Living as a Dying Child: A Gadamerian Analysis of the Poetry of Mattie J. T. Stepanek

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LIVING AS A DYING CHILD:
A GADAMERIAN ANALYSIS OF
THE POETRY OF MATTIE J. T. STEPA NEK

by

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A dissertation submitted to the Graduate Faculty in Nursing in partial fulfillment of the requirements for the degree of Doctor of Philosophy, The City University of New York

2019
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This manuscript has been read and accepted for the Graduate Faculty in Nursing
in satisfaction of the dissertation requirement for the degree of
Doctor of Philosophy.

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ABSTRACT

Living as a Dying Child: A Gadamerian Analysis of the Poetry of Mattie J. T. Stepanek

by

Corinne Ann Settecase-Wu

Advisor: Dr. Martha Velasco-Whetsell

Yearly, approximately 500,000 children live with life-limiting conditions in the United States; 50,000 die. Yet, details regarding children’s days of living as dying are unknown. The aim of this qualitative hermeneutic study is to gain understanding of the phenomenon of living as a dying child. A Gadamerian-inspired approach was implemented to underpin the study, and to analyze poetic text to address the research question: What is it to be living as a dying child? The text sample included 499 poems written by Mattie J. T. Stepanek, a dying child. The Settecase-Wu Conceptual Guide was developed and implemented to ensure accuracy of the hermeneutic process application, and to provide a decision trail for the research findings. Three themes regarding the phenomenon emerged from this hermeneutic analysis: tenderness, time, and transcendence. Rich descriptions with textual representation of these themes in the poetic sample illustrate a shared understanding of the phenomenon between this researcher and the author regarding living as a dying child. Trustworthiness of the findings is established. Examination of the themes through a Rogerian theoretical lens enables application of the themes in Nursing Practice. Implications for Nursing, limitations and strengths of the study, recommendations for further Nursing research, and reflection of the researcher’s experience conclude the study.
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Acknowledgments

I would like to express my sincere gratitude to those who have helped me on this journey:

Lissie Velasco Whetsell – the inspiration and vital force behind this research. You brought me to your mom.

Research Chair, Dr. Martha Velasco-Whetsell – for your love, dedication and support, and for keeping me on course. You share your home and family, and always make me feel wonderful about myself, and my research. Your knowledge and fortitude are astounding.

Vinson H. Whetsell – for giving so much of your time and effort, and for making this experience enjoyable.

Research Committee, Drs. Steven L. Baumann, Carole A. Baraldi, Claudette V. Gordon, and Violet M. Malinski – an outstanding team of scholars who keep me striving for excellence.

Tricia Plummer – for being a friend and confidant, and ensuring that things get done right.

Cohort #8 Colleagues – your camaraderie is unparalleled. Sandy Russo, my work and school pal – we did it! Cathy Lorenzo, you are always with us in spirit.

Dean Louis H. Primavera, Touro College – for giving me the opportunity to fulfill my dream.
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Dr. Medel S. Paguirigan – for continuously reminding me that life should be fun, and not too serious.

My dear friends Dr. Patricia Burke, Janet Fegan, and Dr. Edward Lemmo – you always listen, give me sound advice, and cheer me on.

David J. Perkins – for your continued love, help, and unwavering patience. I could not have done this without you.

My loving and supportive family – especially my Godchild Nadia who inspires me every day to persevere.

My daughter Mallory and son Casey – you are my heart and the reason for all that I do. I love you both.

Mattie J. T. Stepanek – for your *Heartsongs*, which spark a desire to understand
For Gloria & Anthony Settecase,

Mommy & Daddy

❤
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Living as a Dying Child:
A Gadamerian Analysis of the Poetry of Mattie J. T. Stepanek

The job of the poet
Is to give birth to the words
That give breath to expressions
Of the essence of life.

The job of the poet
Is to leave stains of the storms
Yet echo laughter of the light
That is seen from the soul.

The job of the poet
Is to weave ashes of yesterthoughts
Into silhouettes that rise gently
On the horizon of dawning hope.

The job of the poet
Is to create and to capture
And to spirit and to script
The pulse of life.

— Mattie J. T. Stepanek, “Duties as Designed”
Children aren't supposed to die (Wolfelt, n.d.). Most assume the heartfelt stance that people will, and do die … when they are old. Physically, mentally, and spiritually, it is difficult for anyone to imagine, let alone, comprehend, what it is to be living as a dying child. The predominant concern of health care practitioners and systems is to stop children from dying (Hinds, Schum, Baker, & Wolfe, 2005). Yet regrettably, children are dying, and living while they are doing it. Yearly, roughly 500,000 children in the United States deal with chronic, life-limiting conditions, and approximately 50,000 die; worldwide, these figures are in the millions (Himelstein et al., 2004). Although these numbers are calculable, the particulars regarding these children’s years, months, days, or hours of living while dying are unknown (Hinds et al., 2005). To explore the phenomenon living as a dying child in depth and breadth, a Gadamerian approach is put forth for hermeneutic analysis of the poetic text of a dying child. The research works through a series of four chapters as follows, (Working out the Hermeneutic Situation, Hermeneutic Preparation: Identification of Fore-Understanding, The Nature of the Study, and Process Application for Text Inquiry), to ensure the study is well rooted in philosophy and theory, and trustworthiness is high. Two additional chapters follow, upon completion of the research, (Findings of the Study, and Reflection on Understanding) to enlighten the reader regarding the phenomenon of interest, and to provide new knowledge for Nursing science and practice.
CHAPTER I  WORKING OUT THE HERMENEUTIC SITUATION

Hermeneutic “research carried out in a Gadamerian tradition is developed from a desire to achieve a deep understanding of a phenomenon” (Fleming, Gaidys & Robb, 2003, p. 117). The text as poetry, written by Mattie J. T. Stepanek, is examined using the Gadamerian approach as developed by Austgard (2012) to gain a deep understanding of what it is to be living as a dying child.

According to Austgard (2012), the initial step in the process of hermeneutics is for the researcher to acquire the right vantage point from whence to ask the research question – the right horizon of inquiry. Gadamer explains the concept of horizon as an expression of “the superior breadth of vision the person who is trying to understand must have” that determines the hermeneutical situation (Gadamer, 1960/2013, p. 316). That is to say, the research question is evoked by the researcher’s encounters with the tradition of the phenomenon, and the questioning that occurs with these encounters. This chapter works out the hermeneutic situation by first exploring the tradition, or background, of the phenomenon of living as a dying child. It then charts the following: development of the statement of the problem, aim of the study, research question, justification for the study, assumptions and biases, hermeneutic process, and significance in Nursing. This first step provides a foundation with truth and trustworthiness to the subsequent hermeneutic process of the study (Austgard, 2012).

Tradition

Despite the fact that no empirical instrument exists for examining the phenomenon of living as a dying child (Hinds et al., 2005), shedding light on existing literature regarding dying children’s wants and needs helps the hermeneutic researcher acquire the right horizon of inquiry of the phenomenon. Upon review of the research regarding the phenomenon of interest – living
as a dying child – information provided is sparse, indirect, and ambiguous. Literature on dying children is ample regarding pediatric palliative care and hospice; however, the majority of the research findings do not evolve directly from children. Most relevant studies focus on parents and/or survivors of dying children (Dicker, 2012; Dighe, Jadhav, Muckaden & Sovani, 2008; Hinds et al., 2005; Kreicbergs, Valdimarsdóttir, Onelöv, Henter, & Steineck, 2004; McGraw, Truog, Solomon, Cohen-Bearak, Sellers, & Meyer, 2012; Steele, 2010), or health care professionals and their points of view (Beale, Baile, & Aaron, 2005; Bluebond-Langner, Chambers, Lapwood, & Noyes, 2016; Dunlop, 2008; Kreicbergs, 2018; Kübler-Ross, Wessler, & Avioli, 1972; Stayer & Lockhart, 2016). Historical studies (Newton, 2015; Sisk, Bluebond-Langner, Wiener, Mack, & Wolfe, 2016) provide insight into living as a dying child but without explanation of the phenomenon. Several publications involving children while dying (Adler & Taylor, n. d.; Arkansas Children’s Hospital, n. d.; Bluebond-Langner, 1978; Champagne, 2008; Jankovic et al., 2004; Tedeschi, 2016; Wolfelt, n.d.) reveal some knowledge, but information provided is based primarily on clinical experience or human-interest journalism concerning dying children, rather than rigorous research.

Careful analysis of existing research, essential for identification of fore-understandings and hermeneutic preparation (as detailed in Chapter II), reveals ten noteworthy themes relating to dying children: (1) truth disclosure, (2) open, honest communication, (3) potential obstacles - parents and health care professionals, (4) awareness of dying, (5) the need to be heard, (6) mixed emotions, (7) the fight for life, (8) a need for control, (9) hope, and, (10) Heaven. Although informative, there are gaps in the literature regarding these topics. Open, honest communication and prognosis disclosure are currently, and widely recommended with children who are dying, yet recommendations are mainly based on health care providers’ clinical experiences and
perspectives, or on research conducted from parents’ viewpoints; no controlled clinical research studies with children are evident (Hinds et al., 2005; Sisk et al., 2016). While parents and health care professionals recognize circumstances that may impede forthright communication with dying children (Newton, 2015), there is a lack of data related to overcoming communication obstacles, content and approach in communication, and, most notably, communication needs and experiences from the dying child’s perspective (Hinds et al., 2005; Kreicbergs, 2004; Sisk et al., 2016). Furthermore, there is no professional consensus for death discussion methods (Dicker, 2012; Tedeschi, 2016). The research shows that dying children fight in various ways to live (Arkansas Children’s Hospital, n.d.), and want and should have some control of their living and dying (Beale et al., 2005). Nonetheless, there is neither literature that implicates supportive strategies for the dying child’s fight for living (Arkansas Children’s Hospital, n.d.), nor information regarding how and when they should decide to stop their fight (Hinds et al., 2008).

**Statement of the Problem**

Though some prominent themes have emerged from the research, crucial supporting data and interventional information pertaining to these themes are inadequate. Overall, research and knowledge, with respect to understanding the comprehensive phenomenon of interest – living as a dying child – is essentially non-existent.

**Aim of the Study**

The aim of this study is to gain understanding of the phenomenon of living as a dying child. A Gadamerian hermeneutic approach to the poetic text of a dying child, Mattie J. T. Stepanek, during his lifetime provides insight into the true meaning of what living is for a dying child. Understanding this phenomenon will furnish nurses with information for guiding an optimal living experience for a dying child.
Research Question

The essence of this research question is appropriate for a hermeneutic research study, and for underpinning its Gadamerian assumptions; the research question fittingly opens up possibilities to grasp and understand the phenomenon investigated, and will evoke knowledge within the discipline of Nursing:

What is it to be living as a dying child?

Justification for the Study

This research seeks to explore and understand the phenomenon of what it is to be living as a dying child. Several reasons are stated for justification of this research. Firstly, advances in medicine, pharmacology, and technology enable children with life-limiting illness to live longer while dying (Steele, 2000), yet there is no evident pediatric research investigating this phenomenon. Of the publications involving dying children, few have been conducted from the child’s perspective (Adler & Taylor, n. d.; Arkansas Children’s Hospital, n. d.; Bluebond-Langner, 1978; Champagne, 2008; Jankovic et al., 2004; Tedeschi, 2016; Wolfelt, n.d.). These few publications, with the exception of one (Adler & Taylor, n. d.), are from disciplines other than Nursing (Anthropology, Journalism, Medicine, Psychology, Sociology, and Theology), and are written based on experiential and clinical points of view, rather than sound research.

Secondly, nurse researchers face significant challenges when attempting to conduct studies with living-while-dying children. Ethical concerns prompt institutional review boards to shield the population of children with life-limiting illness from research. Concerns include potential psychological distress due to subject matter, burdens with time and effort involved, and the abilities of dying children to give approval of participation (Hinds et al., 2005). The benefits of gaining new knowledge are often outweighed by these concerns.
Thirdly, the poetic writings of Mattie J. T. Stepanek have never been analyzed scientifically. This rich and creative body of text is the voice of a child experiencing the phenomenon of interest. The first-hand writings behoove the nurse researcher to engage conversationally with the text to interpret and understand what it is to be living as a dying child.

In short, the gap in the literature regarding the phenomenon, a lack of research from the child’s vantage point (especially in Nursing), barriers that make conducting pediatric research difficult, and the necessity to explore significant, documented accounts of the phenomenon, justify this research.

Assumptions and Biases

Several assumptions regarding this study are noted. First, that the words of Mattie J. T. Stepanek are an honest and true expression of his own living experience while dying. Second, it is assumed that Stepanek’s written words are his own. Third, that the interpretation is an accurate, genuine reflection of Stepanek’s words and feelings regarding the phenomenon of interest. Lastly, that the interpretive analysis truly reveals what it is to be living as a dying child.

Reflection upon fore-understandings of a phenomenon, according to Gadamer, enables the researcher to transcend their personal views, or horizon, and move beyond their biases or fore-understandings, towards understanding the phenomenon (Fleming et al., 2003; Gadamer 1960/2013). I readily acknowledge immediate personal bias, as a mother and parent whose heart runneth over with deep love for her two children. I can imagine the phenomenon to be extremely painful, challenging, emotional, fearful, frustrating and sorrowful. In recognition of this, and additional fore-understandings as brought forth in Chapter II, I also believe that nurses, other health care providers, family, and friends, though integral to a child’s life, do not fully understand what living is for a child who is dying. I believe it is difficult for feelings and life
desires to be expressed and shared due to humanistic presumptions that children are not supposed
to die, and that each child does not face living and dying in the same way as another, or as adults
do. Furthermore, I believe each individual lives and dies, and interprets living and dying,
uniquely from one another.

**Research Process**

A Gadamerian, hermeneutic approach in qualitative research incorporates philosophical
theory and process into the interpretation of textual art forms (Polit & Beck, 2014) – in this
instance, the poetic writings of Mattie J. T. Stepanek. In order to bring this living text of a dying
child to understanding, an interpretive process via the hermeneutic circle is engaged in (as
detailed in Chapters III and IV), cyclically moving from the whole of the text to its parts, and
back to the whole, until meaning of the phenomenon – *living as a dying child* – becomes
apparent (Austgard, 2012; Fleming et al., 2003; Gadamer 1960/2013; Geanellos, 1998a; Polit &
Beck, 2014). The researcher/interpreter openly encounters the written poetry to “hear” what it is
telling, incorporating fore-understandings through continuous dialogue with the text, until truth
and understanding emerge (Porter & Robinson, 2011).

The poetry of Mattie J. T. Stepanek is an artistic expression of his living as dying world.
His poetic abundance within his *New York Times* best-selling *Heartsongs* book series sparks a
desire of the researcher/interpreter to read about and analyze the perceived love for humanity and
life wisdom of Mattie J. T. Stepanek, and opens up the researcher/interpreter to meaning and
understanding, permits access to the unexplored world through written language, and fuels the
cyclical reading and interpreting until truth is uncovered. The phenomenon of interest, *living as
a dying child*, matches this desire to understand what transcends what is known about the
phenomenon. It is from this desire that the research question, the Gadamerian underpinnings and
hermeneutic process are constructed and implemented. Congruency of the research question, philosophy, and process ensures that the found understandings will be trustworthy and applicable to Nursing science (Fleming et al., 2003).

**Significance in Nursing**

Gadamerian hermeneutic research in Nursing, and new knowledge regarding understanding *living as a dying child* have strong significance in Nursing. Hermeneutic publications regarding the Gadamerian approach are scarce in Nursing. Of nine found, three are narrative research studies (Carlsund, & Söderberg, 2018; Geanellos, 1998b; Robstad, Söderhamn, & Fegran, 2018); the others (Austgard, 2012; Fleming et al., 2003; Geanellos, 1998a; Nyholm, Nyström, & Lindström, 2018; Rolfe, G., 2015; Söderlund, M., & Eriksson, K., 2006) explain concepts, philosophical underpinnings, and process development for Nursing research. None of the Nursing publications are from the United States (US). There is a need for hermeneutic research with a Gadamerian approach in Nursing. This study begins to fill that need, while breaking ground for this type of qualitative research in the US, and provides future nurse researchers with a philosophical framework and process that is trustworthy for generating further studies of its kind.

There is much to be gleaned from the written words of a child who is living while dying, especially for Nursing science: insight into day-to-day living experiences, physical, emotional, and spiritual challenges, thoughts and ideas about death and dying, and expectations about moving beyond living, and dying. Though nurses spend much time at the bedside talking and interacting with children with life-limiting illness, much of the conversation exchanged is oriented towards physical well-being and assessment, medications and treatments, and documentation. Knowledge gained with analysis and understanding of the phenomenon of
interest provides nurses with key information needed to zero in on, and meet, the wants and needs of children living as dying. Nurses may use research findings to develop relevant, child-orientated care plans with evidenced-based protocols and practices for improved health care delivery, and patient outcomes. Knowledge generated can also augment patient educational programs and teaching strategies geared to help children with life-limiting illness improve life quality, and make living more meaningful.

Nursing education is developed and implemented around the most recent, evidence-based practices. Research findings may improve and update Nursing curricula, and pique nurse awareness regarding the phenomenon, leading to quality, targeted clinical practice for both current and future nurses. Nursing education will be more appropriate, efficient, and effective, resulting in practitioners who are exceptional patient advocates, and leaders in Nursing.

The literature reveals a paucity of Nursing research that obtains data from children with life-limiting illness. This study, a first-of-its-kind within the profession, may contribute significant information to death and dying research. Moreover, the study may illuminate and disseminate new Nursing knowledge surrounding the phenomenon of interest, and will suggest future research studies regarding understanding living as a dying child.

Summary of Chapter

Chapter I, Working Out the Hermeneutic Situation, includes exploration of the tradition of the phenomenon, followed by the statement of the problem, the aim of the study, and the research question. Justification for the study, and assumptions and biases are then declared, followed by description of the interpretive process. Finally, the study’s significance in Nursing is presented. Completion of the hermeneutic situation furnishes trustworthy groundwork from which hermeneutic preparation with identification of fore-understandings proceeds (Chapter II).
A Gadamerian research approach requires preparation for the hermeneutic circle by identifying fore-understandings of the phenomenon (Geanellos, 1998b). Acquiring the right horizon of inquiry, by reflecting upon history, personal experiences, knowledge, and worldviews (foregrounding), not only brings forth the researcher’s fore-understandings and personal prejudices, but also adds truth and trustworthiness to the hermeneutic research process (Austgard, 2012; Gadamer, 1960/2013). Gadamer (1960/2013) explains that understanding begins with awareness and provocation of the researcher’s fore-understandings, which will transcend and change through the hermeneutic process (Austgard, 2012). The researcher must bring these fore-understandings to consciousness (Geanellos, 1998b), and write them down to allow awareness of the hermeneutic situation, and prepare for a relationship with the text (Austgard, 2012). Identification of and reflection upon fore-understandings not only enables the interpretive researcher to institute dependable efforts for disclosing the phenomenon of interest, but also sanctions the researcher to query the emergence, acceptability, and credibility of these fore-understandings in connection with the interpretation of the text (Geanellos, 1998b). Failure to identify or acknowledge fore-understandings increases the researcher’s vulnerability for validating personal beliefs and opinions, instead of illuminating the true concepts of the phenomenon studied (Geanellos, 1998b).

In order to address the researcher’s fore-understandings of living as a dying child, three efforts, as suggested by Geanellos (1998b), are implemented: understanding and conceptualizing the phenomenon through a literature review, developing forestructures and fore-understanding based on personal beliefs and opinions, and bringing fore-understandings to consciousness via
Understanding and Conceptualizing *Living as a Dying Child*

Reviewing the literature explicates knowledge regarding the phenomenon, as well as revealing the unknown. It enables the researcher to bring to consciousness all fore-understandings regarding *living as a dying child* that are based in tradition and practice. Analysis of existing research reveals ten significant themes regarding the phenomenon of interest: (1) truth disclosure, (2) open, honest communication, (3) potential obstacles - parents and health care professionals, (4) awareness of dying, (5) the need to be heard, (6) mixed emotions, (7) the fight for life, (8) a need for control, (9) hope, and (10) Heaven. Two prominent researchers (Bluebond-Langner, and Kübler-Ross) are also noted throughout the literature review, as well as information regarding the author of the poems examined, Mattie J. T. Stepanek. Synthesis and conceptualization of these themes, and the documentation of discovered knowledge, bring to light the shared history, culture, and language surrounding the phenomenon, thus providing the ground and background for the future development of new knowledge through the hermeneutic process (Gadamer, 1960/2013).

