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Listening to the “Voices” of Children with Serious Illness: Art, Metaphor, and Silence

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Listening to the “Voices” of Children with Serious Illness: Art, Metaphor, and Silence

by

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Abstract

Children with serious illness, including life-shortening and life-threatening illnesses, must contend with significant challenges related to limitations of their illness, the loss of physical functioning, and the threat of death. Social conceptions of childhood and death influence how children and adults understand serious illness and death in childhood. The ways in which children express the complexity of their experiences is not always as simple as making a verbal statement. In this philosophical hermeneutic inquiry, my aim was to explore how we might understand children's experiences of serious illness from their perspectives and in their own "voices." Six participants between the ages of seven and 17 years were interviewed to understand how children experience serious illness. Their "voices" included art, metaphor, and silence. The interpretive results generated from this research involve a different conception of children's "voices," their experiences of clinical places and relational spaces, physical and psychological apprehension in serious illness, and the silence that expresses inexplicable experiences. I conclude by exploring the practice implications for this research and the possibilities that children recognized for their own lives, despite the significant limitations that serious illness in childhood presents.

Keywords: pediatric palliative care, pediatric life-threatening/life-shortening illness, hermeneutic research, death, childhood, children's voices, nursing

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Dedication

This thesis is dedicated to my patients and to my dear friend and colleague, Gina Burgos, who died of cancer during my studies.

To my patients, both living and those who have died in my care, you have brought so much joy to the world – I will never be able to thank you enough for all that you have taught me.

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Chapter One: Coming to the Topic

Children with serious illness, including life-shortening and life-threatening illnesses, live and grow while dealing with the threats of sickness and death in a period of life that is typically associated with innocence, fun, and assuming a future in which one grows up. Pediatric palliative care (PPC) teams have the privilege of caring for and learning from children with serious illness and their families but must do so with a paucity of research to help them understand the experiences of the children in their care (Chong et al., 2018; Ciobanu & Preston, 2021; Ghirotto et al., 2018; Rahimzadeh et al., 2015). While the experiences of parents, siblings, and healthcare providers who interact with children with serious illness are relatively well documented, research on children's experiences of living with the threat or reality of death is limited. Insufficient evidence on the experiences of children with serious illness has left a major stakeholder out of the literature that informs PPC policy and practice (Rahimzadeh et al., 2015).

My interest in this topic has evolved over a twelve-year career as a pediatric hospice and palliative care nurse working with children with serious illness, many of whom have died in hospital, hospice, and home settings. In my practice, children's experiences might be influenced by several factors, including their knowledge of their prognosis, the severity of their illness, their age, their engagement with their care team and family, and their understanding of death. I often felt that our healthcare team's focus was on the experience of the child's parents. I recall one conversation with a colleague who stated that the parental experiences at the end of their child's life were more important as they were the ones who remained after the child had died. I was, at times, under the assumption that what the adults thought about the situation held true for the children, but in an encounter with the sister of one of my deceased patients, I realized that this was not the case. Throughout my graduate studies, I have learned to be wary of assumptions, for

they imply that the things and people we encounter in the world provide no recourse for thinking and understanding differently.

"Art Addresses Us"

Philosophical hermeneutics is the practice and art of interpretation (Gadamer, 1960/2004; Zimmerman, 2015). Moules et al. (2015) have utilized Gadamer's (1960/2004) hermeneutic philosophy to describe a hermeneutic research method. Hermeneutic inquiry begins when someone is addressed by an event, topic, or phenomenon that upsets ordinary routine and previously held assumptions (Gadamer, 2004; Moules et al., 2015). An address in this sense invites one to consider that which is questionable, of "being called or summoned" to respond with one's best efforts at coming to a new understanding of what one had previously, though perhaps unintentionally, misunderstood (Moules et al., 2015, p. 71). My address came in the form of a work of art created by a six-year-old after witnessing her sister's death.

In my nursing practice, I have had many encounters with children with serious illness and their siblings that demonstrated children's capacity for understanding difficult life events and concepts, such as death and grief. Years ago, I cared for Thea and her family (who have given me permission to share their story and use her name) in the four months leading up to her death. Despite her terminal cancer diagnosis, Thea was a vibrant, feisty, and loving child. The morning she died, her family and I prepared Thea's body to leave for the funeral home. Thea's younger sister had insisted on being present for Thea's after-death care, which concerned both her parents and the hospice staff. Despite our apprehension, this younger sibling stood at the head of the bed throughout the morning, until she left to draw in the corner of the room while her mother and I finished dressing Thea in her favourite outfit.

As Thea's body was about to leave for the funeral home, her sister rushed to her bedside and placed a drawing on Thea's chest. Unable to make sense of the drawing of a stick-figure old man and a girl holding hands, with swirls and a square at the bottom, I asked her what she had drawn. "This is Thea in her bedroom in Heaven with God," she replied. "Do you think they will have a waterslide for her?" What followed was a lengthy description of what Thea was experiencing in heaven, who was with her, what she was wearing, and how her accommodations had been outfitted with everything that she enjoyed. I recall thinking that I should not have worried about what this sibling had observed in Thea's after-death care, as her artwork revealed that she had a much different view of where Thea was. Thea's younger sister had concerned herself more with what Thea was doing in her heavenly bedroom than what we were doing in Thea's room at the hospice.

It may seem odd to consider a child's drawing as art, at least in the sense of a classical painting or sculpture. Adults may consider children's artwork to be "refrigerator art" that is worthy of display, but not contemplation (Matthews & Mullen, 2020). However, Gadamer wrote that "art is present whenever a work succeeds in elevating what it is or represents to a new configuration" (Gadamer, 1986, p. 103). Artwork, when interpreted hermeneutically, does not provide a copy or representation of a given subject or world, but allows that which is captured in the artwork to present or realize itself more fully (Davey, 2002; Gadamer, 1986). Such a conception of a work of art extends beyond aesthetic topics, such as taste or technique, allowing the artwork to bring a presented world to language and understanding through a network of associations attached to an image, poem, sculpture, or musical score (Davey, 2002; Gadamer, 1986). In the manner that topics address hermeneutic researchers (Moules et al., 2015), "art addresses us" in its power to affect us immediately (Davey, 2016, p. 2). What I came to

understand from her sibling's drawing was a new configuration of Thea, portrayed in a way that allowed her sister to make sense of Thea's death and express her hopes for Thea's afterlife. I was addressed by the depth of meaning shown in what was ostensibly a simple stick-figure drawing. I began to question what I might have inadvertently overlooked when viewing the artistic creations of children, and what may be revealed in the artwork that they create.

This sibling's spontaneous drawing allowed her to bring language to her experience during the time immediately following Thea's death. PPC teams frequently utilize art-based therapies to encourage children with serious illness and their siblings to express themselves through their creations, to facilitate conversation, for psychotherapeutic analysis, and as an enjoyable activity that can either distract or confront children's experiences of illness (Aasgaard & Edwards, 2012; Kramer, 1971; Sourkes, 1991, 2018). Children's works of art, and what children have to say about them, can be used as data in hermeneutic research to understand children's experiences of serious illness and the threat of death in childhood to help inform PPC practice (Wong, 2019).

Pediatric Palliative Care

Established in the late 1970s in response to the perceived suffering of children for whom cure was not possible, PPC has grown from fragmented consult services in select cities to an internationally recognized specialty (Liben et al., 2014; Morgan, 2009; Sisk et al., 2020; Sourkes et al., 2005). PPC promotes the physical, psychological, spiritual, social, and developmental wellbeing of children with serious illness and their families, with the goal to ameliorate suffering and improve quality of life (World Health Organization, 2018). PPC philosophy emphasizes care over the trajectory of a child's disease, from diagnosis to bereavement, and may be delivered even when curative treatments such as radiation, surgery, or chemotherapy are being pursued

(Friedrichsdorf & Bruera, 2018; Himelstein et al., 2004; Sourkes et al., 2005; World Health Organization, 2018). Advancements in medicine and technology have resulted in improved symptom management and equipment that can prolong the lives of children with serious illness, sometimes for many years or decades, while mitigating suffering (Connor et al., 2017; Himelstein et al., 2004; Liben et al., 2014). As such, children who could benefit from PPC services include children with life-shortening illnesses, where death in childhood is expected, and life-threatening illnesses, who may live to adulthood with a shortened life expectancy or die from an illness related complication (Connor et al., 2017). PPC teams care for children with serious illness and their families during periods of health stability and crisis, either on a consultative basis or as the child's primary healthcare team (Himelstein, 2004).

The diseases and conditions that cause death in childhood include congenital malformations, acquired immunodeficiency syndrome (AIDS), chromosomal abnormalities, diseases of the nervous system, kidney disease, cancer, and endocrine, blood, and immune disorders (Connor et al., 2017; Davies, 1996; Widger et al., 2016). These serious illnesses are often rare, under-researched, have few options for treatment, and have unpredictable illness trajectories, making it difficult for clinicians to predict how long children with serious illness will live (Davies, 1996; Friedrichsdorf & Bruera, 2018; Himelstein et al., 2004; Rushton, 2005; Sourkes et al., 2005). With comprehensive care, children with serious illness may live for years and into adulthood with adequate symptom management, but with progressively worsening health status (Himelstein, 2005). The mandate to intervene early in the illness trajectory and the unpredictable prognoses associated with serious illness in childhood mean that children with serious illness are growing up in the care of PPC teams, and frequently hospitalized due to the

increased medical fragility and the progressive decline associated with their illnesses (Feudtner et al., 2011; Himelstein et al., 2004; Ng et al., 2024; Sourkes et al., 2005).

Utilization of Pediatric Palliative Care Services

Globally, over 21 million children from birth to 19 years of age would benefit from PPC services annually, with over 8 million requiring specialized PPC care (Connor et al., 2017; Friedrichsdorf & Bruera, 2018). Canadian children with serious illness may receive PPC services in hospital, in the hospice setting, and at home, provided those services are available in their area. In their study of 13 Canadian PPC programs, Widger et al. (2016) estimated that 2317 children 19 years of age or younger who died in Canada in 2012 could have benefited from PPC services based on their diagnosis. While only 431 (18.6%) of these children received PPC services, this is a fourfold increase in the use of PPC services since 2002, where only 5% of children who could have benefitted from PPC services actually received specialized palliative care (Widger et al., 2007; Widger et al., 2016). This increase in utilization of PPC services may be largely due to an increase in the number of PPC programs available to children with serious illness in Canada between 2002 and 2012 (Widger et al., 2016). The Canadian Institute for Health Information (2020) reported that less than 1% of children with medical fragility (which would include children with serious illness) had a PPC consult during their hospital stays in the last two years of their lives.

PPC services in Canada have expanded in recent decades but remain under-utilized by children with serious illness and their families, which may be attributed to persistent beliefs about palliative care that influence both healthcare professionals, families, and laypeople. Families and pediatric healthcare providers may be reluctant to agree to work with PPC teams if they perceive it as “giving up hope” for the child (Friedrichsdorf & Bruera, 2018). Healthcare

teams may pursue life-sustaining and life-saving interventions to a greater extent than they might for an adult, even if such efforts result in increased suffering (Feudnter & Nathanson, 2014).

Research Gaps, Barriers, and Opportunities

To advocate for improved access to services, improve current PPC, and to continue to develop PPC as a medical specialty, it is important to understand the experiences of children who face serious illness and death. Retrospective quantitative studies have reported that children with serious illness who are in the final weeks to months of life often experience increased invasive procedures, polypharmacy, hospitalization in pediatric intensive care units, and burdensome symptoms such as pain, nausea, dyspnea, anxiety, and sleep disturbance (Feudtner et al., 2011; Friedrichsdorf et al., 2015; Siden & Steele, 2015; Widger et al., 2017). With few notable exceptions (Bluebond-Langner, 1978; Bristowe et al., 2024; Ciobanu & Preston, 2021; Hsiao et al., 2007; Spinetta et al., 1973; Spinetta & Maloney, 1975; Waetcher, 1971), there is a paucity of prospective qualitative research in PPC that includes children with serious illness as participants (Chong et al., 2018; Ciobanu & Preston, 2021; Ghirotto et al., 2018; Rahimzadeh et al., 2015).

Communicating with children, misconceptions around the goals of PPC, a shortage of PPC researchers, and stringent regulations for the involvement of children in research have been identified as barriers to research in PPC and can be attributed to the absence of literature on the experiences of children with serious illness (Liben et al., 2014; Rahimzadeh et al., 2015). The taboo surrounding pediatric death and the assumption that children with serious illness may not be aware of the severity of their situation hinders thoughtful and open discussion or inquiry with children (Feudtner & Nathanson, 2014; Rahimzadeh et al., 2015). Research and practice in PPC are heavily informed by adult perspectives of what children with serious illness experience (Ghirotto et al., 2018; Rahimzadeh et al., 2015). However, there is evidence to suggest that

parents may have difficulty reliably interpreting their children's perspectives, despite being heavily involved in their care and lives (Ciobanu & Preston, 2021; Kars et al., 2015). Children with serious illness often understand the fatal nature of their illnesses more than their parents and healthcare providers realize (Ciobanu & Preston, 2021; Bluebond-Langner, 1978; Waechter, 1971).

Without adequate inquiry into the experiences of children with serious illness, the ability to provide the highest quality end-of-life care to children and families is limited, and what children consider to be important in palliative care may be misinformed by adult perspectives (Ghirotto et al., 2018; Rahimzadeh et al., 2015). The underestimation of what children with serious illness understand of death and dying (Blubond-Langner, 1978; Rahimzadeh et al., 2015), the perception that children are less reliable research informants than adults (Docherty & Sandelowski, 1999), difficulties that children with serious illness may have expressing themselves to meet the needs of some research methods (Nilsson et al., 2015), and deficient conceptions of children that inform most child development theories (Matthews & Mullen, 2020) may have contributed to the scarcity of the perspectives of children with serious illness in the PPC literature.

These research barriers are not insurmountable and may benefit from learnings from PPC practice. Issues regarding children's communication, reliability, and understanding are frequently encountered in practice and worked through with creativity, active listening, and conversation. In the same manner that different modalities are used to elicit children's perspectives in practice, exploring research methodologies that allow children to express themselves, and for those expressions to be accepted as reliable, can allow these research barriers to be overcome.

Chapter Two: Children's Experiences of Serious Illness and their Artistic Forms of Expression

In this chapter, I situate the topic of understanding the experiences of children with serious illness through their artistic forms of expression. My aim in this literature review is to evaluate what is known about the topic in keeping with research and academic standards (Polit & Beck, 2017). Additionally, the literature review followed the recommendation of Webber et al. (2023) to interpret the literature in a way that is philosophically consistent with hermeneutics. In addition to the literature on pediatric palliative care and children's experiences of serious illness, Western society's historical conceptions of children and their development, particularly as it relates to their understanding of death, were explored.

Literature Review Process

The prevalent expectation of the research community for literature reviews reflects the assumptions and priorities of positivist approaches to knowledge generation (Greenhalgh et al., 2018). One may conduct a literature review with the assistance of a methods handbook, tools for the evaluation of quality and synthesis, and checklists, such that the process may be replicated by others (Greenhalgh et al., 2018). However, not all research methods align with a prescriptive process for reviewing and synthesizing existing literature on a given topic, as "different kinds of reviews offer different kinds of truth" (Greenhalgh et al., 2018, p. 3).

Conducting Literature Reviews Hermeneutically

Webber et al. (2023) have presented recommendations, rather than a method, for conducting literature reviews hermeneutically, rather than conducting a hermeneutic literature review.

There is a subtle, but arguably necessary, distinction here. Hermeneutic, as used

> in a hermeneutic literature review is an adjective—a word that describes the noun, which in this case is: literature review. However, hermeneutically, as used in conducting a literature review hermeneutically, is an adverb—a word that describes a verb. (Webber et al., 2023, p. 2)

The minute grammatical change that Webber et al. (2023) suggested reflects an active, rather than passive, approach to literature reviews that is consistent with hermeneutic philosophy. The aim of hermeneutic philosophy and research is understanding, rather than explanation, and the event of understanding requires interpretive action on the part of the individual who is attempting to understand something (Gadamer, 1960/2004; Moules et al., 2015). Conducting a literature review hermeneutically requires active interpretation to meaningfully grasp how the topic is situated historically and contextually, as well as to build a foundation of what is already understood about the topic.

Literature Review Process

As one of the authors of Webber et al. (2023), some of the following section has been adapted from our publication in the *Journal of Applied Hermeneutics*, where I shared my approach to this literature review. I came to the topic of children's experiences of serious illness and their artistic forms of expression through many years of practice expertise. As such, I approached my literature review with the hermeneutic concept of prejudice in mind. Gadamer (1960/2004) avoided the commonly understood negative connotations of prejudice by defining it as simply the preunderstanding that informs what we understand, which is neither negative nor positive. Prejudices provide one with the foundation for understanding but are subject to revision when we are presented with a new way of thinking about a topic (Gadamer, 2007). My prejudices, informed by my practical experience and conversations with children, provided me

with a unique insight into the topic of children's experiences of serious illness from the standpoint of an adult caregiver.

My literature review began early in my graduate studies as I was fortunate to arrive at my topic within a few months of beginning my coursework. I used several databases (CINAHL, Medline, PubMed, and PsychInfo) to search for peer reviewed research or expert opinion articles available in English. I also accessed textbooks and grey literature, including government and organizational reports that informed the topic. As my research addresses a significant gap in the literature, my literature review encompassed several related topics that would further establish my foundation for research. The keywords to search these topics included: *adult palliative care*, *pediatric palliative care*, *end of life care*, *pediatric serious illness*, *child development theory*, *children's understanding of death*, *art therapy*, and *arts-based research*. Substitution words, including *youth* and *young people*, *terminal illness*, and *life-threatening/shortening illness*, were also included. Neighbouring topics added depth to my inquiry and helped to understand my approach to this topic more fully. I began by reviewing the literature on pediatric palliative care and children's experiences of serious illness. I explored what is known about children's understanding of death, with a critical lens regarding to how those theories were established. I then sought to address some of the challenges identified in the literature for conducting research in pediatric palliative care with children.

Next, I reviewed literature on communicating with children in a research interview, including methods that used arts-based research to elicit the perspectives of children. These studies helped to inform how I might conduct research with children, rather than on them, and included multidisciplinary approaches to research with children in social work, childhood

anthropology, education, nursing and medical research, and psychology. The hermeneutic concept of prejudice served as an important guide to building a foundation to understand the topic differently, while allowing me to utilize my expertise.

Children, Serious Illness, and Death

The death of a child throws an assumed sequence of life out of order and arouses the fear of death before fulfillment (Buckingham, 1990; Rallison & Moules, 2004; Waechter, 1971). As Morgan (2009) stated, "Children, the hope and future for our society, are not supposed to die" (p. 87). For families, the death of a child is an unspeakable loss (Rallison & Moules, 2004). For healthcare providers who are unsuccessful in their attempts to save a child from serious illness or after a life-threatening event, the death of a pediatric patient is seen as a "triple failure,"

> First, because they did not have the means, skills, or abilities to save a life; second, because in their social role as adults they were unable to protect the child from harm; and, third, because they 'betrayed' parents who trusted them with the most valuable being in their life. (Papadatou, 1997, pp. 576-577)

Western conceptions of children and childhood can offer some context to understand why the death of a child is incomprehensible to those who do not regularly interact with children who live with serious illnesses. Considering the history of conceptions of childhood may also help explain the limited research in PPC on children's experiences of serious illness and end of life.

Social Constructions and Conceptions of Childhood

Adult attitudes towards children in Western society are shaped by a history of philosophical, theological, sociological, and scientific conceptualizations of childhood. In his influential book, *Centuries of Childhood*, Phillippe Ariés (1962/1960) analyzed depictions of infants and children in medieval artwork and concluded that medieval children were perceived as

"little adults" who were represented as figures "reduced to a smaller scale than adults" (p. 33). Ariès (1962/1960) determined that medieval society had yet to recognize childhood as a relevant stage of life. According to Heywood (2001), Ariés has been criticized for his background as an amateur historian, his use of iconographic evidence, and his assertion that the absence of children in medieval art signified that childhood was considered an "unimportant phase of which there was no need to keep any record" (Ariés, 1962/1960, p. 38). However, Ariés is often credited with highlighting that what one thinks about children and childhood is historically and socially constructed, rather than natural inclinations (Heywood, 2001; Matthews & Mullen, 2020).

There is reason to be skeptical of assertions of any drastic discontinuity in Western conceptions of childhood, as Matthews and Mullen (2020) noted that many contemporary adults have an Aristotelian notion of childhood. Aristotle's idea of formal and final cause, an organism that moves from an immature specimen (formal) with the potential to develop into a fully functioning and mature specimen with structure (final), inform how many modern-day adults conceptualize how children are thought of and raised (Falcon, 2019; Matthews & Mullen, 2020). Jean Piaget, an influential child psychologist, established a similar step-wise theory that children develop in age-related stages of distinguishable cognitive and structural change until they reach maturity (Piaget & Inhelder, 1966/1969). Developmental psychologist and psychoanalyst Erik Erikson, who was heavily influenced by Freudian thought, viewed the development of self-identity as a series of stages occurring throughout the lifespan, rather than focusing only on childhood as Piaget had (Erikson, 1950). Erikson also took into consideration the sociocultural and historical influences on the development of the self, and the ramifications should one fail to cope with life crises at any stage (Erikson, 1950).

Stage-oriented theories of child and cognitive development have had a widespread influence on adult perceptions of children and suggest that maturity is a goal that children must attain, with the tacit assumption that earlier stages of development are less satisfactory (Matthews, 1994). The notion that children develop in stages are "deficient conceptions" in which the child is understood as lacking or deficient in the capacities that adults possess and consider childhood to be a preparatory period for life as an adult (Matthews, 1994; Matthews & Mullen, 2020. p. 4). The phrase "raising children" may also be interpreted as a deficient conception of the progression from childhood to adulthood (Wong, 2019). Matthews (1994) suggested that while developmental theories have their uses, there is no reason to presume that growing up in a standard way will result in the achievement of "maturity," and such deficient conceptions neglect to consider why it is that children have an easier time than adults in learning new languages or pose an imaginative, stimulating question that is no different from one that a professional philosopher might ask. While it is not my intention to suggest that child development theories are inherently oppressive of children or that children do not need adult assistance in their upbringing, it is worthwhile to consider what such theories fail to acknowledge about children and how they interpret and understand the world.

I recall one preadolescent patient who exclaimed, "I'm not a kid! I'm almost human!" to argue for a later bedtime. Such comments highlight the potential harm of deficient conceptions of children in practice settings where children have a central role, such as an elementary school classroom or a pediatric hospital. Developmental theories that focus on the progression through pre-determined stages or ages of life become particularly problematic in the PPC population. Childhood, when seen as a condition of becoming, may have significant implications for children

with serious illness who face the threat of dying before they become (Bluebond-Langner, 1978; Matthews, 1992; Wong, 2019).

Children's Understanding of Death

Developmental theories have influenced how researchers and clinicians have approached investigations in children's understanding of death and dying (Glicken, 1978; Kenyon, 2001; Solnit, 1965), which in turn have explicitly and implicitly informed the involvement of children with serious illness in clinical decision-making, adult interactions with children with serious illness, and whether a terminal prognosis should be disclosed to a child (Bluebond-Langner, 1978; Buckingham, 1983; Larcher & Carnevale, 2012; Matthews, 1994). An "adult" or "mature" concept of death requires one to understand that death is irreversible, universal, inevitable, involves the cessation of bodily functions (i.e., non-functionality), and is ultimately caused by a breakdown of bodily function (i.e., causality) (Bluebond-Langner et al., 2012; Glicken, 1978; Ellis & Stump, 2000; Slaughter & Griffiths, 2007; Speece & Brent, 1984).

The literature on children's conceptual understanding of death is largely informed by developmental frameworks, with the assumption that, like other abstract concepts, children's views of death evolve along a linear path in predictable stages (Glicken, 1978; Kenyon, 2001; Slaughter & Griffiths, 2007). According to developmental theory, young children consider death to be a reversible, temporary separation or as a continuation of life in another form or changed circumstances (Bluebond-Langner et al., 2012; Koocher, 1973; Nagy, 1948/1959; Slaughter & Griffiths, 2007). Children between the ages of five and nine believe that death is caused by external forces, is avoidable, and involves the cessation of bodily activities (Bluebond-Langner et al., 2012; Koocher, 1973; Nagy, 1948/1959; Slaughter & Griffiths, 2007). Nagy (1948/1959) found that children in this age group also viewed death as if it were a person, skeleton, ghost, or

non-corporeal entity that would "carry you off with him" (p. 89). Children over 10 years understand that death is irreversible, universal, inevitable, and can describe what causes death (Bluebond-Langner et al., 2012; Koocher, 1973; Nagy, 1948/1959; Slaughter & Griffiths, 2007). However, Mahon et al. (1999) found that children as young as six years old had an "accurate conception of death" (p. 55).

The focus on children's beliefs about death as generalizable to a certain age or developmental stage do not account for the influence that religion, parental beliefs, culture, and experience may have on a child's conceptual understanding of death (Kenyon, 2001; Speece & Brent, 1984). The literature also focuses heavily on how children understand the biological facts of death and dead people or things, rather than the meaning of death from a spiritual or philosophical context (Kenyon, 2001). Finally, developmental frameworks for understanding death assume that there is a universal structure to a "mature" or "adult" concept of death (Kenyon, 2001). Developmental theory is informed by studies that included children who were healthy, developmentally "normal" or "typical," and who had some or no exposure to the death of a loved one or pet (Koocher, 1973; Nagy, 1948/1959; Slaughter & Griffiths, 2007). Children with serious illness have atypical life experiences that inform their understanding of death that may not correspond with the predominant theories that posit the evolution of children's conceptual understanding that begin in childhood and are achieved in adulthood.

Awareness of Death for Children with Serious Illnesses

Children who face serious illness and death in childhood are forced to confront their personal mortality earlier in life as compared to their healthy peers and may have a different understanding or awareness of death than would be expected of them developmentally (Bluebond-Langner, 1978; Sourkes, 1995; Spinetta et al., 1973; Spinetta & Maloney, 1975).

Spinetta et al. (1973) found that children with serious illness were more anxious about death and more preoccupied with the functionality of their bodies than children who had chronic, but non-life-threatening, illnesses. Spinetta et al. (1973) also identified that children with serious illness appeared to be aware of the severity of their situation but were unable to verbally express that awareness in "adult terms," (p. 844). Waechter (1971) presented a series of pictures depicting regular hospital activities to hospitalized children with serious illness and children with chronic illnesses and encouraged them to make up a story for each picture. In Waechter's (1971) sample, children with LLI mentioned death and threats to bodily integrity more frequently than the children with chronic illness. She noted that some children with serious illness were more aware of their prognosis than their parents had thought (Waechter, 1971).

In her ground-breaking ethnographic study on children's awareness of dying in the pediatric oncology population, Bluebond-Langner (1978) found that children with terminal cancer were not only thinking about the possibility of death, but were aware that they were dying, even if they were never explicitly informed of their prognosis by the adults in their lives. Bluebond-Langner (1978) identified that the children in her sample acquired information about their illness in stages: (a) it is a serious illness, (b) knowledge of their medications and side effects, (c) knowledge of the purposes of medical procedures, (d) disease as a series of relapses and remissions, and (e) disease as a series of relapses and death. The children in her study maintained the pretense that they were unaware of their impending death in situations where they believed they were not supposed to know, or if they believed their parents were unaware and wished to protect them from the devastating news (Bluebond-Langner, 1978). Children are interpretive beings, and their open curiosity allows them to build their understanding of the world (Wong, 2019). Like all children, those with serious illness seek to make sense of their

experiences by interpreting the world around them, with whatever information and resources are available to them (Aasgaard & Edwards, 2012). Through what Sourkes (1995) called "the wisdom of the body" (p. 107), children may interpret their own physical senses, the changes in their outward appearance, and their inability to participate in play or activities of daily living as ominous indicators of the severity of their illness.

Children may also be made conscious of their poor prognosis by interpreting the facial expressions and body language of their carers or by noticing an increase – or sudden decrease – in the intensity of their treatments (Bluebond-Langner, 1978; Sourkes, 1995; Stein et al., 2019). In situations where serious illness and death are not openly discussed, they may note the reluctance of parents and healthcare providers to acknowledge these changes and interpret the silence on the matter to mean that it is not to be discussed, preventing further understanding that could be achieved through conversation (Bluebond-Langner, 1978; Sourkes, 1995; Stein et al., 2019). Presently, children with serious illness have access to more information than ever before; they may do their own research and draw their own conclusions about their illness and prognosis. It may be that for some children with serious illness, their awareness or experiences of death and dying precede the vocabulary required to express what they know and understand (Aasgaard & Edwards, 2012; Spinetta et al., 1973). In PPC practice, arts-based approaches to therapy and communication that utilize activities that children regularly use to express themselves, like drawing and play, help children with serious illness discuss their experiences, beliefs, and feelings about death and dying (Aasgaard & Edwards, 2012; Sourkes et al., 2005).

Experiences of Children with Serious Illness

Much of what is known about children's experiences of serious illness is informed by parents, healthcare providers, and retrospective health data on the children's treatments,

symptoms, and care settings. Feudnter et al. (2011) found that the cohort of patients referred to palliative care teams in their quantitative study most frequently experienced cognitive impairment, speech difficulties, feeding problems, seizures, fatigue, and pain. Wolfe et al. (2000) interviewed bereaved parents and found that while there were discrepancies between what healthcare providers had documented and what parents reported, children experienced fatigue, pain, dyspnea, poor appetite, nausea and vomiting, constipation, and diarrhea. Parents reported that while these symptoms were addressed, symptom management was successful in less than 30% of the children, with 89% of children perceived to have experienced "substantial suffering" (p. 332) from at least one symptom in the last month of life. Most of the children in this study died in an intensive care unit and parents reported that their child had little or no fun, were afraid, and were not calm and peaceful in the last month of life. In a scoping review by Ng et al. (2024), most children with serious illness died in hospital with increased intensive care interventions, such as mechanical ventilation, though the authors found that, increasingly, children died at home.

More recent studies that involve children as participants reported that children with serious illness experienced distress related to physical symptoms, such as pain, decreased physical functioning, and time consuming and burdensome treatments (Namisango et al., 2020; Nicholas et al., 2011; Tan et al., 2024). Children also reported feeling socially isolated because of the infection risks associated with their illness, but also because of being hospitalized, having to miss school, and not being able to participate in activities because of their treatments (Bristowe et al., 2024; Namisango et al., 2020; Nicholas et al., 2011; Tan et al., 2024). In their study on children's preferences at end of life, Mitchell et al. (2021) reported that children were often aware they were discussing their own death, even if it was not directly stated, and made

decisions about their health considering its impact on their family members. The children in this study also refrained from discussing death and often deflected the conversation away from the topic of their illness.

Application of Art in Practice and Research

Art as Therapy

Children with serious illness may face concepts and experience events that they do not have the vocabulary to articulate with words alone (Aasgaard & Edwards, 2012; Kramer, 1971; Sourkes, 1991, 2018). PPC teams often include child-life and art therapists who utilize arts-based therapies to facilitate communication and understanding with children, to assess coping skills, and to allow children the opportunity to release their inner emotions in a safe and non-judgemental way (Aasgaard & Edwards, 2012; Councill & Ramsey, 2019; Devlin, 2006; Jones & Weisenfluh, 2006; Sourkes, 1991, 1995, 2018; Sourkes et al., 2005). The Canadian Art Therapy Association (n.d.) defined art therapy as a combination of "the creative process and psychotherapy, facilitating self-exploration and understanding" and uses imagery, colour, and shape as part of the creative therapeutic process, to elicit the expression of thoughts and feelings that would "otherwise be difficult to articulate." Creating art is an appropriate medium for children to express themselves and to be understood, regardless of their ability to articulate their experiences verbally (Aasgaard & Edwards, 2012; Kramer, 1971; Sourkes, 1991, 1995, 2018; Sourkes et al., 2005).

Edith Kramer (1971) was among the first people to define art therapy in the 1940s and utilized it with children with emotional and social disorders. She emphasized that her approach to art as therapy, rather than art as a tool in psychotherapy, served to support the ego, foster the development of a sense of identity, and to promote growth and maturation in children (Kramer,

1971). When the creation of art is the primary focus of the exercise, children can be reminded of their energy, creativity, independence, and their life outside the hospital setting and their illness (Aasgaard & Edwards, 2012; Councill & Ramsey, 2019; Devlin, 2006; Hendricks et al., 2019; Sourkes, 2018). Art as therapy functioned as a means of distraction for children who were undergoing significant physical and psychological trauma in the form of a familiar, safe, and enjoyable activity (Aasgaard & Edwards, 2012; Abdulah & Abdulla, 2018; Aguilar, 2017; Councill & Ramsey, 2019; Hendricks et al., 2019; Jones & Weisenfluh, 2006; Kramer, 1971; Madden et al., 2010; Sourkes, 1991, 1995, 2018; Sourkes et al., 2005).

Art for Therapy

Art may also be used as an adjunct to traditional psychotherapy to reveal unconscious emotions, thoughts, and areas of concern (Askins & Moore, 2008; de Souza Fernandes & de Souza, 2019; Devlin, 2006; Furth, 1988; Hendricks et al., 2019; Sourkes 1991, 1995, 2018). Child psychologists utilize several art-based tools to assess children's coping, maturity, developmental capacity, and emotional well-being (Askins & Moore, 2008; de Souza Fernandes & de Souza, 2019; Devlin, 2006; Hendricks et al., 2019; Sourkes 1991, 1995, 2018). These tools include the mandala, the "Change in Family" drawing, the "Scariest Image" drawing, the "Closure Drawing," and the "Drawing of a Person Picking an Apple from a Tree" (Rollins, 2005; Sourkes, 1991). These techniques invite children to safely express the social changes they experience due to their illness, their most frightening experiences, and provide the therapist with a projection of the child's unconscious thought with minimal conscious effort on the part of the child (Rollins, 2005; Sourkes, 1991, 1995, 2018).

Art as Language

The creation of art is a long-standing form of human communication that has been demonstrated to be an appropriate medium through which adults may converse with children, as drawing and play are considered the universal languages of children (Aasgaard & Edwards, 2012; Abdulah & Abdulla, 2018; Aguilar, 2017; Hendricks et al., 2019). Art therapy may be used to allow children with limited vocabulary or restricted verbal capabilities to communicate in a medium that is recognizable to both the child and their caregivers (Aasgaard & Edwards, 2012; Councill & Ramsey, 2019; Devlin, 2006; Hendricks et al., 2019; Massimo et al., 2008; Rollins, 2005; Sourkes. 1991, 2018). In very young children with serious illness, art was able to convey children's understanding of death and grief (Councill & Ramsey, 2019; de Souza Fernandes & de Souza, 2019; Devlin, 2006; Hendricks et al., 2019; Rollins, 2005; Sourkes, 1991). Art allowed children to confront negative life experiences in a safe manner and served to trigger memories when children were able to structure their narratives through their art (Bat-Or & Garti, 2019; Councill & Ramsey, 2019; Devlin, 2006; Rollins, 2005; Sourkes, 1991). Additionally, art may be used to help healthcare providers communicate with children by facilitating conversations that explain procedures, to discuss the meaning of death and its causes, and to help discover and give name to the emotions associated with negative symptoms or senses (Councill & Ramsey, 2019; de Souza Fernandes & de Souza, 2019; Devlin, 2006; Massimo et al., 2008; Sourkes, 2018). Massimo et al. (2008) used art to communicate with children and families who had left their home countries to seek treatment for cancer in Italy; art was able to overcome significant language barriers, thereby improving care.

Art as Data

As art therapy has been demonstrated to be an effective tool to communicate with children in a clinical or therapeutic setting (Aasgaard & Edwards, 2012; Aguilar, 2017; Askins & Moore, 2008; Bat-Or & Garti, 2019; Councill & Ramsey, 2019; Devlin, 2006; Hendricks et al., 2019; Jones & Weisenfluh, 2006; Kramer, 1971; Sourkes 1995, 2018), the ability of art to help children communicate their experiences should extend to the use of art in data collection and analysis in research that utilizes an appropriate methodology (Wong, 2020). Many studies have utilized art to facilitate conversation in data collection, but very few studies have included art as part of the data to be collected when researching children's experiences of serious illness, grief, and bereavement.

