

Shared Death Experiences: A Little-Known Type of End-of-Life Phenomena Reported by Caregivers and Loved Ones

American Journal of Hospice & Palliative Medicine®
1-9
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DOI: 10.1177/10499091211000045
journals.sagepub.com/home/ajh


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Abstract

Anecdotal evidence suggests that some loved ones and caregivers of dying patients undergo a type of end-of-life phenomena known as a shared death experience or SDE, whereby one feels that one has participated in a dying person's transition to a post-mortem existence. Anecdotal evidence also suggests that SDEs can have a range of profound psycho-spiritual-emotional effects. However, SDEs have been all but ignored in hospice and palliative medicine, leaving professional bereavement services uninformed about SDEs and leaving individuals who report SDEs without adequate professional support to process and integrate them. To better understand the features and effects of SDEs, an inductive content analysis was performed on written accounts and transcripts of semi-structured interviews with 107 persons reporting a total of 164 SDEs. Analysis revealed 4 distinct though non-exclusive modes of an SDE: remotely sensing a death, witnessing unusual phenomena, feelings of accompanying the dying, and feelings of assisting the dying. Analysis also revealed 3 major domains of SDE effects: changes in belief, the reconciliation of grief, and the perception of continued relational bonds with the deceased. Interviews highlighted both difficulties and therapeutic value in people openly discussing their experiences with health professionals. We believe that integration of information about SDEs offers an opportunity to add to the breadth and quality of psychological, spiritual, and bereavement care.

Keywords

end of life, end-of-life experiences, visions, spirituality, experience, bereavement

Introduction

In 1926, Sir William Barrett's *Deathbed Visions* introduced a typology of deathbed visions or what is now more commonly referred to as end-of-life phenomena (EOLP) that consisted of: 1) visions seen by the dying of persons unknown by them to be dead; 2) visions seen by the dying of persons known by them to be dead, and deathbed visions seen by others; 3) visions seen by the dying of living persons at a distance (in some cases reciprocal); 4) music heard at the time of death by the dying or by persons present at a deathbed; and 5) visions of the spirit of a dying person leaving the body. Of the 58 cases presented by Barrett, 20 included instances of EOLP experienced directly by caregivers and loved ones, most of whom were profoundly impacted by the event. For instance, a Dean of an Australian Church reported that both he and his wife were at the deathbed of their son when they noticed "something rise as it were from his face like a delicate veil or mist, and slowly pass away . . . We were deeply impressed and remarked, 'How wonderful! Surely, that must be the departure of his spirit.'"^{1(p83)} And yet while *Deathbed Visions* introduced EOLP reported by loved ones, caregivers, and dying persons, subsequent studies on EOLP, with very few exceptions, have come to focus solely on experiences reported by the dying.^{2,3}

A few empirical researchers have noted that caregivers and loved ones of dying persons do report first-hand experiences with EOLP, though this fact is always presented by way of summaries of anecdotal accounts.^{4,5} Neuropsychiatrist and end-of-life specialist Peter Fenwick identified such phenomena as "deathbed coincidences," which are

coincidences, reported usually by family or friends of the person who is dying, in which they say that the dying person has visited them at the hour of death. Many relatives are reluctant to describe these phenomena, but nevertheless they are frequently reported.⁶

Fenwick listed the major phenomenological features of deathbed coincidences as consisting of: feelings of unease, the appearance of the dying in visions or dreams,

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Table 1. Demographic Information.

Characteristics	N = 107	%
Age Range ¹		
21-30	2	1.9
31-40	3	2.8
41-50	12	11.2
51-60	30	28.0
61-70	42	39.3
71-80	15	14.0
81 +	3	2.8
Gender		
Female	91	85.0
Male	16	15.0
Ethnicity		
Caucasian	99	92.5
Asian American / Canadian	4	3.7
Latino/Hispanic	3	2.8
African American	1	0.9
Current Religion/Spirituality		
Spiritual not Religious	56	52.3
Christian	28	26.2
None	12	11.2
Jewish	6	5.6
Buddhist	3	2.8
Hindu	2	1.9

¹Age range refers to the age of participants at the time they reported their experiences to us rather than at the time of their experience.

unaccounted-for tactile and olfactory phenomena, the sudden onset of physical symptoms that might correspond to those of the dying, and dreams that seem to predict death.^{7(p47-53)} Fenwick also reported that persons at a deathbed sometimes observe the appearance of “a radiant white light...surrounding those who experience it with love.”⁶ Most but not all of these deathbed coincidences are viewed positively; a minority are reported as being disconcerting or even frightening.^{7(p71-73)}

