

# End-of-life dreams and visions as perceived by palliative care professionals: A qualitative study

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## Original Article

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### Abstract

**Objective.** End-of-life dreams and visions (ELDVs) have been suggested to be prevalent psychic phenomena near death that can provide meaning and comfort for the dying. There is a lack of studies from the secular Nordic countries. The aim of this study was to determine whether palliative care professionals in a Nordic country have experience of patients expressing dreams, visions, and/or inner experiences and, if so, how they are perceived.

**Method.** Focus-group interviews with 18 professionals in end-of-life palliative care were subjected to qualitative content analysis.

**Results.** Most (15/18) professionals had experience of patients with ELDVs. A dominant content was deceased loved ones. According to most professionals, many patients perceived their ELDVs as real and could report them with clarity. The experience could result in peacefulness for patients, as well as loved ones, and reduce fear of death. Some professionals themselves perceived ELDVs to be real and a normal part of dying while a few found them scary. Most professionals, however, found ELDVs hard to grasp. Many tried to explain the phenomena as the result of medical circumstances and confusion, although reporting that they considered most patients to be normal and of sound mind in connection with their reports on ELDVs. Most patients wanted to talk about their ELDVs, but some could be reluctant due to fear of being considered crazy. The professionals were open-minded and reported having no problem talking about it with the patients and tried to normalize the experience thereby calming the patient and loved ones.

**Significance of results.** The results strengthen the suggestion that ELDVs are common phenomena near death, worldwide. Although most professionals in palliative care recognized ELDVs as beneficial to patients, many found the phenomena hard to grasp and sometimes difficult to distinguish from confusion, indicating a continuous need for exploration and education.

### Introduction

When death is imminent, the aim of palliative care is to ease the journey toward the end. Care of the dying and their loved ones focuses on early intervention to alleviate distress, be it physical, psychosocial, or existential (WHO). Also, finding and reinforcing that which the patient and their loved ones find positive is desirable. Profound psychic phenomena near death are reported to be such positive events that can have a significant role in easing many of the negative aspects of the dying process. This includes a spectrum of related experiences, often of a transpersonal, reassuring nature that seems to be independent of age, gender, socioeconomic status, culture, and religion. The most extensively studied among these is the near-death experience (NDE). In most cases, NDEs are preceded by a sudden shift in physical condition caused by, for example, near-fatal accidents or cardiac arrest that do not lead to death and occur in a coma or an unresponsive state, often including an out-of-body experience (Moody, 1975). However, other experiences, although of similar nature, occur instead during progressive deterioration of the person's condition, commonly in people who are dying, can be reported while fully awake, and seldom include out-of-body experiences. End-of-life experiences (ELEs) are examples of the latter and has been thoroughly described by Fenwick et al. (2007, 2010). It covers many aspects of psychic phenomena near death, such as end-of-life dreams and visions (ELDVs), synchronistic events (e.g., clocks stopping, bells ringing, strange pet behavior), terminal lucidity among others. ELDVs can occur hours to months before death and has in recent studies been shown to be present in the majority of patients near death (Kerr et al., 2014). They are most often expressed as vivid dreams or visions while awake and typically contain deceased and/or living loved ones (Lawrence and Repede, 2013; Kerr et al., 2014). In many cases, they are perceived as deeply meaningful (Fenwick and Brayne, 2011; Lawrence and Repede, 2013) and beneficial for both patients and loved ones (Fenwick et al., 2010; Mazzarino-Willett, 2010; Nosek et al., 2015).

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It has been suggested that ELDVs are intrinsic to the process of dying, helping patients prepare for their impending death (Wills-Brandon, 2000; Lawrence and Repede, 2013) and it has been speculated that visions included in the ELDV context are veridical (Betty, 2006). This emphasizes the importance to distinguish these phenomena from delirium and confusion, states not uncommon at the end of life (Gofton, 2011; Moyer, 2011). There is a reported difference between ELDVs and delirium in their typical character consisting of the feelings they evoke (well-being versus anxiety and fear), how they are reported (clear and structured versus disorganized, confused), type (mainly visual versus predominantly auditory), content (deceased loved ones versus living people of little significance to their lives) (Betty, 2006; Mazzarino-Willet, 2010; Depner, 2020).

Studies of ELDVs are in most cases based on reports from healthcare personnel and patients' significant others (Fenwick et al., 2010; Kellehear et al., 2011; Lawrence and Repede, 2013; Morita et al., 2016; Claxton-Oldfield and Richard, 2020; Grant et al., 2020), whereas only a few have focused on patients' own reports (Kerr et al., 2014; Dam, 2016; Nyblom et al., 2020).

