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Challenging child development theory on the understanding of death : learning through the experiences of child life specialists

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CHALLENGING CHILD DEVELOPMENT THEORY ON THE UNDERSTANDING
OF DEATH; LEARNING THROUGH THE EXPERIENCES OF CHILD LIFE
SPECIALISTS

by

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A major research paper

presented to Ryerson University

in partial fulfillment of the
requirements for the degree of

Masters of Arts

in the program of

Early Childhood Studies

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Abstract

The purpose of this research was to review the experiences of Child Life Specialists, to determine whether or not children with a terminal illness have a more advanced knowledge of death than traditional child developmental theory suggests. This research was a qualitative design in the form of a questionnaire and examined the experiences of five professional Child Life Specialists in the Greater Toronto Area. The findings revealed that Child Life Specialists have found that there is a difference of understanding of death between a healthy and terminally ill child. This information could lead to better practices for pediatric palliative care by providing those who work with palliative children, a better understanding of their perceptions and understanding of death.

Keywords; child development, death, child's understanding, child life specialist, palliative care, end-of-life

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Table of contents

Abstract	iii
Acknowledgements	iv
General Introduction	1
Chapter 1	6
Introduction	6
What do children understand? Death and child development theory.	7
Piaget's Cognitive Development Theory	8
Bronfenbrenner's ecological systems theory	9
Age and irreversibility; a child's understanding	10
Death experience	11
Voices of dying children	12
Children and Grief	14
Palliative and End of life Care	15
Child Life Specialists	16
Conclusions	17
Chapter 2	19
Introduction	19
Subjects and Design	20
Risk management	22
Confidentiality	22
Results	22
Questionnaire responses	23
Experience and education	23
Experience working with dying children	24
Child Life Specialists' perception of traditional theory	25
Differences between a sick and healthy child's perception of death	26
Challenging traditional theory	26
Discussion	27
Limitations	29
Implications for further research	30
References	31
Appendices	37

List of appendices

Appendix 1 – Letter to Members of Child Life Interest Group.....	37
Appendix 2 – Questionnaire sent to Child Life Specialists.....	40
Appendix 3 – Consent Agreement.....	43

General Introduction

Palliative care has changed and progressed in recent years to include the treatment of children (Donnelly et al, 2005). There has been a shift in traditional adult centered palliative care in order to service the pediatric palliative care population with end of life issues. In fact the need to improve the care of palliative children and their families is now seen as “urgent” (Hynson et al, 2006). The shift to pediatric palliative care places great emphasis on treating the whole mind and body in end of life issues. In order to ensure that professionals and caregivers have the most current support and education regarding palliative care, it is important to examine the current theories and approaches used to explain death to children. How can we best serve a population using developmental theories that may not be completely applicable to that population? Does traditional child development theory take into account the voices of sick children? Are Child Life Specialists (child development experts in hospital settings) equipped with appropriate developmental theory to explain death to sick and dying children? Is there one theory that can help to make the transition to death and palliative care the most effective for the child that it possibly can be? This research strives to begin to answer these questions.

Child Life Specialists are child development experts that use their knowledge of the child to help the child cope in stressful settings (Child Life Council, 2008). A major responsibility of a Child Life Specialist is to help a child cope with illness and hospitalization (Child Life Council, 2008). The Child Life Specialist often uses play to facilitate coping with the child’s illness, condition or needs, explain hospital procedures, and explore a child’s questions and/or misconceptions. The use of non-invasive play techniques designates the Child Life Specialist as a “safe” person. Children often respond

to Child Life Specialist by having conversations and/or disclosing information that they may not disclose to others. Past experiences have revealed this to include children who are terminally ill talking about their own impending death. Often the children who have these conversations are younger than previously anticipated by child development experts.

There are two main developmental theorists that have been very influential in explaining a child's ability to understand death in current research. It is widely believed that the basis of a child's understanding of death rests upon two things: their development and their experience with death (Clinical Centre National Institute of Health, 2006). The two theorists that represent these points are Jean Piaget with his cognitive development theory and Urie Brofenbrenner with his socio-cultural Ecosystems theory (Hunter & Smith, 2008).

Maria Nagy was a pioneer in the examination and understanding of children and death. She recognized that there was very little attention paid to a child's understanding of death in prior research (Nagy, 1948). In her subsequent research, Nagy determined that a child's understanding of death was related to age (Kenyon, 2001). These findings were later supported by the research fueled by the Piagetian cognitive framework that stated that each child goes through a sequence of developmental stages. According to Piaget, there are four stages that a child goes through in order to develop more concrete, mature and rational thinking. As children get older, their thinking progresses through, first, the sensory motor stage; second, the pre-operational stage; third, the concrete operational stage; and finally, in adolescence, the formal operations stage (Gallagher & Reid 2002,

Day 1981). One can then assume, that the more mature their cognitive development, the more mature their understanding of death.

Much of the research regarding a child's understanding of death has been based on the research and theory of Piaget (Hunter & Smith, 2008). A distinguishing feature for examining his theories and determining where, developmentally, children should be, has been age. Similar research findings have been produced in various research studies. Urie Bronfenbrenner's ecosystems theory can be used to explain the fairly recent research trend that examines death experience as a mitigating factor in a child's understanding of death (Hunter & Smith, 2008, Kenyon, 2001).