While several non-academic publications on EOLP exist, arguably none have done more to popularize EOLP experienced by caregivers and loved ones than Raymond Moody's *Glimpses of Eternity*.⁸ This book introduced the general public to “shared death experiences” or SDEs as a term to identify a range of experiences whereby a loved one or caregiver has the sense that they are accompanying the dying “partway to a heavenly realm.”^{8(jacket cover)} Moody listed the main features of an SDE as consisting of: changes in geometry (rooms may become somehow different in shape, or another reality might appear); the appearance of mystical light; hearing music and musical sounds; out-of-body experiences; co-living a life review (involving witnessing or experiencing a review of the life of the dying); encountering unworldly or “heavenly” realms; seeing a mist leave the body at death; and ineffability.^{8(p75-104)} Just as his earlier book *Life After Life*⁹ popularized the term “near-death experience” and gave readers a way to name their own experiences, so too did *Glimpses of Eternity* offer caregivers and loved ones a name for their own EOLP experiences.

Research has provided significant insight into the general content of end-of-life dreams and visions of the dying,¹⁰⁻¹² as well as the importance that dying persons often place on them.¹³ Healthcare professionals have become more aware that: EOLP generally have a positive impact on the dying process,¹⁴ although they may bring about existential crises for both patients and caregivers⁴; there is need for specialized training in working with individuals who report EOLP⁵; and EOLP are underrepresented in death education.² Given the impact that EOLP can have and the lack of information and education regarding them, it makes sense to further our understanding of them. This includes those EOLP reported by caregivers and loved ones of the dying, especially since we only have anecdotal accounts with which to approach them. Like the dying, caregivers and loved ones should be able to discuss, process, and integrate these experiences in a safe and supportive environment. Equally, bereavement professionals should be better informed about these experiences and their possible effects. In order to develop and incorporate “best practice” to accommodate these objectives, a better understanding of the types and effects of EOLP reported by caregivers and loved ones is first required.

Methods

This study draws upon first-person accounts of 164 shared death experiences, a type of EOLP in which caregivers and loved ones (and sometimes even bystanders) feel that they have participated in a dying person's transition to a post-mortem existence. SDEs are distinct from other kinds of EOLP reported by caregivers and loved ones, such as meaningful coincidences occurring at the moment of a death or premonitions of a death that occur via dreams or visions. The personal accounts informing this study come from 107 participants: 96 participants reported 1 or more SDEs with loved ones or acquaintances, 9 participants were professional caregivers who reported one or more SDEs with patients, and 2 participants were professional caregivers who reported 2 or more SDEs with both loved ones and patients. We did not restrict participants to those only reporting SDEs while in a normal, waking state because although many participants reported that their experiences occurred while dreaming, they added that these dreams had an intense clarity and were qualitatively different than other, “normal” dreams.

To learn more about features and effects of SDEs, as well as who reports them, we invited individuals who described feeling that they have participated in a dying person's transition to a post-mortem existence to participate in interviews from Winter 2018 to Spring 2020. Excluded from these interviews were 4 individuals who reported being professional psychic/spiritual mediums, 3 individuals who appeared to be heavy fantasizers, and 12 individuals whose experiences were not in close proximity to the time of a death. Interview protocol consisted of Kinsella and Peters using a semi-structured interview questionnaire to collect demographic information and to ask each

participant to describe: 1) their religious or spiritual history (including any introspective or contemplative practices) and whether they have had other anomalous experiences, 2) their relationship to individuals whose deaths they identified as catalysts for their experiences, 3) the circumstances and features of their experiences, 4) any effects they attributed to their experiences, 5) whether they had shared their experiences with others, and 6) whether there was anything else that they would like to say about their experiences. Interviews were recorded, and most were conducted through a remote conferencing service. There were a few exceptions to this format, as Peters conducted 4 interviews in-person. Recordings were transcribed and, together with original write-ups, coded for content. All individuals contributing to this study gave documented informed written consent. Demographic information is provided in Table 1.

