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Effective and Compassionate Communication Between Hospital Staff and Parents of Children with Newly Diagnosed Cancer

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Effective and Compassionate Communication between Hospital Staff and Parents of
Children with Newly Diagnosed Cancer

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**FINAL APPROVAL OF MASTER'S PROJECT
HSA696 MASTER'S PROJECT**

I have **READ AND ACCEPTED**

the Master's Project by:

Natalie Volz

Effective and Compassionate Communication between Hospital Staff and Parents of
Children with Newly Diagnosed Cancer

Submitted in partial fulfillment of
requirements for the
Master of Science in Health Services Administration
degree at
Regis University

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Abstract

This study was conducted to determine the most effective and compassionate modes of communication for hospital staff at The Children's Hospital to use when conveying information to parents of children with cancer. Twelve parents whose children were four to twelve weeks post diagnosis were interviewed. Parents were asked a series of eleven open-ended questions addressing their experience with hospital staff's communication skills. Recurring themes resulting from the interviews include delivery of diagnosis, value of information, receptiveness to questions and availability of hospital staff. These themes reveal that parents value thorough and complete explanations of their child's diagnosis and treatment plans, hospital staff's willingness to answer all questions and hospital staff's availability in person, over the phone and through email. Staff at The Children's Hospital has demonstrated competency in their communication with parents of children with cancer. Health services administrators are responsible for implementing programs to further improve hospital staff's communication skills and to facilitate effective and compassionate communication.

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Chapter 1 Introduction

Approximately 55,000 children die in the United States each year. Congenital abnormalities, complications associated with pre-maturity, pregnancy or childbirth, sudden infant death syndrome (SIDS), unintentional injuries and intentional injuries are the most common causes. Among fatal chronic conditions, cancer, diseases of the heart and lower respiratory conditions are significant contributors to childhood deaths. Nearly seventy percent of childhood deaths occur in hospitals (Field and Behrman, 2003).

These sensitive statistics have compelled the Institute of Medicine to issue an urgent call to improve the quality and delivery of pediatric palliative care (Meyer, Ritholz, Burns, and Truog, 2006). Aspects of delivery of pediatric palliative care include effective and compassionate communication with parents of children with life threatening illnesses. A physician's competence in communication, decision making and building relationships has been found to directly correlate with patient and parent satisfaction with their medical care and adherence to medical advice. In addition, a physician's competence in this area may significantly improve his or her own experience in providing care (von Gunten, Ferris, and Emanuel, 2000).

Due to the above stated statistics and the pertinence of appropriate communication between hospital staff and parents of seriously ill children, this aspect of pediatric palliative care is an issue that must be extensively addressed. The purpose of this study is to determine the most effective and compassionate modes of communication for hospital staff at The Children's Hospital to use when conveying information to parents of children with cancer. The research questions being examined by this study are: What are the most effective ways for hospital staff to communicate

with parents of children with cancer? What are the most compassionate ways for hospital staff to communicate with parents of children with cancer?

Because parents of seriously ill children come in contact with practitioners during times of enormous vulnerability, they often heavily rely on practitioners for support. In difficult times, parents frequently refer to physicians and staff as family or friends, and they sense a rapid connection with these individuals. Explanations for this phenomenon include practitioners' expertise and availability as well as their familiarity with the hospital culture in the context of the family's emotional needs and vulnerability (Meyer, Burns, Griffith, and Truog, 2002).

In addition, interviews with parents of children with life threatening conditions reveal kindness, genuineness and empathy by healthcare professionals and clear communication, accessibility and continuity of care as extremely important and memorable aspects of their child's care (Meyer et al., 2002).

Browning (2004, p. 23) also states, "There are times when children and family members need to sense that their professional caregivers acknowledge and, at times, share their suffering. At other times, they need their practitioners to step out of a narrowly defined professional role to reveal a more human side."

The genuine expression of emotion and concern is positively perceived by parents of ill children. In general, parents encourage this display of emotion and they recall it in a positive realm (Meyer et al., 2006). The grandmother of a child with a life threatening condition describes her positive experience with a caring and communicative physician.

