2.42, p = 0.02$). The test of seeing only the living, and the test of seeing other content were not significant. Dream/vision content and comfort at weekly report level: Increasing numbers of comforting dreams as end of life approached. In a mixed-model analysis of comforting dreams and visions, the main effect of content was significant, $F(1, 25) = 16.77, p < .001$ as was the effect of time (weeks before death), $F(1, 25) = 13.84, p = .001$. In addition the interaction of content and time was significant, $F(3,25) = 5.77, p = .004$. Univariate contrasts between seeing the deceased versus the other two categories were both significant at $p < .001$.</p>
<p>Levy, K. et al., (2020) End-of-Life Dreams and Visions and Posttraumatic Growth: A Comparison Study. <i>Journal of palliative medicine</i>, 23(3), 319–324.</p>	<p>End of life dreams and visions</p>	<p>2020 USA</p>	<p>To explore differences in posttraumatic growth between hospice patients experiencing ELDV and those who did not.</p>	<p>ACSS</p>	<p>70</p>	<p>Hospice</p>	<p>Instruments (Posttraumatic Growth Inventory-PTGI, Confusion Assessment Method - CAM) +interviews</p>	<p>Significant differences emerged between groups in terms of personal strength ($p = 0.012$), spiritual change ($p = 0.002$), and overall PTGI ($p = 0.019$). Patients with ELDV experiences had higher scores on all subscales as well as overall PTGI compared to nondreaming patients. No significant differences were found between groups in terms of relating to others or appreciation for life. The results of this study suggest that patients who experience ELDV may be able to garner new insights and understanding, leading to overall growth.</p>
<p>Levy, K., Grant, P. C., & Kerr, C. W. (2020) End-of-Life Dreams and Visions in Pediatric</p>	<p>End of life dreams and visions</p>	<p>2020 USA</p>	<p>To describe the case of a pediatric palliative care patient and the impact of her ELDV on both the patient and her family.</p>	<p>CR</p>	<p>1</p>	<p>Hospice</p>	<p>Case report</p>	<p>A 15-year-old girl with terminal glioblastoma who was enrolled in a pediatric palliative care program and later in hospice care. 2 distinct ELDV experiences: Her first vivid ELDV experience occurred while in an MRI machine, during which she described being in a “deep sleep”. Dream in which she was playing dolls and singing songs with her deceased aunt. She described being in a beautiful castle filled with warmth and light. Adorning one of the walls was a stained-glass window depicting “a baby and you can see the sun through it.” In her own words, Ginny described the castle as a safe place, and emphasized that she was not alone. In addition to her aunt, the castle was also populated with numerous family pets (now deceased) that now appeared alive, healthy, and playful. The castle also included a pool; swimming had been an activity she had enjoyed before her decline. Upon waking from sleep, Ginny found immediate meaning from her ELDV experience, telling her mother, “I’m going to be okay, I’m not alone.”</p>

Patients: A Case Study. Journal of palliative medicine, 23(11), 1549–1552.								Ginny's ELDV experiences continued for several months, the frequency and meaning of her dreams intensified with repeated visits from her deceased aunt and pets. 4 days before her death, the content of Ginny's ELDV changed and would profoundly influence how she and her loved ones would experience her dying process. Second experience: Her mom heard an animated conversation through a baby monitor that was kept beside Ginny's bed. When she asked Ginny who she was talking to, Ginny responded, "I was talking to God." She added "He's old, but he's kinda cute."
Lim et al. (2020). Terminal lucidity in the teaching hospital setting. Death studies, 44(5), 285–291.	Terminal Lucidity	2020 Republic of Korea	To describe the implications of Terminal Lucidity for terminally ill patients and evaluate its incidence and characteristics in a teaching hospital setting.	RETRO ACSS	338	Hospital	Analysis of medical records	Among the 151 patients who died in general wards, 6 patients (3.98%) experienced terminal lucidity; four were male and two were female. There was no significant difference between the two groups in terms of whether patients experienced terminal lucidity or not. Among the patients with terminal lucidity, at the time of admission, three were alert, while the remaining three were drowsy. All six patients refused life-sustaining treatments and ICU care. The periods of lucidity varied from several hours up to four days. Prior to terminal lucidity, three patients were in a drowsy state, two showed signs of stupor, and one was in a coma. The unconscious state before terminal lucidity lasted for periods ranging from one to nine days. After experiencing terminal lucidity, one patient expired a day later (16.7%), two passed away five days later (33.3%), one died eight days later (16.7%), and two succumbed nine days later (33.3%). The phenomenon was not predictable based on patient characteristics.
Macleod A. D. (2009) Lightning up before death. Palliative & supportive care, 7(4), 513–516.	Lightening up before death	2009 New Zealand	To describe 6 cases of terminal lucidity	CR	6	Hospice	Case report	There were no obvious characteristics of these patients to indicate that such a phenomenon would occur. The periods of lucidity tended to last less than 12 hours and were invariably followed by a precipitous clinical decline. Case report: A 73- year-old retired electrician. Chest X-ray indicated a lung lesion that was determined to be non-small cell carcinoma. Six months after a lobectomy, he suffered an epileptic seizure. Whole brain irradiation palliated the symptoms of cerebral metastases for a further 6 months, at which time he developed an uncontrollable series of major seizures and left upper limb weakness. Corticosteroids and anticonvulsants promptly relieved the cerebral symptoms and signs, though within weeks his neurology had progressed. On admission to the hospice, he was aphasic, doubly incontinent, had a dense hemiplegia, and had fitted the previous night. He could no longer comply with his oral medications. Subcutaneous medications: clonazepam (2 mg SC/24 hours), morphine (20 mg/24 hours); dexamethasone (4 mg SC/24 hours) were continued. His clinical state settled for 36 hours, though the neurological signs only partially remitted. Then, remarkably, he regained speech and became alert and verbally responsive to his family. Within 12 hours he lapsed into a coma and died the following day peacefully.
Nosek et al. (2015) End-of-Life Dreams and Visions: A Qualitative Perspective From Hospice Patients. The American journal of hospice & palliative care, 32(3), 269–274.	End-of-life dreams and visions	2015 USA	To address the noted gap through direct patient interviews to gain greater understanding of the ELDV.	MMS	63	Hospice	Semi-structured interviews contained closed and open-ended questions	52 (82.5%) reported at least 1 ELDV. <u>Six categories emerged</u> : comforting presence, preparing to go, watching or engaging with the deceased, loved ones waiting, distressing experiences, and unfinished business. <u>Comforting Presence</u> : Dreams and visions that featured the presence of dead friends and relatives; Some also included living friends and relatives as well as dead pets or other animals; These ELDV were overwhelmingly described as comforting to the patient. <u>Preparing to Go</u> : Some participants reported that in their dreams they seemed to be preparing to go somewhere; Although there were a few reports of distress because dreamers felt "hurried," the participants primarily found this experience of preparing to go somewhere to be comforting. <u>Watching or Engaging with the Dead</u> : Participants in this category described the presence of others in their dreams/visions as simply being there or watching but not engaging with the patient; There were also reports, however, where patients described themselves as engaging with people in their dreams; Again, these experiences were largely reported as comforting. <u>Loved Ones Waiting</u> : Some patients in the study described dead friends and relatives in their dreams as "waiting for them."; Once again, the presence of these dead friends and family members was primarily experienced as comforting; There were, however, some patients who expressed that they were not ready to die. These patients experienced some distress at the fact that the dead were "waiting" for them. <u>Distressing Experiences</u> : There were also reports of distressing dreams, some of which replayed traumatic life experiences; Several patients had dreams about abusive childhood experiences; Other distressing dreams were reminiscent of

								difficult situations or relationships; Some of the dreams in this category were described as reminiscent of negative past experiences with friends or family members, which were perceived as distressing. <u>Unfinished Business</u> : Participants also reported dreams that centered on their fears of no longer being able to do the things they felt they needed to accomplish in life.
Nyblom et al. (2021) End-of-Life Experiences (ELEs) of Spiritual Nature Are Reported Directly by Patients Receiving Palliative Care in a Highly Secular Country: A Qualitative Study. The American journal of hospice & palliative care, 38(9), 1106–1111.	End of life experiences	2021 Sweden	To investigate if ELE in the form of dreams, visions and/or inner experiences, are reported directly by Swedish patients, oriented in time, place and person and receiving palliative end-of-life care. If so, what do ELE contain and what are patients' subjective experiences of them.	QUALS	25	Home/Hospice	Semi-structured interviews	A total of 41 interviews were conducted. 16/25 patients reported ELE of which the majority were perceived to be positive. In 14/41 interviews, ELE was not mentioned by the participant. None of the participants revealed any religious content in their present experiences. Themes identified - 1) <u>Vivid dreams while asleep</u> : Many patients affirmed having vivid dreams. They noted that the dreams had a different character and occurred more often lately. The dreams contained the following subthemes; 1a) loved ones and 1b) traveling. Prevalent content of patients' dreams included the presence of loved ones both living and deceased. References to traveling included preparing to go or being on a journey. 2) <u>Experiences While Awake</u> : Visions and auditory experiences and a sense of a comforting presence. One patient reported seeing her deceased father. Another patient clearly heard her deceased siblings calling her name, wanting her to come. A sense of the comforting presence of deceased loved ones was reported by some patients. A tangible presence of her dead husband was felt by one patient. <u>References to Medical Circumstances</u> : Negative experiences that were obscure or expected to come, were most often interpreted as being caused by medical circumstances. Absence of "bad" dreams, and difference between ELE and hallucinations/ nightmares. The predominantly positive content of their dreams astonished some patients. They had expected "bad" dreams given their medical situation. Patients could report having had both hallucinations/nightmares and ELE in the form of visions/vivid dreams, of which the former were perceived as disturbing and unclear and ELE as clear, positive and supporting. 4) <u>Communication about ELE</u> : A few of the participants of this study had not talked to anyone. If the patient decided to tell others about their ELE, the reaction varied depending on the person that they approached. One patient who had told her loved ones said they did not believe her. However, quite a few patients reported that they could talk to their loved ones about ELE and be met with understanding.
Pan, C. X., Thomson, K., Costa, B. A., & Morris, J. (2021) Questioning Capacity in an Elderly Jamaican Man with Terminal Cancer Exhibiting Near-Death Awareness: A Case Report and Review of Literature. Journal of palliative medicine, 24(9), 1413–1417.	Near-Death Awareness	2021 USA	To describe the case of a terminally ill, elderly Jamaican male who reported comforting visions of his deceased mother during hospitalization. To discuss recognition of NDA and its impact on patient centered care, and cultural/spiritual approaches to providing high-quality EOL care	CR	1	Hospital	Case report	Mr. J, a 68-year-old Jamaican male diagnosed with cholangiocarcinoma. It was offered palliative chemotherapy, but he declined it, preferring his own remedy of "bitters and herbs," which the primary team did not address. While hospitalized, Mr. J began experiencing visions of his deceased mother, which comforted him. He had no psychotic symptoms or fluctuation of consciousness and denied prior psychiatric disturbances or substance use disorder. Psychiatry determined that Mr. J lacked capacity due to confusion, limited insight/judgment, and impaired understanding of the benefits/risks of the recommended palliative oncologic treatment. Mr. J also confided that he saw his mother twice, although he knew it was not logical because she was deceased. When his mother appeared, she told him he would be "joining her in her world soon." He was not frightened by the visions and expressed the comfort and peace he experienced from these encounters. Throughout the interview, Mr. J remained attentive, calm, and rational. In this case, Mr. J's capacity was questioned for two main reasons. First, the patient reported NDA visions, which were interpreted as delirium-related hallucinations. Second, Mr. J wished to be treated with "bitters and herbs" instead of palliative chemotherapy. This request might have been unfamiliar to the primary team, and might not have aligned with standard clinical practice. In this instance, the possibility of integrating dual modalities of palliative chemotherapy and herbal therapies was not explored or pursued. Conclusions: Need to educate health care professionals on (1) diagnosing NDA and distinguishing NDA from delirium; (2) using cultural analysis tools to provide culturally humble care; and (3) the importance of capacity assessment. With more awareness about NDA, clinicians can better recognize and distinguish it when assessing capacity at EOL, thus honoring patient-centered decision making and allowing room for "good deaths."
								2084 O-Protocols in 2 years' time (site 1: 1005; site 2: 1079). We had 526 double observations (n ¼1052; 50.5% O-Protocols). Most patients showed spiritual experiences (72; 90%; 550 O-Protocols) at least once; Among patients with SE, 60 (75%) were Christians, 9 (11.3%) patients

Renz et al. (2018). Fear, Pain, Denial, and Spiritual Experiences in Dying Processes. The American journal of hospice & palliative care, 35(3), 478–491.	Spiritual Experiences End of life experiences	2018 Switzerl and	How does this patient perception transformation coincide with distress, and SE comprising experiences of transcendence? When do distress and when do SE erupt and subside? Are SE associated with patients' religious attitude? What is the impact of previous NDEs, previous SE, and previous fear and coping patterns?	PROSP COHS	80	Palliative care units at 2 hospitals	Participant observation based on semistructured observation protocol + Supplementarily semi-structured questionnaire	were without religious affiliation, 1 Buddhist, 1 Muslim, and 1 was adherent of natural religion. Associations between peace and spiritual experience: 46 (57.5%) graphs illustrated clear, 23 (28.8%) partial, 3 (3.8%) no associations, and 8 (10%) showed no spiritual experiences. Most patients (69; 86.3%) seemed to undergo a transformation of perception with all 3 stages. Post-transition was clearly observed (= in both parameters) in 75 (93.8%) patients (559 O-Protocols); Post-transition was induced by medication in 5 (6.3%) patients. Pre-transition and in particular post-transition showed associations with peace and SE - of 559 O-Protocols stating post-transition, 516 (92.3%) indicated no fear, and 248 (44.4%) reported SE. Among patients with "no/almost no" or "mild suffering" (49; 61.3%) were many with previous NDEs or spiritual/mystical experiences. Concerning attitudes, coping strategies, and spiritual practices—particularly curiosity about afterlife—had a positive, repressing almost no impact. In contrast to existing literature, we registered 31 visions/experiences of light and 21 visions of angels (among them some appearances of deceased relatives); Spiritual experiences happened in 46 (57.5%) patients as hypothesized in periods of peace and in post-transition and slightly less in pre-transition. Unexpectedly, 41 (51.3%) patients had at least 1 spiritual experience followed by fear/pain/denial. Spiritual experiences at the last observation before death were seen in 38 (47.5%) patients, mostly combined with peace. Anyway, spiritual experiences were observed as highly effective. However, we had 35 (1.7%, N=2084) experiences of darkness/ambivalence by 25 (31.3%) patients.
Shinar, Y. R., & Marks, A. D. (2015) Distressing Visions at the End of Life: Case Report and Review of the Literature. The journal of pastoral care & counseling : JPCC, 69(4), 251–253.	Visions at the End of Life End of life dreams and visions	2015 USA	To describe a case involving distressing VEL; To provide a review of existing literature around ELDV; To provide a framework within which to approach the patient experiencing distressing ELDV.	CR	1	Hospice unit within the hospital	Case report	Medical history: tobacco and alcohol abuse, bipolar disorder, and hypertension. He was confirmed to have stage IV nonsmall-cell lung cancer. BT was in-patient hospice unit within the hospital. Important family conflicts: he had an ex-wife and three grown children, whom he abandoned while the children were young. Only one BT's son came to the hospital and related a long history of erratic and abusive behavior on the part of the patient towards his family. Spiritual history: He had been raised Catholic, but no longer identified as such. He expressed a belief in God and an afterlife, but denied offers of prayer or spiritual support. 2 Distressing ELDV: As he described, the first involved a vision of the devil, standing at the foot of his hospital bed, rubbing his hands in glee in anticipation of taking BT to hell. The second occurred one night later. BT described the second ELDV as involving his deceased loved ones – his brother, his parents, his now-deceased ex-wife – standing in a ring around his bed, with their backs to him. He attempted to communicate with them, and they refused to turn to him or to acknowledge him. Two days after BT's final vision, he passed away, with what was perceived by the hospice staff as great agitation, despite aggressive medical management. He declined a visit with the hospice spiritual care provider. A history of past trauma, substance abuse, and mental health disorders may increase the risk for such distressing ELDV as the one described by our patient above.
Relatives Studies (n=9)								
Study/ Authors	Terminology	Year/ Country	Aims	Design	Sample	Data Collection Setting	Data Collection Methods	Key Findings
Barbato et al., (1999) Parapsychological phenomena near the time of death.	PP near the time of death	1999 Australia	To determine the range, frequency, and effect of PP experienced by the next of kin within 1 month of the death of a loved one; To ascertain the next of kin's knowledge of	RETRO DCSS	47	Palliative care unit at hospital	Questionnaire	23 (49%) reported a PP (significant dream or hallucination). Of them: 50% sense of presence of the deceased, 33% auditory or olfactory hallucination, 16% unusual occurrence, 11% tactile hallucination, 5% visual hallucination, 5 % dream. Of those who reported a PP, 92% were women, 76% believed in an afterlife, and 40% indicated that the belief increased after the experience. In the group of those who did not PP, the gender distribution is balanced and there is no impact on belief.