Three researchers (Kinsella, Peters, and research assistant Noël Christensen) performed inductive content analysis on written reports and interview transcripts. To help ensure trustworthiness, this analysis consisted of a 3-stage process as outlined by Elo and Kyngäs: preparation—selecting basic criterion; organization—open coding, identifying recurrent features, and abstraction; and reporting—the content of categories.¹⁵ Inter-rater reliability was not utilized as the researchers were embedded in the research context, coding required little interpretation, and analysis was driven by participants' own interpretations of the data.¹⁶ Insofar as being embedded in the research, we should highlight that all participants initially contacted us to share their own personal accounts after they had determined that our prior work in EOLP effectively legitimized their experiences. Qualitative findings included the identification of features, contexts, effects, and participant assessments that were well represented throughout the data. 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. We compared the content and effects of experiences occurring at different times relative to the actual death and could find no differences.

Results

Of 107 participants reporting 1 or more SDE, 99 (92.5%) were Caucasian; 91 (85%) were women; 68 (63.5%) reported engaging in various kinds of introspective and/or contemplative activities (e.g., meditation, mindfulness, prayer, tai chi, yoga—some participants considered these activities to be humanistic or health-oriented rather than religious or spiritual); and 56 (52.2%) identified as being “spiritual not religious.” Furthermore, 87 participants (81.3%) were between the ages of 51-80 at the time they reported their experiences to us.

We found that the majority of SDEs—105 (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. Inductive content analysis revealed 4 distinct though non-exclusive participatory modes of an SDE: remotely sensing a death, witnessing unusual phenomena attributed to a death, accompanying the dying in a visionary realm, and assisting the dying in transitioning (see table 2 below). Inductive content analysis of reported SDE effects also revealed 3 major domains: changes in beliefs, the reconciliation of grief, and the perception of continued relational bonds with the deceased. Furthermore, every participant interviewed expressed gratitude for the opportunity to share their experiences and to learn more about SDEs. Descriptions and examples are provided below.

Remotely Sensing a Death

Remotely sensing the death of an individual characterized 34 SDE reports (20.7%). A total of 20 of these reports (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. Individuals also frequently reported having received messages imparting a final farewell. One participant shared the following experience, which occurred in the United States right before she received a phone call informing her of a childhood friend's death:

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.

Table 2. SDE Modes of Participation (Non-Exclusive).

MODE	DESCRIPTION	N = 164	%
Remotely Sensing a Death	Mental impressions or acute physical symptoms	34	20.7
Witnessing Unusual Phenomena	Visions and/or altered perceptions	145	88.4
Accompanying the Dying	Entering visionary realm w/ dying person	25	15.2
Assisting the Dying	Entering visionary realm w/ dying person & feeling that one is actively helping the dying person to transition	15	9.1

A total of 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. Some individuals reported knowing a physically distant loved one had died at this time, whereas others made this connection retroactively. One participant said:

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.

Witnessing Unusual Phenomena Attributed to a Death

A total of 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. A vision of the dying (typically described as appearing younger and more vibrant) was most common and occurred in 83 accounts (50.6%), followed by 41 accounts (25.0%) of the appearance of a transcendent light, 32 accounts (19.5%) of sensing energy, 31 accounts (18.9%) of alterations in time and space, 26 accounts (15.8%) of encounters with non-human beings and entities, 24 accounts (14.6%) of seeing light or material believed to be the spirit leaving the body, 22 accounts (13.4%) of the appearance or presence of previously deceased loved ones, and 20 accounts (12.1%) of visions of otherworldly or heavenly realms. Less common recurrent phenomena included 14 accounts (8.5%) of the appearance of tunnels or gateways and 7 accounts (4.2%) of life reviews in which individuals reported having witnessed past events in the lives of the dying.

One participant described a series of events that transpired at the deathbed of her husband:

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.

Accompanying the Dying in a Visionary Realm

A total of 25 accounts (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. Participants stated that while in these realms they had knowledge about reality that was otherwise inaccessible or indescribable. 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. One participant shared an experience she had at the time of her mother's death, which had occurred in a hospice across town:

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, 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.

Assisting the Dying in Transitioning

There were 15 SDE reports (9.1%) in which 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. One individual reported helping her ex-husband transition while she was watching a film in a movie theater:

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.

Changes in Beliefs, Attitudes, and Behavior

Participants reported a number of changes in beliefs, attitudes, and behavior arising from their SDEs (see table 3 above). These reports arose spontaneously during interviews, so the following numbers represent minimum figures. Most notably, 93 participants (86.9%) stated that their experience had left them absolutely convinced of the reality of a benevolent afterlife. One participant said:

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,

and it's all okay, too. I just wanted everybody to have the experience I had.