“When we was in the waiting room, the surgeon, he came out and he explained to us how serious it was. He even told us how long she might live...To me, he was just like part of us at that moment. And I really appreciate him for that. Because that was the beginning of it and that would have been the most important part right there...the way he handled it, the way he took care of it...He even got a little room off to the side for us to go in by ourself for a minute. That particular surgeon, I'll never, never forget him. I can just picture him, the way he express himself, the body movements, the caring. I mean he let you know...You can just feel it” (Browning, 2004, p. 26).

Dr. Robert D. Truog further supports the importance of pediatric palliative care.

“To have the freedom to be open and to reach out emotionally to the parents of ill children is one of the most cherished aspects of pediatric practice for many clinicians, and certainly a perspective that is equally valued by many families” (Truog, 1999, p. 154).

However, some parents report negative experiences that include insensitive delivery of bad news, feeling dismissed or patronized, perceived disregard for parents' judgment regarding the care of their child and poor communication of important information (Contro, Larson, Scofield, Sourkes, and Cohen, 2002). Parents also become frustrated when they feel as if they are the ones working hard to create effective communication. Some parents report frustrations with having to determine the right questions to ask, trying to track down the right people for information and trying to be at their child's bedside at the appropriate time. These stressors add to the already established emotional burden experienced by parents (Davies and Connaughty, 2002).

Recently, several steps have been taken to improve the quality of healthcare for children with life threatening conditions and their families (Field and Behrman, 2003).

Von Gunten, Ferris, and Emanuel (2000) present a seven step approach for physicians to undertake when communicating with patients and families regarding end-of-life care.

These seven steps include preparing for discussions by confirming medical facts and establishing an appropriate environment, establishing what the patient and family know by using open-ended questions, determining how information is to be handled at the beginning of the patient-physician relationship, delivering the information in a sensitive but straightforward manner, responding to emotions of the patients, parents and families, establishing goals for care and treatment priorities when possible and establishing an overall plan (von Gunten et al., 2000).

In addition, the Critical Care Family Needs Inventory is a tool used to identify pertinent needs of families during these especially difficult times. Truog et al. (2001) combined information from several different studies to summarize the needs of families of critically ill patients. Expressed needs were to be with the person, to be helpful to the dying person, to be informed of the dying person's changing condition, to understand what is being done to the patient and why, to be assured of the patient's comfort, to be comforted, to ventilate emotions, to be assured that their decisions were right, to find meaning in the dying of their loved one and to be fed, hydrated and rested.

Meyer et al. (2006) utilized the Parental Perspectives Questionnaire to determine parents' views on end-of-life care, adequacy and pain management, decision making and social support. Derived from this tool are six parental priorities for pediatric palliative care. Priorities include honest and complete information, ready access to staff,

communication and care coordination, emotional expression and support by staff, preservation of integrity of the parent-child relationship and faith.

Several studies report that parents desire both honest and complete information about their child's illness and prognosis. However, they prefer a wide variety of communication modes based on cultural and religious backgrounds, the child's prognosis, individual and family coping styles and previous experience with loss (Meyer et al., 2002). Browning (2004) stresses that, in order for communication to be effective, the practitioner must enter the culture of the family. Meyer et al. (2006) encourages clinicians to assess and accommodate parents' preferences regarding how information should be communicated. Clinicians should then periodically check that the communication style being used is both effective and comfortable for the parents (Jellinek, Catlin, Todres, and Cassem, 1992).

International medical organizations require competency in communication skills (Rider & Keefer, 2006). Medical students applying to train in the United States are now required to demonstrate competence in clinical, interpersonal and communication skills on the United States Medical Licensing Examination (USMLE) Clinical Skills Examination (Klass, De Champlian, Fletcher, King, and Macmillan, 1998).

Browning (2004) stresses the importance of hospital administration to take an active role in the implementation and delivery of communication training programs for all hospital staff. The Accreditation Council for Graduate Medical Education (ACGME) provides tools that health services administrators can use to assess communication skills (Rider & Keefer, 2006). Programs also include providing ongoing refinement of writing guidelines and debriefing sessions (Truog, Christ, Browning, and Meyer, 2006).

Effective communication with parents of seriously ill children is essential to the successful delivery of health care. Ongoing communication has been associated with decreased parental anxiety and worry (Curley and Meyer, 2003). Establishing programs for continued education for hospital staff will help to further improve both effective and compassionate communication between staff and parents.