**Truth Disclosure**

Historically, disclosure to children of the truth about dying has taken several turns. Documents recorded in England between 1580 and 1720, times when children frequently succumbed to illness and infection, reveal parents encouraging children to ponder their own mortality, and to talk about it with their siblings (Newton, 2015). By urging this, parents hoped to take the fear out of the unknown by discussing death and dying, and making mortality familiar (Newton, 2015). In the United States (US) before 1948, however, no literature was found which primarily focuses on disclosing a life-limiting diagnosis to a child (Sisk et al., 2016).
As clinical and research publications emerged in the US in the 1950s and 1960s, the widespread professional opinion was to protect the dying child from the detriment of a poor prognosis (Sisk et al., 2016). It was thought that children were incapable of understanding, fearing, or having anxiety about dying, and so, they should not discuss it (Sisk et al., 2016). It was also assumed that if dying children did not ask questions, false reassurances about getting better were enough (Sisk et al., 2016). Arguments against prognosis disclosure to dying children during this time period also included possible misdiagnosis, and potential self-harm or suicide (Sisk et al., 2016). In the 1960s, most pediatric and psychological literature viewed children as vulnerable and hypersensitive, in support of non-disclosure (Sisk et al., 2016).

As child deaths from acute infections decreased with the development of vaccines and antibiotics, cancer and other life-limiting illness were brought into focus. These changes in childhood illnesses prompted health care professionals and researchers to question whether or not dying children should know their probable outcomes (Sisk et al., 2016). Support for prognosis disclosure grew because clinicians suspected that children were in-tune to their prognosis, whether they were formally told, or not, warranting accurate and truthful conversations and answers (Sisk et al., 2016). By the late 1960s, professional recommendations were shifting towards discussion of diagnoses and prognoses with dying children (Sisk et al., 2016). Pediatric clinical and psychological research continued through the 1970s and 1980s, objectively supporting the premise that honest and safe communication was helpful to dying children (Sisk et al., 2016). These studies thwarted the opinion-based literature of the previous decades. “By the late 1980s, the recommended approach to prognostic disclosure in pediatrics shifted largely from “never tell” to “always tell” (Sisk et al., 2016, p. 1).

Current literature generally supports prognosis disclosure and revelation of the truth to
dying children (Hinds et al., 2005; Sisk et al., 2016). These recommendations, however, are mostly based on experiences in clinical practice, and research exploring health care provider or parent perspectives, rather than on controlled clinical trials involving children (Hinds et al., 2005; Sisk et al., 2016).

**Open, Honest Communication**

Open, honest communication is the foundation of the dying child-parent-health care provider relationship (Beale et al., 2005; Bluebond-Langner, 1978; Dicker, 2012; Dighe, et al, 2008; Dunlop, 2008; Kreicbergs et al., 2004; Kübler-Ross, 1983/1997; Lyon et al 2004; Newton, 2015; Sisk et al, 2016), and is supported by the International Society of Paediatric Oncology (Kreicbergs et al., 2004). As dying children begin to understand the complexity and severity of their illnesses, health care professionals and parents should offer suitable and accurate explanations of their life and illness trajectories in understandable language (Beale et al., 2005; Dicker, 2012; Kreicbergs et al., 2004; Wolfelt, n.d.). This “honest love” is what children “need most” (Wolfelt, n.d., p. 1) to permit their own awareness of dying (inner life) to fuse with the information they receive (outer world), thus avoiding frustration (Kreicbergs et al., 2004). Dying children derive comfort from sharing hopes and fears, and receiving compassionate, loving reassurance (Kübler-Ross, 1983/1997; Newton, 2015). Open and truthful conversation enables children to incorporate dying into their remaining life, affords them opportunities to think and ask questions, express grief, discuss preferences, achieve goals (Lyon et al 2004; Wolfelt, n.d.), and allows them the “privilege of saying goodbye” (Wolfelt, n.d., p. 1). Such communication, in an open environment, should be chosen and initiated by the child, sans pressure or force, ensure the child’s well-being and acclimation, as well as sound decision-making and minimal suffering (Dunlop, 2008; Sisk et al., 2016).
In contrast, untruthful communication can undermine good decision-making and informed consent, and can ultimately lead to increased child and parent suffering (Sisk et al., 2016). When parents or health care providers withhold information, or make decisions that are incongruent with a dying child’s views, ethical dilemmas ensue, endangering the psychological welfare of the child (Dighe et al., 2008). The child will surely notice the disparities in communication, and may become angry, frustrated, and confused (Wolfelt, n.d.).

Parents and health care professionals may encounter certain obstacles that impede forthright communication with the dying child, making conversation extremely challenging (Newton, 2015). Such obstacles include doubts about what to say, and fear of increasing anxiety or sorrow for the child (Newton, 2015). Data is lacking in the literature regarding overcoming such obstacles for effective communication with dying children. Future research is needed regarding when discussions should begin, who should disclose, what information should be exchanged, how that information should be presented, and most significantly, the dying child’s perspective (Hinds et al., 2005; Sisk et al., 2016).

Potential Obstacles - Parents and Health Care Professionals

The topic of death, and how to prepare for dying, for the most part, remains taboo for dying children (Tedeschi, 2016). There is no single, right way to discuss death (Dicker, 2012). Some pediatric experts attribute their difficulty in broaching the subject to the children’s oscillations between acceptance and denial of their likely death, as well as their widely varied responses to treatments and therapies, that make it hard to determine when and how to start the conversation (Tedeschi, 2016).

Parents of children with life-limiting illness often question whether or not to talk about death with their child (Kreicbergs et al., 2004). Though most prognosis disclosures are initiated
by parents (Hinds et al., 2005), they struggle with emotions and the sensitivity of the subject, wanting to protect their child from sadness and fear, and preserve hope (Dighe et al., 2008; Hinds et al., 2005; Tedeschi, 2016). In some cases, parents want to protect themselves from a harsh reality, or their ethnic or cultural influences cause them to shield the child (Hinds et al., 2005). One retrospective study of parents with children who had died (Kreicbergs et al., 2004) showed that 66% of the parents surveyed had not talked about death with their child, and 27% of them regretted not having done so. None of the parents who had talked about death regretted it. As reported by the parents, only 25% of them used the word death, and 63% of the children were not informed that their illness was incurable. In only 17% of the cases, information was delivered by the physician with both parents. This evidence suggests that when a child is dying, the basic rule of telling the truth can be broken or manipulated by parents or health care professionals (Dunlop, 2008).

Though the literature suggests that dying children benefit by talking about their prognosis (Kreicbergs, 2004), there is no research that explores dying children’s communication with their parents and health care professionals from the child’s point of view.

**Awareness of Dying**

The majority of dying children understand, from what they sense going on around them, that something serious is happening to them (Bluebond-Langner, 1978; Dunlop, 2008; Jankovic et al., 2004; Kreicbergs, 2004; Kübler-Ross, 1983/1997; Kübler-Ross et al., 1972; Sisk et al., 2016). They eventually become aware of their grave prognosis without being told, gathering information, and reasoning about treatments and health care experiences over periods of time (Bluebond-Langner, 1978; Kreicbergs, 2004; Kübler-Ross, 1983/1997). Children with life-limiting conditions often witness other children around them deteriorating, and even dying, in the
health care setting (Wolfe, 2004, as cited in Dunlop, 2008). They may clearly express awareness of their own dying in words, by asking questions, or by indirectly communicating around the subject with stories, words, poems, gestures, or pictures (Dunlop, 2008; Kreicbergs et al., 2004). Both parents and health care workers recognize the dying child’s need to be reassured about their concerns regarding what is happening to them (Jankovic et al., 2004), but neither can always sense that the child knows the prognosis if it hasn’t been disclosed (Bluebond-Langner, 1978; Kreicbergs, 2004).

Children who know they are dying, without being told, can be reluctant to broach the subject themselves (Tedeschi, 2016). According to Bluebond-Langner (1978), they may choose to conceal this knowledge from their parents and health care professionals as part of a socialization process of how they are expected to die, in society. In other words, children know that their parents are withholding prognostic information from them, so they choose to conceal their awareness from their parents so as not to disappoint or upset them. Bluebond-Langner (1978) calls this mutual pretense – when both parents and child are aware of the prognosis, but neither acknowledges it to the other. Some experts feel mutual pretense can be harmful for dying children, leading to an increase in stress and anxiety, and social or emotional isolation, as they have no one to confide in (Bluebond-Langner, 1978; Sisk et al., 2016). Others view mutual pretense as a foundational mode of interaction in the family that should be respected (Bluebond-Langner, 1978). Bluebond-Langner (1978) recommends a protocol that permits children to have open awareness and communication with those children who can handle the truth, and maintains mutual pretense with those who cannot.

The Need to be Heard

Children are capable of understanding more than they are expected to (Wolfelt, n.d.).
They view and express dying and death from their own horizons (Jankovic et al., 2004), and
deserve nothing but honesty, respect, and compassion from all who observe and listen (Wolfelt,
n.d.). (Jankovic et al., 2004). Dying children want to be heard and to be listened to; in doing
this, others may learn the concerns that they want and need to be reassured of (Jankovic et al.,
2004). Not only is it important to respect the readiness of children to discuss their mortality at a
level of comfort for them (Jankovic et al., 2004); it is essential to follow their lead, listen to
them, and watch for non-verbal cues (Jankovic et al., 2004; Wolfelt, n.d.). Many dying children
alternate between wanting to know all about their prognosis, and not acknowledging their illness
(Wolfelt, n.d.). They “naturally dose themselves” (Wolfelt, n.d., p. 2), not wanting too much
information at once, or perhaps, not able to take it (Wolfelt, n.d.). Awareness of mortality may
depend on context, and for dying children, it evolves in different ways over time (Dunlop, 2008;
Sisk et al., 2016). Some children have a mature understanding of their dying, asking questions
and wanting details (Dighe et al., 2008; Hinds et al., 2005). These children cope well with what
they know and have difficulty coping with the unknown (Wolfelt, n.d.). Other children impose
limits on what they want to know, and may even ask their parents to listen on their behalf (Hinds
et al., 2005; Stayer & Lockhart, 2016) in order to avoid dealing with details of the situation.

In some cases, parents may believe that talking about death and dying will depress their
child, so they refuse to discuss it (Beale et al., 2005). This misguided attempt to protect their
children and shield them from truth actually places barriers between them, and the health care
professionals who can help children understand and deal with their experience (Beale et al.,
2005). For children engaged in mutual pretense, discussion of their awareness of prognosis will
not occur because they know their parents prohibit it (Bluebond-Langner, 1978; Jankovic et al.,
2004). They will be more indirect about their thoughts and feelings (Wolfelt, n.d.), becoming
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non-verbal, isolated, downhearted, introverted, apprehensive, and even stubborn (Beale et al., 2005; Bluebond-Langner, 1978; Dighe et al., 2008). These children may know more or less about their prognosis than parents or health care professionals perceive them to know (Dighe et al., 2008). Children who are non-verbal should not be forced into conversation, because it can be harmful (Sisk et al., 2016). Behaviors and non-verbal cues reflect underlying needs and deserve loving responses (Wolfelt, n.d.). Health care professionals need to be attuned to these cues, and listen carefully for indirect, verbal expressions, so they can approach the parents for permission to provide the necessary informative and loving responses when the parents cannot. Dighe et al. (2008) noted that dying children have inadequate opportunities to meet with health care professionals on their own. These opportunities should be promoted to allow the children to be heard, and to give parents relief by “passing the buck” to the experts when it is uncomfortable, or too painful for them, to listen. Honest dialogue, good observation, and listening can not only optimize care for dying children, but help them find purpose and meaning in their living (Champagne, 2008).

Mixed Emotions

“Dying affects a child's head, heart and spirit” (Wolfelt, n.d., p. 2), often resulting in the child feeling and expressing various emotions at once (Wolfelt, n.d.). Research reveals that even when their prognosis has not been told to them, dying children exhibit extreme anxiety (Bluebond-Langner, 1978; Wolfelt, n.d.). Deprivation of the truth initiates a fear of the unknown (Bluebond-Langer, 1978; Dicker, 2012), and unless the child is helped to understand what is happening or to control this fear, the remaining life will include feelings of isolation and loneliness (Beale et al., 2005; Bluebond-Langer, 1978; Dunlop, 2008; Dighe et al., 2008; Kübler-Ross, 1983/1997). Children with life-limiting illness often experience ongoing struggles
between physiological dependency and independence. During harsh treatments and worsening physical symptoms, these children may feel concern, loss of control, and fear of body mutilation or dysfunction (Dighe et al., 2008), leading to withdrawal and depression (Adler & Taylor, n.d.). How these treatments and symptoms will affect their daily lives weighs heavy on their hearts (Beale et al., 2005).

Likely to understand death’s permanence, children with life-limiting illness may experience distress when they see their parents suffering because of their dying: this is “special sorrow” (Velasco-Whetsell & Baumann, 2019, p. 135). Children may also suffer worry about being forgotten, guilt about leaving their family and friends behind in sorrow (Jankovic et al., 2004; Kübler-Ross, 1983/1997; Newton, 2015), and abandonment (Dighe et al., 2008; Hinds et al., 2005). They may fluctuate between reluctant acceptance of, and outright anger towards, imminent death (Jankovic et al., 2004). Defense mechanisms, such as denial and avoidance may also be exhibited (Dunlop, 2008). As physical symptoms worsen, doubts regarding treatments and fear of separation are expressed; the deaths of friends with similar diagnoses heighten these feelings (Beale et al., 2005). Dying children grieve loss of function and loss of things to come (Hinds et al., 2005), resulting in sadness (Wolfelt, n.d.). They may also experience agitation, crying episodes, loss of appetite, and uncooperative behaviors (Beale et al., 2005). They may verbalize a need to openly discuss end-of-life (Beale et al., 2005), or have significant fears about dying alone (Adler & Taylor, n.d.). Dying children need reassurance from parents and health care professionals that they will not die alone, that they will be missed, and that they will die peacefully, and without pain (Adler & Taylor, n.d.; Jankovic et al., 2004). When it is time to stop living, some children seek permission (Adler & Taylor, n.d.). Clinicians have observed children clinging to life, suffering, and in pain, until their parents tell them that it is all right to die.
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(Adler & Taylor, n.d.). Their fears and sadness about hurting and leaving their parents are alleviated, once permission is granted and acknowledged (Adler & Taylor, n.d.). Children intuitively know when they will die, and find comfort and peace in being touched and held at their time of death (Adler & Taylor, n.d. Küber-Ross, 1983/1997). “They will tell you goodbye, and you know this is the last time you will see them” (Küber-Ross et al., 1972, p. 176).

**The Fight for Life**

Dying children know they are dying, yet they still want to live (Wolfelt, n.d.). When communication with them is honest and open, dying children are fully aware of their limited lives, but they still intend to go on, laughing and playing and doing everything they can, as often as they can, to live their lives (Wolfelt, n.d.). The fight for life is a struggle for children from the time of diagnosis (Arkansas Children’s Hospital, n.d.). Dying children fight the illness; they fight the caustic treatments and side effects; they fight the fears and concerns, and occasionally, they fight their parents, family, friends, or health care professionals – in order to continue living (Arkansas Children’s Hospital, n.d.). This fighting is determined, brave, and inspiring; it can save lives, beat odds, and improve quality of life (Arkansas Children’s Hospital, n.d.). The arduous fighting for a cure, until death, is admirable, and can be fully supported so long as it does a dying child no harm (Arkansas Children’s Hospital, n.d.). But some dying children reach a point during the fight when their goals change. Instead of an improbable cure, they begin fighting for good days rather than bad ones, for making their life meaningful, for making memories, or for avoiding pain and suffering (Arkansas Children’s Hospital, n.d.). These children conserve energy and strength, concentrating on how they can make a difference in their lives, and in other’s lives (Arkansas Children’s Hospital, n.d.). Fighting can take different forms for different children, and whether one way or the other is easier or more difficult, is unknown
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(Arkansas Children’s Hospital, n. d.). However, the fighting is always for living, and not giving up (Arkansas Children’s Hospital, n.d.).

Children need a great deal of support in their fight for life (Wolfelt, n.d.). Not only do they need open communication and support from parents, family, and health care professionals, but also from neighbors, friends, schools, and communities (Kreicbergs, U., 2018). The dying child’s illness is likely to create physical, social, and emotional barriers to relationships with others (Wolfelt, n.d.). It is important to ensure that relationships and friendships are nurtured as much as possible (Wolfelt, n.d.). The child’s daily routines should be adhered to in order to maintain feelings of protection, and a sense of control (Wolfelt, n.d.). Emphasis should be placed on supporting living rather than dying (Kreicbergs, U., 2018; McGraw et al., 2012), and encouraging the dying child to frequently engage in enjoyable activities with their peers (Adler & Taylor, n.d.; Dighe et al., 2008). Children with life-limiting illness need others to talk to about their fears, joys, anger, or just things like television, toys, video games and sports (Adler & Taylor, n.d.). It is important to accept that they may not want to discuss their illness (Adler & Taylor, n.d.). Children need to be recognized as the individuals they are (McGraw et al., 2012), and listened to with a non-judgmental and caring presence (Adler & Taylor, n.d.). Their fight to live as a social being and not a patient commands respect (McGraw et al., 2012). Children have the right to fight to be nurtured, to make choices, and to make every day count for living, while dying (Wolfelt, n.d.).

A Need for Control

Children with life-limiting illness experience uncertainties about the future, and may feel some loss of control over life. The literature not only suggests open, honest communication to minimize these feelings, but also supports the idea that children should be informed, and take some control regarding their illness, plans for treatment, and their dying process (Beale et al.,
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2005). There is, however, a paucity of information regarding how and when children with life-limiting illness make decisions regarding when to end curative and life-extending efforts, resuscitation, life support, end-of-life care, and place of death (Hinds et al., 2008). Historical accounts from the 1600s in England reveal that children express concern regarding who should inherit their possessions (Newton, 2015). Modern research indicates that some children make plans, and possibly make a will, controlling who will get their favorite belongings, and what will become of their pets (Dicker, 2012). While not all children want to talk about or plan their dying ahead of time, when they become aware that their distant future is limited, they may adjust by paying close attention to, and planning for, more immediate special events, such as the next birthday, a specific holiday, or a vacation (Beale et al., 2005). Children with life-limiting illness realize that, as they become closer to dying, trying to hold on to things, over which they have no control, does little good and depletes energy (Arkansas Children’s Hospital, n.d.). By letting go and not to trying to control some things that take away life, their energy and attention can be focused on what they can control, and where they can make a difference, so as not to give up (Arkansas Children’s Hospital, n.d.).