Bronfenbrenner examines outside influences that can help to shape a child's development. He focuses specifically on four systems that influence the child; the microsystem, the mesosystem, the exosystem and the macrosystem (Harvey & Dillabro, 2004). The microsystem involves direct influences on the person's life such as relationships in their personal surroundings (Feinstein et al 2008). The mesosystem involves the interrelations between the microsystems (Bronfenbrenner 1977). For example the mesosystem would examine the relationship between parents and peers (Feinstein et al 2008). The context of the exosystem is an extension of the mesosystem without directly involving the child (Bronfenbrenner 1977). Finally the macrosystem is a representation and influence of the person's overall culture and social structure (ibid 1977). Having said this neither Piaget nor Bronfenbrenner focused on a sick child's understanding of death.

While, the topic of children and death has been highly examined (Slaughter, 2005, Reilly, Hasazi, and Bond, 1983) there is little research regarding a sick child's perception

of death. There has been a great deal of research and publications on children and death. One of the most influential and published authors on talking to children about death is Elisabeth Kubler- Ross. She has authored and edited numerous books for professionals and parents, on how to explain death to a child. Kubler-Ross's (1983; 1981) work has been very influential on how to help a child effectively deal with grief and loss. She has written books on children and dying, with a particular focus on how to help bereaved parents deal with the loss of a child. However, what is not clear in regards to the works of Kubler-Ross is at what level does a sick child understand death?

Pediatric palliative care has evolved greatly to the point where it has come to be seen as a necessary service in the last twenty years (O'Leary et al, 2006). Palliative care includes and emphasizes open and honest communication with the family regarding the illness (Rallison, Limacher, & Clinton, 2006). However, there remains a stigma around or reluctance towards talking to children about death; and parents who choose to shelter a child from this topic can hamper the bereavement process (Giovanola, 2005). The denial of these difficult conversations at end of life makes the acceptance of death for professionals and family members extremely difficult (Norouzieh, 2005). This uncertainty can again be linked to a lack of empirical research examining a sick child's own understanding of death. Other than studies by Jay et al. (1987) and Bluebond-Langer (1977), which determined that a sick child's understanding of death is different than that of a healthy child, there has been a lack of research in this evolving field.

This study attempts to explore the experiences of terminally ill children in regards to their understanding of the permanence of death. By examining the views of Child Life Specialists and their work with terminally ill children this research will question

traditional developmental theory to determine what level of understanding sick children actually have of death. These findings may shed light on the fact that children with a terminal diagnosis may have a different perception of death than previously believed, and may lead us to rethink the currently used theories of Piaget and Bronfenbrenner, in order to better serve their needs. After all, the topic of children's death is such a difficult and delicate issue that it should command a great deal of research and better understanding in order to serve this population to the best of the ability of all involved. As a Child Life Specialist I have found a real disconnect between the theory used to explain a child's understanding of death and what knowledge is exhibited by the children that I work with. It is important to determine through research if this disconnect is felt across the profession. This research could be important in the training and educating of professionals because it questions whether or not a Child Life Specialist feels that traditional developmental theory in a child's understanding of death has prepared them for working with dying children. This is particularly important, because for children with a terminal illness, death is a reality at a young age. Ultimately, this information can be used by professionals and families to better understand the needs of dying children and enhance palliative care.

Chapter 1

A review of the research relating to the importance and depth of a child's understanding of their death

Introduction

Pediatric palliative care has emerged in the last few years as a necessary service for children and their families (O'Leary et al, 2006). Pediatric palliative care focuses on providing the best quality of life at end of life. This would include supporting parents and children through the difficult conversations regarding death. Parents have identified honest and open communication with the health care team as an essential need when their child becomes palliative (Rallison, Limacher, & Clinton, 2006). Support and education are also absolutely necessary for professionals and caregivers to be prepared to have these difficult conversations. However, the research that has been conducted on a child's understanding of death has primarily been based on developmental theories of healthy children. In order to examine what future research is needed regarding a sick child's understanding of death, it is important to examine what has been done in the field to date. This chapter will focus on what has been researched using developmental theory to explain a child's understanding of death, particularly in relation to Piaget's cognitive development theory and Bronfenbrenner's ecological systems theory.

What do children understand? Death and child development theory.

Although a child's concept of death was originally researched to examine the child's overall emotional reaction to the image of death (Anthony 1939: Schilder & Wechsler, 1934 as cited in Kenyon, 2001), a second wave of research examined a child's cognitive ability to understand death (Slaughter, 2005, Reilly, Hasazi, & Bond, 1983). Hunter and Smith (2008) and McEntire (2003) suggest there are some death concepts included in a child's understanding of death. The most important concepts that have been identified in children's understanding of death are irreversibility, non-functionality, causality and universality (Speece & Brent, 1984). Most research so far has been interested in the age at which a child understands one or more of these four concepts. While Piaget himself did not address the issue of a child's understanding of death, his cognitive development theory has provided most of the framework for research that examines a child's concept of death (Hunter & Smith, 2008, Kenyon 2001, Jay et al 1987 Cotton & Range, 1990, Speece & Brent, 1984, Reilly, Hasazi, & Bond, 1983). Of particular interest for researchers have been Piaget's concrete operational stage, and the development of the concepts of reversibility (Cotton & Range, 1990) and conservation (Hunter & Smith, 2008). Bronfenbrenner's ecosystems theory, once applied, has also provided a multilayered behavioral framework of a child's understanding of death. Bronfenbrenner's theory has been used to examine a child's understanding of death (Hunter & Smith, 2008). These two theoretical foundations have been very influential in publications on how to talk to children about death.

Piaget's Cognitive Development Theory

Piaget identified four stages in a child's development that correspond with a child's age. The first stage is the sensorimotor stage, from birth until age two (Gruber & Voneche, 1977). In this stage the infant is trying to make sense of the world around them him/her. This stage is subdivided into categories that involve the child developing his/her reflexes, reactions and early representational thought (Van Wagner, 2008).

