End-of-Life Dreams and Visions in Pediatric Patients: A Case Study

Kathryn Levy, MSW, AdvStat, Pei C. Grant, PhD, and Christopher W. Kerr, MD, PhD

Abstract

Background: End-of-life dreams and visions (ELDVs) are a recognized phenomenon that can occur as part of the normal dying process. Data suggest that ELDVs can provide comfort, foster discussion of waking life concerns, and lessen the fear of death. Current literature on ELDVs focuses on the prevalence, content, and effects of ELDVs exclusively in adult populations.

Methods: We present the case of a 15-year-old girl with terminal glioblastoma who was enrolled in a pediatric palliative care program and later in hospice care. During her end-of-life trajectory, the patient experienced two distinct ELDV experiences, from which she recalled vivid details regarding the setting, characters, and content. These ELDV experiences afforded comfort and meaning to the patient and her family through her end-of-life trajectory as well as provided relief for her grieving family.

Conclusion: In the case presented, ELDVs appear to show similar characteristics and impact in the adolescent population as described in the previous literature examining adult ELDVs. In addition, this case demonstrates the potential benefits of ELDV awareness for the bereaved. Clinicians working with pediatric and adolescent end-of-life populations should take note of the potential for ELDVs and the impact they can have on both patients and families.

Keywords: adolescents; children; dreams; end of life; end-of-life dreams and visions; end-of-life experiences; hospice; palliative care; pediatric

Introduction

In the current medical model, perspectives on the dying process are heavily focused on physical symptomatology. Experience from the patient perspective may encompass less observable phenomena, including subjective experiences such as end-of-life dreams and visions (ELDVs). ELDVs have been noted throughout history, are often described as vivid and memorable,1–3 and can occur in both sleeping (dreams) and waking (visions) states.1,3–11 ELDVs have been shown to comfort the dying by providing meaning while addressing existential and spiritual concerns.1,6 The literature on ELDVs emphasizes that such experiences are separate from states of cognitive dysfunction such as delirium, dementia, and other neurological or psychiatric disorders.1,8,9,11–13 This distinction is of utmost importance, as ELDVs have historically been dismissed as an effect of these cognitive states,12 causing fewer individuals to report these experiences in fear of judgment and ridicule.14 In reality, the incident rate of ELDVs is variable and may be up to 88.1%,1,15,16 with common themes, including dreams of deceased and/or living loved ones and travel.3 Recent research has expanded beyond prevalence and content of ELDVs and has begun to explore the deeper impact of these events on both patients and their loved ones. Individuals who have experienced ELDVs exhibit greater psychological gain in the form of post-traumatic growth compared with those who have not.17,18 The experience of ELDVs can impact the process of working through grief (as outlined by Worden), specifically the ability of the bereaved to accept loss, work through emotional pain associated with loss, adjust to a new reality, and maintain a connection with the deceased.19,20

No research has previously been conducted on ELDVs in the pediatric population. Although children and adolescents process the experience of illness and impending death in ways that are distinct from adults, they still contend with existential and spiritual concerns that can be difficult for them to express.21,22 Anecdotally, children also experience ELDVs, which are not only meaningful and comforting but also may help lessen the fear of dying. This article describes the case of a pediatric palliative care patient and the impact of her ELDVs on both the patient and her family.
Case Description

Ginny* was a 15-year-old girl who was diagnosed with leukemia at age four. Although her disease went into remission after aggressive treatment, she suffered physical and neurological consequences, including stunted growth and developmental delays. Another sequela of her earlier treatment was the diagnosis of a glioblastoma at age 14. As her disease advanced, she eventually was admitted to a pediatric palliative care program and later to hospice care.

During the course of illness, Ginny described two distinct ELDV experiences to her family and clinical team. Her first vivid ELDV experience occurred while in an MRI machine, during which she described being in a “deep sleep” (see Supplementary Video S1). Leading up to this experience, Ginny’s mother, Michele, noted “I thought she was dying then I was ready to call hospice.” After the MRI, Michele was amazed by Ginny’s change in disposition. She described Ginny as, “wide awake, as if nothing had ever happened” and asked, “Ginny, where have you been!” With exceptional detail, Ginny recounted a dream in which she was playing dolls and singing songs with her deceased aunt. She described being in a beautiful castle filled with warmth and light. Adorning one of the walls was a stained glass window depicting “a baby and you can see the sun through it.” In her own words, Ginny described the castle as a safe place, and emphasized that she was not alone. In addition to her aunt, the castle was also populated with numerous family pets (now deceased) that now appeared alive, healthy, and playful. The castle also included a pool; swimming had been an activity she had enjoyed before her decline. Upon waking from sleep, Ginny found immediate meaning from her ELDV experience, telling her mother, “I’m going to be okay, I’m not alone.” Ginny’s ELDV experiences continued for several months, the frequency and meaning of her dreams intensified with repeated visits from her deceased aunt and pets. For Michele, Ginny’s dreams initially left her with “the weirdest feeling ever. I don’t know how to explain it,” noting that each aspect felt so realistic that there was “no choice but to believe.”

Four days before her death, the content of Ginny’s ELDVs changed and would profoundly influence how she and her loved ones would experience her dying process (see Supplementary Video S2). On what had been a quiet afternoon, Michele heard an animated conversation through a baby monitor that was kept beside Ginny’s bed. When Michele asked Ginny who she was talking to, Ginny responded, “I was talking to God.” She added “He’s old, but he’s kinda cute.” She said to her mother, “I’m not going to be sick, you know... where I’m going. You know... to the castle.” Ginny’s conversation with God also addressed her concerns as to whether her family would be able to join her when their time came. She was especially worried about her father, who had denounced God and Catholicism in light of his daughter’s terminal diagnosis. These deep fears were relieved as Ginny relayed that God had assured her that, when it was time, her whole family would be able to come to the castle, including her father.