A total of 74 participants (69.1%) reported that their SDEs had ameliorated or even reconciled their grief. Nearly all of these participants additionally reported being at peace knowing that their loved ones were doing well. One participant said:

The experience gave me some peace that he was where he wanted to be and so instead of grieving for him, I can just grieve for my own loss. I can't pick up the phone and talk to him, but I don't grieve, because of what I felt and experienced . . . I can just be sad that my dad's not here and rest in the comfort that he's happy and taken care of and loved.

There were 56 participants (52.3%) who reported that their shared death experiences had alleviated or completely removed their fear of death and dying. One participant said:

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].

Participants routinely commented upon the impact of their SDEs, and 46 participants (42.9%) described their experiences in terms of having left a profound mark on what they perceived to be life's meaning or purpose. One participant said:

Everything I do today, all the intuitive work and all that, is a direct response to my [shared death experience] . . . I used to sell main-frame software . . . and my life is completely different because of it.

While there were 56 participants (52.3%) who identified as “spiritual not religious,” 39 participants (36.4%) declared that their SDE had resulted in them becoming “more spiritual.” A substantial minority—28 participants (26.1%)—identified as being Christian, though all expressed that their experiences had shaped their views on Christianity. One participant said:

I had settled at that time on Christianity, and was in the church when I had this experience . . . It's interesting to me that my belief

Table 3. Reported Major SDE Effects.

EFFECTS	DESCRIPTION	N = 107	%
Conviction of an Afterlife	Experiential knowledge regarding nature of the soul and a benevolent life after death	93	86.9
Reconciliation of Grief	Bereavement recontextualized by experiential knowledge that deceased persons are essentially “alive and well”	74	69.1
Loss of Fear of Death	Fears and anxieties surrounding one's own death lessened or disappeared	56	52.3
Renewed Purpose / Sense of Meaning	Changes in one's motivations and intentions	46	42.9
Movement Toward Spirituality	Align more with individual spirituality and less with institutional forms of religion	39	36.4

system in Christianity has really almost completely changed, and my recollection of my experience has not changed at all.

Continuing Bonds With the Deceased

A total of 26 participants (24.2%) reported having the perception of an ongoing relationship with a deceased loved one. The modes of communication in these relationships were described in various ways, the most common being direct mental contact. For instance, one participant shared the following:

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.

Individuals reporting ongoing relations with the deceased align with an aspect of contemporary grief counseling known as continuing bonds, which presents a model of grief whereby individuals redefine rather than terminate their relationships with deceased loved ones.¹⁷ Unlike earlier models of grief, the continuing bonds model views these ongoing relationships as normal and healthy, and it highlights the value in therapists remaining open to the ontological status of these relationships.¹⁸

Challenges Regarding Integration and Disclosure

A number of participants discussed facing various challenges arising from their SDEs (see table 4 above). Out of 107 participants, 37 (34.5%) reported sharing parts or all of their accounts with others. There were 31 participants (28.9%) who discussed having wanted to talk about their experiences but were afraid of social ridicule or rejection. One participant shared the following:

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.

A total of 21 participants (19.6%) also reported various struggles to navigate around the aforementioned sociocultural expectations surrounding grief and bereavement. One participant, a group leader for Helping Parents Heal, a bereavement support group, shared the following:

There's not a whole lot of people in my world that will openly talk about these kinds of things. And even the ones who are the leaders in Helping Parents Heal, a lot of them don't get any signs at all. So, I almost feel like if I talk too much about my experiences with my kids, that I'm bragging and I'm not bragging. I just feel like I have a particularly incredible connection.

Out of all participants, 16 (14.9%) recounted having received negative responses to the sharing of their experiences. For instance, 3 individuals stated that leaders in their religious communities had outright dismissed their experiences when shared; all 3 of these individuals subsequently struggled with their respective faiths. One individual even shared with us that both she and her mother experienced EOLP at the time of her husband's death, and that her mother had found the experience so bewildering that she eventually spoke to a psychiatrist and was subsequently administered an antipsychotic.

There were 5 participants (4.6%) who initially reached out to us because they were struggling to make sense of having experienced uncomfortable physical symptoms thought to correspond with those of a dying loved one. For example, one individual reported that while she thought she was having a heart attack, she kept seeing visions of a friend with "glassy, dead eyes" (she learned shortly afterward that this friend had died from a drug overdose at the time of her experience). Upon learning more about EOLP, particularly about other instances where people reported unusual physical symptoms at the time of death of a loved one, every one of these participants came to positively recontextualize their experiences as final farewells. In fact, nearly every participant in this study said that they wanted to learn more about EOLP and were pleased to have discovered that others had had similar experiences.