Bat-Or and Garti (2019) researched Israeli art therapists' perspectives on the role of art in bereavement therapy for adults and children. The participants' (art therapists) interpretations as well as the researchers' thematic analysis identified that art served as an inter-relational creative experience between the client, the art therapist, and the artwork itself (Bat-Or & Garti, 2019). The participants considered the medium of art to be strong enough to arouse, contain, and express the most intense and primal of emotions (Bat-Or & Garti, 2019). Cakirer Callbayram et al. (2018) asked Turkish hospitalized children to draw their nurses to investigate children's perceptions of nursing care using a mixed-methods research design to analyze the artwork, but did not analyze children's conversations about their art. Their findings suggested that children thought of nurses as playing a vital role in the health and wellness of individuals (Cakirer Callbayram et al., 2018). Steyn and Moen (2019) asked 240 South African school-aged children to draw "sadness," and found that children associated sadness with violence and the death of loved ones through their drawings of acts of bullying and funerals in graveyards. Rollins (2005)

conducted a mixed-methods study using established art psychotherapy tools in her data collection and analysis, and her findings suggested that children with cancer, regardless of cultural or ethnic backgrounds, experienced cancer in a similar way. Participants used drawing as a form of symbolic communication to explore difficult issues in a safe manner, and the artwork served as an instrument to focus and deepen conversations in what Rollins (2005) called the "campfire effect" (p. 213).

The studies that involved children as participants all used a measurement tool as part of their data analysis, which strengthened the quantitative rigor and validity of their findings but may have limited the interpretive potential of art as data and suppressed the expressive voice contained within the image. To better understand the experiences of children with serious illness requires a research methodology that can provide a substantive philosophical underpinning for the interpretation and experience of art and its ability to help us examine what it means to be in the world. Hermeneutic philosopher Hans-Georg Gadamer wrote, "a work of art 'says something to someone'" (Gadamer, 2001, p. 70), and that "all artistic creation challenges each of us to listen to the language in which the work of art speaks and to make it our own" (Gadamer, 1986, p. 39). By fusing the principles of art therapy with hermeneutic interpretation, the experiences of children who are dying may be explored in a manner that is enjoyable, safe, and familiar to children, while maintaining the rigour required for illuminating and practically useful research.

Anticipated Contributions

The aims of PPC research and literature are shifting from the explanation of what PPC is and accomplishes, towards PPC processes and outcomes (Liben et al., 2014). Such outcomes include the effect of PPC on the child as death approaches. The current definition of PPC emphasizes the promotion of the emotional, spiritual, social, and psychological well-being of

children with serious illness (World Health Organization, 2018); therefore, it is necessary to understand the emotional, spiritual, social, and psychological experiences of children with serious illness. The societal assumptions about childhood as a time of "becoming," and not a time of "being," become existentially complicated when children are diagnosed with terminal illness because, as Bluebond-Langner (1978) wrote, "dying children . . . will not 'become,' they have no future" (p. 213). Without the input and insight of this crucial stakeholder population in the PPC literature, the policies, practices, and outcomes for whom PPC services are established may be inadvertently misguided (Rahimzadeh et al., 2015).

The ability to advocate for increased access to PPC services and the value of PPC in pediatric healthcare, as well as the education of nurses and other providers who care for this population, will be advanced by the new insights that this thesis work may uncover. PPC providers will have additional evidence to support difficult conversations with children with serious illness and their families and to assist with decision-making. In addition to new evidence to add to the PPC literature, this thesis work may demonstrate the ability to use arts-based approaches in hermeneutic research conducted with this population. This may be the first hermeneutic study to combine art and the perspectives of children with serious illness. Should the inclusion of art in data collection and analysis contribute to the literature in a meaningful way, it may provide an opportunity to explore other mediums through which children communicate, such as play or music, using hermeneutic research methodology (Wong, 2020).

In reviewing the literature on arts-based research methods with children, I noted that hermeneutical aesthetics has its own contributions to this topic, in addition to what arts-based research can achieve. I noted that arts-based research with children often lets the art speak for itself, rather than using their art as a provocation for interpretation. Hermeneutical aesthetics, as

described by Gadamer (1986) and expanded on by contemporary hermeneutic philosophers, such as Professors Dennis Schmidt, Nicholas Davey, Theodore George, and James Risser, provided the philosophical foundation for the interpretation of art and the claim that art "can help to make visible aspects of our life in common" (George, 2020, p. 150). These ideas will be expanded on in the next chapter on hermeneutic research methodology.

An Invitation for Further Inquiry

In my clinical work, I have learned that while some children with serious illness may not possess "adult" concepts of illness and death, they have still developed an understanding of what is happening to them that is meaningful to them. A child's unique understanding of death and how it might direct what they wish to do in their life is where my engagement with children with serious illness is the most significant. Presenting the voices of children in research is not merely about letting children express themselves; it is also about investigating the distinct contribution to understanding the world that children's perspectives can provide (James, 2007). Arts-based therapies and research methods have been utilized to conduct care and research with children as participants, rather than on children as objects of adult investigation (Docherty & Sandelowski, 1999; James, 2007). Any gaps in the literature on children's experiences of serious illness present an invitation; an opportunity to learn more from children with serious illness so that future children may benefit from their expertise and insights. By applying arts-based approaches to hermeneutic research, the experiences of children with serious illness may be revealed through their artistic forms of expression.

Chapter Three: Hermeneutic Philosophy and Research

Play and art are recognized as languages of children that allow them to understand their world and to be understood by those who engage in these activities with children (Aasgaard & Edwards., 2012; Kramer, 1971; Piaget & Inhelder, 1966/1969; Sourkes, 1995). While arts-based research methods are commonly used to elicit the perspectives of children in research, to my knowledge, no studies have utilized a hermeneutic methodology for the analysis of artwork created to explore the experiences of children with serious illness. Hermeneutics is a philosophical exploration of human interpretation and understanding, with an emphasis on the interpretation and understanding that arises out of the experience of art (Gadamer, 1960/2004). Moules et al. (2015) have developed a research methodology founded on Gadamer's philosophical hermeneutics that inquires through open dialogue, careful listening, deep reading, and interpretation to understand phenomena and experiences, rather than explain them. In the following chapter, I discuss the history and tradition of philosophical hermeneutics and how it may be applied as a research method to address children's experiences of serious illness.

Part I: A Brief History of Hermeneutic Thinkers

> *"Hermeneutics" refers, first of all, to a practice, an art, that requires a special skill. This points to a further Greek word, namely techne. Hermeneutics is the practical art, that is, a techne, involved in such things as preaching, interpreting other languages, explaining and explicating texts, and, as the basis of all these, the art of understanding, an art particularly required any time the meaning of something is not clear and unambiguous. (Hans-Georg Gadamer, The Gadamer Reader, 2007, p. 44)*

Simply defined, hermeneutics is the science, art, and practice of interpretation (Grondin, 1994; Moules et al. 2015). As the technique or art of interpretation, hermeneutics developed from

the human desire to interpret and understand, stemming from theology and philosophy (Gadamer, 1960/2004), and is now discussed in many fields of study, including law and research in the humanities and practice disciplines (Moules et al., 2015; Zimmermann, 2015). Despite its many forms and functions throughout its extensive history, hermeneutics has always been at work in the in-between of things: between the divine and mortal, between the text and reader, between mother tongue and foreign languages, between what is clear and what is ambiguous, between interlocutors, and between the past and the present. As Grondin (1994) elaborated, hermeneutics has etymological roots in the Greek verb *hermeneuein*, which can mean expression (speaking), explication (interpretation or explanation), and translation (acting as an interpreter). Fundamentally, *hermeneuein* concerns expression and interpretation, both of which involve understanding as the communication and translation of the spirit of an inner thought as an external utterance.

> In "expression" spirit, as it were, makes what is contained within knowable from without, whereas "interpretation" tries to penetrate an uttered expression to see the spirit contained within it. What is involved in both is making sense or communicating it. Interpretation inquires into the tacit, inner sense behind the explicit; speaking ex-presses the inner. (Grondin, 1994, p. 21)

While a comprehensive exploration of the history of hermeneutics is outside of the scope of this thesis, contextualizing hermeneutics, as it pertains to contemporary hermeneutic research methods, is helpful to understand hermeneutics between its past and present conceptions.

Ancient Hermeneutics: Between Mortals and Gods, Between Thought and Speech

> *Socrates: I should imagine that the name Hermes has to do with speech, and signifies that he is the interpreter ([h]ermeneus), or messenger, or thief, or*

> *liar, or bargainer; all that sort of thing has a great deal to do with language. (Plato, Cratylus, 1999, 407e, p. 56)*

The origins of the word hermeneutics, *hermeneuin* or *hermeneia*, have a history of oscillating in-between meanings. Gadamer (2007) explained that the meaning of *hermeneuein* in Ancient Greece shifted back and forth between translation, the practical communication of instructions, reporting, and demanding obedience. *Hermeneia* means the expression of thought but was used by Plato to refer to statements with the character of commands or instructions about a matter from kings and heralds (Gadamer, 2007). In *Cratylus*, Plato made the connection between "the task of the 'hermeneut' with that of the god" Hermes (Gonzalez, 2015, p. 13), namely, that of being a messenger. Indeed, hermeneutics is often associated with the Greek messenger god Hermes, whose enigmatic messages had to be interpreted by mortals (Moules et al., 2015; Zimmermann, 2015). There are other examples of the need to interpret the words of the Gods in Ancient Greek literature. In *Symposium*, Plato described Eros, or Love, as a spirit who is tasked to

> interpret and carry messages from humans to gods and from gods to humans. They convey prayers and sacrifices from humans, and commands and gifts in return for sacrifices from the gods. Being intermediate between the other two, they fill the gap between them, and enabled the universe to form an interconnected whole. (Plato, 1999, 203a)

As neither God nor human, Eros served as a conveyer, transmitter, and mediator between the two.

Aristotle used the word *hermeneias* to mean expression, particularly expression through words (Gonzalez, 2015) or the sense of an expression being true or false (Gadamer, 2007). In

later Greek culture, *hermeneia* and *hermeneus* referred to a person who made scholarly explanations or a translator, respectively (Gadamer, 2007). These abilities were recognized with admiration and respect, as it was considered an art to understand and explain hidden things, such as the ability to translate a foreign tongue, or to intuit the "unexpressed conviction of another person" (Gadamer, 2007, p. 45). Gonzalez (2015) asserted that the claim of hermeneutics for the Classical Greeks was that "all understanding is *communication*, understanding each other in conversation, expressing oneself clearly to others, and understanding what they have to say" (p. 19, italics in original). Gadamer (2007) and Grondin (1994) argued that allegorical interpretation was significant to the Ancient Greeks for the rational interpretation of Greek myths and in the interpretative effort required to understand ambiguous and hidden meanings.

Interpreting Holy Texts: Between the Divine Author and the Interpreter

The exegesis of Holy texts also shares a significant history with hermeneutics. Theologically, hermeneutics is the art of correctly interpreting scripture. Augustine of Hippo (354-430) is sometimes regarded as a "proto-existentialist," as his writings reflected humanity's fundamental desire to discover meaning (Grondin, 1994, p. 34). In his effort to refine his stance on the Old Testament, Augustine reflected on the meaning of understanding and the interpretive pitfalls in scripture when reading passages as figurative or literal (Gadamer, 2007; Glowasky, 2018). Augustine recognized that words are signs of things, and as a sign, a word must be audible or visible (Tooms, 2016). When interpreting text, the exegete does not have access to spoken devices that help to clarify meaning, such as tone, gesture, a pause, or proximity to the context of the conversation (Tooms, 2016). Therefore, Augustine emphasized that understanding the context of the literature one is interpreting helps to reduce the ambiguity of a written text.

Augustine proposed that understanding is internal, and what provides the "true knowledge of things is the mental 'seeing,' the interior enlightenment by Christ" (Tooms, 2016, p. 89), explaining how things can be known prior to the words required to signify them. According to Tooms (2016), Augustine was among the first to apply the idea that words are signs to the work of interpreting Scripture. In *De doctrina Christiana*, Augustine provided the hermeneutical theory required for the practice of interpreting the proper meaning of Scripture. He argued that because the Scripture is a "double-authored text," signs from God contained within texts that were written and communicated by humans, the authorial intention of a text has significant interpretive implications (Tooms, 2016, p. 97). The interpreter must prioritize what God intended to say but must also ascertain the thoughts and hopes of the humans who wrote the text. Additionally, a Holy text cannot be "restricted to the humanly intended historical meaning in the original context of an utterance, because the Spirit of God may intend meanings beyond it to people in other circumstances and times" (Tooms, 2016, p. 97).

Augustine also considered the context of the reader, and the communicative fractures that may arise when spoken word is translated to text, particularly when it is translated to other languages. Therefore, the interpreter of Scripture must understand the linguistic signification of the ancient languages in which the Bible was written. When a translation results in an unclear term or passage, one must compare the difficult passage with simpler ones and other versions of the text; said another way, one must consider a part in relation to a whole (Tooms, 2016). In language, sign and referent are agreed upon *a priori*, but there is nothing inherent in a word that requires it to signify a particular referent (Glowasky, 2018). Words as signs carry meaning (Tooms, 2016), but because of the arbitrary relationship between a sign and what it stands for, there is an increased potential for misinterpretation if one does not understand the conventions of

language (Glowasky, 2018). For example, for one to understand what is meant by the term "couch potato," one must understand the association between laziness and the stationary, vegetative character of a potato, while also relating a sedentary lifestyle with the idea that one might sit on a couch and watch television for hours on end. One might also need to know what a couch is, as they may know it as a chesterfield or sofa depending on their place of birth. In this sense, language requires a previously established network of meaning relations, including words and signs, to be understood (Gadamer, 1960/2004; Glowasky, 2018). Augustine's work was a significant influence for his contemporary hermeneutic thinkers.

Protestant Reformation

Martin Luther (1483-1546), who was an Augustinian friar, is often recognized for his significant contributions within Christian history and hermeneutics. Luther's conception of hermeneutics originated entirely from biblical exegesis, as he did not consider philosophy to be a worthy pursuit (Grondin, 1994). He conducted considerable hermeneutic work in translating the Bible from Latin to German, and in doing so, made it accessible to a wider audience (Zimmermann, 2015). As prominent figure of the Protestant Reformation in Germany, he asserted the Bible's own interpretive clarity, independent from the scriptural interpretations and traditions of the Church as an institution (Zimmermann, 2015). In other words, by itself, Scripture is clear, accessible, and, therefore, interpretable (Grondin, 1994; Zimmermann, 2015). Luther and the Reformers believed that the literal sense of Holy texts, correctly understood, contains its own spiritual meaning, and that "the word in which God presents himself waits upon the fulfillment that occurs when Scripture is understood through faith," not interpreted allegorically by the Church (Grondin, 1994, pp. 40-41). He recognized that the Bible is always read through some interpretive lens and wrote guides for interpreting Scripture so that it may be

understood properly within the context of Christian tradition and history (Zimmermann, 2015). Grondin (1994) suggested that part of Luther's influence on modern hermeneutics may be because his hermeneutic successors, including Schleiermacher, Dilthey, and Gadamer, were Protestant.

Methods of Understanding: Towards a Hermeneutic Science

The conflicts resulting from the wave of religious Reformations across Europe, taking inspiration from Luther, led to anxieties about how one might attain a strong foundation for the truth, as it seemed the truth could be interpreted in a multitude of ways (Zimmermann, 2015). The desire for a firmer knowledge base led a shift in thinking "from edification to verification," and a preoccupation with epistemology (Zimmermann 2015, p. 21). The advent of modern science and the split between the mind and world, as well as between those who adhered to religion or science, resulted in a fragmented society (Zimmermann, 2015). To further complicate how one might reach an understanding given the many interpretations of the truth available, Emmanuel Kant's *Critique of Pure Reason* presented a highly influential philosophy that created new avenues for thinking about subjectivity and objectivity (Grondin, 1994; Moules et al., 2015). It is within this context that modern hermeneutics surfaced.

Fredrich Schleiermacher (1768-1834)

Schleiermacher trained at the University of Halle with a focus in theology, with philosophy and classical philology as minor fields (Forster, 2022). During this period, hermeneutics had been adopted by numerous disciplines, including law and theology, which had adapted their own methods for the interpretation of a particular kind of text (Moules et al., 2015; Palmer, 1969). Recognizing the growing conflict between science and religion, Schleiermacher sought a more universal and unifying approach to knowledge and understanding (Zimmermann,

2015). His aim was to elucidate how any spoken or written word, regardless of the discipline in which they were written for, could be understood (Palmer, 1969). He also sought to develop a method or system for interpretation, one that steered hermeneutics in the direction of becoming a science (Palmer, 1969).

Schleiermacher recognized that understanding was dialogical in character, where a speaker or writer forms an expression of meaning that is received by a reader or listener, who is then able to perceive their meaning (Palmer, 1969). He believed that understanding texts required the reader to reconstruct the author's mental processes, beginning with the static and completed expression of the text and back to the mental life or thought from which it was authored (Moules et al., 2015; Palmer, 1969). The reader must also comprehend the structure of the author's sentence to ascertain its meaning. Thus, understanding for Schleiermacher consisted of grammatical and psychological processes in interaction with each other (Moules et al., 2015; Palmer, 1969). The grammatical element of interpretation was grounded in the conventions and context of language. This included the context of part of a text in relation to the whole, as well as the language in which the text is written (Moules et al., 2015). The psychological component of interpretation reflected the reader's attempt to reconstruct the author's thought and the broader context of their life. Both components of Schleiermacher's concept of interpretation involve the circular integration of parts into a meaningful whole, now commonly referred to as the hermeneutic circle (Palmer, 1969).

Importantly, Schleiermacher's hermeneutics emphasized the need for conversation in light of the finitude of human knowledge (Grondin, 1994). His focus on language as the medium for understanding and the acknowledgement that misunderstanding is inventible were significant

contributions to modern hermeneutics (Grondin, 1994; Moules et al., 2015; Palmer, 1969). Schleiermacher understood the magnitude of language beyond its utility for expression, as

> neither the speaker nor the interpreter merely reaches for words the way we reach for a tool in our toolbox, but that words are the flesh and blood by which our notions about anything gain form and life. We think in language. (Zimmermann, 2015, pp. 28-29)

However, he has been criticized for his concept of understanding, which is reduced to the imitation or reconstruction the author's mind and thought with no regard to the context of the interpreter or reader (Zimmermann, 2015). Despite this, Schleiermacher is often considered the "father of modern hermeneutics" for his development of hermeneutics as a general study of the art of understanding (Palmer, 1969, p. 97).

Wilhelm Dilthey (1833-1911)

Dilthey was a literary historian and philosopher who, like Schleiermacher, aimed to overcome the split between world and mind that was characteristic of the modern ideal of knowledge following the Enlightenment (Zimmermann, 2015). Dilthey asserted that a firm foundation for knowledge was life itself, rather than the natural sciences or a spiritual entity (Palmer, 1969; Zimmermann, 2015). Dilthey was critical of claims that empirical science and rational thinking were the superior means of obtaining knowledge about the inner world of humans. He argued that empiricism neglected to acknowledge that humans rarely conform to the natural laws of physics and mathematics, and that rationalism overlooked the human experience of the world, which does not present itself as abstract theoretical deductions (Zimmermann, 2015). Historicism, the idea that historical events must be understood in the context of their own time and not by the standards of the present, further complicated questions about the attainment of objective knowledge in history and the human sciences (Grondin, 1994; Moules et al. 2015).

To overcome these problems, Dilthey attempted to develop methodology in the human sciences for obtaining objectively valid interpretations of the inner expressions of humans (Palmer, 1969). While hermeneutics may not have been the methodology for understanding in the human sciences that Dilthey had attempted to develop (Grondin, 1994), his contributions to central concepts in hermeneutics are widely recognized. Dilthey argued that while the natural sciences are adequate for explaining phenomena as it occurs in the natural world, it was incapable of explaining "the inner world of the human spirit" (Zimmermann, 2015, p. 30), that is, the human aspects of life that form culture. For Dilthey, the proper way to examine the human world was through understanding the human-made, objective expressions of life (such as art, literature, institutions, or poetry) studied through "the sciences of the mind," or *Geisteswissenschaften* (Palmer, 1969; Zimmermann, 2015, p. 31). His methodology for the human sciences focused on the systematic associations between the concepts of life, expression, and understanding (Moules et al., 2015; Palmer, 1969). The term "lived experience" (*erlebnis*) as a singular noun was nearly absent from the German lexicon prior to Dilthey's use of the word (Palmer, 1969). Dilthey used *erlebnis* to articulate "the formation of meaning across time by making connections between disparate events" (Moules et al., 2015, p. 16). Gadamer would build on Dilthey's idea of *erlebnis* in his philosophical hermeneutics, and a more detailed description of this concept will be presented in a following section on Gadamer's hermeneutics.

Another important idea in Dilthey's work included his emphasis on the historical character of human beings (Palmer, 1969). He considered knowledge in the human sciences to be objective, as Dilthey focused on the verifiable cultural history of any given text, rather than trying to enter the mind of its author (Zimmermann, 2015). Understanding, according to Dilthey, was historical insofar as humans can only know what history tells them, meaning a person's self-

understanding occurs indirectly through interpretations of the life expressions of others and is dependent on history (Palmer, 1969). For Dilthey, "past and present experiences are connected through the "stream of history in which we all stand" (Zimmermann, 2015, p. 32), and we understand ourselves through history. Dilthey's concepts of lived experience and historicality become vital ideas in the development of contemporary philosophical hermeneutics.

Phenomenology: Towards a Hermeneutic Philosophy

Phenomenology, as a disciplinary field in philosophy, flourished in the early 20th century thanks to the works of prominent philosophers, some of whom were undoubtedly influential in the development of philosophical hermeneutics (Moules et al., 2015; Smith, 2013; Zimmermann, 2015). Initially defined as the study of the structures of human experience and consciousness, phenomenology encompasses the meaning things have in our experience, including the importance of objects, events, tools, time, selfhood, and encounters with others, as they appear or are experienced in the world (Smith, 2013).

Edmund Husserl (1859-1938)

Edmund Husserl, a scholar of mathematics, physics, and philosophy, was the primary founder of phenomenology; as such, he is considered among the most influential philosophers of the 20th century (Beyer, 2022). Like Dilthey, Husserl challenged the positivist claim to knowledge as the objective truth. Husserl's phenomenology stemmed from his belief that knowledge about the world is understood through a careful attentiveness and analytic reflection on the things themselves, with the goal to understand human life in a rigorous way (Moules et al., 2015). For Husserl, human perception of the world is always endowed with meaning, and phenomenology provided a lens to describe how "phenomena disclose themselves to us in their meaning" (Zimmermann, 2015, p. 33). To perceive an object's essence, or the characteristics of a

thing that distinguishes itself as that thing, required a process for consciously setting aside one's natural attitude, our ordinary awareness, in a process Husserl called bracketing (Moules et al., 2015). *Lebenswelt*, or the lifeworld, was Husserl's concept of the connection of everyday experiences and objects and their meanings that situate us in the world (Moules et al., 2015; Zimmermann, 2015). The lifeworld provided the foundation for Husserl's student, Martin Heidegger, to take the concept of knowledge from epistemology to ontology, from "theories about knowledge to the life context that provides the conditions for knowledge in the first place" (Zimmermann, 2015, p. 34).

Martin Heidegger (1889-1976)

Heidegger built on Husserl's *Lebenswelt* to argue that things and their meanings do not disclose themselves to us conceptually, but through our practical relation to them in everyday life (Zimmermann, 2015). He challenged the Cartesian duality of the world "out there" separated from the mind "in here" and asserted that scientific knowledge was incapable of holding the greater truths of human life that could be articulated through the arts (Moules et al., 2015; Zimmermann, 2015). Heidegger's phenomenology was not a theory or practice of interpretation, rather a philosophical investigation of the way we go about being in the world (Zimmermann, 2015). Departing from Schleiermacher and Dilthey's version of understanding as something gained through conscious interpretive effort and bracketing, Heidegger considered knowledge to be derived from a more basic and universal form of understanding (Grondin, 1994; Moules et al., 2015; Zimmermann, 2015).

Heidegger believed understanding is instinctual, as we come into being fully immersed in the totality of meaning relations that structure the world (Moules et al., 2015; Zimmermann, 2015). To "be at home with something" is a way of understanding that is more like "readiness or

facility than knowledge" (Grondin, 1994, p. 93). Understanding is pre-woven into the whole of life through history and is the fundamental mode of Being to cope with and navigate our world (Grondin, 1994; Zimmermann, 2015). Our "being there" (*Dasein*) in the world is self-evident, but so obvious that our everyday intelligibility of Being obstructs the enigma that is Being; "the very fact that we already live in an understanding of Being and that the meaning of Being is still veiled in darkness" (Heidegger, 1927, p. 23) compelled his inquiry. Heidegger encouraged the active situating of oneself within the finitude of our Being and the consideration of our fore-structures to allow Dasein to become aware of its own potential (Grondin, 1994). His version of the hermeneutic circle suggested that our constant task of interpreting is to never allow our fore-structures and preconceptions to be constructed for us by common knowledge or popular culture, but to work out our pre-understandings in terms of the things themselves (Grondin, 1994; Heidegger, 1927/1962; Moules et al., 2015).

Heidegger created an important bridge between phenomenology and hermeneutics, but did not continue to develop hermeneutics philosophically (Grondin, 1994; Moules et al., 2015). The momentum of his work pushed the conversation about knowledge into the ontological domain, and for this, he is considered one of the most influential philosophers of the 20th century (Moules et al., 2015; Zimmermann, 2015). Hermeneutics after Heidegger is characterized by two themes: that pre-understanding is an intrinsic part of interpretation, and that the temporal, historical nature of our being allows us to engage meaningfully in the world (Zimmermann, 2015). These revelations provided the philosophical impetus for Heidegger's student, Hans-Georg Gadamer (1900-2002), to revitalize hermeneutics for the modern world.

Gadamer's Philosophical Hermeneutics

In his magnum opus *Truth and Method*, Gadamer (1960/2004) presented a philosophical examination of human understanding through interpretation. Gadamer was deconstructing of the cultural privileging of the natural sciences and the scientific method as the only valid way of understanding the world (Davey, 2016; Gadamer, 1960/2004). In defense of the ways of knowing that reveal themselves in the humanities, Gadamer expounded a powerful argument for the truth claim of art (Gadamer, 1960/2004). Gadamer's aim was not to develop a methodology for human sciences, rather a philosophical endeavour to explicate human understanding and what happens to us in our experiencing and attending to that which is questionable (Gadamer, 1960/2004; Moules et al., 2015).

Universality and Language

Gadamer stressed the ontological significance of language as universal to all beings, as "man's relation to the world is absolutely and fundamentally verbal in nature, and hence intelligible" (Gadamer, 1960/2004, p. 471). To be situated in a meaningful world is to live in a world that is understood and interpreted through language: the language of art, nature, and "in short, any language that things have" (Gadamer, 1960/2004, p. 470; Moules et al., 2015). Language is not simply the verbal narration that can describe experiences or phenomena but provides humans with a foundation for understanding the world, as "*being that is understood is language*" (Gadamer, 1960/2004, p. 470, italics in original). Gadamer (2007) stated that "there is always a world already interpreted, already organized in its basic relations, into which experience steps as something new, upsetting what has led our expectations and undergoing reorganization itself in the upheaval" (p. 87). Understanding through language occurs in conversation with another person, with a work of art, or with a text (Gadamer, 1960/2004). In conversation, one

must be ready to consider the truth of what the other has to say, at the risk of amending one's own beliefs:

> Language is a *we*, in that we are assigned our place in relation to each other…we all must overstep our own personal borders/limits of understanding in order to understand…All living together in community is living together in language, and language only exists in conversation. (Gadamer, 2001, p. 56)

If understanding is realized through language, then all understanding is an act of interpretation (Zimmermann, 2015), and Gadamer (1960/2004) was adamant that "understanding and interpretation are indissolubly bound together" (p. 400). Interpretation, however, is more than something that humans do; humans are interpretive beings and are constantly integrating new experiences into a comprehensible whole of previously organized meaning relations (Gadamer, 2007; Zimmermann, 2015). This prearranged network of meaning relations make understanding possible in the first place, as understanding is always about something that is already there, already meaningful, and already linguistic, as "language as the medium and material of expression can never fully emancipate itself from meaning" (Gadamer, 1960/2004, p. 69; Grondin, 1994; Moules et al., 2015). The always already established conditions that allow one to understand are what Gadamer (1960/2004) referred to as "historically effected consciousness" (p. 336), the background that informs one's awareness and perception of the world, which has already been established and contextualized prior to one's existence (being) in the world (Gadamer, 1960/2004; Grondin 1994; Zimmermann, 2015).

Experience

Gadamer (1960/2004) expanded on the notion of experience derived from the natural sciences (i.e., observation, awareness, confirmation, and repetition) to conceptualize experience

as the immediacy of being in the world, where truth and knowledge are communicated through the interruption of habitual and expected events in ways that cannot be verified by through the scientific method. Gadamer employed two German words for experience, *erlebnis* and *erfahrung*, to develop his assertion. *Erlebnis*, for Gadamer, has the quality of a singular event that interrupts or destabilizes one's expectations, a significant happening that stands out above everyday occurrences and prompts reflection and contemplation (Gadamer, 1960/2004; Moules et al., 2015). Experience as *erlebnis* is a starting point for interpretation and understanding that which one does not understand or anticipate (Gadamer, 1960/2004). *Erfahrung* has a "binding quality" and a more recursive connotation, where experience happens together with the network of meaning relations already present in the world (Gadamer, 1960/2004, p. 84; Moules et al., 2015). In *erlebnis*, the striking and abrupt introduction of that which one does not understand, is an opportunity.

Gadamer believed that avoiding misunderstanding was not the primary aim of hermeneutics, as it is only with the foundation of the things that one already understands that makes it possible to explore the unfamiliar (*erlebnis*), thereby enriching one's experience (*erfahrung*) of the world (Gadamer, 2007). What Gadamer called the "fusion of horizons" is the event of understanding that occurs when past horizons meet with the present, between the history and fore-understandings, or prejudices, of the interpreter and the object of interpretation (Gadamer, 1960/2004). Prejudice, for Gadamer, does not have the negative connotation that it has garnered since the Enlightenment; it is simply what one already understands when one encounters something new. In acknowledging one's own prejudices, one becomes more open to experiencing the unfamiliar, as well as the opportunity to learn from that experience (Gadamer, 1960/2004).

Truth

When one understands a fact, word, or sign, it makes sense through its application in the context of one's lifeworld as "true" (Zimmermann, 2015). Truth, in the hermeneutic sense, should not be mistaken as mere fact; rather, truth is an event or experience where something is disclosed, uncovered, and grasped by the person undergoing the experience (Gadamer, 1986; Moules et al., 2015). *Aletheia*, the Ancient Greek word for the event of truth, is a simultaneous concealment and unconcealment, where the experience of something that was previously unfamiliar becomes accessible (Gadamer, 1986). Gadamer (1960/2004) likened the event of truth to the experience of art. Hermeneutics is at work when considering that which is questionable, wherever what is said is not immediately intelligible, and when there is an anticipation of meaning (Gadamer, 2007). A work of art presents all three situations at once, for a it has been created to communicate something and has meaning in its being-there, while simultaneously containing an "inexhaustible ambiguity" which requires an interpretive effort to probe the possible meanings that one encounters within the work (Gadamer, 1986, p. 69).

The Experience of the Work of Art

Art and its ability to depict the enigmatic truths of human life is an important subject in philosophical hermeneutics, as it encompasses both the event of understanding and of making oneself understood (Zimmermann, 2015). Gadamer strongly opposed a philosophy of aesthetics that focused on the quality or subjective enjoyment of artworks and objects:

> The shift in the ontological definition of the aesthetic toward the concept of aesthetic appearance has its theoretical basis in the fact that the domination of the scientific model of epistemology leads to discrediting all the possibilities of knowing that lie outside this new methodology. (Gadamer, 1960/2004, p. 73)

Gadamer believed that poetry, literature, theatre, architecture, music, and the plastic arts, such as painting or sculpture, were not simply beautiful objects or words, but held within them the capacity to disclose truths about the world (Davey, 2016; Gadamer, 1992/2006). Art, in its being-there, presents the reader, listener, or spectator with "an excess of meaning" that demands interpretation (Gadamer, 2007, p. 130). The linguistic character of art is attributed to Gadamer's belief that "all artistic creation challenges each of us to listen to the language in which the work of art speaks and to make it our own" (Gadamer, 1986, p. 39); art succeeds when it takes what it is or represents and elevates it to a new configuration (Gadamer, 1986).

In Gadamer's hermeneutics, the very idea of art is transformed from the appearance of a subjectively beautiful object that is separate from reality (e.g., as with Plato and Kant) to a conception of art that can make legitimate claims to truth through the experience of art and its presentation of and relation to reality (Gadamer, 1960/2004, 1986; Risser, 2012; Schmidt, 2013). Gadamer's hermeneutic aesthetics emphasized the experience of art and that such an experience involves a disclosure of the historical and linguistic realities that manifest themselves in a work of art (Davey, 2016; Gadamer, 1968, 1992/2006, 2007). In his effort to absorb aesthetics into hermeneutics as an interpretive, ontological, and conversational event, Gadamer described a simultaneous unfamiliarity and universal relation in the viewer, as a work of art at once removes the person experiencing it from the context of their life while also relating them back to the whole of their existence: "In the experience of art is a present fullness of meaning that belongs not only to this particular content or object but rather stands for the meaningful whole of life" (Gadamer, 1960/2004, p. 61).

A work of art goes through a process from what the Ancient Greeks called *poiesis*, which means "to make" something that did not exist before, or "a thing made," where "non-being

comes to be being" (Gadamer, 1992/2006, p. 63). Once made, the work of art stands and speaks for itself, it has its own being and is there to be encountered, contemplated, and experienced by the other (Gadamer, 1986). In standing for itself, a work of art is absolute; it is "there" completely, and ready to be encountered by those who read, view, or listen to it (Gadamer, 1986; 1992/2006). Gadamer considered works of art as possessing an "elevated rank in being, and this is seen in the fact that in encountering a work of art we have the experience of something emerging [*aletheia*] – and this one can call truth" (Gadamer, 1992/2006, p. 67). Artwork has its mode of being in that it becomes an experience that alters the person who experiences it, a change which occurs through the play of art (Gadamer, 1960/2004).

The Play of Art. Through his emphasis on the experience of truth in art, Gadamer distanced himself from more conventional philosophical approaches to art and beauty, as matters of aesthetic judgement and disinterested pleasure, as with Kant (Davey, 2016; Gadamer, 1968; Ginsborg, 2019; Scruton, 1982/2001), or as imitations detached from reality, as with Plato (Gadamer, 1986; Pappas, 2020). An encounter with a work of art is the emergence of something that "addresses" a person, and the person being addressed is "as if in conversation with what comes forth" (Gadamer, 1992/2004, p. 71). The speechless back-and-forth movement between the viewer and the work of art brings the viewer closer to understanding, for when one is at a loss for words, what one really wants to say is brought closer to the surface as one seeks to find new words to make sense of the experience (Gadamer, 1986).

This back-and-forth encounter is the "play of art" (Gadamer, 1986, pp. 123-130). Entering into play is to step outside of oneself, immerse oneself in the game, and become open to the possible outcomes of interpretation and re-interpretation (Gadamer, 1986; Zimmermann, 2015). Kant's aesthetics involved the "free play" of the mental faculties of imagination and

understanding in an encounter with something beautiful, but it is a disinterested, non-purposive, and non-conceptual kind of act that includes judgements of pleasure or delight, and not the event of truth (Gadamer, 1986; Ginsborg, 2019; Scruton, 1982/2001). Far from disinterested, Gadamer's concept of the play of art is not about escaping reality, but fully engaging in it. It is an encounter with a work of art as "the Other" and an encounter with the self, "a mirror that . . . constantly arises anew, and in which we catch sight of ourselves in a way that is often unexpected or unfamiliar: what we are, what we might be, and what we are about" (Gadamer, 1986, p. 130). Unfamiliarity still must relate back to the person experiencing the artwork for the experience of art to be one of recognition and representation (Gadamer, 1992/2006). The recognition of which Gadamer speaks is not to be understood as merely referential or reproduction, but the re-cognition of something that is "actually there" and "signifies an increase in being" (Gadamer, 1968, p. 35, emphasis added).

Mens Auctoris. Gadamer's essays on art stressed that the fusion of horizons is between the work of art and the person who encounters it (Davey, 2016; Gadamer, 1986, 1992/2006, 2007). As it is with the interpretation of text, Gadamer's focus remained on the self-encounter and understanding that arises in the experience of art. Gadamer quoted Rainer Maria Rilke's poem *Archaic Torso of Apollo* to emphasize how the work addresses the beholder and says: "You must change your life!" (Gadamer, 1986, p. 34). When one is fully engaged in the play of art, an impression of appropriateness or harmony grows on the viewer, as what is present in the work emerges and leads up to a sense of "That's right!" (Gadamer, 1992/2006, p. 71). For Gadamer, a work of art is an autonomous expression of truth that cannot be reduced to the artist's *mens auctoris* (original meaning or intention), as when "the work of art has indeed succeeded in its

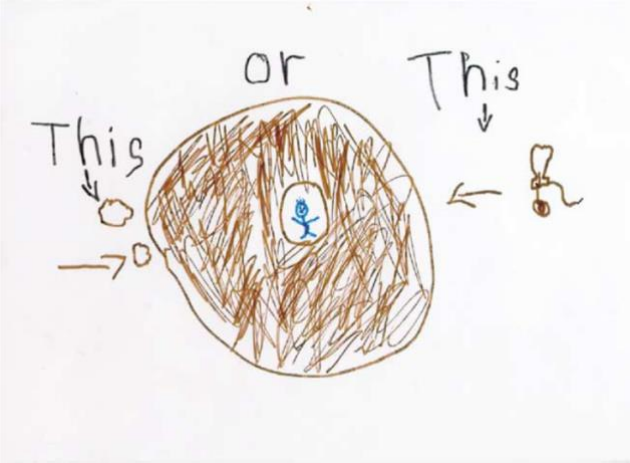
ungraspable rightness … it is meaningless, when it comes to art, to ask the artist what he or she meant" (Gadamer, 1992/2006, p. 71, 2007).