Although these types of experiences have been reported throughout history in different cultures and have evoked increasing scientific interest since the mid-1990s (Osis and Haraldsson, 1977), they are not well known among medical professionals (Barbato et al., 1999; Fenwick et al., 2010). It has previously been suggested that ELDVs are influenced by culture and religion (Osis and Haraldsson, 1977; Muthumana et al., 2010). However, ELDVs have now been scientifically explored in several different countries revealing many similarities, indicating that ELDVs are common experience among people nearing death worldwide (Brayne et al., 2008; Kellehear et al., 2011; Kerr et al., 2014; Dam, 2016; Morita et al., 2016; Santos et al., 2017). There is, however, a scarcity of studies from the more secular Nordic countries (Nyblom et al., 2020) and, to our knowledge, none investigating the experience of ELDVs among professionals. Thus, the aim of this study was to investigate whether professionals in palliative care have experience of patients expressing dreams, visions, and/or inner experiences and, if so, how they are perceived.

## Method

To obtain a deeper understanding of how ELDVs are perceived among professionals working in end-of-life palliative care, a qualitative design was chosen (Harris, 2017).

## Participants

Of the 18 participating professionals, 16 were women and 2 men, evenly distributed between 25 and 65 years of age (median: 47). Eleven were registered nurses and 7 were assistant nurses, with employment years ranging from 5 to 41 (median: 18).

## Procedure

Professionals in one palliative home care unit and three hospice inpatient units in our region were invited to participate in focus-group interviews through written information delivered by their unit manager. Participants were informed that the interviewers were palliative care professionals working in their region and, as such, could be known to them. Participation was voluntary. Time for interviews was scheduled beforehand. Semi-structured interviews took place at the professionals' workplace, with a

duration between 25 and 50 min. A majority of the professionals in service that day joined the focus group with a written consent. Four focus-group interviews were conducted with a total of 18 professionals (7 from palliative home care and 11 from hospice inpatient units). Two of the authors, with prior experience of group interviews, conducted the interviews (SN: interviewer, IB: observer taking field notes). The interviews were digitally recorded and professionally transcribed verbatim. The research questions were: Do you have experience of patients expressing dreams, visions, or inner experiences? If so, what do they contain? How are they perceived by the patient and by you? The term "inner experience" was chosen as it, in native language, opened the question more toward a spiritual experience. Data were collected between March 2018 and August 2019. Transcripts were not returned to participants for comment. The study was approved by the Regional Ethical Review Board (999-17).

## Data analysis

Transcribed focus-group interviews were analyzed using qualitative content analysis (Graneheim and Lundman, 2004). The hermeneutic analysis process is sensitive in relation to the underlying meaning and not immediately understandable. The circular interpretation is going forth and back, finding both the manifest and latent meaning. Analysis was done in cooperation by all three authors in order to interpret the results as objectively as possible. All authors individually marked text relevant to the research questions. Units of meaning were thereafter identified and grouped into themes and subthemes derived from the data, until data saturation was found in the themes. Any discrepancies were discussed until a common conclusion was reached.

## Results

Most (15/18) participating healthcare professionals had experience of ELDVs, by reports from patients, and some also from their own loved ones. The observer noted that the majority of the participants took active part in the discussions, which were characterized by openness, without fear of the subject or to express opposing views. Four themes were identified: content of ELDVs, how ELDVs are perceived, explanations to ELDVs, and communication about ELDVs.

### Content of ELDVs

Content reported in this theme refers to experiences near death, i.e., before death as well as shortly after. ELDVs occur "more and more as it nears the end" (P1) according to many professionals and can foretell death: "we understood that, perhaps that it was that the patient was approaching death" (P13). This theme contained three subthemes: loved ones, animals, and traveling.

### Loved ones

ELDVs in the form of vivid dreams and/or visions as well as a sense of a comforting presence of deceased loved ones were common. The professionals said that patients often tell that "they have dreamed of their dead parents or relatives" (P1). One nurse recalled a patient: "He was a grumpy man but suddenly his face sort of lit up and he said 'Awh, do you see? My wife! [deceased]' 'Yes, there, in the corner of the bed there. She is here!'. After that he was changed, he was so happy. 'Now I know that she's there, that we'll meet soon'" (P7). The patient died a few days later.