Chapter 2 Literature Review

Effective and compassionate communication with parents of seriously ill children is essential to the successful delivery of healthcare. In several studies, parents reported a desire for honest, complete and compassionate information about their child's illness and prognosis (Hsiao, Evan, and Zeltzer, 2007; Jackson et al., 2007; Mack et al., 2005; Meyer et al., 2006; Michelson and Steinhorn, 2007; Truog et al., 2001). The research questions addressed by this study are: What are the most effective ways for hospital staff to communicate with parents of children with cancer? What are the most compassionate ways for hospital staff to communicate with parents of children with cancer?

Communication and Pediatric Palliative Care

The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Rather than focusing on a curative approach to care, palliative care focuses on the relief of pain and suffering associated with serious illness.

In specific reference to children, the Initiative for Pediatric Palliative Care defines the areas of high quality and family centered care as maximizing family involvement in decision making and care planning to the extent that family members feel comfortable, appropriately informing and involving children with life threatening illnesses in decisions about their care, reducing pain and distressful symptoms in children with life threatening

illnesses, providing emotional and spiritual support to children and their families, facilitating the resolution of families' needs, facilitating continuity of care and offering bereavement and support to children and families before and after a child's death (Browning and Solomon, 2005).

Several studies have researched the communication aspect involved in pediatric palliative care. In their overview of pediatric palliative care, Michelson and Steinhorn (2007) stressed that communication is pertinent to adequately address patient and family needs. Compassionate and sensitive communication provides the patient and family with the highest possible quality of life. Furthermore, Michelson and Steinhorn (2007) stated that communication between pediatric palliative care providers is an essential aspect of successful pediatric palliative care. Effective team communication allows for proper symptom management, improved quality of life and the understanding of the family's wishes regarding therapy and treatment.

Hsiao et al. (2007) examined both the facilitative and the obstructive aspects of physician communication as perceived by parents and children in the pediatric palliative care setting. Both parents and children reported relationship building, demonstration of effort and competence, information exchanges, availability and appropriate level of child and parent involvement as facilitative and significant communication skills. Parents also identified coordination of care as a facilitative communication skill. These positive aspects of communication incorporated a sense of trust, mutual respect, security, "emotional peace" and confidence in continuity of care for patients and their parents.

Obstructive aspects of communication identified by parents and children included a physician's disrespectful or arrogant manner, lack of relationship building with the

family, insensitive delivery of bad news, failure to disclose information to parents and lack of preparing the patient and family for a new treatment course (Hsiao et al., 2007).

Hays et al. (2006) examined the success of a pediatric palliative care program implemented at Seattle's Children's Hospital and Regional Medical Center. This program focused on a family centered communication approach that required significant and specific communication skills.

Researchers studied health related quality of life and family satisfaction as reported by parents of ill children in the program. After entering the program, parents reported significantly improved experiences regarding several aspects of communication. These improved modes of parent-provider communication included emotional support received by the family, quality of information received by the child regarding his or her condition, quality of information received by the child about what might happen to him or her in the future, degree to which the child understood the information, how well the providers told the parents this information, providers' abilities to listen and to answer parents' and children's questions, sensitivity of providers to parents' and children's needs, providers' commitment to joint care decisions, preparation of the child for leaving the hospital and how quickly the providers responded to the child's needs (Hays et al., 2006).

Communication and End-of-Life Care

Effective and compassionate communication between parents and hospital staff is also a pertinent aspect of a child's end-of-life care. In his research on the psychosocial and physical concerns surrounding children with cancer, Collins (2002) found that parents desire information on the way their child may die and on what they

can do to relieve their child's pain and discomfort. In regards to loss and grief surrounding the death of a loved one, von Gunten et al. (2001) stated that a physician's effective end-of-life care involves recognizing the patient's, family members' and his or her own grief and assisting with necessary and appropriate interventions. Hospital staff can help parents by preparing them about what to expect and about what to do when death approaches.

The importance of effective communication to address the needs of families of those nearing death is further supported by the information gathered by Truog et al. (2001) and previously discussed in Chapter One. Again, family members' needs include to be with the person, to be helpful to the dying person, to be informed of the dying person's changing condition, to understand what is being done to the patient and why, to be assured of the patient's comfort, to be comforted, to ventilate emotions, to be assured that their decisions are right, to find meaning in the dying of their loved one and to be fed, hydrated and rested.

