

5-2013

Communication and End-of-Life Decision Making about Death with Children who have Terminal Cancer: The Social Worker's Perspective

Jessica Convy
St. Catherine University

Recommended Citation

Convy, Jessica, "Communication and End-of-Life Decision Making about Death with Children who have Terminal Cancer: The Social Worker's Perspective" (2013). *Master of Social Work Clinical Research Papers*. Paper 163.
http://sophia.stkate.edu/msw_papers/163

This Clinical research paper is brought to you for free and open access by the School of Social Work at SOPHIA. It has been accepted for inclusion in Master of Social Work Clinical Research Papers by an authorized administrator of SOPHIA. For more information, please contact ejasch@stkate.edu.

Communication and End-of-Life Decision Making about Death with
Children who have Terminal Cancer: The Social Worker's Perspective

by

Jessica Convy, B.A.

MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work

St. Catherine University and the University of St. Thomas

St. Paul, Minnesota

in Partial fulfillment of the Requirements for the Degree of

Master of Social Work

Committee Members

Colin Hollidge, Ph.D., (Chair)

George Baboila, LICSW

Jane Hurley-Johncox, LICSW

The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

COMMUNICATION AND END-OF-LIFE

Abstract

Purpose: The purpose of this study was to determine how parents address communication and decision making about death with their terminally ill child from social workers who work with these families. **Methods:** To add to the existing limited research studies on communication about death and end-of-life care decision making, the researcher conducted a qualitative study consisting of six interviews with social workers in a large, Midwestern pediatric hospital. The data was analyzed using thematic clustering. **Results:** The qualitative study focuses on two themes: discussing death with a terminally ill child and decision making. The researcher found that, with regards to discussing death with a terminally ill child, that parents had several reasons for either not telling their child about death or telling their child. The researcher also found that there were varying responses to whether or not parents experienced regret about not talking to their child about death and that most children would like to talk to their parents about death. In addition, the researcher found that, with regards to decision making, that parents are generally the principle decision makers. However, the researcher found that a child's input in the decision-making process depends on the child's age and development. The researcher also found that parents and children may disagree about end of life decisions, and when this happens, there are several tools in place to help a family reach a compromise. **Implications:** This study suggests that further research is needed on end-of-life decision making in order to address the emerging themes found. Social workers need to understand how families address end-of-life decisions in order to better help the families they serve.

COMMUNICATION AND END-OF-LIFE

Table of Contents

I. Introduction.....4

II. Literature Review.....6

III. Conceptual Framework.....20

IV. Methods.....24

V. Findings.....28

VI. Discussion.....40

VII. References.....50

VIII. Appendices.....56

 Appendix A – Email to Potential Participants

 Appendix B – Informed Consent Form

 Appendix C – Interview Questions

COMMUNICATION AND END-OF-LIFE

Introduction

In 2007, there were approximately 10,400 children from the ages of 0-15 diagnosed with some form of childhood cancer (National Cancer Institute, 2008). Of those 10,400 children, roughly 1,545 children will end up dying from their cancer. Approximately 25% of childhood cancer patients die from their disease (Hurwitz, Duncan, & Wolfe, 2004). Childhood cancer is the most common cause of death in children between the ages of one and fourteen (Chambers & Oakhill, 1995). Over the last 30 years, advances in science and technology have allowed for an overall survival of childhood cancer from 10% to more than 70% today (Tadmor, 2004). There are many forms of childhood terminal cancer. Types of childhood cancer include, but are not limited to, bone, leukemia, brain, and central nervous system cancers. However, leukemia, brain, and central nervous system cancer make up roughly half of the new cases in childhood cancer (National Cancer Institute, 2008).

Terminally ill children or children with a life-limiting condition are a population that social workers may encounter during their careers. Terminal illness or life-limiting condition in children can have a devastating impact on the parents and extended family. There are many definitions of what it means to be terminally ill. For the purposes of this research study, terminally ill children, or children with a life-limiting condition, are children without the expectation of a cure from the illness they are suffering, but nonetheless children who require as much care and comfort as can be provided (Children's Hospital of the King's Daughters, 2005). For the purposes of this study, the researcher will be looking at social workers who have worked with children who have been diagnosed with terminal cancer. The researcher will also use the terms terminal illness and life-limiting condition interchangeably.

COMMUNICATION AND END-OF-LIFE

A terminal diagnosis in a child or adolescent provides a major life stressor for the child and parents (Binger, 1984). Parents explain that end of life decisions are often the most difficult treatment related decisions they encounter during their child's terminal stage (Hinds et al., 2005). Parents are unsure of what to tell their dying child and how they can help their child. There are many decisions a family is faced with when one of their children is terminally ill. Examples of end of life decisions in pediatric oncology include, but are not limited to, do not resuscitate orders withdrawal of life support, terminal care, or an enrollment on a Phase I trial (Hinds, Schum, Baker, & Wolfe, 2005). Parents have reported that end of life decisions are some of the hardest decisions they have had to make on behalf of their terminally ill child. The purpose of this paper is to determine how parents address communication and decision making about death with a terminally ill child from social workers who work with these families.

COMMUNICATION AND END-OF-LIFE

Literature Review

During the end-of-life care of pediatric cancer patients, parents are often left with the daunting task of making end-of-life decisions for their child. Parents need to decide whether or not to talk with their child about dying, the reasons for and against discussing death and the child's terminal diagnosis with the child, whether or not to involve children in the decision making process, the child's preferences for involvement in end-of-life decision making and communication, and disagreements in decision making between parents and children.

Whether or not to tell a Child about Death

It can be difficult for parents to know when it is appropriate to discuss death with their terminally ill child. Whether or not to tell a child that they will die is often a hard experience for both parents and health care professionals (Freyer, 2004). According to Dunlop (2008), in a discussion exploring whether or not to tell the truth about dying to children, truthfulness is necessary when children ask clear questions regarding death. In addition, facts about the terminally ill child's death should not be kept hidden when it appears a child wants to know (Dunlop, 2008). Furthermore, Freyer (2004) expressed, in a discussion on dying adolescents, that physicians must tell parents that they are professionally obligated to tell the truth to their adolescent if the adolescent directly asks about dying.

On the other hand, Tadmor (2004) suggests, in a discussion on interventions at the end of life for children with cancer and their families, that children should not be told about their impending death when it appears children are in denial about the seriousness of their condition as it may end up breaching their psychological defenses. Children should also not be told about their impending death if they verbalize suicidal ideations or their parents refuse to tell their

COMMUNICATION AND END-OF-LIFE

children (Tadmor, 2004). Additionally, Beale, Baile, and Aaron (2005) explained, in a discussion on communication with children dying from cancer, that there are several reasons given for why a child is not told about end-of-life information and issues. Some individuals mistakenly believe that discussing death with a child will make the child further depressed and that the child will not have an understanding of concepts related to death. This is done as an attempt to protect the child (Beale et al., 2005). However, children can become more anxious and isolated when they are shielded from the truth (Beale et al., 2005). A parent's decision on whether or not to tell their child that he or she is dying is often individualized to each family and situation.

Withholding the Child's Terminal Diagnosis

One of the first decisions a parent must make is whether or not to tell their child about their prognosis. Binger (1984) explained, in a discussion on psychosocial intervention for child cancer patients and their families, that there are times when the parents and physicians involved try to shield the child from their prognosis being terminal. Furthermore, Dunlop (2008) suggests a parent's prime aim in raising a child is ensuring their survival. A parent's instinct from birth is to protect their child (Puckey & Bush, 2011). When a child is dying a parent may experience a sense of failure in that they were unable to protect their child (Dunlop, 2008). Puckey and Bush (2011) explained that parents do not like the idea of telling their child painful and damaging truths about the child's disease.

In addition, Anderzen-Carlsson, Kihlgren, Svantesson, and Sorlie (2010) conducted a focus group consisting of 15 parents of 11 children with cancer in Sweden. However, parents who had a child with terminal cancer or whose child was recently diagnosed were not

COMMUNICATION AND END-OF-LIFE

approached for this study. The aim of this study was to better understand how parents handle fear in their children when their children have cancer. Anderzen-Carlsson et al. (2010) found that in certain situations the parents took on an assertive role whereby they used their authority as a parent to act in a controlling way and ended discussions with their child when dealing with their child's fear. In these situations, the parent put more emphasis on the child's physical wellbeing than the child's sense of security.

Furthermore, Young, Dixon-Woods, Windridge, and Heney (2003) conducted a study involving semistructured interviews to explore young people's and parents' experiences of communication about cancer during childhood. The study was conducted at an English pediatric oncology unit and involved 13 families, made up of 19 parents and 13 patients who ranged in age from 8-17 years old. Young et al. found that some parents mentioned experiencing dread at the time their child would be informed of his or her diagnosis and how difficult it would be to manage their child's reaction. A parent said, "But we decided not to say anything to her, she was only 10 years old and we thought oh no, we, we can't tell her (Young et al., 2003, p. 2)." Additionally, according to Kang et al. (2005), in a discussion focused on pediatric palliative care and end of life care, even though children are often aware of their condition, parents still have a difficult time talking with their children about death.

Hutton, Jones, and Hilden (2006) suggest, in a discussion exploring the transition from curative treatments to palliative care, that in some cases, parents are reluctant about introducing the concept of dying to their child because the concept of dying has not been considered by the child yet. The parent fears that the child will become hopeless and decide to give up. Additionally, Stillion and Papadatou (2002) explained, in a discussion on psychosocial issues in children and adolescents with cancer, that some parents will not disclose a child's impending

COMMUNICATION AND END-OF-LIFE

death in order to guard their child, to maintain hope, and to shield the parents from the devastating reality. Freyer (2004) contended that a parent's hesitancy towards being honest with their child often characterizes their own hurt and inability to accept their adolescent's death.

