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An Ephemeral Light:

The Question of Death in the Artwork of Children who are Dying

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Abstract

The question of death, and what happens after, is a query with no certain answer. Philosophers, scientists, artists, poets, and healthcare providers have grappled with the question of death and how best to answer it. Children with life-limiting illnesses (LLI) who face death in childhood are in a unique situation where their typical sources of information (i.e., the adults in their lives) may not be able to come up with a suitable answer when asked what happens when we die. As Plato stated, there is an inner child in all of us who is not totally convinced by assurances of an afterlife. What children with LLI understand of death and dying is not always easily conveyed in everyday language but can be revealed in their artistic forms of expression. Artwork, poetry, and stories seem to carry the unintelligibility of death so that both children and adults may cope with it.

Keywords

children, life-limiting illness, understanding death, pediatric palliative care, hermeneutic philosophy

For children with life-limiting illnesses and conditions (LLI), their families, and their pediatric palliative care (PPC) providers, death in childhood is a present and looming threat. The experiences of children who are dying are not well researched (Ghirotto et al., 2018; Rahimzadeh et al., 2015); however, the artistic expressions of children with LLI that are featured in scholarly literature (e.g., examples of drawings from therapy sessions) and in the humanities serve to

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illuminate what such an experience may be like. The drawings and poems that are featured in this paper are some rare examples of the art of children with LLI who are now deceased. Their creations are not bound by the temporal and physiological limits of human beings, and their art is the stable and lasting form of their fleeting experiences, ready to be viewed by those who wish to understand (Gadamer, 1986). Hermeneutical interpretation of art has the quality of an encounter or experience, rather than a focus on taste or beauty, in which the viewer and the artwork engage in a kind of conversation that can lead to a different understanding of what is presented in the work (Gadamer, 1986).

My thesis work focuses on understanding the experiences of children who are dying through their artistic forms of expression. Children with LLI, especially young children and children with developmental delays, may face concepts and experience events that they do not have the vocabulary to articulate with words alone (Aasgaard & Edwards, 2012; Kramer, 1971; Sourkes, 1991, 2018). PPC teams often include child-life and art therapists who utilize arts-based therapies to facilitate communication and understanding with children, to assess coping skills, and to allow children the opportunity to express themselves in a safe and non-judgemental way (Aasgaard & Edwards, 2012; Councill & Ramsey, 2019; Devlin, 2006; Jones & Weisenfluh, 2006; Sourkes, 1991, 1995, 2018; Sourkes et al., 2005). This paper was part of my doctoral candidacy examination and was written in response to the following statement and question: *In examining the topic of the artistic expression of children who are dying, you have indicated that sometimes children may not have the language through words to express what they are thinking or feeling but they do have other forms of expression. Is the difference in expression due to lack of words or connected to the unfathomable experience they are undergoing?* In experiencing the artwork of children who are dying, both in my practice as a pediatric hospice nurse and in my scholarly undertakings, I have come to understand that, concealed in seemingly naïve and innocent words and images, is the ungraspable, unfathomable character of death. Perhaps it is not always the case that children lack the vocabulary to express their experiences of dying, but that death itself presents all human beings, young and old, with the unsayable and the unthinkable.

Children's Understanding of Death Revisited

The literature on children's understanding of death has focused on developmental theory and standardized ways in which children come to a mature concept of death. The PPC literature has indicated that children who face LLI may not yet possess the vocabulary necessary to express their feelings, experiences, and concerns about death and dying, as they are encountering these life events earlier than what is typical for their developmental stage (Aasgaard & Edwards, 2012; Buckingham, 1983; Councill & Ramsey, 2019; Devlin, 2006; Rollins, 2005; Sourkes, 1995, 2018a, 2018b). Spinetta et al. (1973) indicated that children's awareness of death may precede their ability to talk about it, and that a child who is dying may understand that they are going to die before they are able to verbally express it. How a child with LLI understands death may affect the language they use to communicate their experiences of dying to their adult caregivers (Buckingham, 1983; Spinetta, 1975; Sourkes, 1995; 2018a, 2018b). Young children may equate death with a reversible separation, sleep, or the continuation of life under changed circumstances or form (Bluebond-Langner et al., 2012; Koocher, 1973; Nagy, 1948/1959; Slaughter & Griffiths, 2007). Children between the ages of five and nine years may view death as a personified being, such as a skeleton or the Grim Reaper (Nagy, 1948/1959). Between six and 10 years of age,

children demonstrate an "adult," "mature," or "complete" understanding of death as inevitable, universal, irreversible, and caused by illness or injury that results in the cessation of bodily functions (Bluebond-Langner et al., 2012; Glicken, 1978; Ellis & Stump, 2000; Slaughter & Griffiths, 2007; Speece & Brent, 1984).