Journal of palliative care, 15(2), 30–37.			and feelings toward any PP experienced by the loved one around the time of his or her death; To determine the relationship of such phenomena to religious, spiritual, and cultural beliefs				18 (38%) reported unusual experience in the first month after death. Of them: 4 (22%) 48 hours after death, 6 (33%) 2 to 7 days after death, 8 (45%) after 1 week of death. 66% reported very extremely or moderately lived experiences. 29% reported the experience as negative. 10 of them told a relative or close friend about the experience that they said was helpful. 11 reported an unusual experience lived by the patient before death, including: 7 visions of relatives by the deceased, 4 perceptions of peaceful experience by the patient as if he were seeing something or someone in space. Of these 11 patients' experiences, only 3 described a positive impact, 6 negative and 2 mixed or undefined. Of the family members, 82% felt anxious or threatened by the perception and 18% felt at peace.
Fenwick, P., & Brayne, S. (2011) End-of-life experiences: reaching out for compassion, communication, and connection-meaning of deathbed visions and coincidences. The American journal of hospice & palliative care, 28(1), 7–15.	End of life experiences Deathbed Visions and Coincidences	2011 UK	To explore and classify end-of-life phenomena	DCSS	300 relative/friends accounts	Emails sent spontaneously	<p>DV: 85% primary sources, 50% were daughters and 40% were alone with the deceased. 58% hospital/hospice deaths and (witnessed or heard the deceased person's account), 54% occurred 12 hours before death, 62% the person was dying, 14% the death did not was expected and they had the experience in a paradoxical lucidity. 70% visions of relatives or friends and 73% had only one vision and 3% religious images, 78% were convinced of the validity of the experience, experience was comforting for 45% of the reporters and 33% of the deceased. 93% of the reports were referred to situations that occurred more than 1 year ago,</p> <p>DC: 90% primary sources, all reports occurred more than 5 years ago, 80% were 1st degree relatives (granddaughters 17%), 67% 30 minutes before death, 43% hospital death, 79% at night, 35% were awake (greater relationship with discomfort), 38% sleeping and 26% dreaming. Most common occur in dreams (love, light, compassion after waking up from the dream), 49% came to say goodbye and assure that everything was ok, 32% messengers were dying or warning that they would die. Almost all were unexpected phenomena and not attributed to religious figures or belief. 13% believe in life after death. 36% comforting impact, 36% uncomfortable and then comforting.</p>
Grant et al. (2020). Family Caregiver Perspectives on End-of-Life Dreams and Visions during Bereavement: A Mixed Methods Approach. Journal of palliative medicine, 23(1), 48–53.	End-of-life dreams and visions	2020 USA	To explore differences in self-reported grief for people whose loved ones shared ELDV and those who did not, and to describe the role of ELDV in the grieving process.	MMS	228	Hospice	<p>27.2% (n = 62) of respondents indicated that their loved ones experienced an ELDV. Of the reported ELDV, 29% occurred while awake, 22.6% occurred while asleep, and 48.4% occurred while both awake and sleep. 47.5% believed these ELDV brought comfort to their loved one (agree or strongly agree). Of those whose loved ones reported ELDV, more than half (58.2%) reported they helped with overall grief (rating as moderate, quite a bit, or a great deal). Almost half (49.3%) said they helped with accepting the reality of their loss, 46.1% said that they helped them work through the pain of their grief, 39% said that they helped them adjust to their new world without the deceased, and 45.9% believed ELDV helped maintain their enduring connection with their loved one. Comfort from dreams significantly related to total CBI score (r = 0.224, p = 0.047) as well as the images and thoughts (r = 0.258, p = 0.025) and acute separation subscales (r = 0.224, p = 0.047) - negative relationships. Comfort from dreams had a positive relationship with accepting the reality of loss (r = -0.511, p < 0.001), working through the pain of grief (r = -0.556, p < 0.001), adjusting to the new environment (r = -0.405, p = 0.001), and continuing bonds (r = -0.538, p < 0.001). CBI scores were not significantly different between caregivers who reported loved ones with ELDV and others. Open-ended responses were thematically analyzed resulting in 3 emergent themes: <u>Comfort</u> (Participants commonly noted comfort provided by ELDV describing solace, peace, or reassurance), <u>Reflection And Emotions</u> (a variety of feelings and emotions emerged, including positive, negative, or mixed/contrasting. The majority of emotions were traditionally positive.), and <u>Sense-Making</u> (how caregivers tried to understand, explain, or conceptualize ELDV and incorporate them into their own worldview. The subtheme of Religious/Spiritual Process was the most apparent; Others considered ELDV to be medically related, due to either cognitive decline or medication).</p>

<p>Grant et al. (2021) Attitudes and Perceptions of End-of-Life Dreams and Visions and Their Implication to the Bereaved Family Caregiver Experience. The American journal of hospice & palliative care, 38(7), 778–784.</p>	<p>End-of-life dreams and visions</p>	<p>2021 USA</p>	<p>To explore FCG attitudes toward dreams and perspectives on ELDV of the bereaved.</p>	<p>MMS</p>	<p>500</p>	<p>Hospice</p>	<p>Survey + focus group</p>	<p>40.2% of participants reported their loved one experienced an ELDV while receiving hospice care (17.1% reported no ELDV and 42.8% were unsure). FCGs were most commonly told of the experience directly by their loved one (64.3%) and 30.2% reported being present during the ELDV. These dream experiences occurred during both waking and sleeping states (39.9%). Participants whose loved ones had an ELDV felt dreaming was more valuable ($p < .001$) and more often aimed to analyze their own dreams ($p < .001$) than those who did not report this type of experience. FCGs that did not report their loved one experiencing ELDV did not take dreaming seriously ($p < .001$) and more commonly felt that dreams are nonsense products of the brain ($p < .001$). Participants reporting ELDV were significantly more validating of everyday dreams ($p < .001$). Positive attitudes toward dreams strongly correlated with comfort from ELDV for both patients and FCGs. Openness correlated positively with comfort from the ELDV for both the patient ($r = .149, p = .038$) and FCG ($r = .217, p = 0.002$) and negatively with fear/anxiety ($r = .141, p = 0.050$). Individuals that did not take dreams seriously were correlated with feeling ELDV were a side effect of drugs ($r = .180, p = .012$) and not part of the natural dying process ($r = -.262, p < .001$). Positive ELDV experiences highly correlated with grief experiences of FCGs. The more individuals felt their deceased loved one was comforted by ELDV, were comforted themselves, or saw ELDV as a natural part of dying, the greater the experience positively affected their grieving process, made accepting their loss easier, and felt a greater connection with their deceased loved one (significant at $p = .05$ or $p = .01$). Those who viewed their loved one's ELDV as negative had opposing experiences, accepting the loss was increasingly more difficult for FCGs who felt their loved one was made anxious by their ELDV ($r = .212, p = .003$) or themselves were made anxious ($r = .197, p = .006$). When the ELDV was anxiety- or fear-inducing for the patient, it also negatively impacted the ongoing connection of the FCG with the deceased ($r = .211, p = .003$). The greater a caregiver felt that the ELDV was caused by disease or a side effect of medication, the more negatively it impacted their ability to accept the loss, the continued bond with the deceased, and their overall coping when recollecting the experience. Negative ELDV perceptions (ex. ELDV were caused by medications) affected grief in areas such as accepting the loss ($r = .235, p = .010$) or maintaining connection ($r = .255, p = .010$) with the deceased. Focus group discussions were thematically analyzed resulting in 4 themes: ELDV narrative (Participants constructed narratives by interpreting the ELDV within the context of their loved one's life and illness experience; In sharing their stories, FCGs talked about dream content, or who was in the dream and what happened; FCGs also shared the patient affect/reflection of the experience. Connection (Participants spoke about ELDV as a means to deepen relationships with the patient or family and friends; Participants also desired support from others, such as healthcare providers, or offered support through advice about ELDV, explaining they are part of "a normal dying process). Reflection (Participants shared ELDV reflections and how they impacted them during caregiving. Responses included feelings such as amazement, peace, curiosity; ELDV also impacted FCGs during bereavement; Lastly, during reflection, many participants engaged in sense-making, or assigning meaning and purpose to their loved one's ELDV). Other Experiences (These experiences helped validate their belief in a connection between the living world and that of the deceased. Many participants talked about grief dreams, or dreams FCGs had of their loved one after death; FCGs also talked about signs- items such as sparrows, pennies, rainbows- that strengthen their connection with the deceased; The last subtheme that emerged was deathbed coincidences, or unexplainable events that coincided with time of death of their loved one.</p>
<p>Kellehear et al. (2011) Deathbed visions from the Republic of Moldova: a</p>	<p>Deathbed visions</p>	<p>2011 Republic of Moldova</p>	<p>To provide a content analysis of deathbed visions that will identify psychosocial categories important to the well-being of the</p>	<p>QUALS</p>	<p>102</p>	<p>Hospitals/clinics in urban and rural areas.</p>	<p>Semi-structured interviews</p>	<p>The prevalence of all DV and other hallucinations is approximately 40% of the total sample. Classic forms of DV numbered 34 cases of the total sample. Obvious hallucinations (07) and both common hallucinations and DV (03). Prevalence of specifically DV: approximately 36%. The most common person sighted is a deceased mother (13 cases) and the median number of deceased visitors was 2. There were no reports of frightening or threatening visions. 6 themes emerged: <u>Support (5)</u>: DV characterized by some expression of comfort or satisfaction at the prospect that someone important to the dying person was waiting for them. <u>Comfort (2)</u>: comfort</p>

content analysis of family observations. <i>Omega</i> , 64(4), 303–317.			dying person. In other words, we were interested to know what psychological or social role that these visions played, if any, in the overall health and well-being of the dying person.					from their visions either because they could see that some of the deceased loved ones were well and happy in the other world or because they received communications about their current situation that provided comfort to them in their final hours. <i>Companionship</i> (12): visions of the dead would be a repeated occurrence that would be characterized by regular or prolonged conversation. <i>Reunion</i> (10): The nature of the call is to be more quickly reunite with a deceased loved one. <i>Prognosis</i> (6): DV that seemed to either provide the dying person with a prognosis or indication of impending death. <i>Choice and Control</i> (2): stories that conveyed a sense of choice and control to the dying person (an active negotiator or equal actor in the events he or she describes).
Morita et al. (2016) Nationwide Japanese Survey About Deathbed Visions: "My Deceased Mother Took Me to Heaven". <i>Journal of pain and symptom management</i> , 52(5), 646–654.e5.	Deathbed Visions	2016 Japan	To clarify the prevalence and factors associated with the occurrence of DV, explore associations among DV, a good death, and family depression. To explore the emotional reaction, perception, and preferred clinical practice regarding DV from the view of bereaved family members	ACSS	2221	20 Hospitals/ 133 palliative care units/ 22 home hospice service	Multicenter questionnaire survey	DV were reported in 21%. Of patients with DV, 87% had visions of deceased persons, and 54% had visions of afterlife scenes. Among the deceased persons, parents were most frequently listed, followed by siblings and friends. DV were significantly more likely to be observed in older patients, female patients, female family members, family members other than spouses, more religious families, and families who believed that the soul survives the body after death. Good death scores for the patients were not significantly different between the families who reported that the patients had experienced DV those who did not, whereas depression was more frequently observed in the former than latter, with marginal significance (20 vs. 16%, respectively, adjusted $P = 0.068$). Respondents who reported DV as causing fear were 19% for patients and 22% for families. Respondents who reported DV as comfortable were 24% for patients and 13% for families. 35% agreed that DV were hallucinations, 38% agreed that such visions were a natural and transpersonal phenomenon in the dying process. Female family members and those with a belief that the soul survives the body after death were significantly more likely to agree that deathbed visions were natural and transpersonal phenomena (male, 26% vs. female, 45%, $P < 0.001$; belief, 44% vs. nonbelief, 26%, $P < 0.001$). 81% regarded it as necessary or very necessary for clinicians to share the phenomenon neutrally, not automatically labeling them as medically abnormal. 83% regarded use psychotropics if a patient was distressed because of the DV.
Muthumana et al. (2010) Deathbed visions from India: a study of family observations in northern Kerala. <i>Omega</i> , 62(2), 97–109.	Deathbed Visions	2010 India	To employ phenomenological criteria in assessing the prevalence of DV	RETRO DCSS	104	Home	Interview	Nearly all dying patients were either Hindu (70) or Muslim (31), Christian (3). Demographics measures were not correlated with DV, not significant statistically. Religion was found to influence the experience of vision in the sample studied. While 44% of Hindus had visions only 28% non-Hindus experienced visions ($p = 0.10$). Muslims had fewer visions than the rest of the community. While only 21.2% Muslims experienced vision, 46.5% of non-Muslims had visions ($p = 0.01$). This is statistically significant. While 45% of those taking opioids had visions, only 30% of those who were not taking opioids experienced visions. This, however, was also not statistically significant ($p = 0.11$). 40/104 families did report "unusual experiences or behaviors" by the dying person some weeks, days, or hours before death. Of these, 06 were premonitions of death, 05 were visions that appeared to represent confusional states or, in 01 case, a mix of confusional and DV. 29 recognizable DV – prevalence of a 30%. Only 03 people reported "seeing" religious figures—02 of these patients saw God and 01 of these—a Christian patient—reported seeing an angel. The most common sighting was a mother (17/30), the appearance of both parents (9/30). The range of visitors consisted of between 1 and 4 with a median of 2 visitors per sighting. Except for 2 cases (4 weeks and 2.5 weeks respectively) most dying people experienced their visions in the week prior to their death. The median time for the appearance of these visions was 2 days.
Rivera, W. P. (2013) The impact of deathbed dreams/vision	Deathbed dreams/visions	2013 USA	To examine the psychological and emotional impact of the patient's end-of-life dreams/visions on their family, friends and/or caregivers;	RETRO MMS	159 family/friends/caregivers	Hospice	Mailed survey with close and open-ended questions	141 participants responded to the question about the occurrence of dreams/visions. 57% witnessed behaviors consistent with deathbed dreams/visions, or their deceased loved ones reported these visions during their last days or hours of life. 20.1% indicated that their deceased loved one experienced end-of-life dreams/visions both while awake and while asleep. The most frequently sighted persons were deceased parents 25.3% ($n=23$), deceased spouse 15.4% ($n=14$), and siblings 15.4% ($n=14$). 62 participants responded to the question about their views and reactions resulting from the actual experience of deathbed dreams/visions. Most of the respondents 85.5% ($n=53$) perceived that end-of-life dreams/visions enabled their deceased