Hope

Hope for many people, in terms of life-limiting illness, has been thought of as a hope of narrow scope – a hope for a cure (Arkansas Children’s Hospital, n.d.). If hope for a cure is not supported medically, the situation may seem hopeless (Arkansas Children’s Hospital, n.d.). Dying children search for, have, and cling to hope (Arkansas Children’s Hospital, n.d.; Sisk et al., 2016). Yet their definition of hope is broad, with many faces, which need not be mutually exclusive of each other, as follows (Arkansas Children’s Hospital, n.d.; Sisk et al., 2016):

Hope may be the search for hope itself – something to grasp onto. Hope may be to live without
pain or suffering. Hope may be to live longer than expected to reach a certain milestone. Hope may be for a good quality life, no matter how long. Hope may be for a meaningful and purposeful life. Hope may be for a peaceful and dignified death. Hope may be for a miracle. Hope may be for more hope. Hope is elastic and resilient, with an ever-changing shape and scope (Arkansas Children’s Hospital, n.d.; Sisk et al., 2016). A child may need to let go of one form of hope in order to gain another (Arkansas Children’s Hospital, n.d.). Initially, it was thought that dying children with knowledge about their prognosis would lose hope, and not be able to find it (Arkansas Children’s Hospital, n.d.). This may happen when only half-truths are disclosed to children about length and quality of life, in an effort to prevent them from losing hope (Arkansas Children’s Hospital, n.d.). Such practice is unwarranted, and current literature reveals that prognosis disclosure actually supports and helps the child to find hope, even when the prognosis is grim (Sisk et al., 2016). Children believe in, and search for hope for a very long time, up until death (Sisk et al., 2016). The child’s “need for hope deserves understanding and respect. Hope (itself) also deserves understanding and respect for the resilient and expansive thing that it is, and can be” (Arkansas Children’s Hospital, n.d., p. 3)

Heaven

Though it is important for children to understand their biological dying, its spiritual relevance cannot be overlooked (Champagne, 2008). Children with life-limiting illness often convey recognition of their expected death with questions about where they will go when they die (Jankovic et al., 2004). Religious families rooted in faith are more likely to converse about death with their children (Kreicbergs et al., 2004). Spiritual concepts of life-after-death, and Heaven, are discussed more readily (Kreicbergs et al., 2004), and religious stories, rather than explanations, can be supportive of the child’s dying process (Champagne, 2008). Such religious
stories, passed down through tradition, contain significant symbolism and concepts (e.g. God, Heaven, and Paradise), enabling the child to reconstruct the stories around themselves, making sense of their transition with less fear (Champagne, 2008). Through these conversations, dying children accept the inevitable, and may even express calmness and delight about going to Heaven, or some other faraway place (Jankovic et al., 2004; Newton, 2015). They are capable of extraordinary faith, and believe they are loved by God (Newton, 2015). Depending on religious beliefs and spiritual upbringing, children who are dying may perceive their death as an extended journey, not an end (Jankovic et al., 2004). As their illness progresses, they may seem to give up the physical fight (Newton, 2015), yet continue to battle for decision-making rights and support (Wolfelt, n.d.). At this stage, their focus shifts to moving on, and they look to their parents, health care professionals, and friends to relieve any doubts and fears about doing so (Jankovic et al., 2004). Dying children want reassurance that they will not die alone, and when they get to their faraway place, they will not be by themselves (Jankovic et al., 2004). They often mention talking with deceased loved ones “in their hearts” (Champagne, 2008, p. 258), believing they are heard, and that they will see them again soon. (Jankovic et al., 2004, p. 2). Parents and families who support dying children in spiritual expression not only reinforce the children’s beliefs with religion and tradition, but also relieve their own fears and grief, relying on their faith for consolation. Children are in a special, spiritual state as they prepare to reach death, some with contentment for passing on (Newton, 2015). It is important to note that the nature of any spiritual suffering of dying children is unknown (Dighe et al., 2008). Religious and cultural needs should be respected and provided for (Adler & Taylor, n.d.). Children may express jubilation at the thought of seeing lost loved ones once more, or God’s angels coming to take them in salvation; this is comforting to many (Newton, 2015). Practices allowing the dying child
to remember, show gratitude, and say goodbye honor the dying transition, and permit the child to let go, - and go to their Heaven, in peace (Adler & Taylor, n.d.).

**Significant Researchers**

In addition to the ten prominent themes found in the existing literature regarding *living as a dying child*, it is important to recognize two significant researchers whose works directly involve dying children, and have made an impression in Pediatric research and tradition: Bluebond-Langner and Kübler-Ross, neither of whom is a nurse.

**Bluebond-Langner.** Myra Bluebond-Langner received her PhD from the Department of Anthropology at the University of Illinois in 1975. Dr. Bluebond-Langner’s doctoral thesis is an ethnographical study of dying children and the people around them. This innovative study of awareness and communication of terminally ill children became the basis for her award-winning book, *The Private Worlds of Dying Children* (Bluebond-Langner, 1978). For each child observed in the study, Bluebond-Langner (1978) constructed a play from field notes (taped transcriptions and recorded observations). The individual plays were then assembled to form a composite play in order to include a broad range of characteristics and experiences, sustain a comprehensive analysis, and preserve anonymity (Bluebond-Langner, 1978). This composite, ethnographic play has five acts, which represent the extended process of living with dying; the five acts reflect the length of various aspects of this process, and the five stages of the socialization process (Bluebond-Langner, 1978). Analysis of Bluebond-Langner’s (1980) fieldwork reveals that children, by age three, can understand that they have a terminal illness and know their prognosis, even if never told. Viewing death as a sociocultural phenomenon, Bluebond-Langner (1978) claims that mutual pretense is the primary interactive mode between dying children and those around them. Children decide to conceal knowledge of their prognosis
from others to preserve social order, and ironically, come to see their living role as supporting others (Bluebond-Langner, 1978). It is possible to measure a child’s awareness of prognosis by certain exhibited behaviors, yet parents and health care providers avoid discussion, and may be in denial regarding impending death as a manifestation of the conflict between their roles as nurturers, and allowing the unthinkable to occur (Bluebond-Langner, 1978). The author (Bluebond-Langner, 1978) states that in order to meet the conflicting needs of all involved, dying children should be allowed open awareness with those who can handle it, and also maintain mutual pretense with those who prefer to use it; “children know what their parents know and what they want to hear” (p. 235), but have a need to share their knowledge with others to avoid emotional isolation and loneliness. Bluebond-Langner (1978) brilliantly presents dying children from an interactional point-of-view, yet falls short of describing what it means to be living as a dying child. To her credit, Dr. Bluebond-Langner continues to conduct and promote high-quality research with life-limited children and other disciplines (including Nursing) to improve the evidence base for children’s palliative care (Bluebond-Langner et al., 2016).

Kübler-Ross. Dr. Elisabeth Kübler-Ross was a pioneering psychiatrist whose lifelong work with dying patients revolutionized the care of the terminally ill (Noble, 2004). In 1969, Kübler-Ross’ groundbreaking book, On Death and Dying, emerged from in-depth analyses of over 200 interviews with individuals facing death. In On Death and Dying (1969/2014), Kübler-Ross delineated and explored the renowned five stages of death: Denial and isolation, Anger, Bargaining, Depression, and Acceptance. On Death and Dying was instrumental in raising awareness among the general public and the health care community regarding important issues surrounding death and dying (Noble, 2004). In turn, by the 1980s, Kübler-Ross’ work (1969/2014) was a powerful force in thanatology (the study of physical, psychological, and
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social aspects of dying), becoming a routine part of health care education, and in the creation of
the hospice system in the United States (Noble, 2004). It wasn’t until 1983, however, with the
publication of *On Children and Death*, that Elisabeth Kübler-Ross publicly broached the topic of
dying children. Through focusing primarily on parents dealing with the death of their children,
*On Children and Death* reveals glimpses of what it is to be a dying child. Death is a great
transition – the culmination of life, and the end before another beginning; it is the door of
understanding into human nature, human struggle and survival, and human spiritual evolution
(Kübler-Ross, 1983/1997). Kübler-Ross states that our teachers about life are those who learn to
know death, rather than to fear and fight it (1983/1997). Children living with dying do better
with open, honest family communication (Kübler-Ross, 1983/1997). Shared sorrow is easier for
children to bear, rather than leaving them with anxiety that is manifested by feelings of fear and
guilt (Kübler-Ross, 1983/1997). Regarding this prerogative, Kübler-Ross metaphorically
explains, “should you shield the canyons from the windstorms, you would never see the beauty
of their carvings” (Kübler-Ross, 1983/1997, p. xv).

Throughout *On Children and Death*, extensive interviews with dying children and their
families provide experiential data that supports the premises that children die when they want to,
when they are ready, and when they decide to go (Kübler-Ross, 1983/1997). Children accept the
permanence of death, improve their interpersonal relationships, and seemingly put their lives in
order; they may even leave a last will and testament (Kübler-Ross, 1983/1997). Whether or not
told a prognosis, children express intuitive knowledge of their impending death through
symbolic language and premonitions about heaven, with excitement about going (Kübler-Ross,
1983/1997). Kübler-Ross explains this intuitive knowledge as a “preconscious awareness” that
emerges from the “inner, spiritual, intuitive quadrant and gradually prepares the child to face the
forthcoming transition, even if adults deny or avoid this reality” (Kübler-Ross, 1983/1997, p. 134). Kübler-Ross’ work (1983/1997) offers families assistance and hope they need to confront their dying child, but provides little insight into what it is like to be *living as a dying child.*

**Mattie J. T. Stepanek**

To fully understand and conceptualize what it means to be *living as a dying child,* it is crucial to examine what is known regarding the author of the poems to be analyzed, Mattie J. T. Stepanek. This allows the researcher to bring to consciousness any fore-understandings regarding the phenomenon that are rooted in who the author is, what he is about, and what is written about him.

Mattie J. T. Stepanek was born on July 17th, 1990, the youngest of four children, all of whom were born with a rare and fatal form of muscular dystrophy (Associated Press, 2004; Stepanek, n.d.; The Mattie J.T. Stepanek Foundation, 2012). It wasn’t until 1992, when Mattie’s mother was diagnosed with an adult-onset version of dysautonomic mitochondrial myopathy (DMM), that their grave, genetic disease was identified (Johnson, 2006; The Mattie J.T. Stepanek Foundation, 2012). All of Mattie’s siblings died from complications related to DMM at early ages; Mattie survived longer as research made more information known about his disease (The Mattie J.T. Stepanek Foundation, 2012). DMM causes progressive, generalized muscle weakness and impairs automatic body operations such as respiration and oxygenation, blood pressure and heart rate, digestion, and excretion (Muscular Dystrophy Association, 2015; The Mattie J.T. Stepanek Foundation, 2012). Mattie spent significant amounts of time living in the hospital, and eventually became dependent on a mechanical ventilator, oxygen, vital sign monitors, a feeding tube, medications, and a wheelchair (Associated Press, 2004; The Mattie J.T. Stepanek Foundation, 2012).
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Mattie J. T. Stepanek witnessed the effects of DMM first-hand at age three, when he experienced the death of his four-year-old brother Jamie (Johnson, 2006; The Mattie J.T. Stepanek Foundation, 2012). He initially expressed feelings of anger, sadness, fear, and confusion over the loss of his siblings and his DMM. His mother encouraged him to create stories and poetry as a coping strategy, and taught Mattie how to record them on a tape recorder at age three (Associated Press, 2004; Stepanek, n.d.; The Mattie J.T. Stepanek Foundation, 2012). By the age of five, Mattie began writing his poems by hand, and eventually, learned to type (The Mattie J. T. Stepanek Foundation, 2012). Mattie’s poetry evolved through his years, from creative expression of his personal living experiences, to articulation of his understanding of the world around him, and ultimately, of his assertion of the humanistic need for hope and peace (The Mattie J.T. Stepanek Foundation, 2012). During his lifetime, Mattie J. T. Stepanek published five poetry books, all of which were New York Times Bestsellers: Heartsongs (2001), Journey through Heartsongs (2001), Hope through Heartsongs (2002), Celebrate through Heartsongs (2002), and Loving through Heartsongs (2003). Upon publication of his works, Mattie shared his life message on television as a guest on The Oprah Winfrey Show, Good Morning America, The Today Show, Larry King Live, and the Jerry Lewis Labor Day Telethon for Muscular Dystrophy (Johnson, 2006; Stepanek, n.d.; The Mattie J. T. Stepanek Foundation, 2012). He developed personal friendships with President Jimmy Carter and Maya Angelou, and often discussed his good fortune in life, his awareness of dying, and his wishes for hope and peace throughout the world (Johnson, 2006; Stepanek, n.d).

Mattie was working on before he died: Another poetry collection, *Reflections of a Peacemaker: A Portrait through Heartsongs* (2005), and *Just Peace: A Message of Hope* (2006), a compilation of essays and e-mail correspondence between Mattie and President Jimmy Carter. Both of these books also became *New York Times* Bestsellers, and in 2007, *Just Peace* won the Independent Publisher Book Award for Outstanding Peacemaker Book of the Year (The Mattie J.T. Stepanek Foundation, 2012)

Mattie J. T. Stepanek was an exemplar of the phenomenon of *living as a dying child*. He left behind an extensive collection of thoughts and feelings, his *Heartsongs*, emoted through written poetry. Mattie J. T. Stepanek’s wisdom and humanistic love for life and for others sparked my interest in a hermeneutic study of his writings to gain the truth of *living as a dying child*.

**Developing Forestructures and Fore-Understandings**

The hermeneutic circle is not a haphazard course of knowledge and understanding, but rather a revelation of the interpretive researcher’s forestructures (Geanellos, 1998b). As the researcher prepares to enter the hermeneutic circle by acquiring the right horizon of inquiry (Gadamer, 1960/2013), forestructures are developed by taking into account the researcher’s history, knowledge, beliefs and experiences regarding the phenomenon (Geanellos, 1998b). Johnson (1987) explains that forestructures include *forehaving* (experiences in life which make interpretation possible), *foresight* (life experiences and practices that pose a viewpoint from which interpretation is made), and *foreconception* (background practices that promote assumptions about what one may anticipate in interpretation).

As I seek to answer what it is like to be *living as a dying child*, and in bringing forestructures to consciousness, I present seven contemplative and spontaneous attributes that
support my own convictions regarding the nature of the phenomenon: (1) fun, (2) low times, (3) bounce-back, (4) faith, (5) courage, (6) knowingness, and (7) love. I then reflect on each attribute, analyze its significance in my understanding, and bring forth interpretation and assumptions regarding my beliefs about the phenomenon. Finally, I develop forestructures by reinterpreting and conceptualizing each attribute with regard to the phenomenon in my life and professional experience. Through this process, I bring awareness to my forestructures and foreunderstandings as I enter the hermeneutic circle for this study, enabling the phenomenon within the poetic text, to speak.

1. Fun

**Interpretation.** Despite ongoing struggles with physical changes manifested by life-limiting illness, emotional flux, and social limitations, dying children still want to have fun while living, and enjoy the people, places, and things around them while doing it. Engaging in lighthearted pleasures enables them to “blow off steam,” focus themselves in a more positive direction, and direct their energy towards something they feel happy or passionate about. Fun is necessary for life’s balance, and readily received. No obstacle is too difficult or too big for dying children not to have fun.

**Forestructures.** Children with life-limiting illness do as much as they possibly can to have fun. They will often decorate their wheelchairs and assistive devices with bright colors, popular characters, and frivolous accessories to make seeing and using them more fun. Games, arts and crafts, singing, dancing, writing, practical jokes, imaginary stories and characters, parties, and movies are all part of a dying child’s fun repertoire. They may want to have fun by themselves, or engage with peers, family, or even health care professionals, when possible. If something presents as a hindrance to fun, such as physical illness or inaccessibility, children look
beyond the obstacle towards future planning, and having fun once more. They ask questions about when they will be able to play with friends or pets; they want schedules regarding activities that are being offered around them; they seek out people to talk and joke around with. Children laugh and smile when they are content and while they are having fun, even if other things in their lives are difficult for them. They want and need fun to offset life’s low times, and will do anything they can to have it – fun.

2. Low Times

Interpretation. It is only natural for children with life-limiting illness to experience low times. Low times are not labeled with emotions and behaviors such as depression and despondency, but include quiet, introspective periods needed to slow down life’s pace, reflect, and regroup. Low times conserve physical, emotional, and spiritual energy, allowing the dying child to think and decide for themselves, on their own terms. Low times may be decided on by the child, or encouraged by physical limitations or illness. Low times are not necessarily indicative of unhappiness or sorrow. They are necessary for life sustenance, and enable the dying child to persist and to keep on living.

Forestructures. Dying children often take rest periods with minimal extrasensory stimulation. They may want the lights and television off, and may even refuse to eat. They may not feel like talking, and interaction with others may be minimal. These low times often include napping, reflecting, and observing. Low times for children who are dying can serve different purposes. On one hand, they may be needed due to being overwhelmed and exhausted, allowing themselves Rogers, 1992ime to take it easy, save energy, and preserve strength. Instead of reading themselves, dying children may ask parents to read to them, or say prayers for them, as they silently listen and ponder. The environment and other people may be shut out deliberately,
and they will sleep, completely resting their tired bodies, minds, and spirits. On the other hand, low times may be introspective and internally quite productive. Dying children may quietly plan how they are going to do things, and sometimes write short thoughts, poems, or stories on paper to reflect their feelings. Questions regarding life and its meaning often arise, manifesting a deeply contemplative state. Observation of nature and people around them can be super-acute and wide in scope, absorbing everything and the energy that accompanies it, all at once. The nature and frequency of low times varies, as does purpose, yet their presence in dying children is recurrent.

3. Bounce-Back

**Interpretation.** Children who are living as dying have a tremendous capacity for recovering quickly from tough circumstances – a super-elastic bounce-back. They endure tremendously difficult physical, mental, emotional, and social challenges, yet they have an uncanny ability to snap back, refusing to let their adversities define them. They generally cope well under pressure. Unlike most adults, dying children recover from challenges quickly; they are more apt to accept things they cannot change, and trust that they will rebound from them. Dying children believe in themselves, and in their ability to come back and to move forward wholeheartedly, no matter how crippling the circumstances.

**Forestructures.** Life-limiting illnesses in children, regardless of diagnosis, present extreme challenges: potent medications with intense side effects, invasive procedures accompanied by pain and suffering, and permanent, debilitating physical changes. Dying children also experience social challenges related to the way they look, feel, or act, yet they readily accept these challenges and endure them, always moving ahead with efforts to be the best they can be, as soon as possible, once again. They appreciate interaction with others, and want
to talk about things they like, such as television, school, or hobbies. They often develop talents, such as drawing or writing to express their feelings, change their focus, and forge through their difficult times. Dying children want some control as to when to take their medication, what activities to participate in, and what treatment strategies to pursue; this boosts their confidence as they overcome obstacles, and strengthens their ability to bounce back.

4. Faith

Interpretation. Children facing death have faith in abundance, and in various capacities – faith that incorporates strong conviction, implicit trust, and strong beliefs. Dying children have faith in their parents’ loyalty, trustworthiness, and reliability. They have faith in their health care professionals’ knowledge and expertise for providing the best interventions with optimal outcomes. They have faith in themselves for being strong and clever in fighting their illness and maximizing their potential. Children have faith in a God or a higher power that gives them strength, offers comfort, and delivers hope. They have faith that dying and death are not their demise, but are part of their journey that leads them beyond this world to somewhere or something that is extraordinary, and divine. Faith, for children, is the impetus for living as dying.

Forestructures. Dying children trust that parents and health care providers have their well-being at heart. They understand that they cannot undergo procedures, treatments, and medication regimes alone, and express faith in the opinions and recommendations of those caring for them. These children ask many questions regarding what they might have to withstand to improve their abilities and slow their disease process. As they gain knowledge and informative support from those around them, they build faith in themselves to participate in decision-making. Fears are minimized as they move forward with aplomb, often reassuring family that they will be
okay, no matter the outcome. Children speak of going to Heaven and rejoining family and friends who have passed away. They describe what God and Heaven might be like, as well as their bodies being whole, able, and well, when they get there. They speak of, write about, and illustrate their faith in all possible circumstances, planning future celebratory activities with others, and leaving messages, instructions, and personal belongings, should they not see their loved ones again.

5. Courage

**Interpretation.** Strengthened with faith, children with life-limiting illness exhibit great courage. They appreciate honesty and trustworthy communication to educate themselves regarding their abilities, limitations, and disease progression. They strongly believe in themselves, have the ability to stare adversity in the eye with conviction, and make choices with confidence and determination. Dying children knowingly come out of their comfort zones to embrace change, and the unknown that lies ahead. They have an uncanny ability to squelch their fears and keep going, even when circumstances are dire.

**Forestructures.** Courage is steadily exhibited by dying children. They want to be well versed in what has occurred, is happening, and what will happen to them. They will confront parents and health care providers head-on for answers. If answers are vague or confusing, they will press for details, insisting on the truth. When questioned about their conditions, or changes in appearance (such as loss of hair, immobility, or weight fluctuation), they are usually direct and forthright, giving elaborate and factual responses related to medication, treatment, and illness progression. Dying children want to live, and believe they can. They are determined to overcome chemotherapy, physical alterations, and disabilities, and social challenges, no matter how afraid they are. They may express their fears regarding leaving parents, family, and friends
behind, and even inquire about what will happen when they die, and when they are gone. However, they courageously forge ahead, planning activities and social events for the best of outcomes, while bracing themselves for the inevitable.

6. Knowingness

**Interpretation.** Dying children have a keen knowingness. They know when things are progressing swimmingly, and also when something is going awry. They know when someone is honest and forthcoming, and also when the truth is concealed from them. Children have extra-sharp senses, and are fully aware of everything concerning them, and everyone and everything going on around them. They know who can help them and when they can be helped. They also know when dying is inevitable and living, as they know it, is impossible. Dying children know what they will die from, why, where, when, and how they will die, and who will be with them when they do. They know.

