

Raising Children: Philosophical Hermeneutics and Children with Life-Limiting Illness

Katherine Wong

Abstract

Children are authentically hermeneutic beings; they are not only open to the possibility that the other may be right, but often expect that the perspective of the other is correct. The hermeneutic tenets of history, tradition, and authority shape how children and childrearing are perceived in society. Children are often regarded as in-progress, and this has implications for children diagnosed with life-limiting illness and the pediatric palliative healthcare providers that care for them. Children who experience unique phenomena, such as dying in childhood, may possess an authority gained through superior insight that adults often overlook. Art is a common language that can be used in hermeneutic research to better understand children's experiences of life-limiting illness. Researchers who work with children must raise the value of children's perspectives, find a shared language to foster understanding, and enter the circle with the same genuine hermeneutic spirit that children exemplify.

Keywords

hermeneutics, children, authority, art, pediatric palliative care

Play, art, talking stuffed-animals, and story-telling are part of the language of children (Aasgaard & Edwards, 2012; Bluebond-Langner, DeCicco, & Nordquest Schwallie, 2012; Sourkes, 2018; Sourkes et al., 2005) and capture the essence of a child's reality, expressed in a way that must be interpreted to be understood. Philosophical hermeneutics is "the art of understanding and of making oneself understood" (Zimmermann, 2015, p. 2), and is used as a underpinning in qualitative research that seeks to better understand the experience of another (Moules, McCaffrey, Field,

Corresponding Author:

Katherine Wong, RN, Master's Student
Email: katherine.wong1@ucalgary.ca

& Laing, 2015). In this paper, I discuss how the hermeneutic tenets of history, tradition, and authority influence the position of children in society; childhood as a hermeneutic state of being; the address of children with life-limiting illness (LLI); and how hermeneutic interpretations of the language of children with LLI can offer new insight into their experiences. Fusing art therapy techniques commonly used in Pediatric Palliative Care (PPC) with hermeneutic interpretation, I will explore how adults might understand the language of art for children who are dying.

Thrown at Birth

Humans are self-interpreting beings who navigate a complex world of meaning relations into which we are “thrown at birth” (Zimmermann, 2015, p. 35): cast into the hermeneutic circle, immediately situated in our environment, and surrounded by family, friends, and teachers who contribute to our knowledge of that environment. Understanding the world is a matter of interpreting through the piecing together of things such as words, symbols, and experiences into a meaningful whole (Zimmermann, 2015). Hermeneutic philosopher, Hans-Georg Gadamer, connected the importance of history, tradition, authority, and language in shaping our understanding of the world (Zimmermann, 2015). He posited that we cannot come to an understanding of anything from an objective, outside position; we cannot step outside of the context of our reality to view anything from a blank slate (Moules et al., 2015; Zimmermann, 2015). Rather, history provides the foundation upon which understanding is made possible. Our ability to interpret and understand the world is “always already” situated in a complex web of previously organized and interpreted conceptions – or traditions – within which we live and think (Moules et al., 2015; Zimmermann, 2015). Authority is the recognition of superior insight, ability, and knowledge in the other (Gadamer, 1996). In this positive sense of the word, authority is not meant as the exertion of power over another; it is the expectation that one’s authority will benefit the other. For example, the superior knowledge of a physician informs his or her ability to help a patient. Tradition and authority are connected to our understanding of the world, insofar as understanding “always draws from the handed-down experience of tradition through recognized authorities” (Zimmermann, 2015, p. 45). One may think for oneself, but one cannot think by oneself, as it is impossible to isolate one’s interpretations of reality from the authorities and traditions that construct it (Zimmermann, 2015).

A genuine experience is derived from an encounter that challenges our *pre-understanding* of the world as we have interpreted it, something new that refutes the expectations we have established from our initial construction of reality (Moules et al., 2015; Risser, 2019a; Zimmermann, 2015). The new experience presents its own truth against our previous understanding (Risser, 2019a). The repositioning of the familiar and unfamiliar – our becoming experienced – calls for an openness to the other and the alien, and a humble acknowledgement that what we understand may be revised by our encounters with something new (Moules et al., 2015; Risser, 2019a; Zimmermann, 2015). Early childhood and childrearing are a confluence of tradition, history, authority, and experience: a child’s main pursuit is to interpret a new and unfamiliar world by integrating their own experiences with the authority and handed-down traditions of the adults in their lives.

Expanding the Circle

Hermeneutics is new to me; my beginning interpretations of hermeneutics as a philosophy and research underpinning overlay the areas of my life where I consider myself to be more experienced. My career in PPC and pediatric nursing have a significant influence on how I interpret and understand my reality – I have been addressed by children with LLI and the way that they go about being in the world. My pre-understandings of children as innocent and amusingly naïve have been revised over the course of my career; children have been my wisest teachers. The experience of witnessing children confront death led me to question the position of children, communicating with children, and the experiences of children who are dying.