s on the bereaved.			To expand research into ELE by assessing hospice patients' family systems understanding and meaning of end-of-life dreams/visions, and to further define and elucidate the potential therapeutic meaning intrinsic to End-of-Life Dreams/Visions on the bereaved.					<p>loved one to have a peaceful death. The majority of respondents (62.3%) perceived end-of-life dreams/visions to be pleasant with 27.9% assessing these experiences as both pleasant and disturbing. Acceptance was the most frequently cited (n=46) grief response to be positively affected by dreams/visions, followed by Sadness (n=34); Spiritual Belief (n=32); and Quality of Life (n=25). Approximately 40% (n=27) of the respondents (n=68) indicated that their deceased loved one's deathbed dreams/visions experience positively affected five or more of the 13 grief responses included in the list. The correlation between the total positive impact on grief variable and age revealed no significant relationship ($r = -.082, p = .524$). There was no difference between female and male participants on positive impact on grief (Female $M = 3.85, SD = 2.44$; Male $M = 3.86, SD = 2.82; t = .007, p = .99$). 68.1% (n=47) perceived that their loved ones' deathbed dreams/visions positively affected their spiritual and existential views. 76.8% (n=53), reported that their loved one's deathbed dreams/visions helped them cope with their grieving process. 76.8% (n=53) indicated that their loved one's dreams/visions provided emotional warmth and comfort during the time of death. 71.4% (n=50) reported that their attitude about the after-life was significantly impacted by their loved one's deathbed experiences. 79.4% (n=54) of the respondents reported that as a result of their loved one's end-of-life experiences, they felt less afraid and more comfortable talking about deathbed dreams/visions with others. 62.3% (n=38) indicated positive attitudes towards their loved one's deathbed dreams/visions. A Pearson correlation analysis shows a low, positive and non-significant association ($r = .20, p = .15$) between the attitude mean and the total positive impact on grief. This finding suggests that the two variables represent different constructs that could be positively affected by dreams/visions of their deceased loved ones. The attitude mean was not significantly related to age or gender.</p>
<p>Shared Crossing Research Initiative (SCRI) (2021) Shared Death Experiences: A Little-Known Type of End-of-Life Phenomena Reported by Caregivers and Loved Ones. The American journal of hospice & palliative care, 10499091211000045. Advance online publication.</p>	<p>Shared death experiences End-of-life phenomena</p>	<p>2021 USA</p>	<p>To better understand the features and effects of SDE</p>	<p>QUALS</p>	<p>107 caregivers/ loved ones</p>	<p>Remote conference service</p>	<p>Semi-structured interviews</p>	<p>Though most of the 164 SDE accounts we analyzed occurred right around the time of a death, 11 (6.7%) occurred hours to days before a death and 23 (14.0%) occurred hours to days after a death. 105 SDEs (64.0% of 164)— were reported by individuals who were physically distant from the dying patient or loved one at the time of death. A total of 44 participants (41.1% of 107) reported having had 2 or more SDEs, and 85 individuals (79.4%) reported experiencing additional kinds of death-related phenomena, the most common being visions of the deceased, followed by direct post-death communication. 4 distinct though non-exclusive participatory modes of an SDE: <u>Remotely sensing the death of an individual</u>: 34 SDE reports (20.7%). 12.1% included descriptions of brief thoughts, feelings, and/or a sense of the dying's presence usually at a time later determined to correspond to the moment of death. 14 SDE reports (8.5%) described the sudden onset of unusual physical symptoms thought to correspond to those experienced by a loved one immediately prior to death. <u>Witnessing Unusual Phenomena Attributed to a Death</u>: - 145 accounts (88.4%) included the appearance of unusual phenomena that participants either present or apart from the dying person attributed to the event of a death. 50.6% vision of the dying (typically described as appearing younger and more vibrant), 25.0% of the appearance of a transcendent light, 19.5% of sensing energy, 18.9% of alterations in time and space, 15.8% of encounters with non-human beings and entities, 14.6% of seeing light or material believed to be the spirit leaving the body, 13.4% of the appearance or presence of previously deceased loved ones, and 12.1% of visions of otherworldly or heavenly realms. 8.5% of the appearance of tunnels or gateways and 4.2% of life reviews in which individuals reported having witnessed past events in the lives of the dying. <u>Accompanying the Dying in a Visionary Real</u>: 15.2% of SDEs that occurred either at or apart from the bedside of the dying included descriptions of having accompanied the dying partway through their transition to an apparent post-mortem existence. According to these reports, participants suddenly found themselves out-of-body and/or in a visionary realm together with the dying (and sometimes with other deceased loved ones and/or unknown entities). These realms were most often described as gardens, castles, otherworldly regions, or a void. One feature that appeared in 18 accounts (10.9%) was a border or boundary that participants encountered and said they were not able or "permitted" to go beyond, upon which they suddenly found themselves back in daily life. <u>Assisting the Dying in Transitioning</u>: 9.1% of participants described having taken an active role in assisting a loved one</p>

								in the process of transitioning. Every one of these experiences occurred physically apart from the dying. These experiences were similar to those in which people accompanied the dying in a visionary realm but included individuals feeling that their attention, presence, and assistance was required by the dying to successfully transition. <u>Changes in Beliefs, Attitudes, and Behavior</u> : Participants reported a number of changes in beliefs, attitudes, and behavior arising from their SDEs. These reports arose spontaneously during interviews, so the following numbers represent minimum figures. 86.9% stated that their experience had left them absolutely convinced of the reality of a benevolent afterlife. 69.1% SDEs had ameliorated or even reconciled their grief. 52.3% shared death experiences had alleviated or completely removed their fear of death and dying. 42.9% having left a profound mark on what they perceived to be life's meaning or purpose. 36.4% SDE had resulted in them becoming "more spiritual." 26.1% identified as being Christian, though all expressed that their experiences had shaped their views on Christianity. <u>Continuing Bonds with the Deceased</u> : 24.2% having the perception of an ongoing relationship with a deceased loved one. <u>Challenges Regarding Integration and Disclosure</u> : 28.9% wanted to talk about their experiences but were afraid of social ridicule or rejection. 19.6% reported various struggles to navigate around the aforementioned sociocultural expectations surrounding grief and bereavement. 14.9% received negative responses to the sharing of their experiences. <u>Gratitude for Opportunity to Share and Learn</u> : Every interviewee expressed gratitude for the opportunity to share their stories and to discuss SDEs.
Health Care Professionals Studies (n=15)								
Study/ Authors	Terminology	Year/ Country	Aims	Design	Sample	Data Collection Setting	Data Collection Methods	Key Findings
Batthyány, A., & Greyson, B. (2021) Spontaneous remission of dementia before death: Results from a study on paradoxical lucidity. Psychology of Consciousness: Theory, Research, and Practice, 8(1), 1–8.	Paradoxical lucidity	2021 USA and Europe	To elucidate further the phenomenology and structure of paradoxical lucid episodes in a contemporary convenience sample of patients with dementia.	RETRO DCSS	187 HCP/ family member/ informal caregivers	Palliative care units/ neurologic al clinics/ hospices/ dementia care locations	Survey	The most common diagnosis among the 124 patients was dementia, not otherwise unspecified (45%), followed by Alzheimer's disease (25%). order of frequency. Assessment of the patients' cognitive state on a typical day before the lucid episode: Almost 2/3 of the patients had been unresponsive (39%) or unconscious (27%) most of the time. Assessment of the patients' cognitive state during the lucid episode: Almost 80% of the patients were rated as "clear, coherent, and just about normal verbal communication" during the lucid episode. In terms of the duration of the lucid episode, the median value was between 30 and 60 min. Information on the proximity of the lucid episode to the patient's death only for 123 reports: the median survival after the lucid episode was between 2 and 24 hr. Despite the fact that, prior to their lucid episode, more than 90% of the sample had been extremely impaired cognitively, in more than 80% of these cases, complete remission with return of memory, orientation, and responsive verbal ability was reported by observers of the lucid episode. The majority of patients died within hours to days after the episode. Neither age nor gender of the patients was significantly associated with any of the clinical variables. Those patients who had been unresponsive or unconscious prior to the lucid episode tended to have shorter lucid episodes than those patients who had been awake and responsive, despite cognitive impairments ($X^2 = 23.61$, $df = 10$; $p = 0.009$). Those whose lucid episodes lasted more than one day tended to live longer after the episode than those whose lucid episode lasted one day or less ($X^2=39.19$, $df=5$, $p=0.001$).
Brayne, S., Farnham, C., & Fenwick, P. (2006) Deathbed phenomena and their effect on a palliative	Deathbed phenomena	2006 UK	In order to prepare for a future comprehensive study of DBP, the authors approached the Camden palliative care team in July 2003, and invited them	RETRO QUALS	3 doctors/ 5 nurses/ 1 support worker	Palliative care unit	Questionnaire + semi-structured interview	All had at least 5years of experience working with the dying and had been present many times in the 48 hours before death and at the moment of death. All had either been told of DBP by their patients or had experienced DBP themselves. DBP occur relatively frequently, and those patients and relatives tend to talk about them to nurses more than to doctors. 9 interviewees believed DBP not only existed but are an intrinsic part of the dying process. It was commonly agreed that DBP are an intensely personal and often spiritual experience that helps the patient to become reconciled with events in their life and, therefore, to come to terms with their death. 8 had either witnessed patients experiencing DBP at the time they occurred, or patients had talked to them about the experience after the event. 7 interviewees had also heard accounts from

care team: a pilot study. The American journal of hospice & palliative care, 23(1), 17–24.			to take part in a pilot survey.					patients' relatives. None of the interviewees considered their personal religious or spiritual beliefs to have been influenced or changed by witnessing DBP or by hearing stories from relatives. Some of the interviewees found DBP hard to define clinically. 9 interviewees clearly defined the difference between DBP and drug-induced hallucinations. The interviewees believed that DBP differ from drug-induced hallucinations because they hold some kind of profound meaning for the patient. Several interviewees spoke of DBP as a prognostic indicator for nearing death, which is encapsulated in the language used by patients. The interviewees considered DBP to be far broader than the archetypal image of "take-away" apparitions or visions at the end of the bed. 9 interviewees referred to the importance that dreams and waking dreams play in helping patients to reconcile with their lives and to let go. Nevertheless, sometimes these dreams are far from immediately comforting. The issue of encouraging patients to talk about their DBP experiences emerged as a poignant theme during the interviews.
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. The American journal of hospice & palliative care, 25(3), 195–206.	End of life experiences	2008 UK	To establish whether those who are dying naturally of old age experience ELE that are similar to those who are dying of a terminal illness; To explore the differential diagnostic markers to distinguish between genuine spiritual experiences and those of psychosis that are related to the physical process of dying; To examine the characteristics and prevalence of ELE.	RETRO PROSP MMS	5 nurses/ 5 care assistant	Nursing Home	Questionnaire + interview	7 reported unconscious or confused residents who unexpectedly became lucid enough just before they died to interact with relatives and carers; 6 reported dreams that help to prepare for death, and 2 reported dreams or visions that held significant meaning for the dying to help with unfinished business; 5 reported dying residents expressing a desire to heal family rifts; 5 reported the dying seeing dead relatives visiting just before death, and 4 reported the dying seeing dead relatives sitting on or near the bed; 4 reported the dying seeing groups of children shortly before death; 4 reported the synchronistic appearance of birds or animals around or just before the time of death, 3 of them from the Philippines spoke of seeing black butterflies around the time of someone's death; 4 reported a change of room temperature around the time of death; 3 reported a sense of being "pulled" shortly after a patient's death; 3 reported synchronistic events at the time of death, such as clocks stopping and bells ringing in rooms of those who had recently died; 2 reported the dying speaking about transiting to a new reality; None of the carers reported the writing of poetry, the singing of songs, or light around the dying at the point of death. Most ELE were reported shortly before death, in the final days or hours. 3 interviewees talked about the difficulties of distinguishing between ELE and drug-induced hallucinations, dementia, and confusion, 1 said that ELE and hallucinations might be the same thing. Of the 10 interviewees, however, 5 were clear about the difference between hallucinations and ELE. Interviewees reported a further ELE where reunion with beloved relatives is paramount to the dying resident, even when they are comatose. All the interviewees talked of what might be described as paranormal incidents, such as lights going on and off in the room of a resident who had recently died. Others reported an episode involving a bell in the room of a resident who had died.
Chang et al., (2017) Identifying Perceptions of Health Professionals Regarding Deathbed Visions and Spiritual Care in End-of-Life Care: A Delphi Consensus Study. Journal of Hospice and Palliative	Deathbed visions	2017 Republic of Korea	To gain a reliable consensus of opinions about deathbed visions from end-of-life care experts.	DE	18 nurses/ 13 doctors	Hospitals/ nursing homes	Questionnaire 2 panels formed after a literature review + 3 meetings to review the questionnaires	DV: characterized as visions of deceased relatives or friends, religious figures, or a visionary language pertaining to travel. 3 items of nurses and doctors's consensus in round 2 Delphi: The most agreed-upon item "the spiritual experiences of patients for a peaceful death." The next-agreed-upon item was "increased secretion of neurotransmitters (such as endorphins) in response to extreme circumstances." Meanwhile, the items that received low consensus ratings were "the evidence of someone invisible welcoming the patient" and "a vision seen in the dying process of nerve cells." Doctors showed the highest consensus on "changes in cognitive function because of delirium in the end stage of life," whereas nurses reached the highest consensus on "the spiritual experiences of patients for a peaceful death." The item "delirium caused by medication" was ranked the eighth most-agreed-upon item among nurses, whereas it was the fifth most-agreed-upon item among doctors. The most-agreed-upon item among doctors for spiritual care was "helping meet patients' religious needs in the process of preparing to accept death," whereas the most-agreed-upon item among nurses was "listening attentively to the patient's spiritual experience." For perceptions on the proper approach for end-of-life care for dying patients who are experiencing deathbed visions, "taking a perspective that lends devotion to each patient's religious view of death" was the most-agreed-upon item. The next most-agreed-upon item was "acknowledging the existence of a spiritual world that is perceived at the time of death by the patient." The least-agreed-upon item was "dealing with a DV as an