Another professional shared: “She often talked about her sister, that she felt her presence in the room. She was dead, her sister ... It also looked like she became very secure” (P6). At several occasions, a patient told the professionals about loved ones visiting: “‘imagine, he was sitting there’ or ‘she was standing there’ and we understood that they had passed away” (P3). References to deceased loved ones outside the close family, such as friends, as well as living loved ones were rarely reported by the professionals.

Although specifically asked about patients expressing ELDVs, some professionals also reported ELDVs experienced by their own loved ones. Their experiences were first-hand, most often witnessing the death of a close family member. “When my dad was lying there on his deathbed he said: ‘Now they are standing here waiting ... there are a lot of people here, but they say it’s not time yet, not quite yet’ ... But he was not afraid” (P2).

### *Animals*

Animals were found to be a rather common feature of ELDVs. “Pets are a recurring theme” (P16), but also wild animals. A patient told the professionals that her room “was full of animals, forest animals were present in the room with her.” This vision was “not anxiety related in any way, but it was just sort of a security” ... “harmoniously sort of, it was an experience that was good” (P8). The patient died within a week. Quite a few professionals talked about the arrival of birds at death, or shortly after. It was interpreted as a message from the recently deceased. One week before death, a patient that loved birds, jokingly told the nurse: “it is probably not long left [until death], but then I will come and haunt you.” Shortly after her death the nurse noticed a bird with an odd behavior: “Then I get a sensation of her [the patient’s] smell, so I just became like this: Gosh, it’s you! How nice you are haunting!” ... “it was a very nice, yes, event, that I carry with me” (P2). A patient had told her nurse that she loved robins and wanted to become one in her next life. Loved ones, present at the time of her death, told the nurse: “Yes, you see, then a robin came and sat down outside the window and where we live, there a robin sat down at the neighbours and then they thought that now she is on the other side’. I shiver” (P12).

### *Traveling*

References to traveling were mainly about preparing to go somewhere, such as a woman that “dreamed that she would be picked up” (P7) and arrangements for a journey: “I don’t think she said dream but ‘experience’, and her husband [deceased] had ‘ordered a travel service for both of us. So now everything is in order’. Now everything was as it should be, it was perfectly OK and she knew this time that she would, she would die soon” ... “Then it was done, then everything was in order, then she was happy” (P3).

### *How ELDVs are perceived*

Most ELDVs were perceived as a positive experience, with a clarity and sense of reality. Feelings of comfort, security, inner peace, and hope are reported as a result of ELDVs. The following three subthemes were found: positive experiences, sense of reality, and scary for professionals and loved ones.

#### *Positive experiences*

Most professionals considered ELDVs a positive comforting patient experience. The participants reported that ELDVs resulted in a feeling of safety and peace for the patient. “You get the feeling that they get some kind of hope ... Most of them are not afraid to

die either ... They have found, have someone as an escort, they have a companion, and then they find security in it, I think” (P3). “It gives some kind of inner peace, I think” (P4). “They calm down” (P14).

#### *Sense of reality*

A reported characteristic of ELDVs was the clarity in the report: “They can tell quite in detail, such as how it was, how he or she was dressed or how that person said something” (P10). It became clear that most of the professionals believed that the patients perceived their ELDVs as real: “She dreamed very frequently about her dead husband in the last weeks of life, it was very real for her” (P9). “It’s so incredibly real to them” (P2). “They are a bit bewildered from the experience, I think, and maybe that the one who came in the dream was so real. Or suddenly just sat there” (P10). The clarity and perceived reality were considered by many to be the hallmarks of ELDVs. Yet, the professionals’ personal perception of the reality in ELDVs varied. Many tended to think it was due to confusion or “did not know what to think,” and a few found it real: “It feels like that when they tell. It feels real what they’re saying, so to say” (P15).

#### *Scary for professionals and loved ones*

The patients ELDVs could sometimes scare the professionals. It could be spooky and was something they could not know what it really was. “I think that kind of thing is pretty nasty, there are some that can scare me.” “So, of course, I thought it was pretty scary” (P11). Nevertheless, when the patient’s loved ones thought that ELDVs were scary and the patient not of sound mind, the professionals could talk to them, trying to normalize the phenomena.

#### *Explanations to ELDVs*

Professionals expressed their own thoughts about the underlying cause of ELDVs as well as speculations coming from loved ones and often referred to medical circumstances. This is described in two subthemes: professionals and loved ones.