In the days before this experience, Ginny had been agitated and calling for her mother multiple times an hour. After sharing her ELDV, her nails and toenails to match her “goodbye” dress. Subsequently, Ginny drifted comfortably asleep until death.

For Michele, Ginny’s ELDVs provided meaning, acceptance, and solace (see Supplementary Video S3). It was Ginny’s comfort that allowed Michele to recognize the inevitable and address the unimaginable task of making funeral arrangements. Even today, Michele reflects on the meaningfulness of bearing witness to Ginny’s experiences: “I hear her in the back of my head all the time talking about the castle and that she’s waiting for me there.” Michele revisits the ELDVs often, adding, “now when it rains out I kiddingly tell her ‘would you stop jumping in your pool, Ginny?’” Michele believes that Ginny is now healthy “with blonde hair down to her butt,” surrounded by family and her beloved pets, and safe in her beautiful castle.

Discussion

When facing serious illness, children are confronted with an unimaginable reality for which both context and language are limited. As they struggle with illness, they also have to cope with fears around death, including existential questions that are challenging to communicate and equally difficult for clinicians to answer. In this patient population specifically, one could argue that the management of the physical symptomatology is often secondary to the challenge of lessening psychogenic and spiritual distress. As the aforementioned case illustrates, ELDVs may provide comfort and meaning in the pediatric population, while also reducing fears around death.

With Ginny’s case, the content and significance of ELDVs closely resemble what has been extensively reported on in adults.1,3,4,6-9,23 Similarly, Ginny’s experiences occurred at times of both wakefulness (visions) and sleep (dreams). She described her ELDV experiences with vivid detail and clarity. Deceased relatives and pets were present, as well as known religious figures, which coincide with other studies on ELDV content.1,3 Ginny also spoke of somatic experiences within her ELDVs, such as the feeling of “warmth” when describing sunshine and light. The psychological and spiritual impacts of Ginny’s ELDVs were equally powerful. Ginny’s feeling of reassurance was evidenced by statements such as I was ‘made to feel safe,’ and ‘I will be loved and not be alone.’ She was also able to remember her ELDVs far beyond their occurrence and with each telling would feel solace, security, and joy. In this way, ELDVs were accessible and their effect sustained. Ginny also relayed these events with absolute confidence and without fear of judgment or ridicule, even welcoming the opportunity to be interviewed and filmed on multiple occasions as part of an ongoing effort to normalize these experiences. It is also of note that Ginny’s inner experiences did not deny the inevitability of her death but seemed to transcend it.

For adults with terminal illness, ELDVs have been conceptualized as a means to work through waking life concerns while psychologically preparing for death.9,24 Earlier studies have shown a temporal change in ELDV frequency and content as patients approach death.7 Ginny’s ELDVs also reflected what was most salient in her waking life and changed thematically in correspondence with her proximity to death. Her initial dreams began when Ginny was first confronted with the reality of a terminal diagnosis. As her disease progressed, her concerns began to focus on an existence without the

*Patient’s mother provided written consent to utilize names of both patient and mother.
presence of living loved ones. In their absence, Ginny dreamed of a new reality, secure in a castle and surrounded by deceased animals and people she had loved and lost. Within days of dying, her ELDVs began to incorporate spiritual and religious meaning, which further eased her dying process and reassured her family that Ginny was at peace and cared for.

The management of children in particular never occurs in isolation but in the context of those they leave behind. In this regard, ELDVs are meaningful to the bereaved as noted by Michele. Describing her grief experiences, she notes, “when I’m having a moment of that heart-crushing, wanna-cry feeling, I picture her in that castle and I’m okay.” This experience is comparable with what is known about how ELDVs affect the grieving process.19 The bereaved often report a sense of relief if their loved one experienced comforting ELDVs, with the level of caregiver relief mirroring the level of patient comfort. For Michele, the most pronounced effect of Ginny’s ELDVs is their role in maintaining and strengthening the bond between mother and daughter. She notes, “Ginny is more with me now than she was when she was here.”

Good end-of-life care requires acknowledgment of nonphysical states, including ELDVs. Experiences such as these are easily overlooked or dismissed as alterations in cognition, including delirium. Yet, for the pediatric patient and their loved ones, ELDVs represent a therapeutic opportunity to provide comfort and meaning while lessening the fears around death. In this particular case, Ginny’s dreams were validated by those around her as meaningful experiences, creating the described environment at the end of life. Her death could have been distinctly different if her mother and clinical team simply dismissed her ELDVs as side effects to her diagnosis. Although larger studies have not been conducted on the ELDVs of children and adolescents, it does not make the experience any less salient. ELDVs provide an opportunity to integrate physical, psychological, and spiritual support. Clinicians working with this terminal population must take special care to explore ELDV experiences and recognize their potential impact on terminally ill children, adolescents, and their families. In the words of Michele, “Medical doctors out there need to have a little more compassion and belief when it comes to dreams and visions. Listen to patients when they are talking about dying, death, and dreams. They need to believe them.”

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Supplementary Material

Supplementary Video S1
Supplementary Video S2
Supplementary Video S3

References


Address correspondence to:
Kathryn Levy, MSW, AdvStat Palliative Care Institute Center for Hospice and Palliative Care 225 Como Park Boulevard Cheektowaga, NY 14227 E-mail: klevy@palliativecare.org