Children's understanding of death as described in developmental theories have provided a significant foundation for research and practice in PPC, informing when and how children with LLI should be involved in decision-making (Bluebond-Langner et al., 2012; Buckingham, 1983; Larcher & Carnevale, 2012), in research (Ghirotto et al., 2018, Rahimzadeh et al., 2015), and whether the diagnosis of LLI should be disclosed to a child (Buckingham, 1983; Larcher & Carnevale, 2012; Stein et al., 2019). However, developmental theories have also been used to justify non-disclosure of illness or impending death for both children with LLI and their siblings (Matthews, 1989). For some adults facing the unspeakable character of pediatric death (Rallison & Moules, 2004), it may be comforting to think that a child who is dying does not understand the severity of their circumstances (Matthews, 1989); as William Wordsworth (2014) wrote, "A simple child . . .that lightly draws its breath, and feels its life in every limb, *what should it know of death*?" ("We are Seven," para. 1, emphasis added).

A mature understanding of death that includes a conceptual grasp of irreversibility, inevitability, universality, causality, and non-functionality is a demonstration that one can describe a biological account of death. According to Gadamer (1996), the "second Enlightenment" that emerged as a result of advancements in the natural sciences has also brought about a "demythologizing of death" (p. 61). To maintain that describing the physiological facts of death is enough to shape one's understanding of it is an oversimplification that neglects to consider the cultural, theological, or philosophical foundations for the understanding or meaning of death that many children and adults ascribe to (Kenyon, 2001; Speece & Brent, 1984). The developmental approach to children's views of death assumes that there is such a thing as an "adult" concept of death (Kenyon, 2001). While developmental frameworks can be useful and informative for practitioners who regularly encounter children who are dying or bereaved, children's reportedly immature understanding of death is often one that is shared with adults. When one considers how death appears in art, holy texts, and literature that are created by, and often for, adults, the concept of death frequently reverts to its supposedly childish origins.

The History and Tradition of Death in the Arts and Humanities

One's understanding of death is informed by the history and tradition, the handed down meaning relations that structure one's understanding of the world, into which one is thrown at birth (Gadamer, 1960/2004). In the history of Western thought, what someone believes about death may be informed by an explanation of physiological death as found in the natural sciences, while for others it may be situated in the tradition of the humanities or theology. The modern Western tradition has also repressed the topic of death in conversation, emphasized the prolongation of life through artificial means, and removed death from family homes to institutions, culminating in a gradual removal of death from everyday life (Buckingham, 1983; Gadamer, 1996). The disappearance of death in society has limited the opportunities for children to witness and experience the death of others, which may have contributed to children's incomplete or immature understanding of death as it appears in developmental and PPC literature. Children's views of

death may also be influenced by the history and tradition found in art and the humanities, as these disciplines have the quality making visible the subjects that matter to humans (George, 2020).

Figure 1
Klimt, G. (1910-1915). *Death and life* [Painting]. In the public domain.

Figure 2
Stokes. M. (1908) *Death and the maiden* [Painting]. In the public domain.

Adult artists and authors have frequently utilized an embodied being as a symbol of death in literature and art. Klimt's *Death and Life* (1910-1915, Figure 1) and Stokes's *Death and the Maiden* (1908, Figure 2) both feature personifications of death as a menace to the living. Klimt's painting denotes a clear separation of death from a group of sleeping, intertwined, humans flushed with life. In the Brothers Grimm fairy tale *Godfather Death* (2002), Death presided over thousands of candles, representing the lives of humans, as they burn and extinguish. Perhaps the

personification of death in Nagy's (1948/1959) investigation of Hungarian children reflected the ways in which children interpret death as it appears in art and literature, especially fairy tales aimed at teaching a moral or lesson to children, rather than a pre-mature concept of biological death.

