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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

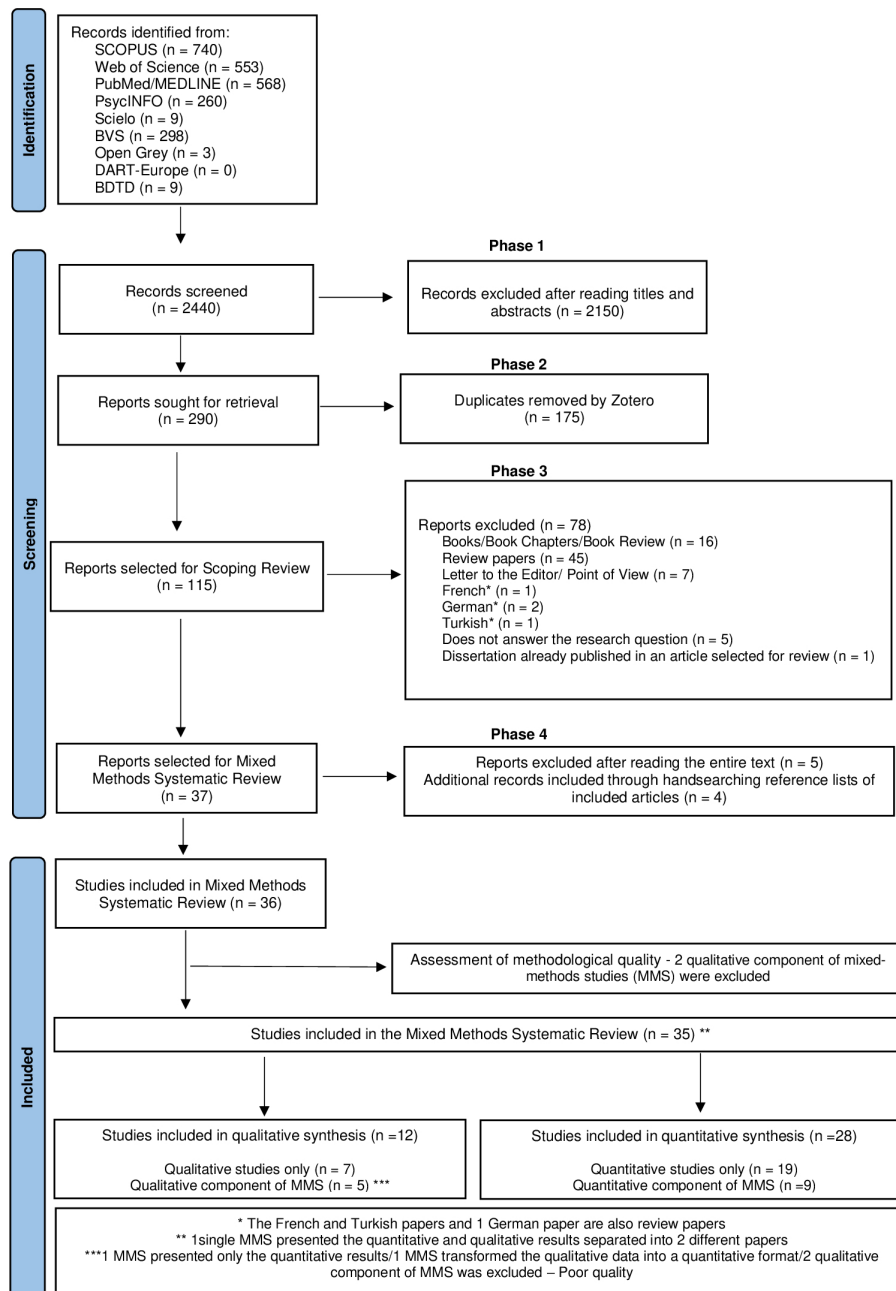


Figure 1 Flow diagram of study selection.