Mack et al. (2005) conducted a survey of fifty-two pediatric oncologists and 144 parents of children who received cancer treatment at pediatric and oncology facilities in Massachusetts and Minnesota. Parental surveys of end-of-life care for children with cancer revealed that eighty-two percent of parents felt physician care at the end of life was excellent or very good and that a positive rating was closely correlated with proper communication.

Aspects of effective communication associated with positive parental perceptions included the physician communicating bad news in a sensitive and caring manner, giving clear information about what to expect, establishing a sense of trust from the

child and family, preparing the family for circumstances surrounding the child's death and communicating with the child when appropriate. Parents favored direct physician-child communication if the physician was sensitive to the child's understanding of the illness and developmental level and if the parents deemed the communication appropriate for the child. Communication factors negatively perceived by parents included the physician relaying conflicting information. Conflicting information resulted from the physician's inconsistent reports regarding the child's illness (Mack et al., 2005).

When coping with the sudden and traumatic death of a child, hospital staff must simultaneously attend to an intense and evolving medical situation and the sudden and unexpected communication and emotional needs of the family. Truog et al. (2006) discussed the circumstances surrounding the sudden death of an eighteen-month-old toddler who was struck by a car. A physician directly involved with this case stressed it is pertinent that physicians know when and how to give tragic news. In addition, an overly optimistic or pessimistic prognosis must be avoided, as this can betray a parent's much needed sense of trust and confidence in the physicians.

Additional communication modes that helped ease the pain of this tragic death included effective and purposeful team communication, assessment of family members' roles through the expertise of a social worker and identification of family members who would likely be vulnerable to excessive grief (Truog et al., 2006).

Approximately sixty percent of deaths in the pediatric intensive care unit (PICU) follow the limitation or the withdrawal of life-sustaining treatment (LST) (Garros, Rosychuk, and Cox, 2003). Garros et al. (2003) conducted a prospective, descriptive study based on surveys of critical care specialists following a child's death in the PICU.

Ninety-nine surveys were completed. Regarding the limitation or withdrawal of LST, physician-parent consultations arose as a result of staff determination that prolonging treatment would be inappropriate and not beneficial. In almost fifty percent of cases, two or more meetings between physicians and parents were needed to agree on the discontinuation of LST. Garros et al. (2003) further reported that in several cases this shared decision was reached with great difficulty and with intense communication.

Communication and Outpatient Pediatric Care

Research has found that effective parent-provider communication is associated with parental satisfaction with care in the primary care setting. Seid et al. (2001) stressed that proper coordination of pediatric primary care involves communicating this process and its outcomes with the child's parents. To address this issue, Seid et al. developed the Parent's Perceptions of Primary Care measure (P3C). They emphasized the relevance of this tool to measure parents' perceptions of the quality of their child's primary care.

Nobile Hart, Drotar, Gori, and Lewin (2005) researched the effectiveness of a brief intervention aimed at improving the communication skills of medical residents in the ambulatory care setting at two teaching hospitals in the Midwest. This intervention addressed the utilization of empathy, positive affect, support and collaboration with parents.

Parents' perceptions of communication and their satisfaction with care before and after this intervention were assessed. At both baseline and follow-up, parents perceived good communication by residents with no significant change in perception.

Regarding parental satisfaction with care, satisfaction increased significantly following the communication intervention (Nobile Hart et al., 2005).

The systematic review conducted by Nobile and Drotar (2003) addressed the correlation between interventions associated with improving parent-provider communication and the effectiveness of this improved communication in outpatient settings. The fifteen articles addressing the relationship between communication and parental satisfaction with care indicated a consistent association between improved communication and increased parental satisfaction. In concurrence with the findings of Nobile Hart et al. (2005), this review found the communication aspects of positive affect, empathy and alliance with parents to be significant correlates with parental satisfaction.

Communication with Pediatric Cancer Survivors

The five year survival rate for pediatric cancer has significantly improved to 79.6 percent (National Cancer Institute, n.d.). This improved rate has facilitated research addressing the importance of continued communication with survivors of pediatric cancer throughout both treatment and the subsequent long-term follow-up. Regarding adolescents and young adults who have been off treatment for several years, Decker, Haase, and Bell (2007) stressed that health care providers should nurture continued relationships and communication, therefore facilitating the development of self-management and advocacy skills during long-term survival.