According to developmental theory, people over the age of five years should understand that death is different from ordinary separation, that it is not the continuation of life in an alternate form, and that it is irreversible. However, in his *Theology of the* Body, Pope John Paul II (2005) described the resurrection as a reunion of the soul and body: "The resurrection is not only a manifestation of the life that conquers death . . . but it is also a revelation of the ultimate destiny of man in all the fullness of his psychosomatic nature" (p. 183). In Plato's *Apology* (ca. 399 B.C.E./1954), Socrates stated,

> Death is one of two things. Either it is annihilation, and the dead have no consciousness of anything, or, as we are told, it is really a change: a migration of the soul from this place to another. Now if there is no consciousness but only a dreamless sleep, death must be a marvelous gain. (40c)

In these texts, death might be considered the continuation of life in an altered form or in a different space. Death might be like sleep, it might be a separation of the soul and body, sometimes with the opportunity to reunite with one's body in the afterlife. Socrates readily admitted his own ignorance of death in *Apology* (Gosetti-Ferencei, 2014; Plato, ca. 399 B.C.E./1954), despite his adamant defence of "evidence that the soul is deathless" in *Phaedo* (Plato, ca. 360 B.C.E./1954, 114d). Moreover, it is the inner child of the adults in *Phaedo* who require reassurances for the immortality of the soul (Gadamer, 2016; Plato, ca. 360 B.C.E./1954); as Cebes remarked, "Suppose that we are afraid Socrates, and try to convince us. Or not so much that it is our true selves who are afraid – perhaps there is a child with this kind of fear hidden in us too" (77e). If historical leaders of thought and faith did not, or could not, offer a "mature" concept of death, to conclude that children's views of death are pre-mature or incomplete is unwarranted.

Death anxiety in adults may compel them to shield children from death, under the pretext that it may be "too much" for them (Buckingham, 1985); however, in these situations, it may be the adult who is protecting themselves from facing the unintelligibility of death (Bluebond-Langner, 1978; Matthews, 1989), for no matter the circumstances that one is born into, a genuine understanding of death itself is beyond the limits of human experience (Gadamer, 1996, 2016; Heidegger, 1927/1962). On understanding death, Gadamer (1996) offered,

> . . .we can ask ourselves when is it that a child learns to grasp the fact of death. I am not sure if modern psychology is able to give any sort of clear answer to this question which would be acceptable to the enlightened society of our culture. Presumably it is bound up with that interconnection . . . between life and the repression of death that the knowledge that we ourselves must die remains almost veiled, even when, as mature adults, this knowledge has become established at the deepest inner level within us. (p. 65)

The differences between mature and immature concepts of death become secondary considerations when one contemplates whether an understanding of death itself is possible for human beings. Death is not, strictly speaking, an experience or event that one can encounter and relate back to a meaningful whole of life (Gadamer, 2016). While developmental frameworks for children's views of death may be useful in practice, the focus on the sequential evolution of children's understanding of death fails to address how human beings might comprehend a situation in which they no longer exist. The distance between adult and child horizons of understanding, and all the life experiences that unfold in between, may explain the level of sophistication with which children and adults can discuss or theorize death. However, when it comes to the question of death itself, children and adults are equally unexperienced; as Rilke (1923/2009) said of death, "We know nothing of this going. It excludes us" (*Enter Death I*, para. 1).

Death as an Unanswered Question

Mattie Stepanek (1990-2004) was a child poet who died of autonomic mitochondrial myopathy, a progressive, neurodegenerative disease that causes complications such as seizures, muscle weakness, and heart failure. He was predeceased by two siblings with the same LLI, and wrote several poems about bereavement, living with LLI, his experiences with hospitalization, and dying. Stepanek was a child who was able to frame his experiences in poetic language, and his poems speak to the unintelligibility of death. In his poem *Unanswered Questions*, following the death of his brother, Stepanek wrote, "I know why he died, but I also don't know why" (Stepanek, 2001, p. 31). The simultaneous knowledge and ignorance of death highlights the distinction between a child's ability to *explain* death as a physiological fact and their *understanding* of death as an "existential-ontological" perplexity (Heidegger, 1927/1962, p. 280). The artwork of children who are dying express that, like adults, children grapple with the unintelligibility of death. As the title of Stepanek's poem suggested, questions of what death is, when it reveals itself, and why it must occur have no answers (Gadamer, 2016).