**Forestructures.** Children living as dying are astute. They make it their business to inquire and educate themselves about their illness, its progression, and all things associated and changing with the process. They know when their physical abilities are debilitating, when they are incapable of attending school or participating in social activities, and when they need acute intervention or hospitalization. Children can tell whether parents, family, and health care providers are concealing information, or being forthright with prognosis and expected outcomes. When they sense uneasiness, disappointment, sadness, frustration, or anger in others, they probe diligently for reasons and answers, cope with the truth, and even suggest alternative treatment measures. Those caring for dying children undergo intense scrutiny with each interaction; all words, steps, actions, and intents are cognitively assessed for precision, authenticity, and sincerity. Dying children recognize vagueness, hesitancy, and deception. They know when a
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caregiver is just going through the motions with little credence. They also know when they are transitioning; when, despite intensive efforts, death ensues. Children know how and where they want to die, and, if possible, will ask to be in a certain place with certain people. If no request is made, they will wait until they encounter certain individuals. They often ask for minimal or no life support when they are ready, and exhibit an unsuspected calm as they knowingly leave us.

7. Love

**Interpretation.** Children, especially those who are dying, engage in loving relationships with those who are reflections of their pure and true selves. Their unique magnetism draws loving people like them, towards them, effortlessly. Children love selflessly, accept others openly, and trust that those who love them in return will help to heal them, give companionship willingly, and work with them to achieve mutual goals. Love between dying children and those they love is pure, fearless and sacred.

**Forestructures.** Loving relationships with dying children are those of mutual respect, and open, honest communication. Children sense when health care professionals show love, and they are more apt to open up about their thoughts and feelings when the relationship is compassionate. They express love through anticipation of those they care about, spending meaningful time with them, and engaging with abandon. Dying children want to love and be with their parents, friends, and health care providers. In return, they expect only love back. They want loving company instead of being alone. Children express love through acts of kindness, such as drawing pictures, making crafts, or singing songs for those they care about. Their expressions of love are free, trusting that those they love will not harm them – just love them unconditionally, until they die.
Bringing Fore-Understandings to Consciousness

The hermeneutic researcher must consciously designate and qualify their fore-understandings – their own opinions and prejudices (Gadamer & Fantel, 1975). In doing so, these fore-understandings are “stripped of their extreme character” (Gadamer & Fantel, 1975, p. 44) in order to allow “the text the opportunity to appear as an authentically different being and to manifest its own truth, over and against … pre-conceived notions” (Gadamer & Fantel, 1975, p. 44). To consider my presuppositions of the hermeneutic situation, I begin by writing a story, incorporating my experiences regarding living as a dying child. Writing the story enables me to remember significant phenomenal life accounts, and weave them into the story. I then reflect upon the story to examine why certain incidences are significant to me, what they represent, and what I learn from them. I try to understand the implications that the story has with regard to living as a dying child, and I present the fore-understandings developed from the story, in list form. Despite my efforts, I am aware that some of my prejudices may remain unexposed. However, writing such a story before entering the hermeneutic situation with the text brings forth as many fore-understandings as possible to ensure a right horizon of inquiry and strengthen the interpretive quality.

My Story: Gloria

It was September, and Gloria was in second-grade. A small, thin girl with chestnut hair and long eyelashes, Gloria was always tidy, and carefully groomed. She was soft-spoken, and unusually calm, always avoiding large groups of people. The nuns in Catholic school clamored around her with nervous excitement – as if waiting for a shoe to drop. So much so, that Gloria did not play a lot. It was as if she was being protected from something. Most of the time, Gloria was either alone, or with her best friend Toni. During recess, if Gloria was by herself, she would
sit by the lake daydreaming. When Toni was around, Gloria would sit or walk steadily and straight, while Toni darted around her, encouraging her, and making her laugh.

One day, Gloria was absent … and then the next day, and then the next whole week. Gloria tried doing her school work at home, calling Toni for assistance, and trying to catch up on social events. She tried to concentrate, but her head ached, and fatigue always ensued. Soon after, an announcement was made in school for students to keep Gloria in their prayers. Gloria was sick. She had a brain tumor.

Gloria underwent brain surgery in November, and six weeks later began aggressive chemotherapy. Her treatments involved cyclical admissions to the pediatric oncology unit for several days per cycle. Each time she entered the hospital, she knew she would face tough challenges. Gloria was poked with needles, pumped with drugs, and monitored, almost too closely. She felt nauseous and threw up, and sometimes had diarrhea. Gloria could barely eat, and occasionally was short of breath. She understood that in order to get better, she must go for treatment, and she reassured her parents every time that she would be okay, and get through it. Her parents looked worried and forlorn all the time. They did not want to speak about what was happening, and Gloria did not want to hurt them by asking questions. She found that information was easier to obtain while she was undergoing treatment. Gloria became keenly observant and knowledgeable regarding every aspect of her care. She asked the nurses about her specific medications: “What does cis-plat do? Why do I need vincristine?” Most of the time, Gloria got truthful, straightforward answers, with senses of hope and compassion. Once-in-a-while, she would get a response of, “you should ask your doctor or parents about that,” from an obviously uncomfortable RN. In those instances, when her physicians were not around to be interrogated, Gloria was a “super hearer.” Her golden ears listened cautiously to the nurses giving report,
multidisciplinary rounds, and conversations of other children and their parents, patient care technicians, visitors, the dietary staff, and anyone else with a remote interest in her condition. Being quiet and soft-spoken had its advantages: those around her weren’t always aware of her presence. In addition to listening, Gloria acutely eyed health care providers’ procedures and protocols, and was attuned to regimens and schedules. She recognized accuracy, and had no difficulty verbalizing a rare breech in compliance. “Isn’t it time for my medicine?” and “the doctor should have come already” are some things she would point out. Her health, and happiness were riding on things done right.

When her physical state was stable during hospitalization, Gloria wandered to the playroom. She went there to give her mother a break. There she lightly chatted with the other children, but focused mostly on painting with watercolors. It was important for Gloria to paint a picture every time she had treatment. She tried to incorporate as many hues and details as possible. She admired her work as it hung on an indoor clothesline to dry. She saved all of her paintings in a wooden cubby with her name on it.

For every hospital discharge, Gloria’s parents always brought cookies, thanked the staff, gathered up their belongings, and carried Gloria away. They breathed heavily, wondering with everyone else, whether Gloria would return. If she did come back, would it be because treatment was working, or her health was failing? Would Gloria not return because she went into remission, or because further treatment would be consequential, or because she died?

At home, Gloria tried as hard as possible to live as she has before the tumor. She called Toni on the phone every day, asking how school was, and what she was missing. Gloria told Toni she felt alone sometimes, and wished she could play more. Gloria’s hair was falling out, she was having trouble focusing, and her gait was unsteady. Everything she ate tasted like metal,
and her favorite foods weren’t her favorites anymore. Her spirit was imprisoned. On Saturdays, Toni would come over for a short while. She and Gloria reviewed schoolwork, played Barbie, and watched movies. After a few hours, Gloria’s mom would tell Toni to call her mom to pick her up because Gloria was tired and had to take a nap. When Toni left, Gloria always gave Toni one of her Barbie dresses to keep. She hardly ever took a nap afterwards. That was an excuse Gloria’s mom would use to end the play dates; they were too much for her to bear, and she often cried afterwards. It made Gloria feel bad to think that she made her mother sad. She prayed that she would heal quickly to bring relief to her parents.

April came quickly, and Gloria told Toni that she was traveling to France with her family to bathe in the water at the Sanctuary of Our Lady of Lourdes. God provided them with the strength to break from chemotherapy, and reconfirm their faith. Meanwhile, each morning at school, the student body prayed for a miraculous cure … for Gloria.

When Gloria came home from France, she was fragile, and looked pasty. She returned to the hospital to resume treatment. She went into the playroom and tried to paint, but was too weak to do so. She asked the play therapist if she could have all of her watercolor paintings because she wanted to “see them altogether.” After scrutinizing each one, Gloria took the art pile to her room and she climbed on the bed. Gloria’s mother was curious when she saw how many there were. Gloria said, “I made a remembrance of all our fun times so you and Daddy wouldn’t forget them when I am not here. Every time I came to the hospital, I thought of, and painted good things to get me through. It worked every time – until today.” She went over each painting with her mother, numbering them, and pointing out her favorites. Gloria’s mother began to cry as Gloria’s breathing became slow and shallow. For the next twelve hours, Gloria had an oxygen mask. Her mother laid on the bed next to her, and her father sat on the far end,
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staring at her. Gloria struggled quietly, in and out of sleep. She found a bit of strength to remove the mask, and whispered, “This is how it’s supposed to be. I love you. Don’t forget.” Gloria closed her eyes and died peacefully. It was May 30th.

Fore-Understandings

The following are fore-understandings of children who are living as dying, as developed from the story:

- Children are brave. Even when they are fully aware of adversity, they are willingly to take risks and face consequences, if living depends on it.
- When children suspect that their parents and loved ones are worried and hurting, they will avoid discussion and asking questions, so as not to upset them further. Concern for parents often leads to children withholding their own feelings and emotions.
- Dying children want and need knowledge about their prognosis, treatment, and illness progression. They ask many questions.
- Children want to know the truth, and are often aware when people are dishonest or hesitant.
- Observing and listening intently are two ways children gather and process information. They may be calm and quiet, yet fully engaged to “get the scoop” on their situations.
- Children with life-limiting illness want and need things to go as planned. Often, scrutiny may give them a sense of control.
- Dying children recognize pain and suffering in those around them. They frequently try to carry their burden alone so as not to disrupt normal activity. They want to live as normally as they can, for them; they do not want to miss anything.
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- Children with life-limiting illness may feel trapped in their physically-limiting bodies; mentally and spiritually, however, they still long to soar.
- Children who are living as dying want and need friends. They often give their friends personal belongings as symbols of their friendship.
- Faith in God, and family support are sources of strength and guidance for children who are confronting their dying.
- Detailed planning is important for a dying child. Often, they plan in detail; they know how and when they want to die.
- Dying children do not want to be forgotten after they are gone. They often leave things to certain individuals as reminders of themselves.

**Summary of Chapter**

To summarize, Chapter II explains preparation for the hermeneutic circle with identification and development of the researcher’s fore-understandings. Three efforts are implemented to accomplish this: understanding and conceptualizing the phenomenon through a literature review, developing forestuctures and fore-understandings based on personal beliefs and opinions, and bringing fore-understandings to consciousness via reflective storytelling.

Review of existing literature reveals ten significant themes relating to the phenomenon of interest: (1) truth disclosure, (2) open, honest communication, (3) potential obstacles - parents and health care professionals, (4) awareness of dying, (5) the need to be heard, (6) mixed emotions, (7) the fight for life, (8) a need for control, (9) hope, and (10) Heaven. Two prominent researchers (Bluebond-Langner, and Kübler-Ross), as well as background information regarding the author of the poems, Mattie J. T. Stepanek, are also examined.

To bring forth personal fore-understandings, seven attributes that support personal beliefs
regarding *living as a dying child* are presented: (1) fun, (2) low times, (3) bounce-back, (4) faith, (5) courage, (6) knowingness, and (7) love. Reflection on each attribute reveals personal interpretations and forestructures regarding the phenomenon of interest.

Reinterpreting and conceptualizing life and professional experiences through storytelling brings personal fore-understandings to consciousness. Story analysis identifies personal forestructures with regard to the phenomenon of interest. Completion of these efforts brings awareness to the researcher’s forestructures and fore-understandings as the hermeneutic circle is entered. Preparation in this manner ensures trustworthiness of the study, and enables the phenomenon of interest within the text to be brought to light.
Chapter III  THE NATURE OF THE STUDY

This chapter introduces the hermeneutic approach as a suitable research process for the study of the text and poetry of Mattie J. T. Stepanek. Rationale for selection of this process is then discussed, followed by a historical account of the evolution of hermeneutics. This historical evolution includes hermeneutic origins, the development of phenomenological thought and its relationship with hermeneutics, Heideggerian hermeneutic phenomenology, and finally, Gadamerian hermeneutics.

The Hermeneutic Approach

Hermeneutics is a qualitative research approach that focuses on interpretation of art forms (Polit & Beck, 2014). Gadamerian hermeneutic researchers study written accounts of a phenomenon of interest (Polit & Beck, 2014). The core of the Gadamerian hermeneutic effort is the task of bringing text into understanding (Austgard, 2012; Fleming et al., 2003; Gadamer 1960/2013; Geanellos, 1998a). Transcripts of in-depth interviews, as well as novels, letters, poetry, or other artistic works of expression may be interpreted for meaning and understanding (Baumann, 1999; Nyholm et al., 2018; Polit & Beck, 2014). Gadamer’s philosophical hermeneutics describes the process of interpretation as a dialogical relationship between the interpreter and the text (Gadamer 1960/2013; Polit & Beck, 2014). The interpreter approaches the text with an openness to hearing what the text is saying (Polit & Beck, 2014). Through engagement in this process, the researcher examines the whole of the text in terms of its parts, and the parts in terms of the whole (Gadamer 1960/2013; Geanellos, 1998a; Polit & Beck, 2014). Working through this hermeneutic circle, the researcher cyclically questions and re-questions the meaning of the text, until an understanding of the phenomenon becomes clear (Polit & Beck, 2014). Hermeneutics does not just represent a description of understanding (Porter & Robinson,
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2011). It is the human process of understanding in which truth emerges through the incorporation of our previous understandings and constant dialogue with a written text (Porter & Robinson, 2011).

The desire of the hermeneutic researcher is to gain access to the artist’s or author’s world regarding their lived experiences, and to unearth the wisdom, knowledge, and understanding found there (Polit & Beck, 2014). It is through text and language that we enter the author’s world as we continuously open ourselves up to meaning and interpretation (Gadamer 1960/2013; Porter & Robinson, 2011). The phenomenon of interest for a hermeneutic study must be congruent with this desire, because it is from this desire that the research question and the Gadamerian underpinnings and process are developed and carried out (Fleming et al., 2003). This ensures that the understandings reached will be appropriate and useful for Nursing science (Fleming et al., 2003).

**Rationale for Selection of Research Process**

The poetry of Mattie J. T. Stepanek is an artistic, textual expression of the young author’s *living as a dying child*. In order to examine and gain a deeper understanding of this phenomenon, the way Mattie experienced the meaning of the world, and his place within it, a Gadamerian hermeneutic approach will be implemented. The rationale for selection of this interpretive process is multifold. Firstly, this beautiful art in text, as documented by a child who is dying, is a path of inquiry that not only provides insight regarding the phenomenon as humanly experienced, but also has the distinct possibility for revealing that which is difficult to vocalize (Baumann, 1999). The poetry of Mattie J. T. Stepanek has not yet been interpreted, yet the collective title of Stepanek’s works, *Heartsongs*, overtly conveys an intent to be heard and listened to, to be interpreted, and understood. Secondly, hermeneutics has long been used, and
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proves invaluable as a rigorous research methodology in other disciplines including theology, philology, art, and history (Austgard, 2012; Kinsella, 2006; Moules, 2002). First designed to examine sacred and classic texts (Baumann, 1999; Kinsella, 2006; Moules, 2002), hermeneutics has evolved through the ages into different schools of thought, faithfully remaining open to life’s mystery and understanding (Dilthey, 1910/2010; Gadamer, 1960/2013; Heidegger, 1927/1962; Schleiermacher, 1819/1978). The strength and credibility of hermeneutics lies in its long-standing tradition of literacy, history and ancestry (Moules, 2002). Thirdly, nurse scientists have expressed interest in the implementation of the philosophy of hermeneutics as a research foundation (Austgard, 2012; Fleming et al., 2003; Geanellos, 1998a), and a need exists to promote the use of human sciences and humanistic philosophy in Nursing research (Pratt, 2012). Increasingly, Nursing is referred to as a human science (Pratt, 2012; Rolfe, 2015) involving the study of human beings and their experiences as a source for knowledge and understanding (Dilthey, 1910/2010). Fourthly, human science-based research, such as Gadamer’s hermeneutics, lends itself to examining phenomena that would otherwise be difficult, or even impossible to explore, and provides a valuable research methodology that can reveal what human beings share while recognizing importance differences (Baumann, 1999). The rich language of Mattie J. T. Stepanek in his poetic text, inseparably accompanies his life experiences and remains as data written in a path frozen in time. The Gadamerian approach has the possibility to uncover the dynamic truths concealed within the text-language-experience relationship, and thus, to also reveal a mode of being for the experience of living as a dying child (Nosál, 2015). Lastly, Nursing as a human science is convergent with this researcher’s perspective as a human being and nurse researcher; the choice of a Gadamerian research approach is most appropriate for answering the research question: What does it mean to be living as a dying child? Understanding
the phenomenon will provide truth and essential knowledge for Nursing. The ability to sense the needs and desires of others in a caring relationship is the foundation of Nursing practice (Rolfe, 2015). Nurses can use this newly-acquired knowledge to heighten their senses in caring relationships with children who are dying. To fully comprehend the Gadamerian hermeneutic research methodology and the rationale in selecting this approach, it is essential to present the historical background and development of hermeneutics.

**Historical Evolution of Hermeneutics**

Gadamer’s philosophical hermeneutics, when used as an approach for interpretation of a text, requires that not only the researcher, but also the readers and evaluators of the study have a comprehensive knowledge of the philosophy’s basic premises and key concepts (Austgard, 2012). Often, nurse researchers mistakenly consider phenomenology and hermeneutics without differentiation (Austgard, 2012; Fleming et al., 2003). In order to gain insight into the complexity of philosophical hermeneutics, it is necessary to consider the origins of hermeneutics, an overview of phenomenological thought, the evolution of hermeneutics from Husserl to Heidegger, and finally, the original development of Gadamer’s philosophical hermeneutics from Heidegger’s philosophical underpinnings.

**Hermeneutic Origins**

Hermeneutics, in its most basic sense, dates back to the ancient Greeks (Leonard, 1989; Mantzavanos, 2016; Porter & Robinson, 2011). Derived from the Greek verb *hermeneuein*, meaning to interpret or to translate, hermeneutics refers to the science, theory and practice of human interpretation (Moules, 2002; Porter & Robinson, 2011). Hermeneutics was employed by the Greeks, beginning in the 6th century BC, to interpret, understand, and find hidden messages in the Homeric epics (Manzavinos, 2016). This method of nonliteral interpretation with intent to
discover deeper, underlying meanings was used widely up through the 3rd century AD, and later (Manzavinos, 2016). Through the Middle Ages (5th – 15th century AD), a primary purpose of hermeneutics was to explain the true meanings of biblical texts, and focused on the many complex relationships between the text, the author and the reader (Porter & Robinson, 2011). Neoplatonic Christians during this period, heavily influenced by Plato, drew humanistic inferences between Plato’s philosophy and Christianity, which were manifested in allegorical interpretations of bible passages (Palmer, 2010).

In 1630, German philosopher and theologian Johann Conrad Dannhauer published the first hermeneutica textbook, *Idea boni interpretis et malitiosi calumniatoris*, thus providing a systematic, hermeneutic method for distinguishing between the true and false meanings of any text (Manzavinos, 2016). Many authors followed suit, but Johann Clauberg, in 1654, created distinct, interpretive rules with respect to their generality, and also highlighted an author’s intentions as a valuable goal of interpretation (Manzavinos, 2016). Over the next two centuries, hermeneutics was relevant for all scientific domains and texts of all kinds (Manzavinos, 2016).

The beginning of the 19th century saw a movement towards romantic hermeneutics, with the works of Friedrich Schleiermacher and Wilhelm Dilthey (Porter & Robinson, 2011). Schleiermacher, a German biblical scholar, theologian, and philosopher was the first to describe hermeneutics as the art of understanding (Porter & Robinson, 2011; Schleiermacher, 1978), and moved interpretation away from being considered a body of rules intended for text application (Porter & Robinson, 2011). Schleiermacher recognized text to be a vehicle for the conveyance of the author’s thoughts; thoughts that developed before the text was written (Schleiermacher, 1819/1978). Schleiermacher realized the reading of a text was communicative interaction between the reader and the text itself (Schleiermacher, 1819/1978). These concepts led
Schleiermacher to define hermeneutics as the study of understanding (Leonard, 1989). Inspired by Schleiermacher, Wilhelm Dilthey, a German historian, psychologist, sociologist, and philosopher, argued that the meaningfulness of human actions distinguishes them from natural science phenomena (Porter & Robinson, 2011). Dilthey claimed both natural and human sciences were empirical, but recognized understanding, instead of explanation, as the foundation of the human sciences (Polifrani & Packard, 1999).

Both Schleiermacher and Dilthey focused interpretative efforts on understanding an author, and the author’s thoughts and historical and cultural context, as transcending the written text itself (Mantzavinos, 2016). Schleiermacher’s and Dilthey’s perspectives significantly influenced the evolution of hermeneutics as a methodological discipline for human science and phenomenological descriptions of the lifeworld (Mantzavinos, 2016; Porter & Robinson, 2011).