There are instances where it is useful and sometimes necessary to ask the artist what they meant to convey, where art serves a practical purpose in life while managing to draw the viewer in, compelling them to tarry with the work, to bring words to the surface, and to understand; the ways in which children employ symbol in their artwork in art therapy is an example of this (Kramer, 1971). I am confident that Gadamer was not referring to children and their artistic forms of expression when he discussed aesthetics in philosophical hermeneutics, but when viewing an image created for the purpose of art therapy, there are elements of his views on the interpretation of art that are helpful when applied in practice. Rather than reducing one's understanding of the work of art through the creative intentions of the artist, the application of Gadamer's ontologically motivated aesthetics is useful in the context of art therapy, where art is created with the intent to help an individual make sense of their experiences (Aasgaard & Edwards, 2012; Kramer, 1971; Sourkes, 1991).

Art and Application

Art therapy is precisely a convergence of praxis, interpretation, self-presentation, and understanding (Aasgaard & Edwards, 2012; Kramer, 1971; Sourkes 1991). Art created for therapeutic purposes functions in the same manner that Gadamer's experience of artwork provides the viewer with a heighted understanding of the subject of the artwork, though what emerges may also include a realization and self-understanding on the part of the artist. In the case of art therapy with children, it is the conversation between the child, the clinician, and the artwork that manifests the truth, allowing the child and clinician to put words to an experience that the child may not have the vocabulary to express without assistance, to help them understand

their own experiences, and to help their clinicians to understand their experiences (Aasgaard & Edwards, 2012; Kramer, 1971; Sourkes 1991). PPC teams regularly employ art-based therapies to facilitate understanding between the children with serious illness and their care team (Sourkes, 2018). Children, especially very young children, who live with the threat of death are often confronted with concepts and life events earlier than would normally be expected of them developmentally and may lack the language to verbalize their experiences; art is an effective mode of communication in the absence of the words to describe children's experiences (Sourkes, 1995). Gadamer (1992/2006) stated that when it comes to understanding through image and sculpture, "the barriers of language do not enter in as much, or at least they can be easily overcome" (p. 61). However, unlike the great classical paintings and poems that Gadamer wrote about, children's artwork often not intelligible or recognizable. In these situations, understanding requires an explanation of the artist's intended meaning, as the concepts or experiences that children's artwork represents may not always be identifiable.



This or This? (shown above) is a drawing by a 10-year-old child with cancer from an art therapy session from Sourkes et al. (2005, p. 368). It is perplexing – some elements, such as the words and the stick-figure person are decipherable, but these parts do not necessarily add to the whole meaning of the image. It demands interpretation, which may be limited by a lack of

recognizability. The image speaks for itself, but when combined with what the child had to say about their drawing, there is more being expressed than what emerges from the image alone:

> I hate needles and spinal taps, but I also don't want my tumor to come back. If I don't have all the needles, then more tumor cells will grow. So, if I don't want them to grow, I have to have all those awful needles. That's why I feel as if I am stuck in the middle of a doughnut . . . What I mean by 'I was stuck in a doughnut' is that I had two choices and I didn't want to make either of them. (Sourkes et al., 2005, p. 368)

While there are some who may not consider an image such as *This or This?* as art in the classical sense, the image elevates what it represents to a new configuration when the artist's intention is revealed. The image brings words to the surface, but in the case of art therapy, it is the words of the artist that allow the clinician to understand. If the therapist were to interpret the art only as it speaks for itself, it would be at the expense of the meaning it has for the child who created it, which would nullify the purpose of using art therapy in the first place.

Gadamer most often emphasized the hermeneutical mode in which art speaks to someone but did not spare as much attention to the ways in which art may speak for someone. He did provide some examples in his collection of essays on art, *The Relevance of the Beautiful and Other Essays* (1986). In *The Speechless Image*, Gadamer reasoned that to say that something is speechless does not mean it has nothing to say and recalled the etymological root of the German word *stumm* (mute) is *stammeln* (to stutter or stammer). The trouble for the stutterer does not lie in the fact that they have nothing to say, but that they have too much to say at once and are unable to find the words to express the wealth of things on their mind (Gadamer, 1986). Similarly, if an artist could express what they had to say in words, they would not feel the need to create the form of their ideas (Gadamer, 1986). As with one's experience of art, the experience

of creating art for therapeutic purposes may serve to bring what one wants to say closer to the surface. In such circumstances, the *mens auctoris* becomes a critical horizon for reflection and understanding, and is part of the excess of meaning that emerges in a work of art. A clinician can understand the other person, not only the otherness of the work itself, when one considers the significance of the artwork for the artist: this is not a reduction of meaning, but an addition.

Caputo (2018) stated that, "when it comes to hermeneutics . . . The right question is, 'These are good practices, how do they work in theory?'" (p. 221). My wager is that what is effective in PPC practice to elicit a child's interpretation of the meaning of their illness experience will be equally useful in applied hermeneutic research. Gadamer's extensive philosophical reflection on the hermeneutic interpretation and understanding of art as an underpinning for arts-based hermeneutic research may have practical and existential implications for how serious illness and the threat of death is experienced by children.

Part II: Applied Hermeneutic Research

As mentioned, Moules et al. (2015) have developed hermeneutics as a qualitative research methodology, underpinned by Gadamer's philosophical hermeneutics, that inquires through open dialogue, careful listening, and deep reading to better understand phenomena and experiences, rather than explain them. Hermeneutics offers a substantive philosophy to guide research, rather than a strict or premeditated method (Moules et al., 2015). Hermeneutic research is guided by the topic, where the researcher must intentionally allow the topic to direct where the work will go (Moules et al., 2015). Method in hermeneutic research may be defined as "simply a means of knowing one's way around a particular topography" or topic (Moules et al., 2015, p. 5). Koch (1996) defined hermeneutic methodology as "the process by which insights about the world and the human condition are generated, interpreted, and communicated" (p. 174). Thus, to

describe methodology in hermeneutic research means to establish a philosophical foundation that points research in the right direction, while remaining true to its philosophical origins and traditions.

Research Question

PPC research has established a good explanation of "what we in PPC do" (Liben et al., 2014, p. 311); there is little evidence that aims to understand how children situate themselves as PPC patients and as people who may, or will, die before they reach adulthood (Rahimzadeh et al., 2015). As a research method, hermeneutics provides a robust philosophical foundation for the examination of language, art, the interpretation of emotions and physical senses, and the enigma of illness and death. My research question was: How might we understand the experiences of children with serious illness through their artistic forms of expression?

Participant Recruitment

Participants were purposively selected for their insights on the topic of experiencing serious illness and dying in childhood. Sample sizes in hermeneutic research are not determined through power analysis, and the completeness of the interpretation is not driven by data saturation; hermeneutic research produces a work that is never complete in its examining of the topic, but it does unveil a deeper, manifold understanding of experience (Moules et al., 2015). Therefore, hermeneutic studies often have smaller sample sizes than other qualitative methodologies, which in the niche population of PPC patients is more of a help than a hindrance. In keeping with the expectations for a hermeneutic study and the scope of a doctoral research project, I aimed to recruit 6-10 participants.

Eligibility

Participants in this study met the following criteria: (a) individuals who are between the ages of seven and 18 years, chronologically or developmentally; (b) individuals who are diagnosed with serious illness a for longer than one month; (c) individuals in the care of PPC, complex care, or oncology/hematology teams; (d) individuals who are physically able to create art; (e) individuals who can speak and understand English; and (f) individuals who can provide consent/assent, with parents or guardians who can provide consent, to participate. While cognitive development theory is not always an indication of the capabilities of a child (Matthews, 1994), it was helpful in determining the inclusion criteria for this study. Children in the concrete operational stage of development, between the ages of seven to 11 years, typically understand death as the cessation of bodily functions, that is irreversible, universal, and inevitable (Bluebond-Langner et al., 2012; Piaget & Inhelder, 1969). In this stage of cognitive development, children can create mental images from their experiences and re-produce them in the form of art (Parsons, 1987; Piaget & Inhelder, 1969). Adolescent children can recognize and use metaphor and symbol in art (Parsons, 1987), which yielded rich data in this study.

Recruitment

Following institutional ethics approval, participants were recruited from organizations that frequently interact with children with serious illness and their families. Three children were recruited from a local charities and foundations that regularly interact with children with serious illness and their families. These organizations posted a recruitment poster in their newsletters to families, and the children's parents contacted me by email to learn more about the study. I spoke with each parent prior to the interview to determine the child's eligibility, address any concerns, and to confirm that the child was interested in participating. Two families who had expressed

interest in participating subsequently declined an interview due to medical events: one child had to undergo heart surgery, and another experienced a significant and rapid decline in health. Recruitment was a significant challenge given the small population of children with serious illness who met the eligibility criteria for this study. A local children's hospital agreed to assist with the recruitment of the final three participants through the hospital's pediatric intensive care unit and the pediatric hospice.

Participant Description

Six children were recruited to participate in this study. While detailed demographic data is not required for a hermeneutic study, some basic information on the participants is helpful in contextualizing their experiences and artwork about having a serious illness as a child. Three of the participants had serious cancer, two had serious hematological diseases, and one was diagnosed with a neurodegenerative disease. Three participants were patients in the care of a pediatric hospice and palliative care team and three participants were in the care of oncology/hematology healthcare teams. One participant was in remission but had lived nearly her entire life with a serious illness. Two participants have died since their interview. The children's age ranged from 7-17 years, including two children who were seven years old, two children who were nine, and two children who were 17.

Ethics and Confidentiality

Hermeneutic research must meet the same standards for ethics approval as any other research endeavour that involves human participants (Moules et al., 2015). The Conjoint Health Research Ethics Board (CHREB) at the University of Calgary approved this study (REB21-1868), including a modification to include recruitment through Alberta Health Services. Parental consent to participate in the study was required for children to participate, and parents were be

presented with consent forms written below a ninth grade reading level. CHREB guidelines for "Assent, Consent, and Decision Making Capacity in Minors" (2019) determined my conduct regarding confidentiality, whether to obtain consent or assent from a mature minor, assessing decision-making capacity, and other processes for seeking assent/consent in pediatric populations.

Assent, as well as consent from mature minors (17-year-old children), was obtained from the children (any participant under 18 years of age) who participated in the study. Children under 10 years of age and younger were presented with assent forms that read at a second-grade level, and children 11 years of age and older were presented with assent forms that read at a fourth-grade level, as per CHREB (2019) guidelines. However, the population of children with serious illness includes children with moderate to severe developmental, neurological, and cognitive delays (Feudtner et al., 2011; Pawliuk et al., 2019). While it was not required for this study, if the child's decision-making capacity was unclear, I had arranged to consult the PPC team's child life specialist to determine which form to use for consent or assent. Consent and assent to participate in research is an ongoing process (Moules et al., 2015) and was sought throughout the interview. Participants were informed that they may withdraw from the study up until the data analysis stage. Efforts were made to conceal participant identities (and diagnoses if they are rare enough to be a participant identifier), but participants were aware that they may be recognised given the small population of children with serious illness and their families in Alberta. Children and families were also made aware that there are no anticipated benefits to their participation in this study.

Children and people who are terminally ill are considered vulnerable populations by research ethics boards (Liben et al., 2014; Peake et al., 2018). While there were no anticipated

risks in participating in this study, there was a chance that topics that are sensitive or upsetting would arise during the interview. While no participants required follow-up, counselling services were available to children or parents who might require extra support following the interview. However, it is important to note that the risk of participating in this study was no greater than the risk of participating in everyday life for these children (Corbin & Morse, 2003). It is perhaps more dangerous to assume that the adult perspectives that currently inform PPC literature, research, and practice are sufficient.

I had a previous nurse-patient relationship with one of the participants, who was made aware that our conversation was confidential. I cared for two participants as their nurse following their interview with me, and those participants were also aware that their conversations were confidential and were given the option to request a different nurse. Prior relationships between the participants and researcher were discussed as a possibility in the ethics application and the proposed management of such interactions were approved by the CHREB.

Data Collection

Everything that helps to further clarify an interpretation of a topic may be considered data in hermeneutic research; the visual arts, textbooks, policy, poetry, literary or scholarly texts, and interview dialogue may all be included as data (Moules et al., 2015). In hermeneutic research, saturation is the start of data collection, rather than an indication that there is enough data to analyze, as the topic is already laden with meaning for the researcher and the participants (Moules et al., 2015). Data collection in hermeneutic research involves interviews that are conducted intentionally, thoughtfully, and openly to create space for the participant to share their superior insight and shape a new understanding of the topic through the manifold reality of the researcher, participant, and in this case, art (Moules et al., 2015). In the same way that the

application of the Gadamer's hermeneutical approach to art in art therapy differs from a genuine experience of artwork, hermeneutic interviews, while occurring in conversation, are not genuine conversations in the Gadamerian sense (Moules et al., 2015). An interview question guide was developed for data collection and ethics approval (see Appendix F); however, the interviews with children were structured by the topic (Moules et al., 2015), rather than a pre-determined set of questions.

Interviews were conducted over 45-60 minutes in the environment of the child and parent's choosing. Four children were interviewed in their homes and two children were interviewed in their patient rooms at a pediatric hospice. Children were given the option of having their parents absent, nearby, or present during the interviews. One parent sat in during the interview at their child's request, two children interviewed alone (both mature minors), and three children chose to have their parents nearby in an adjacent room.

The artwork of children with serious illness was created during the interviews and was also included as data for analysis. For the purposes of this study, I considered children's creations (e.g., drawings, poetry, sculpture, and theatrical productions) as artistic data; however, all children chose to create a drawing or painting. Children were provided with an assortment of supplies to create art in the medium of their choosing, and the interview proceeded as the child used art as an expressive tool or a distraction to engage with, but not directly confront, the topic of discussion. Interviews were audio-recorded and transcribed verbatim; however, one participant was unable to communicate verbally due to their diagnosis, and they responded to my questions by typing out their answers on a laptop. Interview transcripts and other confidential electronic data were stored on a password encrypted computer, and paper documents and artwork were stored in a locked filing cabinet in my office at the University of Calgary. Data will be

stored for five years and subsequently destroyed. One child wished to have their artwork returned to them following their interview, and one parent requested and was given their child's artwork following their child's death.

Covid-19 Precautions

Due to infection prevention and control concerns in the context of the COVID-19 pandemic, the children were gifted their supplies as an honorarium to minimize the risk of infection in this medically fragile population. Families were given the option of conducting their interview using an online video conferencing platform; however, all families agreed to in-person interviews. Three interviews occurred while some COVID restrictions were still in place in the province of Alberta. I performed a self-assessment using a COVID-19 screening tool from Alberta Health Services (n.d.) prior to each interview and asked each family to do the same. I wore a surgical face mask to interviews and practiced good hand hygiene, but personal protective equipment was optional for participants and their family members if the interview was conducted in their own home. When COVID restrictions were lifted in residential and hospital environments, families were aware that I was willing and prepared to wear personal protective equipment during the interview at their request.

Data Analysis

Data analysis in hermeneutic research is synonymous with interpretation, with a focus on a particular topic in relation to how it is experienced in the world—in history, practice, culture, and what it means to the people involved (Moules et al., 2015). Analysis is divergent, meaning that associations and interpretations that deepen the understanding of the topic are analyzed, rather than focusing on one overarching theme (Moules et al., 2015). The philosophical underpinnings of hermeneutics guide data analysis, looking for new ways to understand a topic

through the critical interpretation of text and establishing the justification for the interpretations that emerge from the data (Moules et al., 2015). Gadamer advised to approach text with an open mind: “a person trying to understand a text is prepared for it to tell him something” (Gadamer, 1960/2004, p. 270). Thus, the analysis involved careful reading, re-reading, and writing interpretive conjectures about what emerges from the data, with an awareness that the result cannot consist only of my perception and reflections on the topic (Moules et al., 2015).

Transcription analysis and interpretation of the artwork of children was conducted in a thoughtful, open, curious, and tentative manner. Interpretative conjectures, similar to field notes, were written to keep track of ideas as the evolving understanding of the topic unfolded (Moules et al., 2015). The hermeneutic circle, a metaphor for the movement of the parts (i.e., the participants and the researcher) and the whole (the topic), encourages the open and curious response of the researcher to the text, and allows the researcher to relate the new perspectives back to the topic and generate an expanded understating of the topic (Moules et al., 2015). Interpretation involves “a deconstruction of data and a reconstruction of meaning” and the questioning of traditional assumptions and prejudices (Moules et al., 2015, p. 129), such as children as “un-knowing,” rather than a potential source of rich data.

The play of art (Gadamer, 1986) guided the interpretation of children’s artwork. Philosophical hermeneutics emphasizes the ability of art to convey real knowledge about ourselves and reveal the invisible forces that shape our lives, allowing us to cope with them (Zimmermann, 2015); the goals of art therapy align particularly well with hermeneutics in this sense. Artwork can help explore the meaning of a person’s experience (Devlin, 2006), and can be analyzed hermeneutically to construct new meanings that arise from careful interpretation and the play of art. The interview with the child helped to contextualize their artwork and ensured

that interpretations are derived from the meaning they ascribed to their experiences of serious illness and the threat of death, rather than relying solely on my adult interpretation of their artwork.

Interpretive writing should move past a surface description of phenomena with the goal of understanding the topic in a deeper or novel way (Moules et al., 2015). Researchers must reflect on how their own prejudices and pre-understandings influence their interpretations, and how the context of the topic influences understanding (Moules et al., 2015). As recommended by Moules et al. (2015), I was attentive to the language used by participants in their interviews, and explored different metaphors that might enhance understanding of the topic. In the tradition of hermeneutic philosophy and its emphasis on language, the tracing of the etymological roots of a word or phrase that stood out was helpful in developing interpretations (Moules et al., 2015). The final product of this research is a different understanding of the experiences of children with serious illness, developed by looking for previously overlooked ways of knowing from previously overlooked participants. By researching children's experiences, a part can be added to the whole of the PPC literature, elevating our understanding of what it means to be a child facing serious illness and possible death and how best to care for them.

Unconcealment Through Art

The term palliate is derived from the Latin word *pallium*, which means to disguise, cloak, or conceal (Online Etymology Dictionary, n.d.), and at this time, there is much about the experiences of children wish serious illness that is unknown or concealed. The aim of hermeneutic research is to reveal hidden truths, through what the ancient Greeks referred to as *aletheia*, the moment when something that was closed or hidden is opened or revealed (Heidegger, 1971; Moules et al., 2015). It may be that adults palliate something in the

experiences of children with serious illness. The hesitancy to ask uncomfortable questions or explore difficult perspectives prevents a deeper understanding of what it means to be a child who is dying, and how PPC providers may best care for them. As Rahimzedah et al. (2015) stated, "There is yet so much to learn from children of the death and dying process in order to better care for future children during the death and dying process" (p. 4). The purpose of art is to express someone's experience (Parsons, 1987), the infinite ambiguity of art demands interpretation, and "art of any kind is a form of recognition that serves to deepen our knowledge of ourselves, and thus our familiarity with the world as well" (Gadamer, 1986, p. 100); this thesis work is a confluence of art, expression, interpretation, and meaning to discover how we might understand the experiences of children who are dying. I engage in the hermeneutic wager that new understanding may be revealed through the artistic creations of children with serious illness.

Chapter Four: Contextualizing the Participants

While it is not customary to describe or represent participants in hermeneutic studies (Moules et al., 2015), I do find a brief description of the participants is helpful to contextualize the topic of my thesis work. I have chosen to use pseudonyms to designate each participant for practical reasons. By naming the participants, one is able to contextualize their age and their artwork while reading this manuscript. This chapter is meant to provide a brief description of the participants' age, diagnosis, care setting, and artwork in a larger scale than what will be presented in the interpretive chapters.

Participants

Sam

My first interview was with Sam, a seven-year-old boy who was diagnosed with idiopathic thrombocytopenia purpura (ITP) when he was a toddler. ITP is a rare and serious hematological disease where the component of blood responsible for forming blood clots, called platelets, is so low that even a small injury could result in life-threatening blood loss. He was able to receive a medication infusion (intravenous immunoglobulin or IVIG) that would increase his platelet count, and for a short time afterwards, he did not need to worry about the consequences of an injury. I interviewed Sam in his home with his mother present.

Figure 1.1 (Sam)

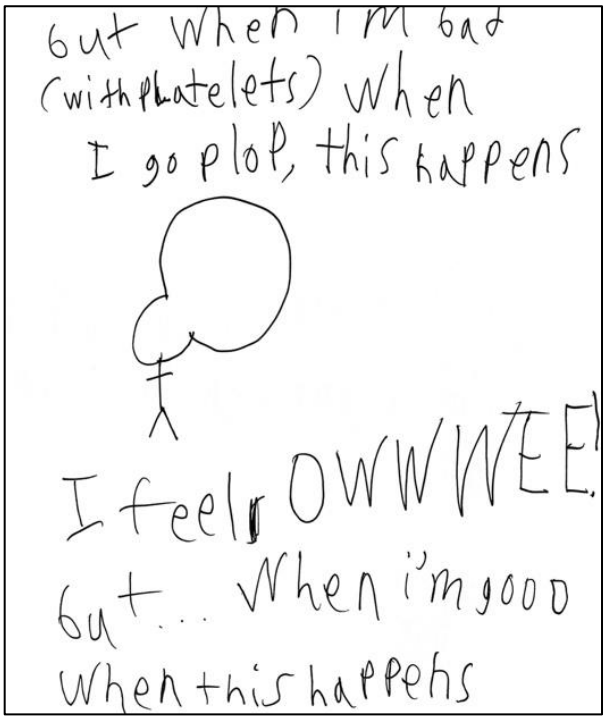


Figure 1.2 (Sam)

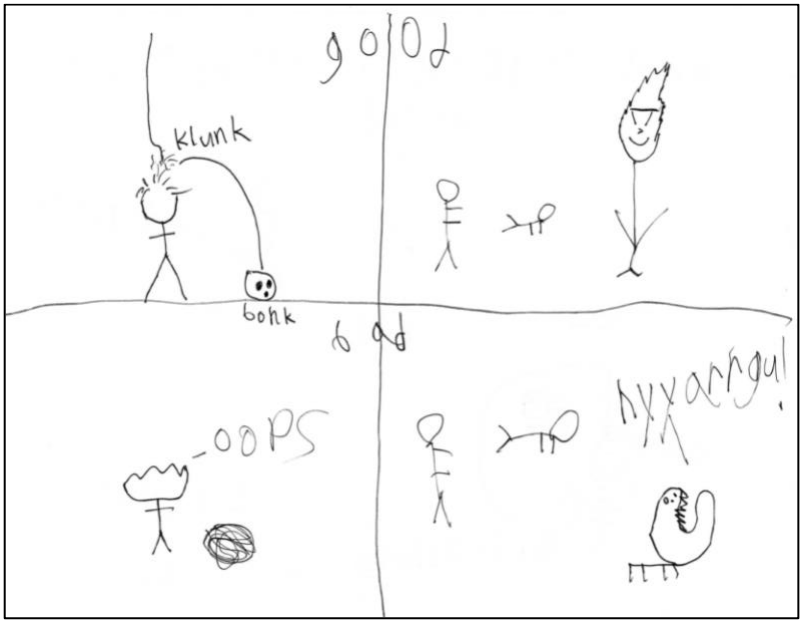


Figure 1.3 (Sam)

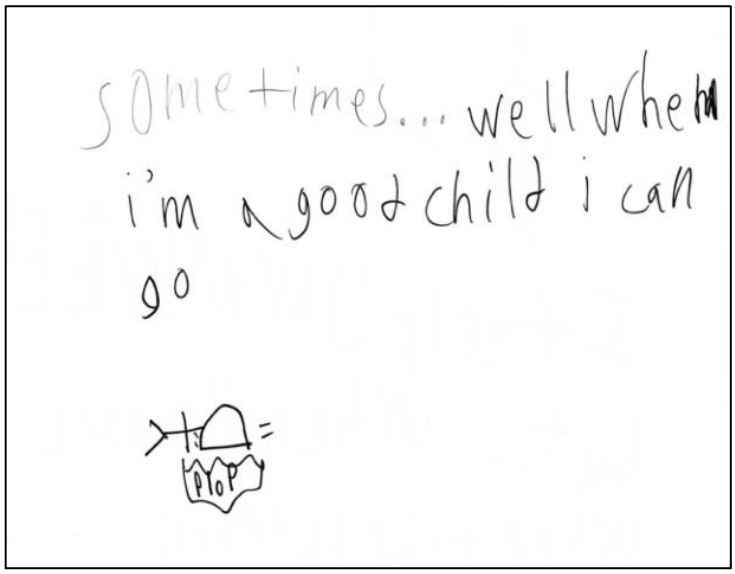


Figure 1.4 (Sam)

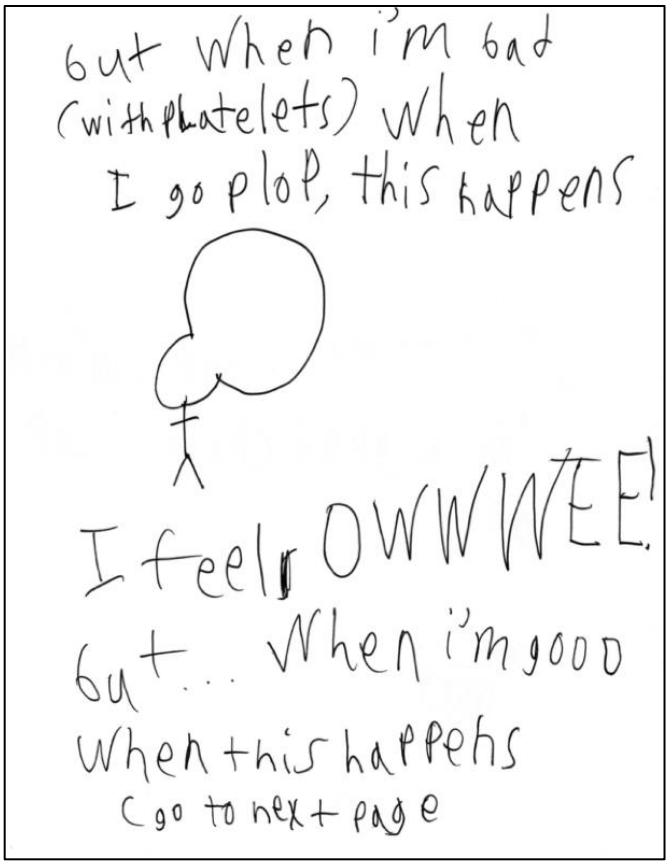
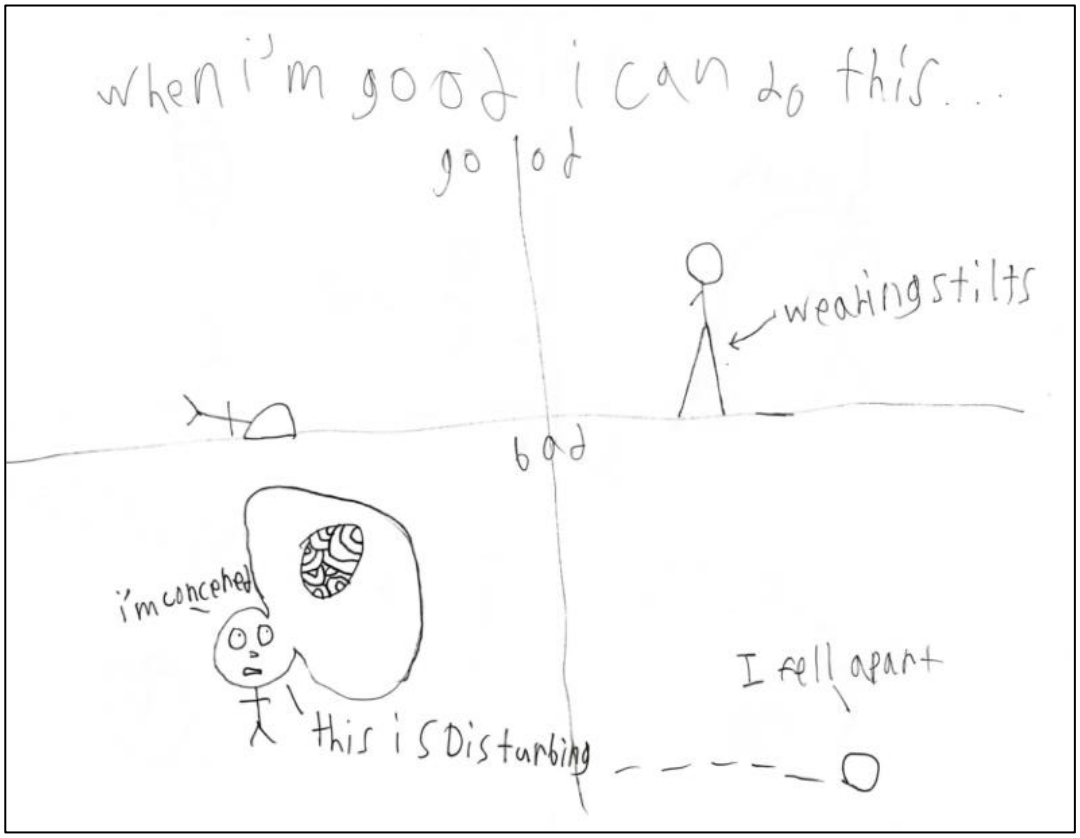


Figure 1.5 (Sam)



Maddie

Maddie was undergoing chemotherapy treatments and was seven years old at the time of her interview. She had been diagnosed with high-risk acute lymphoblastic leukemia and had been travelling back and forth from her hometown to a larger city with a children's hospital. Maddie was very articulate and was proud to inform me that after our interaction, she would have been featured in a radio, television, and research interviews related to her cancer diagnosis. I interviewed Maddie in her home, with her parents in the other room. She enthusiastically showed me her room with all the mementos she collected during her time with cancer.

Figure 2.1 (Maddie)

Figure 2.2 (Maddie)

Angela

Angela, a 17-year-old at the time of her interview, had recently undergone a novel treatment for sickle cell anemia and was in remission. Her inherited disease was named for the sickle-shaped red blood cells that are more rigid, sticky, and misshapen, which can cause strokes, pain crises caused by a buildup of blood cells, severely blocked vessels in the lungs (i.e., acute chest syndrome), the death of marrow and bone cells (i.e., avascular necrosis), and other serious health complications. I interviewed Angela in her home while her family was on a different floor.

Figure 3.1 (Angela)

J-Bird

At a young age, J-Bird (a pseudonym of his own choosing) started to notice that he was unable to maintain his balance and his legs were becoming weaker. He was diagnosed with giant axonal neuropathy, a rare and severe neurodegenerative disorder. As he grew in age, his physical abilities declined, which is typical of the slow progression of neurodegenerative disorders (Opal, 2023). At the time of his interview, J-Bird was seven years old and had mostly presented with peripheral motor and sensory neuropathy, but the disease typically evolves to include central nervous system impairment, including seizures and intellectual disabilities (Opal, 2003).

Figure 4.1 (J-Bird)

Figure 4.2 (J-Bird)

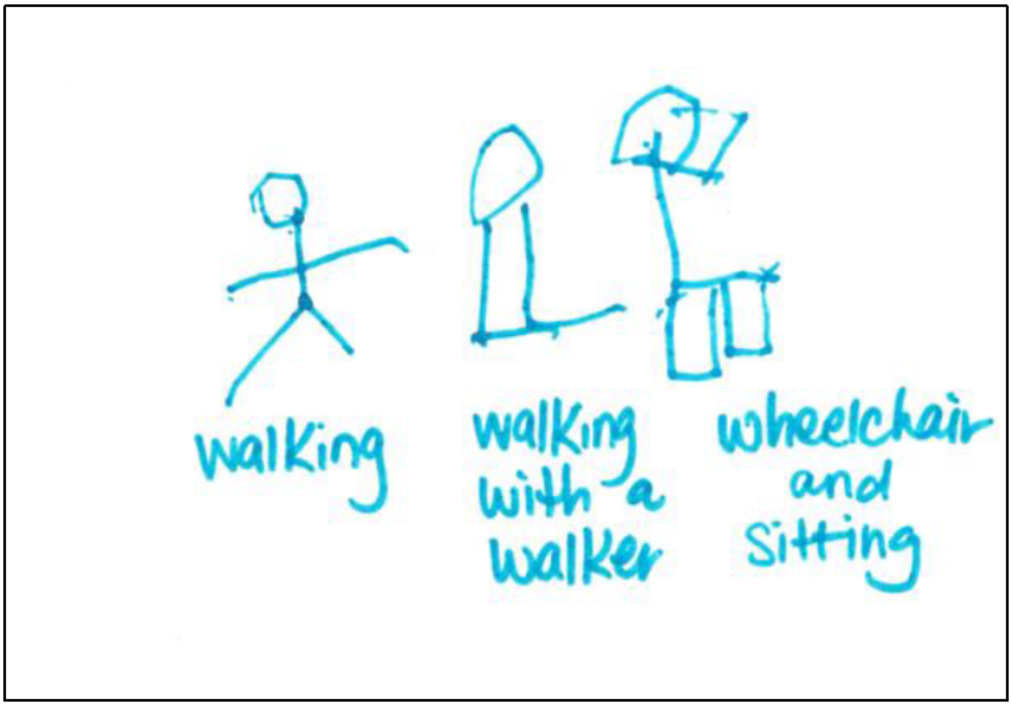


Figure 4.3 (J-Bird)

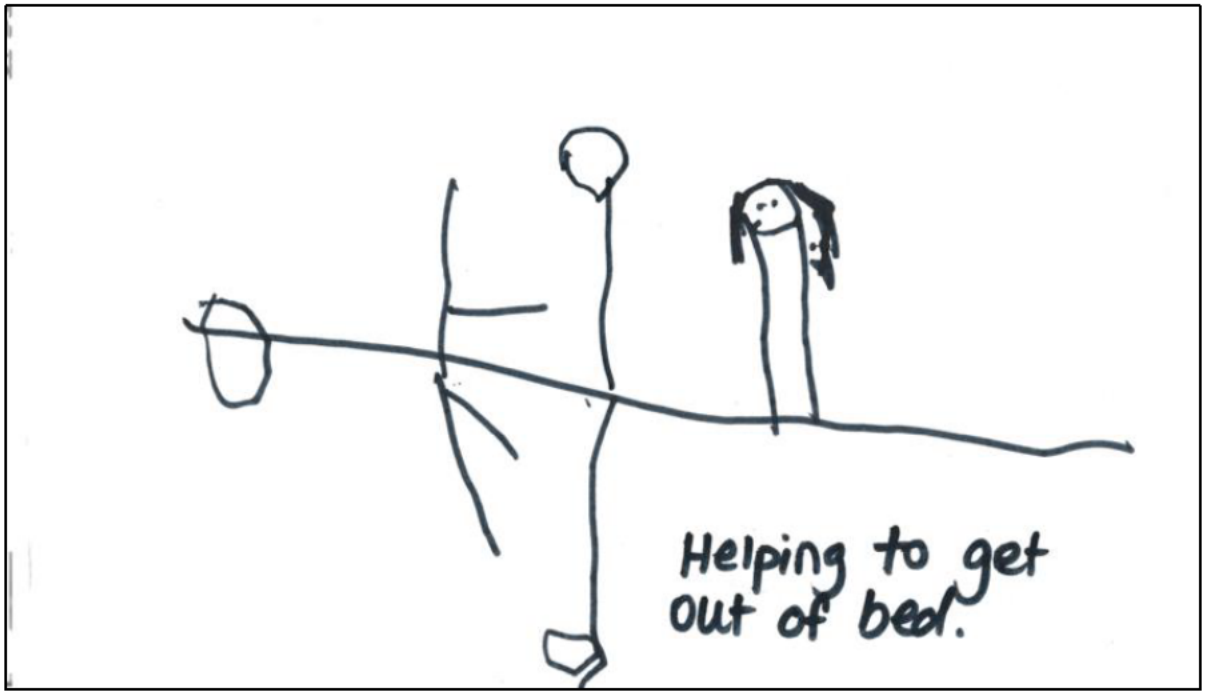
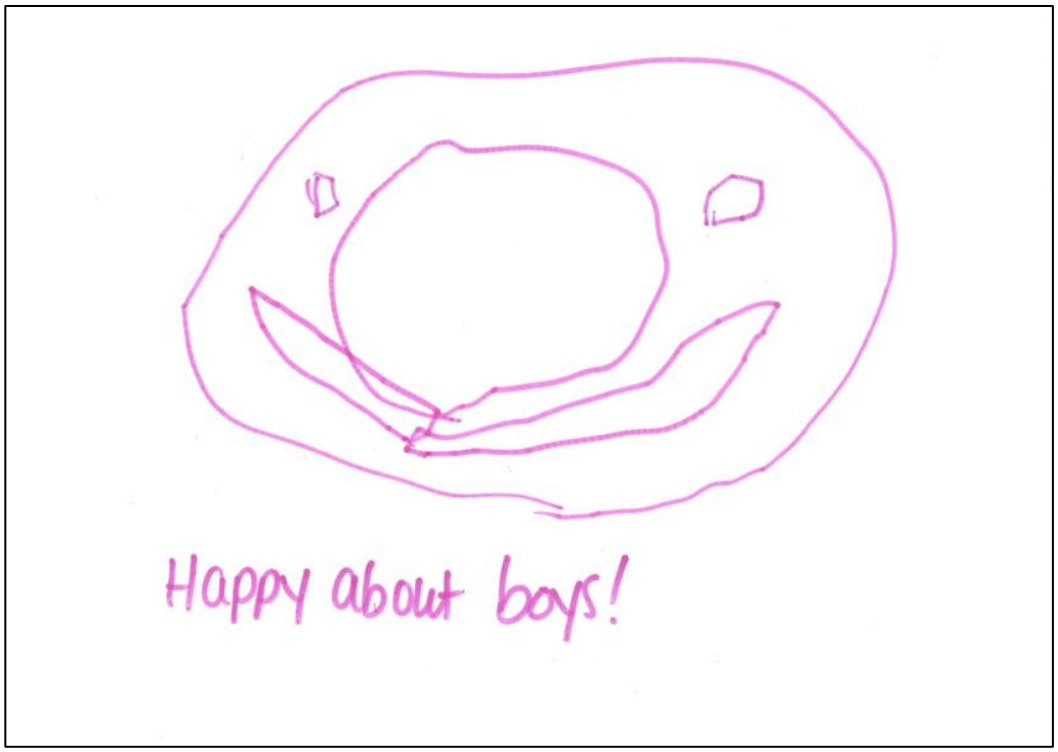


Figure 4.4 (J-Bird)

Figure 4.5 (J-Bird)



Vinnie

What had begun as a small lump on the inside of the cheek of a healthy 17-year-old was soon discovered to be a rhabdomyosarcoma, a tumour affecting skeletal muscle. Vinnie's tumour did not respond to two rounds of chemotherapy and three cycles of radiation, and she was admitted to a pediatric hospice for a prolonged end of life stay. Vinnie's interview was conducted in her hospice room with her parents in another room. In addition, Vinnie communicated using a laptop computer, gestures, and vocalizations, as she was unable to have a full conversation due to a large tumour in her mouth.