Nursing, 19(2), 177-184.								objective reality that needs to be proved scientifically." The groups differed on the item "taking the perspective that death is a transfer to another dimension rather than the end," which was ranked as the third most-agreed-upon item among nurses but was the least-agreed-upon item, ranking seventh, among doctors.
Claxton-Oldfield, S., & Dunnett, A. (2018). Hospice Palliative Care Volunteers' Experiences With Unusual End-of-Life Phenomena. OMEGA - Journal of Death and Dying, 77(1), 3-14.	Unusual end-of-life phenomena	2018 Canada	To examine whether hospice palliative care volunteers have witnessed or been told about a number of different EOLP in their work with dying patients and their families and to examine volunteers' beliefs about EOLP.	RETRO DCSS	45 volunteer s	Hospice	Mailed survey	34% witnessed EOLP were patients talking to or reaching out their hands toward deceased relatives or friends, 33% occurrences of terminal lucidity, 28% patients seemingly getting ready for a trip or journey, 1/3 of volunteers indicated that a patient or a patient's family member had told them about visions or dreams of deceased relatives or friends (47% and 44%, respectively), seeing beautiful places or colors or hearing wonderful music (38%), terminal lucidity (38%), and deathbed coincidences (33%). 64.3% of the volunteers consider EOLP to be a transpersonal experience; 69.8% consider EOLP to be profoundly spiritual events; 72.1% EOLP are a source of comfort to the dying patient; 66.6% EOLP are a source of comfort to the dying patient's family members; 47.6% of patients who experience EOLP have a peaceful death; 11.7% consider EOLP to be the result of oxygen deprivation; 14.0% consider EOLP to be hallucinations brought on by painkilling and sedative drugs like morphine; 11.7% consider EOLP to be brought on by delusional states such as delirium or dementia; 21.0% consider EOLP to be the result of a dying or deteriorating brain). 96% of the volunteers felt that information about EOLP should be included as part of their volunteer training.
Claxton-Oldfield, S., Gallant, M., & Claxton-Oldfield, J. (2020) The Impact of Unusual End-of-Life Phenomena on Hospice Palliative Care Volunteers and Their Perceived Needs for Training to Respond to Them. Omega, 81(4), 577-591.	Unusual end-of-life phenomena	2020 Canada	To examine hospice palliative care volunteers' beliefs about EOLP, the impact of EOLP on their lives, and (c) their perceived needs for training to deal with or respond to them.	RETRO DCSS	39 volunteer s	Hospice	Mailed survey with close and open-ended questions	82.1% of the volunteers indicated that they had heard or read about EOLP, 40.5% had personally witnessed an EOLP in their work as a volunteer, 36.8% had a patient or patient's family member report an EOLP to them. 48.6% had either personally witnessed and/or been told about an EOLP. +3/4 of the volunteers strongly agreed/agreed that EOLP are a source of comfort to dying patients. +68.4% strongly agreed/agreed that EOLP are more common than we think and that encouraging patients or families to talk about EOLP may enable a better dying process (70.3%). 41.2% strongly agreed/agreed that EOLP are a source of distress to patients or their family members and 56.8% strongly agreed/agreed that EOLP are a part of, and have a positive influence on, the dying process. 61.5% strongly disagreed/disagreed that EOLP are emotionally distressing to them (only 2.6% strongly agreed/ agreed that they were). More than half of the volunteers strongly agreed/agreed that EOLP have influenced their religious beliefs or their spirituality in a positive way (52.6%, 59.0% respectively) and have made the prospect of death less scary for them (53.8%). 44.7% said that EOLP have convinced me that consciousness survives bodily death. 64.1% strongly agreed/agreed that they were comfortable talking about EOLP with patients or families and 74.4% strongly agreed/agreed that they were comfortable talking about EOLP with other members of the hospice team. 89% had never received any training about EOLP, and nearly all of the volunteers were interested in learning more about EOLP. After completing the survey, 59% (23 volunteers) of the volunteers shared stories about EOLP they had either personally witnessed or been told about. The most frequently reported experiences involved DV.
Claxton-Oldfield, S., & Richard, N. (2020) Nursing Home Staff Members' Experiences With and Beliefs About	Unusual end-of-life phenomena	2020 Canada	To examine Canadian nursing home staff members' experiences with unusual EOLP and their beliefs about them.	RETRO DCSS	22 female staff	Nursing Home	Survey with closed/opened questions	59.1% shared non-nursing home-related experiences. 6 experiences involving loved ones choosing the time of their death. 4 participants described DV. 4 Apparitions. 2 Animals appearing or behaving strangely. 1 emanations before someone dies, seeing bright lights, the room turning cold, and an out-of-body experience. 95% had personally witnessed a resident waiting for someone to arrive, or for an important event to happen, before letting go. 77% a resident talking to, or reaching out their hands toward, a deceased relative or friend who had appeared to them, 73% terminal lucidity, a sense or feeling that a deceased resident is present (73%), and residents reporting vivid and memorable dreams during sleep involving people and pets who are dead (64%). 46% witnessing a resident wanting to reconcile with estranged loved ones, a resident seemingly getting ready for a trip or journey (41%), changes in room temperature just before or after a resident's death (32%), and synchronistic events (e.g., clocks stopping or bells ringing at

<p>Unusual End-of-Life Phenomena. Omega, 30222820981 238. Advance online publication.</p>								<p>the exact time of a resident's death) (27%). 91% of the participants reported that a resident's family member had told them about a resident waiting for an important loved one to arrive or for a specific event to occur before dying, residents who were unconscious, confused, or demented having lucid moments (64%), a sense or feeling that a deceased resident is present (64%), vivid and memorable dreams during sleep involving people and pets who are dead (55%), a desire for reconciliation with estranged loved ones (52%), and visions of deceased relatives or friends (50%). 81% strongly agreed or agreed that EOLP are transpersonal experiences. Either "strongly agree" or "agree" in response to the following statements: "EOLP are a source of comfort to dying residents" (77%), "EOLP are a source of comfort to a dying resident's family members" (77%), and "EOLP are a part of the dying process" (77%). 64% strongly agreed or agreed that EOLP are profoundly spiritual events and 59% strongly agreed or agreed that EOLP have influenced their beliefs about what happens after death. Participants disagreed or strongly disagreed: "EOLP are emotionally distressing to me" (82%), "EOLP are figments of the imagination" (81%), and "EOLP are the result of a dying or deteriorating brain" (68%). 14 described experiences they had had with EOLP: 8 apparitions, 6 after-death communications, 5 DV, 4 electrical equipment malfunctioning in residents' rooms, 3 choosing the time of death, 2 bright lights. 1 a puff of black smoke or cloud before a resident passed, 1 cold in the room after a resident has died, 1 a shadow outside a resident's window when they passed.</p>
<p>Curtis, L. (2012) Deathbed Visions: Social Workers' Experiences, Perspectives, Therapeutic Responses, and Direction for Practice. Retrieved from Sophia, the St. Catherine University repository Website.</p>	<p>Deathbed visions</p>	<p>2012 USA</p>	<p>To explore the knowledge and experiences of social workers or other health care professionals who may have been exposed to DBV's, to explore their practice approach when working with terminally ill patients, loved ones or their caregivers who have experienced DBV's, and how this issue may have impacted them personally.</p>	<p>RETRO QUALS</p>	<p>2 social workers/ 2 nurses</p>	<p>Hospice/ palliative care settings</p>	<p>Semi-structured interview</p>	<p>3 main themes: <u>Experiences</u>, <u>The Perspectives</u>, <u>Therapeutic Responses of the Participants</u>. <u>Experiences</u>: fear of pain and the transition process, providing education for patients and families to reduce fears of what to expect, interpretation for when patient becomes less communicative - reflects need to save energy and strength for visits from loved ones, patient becomes more reflective and introspective as he approaches death / restlessness, confusion and agitation in the pre-active phase of death is usual. <u>Perspectives</u>: DV are precursors of death / decline in vital functions preceding death shortly after DV. Patients could control the time of death. The DV were no frightening. The beliefs doesn't matter on the dying experience. <u>Therapeutic responses</u>: defining which intervention is most useful depends on the experience and knowledge of professionals and the patient / being a reassuring presence can bring peace and comfort to the patient in the end / ALL participants were sensitive to the danger of discarding or ignoring the patients' experiences / said that music, aroma and massage have potentially healing properties that can adjust chemical and other imbalances in the body / They understand that these different non-pharmacological approaches can be highly effective in alleviating the discomfort associated with the dimensions of pain. <u>Impact of working with dying people on life and professional practice</u>: EVERYONE said that work had an impact on their professional and personal lives / Reduction of fear of dying / vision of spirituality (importance of having a belief in something).</p>
<p>Fenwick, P., Lovelace, H., & Brayne, S. (2010). Comfort for the dying: five year retrospective and one year prospective studies of end of life experiences. Archives of</p>	<p>End of life experiences</p>	<p>2010 UK</p>	<p>To explore the occurrence and perception of ELE among palliative care professionals</p>	<p>RETRO PROSP MMS</p>	<p>38 RETRO/ 30 PROSP (nurses/ doctors/ chaplains)</p>	<p>Hospices/ Nursing Home</p>	<p>Questionnaire + interview</p>	<p>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) saw or felt the take-away apparition sitting on the bed. Although in most of the accounts we were given the 'visitors' were deceased relatives, religious figures were occasionally seen. Very rarely an interviewee reported seeing the 'visitor' too. Accounts of moving to a different reality were less common, but were reported by 33% (48%, ns). More than 25% (35%, p < 0.01) reported second hand accounts of the dying person surrounded by light at the time of death. 45% of interviewees (35%, ns) mentioned an animal that seemed to hold some significance for the dying person appearing at the time of death. A third of the interviewees gave accounts of clocks stopping synchronistically at the time of death. 55% (48%, ns) of interviewees reported second-hand accounts of deathbed coincidences. 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. 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</p>

gerontology and geriatrics, 51(2), 173–179.								to resolve unfinished business. 68% (18%, $p < 0.05$) reported patients wanting to mend family rifts. Profound: 70% (89%, ns) of the interviewees indicated that ELE were intense subjective experiences which held profound personal meaning for the dying person. 45% (59%, ns) thought ELE were an altered state of consciousness. 68% (68%, ns) felt ELE were spiritual events. 92% (82%, ns) agreed on was that ELE offered spiritual comfort to the patient and 86% (79%, ns) to the relatives. Organic or part of dying process: 76% (79%, ns) said that ELE could not just be attributed to chemical change within the brain. 67% (65%, ns) said ELE were not due to medication or fever. Helpful or not: 42% (43%, ns) thought that ELE helped patients review and come to terms with their life. 39% (50%, ns) felt patients who experienced ELE had a peaceful death. Impact of ELE: 25% (18%, ns) believed it was easy for the dying to talk about ELE. Asked whether ELE helped the dying to resolve unfinished business, 39% (36%, ns) agreed. Predicting time of death: 39% (29%, ns) thought ELE occurred in the last month of life. 35% (46%, ns) felt ELE 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.
Lawrence, M., & Repede, E. (2013) The incidence of deathbed communications and their impact on the dying process. The American journal of hospice & palliative care, 30(7), 632–639.	Deathbed communications	2013 USA	To document the degree to which dying patients and their family members experience DBCs 30 days before death; To collect data on the impact DBCs have on the quality of the dying process.	DCSS	75 nurses	Hospice/ Home	Chart audits + survey	Phase I: 5/60 charts (8.3%) were clear descriptions of DBCs, 5 (8.3%) descriptions of possible DBCs, and 3 (5%) patients who raised their hands up at the time of death. Phase II: Patients who had a DBC within the last 30 days was 363 with an average of 4.8 hospice patients per nurse a month that experienced a DBC. 25% to 95% of their patients having DBCs in the last weeks of their lives. 89.3% of the nurses said the patients who had a DBC had a peaceful and calm death. The nurses stated patients experiencing DBCs only occasionally required extra medication or experienced terminal restlessness. Although 44% of the nurses said the experience was pleasant and 84% said the experience was not distressing or negative, 14 of the nurses commented patients were unable to communicate their responses to the experience. 65 of the nurses reported dying patients lifting their hands up at the time of death. In all, there were 241 reports of patients raising their arms up at the time of death, with an average of 3.3 patient occurrences per nurse at the time of the patient's death. In all, 55 of the hospice nurses surveyed said they either did not do the bereavement visits or did not have the experience of family members reported ADCs. 20 nurses spoke with family members who had ADCs.
McDonald, C., Murray, C. & Atkin, H. (2014) Palliative-care professionals' experiences of unusual spiritual phenomena at the end of life, Mental Health, Religion & Culture, 17:5, 479-493.	Unusual spiritual phenomena at the end of life	2014 UK	To build upon what is known about unusual end-of-life phenomena and furthermore provide an in-depth examination of the meanings and interpretations that are ascribed to these experiences by palliative-care professionals.	QUALS	7 nurses/ 1 hypno therapist	Palliative care units/ hospices	Semi-structured interview	Experiences reported: Reported hearing an unconscious patient speaking to her; Patient described an out-of-body experience; Observed an apparition (skull image) appear over a patient's face. Another patient also experienced a premonition of his death; Patient reported seeing ghost of deceased son; Patients reported seeing deceased family members. Also saw a guardian angel appear over a patient's body; Observed something leave a patient's body. Also worked with patient who saw something appear at her window; Experienced very ill patients "holding on" until a specific moment before dying (until a specific event had occurred or a certain visitor had arrived before dying); Nursed many patients who reported seeing deceased family members at their bedside. 4 themes: Who are we to say what's out there? - a connection with something beyond what can be seen. All of the participants indicated an awareness of scientific explanations for these unusual experiences at end of life, based upon their professional training and experience of working in a medical environment, and through reading and discussing possible explanations with others. Other participants also rejected more "rational" explanations on the basis that they did not completely "fit" with their perception of the experience at that time, which for some created a source of internal conflict about the nature of these phenomena. It opened up conversations - Where conversations about unusual or spiritual phenomena were introduced by patients, participants unanimously felt it was important not to dismiss these. The participants varied in their perceptions towards having discussions about unusual phenomena with other professionals. The majority of participants who were nurses described feeling comfortable discussing these experiences with other nurses on an informal basis. Participants generally held the assumption that medical staff would be dismissive of such experiences, and felt that such phenomena did not fit easily within a medical framework. It knocked me sideways:

								The emotional impact of these experiences appeared to be heavily influenced by the emotional response of their patient. Some participants did not emotionally process their response to these phenomena at the time, and focused on aspects of their work role rather than thinking overly about how they felt about these experiences. Discussion of negative emotions within the context of individual or peer supervision alleviated feelings of guilt, and enabled participants to recognize that they had fulfilled their professional responsibilities in these difficult situations. <u>The fact that she was so accepting made it easier</u> : feeling that these unusual experiences often represented a moment of acceptance of death for the patients. Furthermore, participants believed that it was part of their professional role to mirror and facilitate this acceptance through taking an open-minded approach to discussing these experiences with patients. These discussions with patients about seeing deceased family members were interpreted by several participants as a sign of the patient's awareness that they would be dying soon. Several participants felt that it was their responsibility to facilitate acceptance through engaging in such conversations. Participants viewed patients' acceptance of unusual phenomena as being related to their psychological preparedness for death.
Moore, L., & Pate, C. L. (2013). Reflections of near-death experiences and deathbed visions: A study of nursing faculty's perceptions. <i>Journal of Near-Death Studies</i> , 32(2), 81–106.	Deathbed visions	2013 USA	To investigate nurse educators' knowledge and attitudes toward near-death phenomena and reported experiences that the nurses may have encountered.	MMS	571 Nursing Faculty	Nursing faculties	Electronic administration of an instrument (NDPKAQ - Near Death Phenomena Knowledge and Attitudes Questionnaire) + open-ended questions	Out of 3,673 nursing faculty members to whom we distributed questionnaires, 588 accessed the survey and, of these, 17 elected not to participate, leaving 571 (15.55%) participants who responded to enough of the survey to make their responses usable. The participants were female (94%), and the reported age of respondents ranged from 28 to 76 years. Over half of respondents were master's-prepared nurses, and 25% were doctorate-prepared. 442 (80%) indicated Caucasian, 38 (7%) indicated African-American, 25 (5%) indicated blended ethnicity, 22 (4%) indicated Hispanic, and the remaining 22 (4%) indicated American Indian, Asian, or other. 88% of participants indicated Christian, and the remaining 12% reported being of various belief systems, including Muslim, Universalist, Hindu, Buddhist, Atheist, Wiccan, and Scientist. Regarding career experience, of the 552 participants who responded, 256 (46%) indicated that their career had included teaching or mentoring entry-level licensed nurses. Some participants reported they had personally had an NDE (71; 13%), had cared for a patient who reported an NDE (262; 48%), had a family member who reported an NDE (127; 23%), had provided care for a patient or family member who reported a DBV (250; 46%), and had personally experienced a DBV or had a family member who reported a DBV (151; 21%). A total of 168 (29.42%) of the nurse educators described either single or multiple DBV anecdotes.
Osis, K., & Haraldsson, E. (1977). Deathbed observations by physicians and nurses: A cross-cultural survey. <i>Journal of the American Society for Psychological Research</i> , 71(3), 237–259.	Deathbed observations Apparitions	1977 USA and India	To describe conducted surveys in the USA and India of deathbed observations to replicate a pilot study made in 1959–1960 and to gather data relevant to the question of survival.	MMS	1708 Nurses/ Doctors	Mailed questionnaire + hospital	Survey + Interview	In the US, questionnaires were mailed to 2,500 doctors and 2,500 nurses, a total of 1004 responses were received. In India, the questionnaires were distributed personally - practically all doctors and nurses returned the completed questionnaires (a total of 704). 442 interviews in US and 435 in India. A total of 877 cases comprise the main part of the data. 714 were terminally ill patients. 163 cases who recovered from near-death conditions. Hallucinations of human figures were the most reported (591 patients). 112 visions cases were of heavenly abodes and landscapes. In 174 cases, their moods became elevated to serenity, peace, elation or religious emotions. These reports cover only cases of apparitions of human figures seen by terminal patients (471 cases). The samples derive from 216 interviews (US) and 255 (India). <u>Duration of the apparition</u> : 48% lasted for 5 min or less; 17% from 6 to 15 min and 17% more than an hour. <u>Timing of apparition</u> : the closer in time the apparition was to the patient's death, the more frequently it had characteristics suggestive of an after-life. <u>Identity of the apparition</u> : living persons, dead persons, and mythological or historical religious figures. Survival-related apparitions - 83% in the US and 79% in India. Terminal patients saw apparitions of the dead and religious figures three times more than the general population in both the pilot and in the present survey. US patients saw deceased persons while Indian patients saw predominantly religious figures - the characteristics of these apparitions are strongly molded by cultural forces. 91% of the apparitions of persons were relatives of the patients. <u>Purpose of the apparition</u> : 65% to take them away (US 69; India 79%). Patients' response to the apparition: 72% of the patients consented and 28% did not consent. <u>Emotions</u> : 70% of the cases reacted with emotions to the apparition (41% with positive and 29% with negative emotions). 35% of those positive emotions