**Phenomenological Thought**

Rooted deeply in philosophy, phenomenology principally focuses on people’s perceptions of the world around them, and is often defined with regard to the study of phenomena and their nature and meaning, as people experience those phenomena (Kafle, 2011; Sloan & Bowe, 2014). The word “phenomenon” is derived from the Greek expression, which means, “that which shows itself; the manifest; to bring forth into light; appearance” (De Chesnay, 2015, p. 3; Heidegger, (1927/1962), p. 290). Phenomenology is an approach to exploring and understanding people’s everyday life experiences (De Chesnay, 2015; Polit & Beck, 2014). When a phenomenological study approach is employed, the researcher attempts to contemplate and theorize the various ways things become apparent in and through being in the world (Vagle, 2014). Phenomenologists assume there is an essence – an essential component – that can be understood; it is this “essence that makes a phenomenon what it is, and without
which, it would not be what it is” (Polit & Beck, 2014, p. 270). Generally, phenomenology is a qualitative research method, and there are two main types of phenomenological approaches that overlap philosophy and methodology: descriptive phenomenology, and hermeneutics, also referred to as interpretive or existential phenomenology (De Chesnay, 2015; Dowling & Cooney, 2012; Sloan & Bowe, 2013; Tuohy et al., 2013). In order to craft a hermeneutic research design with rigor that is harmonious with its philosophy, immersion into the history and philosophical underpinnings of interpretive phenomenology is essential (Munhall, 2012).

**Husserlian phenomenology.** Edmund Husserl (1859-1938) is widely recognized as the father of the phenomenological movement that originated in Germany in the early 1900s (Converse, 2012; De Chesnay, 2015; Polit & Beck, 2014; Tuohy, Cooney, Dowling, Murphy, & Sixsmith, 2013). At that time, progress in the natural sciences and scientific methods attempted to answer all questions of the natural world as well as human issues, and was touted as the only “route to truth” (De Chesnay, 2015, p. 3). Husserl and his colleagues were intent on the development of phenomenology as a robust human science with a methodology that would deem it comparable to the natural sciences (Converse, 2012; Dowling & Cooney, 2012; De Chesnay, 2015; Welch, 1999). However, Husserl’s philosophy was centered on descriptions of the world as it is lived, and not in the world as it is measured empirically (Polit & Beck, 2014; Vagle, 2014). Husserl’s goal was to answer the question: *What and how do we know, as humans?* (Polit & Beck, 2014; Welch, 1999).

Husserl believed that intentionality and consciousness are conditions of all human experiences (De Chesnay, 2015; Husserl, 1936/1970; Polifrani & Welch, 1999). Husserl, who studied under Franz Brentano (19th century psychologist), applied Brentano’s concept of intentionality to phenomenology (Converse, 2012; Dowling & Cooney, 2012). Intentionality is
the distinction between mental and physical phenomena, and refers to the reality that any mindful act is directed toward an object; for example, whenever a person thinks, they think something, whenever a person desires, they desire something, and so forth (Dowling & Cooney, 2012; Tuohy et al., 2013). Intentionality implies that all perceptions have meaning (Converse, 2012). Husserl further contended that intentionality was the distinctive feature of consciousness, as consciousness is always conscious of something (Dowling & Cooney, 2012). Husserl’s assumption was that a phenomenon only occurs when there is a subject who experiences the phenomenon (meaning is projected onto the object by the perceiving subject), and, as a result, subject and object are related, but separate (Dowling & Cooney, 2012).

The epistemological aim of Husserl’s phenomenological inquiry was to describe and understand the reality of human phenomena (thoughts and experiences) through a rigorous and unbiased examination of things as they appear to consciousness (Converse, 2012; Dowling & Cooney, 2012; Tuohy et al., 2013). Husserlian, or transcendental phenomenology, a descriptive phenomenology, requires that human experience is to be transcended to reveal reality (Converse, 2012; Kafle, 2011). That is, the researcher’s preconceived ideas, personal opinions, and understandings of a phenomenon must be removed to describe the true meaning of the phenomenon (Converse, 2012; De Chesnay, 2015; Kafle, 2011). Subjectivity of the researcher using Husserl’s approach is accomplished by employing transcendental reduction (Converse, 2012; Vagle, 2014). Transcendental reduction, or époché (bracketing), is the setting aside of, or applying parentheses to, the researcher’s beliefs, assumptions, and presuppositions, in order to experience and describe the phenomenon in the least prejudiced manner (Porter & Robinson, 2011). Intent is solely on the consciousness, disregarding context, time, and space (Husserl, 1964; Tuohy et al., 2013). According to Husserl, transcendental reduction discloses the
necessary and universal components – the essence - of the phenomenon, in pure form (De Chesnay, 2015; Polit & Beck, 2014; Porter & Robinson, 2011).

**Hermeneutic (Heideggerian) phenomenology.** As a student and assistant to Husserl in Germany, Martin Heidegger (1889–1976) recognized the significance of descriptive phenomenology, but swiftly expanded on Husserl’s work (Converse, 2012; Dowling & Cooney, 2012; Welch, 1999; Polit & Beck, 2014). Influenced by Aristotle, Heidegger believed that in addition to knowledge and description, human experience intrinsically subsumes interpretation and understanding (Welch, 1999; Polit & Beck, 2014). Heidegger argued that people make sense of the world from the viewpoint of their experiences and are not disconnected from the world around them (Converse, 2012; Dowling & Cooney, 2012; Heidegger, 1927/1962). Unlike Husserl, Heidegger’s critical query was *What is the meaning of Being?* (Converse, 2012; Heidegger, 1927/1962; Polit & Beck, 2012; Porter & Robinson, 2011). Heidegger’s transition from an epistemological (knowing) philosophy to an ontological (being) one, confirms his assumption that human beings interpret, and attach meanings to, their life experiences (Converse, 2012; De Chesnay, 2015). Heidegger’s interpretive (hermeneutic) phenomenology is “a study of Being through an investigation of beings” under which reduction, or bracketing, as posited by Husserl, is impossible (De Chesnay, 2015, p. 5; Heidegger, 1927/1962; Polit & Beck, 2012).

Hermeneutic phenomenology, as founded by Heidegger, is the process of human understanding that tries to make sense of Being-in-the-world (*dasein*); the perception of meaning proceeds this understanding (Heidegger, 1927/1962; Munhall, 2012; Porter & Robinson, 2011). An assumption of hermeneutics is that the researcher approaches the participant’s phenomenal experience with a presupposed understanding based on meanings given by personal life experiences (Leonard, 1989). Heidegger presumed that all understanding is interpretation from a
specific perspective, bringing to light how the researcher’s world can influence understanding of the essence of the phenomenon being studied (Converse, 2012); and “no experience could be like another” (Fleming et al., 2003, p. 114). Yet, dasein includes awareness of one’s Being, belonging to the world, availability and use of the world, and relating with others (Fleming et al., 2003). Such as the Olympian Greek god, Hermes, who communicated as an intermediary, interpreting messages from the gods to mortals, hermeneutics acts as intermediary between the familiar and the unknown, relating historical context, language, culture, social customs, and perspective (Moules, 2002; Munhall, 2012; Porter & Robinson, 2011). It is through systematic analysis of these relations of the whole that a new perspective and deeper understanding of the phenomenon evolve (Welch, 1999).

In 1927, Heidegger developed the concept of the hermeneutic circle as a means to generate the ultimate interpretation of the description of a phenomenon (Kafle, 2011; Porter & Robinson, 2011). The concept enables the researcher to visualize a whole, with regards to a reality, that is contextually embedded in the comprehensive experience of everyday existence (phenomenon) by an individual (Heidegger, 1927/1962). Heidegger’s hermeneutic circle symbolizes dialectic shifting between the parts and the whole, and provides a manner of voicing what transpires in understanding (Heidegger, 1927/1962; Welch, 1999). The hermeneutic circle is best characterized in terms of preliminary awareness and existence within time (Heidegger, 1927/1962; Porter & Robinson, 2011). For example, the researcher becomes involved with a text description of the phenomenon of interest with anticipation and expectation of what can be – presuppositions, or fore-meanings that are rooted in historical existence, and influenced by personal culture and language (Converse, 2012; Geanallos, 1998a; Porter & Robinson, 2011). As the researcher reads, and relates to, parts of the descriptive text, opinions and interpretations
regarding the imagined whole of the phenomenon are formed (Porter & Robinson, 2011). As the researcher reflects on what the whole must be like, more parts of the text are read, and the researcher’s interpretation and sense of the whole changes again as a result of knowing more and more parts. The circularity of this interpretive engagement moves to and fro, from part to whole, and so on; hence, the hermeneutic circle. Therefore, what the researcher initially knows and understands about the phenomenon before engaging with the text, changes with cycles of self-reference (Porter & Robinson, 2011). Understanding is ontological and ongoing, and that which is already understood is made evident, as fragmented, confusing, and hidden meanings are disclosed (Geanellos, 1998a; Porter & Robinson, 2011).

**Gadamerian Hermeneutics**

Just as Heidegger’s complex philosophical thinking was spurred by Husserl’s descriptive phenomenology, Hans-George Gadamer’s (1900–2002) original hermeneutic description of human understanding stemmed from Heidegger’s hermeneutic phenomenology (Austgard, 2012; Converse, 2012; De Chesnay, 2015; Dowling & Cooney, 2012; Porter & Robinson, 2011). A student of Heidegger, Gadamer also maintained an ontological view of understanding, presuming that giving credence to just a scientific mindset inhibits accessibility to important experiences of truth (Austgard, 2012; Porter & Robinson, 2011). Gadamer supposed that a basic and universal manner of human understanding is to experience a living activity in the moment, allowing it to intimately engage us (Porter & Robinson, 2011). He argued that opening ourselves to another in conversation, while developing novel relationships with people, cultures, language and text, etc., makes both objectivism and subjectivism impossible (Porter & Robinson, 2011).

Gadamer’s philosophical hermeneutics posits that meanings present in text, conversation, and artwork are always separate from the creator/author, and that the essence of the phenomenon
in question, or the experience at hand, will always be greater than the visible forms may reveal (Porter & Robinson, 2011). In other words, one’s interpretation will always be a living and dynamic experience in which the interpreter allows the text to draw him into its world, yet the interpreter remains rooted in the present (Porter & Robinson, 2011). That is, hermeneutical understanding of text represents the same structure as any other life experience (Porter & Robinson, 2011). Gadamer’s philosophical hermeneutics claims that understanding is not only in how we know texts and works of art, but is also a way to uncover what it means to have an experience of understanding universally (Porter & Robinson, 2011). Hermeneutics’ purpose is not only to describe how humans think and live, but also to be a description of what occurs over and above our doing and desire (Porter & Robinson, 2011). In his most notable work, Truth and Method (1960), Gadamer describes how our experiences of art (poetry, sculpture, painting) divulge how hermeneutically, we stay clear of being objective (extremely relative) or subjective as if it is only our own thoughts that exist), and remain assured that what we know is reliable and true (Gadamer, 1960/2013; Porter & Robinson, 2011). Gadamer’s aim to minimize both subjectivity and objectivity is grounded in human experiences of truth with art (Porter & Robinson, 2011). “Art is a form of representation that is superseded in the concept and in philosophy” (Gadamer, 1960/2013, p. 502).

Gadamer denotes that one’s present horizon – one’s knowledge and experience – is the foundation of understanding that may be partially transcended with exposure to other viewpoints (Porter & Robinson, 2011). Truth is an occurrence in which there is revealing and concealing, rather than straight communication of facts or a transcription of observations (Porter & Robinson, 2011). One must work through the hermeneutic circle, anticipating disclosure of the truth, within which there are new presuppositions to be questioned (Porter & Robinson, 2011).
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Working through the circle, subjective and objective elements blend, spiraling towards clarity of understanding (Converse, 2012; Koch, 1995; Porter & Robinson, 2011).

One of Gadamer’s primary concepts is that individual prejudices, biases, and traditions make possible our experiences of the world, and give us a sense of how we are to approach a subject matter (Austgard, 2012; Porter & Robinson, 2011). Language for Gadamer, is the universal perspective of the hermeneutic experience, with dialog being the basic mode of understanding (De Chesnay, 2015; Gadamer, 1960/2013; Porter & Robinson, 2011). Gadamer claims that all written text is a form of isolated speech that needs transformation back into language and meaning (Austgard, 2012). The researcher, belonging to tradition, approaches a written text with anticipation of meaning that stems from commonalities (field of study, beliefs, culture, history, and language) between the researcher and the text (Austgard, 2012; Gadamer, 1975/2013). The researcher’s fore-understandings and fore-meanings, influenced by tradition and evolving from being concerned with the same life experience, are what make understanding possible (Austgard, 2012; Porter & Robinson, 2011). The researcher already has some relationship with the phenomenon to be studied, the way the phenomenon is traditionally viewed, and the culture in which it occurs (Austgard, 2012; Porter & Robinson, 2011). The interpreter possesses a historical consciousness – a keen awareness that the interpreter meets the text with prejudice and bias (Austgard, 2012; Fleming et al., 2003; Gadamer 1960/2013). In a positive light, Gadamer further explains that when we understand, we are engaged in dialogue that involves both our own self-understanding and our understanding of the phenomenon being studied (Fleming et al., 2003; Malpas, 2015). In this dialogue of understanding, our prejudices surface, playing a crucial role in releasing what is to be understood, and becoming evident in the process (Malpas, 2015). Gadamer calls this the principle of history of effect (Austgard, 2012;

Gadamer points out that the consciousness of being affected by history is mainly the consciousness of the hermeneutical situation (Fleming et al., 2003; Gadamer 1960/2013). He explains a situation as a “standpoint that limits the possibility of vision” (Austgard, 2012, p. 830; Gadamer 1960/2013, p. 313). In keeping with the concept of the principle of history effect, “we are always affected in hope and fear by what is nearest to us” (Gadamer 1960/2013, p. 316). We are never outside a situation, observing with objectivity, but present in the situation, illuminating it from that vantage point with reflection on effective history (Gadamer 1960/2013). Gadamer argues that every finite presence in a situation is limited to the range of vision that includes everything that can be seen from a particular vantage point (Gadamer, 1960/2013). When one works out the hermeneutic situation, one is obtaining the right horizon of inquiry (the manner in which reality is perceived and interpreted) for the questions brought forth by confronting the text (Austgard, 2012; Gadamer, 1960/2013).

To begin, the hermeneutic situation is determined by the prejudices brought by the interpreter, constituting the horizon of a particular present; the awareness of these prejudices and fore-understandings by the interpreter is called foregrounding (Gadamer 1960/ 2013). As the interpreter encounters the text, he/she eventually suspends these prejudices as the hermeneutic situation works through the hermeneutic circle (Austgard, 2012). It is important to note that the horizon is not a fixed set of valuations and opinions, but is continually in the process of being formed through the testing of all prejudices by encountering the past, and understanding the tradition from which we come (Gadamer 1960/2013). Prejudices must be evoked in order for their validity to be suspended, and allow for truth and understanding (Austgard, 2012). This provocation occurs in encounters with the text in the hermeneutic process (Austgard, 2012).
Gadamer describes the structure of our experiences of understanding as an event in which we participate (Porter & Robinson, 2011). The “fusion of horizons” is the event of opening ourselves – our horizons – to others (lives, questions, ideas, artworks, text) (Austgard, 2012; Gadamer, 1960/2013; Porter & Robinson, 2011). The marvel of understanding happens with gradual and perpetual interplay – conversation/dialogue – between the subject matter and details in the text and the interpreter’s initial position – a fusion of one’s own horizon and the horizon of the text, or the author (Austgard, 2012; Converse, 2012; Porter & Robinson, 2011). Within this fusion of horizons – this understanding – one is not restricted to a subjective viewpoint, nor is there a possibility of a completely subjective interpretation that transcends all viewpoints (Porter & Robinson, 2011). A fusion of horizons brings the hermeneutic process to where the interpreter captures the wholeness and consistency of the author’s text, and the text as the author’s meaning can now convey its meaning about the phenomenon (Austgard, 2012). As the researcher’s historical horizon is extended, it is not reinforced, but taken over by his/her own present of understanding with each textual encounter and dialogue, until it is simultaneously supplanted with truth and understanding (Gadamer, 1960/2013). It is important to note that the fusion of horizons does not end the dialogue, nor understanding; newly generated knowledge is transformed into the present, becomes visible in a much broader perspective, and enables a better understanding of the phenomenon in the here and now (Austgard, 2012).

Summary of Chapter

In summary, Chapter III, the Nature of the Study, begins with the introduction of the hermeneutic approach for Nursing research. Specific rationale for selection of the Gadamerian interpretive process is considered, followed by a historical evolution of hermeneutics. Hermeneutic historical evolution includes the origins of hermeneutics, the development of
phenomenological thought and its relationship with hermeneutics, Heideggerian hermeneutic
phenomenology, and Gadamerian hermeneutics. The following chapter explains how the
Gadamerian hermeneutic approach is used for text inquiry.
This chapter discusses the hermeneutic process for text inquiry with a Gadamerian approach. Text selected for analysis is introduced, followed by a four-step process of inquiry as designed by Austgard (2012). Austgard’s four-step process (Working Out the Hermeneutic Situation, Hermeneutic Preparation: Identification of Fore-Understandings, Hermeneutic Dialogue with the Text, and Fusion of Horizons) is explained in detail, rooting the research from inception to completion in philosophy and theory. The chapter then examines the importance of trustworthiness in qualitative research, citing four essential criteria (credibility, dependability, transferability, and confirmability), as suggested by Lincoln & Guba (1986) for its installation. Finally, ethical considerations regarding the research study are explored.

Poetic Text Selection


Process of Inquiry

Gadamer’s philosophy is just that, providing no clear method or steps follow for conducting hermeneutic research (Austgard, 2012; Fleming et al., 2002; Nyholm et al., 2018). Therefore, this qualitative, hermeneutic study implements a Gadamerian-inspired, creative research approach to understanding. Reflection, insightfulness, openness, and sensitivity to language are imperative for the researcher. The four-step process, as outlined by Austgard...
(2012) for nurse researchers, provides the systematic approach with which the research plan is developed. These four steps, (1) working out the hermeneutic situation, (2) hermeneutic preparation: identification of fore-understanding, (3) hermeneutic dialogue with the text, and (4) fusion of horizon are implemented throughout the study, as described below.

**Working Out the Hermeneutic Situation**

Acquisition of the right horizon of inquiry for the research question evoked by encounter with tradition (background of the phenomenon) is described and developed in detail in Chapter I of this study. Working out the hermeneutic situation also involves examination of the relevancy of the research question, its purpose and aim, and the “openness” of the question (does the question open up possibilities to grasp the phenomenon?) (Austgard, 2012). This initial step provides groundwork that influences the entire subsequential hermeneutic process, as well as adding truth and trustworthiness to the study (Austgard, 2012).

**Hermeneutic Preparation: Identification of Fore- Understandings**

Gadamerian hermeneutics requires the researcher to reflect upon personal knowledge and life views of the phenomenon, as well as exploring different opinions and experiences of other researchers, varied knowledge, and worldviews. Identification and documentation of existing fore-understandings of the phenomenon, as evidenced in Chapter II, not only prepares the researcher to enter the hermeneutic circle with full consciousness of the hermeneutic situation, but enables the researcher to move beyond them. Once accomplished, the researcher may proceed into hermeneutic dialogue with the text.

**Hermeneutic Dialogue with the Text**

In describing human thought, Gadamer (1960/2013) states “the mind hurries from one thing to the other, turns this way and that, considering this and that, and seeks the perfect
expression of its thoughts through inquiry and thoughtfulness” (p. 442). This is the way the analysis of text is conducted. The researcher enters the hermeneutic circle, interpreting and understanding the text as a whole, allowing the text to “speak”, as questions and understanding are written down. The researcher then engages with the parts of the text, then back to the whole, cyclically interpreting and understanding, guided by the dialectical flux between the questions and answers discovered in the text (Austgard, 2012).

To clarify this hermeneutic circle, four mutually-exclusive phases, as developed by Fleming et al. (2003) are used for text analysis. These phases ensure that the process of gaining understanding is structured, systematic, and accurate, with every phase being enriched throughout the process (Austgard, 2012; Fleming et al., 2003).