Figure 5.1 (Vinnie, Unfinished)

Nate

Nate was also admitted for hospice care following a cancer relapse that had resulted in a metastasized neuroblastoma. He was nine years old at the time of his interview, and as he loved research and learning new things, he agreed to speak with me to help nurses and doctors care for children like him. Despite being attached to oxygen, intravenous infusions, and a feeding tube, Nate was optimistic and gracious throughout the interview. I interviewed Nate in his hospice room, as he was largely confined to bed, with his mother in the next room.

Figure 6.1 (Nate)

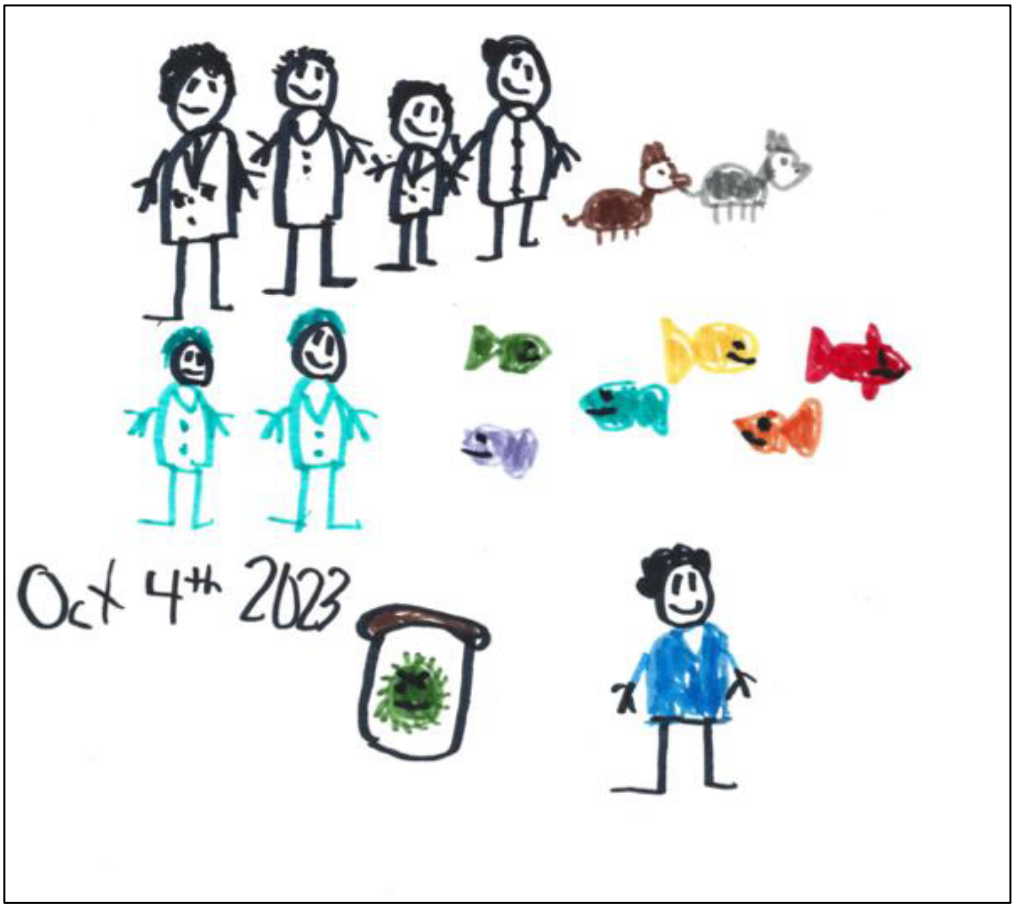


Figure 6.2 (Nate)

Chapter Five: The "Voices" of Children: Art, Metaphor, and Silence

> *The child shall have the right to freedom of expression; this right shall include freedom to seek, receive, and impart information and ideas of all kinds, regardless of frontiers, either orally or in print, in the form of art, or through any other media of the child's choice. (United Nations Convention on the Rights of the Child, 1989)*

In my methods chapter, I mentioned my wager that artwork used to elicit a child's experience of serious illness would be useful in research. This wager has resulted in the creation of children's artwork worthy of contemplation, and interpretations that have deepened my understanding of children's experiences of serious illness. However, in all my participant interactions, art did not serve as the necessary mediator for understanding that I had imagined it would. It was not that the artwork was unnecessary, as it provided an excess of meaning. Rather, I often felt that the participants created artwork because it was an activity they enjoyed doing or because I had asked them to. Art was not the only form of expression the participants used, and they offered detailed descriptions or striking metaphors to describe their illness experiences. There were also moments of where they were unable to summon the language to speak to an experience.

During my analysis and in conversation with my supervisor, Dr. Moules, it became apparent that, while the artwork was a meaningful addition to the data, the participants did not need to create artwork to say something of their experiences. The children's experiences of serious illness, and the ways in which they communicated them, was the phenomenon of interest. The original inquiry, understanding the experiences of children who are seriously ill through their artistic forms of expression, became secondary to the primacy of children's voices in shaping understanding. Dr. Moules encouraged me to reconsider what was exposed in the

analysis and the ways in which children conveyed their experiences. She proposed that we consider a new research question that both encapsulated the original topic, while broadening the analysis in a meaningful way: how might we understand the "voices" of children who are seriously ill? With this revised question came the need to clarify how voice might be interpreted, rather than focusing solely on what children said.

Reflecting on Method

My initial reaction to the suggestion put forward by Dr. Moules was to question if amending the research question was possible. In other research methods, this would be an unconventional change that might call into question the rigour of the work (e.g., changing the question after discovering that the findings do not answer it). I was concerned that I would be criticized as having interpreted a "common reading of Gadamerian hermeneutics" (Moules et al., 2015, p. 55), where Gadamer's critique of method meant that I could do whatever I wanted as a researcher. I considered if the change could be justified methodologically and what possibilities might appear because of it. Moules et al. (2015) suggested that, in hermeneutic research, questions evolve as the researcher engages with the data and the question becomes more apparent. For the purposes of a doctoral thesis, it is important to elaborate on why such a change might be permissible hermeneutically.

The distinction between conventional research methods (e.g., the scientific method) as the adherence to a pre-determined procedure, and the demand of hermeneutics to consider what such methods neglect, is of import here. Hermeneutic research is a practice, one that requires the researcher to make appropriate choices to advance our understanding of the phenomena under investigation (Moules et al., 2015). The master of a method is, for Gadamer (2007), not the defining feature of the "productive scholar" (p. 85), as the ability to learn and follow a method

does not guarantee that anything worth knowing will be produced. Indeed, the participants expressed their illness experiences in their artwork, but not only in their artwork; what they spoke about, how they spoke, and what they were silent about during their interviews was equally informative and too significant to omit for the sake of doing research in a certain order.

> In hermeneutic work, being called by a phenomenon does not immediately license one to rush into the world armed with a method, but rather, calls for the careful probing and questioning of what appears . . . every experience of learning from the phenomenon requires a new set of questions to be generated, because if the encounter "works," it produces new understanding, and hence a different course of action. In this way, practice is not so much driven by procedure as it is by substance (*die Sache*), *by the subject that matters*. (Moules et al., 2015, p. 63, emphasis added)

There was also an ethical dimension that prompted the research question to change. Children's experiences of serious illness matter, and too often, children's voices are absent from important conversations on issues that affect them and research that aims to generate knowledge about them (Bluebond-Langner, 2007; James, 2007; Montreuil & Carnevale, 2016). Such an omission would be antithetical to the intentions of this research endeavour. From the interviews with the participants, the analysis, and my obligations as a researcher, another question emerged that was better suited to attend to the phenomenon. However, this question brought to light what is at stake in the concept of voice and its meaning in the context of research with children.

Children's Voices

Perhaps part of my assumptions about giving voice to children through art is related to the ambiguity of "children's voices" as it is described in literature and in the broader, everyday discourse about children. The ways in which voice and children are conceptualized has

implications for how children's voices are interpreted in hermeneutic research. Voice can be simply defined as a sound produced by human beings, the faculty of utterance, or the right of expression (Merriam Webster, n.d.). Voice can also be defined as a "construct that operationalises access to a person's perspective" (Singh et al., 2020, p. 400).

Carnevale (2020) identified several reasons why children's perspectives might be missing from the literature. First, professionals and researchers tend to view children from universal stage-based models of childhood development that characterize children's perspectives as immature, and therefore not substantively significant. Second, he noted that initiatives calling for increased consideration of children's voices are often rooted in the desire to compassionately demonstrate having listened to children, rather than recognizing that their expressions come with an ethical demand. Certain frameworks conflate agency with autonomy, which limits which people can be recognized as having the capacity and right to speak for oneself. Finally, participation in decision-making, such as the ability to provide consent or assent to participate in research, is frequently restricted to those who are deemed as having cognitive and communicative capacity in a legal sense. This impedes those who have different cognitive or communication abilities from participating in decision-making, research, or conversations in which they may have something to contribute.

Spyrou (2016) argued that for the last three decades, the field of Childhood Studies has taken up this definition of voice as the "all-too-easy and unproblematic desire to render children and their words comprehensible and transparent through a surface reading of their utterances" (p. 106). Carnevale (2020) described such approaches as "thin conceptions" (p. 2) of voice, which regard statements made by children, or a person of any age, as a direct representation of their independent preferences, desires, or perspectives. A simple definition of voice is insufficient for

the population of children with serious illness, as many of these children are non-speaking or have illness-related speech impediments. It is important, then, to consider the possibilities for how voice might be interpreted within and beyond what children "say" in trying to understand how children experience serious illness. I have come to understand "children's voices" for this research as the unity of testimonial justice, agency, and recognition.

Voice as Testimonial Justice

Importantly, children's voices in the context of research involve encounters between adults (i.e., the researcher) and children (i.e., as participants or as subjects of observation). Miranda Fricker's (2007) work on epistemic injustice highlights what is at stake in the interactions between children and adults, namely "the sharing of meaning" (Risser, 2012, p. 92). Epistemic injustice arises when someone is "wronged specifically in their capacity as a knower" (Fricker, 2007, p. 1), which Fricker further categorized as testimonial injustice and hermeneutical injustice. Testimonial injustice occurs when prejudice (in a negative sense) causes a listener to assign a reduced level of credibility to a speaker's word, usually due to their social identity. Hermeneutical injustice occurs "at a prior stage, when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experience" (p. 1).

Burroughs and Tollefson (2016) argued that children, as a social identity, are subject to testimonial injustice due to being categorized as irrational, suggestible, and unreliable, which results in children receiving less testimonial credibility than they deserve without having to utter a single word. This perceived lack of credibility also contributes to a paucity of research in which children are participants, as children's accounts of their experiences are deemed less reliable or credible than those of their adult counterparts (Docherty & Sandelowski, 1999). This perpetuates

testimonial injustices for children as they are, at times, not meaningfully involved in research about their own experiences. Children and adults are at risk of hermeneutical injustice in situations, such as the diagnosis of a pediatric terminal illness, that render everyone speechless and at a loss for the words to adequately convey the unfairness of the fact that children die (Rallison & Moules, 2004; Wong, 2022). Carel and Gyorffy (2014) argued that children in medical settings may be particularly vulnerable to both testimonial and hermeneutical injustices due to their intersecting social identities as an ill person and a child.

> Not only children's testimonies, but also their interpretive frameworks are at risk of rejection by adults, who, with few exceptions, cease to readily understand the child's world. When the two interpretive frameworks clash, the adult interpretation usually trumps the child's. This is a problem when we consider the ways in which children perceive illnesses in themselves or in an adult, and how it is explained to them (or not) by adults. It is also a problem when a child interprets or reports a symptom in ways that do not make it salient enough for adult attention. (p. 1256)

Voice might be partially defined as testimony, with the caveat that the testimony of the speaker is deemed reliable regardless of their social identity. Children are the experts in their own experiences (Carnevale, 2021), and their testimony of their illness experiences are credible – far more credible than what I might have to say on the matter, as I was never a child with a serious illness. However, testimonial justice for children in research is unlikely to be achieved by acknowledging the credibility of what children have to say alone, particularly if their interpretive frameworks, their ability to assign meaning to something, is also in question. By itself, testimony might run the risk of being too close to "thin conceptions" of children's voices (Carnevale, 2020) if presented simply as the recitation of what children said.

Voice as Agency

The work of bioethicist Franco Carnevale, who applied Charles Taylor's philosophy to construct a framework for children's agency, is helpful in considering how voice might be understood as agency. Taylor (1985) presented two conceptions of agential persons. First, "the ordinary notion of a person, defined by certain capacities: a person is an agent who has a sense of self, of [their] own life, who can evaluate it, and who can make choices about it" (Taylor, 1985, p. 103). In this view, what makes an agent a person, is the power to plan and act on those plans. This is problematic for children, as they are often seen as lacking certain capacities, such as the ability to make informed decisions, perform critical reflection, and speak or act on their behalf (Carnevale, 2021). Taylor's (1985) second conception of a person posits that

> agents are beings for whom things matter, who are subjects of significance. This gives them a point of view on the world. But what distinguishes person from other agents is not strategic power, that is, the capacity to deal with the same matter of concern more effectively. Once one focusses on the significance of things for agents, then what springs to view is that persons have qualitatively different concerns. (p. 104)

In this view, a person's valuation of matters of significance will inform their actions and decisions, which are always contextualized in the agent's situatedness in the world (Carnevale, 2021; Taylor, 1985). Using Taylor's conception of a person as someone for whom things matter, Carnevale (2021) emphasized that children's voices must be recognized and interpreted as agential expressions of meaning. With testimony and agency, children's voices can be acknowledged as credible statements about matters of meaning for children. One additional concept, hermeneutical recognition, will further clarify that children's voices also reveal possibilities for understanding differently.

Voice as Hermeneutical Recognition

Voice, from the Latin root *vocem*, can be translated as "sound, utterance, cry, speech, language, or word," but it can also mean a "call" (Online Etymology Dictionary, n.d.). A call carries with it an attempt to reach someone, as well as the demand for a response. As George (2020) showed, in working through Gadamer's moral gradations of our recognition of the Other, such a response can come in different forms. First, a response to the call of the Other may be diminished to generalisation, where rather than recognizing others as having their own voice, we look for what is predictable about them as a means to our own ends. James (2007) warned that the conception of "children's voices" risks ignoring the diversity of children's individual lives and experiences by "uncritically clump[ing] children together as members of a category" (p. 262).

The second level of recognition positions the Other as a "person with an independent voice, but, instead of allowing them to say something of their own, we demand that they confirm the validity of what we have to say" (George, 2020, p. 108). In what George called subjugation, we look to the Other to endorse what we have to say as valid. Regarding the subjugation of children in research, James (2007) asked, "What is the risk that children's voices may be employed simply to confirm established prejudices rather than to present new insights based on children's own perspectives as social actors?" (p. 262). Examples of the subjugation of children can be seen in studies that first categorized child participants into assumed stages of development with separate measurement tools assigned for each group before testing their understanding of death, thus presenting a biased confirmation of what they already presumed children to understand (e.g., see Slaughter & Griffiths, 2007, and Koocher, 1973).

The third moral gradation recognizes the Other as having a voice of their own, and, importantly, listening for the possibility of validity in what the Other has to say (Gadamer, 1960/2004; George, 2020). This does not mean that the listener should blindly accept the Other's claim, but that the listener is willing to place their own beliefs and understandings aside when considering the call of the Other. In being open to the voice of the Other, the listener must be prepared to acknowledge that they may need to change their mind: "Openness to the other, then, involves recognizing that I myself must accept some things that are against me, even though no one else forces me to do so" (Gadamer, 2004, p. 355). This kind of open listening requires interpretation and is enacted through a back-and-forth of question and answer (Risser, 2012), in a call and its open response. Listening to children's voices is the recognition that when they speak about their experiences, their voices carry testimonial credibility, agential expressions of meaning, and the possibility that we might learn something from them and come to understand differently.

Appearing Voices: Art, Metaphor, and Silence

> *"In acting and speaking, men show who they are, reveal actively their unique personal identities and thus make their appearance in the world" (Arendt, 1998, p. 179).*

In this research, the participant's "voices" came in different forms. Often, their experiences of serious illness were relayed through narration and storytelling. However, they also conveyed their experiences through other kinds of "voices": artworks, metaphors, and silences. These voices also carry with them testimony, meaning, and possibility.

The Voice of Art

Philosophical hermeneutics places a special emphasis on the revelatory function of art. In the case of children's artwork, the viewer may not pay close attention to what an image "says"

insofar as children's artwork is regularly regarded as decorative, rather than a work to contemplate (Matthews & Mullen, 2020). Considered hermeneutically, children's artwork might reveal possibilities for understanding their experiences of the world. Gadamer's notion that a picture is a "speechless language" (1986, p. 83), rather than a thing created for pleasure and considered for its mere beauty, suggests that it has something to say. A work of art manifests through a process of what the Ancient Greeks called *poiesis*, which means "to make" something that did not exist before, or "a thing made," where "non-being comes to be being" (Gadamer, 2006, p. 63).

Once made, the work of art stands and speaks for itself (Gadamer, 1986): it has a voice. In standing and speaking for itself, a work of art is absolute; it is "there" completely, and ready to be encountered by those who view it (Gadamer, 1986; 1992/2006). Gadamer considered works of art as possessing an "elevated rank in being, and this is seen in the fact that in encountering a work of art we have the experience of something emerging [*aletheia*] – and this one can call truth" (Gadamer, 1992/2006, p. 67). As I mentioned earlier, I do not think Gadamer was referring to children's artwork when he developed his philosophy of hermeneutical aesthetics. However, hermeneutics has interpretive implications for how children's artwork is viewed and engaged with.

Things That Matter

> *The arts and humanities . . . aim at nothing else than making things that matter to us visible (George, 2020, p. 143).*

The participants in this study used artwork as voice to say something about their illness experiences and present their matters of concern. Nate and Maddie chose to draw the things that

were important to them after being diagnosed with cancer. These drawings helped them to expand on why the things and people depicted in these images were significant to them.

Figure 6.1 (Nate)

For Nate, his family, his dogs, his healthcare providers, decorative aspects of the hospital, and remaining free of infection were matters of significance. Even the addition of a ponytail on his mother's head was meaningful to him.

> *Nate: She used to have a ponytail so I'm just gonna add that . . .Yeah, see I'm grown my hair after I cut it, my brother already grown his hair, and my dad is, but she still doesn't have her hair [i.e., his mother kept her hair short].*
>
> *KW: No? Did you shave your head at one point?*
>
> *Nate: Yeah, because of my chemo that I've been doing.*
>
> *KW: So, did everyone shave their head?*
>
> *Nate: Yeah . . . to make me feel like I'm not the only one with a shaved head.*

The addition of a drawing of Nate's pet was significant because he did not have access to his dog, who was an important source of comfort, while admitted at the hospital.

Nate: . . . the brown dog, he's my dog. He's really attracted to me, and he loves to play, and he protects me too . . . he comforts me because he's so soft, so I just hold him, and he just sits there. He doesn't care how I hold him; he will just fall asleep on me.

In one image, Nate's world and the things that matter to him are presented in a unifying way.

Figure 2.1 (Maddie)

Maddie also drew her dog, who was a supportive presence in her life after she was diagnosed with cancer. Her dog was present during our interview, and the bell on its collar can be heard jingling throughout the audio recording.

Maddie: Well, my dog has always been really important to me. She helps me take meds. All I have to say is "Spot [pseudonym] meds!" and she comes up and lets me hold her paw and my mom gives me the medicine.

Maddie's matters of significance were not all positive. The hospital and the treatments she had to undergo there were a source of concern and anxiety, which added to the development of the interpretive chapter on children's clinical environments. Maddie also included her best friend,

pictured in the centre of the drawing, as an important source of support and connection to her normal life during her admission to the hospital.

> *Maddie: [Her friends are important because] like just how they support me when I was in the hospital, [my best friend] wrote me notes.*

The aim of hermeneutic research is not to re-present the participants, but to interpret what they can speak to about the topic, such that the topic is expanded in new ways (Moules et al., 2015). Thus, the point would not be to say that children with serious illness should always have their dogs with them, but to recognize that children have matters of concern that can appear and be given shape in their artwork. Important aspects of their illness experiences, such as comfort, solidarity, anxiety, and friendship, are presented in art "with a unity, a structure, and thus an intelligibility that experience itself lacks" (Schmidt, 2015, p. 347). Through such a creation, experiences are transformed into something immediately perceptible with an abundance of possible meanings (Gadamer, 2004; George, 2020; Schmidt, 2015). In pictures of dogs, friends, and a mother's ponytail, children's voices appear and demand a response.

The Voice of Metaphor

The participants in this study were also able to make their experiences intelligible through comparative language. Metaphors rely on the power of human imagination to turn reality into a meaningful whole through symbolic representation (Ricoeur, 1978; Zimmermann, 2015). For example, personifying the environment through metaphor in the phrase "mother nature" is more accessible to humans than the abstract, conceptual language that is prominent in the natural sciences (Zimmermann, 2015). Hermeneutic understanding functions in the same way that metaphors do, through the integration of the familiar and unfamiliar in such a way that widens one's perspective and discloses reality (Moules et al., 2015; Ricoeur, 1978; Zimmermann, 2015).

The ability to see the similarity in the difference that a metaphor presents requires an act of imagination to suspend reality such that one can consider the metaphor's meaning (Ricoeur, 1978; Zimmermann, 2015). In order to bring the literal and figurative interpretations closer together, Ricoeur (1978) posited that metaphor requires a semantic and mental theory of imagination. A vivid metaphor has the capacity to "set before the eyes" the similarity between the literal and figurative meaning despite the obvious difference, which suggests a "picturing function of metaphorical meaning" (Ricoeur, 1978, p. 144). The participants used metaphor to make their experiences, particularly their most challenging or indescribable experiences, more accessible and transmittable.

Angela: I really didn't have a life with sickle cell.

Sam: [When I am sick] I fall apart.

Nate: I'm happy that I was able to beat cancer.

Sontag (1978) opposed the use of metaphors to describe illness, including the common metaphor that cancer is a battle which Nate employed. Sontag deemed metaphors unhelpful to people who are ill as they often come across as punitive and are not a truthful way of thinking about illness. While it is the case that metaphors are not literally true statements, Lakoff and Johnson (1980) argued that the goal of metaphor is understanding, and the spirit of metaphor supports understanding by experiencing one concept or thing in terms of another. Metaphors might be considered a hermeneutically truthful way of thinking about illness experiences if they serve to expand understanding. The participants' use of metaphor during their interviews allowed them to describe an amorphous experience through the excess and transfer of meaning that their

metaphors supplied. Sam was not able to provide a description of how he felt when he was ill that was more comprehensible, to himself or to me, other than "*I fall apart*." Some participants used similes followed by metaphors that appear in everyday speech (e.g., "moving on" or "moving forward" in life) to expand on their meaning.

Vinnie: I feel like I'm stuck re-reading a chapter while everyone else gets to move on.

KW: What does the AARRGGHH [in the picture] mean?

Sam: It's like a scream . . . it's every single emotion feeling in one.

Just as the experience of art helps to bring ambiguous and incongruous aspects of life into special focus (George, 2020), metaphor and other figures of speech provide a linguistic structure to experiences that would otherwise remain unintelligible. As Moules et al. (2004) wrote,

> metaphors provide a view of something from a viewpoint of another thing and yet they work to make one 'feel at home.' 'Yes that is right; that is what it is like; I recognize that.' Paradoxically, a metaphor simultaneously serves to remove us, while at the same time offering us a home in language and understanding (p. 105)

Metaphors transmitted the children's testimonies and concerns, while shaping how we might understand their illness experiences, while allowing them to distance themselves from a difficult topic

The Voice of Silence

What is not voiced is often as telling as what is said, and this was the case for the participants. One motivation for conducting this study was to understand the experiences of children who were dying from a life-shortening or life-threatening illness, but on the topic of death, the children were silent. An interpretation of what that children were silent about will be

addressed in chapter eight, but what is required first is an interpretation of the voice of silence. Risser (2019) explained Heidegger's recognition of the relation between silence and speaking, such that in silence, "the speaking voice simply withdraws, while the voice remains present" (p. 3). Silence, like metaphor, involves a suspension or a pause that allows an opening for imminent meaning (Risser, 2019). Silence may demand more interpretive consideration than what was spoken, as in any statement, there is, inevitably, more that goes unsaid than what one says (Mazzei, 2007). However, what is unsaid is equally important to what is spoken in coming to an understanding. Silence might also carry meaning in a sigh or a pause as one contemplates the "right" language to describe an experience (Risser, 2019). Importantly, the perceived limitations of silence should be considered for their generative possibilities.

> Nothing that is said has its truth simply in itself, but refers instead backward and forward to what is unsaid. Every assertion is motivated, that is, one can sensibly ask of everything said, 'Why do you say that?' And only when what is not said is understood along with what is said is an assertion understandable. (Gadamer, 1976, p. 67).

Mazzei (2007) argued that qualitative research is often preoccupied with what is said, and therefore accessible, with little attention to silence. Rather than understanding silence as an omission or the absence of data, what goes unsaid may be purposeful, unconscious, or meaningful to participants. In research, silence is not a lack of voice, nor the opposite of speech (Baurain, 2011), but "a place where the researcher goes to find out more" (Mazzei, 2007, p. 10). The silence of children in research comes in many forms, including the absence of speech due to power imbalances in the adult-child interaction, things that go unmentioned as taken-for-granted common sense, deflecting from a topic they do not wish to discuss, or simply that which is unthinkable, and therefore, unsayable (Rallison & Moules, 2004; Spyrou, 2016). The matters

children are silent about may not indicate they lack the knowledge or experience to discuss those matters. In Bluebond-Langner's (1978) study of children with cancer, children did not voice that they were aware that they were dying to protect their parents, maintain their social roles as children, and to sustain the illusion that everything was normal.

Children in this study used silence during interviews in the forms of omission, deflection, evasion, and the request to move on to different topics. Mazzei (2007) explained that children often use the phrase "I don't know" in response to lines of questioning they do not wish to pursue.

KW: [Revisiting a question posed by Sam's mother]. What's the worst thing that could happen to you?

Sam: [mumbles] I don't know what the worst thing that can happen is.

Sam's Mother: Can ITP [Sam's disease] hurt you?

Sam: Yes, it can.

There were several instances where it was clear that the topic of my question was not up for discussion. Angela requested to move on to a different topic after describing the guilt she felt after receiving a treatment for sickle cell anemia that her younger sister was not eligible for.

KW: How does that make you feel, if you don't mind me asking?

Angela: Horrible. I feel just really guilty and sad that I can have – [Sighs. Pauses. Begins to cry].

KW: You don't have to go down there if you don't want to.

Angela: It's ok. I just feel really sad that – [cries] . . . Can we talk about something else?

Another silent voice in this research was my own. Silence was necessary so that I might receive what the participants had to tell me. Listening enacts the spacing required to allow the

appearance of speech and meaning from the Other (Risser, 2012). There were moments when I needed to contemplate, or tarry with as Gadamer might say, the participant's words while formulating my response. When probing questions were appropriate, I was able to elicit more information following a silence, deflection, or a one-word answer. However, there were questions I wanted to ask after a silence that I omitted, as I did not feel it was my place to ask them. Children have the right to decide what they are silent about, just as they have the right to determine what they will speak to (Spyrou, 2016). In the moment, I often found the most ethical response to silence was to let it be.

The Weight and Lightness of Children's Voices

"The world is gone, I must carry you" (Celan, 1984, p. 15).

Art, metaphor, and silence have the ability to carry the testimonies, meaning, and possibilities in children's voices in such a way that their experiences are intelligible and interpretable. Some of the participants have died since their interviews, and their voices are now carried by this work. The things that children had to say were not easy to listen to, and at times, I found sitting with their words to be more difficult than some of the most challenging situations I have encountered in clinical practice. The weight of their voices is something I now carry, and at times, this has felt burdensome. While there were moments when children's voices were heavy, sometimes their voices were joyful, cheeky, and even silly.

> *Sam: [After discussing waffles at length while dancing] . . . we're not even a quarter through [my story] and it's like almost an hour.*
>
> *KW: What are the things that you want to tell me, now that we've been chatting for a bit?*
>
> *Sam: Um, so . . . well, you're the one who's doing the study. You're the one who is supposed to ask me questions!*

J-Bird: [burps loudly into the recorder]

KW: Excuuuuseee you! Big burp.

J-Bird: Hi folks, I burped.

Nate: [Discussing his progress with nutrition despite his nasogastric feeding tube] I ate quite a few Baconaters [a type of hamburger] yesterday.

Maddie: When I found out I had cancer, I had to go to [the city] right away in an ambulance. And they wouldn't stop at Chuckie Cheese! It was a very uncomfortable ride to the hostable. [Maddie pronounced hospital "hostable"]

Figure 4.4 (J-Bird)

Figure 4.5 (J-Bird)

These moments of lightness served to remind me that while these participants had experiences that are difficult to imagine, children can remain playful, silly, and light despite the burdens of serious illness. For me, this lightness has always been the joy of working with children.

Reflecting on Prejudice

In the process of changing my research question was the evaluation of my prejudices as a researcher. Involving children in research as participants is of great importance to me and the notable lack of children's perspectives in existing PPC research is concerning. In my attempts to give voice to children with serious illness in research, I had concluded that using art during the interview process to aid communication and the use of an interpretive research method was the best way to go about bridging this knowledge gap. However, as the interviews progressed, it was clear that my prejudice that children needed to be given a voice in research, through art or other mediums, required an amendment. Without intending to, I had allowed deficit conceptions of children direct my approach. Gadamer (2007) wrote, "prejudices are biases of our openness to the world. They are simply conditions whereby we experience something – whereby what we encounter says something to us" (p. 82). This adjustment to my understanding need not be a

source of shame, as the goal of hermeneutics is not to arrive at an answer that is “correct,” but to understand and be open to understanding differently (Gadamer, 1960/200). What we think we understand provides the foundation upon which to build a different understanding when encountering something new (Gadamer, 2007). Without the prejudice that children need to be given a voice in research, I may not have arrived at the understanding that children are already in possession of a voice – they have a voice in their testimonies, in their creation of meaning, and in the possibilities for understanding in what they have to say.

Chapter Six: "Nope, I'm Outta Here!": Children's Experiences of Clinical Environments

The ethos of hospitality is never guaranteed. It is always shadowed by its twin: hostility (Richard Kearney, Hospitality: Possible or Impossible, 2015, p. 173).

The Alberta Children's Hospital (ACH) has been available to children and their families since 1922 (ACH Foundation, n.d.), albeit in different buildings and locations over the years. In his TEDxCalgary (2023) talk, Architect Bill Chomik explained that he designed the "new" Children's Hospital, established in 2006, with its primary patrons in mind (ACH Foundation, n.d.; TEDxCalgary, 2023). A panel of children advised that the exterior of the building should look like Lego blocks (TEDxCalgary, 2023) and the font in the sign above the main entrance mimics a child's handwriting. The hospital's address is on Oki Drive; "oki" means "welcome" in Blackfoot, one of the languages of the Indigenous Peoples of Alberta. The threshold of the building features pictures of smiling children and adolescents, and there is an impressive aquarium in the lobby full of clown fish and blue tangs, the favourite sea creatures of children since the release of the Disney film *Finding Nemo*. The interior decorations were chosen to promote healing and assist with children's wayfinding (TEDxCalgary, 2023). I have been told that extensive research went into the selection of periwinkle blue, the colour that best encouraged a sense of serenity, for the walls of the Spiritual Space. Each child has their own room, outfitted with parent beds, private bathrooms, and large windows, some of which overlook the Rocky Mountains west of the city.

Across Oki Drive is the pediatric hospice, Rotary Flames House (RFH), that was built in 2009 to serve children with life-shortening illnesses and their families (ACH Foundation, n.d.). RFH was built to look and feel like a house, rather than a medical facility, complete with a garden and playground, a sunroom, and a spacious family-style kitchen. Hand-made quilts lie on

each bed, and the medical equipment on the walls is cleverly concealed with artwork. I once designed a logo for our team apparel to show that love and care were so abundant in the house, the excess floated out of the chimney (below). The thoughtful and welcoming design of these buildings, and other children's health centers, is intentionally done to "allow children and parents to forget they are in a hospital" (Adams & Theodore, 2002, p. 236).

Spaces for Children who are Acutely Ill

Pediatrics is a relatively new medical specialty, but the health care of children has been of interest for some time. According to Mahnke (2000), Roman physicians as early as 50 A.D. wrote texts on care specific to children and suggested that their treatment should be different from the care of adults. In the Middle Ages, the greatest contribution to the care of children came from the Church, who were responsible for laws prohibiting child slavery and infanticide, as well as notion of Christian hospitality for individuals struggling with poverty and ill health (Risse, 1999; Mahnke, 2000). Prior to the advent of children's hospitals, children were cared for at home or in general hospitals alongside women (Adams & Theodore, 2000; James & Curtis, 2012; Mahnke, 2000).

The Hôpital des Enfants Malades in Paris was the first hospital built specifically for children in 1802 during the same time that other establishments for children, like orphanages and schools, were being constructed (Adams & Theodore, 2002; Mahnke, 2000). One of the

motivations for building spaces for children to be cared for separately from adults was the high frequency of communicable diseases among children and the need to isolate them from the general population (Adams & Theodore, 2002). Another factor was the need to move impoverished children who were ill away from high-density, low-income areas to the more spacious hospital wards (Adams & Theodore, 2002). In Canada, Toronto's Hospital for Sick Children was founded in 1875, "appearing to be a 'big house'" that provided children who were impoverished and ill with "both protection and a surrogate family atmosphere" (Adams & Theodore, 2002, p. 205).