In their research, Zwaanswijk, Tates, van Dulmen, Hoogerbrugge, Kamps, and Bensing (2007) defined childhood cancer survivors as those who were eight to seventeen years of age at diagnosis and whose treatment had been successfully completed during the preceding five years. In online focus groups, survivors stressed

the importance of open and honest communication. They also discussed age appropriate communication. Adolescent survivors emphasized the lack of information designed specifically for their age. They wanted information to be presented to them as adolescents rather than children or adults. Survivors also desired an active role in decision making. Again, they stressed the importance of an age appropriate level of participation in this decision making process.

Decker et al. (2007) examined levels of uncertainty in adolescents and young adults at different times following diagnosis. Those diagnosed for five or more years stated they have “a lot of questions without answers” regarding the long-term effects of cancer on their lives. Decker et al. affirmed that longer-term survivors did not have regular interaction with health care providers. This, in turn, limited their opportunities to ask questions and to manage their uncertainty.

Communication with Parents of Children with Cancer

Focus on the stressors and communication needs specific to parents of children with cancer is of great importance. Child patients and parents are often overwhelmed with the complex information they receive at diagnosis, and this information may rapidly change and become more complex as relapses occur and treatment plans change (Spinetta et al., 2003).

Masera et al. (1998) stressed, “The diagnosis of a malignant disease in a child produces sudden and overwhelming challenges for the family.” To ease these challenges, the 1998 SIOP Working Committee on Psychosocial Issues in Pediatric Oncology established guidelines for pediatric oncology staff to follow when communicating with both family members and staff members.

Guidelines specific to parent-provider communication include:

1. Treat parents and children with respect in acknowledgement of their unique value systems and skills.
2. Ask parents and children about their preferences and needs for psychological care.
3. Educate parents and children about the nature of the diagnosis and treatment, and involve them as appropriate in critical decisions regarding treatment.
4. Ensure that other family members understand the diagnosis and treatment.
5. Help parents deal with the negative aspects of bureaucratization.
6. Have regular (weekly if possible) staff meetings attended by physicians, nurses and psychosocial staff to discuss the psychosocial problems of children and families so as to improve the contact. Try to discuss in these psychosocial case reviews the relationships of staff members to the family members.
7. Give the individual child/patient/young adult the guidance and support needed to regain and establish his or her personal autonomy after the setbacks and restrictions that occur during treatment of childhood cancer (Masera et al., 1998).

Jackson et al. (2007) interviewed parents of children who had been diagnosed with a brain tumor. Interviews addressed parents' perceptions of the hospital experience at time of diagnosis, six months post-diagnosis, one year post-diagnosis and two years post-diagnosis. This particular study focused on the open-ended question, "How has your experience with the hospital been so far?" Themes identified through answers to this question included communication, quality of the relationships with staff, information, perception of care, perception of support and hospital facilities and processes.

Parents' need for information was a consistent theme at all points of diagnosis. At the time of diagnosis, parents expressed the need for an appropriate amount of information. Due to the initial shock and extreme stress at this time, parents did not want to process too much information. One father stated, "You want all the information. But you don't want to know either." Parents also appreciated a physician's frankness, honesty and compassion in the diagnosis delivery. Negative experiences at time of diagnosis included delays around the diagnosis, misdiagnosis, ambiguous answers given by staff, forgetfulness of staff and poor communication between hospital units.

Overall, parents interviewed at six months post-diagnosis reported good parent-provider communication and the importance of an established relationship with hospital staff. Honest communication and trust in physicians were found to be of great importance. Several parents reported an improved relationship with nursing staff at six months post-diagnosis. However, after settling into their treatment routine, some parents expressed frustration with their perceived lack of attention and interest by hospital staff. They also expressed frustration with conflict of medical opinions given by staff.

Parents at one year post-diagnosis conveyed a continued need for support from hospital staff. Most parents reported an adequate amount of care and support, stating this provided reassurance and "peace of mind." Parents did convey some dissatisfaction regarding difficulty contacting staff. However, most parents quickly justified staff's unavailability by stating staff was overworked, undermanned or under pressure. They also stated their gratefulness for any contact with their child's health care team.