#### *Professionals*

The professionals spontaneously commented on the difficulty of knowing whether ELDVs were a form of confusion. It was not uncommon to seek a physiological explanation to ELDVs, as for example the underlying disease “I do not really know how to connect it because if there is someone who has a brain tumour, you do not really know what is what” (P5), or hallucinations due to medication: “But then I think, our guests [patients] have a lot, a lot of medication and so on and how it affects them and such” (P12). Despite this many professionals stated that they considered the patient to be normal and of sound mind in connection with their report on specific cases of ELDVs. For example, the patient sensing the presence of her dead sister: “She was of sound mind, completely of sound mind. I think so, absolutely” (P6), and the patient with visions of his deceased wife: “He was not confused either. He was normal” (P7). Being familiar with drug-induced confusion or terminal delirium affecting their patients, many professionals found the different character of ELDVs hard to grasp: “Others are affected so then you cannot know, but I still think somewhere there (pause), maybe some reality (pause), I do not know. It’s very difficult” (P12).

Some regarded ELDVs as a normal phenomenon, “It’s no wonder. A part of coming to life and leaving life” (P4), and

found it exciting: “who is coming to get me?” (P15). These professionals considered themselves, as well as the patients, capable of recognizing an ELDV: “And it feels like they are much more, that the guest [patient] is much more aware and on other levels than what you usually talk to everyone about. I can feel that many times. They just look you straight into the soul and...” (P3). Although none of the professionals mentioned any religious content in ELDVs, a few professionals connected ELDVs to faith: “maybe, if it has to do with religion, thus it will be a security. Some turn to God, and then I thought that this could be a similar thing and because it made her [the patient] calm” (P13). According to the professionals, the patients sometimes themselves questioned whether they were confused: “Many can say ‘am I going crazy or is it a dream or reality?’, because it’s so incredibly real to them” (P2). A few professionals thought that confusion could be explained in the context of ELDVs, saying that patients “are somehow commuting between the different worlds, just like you try your hand a little, feel the new world and then you are still in this physical body, but then you make a small protrusion, a small excursion and so you come back. And sometimes they are confused because they do not really know where they are, are they here? So sometimes they say, ‘Am I dead now?’” (P3).

### Loved ones

The professionals reported that loved ones often see ELDVs as confusion caused by medication: “Loved ones could not take it at all. They thought she had become so confused and was it the medication or what was wrong?” (P3). “Now mom is lying in there calling her mom sort of, why is that?,” “Or says that she is standing next to you” (P4). “You get the question; does it depend on the medicine?” (P10). However, some loved ones had an open mind toward the phenomenon: “On the contrary, almost hopeful, that ‘yes, grandma came to pick up dad’” (P9) and find it a positive and natural expression: “She was very positive, the daughter there, because she herself was incredibly enough on the same wavelength, so to say, she really was” (P6).

### Communication about ELDVs

The professionals reported a reluctance to talk about ELDVs among some patients that “maybe get a little nervous about what others will think if they tell, that people should think that, that they are crazy” (P10). Some professionals thought that dreams “can be very private and personal.” As one patient expressed it: “It’s about the only private thing I have left” and “She simply wanted them for herself” (P8). However, most professionals were open-minded and reported having no problem talking about it with the patients. Many had found that patients wanted to talk about their experiences, and that “they have a need to have it confirmed in some way, that it is not something strange” (P3). Talking about ELDVs “is more accepted here than it is out in the community, I think, absolutely” (P15) and the majority of the professionals felt that they could help the patient and their loved ones by confirming that “it is not so unusual, there are several who tell of such experiences”.... “Then they [the loved ones] calmed down and then she [the patient] was also a little happier” (P3).

### Discussion

To our knowledge, this is the first study of ELDVs reported by professionals in palliative care in the Nordic countries. The results show that professionals are aware of and report the presence of

ELDVs among their patients. This is in accordance with direct reports from patients in the same context and strengthens the previous finding that ELDVs are a common phenomenon also in a highly secular country (Nyblom *et al.*, 2020), supporting the suggestion that ELDVs are a universal experience among people nearing death, regardless of religion and culture (Brayne *et al.*, 2008; Kellehear *et al.*, 2011; Kerr *et al.*, 2014; Dam, 2016; Morita *et al.*, 2016; Santos *et al.*, 2017).