Children's Hospitals, Hospitable to Children

According to Adams and Theodore (2002), following World War II, children's hospitals shifted to focus more on medical and research innovations, rather than the custodial care of marginalized children. The architecture of the hospitals during this time openly conveyed the emphasis on medicine and science, with modern layouts and technology on display, and their exteriors appeared no different from adult hospitals or office towers. However, as conceptions of childhood became increasingly whimsical and playful, so too did the architecture and design of children's hospitals (James & Curtis, 2012; Lomax, 1996; Mahnke, 2000). By the 1980s, children's hospitals began to include references to children's popular culture and entertaining features, such as the large statues of flying animals seen in the atrium of Sick Kids (Adams & Theodore, 2002). The design of these spaces took cues from psychology, where new research suggested that children needed to be distracted when ill (Adams & Theodore, 2002). One can now expect children's hospitals to be brightly coloured, imaginative, and lively spaces.

It may also be the case that children's hospitals and their design took cues from the prioritization of patient experience in adult health centers. Practices from the hospitality industry

are gradually influencing the services and design of hospitals, with the goal of providing exceptional experiences for patients who are treated as customers, rather than the recipients of healthcare (Ocak et al., 2024). For patients, the technical aspects of care delivery may be concealed by the "actions of the employees, the layout of the hospital rooms, and the atmosphere of the service" (Ocak et al., 2024, p. 1). Patient experience is increasingly prioritized at the children's hospital where I work. Children now have the option of attending art, pet, horticulture, music, and play therapy. They may also enjoy the spaces and things within the hospital, including the clown fish, a Slurpee machine, and unit playrooms. Hospital policies also reflect the specific needs of children: visiting hours are exempt for parents, hospitals can receive accreditation for introducing child-friendly practices, and nurses have a smaller patient load to accommodate the extra attention (social and medical monitoring) that children require.

It is not surprising that modern hospitals have adopted practices from the hospitality sector. The word hospital stems from a group of words sharing similar etymological roots and histories as hospitality (Benveniste, 1973; Derrida, 2023; Online Etymology Dictionary, n.d.). The first hospitals were established by churches as charitable organizations and among the first institutions to apply the concept of hospitality (Guenter, 1999; Ocak et al., 2024; Öresland et al., 2013). In a sense, hospitals have gone back to their roots, acknowledging that a cold and clinical environment with medical innovation as the focal point may not promote holistic healing. Children's hospitals are often built and designed to be hospitable to children, amenable to their unique needs and distinct tastes. However, there is one more word that shares its etymological and historical roots with hospitality: hostility.

Children's Experiences of the Hospital

Vinnie: The hospital just feels like I'm in a hostile environment.

In his work on Indo-European languages, Benveniste (1973) noted the expansive history of the concept of hospitality. From the Latin root *hospes* or *hostis*, hospitality has linguistic ties with the words guest and stranger. According to Benveniste, through developments that are partially understood but related to relational shifts from smaller communities or clans to nations, *hostis*, as stranger, assumed a hostile connotation and subsequently only pertained to the enemy. A strange guest entering one's home is as likely to be a friend as they are to be a foe (Kearney, 2015). As Kearney (2015) noted, hospitality is never guaranteed, "it is always a challenge and a choice" (p. 178). An offer of hospitality simultaneously introduces the possibility of hostility.

Hospitality, at first glance, may seem implicit in the care of patients in the hospital, particularly in countries with universal health care. As stated in the International Council of Nurses' Pledge, patients are received as both guests and strangers to be treated "without regard to race, creed, colour, politics or social status" (University of Calgary, n.d.). There are, however, conditions to meet on the part of the patient as a guest in the hospital. Patients must abide by hospital policies, demonstrate respect to staff and other patients, and are expected to follow the advice of their healthcare professionals. While receiving the hospitality of the healthcare team, patients may undergo treatments that might be experienced as hostile, such as chemotherapy. Importantly, most patients in the hospital do not want to be there, and any hospitality offered by nurses may be received begrudgingly. Most of the literature about hospitality in hospitals is related to introducing concepts from the hospitality industry or the "unconditional hospitality," a concept from Derrida, that patients should receive. Hostility has been researched in the context of horizontal violence and patient-to-nurse abuse. The participants in this study did not describe hostilities arising from interactions with people; they experienced the hospital itself, and the things inside it, as hostile.

"I Didn't Feel so Happy Being There": The Hostility of the Hospital

Vinnie: I actually get real bad anxiety knowing I have to go to the hospital. I need to be told at least a day before and know what is going to be happening but even then, once I get there, I feel the worst. The hospital just feels like I'm in a hostile environment. I always feel like something bad is going to happen to me emotionally or just getting tests like MRIs and being poked. It just doesn't feel good. It's just a place where I've been told the worst things, so continuously being here just scares me.

KW: Yeah, I can understand that. Do you think there's anything that healthcare providers can do to make it not feel so hostile?

Vinnie: [vocalizes, no]

There are some comments from the children I interviewed that have settled uncomfortably in my mind; among those comments are that the children's hospital is a "*hostile environment*" and that it is the "*place where I've been told the worst things*." I have heard parents describe the children's hospital as "the best place you never want to be," and our community partners often refer to it as a "special place." It is a place that was built to be child-friendly, where the nurses' approach to children has been so diligently crafted, and the attention to patient experience is so heavily prioritized. However, these efforts did not make the hospital any less hostile for Vinnie and there was nothing, in her mind, that could be done to make the hospital a less hostile place.

What intrigued me about these comments was not that Vinnie did not like going to the children's hospital –most children do not, even if they have a clear path to recovery. It was that her enemy was not the physician telling her "*the worst things*" or the nurse administering the "*pokes*," it was the hospital itself. I am well acquainted with the hospital and very comfortable

going about my work inside. Perhaps I had become too comfortable and allowed my familiarity with the building to conceal its place *qua* place, one that can be interpreted as hostile to a child with serious illness. As Kearney (2015) wrote, "estrangement happens not only when we travel, but also in the most familiar places" (p. 175).

Much like art and text, place may be interpreted with an abundance of possible meanings. Place not only stands as something to be interpreted, but as central to hermeneutic understanding itself, as interpretation stands in relation to the world, and the world appears "in and through a certain happening of place" (Malpas, 2015, p. 360).

> Even if the point is sometimes obscured, the essential insight of hermeneutic thinking is that knowledge and understanding are grounded in human situatedness – in the being of the human in place – and on this basis hermeneutics can be seen to consist precisely in the attempt to elucidate this fundamental situatedness. (Malpas, 2015, p. 356)

However, place is often reduced to ideas of our position or location within a physical space or obscured by its familiarity and proximity to us (Kearney, 2015; Malpas, 2018), as was the case in my experience of the hospital. In this chapter, I wish to distinguish place from location in the ordinary sense to consider how one's response to physical surroundings or locations might shape experience and understanding. The participants' experience of their clinical environments has prompted me to consider how place, in its exteriority and objectivity, might be interpreted and structure understanding, rather than one's situatedness in other hermeneutic ideas, such as time, history, or tradition. As Malpas (2018) noted, the relationship between place and experience is not that "place is properly something only encountered 'in' experience, but rather that place *is integral to the very structure and possibility of experience*" (p. 31, italics in original).

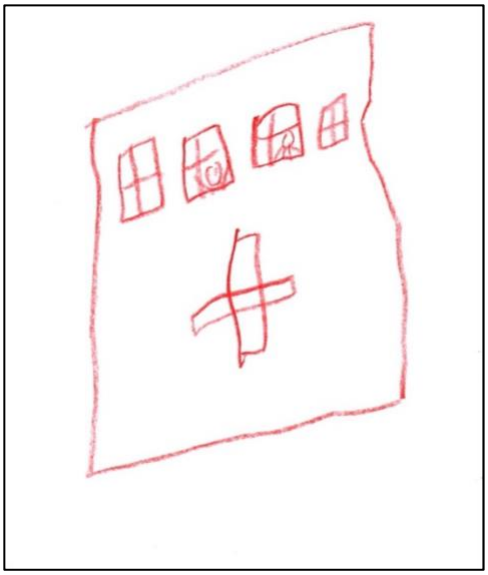
Nate: I had to do my chemo, and it was really long, and I didn't feel so happy, and I got sad quite a bit. I was away from home, and I didn't feel so happy being there.

For many of the children in this study, illness arrived with abrupt changes to their body and their environment. Going to the hospital was often the first indication that something was wrong, and for many of the participants, the hospital was the place where their illness experience originated.

Sam: My first memory [of having ITP] was going to the hospital and getting an IV [intravenous line] . . . I'm like "nope! I'm out of here!" I can't stand this anymore.

Often, children with serious illness spend many days or months in the hospital, sometimes with little indication of when their stay will end. Maddie drew the hospital among her most important things, because it was a place where she could be made to feel better but acknowledged that it was also a place she wished to escape from.

Partial Image from Figure 2.1 (Maddie)



Maddie: When I was in the hostable [hospital], I was always trying to figure out a plan to break out. I even tried like to make something out of pipe cleaners to, like, drill a hole in

the wall. I was so close, I even tried digging my way out with a plastic spoon. I covered it over with like a piece of paper, but instead of making a giant hole, I just kept on making little dents on the wall. Yeah, I wanted out. Gonna draw me trying to escape, "let me outta here!"

As Coyne et al. (2006) found, the familiarity of the place due to frequent or extended hospitalizations does not necessarily eliminate or decrease children's distaste for the hospital. The knowledge of what happens in the hospital can be both a comfort, as the child has some idea of what to expect, but also a source of fear, as what they expect might involve pain, anxiety, and being separated from their familiar people and places (Russell et al., 2016; Wood, 2022).

KW: Did you find you were less nervous the second time you had your surgery?

Nate: Second? Um, yeah. Maybe the second time I felt a bit more nervous because when I had it before, because I just started – I didn't know anything at all because I wasn't sure what was going to happen. But the second time I knew what was happening, so I was thinking more about it. And the second time I felt more prepared, and I thought what not to think about, and what to think about to comfort myself. Just try not to think about what's gonna be scary, but think about what's going to be after it.

Wood (2022) used children's poetry to thematize their experiences of hospitalization and found that children's senses were bombarded by the unfamiliar smells, sounds, and even tastes (e.g., food and medicine) of the hospital.

KW: What did it feel like in your room then, what made you want to get out?

Maddie: Probably that the water there tasted different than the water at home. It smelled different. I kept on hearing babies cry.

Nate explained that some of the sights in the hospital, elements that were part of its child-friendly design, helped with the unfamiliarity of the place and was upset when the places that brought him comfort in the hospital changed.

Partial Image from Figure 6.1 (Nate)

KW: What are some things about the hospital as a building, with all the stuff in it, that you like?

Nate: I remember there used to be a little room, like when you go into your surgery, like a little fish room. But they don't have that anymore. Yeah, it was a nice hallway too. . . I'm gonna draw the fish from the side . . . lots of colourful fish just on the wall . . . Yeah but – I miss it. I kind of miss it a bit. It was a nice little wall where you could just look at before you walk into your surgery.

While the hospital was unfamiliar, the participants became accustomed to the place and spaces within it and found ways to add their personal touches to make the spaces more their own, more homelike, such as bringing in comfort toys from home.

Hostile Things in the Hospital

KW: I wonder if you could draw me a picture of something that was a little scary in the hospital.

Maddie: Probably when I have surgeries. I remember there's like a little bed in there with a pillow, a blanket, and an IV pole. I have a lot of experience with "Wallies." I call them Wall-E [after the Disney movie robot]. The buttons look like little eyes like Wall-E. And there were always a lot of doctors with like these big, long dress thingies. Holding these needles and tools. They're wearing masks. I don't know how to draw a mask. With these caps on their head. It looks like a giant feather. All I remember is like when I'm going to sleep everything turns blurry and the doctor's leaning over me, it's creepy. Just kind of the thought that there's gonna be a needle going into my back, in a big room, with a Wall-E lookin' at me. Staring at me with his eyes. His creepy little eyes.

Partial Image from Figure 2.1 (Maddie)

Once more, I was surprised by comments from children that indicated they interpreted things and equipment, rather than the people using them, as hostile. Inanimate objects, like an intravenous (IV) pole and a needle, were the enemy. Heidegger (1971/2001) and Figal (2010) have conceptualized how displacement may occur as one confronts things (George, 2020). Heidegger wrote that one might be exposed to the event of being in one's involvement with artworks, text, but also through our encounters with the things in our everyday lives (George,

2020; Heidegger, 1971/2001). Figal's notion of hermeneutical objectivity suggested that human meaning relations only occur "due to the interactions of the spheres of human endeavors and what stands outside of our purview, mere things" (George, 2009, p. 908). I recognize this explanation of thingness and objectivity is an oversimplification of Heidegger and Figal's work, but it is helpful to consider the relations between human beings and things, and how a thing might be encountered and interpreted as hostile.

Importantly, the things children referred to as potentially hostile were things involved in invasive procedures. Things like needles and IV poles are used to infuse exterior, foreign compounds into someone's body, and such procedures are often accompanied by pain and anxiety. The operating room, as Maddie described it, was full of unfamiliar things, or things that concealed the familiarity of something, such as a surgical mask that covered the face of her favourite nurse. There was the IV pole that Maddie imagined to be looking at her as she drifted off to sleep, and other unknown things were used on her during the procedure while she is unconscious. Children with serious illness, particularly in their last weeks of life, are exposed to a multitude of invasive things and procedures, including feeding tubes inserted into the nose or stomach, breathing tubes and masks for mechanical ventilation, needles, and tracheostomies (Feudtner, 2011; Sourkes, 2018; Woods, 2022). Children in hospital settings are exposed to many hostile things.

Children's Experiences of the Hospice

Nate: It's a little house here.

Hospice, like hospital, shares the same etymological root, *hospes*, with hospitality (Online Etymology Dictionary, n.d.). The connection between hospitality and hospice is well documented in the palliative care literature, especially as it pertains to the hospitality extended to

guests in liminal places, between destinations. Similarly to the history of hospitals, hospices were originally built and operated by the Church to exemplify the virtue of Christian hospitality (Guenter, 1999). The first establishment built for the sole purpose of caring for the dying was St. Christopher's House in the United Kingdom, named for the patron saint of travelers (McNamara-Goodger & Feudtner, 2012). For the participants in this study, the children's hospice was more hospitable than the hospital.

> *KW: What do you think about being over here [the hospice] instead of over at [the hospital]?*
>
> *Nate: I actually think I like it here better, it's a nicer room. And it's a little house here. I like that the bed is nicer and we have a lot of space, and a tiny little snack area.*

As I described in the beginning of the chapter, the pediatric hospice where I work looks like "*a little house*" and was designed and furnished to feel homelike. It is a liminal space, as it is where children exist between living and dying (Carter, 2017; Rallison & Raffin-Bouchal, 2013), but it is also a liminal place, somewhere in-between home and the hospital. Vinnie used simile to express her sentiments on the not-quite-home feeling of the hospice.

> *Vinnie: At [the hospice], it's like being in a friend's house for the first time, I guess is how I feel, and being at home, it is still where I feel the most comfortable. [The hospice], although being more comfortable, I feel like I can't be my true self here. It's just like not knowing where things are and having to be led in a friend's house and being scared to open the fridge or use other supplies.*

For J-Bird, who at the time of his interview utilized the hospice for respite, rather than end of life care, the not-quite-home feeling of the hospice was something positive. It was a change from his

everyday life and a place where he could play with different games and toys, as well as interact with new people.

KW: Do you think there's some things about your illness that make you special?

J-Bird: Yeah. [The hospice].

I: Yeah? Because you get to go there? What do you like about it there?

J-Bird: Everything. Like seeing new people, meeting them, kissing them.

KW: [Laughs] You do give kisses on the cheek.

J-Bird: Yeah.

KW: Oh, we're jumping we're so excited, we're jumping in our wheelchair!

As a very social boy, the change of scenery and social circle was a welcome distraction from J-Bird's illness. The hospice was a hospitable place for him, and he mentioned several features of the building, including the importance of a wheelchair accessible place, having a call-bell to ring for help, and the regular flow of new staff and volunteers with whom to play.

Dying In Place

In gerontological care, "aging in place" is a popular term that is defined as remaining in one's community and home as one ages, while maintaining some level of independence, rather than moving into a facility for older adults (Wiles et al., 2011). As Andrews et al. (2007) noted, place may be understood conceptually as one's context, as in clinical or home environments, and place can also be considered as something that produces and shapes certain health outcomes for the individual aging in place. In their study of what aging in place meant to older adults, Wiles et al. (2011) found that remaining at home was important to older adults for several reasons, including the maintenance of social connections, the preservation of a sentimental attachment to

a place, and the promotion of a sense of security and familiarity in one's environment and self-identity.

For similar reasons, most Canadian adults would prefer to die at home (Health Canada, 2018). While there is a significant gap in the literature around children's preferences of the place of their dying, in my experience, most children who are dying would have preferred to remain at home instead of being cared for at the hospice. Unfortunately, for many children in Canada, the supports required for end-of-life care in the home are not widely available and most children with serious illness die in hospitals (Canadian Institute for Health Information, 2020; Widger, 2016). Many of the families I have cared for have remained at the hospice because they were unable to manage the care of their child without the support of around-the-clock healthcare professionals. Such was the case for Vinnie.

Vinnie had an unusually long stay at the pediatric hospice; most of the last year of her life was spent in her hospice room in bed. While she was unable to finish her painting, she shared with me her intentions for what the artwork was meant to convey.

Figure 5.1 (Unfinished; Vinnie)

> *Vinnie: I painted a bedroom, since that's what I've been staying in for months, and the windows were supposed to show different backgrounds to show how much has changed while I've just been here.*

Vinnie was dying-in-place while she conceptualized what her painting might be. The room, the place where she had spent her last months of her life, might be understood to have helped structure a narrative of her illness experience. While the outside world changed, Vinnie remained stagnant. Her comment that her "*whole life was on pause*" when she was diagnosed with cancer might be shown in her painting as something she continued to experience as her cancer progressed. As George noted (personal communication, August 12, 2014), when one is healthy, it is easy for time to be the appropriate framework for developing the story of who one is and wants to be, as healthy individuals are permitted a certain freedom to project themselves into the future (Carel, 2016). When one is dying and the temporal structure of one's being is either too daunting to cope with or lost, perhaps place becomes a better way to make sense of one's experiences and situation. If this is so, it is even more important to ensure that children and their families can access palliative and end-of-life care services in their homes, so that they may die in a place of their choosing.

"I Like the Work They're Doin'": Hospitable Spaces in a Hostile Place

As mentioned earlier in this chapter, what intrigued me about the participants' comments about the hostility of the hospital and the things inside was that their aversion did not extend to the healthcare professionals who told them "*the worst things*" or poked them with needles. In fact, despite being the instigators of challenging conversations and painful procedures, the participants had very little negative feedback for their healthcare providers. The most critical

comment came from Vinnie, who mentioned that sometimes, nurses appeared irritated if they were asked to do something for her too often.

> *Vinnie: Another thing is the nurses here [at the hospice] feel more like they've done this so many times before, while the clinic or unit nurses are less assuming. I don't know how to explain, but it's weird . . . It feels more like they're being annoyed to do it again which is where I feel is the part of why I feel I can't be myself here, or my family members need to act a certain way.*
>
> *KW: Ok. So, you feel like sometimes people seem annoyed to help you?*
>
> *Vinnie: [nods yes].*

Nate and J-Bird included images of their nurses and doctors in their drawings of what was most important to them.

Partial Image from Figure 6.1 (Nate)

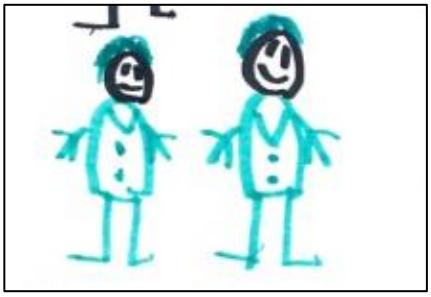
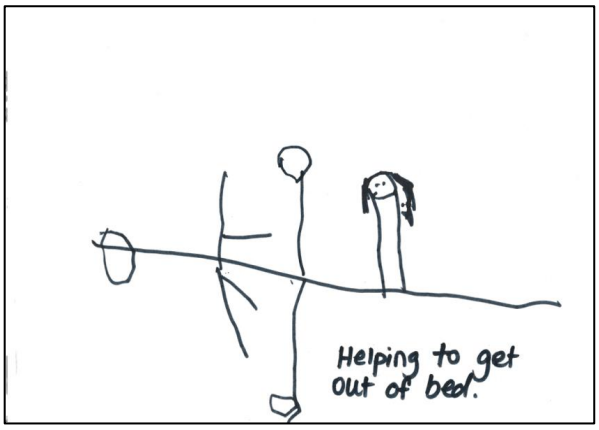


Figure 6.2 (Nate)

Figure 4.3 (J-Bird)



While the hospital was hostile, the hospitality of the people inside it appeared to ameliorate the participant's negative experiences of the place. The participants had many positive things to say about the hospitality of their healthcare providers.

Angela: I do trust them [doctors and nurses], like I love them all, they love me.

KW: Anything else that was comforting while you were there?

Maddie: Um, well I think maybe [the child life specialist]. All my stuffies, and my mom.

Nate: . . . they're [the nurses] all just nice to me and they're polite to me and they help me do my medicine.

Some children even described their doctors and nurses to be role models, giving them something new to aspire to.

Maddie: The hostable [hospital] has a lot of my friends in it . . .I like learning stuff about the nurses in the hostable and I find all the equipment in the hostable fascinating. Since I want to be a doctor when I grow up. . .when I didn't have cancer, I wasn't really that interested in being a doctor.

Angela: . . . my nurse actually was one of the first adults to do BMT [bone marrow transplant] for sickle cell.

KW: What was it like having a nurse who kind of understood –

Angela: That was really cool! It was nice to have someone to relate to and get advice from, going for this major thing. It actually reassured me, um, on this career path that I had wanted. I wanted to be a doctor, and so her being my nurse having had sickle cell, it was really cool to see like, being able to help inspire other kids like that. Um, I don't want to be a doctor anymore, but a nurse practitioner.

Nate described how the nursing staff on his oncology unit helped to minimize the hostility of having his implanted port needle changed by allowing him to instruct them on how to make the procedure as comfortable as possible.

Nate: [on helping the nurses] Well, I explain in lots of detail to them on how I'm feeling or how I'm going, and what would be probably the best thing to give me. And help them comfort me as well.

KW: What kinds of things comfort you?

Nate: Having my mom nearby. Yeah, hold them [his parents] and I feel safe. I feel safe with them, and especially my brother because my brother takes care of me a lot. He really checks up on me too, like he asks me if I'm ok a lot.

Developing relationships with staff members and having access to familiar loved ones created hospitable, relational spaces, that appeared to ameliorate the hostilities of the clinical environment and unpleasant procedures.

The Importance of Place

For healthcare providers who work in hospitals and hospices, the everydayness of clinical environments and our familiarity with them may conceal how these places are experienced by children. Along with time, tradition, and history, place may provide the structure for children's illness stories, whether it is experienced as a hostile place, a fun and exciting place, or "*like being in a friend's house for the first time*." The importance of place in a child's illness experience, and what their familiar places might mean to them, is something for healthcare providers to be mindful of. It may be that clinical places for children are not as child friendly as adults hope for them to be. However, the interactions between healthcare providers and children with serious illness can, and do, make their experiences less hostile. As two opposing meanings rooted in the word *hospes*, I suppose I should not have been surprised that a children's hospital can be both hospitable and hostile.

Chapter Seven: The "Good," the "Bad," and Everything In-Between: Apprehension in Serious Illness

> *Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick (Susan Sontag, Illness as Metaphor, 1977, p. 3).*

The experience of illness, while a common and inevitable occurrence for even the healthiest among us, not only reveals something amiss in the body, but also highlights our own health in a peculiar way: our experience of health is most noticeable to us when we are ill. In other words, as Gadamer (1993/1996) stated, health is most noticeable in its absence. Illness can turn a healthy, inconspicuous body into an obstacle, where the ease of being-in-the-world is hindered by a loss of freedom and function (Carel, 2018; Gadamer, 1993/1996). The children in this study reported complex experiences of illness and health: a gradual decline in physical ability, the appearance of a small lump on the cheek (that was not so small after all), periods of relative stability, or a novel treatment that unexpectedly made health attainable. The participants in this study included children who were previously healthy and acquired a serious illness, as well as those who were born with diseases that caused gradual declines in bodily function. Some children, through treatments and prevention strategies, experienced periods of relative wellness where their illness was partially concealed from them. The participants' data revealed the insight that children have about their illness experiences and their awareness of how fragile the balance between health and illness can be.

Illness as Apprehension

In deciding on a word to describe how the participants talked about their bodies, health, and illness experiences, apprehension seemed appropriate. Apprehension can mean to detect,

discern, or comprehend something (Merriam-Webster, n.d.). Apprehension can also mean the fear of a future evil, a sense of foreboding, or indicate anxiety about something (Merriam-Webster, n.d.). For the participants in this study, serious illness made their bodies apprehensible; they did not experience the ease of being in the world that accompanies health and were hyper-conscious of their bodies and limitations. Additionally, children described experiencing constant border-crossings between the "kingdom of the well" and the "kingdom of the sick," where "dual citizenship" became less of a dichotomy and more of an existence in-between health and illness, with one foot balanced precariously in each kingdom (Sontag, 1977, p. 3). The apprehension of living in-between health and illness, of constantly waiting for the next physical decline or even the departure from the familiarity of serious illness, featured heavily in the participants' artwork and interview transcripts. Illness as apprehension, of both the body and the future, also colours the interpretations explored in the next chapter and seemed to be a central experience for the participants.

The Experience of Health and Illness

Several philosophers have theorized ways of understanding health that focus on the experience of the person who is healthy or ill, rather than a statistical, biomedical understanding of health. Gadamer's (1993/1996) *Enigma of Health*, a collection of essays on health and modern medicine, explored the hidden character of health and offered a critique of the biomedical model. For Gadamer, objective and standardized measurements for health are not to be privileged over how one might experience their health. My experience of dyspnea and a cough might inform me that I have a respiratory illness before I can measure my oxygen saturation or have my illness verified for me by a healthcare provider.

Gadamer argued that when we are healthy, our state of wellness is largely hidden from us, as we can move through the world unhindered and able to immerse ourselves in our daily lives.

> Without a doubt it is part of our nature as living beings that our conscious self-awareness remains largely in the background so that our enjoyment of good health is constantly concealed from us. Yet despite its hidden character, health none the less manifests itself in a general feeling of well-being. It shows itself above all where such a feeling of well-being means we are open to new things, ready to embark on new enterprises and, forgetful of ourselves, scarcely notice the demands and strains which are put on us. This is what health is. (Gadamer, 1993/1996, p. 112)

As noted by Aho (2022), Gadamer's idea of health is not defined by the absence of discomfort or the dysfunction of our physiology; rather, it is an experience of the "transparency" of the body (p. 181). Gadamer (1993/1996) posited that health is the freedom to be engaged in the world, to be with others, and to absorb ourselves in our projects and tasks. Illness is an impediment to health and its transparency, bringing our attention to activities that once required minimal, if any, effort or thought (Gadamer, 1993/1996; Svenaeus, 2000). I am not usually conscious of my breathing during my everyday happenings until illness causes dyspnea.

Havi Carel (2016a, 2016b, 2018) focused on the phenomenology of illness from the standpoint of a philosopher who had been diagnosed with a life-shortening respiratory illness. Her first-hand experiences of medical objectification and the frustrations and dread of living with a life-limiting illness highlight the need for nurses and other healthcare providers to be more attentive to a patient's experiences of illness, rather than only focusing on the disease itself. Carel (2016a) noted that death has been a preoccupation for many philosophers and argued that illness

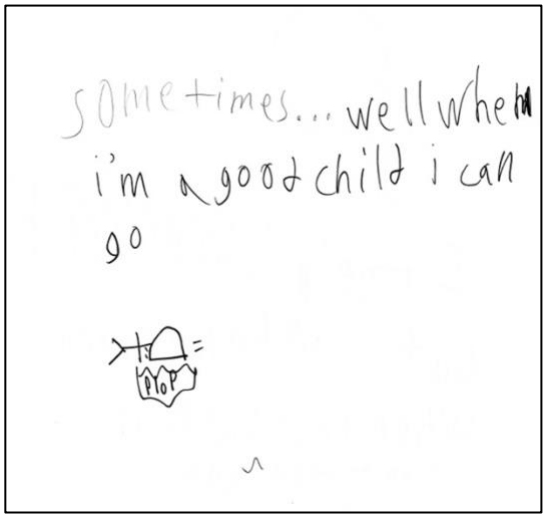
and the experience of being ill also presents important philosophical considerations. In illness, our experience of the world and how we inhabit it is transformed (Carel, 2016a).

"When I'm a Good Child": The Transparency and Ease of Health

Sam, whose ITP can cause a life-threatening drop in platelets and serious bleeding, drew a picture to show that when his platelet count was adequate, he could fall and "*go plop*" without concerning himself. He referred to times when his platelets were high as "*when I'm a good child*" or "*when I'm good*." Gadamer (1993/1996) described health as the experience of equilibrium or harmony, rather than meeting objective standards for health. Sam's treatments restored his equilibrium, and in doing so, allowed him to act as if he did not have a serious illness. However, he was aware that this was an act, and while his body could perform as if he did not have a serious illness, it did not mean that Sam could completely forget that he had ITP. He described the precautions he took to avoid situations that might cause a drop in his platelet count and made sure to make the most of the times when he was "*a good child*."

Good Times . . . Sometimes

Figure 1.3 (Sam)



KW: [Reads Sam's writing and looks at his drawing] You can go plop?! Your head is very flat in that picture! [Laughs] Sometimes you can go plop and it's ok, hey?

Sam: Yeah! [Laughs, runs around, and dances for several minutes]

Sam's interview was chaotic, but fun; he spent most of it dancing, rolling around on the floor, making funny noises, eating popsicles, and showing me his pets. He could not sit to talk for very long before his attention drifted elsewhere, but he was able to express himself through art. His artwork was engaging, provoking, and conveyed the challenges he experienced living with ITP. Sam's spoken answers were more fragmented and disorganized, which was challenging for me as an interviewer. Reflecting on his interview, I realized that I interviewed Sam following his IVIG treatment, during a time when he was well. He was free to dance, run, jump, and "*go plop*" on the floor, and so he did. I was not about to impose on his good time by asking him to sit still through an interview.

Mother: Sam, do you remember what we used to do after your IVIG? After your sleeping sickness? What did we do?

Sam: Mmmm . . .

Mother: We'd go to every playground. It's a big deal.

KW: [Laughs] So, once you've had your IVIG, it's a good time to go. It's a good time to go to every playground you can.

Mother: Do you remember going to the [inaudible] center and sliding and sliding? Do you remember going to visit grandma and grandpa on the airplane and using every slide, even at the airport playground?

KW: So, when you're good, you take advantage of it?

Sam: Yeah. [drawing]

KW: You do all the things that you can do.

With health comes harmony, predictability, and a sense of control (Carel, 2016a; Toombs, 1987). When our bodies function as we anticipate them to, our attention is "deflected away from our bodies" (Carel, 2016a, p. 57) toward other concerns and goals. Sam utilized the times when he was well to live a most vibrant and lighthearted life, as if to make up for the times when he was unwell. When Sam's platelets were adequate, his attention was drawn to more playful pursuits, rather than his illness or the limitations that his disease imposed on him. Despite Sam's enthusiasm for the times when he was well, he did not describe being able to overlook that he had ITP following his treatments. While he could "*sometimes*" enjoy playgrounds and worry less about injuries, he was aware that the short period of time following his treatments was something he had to take advantage of and that this state of health was not permanent. His experience of being "*good*" was something in-between illness and health.

"Stuck" In-Between Health and Illness: Boundaries and Becoming

Carel (2018) noted that while the question of what health and a good life is has been the subject of thought for many philosophers, the perpetual absence of health presented by chronic illness has been largely ignored. While Sontag (1977) proposed that health and illness were dichotomous, describing illness as the "night-side of life" (p. 3), Carel (2016a) suggested that, just as one can be healthy and experience episodes of illness, one can also experience health within chronic illness. Rather than exclusive counterparts, health and illness can be seen as a "continuum or blend of the two," allowing for periods of stability or equilibrium for those who are diagnosed with incurable illness (Carel, 2016a, p. 97; Gadamer, 1993/1996). The children in this study who were able to undergo treatments to stabilize their condition were never free from the underlying apprehension that their equilibrium could be disrupted at any moment.

Children's Apprehension of the Boundaries Between Health and Illness

Angela underwent a bone marrow transplant that put her sickle cell anemia in remission. Before her treatment, if Angela was careful, she could avoid the complications associated with her disease, but at the cost of engaging fully in the activities that she wished to do. She painted herself as a bird in the cage, with the cage representing sickle cell anemia, keeping her from "*feeling as free as the others*." While she acknowledged that on a good day, she may not feel like she had sickle cell anemia, she knew that her awareness of her limitations was what allowed her to feel well.

> *Angela: They [my peers] don't think about the things that I'm thinking about. Like, when they're thinking about parties, I'm thinking about not going to a party because I don't want to have pain.*

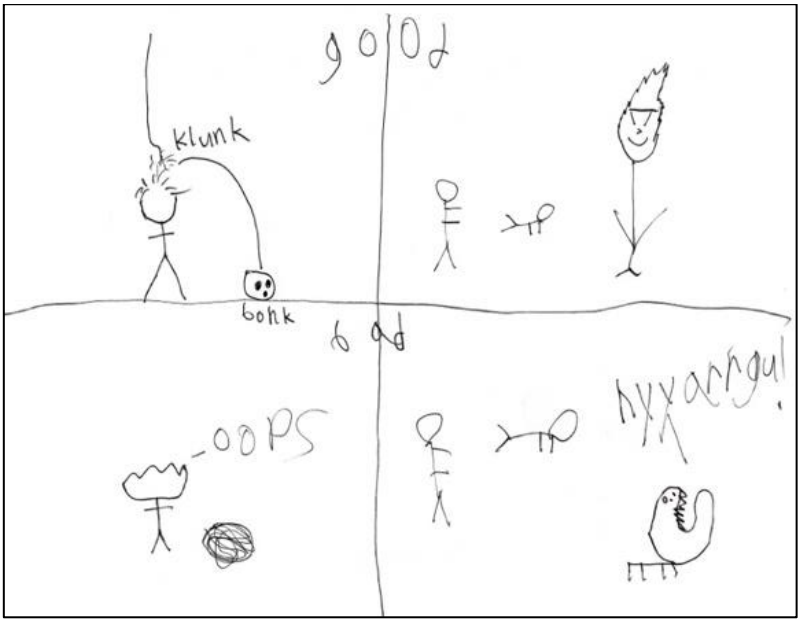
Sam avoided certain activities that might cause an injury as well as interactions with people who were sick. A cold or flu could cause a drop in his platelets, leading to more hospital admissions for IVIG treatment.

> *Sam: [Having ITP] is pretty normal, but at certain times, I can't do certain things, like sledding, riding a bike.*

Maintaining stability despite their serious illness was a priority for many of the participants. Any discussion about the times that they experienced a healthy equilibrium were tempered with an undertone of apprehension and the acknowledgement at any time, their disease could once again become the center of their attention. Sam and Angela, who were able to undergo treatments to stabilize their condition, described experiencing something that was not quite health, but not quite illness, during periods of relative wellness. Their artwork and verbal data revealed an experience in-between health and illness, rather than the full freedom and

transparency of the healthy body (Carel, 2018; Gadamer, 1993/1996; Svenaeus, 2000). The task of living in-between health and illness resulted in an abundance of caution and apprehension, such that even during "*good times*," children were never free from their illness.

Figure 1.2 (Sam)



"Everything was Normal": Apprehension In-Between Being Healthy and Ill

> *Vinnie: When I first noticed it [a lump] growing, I had thought it was an infection because a few days before I felt it, I bit my cheek pretty hard and coincidentally my sister got an infection in her eye at the same time, so that's what we went to the clinic for, and I was prescribed antibiotics that would last for a week. After a week of taking them, it [the lump] never went down which was confusing because my sister's antibiotics worked, so we went back and they [healthcare providers] told us that we should go to the emergency room, which is when they took my blood and, if I remember right, we were told to go home and come back another day. Everything was normal for those few days, so when we came back and we were told to go to oncology is when I, like, I knew things were serious,*

but I couldn't really feel it. I think it was about two weeks into chemo when I shaved my head is when I felt that this was really happening to me.

At the time of her diagnosis, Vinnie noticed a change in her body, but the severity of the change did not correspond to the way that she felt; in a sense, she had no apprehension of the significance of her diagnosis. She noted that "*everything was normal for those few days*" in-between being healthy and finding out that she was, in fact, quite sick. There is an apprehensive anticipation in awaiting the diagnosis of a disease, in-between the possibility and actualization of illness, especially when one might not necessarily feel any significant changes in their body. Sourkes (2005) described an encounter with a pediatric patient, who was waiting to hear if her cancer had relapsed and used art (shown below) to help her describe her experience as "not knowing which side of the rainbow I am on" (p. 379).