Parents at two years post-diagnosis were often in contact with hospital staff through outpatient visits. They expressed satisfaction with the personalized attention they received by staff at this point after diagnosis.

In reference to the informed consent process, Eder, Yomokoski, Wittmann, and Kodish (2007) addressed the communication needs of parents when discussing their child's participation in a clinical trial. Parents of children with leukemia offered their perspectives and recommendations. Recommendations included communicating in an honest and empathetic manner with use of limited medical jargon, allowing opportunity for parents to ask questions, allowing more time and at least two meetings for decision making, providing more information about the clinical trial (i.e., risks and benefits), tailoring the amount of information to individual parents' needs, offering additional materials about the clinical trial (i.e., videos, books and literature), presenting the information in a logical sequence and checking for parents' understanding of the information.

Conclusion

Honest, complete and compassionate communication between hospital staff and parents of ill children is a pertinent aspect of parental satisfaction with care. More specifically, parents of children with cancer desire adequate information about their child's diagnosis and treatment.

Chapter 3 Methods

The purpose of this study was to determine the most effective and compassionate modes of communication for hospital staff at The Children's Hospital to use when conveying information to parents of children with cancer.

Research Design

The research design best suited for this study was qualitative research. Qualitative research focuses on capturing the perspectives of individuals or groups of individuals (Basset, 2004). It is the analysis of words generated in a natural setting. Theories are then developed from the interpretation of these words. Qualitative research also reflects an intimate relationship between the researcher and the respondents.

This study analyzed parents' perceptions of parent-provider communication at The Children's Hospital. Qualitative research through interviews was the best suited design for this research as the parents' words provided the best information regarding this topic.

After determining the study's research design, research approval was obtained from both Regis University's Institutional Review Board (IRB) and the Colorado Multiple Institutional Review Board (COMIRB).

Research Sample

The sample consisted of parents of children with cancer receiving treatment at The Children's Hospital. It was limited to English speaking parents over the age of eighteen. This purposive sample was used because these parents shared a common characteristic and they were deemed representative of the population.

Parents were approached at the hospital and asked if they would be interested in participating in an interview regarding their experience with the communication surrounding their child's diagnosis. Interviews were conducted at four to twelve weeks post-diagnosis. Twelve interviews were administered over a six week period.

Prior to the interviews, the researcher explained the research project and the respondents' participation in both verbal form and written form (Appendix A). Consent forms were also presented to the respondents and signatures were required to proceed (Appendix B). Respondents were allowed to decline participation at any point during the interview process.

The researcher asked eleven open-ended questions during the approximately twenty minute interviews. The interview questions addressed the parents' perceptions of clarity of information, sensitivity in delivery of the diagnosis, listening skills of hospital staff and availability of hospital staff (Appendix C). Hospital staff in question was described to the parents as those providing care for their child. Office staff was excluded from the evaluation.

The interviews were recorded through both audiotape recording and note taking. The researcher then transcribed the audiotape recordings. To ensure confidentiality, both the transcriptions and the notes were stored in a locked office environment.

Data Analysis

Using the transcribed interviews, the researcher developed a code sheet and identified recurring themes. This was accomplished by reading the transcripts, identifying relevant comments from the interviewees and organizing these comments into categories.

The researcher also utilized a second reviewer to ensure inter-rater reliability. The researcher sent the first two transcripts and the coinciding code sheet to the second reviewer. After adequate agreement between the researcher's analysis and the second reviewer's analysis was confirmed, the researcher sent the remaining ten transcripts to the second reviewer for further analysis. Overall percent of agreement between the researcher and the second reviewer was 86.14%.

Establishing Trustworthiness

Several measures were taken to strengthen the trustworthiness of the study. The use of member checking allowed the parents to review the transcripts and to ensure the researcher had recorded their responses accurately. The use of a second reviewer was used to control for bias in theme identification. As previously mentioned, inter-rater reliability was also obtained through the use of the second reviewer. In addition, all code and analysis sheets were constructed a priori, or prior to the analysis of all transcripts.