**Phase 1.** All poems are examined to find an expression that reflects the basic meaning of the text as a whole. Gaining understanding of the whole text is the commencement of analysis. The meaning of the whole will influence understanding of every other part of the text. The initial engagement with the text is influenced by a sense of expectancy, which has developed through the researcher’s fore-understandings. The researcher’s fore-understandings, documented and made clear in Chapter II, guide the inquiry and search for meaning.

**Phase 2.** Every sentence or section is investigated individually to expose its meaning for the essence of the phenomenon. This facilitates the recognition of patterns or themes – “keys”– which in turn, open up to a rich, comprehensive understanding (Austgard, 2012; Fleming et al., 2003). These themes will then be questioned by, and in turn, question the researcher’s prejudices and fore-understandings, which constantly change as deeper understanding emerges. The researcher journals all questions, patterns, and themes as fore-understandings evolve.
Phase 3. Each sentence or section is then related to the meaning of the whole text, and with it, the sense of the text as a whole is expanded. With the expanded understanding of the whole text, meaning of the parts deepen. And, with each relation to the whole, the researcher documents any changes in fore-understandings.

Phase 4. The researcher identifies passages of the text that most represent the shared understandings between the researcher and the text (author). Such passages, which may appear in the dissertation, give the reader insight into that aspect of the phenomenon of interest. This four-phase process could go on indefinitely, as every understanding will change as time goes on. For practical purposes, the cycle continues until few questions are found in the text.

Fusion of Horizon

Continuing through the hermeneutic circle, interpretation and understanding gradually reach a point where consistent patterns and themes can be identified in the text. This point is Gadamer’s (1960/2013) “fusion of horizons” – understanding – when “old and new are … combining into something of living value without either being explicitly foregrounded from the other” (p. 317). In simpler terms, the researcher develops a comprehensive understanding of all material related to the phenomenon, and an understanding of the texts, including the researcher’s fore-understandings which change throughout the process. Only when this understanding occurs is the researcher positioned to concur with, or oppose the assumptions of the text. Lindholm (as cited in Austgard, 2012) asserts that understanding can only be achieved when one has the ability to actively apply the truths from the text into one’s own life, situation, or project. This active application requires a special foregrounding, which is accomplished by discussing the new knowledge in light of existing Nursing science knowledge regarding the phenomenon. This final hermeneutic step establishes the development of new knowledge based on the questions posed,
and this new knowledge opens another horizon for additional research and deeper understanding.

**Trustworthiness**

To establish trustworthiness (a parallel to the quantitative term, *rigor*) in hermeneutic research (Lincoln & Guba, 1986), the process needs to be rooted in the philosophy chosen (Laverty, 2003); as is the four-step, Gadamerian-inspired process developed by Austgard (2012). Implementation of Austgard’s process carries and reflects on Gadamerian principles throughout the entire study, ensuring that the research is sound and consistent with its philosophical foundation.

Lincoln & Guba (1986) suggest four criteria for establishing trustworthiness in qualitative research, each being an analog to its quantitative counterpart: credibility (*internal validity*), dependability (*reliability*), transferability (*external validity*), and confirmability (*objectivity*). Each criterion is explained, and techniques suggested to increase the likelihood of the criteria being met.

**Credibility**

Credibility, in Gadamerian research, is established through prolonged engagement with the text (Lincoln & Guba, 1986). Intensive dialogue with the text while engaging in the hermeneutic circle ensures adequate assessment of the phenomenon for possible sources of misrepresentation, as well as identification of prominent concepts. Active questioning and searching for negative circumstances related to emerging themes or patterns (negative case analysis) until no questions or contradictory instances are found, assumes a meticulous analysis of the text, and institutes credibility (Lincoln & Guba, 1986). Detailed documentation of the hermeneutic process in a reflective journal not only records the rationale and evaluation of all outcomes of the interpretive process, but also provides a rich description of the experience itself.
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The reflective journal is evidence of the self-reflexivity of the researcher; the ongoing conversation with the text while simultaneously living in the moment, suspending prejudices, actively constructing interpretations of the phenomenon, and questioning how those interpretations evolved (Laverty, 2003). According to Moules (2002), “veracity, or truth value” (p. 34) is amplified when the researcher’s interpretations of the phenomenon are believable, and ring “true” – that is, they take the reader to an identifiable place in human existence. It is important to note that Gadamerian research does not present these interpretations as absolute “truth” (Gadamer, 1960/2013). The reader identifies different interpretations, which may even oppose interpretations generated in the research (Moules, 2002). Nevertheless, the reader experiences a believable, self-validating sense of human fitness in the interpretations of the phenomenon (Laverty, 2003). This generative process of referential and relational interpretation, as documented in the reflective journal, is not contradictory, but is detailed evidence of the prolificity of hermeneutics and a statement of the experience, itself (Laverty, 2003). This is the commitment to trustworthiness (Moule, 2002).

**Dependability**

Dependability of hermeneutic research hinges on the exactness and thoroughness of documentation of how the researcher arrives at interpretations (Moules, 2002). Through the hermeneutic circle, the researcher is continually called upon to consider personal history, experiences and prejudices, and to explicitly describe how personal accounts and views relate to the research phenomenon of interest (Laverty, 2003). The researcher’s biases and assumptions are essential as dialectical movement between parts and whole of the text bring forth interpretations of meaning, in which these fore-understandings are embedded (Laverty, 2003). It is critical for dependability and trustworthiness to account for the researcher’s position; to read
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and write, and to trace the researcher’s progression through multiple stages of interpretation that allow patterns to emerge, and discussion of how interpretations are developed from the text (Laverty, 2003).

Transferability

Transferability is the idea that Gadamerian research interpretations of the text are deemed suitable in situations of the phenomenon outside the study when a reader sees the research findings as meaningful and fitting to their own life experiences (Anney, 2014; Koch, 1994/2006; Lincoln & Guba, 1986; Moules, 2002). Interpretations are developed using thick descriptive narratives that explain, not just behaviors and themes, but their original contexts as well (Koch, 1994/2006; Lincoln & Guba, 1986). This is evidenced in the thoroughness and detail of the selected parts of the researcher’s journal that reflect the interpretations (Moules, 2002). Comprehensive descriptions enable others to judge whether or not the research findings may be applied elsewhere (Moules, 2002).

Confirmability

Confirmability requires the hermeneutic researcher to map out the way in which interpretations have been arrived at via conversations with the text (Koch, 1994/2006). Lincoln & Guba (1986) pose that qualitative research be auditable for adherence to the hermeneutic process’ (dependability), as well as development of the interpretations and understanding (confirmability). This allows another researcher to clearly follow the “decision trail” documented by the researcher in the study, as well as understand how the researcher arrived at the conclusive interpretations, given the researcher’s fore-understandings, perspective, and the text (Koch, 1994/2006; Moules). Accuracy is ensured by examining all entries in the reflective journal leading to interpretations of the phenomenon. Explicit discussion of decisions made
about methodological, theoretical, and analytic choices throughout the study (the decision trail) in the research findings confirms the trustworthiness of both the hermeneutic process and the interpreted understanding (Koch, 1994/2006).

In summary, development of a hermeneutic research study using Lincoln & Guba’s (1986) criteria of credibility, dependability, transferability, and confirmability increases the trustworthiness of the research and its outcomes.

**Ethical Considerations**

The research protocol for this Gadamerian hermeneutic study was submitted to The Institutional Review Board for the Protection of Human Subjects (IRB) at Lehman College, City University of New York. The IRB ensures compliance with state and federal regulations regarding research with human beings, provides education, and ensures that all research is conducted in an ethical manner. This research proposal was reviewed at Lehman College; determination notice is provided (Appendix A).

In addition, all dialogue with, and interpretation of the poetic text, were conducted and transcribed with utmost respect and dignity for the deceased author, Mattie J. T. Stepanek. All excerpts of his work used in this research are for non-profit, educational purposes and are cited appropriately. Portions of poetry used are to support the research arguments and findings.

**Summary of Chapter**

Chapter IV discusses the process for a Gadamerian approach for text inquiry. Selection of the text is followed by a detailed description of Austgard’s (2012) four-step process of inquiry (Working Out the Hermeneutic Situation, Hermeneutic Preparation: Identification of Fore-Understanding, Hermeneutic Dialogue with the Text, and Fusion of Horizon). Trustworthiness and Lincoln & Guba’s (1986) four essential criteria (credibility, dependability, transferability,
and confirmability) for trustworthiness are then delineated. Finally, ethical considerations for the research are presented.
Chapter V FINDINGS OF THE STUDY

Presentation of the research findings of this Gadamerian hermeneutic study are precisely delineated to give the reader insight into exactly how understanding was attained. The poetic text sample is defined, followed by comprehensive description of this researcher’s hermeneutic dialogue with the text. The hermeneutic dialogue with the text also includes this researcher’s development of a conceptual guide which is implemented in the study. Passages of the text which support pre-existing fore-understandings are presented, followed by the fusion of horizons (understanding) of this researcher, and the text’s author, Mattie J. T. Stepanek. Three themes, tenderness, time, and transcendence are discussed, with textual representations of these themes in understanding the essence of the phenomenon living as a dying child. Study findings conclude with discussion and evaluation of criteria met (credibility, dependability, transferability, confirmability) for trustworthiness of the study.

Poetic Text Sample

The poetry of Mattie J. T. Stepanek is published within six books: Heartsongs (2001), Journey through Heartsongs (2001), Hope through Heartsongs (2002), Celebrate through Heartsongs (2002), Loving through Heartsongs (2003), and Reflections of a Peacemaker: A Portrait through Heartsongs (2005). For practical purposes, all six books were photocopied and collated. Each 8½ by 11 inch page resulted in one or two poems per page. This left ample room next to each poem for this researcher to document encounters with the text. All six text volumes were compared with one another for duplicates (11 duplicate poems were found). Individual poems were then numbered next to each title; duplicates were counted and numbered just once, to ensure each individual poetic encounter was the same. A total of 499 unique, individual poems constituted the text sample included in this Gadamerian hermeneutic analysis.
Hermeneutic Dialogue with the Text

Hermeneutics is traditionally classified as an interpretive, qualitative method. Nevertheless, Gadamer (1960/2013) considers hermeneutics an approach, providing no steadfast guidelines for knowledge acquisition (Debesay, Nåden, & Slettebø, 2008). To direct this study and to ensure trustworthiness, this researcher has incorporated Gadamer’s ontological philosophy, and a systematic process developed in 2003 by Fleming et al. (as explained in Chapter IV), into the Settecase-Wu Conceptual Guide: A Gadamerian Hermeneutic Approach for Text Analysis (Figure 1). As depicted, the interrelationship between the whole of the text and its individual parts, does not remain in the same place, nor is it a cycle from which the researcher cannot break from (Debesay et al., 2008). The researcher is continuously acquiring new knowledge and deeper understanding with each textual encounter. For this reason, the Gadamerian hermeneutic circle is depicted as a spiral, circling along a distance in time. It is this positive condition of temporal distance (Gadamer, 2013/1960) that allows the researcher to reassess prejudices and question fore-understandings (Debesay et al., 2008). As prejudices, which lead to misunderstanding, change and evolve through the interplay of the whole and the parts, true understanding of the whole of the text emerges. This researcher’s conceptual guide, Settecase-Wu Conceptual Guide: A Gadamerian Hermeneutic Approach for Text Analysis (Figure 1) was established for guiding interpretation in this study.
Figure 1.

Settecase-Wu Conceptual Guide: A Gadamerian Hermeneutic Approach for Text Analysis

Fusion of Horizons
Identify text passages which represent shared understanding of researcher & author

Again, relate deepened meanings of parts to the whole
Document further expanded sense of whole & changes in fore-understandings

Relate each section/line/word to meaning of whole
Document expanded sense of whole & changes in fore-understandings

Commencement - Document basic understandings of text as a whole (influences meaning of every other part)

Initial Text Encounter
Anticipation/Expectancy (fore-understandings guide inquiry & meaning)

Continue cycle between whole & parts, document meanings, until patterns/themes are developed, & few questions are found in text

With expanding meaning of whole, document deepened meaning of parts & emerging patterns/themes
Fore-understandings continue to change

Examine every section/line/word for essence of phenomenon.
Document key concepts
Fore-understandings are questioned/change with deeper understanding
LIVING AS A DYING CHILD

Understanding the meaning of the text involves self-understanding (Debesay et al., 2008), which is achieved by the researcher interpreting within a circular process, moving from a whole to individual parts, and back to the whole, through the hermeneutic circle. In order for the reader to visualize and comprehend how this researcher reached understanding, the Settecase-Wu Conceptual Guide Reflecting this Researcher’s Process for this Study is also provided (Figure 2). Examples of this researcher’s key concepts, changing meanings, and fore-understandings are in italics for the reader to follow and visualize how the thematic findings developed.
Figure 2.

*Settecase-Wu Conceptual Guide Reflecting this Researcher’s Process for this Study*

**First Reading**
Basic understandings: 
e.g. Concern for nature/humanity, Grateful for living/people, Belief in God/Heaven, Grieving lost siblings, Dying is not final

**2nd Reading**
Documented *key concepts* for each poem/section/line:  
e.g. *Heartsongs, Love, Friends, Angels, Heaven Birthday, Sunsets, Butterflies, Snow, Rainbows Intangible things, life-after-death*  
Fore-understandings changed: e.g. *Not only for children, Insightful, Moving, Awareness*

**3rd Reading**
Related key concepts to expanded sense of whole  
e.g. *Metaphors for Transformation, Living in Heaven, Life Milestones*  
Fore-understandings changed: e.g. *Life message for humanity, Timelessness*

**4th Reading**
Documented deeper key concepts. Patterns/themes became apparent  
e.g. *Compassion for living/others, past-present-future, Being goes on after dying*  
Fore-understandings changed: e.g. *Spirit lives beyond physicality*

**5th Reading**
Deepened meanings/further expanded sense of whole: 
*Themes:*  
*Tenderness*  
*Time*  
*Transcendence*

**6th and 7th Readings**
Identified text passages which represent *themes/Shared understanding*.

**Anticipation/Expectations**
e.g. *Life-limiting illness*  
Wants to be heard  
*Whimsical, Sad, Courageous, Heart-warming, Children’s literature*
LIVING AS A DYING CHILD

This researcher’s anticipated and expected sense about the *Heartsongs* poetic series, fostered by fore-understandings as delineated in Chapter II, were first journaled in a notebook and include ideas about the poems’ purposes, what they might be about, etc. For commencement of analysis, the beginning of the researcher’s hermeneutic dialogue with the text, all poems were read as a whole body of writing; the researcher’s fore-understandings (as delineated in Chapter II), as well as anticipated and expected ideas, guided the inquiry and exploration for meaning during this First Reading. After completion of the First Reading, this researcher journaled all basic understandings in a designated notebook.

For the Second Reading of the poetic sample, each poem/section/line/word (part) was examined individually for the essence of the phenomenon *living as a dying child*. Key concepts and meanings were noted in the margin of the page next to each respective poem. Several poems had no notations; in these instances, no concepts or meanings for phenomenal essence were revealed. As key concepts and meanings were written, the researcher’s fore-understandings began to be questioned and re-fashioned (Figure 2). This researcher’s changes in fore-understandings and questions were documented on a separate page from the meanings of the whole in a notebook.

During the Third Reading, each poem, with documented key concepts and meanings, were related to the meaning of the whole, and the expanded meanings of the whole were again journaled in a notebook under the initial, basic understandings of the whole from the First Reading. The researcher’s changed fore-understandings were also journaled underneath the fore-understandings and questions from the Second Reading, as they emerged. Documentation of meanings, questions, and fore-understandings, in a sequential manner provided this researcher with a decision trail of the interpretive process, and how it evolves along a temporal distance.
When the poems were read for the Fourth Reading, each part was again examined with influence from the expanded meanings of the whole, and the meanings of the parts deepened. Additional key phenomenal concepts were again written in the margin of the poem, opening up a richer understanding of the whole poetic sample. Patterns and themes began to become apparent, and the researcher’s fore-understandings were minimally questioned, with little change. Questions and changed fore-understandings were journaled in the notebook under the questions and fore-understandings from the Third Reading.

By the Fifth Reading of the poems, the poems were read as a whole and three themes emerged – tenderness, time, and transcendence. There were no further questions or changes regarding this researcher’s fore-understandings. The themes were journaled in a notebook under the expanded understanding of the whole from the Third Reading. At this point, the understanding of the phenomenon with Mattie J. T. Stepanek (fusion of horizons) was attained.

All 499 poems were read twice more; this enabled this researcher to identify passages in the text, which represent the themes uncovered by the analysis, as well as the shared understanding of researcher and author (fusion of horizons). These passages are presented with, and in support of, the research findings – the essential themes and shared understanding of the phenomenon. In addition, textual representations of fore-understandings from Chapter II were identified.

**Textual Representations of Fore-Understandings**

Preceding the discussion of the essential phenomenal themes as revealed by this Gadamerian hermeneutic research, textual representations in support of themes in existing research, attributes that support the researcher’s initial beliefs, and fore-understandings as developed from the researcher’s story (Chapter II) are presented. Revelation of such passages in
the poetic sample provides evidence of this researcher’s detailed analysis, broadens the evidence-based scope of the research, and provides data furnished by a living as dying child. Three tables were constructed (see Appendix B) to present such textual representations: Themes in Existing Research Related to the Phenomenon (Table B1), Attributes that Support Researcher’s Initial Beliefs Regarding the Phenomenon (Table B2), and Fore-understandings of the Phenomenon as Developed from the Researcher’s Story (Table B3). Note that all textual representations cited are in support of the related theme, attribute, or fore-understanding; no text examples were found to oppose any theme, attribute or fore-understanding. An asterisk (*) denotes a lack of textual evidence revealed by the analysis relating to a theme, attribute, or fore-understanding.

**Fusion of Horizons (Understanding)**

Bringing together the parts into one whole is Gadamer’s (2013/1960) criterion for proper understanding. Continuing through the hermeneutic circle for text analysis, this researcher has developed a comprehensive understanding of all information related to the phenomenon, *living as a dying child*. In addition, understanding of the poetic sample has been achieved, including this researcher’s fore-understandings (which have evolved through the process). Gadamer (2013/1960) calls this point in the hermeneutic circle the fusion of horizons between the researcher and the author of the text (Mattie J. T. Stepanek). Upon understanding of the text, three consistent themes became apparent: tenderness, time, and transcendence. These recurrent themes are presented with relevant, poetic passages in support of each theme.

**Tenderness**

Tenderness, a complex, and multi-faceted theme, is at the essence of Stepanek’s poetry—“We must / Think gently, / Speak gently, / Live gently… / Love others…” (2005, p. 177). Tenderness is overtly understood in the author’s purpose for writing: the widespread publication
of life experiences while dying, to share with others. Stepanek’s prodigious ability to openly express and share his thoughts, as well as the immortalization of his words in print, suggest a tenderness that is congruent with his compassion for interpersonal communication on a large scale:

… Among the most powerful

Of all weapons.

Words can tear and hurt …

Words can heal and comfort …

Use words with care. (Stepanek, 2003, p. 59).

The title of Stepanek’s poetic series, *Heartsongs*, conveys this tenderness, along with desires to be heard, and to reach others way beyond himself. Readers can engage with the text, analyze and understand in their unique ways, and in doing so perpetuate Stepanek’s tenderness for humanity, long after his physical presence has gone. This passage from “If My Arms Were as Long as a Rainbow” is an example:

…So the only way I can hug and kiss the whole world

Is by closing my eyes,

And reaching out with my mind,

And believing in my Heartsongs,

And sharing them with everyone and everything.

So in the end,

We know that our arms and our minds and our hearts

Are all as big as we believe them to be … (Stepanek, 2005, p. 176)

Lovingness, and kindness, characteristics of the author’s tenderness, resonate freely
throughout the poetic sample. These characteristics of affection are not only indicative of
Stepanek’s genuine caring for people, and his willingness to do what he can to help them, but
also reflect his sincere appreciation for living, and a reciprocity towards the people in his life
who love and care for him: “…My mother . . . / My greatest teacher in life. / About life. / For life.
/ I love you, my mother” (2005, p. 117). The gentleness in Stepanek’s prose projects the warm-
heartedness of the author, and the benevolence of his intentions: “Peace grows from a gentle
heart / Not one filled with spite” (2002b, p. 22). The author’s tenderness is understood on
several planes. Despite his adversities, the author displays genuine empathy for the human
condition, deeply considering all that is going on around him in the world:

    Perhaps,
    We should all cry
    More,
    Together,
    For each other… (Stepanek, 2002b, p. 23).