Gratitude for Opportunity to Share and Learn

Every interviewee expressed gratitude for the opportunity to share their stories and to discuss SDEs. One participant said,

Table 4. Challenges to Integrate and Disclose SDEs.

CHALLENGES	DESCRIPTION	N = 107	%
Social Ridicule	Scared of being viewed as mentally unstable	31	28.9
Breaching Bereavement Norms	Worried that lack of actively grieving would be viewed negatively	21	19.6
Dismissal	Anxious about specialness or sacredness of experience being dismissed or denigrated by others	16	14.9
Meaning Making	Struggled to process and integrate (frightening) experience	5	4.6

“It feels liberating to talk about this.” Another said, “I had never had anyone to even talk to about any of these events. I never had anywhere to go to for resources.” And one participant told us,

I am relieved and hopeful that a study like this can help create an environment where more people feel safe to talk about this kind of thing because it is so helpful to not just keep it to ourselves. We’re accustomed to living in a society that’s not accepting and very dismissive of this type of thing.

Discussion

Our review of the professional literature revealed our study to be the first to qualitatively analyze the contents of reports by caregivers and loved ones who have experienced a type of EOLP categorized as shared death experiences. Four participatory modes were identified, as were a particular set of recurrent features. We also noted a series of transformational effects of SDEs upon participants, the most prevalent being the conviction that the experience was objectively real and that it had disclosed special knowledge that deceased loved ones are, in the words of one individual, “alive and well somewhere.” This special knowledge effectively operates as a modern-day revelation: the majority of participants reported having shifted their worldview in order to accommodate their experiences. We learned that many participants are hesitant if not fearful of sharing their experiences with others. And we gained significant insight into the therapeutic value of people being supported and encouraged to discuss their experiences.

Every one of our participants initially contacted us after having come across our presentations, media appearances, or our website, all of which are sympathetic to and outline a range of EOLP. Hence, there is an obvious self-selection bias in our study. However, given the anxiety and trepidation that several participants reported in relation to sharing their stories, as well as the relief that participants reported having upon feeling safe to discuss their experiences with sympathetic professionals knowledgeable about SDEs, a random and completely unbiased study of multiple shared death experience narratives seems at present highly improbable. Though our study has a self-selection bias, we nonetheless believe that this is a requisite “first step” toward raising awareness about SDEs within hospice and palliative medicine.

Contrary to published summaries of anecdotal accounts of shared death experiences gathered by others, we found that the majority of SDEs (105 or 64.0%) were reported by individuals who were physically distant from the dying patient or loved one at the time of death. We assume that earlier summaries were heavily influenced by Barrett’s *Deathbed Visions*, which emphasized those experiences reported at the deathbeds of patients and loved ones. Some of our participants reported having searched for accounts similar to their own but were unable to find anything that offered a “name”

for experiences that transpired some physical distance away from the dying.

Out of the 164 SDE accounts we reviewed, 41 (25.0%) occurred when participants were falling asleep, waking up, or dreaming. Participants who reported SDEs in these contexts routinely struggled to articulate the unique qualities of their experiences and sought to differentiate them from other kinds of sensory experiences previously encountered in these states: terms such as “coherence,” “clarity,” “hyperreality,” and “significance” were commonly used. While some participants remained uncertain as to whether the entirety of their SDEs had unfolded in a hypnogogic, hypnopompic, or dream state, others declared that their experiences were distinct from these states.

Women comprised the majority of participants (85.0%) reporting SDEs. Perhaps this is because women tend to be the caregivers at end of life, and this role seems to invite connection and bonding with the dying person. Or perhaps women are generally better than men at empathizing with others’ emotional states.^{19,20} Studies do suggest that women tend to be more inclined toward a relational form of spirituality.^{21,22} Additionally, men might be less inclined or willing to publicly admit that they have had these kinds of experiences. In terms of age distribution of individuals reporting SDEs, we captured only the ages of people at the time that they reported their experiences to us, and several individuals shared experiences they had had years ago. The majority of individuals interviewed were baby-boomers, and it may be considerably relevant that boomers are more likely than other generations to affirm a link between spirituality and personal experience.^{23,24} The strong bias toward Caucasian participants (92.5%) might be due in part to new age spirituality being one of the only popular interpretive frameworks to highlight end-of-life experiences as spiritually transformative events.²⁵ New age spirituality is non-exclusive in membership,²⁶ though adherents tend to fall within the category of “Unaffiliated (religious “nones”),” of which 68% identify as Caucasian.²⁷ It remains unclear as to the distinctions (if any) between the 12 participants (11.2%) who identified as having no religion (“none”) and the 56 participants (52.3%) who identified as “spiritual not religious.” But religious affiliation of participants in our study (39 participants or 36.4%) is well below the national average, which stands at around 76%.²⁷