Carel (2016b) distinguished the difference between illness and disease, with disease being a biological and objective malady of the body and describing illness as the subjective experience of disease.

> The ill person is the only and ever the one who experiences illness from within . . . disease, on the other hand, is a process in the objective body that may be observed by another person and may yield information that is not available through first-hand reports . . . often such knowledge comes from medical tests that yield objective facts with no experiential correlate. (Carel, 2016b, p. 469)

Without venturing too far into discussions of subjectivity and objectivity, in Vinnie's case it is perhaps helpful to think about how one's experience of health as incongruous with the diagnosis of a disease might be something like being in-between health and illness. An experiential component of illness might be required for one who was previously healthy to understand oneself as ill.

"Now I Can Be Free, Right?": Apprehension In-Between Being Ill and Healthy

Figure 3.1 (Angela)

The caged bird sings

with a fearful trill

of things unknown

but longed for still

and his tune is heard

on the distant hill

for the caged bird

sings of freedom.

(Angelou, 1983, p. 16)

Fredrik Svenaeus (2000), in his phenomenological account of health and illness, described health as *homelikeness*. Drawing from Heidegger, Svenaeus theorized that health is a "non-apparent attunement, rhythmic, balancing mood that supports our understanding in a homelike way, without calling for our attention" (p. 94). The attunement of illness, particularly serious illness, can cause a breakdown in understanding, as one's "meaning-patterns" of the world are disrupted (p. 109). Illness is unhomelike and reveals the body in its otherness and conspicuousness (Svenaeus, 2000).

Not all the participants in this study experienced homelikeness in health. Angela had lived with sickle cell anemia for as long as she could remember and was still adjusting to life following her bone marrow transplant. Angela had painted herself trapped in a cage. For a bird, a cage can be homelike, or at least a familiar space in which to dwell, even if the bird is "*stuck*" there.

KW: Do you still feel, now that you've had your transplant, like you're the bird in the cage?

Angela: Um, kind of. I don't think I've been let out of the cage just quite yet.

KW: No? What do you think keeps you in the cage?

> *Angela: I don't know, I feel like I'm stuck between having sickle cell and not having it anymore. It feels weird. It just doesn't feel like anything different. I don't feel like anything much has changed. Because, like I said, coming to Canada things are a lot better so I've been having, like, less pain crises in a year. So, I feel like if I'm not having a pain crisis right now, I'd still feel like this, I'd feel normal. I don't know how to feel. Just stuck.*

In their study on the language children use to describe their own serious illnesses, Bristowe et al. (2024) reported that adolescent participants demonstrated a certain level of acceptance of their illness, as it had become, or always had been, the norm for them. For Angela, illness was a state of homelikeness and the decision to undergo a bone marrow transplant was a source of apprehension.

> *Angela: One of my main things was like, having this disease all my life and now it's going to be gone. Like, what am I going to do with my life? It's, you know, weird not having to think about this [sickle cell anemia] anymore. [My dad] was like "you know that's a good point but. . ." Like, my life is going to get started. "You'll have more opportunities to do things that you couldn't do before."*

What surprised me about Angela's interview was her uncertain feelings about being in remission. In my practice caring for children who have had a successful treatment, I had always assumed that they felt comforted in the knowledge that they were now healthy. I had not imagined that a child might feel apprehensive about being healthy after enduring so much throughout their illness, or question if they could trust that they were free to take hold of their lives in new ways. I had thought that knowing their "*life is going to get started*" would be a source of relief and excitement. I certainly had not considered that Angela might not even realize that she was medically healthy.

KW: Is that a word that comes to mind now that you've had your BMT [bone marrow transplant]? Are you healthy now or what's the big shift?

Angela: I haven't actually thought about that, that I'm healthy now.

KW: You may not have felt unhealthy or unwell all the time before.

Angela: I mean I don't think I've ever thought of myself as a healthy person. I don't think that word has come across my mind.

KW: What do you think healthy means?

Angela: Um, well, we can be mentally healthy and physically healthy. It's like people with disabilities that you can't see, like you wouldn't know that something is wrong with them. If they're unhealthy, like how would you know?

KW: How do you know that you're healthy? Or do you know that after your BMT?

Angela: I don't know, like, I'm still the same. I guess bloodwork tells me if I'm okay or not. I don't know. I feel the same. Mentally, I feel the same. Physically, I think I'm better.

The people in Angela's life expected that she would be able to articulate how she felt following her treatment. Regardless of whether they were becoming ill or healthy, feeling in-between health and illness was challenging for many of the participants to describe.

Angela: Everyone asks me, how do you feel? This is like a major thing that's happened, but like I don't know how to feel. . .like, how do you feel when your life is suddenly changed like that? It's a good feeling, but I still don't know how to feel.

For Angela, everything was different, and yet, the same. She reported that because she had been so careful to evade the complications associated with sickle cell anemia, she had yet to apprehend the freedom and ease of health, without the apprehension of her disease. She was,

however, beginning to consider what it might mean for her to be healthy, despite feeling "*stuck between having and not having sickle cell*."

Angela: Maybe I could put a door on the cage. [Paints door on the cage]

KW: Yeah, for when you're ready to go out. What do you think – maybe we can talk about that weirdness a little bit more…what is it like being in the cage with the door open now?

Angela: Well, now I can be free right? I can be free but, can I? Can I really?

In the opposite way that illness can shrink one's world (Carel, 2018) and impose limitations, Angela felt apprehensive about having a new world of possibilities opened before her in health. The breakdown in meaning-structures that result in feelings of unhomelikeness and the sudden opening of possibilities is related to what Heidegger described as *anxiety*. "Anxiety makes manifest in Dasein its *Being towards* its ownmost potentiality-for-Being – that is, its *Being-free for* the freedom of choosing itself and taking hold of itself" (Heidegger, 1927/1962, p. 232, italics in original). I often wonder if Angela found the possibilities of health more daunting than the limitations of serious illness.

KW: No wild parties yet?

Angela: No [laughs]. No wild parties.

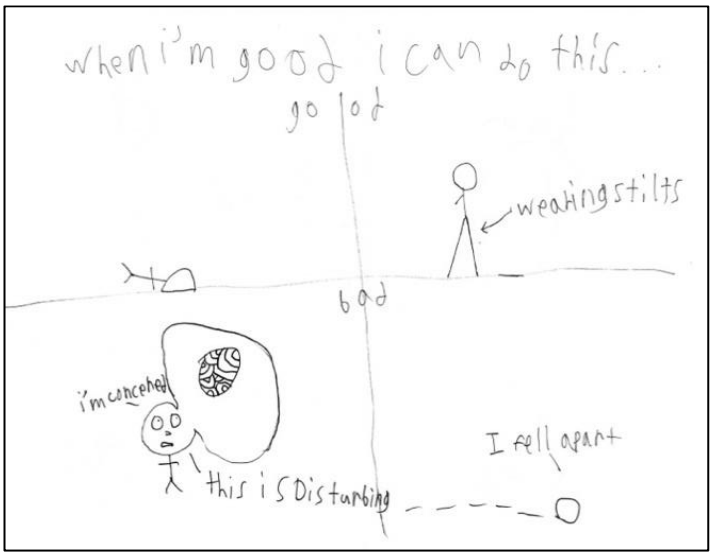
KW: How do you think you'll know that you're out of the cage completely? What will be different?

Angela: I mean, I don't think I'll ever be an extrovert, that's just too much. But knowing that I can do those things, I think that's when I'll be free. I can say that I can just wake up one morning and say, "I want to go swimming today. I want to go shopping without getting tired."

While Angela admitted to not feeling like she was out of the cage yet, by placing a door on the cage, she opened herself to the possibility of possibilities that she had never imagined for herself while ill.

"I Fell Apart": Apprehension in Serious Illness

Figure 1.5 (Sam)



In addition to the apprehension related to becoming ill, becoming healthy, and living in-between health and illness, participants also described their uncertainty about living with a serious illness and how it felt when they were unwell. In the bottom half of the picture above (Figure 1.5), Sam drew himself injured with "*bad*" platelets and wrote, "*I fell apart*." ITP causes Sam's platelets to literally fall apart when he is "*bad*," but he explained:

Sam: Yeah, I mentally fall apart, but I physically just bumped my arm.

KW: What is falling apart mentally, what does that mean?

Sam: I mean, it's like I can't stand this anymore, what is this? What is this?

KW: The lump?

Sam: No, I'm talking about like sometimes I, yeah, sometimes this is crazy. Yeah, I'm like this is crazy! I can't stand this bump!

The children described their experiences of physical disabilities, declines in health, and the anxiety related to the unpredictability of serious illness after losing the equilibrium (Gadamer, 1993/1996) that comes with health or a period of stability.

"I Lost Balance": The Apprehension of Changes to the Body

Toombs (1987), a philosopher diagnosed with multiple sclerosis, described illness as a loss of wholeness, certainty, control, freedom, and familiarity. As Vinnie came to notice the effects of her cancer beyond a small lump in her mouth, her perspective of herself changed. It was not until a vestige of her healthy self was lost that she apprehended herself as seriously ill.

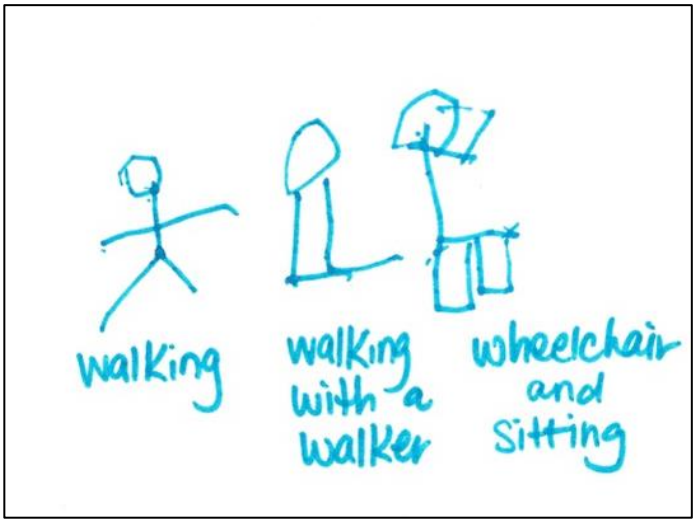
Vinnie: . . . I think it was about two weeks into chemo when I shaved my head is when I felt that this was really happening to me . . . My whole life I guess hair was a really big and important thing to me. I always kept it very long and in the same haircut. So, when it was gone it feels like that's when, I guess, felt like this was going to affect me for, if not the rest of my life, at least a big portion of it.

In an excerpt from her clinical work, Sourkes (1995) described an encounter with a girl diagnosed with cancer who, upon losing her hair, told her therapist, "I keep looking for myself in the mirror, but I can't find me" (p. 48). Changes in appearance and other physical losses often occur as the newly diagnosed child is negotiating the immediate ramifications of their diagnosis and treatment (Sourkes, 1995). In losing the homelikeness of her hair and the appearance that she associated with herself, Vinnie began to apprehend the severity of her illness.

J- Bird: When I was young, my legs stopped working so they're not physical like you are. You guys all can walk 'cause you're balanced, and I lost balance when I was three of four.

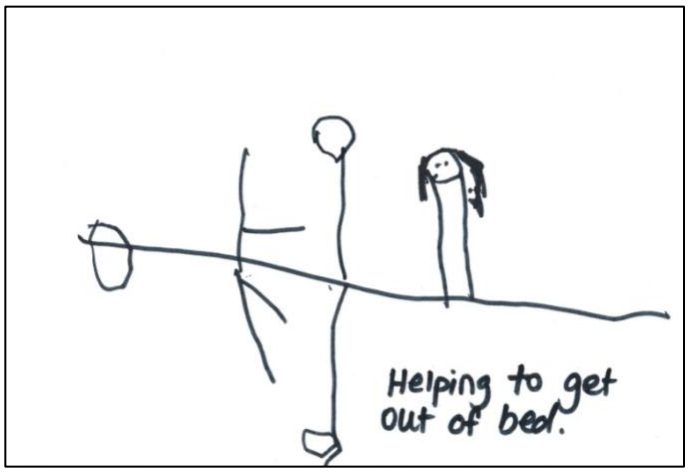
Some participants described illness experiences were less challenging to apprehend, as their illnesses arrived with significant shifts in physical abilities or an obvious symptom. For J-Bird, who was diagnosed with giant axonal neuropathy affecting his motor and sensory function, it was challenging to move his arms and sit upright; at one point in the interview, he lost balance in his upper torso and required my help to be seated upright again. While listening to his interview audio recording, without being able to see his cheeky smile and expressive face, the effort required of him to talk was especially noticeable. As J-Bird, quite literally, lost his sense of balance in his body, his sense of equilibrium and health became unbalanced as well. He was no longer able to move freely in the world. The transparency of his body was lost, as the gradual loss of function only served to highlight that his body was not something he could put in the background of his everyday life. J-Bird's physical declines were particularly noticeable to him, as he required new equipment, including wheelchairs and mechanical lifts, with each deterioration. J-Bird drew his declining ability to walk in an image, stating that it was simply "*hard*" to transition from a running, walking boy to one who requires a wheelchair to get himself around.

Figure 4.2 (J-Bird)



J-Bird also noticed the gradual increase in his need for help from equipment and other people, along with his declining independence and health. He stated that it was important for his nurses and doctors to know "*how to help me*" and drew a picture of nurses helping him to get out of bed.

Figure 4.3 (J-Bird)



The loss of control and freedom may be most acutely felt when the ill person must rely on others to do what they had previously been able to do for themselves (Toombs, 1987). This can be particularly frustrating for children who are growing up while seriously ill, as children are expected to gain independence as they age (Namisango et al., 2020). Bristowe et al. (2024) found that children used language that implied that they related their serious illness to deficits and loss, including the loss of function and independence. Patients with progressive neurodegenerative illnesses, in my experience, have been some of the most emotionally challenging to care for, as the physical and cognitive abilities that are meant to be developing as the child grows are, instead, in decline. Watching a child require increasingly more assistance, while wishing for more independence, is, as J-Bird put it, "*hard*."

In describing her own experience of serious illness, Carel (2016a) wrote about a looming apprehensiveness for any downward trending changes due to disease progression.

> I always brace myself for a decline, telling myself, you *know* it will be worse this time. A further deterioration brings with it a further shrinking of my world, fewer things I am able to do easily, or do at all. (p. 47, italics in original)

As one's health declines, the possibilities for what one can do, as well as what one can be, are reduced (Carel, 2016a; Toombs, 1987). While no one's future is certain, healthy individuals can take for granted that the future will be available to them to accomplish their goals and plan for future possibilities (Toombs, 1987). The illusion of control and predictability is less accessible to those living with serious illness.

Apprehension as Anxiety

In addition to physical changes, Vinnie also contended with what her illness might mean for her future, stating, "*this was going to affect me for, if not the rest of my life, at least a big portion of it*." In *Being and Time*, Heidegger used the term angst, commonly translated as anxiety, to describe the disclosive state-of-mind or mood in which Dasein undergoes a breakdown in familiarity (Heidegger, 1927/1962; Sveneaus, 2000; Withy, 2021). Dasein is confronted with the world and with itself as Being-in, with its own individualized potentiality-for-Being (Heidegger, 1927/1962). In anxiety, Dasein feels "uncanny," which can also mean "not-being-at-home" (Heidegger, 1927/1962, p. 233). The German word for uncanny, *unheimlich*, may also be translated as "unhomelike," which Sveneaus (2000) used to describe the unfamiliarity of the body in illness.

> What authentic anxiety makes evident is essentially the same phenomenon that is brought to attention, not in healthy, but in *ill* forms of life – the *not* being at home in the world . . . Health is to be understood as a being at home that keeps the not being at home in the world from becoming apparent . . . One of two *a priori* structures of existence – not being

> at home and being at home – wins out over the other: unhomelikeness takes control of our being-in-the-world. (Sveneaus, 2000, p. 93, italics in original)

In being diagnosed with cancer and losing her hair, one might say that Vinnie was experiencing the unhomelike anxiety of illness. The familiarity of her world and body were gone and she understood that her illness would change her future possibilities in uncertain ways.

Maddie also described her experience of apprehensive anxiety when she was diagnosed with leukemia.

> *Maddie: [When I first got cancer] I was confused, scared . . . I was like, how did this happen? When did this happen? Why did this happen?*

Maddie used the word "*scared*" to describe how she felt, but her subsequent questions could be interpreted as something closer to existential anxiety. Heidegger (1962) clarified that fear is experienced in the face of things present-at-hand, that which we encounter within-the-world, and is only possible through an *a priori* anxiety. Maddie's how, when, and why questions can be explained biologically, to an extent. She did report feeling afraid of needles and having to undergo intrathecal chemotherapy; cancer and its treatments are things within-the-world. However, as we engaged in further conversation and as she drew an angry cancer cell, she seemed to be alluding to her apprehension of the sudden unhomelikeness of her body and the uncertainty of her future.

> *KW: Were you not feeling good during that time too?*
>
> *Maddie: Um, well I was more not really feeling good when I had – like when I was first in the stage of cancer, I can't really explain it. It's a bit hard to explain.*
>
> *KW: Do you think you could draw it for me if it's hard to explain?*
>
> *[Starts to draw a leukemia cell while talking about her previous drawing]*

Maddie: And I always felt like those leukemia cells were like multiplying in my body.

KW: Yeah? Even though you were having your treatments?

Maddie: Yeah.

KW: Was that because you were nervous about it multiplying?

Maddie: [nods] Nervous about it multiplying.

KW: So, it just felt like they were?

Maddie: Yeah.

KW: So, in your bloodstream, you felt like you had multiplying leukemia cells. So not even just feeling sick because of it [cancer], but worried that –

Maddie: It's going to last forever.

Figure 2.2 (Maddie)

Heidegger (1927/1962) commented that unhomelikeness/uncanniness is always present in the world, but Dasein frequently turns away from it in favour of the homelikeness of the familiar. Illness as apprehension has a dual meaning: the unconcealment of the body, as well as the disclosive anxiety and forced unhomelikeness that gives the ill person nothing familiar to fall back on.

"Everyone Else Gets to Move On": Being-Unable-to-Be

A distinctive feature of Dasein is its Ability-to-be (*Seinkönnen*), the "capacity to inhabit a particular range of possibilities" (Large, 2021, para. 1; Heidegger, 1927/1962). As Dasein is

constantly projecting itself into the future, our present actions have meaning by virtue of a possible future where we imagine ourselves as being able to do or be a particular thing (Carel, 2018; Large, 2021; Heidegger, 1927/1962). This characterization of human existence allows us the freedom to become what we want, and to "transcend our present self with a future self that is more developed, more able" (Carel, 2018, p. 84). Carel (2018) suggested that Heidegger's notion of the Ability-to-be omitted important aspects of Being: that of the decline, the disability or inability, and the failure to be. Aging and illness are two disclosive periods of life characterized by our becoming gradually unable to act, where our possibilities are truncated (Carel, 2018; Svenaeus, 2000). Being unable-to-be, according to Carel, must be recognized as a way of Being.

The idea of projection is especially significant for children, as so much of how childhood is understood in western society is related to children's preparation for adulthood and the expectation that children have a future to grow into (Wong, 2023). Additionally, children are limited in ways that adults are not: they are still growing physically and cognitively and are not permitted the same agency and autonomy that adults are. For children who live with serious illness or children who are dying, the inability-to-be or the impossibility of a future, coupled with their present limitations and the normative expectation that they should become increasingly able-to-be, can be remarkably challenging.

> *Nate: Um, sometimes well – me being sick, because I don't like to feel sick, it really bothers me and it's not comfortable. And also, it would make me sad, as well, whenever I see something I can't do.*

The inability-to-be is more pronounced when children with serious illness are contrasted against their healthy peers. Vinnie stated, "*I feel like I'm stuck re-reading a chapter while everyone else gets to move on*" and noted that her younger sister was now a grade ahead of her in school, as she

had "*kind of just stopped doing school because the chemo was affecting me really bad*." At the time she was diagnosed, Vinnie was experiencing other changes brought on by the pandemic and a new living situation. Reflecting on that time, she said, "*my whole life just paused*."

As Vinnie's tumour made verbal communication very difficult, she spent the interview typing out her answers and agreed to complete her artwork after. She had her canvas and paints for some time, and eventually let me know that she was unable to finish her artwork due to her evolving illness. When I went to see her and pick up her painting, I asked her if there was any wisdom that she gained from her experience that she wanted to share.

> *Vinnie: You can do so much if you just have the want to do it . . . Do whatever you want, there's never a better time than when you're motivated to do it.*

When I received her painting, Vinnie's tumour had grown through her cheek, into her mouth, and was beginning to block her airway; she died a month after that encounter. Reflecting on her comment, I often wonder if there were things that Vinnie was unable to do because of her illness that she wished she could have done, had she been given more time or a less cumbersome diagnosis. Conversely, I wonder if there are things that Vinnie did precisely because she was seriously ill, that she may not have been motivated to do otherwise.

While Carel's (2018) idea of Being-unable-to-be and its relation to the experience of serious illness is intriguing, I wish to point out that by virtue of some possibilities being concealed, others are simultaneously revealed. For some participants, while being seriously ill created limitations on some of their possibilities for Being, it also disclosed others. Illness made what was truly important for them apprehensible, as well as revealing a kind of wisdom that they may not have gained if it were not for their illness.

Vinnie: I think the biggest change I've seen in myself is how much I've learned not to care what others think about me.

KW: What advice do you have for other kids who get sick, as a kid who has gone through it?

Nate: Well, tell them not to worry and feel happy about it. Don't get sad and know that have a positive attitude and believe in yourself . . . To know that they're loved by people.

Sam: When you have ITP, sometimes it's a whole new discovery in life and sometimes it's just something that gets in the way. . . like, there's way more things that can happen.

In hermeneutic work, a limit rarely signifies a dead-end or closure, it is always related to possibilities (T. George, personal communication August 12, 2024). Despite the limitations that illness created for him, Sam shared that life with his illness was "*more exciting*" and that "*if I didn't have ITP, [my life] would be wwwwaaaayyyyy more boring*." Put another way, living with illness is also a life of possibility.

Showing What Matters

Apprehension in serious illness is multifaceted: it is the unconcealment of the body, the uneasiness of living in-between being healthy and being ill, the anxiety of the unpredictability and unhomelikeness of illness, and the revelation of other ways of Being. Illness, like art, served to make the things that matter to us apprehensible (George, 2020). The metaphors, similes, and artworks used by the children allowed me to apprehend what was important to them in their illness experience. The children also revealed how they explore their possibilities despite the

limitations imposed on them by illness. However, some experiences were left concealed in the "voice" of silence.

Chapter Eight: "Can We Talk About Something Else?" Things Unspoken, Not Unsaid

> *Silence is not simply what happens when we stop talking. It is more than the mere negative renunciation of language; it is more than simply a condition that we can produce at will.*
>
> *When language ceases, silence begins. But it does not begin because language ceases. The absence of language simply makes the presence of Silence more apparent.*
>
> *Silence is an autonomous phenomenon. It is therefore not identical with the suspension of language. . . It is creative, as language is creative; and it is formative of human begins as language is formative . . . Language and silence belong together. (Max Picard, The World of Silence, 1988, pp. 15-16)*

All the children I interviewed had quite a bit to say to me. The excitement of someone coming to speak to them – just them, and not their parents or healthcare providers – seemed to be something of a novelty. When I asked Sam if he was nervous to talk to me during his interview, his response was, "*I'm not nervous. I'm fine. I'm excited!*" Gadamer (1986) wrote that the trouble with the stutterer is not that they have nothing to say, but so much to say at once that they have difficulty expressing everything on their mind; I often found that the children's excitement at being interviewed resulted in a similar dilemma to Gadamer's stutterer. In these situations, the task of creating art helped to focus the conversation and direct their energy. However, there were topics that revealed themselves to be off-limits and questions that children could not, or would not, answer. One of the major aims of my thesis work, to understand how dying or the threat of death is experienced by children, was rarely spoken about. When death was addressed, it was mentioned and quickly passed over, as if to say it out loud once was enough of an

acknowledgement. There were times when death was never spoken of, but it still loomed over the conversation.

Silence is no stranger to hermeneutics. If silence, as Picard (1988) suggested, belongs with language, then it properly belongs among human expression as something that can be interpreted. Insofar as language never expresses everything a person wishes to say (Gadamer, 1960/2004), silence, then, presents further interpretive ambiguity. Nothing is said in silence if one thinks of silence as a negative (Picard, 1988); however, a multitude of possibilities reside in silence if one considers it a positive, creative force of language and expression.

Silent Languages

As I sat in Vinnie's hospice room during her interview, and later as I listened to the audio recording of our interaction, what struck me was the absence of speech. In contrast to the vibrant, (and sometimes meandering, sometimes silly) research conversations with the other participants, Vinnie's interview was somewhat unsettling for me as a researcher. Vinnie was non-speaking due to a large facial tumour; she could not talk, but she could produce a sound or gesture that could be interpreted as a response. She was accustomed to communicating with written or typed text, and she was comfortable answering my questions by typing them on a computer. She was not able to type her answers and create artwork at the same time, so I did not have access to her artistic expressions during the interview, though she did present me with an artwork afterwards. The silence during Vinnie's interview was broken by my questions, a vocalization of hers, by the whirling noises of her medication pump, and the clicking of the computer's keyboard as she typed. The pauses in her typing while she thought about her responses, as well as the increase in the speed of her typing when she had an answer readily available, were also audible. These sounds over the

audio-recording hold a kind of silent language that can be interpreted for research purposes using a hermeneutic methodology.

The Silent Language of Gesture

Reflecting on Vinnie's interview, I regret that I had not thought to film our interaction, rather than audio-record it. While she was proficient in communicating what she wished to say by typing on a computer and, later, in her artwork, so much of what she had to say was expressed in gesture. Unlike spoken language, the language of gesture, like the language of art, speaks in the realm of the visible (Schmidt, 2013).

> What a gesture expresses is "there" in the gesture itself. A gesture is something wholly corporeal and wholly spiritual at one in the same. The gesture reveals no inner meaning behind itself. The whole being of the gesture lies in what it says. At the same time every gesture is also opaque in an enigmatic fashion. It is a mystery that holds back as much as it reveals. For what the gesture reveals is the being of meaning rather than the knowledge of meaning. (Gadamer, 1986, p. 79)

Schmidt (2013) wrote that gesture "is a 'language' only as the language of the lived body. Gesture is how the human being moves in the world" (p. 132). In its appearing, gesture is the response of a language-bound being to that which is inexpressible in words, yet still belongs to what can be interpreted and understood (Schmidt, 2013). Gesture, like language, belongs to the network of meaning relations that make up our understanding of the world.

While I do not have her gestures recorded as data, I recall her gestures of excitement, disgust, dismissal, and hesitation during the interview. I had prepared for an interview without speech; I brought my laptop for Vinnie to type on, I was ready to sit (however uncomfortably) in silence while she answered my questions, but I had not anticipated the importance of the

language of the body. Moules et al. (2015) noted that the transcription of a research interview includes hesitations, silences, pauses, and body language; this was much harder to capture through audio-recording with a non-speaking participant. Gesture is part of our everyday language, but Vinnie's gestures were even more noticeable in the absence of her ability to speak. Spyrou (2016) noted that, in qualitative research, there is a risk involved in attending to silences, particularly because we can never fully comprehend them; though, he does not acknowledge that what is meant when one speaks can never be fully comprehended or articulated either (Gadamer, 1960/2004). Vinnie's silence was not the kind of silence during interviews that Syprou (2016) and Mazzei (2003) referred to– it was not always the omission of speech to be polite, to evade, or to conceal something. Rather, her silent language of gesture showed that "our movements *mean* something and can be *interpreted*" (Schmidt, 2013, p. 133, emphasis in original). In attending to gesture, one is attuned to the other in the back-and-forth exchange that Gadamer referred to as play; and it is play that overcomes the gap between gesture and language in a "pre-linguistic dialogue" (Gadamer, 1985, p. 14). Play is also at work in the interpretation of images.

The Silent Language of Images

> *"Gesture is the point of contact, the limit point where there is a meeting, of both word and image" (Schmidt, 2013, p. 134).*

For the most part, I have interpreted the images that my participants created with the consideration of their intentions of the meaning of the work in mind. I have acknowledged that many of the participants did not need to create art to offer important insights into the topic of serious illness in childhood. I must also acknowledge that these images stand on their own, ready to be interpreted by those who encounter them (Gadamer, 1968). While all the images the children

created added something to the understanding of the topic, two images continue to pull me back in and tarry with them.

Figure 3.1 (Angela)

Figure 5.1 (Vinnie, Unfinished)

The interviews with the younger participants included multiple drawings. Interestingly, the paintings by the two eldest participants, Angela and Vinnie, were the sole artistic creations from their interviews. Angela completed her painting during our interview, but not in response to my questions as the younger children had done. Vinnie's painting was created after her interview, over a period of several weeks. I do not wish to diminish the images created by younger children, as they succeeded in making visible the things that mattered most to them during their illness experiences (George, 2020). However, I find there is something heightened in Angela and Vinnie's artwork that point to an "increase in being" (Schmidt, 2013, p. 136). These images, in their silent language, carry meaning, intelligibility, and unity.

Angela and Vinnie's paintings are not mere representations or copies of their illness experience. Angela acknowledged that the cage in her painting is sickle cell anemia, and Vinnie described that the windows in her painting were meant to show the passage of time through changing seasons while she remained in her room. However, these images show much more than what their artists had to say about them. They "speak" to the profound loneliness and isolation that accompanies serious illness. They show the limits that illness imposes on our Being, and a sense that the illness experience is like being trapped or immobile while, as Vinnie said, "*everyone else gets to move on*." These images reveal more than I expected the art of a 17-year-old would, and I did not have low expectations of what I would come to understand when I set out to conduct this research. Like gesture, image has a language that is different from the language of signs and symbols that direct the viewer away from themselves; gesture and image are simply what is shown (Schmidt, 2013). These images will likely say something different to anyone who comes to encounter them in the future, and there is more in these images than I will ever be able to articulate. Both images, to me, have something of the truth in them.

The Silence of Unspeakable Things

"In silence truth is passive and slumbering, but in language it is wide-awake" (Picard, 1988, p. 30).

There were encounters during my interviews where children were silent in response to a question. These situations involved the discussion of topics that lie on the limits of human being and language, and both children tried to articulate something of their experience. Risser (2019) described two situations in which language fails to fulfil its role in communication: in the experience of the sublime, and in the "awkward situation of speaking in the face of death" (p. 2). The difficulty in expressing experiences such as these does not signal the impossibility of speech, but that language carries meaning along with what is unsaid and the fact that we can never say all that we want to express (Gadamer, 1960/2004; Risser, 2012, 2019). There may also be things that one does not wish to express. In silence, the truth is allowed to lay dormant, while in saying something out loud, the truth appears and "is wide-awake" (Picard, 1988, p. 30). "By virtue of the voice, there are acts of silence" where one chooses not to speak (Risser, 2019, p. 2). For a researcher, there are ethical implications in responding to participants' silence. Children may not wish to bring up painful topics and have a right to remain silent on certain issues or topics for their own reasons (Spyrou, 2015). In pushing the participant to say more, a researcher may overlook what is conveyed in silence.

Silence and Guilt

Angela was fortunate to have undergone a novel treatment, a bone marrow transplant, for sickle cell anemia and was in remission during our interview. As discussed in chapter seven, she had not yet recognized herself as healthy post-treatment, but did acknowledge that it was something she had conflicting feelings about. Perhaps the most challenging experience following

her treatment was the realization that her younger sister, who also had sickle cell anemia, was not eligible for a bone marrow transplant due to the risks associated with chemotherapy.

> *KW: How do you feel being the bigger sister who had sickle cell with a younger sister?*
>
> *Angela: It's hard actually, I just want to open her eyes and like help her understand. She's 10, so maybe she'll understand soon enough, but she just has a hard time understanding, like, these are the things that you can't and can do. But she knows, but she just wants to be a kid. It's hard watching her to not be like other kids. She actually had – her friend had a birthday party at a trampoline park, but she couldn't go. She might've been able to go but something's wrong with her hip. It's really bad. So, she can't really – she just is doing physio. She can't do things, and it just started getting really bad and I don't know what happened . . . [the doctors] said the chemo that they'd have to give her would be a lot, and she might be barren, and she might be sicker than she is. So – she doesn't know, because it's too heartbreaking.*
>
> *KW: How does that make you feel, if you don't mind me asking?*
>
> *Angela: Horrible. I feel just really guilty and sad that I can have – [Sighs. Pauses. Begins to cry]. I just feel really sad that – [cries] . . . Can we talk about something else?*

Unable to continue to speak about this experience due to her feelings of guilt, we moved on to a different topic.

While it is clear that Angela has done nothing morally wrong to feel this way, perhaps the work of Karl Jaspers on limit or boundary situations is helpful to expand on the speechlessness associated with guilt. Limit situations occur when one is confronted by something questionable, displacing, or disquieting (Papastephanous, 2021; Young, 2023). Jaspers classified guilt among the limit situations he discussed. Limit situations, perhaps similarly to Heidegger's idea of the

uncanny or Gadamer's concept of *erlebnis*, present us with something unsettling that disrupts our assumptions and worldview. For Angela, the limit situation of guilt was enough to leave her speechless, unable to continue the conversation. However, her silence on the topic does not reduce what we might understand from her experience of guilt.

According to McConnell (2024), guilt is comprised of two components: experiential and cognitive. The experiential component includes the negative feeling that one has, while the cognitive component, the belief that one has done something wrong and must take responsibility for it, distinguishes guilt or remorse from other feelings like regret. While Angela had done nothing wrong in receiving a treatment her sister was not eligible for, she did feel a sense of responsibility towards her sister as a caregiver and role model. Angela recounted several situations where her younger sister wished to emulate her and described the differences in Angela's introverted character and her sister's outgoing personality: "*No, she's [my sister is] really different from me [laughs] . . . but she copies everything I do*." As the only other family member with sickle cell anemia, perhaps Angela felt a stronger sense of responsibility to her younger sister. Young (2023) suggested that one might feel guilt when one cannot realise a positive value without also realising a negative value; Angela may not be able to realize the positive value of her treatment without also recognising that her sister would not receive the same benefit. Jaspers (1947/2001) also considered guilt following the atrocities of World War II, and in defining his concept of metaphysical guilt, he wrote, "there exists a solidarity among . . . human beings that makes each responsible for every wrong and every injustice in the world" (p. 26). In a showing of solidarity with her younger sister, having experienced the same serious illness, and in recognizing the biological injustice done to her sister, Angela experienced something like metaphysical guilt.

Silence and Death

> *We can ask ourselves when is it that a child learns to grasp the fact of death. I am not sure if modern psychology is able to give any sort of clear answer to this question which would be acceptable to the enlightened society of our culture. Presumably it is bound up with that interconnection . . . between life and the repression of death that the knowledge that we ourselves must die remains almost veiled, even when, as mature adults, this knowledge has become established at the deepest inner level within us. (Gadamer, 1993/1996, p. 65)*

Nate and Vinnie have both died since my interviews with them. Their silence on the topic of death happened in two distinctly different ways. Nate was in hospice care following a cancer relapse. In a conversation that Nate's mother has given me permission to share, she explained that Nate had been shown the X-ray of the large tumour in his stomach and was told that his prognosis was not promising. Anecdotally, as I would not count this among the data collected for this study, Nate's mother shared that he once told her that he "came as a soul" and that she should not expect him to be with her for long. Despite this, Nate was of the firm belief that he was "*cancer free*" and that his illness during the interview was simply an infection. He counted his experience of overcoming cancer among his life's achievements.

> *Nate: Well, um I'm happy that I was able to beat cancer, and it was a great accomplishment that I had.*

It is sometimes the case that children are not told they are dying, or that they withhold from others that they are aware that they are dying. In Bluebond-Langner's (1978) ethnography, children who were dying of cancer would sometimes lie or deny their own awareness that they were dying to protect their loved ones or to uphold their social role as children. In this case,

Nate's terminal illness was no secret. I often wonder if Nate was silent about his own death to protect himself. He had already "*beat cancer*" and he did not consider himself to be as ill as he was before.

> *Nate: When I was sick, um, well my healthcare was much more important a long time ago, because I had to be careful with my cancer. Because if I got another sickness with my cancer, that would be harder on my body, and I'd have to go to the hospital . . . Because my healthcare is more fragile, but now it's not as fragile as it was before, but it still is.*

He was a talkative boy, but when the topic of his physical limitations came up, he was not able to continue the conversation.