Language, Conversation, and Questions

A child's first word is not the beginning of language; it is the start of a child's ability to talk (Risser, 2019b). The word is always preceded by the child's interpretations of the world in which he or she occupies (Risser, 2019b). Reality presents itself to the child first, and language comes second to "re-present" the child's reality with words (Risser, 2019a, p. 4). Along with the ability to talk comes the opportunity to converse and ask questions, and my experience as a pediatric nurse has led to the expectation that a considerable amount of my time spent with a young child will be *full* of questions. Indeed, much of what young children encounter in their realities is experienced as something new or an added layer of complexity to a previous understanding.

The posing of a question is the recognition of the limitations of one's own knowledge on a subject, and the acknowledgement of the authority of the other, who is being questioned (Gadamer, 1996; Moules et al., 2015). Questioning requires humility and curiosity in order to recognize one's own ignorance and an openness to the unfamiliar. Genuine conversation, the process of arriving at an understanding, requires each person to be open to the other, and accept the perspective of the other is truly valid (Gadamer, 1960/2004).

The hermeneutic circle becomes quite intelligible when equated with the rapidly expanding horizons of young children and their efforts to interpret and understand their world. When young children ask questions, they are not only open to the possibility that the perspective of the other may be right, they *expect* that the other possesses superior insight. Children do not go about questioning with a conscious effort to be humble about their limitations, they are genuinely open to the other. The endlessly/perpetually curious and repetitive nature of a child's line of questioning is authentically hermeneutic, as it is a continual effort to reconcile his or her interpretations of reality along with the knowledge of their authorities. The process by which an adult interprets and understands his or her reality may have a level of sophistication that a child does not yet possess, but this should not imply that the child's reality is any less valid than that of the adult's. Historically, children's genuine hermeneutic nature has been misinterpreted for inferiority or lack of insight, and these traditions may have significant implications for parents and healthcare providers of children with LLI.

Childrearing and Childhood

Parents often serve as the main authority in a child's world. The concepts of tradition, history, and authority have a significant influence on childrearing practices in modern society. To *rear* is to "bring into being" or "to bring up" (rear, n.d.). To "raise" a child suggests that the parent is an authority, for their power and superior insight, and that the child's lower position can be elevated over time. There are social roles imbedded into the meaning of childrearing, placing the parent in the role of the nurturing superior, and the child as the subordinate. The history and tradition of childrearing has influenced the societal perception of children as deficient adults. Historically, adults have not acknowledged children's views to be of equal value, and often children are thought of as "in progress," best seen and not heard (Larcher & Carnevale, 2012).

Childhood is often regarded as the process of "becoming," and the precursor to, or absence of, mature rational capacity (Bluebond-Langner, 1978; Hatab, 2014). The traditional perception of childhood becomes problematic when a child is diagnosed with LLI. Children who are dying will not be raised, will not "become," and are thrown into experiences that force them to prematurely conceptualize things that would typically lie beyond their grasp developmentally (Bluebond-Langner, 1978; Sourkes, 1995). The experience of LLI in childhood challenges society's expectations of childrearing and of being raised, as what it means to be a child and what it means to be dying are conflicting concepts in Western culture (Wong, 2019b).

Thrown Out of the Circle

The beginning and end of life occurring simultaneously throws an assumed sequence of life out of order (Wong, 2019a): parents are not meant to outlive their child, palliative care programs for children should not need to exist, and, as Morgan (2009) stated, "Children, the hope and future for our society, are not supposed to die" (p. 87). Everything that history and tradition has taught about childrearing is thrown out of the realm of understanding with such a drastic disruption of the traditional succession of family life.

The perceived innocence and vulnerability of children influences how involved they are allowed to be in their care and decision-making at end of life, and how much information is shared with them (Larcher & Carnevale, 2012; Rahimzadeh et al., 2015; Stein et al., 2019). My work with children with LLI was often complicated by parental wishes to keep their child ignorant of the fact that he or she was dying. Historically, parents and healthcare providers have been unwilling to disclose information regarding a terminal prognosis to children, with the hope that their ignorance would protect them from the distress and anxiety that arise when one realizes their death is imminent (Larcher & Carnevale, 2012; Stein et al., 2019). While there has been a substantial change in practice over the past 70 years regarding information-sharing with children about their illness and prognosis (Stein et al., 2019), I frequently encounter families who adhere to the once-prevailing belief that children are better left unaware. However, it has been my experience that no matter how much information is withheld from children with LLI, many children have some level of uncertainty about whether they will continue to live, and may be explicitly conscious that they will die from their illness.