Additionally, Zwaanswijk et al. (2010) conducted a study using vignettes in order to determine communication preferences of child patients, parents, and survivors. This study looked at health-care provider empathy in consultations and the child's involvement in the exchange of information and decision making. There were 1,440 vignettes evaluated by 34 children with cancer aged 8-16, 59 parents, and 51 survivors. The study was conducted at three Dutch university pediatric oncology centers. Zwaanswijk et al. (2010) found that in 31%-51% of the situations, the participants wanted patients shielded from information. The study also found that parents wanted information not to be shared with their child at the same time as them if the child's prognosis was poor or moderate.

Additionally, Anderzen-Carlsson et al. (2010) found in certain circumstances the parents wanted to avoid frightening or upsetting their child. In these situations, Anderzen-Carlsson found that parents would try to hide their own fear or sadness in front of their child. When parents tried to shield their children they would avoid discussing the seriousness of the child's cancer or the possibility of the child dying.

Dunlop (2008) suggests that parents may withhold telling their child that they are going to die because of the fear that doing so will cause distress, anxiety, and worry. However, Bluebond-Langer (1978) found, in a study of terminally ill children in the department of pediatrics at a large Midwestern teaching hospital, that children who were never told the truth about their prognosis and impending death exhibited fear and isolation. In addition, Freyer

COMMUNICATION AND END-OF-LIFE

(2004) mentioned that a communication problem exists when parents do not want to disclose their adolescent's move to terminal care. Freyer concludes that parents should be encouraged to act in a truthful manner with their child from the initial diagnosis. Being truthful and providing knowledge to the adolescent the parent tends to help in alleviating anxiety and increasing trust in their adolescent (Freyer, 2004).

Additionally, Hutton et al. (2006) explained that cultural factors need to be thought about because honest communication about death may be taboo and can lead to more suffering in certain cultures. Puckey and Bush (2011) state as long as withholding certain information from the child is not damaging to the child, it is viewed as acceptable for the parent to limit what the child is told. Parents withhold discussing a child's terminal diagnosis for many reasons. However, there appears to be a lack of consensus about what is in the best interests of the terminally ill child in the literature.

Disclosing a Child's Terminal Diagnosis

Some parents make a choice to discuss the child's terminal diagnosis and death with their child. Bluebond-Langer (1978) stated that when parents discuss a child's prognosis and death that the parents should use words and phrases that are comfortable to them. The parent may not discuss the prognosis explicitly but, rather find ways to recognize what the child may be aware of but not able to put into words. Hurwitz et al. (2004) explained, in a discussion on caring for children with cancer, that communication between families is not always verbal and an observed lack in vocal communication does not mean that meaningful communication is not taking place between the parent and child.

COMMUNICATION AND END-OF-LIFE

Faulkner (1997) explained, in a discussion talking about death with a child, that a family Faulkner worked with discovered that dying children are less prone to experience isolation, anxiety and withdrawal when there is honest communication about death. In addition, Anderzen-Carlsson et. al (2010) found when parents discussed staying close with their child they mentioned the ability to have open and honest discussions with their child. “The parents spoke about not hiding anything from the child. They explicitly talked about the seriousness of the illness and the risks of late side effects from the treatment (Anderzen-Carlsson et al., 2010, p. 320).” Ellis and Leventhal (1993) conducted a study consisting of a survey that looked at the information needs and decision-making preferences of children with cancer. The child participants were screened for eligibility by Johns Hopkins Pediatric Oncology Clinic. There were 50 child cancer participants who ranged in age from 8-17 years old and 60 accompanying parents. The study found that 98% of parents felt their child should be told when their cancer was diagnosed. However, only 64% of parents wanted their child to be told if their cancer was not improving and the child was likely to die (Ellis & Leventhal, 1993).

Hinds et al. (2005) explained, in a discussion on factors affecting dying children and their families, that clinicians generally agree that terminally ill children should be told of their prognosis, as this will help to open communication about the child’s approaching death. In another study by Young et al. (2003), they found that during the course of the child’s illness, some parents reported moving away from the executive role and switching to a partnership based role with their child. This allowed for the roles to become more equal and communication to become more open. When a parent decides to tell their child about their prognosis it allows for a truthful atmosphere for the family and child (Dunlop, 2008). This truthfulness allows the children to express their grief, fears, and preferences in their final treatment. Kohler and Radford

COMMUNICATION AND END-OF-LIFE

(1985) found, in a semistructured interview of 18 families who lost a child to cancer, that only one family had a conversation with their terminally ill child about death.

A research study by Zwaanswijk et al. (2010) found that patients, parents, and survivors preferred information to be shared with the child and parents together for most situations. In 49%-69% of situations, the participants wanted patients to be given information despite not explicitly asking for information. The study also found that most of the time participants wanted the child to be involved in the medical decision making (Zwaanswijk et. al, 2010).

Kreicbergs, Valdimarsdottir, Onelov, Henter, and Steineck (2004) conducted a study in Sweden with parents who lost a child to cancer. The questionnaire was sent to 429 parents who lost their child to cancer and found that none of the 147 parents who talked about death with their child felt any regret about telling their child their prognosis. Furthermore, 69 of the 258 parents who did not talk about death with their child regretted it. Kreicbergs et al. (2004) also found that parents who sensed their child's awareness about his or her death regretted not having talked to their child about death. There is a distinct responsibility for the care team to help parents react to the wishes and needs of their terminally ill child. The study also found that parents of older children were more likely than the parents of younger children to talk about death with them (Kreicbergs et al., 2004). Parents provide several reasons for discussing their child's terminal diagnosis with their child. However, there does not appear to be a consensus among the literature as to why parents disclose a child's terminal diagnosis.

Involving Children in the Decision Making Process

Parents need to decide how much, if any, involvement their child will have in the decision making process. Involving the child in the decision making process is generally

COMMUNICATION AND END-OF-LIFE

welcomed by the children. Nitschke et al. (1982) found, in a study of 68 parents with children who had terminal cancer that 43 parents allowed their child to participate in the care conference and make further treatment therapy decisions. The authors report that when children were allowed to participate in the decision making process they were better able to understand their declining health. As a result of being included in the decision-making process, communication between the parents and children grew.

On the other hand, Hallstrom and Elander (2004) conducted a study over a nine week period observing 24 children and their parents in the pediatric department of a university hospital in southern Sweden. The purpose of this study was to examine the types of decisions involved during hospitalization and how the decisions were made. Hallstrom and Elander (2004), during the course of this study, noted 218 observed situations involving decision making. In three of those situations a child was solely responsible for making the decision. However, two of the three situations mentioned were made by the same child. Additionally, In 10 of the 218 situations, roughly 5%, the parent was responsible for making the decision alone. The parents stated that “they knew what was best for their child” (Hallstrom & Elander, 2004, p. 371). When parents made the decisions on behalf of their child they made their opinions known and ensured that their decisions were followed. However, it is important to note that the study completed by Hallstrom and Elander does not focus on children with cancer or end-of-life decisions whereas Nitschke et. al does.

Stevens, Jones, and O’Riordan (1996) explained, in a discussion on family reactions to children in palliative care, that when a family makes decisions regarding end of life care, they should be assisted by the care team in order to make informed decisions. This will help to ensure that the family will be left knowing they made the best possible decisions for their family and

COMMUNICATION AND END-OF-LIFE

child (Stevens et al., 1996). It is suggested that children be involved in at least some of the conversations on future management of end of life care. Traugott and Alpers (1997), in a discussion on adolescents' refusals of medical treatment, believe that adolescents should be allowed to make decisions regarding their treatment when they are capable and have their parents approval.

In a discussion on the impact of a dying child on the family system, Martin et al. (1984) explain that children are often more aware of their prognosis than parents think they are. Children do not appreciate being lied to. Duncan, Joselow, and Hilden (2006) suggest, in a discussion focused on program interventions for terminally ill children and their siblings, that children are very perceptive and intuitive, especially with regards to what is taking place in their bodies. It may be beneficial for the parents to ask children about what is important to them and to provide the children with options when possible. This will allow children to have an active role in their end of life care (Duncan et al., 2006). Furthermore, Anderzen-Carlsson et al. (2010) found another way to address children's fear was to be thoughtful with regards to the child's needs and to allow the child to make decisions when appropriate. "So she was the one to decide. Whatever was reasonable for her to decide about, she was allowed to decide about" (Anderzen-Carlsson et al., 2010, p. 321).

It is important to take into account the amount of duress a parent may be under and the competency of the terminal child when having them participate in the decision making process (Hinds et al., 2005). The care team can try to assess this through a number of interview questions. If a child is found to be competent for the decision making process, the parents can involve them in where the child wants to die and the type of care service involved (Hinds et al., 2005). Furthermore, when involving the child in the decision making process it is important to

COMMUNICATION AND END-OF-LIFE

remember their cognitive abilities and limits. It may be beneficial to talk with the care team to help understand the patient's concept of death. Hallstrom and Elander (2004) state that children are not always at a high enough maturity level to make decisions. For example, a child may not understand that enduring pain now is necessary in order to avoid potential problems in the future. This is one reason children are not always allowed to make decisions of a medical nature. However, Hallstrom and Elander state that children can usually, in some capacity, participate when decisions are being made.

It is also important to keep in mind the child's hopes and dreams when involving them in the process (Hutton et al., 2006). Anderzen-Carlsson et al. (2010) found that a part of being adaptable was parents being able to respond to their child's wishes with regards to the child's medical exams and treatments. There are several factors parents of terminally ill children need to consider when deciding to include a child in the decision making process.

Child's Preference in End-of-Life Decision Making and Communication Involvement

Children with terminal cancer exhibit preferences for their involvement in end-of life decision making and communication. Ellis and Leventhal's (1993) study compared patients who had a complete understanding of their diagnosis to patients who had a partial or inadequate understanding of their diagnosis. The study found that 87% of children with a complete understanding of their cancer "wanted to be told what the cancer was doing to them, compared to 53% of the others" (Ellis & Leventhal, 1993, p.279). Ellis and Leventhal indicate that patients who had a limited understanding of their diagnosis wanted and remembered less information about their cancer. The study also found that all patients and parents wanted to be informed when the cancer was diagnosed. Additionally, "96% of patients and 84% of parents wanted to be

COMMUNICATION AND END-OF-LIFE

told if they were not getting better and were likely to die. However, only 64% of parents wanted their children to be given this information. 10% of patients and 44% of parents felt that their treatment was very much their own decision” (Ellis & Leventhal, 1993, p. 281). 39% of patients felt that the decision for treatment was little or not at all their decision.