							were of religious nature. 61% of 425 patients had not received drugs which could cause hallucinations. Of the 20% who were influenced by drugs, 11% were said to be only mildly affected, 8% were moderately affected and only 1% were strongly affected. Only 8% had fever of over 103 degrees which might have facilitated hallucinatory behavior. Hallucinogenic index was present in only 38% of the cases.
Santos et al. (2017) End-of-life experiences and deathbed phenomena as reported by Brazilian healthcare professionals in different healthcare settings. Palliative & supportive care, 15(4), 425–433.	End of life experiences Deathbed phenomena	2017 Brazil	To describe and compare the characteristics and reports of end-of-life experiences (ELE) by healthcare professionals at different institutions and to investigate the influence of religious beliefs on these reports.	ACSS	133	Nursing home/palliative care unit at hospital/cancer center at hospital	Questionnaires + Scales Fenwick's questionnaire, the Duke Religion Index, the Spirituality Self-Rating Scale, the DASS-21 questionnaire 133 participants enrolled (46 ONC, 36 PC, and 51 NH). Overall, the sample comprised predominantly individuals who were female, married, had a high level of education, were nurses or nurse assistants, and had a mean age of 41 (SD = 10) years. 70.7% reported observing ELE or having these experiences reported to them. Palliative care professionals reported more ELE than those from the other two settings (94.4 PC vs. 63 ONC vs. 60.8% NH, $p = 0.001$). The most common ELE were "visions of dead relatives collecting the dying person" (88.2%), "a desire to mend family rifts" (84.9%), "visions of dead relatives near the bed providing emotional comfort" (80.6%) and "coincidences, usually reported by friends or members of the family of the dying person, who say that the dying person visited them at the time of their death" (76.3%). Most healthcare professionals (70–80%) believed that these experiences had a spiritual significance and were not due to biological effects. Comparison among settings revealed that those working in the PC unit had more reports, a greater openness about the issue, and more interest in training. Individual religious beliefs had no influence on perception of ELE.
Schreiber, T. P.; Bennett, M. J. (2014) Identification and Validation of Premortem Surge Journal of Hospice & Palliative Nursing 16 (7) - p 430-437	Premortem Surge	2014 USA	To identify and characterize PS through observational experiences, opinions, and perceptions of PS from a panel of end-of-life (EOL) care nurse experts; To systematically analyze identified characteristics of PS; To validate through consensus, a list of characteristics delineating PS; To validate through consensus that PS manifests in the final phase of the dying trajectory.	DE	64	Hospice/Palliative Nurses Palliative care units/hospices	Questionnaire Round 1: questionnaire + semistructure open-ended questions; Round 2: panelists were asked to rate their level of agreement or disagreement; Round 3: Rerate the statements and consensus Round 1 - 3 cases were described. It is the panel's consensus that PS is an observable, unexplainable phenomenon that frequently occurs but unpredictably. Premortem surge is best described as a phenomenon that manifests as an isolated, 1-time event before death and often manifests in a similar manner. Often manifesting more than 24 hours to 48 hours before death, PS is often sustained from 6 to 24 hours. Premortem surge can be described as a possible spiritual or psychological experience. The person who experiences PS is most often bedbound or in a weakened condition and either minimally responsive or unresponsive prior to the event. During PS, the person often exhibits a resurgence of energy and improved mental acuity or clarity. The person appears to suddenly awaken or rouse and exhibits an improved ability to communicate with others. During PS, the person appears neither distressed nor agitated. Improvement in physical ability and function and an increased desire and renewed ability to eat are often exhibited by the person experiencing PS. The person often appears to express final goodbyes and exhibits a desire to complete or perform an action or task during PS. Family too have observed or described PS and family might perceive the person's condition has improved during their observation of PS. The event is often described as a pleasant, comforting experience for/by the family, yet observations of PS are often surprising and perplexing. Premortem surge is described as a phenomenon with positive, memorable implications for the family. The family's observation of PS can possibly create a false sense of hope and a sense of confusion for the family. Manifestation of PS can also create opportunity for the person and/or family to complete tasks or have closure. Observations of PS made by the family can also create a sense of uncertainty or regret about treatment decisions for the family. It is a consensus that nurses' awareness and recognition of PS afford nurses opportunity to better prepare the family. Educating the family regarding PS and the possibility of PS occurring can facilitate opportunity for a positive experience for the family. Furthermore, it is a consensus that the phenomenon warrants further scientific inquiry.
Subtitles - ACSS: Analytical Cross-Sectional Study; CR: Case Reports; DCSS: Descriptive Cross-Sectional Study; DE: Delphi Study; MMS: Mixed Methods Study; PROSP COHS: Prospective Cohort Study; PROSP MMS: Prospective Mixed Methods Study; QUALS: Qualitative Study; RETRO ACSS: Retrospective Analytical Cross-Sectional Study; RETRO DCSS: Retrospective Descriptive Cross-Sectional Study; RETRO MMS: Retrospective Mixed Methods Study; RETRO PROSP MMS: Retrospective/ Prospective Mixed Methods Study; RETRO QUALS: Retrospective Qualitative Study.							

SUPPLEMENTARY MATERIAL VII - BIBLIOMETRIC CHARACTERISTICS OF INCLUDED STUDIES

Main Authors	N (%)	<i>h</i>-Index + author's total publications + author's total citations
C. Kerr	7 (19.4%)	10 / 24 / 299
P. Grant	7 (19.4%)	8 / 24 / 190
P. Fenwick	5 (13.9%)	36 / 155 / 3922
S. Brayne	4 (11.1%)	6 / 6 / 197
A. Kellehear	2 (5.5%)	19 / 76 / 1489
Main Journals		Journals' CiteScore 2020
The American Journal of Hospice & Palliative Care	9 (25%)	3.3
Journal of Palliative Medicine	5 (13.9%)	3.3
Omega-Journal of Death and Dying	5 (13.9%)	2.5
Palliative & Supportive Care	2 (5.5%)	3.1
Journal of Hospice and Palliative Nursing	2 (5.5%)	1.4
Journal of Pain and Symptom Management	1 (2.8%)	5.7
Archives of Gerontology and Geriatrics	1 (2.8%)	4.3

ACRONYMS

PARTICIPANTS

Patients (P)

Relatives (R)

Health Care Professionals (HCP)

LEVEL OF EVIDENCE

Unequivocal (U)

Credible (C)

Not Supported (N)

The PICO mnemonic was used to frame our research question.

- Population: patients, relatives and health care professionals
- Phenomena of Interest: end of life experiences and your impact in the dying process
- Context: any context (home, hospice, hospital in any country)
- Outcome: experiences and perceptions

SUPPLEMENTARY MATERIAL VIII - LIST OF STUDY FINDINGS (for full citation see References in the paper)

Brayne, S., Farnham, C. & Fenwick, P. (2006). Deathbed phenomena and their effect on a palliative care team: A pilot study. (HCP)	
<p>Finding 1 Deathbed Phenomena (DBP) are an intrinsic part of the dying process (HCP) (C).</p>	<p>Illustration "It's about letting go of this physical world and about preparing for what's going to happen next." (p.19)</p>
<p>Finding 2 DBP is hard to define clinically (HCP) (U).</p>	<p>Illustration "I find it [DBP] difficult to explain, because maybe it's some kind of psychological construct where they are reviewing their life, and that's manifesting itself in some kind of voice for some people or vision for others. Maybe it is ghosts, I don't know. There are a lot of unexplained things." (p.19)</p>
<p>Finding 3 DBP differ from drug-induced hallucinations because they hold some kind of profound meaning for the patient (HCP) (U).</p>	<p>Illustration "The ones who've had [drug-induced] hallucinations know that it's a hallucination, whereas the people who talk about what I would call a deathbed vision—if you can get them to talk about it—they'll explain, and suddenly stuff comes out that you get blown away by, something that's happened in their life that this [DBP] relates to." (p.19)</p>
<p>Finding 4 DBP as a prognostic indicator for nearing death, which is encapsulated in the language used by patients (HCP) (U).</p>	<p>Illustration "It's the language that I home in on, and I think 'this is different.' That's the switch; it's the strange dream, it's Granny visiting. It's a transition that once Granny has visited, or whatever, I know then they are almost certainly going to be peaceful as they let go of this physical world, and they've got this peace to look forward to what's next." (p.20)</p>

<p>Finding 5 Reconciling to death as part of DBP (HCP) (U).</p>	<p>Illustration “They [patients] are processing their life and looking towards where they are going, who may be there, or what spiritual aspects of life they are going to have. They are definitely taking stock of what’s gone on and also dealing with their inner selves, facing themselves—maybe for the first time, because they haven’t done it before. There is nowhere to go—no escape when you’re dying.” (p.20)</p>
<p>Finding 6 DBP is broader than the archetypal image of “take-away” apparitions or visions at the end of the bed (HCP) (U).</p>	<p>Illustration “You almost want the Madonna at the end of the bed to say, ‘Well, it’s a deathbed vision.’ But I think it’s much wider, more subtle, than that. I think there are deathbed spiritual changes that happen, and sometimes it can just be a patient saying, ‘I felt very warm. Something came round me and I felt incredibly secure; I can’t describe it to you, I just felt okay and I knew things were going to be okay.’” (p.20)</p>
<p>Finding 7 Dreams and waking dreams help patients to reconcile with their lives and to let go (HCP) (U).</p>	<p>Illustration “I’ve got a patient who dreams that he is dead. He knows he’s dead because only other dead people are in the dream; it’s usually family members who have died. He was very comforted by this, so this is something I relate to deathbed phenomena.” (p.21)</p>
<p>Finding 8 Patients and relatives are reluctant to talk about DBP through fear of ridicule or dismissal as well as lack of public awareness (HCP) (U).</p>	<p>Illustration “I think a lot of people don’t talk about experiences like this because they feel, ‘What are they going to think of me if I start talking about ghosts?’.” (p.21)</p>
<p>Finding 9 The qualities of openness and honesty, a willingness to listen, and normalizing DBP were considered to be important factors in encouraging patients to speak of DBP experiences (HCP) (U).</p>	<p>Illustration “I deal with it by being open-minded and saying to my patients that it’s okay to talk about it. Some of them are not sure and wonder if it’s the morphine. It’s about reassuring them that this is quite normal, and it happens to quite a few people, and most people find it comforting.” (p. 22)</p>
<p>Finding 10 Need for further education and training to deal with existential issues (HCP) (U).</p>	<p>Illustration “We take them apart emotionally by exploring things with them, but we don’t have the skills to put it all back together again all the time. There’s a danger you</p>

	could be left with a broken patient. With the best will in the world, if we are not careful, we can make things far worse.” (p. 22)
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. (HCP)	
<p>Finding 1 Difficulties of distinguishing between ELE and drug-induced hallucinations, dementia, and confusion (HCP) (U).</p>	<p>Illustration “It’s hard to tell really because I don’t know if the medication may cause them to hallucinate or make them confused. I know some drugs may cause hallucinations.” (p.199)</p>
<p>Finding 2 There are differences between hallucinations and ELE (HCP) (U).</p>	<p>Illustration “You can tell from their eyes. When they have a high temperature, they see things and it’s an anxiety-based thing. You can see there’s an underlying fear because they don’t understand it . . . Whereas with the end-of- life experience it’s like a process and once they have experienced it, they move onto a different level. End-of-life experience is usually such a positive thing. It’s like a journey”. (p.199)</p>
<p>Finding 3 Patients seeing apparitions of children shortly before they died (HCP) (U).</p>	<p>Illustration “They both (two residents) talked about these children coming into their room in the evening. They were quite specific about it. It wasn’t rambling. And it happened on a couple of nights in succession for them, and they didn’t talk about it again . . . They didn’t find it alarming. They mentioned it because they obviously thought it was strange, but it didn’t bother them particularly.” (p.200)</p>
<p>Finding 4 Change of room temperature in the time of death (HCP) (U).</p>	<p>Illustration “Sometimes the room is freezing. At other times it is really, really hot. Opening a window often helps. You feel a calm going out of the window.” (p.200)</p>
<p>Finding 5 End of life dreams were widely reported (HCP) (U).</p>	<p>Illustration “He said he saw animals he had owned during his life that were obviously dead. He felt they were waiting for him.” (p.200)</p>
<p>Finding 6 HCP’s end of life dreams were also reported (HCP) (U).</p>	<p>Illustration</p>

<p>Finding 7 Visions of animals, birds, and black butterflies (HCP) (U).</p>	<p>“We were both standing in front of the mosque and he (Muslim patient) asked me to take him to the altar. So, I took him to the altar and he waved goodbye. That was in my dream. The next day he died.” (p.200)</p>
<p>Finding 8 Lucid moments – Patients who had dementia and confusion becoming lucid in the last few days of life (HCP) (U).</p>	<p>Illustration “The residents were saying, ‘There’s a big bird.’ They saw it . . . I saw it; it was a real bird.” (p.201)</p>
<p>Finding 9 The need for reconciliation - ELE include the need for some residents to put past wrongs to right (HCP) (U).</p>	<p>Illustration “It happens quite often . . . they just seem to lighten and are able to acknowledge who is with them and sometimes say things. It happened with my mother. She had dementia and didn’t really know any of us before the end. But for the last twenty-four hours she certainly did . . . just before she died, she said to me ‘I love you.’” (p.201)</p>
<p>Finding 10 Reunion with beloved relatives is paramount to the dying even when they are comatose (HCP) (U).</p>	<p>Illustration “Only before she died did she tell one of the carers what had happened (She had been abused as a child). Nobody had ever been there for her to resolve it. Once she told the carer, who she particularly liked, she was fine. Everything fell into place then – why she’d been so bitter.” (p.202)</p>
<p>Finding 11 Paranormal incidents – apparitions, lights going on and off in the room of a resident who had recently died, to heard footsteps in the corridor although no one was there, etc. (HCP) (C).</p>	<p>Illustration “It’s almost like they know. Sometimes they will just hang on until the person gets there. The person can just walk into the room sometimes and then they go. It’s almost like they hang on and just wait for that time to be right for them. It’s strange but it happens a lot.” (p.202)</p>
<p>Finding 12</p>	<p>Illustration “I remember I thought I had tripped and it’s just like a sensation coming on the shoulder. A lot of things happen at night when residents are dying.” (p.203) – [One interviewee remarked on being pushed on the shoulder after she had entered the room of a resident who had died].</p>
<p>Finding 12</p>	<p>Illustration “Quite often they can’t talk to their relatives about it because their relatives can’t bear the idea of their going. So, who can they turn to and talk to about any fears</p>