Traces of Death

Death is a fact of life that conceals itself in everyday living. Heidegger's (1927/1962) extensive examination of human being-in-the-world, which he called *Dasein*, is self-evident and universal, while simultaneously veiled in an *a priori* enigma in "the fact that we already live in an understanding of Being" (p. 23). *Dasein* is always "ahead-of-itself" and continuously projecting its being into a future in which death is certain (Heidegger, 1927/1962, p. 279). Heidegger (1927/1962) maintained that *Dasein* can either evade death by situating it as a "not-yet" possibility (p. 303), or *Dasein* can realize death as "the possibility of the impossibility of existence" (p. 307) and use the prospect of non-being to inform the present. Ricoeur (2009) wrote that any answers we may have regarding the survival of the dead in the afterlife are connected to a "question not called into question" (p. 10), and all responses are answers to a question posed by survivors, concerning the state of those already deceased. Gadamer (2016), wrote that death is always necessarily concealed in its unintelligibility: Being cannot even *think* death, let alone face it as life's most extreme possibility (J. Grondin, N. Keane, & J. Risser, personal communication, April 25, 2021). For Gadamer, one can merely grasp "a trace of death" (2016, p. 69) when thinking of it, for there is something incomprehensible about the fact that a

being who can anticipate the future will one day cease to exist (Gadamer, 1996, 2016). These traces come into sharp focus when one experiences the death of the Other, as death always leaves an impression on those who remain, along with the reminder that it is *there*. In his poem *Rebecca's Reminder*, Stepanek (2001) wrote:

> It is sad
> When a friend
> Dies.
> Death becomes
> Suddenly
> Painful.
> Suddenly
> Real.
> Suddenly
> Reminding.[1]

The abrupt reminder that being is finite, that non-being is a real possibility at any time and not simply a perpetual-not-yet, is the anxiety of being anxious about nothing, or a "no-thingness" as far as empirical objects are concerned (N. Keane, personal communication, September 24., 2021): it is "the uncanniness of being anxious about nothing is precisely the true anxiety" that is often concealed by one's certainty of being alive (Gadamer, 2016, p. 69; Heidegger, 1927/1962). It is conceivable that the facts of physiological expiry is also a trace of death for those who survive the deceased person: It is the inevitable, universal, irreversible state of the non-functionality of the human body, that allows the bereaved to state, "I know why he died," while simultaneously leaving no reassurances for when one correspondingly acknowledges "I also don't know why he died" (Stepanek, 2001, p. 31).

The Uncertainty of Life in the Face of Life-Limiting Illness

Figure 3
I don't know which side of the rainbow I am on. From "Food, Toys, and Love: Pediatric Palliative Care," by Sourkes et al., 2005, *Current Problems in Pediatric and Adolescent Health Care, 35*(9), p. 370 (https://doi.org/10.1016/j.cppeds.2005.09.002). Copyright 2005 by Elsevier. Reprinted with permission.

Life-limiting or life-threatening illnesses leave traces of death. A drawing of a rainbow by a seven-year-old girl (Sourkes et al., 2005, Figure. 3) waiting to hear if her cancer had relapsed is an example of art that children with LLI create in PPC practice (Sourkes et al., 2005). According to Sourkes et al. (2005), the girl drew a series of rainbows as she waited for her results. The rainbow cuts through the middle of the page, between a sun on one side and dark flecks on the other. Gadamer (1986) wrote that the language in which images speak is a speechless language, though not in the sense that an image has nothing to say. There is a presented world in an image, one that summons language to re-present what is shown in words; it is a disclosure of "the matter at issue or the thing that is meant" (Gadamer, 1986; Risser, 2019, p. 4). For the girl who was awaiting her test results, her rainbow allowed her to summon the language to disclose: "I don't know which side of the rainbow I'm on."