Zwaanswijk et al. (2007) conducted an online focus group that examined young patients’, parents’, and survivors’ communication preferences in pediatric oncology. This study took place in two Dutch university oncology wards. The participants included 7 patients aged 8-17, 11 parents, and 18 survivors. The respondents all stated that it was a young patient’s “basic right to be fully informed about the illness and treatment” (Zwaanswijk et al., 2007, p. 6). A 10 year old child remarked that, “I usually listen in, even when I have to do something else...I usually want to know everything they talk about” (Zwaanswijk et al., 2007, p. 6). Zwaanswijk et al. also found that the participants’ beliefs about including a young patient during consultations varied considerably. Some patients and survivors wanted to participate during all consultations; others didn’t mind their parents occasionally talking with the doctor separately. However, a patient not being involved could give them the impression that certain information was being withheld (Zwaanswijk et al., 2007). The study also found that most of the participants wanted decisions about treatment to be handled collaboratively between patients, parents, and the health care team.

Hsiao et al. (2007) conducted a qualitative study involving 20 parent and child pairs of pediatric oncology and cardiology patients. The children who participated in the study were given less than 20% survival beyond three years. The children ranged in age from 9-21 years old and the study was conducted in two hospitals and one pediatric hospice in Los Angeles, California. The aim of this study was to examine both parent and child perspectives on physician communication. Hsiao et al. (2007) found that parents and children recognized

COMMUNICATION AND END-OF-LIFE

varying degrees of involvement in communication with physicians and direct participation in the patient's care. 20% of parents and 10% of children noted the importance of active involvement in the child's care and desired that physicians help to facilitate parent child participation. A child said, "More information helps me basically by letting me know what's going on because it's my life, I should know what's going on" (Hsiao et al., 2007, p. 361). Additionally, 30% of parents and 25% of children stated that they would like their physician to be straightforward and open with the child.

Stegenga and Ward-Smith (2008) conducted a study using a semistructured interview involving three adolescents with cancer who ranged in age from 12-17 years old. The study participants were found using health care professionals responsible for the patient's direct care. The purpose of this pilot study was to examine treatment decision making from the perspective of adolescents with cancer. Stegenga and Ward-Smith (2008, p. 114) found that one theme expressed by participants was, "decisions should be made by those who have knowledge to make them." Each of the three participants stated that it was best to leave decision making to the health care team. "We don't know much about it and they've (the health care team) studied it for a long time so they would really be the ones who would know more about it" (Stegenga & Ward-Smith, 2008, p. 114). The adolescents did not observe that their parents made treatment decisions when their cancer was initially diagnosed. Despite the fact that the adolescents with cancer did not feel they needed to be involved in treatment decision making, the adolescents stated a "strong desire to know what was going on and what to expect" (Stegenga & Ward-Smith, 2008, p. 115). All three participants were frustrated with the lack of knowledge provided to them concerning treatment.

COMMUNICATION AND END-OF-LIFE

In addition, Young et al. (2003) found that children mentioned a range of opinions about how their diagnosis was disclosed to them. There were a few children who thought they should be told at the same time as their parents, some thought it was better for their parents to be told first, and other children stated “no strong feelings either way” (Young et al., 2003, p. 2). However, some children reported feeling that communication was guarded or inhibited by their parents. The children mentioned that parents did not always answer their questions and that a disparity may have existed between what the children were told and what the parents had been told. “They didn’t tell you much, they-just told you what-just the minor things...” (Young et al., 2003, p. 3). Consultations were generally held between parents and professionals. Young et al. (2003) stated that this seemed to leave the young people without a voice. The previous literature indicated that children’s’ preferences in end-of-life decision making and communication vary by the individual child but that most children wanted some information on their condition.

Decision Making Conflicts between Parents and Children

When both parents and terminally ill children are involved in end-of-life care decisions conflict may arise. Hutton et al. (2006) explain that the real dilemma occurs when the parent or surrogate decision maker and the child do not agree about health care decisions. Parents are the assumed decision makers for their children and are provided substantial say so in authorizing medical decisions (Traugott & Alpers, 1997). The legal obligation states that the parent or surrogate decision makers choice is to be honored, which presents an ethical challenge for all members of the care team (Hutton et. al, 2006).

Jones (2005) found, in a survey of 131 pediatric oncology social workers looking at current practices for end of life care that ethical issues arise when the parent and child disagree

COMMUNICATION AND END-OF-LIFE

about continuing or ending curative treatments. A parent may want to continue with treatments because the parent does not want to tell the child about their impending death. Understanding children's and their family's hopes, dreams, and goals may help to develop helpful communication between parents and children when a disagreement arises (Hutton et al., 2006). Additionally, Hinds et al. (2005) found, in a study of 20 pediatric patients looking at end of life preferences, that 2 of the 20 pediatric patients, 10%, participated in a phase I trial despite not feeling good about the decision. These children chose this option because they wanted to benefit others despite that fact that these children were no longer interested in curative treatments.

Feudtner (2007) explained, in a discussion on collaborative communication in pediatric palliative care, that during the course of a child's clinical care conflict may arise. Difficult conversations are usually seen as individuals debating between who is right and who is wrong in a particular situation. It is important to note that individuals do not always know the intentions of the other individual. It may be helpful for people engaged in conflict to avoid making assumptions on each other's part and instead open up communication about how certain behaviors or actions impacted one another (Feudtner, 2007).

Traugott and Alpers (1997) stated that disagreements surrounding the adolescent's treatment and care should be addressed by the patient, parents, and doctor. The authors suggest that a doctor should take the lead when disagreements present. The doctor should ask the adolescent about his or her concerns and why the adolescent wants to refuse a given treatment. Furthermore, Tadmor (2004) explains that the parent's and child's needs during the decision making process may not always align and therefore lead to conflict. The ethical dilemma this conflict creates can be addressed by a member on the care team. The care team can help explore

COMMUNICATION AND END-OF-LIFE

the parent's need to protect their child along with the child's need to know more (Tadmor, 2004). Conflicts may arise between a child and parent concerning decisions about curative treatments.

There is very little available in terms of research studies on how parents communicate about death and end of life decision making with their terminally ill child. The previous literature provides many reasons for why parents do or do not discuss death with their child and how children are involved in the decision making process. However, the previous literature does not provide consensus for parents communicating about death and end of life decisions with their terminally ill child. Therefore, the purpose of this research project is to add information to the limited data available on this topic.

Conceptual Framework

Grief and Loss

Recognizing grief is often the initial step toward acknowledging the actuality of a child's condition (Tadmor, 2004). When a child has cancer, the family members often begin to grieve for the child's impending death long before the child passes (Stevens, Jones, & O'Riordan, 1996). There have been many parents who stated that their grieving began the day they received their child's diagnosis.

One of the most representative outlines for grief resolution in Western culture is the one where people who are grieving are just supposed to "get on" with their existences following the death of a child (Sormanti & August, 1997). Parents are expected to let go of the emotional connection they share with their now deceased child. In clinical experiences, the bereaved parents use a sort of continuum consisting of behavioral and thought processes in order to help

COMMUNICATION AND END-OF-LIFE

manage their grief. The individual is then able to assimilate both the passing and the departed person into their life (Sormanti & August, 1997).

If both the parents and child decide to keep secrets from one another during the terminal phase, they will in a sense create an invisible barrier between each other. This invisible barrier will make it extremely difficult for preparatory grief for either the patient or parents (Kubler-Ross, 1975). The objective is to prepare the parents and family for the anticipated death of their child (Tadmor, 2004). It is important to watch for early closure, this generally includes the parents disengaging both physically and emotionally from their dying child.

Parents have found that strong relational connections with the professionals in charge of their child's care have helped with the end of life experience (Konrad-Cohen, 2007). Parents have stated that they want the care team to be open-minded, courteous, and accepting of the parent's bereavement experience. The connection between staff and the parents helps the parents in their grieving process (Sormanti & August, 1997).

The communication and contact with the care team is very important during their child's end of life treatment. The decisions that parents make about end of life treatment for their children and the way the care team treats the family may have an impact on the way the parents grieve the loss of their child (Hooyman & Kramer, 2006). Therefore, when the child passes the parents not only experience the loss of their child but the loss of the care team. The family is used to the close and constant contact of the palliative care team (Stevens, Jones, & O'Riordan, 1996). After their child dies that regular contact tends to cease with most parents and families. Although families may transition to other family members and friends, the loss of the close relationship shared between the parent and health care team is not insignificant (Hinds, Schum,

COMMUNICATION AND END-OF-LIFE

Baker, & Wolfe, 2005). One woman recounted, “I felt like I’d been given the sack” (Stevens, Jones, & O’Riordan, 1996, p. 55).

Another loss experienced by parents is the loss of dreams or unfulfilled wishes they had for their children. When one thinks about deaths, the most unnatural kind of death is that of a child (Martin, Martin, & Pierce, 1984). Childhood is seen as a time of developing and growing. Individuals are taught to look to the future, and not consider childhood a conclusion or summary. The death of a child is not an anticipated event and is often difficult to come to terms with since it is not normal for a child to die before their parents (Tadmor, 2004). Individuals consider the death of a child to fall outside of what they think of as the natural occurrence of events (Soricelli & Utech, 1985). The parents, and even the child, may have dreams that have yet to be fulfilled for the dying child and their family (Stevens, Jones, & O’Riordan, 1996). The parents may come to realize the death of their dreams for the future, for their dying child and themselves (Soricelli & Utech, 1985).