HCP wanted to learn the language of approaching death and how to start conversations with residents about the dying process without causing distress or confusion (HCP) (U).	they've got? But if a carer can't talk about it, they will automatically think it [dying] must be awful if they can't share it with me." (p.203)
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Fenwick, P., Lovelace, H., & Brayne, S. (2010). Comfort for the dying: five year retrospective and one year prospective studies of end of life experiences. (HCP)	
Finding 1 Take-away apparitions or deathbed visions involving deceased relatives (HCP) (U).	Illustration "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." (p.176)
Finding 2 Visions of religious figures (HCP) (U).	Illustration "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." (p.176)
Finding 3 Accounts of the HCP seeing the 'visitor' too (HCP) (U).	Illustration "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)." (p.176)
Finding 4 Accounts of moving to a different reality (HCP) (U).	Illustration

<p>Finding 5 Accounts of the dying person surrounded by light at the time of death (HCP) (U).</p>	<p>“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.’” (p.176)</p> <p>Illustration “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.” (p.176)</p>
<p>Finding 6 Animals that seemed to hold some significance for the dying person appearing at the time of death (HCP) (U).</p>	<p>Illustration 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.’ (p.176)</p>
<p>Finding 7 Accounts of clocks stopping synchronistically at the time of death (HCP) (U).</p>	<p>Illustration “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.’” (p.176)</p>
<p>Finding 8 Second-hand accounts of deathbed coincidences (HCP) (C).</p>	<p>Illustration “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.” (p.176)</p>
<p>Finding 9</p>	<p>Illustration</p>

<p>Patients who sang or hummed religious hymns around the time of death and dying writing poetry which held significant meaning for them (HCP) (N).</p>	
<p>Finding 10 Dying experiencing profound dreams which seemed to comfort and prepare them for death, which helped them to resolve unfinished business (HCP) (N).</p>	<p>Illustration</p>
<p>Finding 11 Patients wanting to mend family rifts (HCP) (N).</p>	<p>Illustration</p>
<p>Finding 12 ELEs were intense subjective experiences which held profound personal meaning for the dying person and offered spiritual comfort to the patient and to the relatives (HCP) (U).</p>	<p>Illustration “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.” (p.176)</p>
<p>Finding 13 ELE could not just be attributed to chemical change within the brain, neither to medication or fever (HCP) (C).</p>	<p>Illustration “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.” (p.176)</p>

Kellehear et al. (2011). Deathbed Visions From The Republic Of Moldova: A Content Analysis Of Family Observations. (R)

<p>Finding 1 Comfort or satisfaction at the prospect that someone important to the dying person was waiting for them (R) (U).</p>	<p>Illustration "He dreamed that his dead mother had come through the door. It happened in the last few days, he spoke often about this and would say that his mother was coming to get him. He would ask me if I could see her too, he was saying this with his eyes open, he would say a few times a day that his mother had come." (p.310)</p>
<p>Finding 2 End of life visions provided comfort to the dying (R) (U).</p>	<p>Illustration "Before he died, we were all in the house together. I was at his feet. At this time he turned his head towards the wall and it was as though he was talking to someone and he said, 'no worries, everything will be alright, everything will be enough, it will be good and beautiful...' We don't know who he spoke to and we don't know what he meant either. But he told out daughter Svetlana, she is our second daughter, 'be aware that everything will be left on your shoulders.'" (p.311)</p>
<p>Finding 3 Visions of the dead would be a repeated occurrence that would be characterized by regular or prolonged conversation (R) (U).</p>	<p>Illustration "Yes, he had visions. He would look out the window and call people who were already dead to come to him inside the house. He would tell me he could see them looking at him. He saw several dead people. He practically listed all our neighbors and relatives who had long died." (p.311)</p>
<p>Finding 4 Visions of a deceased loved one calling to them to be more quickly reunited with them (R) (U).</p>	<p>Illustration "About a month before she died, mother would tell me how she dreamed about those who had died (her mother, [my] father, other dead relatives). She was saying that they were calling her to them." (p.312)</p>
<p>Finding 5 Deathbed visions provide the dying person with a prognosis or indication of impending death (R) (U).</p>	<p>Illustration "He dreamed about my mother, who had already died and whom he missed, he had been extraordinarily fond of her. He also dreamed about my brother (his son), who died suddenly at the age of 32; he had a heart attack and died within half an hour. Father dreamed about both of them, they seemed to be dancing happily at a wedding and they called him. He then told me, 'They will take me away with them.' I tried to console him, told him it would not happen, that he would get well . . . but he said he would die, that I had done everything for him... he had that dream about one month before he died." (p.312)</p>

<p>Finding 6 The dying person as an active negotiator or equal actor in the events he or she describes (R) (U).</p>	<p>Illustration “And I noticed during the day that he was talking to dead people, he had visions. When he recovered from those states, he would tell me his relatives who had already died had come to see him, they would grab him and take him somewhere but he would resist. He told me that he held on to the pole outside the house, with difficulty, but he did not leave with them.” (p.313)</p>
<p>Curtis, L. (2012). <i>Deathbed Visions: Social Workers' Experiences, Perspectives, Therapeutic Responses, and Direction for Practice</i>. (HCP)</p>	
<p>Finding 1 Seeing lights before the death (HCP) (C).</p> <p>Finding 2 Deathbed visions were considered to be a precursor to death (HCP) (C).</p> <p>Finding 3 Accounts of sensing and seeing the patient's energy (HCP) (U).</p>	<p>Illustration “I had a little five-year-old that died at four in the morning two days before Christmas. I went to the home as he was dying and one of the last things that he said to his daddy was, 'I see the yites daddy.' His dad said I think he is worried about the Christmas tree lights. As I drove away that night I thought no, he saw the lights that people very often see. So, at the funeral I went up to the dad and I said I'm sorry I'm so late with this but I think what your son was seeing was the lights that people see as they pass over and his dad said, 'OH my Gosh, I bet you are right.'” (p.32)</p> <p>Illustration “We had a man that took several days for him to die. He was in one of our hospice suites that we had at the time and his wife slept in the next room. For days he saw a lovely lady up in the corner of the room and a small boy kneeling at the foot of his bed. He was Catholic and so was his wife and he believed that the lovely lady was the Virgin Mary and the small boy at the foot of his bed was his brother that died when he was a small boy. I asked the wife how she felt about that and she said, 'Ya know, it is very comforting to me to know that when I'm asleep or not here when he dies he has those two comforting visions with him.' She was very comforted with the fact that he had someone with him” (p.32)</p> <p>Illustration “I had a patient whose son commented that he could see his mother's energy. He said, 'she is just completely wide open and I can see her energy, it's just ready to let go.' It was probably hours after that that she passed.” (p.33)</p>

<p>Finding 4 Patients could seemingly control the timing of their death (HCP) (U).</p>	<p>Illustration “We had a patient that passed. All of the family members were there except for one. All of the family members were concerned because the patient’s eyes were still open and they wanted his eyes to be closed. The staff came in and closed his eyes but his eyes would not stay closed. They kept opening. His eyes would not close and it upset a few of the family members. The one family member who was traveling a long distance showed up a few hours later came in saw the patient and the patient’s eyes closed. It was one of those things, it felt like that was his way of saying I waited for you as long as I could and I wanted you to know how important it was for you to be here. Everyone felt really good about it. It was one of those moments where it was like magic where he was able to give that message from beyond.” (p.33)</p>
<p>Finding 5 Deathbed visions were not distressing or fearful for the patient and family (HCP) (U).</p>	<p>Illustration “I think it is almost always comforting to the family members to know that they are going towards something that’s reassuring to both. For the dying and the family.” (p.34)</p>
<p>Finding 6 Dreams as a way of knowing about death survival (HCP) (C).</p>	<p>Illustration “I lost my fiancé to lung cancer. He was young and we weren’t expecting it to go that quickly. Two days after the death, I had a dream that I was in his hospital room along with his family. In my dream he had died and everyone had left the room except for me. The nurse came in and started taking out his IV’s, and for some reason she left the room. He opened his eyes looked at me and asked me what is going on. I said to him, “I thought you died and now you are awake?” I couldn’t comprehend it. He said, ‘You know what, I feel great, I feel good. For the first time in a long time, I feel really good.’ The nurse came back in and started unhooking more things and I started saying he’s alive, he’s alive, don’t take him off the IV.’ She said, ‘Oh, that happens sometimes, he’ll die again,’ and she left. I woke up and I was a little traumatized and I realized that it felt like he was telling me that I don’t know what happened, but I’m good now. I’m OK and you don’t have to worry.” (p.35)</p>
<p>Finding 7 Dangers of dismissing or ignoring patients’ experiences (HCP) (C).</p>	<p>Illustration “What we try to tell families and what we try to role model for them is to say things like, tell me what that’s like for you? (If they see something or they see a</p>

	<p>loved one who has passed) or tell me more, what is that person doing? Where are they at? Tell me what you see. What's happening at the time? Is it frightening for you? How does it make you feel? I think that is really helpful for the family and friends." (p.36)</p>
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Mcdonald, C., Murray, C., & Atkin, H. (2014). Palliative-care professionals' experiences of unusual spiritual phenomena at the end of life. (HCP)	
<p>Finding 1 Sense that the unusual experiences they had encountered were connected to "something" or "somewhere" else beyond what can be seen (HCP) (C).</p>	<p>Illustration "A foretaste of a higher spiritual existence – if you want to call it God or heaven or whatever that's fine." – HCP talking about her patient's out-of-body experience. (p.483)</p>
<p>Finding 2 Rejection of more "scientific" explanations on the basis of how these experiences made her feel subjectively (HCP) (U).</p>	<p>Illustration "I guess for both you could explain them away...like for the lady [female patient] maybe she was recovering, and for him [male patient], maybe there was something physiological that happened, you know some synapse could've burst and he just did whatever he did but you know, they both felt like it was beyond the normal.... I think that with the lady, because of the feeling around her – the electric feeling – that kind of gave it a different aura, and because she didn't speak again on that shift, as far as I know. I went home on my shift and nothing else happened, so it felt like she wasn't recovering, so it felt like it was something else. (p.483)</p>
<p>Finding 3 Deathbed visions weren't purely induced by drugs (HCP) (U).</p>	<p>Illustration "I mean with some patients, they on anything, and it happens. So, if it was purely drug induced, you wouldn't expect it to happen with patients who are on say paracetamol that wouldn't cause it." (p.484)</p>
<p>Finding 4 Discussion of unusual experiences facilitated a deeper understanding of patients and of their needs (HCP) (C).</p>	<p>Illustration "It's not really [strange] to be honest, because you end up talking about the patient's life with them, and I think it's being able to talk to people and you can just say "Aw what did he used to do, or what was his job, and where did you live" and they can then talk about it, if they're able to, and they can talk about their lives. And I think you can talk and treat them more like people and less like patients then." – HCP described how she used the disclosure of seeing</p>

<p>Finding 5 Medical staff would be dismissive of such experiences, that did not fit easily within a medical framework (HCP) (U).</p>	<p>deceased family members as a way of asking patients about their background. (p.484)</p> <p>Illustration “Because when you’re very junior, you’re looking for other people’s reactions to know how to respond, and really the medical team were very dismissive but the nursing team were much more supportive.” (p.485)</p>
<p>Finding 6 The emotional impact of these experiences for the HCP appeared to be heavily influenced by the emotional response of their patient (HCP) (U).</p>	<p>Illustration “I mean if the patients were distressed and upset then yeah it would upset you, but because I’ve never seen any of that – it’s always been that the patient has been very accepting of it so I think that helps you accept the situation.” (p.485)</p>
<p>Finding 7 These unusual experiences often represented a moment of acceptance of death for the patients (HCP) (U).</p>	<p>Illustration “She just said ‘you know, I wish it’d hurry up, I wish I could go with him’. She was ready to go and I think that’s what happened.” (p.487)</p>
<p>Finding 8 It is important to mirror the patients’ “matter of fact” approach to these phenomena, even if you did not share their beliefs (HCP) (U).</p>	<p>Illustration “I kinda try to just accept, make sure it’s accepted, you know so they feel comfortable and make sure you’re not dismissing something that you can’t see or don’t believe in.” (p.488)</p>

<p>Nosek, C. L. et al. (2015). End-of-Life Dreams and Visions: A Qualitative Perspective From Hospice Patients. (P)</p>	
<p>Finding 1 Dreams and visions were overwhelmingly described as comforting to the patient (P) (C).</p>	<p>Illustration “I am not going alone — [my sister] will be with me.” – Patient described dreams of her dead sister sitting beside her bed as extremely comforting. (p.3)</p>
<p>Finding 2 In their dreams, patients seemed to be preparing to go somewhere (P) (U).</p>	<p>Illustration “I know we are going somewhere, but don’t know where.” – Patient described seeing his parents, grandparents, and old friends in his dreams. (p.3)</p>
<p>Finding 3 The presence of others in their dreams/visions as simply being there, watching or engaging with the patient (P) (C).</p>	<p>Illustration Another patient dreamed that her father and 2 brothers, all dead, were silently hugging her and playing games; then she described how “they were welcoming [her] to the dead.” (p.3)</p>

<p>Finding 4 Dead friends and relatives in their dreams as “waiting for them” (P) (U).</p>	<p>Illustration “They were waiting for me.” - One woman reported that she had both waking and sleeping dreams of 6 dead family members in her room. (p.3)</p>
<p>Finding 5 Distressing dreams, some of which replayed traumatic life experiences, others were reminiscent of difficult situations or relationships (P) (N).</p>	<p>Illustration A male patient reported having distressing dreams of his brother being very critical of him and also reported distressing, anxiety-provoking dreams about his work, both of which he reported were based on actual past experiences. (p.3)</p>
<p>Finding 6 Dreams that centered on their fears of no longer being able to do the things they felt they needed to accomplish in life (P) (N).</p>	<p>Illustration A 58-year-old woman had dreams about her living family members and reported distress over whether her daughter would get her cell phone. (p.4)</p>

<p>Depner et al. (2020). Expanding the Understanding of Content of End-of-Life Dreams and Visions: A Consensual Qualitative Research Analysis. (P)</p>	
<p>Finding 1 Typical characters in the ELDV were: dreamer, family, people who were unfamiliar/unknown and miscellaneous characters (P) (U).</p>	<p>Illustration “I see my mother and she talks to me.” (p.105) / “Other people were standing around us but I did not recognize anyone else.” (p.105) / “I remember Mrs. Peloquin, first person to be a weekly client. I did her hair for a very long time.” (p.105)</p>
<p>Finding 2 The typical relational interactions in the ELDV were: close connections (any relational description that is intimate and/or emotionally close), neutral connections (a lower level of relational engagement) (P) (U).</p>	<p>Illustration “[I am] very happy, especially at night, when I wake up and feel like he was snuggled up against me.” (p. 106) / “My dad came to me in a dream and we were doing day-today things.” (p. 106)</p>
<p>Finding 3 Participants generally described their dreams with feelings/emotions, including traditionally positive and distressing emotions (P) (U).</p>	<p>Illustration “It was comforting to see the trees and it was a beautiful fall day, I felt happy.” (p.107) / “I was watching children play in my house and someone got hurt I was very upset by this. I woke up crying.” (p. 107)</p>
<p>Finding 4 Participants typically reflected on an element of nostalgia, a longing to reconnect with a person, place, or experience from the past (P) (U).</p>	<p>Illustration “She is not interacting with me but I like having her there. When I wake up, I think, oh man, get back here!” (p. 107)</p>