Piaget's second stage in cognitive development is the pre-operational stage. This stage represents the ages two until six. A major development in this phase is language acquisition (Van Wagner, 2008). The important concept within this stage is that a child's thinking is perceived as non-logical and nonreversible (Huitt & Hummel, 2003). According to research using Piaget's theory, children likely cannot understand death in this stage because they have not yet developed the ability to conserve (the idea that quantity remains the same despite differences in appearance; Boeree, 2006), a determined pre-requisite to understanding death (Hunter & Smith, 2008). It is also believed that a child in this stage of understanding views death as temporary (Kerr, 2007).

The most explored stage in regards to a child's understanding of death is Piaget's concrete operational stage. This stage is identified as the age period between seven and eleven for children (Van Wagner, 2008). The most important concept developed by children in this stage is operational thinking. It is this stage that Piaget believes a child will begin to understand that his/her actions are reversible (Van Wagner 2008, Huitt & Hummel 2003). A concept believed to be developed in this phase, is the concept of universality. An example of universality would be the point when children realize that when they play a game, the rules apply to all those who are playing (White, Elsom &

Prawat, 1978). This is also the stage that a child begins to think logically (Atherton, 2005). The bulk of the research on children and death has determined that a child's understanding of death becomes present in this stage of development.

The final stage in Piaget's cognitive development theory is the formal operational stage. This represents a child's development from adolescence into adulthood. It is in this final stage that a child is able to think in abstract concepts (Van Wagner 2008, Huitt & Hummel 2003, Gruber & Voneche, 1977).

Piaget's theory is important because it suggests that a child cannot understand death until he or she advances into the correct developmental stage. According to Piagetian framework, it is the concrete operational stage where children begin to develop the ability to conserve (Hunter & Smith 2008, Gruber & Voneche 1977). Nevertheless it is important to report that some researchers have found that the ability to conserve has little to do with a child's understanding of death. Kenyon (2001) reported that "...results of experiments involving conservation tasks generally yielded inconclusive evidence of a relationship between cognitive developmental stage and death concepts" (p. 66).

Bronfenbrenner's ecological systems theory

Urie Bronfenbrenner's ecological systems theory was developed in the mid 1970's, about twenty five years after Piaget's work was first published. Bronfenbrenner (1979) believed that children develop in a multitude of social contexts. His theory is defined as "complex layers of environment, each having an effect on a child's development (Paquette & Ryan, 2001). This theory looks at a child's development within the context of the system of relationships that form his or her environment (ibid, 2001). It focuses on the assumption that "...the individual is a central figure in a series of nested

systems that encompass internal and external influences” (Harvey & Delfabbro, 2004, p. 9). Bronfenbrenner postulates that “...human development occurs through a complex reciprocal interaction between individuals and the people, objects, symbols and institutions around them” (ibid, 2004, p.9). Bronfenbrenner looks specifically at ecosystems that can influence a child’s development like; parent’s workplace, parent’s social networks, and community influences on the family (Bronfenbrenner, 1986). It is these influences that provide the framework for researchers to examine a child’s understanding of death through the Bronfenbrenner’s ecological systems theory. The influence that death experience plays in a child’s understanding of death would best be explained by Bronfenbrenner’s ecological systems theory. Death experience would include everything from the child’s exposure through movies or television to the death of a pet or loved one. Although Bronfenbrenner has provided an effective theory to examine the social contexts that can influence a child’s understanding of death, the validity of its importance regarding a child’s understanding of death is still questioned by some researchers. For example, Slaughter (2005) concludes that cognitive development remains the main factor that influences a child’s understanding of death.

Age and irreversibility; a child’s understanding

Age has been revealed to be a distinguishing factor in a child’s overall understanding of death. Interestingly, the only death concept found not concretely related to a specific age was irreversibility (also known as irrevocability) (Hunter & Smith, 2008). Childers and Wilmer (1971), interviewed children aged four to ten to measure their understanding of irreversibility and universality. They found that at approximately age seven, children had an understanding of the universality of death. Childers and

Wilmer (1971) also found through their study that children under age 10 were not certain of the irreversibility of death. Speece and Brent (1984) reiterated these findings in a review of the research regarding a child's understanding of death. Although Reilly, Hasazi and Bond (1983) found that children aged six and above had some general understanding of death, this has been found to be the youngest age able to grasp the concept. In a review of the research dedicated to determining a child's understanding of the individual components of death, Speece and Brent (1984) found the average age to be higher. They conclude that "...this body of data collectively yields a median and a modal age of acquisition of seven years for each component" (Speece & Brent, 1984, p.1678). According to these findings, the age of acquisition for a child's understanding of the irreversibility of death exists at age seven, coinciding with the beginning of Piaget's concrete operational stage. These findings remain consistent with Piaget's cognitive development theory and the capabilities represented by each stage.

Death experience

It is a realistic claim that a child's experience with death would increase overall knowledge of the concepts. There have been a few researchers who have examined what impact experiences with death have on a child's understanding of death. The research has shown that children who have experienced a death in their nuclear family have a greater understanding of death (Reilly, Hasazi & Bond). Similarly, Cotton and Range (1990) reported that children who had experienced the death of a family member were more likely to believe in their personal mortality. Bronfenbrenner himself researched the influence that a hospital can play on a child, but from the perspective of parental involvement on IQ and emotional distress (Bronfenbrenner, 1986). His theory has not

been used to specifically address the impact of the ecological systems on the understanding of death for the dying child.

Bluebond-Langer originally examined the voices of dying children in her book, *The Private worlds of dying children*, in 1977. Jay et al. (1987) replicated this research by examining the voices of children who were dying of cancer. Both studies found that dying children had a different understanding of death than healthy children.