The parents may also experience an ambiguous loss while their child is dying from cancer. The type of ambiguous loss the parent may experience is one in which their child is physically present but psychologically absent. Ambiguous loss has the potential to intrude and fracture relational boundaries (Boss, 2006). With this type of ambiguous loss, parents and individuals do not often know how they should act or what they should do. An ambiguous loss is not necessarily experienced by all parents of children with terminal cancer. However, there are certain forms of childhood cancer, such as brain and central nervous system, which may have an effect on the child’s cognitive capacities (National Cancer Institute, 2008). The child may have trouble with their memory, thought processes, and speech in the later stages of their cancer.

COMMUNICATION AND END-OF-LIFE

The parents may struggle with the idea that their child is there, they can see him or her, but that the child that they know is truly not there anymore.

Psychologically, the course of grieving for the parent's child does not involve just grieving the loss of the child, but with it the loss of the part of a parent's self (Rando, 1985). Parental attachment involves both the love of one's self and object love. The death of a child or loved one can have a tremendous impact on a parent's sense of who they are, and this is due in large part to the fact that parents create their identities through the reflections of their children and others (Hooyman & Kramer, 2006). The irreplaceable dynamics of the relationship between parent and child increases the loss of self felt by the parent (Rando, 1985). Parents continue to live after their child's death but a part of themselves and their identity perish (Hooyman & Kramer, 2006). The death of a child takes away a parent's purposeful role and leaves them with a tremendous sense of failure, and assaults their feeling of power and ability (Rando, 1985). The bereaved parents need to restructure their world for it to make sense to them and to reestablish meaning and purpose to their life.

COMMUNICATION AND END-OF-LIFE

Methods

Through the lens of clinical social workers, this study examined parents' experiences addressing communication and end-of-life decision making about death with their terminally ill child. The researcher utilized a qualitative design that is exploratory in nature. The study consisted of semistructured interviews.

Sample

The researcher conducted six interviews with social workers (LICSWs), who are at least 18 years old, and have had experience working with children who have passed away from terminal cancer. The participants either worked in the oncology department or pain and palliative care. The participants experience working with families who have had a child with terminal cancer ranged from 5-25 years. All social workers who participated in this study were female. The interviews took place in a large Midwestern pediatric hospital. The sample size for this study is six participants. The purpose of the interview was to gain a better understanding as to how parents address communication and end-of-life decision making about death with a terminally ill child. The sampling strategy used was a purposive sample.

In order for participants to be eligible for this study, participants needed to be licensed social workers. Potential participants were taken from the hospital's social work directory and from the internet. Potential participants needed to have experience with end-of-life issues and experience working with children and their families who have cancer. This was determined by reviewing potential participants departments and/or talking with the manager of social work at the hospital. The data were gathered once the project was approved by the IRB.

COMMUNICATION AND END-OF-LIFE

Data Collection/Procedure

Participants for this study were gathered from a large Midwestern pediatric hospital. The participants were identified using the social work department's contact list for current social workers. The researcher sent out an email (Appendix A) to potential participants, social workers at the hospital, to explain the research study.

Data Gathering Procedure

An email which explained the nature of the research project was sent to each potential participant who met the research criteria at the hospital. The social workers let the researcher know of their interest in participating in the study by either phone or email. Once participants were selected and approved for the study, the researcher set up a time with each participant to conduct the semistructured interview.

Before the interview began participants were asked to sign a consent form (Appendix B). The researcher then asked the questions to the participant and audio recorded the entire interview.

Measurement

This study utilized a semistructured interview that consisted of 12 questions (Appendix C). The themes that this study looked to address were disclosing or withholding a child's terminal diagnosis from the terminally ill child, involvement of the child in the decision-making process, the terminally ill child's preferences for end-of-life decision making and communication involvement, and decision making conflicts between parents and the terminally ill child.

COMMUNICATION AND END-OF-LIFE

Protection of Human Subjects

The participants received an informed consent form from the researcher prior to the interview beginning. The informed consent form explained the purpose of the study to the participants, why the participants were chosen, what the data gathering process looked like, and what would be done with the data collected. The participants were informed that their participation in the study was voluntary. The participants were also informed that the interview would be audio recorded and transcribed by the researcher. The participants were informed that the transcript would be shared with the researcher's faculty advisor but that no identifying information would be shared with the faculty advisor. The participants were also told that if they chose to withdraw from the study at any time, the data collected from the participants would not be used in the study.

The researcher did not use the participants' names or any other identifying information about the participants in this study. All data that the researcher collected with identifying information or names of the participants was kept in a locked drawer of the researcher's desk at the hospital. The audio recordings and transcripts of the interviews were kept at the researcher's home in a locked drawer. The transcripts were stored electronically on the researcher's laptop which needs a password to gain access to.

An area that the researcher needed to be cognizant of was the potential for the participants to feel obligated to participate in the study. The researcher was a social work intern at the large Midwestern pediatric hospital and all potential participants were social workers from that hospital. The researcher made it clear in the email sent to potential participants that they were not obligated to participate in the study and that no one in the hospital would know if they

COMMUNICATION AND END-OF-LIFE

chose to participate in the study or not. The email also made it clear that whether or not the potential participants chose to participate in the study would not affect their relationships with the hospital. The study had the potential to stimulate unpleasant memories for participants. The participants were made aware of this by receiving the list of interview questions in the introductory email and it was pointed out in the informed consent. The researcher ended the interview with a debriefing section, consisting of positive questions, if participants experienced upsetting emotions.

Data Analysis

After the data was collected, the researcher used thematic clustering to create predetermined categories in order to code the responses. The researcher reviewed the previous literature for available categories. Once the researcher compiled a list of predetermined categories, the researcher then reviewed the audio recorded interview. The researcher then pulled out relevant data that fit the predetermined categories and also looked for categories not covered in the literature.

COMMUNICATION AND END-OF-LIFE

Findings

There were two main qualitative themes that arose from the interviews; discussing dying with terminally ill children and the experience of making decisions with terminally ill children.

Discussing Dying with Terminally Ill Children

How Many Families Discuss Dying with Terminally Ill Child

According to the data collected, the respondents agreed that most families discuss dying with their terminally ill child. Four respondents commented that most parents have some sort of discussion with their child about dying. Some parents are more open in their discussions while others are less direct with their children. One respondent said, "...I would say that it is more rare that families choose not to." Another respondent commented that the number is much lower when it comes to parents specifically addressing death with their dying child. One respondent mentioned that discussing death with a terminally ill child varies. She said, "Usually, probably the biggest determinant is the age of the child...The older the child the more likely it is that the parents will talk to them."

Importance of Discussing Death with Terminally Ill Child

All respondents agreed that it was important for parents to discuss dying with their terminally ill child. However, the respondents listed several different reasons for that importance. Two respondents mentioned that children are aware of what is happening in their bodies. One respondent said, "I think even if, I think that the child no matter how old they are knows what's happening to their body..." A respondent also said it was important because it

COMMUNICATION AND END-OF-LIFE

allows the children to ask questions and offers reassurance to both the child and parents. It also allows for the family to have chance to say goodbye to one another.

Another participant stated that it is important because it allows for honesty between the parent and child. The participant also stated that it is ok if parents do not feel comfortable going into detailed conversation but it is important for parents to engage in those discussions with their dying child. Also, children are aware when their parents are uncomfortable having the discussion about death and do not bring it up to protect their parents.

One respondent said... A lot of times if parents don't feel comfortable having that conversation with their children themselves, children pick up on that, and children are smart and they don't have that conversation in and of themselves because they want to protect their parent.

Another participant mentioned that it is good for children to know what is going on with them and that children often know that they are dying before their parents.

One respondent said...What I often find is kids usually know before the parents that they're going to pass away, like, they just have a feeling in them, it's kind of a weird thing but the kids usually know either when treatment isn't working or their tumor is growing...it's very important for kids to know the process of dying and why they're dying...

The participant said it was important for children to know that dying was not the child's fault or a result of anything they did and also nothing that the parents did.

COMMUNICATION AND END-OF-LIFE

Another respondent commented that it is important for parents to discuss dying with their child, but do not have to tell the child they are dying, and that it is also dependent upon the child's development. She said, "So I think for every child, other than infancy, I think that there is a way that you can communicate and have those conversations."

One respondent said it was important because it allows for the parents and child to develop a foundation of truth.

She said, "...It's important to lay a foundation of truth and then build upon that truth otherwise kids learn, ok there's information I need to get but mom or dad in this situation is not the person that I'm going to be able to get that information from and they'll go somewhere else.

Not Talking about Death with a Terminally Ill Child

The respondents provided several different reasons for why parents do not discuss death with their terminally ill child. One reason parents do not discuss this information is that think their dying child does not know and therefore are afraid to share that news with their child. Along those same lines, three respondents mentioned parents were afraid to give that information to their child. Two participants, 33%, mentioned that parents are often in shock and afraid to think about it and are unable to discuss it with their child. One respondent said, "The parents are in shock themselves so when they don't know how to think about it or process it themselves, I think it becomes much harder for them to talk to other people about it, especially the child themselves..."

Additionally, several respondents mentioned that parents are often afraid to scare or shock their child. It would seem that the parents do not want to stress their child out. Another

COMMUNICATION AND END-OF-LIFE

reason parents do not discuss dying with their child is because parents do not want the child to think they are giving up hope and they do not want the child to give up hope. One respondent said, “I think that parents are often just scared to tell them because they don’t want the child to think they’ve given up hope and by telling them that they’re dying they’re giving up on them.” A final reason provided by the respondents was that parents wanted to protect their child. One respondent said, “I think a lot of parents try to protect their children, so they kind of try to build a bubble around them and try to umm, protect them and not let them know about some of those things.”

Talking about Death with a Terminally Ill Child

According to the respondents, there are several different reasons why parents discuss dying with their terminally ill child. One respondent mentioned that it offers reassurance to the child as well as the parents. It allows the child to know what is happening with them. Another respondent said it gives the child permission to let go.

She said...I, just yesterday, had a three and a half year old pass away...and his parents, in their own way, were having that talk with him and giving him permission to just rest...and even though the concept of death was not something that he would understand, they were still communicating in their own way with him that it was ok to let those things happen and not to be scared of them, and that they would be ok, and that his brother would be ok.