<p>Finding 5 It was typical ELDV in which participants spontaneously engaged in sense making (P) (U).</p> <p>Finding 6 Typically, within the ELDV, participants reported activities related to traveling/movement and an attempt to do something, including working toward a specific goal (P) (U).</p> <p>Finding 7 Individuals typically reported that the environment was familiar/known and involved the natural environment (P) (U).</p> <p>Finding 8 Participants typically described settings related to: transportation and travel; home/residence (an overall home, structure, or building as well as objects or rooms associated with home); spatial awareness and directionality (references to top, bottom, up, down, side to side, inside/indoors, and outside/outdoors); institutions of daily life (weddings, picnics, and graduations, places of work, places of business, places of education, places of play and places of worship (P) (C).</p>	<p>Illustration “...my dreams have increased and I think I’m working things out in my dreams or trying to come to terms with my sickness in my dream.” (p. 107)</p> <p>Illustration “I am on a bicycle coming down a steep curving mountain highway. I find that the speed of the bike is getting dangerously fast.” (p. 107) / “I was going to my friend’s cottage up a mountain, was snowing hard, had to walk back but never got anywhere.” (p. 107)</p> <p>Illustration “I was in a creek... searching for a certain kind of rusty rocks.” (p. 108)</p> <p>Illustration “I was sitting in a kiddie pool outside in the grass with my home health aide.” (p.108)</p>
<p>Grant et al. (2020). Family Caregiver Perspectives on End-of-Life Dreams and Visions during Bereavement: A Mixed Methods Approach. (R)</p>	
<p>Finding 1 Participants commonly noted comfort provided by ELDV describing solace, peace, or reassurance (R) (U).</p> <p>Finding 2 Upon reflecting about ELDV experiences, a variety of feelings and emotions emerged, including positive, negative, or mixed/contrasting. The majority of emotions were traditionally positive (R) (U).</p> <p>Finding 3</p>	<p>Illustration “When he told me that he saw his favorite sister [deceased] hold out her hands to him, it made me feel comforted because I knew it comforted him.” (p.51)</p> <p>Illustration “I was happy to think our loved ones had come to make his passing easy.” (p.51) / “The fact that he was fearful of some things troubled me. Not knowing if he came to peace with these fears bothers me at times.” (p.51) / “I was glad he saw his brother, but did not want him to go with him.” (p.51)</p> <p>Illustration</p>

<p>Caregivers tried to understand, explain, or conceptualize ELDV and incorporate them into their own worldview. Subthemes: religious/spiritual process (the most apparent) and medically related (cognitive decline or medication) (R) (U).</p>	<p>“It gave me great comfort to know that angels were waiting for him to escort him to heaven.” (p.52) / “It was the pain medication alone causing these visions and had no more significance other than being a side effect of the drug’s affecting her brain chemically.” (p.52)</p>
<p>Grant et al. (2021). Attitudes and Perceptions of End-of-Life Dreams and Visions and Their Implication to the Bereaved Family Caregiver Experience. (R)</p>	
<p>Finding 1 Participants constructed narratives by interpreting the ELDV within the context of their loved one’s life and illness experience (R) (U).</p>	<p>Illustration “She fought cancer for 15 years and she was in hospice for 6 days . . . and it [the ELDV] was basically [on] her last day here.” (p.4)</p>
<p>Finding 2 In sharing their stories, FCGs talked about dream content, or who was in the dream and what happened (R) (U).</p>	<p>Illustration One daughter said her mother would dream of her deceased father on an airplane, telling her: “You don’t have your passport. You can’t come. You have to stay where you are.” (p.4)</p>
<p>Finding 3 Participants spoke about ELDV as a means to deepen relationships with the patient or family and friends (R) (U).</p>	<p>Illustration One FCG said that ELDVs helped “in understanding my relationship with my mom.” Another stated there were “people that I knew well enough that I’d tell them and it made me feel very good.” (p.4)</p>
<p>Finding 4 Participants desire to form relationships and support others who have ELDV experiences, talking to healthcare providers and acquaintances about ELDV, advice offering, gratitude to be able to share or given a space to share about ELDV (R) (U).</p>	<p>Illustration So, it’s nothing to be alarmed about.” and “it shouldn’t be something that’s shamed upon or people think that’s weird.” (p.4)</p>
<p>Finding 5 Participants selectively choosing not to share ELDV of loved one, generally for protection of self or to preserve positive memory (R) (U).</p>	<p>Illustration “You don’t want people to think you’re crazy” or “their reaction is not gonna be supportive to how I feel.” (p.5)</p>
<p>Finding 6 Participants shared ELDV reflections and how they impacted them during caregiving. Responses included feelings such as amazement, peace, curiosity (R) (U).</p>	<p>Illustration “It’s just the most profound, marvelous experience done right in the entire world, and I firmly believe in it.” (p.5)</p>

<p>Finding 7 ELDV also impacted FCGs during bereavement (R) (U).</p>	<p>Illustration “You grieve for yourself, but how can I not be happy if that’s where she wants to be?” (p.5)</p>
<p>Finding 8 Many participants engaged in sense-making, or assigning meaning and purpose to their loved one’s ELDV (R) (U).</p>	<p>Illustration “I’ve always believed that, we have an eternal life ... there’s connection between ancestors.” (p.5)</p>
<p>Finding 9 FCGs also talked about signs - items such as sparrows, pennies, rainbows- that strengthen their connection with the deceased (R) (C).</p>	<p>Illustration A participant talked about a song, “And I’m like alright, that’s my father’s way of saying ‘I’m okay’ or ‘I’m with you.’” (p.5)</p>
<p>Finding 10 Deathbed coincidences, or unexplainable events that coincided with time of death of their loved one (R) (U).</p>	<p>Illustration “I saw his spirit leave his body. I’ve seen a lot of death, and I’ve never seen it like that. So, I just sat there, and just as I realized he had died.” (p.5)</p>

<p>Nyblom et al. (2021). End-of-Life Experiences (ELEs) of Spiritual Nature Are Reported Directly by Patients Receiving Palliative Care in a Highly Secular Country: A Qualitative Study. (P)</p>	
<p>Finding 1 In the majority of cases, ELE were experienced positively (P) (U).</p>	<p>Illustration “Absolutely wonderful, wonderful dreams.” (p.3)</p>
<p>Finding 2 Many patients affirmed having vivid dreams while asleep with the presence of loved ones both living and deceased (P) (U).</p>	<p>Illustration “It feels great to meet mum (deceased) this way!.” (p.3) / “it’s so clear, so clear!.” (p.3) - A patient who dreamed about her deceased parents exclaimed.</p>
<p>Finding 3 In these dreams, there were seldom any specific conversations with the deceased and their loved ones were seen as in their prime of health despite having died in old age or with severe illnesses (P) (U).</p>	<p>Illustration “No, not directly spoke, no. We shared something with each other” (p.3) - patient, who had dreamed about his deceased wife / “Beautiful and very healthy.” (p.3)</p>
<p>Finding 4 In these dreams, there were references to traveling included preparing to go or being on a journey, sometimes with a specific goal (P) (U).</p>	<p>Illustration One patient was going on “a transport route for armies” in a “war we were on our way of winning.” (p.3)</p>

<p>Finding 5 Participants reported visions and auditory experiences and a sense of the comforting presence of deceased loved ones (P) (U).</p> <p>Finding 6 The predominantly positive content of their dreams astonished some patients. They had expected “bad” dreams given their medical situation (P) (U).</p> <p>Finding 7 Some patients reported differences between ELE and negative inner experiences they considered caused by medication. The hallucinations/nightmares were perceived as disturbing and unclear and their occurrence and ceasing coincided with their taking a specific medication. The ELEs as clear, positive and supporting (P) (U).</p> <p>Finding 8 If the patient decided to tell others about their ELE, the reaction varied depending on the person that they approached. Some loved ones did not believe them, others were met with understanding (P) (U).</p>	<p>Illustration “He’s (deceased father) here now, he’s sitting here. He sits here and listens.” (p.3) / “Those [deceased] who have known me well are coming back.” (p.3)</p> <p>Illustration “Unexpectedly positive! It is extremely strange, one might think.” (p.4)</p> <p>Illustration “To me it feels like I get hallucinations from it [oxycodone]” seeing “a jellyfish up in that corner over there.” (p.4) / The same patient reported positive visions of loved ones, without reference to medication, and referred to it as reality; “It is not a dream, it’s reality.” (p.4)</p> <p>Illustration “And the children think I make it up, but I don’t. Why would I make it up?.” (p.4) / After hesitating, one patient told his children about his visions and was very relieved by their response; “Yes, but dad, it’s no wonder.” (p.4)</p>
<p>SCRI (2021). Shared Death Experiences: A Little-Known Type of End-of-Life Phenomena Reported by Caregivers and Loved Ones. (HCP/R)</p>	
<p>Finding 1 SDE - remotely sensing a death (Brief thoughts, feelings, and/or a sense of the dying’s presence usually at a time later determined to correspond to the moment of death. Individuals also frequently reported having received messages imparting a final farewell) (HCP/R) (U).</p> <p>Finding 2</p>	<p>Illustration “I was doing some clothes shopping when, suddenly, very vivid images of Jane [a pseudonym for her childhood friend who lived in England] came to me. I just could not stop thinking about Jane. All the stuff we’d done together. And then she actually came to me and she said, ‘I’m really sorry, but I have to leave. I just couldn’t do it anymore. I just couldn’t do it.’ And then I got this vision of Jane being 16 years old and utterly free, she was so grateful to be free from her body. I’m sitting there overwhelmed with thoughts about Jane and my phone rings and I knew what was coming next. I was told that Jane had died.” (p.3)</p> <p>Illustration</p>

SDE - remotely sensing a death (Sudden onset of unusual physical symptoms thought to correspond to those experienced by a loved one immediately prior to death. Some individuals reported knowing a physically distant loved one had died at this time, whereas others made this connection retroactively) (HCP/R) (U).

Finding 3

SDE - witnessing unusual phenomena attributed to a death (vision of the dying; appearance of a transcendent light; sensing energy; alterations in time and space; seeing light or material believed to be the spirit leaving the body; the appearance or presence of previously deceased loved ones; visions of otherworldly or heavenly realms, etc.) (HCP/R) (U).

Finding 4

SDE - accompanying the dying in a visionary realm (descriptions of having accompanied the dying partway through their transition to an apparent post-mortem existence. According to these reports, participants suddenly found themselves out-of-body and/or in a visionary realm together with the dying (and sometimes with other deceased loved ones and/or unknown entities). These realms were most often described as gardens, castles, otherworldly regions, or a void. Participants stated that while in these realms they had knowledge about reality that was otherwise inaccessible or indescribable) (HCP/R) (U).

"I was sleeping on my own and about five o'clock in the morning I noticed that I was sweating and feeling out of breath. I couldn't breathe. It was agonizing. My pajamas were drenched with sweat, though it wasn't especially hot. That lasted for a while, and then I started to feel cold. I became so cold that I couldn't move. I felt paralyzed. It was a very strange feeling. And then I remember feeling a sense of bliss. Profound, profound, profound bliss! I remember very clearly that I even smiled and thought to myself that I would be able to sleep really well. And I did! When I woke up, I found that I had received a text from my sister. Before I even opened it, I knew what it said. My mom had come to me that night to say goodbye." (p.4)

Illustration

"His spirit left his body. Then his whole being went and stood behind my right shoulder. It was like the side of my head was completely activated. It's like I had a different vision coming through from my right side. In that vision there I saw [her husband]. He was alive, moving, cartwheeling, somersaulting, running, and whooping down the hospital hallway. He was totally exuberant! He looked younger, as young as when I first met him. He looked brilliant. His energy was absolutely boundless, and he was happy and free. Then he came right up to my face and showed me his face and his happiness. Then the hospital wall—it's hard to describe—the wall just disappeared. What was out there, even though it was 2 am, was a pink sky, and then all sorts of gray clouds that came through the pink and orangish colors. It was almost like dawn. What happened then was his spirit turned into something like a heat haze, and it drifted out into that pink sky." (p.4)

Illustration

"I woke up and the room was just filled with this extreme light. I could feel that my mother was close and was coming to say good-bye. She was in the room, but not with a body. It sounds impossible, but she was there, and she was telling me that she loved me but there were no words said. It was like it was all telepathic communication. Time didn't exist in this realm. I say "realm" because suddenly the walls and the ceiling and everything was crooked or somehow off. The law of physics didn't abide. She slowly went upwards into the so-called ceiling. Behind her, I could see this being of light that was making the whole room shine. My mom invited me up to this being that was complete love,

<p>Finding 5 SDE - assisting the dying in transitioning (participants described having taken an active role in assisting a loved one in the process of transitioning. Every one of these experiences occurred physically apart from the dying. These experiences were similar to those in which people accompanied the dying in a visionary realm but included individuals feeling that their attention, presence, and assistance was required by the dying to successfully transition) (HCP/R) (U).</p> <p>Finding 6 Effects of SDE - changes in beliefs, attitudes, and behavior (SDE convinced them of the reality of a benevolent afterlife; had alleviated or completely removed their fear of death and dying; left a profound mark on what they perceived to be life's meaning or purpose) (HCP/R) (U).</p>	<p>complete knowledge, complete compassion. It was all those things. I acknowledged that it must be a divine being of some kind. We went to this black void. There I felt the presence of other souls. The strangest thing! We were floating around in this realm, and every question I ever had was answered in some strange way. What was also extremely strange was that I felt connected with the souls around me and this divine being and my mother. I felt like we were one. I didn't want to leave but I understood that my mother was going further. I couldn't go with her. I was just visiting, and I had to go back. The next thing I remember is being woke up the next morning from the phone call from hospice telling me my mother had died, which I was perfectly aware of." (p.4)</p> <p>Illustration "Halfway through the movie, I had a distracting impression that [her ex-husband's] condition was changing. He was going. I pushed the thought away as imagination, but it stayed and was hard to ignore. I closed my eyes and time and space changed. I was with him in this new space—the movie screen and sounds were completely gone. He was moving upwards to the light above his head. I looked at it. A beautiful, diffuse light that was more than light: it was a place, a space, an energy. It was freedom and release and forgiveness and acceptance. I was glimpsing eternity. He was saying 'I have to go. I can't hang on.' This wasn't said with words. It was clearer than words—it was a knowing. Then I understood I was there to help him pass. He had to go and somehow, I was part of it. My spirit surged and I sent my energy to help propel his spirit upwards to pass. It was the most profound, indescribable, and most peaceful feeling I have ever experienced. I decided to text my daughter who was at his bedside. I simply texted, 'Weird feeling.' Immediately she responded with, 'I think Dad just died.' 'I know,' I texted back, 'I felt it.' Felt? What an insufficient word for what had just happened. I realized how hard this was going to be to tell anyone. It transcended words." (p.5)</p> <p>Illustration "I wish I could shake the world with what I experienced in those few moments. I wish I could wake us all up. I'm sorry that you all—some of you—believe what you believe, but I'm here to tell you it exists. This is not it. This is not all there is. This is real. I just felt really sad for us, you know, especially the nonbelievers,</p>
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	<p>and it's all okay, too. I just wanted everybody to have the experience I had." (p.5) / "I don't have the same degree of fear of dying that many others do, and I think I had that before. I think I might have been very fearful of dying as a child. I do remember fear of annihilation or death, and I don't think of death that way anymore. It doesn't seem like an annihilation at all to me, and I think it is probably because of [her SDE]." (p.5) / "Everything I do today, all the intuitive work and all that, is a direct response to my [shared death experience] . . . I used to sell mainframe software . . . and my life is completely different because of it." (p.5)</p>
<p>Finding 7 Effects of SDE - ongoing relationship with a deceased loved one (the most common mode of communication was direct mental contact) (HCP/R) (U).</p>	<p>Illustration "I'm in contact with [her son] all the time. I feel that whenever I need him now, he's there with me and in contact, I wouldn't say that I necessarily talk to him, although I talk to him out loud a lot, but I do feel him with me all the time . . . whenever I'm in doubt about different things and I'm trying to figure out a solution, it never fails. I'll be driving along, and I'll think, 'I think maybe this is the right solution,' and if I see a red Toyota Tacoma truck coming in the opposite direction or if I see one right in front of me, this is [her son's] truck, I know right away that I'm making the right decision. He sends me these signs all the time, and so that communication to me is huge. I put a lot of credence in what I get from him, and he never has steered me wrong." (p.6)</p>
<p>Finding 8 Challenges regarding integration and disclosure (fear of social ridicule or rejection) (HCP/R) (U).</p>	<p>Illustration "I felt alone for a long time . . . it felt like something I couldn't bring back to my family and my Presbyterian community. It didn't feel safe. Not that they are dangerous people or whatever, but it's just that there's a preciousness about the experience that you don't want anybody else to step on. And you don't know where people are going to come from. And so, that risk of disclosure was really present for me." (p.6)</p>
<p>Finding 9 Gratitude for opportunity to share and learn about SDE (HCP/R) (U).</p>	<p>Illustration "I had never had anyone to even talk to about any of these events. I never had anywhere to go to for resources." (p.7)</p>

SUPPLEMENTARY MATERIAL IX - RESULTS OF META-AGGREGATION OF QUALITATIVE RESEARCH FINDINGS

Meta-aggregation of studies included in the review generated four synthesized topics. These synthesised topics were derived from 100 study findings that were subsequently aggregated into eight categories.