Viewed interpretively, one could begin to understand the experience of residing in the liminal space between the enigma of health and its counterpoint in the actuality of illness, as the character of health is most apparent in its absence (Gadamer, 1996). It may be that she would not have concerned herself with the other side of the rainbow if the status of her health had not been in question. In health and in everyday living, "our own impermanence is concealed from us" (Rilke, 2009, *The Impermanence We Are*, para. 1), but when one is presented with a possibility or certainty of illness, one's ephemerality is felt (Gadamer, 1996).

Sourkes (1995) commented that even if a child has not concluded that their illness will result in their death, they may express an awareness that their life is in jeopardy or their uncertainty about living. In *Tombstone* (Sourkes, 2018a, p. 4), a boy drew a picture of himself lying in bed with a thought bubble of a grave inscribed with "R.I.P" above his head and stated: "When I'm just lying in bed in the hospital and in pain, this [the drawing] is what I'm thinking about" (Sourkes, 2018a, p. 4). The boy expressed his concern over the possibility of dying from his illness without ever saying the word death, for he said "this," the drawing, and not "dying" was what he had thought about. In the uncertain space between terminal illness and health, the threat of death "becomes suddenly real, suddenly reminding" (Stepanek, 2001, p. 37). The child hidden in the human being that is not convinced of any claims to knowledge or understanding of death (Gadamer, 2016; Plato, ca. 360 B.C.E./1954) expressed their uncertainty in Stepanek's poetry and in drawings of rainbows.

Figure 4
Hirémy-Hirschl, A. (1898) *Souls on the banks of the Acheron* [Painting]. In the public domain.

If one cannot think of death, it would follow that scientific or conceptual language cannot adequately carry the unfathomable character of non-being: Scientific and theoretical language are one's mode of relating to the world-that-is. Even Hermes, the messenger god after whom hermeneutics was named (Grondin, 1994; Moules et al., 2015), offers no words on death for mortal souls to interpret in Hirémy-Hirschl's (1898) *Souls on the Banks of the Acheron* (Figure. 4). However, when confronted with the unintelligibility of death, as it is when one encounters an image, there is still an attempt to summon language of some kind, to try to understand. On Routledge's (2016) podcast, speaker Dennis Schmitt stated,

> The truth of mortality is not at all to be understood conceptually . . . it is a singular truth. It is, however, the province of literature. Above all, it belongs to the language of poetry, in which language is pressed most powerfully into its idiomatic being. (Routledge, 2016)

It is in the broader domain of art and the humanities that one might find something of the unintelligibility of death to understand. In death, something absolute happens (Routledge, 2016), and in thinking death, one thinks beyond oneself and thinks oneself away, while at once revealing the certainty of one's being-in-the-world through the very act of thinking (Gadamer, 2016). Likewise, the creation of art is the occurrence of an absolute (Gadamer, 1986): In its being made and in its being encountered, a work of art stands for itself, resisting "pure conceptualization" (p. 37) and imposing its own temporality on the viewer. The experience of art is also a thinking beyond oneself, as a work of art simultaneously removes the person experiencing it from the context of their life while relating them back to the whole of their being-in-the-world (Gadamer, 1986). There are traces of the unintelligibility of death in art and the humanities: in Klimt's skeleton (1910-1915, Appendix, Figure 1), in drawings of rainbows and tombstones (Appendix, Figures 3, 4), and in the poetry of Stepanek and Rilke.

A Question of Dying

The current literature on children's understanding of death and PPC is informed by a comprehensive collection of statistical data from research conducted *on* children (Kenyon, 2001; Speece & Brent, 1984). Research conducted *with* children, especially those who are experiencing dying, would likely yield different results. As Gadamer (2007) emphasized,

> Thus, what is established by statistics seems to be a language of facts, but which questions these facts answer and which facts would begin to speak if other questions were asked are hermeneutical questions. (p. 84)

The questions about death that researchers have posed to establish theories for children's understanding of death are ones that had anticipated responses which aligned with the developmental stage of the participants. Koocher (1973) categorized children based on their age, intelligence, and cognitive functioning, and asked questions (e.g., "What makes things die?") to determine if children's responses best reflected their age or developmental stage. As Stepanek's (2001) poem *Unanswered Questions* alluded to, knowing the "what" of why things die, and knowing the "why" of why things die, are two separate questions; one which has a possible answer, and one that does not. A death anxiety scale might reveal a statistically significant difference between the stage of development in which children with LLI are aware of death compared to children with chronic illness (Spinetta et al., 1973); but a researcher who acknowledges that children and adults are equally perplexed by the unintelligibility of death might ask different questions of children with LLI. Death, according to Gadamer (2016) and Heidegger (1927/1962), is not an in-the-world phenomenon, event, or intelligible thought; dying and witnessing the death of the Other, however, are experiences in the purview of human beings.