On a universal level, Stepanek exhibits sympathy and concern for countries unsettled by the
conflicts of war and terrorism, outwardly wishing for peace and harmony across the globe, as in
“Tele Vision”:

    I kept my eyes
    Open to the future…
    But 9/11 blew up
    So very much dust
    That we had to
    Keep our eyes
Closed to the pain...
Now together, let us…
Bow our heads, reverently…
Touching the world with
A meek and humble
Gesture of humanity.
And perhaps,
We can one day,
Open our eyes
To a gentle tomorrow… (Stepanek, 2005, p. 107)

In social and family circles, the author conveys genuine concern regarding loved ones. For those who are suffering, he prays for their consolation, and for those that have died, he prays for their angelic transformation into Heaven:

I know Margie is sad, even though
She never got to see or touch or
Hold her little baby…
Please take care of Margie, God…
Please help them to be happy
Until they finally meet their
Baby in Heaven. (Stepanek, 2005, p. 95)

Stepanek’s personal sentiment for the environment and living things provides him with numerous analogies in nature with which he presents his tender feelings and emotions. The poem “When the Trees Sing” is one example:
When the trees sing,
It doesn’t really matter
If you know the song.
Or if you know the words,
Or even if you know the tune.
What really matters is knowing
That the trees are singing at all. (Stepanek, 2002a, p. 35)

His tenderness is not just love and kindness for others, but for himself, as part of humanity.

Stepanek is positive and hopes to see his glass as half full – “Because if you live feeling like /
Your glass is half empty, well, / It may as well be empty all the way” (2001b. p. 19). Mattie J. T.

Stepanek is, for the most part, happy, and he teaches us how to be happy, despite any circumstance:

… We must remember to play after
each storm.
We must not live in fear of bad
things
Blocking our way or overcoming
our optimism …

We must celebrate life everyday, … (2002a, p. 57)

He loves living, and wants his life, yet personal sensitivity for physical, emotional, and spiritual pain and suffering is evident in tender descriptions in *Death*:

… Isn’t it sombering
That such a grown-up, dreaded word
LIVING AS A DYING CHILD

Plays with my memories, my thoughts, my life? (Stepanek, 2003, p. 51)

This sensitivity is not interpreted as a fragility, nor a delicateness of constitution; it takes
tremendous strength to fight and to endure, and to simultaneously be a tolerant, heartful person:

Dear God,

Help us to always be able

To use the feelings of

Hope and fear, together,

In one great force …

Bravery… (Stepanek, 2002a, p. 15).

The succulence of Stepanek’s poetry as a whole, exemplifies the intrinsic tenderness of the
author living as a dying child.

Time

The concept of time encompasses the poetry of Mattie J. T. Stepanek. The author
broaches the topic from mixed perspectives, varying from absolute, incremental measurement, to
more nebulous concepts of existence. Time is key to Mattie J. T. Stepanek, and is at the very
basis of his written expression: he is aware that his Being cannot be fully understood, but time is
did not regard text as simply past, but able to overcome temporal distance with its own
meaningful presence, and its offering of future understandings. And so, Stepanek has
permanently secured thoughts and emotions of his Being in his poetic text, ergo providing this
researcher, and all who read, the incredible and indelible journey of his living-dying experience.
Evidence of Stepanek’s keen awareness of time is evident in each documented thought (his
Being-as-experienced), however the thought may be presented (Gadamer, 2013/1960).
LIVING AS A DYING CHILD

Mattie J. T. Stepanek discusses his Being – his time – as an indefinite, continual evolution of existence and events. His temporality is not always a clear linear progression, and he seems to oscillate his Being between past, present and future:

… I’ve got one foot planted
In my here, now, today,
And one foot planted
In some heartbeat away,
I straddle the line
Of my earth-life, and Then
I touch what I’m creating –
My reality some-When. (Stepanek, 2005, p. 193)

Stepanek describes his existence as making significant memories for his future past, in his present, for his tomorrow:

The next century, the next millennium
Is being made, now. Today. Each
second. …
even though the future seems far away,
It is actually beginning right now.
And while we are living in the present,
We must celebrate life everyday. …
Because we, today, are the history
LIVING AS A DYING CHILD

Of tomorrow … (Stepanek, 2002a, p. 57)

The author’s knowledge regarding his loss of siblings and medical prognosis is evident throughout the sample. He speaks of his impending death often, yet he does not envision it as time running out; Stepanek’s descriptions of death are of an everlasting nature: “Isn’t it odd / That such a short word / Means something so eternal?” (Stepanek, 2003, p. 51). They are generally anticipatory for moving beyond Being in his physical presence towards Being in a spiritual, ethereal space-time continuum:

… Each cycle of seasons, …

Inspires me to live on,
And on, and on, and on,
Until my time comes
To be a part of the eternal future. (Stepanek, 2003, p. 23)

There is no differentiation between himself and his peers – Stepanek believes transformation of Being happens in all humans, at some point in time, as, and when, it comes:

... I will visit the spirits
Considering their Heaven
To cheer them up and
To inspire them
Toward their eternal goal, so
That their vision of a perfect
Forever can become a reality. (Stepanek, 2005, p. 25)

The author also writes about his present living-dying experiences becoming the memories of tomorrow, shaping his legacy of what remains in the physical world as he transcends to
LIVING AS A DYING CHILD

something greater than himself. Stepanek, in accordance with Gadamer (2013/1960) and Heidegger (1962, 1927) proclaims his truth in written disclosure of his Being with authentic existence in “Coming of Age”:

One day,
Yet all too soon,
My memory will
Simply be a
Silhouette in time…
My mortality will
Fade and be
Ashes scattered in the winds of existence…
My legacy will
Prayerfully be an
Echo of hope, a
Spiritual home, a
Pinch of peace
For the yearning soul…
My eternity will
Forever and for all be
The shape of the life
Which I leave behind (Stepanek, 2005, p. 190)

Daily and seasonal intervals in time are often depicted in the poetic sample. Stepanek’s colorful descriptions of natural time spans, such as sunrise-to-sunset, or season-to-season, not
only allude to time passing, but in addition, illustrate continuous evolution and transformation of the world around him, and with him:

   When the moon sets
   Over your shoulder
   As the sun rises
   Bright towards your face
   What’s in the middle?
   Your life is …
   Filled with choices
   For each moment, each place
   We live between the
   Past and the future,
   In the moment of our
   Here, now, today… (Stepanek, 2002a, p. 53)

There is occasional indication of haste from the author’s perspective. For Stepanek, time is not of the essence for the most part, and living-dying progresses at its pace. However, the author wants to achieve some self-set milestones, and suggests skipping over some time intervals to get to where he wants to go, and do what he wants to do:

   Tomorrow,
   I will turn into four years old ...
   If I was twenty-five,
   I could put three gumballs
   Into my mouth
At the same time …
I could hang upside-
Down in a tree.
And I could have children
Of my very own…. (Stepanek, 2005, p. 9)

In these instances, a temporal distance is envisioned, and the author expresses some desire to jump ahead in time to maximize his physical Being before his transition at death.

Often, Stepanek refers to his time as the pivotal point where he is no longer physically present – his death. This time, his time, has a suitable purpose; it is when the author’s physical presence will no longer Be:

… Life is like a great waiting…

… We must understand
That anytime
Could be the Time
That we face the fact of Heaven, … (Stepanek, 2002a, p. 54)

Stepanek assures himself that when he dies – when his time comes – he will evolve into a spiritual Being who will transcend and be with God, deceased siblings and loved ones. Stepanek is explicit in that his Being (time) will continue:

… But in Heaven …
I will Finally have
“All the time in the world”
To Eternally Live
My Ultimate To-Do List … (Stepanek, 2005, p. 198)
There are a few instances in the sample where specific, measured intervals of time are referred to: minutes, hours, days, months, years. This specificity of conventional, standard time reflects the exactness of the author and his Being at those particular moments, or points of time along a continuum:

8:00 a.m.
I am going to die…
Heaven is a very wonderful place.
And I will be very happy.

8:10 a.m.
Something got into
My eye. …
I don’t want
My eye to die…
It will go to Heaven. …

8:15 a.m.
But I don’t want to
Go to Heaven, yet. … (Stepanek, 2005, p. 53)

Finally, the author’s presentation of his words as poetry has its own time signature. Each poem is metered for the reader; the pattern of words is punctuated and rhythmically timed by the author. The cadence and flow of Stepanek’s ideas are led to, and processed by the reader in the time he assigns to each thought – a deliberate exhibition of time management:

I am
Living
LIVING AS A DYING CHILD

On the edge
Of breath,
Where a
Single
Element
Of a moment
In time
Can make
The difference,
Determining
From which side
Of the veil
Life is viewed
For the
Realization
Of that which
I am (Stepanek, 2005, p. 196)

Transcendence

The intrinsic nature of transcendence is to stretch beyond the limits of ordinary experience or circumstance. The transcendental theme is significant in various manifestations for Mattie J. T. Stepanek. Before hermeneutically encountering the poetic text, the written words of the text itself are evidence of the author’s transcendence. Stepanek’s written verses provide affirmation of Stepanek’s moving beyond the boundaries of his own mind – reflecting and
revealing both conscious and unconscious thoughts, in writing. Stepanek surpasses his own confines, opening up to universal inspiration, and forging a written, transcendental course for personal growth, transformation, and empowerment. The purposefully widespread dissemination of Stepanek’s writings in publication exceeds how living-dying children usually express themselves, consequently exemplifying the transcendent wisdom of the author’s wish to extend limitlessly and indefinitely, outside his physical realm:

… Be inspired…

Let the feeling move your heart,

Let the heart bring words to your mind,

Let the mind create a poem from your hand, …

The poetry is then shared.

And so, other people will …

Be inspired… (Stepanek, 2002b, p.3)

All through his poetry, the author acknowledges his impending death, never describing it as cessation of life. Stepanek “speaks” with expectancy and, at times, anticipation regarding his spiritual living beyond his physical demise:

… no one ever knows

If they will grow up, or not.

So really, the most important

Goal of all …

Is that I want to BE. (2005, p. 11)

He is certain, when his body fails, his soul will be freed from not only corporeal constraints, but from the palpable limitations of life on Earth. Stepanek (2005) welcomes death with dignity, and
tells of his eventual transcendence of spirit, beyond the scope of ordinary life existence: “… Light the eleventh light of Christmas for spirit… / The strongest part of us that rises out of death forever. …” (p. 77). Descriptions of Stepanek’s spirit reuniting with those of deceased loved ones abound, living and Being in a Heavenly realm, for which there is no validation – only faith:

And, Heaven is a forever place.

That transcends our mortal Sense of time and space…

To go to Heaven,

A person must be Pure in heart…

So, we should live each moment Of life in a state of readiness … (Stepanek, 2005, p. 150)

The author’s evolutionary transcendence after dying is his truth of the soul’s everlasting life: “… But once death is over / We can actually Live / Forever in Heaven” (Stepanek, 2002b, p. 17).

Though not ontologically clarifiable, Stepanek’s soul – his spirit – is his entity, living apart from the material universe (Heidegger, 1927/1962):

… Then, even when we are Gone into our future,

We still live in

The present of our past. (2003, p. 68)

Stepanek’s Heavenly realm is at the hand of a higher God; a domain of divine good in which he, and other’s whom have transcended, will spiritually live on in peace and eternal freedom:
I will paint rainbows
When the spring comes,
And children will dance …
I will shape clouds
When the summer comes,
And children will chant …
I will whistle winds
When the fall comes,
And children will listen …
I will jingle stars
When the winter comes,
And children will laugh …
I will revolve seasonally
When my death comes,
And children will remember … (Stepanek, 2002b, p. 52)

**Trustworthiness**

Every effort has been made throughout this Gadmerian hermeneutic study to establish and ensure trustworthiness of the research findings. In addition to grounding each phase of the research in Gadamerian philosophy, a conceptual guide has been constructed, and specific techniques have been employed to meet Lincoln & Guba’s (1986) four criteria of trustworthiness: credibility, dependability, and transferability, and confirmability.

**Credibility**

Development of a conceptual guide for hermeneutic analysis of the poetic sample
illustrates the embedment of Gadamerian philosophy in this researcher’s interpretive process, and has helped to guide this study with organization and direction to ensure that the research process and findings are credible and true to their philosophical underpinnings. Documentation and journalization throughout the interpretive process has provided vivid substantiation of the research experience, as well as the logistics and findings of the process, lending credibility to this study.

**Dependability**

To safeguard the dependability of the study, this researcher has provided illustration of progression through the hermeneutic circle to enable the reader to closely and logically follow the process, and to elucidate the precision of how interpretive themes emerged. Comprehensive discussions of interpretations with adequate textual representation additionally supports the dependability of the research findings.

**Transferability**

To enable transferability of the research findings, clear, multi-faceted descriptions of the interpretive themes have been developed; this enables the reader to fully comprehend the findings of the study, and to determine how well the understandings may be applicable in other experiences regarding the phenomenon.

**Confirmability**

The Gadamerian hermeneutic process in which interpretive themes and understandings have emerged in this study has been charted out by this researcher using the developed Settecase-Wu Conceptual Guide. Adherence to this guide, as shown by example (Figure 2), not only ensures dependability, but confirmability, as well. The guided enables the reader to follow this researcher’s decision trail; the reader can decipher how the fusion of horizons
(understanding), given fore-understandings, perspective, and text, is arrived at, by examining exemplary entries in the guide which represent the researcher’s reflective journal.

In light of the above efforts, it may be concluded that the results of this Gadamerian hermeneutic text analysis are trustworthy.

**Summary of Chapter**

Chapter V provides the reader with detailed description as to how understanding (fusion of horizons) is attained. Definition of the poetic sample is stated, and a clear explanation regarding this researcher’s hermeneutic dialogue with the text, is issued. The Settecase-Wu Conceptual Guide, which is developed and implemented in the study, is also provided and explained. Text passages supporting pre-existing fore-understandings are presented in table form (Appendix B). The fusion of horizons (understanding) of this researcher and the author reveals three themes (tenderness, time, and transcendence), which are discussed; textual representations of these themes in relation to the phenomenon are presented. Discussion and evaluation of trustworthiness criteria (credibility, dependability, transferability, confirmability) conclude the chapter.
Chapter VI  REFLECTION ON UNDERSTANDING

To reflect on understanding of the phenomenon, living as a dying child, Chapter VI first views the research findings through a Nursing theoretical lens using Martha E. Rogers’ Science of Unitary Human Beings as the basis of discussion. Theoretical discussion includes two textual representations for each of the three themes (tenderness, time, and transcendence). The pairs of textual representations illustrate contrasting homeodynamic patterning for each theme. Implications for Nursing are then posited, followed by limitations and strengths of the research study, and recommendations for further Nursing research. The chapter concludes with reflections of the researcher’s experience.

Nursing Theoretical Lens - Martha E. Rogers

Understanding can only be achieved when the findings – the truth – that emerge from the hermeneutic process, can actively be applied in one’s own situation (Lindholm, as cited in Austgard, 2012). Discussion of the research and its findings through a Nursing theoretical lens (a special foregrounding) is required for this active application in Nursing practice. Rogers’ Science of Unitary Human Beings is the underpinning of this discussion.

Rogers’ (1992) science incorporates four foundational postulates: energy fields, openness, pattern, and pandimensionality. The energy field is what Rogers (1992) considers “the fundamental unit of the living and the non-living” (p. 29) – field being a unifying concept, and energy, an indication of the field’s dynamic nature. The energy field is infinite, and in continuous motion (Rogers, 1992). The human-environmental energy field, the distinctive cornerstone of Nursing, as defined by Rogers (1994), is “the irreducible human being and its environment” (p. 33); a unitary field that is “identified by patterning and manifesting characteristics that are specific to the whole” (Rogers, 1992, p. 29). Pattern, perceived as a
single wave, is “the distinguishing characteristic of an energy field” (Rogers, 1992, p. 30). The unitary, human-environmental energy field is open, infinite, and continuously flowing, characterized by patterning and manifesting characteristics that are unique to it (Rogers, 1992, p. 30). “With flow, comes change, with change, comes transformation” (Malinski, 2012, p. 240). Rogers’ (1992) unitary worldview is one of pandimensionality; that is, an open, “non-linear domain without special or temporal attributes” (p. 29). “There are no boundaries other than perceptual ones” (Butcher & Malinski, 2015, p. 239).

Rogers’ three principles of homeodynamics – resonancy, helicy, and integrality – “describe the nature and process of change in the human-environmental field process” (Butcher & Malinski, 2015, p. 240). Resonancy, the way change occurs (Phillips, 2010a), is the pandimensional, “continuous change from lower to higher wave patterns in human and environmental fields (Rogers, 1992, p. 31). Helicy is “the continuous, innovative, unpredictable, increasing diversity of the human and environmental field patterns” (Rogers, 1992, p. 31). “Integrality is the continuous, mutual, human field and environmental field process” (Rogers, 1992, p. 31). These three principles of homeodynamics – “the ever changing nature of life and world” (Butcher & Malinski, 2015, p. 239) – indicate that the simultaneous and “mutual patterning process of human and environmental energy field changes continuously, innovatively, and unpredictably, flowing in lower and higher frequencies” (Butcher & Malinski, 2015, p. 240).

Energy patterning is abstract, and is evident in its manifestations (Rogers 1992). Manifestations of energy field patterning are continuously innovative, and emerge out of the integral human-environmental field process of change, “where person and environment are unitary, thus inseparable” (Butcher & Malinski, 2015, p. 240). Unitary field patterning is creative and unpredictable by nature; energy flows continuously, and “change is relative, and
increasingly diverse” (Rogers, 1992, p. 31).

Though Rogers only briefly delineated her perspectives on dying (Malinski, 2012) she described it as a creative process, suggesting it to be a “transformation of energy” (Rogers, 1970, p. 71) – “a moving beyond the visible spectrum in higher frequency, increasingly diverse patterning (Rogers, 1976, as cited in Malinski, 2012). The living-dying process, according to Rogers, is one of nature’s rhythmicites (Malinski, 2012). Phillips (1992) describes living-dying as a “rhythm of the life process that becomes more diverse and innovative in its unfolding” (p. 4). In accordance with Rogers’ pandimensional universe (Phillips, 2010; Rogers, 1992), the living-dying of Mattie J. T. Stepanek is manifested as boundless, rhythmic, continuously flowing energy, with patterning manifested through poetic language.

The four postulates, and the three principles of homeodynamics, of Rogerian Nursing Science, resonate throughout the poems of Mattie J. T. Stepanek. The poetic language is a manifestation of the author’s human-environmental energy field process, flowing continuously, boundlessly open, deepening meanings. The hermeneutic helical process changes understandings integrally within the hermeneutic circle. There is no end to understanding; changes in meaning are infinite, as changing in Stepanek’s unitary field patterning is infinite. Stepanek is ever changing in multiplicity and transformation; his poems are timeless rhythmicites, smoothly fluctuating with life experiences, without order or limits –low frequency, low energy flow patterning, transforming into higher frequency patterning, and always unique. Rhythms are occasionally slow, and sometimes fast, oscillating and varying in scope and breadth. Rogers (1990, p. 31) provides some manifestations of relative diversity in field patterning listed below:
Rogers’ Manifestations of Field Patterning in Unitary Human Beings

<table>
<thead>
<tr>
<th>lesser diversity</th>
<th>greater diversity</th>
</tr>
</thead>
<tbody>
<tr>
<td>longer rhythms</td>
<td>shorter rhythms</td>
</tr>
<tr>
<td>slower motion</td>
<td>faster motion</td>
</tr>
<tr>
<td>time experienced as slower</td>
<td>time experienced as faster</td>
</tr>
<tr>
<td>pragmatic</td>
<td>imaginative</td>
</tr>
<tr>
<td>longer sleeping</td>
<td>longer waking</td>
</tr>
<tr>
<td></td>
<td>beyond waking</td>
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</tbody>
</table>

Tenderness, time, and transcendence, as understood in the findings of this study of living as a dying child, evolve rhythmically with manifestations of patterning. Each of the themes is presented with contrasting, textual examples of continually changing, always unique patterning. Rogers’ manifestations of relative diversity in field patterning are noted above each example, in italics. Stepanek’s keen awareness of change is evident in his language.
Tenderness

Lesser diversity  Greater diversity
Longer rhythms  Shorter rhythms
Slower pace  Faster pace
Pragmatic  Visionary
Longer sleeping  Beyond waking

A peaceful lake  …When the songs in my heart
Is a meditation  Travel out and around the world
For the mind  In the things that I say and
And for the spirit. (Stepanek, 2002b, p. 13)  In the poems and stories that I write …

And when the letters and words
Of those Heartsongs bring some
Peace to the countries and people
Who have war in their lives, (Stepanek, 2003, p. 66)
**Time**

<table>
<thead>
<tr>
<th>Lesser diversity</th>
<th>Greater diversity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shorter rhythms</td>
<td>Longer rhythms</td>
</tr>
<tr>
<td>Faster motion</td>
<td>Seems continuous</td>
</tr>
<tr>
<td>Imaginative</td>
<td>Visionary</td>
</tr>
<tr>
<td>Longer waking</td>
<td>Beyond waking</td>
</tr>
<tr>
<td>Time experienced as faster</td>
<td>Timelessness</td>
</tr>
</tbody>
</table>

... People get to see

The beautiful snows...