Children with LLI 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). Drastic changes in physical appearance, the ability to play and participate in care, and increasing pain and fatigue are examples of what Sourkes (1995) described as the “wisdom of the body” (p. 107), and provide the child with an impression of how sick he or she is. 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 in the intensity of their treatment (Bluebond-Langner, 1978; Sourkes, 1995; Stein et al., 2019). Children 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). Bluebond-Langner (1978) argued that children who are dying may maintain the pretense that they are ignorant of their situation because they understand and wish to uphold their social position as children, as the lesser being. However, childhood is more than a biological phenomenon or antecedent to adulthood: it is a social construction that is influenced by prevailing cultural, historical, and societal beliefs (Rahimzadeh et al., 2015). The prejudice of children’s realities as inferior and incomplete violates the hermeneutic principle that the perspective of the other is valuable, valid, and an opportunity for new understanding. In order to better understand the experiences of children with LLI, the value of children’s worlds must be raised, and adults must enter the conversation with humility and the same genuinely hermeneutic approach that children embrace to understand their reality.

Re-entering the Circle

Qualitative PPC literature is largely informed by studies that overwhelmingly represent the narratives of the parents of children with LLI and their healthcare providers, not from the first-hand account of children with LLI (Liben, Langner, & Bluebond-Langner, 2014; Rahimzadeh et al., 2015). Without adequate inquiry into the experiences of children with LLI, PPC providers have a limited ability to understand how current policies, literature, and practices affect pediatric patients in PPC (Rahimzadeh et al., 2015). Future research in PPC must respect that children have a central role in constructing and interpreting their worlds (Montreuil & Carnevale, 2016) and recognize, as Rahimzadeh 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). If researchers were to recognize children with LLI as authorities on dying in childhood, and re-enter the hermeneutic circle as adults with the same genuine openness that we once possessed as children, what new insights might we discover? What common language might we find to help us merge our horizons?

The position of the participant in hermeneutic research reflects the need to revise the prejudice of children as “becoming.” We do not come into being during our childhood, we are thrown into being at birth, into a world that “always already” has meaning for us to interpret (Zimmermann, 2015). A child who experiences LLI and the threat of death possesses superior insight of what it is like to be a child who is dying, insight that an adult is unlikely to have, simply because he or she has survived to adulthood. Children conceptualize death differently than adults (Bluebond-Langner, 1978; Bluebond-Langner et al., 2012; Sourkes, 1995), and their pre-understanding of the meaning of death may have a significant influence on how they experience LLI and dying.

To better understand the experiences and language of children who are dying, I must recognize a child with LLI as an authority on the topic, and be open to the possibility that he or she may know or understand something that I do not.

Understanding Through Art

PPC healthcare providers often use art therapy to allow children to convey their experiences of living with LLI, to assess coping styles and developmental maturity, and to capture the essence of their realities in the form of creative expression (Aasgaard & Edwards, 2012; Sourkes, 1995). Creative therapeutic approaches are recognised by children to be safe, familiar, and often enjoyable activities, which can be particularly important to children in clinical environments and when experiencing unfamiliar and distressing situations (Aasgaard & Edwards, 2012; Sourkes, 1995). Art therapy also allows children who may not have the vocabulary or ability to articulate their experiences with words to express themselves in a different form of language (Aasgaard & Edwards, 2012; Sourkes, 1995). Utilizing art therapy in a hermeneutic interview may assuage some of the concerns regarding participant vulnerability and the challenge of communication.

How might we understand the language of art for children who are dying? The question necessitates a hermeneutic lens for research, as it asks what artistic expression might reveal about the nature of a child's being in the world. Art and its ability to depict the more enigmatic truths of human life is an important characteristic of philosophical hermeneutics, as it encapsulates both the event of understanding – experiencing art – and of making oneself understood – creating art (Zimmermann, 2015). As a research methodology, hermeneutics provides an interpretive lens that allows the language of art to be weaved into the whole of the participant's story.

Conclusion

Understanding through interpretation is at the heart of philosophical hermeneutics (Zimmerman, 2015). Future research in PPC must recognize that children with LLI are an authority on the experiences of PPC patients, and that the worldviews of children are as valuable to PPC literature as the perspectives of parents and healthcare providers. In this paper, I have discussed how history, tradition, authority, and experience may influence children's realities and how they are positioned in their social roles. I have argued for the recognition of the superior insight of children with LLI, and the need for adults to re-enter the hermeneutic circle as authentically as children do. I concluded with a discussion on how art may be used as a common language in research in PPC so that the experiences of children with LLI can be better understood.