Perhaps in PPC practice and research, the question of death, both physiological and ontological, should come after the question of one's dying (N. Keane, personal communication, April 25, 2021). Attaining a "good death" may not be possible, insofar as death remains a mystery to human beings. However, "good dying," while still living, is not only possible, but is where the dying person, and those caring for that person, are able to learn from the experience. Stepanek (2001) wrote about his living up until death, including his experiences of hospitalization in the intensive care unit: "Lives are not always saved. I feel pain, intense at moments, but I also feel the hurt of anxiety, and neither are good for the spirit" (p. 36). Stepanek's words serve as a reminder for PPC practitioners that the care of children with LLI includes both the relief of physical and spiritual pain (World Health Organization, 2018), and that the care of the spirit may require a better understanding of the experiences of children with LLI.

While Heidegger (1927/1962) attested that "no one can take the Other's dying away from him" (p. 284), it is one's *death*, not the living leading up to dying, that the Other cannot take away. In practice, there are many occasions where the fullness of one's dying is subdued or removed, sometimes for the benefit of the dying person. Palliative sedation, the initiation of medications to induce a comatose state until the time of natural death, in a way removes the dying person from their experience of dying. I frequently encounter situations in practice where adults have chosen not to disclose the diagnosis of LLI to a child, and while it is often the case that children with LLI are aware of the fact they are dying (Bluebond-Langner, 1978; Sourkes, 1995; Stein, 2019), in leaving it unacknowledged, the child's full experience dying could be taken away from them. What children with LLI consider to be good dying may be different from an adult's perspective, not due to an incomplete understanding death, but because children who are dying are experiencing something that adults are unlikely to have encountered, simply because they have survived to adulthood (Wong, 2019).

An Ephemeral Light

When Gadamer (1996) referred to the "demythologizing of death" (p. 61) in modern society, he may have been alluding to *Phaedo* (Plato, ca. 360 B.C.E./1954), to the inner child in the human being who does not feel reassured by the proofs of immortality that Socrates provided. In response to the child who is afraid that their soul will be blown away by the wind when it leaves their body, Socrates offered this advice: "What you should do . . . is to pronounce an enchantment over him every day until you have charmed his fears away" (Plato, ca. 360 B.C.E./1954, 77e). Socrates acknowledged that while his audience may not have been fully convinced by his rational arguments for the immortality of the soul, he emphasized that they should still allow themselves to be comforted (i.e., enchanted) by the stories and myths that allow one to confront the fear of death or imagine an afterlife (Plato, ca. 360 B.C.E./1954, 114d-e). In his essay *Death as a Question*, Gadamer (2016) closed with the fairy tale *Godfather Death* (Grimm & Grimm, 2002), a story that helps carry the unintelligibility of death in a way that theoretical or scientific language cannot (N. Keane, personal communication, April 25, 2021). As the story goes, Death brought his godson to a cave full of thousands of candles:

> "See," said Death, "these are the lights of men's lives. The large ones belong to children, the medium-sized ones to married people in their prime, and the little ones belong to old people; but children and young folks likewise have often only a tiny candle." (p. 179)

In his horror at seeing his rapidly shortening candle, Death's godson tried to place another candle on top of his, but in his haste accidentally extinguished his own flame.