Voices of dying children

Myra Bluebond-Langner (1978) has been influential in her work with dying children. She observed terminally ill children for a period of nine months, in a department of Pediatrics, over thirty years ago. The subjects she used were between the ages of three and nine and all were oncology patients. Bluebond-Langner used a form of play therapy in her conversations with children to determine their knowledge of their illness and death. She chose this technique to allow the children to reflect on their own behavior without having to undergo direct questioning. Bluebond-Langner determined in her research that the children she studied had a good grasp on their understanding of their illness and death. She wrote "All of the leukemic children whom I studied faced death with a great deal of understanding about the world of the seriously ill and their place in it" (1978, p. 135). She reported that age alone does not predict a child's understanding of death (Clunies-Ross & Lansdown, 1988), and claimed that the death of a child underlines the impact of social and cultural factors on the way we die and the way we allow others to die (Bluebond-Langner, 1978). She determined that children with a terminal illness are aware of their prognosis of death, but often do not share their knowledge for fear that their parents will no longer be with them (Ibid, p. 235). This finding was also reported

anecdotally by Kubler-Ross (1981). According to Bluebond-Langner it is this “mutual pretense” that often keeps parents and children from communicating about death (Himmelstein, 2006). Although this ethnomethodological research is important in examining the voices of dying children, researchers have been somewhat hesitant to use the findings because of the fear of over-generalizing the results (Clunies-Ross & Lansdown, 1988).

Clunies-Ross and Lansdown (1988) attempted to systematically examine the issue of a sick child’s understanding of death after the gap in research was identified by Spinetta (1977) and Koocher (1981). The idea was to replicate a study conducted by Lansdown and Benjamin in 1985 that examined a healthy child’s concept of death, this time repeating it with children with a terminal diagnosis. Clunies-Ross and Lansdown examined the death concepts of children aged four to nine, diagnosed with leukemia. The children were read a story about an old woman who dies, and then were asked questions about the story to gather an understanding of their concept of death. Secondly, they were read a special story about a child who has to be in and out of the hospital, and eventually dies. Although the story did not mention leukemia it was designed to be compatible with a child’s history with the illness. The same questions were then asked. Although there was no statistical difference between the overall knowledge of healthy children and sick children, there were statistical differences among the younger sick children’s concept of permanence of death. This finding supports Bluebond-Langner’s finding that age is not the only factor when examining a child’s understanding of death. Research conducted by Jay et al (1987) found similar results regarding the concept of permanence (irreversibility) in young children with cancer (aged 3-6). Jay et al. concluded that death

experience, and loss of a loved one enhanced a sick child's understanding of the concept of death.

Children and Grief

Elisabeth Kubler-Ross is a well published expert on children, grief and death who some argue has revolutionized the way Americans view death (Kramer, 2004-2005). She is widely known for her introduction of the five stages of grief: denial, anger, bargaining, depression and acceptance (Kramer, 2004-2005). Having written a dozen books, Kubler-Ross' work offers practical advice for caregivers and adults on how to help children grieve. She wrote her book *Children and Death*, as a response from bereaved families she had worked with (Kubler-Ross, 1983). The book contains the anecdotal histories and various letters from bereaved families (Kubler Ross, 1983, 1981). However the issue remains that these publications have not been written for dying or sick children. In addition, Kubler-Ross' work has faced a lot of controversy. As a psychiatrist, Kubler-Ross was loved by her patients, but her peers found her work to be anecdotal and unscientific (Clark, 2004). Furthermore, although there are anecdotal references to a child's understanding of their own death, Kubler-Ross makes no specific reference to child development or how a child responds to these stages of grief. In many of her talks, Kubler-Ross refers to the four quadrants of a human being; physical, emotional, intellectual and spiritual (Kramer 2004-2005). She identifies that a typically developing person only develops their spiritual quadrant as a teen but she recognizes that a child with a life-limiting illness would have a "super charged" spiritual side by the time of their death (Kramer, 2004-2005). This finding by Kubler-Ross could also be linked with a child's advanced knowledge of death. However there is no research that supports Kubler-

Ross's stages of grief with children or supports her anecdotal findings of a child's spiritual quadrant. With references to a sick child's understanding of death in comparison to a healthy child's understanding, there remains little concrete and applicable information for parents and professionals.

Palliative and End of life Care

In recent years, palliative care has emerged to try to meet the needs of dying children (O'Leary et al., 2006). Commonly defined, palliative care is "...an approach which improves the quality of life of patients and their families facing life-threatening illness" (Nuss, Hinds, & LaFond, 2005). Research studies have highlighted the need for integrated models of palliative and end of life care (Rushton, 2005). End of life care is healthcare that is provided when all curative options have been exhausted, and care is focused on preparing for an anticipated death (Nuss, Hinds, & LaFond, 2005). The palliative and end of life needs of dying children are finally beginning to be recognized as very different from those of dying adults (Truog, Meyer, & Burns, 2006, O'Leary et al. 2006, Meyer et al, 2006). The shift towards total mind-body care requires specific training and support for professionals and caretakers alike on how to effectively deal with the children and their families. There must be meticulous attention paid to language and word choice when dealing with the issue of pediatric death. Rallison, Limacher, and Clinton (2006) demonstrated that there is particular attention paid to the language in which we address the end of life issues for children, with an emphasis in the sensitivity taken with each word chosen. Not only is the language chosen an important factor but research has found (Meyer et al, 2006, Hinds et al, 2005) that parents with a dying child identified communication with honest and complete information to be a priority for their

child's end of life care. One major problem remains; professionals in the field feel ill equipped to help patients and their families in end of life and palliative care decisions. Nuss, Hinds, and LaFond (2005) reported that health care professionals have repeatedly reported feeling inadequately prepared to deliver poor prognostic information to children, adolescents, and their families, and to assist them in making end of life decisions. Although there has been specific research on the role nurses play in meeting the needs of pediatric palliative patients (Maunder, 2006, Rushton, 2005) there has been little research regarding that of a Child Life Specialists role.