References

- Aasgaard, T., & Edwards, M. (2012). Children expressing themselves. In A. Goldman, R. Hain, & S. Liben (Eds.), *The Oxford textbook of palliative care for children* (2 ed.; pp. 101-116). Oxford, UK: Oxford University Press.
- Bluebond-Langner, M. (1978). *The private worlds of dying children*. Princeton, UK; Princeton University Press.

Bluebond-Langner, M., DeCicco, A., & Nordquest Schwallie, M. (2012). Children's views of death. In A. Goldman, R. Hain, & S. Liben (Eds.), *The Oxford textbook of palliative care for children* (2 ed.; pp. 68-78). Oxford, UK: Oxford University Press.

Gadamer, H.-G. (1960/2004). *Truth and method* (J. Weinsheimer & D. G. Marshal, Trans.). London, UK: Continuum.

Gadamer, H.-G. (1996). *The enigma of health*. Stanford, CA: Stanford University Press.

Hatab, L. J. (2014). Dasein, the early years: Heideggerian reflections on childhood. *International Philosophical Quarterly*, 54(4), 379-391. doi: 10.5840/ipq201410619

Holloway, I., & Galvin, K. (2017). *Qualitative research in nursing and healthcare* (4 ed.). Ames, IA: Wiley Blackwell Publishing.

Larcher, V., & Carnevale, F. A. (2012). Ethics. In A. Goldman, R. Hain, & S. Liben (Eds.), *The Oxford textbook of palliative care for children* (2 ed., pp. 35-49). Oxford, UK: Oxford University Press.

Liben, S., Langner, R., & Bluebond-Langner, M. (2014). Pediatric palliative care in 2014: Much accomplished, much yet to be done. *Journal of Palliative Care*, 30(4), 311-316. doi: 10.1177/082585971403000414

Montreuil, M., & Carnevale, F. A. (2016). A concept analysis of children's agency within the health literature. *Journal of Child Health Care*, 20(4), 503-511. doi:10.1177/1367493515620914

Morgan, D. (2009). Caring for dying children: Assessing the needs of the pediatric palliative care nurse. *Pediatric Nursing*, 35(2), 86-92. Retrieved from <http://www.pediatricnursing.net/ce/2011/article35086090.pdf>

Moules, N. J., McCaffrey, G., Field, J. C., & Laing, C. M. (2015). *Conducting hermeneutic research: From philosophy to practice*. New York, NY: Peter Lang.

Rear. (n.d.). Online etymology dictionary. Retrieved from: https://www.etymonline.com/word/rear#etymonline_v_7344

Rahimzadeh, V., Bartlett, G., Longo, C., Crimi, L., Macdonald, M. E., Jabado, N., & Ells, C. (2015). Promoting an ethic of engagement in pediatric palliative care research. *BMC Palliative Care*, 14(50), doi:10.1186/s12904-015-0048-5

Risser, J. (2019a). When words fail: On the power of language in human experience. *Journal of Applied Hermeneutics*. Article 6. Retrieved from <https://journalhosting.ucalgary.ca/index.php/jah/index>

Risser, J. (2019b). Speaking from silence: On the intimate relation between silence and speaking. *Journal of Applied Hermeneutics*. Article 7. Retrieved from <https://journalhosting.ucalgary.ca/index.php/jah/index>

Sourkes, B. M. (1995). *Armfuls of time: The psychological experience of a child with life-limiting illness*. London, UK: Routledge.

Sourkes, B. M. (2018). Children's experience of symptoms: Narratives through words and images. *Children (Basel)*, 5(4). doi:10.3390/children5040053

Sourkes, B. M., Frankel, L., Brown, M., Contro, N., Benitz, W., Case, C., . . . Sunde, C. (2005). Food, toys, and love: Pediatric palliative care. *Current Problems in Pediatric and Adolescent Health Care*, 35(9), 350-386. doi:10.1016/j.cppeds.2005.09.002

Stein, A., Dalton, L., Rapa, E., Bluebond-Langner, M., Hanington, L., Stein, K. F., . . . Bland, R. (2019). Communication with children and adolescents about the diagnosis of their own life-threatening condition. *Lancet*, 393(10176), 1150-1163. doi:10.1016/s0140-6736(18)33201-x

Wong, K. (2019a). *Holding both: A conceptual analysis of duality in pediatric palliative care*. Unpublished manuscript, Faculty of Nursing, University of Calgary, Calgary, AB, Canada.

Wong, K. (2019b). *Unspeakable, unspoken, and unheard: Hermeneutics and pediatric palliative care*. Unpublished manuscript, Faculty of Nursing, University of Calgary, Calgary, AB, Canada.

Zimmermann, J. (2015). *Hermeneutics: A very short introduction*. Oxford, UK: Oxford University Press.