Another respondent mentioned parents talk to their children to provide comfort and honesty. Providing honesty to the child allows the child to process the information. Another reason is that the child brings it up and then the parents discuss it with their child. Two

COMMUNICATION AND END-OF-LIFE

respondents mentioned that parents will discuss dying with their child as a way to discuss spirituality and a family's belief system around what will happen.

One respondent said...One of the most beautiful exchanges I've ever seen between a parent and child was very much the mother had a strong faith and had clear beliefs...and helped her 12 year old daughter...used imagery with her daughter around what heaven looked like...And even when her daughter said and cried, 'but I'm still going to miss you. Even though those relatives are there and it's a beautiful place, and Jesus is there, and all of this is there, I'm still going to miss you. And the mother's response was, 'when you go to heaven, time, the separation will only be an instant. I will be with you. It will seem instant. You won't have time to miss me.'

Another respondent said parents discuss death with their child to find out what child thinks and what the child's wishes are.

She said...I think the reasons they talk to their child about it is to find out what the child thinks first of all, to figure out what is the child thinking about their death...and I think just talking to them about their wishes too...

A final reason given by a respondent was that parents want to be supportive with their children. She said, "I think parents they can recognize their own feelings and realize oh my goodness I don't want my child in that situation without someone to be supporting them and wow I'm their primary support..."

COMMUNICATION AND END-OF-LIFE

Parents and Regrets

The respondents provided varying responses to whether or not parents experienced regret about not discussing dying with their terminally ill child. One respondent did not think parents experienced any type of regret.

She said...I think when they choose not to talk to their child or when they choose to talk to their child, they're doing it based on their view of the world and so not talking generally supports their view of the world and talking supports the other family's view of the world.

Another respondent commented that parents often have regrets around not being aware that their child is dying or not being able to be at the same place as the child.

She said...I know that a patient I had die more recently, I, I felt that the child knew that she only had very little time left and her mom was still trying to engage in treatment and find alternative protocols, and I think that mom was just not at that place the child was and so I think that for that mother there was some regret about how did I miss that, how was I so unaware that my child was dying

Another respondent mentioned the only regret she was aware of was when the parents were unable to communicate with their child because the child was in a coma. The parents never got the opportunity to explain what was going on with their child or have the opportunity to say goodbye. There was only one respondent who dealt with parental regrets around not discussing dying with their terminally ill child. The parents did not provide much information about their regrets. She mentioned that parents have said, "Oh people thought I should but I didn't think it was the right thing to do..."

COMMUNICATION AND END-OF-LIFE

Child's Interest in Parents Discussing Death with Child

Five participants, 83%, felt that children do want their parents to talk about dying with them. Respondents stated that talking about death with the child allows them to be able to ask questions. It provides children with a better understanding. One respondent said, "Umm, but I think that most children want to be able to engage in honest discussions with their parents..." Another respondent mentioned that exploring spirituality is an important aspect when children and parents discuss dying. She said, "You know, what is a family's belief system in terms of faith and is there an afterlife and so it gives kids a sense of ok even though this is scary maybe it's going to be ok..."

Another reason children want their parents to discuss dying with them is so they can explore how the family will hold the child's memory after death.

A respondent said...To some degree (kids) want to talk about how can their parents continue to hold their memory after they've died, you know I think for some children that's important to know how are you going to continue to engage with me, when I, when my body is no longer here, and how is the family going to continue to uphold my memory.

Another participant stated children want their parents to discuss dying with them because it opens up communication. Children may be aware that something is different or wrong but may not bring it up until the parents say something. One respondent said, "I think by the parent initiating that conversation it really helps the child to be able to talk about it, umm, and opens up communication for them. Children also want their parents to discuss dying because it gives the child permission to do so as well. One respondent said, "I think there are certain kids who want

COMMUNICATION AND END-OF-LIFE

to ask questions and they want to be given permission from their parents that it's ok...it goes back to parents giving them permission to do that and to have those conversations."

One respondent was not sure how to answer the question. This respondent stated that it often depends upon the child's development and the relationship the child has with his or her parents. She said, "I think that all kids want that shared experience with their parents and so depending on what their relationship is with them, they'll find their own way to either have that conversation or let their parents know.

Decision Making

Parents as Decision Makers

Most of the respondents agreed that parents make most of the end-of-life decisions for their terminally ill child. Several of the respondents stated that it was often dependent upon the child's age and development.

One respondent said...I think you know depending upon the age of the child, I think the older the child the more apt they are to participate in making decisions...the younger the child I think parents are going to, umm, make those decisions and they may or may not talk to their child about it, but I think the reason they do it is because they are the parents...

According to one respondent, parents are the decision makers most of the time but the hospital team works together with the family to ensure that the child's voice is heard as well. Another respondent said that once a child is 12 and up it becomes more of a joint decision making process between the parents and child. She said, "...I think that at that point the parents

COMMUNICATION AND END-OF-LIFE

do it jointly or then also give it up, give those decisions up to their child.” The older the child is the more likely they will be involved in the decision making process according to a few of the respondents.

When the parent is acting as the principal decision maker, all of the respondents stated that there were processes in place to ensure that the parent is acting in the best interests of their dying child. One respondent mentioned that if a parent declines a recommended treatment the team would then investigate whether or not it was reasonable to not treat the child. She said, “What’s the outcome going to be if we treat, what’s the outcome going to be if we don’t treat, what’s the burden of treatment, what’s the burden of not treating.” Another way to ensure parents are acting in the best interests of the child is through the hospital team’s assessment of the whole family.

One respondent said...I think as a team we look at the whole family and if we don’t think the parent is maybe making the best decision based on what the child wants then we will intervene, I mean not negatively, we’ll do it in a supportive manner...

According to four participants, 67%, the ethics team can be utilized to ensure parents are acting in the best interest of the child. One respondent said, “...the ethics team doesn’t have to do a formal consultation, you can consult with them informally, you can also go the more formal route where you might say could you (the ethics team) come and talk to our team.” A final option mentioned by 3 respondents, 50%, is involving child protection and seeking a court order when appropriate.

One respondent said...They can ultimately ask for a court order, and lets say if it’s based on religious beliefs, they can go to child protection, I mean those are the formal legal

COMMUNICATION AND END-OF-LIFE

options...If they say there's a 75% chance that this child will survive or be cured, or get five years, that that's the one they're much more likely to say we're going to go to the courts...

Children's Participation in Decision Making

Majority of the respondents felt that children do want to participate in end-of-life decision making. Several respondents commented that a child's desire to participate is often dependent upon the child's age.

One respondent said...I would say for adolescents, yes, that they've wanted, I've consistently seen them wanting to be a part of the process. Those who are younger I don't necessarily know that developmentally that they've been at a point of saying yes I want to be part of this...With younger kids, I think that they have probably already shared in their own way with their parents what they want.

How Children can Participate

Several respondents also mentioned the importance of providing children with opportunities to participate in end-of-life decision making by providing the children with options. One respondent said, "...it's not just about treatment, it is the environment, so kids can participate no matter what age they may be in some of those decisions." Another respondent said, "...so there was this little girl, and I want to say she was 8 this last year...She decided what she was going to wear; she planned pieces of her funeral." According to the respondents, children do have choices in end-of-life even if they are not major decisions.

COMMUNICATION AND END-OF-LIFE

One respondent said...Just sitting down and seeing if the child has any requests, like I said, it could be as simple as I want my mom and dad and brother here, I don't want aunts and uncles and other people here. I want to be at home in my own bedroom in my own bed or I want to be in the hospital in the hospital bed...

Two respondents, 33%, mentioned an option that teenagers can participate in for end-of-life decision making is completing an advanced directive.

One respondent said...the health care directive is something that we talk about. Legally, it's something that's 18 and over, but it's still sometimes a tool for us...about what they see as the direction that they would want their medical care as well as their end-of-life decision making.

A final option mentioned by one respondent was for children to participate in legacy work. She said, "...we look at legacy work and some of our kids that aren't going to make it...we make sure we do like handprints or hand molds or a lock of hair, those sorts of things for the family."

Parent and Child Disagreement about Decision Making

According to the respondents there are several things that can be done when a parent and child disagree about end-of-life care. All respondents mentioned the involvement of the ethics team in helping families come to some sort of a compromise. Another option is to explore the idea of treatment versus no treatment with families.

COMMUNICATION AND END-OF-LIFE

One respondent said...Again it's going to be looking at what's the burden of treatment versus the burden of not treating...what is the expected outcome, is it a, is this some type of cancer or heart disease that is very treatable, with minimal invasive treatment...

Five respondents, 83%, mentioned trying to work as a team with the family to try and resolve the disagreement. One respondent said, "It's taking time to really sit down and know why the family is making the decisions they are making and why the child is making the decision they are making and trying to bridge those two."

Another respondent said...So I think it's just trying to help the family, the parent and child come together and have an understanding of what each other's afraid of, and how do you alleviate those concerns, and how do you help them to bridge the gap.

Another tool used, according to one respondent, when a parent and child disagree is the use of motivational interviewing. One respondent said, "Umm, trying to do motivational interviewing to see what are the goals of the parents and why they want certain things." A final thing that is done, according to one respondent, when parents and children disagree is that children end up undergoing treatment for the sake of their parents.

One respondent described a 19 year old who said...I would not do this. I'm doing this for my mother. It's really important to her and it's important enough then that I'm going to do it for her. I don't think it's going to be worth it and I don't think it's going to save me but I will do it.

Discussion

How Many Families Discuss Dying with Terminally Ill Child

In the current study, the researcher found that the respondents agreed that most families usually have some conversation about death with their dying child. Four respondents said that most families have some sort of discussion with their child, one respondent said the number is much lower when specifically addressing death, and another respondent said it depends on the age of the child. In the study conducted by Ellis and Leventhal (1993), they found that 96% of patients and 84% of parents wanted to know if they were not improving and likely to die. However, only 64% of parents surveyed wanted that information shared with the child.