Child Life Specialists

Child Life Specialists are trained professionals that help children and their families cope with life's most challenging health-related events. They provide emotional support and promote optimal development, particularly in the hospital setting (MacDougall, 2008, Child Life Council 2008a). They are considered experts in child development (Child Life Council 2008b), and typically have undergraduate and graduate degrees in child development (MacDougall 2008).

Child Life Specialists have become commonplace in most pediatric settings (American Academy of Pediatrics, 2006), but because the field is relatively new, it is important that Child Life Specialist use theory and evidence-based practice to keep up to date with the latest research on children and illness. The expertise and opinions of Child Life Specialists are rarely documented in research. One known study conducted by Nuss, Hinds and LaFond (2005) has included the voices of Child Life Specialist in pediatric palliative care. The study asked doctors, nurses, patient care technicians, social workers, psychologists, and child life workers in a pediatric oncology facility, their educational

and practice needs related to end of life care (Nuss, Hinds & LaFond, 2005). An overwhelming 60% reported that there was a lack of knowledge regarding palliative care services. This finding can be viewed as quite alarming when it is considered that these are the people who are supporting the patients and families with palliative and end of life care. The need to support staff members, particularly Child Life Specialists, with training and educating regarding pediatric palliative and end of life care is apparent.

Conclusions

There is no shortage of publications that examines a healthy child's view of death or how to help a healthy child through grief. Nevertheless, there are very few studies that examine the understanding of terminally ill children. With the push in end of life and pediatric palliative care, there is an increasing need to prepare those professionals who are working with palliative children. However the research shows that preparation and education for professionals are lacking. There have been many studies that have identified that a predominant factor in a child's understanding of death is age. Most studies have linked a child's understanding of death to Piaget's concrete operational stage. Another factor that has been identified in a few studies that has influence in shaping a child's understanding of death is their death experience. Bronfenbrenner's ecological systems theory has been linked to factors that would influence a child's understanding, such as the environment, death of a parent and death of a pet. Elisabeth Kubler Ross (1983, 1981) has written books with anecdotes and personal stories of the dying child, similar to the work of Bluebond-Langer (1978). Yet little has been documented since the work of Jay et al (1987) regarding the experience of a dying child, partaking in the hospital with those all around them dying. Does a dying child have an

advanced understanding of death? The new shift in pediatric palliative care means the developmental theories used to explore a child's understanding of death and shape the models on which professionals base their interactions with dying children needs to be evaluated for its effectiveness.

Chapter 2

A survey of experiences of Child Life Specialists regarding child developmental theory and a sick child's understanding of death

Introduction

In the field of Child Life, the role of a Child Life Specialist is to minimize the stress affiliated with hospitalization and illness. Child Life Specialists use their expertise to help explain the medical experience to children in a developmentally appropriate way (MacDougall, 2008). The modality used by these professionals is often play. Due to the non-invasive nature of play, children often see the Child Life Specialists as “safe” persons in whom they often confide. This results in children often disclosing their fears and questions about death to the “safe” Child Life Specialists. As defined in Chapter 1, the educational background of a Child Life Specialist includes vast knowledge of child development theory. This knowledge is used as a framework on which to base the interaction and socialization with the children they work with. However there remains little research on talking to a child about death. To date there has been little research regarding preparing a child for their own impending death. As noted in Chapter 1, traditional cognitive developmental theory has a child's understanding of death at approximately age 7-11 (Piaget's concrete operational stage). There are many measures of a child's concept of death, however for the purpose of this research we will be looking at the relation of age and death experience in children's understanding of death. The question remains as to whether or not these measures of a child's understanding of death include the voices of sick children. Would their understanding be any different than those of healthy children? If so, is it possible to link these findings to current child

developmental theory? This research will examine the experiences of Child Life Specialists, through a questionnaire to determine if they have found a sick child's understanding of death to be different than a healthy child's understanding and whether or not traditional child development theory has helped in this judgment. These findings may enhance the professionals' (Child Life Specialist and all those that work with children with a terminal illness) ability to help a child more effectively in the end stages of life, increasing the overall scope of pediatric palliative care. This research could also serve to demonstrate to parents and caregivers that the knowledge and understanding of a healthy child may differ from that of a sick child when it comes to the concept of death. This information could help to facilitate the very difficult conversations surrounding the death of a child. Ultimately, this information could lead to new theoretical approaches to children's understanding of death to ensure the voices of sick children are represented.

Subjects and Design

The subjects chosen to partake in this research were professional Child Life Specialists. This was the desired population because of their child development expertise and their experience with sick and terminally ill children. The goal was to reach as many Child Life Specialists that worked in the same region. The idea was that those who work in similar regions would have similar experiences working with families from diverse cultures. The target population was the Child Life Interest Group of the Greater Toronto Area (CLIGGTA). This is a self-mandated, professional group that is open to all Child Life Specialists within the region. The group meets quarterly to discuss relevant research in the field of Child Life. There are approximately twenty members in CLIGGTA and for

this reason an adequate sample of this group would be five responses or 25% of the group's members.