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

Table 1 Findings of the scoping review

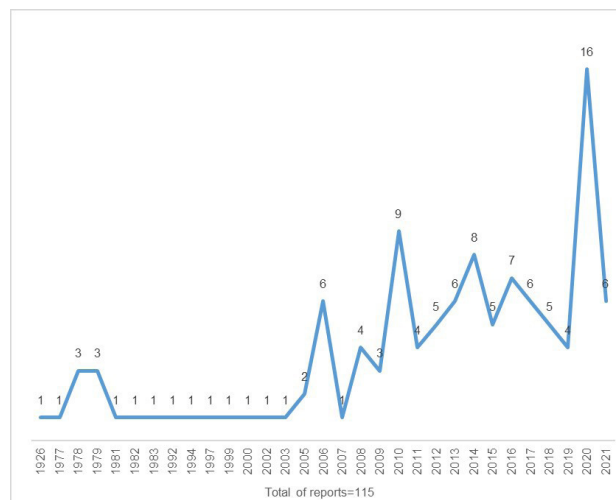
Types of reports	N (%)
Review papers	48 (42)
Original research	42 (36.5)
Books/book chapters/book reviews	16 (14)
Letter to the editor/point of view	7 (6)
Dissertations	2 (1.5)
Country of publication	
USA	64 (55.6)
UK	13 (11.3)
Germany	6 (5.2)
Canada	5 (4.3)
Brazil	4 (3.5)
India	4 (3.5)
Australia	3 (2.6)
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
Studies with Relatives	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% discomfiting 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 22% 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	159	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. 62.3% 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) ⁵⁴	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.	DV is not affected by medical factors.
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.	
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) ⁵⁹	107	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

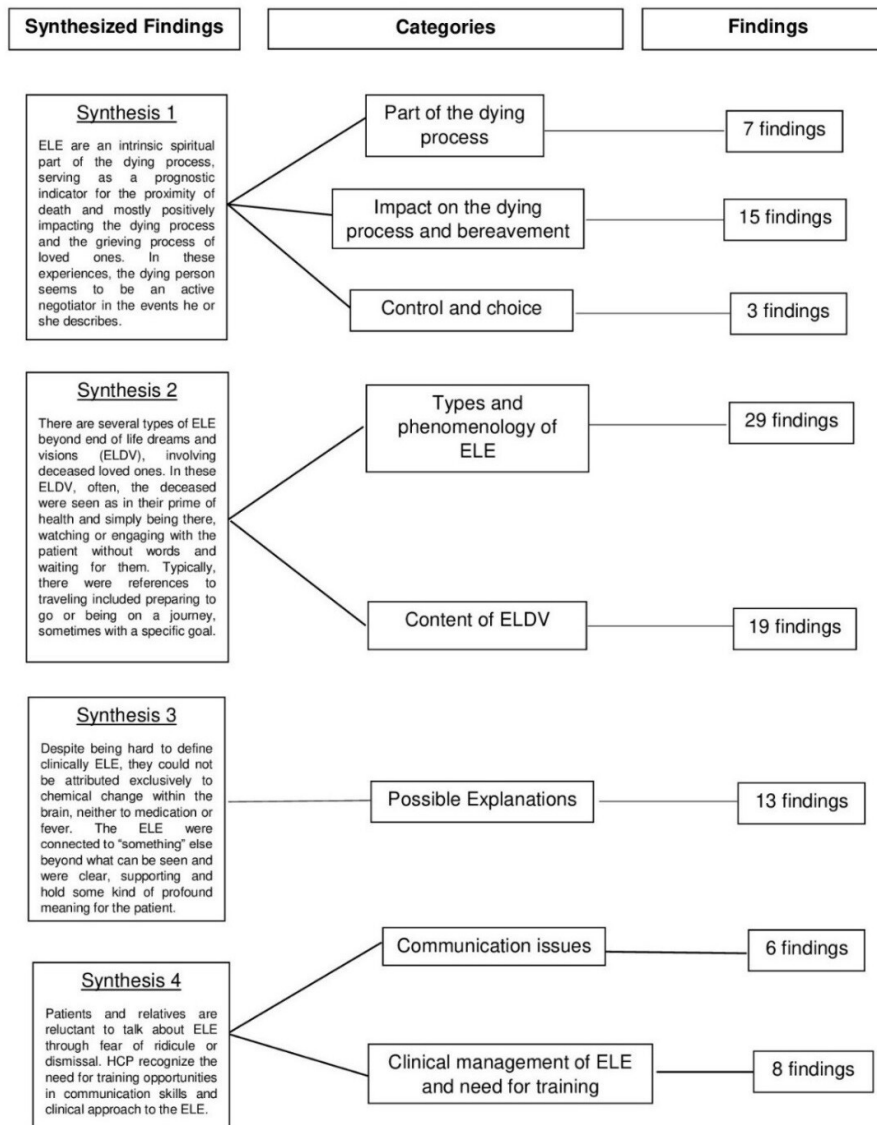


Figure 3 Synthesised findings, categories and findings. ELE, end-of-life experience; HCP, healthcare professional.

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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