The burning candle, Gadamer proposed, is a fitting image for human life and its temporal limits, "because in it the finite and ephemeral character of our existence is symbolically represented" (Gadamer, 2016, p. 70). While the taller candles burn slowly, their flames flickering back and forth in a dimming and brightening sway, "the flickering of the candle on the verge of burning itself out seems at times to spread a wee bit more brightness than the quietly burning candle" (Gadamer, 2016, p. 70). A child's flame, lit on a tiny candlestick and already on the verge of burning out, must then burn brilliantly for the entirety of its existence. One can focus on the length of the candlestick, on the life that will be "snuffed out before it has unfolded" (Solnit, 1965, p. 693), or one can turn their attention to what is illuminated in the glow of that brightly burning flame.

Ricoeur (2009) referred to the "emergence of the *Essential*" (p. 15) as the grace that differentiates individuals at the end of life. Just as a candle seems to burn brighter on the cusp of extinguishing, Ricoeur (2009) similarly described the dying person's "mobilization of the deepest resources of life in the coming to light of the Essential" (p. 15) as an affirmation that they are still living. Ricoeur (2009) offered that where one chooses to direct their gaze in the presence of a person who is dying is an ethical domain, wherein those who truly accompany the dying do so with compassion and a willingness to imagine the struggle of the individual who, while dying, is "still living until dead" (p. 18). Ricoeur (2009) made the distinction between viewing the situation as though one were a "spectator anticipating the already-dead" (p. 22) and the perspective that attends to all that is revealed when one witnesses the end of a life, a "gaze that sees the dying person as still living, as calling on the deepest resources of life" (p. 22). The latter is the gaze of PPC practitioners: It is an attestation offered to the child who is dying, in a

"gesture of accompanying . . . between understanding and friendship" (Ricoeur, 2009, p. 22) that safeguards the quietly burning candle from becoming invisible to the world prior to it being extinguished forever (N. Keane, personal communication, September 24, 2021). Perhaps in situations where adults are unable to answer children's questions of death, the gesture of accompanying them in imagination and in compassion (Ricoeur, 2009) will offer some comfort to the inner child in all of us who is not fully convinced by any claims of knowledge of the afterlife.

Ephemeral, from the Greek root *ephemeros*, means "lasting or living only one day" or "short-lived," but can also mean "for the day" (Online Etymology Dictionary, n.d.). Children with LLI and their families often live "for the day." Sourkes (1995) shared that, during a therapy session, a young child with a LLI drew a picture of her family and stated, "We don't plan ahead like we used to. We live each day as it comes" (p. 119). All Being, not just being-in-childhood, is a process of becoming (Heidegger, 1927/1962). In my accompanying children with LLI in their living and dying, I have observed that some are able to let go of the future that most children expect to live out in a way that allows them to embrace the present, who they are becoming in that moment, and not who they might have grown up to be: "The children too, even the very small ones, didn't just have any child's death; they gathered themselves and died what they already were and what they would have become" (Rilke, 1982, p. 16).

Conclusion

According to his mother, Stepanek's last word was "yes" (Demkovich, 2019); but, just as a child's first utterance is not their first word (Risser, 2019), "yes" was merely Stepanek's last verbalization, as his poetry continues to speak to those who encounter it. While it is a mysterious last word to have spoken, Rilke (2009) may have understood something similar: "Life always says Yes and No simultaneously. Death (I implore you to believe) is the true Yea-sayer. It stands before eternity and says only: Yes" (*Our Closest Friend,* Line 9-15). Children who have died or are dying have something to teach the living. While being is ephemeral, the artworks that children who are dying leave behind endure. Like the luminous glow of a candle on the verge of extinguishing, children's artwork can have a "campfire effect" (Rollins, 2005, p. 215): the ability of art to draw one in, focus attention on the matter at hand, and summon language in such a way that what is presented in the work "shines forth" (Risser, 2012, p. 108). While the question of death may remain unanswerable, those who have tried to convey their experiences of dying and confronting the unintelligibility of death through art and literature have left the living a wonderful gift.

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us about what children understand and what they are experiencing? I was asked to work out a hermeneutic analysis of my thesis topic, the artistic expression of children who are dying, and to approach this paper as though I was writing an interpretation of this phenomenon to demonstrate my readiness to conduct hermeneutic research.

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Notes

[1] From *Journey through Heartsongs* (p. 37), by M. J. T. Stepanek, 2001, Hyperion. Copyright 2001 by Mattie J. T. Stepanek. Reprinted with permission.

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