Chapter 4 Results

Four major themes emerged from this research: delivery of diagnosis, value of information, receptiveness to questions and availability of hospital staff. Delivery of diagnosis addressed the parents' satisfaction with the manner in which their child's diagnosis was delivered as well as their suggestions for a more effective delivery. Value of information discussed the thoroughness and the extent to which hospital staff informed the parents. Receptiveness to questions indicated hospital staff's ability and willingness to address questions. Availability of hospital staff determined how easily parents could contact staff either in person, on the phone or through email.

Five parents said hospital staff delivered the news of their child's diagnosis in person while two said it was over the phone. Three of the parents interviewed were not the parents who initially received the news. Two did not clarify their physical status in which the diagnosis was delivered.

Of the two who received the diagnosis over the phone, one parent preferred this method rather than driving a significant distance for the news. The other parent said the phone delivery created great confusion and stressed the importance of delivery in person.

"And then when you're on the phone too you have other distractions in front of you and you're trying to concentrate on the phone. So, you know, you don't get it all...So it would have been nice, in hindsight, for someone to say, 'You know what. There are some abnormalities. We want to talk to you about it. Could you come down in the next couple hours?' You know, 'As soon as you can come down, please come down.' And then talk face-to-face."

Three parents commented on the thoroughness of hospital staff's explanation of the diagnosis. When asked if they had any suggestions on how this news could have been delivered any more effectively, three parents said there is no "better" or "good" way to tell someone their child has cancer.

All of the parents expressed their significant satisfaction with the value of information they have received at The Children's Hospital. Six parents commented on their high satisfaction with hospital staff's thorough explanation of their child's treatment plan. One mother summarized the views of several of the parents.

"Everything they do, any medications they're giving her, any procedures she's having, they always have been efficient on coming in and going through it step-by-step with us."

One mother said information is not always offered unless the parents ask for it. This same mother then thought about her comment and said some information might be too much information.

"If we ask to see her scans and all of those things, we always get them. They're not always volunteered to us. So if you are not proactive, you probably wouldn't see a lot of that. Maybe some people don't want to see those things. Maybe that's why they don't offer them. It's probably just too much information. It's just one day at a time. I didn't think about it until right now, but maybe that's why they don't give you everything up front. We've spoken to some parents whose children were given a five percent chance and now they're in remission. I think maybe it's good not to get numbers. Just to get the diagnosis. Because kids respond so differently."

Eleven of the twelve parents said hospital staff has met their needs regarding listening to their questions. The remaining one parent did not address this issue. Several parents expressed very significant satisfaction with hospital staff's receptiveness to questions.

Eight parents mentioned hospital staff's willingness to spend time to answer questions and to proactively ask if the parents had any questions. Four parents said hospital staff would find someone to answer a question they themselves could not answer. One father summarized these competencies.

"Having this be a shocking experience, the staff has always made sure if we have any questions. They've always asked us, 'Do you have any questions?' They've just been very, very informative. You know, a lot of the time we don't even ask them what they're doing but they explain it anyway. They show us, you know, what it's going to do for (child). What procedure is going to happen next. If we have any questions or if we needed to talk to somebody else who would explain it better they would get that for us. They've done a very good job."

Six parents discussed hospital staff's availability by phone and their prompt return of phone calls. One father consolidated this satisfaction.

"I think every time we have a question at home, I mean they always think to give us a number to call. And they're always on top with the returned phone calls from either a nurse or a doctor. If we have any concerns with (child) or any questions they're on top of the telephone call right away...They tell you, 'Oh, expect a call within fifteen minutes.' It usually takes about five minutes. They're usually on top of it. They'll call right away."

One mother mentioned her email connection with the fellow assigned to her daughter's case. Two parents expressed frustration with the limited in-person contact with the attending in charge of their children's cases.

Of the twelve interviews, eight were with mothers, two were with fathers and two were with mother-father teams. In reference to the children's diagnoses, six were seven to nine weeks post-diagnosis, four were ten to twelve weeks post-diagnosis and two were four to six weeks post-diagnosis. Five of the children were diagnosed with leukemia, three with sarcoma, two with blastoma, one with lymphoma and one with neurological cancer.

Chapter 5 Discussion

This study examined the most effective and compassionate ways for hospital staff to communicate with parents of children with cancer. Findings indicate delivery of diagnosis, value of information, receptiveness to questions and availability of hospital staff all play important roles in the successful delivery of communication.