A total of 44 participants (41.1%) reported having had 2 or more SDEs, and 85 participants (79.4%) reported experiencing additional kinds of death-related phenomena. The degree to which intrapersonal, interpersonal, intragroup, and intergroup forces have an effect upon the reporting of SDEs remains underexplored.²⁸ It remains uncertain whether there is a personality type more predisposed to an SDE/EOLP or whether the effects of an SDE/EOLP make an individual more prone to additional experiences.

Finally, of particular note is that 3 individuals reported having an “early” SDE with a loved one on life support and, following information acquired during the experience, made

the decision to remove their loved one from life support. These behaviors raise the question of whether clinical engagement of EOLP could inform trajectories of care.

Limitations of Study

Most of the participants in this study were from the United States, though we also had participants from Spain, Scotland, England, New Zealand, Australia, Norway, and Canada. Nearly every participant reached out to us after having come across our work, and so there is an obvious self-selection bias in our research. It is crucial to keep in mind that participants sought us out to share their experiences in a safe and supportive environment, and to learn more about their own experiences. More information on the prevalence and kinds of EOLP reported by other populations is needed. SDEs and other kinds of EOLP are likely experienced by caregivers and loved ones throughout the world, but we know relatively little regarding how these experiences are described, let alone the degree(s) to which these experiences are valorized or deprecated within different sociocultural groups. We assume that these experiences remain underreported in modern Western culture due to personal concerns that these narratives will be dismissed, discounted, or disparaged.

Conclusion

This study demonstrates the existence of a particular kind of EOLP experienced directly by loved ones and caregivers, including healthcare professionals: shared death experiences. These experiences may occur either at or apart from the bedside of the dying, and they may occur before, during, or after a death. SDEs occur via one or more of the following participatory modes: remotely sensing a death, witnessing unusual phenomena attributed to a death, feeling that one has accompanied the dying during their transition to a post-mortem existence, and feeling that one has directly assisted the dying in transitioning. Major recurrent phenomenological features of these experiences include encounters with the dying, previously deceased loved ones, and other presences; the appearance of a transcendent light; alterations in the environment; seeing what is believed to be the spirit leave the body; and visions of otherworldly realms.

Individuals reporting shared death experiences often view their relationship with the deceased not as having ended but rather as continuing and sometimes even evolving, which might help account for the fact that a number of individuals additionally report having had post-death communication. However, the reconciliation of grief that can arise from processing and integrating these experiences as interpersonal spiritual events may be stunted or interrupted if a supportive open dialogue is thwarted. It is one thing for individuals to be without any support; it is quite another for healthcare professionals—including spiritual counseling and mental health—to dismiss, discount, or disparage these experiences as mere fantasy, delusion, or pathology. But both lack of

support and disparagement can be successfully addressed through education in end-of-life care.

We believe that at present, hospice and palliative medicine does not fully acknowledge or understand that caregivers and loved ones do experience EOLP, which can be deeply significant, and which may require help in processing. Our study revealed a need to provide positive support for caregivers and loved ones reporting EOLP that allows for a healthy and complete integration of these experiences. Undoubtedly, this need will take time to be fully understood and met. As a beginning we suggest end-of-life workers become better informed about these experiences, hence the need for more studies. At a minimum, it is imperative to extinguish all uninformed and negative responses by healthcare professionals regarding those EOLP reported by caregivers and loved ones. In best case scenarios, healthcare support in validating and integrating these EOLP experiences will add to the breadth and quality of psychological, spiritual, and bereavement care mandated by core measures in the field of hospice and palliative care.

Author's Note

Individual contributors to the present article include Michael Kinsella, PhD, SCRI Chief of Research, Monica Williams, MD, SCRI Medical Director, and William Peters, MFT, SCRI Founder and Executive Director.

Acknowledgements

SCRI thanks Janice Miner Holden, Pim van Lommel, Bruce Greyson, and Peter Fenwick for their input; SCRI also thanks every participant for sharing their personal stories.

Declaration of Conflicting Interests

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

Funding

The author disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study was funded by the NoVo Foundation, the J.S. Bower Foundation, and the Natalie Orfalea Foundation. Funders had no role in the study design, collection, analysis, interpretation, writing, or decision to submit this article for publication.

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