> *Nate: Um, sometimes well – me being sick, because I don't like to feel sick, it really bothers me and it's not comfortable. And also, it would make me sad, as well, whenever I see something I can't do.*
>
> *KW: Yeah. Like what kinds of things?*
>
> *Nate: [Long pause, starts to cry]*
>
> *KW: You don't have to talk about it if you don't want to.*
>
> *Nate: [Crying, unable to continue talking for the moment. KW goes to get Nate's mother to comfort him at his request]*

The only child to mention death explicitly was Vinnie. I found it surprising that she did so in response to an open prompt to talk about anything we had not discussed, and subsequently denied the desire to continue the conversation on the topic of death. It was as if she wished to acknowledge it, to put the truth into language so that it was "wide-awake" (Picard, 1988, p. 30) and then to conceal it again in silence.

KW: Is there anything you want to tell me that I didn't ask about?

Vinnie: I think it depends because it's kind of morbid but, when I first got cancer, I never thought I was going to die. During this relapse there are definitely times where I did, BUT I hate feeling that way, so I try not to think about that and just try to enjoy myself.

KW: Do you want to talk more about that?

Vinnie: [Shakes head, no]

The Unspeakable Character of Death

It was not surprising that the children I spoke to were unwilling or unable to talk about death. This is a topic I have explored previously, and parts of this section are taken from one of my publications in *The Journal of Applied Hermeneutics* (Wong, 2021). Death is mysterious and enigmatic, yet is a fact of life, one that conceals itself in everyday living. Just as silence and language belong together (Picard, 1988), so do life and death. In Heidegger's (1927/1962) philosophical examination of Dasein, Being is self-evident and universal, while simultaneously veiled in an *a priori* enigma in "the fact that we already live in an understanding of Being" (p. 23). Dasein is always "ahead-of-itself" and continuously projecting its being into a future in which death is certain (Heidegger, 1927/1962, p. 279). Heidegger (1927/1962) maintained that Dasein can either evade death by situating it as a "not-yet" possibility (p. 303), or Dasein can realize death as "the possibility of the impossibility of existence" (p. 307) and use the prospect of non-being to inform present actions. Dasein can also decide to fall back into what is familiar and comfortable, perhaps in a similar manner to what Nate had to do to cope with his impending death.

Gadamer (2016) wrote that death is always necessarily concealed in its unintelligibility. During a Zoom discussion of Gadamer's (2016) *Death as a Question* for the "Gadamer Reading

Group," Grondin, Keane, and Risser argued that Being cannot even *think* death, let alone face it as life's most extreme possibility. For Gadamer, one can merely grasp "a trace of death" when thinking of it, for there is something incomprehensible about the fact that a being who can anticipate the future will one day cease to exist (Gadamer, 1993/1996, 2016, p. 69). These traces come into sharp focus when one experiences the death of the Other, as death always leaves an impression on those who remain, along with the reminder that it is there. Mattie Stepanek was a child poet who died of serious illness and frequently wrote about his experiences. In his poem *Rebecca's Reminder*, Stepanek (2001) wrote:

It is sad

When a friend

Dies.

Death becomes

Suddenly

Painful.

Suddenly

Real.

Suddenly

Reminding. (p. 37)

The abrupt reminder that being is finite, that non-being is a real possibility at any time is the anxiety of being anxious about nothing, for there is no empirical referent in which to direct this anxiety (N. Keane, personal communication, September 24, 2021): it is "the uncanniness of being anxious about nothing is precisely the true anxiety" that is often concealed by one's certainty of being alive (Gadamer, 2016, p. 69; Heidegger, 1927/1962).

If one cannot think of death, it would follow that scientific or conceptual language cannot adequately carry the unfathomable character of non-being: scientific and theoretical language are one's mode of relating to the world-that-is. It should not be surprising, then, that the participants in this study were silent about death. Even Hermes, the messenger god after whom hermeneutics was named (Grondin, 1994; Moules et al., 2015), offers no words on death for mortal souls to interpret in Hirémy-Hirschl's (1898) *Souls on the Banks of the Acheron* (above).

Picard (1988) wrote,

> Language corresponds by its very structure to the truth that is made manifest in it. Therefore, every thing has an impulse to be expressed in language, because it finds fulfilment in language and is raised to a higher level through the truth. (p. 33)

Death is not a "thing," it is nothing, and so it might follow that silence is the proper language of death. However, when confronted with the unintelligibility of death, as it is when one encounters an image, there is still an attempt to summon language of some kind, to try to understand.

On Rutledge's (2016) *Philosopher's Zone* podcast, speaker Dennis Schmidt stated, "the truth of mortality is not at all to be understood conceptually . . . it is a singular truth" that belongs in the province of art and poetry. In the broader domain of art and the humanities, one might

find something of the unintelligibility of death to understand. In death, something absolute happens (Rutledge, 2016), and in thinking death, one thinks beyond oneself and thinks oneself away, while at once revealing the certainty of one's being-in-the-world through the very act of thinking (Gadamer, 2016). Likewise, the creation of art is the occurrence of an absolute: in its being made and in its being encountered, a work of art stands for itself, resisting "pure conceptualization" and imposing its own temporality on the viewer (Gadamer, 1986, p. 37). The experience of art is also a thinking beyond oneself, as a work of art simultaneously removes the person experiencing it from the context of their life while relating them back to the whole of their being-in-the-world (Gadamer, 1986).

While Vinnie refused to continue discussing her illness experience in the face of death in words, if we return to her painting, we can see that she was able to summon a kind of language to help us understand. In her unfinished painting, especially after her death to such a ruthless cancer, I see the

> grief and sorrow that a human being must bear and endure that is inhuman and unbearable . . . without any representation of death, the end of life and its power is, in some sense, visible . . . [and] it goes to the heart of what one must understand in order to understand anything of her life. (Schmidt, 2013, p. 136)

The ability to disrupt our assumptions and prejudices is the power of art (Risser, 2012). That Vinnie's work was left unfinished due to her death challenges the assumption that human beings, especially children, will have a future in which to fulfil our endeavours. There is a tension in the "unfinished world," to borrow a term from Davey (2013), presented in a child's painting that has been interrupted by their death, but the end of Vinnie's life does not limit the expressive capacity of her work. Vinnie's artwork is not bound by the same limitations that her finite life was. There

is an abundance of possibility in an unfinished work of art, and "what is at stake is the universality of *meaningful possibilities*, which are elicited by something presented in its particularity but which cannot, however, be exhaustively determined" (George, 2020, p. 147, italics in original). While some participants have died since I interviewed them, their artwork, will continue to evoke new possibilities for interpretation and understanding.

Figure 5.1 (Vinnie, Unfinished)

Resonating Silence

In belonging to language and among the forms of human expression that can be interpreted, silence should not be considered the absence of or limit to understanding. While not as definitive as the spoken word, the silence of the participants in this study still said something: in gesture, in image, and in expressing that which we cannot adequately articulate in words. Their artwork is a silent language, but one that resonates. It remains present to be encountered, so that any future reader may enter into play with these images to help them understand something of the truth of what experiencing serious illness in childhood is like. Children's artwork can have a "campfire effect" (Rollins, 2005, p. 215): the ability of art to draw one in,

focus attention on the matter at hand, and summon language in such a way that what is presented in the work “shines forth” (Risser, 2012, p. 108).

Chapter Nine: Returning to the Topic and Possibilities for Practice

> *We must accept our reality as vastly as we possibly can; everything, even the unprecedented, must be possible within it. This is in the end the only kind of courage that is required of us: the courage to face the strangest, most unusual, most inexplicable experiences that can meet us. (Ranier Maria Rilke, Letters to a Young Poet, 1984, pp. 88-89)*

I often find that my work, both clinically and academically, can surprise people. Recently, a good friend, who is a nurse in pediatric oncology, and I were discussing how others react to the work that we do, and how few people can relate to it. I am frequently asked why I work in such a challenging area. While there have certainly been difficult situations or interactions, overall, I love working as a nurse for children who have serious illness, and I have loved interviewing children with serious illness for this study as well. In my experience, I have found that children can be remarkably resilient. At the beginning of my career, I used to think this was because of the innocence of children and their lack of knowledge about what was happening to them. From my experiences in my clinical work and in graduate studies, this prejudice has been challenged and revised several times over. This thesis work has also changed my understanding of children's experiences of serious illness, and as I continued to work as a bedside nurse throughout my graduate studies, I have noticed changes in my practice in light of what I have learned. In the following chapter, I will discuss the review the findings and discuss their utility in practice and in life.

Possibilities for Practice

The interpretations presented in this thesis are possibilities for nursing practice, including opportunities for understanding or changing practice, behaviours, approaches, and beliefs.

> Creating space for possibilities of change demands discernment in deciding what is at stake in the topic and the study. [Researchers] study things that matter in human lives and in our disciplines' work. Articulating why it matters often serves to lead us to implications for practice. (Moules et al., 2015, p. 190)

Moules et al. (2015) emphasized the importance of the relationship between practice and philosophy in hermeneutic research. A central consideration in hermeneutic research is to determine if the interpretive findings are useful (Moules et al., 2015). The aim of my study was to understand the "voices" of children with serious illness, but the interpretative findings in this thesis must be taken a step further to be useful to nursing practice. I also think the interpretations ought to be useful to children with serious illness as they are, ultimately, who I had in mind as I conducted this research.

I used the word "possibility" intentionally in this chapter. Hermeneutic research only arrives at a possible understanding of phenomena that address us, rather than a conclusive answer for or explanation of the topic (Moules et al., 2015). In approaching this topic hermeneutically, I do not claim to offer a definitive truth about children's experiences of serious illness, but to offer the possibility of truth in the interpretations of what children with serious illness had voiced regarding their experiences. In doing this work, my contribution is the possibility of understanding a complicated and evolving topic differently, while acknowledging that no method, no researcher, and no words can capture everything there is to understand about it.

Returning to Children's Voices

In chapter five, *The "Voices" of Children: Art, Metaphor, and Silence*, I suggested that in understanding children's voices often contain more than what they articulate verbally, and that

the children in this study "spoke" in art, metaphor, and in silence. Understanding these voices requires interpretive effort and active listening. I presented my interpretation of children's voices as encompassing the concepts of testimonial justice, agency, and hermeneutical recognition. The idea of testimonial justice (Fricker, 2007) is required to recognize that the testimonies of children regarding their illness experiences are reliable and credible, regardless of their social identity as children. Taylor's (1985) concept of human agency as the valuation of matters of significance helped to expand on voice to acknowledge that children are beings who have things that matter to them. Finally, hermeneutical recognition, or listening for the possibility of truth or validity in what the other has to say, recognizes that while children may express themselves in ways that require more interpretive effort, there may be something true in what they have to say.

Application: Listening for and to Children's Voices

This understanding of children's voices and the ways in which children expressed themselves in this study have implications for practice. In this study, children's voices came through in their verbal statements, their artwork, in their use of metaphor, and in their silences. It is, therefore, important for nurses, healthcare providers, and parents to recognize that children may not express themselves in a manner that we expect. What matters to children may be revealed in play, art, or metaphorical statements (Aasgaard & Edwards, 2012; Sourkes, 1995, 2018), and adults must be aware that there may be something else at play in what might seem like childish activities. Bristowe et al. (2024) found that children used figurative language, including "journey metaphors" (p. 7) and simile, in their discourse analysis of how children describe their own serious illness. Gadamer (2000) wrote, "we must admit that a three-year-old-child is much richer and original in dealing with language than an adult" (p. 12). Children can be quite creative in their use of metaphor, which may make it challenging to spot when they are

trying to express something that is difficult to articulate in a more straightforward manner. Sam told me multiple times during his interview that he "*falls apart*" when he is sick, but he was unable to convey what he meant outside of using art and metaphor. While these forms of expression invite further questioning and conversation, they also carry meaning in their own right and can be interpreted to elucidate what children with serious illness may be experiencing.

Providing children with opportunities to express themselves is something that is done relatively well at the children's hospital and hospice where I work. However, children also provide opportunities for adults to listen, and these instances may go unnoticed. Mitchell et al. (2021) reported that the children in their study felt that their wishes and concerns were not heard by their parents or healthcare providers, despite their level of expertise on their own illness and experiences. These feelings arose after being left out of conversations or not being listened to when they did speak up (Mitchell et al., 2021).

Finally, listening to the voices of children may not be enough in some situations. While there is power in being listened to, children's voices also come with an ethical demand (Carnevale, 2020). How adults respond to children's voices in practice, and whether their interpretations go beyond a surface level recitation of what children say, also have practical implications for nursing and research. Advocacy, adjustments to care plans or treatment regimes, and initiating conversations amongst the care team and parents may be required in response to the voices of children in practice. For example, if a child with a serious illness that had a terminal prognosis were to tell her nurse that she really could not stand any more needles and feeling so sick after chemotherapy, her nurse might take these comments as an opportunity to discuss a palliative care consult with the child's family and care team. Listening to children's voices is the acknowledgement that when they communicate their experiences, their voices carry testimonial

credibility, agential expressions of meaning, and the possibility that what they have to say contains a kind of truth from which we can learn.

Returning to Children's Experiences of Clinical Environments

In chapter six, *"Nope I'm Outta Here": Children's Experiences of Clinical Environments*, I presented an overview of the history of the architectural and design influences children's hospitals. I discussed the Latin terms *hospes* and *hostis*, which are the etymological roots for hospital, hospice, hospitality, and hostility. Some of the children in this study experienced the hospital as a "*hostile environment*" and their commentary on the hostility of the hospital was challenging for me, as a nurse, to hear. Vinnie mentioned there was nothing that nurses could do to ease the hostility of the hospital, and that it was the place she associated with the worst experiences of her life. Adams and Theodore (2002) wrote that child-friendly design features in children's hospitals "allow children and parents to forget they are in a hospital" (p. 236); however, the experiences of the participants in this study challenge assumptions about spaces designed to be child-friendly. The instruments and things in the hospital were also experienced as hostile, and the participants reported that even the most mundane and seemingly unthreatening medical equipment could be perceived as intimidating and frightening.

The participants experienced the pediatric hospice environment differently, describing it as "*like being at a friend's house for the first time*." Notably, they identified the hospice as feeling homelike, but not like home. The hospice environment came with uncertain boundaries and the feeling of needing to keep up appearances or behave in a certain way. The hospice was also experienced as not-like-home in a positive way, as a place in which to find new friends, explore accessible spaces, and enjoy a change of scenery. I suggested that hospice patients may experience dying-in-place. I argued that when one is healthy, time is often a helpful way of

structuring one's sense of self; however, when one is dying, it may be more helpful to schematize the meaning of one's experiences through place. Finally, the hospitality of the healthcare staff helped to mitigate the hostility of the hospital. It was never the doctor delivering bad news or the nurse inserting an intravenous cannula who were perceived as hostile, it was the place itself. Having their preferences for care acknowledged and acted on, building relationships, and having access to loved ones ameliorated the hostility or unhomelikeness of being in a clinical environment. Children in this study also reported that their healthcare providers were their role models, in addition to being their caregivers.

Application: Hospitality and No Place Like Home

There is ample literature to support the importance of establishing strong therapeutic relationships between healthcare providers and children and families in PPC. Relationships in PPC determine the success of communication, the support families feel during challenging times, and decision-making (Hsiao et al., 2007; Knapp & Contro, 2009; Sourkes et al., 2005). I could not find any literature on the significance of nursing role models for children with serious illness. Personally, I have been more aware of my behaviours and actions in my nursing practice after considering that a child might consider me as their role model in addition to being their caregiver. While not all children with serious illness live to adulthood, the children in this study still projected themselves into the future and considered what they might wish to be when they grow up based on their interactions with their healthcare providers. Ocak et al. (2024) reported that the hospitality of healthcare staff can influence patients' perceptions of the technical aspects of care, and this study offers that the hospitable relational spaces are also beneficial for children and mitigate distressing aspects of care and the hostility of a place.

The findings of this study regarding clinical environments have implications for the development of hospital-at-home and pediatric palliative home care programs. Access to pediatric palliative home care settings varies significantly depending on where one lives. In the United States, most hospice care occurs in the home, rather than a stand-alone hospice facility (Friedrichsdorf & Bruera, 2018). Depending on the services available, children in Canada may have access to PPC in the hospital, in a stand-alone hospice, or at home, but only in certain major cities (Widger et al., 2016). In Calgary, no formal pediatric palliative home care service exists, and in my experience, adult palliative home care and pediatric home care are reluctant to take on children who are dying. Most children with serious illness die in hospital settings (Canadian Institute for Health Information, 2020; Canadian Hospice and Palliative Care Association, n.d.; Feudtner et al., 2011; Widger, 2016) and considering the perceived hostility of the hospital and unhomelikeness of the hospice, one implication of this study is to advocate and explore options for palliative home care services for children who are dying.

Returning to Apprehension in Serious Illness

In chapter seven, *The "Good," the "Bad," and Everything in Between: Apprehension in Serious Illness*, I explored the dual meaning of apprehension: to detect or comprehend something, or a sense of foreboding, anxiety, or fear of the future (Merriam-Webster, n.d.) as it related to children's experiences of serious illness. Gadamer's idea of the enigma of health was used to discuss the children's apprehension of living in-between health and illness, which included the transition from being healthy to ill, balancing living in-between health and illness in chronic illness, and the experience of becoming healthy following the treatment of a serious illness. I also discussed the existential anxiety of having a serious illness in childhood, as well as the possibilities that serious illness presented these children.

Application: Making the Most of Health and Supporting Apprehension

The implications for practice from the apprehension interpretation is the importance of making the most of periods of relative health in children with serious illness. For children with terminal illness, I have often wondered if there was a pressure to live as much life as possible with whatever time is given. The importance of prioritizing fun for children with serious illness has been discussed in the literature from the perspectives of children (Mitchell et al., 2021; Namisango et al., 2020). Vinnie also shared that she appreciated the encouragement from nursing staff to do something creative and fun: "*I also like doing the colouring and Lego, but sometimes I refuse for no good reason so being asked repeatedly [by the nurses] really helped me feel encouraged to do so.*" Sourkes (1995) shared that during one of her therapy sessions, a young child with serious illness drew a picture of her family and stated, "We don't plan ahead like we used to. We live each day as it comes" (p. 119). For children who experience periods of relative health while seriously ill, nurses can help to encourage patients to make the most of the days when children are "*good*."

Another consideration for practice is how nurses can support children in their transitions from illness to health. I had not reflected on the challenges associated with being cured of a serious illness and was surprised to hear that this was difficult for Angela, who painted herself as a bird in a cage. Dovern et al. (2023) found that their sample of adults who had undergone treatment for sickle cell anemia experienced the "opening of a new world," feelings of relief and grief, and the need to emotionally process their illness experience with a lack of psychosocial guidance (p. 4). The authors also found that patients tended to adhere to the patterns they established while they were ill. Similar results have been found in the cancer survivorship literature. McNeel (2021) recommended that the language of "cure" may not be as helpful as the

language of "healing" in therapy settings, and the same may be applicable to the framing of survivorship in pediatric serious illness. Healing implies a more holistic approach to the transition from being ill to being healthy, especially when living with serious illness is all one knows.

Returning to Silence

In chapter eight, *"Can We Talk About Something Else?": Things Unspoken, Not Unsaid*, I explored the experiences that children were unable to talk about during their interviews, and how their silence, in the forms of withholding speech, gesture, and art, could be interpreted to understand their experiences. Children used gesture and artwork to express themselves when aspects of their illness prevented them from talking. Children used silence to communicate the challenges they had experienced regarding the limitations their illness imposed on them and the unspeakable character of death. One child mentioned death explicitly during the interviews and denied the desire to explore her thoughts about death any further. I discussed how silence is a part of language and part of how children communicated during these interviews.

Application: Listening to Silence

Recognizing that silence itself is part of language also has implications for practice. Silence or responding to questions with "I don't know" may also indicate opportunities for further conversation that are often overlooked (Spyrou, 2015). There is evidence to suggest that children are intentionally silent about aspects of their illness to protect their loved ones, including their awareness of a poor prognosis (Mitchell et al., 2021; Bluebond-Langner, 1989). It is easy to miss a silence that says something during a busy shift, and attending to silence may require a heightened awareness of body language, gestures, and what goes unsaid during

interactions with children. Nurses ought to hold space for silence in the same way that they would for a verbal conversation.

Possibilities for Children

This thesis is more likely to be read in clinical or academic settings but given the increased accessibility to information in this technical age, there is a chance that a child may come across this work as well. Moules et al. (2015) wrote,

> If we listen carefully to the interpretations found in hermeneutic work, we hear invitations and, in some invitations, we might be beckoned by something that sounds like advice on how to proceed in our practices and lives. Advice can be audacious, bold, and certain, but it can also be subtle and embedded, couched within speculation and wonder – and it can also, always, be turned down. (p. 189)

The children in this study had advice for children on how to cope with serious illness. This advice and the insights of these children may be helpful to others in similar situations but may also be turned down if it does not resonate. In the end of chapter seven, in opposition to Carel's (2018) idea of Being-unable-to-be, the children in this study had unique perspectives to offer regarding what can be learned and understood of serious illness and its possibilities. While serious illness comes with limitations, it also comes with potentials and, perhaps, a heightened sense of what matters.

> *Vinnie: I think the biggest change I've seen in myself is how much I've learned not to care what others think about me.*

> *KW: What advice do you have for other kids who get sick, as a kid who has gone through it?*

Nate: Well, tell them not to worry and feel happy about it. Don't get sad and know that have a positive attitude and believe in yourself . . . To know that they're loved by people.

Vinnie: You can do so much if you just have the want to do it . . . Do whatever you want, there's never a better time than when you're motivated to do it.

Sam shared that his life with ITP was "*more exciting*" and that "*if I didn't have ITP, [my life] would be wwwwaaaayyyyy more boring*."

Children with serious illness may have different experiences and understandings compared to their healthy peers (Sourkes, 1995), and because of this, different things may matter to them. What is important to children with serious illness can be voiced in a variety of ways, and it is equally important for their care providers to be attentive to these forms of expression. Children with serious illness ought to be supported to use their "voices," and the children in this study encouraged other children to explore their possibilities, seek help and support from loved ones, and to take advantage of the times when one feels motivated and well.

Possibilities in the Face of Limitations

Following my paper presentation on the hermeneutics of childhood at the 2023 Canadian Hermeneutic Institute, Professor Dennis Schmidt commented in response to my paper, "I am not sure children are fully human, I think they might be more." I have written elsewhere (Wong, 2019) that children exemplify what it means to be hermeneutic. They are open, curious, undogmatic, and rather than listening for the truth in what the other has to say, they often expect it (Wong, 2019). However, in many ways, they face more limitations than adults (e.g., language or physical barriers), and in lacking certain life experiences, they are more vulnerable to errors and missteps in comparison to adults. Children with serious illness must contend with a

multitude of limitations: being children, being ill, and the idea that they might not survive their childhood. Despite these challenges, I have often found that children with serious illness, including the children in this study, are remarkably resilient and optimistic.

During a conversation with Professor Theodore George, in response to Professor Schmidt's comment that children might be "more" than human, he posited that if the task of our Being is to come to the meaning of our own lives, it might be that children are better at Being than adults, and that perhaps, in being thrown into the world with these limitations, children are more open to the possibilities of their existence (personal communication, August 12, 2024). Sam said it well when he explained why he would not want to start his life over without serious illness: "*When you have ITP, sometimes it's a whole new discovery in life and sometimes it's just something that gets in the way. . . like, there's way more things that can happen*." What I have come to understand is the resiliency I associate with children with serious illness may be due to their radical openness to the possibilities of one's existence, or the knowledge that possibilities exist despite the presence of significant limitations in one's life.

Learning from Children

In addition to practice implications, there are implications for life that I have come to understand from these children. I heard the possibilities that stem from being loved while interviewing Nate. From Vinnie, I discovered the possibilities that motivation offers. Sam taught me to take hold of possibilities while I can. I listened to Maddie discuss the possibilities that are opened through relationships with friends and role models. J-Bird showed me that when your body becomes your most significant limitation, surround yourself with people who care for you and can help you do what has become impossible. Finally, from Angela, I came to understand that when a world of possibility presents itself, you do not have to jump into it right away. I

doubt I will ever become apathetic to the kind of courage that is required of children with serious illness, who “face the strangest, most unusual, and most inexplicable experiences” (Rilke, 1929/1984, pp. 88-89), yet remain open to the possibilities that arise from them.

Chapter Ten: The Value of Children's Voices: Integrity and Rigour in Hermeneutic Research

We cannot know his legendary head
with eyes like ripening fruit. And yet his torso
is still suffused with brilliance from inside,
like a lamp, in which his gaze, now turned to low,

gleams in all its power. Otherwise
the curved breast could not dazzle you so, nor could
a smile run through the placid hips and thighs
to that dark center where procreation flared.

Otherwise, this stone would seem defaced
beneath the translucent cascade of the shoulders
and would not glisten like a wild beast's fur:

would not, from all the borders of itself,
burst like a star: for here there is no place
that does not see you. You must change your life.
(Ranier Maria Rilke, Archaic Torso of Apollo, 1995)

The poem *Archaic Torso of Apollo* by Rilke (1995) was discussed interpretively at the 2021 Canadian Hermeneutic Institute and continues to address me and my approach to this work. Gadamer's (1960/2004, 1986) assertion that the experience of art is transformative has been an important consideration for this research. The artwork of the children in this study has the ability to transform how we understand children with serious illness and remains available for others to experience. There is something I find compelling in the idea that an incomplete work of art can still "burst like a star" with meaning and be experienced as life changing. Perhaps this is because I have nursed, and now conducted research with, children with serious illness who die before reaching adulthood. Children who die are often thought of as having an incomplete life, that is "snuffed out before it has unfolded" (Sonlit, 1965, p. 693), but I have always found the experience of interacting with these children to be transformative. Like Rilke's lifechanging

encounter with a sculpture, hermeneutic research has the capacity to be transformative. In the previous chapter, I offered my recommendations for practice, and in this chapter, I outline how research consumers might consider the utility, integrity, limitations, and value of this work. I also discuss areas of future research and possibilities for knowledge dissemination.

Preface: A Note on the Critiques of Hermeneutic Research

No methodology is capable of fully answering all the questions that researchers have, and hermeneutic research is no exception to the finitude of human knowledge (Gadamer, 1960/2004; Moules et al., 2015). Hermeneutic research allows a topic to be revealed in a new way, while acknowledging that there is no singular interpretation that will capture it in its entirety (Moules et al., 2015). Hermeneutic research may also be limited by misunderstanding its potential contributions when it is critiqued using restrictive criteria framed by positivist paradigms (Moules et al., 2015). Common criticisms of hermeneutic research include lack of generalizability, its relatively small sample sizes, the reliability of interpretations, and the absence of a prescribed method. However, as Davey (2006) stated, "What are perceived as the weaknesses of philosophical hermeneutics – its inability to arrive at a final interpretation . . . are indeed its strengths" (p. xv).

The Utility of Hermeneutic Research

The focus of hermeneutic research is on the primacy of the particular and honouring the complexities of human life (Moules et al., 2015). High quality hermeneutic research presents powerful, rather than powered, data from a sample of participants with unique experiences of the topic under study, and a deep and thorough analysis of interview data that would not be feasible with a large sample size. The findings from hermeneutic research are not generalizable, nor are they intended to be. The utility of hermeneutic research lies in its instrumental, symbolic, and

conceptual contributions to practice disciplines (Estabrooks, 1999, 2001; Moules et al., 2015; Sandelowski, 2004). Instrumental utility refers to the visible and concrete application of hermeneutic research findings to, for example, clinical guidelines and pathways, intervention protocols, and standards of care (Estabrooks, 1999, 2001; Moules et al., 2015; Sandelowski, 2004). Symbolic utility involves the use of hermeneutic research findings as a persuasive or political tool, where compelling interpretations offer justification for action, funding, or program development (Estabrooks, 1999, 2001; Moules et al., 2015; Sandelowski, 2004). Finally, conceptual utility refers to the change that happens at the level of individual thinking, where shifts in understanding or beliefs result in changes in behaviour (Estabrooks, 1999, 2001; Moules et al., 2015; Sandelowski, 2004).

In the previous chapter, I made recommendations for the establishment of pediatric palliative home care services, which are examples of the symbolic and instrumental utility of this research that may provide the justification for a new program and transforming standards of care for children with serious illness. I made recommendations that fall under conceptual utility. I suggested that nurses be attentive to the "voices" that children use, including silence and metaphor, in expressing their experiences and wishes, and take note of when children provide an opportunity to understand what they are going through. I recommended that nurses and other healthcare providers be hospitable in their behaviours towards children with serious illness to mitigate the hostility of the hospital environment. Understanding how hermeneutic research is meant to be utilized has implications for how it is received and critiqued in the context of a research community that is more accustomed to quantitative research methods.

Rigour

Hermeneutic research is often criticized as being relativist, and the research findings of hermeneutic studies are frequently dismissed as "just interpretations" (Moules & Estefan, 2018; Moules et al., 2015; Paley, 2005). Rigour could be defined as rigidity, inflexibility, or exactness (Merriam-Webster, n.d.), but can also be defined as the "quality of being detailed, careful, and complete" (Cambridge Dictionary, n.d.). Moules et al. (2015) suggested that rigour in hermeneutic research involves "careful attention to the treatment of topics such that the work engenders trustworthiness and believability" (p. 172), acknowledging that hermeneutic researchers often pursue a "*subject that matters*" (p. 72, emphasis in original). The result ought to provide a dependable and authentic contribution to the understanding of the topic.

Subjectivity and Objectivity

Hermeneutics, along with all qualitative research methods, is often appraised as too subjective, where the subordination of subjective experiences to objective facts results in hermeneutic research being rejected in favour of knowledge generated through quantitative research methods (Caputo, 2018; Greenhalgh et al., 2016; Moules & Estefan, 2018; Paley, 2005). Moules and Estefan (2018) emphasized that subjectivity is a philosophically nuanced phenomenon, which is often distorted and reduced to notions of "opinions" and "multiple realities," leading to a perception that subjective claims lack validity as a source of knowledge about the world. Diminishing subjectivity to a matter of partiality, taste, or opinion neglects to acknowledge that what is subjective is always constituted by an already organized world of meaning relations, the influence of history and tradition, and one's thrownness into the world (Gadamer, 1960/2004; Zimmermann, 2015). Moreover, George (2021) stressed that while interpretations may vary, they are always tied to something real (e.g., suffering, grief, dying, or

art), and even strong interpretations may remain contested because of the richness of the topic under investigation. Hermeneutics is the answer to a question that could have been answered differently (Moules et al., 2015), and rigorous hermeneutic research opens the topic up for new questions and diverse interpretations, precisely because of the complexity of the topics that hermeneutic researchers tend to be addressed by.

Method

Perhaps the most unique feature of hermeneutic research as informed by Gadamer's philosophical hermeneutics is the absence of a prescribed method to guide inquiry (Moules et al., 2015); this may be cause for scepticism in scientists and researchers who are accustomed to utilizing procedural methods and measurement tools that have been deemed reliable and valid. However, in hermeneutic research, it is the topic, not the method, that informs how a study will unfold. Hermeneutic researchers are "guided by, and tethered to, the topics [they] are investigating and, because different topics call for different approaches, the research may show as methodologically different for different studies" (Moules et al., 2015, p. 4). Rigour may also be demonstrated in the fidelity to hermeneutic philosophy to guide methodology (Moules et al., 2015).

One of my guiding hermeneutic principles as a researcher has been Gadamer's (2007) idea of the "productive scholar" (p. 85) and that the strict and exact application of method does not guarantee the result will be something worth knowing (Gadamer, 1960/2004, 2007). For Gadamer, mastery of a method does not indicate the productivity of a scholar, as a person who has demonstrated that they can learn a method or procedure may also be "the person who never produces anything . . . It is imagination [*Phantasie*] that is the decisive function of the scholar" (Gadamer, 2007, p. 85). Gadamer did not have in mind a definition of imagination as something

unproductive, fanciful, or groundless. Imagination is the hermeneutic function that enables the scholar to see that which is questionable, and to pursue novel ways to understand as the result of genuine and productive questioning (Gadamer, 2007). It is perhaps better understood as a scholar's capacity for curiosity in what we encounter and how it could be interpreted and understood. In being open and curious about the topic and what my participants had to contribute to my understanding of it, I have endeavoured to uphold Gadamer's idea of the productive scholar and produce something that adds to the understanding of children's experiences of serious illness.

Validity

In both hermeneutic and quantitative research, the concept of validity refers to study findings as being well-founded and representative of contextualized phenomena (Kvale, 1995; Moules et al., 2015; Polit & Beck, 2017). Hermeneutic interpretations that are persuasive, robust, revealing, and justifiable are valid in the sense that they discover and legitimize the topic of study and how it is "lived out" (Kvale, 1995; Moules, 2002, p. 17). Rather than conceptualizing validity in the positivist sense (i.e., a valid tool measures what it purports to measure), validity in hermeneutic research pertains to whether the researcher's application of the methodology served to investigate the topic that was intended to be investigated in a way that elevates and transforms understanding (Kvale, 1995; Moules et al., 2015). Kvale (1995) suggested that validity in qualitative research is the craftmanship of the research, the convincing communication of knowledge claims, and the application of the study findings as they are presented to the research consumer.

Angen (2000) recommended that interpretivist researchers use the term validation, rather than validity, to emphasize how evaluating the quality and contribution of hermeneutic research

is a continuous process occurring within a community of researchers. Validation within a research community is a conversation, where "truth is constituted through a dialogue; valid knowledge claims emerge as conflicting interpretations and action possibilities are discussed and negotiated among members of a community" (Kvale, 1995, p. 24). Ethical validation in hermeneutic research refers to the moral obligation to arrive at thoughtful, caring, and responsible interpretations of the meaning that participants associate with their deeply personal experiences (Angen, 2000). Hermeneutic interpretations should be assessed based on the capacity to deepen thought, radicalize understanding, and alter conduct in practice (Angen, 2000; Moules et al., 2015). Substantive validation refers to the quality of the research process, including reflexive thinking on how the topic is informed by the societal context and researcher's own experiences of the topic, considering information derived from other scholarly and literary sources, and being accountable for the decisions made throughout the study (Angen, 2000).

Substantive and Ethical Validation of the Research

The interpretations in this research are not "just" my interpretations but were carefully crafted on the foundation of my years of practice expertise, a solid understanding of the literature surrounding the topic, and through the data collected from the participants who have experienced the topic. This foundation is established through my prejudices, which set the conditions for understanding in the first place, as "understanding is always about something that is already there" (Moules et al., 2015, p. 43). The aim of hermeneutic research is to understand phenomena differently, or recover something of the topic, rather than inventing interpretations from thin conceptions of phenomena. Removing or suspending the hermeneutic researcher's fore-understandings is impossible, as it is precisely the foundation that transformative understanding depends on. Prejudices are not fixed, and Gadamer (1960/2000) encouraged reflection on one's

prejudices. In developing my interpretations, I was careful to allow new understandings to emerge, rather than confirm what I already believed.

In conducting this research, I had in mind the groups of people these findings might be useful for, which included the population of interest, but also nurses, parents, teachers, and others who may interact with children who have serious illness. I have endeavoured to present what possibilities these interpretations may open up, and if those possibilities carried sufficient ethical and practical insights. Until the findings of this thesis are published, there is no way of knowing how it will be received by research consumers.

However, the work has been approved by my supervisor, Dr. Nancy Moules, who is recognized globally for her expertise in hermeneutic research and philosophy and has a significant practice background in Family Systems Nursing (Wright & Leahey, 2005). I have no doubt that she understands something of the experiences of children with serious illness, having stood at the bedside of many children with cancer as they died during her time as a family support nurse in pediatric oncology. Dr. Moules has been engaged with this research in meaningful ways, from the inception of the first research question, to the revision of the question, providing feedback on the ethics and care of vulnerable participants, and in her feedback and reflections on the interpretations. Having hit what felt like an interpretive roadblock, I had a conversation with Dr. Moules about my data. After describing the interviews and recognizing that the art of children who have serious illness may not be the topic after all, she recommended I revise my research question. The reflexive thinking required for such a change is detailed in the beginning of chapter five. In many ways, Dr. Moules has contributed to the validity of the work.

Members of my supervisory committee, Drs. Andrew Estefan and Graham McCaffrey, have also contributed to the validity of this research methodologically and interpretively. Additionally, as I have been writing about children's experiences of serious illness and their artwork throughout my graduate studies, my supervisory committee helped to develop my thinking and interpretive capacity through their feedback on my work submitted for their courses, in addition to my thesis work. I have also had conversations with coworkers and fellow nurses, teachers, parents, and children about what I was coming to understand as this research took form and have reflected on their feedback and validation.