The most effective way to illicit the experience of Child Life Specialists was to conduct an open-ended, qualitative questionnaire. The questionnaire was chosen over an interview because it would take less time for the Child Life Specialists to complete. The research was also conducted in the summer and a questionnaire would offer the Child Life Specialists the flexibility to complete on their own time. As well, due to the delicate nature of the subject, a questionnaire would allow the Child Life Specialists control and privacy while completing their answers. The measures were taken in account to try and ensure optimal participation from the Child Life Specialists. The open-ended, qualitative design would allow for responses that were concrete and rich in detail, and those could only be reached by designing a qualitative questionnaire (Neill 2007, Neuman 2006). However, there were also questions that could only be answered quantitatively (ex. How long have you been a Child Life Specialist?). This required a combination of both quantitative and qualitative questions. The tool developed was a three-page questionnaire (Appendix A). The questionnaire consisted of yes/no questions, quantitative questions and both closed and open ended questions. It was designed to take no more than fifteen minutes to complete for the Child Life Specialist.

Method

In order to ensure participation was voluntary, an initial email was sent to the CLIGGTA introducing and outlining the purpose of the research (Appendix B). It was outlined that those who were interested in participating should contact the researcher to obtain a copy of the questionnaire and consent agreement (Appendix C). Once a person indicated that they were interested, a questionnaire and consent agreement was mailed to the participant along with a self-addressed, pre-paid envelope to return the documents once they were completed. Due to an initially low response rate, follow-up was required. This resulted in the initial email being re-sent to recruit more participants.

Risk management

Due to the extremely delicate subject of children and death, the risks of participation were outlined in both the initial letter to the prospective subjects and the consent agreement, to avoid any unnecessary harm. It was also reiterated that if the participants felt uncomfortable at any point in time, they could cease to participate in the research.

Confidentiality

There will be no names used in the study. The only person with access to the results is the primary researcher. The questionnaires will be destroyed once the research has been completed.

Results

There were six Child Life Specialists that responded to the initial email. One person opted not to participate in the study upon learning more about it. This resulted in

five questionnaires being mailed out to be completed. Initially only one response was completed and mailed back by the deadline. A second email was sent out to determine if anyone else was interested in participating. One more Child Life Specialist expressed interest, and another questionnaire was mailed out. After follow up emails were sent, five out of the six surveys were completed and mailed back, resulting in an 83% response rate.

Questionnaire responses

Experience and education

The Child Life Specialists have been working in the field from 2.5 years to 30 years with a median of 7 years and an average of 10.7 years. All of those participating have taken at least two course in child development as well as courses in adult and family development, children and health, exceptionalities in human development, and death studies.

Although two Child Life Specialists reported learning about a child's understanding of death in courses, the other responses were varied. One Child Life Specialist mentioned one course "Death and Dying". While another mentioned that they very briefly learned about a child's understanding of death through Piaget's cognitive development theory. The final response was the vaguest citing "touched on it briefly in undergrad and more in depth in post grad".

Experience working with dying children

There was very little uniformity among the responses to this question. Two of the respondents spoke of the general methods they use, such as open discussions, books, legacy building, expressive arts, medical play, and group discussions. One respondent reported starting with a discussion of lifetimes of all living things in order to assess the child's understanding before having a more specific conversation. One respondent discussed the preparation of loss of function and anticipation of upcoming changes. As well as discussion of end of life wishes, funeral arrangements, maintenance of connection of loved ones, and the importance of expressing messages including "goodbyes". The final respondent included families as the guide to the discussion of death, but expressed the importance of child-friendly language when doing this. This respondent also reported the importance of completing legacy projects.

a) With non- terminally ill children

All respondents reported using the same strategies of talking to children whether the child had a terminal illness or not. The only difference noted by two participants was that the conversations were to be initiated by the healthy child, and they would only answer questions. These two respondents identified that they would not initiate the conversation.

The questionnaires documented experiences of Child Life Specialists who worked with an average of 24.6 dying children. The Child Life Specialist with the least amount of experience working with a dying child had worked with 12 dying children. The Child Life Specialist with the most experience had worked with over 50 dying children.

The youngest age reported was 2.5 years. Two others reported age 3 being the youngest. While two more reported 4 years as the youngest child who had asked about death.

Table 1- Overall results of child life experience and the youngest a child has asked about death.

Participant	How long has the participant worked as a Child Life Specialist?	Youngest age a child asked about death	Did they have a life limiting illness?
A	7 years	4 years	Yes
B	10 years	3 years	Yes
C	2.5 years	4 years	No
D	4 years	2.5 years	No
E	30 years	3 years	Yes

Child Life Specialists' perception of traditional theory

Three of the five responses were in agreement that the average age a child understands the permanence of death may be age seven. However all of the respondents reported that there is more possibility for younger children to understand the permanence of death. All reported having conversations with children ages five and under, with concrete examples of a child's understanding of the permanence of death. Only one respondent mentioned that the conversation was about a child who was dying themselves. The others were in reference to another person's death.

Differences between a sick and healthy child's perception of death

Four out of the five Child Life Specialists reported noticing a difference between what traditional theory predicted a healthy child's perception of death should be, and what a sick child's actually was. Two reported that sick children are able to personalize their own death, whereas a healthy child was not able to do so. Two Child Life Specialists reported that children were able to recognize that they will die at a younger age. Another Child Life Specialist reported that the dying children he/she had worked with were not afraid of death, and had a sense of calm surrounding their own impending death. Interestingly, it was reported that the healthy children he/she worked with feared death. A final difference that was noted was that overall children who were dying had a more advanced knowledge of death than those who were healthy. Even the Child Life Specialist who reported that there was no difference between a sick and healthy child's perception of death, did find that a sick child was more accepting of death than a healthy child.