The current study found that all six respondents believed it was important to discuss dying with their child. However, there were several different reasons provided. One reason provided by respondents was that children are aware of what is happening with their bodies. There were two articles in the previous literature that found children often know what is happening and taking place with their bodies (Duncan et al., 2006; Martin et al., 1984). Another reason provided by respondents was that it lets the children ask questions, offers reassurance both to the parents and child, and allows the family time to say goodbye to each other. However, these emerging themes were not found in the previous literature.

Another reason provided by respondents was that it allowed for honesty between the parent and child. The previous literature cited several examples for the importance of truthfulness and honesty between the parent and child (Faulkner, 1997; Anderzen-Carlsson et al., 2010; Dunlop, 2008; Freyer, 2004). Another reason given by respondents was that it is good for children to know what is going on and children often know they are dying before their parents.

COMMUNICATION AND END-OF-LIFE

Hinds et al. (2005) explained that clinicians feel it is generally a good idea to share the child's prognosis with him or her so that communication can be opened about the child's impending death. Additionally, Ellis and Leventhal (1993) found that 87% of children who had a complete understanding of their cancer wanted to be informed about what the cancer was doing to their bodies. The current study also found that it is important children know that dying is not their fault or the result of anything the child's parents did. However, this emerging theme was not found in the previous literature. A final reason given by one respondent was that it was important to discuss with children but that parents did not need to tell the child they were dying. Puckey and Bush (2011) state that withholding certain information from the child is acceptable as long as it is not damaging.

In the current study, the researcher found there were several reasons for why parents do not discuss death with their dying child. The respondents stated that parents may think the child does not know and are afraid to share that information with the child. Hutton et al. (2006) explained that parents are reluctant to introduce the concept of death to a child because the child has not considered it yet. Another reason provided by the respondents was that parents are in shock and afraid to think about it and are therefore unable to talk to their child about it. Two articles from the previous literature stated that parents want to shield themselves from the painful reality and are not ready to accept their child's death (Freyer, 2004; Stillion & Papadatou, 2002).

In the current study, the researcher also found that parents are afraid of frightening or shocking their child. Two of the research studies from the previous literature also found that parents wanted to avoid scaring their children (Anderzen-Carlsson et al., 2010; Dunlop, 2008). Another reason provided by respondents was that parents do not want their child to think they are giving up hope and they do not want the child to lose hope. Stillion and Papadatou (2002) and

COMMUNICATION AND END-OF-LIFE

Hutton et al. (2006) state that parents are afraid children will give up hope and parents want their children to maintain hope. The current study also found that parents may not talk to their child about death because the parents want to protect their child. The theme of parents wanting to protect their child was found throughout the previous literature (Puckey & Bush, 2011; Dunlop, 2008; Stillion & Papadatou, 2002).

In the current study, the researcher found that there were several different reasons for parents to discuss death with their dying child. One reason provided in the current study was that it offers reassurance to the child and parents. However, this emerging theme was not found in the previous literature. The current study also found that it gives the child permission to let go. Again, this emerging theme was not found in the previous literature. Another reason parents discuss death with their child is to provide comfort and honesty. The previous literature found that parents being truthful with their child helped to open up communication between the parent and child (Freyer, 2004; Faulkner, 1997; Anderzen-Carlsson et al., 2010; Dunlop, 2008).

The current study also found that parents will discuss death with their child because the child brings it up. However, this emerging theme was not found in the previous literature. Additionally, parents discuss death with their child to discuss spirituality and the family's belief system. Again, this emerging theme was not found in the previous literature. The current study also found parents do so to find out what their child thinks and what their child's wishes are. Dunlop (2008) said that parents discuss death in order for the child to be able to express his or her preferences. A final reason provided by the respondents was that parents want to be supportive with their child. This emerging theme was not found in the previous literature.

COMMUNICATION AND END-OF-LIFE

In the current study, the researcher found that there was some variance as to whether or not parents experienced regret about not discussing death with their dying child. However, Kreicbergs et al. (2004) found that of the 147 parents who discussed death with their child, none of those parents experienced regrets. In the current study, one respondent stated that parents may have regrets about not being aware that their child is dying. Kreicsbergs et al. (2004) found that of parents who sensed their child's awareness of his or her death regretted not talking to their child about death. Another regret parents experienced in the current study was being unable to communicate with their child due to the child being in a coma. However, this emerging theme was not discussed in the previous literature.

In the current study, the researcher found that the five out of six participants felt that children wanted their parents to discuss dying with them. One reason found in the current study is that it allows children to ask questions and provides the children with a better understanding. Freyer (2004) stated that parents should be encouraged to be truthful and provide knowledge to the adolescent from diagnosis. Additionally, Dunlop (2008) explained that truthfulness allows the child to express their choices, fears, and grief. Another reason found in the current study is that it allows the child and parent an opportunity to explore spirituality. However, this emerging theme was not found in the previous literature.

The current study also found that children want to discuss death with their parents in order to explore how the family will hold the child's memory after death. This emerging theme was not found in the previous literature. Another reason found in the current study is that it opens up communication. Several articles from the previous literature stated that honest and open communication about death is helpful to the parents and child (Faulkner, 1997; Anderzen-Carlsson, 2010; Hinds et al., 2005, Young et al., 2003). The current study also found that

COMMUNICATION AND END-OF-LIFE

children want their parents to discuss death because it gives the child permission as well.

Dunlop (2008) stated a parent's truthfulness allows the child to express their fears, sadness and preferences. A final reason found in the current research was that it depends on the development of the child and the child's relationship with his or her parents. These emerging themes were not found in the previous literature.

In the current study, the researcher found that most respondents agreed that parents make most of the end-of-life decisions for their dying child. The respondents reported that a child's age and development are often a factor. A few articles stated that a child's competency and cognitive ability need to be considered when children are participating in decision making (Hinds et al., 2005; Hallstrom & Elander, 2004). The current study also found that while parents are often the decision makers, the hospital team works with the family to make sure the child's wishes are heard too. The previous literature found that it is important to consider a child's hopes and wishes during the decision making process (Hutton et al., 2006; Anderzen-Carlsson et al., 2010). The researcher also found that the older the child is the more likely the child will be involved in the decision making process. However, this emerging theme was not found in the previous literature.

In the current study, the researcher found that when parents are acting as the decision maker there are processes in place to ensure the parent is acting in the child's best interests. There were several different tools mentioned by the respondents. The researcher found one thing the hospital team will do if a parent refuses a recommended treatment is to investigate the pros and cons of not treating the child. This emerging theme was not found in the previous literature. The current study also found that the hospital team will assess the whole family. Similarly, Stevens et al. (1996) explained that families should be assisted by the care team in order to make

COMMUNICATION AND END-OF-LIFE

informed decisions. Another tool mentioned by the respondents was the use of the ethics team. However, this emerging theme was not found in the previous literature. A final tool mentioned was the involvement of child protection or a court order when necessary. This emerging theme was also not found in the previous literature.

In the current study, the researcher found that the majority of respondents believed that children do want to participate in end-of-life decision making. In the previous literature, Zwaanswijk et al. (2007) found that respondents felt decisions about treatment should be a collaborative experience. The current study also found that a child's desire to participate is often dependent upon the child's age. Although the previous literature did not mention a child's age, a child's development was mentioned (Hallstrom & Elander, 2004; Hinds et al., 2005).

In the current study, the researcher found that there are different ways to involve children in the decision making process. The researcher found one way children can participate is by providing children with options. The previous literature also mentioned giving the child options during their treatment (Nitschke et al., 1982; Stevens et al., 1996; Duncan et al., 2006; Anderzen-Carlsson et al., 2010; Hinds et al., 2005). Children have choices in the end-of-life even if they are not major decisions. The current study also found that teenagers can participate in end-of-life decision making by completing an advanced directive. However, this emerging theme was not found in the previous literature. A final way children can participate is by engaging in legacy work. This emerging theme was also not found in the previous literature.

In the current study, the researcher found that there are several things that can be done when a parent and child disagree about end-of-life care. The current study found that the ethics team may be involved to reach a compromise. However, this emerging theme was not found in

COMMUNICATION AND END-OF-LIFE

the previous literature. Another option found in the current study was exploring the idea of treatment versus no treatment with families. Again, this emerging theme was not found in the previous literature. The current study also found that the team will work with the family to try and resolve a disagreement. In the previous literature, Tadmor (2004) stated that the care team can help explore a parent's need to protect and the child's need to know more. Another option found in the current study was the use of motivational interviewing. The use of motivational interviewing was not mentioned specifically. However, Jones (2005) found that understanding a family's dreams and goals may be helpful when conflict arises. A final thing that may be done when a parent and child disagree is the child will do a treatment for the sake of his or her parent. Similarly, Hinds et al. (2005) found that 2 of 20 pediatric patients agreed to further treatment to benefit others, despite no longer being interested in further treatments.

Conclusion

Further Research

In general, there is a clear indication that further research is needed on end-of-life decisions, parents, and terminally ill children. The current study produced several emerging themes that were not addressed in the previous literature. An explanation of further research will be discussed below.

The emerging themes found for the importance of discussing death include the child being able to ask questions, offers reassurance to both the parents and child, allows for time to say goodbye, and that dying is not their fault or result of anything they or parents did. The emerging themes found for disclosing a child's terminal diagnosis include providing reassurance to both the parents and child, giving permission to the child to let go, the child brings it up,

COMMUNICATION AND END-OF-LIFE

spirituality/ family belief system, and being supportive of the child. The emerging theme found for parents and regrets was not being able to communicate with their child. The emerging themes found for a child's interest in his or her parents discussing death included parents and child exploring spirituality, exploring how the family will hold the child's memory, and development of the child and his or her relationship with his or her parents.

Additionally, the emerging themes found for parents as decision makers included older children being more likely to participate, investigating the pros and cons of not treating a child, ethics team involvement, and the use of child protection/ court order. The emerging themes found for how children can participate in the decision-making process included teenagers completing advanced directives and children participating in legacy work. Finally, the emerging themes found in parent and child disagreements included involving the ethics team and reviewing treatment vs. no treatment.