And the children get to grow into

Another season and

Be so happy! (Stepanek, 2005, p. 115)

Our life is an echo

Of our spirit today,

Of our essence

As it is,

Caught between

Our yesterday

And our tomorrow.

It is the resounding

Reality of who we are,

As a result of

Where we have been,

And where we will be,

For eternity. (Stepanek, 2001, p. 62)
Transcendence

<table>
<thead>
<tr>
<th>Lesser diversity</th>
<th>Greater diversity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shorter rhythms</td>
<td>Seems continuous</td>
</tr>
<tr>
<td>Faster motion</td>
<td>Seems continuous</td>
</tr>
<tr>
<td>Time experienced as faster</td>
<td>Timelessness</td>
</tr>
<tr>
<td>Imaginative</td>
<td>Visionary</td>
</tr>
<tr>
<td>Longer waking</td>
<td>Beyond waking</td>
</tr>
</tbody>
</table>

… In my fantasy space – …

I will live without

Extra oxygen. …

I will never need

A wheelchair or ventilator. …

And my forever-age will be

Ten-and-one-half Earth years. …

I will visit the spirits …

To inspire them …

I will forever …

Share my Heartsongs … (Stepanek, 2005, p. 25)

Living as a dying child is a phenomenon that is integral with to the child’s relationships with others and the environment; it is not experienced in isolation. Diverse changes occur dynamically and unpredictably with continual energy flow. It is a transformation of living beyond the tangible and perceptible. Viewing the understanding of this phenomenon through a Rogerian lens enables the justification and application of the research findings in Nursing practice.
Implications for Nursing

The findings of this study have multiple implications for Nursing practice and research. Knowledge of the meaning of living as a dying child is necessary for nurses to provide information, care, and support for children with life-limiting illness. Understanding a child’s patterning and perceptions of tenderness, time and transcendence increases awareness of the humanistic qualities of the phenomenon, and enables nurse-patient energy to rhythmically and co-creatively optimize living as dying potentials for well-being. Nurses’ knowledge of philosophical and theoretical underpinnings for understanding is key for unleashing Nursing potential in human science.

The Gadamerian hermeneutic process opens up a different, qualitative avenue for evidence-based practice. By providing open, therapeutic communication and paper and pencil, nurses can encourage both children and adults to document stories, emotions, poetry, and experiences in written form. Writing can be incorporated into recreation, allowing language, individuality, creativity and experiences to be freely expressed at will, in a comfortable manner, without provocation, confrontation, or questioning. Written data can be readily accessible, and may be easily shared with health care providers and researchers. In clinical settings, data can be used to promote optimal health, foresee potential obstacles, personalize treatment modalities, customize plans of care, and assist patients in living, achieving personal milestones, dying, and transcending. In Nursing research, IRB approval may be easier to obtain, and more research with data obtained directly from protected subjects can be hermeneutically conducted. Inquiry of written text can be performed again and again for understanding of various phenomena by different researchers. Each hermeneutic encounter with text will be unique and will reveal deeper understandings of various phenomena experienced by the author.
LIVING AS A DYING CHILD

Expanding the use of the Gadamerian hermeneutic process for text analysis can generate new knowledge through a precise, trustworthy process of logic and questioning. The new knowledge generated opens on a new horizon for deeper understanding and further research, and so on. There is a paucity of Gadamerian hermeneutic studies in Nursing in the United States. This study has comprehensively introduced the process and has provided a resource to inform Nurse researchers and educators in future research development and implementation.

Limitations and Strengths

One limitation of this Gadamerian hermeneutic analysis is that it provides understanding of just one child’s living experiences of the phenomenon; the results are therefore, ungeneralizable. Another limitation is that the findings of this study are limited to what the author has written in his living moments of the phenomenon; Mattie J. T. Stepanek died, and can neither refute nor confirm these findings. Further written accounts of his experiences are unobtainable. In addition, understanding cannot be absolute in Gadamerian hermeneutics. It can continue indefinitely, and be revised and refined constantly; for practical purposes, a plausible endpoint is reached.

Several strengths are noted regarding this study. Firstly, this hermeneutic analysis is entirely rooted and constructed in, and implemented with, Gadamer’s philosophy regarding text analysis, lending trustworthiness to the research and its findings. Secondly, this study has resulted in development of the Settecase-Wu Conceptual Guide: A Gadamerian Hermeneutic Approach for Text Analysis, providing a philosophically rooted, diagramatic guide for the process of Gadamerian hermeneutic text analysis. Thirdly, Mattie J.T. Stepanek has communicated his phenomenal experiences extensively in 499 poems, providing an adequate text sample for analysis, and enabling the hermeneutic process to lead to a rich understanding of
LIVING AS A DYING CHILD

living as a dying child. Lastly, this study has introduced a powerful, quantitative research process for Nursing in the United States.

Recommendations for Further Nursing Research

Several recommendations are offered for further Nursing research:

- Other Nurse researchers may repeat this Gadamerian hermeneutic study, resulting in different, unique understandings of the phenomenon living as a dying child.

- This study may also be repeated to attain deeper meanings and understanding regarding the emergent themes: tenderness, time, and transcendence.

- The poetic sample of Mattie J. T. Stepanek is extensive. Nurse researchers can further analyze the 499 poems for meaning and understanding regarding various other living experiences and phenomena.

- The Gadamerian hermeneutic approach may be implemented by Nurse researchers to examine traditions, cultures, and disciplines that are unfamiliar. The fusion of horizons regarding phenomena in foreign subject areas manifests deeper meaning and understanding of the culture or discipline to be examined.

- The Settcase-Wu Conceptual Guide may be used for further Gadamerian text inquiry to improve trustworthiness of the process, ensure accuracy, and guide documentation of the decision trail towards understanding.

- Future Nursing research can employ the Gadamerian hermeneutic approach to other written works. This not only further establishes Gadamerian hermeneutics as a trustworthy research process, but can provide rich, qualitative findings that are as powerful and meaningful as those of quantitative research.
Reflections of Researcher’s Experience

Gadamer (2013/1960) posits that understanding is a genuine experience. It is disclosure of the researcher and the author as Beings through open dialogue. Truth emerges from this language. Stepanek’s and this researcher’s co-created reality is that we have transparent faith without proof in the mystery of the findings. There are no questions, and there is no reason to say otherwise. Yet keep in mind that this truth cannot be final – it closes the hermeneutic circle of understanding only for now (Debesay, Nåden, & Slettebø, 2008)

Language is a human mode of relaying information – a careful configuration of words to speak to ourselves, and one another. Written language is the sole premise on which history, communication, and art are fixed. The permanence of the written word is an open, continuous invitation for a reader to engage with an author; its history, creativity, and meanings are always there to be questioned and understood, again, and again. As I write and reflect on my experiences in conducting this research, I invite you, the reader, to engage with me – for whatever reason, whenever, and however you choose.

There are several reasons why Mattie J. T. Stepanek may have written poetry: to leave behind a legacy, to provide an outlet for thoughts and emotions, for entertainment, or perhaps, just to pass time. I know he wanted to be heard, but I will always wonder if Mattie really knew the power of his voice. He called me into a lengthy and intimate dialogue, and prompted me to remodel my convictions about a phenomenon. His poetry led me to this point, where I have a good understanding of what it means for him to be living as a dying child. But, did Mattie know that my dialogue with him would never end – that I would be forever drawn into his words, for more? I think he did.

My relationship with Mattie J. T. Stepanek has enlightened me on many things. First,
that words do not always say enough; they say too much at times, and occasionally, they don’t say anything at all. We, as readers of word, reveal truth through continuous interpretation. We need to hear the voice that wants to be heard and listen to the emerging truth. Second, the written word represents the timeless transcendence of humanity – a limitless, open communication of expression that should not be taken for granted. Third, we all should read more, and write more, to keep understanding each other, and the world around us; this is especially true in Nursing, a human science. Lastly, I now know Mattie J. T. Stepanek. I hear and listen to him. I have understanding with him, and, I love him. Thank you, Mattie, for giving us so much.

**Summary of Chapter**

Chapter VI is a reflection on understanding the phenomenon. The findings of the research study are viewed through the theoretical lens of Martha E. Rogers’ *Science of Unitary Human Beings*. Pairs of textual representations for each of the phenomenal themes (tenderness, time, and transcendence) to illustrate different and unique homeodynamic patternings of the phenomenon. Implications for Nursing are then provided, along with limitations and strengths of the study, and recommendations for further Nursing research. Reflections of the researcher’s experience close the chapter.
IRB Determination Notice

University Integrated Institutional Review Board
205 East 42nd Street
New York, NY 10017
http://www.cuny.edu/research/compliance.html

Determination Notice

Activity Does Not Require CUNY HRPP/IRB Review

01/09/2019

Corinne Settecase-Wu,
The Graduate School & University Center

RE: IRB File #2019-0008
LIVING AS A DYING CHILD: A GADAMERIAN ANALYSIS OF THE POETRY OF MATTIE STEPAKEK

Dear Corinne Settecase-Wu,

The above-referenced research proposal was reviewed on 01/09/2019. Based on the information you have provided, the proposed research does not require CUNY HRPP or IRB review because:

[X] It does not meet the CUNY HRPP definition of research: A systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge.

[X] It does not involve human subjects as defined by CUNY HRPP: A living individual about whom an investigator (whether professional or student) conducting research obtains (1) data through intervention or interaction with the individual, or (2) identifiable private information.

[X] CUNY is not engaged in the proposed research: CUNY employees or agents obtain, for the purposes of the research project, (1) data about the subjects of the research through intervention or interaction with them; (2) identifiable private information about the subjects of the research; or (3) the informed consent of human subjects for the research.

Comments:

Please refer to CUNY HRPP Guidance: When is CUNY HRPP or IRB Review Required for further clarification regarding these criteria. Should your proposed activity change, please re-submit to the CUNY HRPP for re-evaluation of this determination.

________________________
Employees or agents refers to individuals who: (1) act on behalf of CUNY; (2) exercise institutional authority or responsibility; or (3) perform institutionally designated activities. Employees or agents can include staff, students, contractors, and volunteers, among others, regardless of whether the individual is receiving compensation.

If you have any questions, please contact:

University Integrated Institutional Review Board
205 East 42nd Street
New York, NY 10017
http://www.cuny.edu/research/compliance.html

Lisa Peralta
lisa.peralta@lehman.cuny.edu
Table B1.

Themes in Existing Research Related to the Phenomenon

<table>
<thead>
<tr>
<th>Theme</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.  Truth Disclosure</td>
<td>*</td>
</tr>
<tr>
<td>2.  Open, Honest Communication</td>
<td>*</td>
</tr>
<tr>
<td>3.  Potential Obstacles - Parents and Health Care Professionals</td>
<td>Too often The doctor is A mosquito Prepared to bite.” (Stepanek, 2005, p. 118)</td>
</tr>
<tr>
<td>4.  Awareness of Dying</td>
<td>Tears of happiness from above, Tears of sadness from below, Tears of heaven for those I love, Tears of eyes, from my heart, my soul. I’ve hear one thousand bells, each ring, Yet, not one of them is mine, How I long and ache for my Angel Wings The gift of eternal Heaven-Time. …(Stepanek, 2005, p. 187) … And I realize the pull Of the ebbing tide Is not so far away, For it is coming, Ever and too soon … (Stepanek, 2005, p. 201)</td>
</tr>
<tr>
<td>5.  The Need to be Heard</td>
<td>… We must resolve Our issues with words. … (Stepanek, 2005, p. 106)</td>
</tr>
<tr>
<td>6.  Mixed Emotions</td>
<td>… When I get scared of dying, or of hurting I am not as well-behaved, and I don’t do such a good job anymore. And sometimes, I am even a little nasty That makes me sad and confused though. (Stepanek, 2005, p. 142)</td>
</tr>
<tr>
<td>7.  The Fight for Life</td>
<td>… Problems, problems, problems Forever causing strife But don’t let problems get you down, Or you’ll miss out on life! (Stepanek, 2005, p. 126)</td>
</tr>
<tr>
<td>8.  A Need for Control</td>
<td>It is good To have a past That is pleasant To reflect upon. Take care To create Such a gift For your future. (Stepanek, 2002a, p. 55)</td>
</tr>
<tr>
<td>Theme</td>
<td>Text</td>
</tr>
<tr>
<td>-------</td>
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</tr>
<tr>
<td><strong>9.</strong> Hope</td>
<td>… Hope is a present Of future each day, A voice from our heart To show us the way. Hope is not passive It’s real and alive, Hope is a strength To guide choices made wise. … (Stepanek, 2005, p. 182)</td>
</tr>
<tr>
<td><strong>10.</strong> Heaven</td>
<td>Life! … To be savored… While it lasts. … Life is not forever. People grow older, And then they die. … But once death is over, We can actually Live Forever in Heaven. (Stepanek, 2002b, p.17) … I’ve heard one thousand bells each ring, Yet, not one of them is mine, How I long and ache for my Angel-Wings, The gift of eternal Heaven-Time. … (Stepanek, 2005, p. 187)</td>
</tr>
</tbody>
</table>

*textual evidence was not revealed by the analysis*
Table B2.
*Attributes that Support Researcher’s Initial Beliefs Regarding the Phenomenon*

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Fun</td>
<td>… We remember how important it is To play after every storm, just because We need to keep playing and living … (Stepanek, 2001b, p. 5)</td>
</tr>
<tr>
<td>2. Low Times</td>
<td>Indeed, The world does Not stop spinning Because I am in pain or Because tragedy exists . . . Perhaps, The world actually Spins even faster With the winds of despair . . . (Stepanek, 2005, p. 196)</td>
</tr>
<tr>
<td>3. Bounce-Back</td>
<td>If you have Enough breath To complain About anything, You have more than Enough reason To give thanks About something. (Stepanek, 2005, p.13)</td>
</tr>
<tr>
<td>4. Faith</td>
<td>I thank God everyday, For the gift of faith… For it is in faith, That I will exist, forever. I can imagine non-existence, … (Stepanek, 2002a, p. 58) … I am inclined to Believing in miracles Relying on grace With the proof of blessings Granted through faith. (Stepanek, 2005, p. 140)</td>
</tr>
<tr>
<td>5. Courage</td>
<td>Life is a treasure People should enjoy it, Even if digging To it, or Through it, Is a challenge (Stepanek, 2001b p. 45) If they would find a cure when I’m buried into Heaven, … I could still be happy knowing that I was a part of the effort. (Stepanek, 2001b, p. 55)</td>
</tr>
<tr>
<td>6. Knowingness</td>
<td>Although I am Greatly anticipating Going to Heaven … We must celebrate The gift of life on earth</td>
</tr>
<tr>
<td>Attribute</td>
<td>Text</td>
</tr>
<tr>
<td>-----------</td>
<td>------</td>
</tr>
<tr>
<td>While we have it, For Ever. (Stepanek, 2002b, p. 50)</td>
<td></td>
</tr>
<tr>
<td>… I move back and forth In the everywhere, And the nowhere … The echo of my spirit … … that sounds like A peaceful, but lonely cry, For the times When I swing Before I die. (Stepanek, 2001b, p. 14)</td>
<td></td>
</tr>
<tr>
<td>7. Love</td>
<td>It is good to have a friend... Friendship is a very special gift. … When one has a friend, One can feel loved for being oneself. … When one has a friend, One can travel through life in contentment. It is good to have a friend... Hand-to-hand, Heart-to-heart … (Stepanek, 2003, p. 28)</td>
</tr>
<tr>
<td>Love is Peaceful. It is an Anytime Gift. (Stepanek, 2005, p.18)</td>
<td></td>
</tr>
</tbody>
</table>

*textual evidence was not revealed by the analysis*
### Fore-understandings of the Phenomenon as Developed from the Researcher’s Story

<table>
<thead>
<tr>
<th>Fore-understanding</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.</strong> Children are brave. Even when they are fully aware of adversity, they are willingly take risks, and face consequences, if living depends on it.</td>
<td>… I feel pain, intense at moments. But I also feel the hurt of anxiety. And neither anguish is good for the spirit. … I will feel my spirit rejuvenated, And I will be filled with hope again. (Stepanek, 2001, p.36)</td>
</tr>
<tr>
<td><strong>2.</strong> When children suspect their parents and loved ones are worried and hurting, they will avoid discussion and asking questions, so as not to upset them further. Concern for parents often leads to children withholding their feelings and emotions.</td>
<td>*</td>
</tr>
<tr>
<td><strong>3.</strong> Dying children want and need knowledge about their prognosis, treatment, and illness progression. They ask many questions.</td>
<td>*</td>
</tr>
<tr>
<td><strong>4.</strong> Children want to know the truth, and are often aware when people are dishonest, or hesitant.</td>
<td>*</td>
</tr>
<tr>
<td><strong>5.</strong> Observing, and listening intently are two ways children gather and process information. They may be calm and quiet, yet be fully Engaged to “get the scoop” on their situation.</td>
<td>… Being smart isn’t just knowing ABCs and numbers. It’s also paying attention and Listening and knowing How to combine Your body power and Your mind power. (Stepanek, 2005, p. 164)</td>
</tr>
<tr>
<td><strong>6.</strong> Children with life-limiting illness want and need things to go as planned. Often, scrutiny may give them a sense of control.</td>
<td>*</td>
</tr>
<tr>
<td><strong>7.</strong> Dying children recognize pain and suffering in those around them. They frequently try to carry their burden alone, so as not to disrupt normal activity. They want to live as normally as they can, for them; they do not want to miss anything.</td>
<td>*</td>
</tr>
<tr>
<td><strong>8.</strong> Children with life-limiting illness may feel trapped in their physically limiting bodies; mentally and spiritually, they still long to soar.</td>
<td>When I go to Heaven, … I will live without Extra oxygen. I will never Be hurt or sick or tired… I will never have</td>
</tr>
</tbody>
</table>
9. Children living as dying want and need friends. They often give their friends personal belongings as symbols of their friendship.

... Lonely loch- ness dragons
Sing a song of solitude …
Of isolated existence and
Needs of friendly love
To express feelings and
Cry out for company. … (Stepanek, 2005, p. 25)

... Friends keep
Each other company.
They play with each other.
They help each other.
They support each other during difficult times.
A friend is someone to share with … (Stepanek, 2005, p. 122)

10. Faith in God and family support are sources of strength and guidance for children who are confronting their dying.

I feel the near-distance
Of Life in my life.
And though it feels sad
And lonely and large,
Even the silence of God
Gives me strength … (Stepanek, 2005, p. 169)

11. Detailed planning is important for a dying child. Often, they plan in detail; they know how and when they want to die.

* … I wish that I will
Become a remembered writer.
I made this wish because
It’s one of my greatest dreams.
I want to be a Peacemaker and
An Ambassador of Humanity. … (Stepanek, 2005, p. 180)

12. Dying children do not want to be forgotten after they are gone. They often leave things to certain individuals as reminders of them.

When I got really scared
About the changes in my life,
I wrote out a will.
I willed my collectible cards
And my stuffed animals
To my friends.
I willed my books and my poetry
To my mom. … (Stepanek, 2005, p. 181)

Have you wondered
If the people will wonder and then
Peacefully ponder the undying
Essence of your echo and the
Silhouette of your legacy that
Spirits the memory after death passes?
I have. … (Stepanek, 2005, p. 205)
<table>
<thead>
<tr>
<th>Fore-understanding</th>
<th>Text</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Have I done enough?</td>
</tr>
<tr>
<td></td>
<td>Will it last? (Stepanek, 2005, p. 206)</td>
</tr>
</tbody>
</table>

*textual evidence was not revealed by the analysis*
References


LIVING AS A DYING CHILD


doi:10.1046/j.1440-1800.2003.00163.x


doi:10.5840/gfpj1975512


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