Challenging traditional theory

Four out of the five Child Life Specialists cited that a sick child's perception of death challenges traditional child development theory. The reasons they identified were a more advanced knowledge of permanence and personal mortality at younger ages, and less fear associated with death. The fifth Child Life Specialist felt that child development theory regarding a child's understanding of death was out of date. All of the Child Life Specialists said that traditional theory is helpful only when used as a baseline for working with children. However, all reported that the frameworks are too linear and not applicable

to all children. The only other tool noted that helped Child Life Specialists consistently with their work with dying children was their previous experiences.

Discussion

Research has suggested that the average age that a healthy child understands death is approximately age seven (Corr & Corr, 1996). However Bluebond-Langner (1977) and Jay et al (1987) have suggested that a sick child's understanding of death is different than that of a healthy child. There was general agreement among participants in this qualitative survey of experts working with dying children supporting the findings of Bluebond-Langner (1977) and Jay et al (1987). Perhaps most notably this study supported the notion that a sick child does have a different perception of death than a healthy child. Four of the five Child Life Specialists reported that there is a difference between the perception of death between a healthy child and a sick child. The respondents reported that they believed that a sick or potentially dying child has the ability to understand death with greater ability at a younger age compared to healthy children. This finding of an advanced knowledge of death for sick children can be attributed to the experiences of these children, particularly those that have seen their friends or acquaintances die or have spent a lot of time in the hospital.

Research has suggested that although a child's prior experience with death plays a factor in the understanding of death, cognitive level and maturity are the main factors in understanding death (Slaughter, 2005, Mishara, 1999). Contrary to this research, this study does not support such findings for those children who are terminally ill. The results provided from this study suggest that experience plays much more of a factor for a child's understanding of death than traditionally thought. One likely explanation for this

discrepancy is the difference in the hospital surroundings (i.e. environment) and the resultant awareness that children attain of deaths. The environment has played a factor in other studies that have examined a child's understanding of death. Mahon, Goldberg, and Washington (1999) conducted a study evaluating the death concepts of five to twelve year olds in a kibbutz in Israel. The researchers based their research on a Piagetian framework. The authors found that children had an accurate concept of death as young as six years of age. The environmental factors unique to the Israeli example were thought to play a role in the earlier understanding of death.

Experience and environment can also explain the difference between what traditional theory has found to be the age a child understands death and the younger ages reported by the Child Life Specialists'. Those who were exposed to illness themselves had a more advanced knowledge of death. For children with a potentially terminal illness, it is their experience in the hospital environment and their familiarity with the deaths of others that advance their knowledge of death. This is reflected in the responses that children with an illness, who were as young as three years old, asked about death. Although these findings challenge traditional child development theory, this would also lead one to believe that Bronfenbrenner's Ecological Systems theory to be more influential on a sick child's understanding of death than previously reported in research.

Another major finding within this study is the lack of uniformity in educational preparation and background and service provided among Child Life Specialists. There was much variation in the number of classes taken in child development, and on children and death. The courses taken varied from Child Life Specialist to Child Life Specialist and the consequence is inconsistent professional training and knowledge of child

development. The overall result is a lack of consistent preparation for Child Life Specialists when they work with terminally ill children. This lack of consistent preparation can be related to the inconsistencies reported among Child Life Specialists and how they talk to children (healthy and terminally ill) about death. It is important to note that experience can account for some difference as well.

One of the most important findings in this research is the evidence that traditional child development theory regarding a child's understanding of death is outdated. There remains a huge disconnect between what theorists perceive a child's understanding to be and what Child Life Specialists are experiencing in the field. The theory is perceived to be linear and not applicable to most children. This requires action on the part of Child Life Specialists' and other professionals who work with sick and dying child to develop a framework that eliminates this disconnect. This will enable those professionals to better serve the pediatric palliative population and their families.

Limitations

The number of participants willing to take part in the study was quite limited. Because of this small sample size, it can be argued that the responses may not be reflective of the general Child Life Specialist population. Also on the survey, there were no questions asked about the Child Life Specialist's cultural background. The approach a Child Life Specialist has when working with a dying child may vary with culture and religion. Had there been questions asked explanations could be made to account for the differences between each Child Life Specialists professional practice and their own personal beliefs.

Implications for further research

With the information that children with an illness may have the capacity to understand death at an earlier age than traditional theories would lead us to believe, due to their experiences and environment, the next step could be to talk to children who are ill about their perception of death. In order to advance the current findings, the subjects would need to be under the age of seven. The perception of death of a sick child needs to be researched further to help to develop a more appropriate theory to help professionals and family member's best meet the needs of the dying child.

Another area that needs to be researched further is the understanding of death across cultures. There is little research accounting for a child's understanding of death that takes into account the cultural values and beliefs of the child and family.

Within the domain of Child Life Specialists, researchers could further examine the exact preparation and education that the Child Life Specialist receives to work with dying children. It would also be interesting to determine whether they feel prepared to carry out this important aspect of their role.

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Appendices

Appendix 1 – Letter to Members of Child Life Interest Group

May 2008

Dear; Members of the Child Life Interest Group

My name is Jessica Miller, a member of the Child Life Interest Group, as well as a Graduate Student from Ryerson University, Early Childhood Studies Program. I am writing to invite you to participate in my research study. This is a study that examines the developmental understanding of death of sick children to determine if it is different than that of healthy children. The purpose of this research is to advance our knowledge about a sick child's understanding of death. All Child Life Specialists in the Child Life Interest Group of Greater Toronto Area are eligible for participation in the study.

If you decide to participate in the study I will mail you a questionnaire to be filled out. The questions will ask you about your previous work experience with children who are terminally ill and your perception of their understanding of death. This may be a difficult subject for some so please know that your participation is completely voluntary. I will include a self addressed envelope to be returned to me when once you have completed the questionnaire. The information gathered will be used towards my thesis and there will be no mention of names, hospitals or any identifiable information. The questionnaire should take no longer than 15-20 minutes.