An explanation for further research may have to do with the location of the research studies. The location of respondents may have impacted how they responded to end-of-life decision making. There may have been certain regions that were more exposed to end-of-life care than others or that have more palliative care centers in their region. Therefore, it is important to assume that location or region may have an impact on respondents' answers to end-of-life decision making. Future research should look into conducting more research in varying locations in order to replicate the previous findings on end-of-life decision making and to look into differences in responses by region or location.

Another explanation for the need for further research may be the population surveyed. The current study and Jones (2005) involved social workers with pediatric pain and palliative

COMMUNICATION AND END-OF-LIFE

care knowledge. However, in the rest of the previous studies the populations surveyed were children, parents, and cancer survivors (Bluebond-Langer, 1978; Anderzen-Carlsson, 2010; Ellis & Leventhal, 1993; Hallstrom & Elander, 2004; Hinds et al., 2005, Hsiao et al., 2007; Kohler & Radford, 1985; Kreicbergs et al., 2004; Nitschke et al., 1982; Stegenga & Ward-Smith, 2008; Young et al., 2003; Zwaanswijk et al., 2007; Zwaanswijk et al., 2010). The current study may have provided emerging themes not covered in the previous literature because the respondents were social workers as opposed to being a parent or child living with the terminal illness. The social worker may experience the situation differently than the child or parent. The social worker may have different views on the situation because they are not living the experience. For future research, it may be beneficial to look into how different populations such as families and the care team explain end-of-life decision making. It may be beneficial to explore whether or not professionals and family members come to the same conclusions or if there may be some differences in their responses.

Limitations

One limitation of this study is its small sample size. Another limitation of this study is the lack of generalizability to the larger population. The sample used for this study consisted of six respondents. This sample did not consist of a nonprobability sample. The generalizability to the general population would be made stronger if there was larger respondent participation and that the respondents had been selected at random as opposed to volunteering. Additionally, the results of the study are specific to the six respondents. Therefore, it is not appropriate to make generalizations about how parents communicate about death and end of life decisions based on six respondents because other potential respondents may have different experiences.

COMMUNICATION AND END-OF-LIFE

Implications and Recommendations

One implication that applies to social work practice is for social workers to become knowledgeable about how families go about addressing the topic of death and decision making. By having a better understanding, social workers will be better able to work with families throughout this difficult process. Another implication from this study is that social workers need to be mindful of parents who are struggling with their child's terminal diagnosis and the decisions that will likely follow. It is important that social workers be able to identify struggling family members so that they can offer tools to help lessen the burden. In addition, social workers need to be mindful of parents and children's readiness in discussing death. Social workers should respect each family member's decision and allow them to discuss death in their own time.

The first recommendation the researcher would make would be to conduct further research on the topic of end-of-life decisions of terminally ill children with their parents. There are far too little research studies on the topic of decision making and parents talking to their terminally ill child about death, especially from varying populations. In addition, the researcher also has some recommendations for future research. Once more research is conducted on how parents communicate about end-of-life decision making and talking about death, it may be beneficial to study how siblings are allowed to participate in end-of-life care and decisions. Furthermore, it may also be beneficial to study how extended family are affected by a child with a terminal illness and what role, if any, they are allowed in the decision making process. Finally, it may be beneficial to explore how the relationship between the care team and parents affects end-of-life care decisions for terminally ill children.

COMMUNICATION AND END-OF-LIFE

References

- Anderzén-Carlsson, A., Kihlgren, M., Svantesson, M., & Sorlie, V. (2010). Parental handling of fear in children with cancer; caring in the best interests of the child. *Journal of Pediatric Nursing, 25*(5), 317-326. doi: 10.1016/j.pedn.2008.10.004
- Beale, E.A., Baile, W.F., & Aaron, J. (2005). Silence is not golden: Communicating with children dying from cancer. *Journal of Clinical Oncology, 23*(15), 3629-3631. doi: 10.1200/JCO.2005.11.015
- Binger, C. M. (1984). Psychosocial intervention with the child cancer patient and family. *Psychosomatics: Journal of Consultation Liaison Psychiatry, 25*(12), 899-902.
- Bluebond-Langer, M. (1978). *The private worlds of dying children*. Princeton, NJ: Princeton University Press.
- Boss, P. (2006). *Loss, trauma, and resilience: Therapeutic work with ambiguous loss*. New York, NY: W.W. Norton & Company.
- Chambers, E. J., & Oakhill, A. (1995). Models of care for children dying of malignant disease. *Palliative Medicine, 9*(3), 181-185. doi:10.1177/026921639500900302
- Children's Hospital of the King's Daughter. (2005). Care of the terminally ill child. Retrieved from <http://www.chkd.org/HealthLibrary/Context.aspx?pageid=P03050>
- Duncan, J., Joselow, M., & Hilden, J. M. (2006). Program interventions for children at the end of life and their siblings. *Child and Adolescent Psychiatric Clinics of North America, 15*(3), 739-758. doi:10.1016/j.chc.2006.02.002

COMMUNICATION AND END-OF-LIFE

Dunlop, S. (2008). The dying child: Should we tell the truth? *Paediatric Nursing*, 20(6), 28-31.

Retrieved from

<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com.ezproxy.stthomas.edu/login.aspx?direct=true&db=aph&AN=33584976&site=ehost-live>

Ellis, R., & Brigid. Leventhal, R. (1993). Information needs and decision-making preferences of

children with cancer. *Psycho-Oncology*, 2(4), 277-284. Retrieved from

<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com.ezproxy.stthomas.edu/login.aspx?direct=true&db=keh&AN=12223187&site=ehost-live>

Faulkner, K. W. (1997). Dealing with death: Talking about death with a dying child. *The*

American Journal of Nursing, 97(6), 64-69. Retrieved from

<http://www.jstor.org.ezproxy.stthomas.edu/stable/3465368>

Feudtner, C. (2007). Collaborative communication in pediatric palliative care: A Foundation for

problem-solving and decision-making. *Pediatric Clinics of North America*, 54(1), 583-607.

doi: 10.1016/j.pcl.2007.07.008

Freyer, D. R. (2004, 02; 2012/11). Care of the dying adolescent: Special considerations. 113,

381+. Retrieved from http://go.galegroup.com/ezproxy.stthomas.edu/ps/i.do?id=GALE%7CA113646350&v=2.1&u=clic_stthomas&it=r&p=EAIM&sw=w

http://go.galegroup.com/ezproxy.stthomas.edu/ps/i.do?id=GALE%7CA113646350&v=2.1&u=clic_stthomas&it=r&p=EAIM&sw=w

Hallström, I., & Elander, G. (2004). Decision-making during hospitalization: Parents' and

children's involvement. *Journal of Clinical Nursing*, 13(3), 367-375. Retrieved from

<http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com.ezproxy.stthomas.edu/login.aspx?direct=true&db=keh&AN=12912473&site=ehost-live>

COMMUNICATION AND END-OF-LIFE

Hinds, P. S., Drew, D., Oakes, L. L., Fouladi, M., Spunt, S. L., Church, C., & Furman, W. L.

(2005). End-of-life care preferences of pediatric patients with cancer. *Journal of Clinical Oncology*, 23(36), 9146-9154. doi:10.1200/JCO.2005.10.538

Hinds, P. S., Schum, L., Baker, J. N., & Wolfe, J. (2005). Key factors affecting dying children and their families. *Journal of Palliative Medicine*, 8, s-70; s-78. doi: 10.1089/jpm.2005.8.s-70

Hooyman, N. R., Kramer, B. J. (2006). Living through loss: Interventions across the life span. New York, NY: Columbia University Press.

Hsiao, J.L., Evan, E.E., & Zeltzer, L.K., (2007). Parent and child perspectives on physician communication in pediatric palliative care. *Palliative and Supportive Care*, 5(1), 355-365. doi: 10.1017/S1478951507000557

Hurwitz, C. A., Duncan, J., & Wolfe, J. (2004). Caring for the child with cancer at the close of life: "There are people who make it, and I'm hoping I'm one of them". *JAMA: Journal of the American Medical Association*, 292(17), 2141-2149. doi:10.1001/jama.292.17.2141

Hutton, N., Jones, B., & Hilden, J. M. (2006). From cure to palliation: Managing the transition. *Child and Adolescent Psychiatric Clinics of North America*, 15(3), 575-584. doi:10.1016/j.chc.2006.05.014

Jones, B. L. (2005) Pediatric palliative and end-of-life care: The role of social work in pediatric oncology. *Journal of Social Work in End-of-Life & Palliative Care*, 1(4), 35-62. doi:10.1300/J457v01n04_04

COMMUNICATION AND END-OF-LIFE

Kang, T., Hoehn, S., Licht, D. J., Mayer, O. H., Santucci, G., Carroll, ...Feudtner, C. (2005).

Pediatric palliative, end-of-life, and bereavement care. *Pediatric Clinics of North America*, 52(4), 1029-1046. doi:10.1016/j.pcl.2005.04.004

Kohler, J. A., & Radford, M. (1985). Terminal care for children dying of cancer: Quantity and quality of life. *British Medical Journal*, 291(6488), 115-116.

Konrad, S. C. (2007). What parents of seriously ill children value: Parent-to-parent connection and mentorship. *Omega - Journal of Death and Dying*, 55(2), 117-117-130. Retrieved from <http://search.proquest.com.ezproxy.stthomas.edu/docview/61410452?accountid=14756>

Kreicbergs, U., Valdimarsdóttir, U., Onelöv, E., Henter, J., & Steineck, G. (2004). Talking about death with children who have severe malignant disease. *The New England Journal of Medicine*, 351(12), 1175-1186. doi:10.1056/NEJMoa040366

Kubler-Ross, E. (1975). *Death: The final stage of growth*. Englewood Cliffs, NJ: Prentice Hall.