Category 1 – Part of the dying process (7 findings): This category describes the perceptions of health care professionals and relatives that ELE are an intrinsic spiritual part of the dying process, contributing to the acceptance of death and providing the dying person with a prognosis or indication of impending death.

1. Deathbed Phenomena (DBP) are an intrinsic part of the dying process (HCP) (C).
2. DBP as a prognostic indicator for nearing death, which is encapsulated in the language used by patients (HCP) (U).
3. Reconciling to death as part of DBP (HCP) (U).
4. Dreams and waking dreams help patients to reconcile with their lives and to let go (HCP) (U).
5. Deathbed visions provide the dying person with a prognosis or indication of impending death (R) (U).
6. Deathbed visions were considered to be a precursor to death (HCP) (C).
7. These unusual experiences often represented a moment of acceptance of death for the patients (HCP) (U).

Category 2 – Types and phenomenology of ELE (29 findings): This category describes the different types and phenomenology of ELE experienced by patients, family members and healthcare professionals. End of life dreams and visions (ELDVs) with deceased loved ones are the most reported experiences, but there are also a number of paranormal incidents, deathbed coincidences and experiences related to unfinished business and farewells.

1. DBP is broader than the archetypal image of “take-away” apparitions or visions at the end of the bed (HCP) (U).
2. Patients seeing apparitions of children shortly before they died. (HCP) (U).
3. Change of room temperature in the time of death (HCP) (U).
4. End of life dreams were widely reported (HCP) (U).
5. HCP’s end of life dreams were also reported (HCP) (U).
6. Visions of animals, birds, and black butterflies (HCP) (U).
7. Lucid moments – Patients who had dementia and confusion becoming lucid in the last few days of life (HCP) (U).
8. The need for reconciliation - ELE include the need for some residents to put past wrongs to right (HCP) (U).
9. Reunion with beloved relatives is paramount to the dying even when they are comatose (HCP) (U).
10. Paranormal incidents – apparitions, lights going on and off in the room of a resident who had recently died, to hear footsteps in the corridor although no one was there, etc. (HCP) (C).
11. Take-away apparitions or deathbed visions involving deceased relatives (HCP) (U).
12. Visions of religious figures (HCP) (U).
13. Accounts of the HCP seeing the ‘visitor’ too (HCP) (U).
14. Accounts of moving to a different reality (HCP) (U).
15. Accounts of the dying person surrounded by light at the time of death (HCP) (U).
16. Animals that seemed to hold some significance for the dying person appearing at the time of death (HCP) (U).

17. Accounts of clocks stopping synchronistically at the time of death (HCP) (U).
18. Second-hand accounts of deathbed coincidences (HCP) (C).
19. Patients who sang or hummed religious hymns around the time of death and dying writing poetry which held significant meaning for them (HCP) (N).
20. Patients wanting to mend family rifts (N).
21. Seeing lights before the death (HCP) (C).
22. Accounts of sensing and seeing the patient's energy (HCP) (U).
23. Deathbed coincidences, or unexplainable events that coincided with time of death of their loved one (R) (U).
24. Many patients affirmed having vivid dreams while asleep with the presence of loved ones both living and deceased (P) (U).
25. Participants reported visions and auditory experiences and a sense of the comforting presence of deceased loved ones (P) (U).
26. SDE - remotely sensing a death (Brief thoughts, feelings, and/or a sense of the dying's presence usually at a time later determined to correspond to the moment of death. Individuals also frequently reported having received messages imparting a final farewell) (HCP/R) (U).
27. SDE - remotely sensing a death (Sudden onset of unusual physical symptoms thought to correspond to those experienced by a loved one immediately prior to death. Some individuals reported knowing a physically distant loved one had died at this time, whereas others made this connection retroactively) (HCP/R) (U).
28. SDE - witnessing unusual phenomena attributed to a death (vision of the dying; appearance of a transcendent light; sensing energy; alterations in time and space; seeing light or material believed to be the spirit leaving the body; the appearance or presence of previously deceased loved ones; visions of otherworldly or heavenly realms, etc.) (HCP/R) (U).
29. SDE - accompanying the dying in a visionary realm (descriptions of having accompanied the dying partway through their transition to an apparent post-mortem existence. According to these reports, participants suddenly found themselves out-of-body and/or in a visionary realm together with the dying (and sometimes with other deceased loved ones and/or unknown entities). These realms were most often described as gardens, castles, otherworldly regions, or a void. Participants stated that while in these realms they had knowledge about reality that was otherwise inaccessible or indescribable) (HCP/R) (U).

Category 3 – Content of ELDV (19 findings): This category includes findings from patients and relatives about the content of the End of life dreams and visions (ELDV). In these experiences, often, the deceased loved ones were seen as in their prime of health and simply being there, watching or engaging with the patient and waiting for them. There are also reports of distressing ELDV often related to traumatic life experiences and unresolved business.

1. Visions of the dead would be a repeated occurrence that would be characterized by regular or prolonged conversation (R) (U).
2. Visions of a deceased loved one calling to them to be more quickly reunited with them (R) (U).
3. In their dreams, patients seemed to be preparing to go somewhere (P) (U).
4. The presence of others in their dreams/visions as simply being there, watching or engaging with the patient (P) (C).
5. Dead friends and relatives in their dreams as “waiting for them.” (P) (U)
6. Distressing dreams, some of which replayed traumatic life experiences, others were reminiscent of difficult situations or relationships (P) (N).
7. Dreams that centered on their fears of no longer being able to do the things they felt they needed to accomplish in life (P) (N).
8. Typical characters in the ELDV were: dreamer, family, people who were unfamiliar/unknown and miscellaneous characters. (P) (U).

9. The typical relational interactions in the ELDV were: close connections (any relational description that is intimate and/or emotionally close), neutral connections (a lower level of relational engagement) (P) (U).
10. Participants generally described their dreams with feelings/emotions, including traditionally positive and distressing emotions (P) (U).
11. Participants typically reflected on an element of nostalgia, a longing to reconnect with a person, place, or experience from the past (P) (U).
12. It was typical ELDV in which participants spontaneously engaged in sense making (P) (U).
13. Typically, within the ELDV, participants reported activities related to traveling/movement and an attempt to do something, including working toward a specific goal (P) (U).
14. Individuals typically reported that the environment was familiar/known and involved the natural environment (P) (U).
15. Participants typically described settings related to: transportation and travel; home/residence (an overall home, structure, or building as well as objects or rooms associated with home); spatial awareness and directionality (references to top, bottom, up, down, side to side, inside/indoors, and outside/outdoors); institutions of daily life (weddings, picnics, and graduations, places of work, places of business, places of education, places of play and places of worship) (P) (C).
16. In sharing their stories, FCGs talked about dream content, or who was in the dream and what happened (R) (U).
17. In these dreams, there were seldom any specific conversations with the deceased and their loved ones were seen as in their prime of health despite having died in old age or with severe illnesses (P) (U).
18. In these dreams, there were references to traveling included preparing to go or being on a journey, sometimes with a specific goal (P) (U).
19. The predominantly positive content of their dreams astonished some patients. They had expected “bad” dreams given their medical situation (P) (U).

Category 4 – Control and choice (3 findings): This category describes experiences of relatives and health care professionals of the dying person as an active negotiator or equal actor in the process of dying, whether deciding not to leave with the loved ones who calls them or close their eyes only when a family member who was traveling a long distance arrived in the hospital to see the patient or requiring attention, presence, and assistance from the relatives to the transition.

1. The dying person as an active negotiator or equal actor in the events he or she describes (R) (U).
2. Patients could seemingly control the timing of their death (HCP) (U).
3. SDE - assisting the dying in transitioning (participants described having taken an active role in assisting a loved one in the process of transitioning. Every one of these experiences occurred physically apart from the dying. These experiences were similar to those in which people accompanied the dying in a visionary realm but included individuals feeling that their attention, presence, and assistance was required by the dying to successfully transition) (HCP/R) (U).

Category 5 – Possible Explanations (13 findings): This category describes the perceptions of patients, relatives and health care professionals regarding the possible explanations of ELE. Despite pointing out some difficulties in clearly defining the causes of ELE, they bring up important differences between ELE, hallucinations and confusion. The former could not be attributed exclusively to chemical change within the brain, neither to drugs or fever, since they were connected to “something” else beyond what can be seen and were clear, supporting and hold some profound meaning for the patient.

1. DBP is hard to define clinically (HCP) (U).

2. DBP differ from drug-induced hallucinations because they hold some kind of profound meaning for the patient (HCP) (U).
3. Difficulties of distinguishing between ELE and drug-induced hallucinations, dementia, and confusion (HCP) (U).
4. There are differences between hallucinations and ELE (HCP) (U).
5. ELE could not just be attributed to chemical change within the brain, neither to medication or fever (HCP) (C).
6. Rejection of more “scientific” explanations on the basis of how these experiences made her feel subjectively (HCP) (U).
7. Dreams as a way of knowing about death survival (HCP) (C).
8. Sense that the unusual experiences they had encountered were connected to “something” or “somewhere” else beyond what can be seen (HCP) (C).
9. Deathbed visions weren’t purely induced by drugs (HCP) (U).
10. Caregivers tried to understand, explain, or conceptualize ELDV and incorporate them into their own worldview. Subthemes: religious/spiritual process (the most apparent) and medically related (cognitive decline or medication) (R) (U).
11. Participants constructed narratives by interpreting the ELDV within the context of their loved one’s life and illness experience (R) (U).
12. Many participants engaged in sense-making, or assigning meaning and purpose to their loved one’s ELDV (R) (U).
13. Some patients reported differences between ELE and negative inner experiences they considered caused by medication. The hallucinations/nightmares were perceived as disturbing and unclear and their occurrence and ceasing coincided with their taking a specific medication. The ELE as clear, positive and supporting (P) (U).

Category 6 – Impact on the dying process and bereavement (15 findings): This category describes the perception of patients, relatives and health care professionals about the mostly positive impact of ELE on the dying process of patients and on the grieving process of loved ones. ELE provided spiritual comfort, solace, peace, happiness or reassurance and were seen as a means to deepen relationships with the patient or family and friends. The main effects of ELE for relatives were to strengthen the connection with the deceased and to left a profound mark on what they perceived to be life’s meaning or purpose.

1. Dying experiencing profound dreams which seemed to comfort and prepare them for death, which helped them to resolve unfinished business (HCP) (N).
2. ELE were intense subjective experiences which held profound personal meaning for the dying person and offered spiritual comfort to the patient and to the relatives (HCP) (U).
3. Comfort or satisfaction at the prospect that someone important to the dying person was waiting for them (R) (U).
4. End of life visions provided comfort to the dying (R) (U).
5. Deathbed visions were not distressing or fearful for the patient and family (HCP) (U).
6. Dreams and visions were overwhelmingly described as comforting to the patient (P) (C).
7. Participants commonly noted comfort provided by ELDV describing solace, peace, or reassurance (R) (U).
8. Upon reflecting about ELDV experiences, a variety of feelings and emotions emerged, including positive, negative, or mixed/contrasting. The majority of emotions were traditionally positive (R) (U).
9. Participants spoke about ELDV as a means to deepen relationships with the patient or family and friends (R) (U).
10. Participants shared ELDV reflections and how they impacted them during caregiving. Responses included feelings such as amazement, peace, curiosity (R) (U).
11. ELDV also impacted FCGs during bereavement (R) (U).
12. FCGs also talked about signs - items such as sparrows, pennies, rainbows- that strengthen their connection with the deceased (R) (C).
13. In the majority of cases, ELE were experienced positively (P) (U).

14. Effects of SDE - changes in beliefs, attitudes, and behavior (SDE convinced them of the reality of a benevolent afterlife; had alleviated or completely removed their fear of death and dying; left a profound mark on what they perceived to be life's meaning or purpose (HCP/R) (U).
15. Effects of SDE - ongoing relationship with a deceased loved one (the most common mode of communication was direct mental contact) (HCP/R) (U).

Category 7 – Communication issues (6 findings): This category includes findings from patients, relatives and health care professionals regarding the difficulty in sharing about ELE for fear of social ridicule or rejection and their desire to have a space to talk about these experiences.

1. Patients and relatives are reluctant to talk about DBP through fear of ridicule or dismissal as well as lack of public awareness (HCP) (U).
2. Participants desire to form relationships and support others who have ELDV experiences, talking to healthcare providers and acquaintances about ELDV, advice offering, gratitude to be able to share or given a space to share about ELDV (R) (U).
3. Participants selectively choosing not to share ELDV of loved one, generally for protection of self or to preserve positive memory (R) (U).
4. If the patient decided to tell others about their ELE, the reaction varied depending on the person that they approached. Some loved ones did not believe them, others were met with understanding (P) (U).
5. Challenges regarding integration and disclosure (fear of social ridicule or rejection) (HCP/R) (U).
6. Gratitude for opportunity to share and learn about SDE (HCP/R) (U).

Category 8 – Clinical management of ELE and need for training (8 findings): This category describes the perception of health care professionals regarding the importance of encouraging patients to speak of their ELE and the recognition of the need for training in communication skills and clinical approach to the ELE.

1. The qualities of openness and honesty, a willingness to listen, and normalizing DBP were considered to be important factors in encouraging patients to speak of DBP experiences (HCP) (U).
2. Medical staff would be dismissive of such experiences, that did not fit easily within a medical framework (HCP) (U).
3. Need for further education and training to deal with existential issues (HCP) (U).
4. HCP wanted to learn the language of approaching death and how to start conversations with residents about the dying process without causing distress or confusion (HCP) (U).
5. Dangers of dismissing or ignoring patients' experiences (HCP) (C).
6. Discussion of unusual experiences facilitated a deeper understanding of patients and of their needs (HCP) (C).
7. The emotional impact of these experiences for the HCP appeared to be heavily influenced by the emotional response of their patient (HCP) (U).
8. It is important to mirror the patients' "matter of fact" approach to these phenomena, even if you did not share their beliefs (HCP) (U).