Veracity

Moules et al. (2015) used the word veracity, or "the power of conveying or perceiving truth" (Merriam-Webster, n.d.), to refer to the extent to which the researcher's interpretations offer convincing, authentic, and recognizable descriptions of the topic that resonate with others. Interpretations are not "just" the researcher's opinion; it must be clear that they emerged during analysis and are explicitly linked to the data, but neither should researchers present participant quotations with no attempt at an insightful interpretation (Moules et al., 2015). Madison (1988) proposed that quality hermeneutic research is supported by comprehensiveness, penetration, thoroughness, contextuality, agreement, suggestiveness, and potential. Interpretations must encompass a unified representation that is intelligible and expands thinking, effective and sensible, culturally and historically contextualized, thought provoking and question generating, and has the potential for future realization of resonance (de Witt & Ploeg, 2006; Madison, 1988; Moules et al., 2015).

Moules et al. (2015) stressed the importance of the veracity hermeneutic research: "its truth value and credibility, depends upon the power of interpretations to offer faithful and

recognizable descriptions of the topic that ring 'true' to others" (Moules et al., 2015, p. 174). The findings do ring true to me and have been transformative in my own practice. While I have done my best to present findings that resonate with the topic and others who may find this research useful, it is ultimately up to the research consumer to determine if the findings are convincing, influential, and offer possibilities for understanding differently (Moules et al, 2015). The truth that we can recognize in a hermeneutic study is similar to Gadamer's (1986) writings on being shown something in art through *mimesis*; "showing something means that the one to whom something is shown sees it correctly for himself" (pp. 128-129) and what is shown is "elicited from the flux of a manifold reality" (p. 129). In our being shown, there is an act of identification, and recognition thereafter (Gadamer, 1986): that we can see the truth in the work speaks to its validity and veracity.

Reliability

In quantitative research, reliability refers to the precision and consistency of information observed in a study (Heale & Twycross, 2015; Kimberlin & Winterstein, 2008; Polit & Beck, 2017). The instruments that researchers select to measure outcomes, such as pain scales or thermometers, must be consistent across populations and conditions, as well as measuring what the concept they claim to measure (Drost, 2011; Kimberlin & Winterstein, 2008; Polit & Beck, 2017). Findings in hermeneutic research depend on the diligence and judgements of a researcher, not on adherence to a method or the reliability of a measurement tool: in qualitative research, the researcher *is* the instrument (Polkinghorne, 2006). Hermeneutic researchers must account for their skill as the instrument of data collection, analysis, and interpretation (Angen, 2000; Corbin & Morse, 2003; Moules et al., 2015). Kvale (1995) wrote that the "craftmanship of research and the credibility of the researcher becomes decisive as to whether other researchers will rely on the

findings reported" (p. 26). As a novice researcher, I engaged in this research with the mentorship and advisement of experienced scholars, who have demonstrated their craft during coursework and in conversations with me. For example, Dr. Moules allowed me to practice conducting interviews during one of her classes on hermeneutic research before I began data collection for this study. My experience as a nurse in PPC has also afforded me a level of comfort and credibility in having difficult conversations with children and in engaging with children relationally.

Interpretation implies pointing in a particular – but open – direction, rather than some final destination, "in the sense that it points toward an open realm that can be filled in a variety of ways" (Gadamer, 1986, p. 68). Therefore, it is important to acknowledge that while a multitude of interpretations may arise out of a single data set, "*some interpretations are better than others*" (Caputo, 2018, p. 13, italics in original). Madison (1988) offered that: strong hermeneutic interpretations are coherent, comprehensive, penetrating, thorough, contextualized, demonstrate agreement between what the researcher means to say and what is said, suggestive, and open up the topic for further interpretation in the future. The interpretation becomes a part of – and adds new meaning to – the ongoing conversation that started before the research began and will continue long after the researcher has done their best to articulate it (Moules et al., 2015). In my interpretations, I have aimed to draw from scholarly literature, consider the context of the experiences of the participants, and be attentive to the many forms of children's voices.

Study Limitations

There are potential limitations for this proposed study. First, the study is limited by me as a researcher. I am new to hermeneutics, and as such, may have a limited understanding of hermeneutic philosophy and research. I also lack the years of experience that a seasoned

researcher would bring to interviews and analysis. Additionally, I was limited by my age. Ultimately, while the aim of this study is to understand the experiences of children with serious illness, the art and interview dialogue of the children who participated in this study was still interpreted by an adult. James (2007) cautioned that "for adult researchers, there is a fine line between presenting children's accounts of the world and the claim to be able to see the world from the child's perspective as a new kind of 'truth'" (p. 263). However, similarly to hermeneutic research with adult participants, the perspectives, words, and artistic creations of children are regarded as data from which analysis commences, rather than conclusive descriptions of phenomena represented in the words that children speak. Data collected from children has been interpreted while considering the "worlds that children create for themselves (e.g., play, peer groups, games), worlds created for them by others (e.g., school, hospitals), and worlds in concert with others (e.g., families, marketplaces, neighbourhoods)" (Bluebond-Langner & Korbin, 2007, p. 245).

Children's interpretations of the world, much like subjective knowledge, are not theirs alone, and what children know, say, and how they behave is negotiated in the context of a world where history and tradition shape how children and childhood are understood. However, this is not to say that children's understanding of the topics that hermeneutic researchers aim to investigate cannot contribute to understanding those topics differently. In the case of children with serious illness, as the experts in their own experiences, the opportunity to listen to the voices of children and explore a perspective different from my own has been informative.

This study did not include participants between the ages of nine and 16 years, and as such, certain unique aspects that age group are not captured; for example, experiencing puberty and the transition to adolescence while living with serious illness might have added to these

interpretations. A large portion of the population of children with serious illness are non-speaking due to their diagnosis (Connor et al., 2017), and while the language of silence did become an interpretation, non-speaking children were excluded from participating for practical reasons. The participants were relatively diverse, including a Caucasian male and female, one Latino male, a Black female, and a Southeast Asian female. The cultural aspects of their experiences were discussed during the interviews, but not to the extent that they were elevated to the interpretative findings. With respect to gender identity, the participants were evenly split.

One of the original aims of this study was to learn more about how dying in childhood was experienced by children with serious illness and while there were participants who were able to speak, in a way, to this topic, I still feel I have more questions for this population of children. I do not think this is an issue of sample size, as the interview data allowed me to explore the topic for the depth expected of a doctoral thesis, though for future research, more targeted recruitment may help narrow the scope of the inquiry. As Kelly (2024) wrote, "when I experience a patient, there is, like a poem, something more" (p. 4); despite the data I collected, the experience of conducting this research pointed me in the direction of something more.

Future Research

The findings from this research have resulted in possibilities for future research that I am excited about. In considering hermeneutic philosophy in light of children, I have found that the combination of hermeneutics and childhood have the potential to contribute developments in philosophy and practice. I intend to pursue the topic of childhood hermeneutics with Dr. Theodore George as my next research project following my doctoral studies. I presented the idea of childhood hermeneutics at the 2023 Canadian Hermeneutic Institute and received feedback that was encouraging from those in attendance. The interviews with Vinnie and Angela have

prompted me to consider what childhood existentialism might entail. Angela described not feeling ready to make decisions about and take hold of her life following her treatments, but did recognize that she was now able to make decisions in the first place. I am interested in considering how adolescence and emerging adulthood might be explored existentially. As medical treatments continue to advance and children with serious illness have more opportunities to survive to adulthood, transitions in care due to survivorship are also something I wish to explore. We have seen several children age-out of our PPC program, and given Angela's experience of survivorship, researching these changes in care will help support children and families as they transition from pediatric to adult care teams.

The silence interpretation has encouraged me to think about communication with non-speaking children with serious illness and how we might understand their silence. Perhaps a good place to begin would be to study how parents interpret and understand the silence of their children. New communication technologies for non-speaking children are being developed at the University of Calgary, and the application of hermeneutics to language that has been communicated through technological devices is another area I am interested in exploring. The application of arts-based research in combination with hermeneutics has felt like a methodological fit for me, and I intend to continue to explore how art, including poetry, images, and theatre, might be used in data collection. Perhaps one of the strengths of this research has been imagining the possibilities that hermeneutics has to offer in understanding topics related to serious illness in childhood.

Chapter Eleven: Closing Remarks Despite the Provocation of Possibilities

"The children too, even the very small ones, didn't just have any child's death; they gathered themselves and died what they already were and what they would have become" (Ranier Maria Rilke, The Notebooks of Malte Laurids Brigge, 1982, p. 16).

Nate died within a few days of my interview with him. Shortly after, I received an email from his mother, asking if it would be possible to have a copy of the audio recording from Nate's interview and his drawings. During his interview, she had asked to see his assent form, as he had never signed a document before, and she was curious to see what his signature looked like. Dr. Moules and I agreed that it was appropriate, ethical, and "right" to grant her request and pass on some mementos of his last days. In her email, she thanked me for my kindness and attention to her boy and told me that he had taken a liking to me during our interview. This was profoundly touching, as I have worried that by leaving clinical practice to pursue research, my interactions might, somehow, not matter as much to the children I love to work with. I do not feel like the one who deserves gratitude in this situation. Nate and his mother shared some of his last hours with me so that we might understand differently, and that is a gift.

Children with serious illness navigate some of the most complex and humbling experiences all at once: the threat of death, growing up, coping with limitations, imagining other possibilities for existence, and significant loss. Children's voices elucidate how we might understand these experiences differently. The children in this study helped me to understand the significance of hostile places and relational spaces, the challenges of living in-between health and illness, the possibilities for understanding in the absence of speech, and the unspeakable character of death. As a result of these interpretations and in coming to understand differently, as Rilke proclaimed, I must change my life.

Perhaps one of the most difficult things, for me, in writing this thesis is its conclusion. Having engaged with this topic for several years, I know that while I must arrive at some kind of understanding in response to my research question, I must also proceed "tentatively, openly, and with the hermeneutic humility that recognizes that no one question can be answered definitely once and for all" (Moules et al., 2015, p. 191). The task of understanding is never over (Gadamer, 1960/2004), and this thesis work presents one of many possibilities for understanding the experiences of children with serious illness. Put another way, the "voices" of children presented in this thesis work do not have the last word.

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Appendix A: Recruitment Poster

RESEARCH PARTICIPANTS NEEDED

UNIVERSITY OF CALGARY

UNDERSTANDING CHILDREN'S EXPERIENCES OF SERIOUS ILLNESS

We are looking to recruit children 7-18 years old who have been living with serious illness for longer than one month. Participation will include an hour-long interview where art will be created to help with expression.

For more information on participating, contact **Kate Wong** (RN BN, Doctoral Student, Faculty of Nursing) at [redacted]

This project has been approved by the University of Calgary Conjoint Health Research Ethics Board (REB21-1868)

Appendix B: Assent Form: Children (7-10 years)

UNIVERSITY OF CALGARY

ASSENT FOR CHILD TO PARTICIPATE IN RESEARCH

TITLE: Understanding the Experiences of Children with Serious Illness through their Artistic Forms of Expression

SPONSOR: University of Calgary, Faculty of Nursing

INVESTIGATORS:

Kate Wong RN, BN, Doctoral Student Post Candidacy, Faculty of Nursing, University of Calgary [redacted]

Dr. Nancy Moules, Faculty of Nursing, University of Calgary [redacted]

INTRODUCTION

We want to tell you about a research study we are doing. A study is a way to learn more about something. We want to find out more about what it is like to be a child with a serious illness. We want to hear about your life so we can learn how to help other kids who are sick. About 10 kids will be in this study.

We want to tell you about some things that will happen to you if you are in this study.

- We would like to sit with you and ask you questions for about 1 hour. Your parents or guardians can be with you if you want.
- We will meet at your house or at the University of Calgary. You will not have to miss school to do talk with us. If we can't meet in person, we can do our talk over a video chat called Zoom. We will send your parents or you a Zoom link, password, and instructions. We will record the Zoom chat and save it in a safe place.
- We will ask you about what it is like to be a kid who is sick. The questions will be about your life and will help us learn how to help kids like you.
- When we talk, we will be asking you to make some art to help us talk to you better. Art can be a pictures, clay shapes, or poems. You can pick what you want to make.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

- It can be very hard to be a kid who is sick. Some things we ask might be hard to talk about. You do not have to talk about anything that makes you feel bad.
- Talking and making art can be tiring. You can stop at any time or only answer questions without making art.

- There are potential risks with meeting during the COVID-19 pandemic. To reduce the risk, we will:
    - Call you or your parents the day before or morning that we will meet with you. We will use an Alberta Health Services form to ask questions about how you are feeling. The form is found online (https://myhealth.alberta.ca/journey/covid-19/Pages/COVID-Self-Assessment.aspx).
    - We will make sure to do very good hand washing.
    - We will clean everything we use.
    - We will follow physical distancing (2 m) when meeting with you.
    - Members of our study team are have had their COVID shots.

WILL THE STUDY HELP ME?

- You might not see a benefit to being in this study, but this study will help us learn more about what it is like to be a kid who is sick.
- We may learn things that will help grown-ups help other kids who are sick.

You don't have to join this study. It is up to you. You can say yes or you can say no. It's OK if you say yes and then you change your mind later. If you want to stop, then all you have to do is tell us or your parents/guardian you want to stop. No one will be mad at you if you don't want to be in the study or if you say yes now then want to stop later.

Before you say yes or no to being in this study, we will answer any questions you have. If you join the study, you can ask questions at any time. Tell us or your parents/guardian that you have a question.

We will talk to your parents about this study. You can talk about this study with them too. They can help you decide.

You might have questions later. If you do, you or your parents can call Kate Wong [redacted] or email [redacted].

WOULD YOU LIKE TO BE IN THIS RESEARCH STUDY?

☐ Yes, I want to be in this study. ☐ No, I don't want to do this.

_____ _____

Name of Child Date

_____

Name of Person who received assent

_____ _____

Signature of Person who received assent Date

You will be given a copy of this paper to keep.

Appendix C: Assent Form: Children (11 years and above)

UNIVERSITY OF CALGARY

GENERAL ASSENT TO PARTICIPATE IN RESEARCH

TITLE: Understanding the Experiences of Children with Serious Illness through their Artistic Forms of Expression

SPONSOR: University of Calgary, Faculty of Nursing

INVESTIGATORS:

Kate Wong RN, BN, Doctoral Student Post Candidacy, Faculty of Nursing, University of Calgary [redacted]

Dr. Nancy Moules, Faculty of Nursing, University of Calgary [redacted]

INTRODUCTION

A research study is a way to find out new information about something. People don't need to take part in a research study if they don't want to take part.

You can talk about this with your parents/guardians before you decide if you want to do this. We will also ask your parents/guardians if it's OK for you to take part in this study. But even if your parents/guardians say "yes" you can still decide not to do this.

WHY IS THIS STUDY BEING DONE?

We are trying to learn more about what it is like to be a kid or teenager with a serious illness. We are asking you to be in the study because we want to learn about your life. Your stories will help us learn how to help other kids/teenagers like you. About 10 children/teenagers will be in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

- We would like to sit with you and ask you questions for 1 hour. The talk will be tape-recorded. Your parents or guardians can be with you if you want.
- We will meet at your house or at the University of Calgary. You will not have to miss school to meet with us. If we can't meet in person, we can do our talk over a video chat called Zoom. We will give you a Zoom link, password, and instructions over email. We will record the Zoom chat and save it in a safe place.
- We will ask you to answer some questions about what it is like to be a child who has a serious illness or condition. The questions will be about your life, what matters to you, and things you think we should know.

- When we talk, we will be asking you to make some art to help us understand you better. Art can be a pictures, painting, photo, or sculpture. You can pick what you want to make.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

- It can be very hard to be a kid or teenager with a serious illness. Some questions we ask might be hard to talk about. You do not have to answer any questions that make you uncomfortable.
- Being interviewed and making art can be tiring. You can stop at any time or decide to answer questions without making art.
- There are potential risks with meeting during the COVID-19 pandemic. To reduce the risk, we will:
    - Call you or your parents the day before or morning that we will meet with you. We will use an Alberta Health Services form to ask questions about how you are feeling. The form is found online (https://myhealth.alberta.ca/journey/covid-19/Pages/COVID-Self-Assessment.aspx).
    - We will make sure to do very good hand washing.
    - We will clean all study equipment before and after each use.
    - We will follow physical distancing (2 m) when meeting with you.
    - Members of our study team are vaccinated.

WILL THE STUDY HELP ME?

- We don't know if being in this study will help you, but it might be nice to share your story.

WILL THE STUDY HELP OTHERS?

- This study might learn things that will help other kids and teenagers like you one day.

WHO WILL SEE THE INFORMATION COLLECTED ABOUT ME?

The information collected about you during this study will stay locked up. Nobody will read it except the people doing the research. Your parents/guardians will not see the information if you don't want them to. We won't tell your friends or anyone else that you are in this study or share any information about you. We will not use your name or anything that will give clues about who you are.

DO I HAVE TO BE IN THE STUDY?

You don't have to be in the study. It is up to you. No one will be upset if you don't want to do this study. You can say yes, or you can say no. You can also take more time to think about being in the study.

If you want to stop, then all you have to do is tell us you want to stop. No one will be mad at you if you don't want to be in the study, or if you say "yes" now then want to stop later.

WHAT DO I GET FOR BEING IN THE STUDY?

You will get to keep any supplies you use to make your art in this study. If you would like to keep your art, we can make sure it gets back to you after we finish learning from it.

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:

You can ask any questions that you may have about the study. You can call us if you have questions later that you didn't think of now. You or your parents can call Kate Wong [redacted] or email me [redacted]. You can also take more time to think about being in the study. You can talk some more with your parents about being in the study.

WOULD YOU LIKE TO BE IN THIS RESEARCH STUDY?

If you decide to be in the study, then please write your name below. You can change your mind and stop being part of the study at any time. All you have to do is tell us. It's okay. The researchers and your parents won't be upset with you

☐ Yes, I want to be in this study. ☐ No, I don't want to do this.

_____

Name of Participant

_____ _____

Signature of Participant Date

SIGNATURE OF PERSON OBTAINING ASSENT

_____

Name of Person who received assent

_____ _____

Signature of Person who received assent Date

You will be given a copy of this paper to keep.

Appendix D: Consent Form: Mature Minors

UNIVERSITY OF CALGARY

CONSENT FOR A MATURE MINOR TO PARTICIPATE IN RESEARC

TITLE: Understanding the Experiences of Children with Serious Illness through their Artistic Forms of Expression

SPONSOR: University of Calgary, Faculty of Nursing

INVESTIGATORS:

Kate Wong RN, BN, Doctoral Student Post Candidacy, Faculty of Nursing, University of Calgary [redacted]

Dr. Nancy Moules, Faculty of Nursing, University of Calgary [redacted]

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to learn about living with a serious illness in childhood. Children and teenagers who have serious illness have important insights that can inform their care. The information from this study will help adults who care for children with serious illnesses. This study may also help future children cope with serious illness.

Sometimes children have a hard time talking about living with serious illness. It might be that they do not have a full vocabulary yet. It may also be that their experiences are hard to explain with words. To address this, we will use art in our interviews to help children express themselves.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 10 children and teenagers will take part in this study through the University of Calgary.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- We would like to sit with you and ask you questions for 1 hour. The talk will be tape-recorded. Your parents or guardians can be with you if you want them to be.
- We will meet at your house or at the University of Calgary. You will not have to miss school to meet with us. If we can't meet in person, we can do our talk over a video chat called Zoom. We will give you a Zoom link, password, and instructions over email. We will record the Zoom chat and save it in a safe place.
- We will ask you to answer some questions about what it is like to be a child or teenager who has a serious illness or condition. The questions will be about your life, what matters to you, and things you think we should know.

- You can decide if you want to have your parents there during your interview or if you want them to go to another room. You can let us know what your decision is, and we can let your parents know if you'd like us to.
- When we talk, we will be asking you to make some art to help us understand you better. Art can be a pictures, painting, photo, or poem. You can pick what you want to make. The point is not to see how talented you are at making art, but to use art to help us understand better, so don't worry if you don't consider yourself an artist.

HOW LONG WILL I BE IN THIS STUDY?

- Your participation in this study will be for a 1 hour interview. We might need to check with you about something after the interview.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

- It can be very hard to be a kid or teenager with a serious illness. Some questions we ask might be hard to talk about. You do not have to answer any questions that make you uncomfortable.
- Being interviewed and making art can be tiring. You can stop at any time or decide to answer questions without making art.
- There are potential risks with meeting during the COVID-19 pandemic. To reduce the risk, we will:
    - Call you or your parents the day before or morning that we will meet with you. We will use an Alberta Health Services form to ask questions about how you are

feeling. The form is found online (https://myhealth.alberta.ca/journey/covid-19/Pages/COVID-Self-Assessment.aspx).

- We will make sure to do very good hand washing.
- We will clean all study equipment before and after each use.
- We will follow physical distancing (2 m) when meeting with you.
- Members of our study team are vaccinated.

ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?

- We don't know if being in this study will help you, but it might be nice to share your story.
- This study might learn some things that will help other kids and teenagers like you who have a serious illness one day. The things we learn might help people who care for children like you too, like parents and healthcare teams.

DO I HAVE TO BE IN THE STUDY?

You don't have to be in the study. It is up to you. No one will be upset if you don't want to do this study. You can say yes, or you can say no. You can also take more time to think about being in the study.

CAN I STOP BEING IN THE STUDY?

Yes. You can decide to stop the interview at any time. Tell the researchers if you are thinking about stopping or decide to stop. No one will be mad at you if you don't want to be in the study, or if you say "yes" now then want to stop later.

WHAT IF RESEARCHERS DISCOVER SOMETHING ABOUT ME?

During the study, the researchers could learn something about you that they didn't expect. For example, during the interview the researchers may find out you have a new symptom that you haven't told your parents or doctors about yet. The researchers will consult with your parents and/or medical experts to make sure you get the care that you need.

You might have some new feelings about your illness or thoughts about things after the interview. We can help you find a professional to talk to if you feel distressed by any new feelings that come up during or after the interview.

WITHDRAWAL OF STUDY DATA

You can decide to withdraw any information collected during the interview at any time before the analysis is complete (probably about 2 months after the interview). It may be impossible to remove any information we learn in the interview during our analysis.

Whether you decide to keep your data in the study or not, we will be doing our absolute best to minimize anything that would identify you.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will get to keep any art supplies that you use to create your artwork. The artwork will be part of our analysis. If you want to keep your artwork, we can return it after the study is over or take a photo of it.

Reimbursement for out-of-pocket expenses:

You will be reimbursed for the cost of parking for on-campus interviews.

WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

The researchers will do their best to make sure that your private information is kept confidential. Information about you will be handled as confidentially as possible but participating in research may involve a loss of privacy and the potential for a breach in confidentiality. The research team will handle data according to the Data Management Plan as outlined below:

- All paper documents with your information (e.g., contact information, interview notes) will be stored in a locked cabinet. Only the study team will have access to it.
- Electronic documents and data (e.g., recordings, transcripts) will be stored on OneDrive for Business, which is password protected and encrypted. Only the study team will have access to it.
- Interviews will be transcribed by a member of the study team. No outside individuals will have access to your data.
- All interviews will take place in a private space.

The study team will make every effort to maintain the confidentiality of your research records, to the extent permitted by law (e.g., disclosed child abuse or neglect must be reported) and legal requests (e.g., court applications seeking disclosure of research data are possible).

- The researchers will do everything that they can to make sure your information and data is kept private/confidential.
- All identifying information (e.g., names, personal descriptors, specific location names) will be removed from the transcripts by the research team.
- The researchers will only collect the information we need for the study.

- The study team may include information about your diagnosis or age in publications or presentations.
- Some serious illnesses are quite rare and unique. It is possible that someone might be able to identify you due to your diagnosis. The research team will do our best to keep your identity as private as possible.
- Families of children with serious illness may know each other. It is possible that someone might be able to identify you, despite our best efforts.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

- After the study is done, we will still need to securely store your records/data that was collected as part of this study. We will need to keep your data and study records for 5 years. Records include research data, recordings, photographs, and consent forms. Study data/records will be destroyed after 5 years.
- Recordings from the interview will be stored in a secure location/password protected computer. They will only be accessible by the study team. Recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed.
- Pictures of artwork and quotes from this study may be used in future presentations or publications.

Any future use of this research data is required to undergo review by a Research Ethics Board.

RESEARCHER CONFLICTS OF INTERESTS

There are no researcher conflicts of interest to report.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

- ❑ YES
- ❑ NO

IF I SUFFER A RESEARCH-RELATED INJURY, WILL I BE COMPENSATED?

It is important that you tell the researchers if you believe that you have been injured because of taking part in this study. We do not expect that you will be physically injured during the interview.

In the event that you suffer injury as a result of participating in this research, no compensation will be provided to you by the University of Calgary, Alberta Health Services or the Researchers. However, you still have all your legal rights. Nothing said in this consent form alters your right to seek damages.

WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:

You may contact Kate Wong at [redacted] or [redacted] with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB):

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

If you would like to see the study results, a link to the publication can be sent. You will be notified if any community presentations will be held.

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.

- You have a right to have all of your questions answered before deciding whether to take part.
- Your decision will not affect the standard medical care you receive.
- If you decide to take part, you may leave the study at any time up until analysis (about 2 months after the interview)

HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

SIGNATURE OF STUDY PARTICIPANT

_____

Name of Participant

_____ _____

Signature of Participant Date

SIGNATURE OF PERSON OBTAINING CONSENT

_____ _____

Name of Person Obtaining Consent Contact Number

_____ _____

Signature of Person Obtaining Consent Date

A signed copy of this consent form has been given to you to keep for your records and reference.

Appendix E: Parental Consent Form

UNIVERSITY OF CALGARY

PARENT CONSENT FOR CHILD TO PARTICIPATE IN RESEARCH

TITLE: Understanding the Experiences of Children with Serious Illness through their Artistic Forms of Expression

SPONSOR: University of Calgary, Faculty of Nursing

INVESTIGATORS:

Kate Wong RN, BN, Doctoral Student Post Candidacy, Faculty of Nursing, University of Calgary [redacted]

Dr. Nancy Moules, Faculty of Nursing, University of Calgary [redacted]

INTRODUCTION

Dr. Nancy Moules, Kate Wong (RN BN, Doctoral student), and associates from the Faculty of Nursing at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about, and what your child's participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

Your child was identified as a possible participant in this study because their diagnosis of, and experiences of living with, a serious illness. Your child's participation in this research study is voluntary.

WHY IS THIS STUDY BEING DONE?

The purpose of this study is to learn about living with a serious illness in childhood. Children who have serious illness have important insights that can inform their care. The information from this study will help adults who care for children with serious illnesses. This study may also help future children cope with serious illness.

Sometimes children have a hard time talking about living with serious illness. It might be that they do not have a full vocabulary yet. It may also be that their experiences are hard to explain with words. To address this, we will use art in our interviews to help children express themselves.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 10 children and teenagers will take part in this study through the University of Calgary.

WHAT WILL HAPPEN IF MY CHILD TAKES PART IN THIS RESEARCH STUDY?

If you agree to allow your child to participate in this study:

- We would like to sit with your child and ask them questions for about 1 hour. You may be there during the interview if you would like to be. The interviews will be tape-recorded and transcribed for analysis.
- We will meet at your house or at the University of Calgary. We will require proof of vaccination and continuous masking for on-campus interviews. Your child will not have to miss school to meet with us.
- If in-person interviews are not allowed due to the COVID-19 pandemic, the interview can happen over Zoom video chat. A member of our study team will send you a Zoom link, password, and instructions over email. Zoom recordings will be saved and stored in a way that protects your child's information.
- We will ask your child some questions about what it is like to be a child who has a serious illness or condition. The questions will be about their life, what matters to them, and things they think we should know.
- Your child will decide if they want you to be present during the interview, or if they would prefer to talk to our study team alone. The study team will talk to you and your child about this before the interview.
- When we talk, we will be asking your child to make some art to help us understand them better. Art can be things like a picture, painting, photo, or sculpture. Your child can pick what they want to make.

HOW LONG WILL MY CHILD BE IN THE RESEARCH STUDY?

Participation will take a total of about 1 hour of your child's time. We will meet at an agreed upon time and place. We may follow up by telephone or email if we have more questions for them.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT MY CHILD CAN EXPECT FROM THIS STUDY?

- Talking about living with a serious illness can be hard for children and teenagers. The questions will be about their everyday lives, but some questions we ask might be hard to talk about. Your child does not have to answer any questions make them uncomfortable.
- Being interviewed and making art can be tiring for children with serious illness. Your child can stop at any time, or continue the interview without making art if they get tired.
- There are potential risks with meeting during the COVID-19 pandemic. To minimize risks, we will:
    - Call you the day before or morning that we will meet with you. We will use an Alberta Health Services form to ask questions about how you are feeling and screen for symptoms. The form is found online (https://myhealth.alberta.ca/journey/covid-19/Pages/COVID-Self-Assessment.aspx).
    - We will wear a mask when meeting with you and your child.
    - We will bring hand sanitizer for you and us to use.
    - We will sanitize all study equipment before and after each use.
    - We will follow physical distancing (2 m) when meeting with you.
    - Members of our study team are vaccinated.

ARE THERE ANY POTENTIAL BENEFITS TO MY CHILD IF THEY PARTICIPATE?

- There will be no direct benefit to your child from participating in this study. However, this study may help researchers learn more about their experiences. This study will inform care for future children with serious illnesses.
- You will be reimbursed for any parking costs.

WHAT OTHER CHOICES DOES MY CHILD HAVE IF THEY DO NOT PARTICIPATE?

You are free to say no to your child participating in the study. If you decide against your child taking part in this study, it will not reflect badly on them.

CAN MY CHILD STOP BEING IN THE STUDY?

Yes. Your child can stop the interview anytime. Tell the researchers if you are thinking about stopping or decide to stop your child's participation.

CAN THE RESEARCHERS REMOVE MY CHILD FROM THIS STUDY?

The researchers may end your child's participation in this study for a number of reasons, such as if their safety and welfare are at risk. The researchers or the study sponsor might also decide to stop the study at any time. We do not anticipate that your child's safety or welfare will be at risk.

WHAT IF RESEARCHERS DISCOVER SOMETHING ABOUT MY CHILD?

During the study, the researchers could learn something about your child that they didn't expect. For example, the researchers may find out that your child has new symptoms that they had not

told anyone about yet. You will be helped with arranging appropriate follow up and care for your child.

I consent for the researchers to share findings about my child with me:

- ❑ YES
- ❑ NO

WITHDRAWAL OF STUDY DATA

You can decide to withdraw any information collected during the interview at any time before the analysis is complete. It may be impossible to remove any information we learn in the interview during our analysis.

WILL MY CHILD BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

Your child will get to keep any art supplies they use to create their artwork. Their artwork will be part of our analysis. If your child wants to keep their artwork, we can return it after the study is over or take a photo of it.

Reimbursement for out-of-pocket expenses:

You will be reimbursed for the cost of parking for on-campus interviews.

WILL INFORMATION ABOUT MY CHILD'S PARTICIPATION BE KEPT CONFIDENTIAL?

The researchers will do their best to make sure that your child's private information is kept confidential. Information about your child will be handled as confidentially as possible but participating in research may involve a loss of privacy and the potential for a breach in confidentiality. The research team will handle data according to the Data Management Plan as outlined below:

- All paper documents with your child's information (e.g., contact information, interview notes) will be stored in a locked cabinet. Only the study team will have access to it.
- Electronic documents and data (e.g., recordings, transcripts) will be stored on OneDrive for Business, which is password protected and encrypted. Only the study team will have access to it.
- Interviews will be transcribed by a member of the study team. No outside individuals will have access to your child's data.
- All interviews will take place in a private space.

The study team will make every effort to maintain the confidentiality of your child's research records, to the extent permitted by law (e.g., disclosed child abuse or neglect must be reported) and legal requests (e.g., court applications seeking disclosure of research data are possible).

- The researchers will do everything that they can to make sure your child's information and data is kept private/confidential.
- All identifying information (e.g., names, personal descriptors, specific location names) will be removed from the transcripts by the research team.
- The researchers will only collect the information we need for the study.

- The study team may include information about your child's diagnosis or age in publications or presentations.
- Some serious illnesses are quite rare and unique. It is possible that someone might be able to identify your child due to their diagnosis. The research team will do our best to omit this information.
- Families of children with serious illness may know each other. It is possible that someone might be able to identify your child, despite our best efforts.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

- After the study is done, we will still need to securely store your child's records/data that was collected as part of this study. We will need to keep your child's data and study records for 5 years. Records include research data, recordings, photographs, and consent forms. Study data/records will be destroyed after 5 years.
- Recordings from the interview will be stored in a secure location/password protected computer. They will only be accessible by the study team. Recordings will be kept until they have been transcribed (turned into written records), and then they will be destroyed.
- Pictures of artwork and quotes from this study may be used in future presentations or publications.

Any future use of this research data is required to undergo review by a Research Ethics Board.

RESEARCHER CONFLICTS OF INTERESTS

There are no researcher conflicts of interest to report.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask for my child to take part in other research studies.

- ☐ YES
- ☐ NO

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:

You may contact Kate Wong at [redacted] or [redacted] with any questions or concerns about the research or your child's participation in this study.

Conjoint Health Research Ethics Board (CHREB):

If you have any questions concerning your child's rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

If you would like to see the study results, a link to the publication can be sent. You will be notified if any community presentations will be held.

WHAT ARE MY CHILD'S RIGHTS IF THEY TAKE PART IN THIS STUDY?

Your child's participation in this study is a choice. You can choose whether or not you want your child to participate. Whatever decision you make, there will be no penalty to you or your child.

- You have a right to have all of your questions answered before deciding whether your child will take part.
- Your decision will not affect the standard medical care your child receives.
- If you decide for your child to take part, they can leave the study at any time.
- Your child may refuse to answer any questions that they do not want to answer and still remain in the study.

HOW DO I INDICATE AGREEMENT FOR MY CHILD TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child's participation in the research project and agree for them to participate as a participant. In no way does this waive your or your child's legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

_____

Name of Child

SIGNATURE OF PARENT OR LEGAL GUARDIAN

_____

Name of Parent or Legal Guardian

_____ _____

Signature of Parent or Legal Guardian Date

SIGNATURE OF PERSON OBTAINING CONSENT

Name of Person Obtaining Consent	Contact Number
Signature of Person Obtaining Consent	Date

SIGNATURE OF THE WITNESS

Name of Witness	
Signature of Witness	Date

A signed copy of this consent form has been given to you to keep for your records and reference.

Appendix F: Guiding Questions for Interviews

It should be noted that hermeneutics research does not work from a strict set of interview questions, but rather the interview is allowed to take a conversational, yet topic focused, format, shaping itself from the responses to questions asked. The focus is on the topic under study and remains central to the conversation, rather than being directed by a list of questions. The interviewer needs to be attentive and responsive to the process. Please see Chapter Six in *Conducting Hermeneutic Research: From Philosophy to Practice* (Moules et al., 2015) for a detailed discussion of how to conduct interviews in hermeneutic research, as well as examples from transcripts of hermeneutic interviews. This interview guide has been adapted from Dr. Moules, who is the Primary Investigator and graduate student researcher's supervisor.

When you thought about coming here today to talk about this topic, what (if any) were the things you were excited to tell me? Is there anything you are nervous about? (This question invites the recounting of the child's illness history; the interviewer will elicit the story of the child's illness progression)

After the context of the child's illness story is elicited, the interviewer narrows the focus to the current state of the child's illness and how it shapes their understanding of life, and, if appropriate, their understanding of death. *Can we talk about when you first learned about your illness? What do you remember about that time? What were you scared or unsure of? How did your illness change how you think about your life? Can you describe how your illness changed/shaped your life?*

Once at this stage in the interview, the interviewer starts to mine for more details around the changes that have occurred, and the line of questioning could go in many different directions. Some possible directions include:

You mentioned that you were scared about the illness being so bad that you could not play or go to school, can you tell me more about that? What kinds of things do you think of when you think about having this illness? What is important to you now that you have this illness that did not seem as important before?

What is it like growing up/being a kid with [name of illness or disease]? How do you know that your illness is getting better or worse? What are some things about your illness that you worry about?

You mentioned that sometimes you are so sick you have to stay in the hospital for a long time; what do you think about when you are in the hospital? Have you ever had a scary experience in the hospital? What made that experience less scary or better?

Some children may not be comfortable talking about dying or their own death, but if the child brings it up or is comfortable talking about it, some possible lines of questioning might include:

What do you think will be important to you when you are dying? What do you think a "good death" looks like? What do you think death means? What do you think is different about dying as

a kid than dying as an adult? Who do you talk to about your hopes and fears? How do you cope with knowing that you are dying?

Because each interview will be unique, it is impossible to predict all the possible directions that the research conversation could take. It is important for the interviewer to be skilled and responsive.

Some general final questions might include:
What are the two most important things about being a kid who has a serious illness that you think I (as a researcher) should know? (for what is high on their list of priorities on this topic)

Do you think there is anything that we (as adults and healthcare providers) could do to be helpful in supporting children who have serious illnesses who may die or are dying?

Is there anything that you were hoping I would ask you that I missed? Do you have anything else that you think is important for me to know?