Martin, D., Martin, M., & Pierce, L. (1984). The dying child: Understanding developmental processes for parents and therapists. *Journal of Child & Adolescent Psychotherapy*, 1(2), 107-110.

National Cancer Institute. (2008). Childhood cancers. Retrieved from <http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood>

Nitschke, R., Humphrey, G. B., Sexauer, C. L., Catron, B., Wunder, S., & Jay, S. (1982).

Therapeutic choices made by patients with end stage cancer. *Journal of Pediatrics*, 101(3), 471-476.

COMMUNICATION AND END-OF-LIFE

- Puckey, M., & Bush, A. (2011). "Passage to paradise" ethics and end-of-life decisions in children. *Pediatric Respiratory Reviews* 12(1), 139-143. doi: 10.1016/j.prrv.2010.10.003
- Rando, T., A. (1985). Bereaved parents: Particular difficulties, unique factors, and treatment issues. *Social Work*, 30(1), 19-23. Retrieved from <http://ezproxy.stthomas.edu/login?url=http://search.ebscohost.com.ezproxy.stthomas.edu/login.aspx?direct=true&db=sw&AN=12060&site=ehost-live>
- Soricelli, B. A., & Utech, C. L. (1985). Mourning the death of a child: The family and group process. *Social Work*, 30(5), 429-434.
- Sormanti, M., & August, J. (1997). PARENTAL BEREAVEMENT: Spiritual connections with deceased children. *American Journal of Orthopsychiatry*, 67(3), 460-469.
doi:10.1037/h0080247
- Stegenga, K., & Ward-Smith, P. (2008, March; 2012/11). The adolescent perspective on participation in treatment decision making: A pilot study.25, 112+. Retrieved from http://go.galegroup.com.ezproxy.stthomas.edu/ps/i.do?id=GALE%7CA175951440&v=2.1&u=clic_stthomas&it=r&p=EAIM&sw=w
- Stevens, M. M., Jones, P., & O'Riordan, E. (1996). Family responses when a child with cancer is in palliative care. *Journal of Palliative Care*, 12(3), 51-55.
- Stillion, J. M., & Papadatou, D. (2002). Suffer the children: An examination of psychosocial issues in children and adolescents with terminal illness. *American Behavioral Scientist*, 46(2), 299-315. doi:10.1177/000276402236679

COMMUNICATION AND END-OF-LIFE

Tadmor, C. S. (2004). Preventive intervention for children with cancer and their families at the end-of-life. *The Journal of Primary Prevention, 24*(3), 311-323. doi:

10.1023/B:JOPP.0000018056.51429.c7

Traugott, I., & Alpers, A. (1997). In their own hands: Adolescents' refusals of medical treatment. *Archives of Pediatric and Adolescent Medicine, 151* (1), 922-927.

Young, B., Dixon-Woods, M., Windridge, K. C., & Heney, D. (2003). Managing communication with young people who have a potentially life threatening chronic illness: Qualitative study of patients and parents. *BMJ: British Medical Journal, 326*(7384), pp. 305-308. Retrieved from <http://www.jstor.org.ezproxy.stthomas.edu/stable/25453609>

Zwaanswijk, M., Tate, K., Van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., & Bensing, J.M. (2007). Young patients', parents', and survivors' communication preferences in paediatric oncology: Results of online focus groups. *BMC Pediatrics, 7*, 35. Retrieved from http://go.galegroup.com.ezproxy.stthomas.edu/ps/i.do?id=GALE%7CA173537559&v=2.1&u=clic_stthomas&it=r&p=HRCA&sw=w

Zwaanswijk, M., Tate, K., van Dulmen, S., Hoogerbrugge, P. M., Kamps, W. A., Beishuizen, A., & Bensing, J. M. (2010). Communicating with child patients in pediatric oncology consultations: A vignette study on child patients', parents', and survivors' communication preferences. *Psycho-Oncology, 20*(3), 269-277. doi: 10.1002/pon.1721

COMMUNICATION AND END-OF-LIFE

Appendix A

Dear (hospital's name) social workers,

My name is Jessica Convy and I am in my final year of graduate school for clinical social work in the joint program at the University of St. Thomas and St. Catherine University. I am currently completing my clinical internship at (hospital's name) in (city) in the pain and palliative care unit. As a requirement for my graduation, I must complete a research study. I am particularly interested in end-of-life issues in pediatrics. I am completing a research project that will explore the social worker's perspective on how parents address communication and end-of-life decision making about death with their children who have terminal cancer. I am interested in interviewing social workers who have experience working with families who have a child with terminal cancer and knowledge of end-of-life issues. The questions that I am interested in will focus on parents' communication and end-of-life decision making with their terminally ill child. The questions that I will be asking are:

1. What percentage of families that you work with discusses dying with their terminally ill child?
2. Is it important for parents to discuss dying with their terminally ill child? Why or why not?
3. What reasons do parents give for not talking about death with their terminally ill child?
4. Do parents have regrets when they decide not to talk about dying with their terminally ill child? If so, what are their regrets?
5. What reasons do parents give for talking about death with their terminally ill child?
6. Do terminally ill children want their parents to talk about dying with them? Why or why not?
7. Do parents make most of the decisions with end of life care for their terminally ill child? Why or why not?
8. If the parent is the principle decision maker, are there processes in place to ensure that the parent is acting in the best interests of the terminally ill child? If so, what are they?
9. How much say do terminally ill children have in their end of life treatment?
10. Do children want to participate in decision making for their end of life care?
11. What is done when a parent and terminally ill child disagree about end of life care?
12. What is the most satisfying part of your job?

I would like you to know that participating in the study is completely voluntary and your personal information will be kept confidential. I will not be using any identifying information in my study. Whether or not you choose to participate in this study will not affect your relationship with (hospital's name). The interview will be audio recorded and later transcribed but your name will not be attached to the study. If you are interested in participating or have questions please feel free to call me at _____ or my cell phone at _____. You may also respond by replying to this email. Thank you for your time.

COMMUNICATION AND END-OF-LIFE

Sincerely,

Jessica Convy

COMMUNICATION AND END-OF-LIFE

Appendix B

RESEARCH CONSENT FORM

Communication and End-of-Life Decision Making with Terminally Ill Children (with Cancer) and Parents

INTRODUCTION

Before agreeing that you/your child will take part in this research, it is important that you read and understand the following explanation. It describes the purpose, benefit, risks and discomforts of the study, and the safeguards that will be taken. It also describes any other options that are available and the right to withdraw (quit) from the study at any time.

BACKGROUND

You are invited to be in a research study about the social worker's perspective on how parents address communication and end-of-life decision making about death with their child who has terminal cancer. You were selected as a possible participant because of your experience working with families who have a child with cancer and your knowledge in end of life issues.

RESEARCH PURPOSE

This study was created in order to explore the social worker's perspective on a parent's decision to discuss the terminal diagnosis with their child. It is also interested in looking at how much the parent allows the terminal child to be involved in the decision making process concerning the end-of-life care.

RESEARCH PROCEDURES

If you agree to participate in this study, you will be asked to participate in an audio recorded interview, which will last approximately 30 minutes. The data from the interview will then be analyzed into a transcript. That transcript will then be shared with my research chair. Finally, the data obtained from the interview will be presented in a presentation and a paper documenting the findings will be turned into the professor and University of St. Thomas. The data used in the study will not include any identifying information.

RISKS

This study is considered low risk because the researcher will not be using any identifying information in the study. There is a minimal risk that the questions asked could bring up unpleasant memories. In order to guard against this risk, the researcher will be sending the questions to potential participants ahead of time. The researcher will also make it clear that participants do not have to answer questions if they don't want to. The researcher will also end the interview by asking more neutral questions.

BENEFITS

COMMUNICATION AND END-OF-LIFE

No direct benefits to participants. As an indirect benefit, information may be provided that is helpful to society and those dealing with dying children.

ALTERNATIVES

Non-participation is always an alternative.

CONFIDENTIALITY

Records of participants in this research are private, and any knowledge that is gained that can be used to identify you will not be given to anyone other than the researcher. Knowledge that is gained from the study may be published in scientific journals without identifying the participants.

FINANCIAL ISSUES

Costs for participation in the study

There are no costs associated with this research project.

Compensation

No compensation will be offered for participating in this study.

VOLUNTARY NATURE OF THE STUDY

Taking part in this study is completely voluntary. By signing this Consent Form, you agree to take part in this research study. You are free to withdraw from this research study at any time without affecting your current or future relationship with (Agency's name).

HOW TO GET ANSWERS TO YOUR QUESTIONS

You are encouraged to ask questions both before you agree to participate in the study and also at any time you need information. If you have any questions at any time, they will be answered.

If you have any questions about this study please contact the researcher, Jessica Convy at (phone number). If you participate in the study and have questions at a later date, please also feel free to ask at any time.

Your signature below means that you have read the above information, that you have had the opportunity to ask questions and receive answers, and that you have decided to take part based on what you have read and discussed.

You will be provided a copy of this form to keep.

COMMUNICATION AND END-OF-LIFE

Research Participant Signature

Date

Researcher Signature

Date

COMMUNICATION AND END-OF-LIFE

Appendix C

Interview Questions:

1. What percentage of families that you work with discusses dying with their terminally ill child?
2. Is it important for parents to discuss dying with their terminally ill child? Why or why not?
3. What reasons do parents give for not talking about death with their terminally ill child?
4. Do parents have regrets when they decide not to talk about dying with their terminally ill child? If so, what are their regrets?
5. What reasons do parents give for talking about death with their terminally ill child?
6. Do terminally ill children want their parents to talk about dying with them? Why or why not?
7. Do parents make most of the decisions with end of life care for their terminally ill child? Why or why not?
8. If the parent is the principle decision maker, are there processes in place to ensure that the parent is acting in the best interests of the terminally ill child? If so, what are they?
9. How much say do terminally ill children have in their end of life treatment?
10. Do children want to participate in decision making for their end of life care?
11. What is done when a parent and terminally ill child disagree about end of life care?
12. What is the most satisfying part of your job?