If you have any questions about the study or are interested in participating in the study please contact me at 416- 855-6385 or at jessica.miller@ryerson.ca

Thank you for your consideration, Jessica Miller MA(candidate)

Appendix 2 – Questionnaire sent to Child Life Specialists

Challenging traditional developmental theory on a child's perception of death; Learning through the experiences of Child Life Specialists

Questionnaire

Please answer questions right on the paper. If you run out of room, please flip the paper over and continue on other side. Attach any additional paper if necessary.

How long have you been a Child Life Specialist?

In your academic career, did you take any child development or related courses? Please list which ones.

Within these courses (or others) did you learn/read about children's understanding of death and dying?

In your experiences, have you worked with dying children?

In what ways do you address the topic of death and dying?

a) with terminally ill children

b) with non-terminally ill children

Approximately how many children have died that you have worked with?

What is the youngest age that a child has asked you about death (either their own or death in general)?

Did this child have a potentially terminal illness?

Most research suggests that at age 7 children are able to understand the permanence of death (Corr & Corr, 1996). Is this your finding? Please explain.

Have you found any differences between traditional theory of a child's perception of death between healthy and sick children? Please explain.

Have you found any differences in a child's perception of death between healthy and sick children? How do these differences support/challenge traditional theory?

Do you feel traditional theory on children's understanding of death helped you to work with these dying children?

A) If yes, was there anything else that helped?

B) If no, what did help you?

Thank you for your participation. Please mail your completed questionnaire in the envelope provided.

Appendix 3 – Consent Agreement

Ryerson University Consent Agreement

Challenging traditional developmental theory on a child's perception of death; Learning through the experiences of Child Life Specialists

You are being asked to participate in a research study. Before you give your consent to be a volunteer, it is important that you read the following information and ask as many questions as necessary to be sure you understand what you will be asked to do.

Investigators: Jessica Miller MA (Cand) Ryerson University. Faculty advisor Dr. Pat Corson of Early Childhood Studies of Ryerson University.

Purpose of the Study: The purpose of this research is to examine the experience of Child Life Specialists to determine how young sick children are speaking of and understanding death. This information will lead to further research regarding a sick child's understanding of death, whether it is more complex and understood at an earlier age and will ultimately lead to better pediatric palliative care. The findings will be related to relevant child development theory. The study is looking for at least five Child Life Specialists from the Child Life Interest Group of Greater Toronto (CLIG) area to participate. All members of CLIG are eligible to participate.

Description of the Study: You have been introduced to the study by a preliminary email outlining the purpose of the study and involvement. You have identified that you are interested in participating in this research and thus have been mailed this consent agreement. Once the consent agreement is returned, you will have a questionnaire mailed to your identified desired address, to be completed, and returned within the week. You will be given a pre paid, pre addressed envelope to mail once completed. The questionnaire will consist of questions regarding the participants experience with sick children and their perception of death. The questionnaire is no longer than 12 questions and will take you no longer than 20-30 minutes.

What is Experimental in this Study: None of the procedures used in this study are experimental in nature. The only experimental aspect of this study is the gathering of information for the purpose of analysis.

Risks or Discomforts: Because of the personal nature of the questions asked, you may reflect on unpleasant memories while responding to a questionnaire. The potential for discomfort has been outlined in the preliminary email sent to the Child Life Interest Group to eliminate the amount of emotional distress during the completion of the questionnaire. You will be asked directly about your work with children who have died. An example of a question you will be asked is; approximately how many children have

died that you have worked with? However if you feel begin to feel uncomfortable, you may discontinue participation, either temporarily or permanently.

Benefits of the Study: The benefits of this study include a more in depth understanding of a sick child's perception of death which could include advancements in traditional child development theory. This information could ultimately lead to better paediatric palliative care and improve the knowledge base for all Child Life Specialists and other health care professionals.

Alternative Methods of Treatment: N/A

Confidentiality: Only the primary researcher, Jessica Miller, will have access to the data. There will be no identifying features on the questionnaire to promote the utmost of confidentiality. Once the academic document has been completed, the original questionnaires will be destroyed by shredding.

Incentives to Participate: You will not be paid to participate in this study.

Costs and/or Compensation for Participation: There are no costs associated with your participation.

Voluntary Nature of Participation: Participation in this study is voluntary. Your choice of whether or not to participate will not influence your future relations with Ryerson University. If you decide to participate, you are free to withdraw your consent and to stop your participation at any time without penalty or loss of benefits to which you are allowed.

At any particular point in the study, you may refuse to answer any particular question or stop participation altogether.

Questions about the Study: If you have any questions about the research now, please ask. If you have questions later about the research, you may contact.

Jessica Miller
Principal Investigator
416-855-6385
Jessica.miller@ryerson.ca

Or
Dr. Patricia Corson
Faculty Advisor
Ryerson University
416-979-5000 ext 7637
pcorson@ryerson.ca

If you have questions regarding your rights as a human subject and participant in this study, you may contact the Ryerson University Research Ethics Board for information.

Research Ethics Board
C/o Office of the Vice President, Research and Innovation
Ryerson University
350 Victoria Street
Toronto, ON M5B 2K3
416-979-5042

Agreement:

Your signature below indicates that you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study and have been told that you can change your mind and withdraw your consent to participate at any time. You have been given a copy of this agreement.

You have been told that by signing this consent agreement you are not giving up any of your legal rights.

Name of Participant (please print)

Signature of Participant

Date

Signature of Investigator

Date