A prominent feature of ELDVs was vivid dreams and visions of deceased loved ones, in agreement with previous studies (Fenwick and Brayne, 2011; Lawrence and Repede, 2013; Kerr *et al.*, 2014; Nyblom *et al.*, 2020). ELDVs can also contain living loved ones but were not reported by the professionals in this study, though present in direct reports by patients in the same context (Nyblom *et al.*, 2020). This could be due to that narratives of living loved ones, although meaningful and real for the patient, is not noted as an ELDV by the professionals, but as a normal dream. The professionals considered animals a common content of ELDVs, many of which concerned events directly after death, with a specific connotation to birds conveying a message from the patient to bystanders that could be very touching. Similar deathbed coincidences, experienced by bystanders at the time of death, has been described previously (Fenwick *et al.*, 2007). Preparing to go on a journey was reported as a content of ELDVs, which has previously been found (Mazzarino-Willett, 2010; Fenwick and Brayne, 2011; Kerr *et al.*, 2014; Nyblom *et al.*, 2020) and interpreted by some as the approach of death (Mazzarino-Willett, 2010). Although our aim was to study professionals’ experiences of ELDVs among patients, some participants also referred to their own loved ones, revealing similar experiences as mentioned for patients. Moss has described how resident deaths and family deaths can be interrelated and structure the meaning for staff of death and bereavement (Moss *et al.*, 2003).

In coherence with previous reports from both patients and professionals, ELDVs were, in most cases, considered a positive, comforting experience, that could result in a feeling of safety and peace, convey hope and, in some cases, reduce fear of death (Fenwick *et al.*, 2010; Kerr *et al.*, 2014; Nyblom *et al.*, 2020). Most participants found that ELDVs were perceived as real by the patients and could be reported with clarity, which are key features of ELDVs as reported earlier (Kerr *et al.*, 2014). Clarity and sense of reality are also what seems to make it possible for some patients to distinguish ELDVs from obscure hallucinations caused by medication (Nyblom *et al.*, 2020). While a few professionals admitted that they themselves perceived that ELDVs are real and considered the phenomenon a normal part of dying, others could find them scary. However, most participants found ELDVs hard to grasp. Although many confirmed that they considered most patients to be normal and of sound mind in connection with their reports on specific cases of ELDVs, the same professionals still had a tendency to try to explain ELDVs as the result of medical circumstances. It seemed difficult for some professionals to determine whether a patient who expresses abnormal experiences, but is otherwise perceived as normal and of sound mind, may be anything but confused. As reported by the professionals, this was also a concern expressed by a few patients. Kellehear (2017) argues that the interpreting of these experiences require an unprejudiced humility before the data. ELDVs could be normal experiences of idiosyncratic perception linked to crisis and transition. In the case of NDEs, Greyson (2000) found that the dissociative symptoms are not consistent with a psychiatric disorder. Difficulty in

distinguishing between ELDVs and confusion has also been reported in previous studies and could entail unnecessary medicalization, depriving the patient of a positive experience (Lawrence and Repede, 2013; Kerr et al., 2014). Although many patients wanted to talk about their experiences, some were reluctant due to fear of ridicule (Fenwick et al., 2007; Nyblom et al., 2020). This can have implications for how the dialog around ELDVs are conducted. The professionals could find it inappropriate to encourage further conversation about the patients' experiences, when in doubt whether it is a result of confusion.

Speculations about the cause of ELDVs were brought up by the professionals in all focus-groups, despite not a research question and is a notable difference from direct interviews with patients, where a strong sense of reality was conveyed without any attempt to an explanation (Nyblom et al., 2020). However, regardless of the underlying cause of ELDVs, the experience can be beneficial for patients, giving a sense of security, provide hope and reduce fear of death and, as such, be valuable to pay attention to and reinforce in palliative care. It is, thus, important to inform health-care personnel about ELDVs and offer education when needed. Hopefully, that could make them more prone to conversation about ELDVs with patients and loved ones, a measure that has been shown to be of benefit in previous studies as well as this study, where normalization of the phenomenon by professionals made both patients and loved more peaceful (Grant et al., 2020). The effects of education in the subject together with a structured conversation strategy to support patients with ELDVs, as well as their loved ones, could be directions for further research.

### Limitations and strengths

Qualitative studies often entail limitations on transferability due to the small sample size. Although, in this study, the sample was quite large, many other limitations can be found. We did not request information about response rate and cannot exclude that professionals with experience of ELDVs were more prone to participate. Memory biases may have influenced the interpretations of ELDVs. Group interviews may cause a reluctance among some participants to talk about matters of spiritual nature like ELDVs. However, the majority took active part in the discussions, all participants are recruited from the same context, data saturation was found in the themes and the findings align with previous studies, thereby strengthening the validity of the results.

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