Findings Related to Literature Review

Results from the current study coincide with several findings from previous studies. Several studies (Hays et al., 2006; Hsiao et al., 2007; Jackson et al., 2007; Masera et al., 1998) reported quality of information as an important contributor to effective communication. Parents in the current study emphasized the importance of this factor as well.

As previously mentioned, child patients and parents are often overwhelmed with the complex information they receive at diagnosis, and this information may rapidly change and become more complex as relapses occur and treatment plans change (Spinnetta et al., 2003). Several parents at The Children's Hospital expressed their appreciation of the "step-by-step" explanations they received from hospital staff.

In agreement with Hsiao et al. (2007), the current study reported staff availability as a facilitative aspect of communication. The current study found that not only did parents appreciate this availability in person when at the hospital, but they also appreciated it via phone or email when the child and parents were at home.

Hays et al. (2006) addressed staff's ability to listen and to answer questions. Parents in the current study identified this competency as critical to the delivery of effective communication.

Several studies (Eder et al., 2007; Hays et al., 2006; Hsiao et al., 2007) indicated parental involvement in decision making was a pertinent aspect of communication. None of the parents in the current study addressed this issue. However, none of the interview questions specifically asked about joint decision making. Therefore, parents may not have been prompted to discuss this issue.

Strengths and Limitations

In-person interviews allowed the researcher to gain the parents' trust. It also allowed the researcher to read facial expressions and to further explore the parents' reactions and answers to certain questions. The researcher was also independent from The Children's Hospital. This allowed the parents the freedom to voice their opinions without the fear of offending anyone directly associated with the hospital.

Due to time constraints and the coinciding small sample size, sample saturation was not obtained. Also, the study was limited to English speaking parents. Non-English speaking parents may have had very different experiences with the communication surrounding their child's diagnosis and treatment.

Recommendations for Future Research

Regarding the current qualitative research design, interviewing parents until nothing new is reported would allow for sample saturation. This would involve significantly more time allowance for a greater number of interviews.

The quantitative research design is also applicable to the study of parent-provider communication. Data could be collected and recorded by quantifying parents' perceptions through the use of surveys. This would allow for a larger and more random subject sample.

In addition, evaluation research is an applied project design that could evaluate an established program for improved parent-provider communication. This study design would allow for continuing improvements to the program and the resulting ongoing betterment of parent-provider communication.

Conclusions and Recommendations

This study addressed the following research questions: What are the most effective ways for hospital staff to communicate with parents of children with cancer? What are the most compassionate ways for hospital staff to communicate with parents of children with cancer? This study found parents prefer thorough and complete explanations of their child's diagnosis and treatment. They also value hospital staff's competence to address and to answer all questions they may have. This sometimes involves finding another staff member to accurately and confidently answer the question. Finally, parents appreciate when hospital staff is readily available for questions, information and support not only in person but also over the phone and through email.

Staff at The Children's Hospital has demonstrated proficiency in their communication with parents of children with cancer. They deliver information, including the diagnosis and treatment plans, in a straightforward and understandable manner. They are also readily available to the parents and they spend the necessary time to listen and to answer all questions. They ensure that no question is unanswered.

Based on this study's findings, it is recommended that hospital staff should be aware of individual parents' preferences regarding the physical status of the diagnosis delivery and the amount of information provided to them. Attendings should also initiate

regular contact with parents to ensure consistent communication and the establishment of the parent-provider relationship.

Effective and compassionate communication between hospital staff and parents of children with cancer is essential to the building of crucial relationships, the establishment of parent-provider trust and the overall successful delivery of health care. This study provides guidelines for health services administrators to utilize when developing and implementing curriculum for improved communication competencies. In turn, this curriculum will facilitate further improvements in effective and compassionate communication between hospital staff and parents of children with cancer.

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Appendix A Invitation to Participate

Dear Parents,

You are being invited to be in a research study. The goal of the study is to learn about the communication between hospital staff and parents of children with cancer. I am interested in hearing from you because your input will help improve hospital staff's communication skills.

The study is being conducted by me, Natalie Volz. I am a graduate student at Regis University.

If you agree to be in this study, you will participate in an interview. The interview will take approximately 30 minutes. You will be asked questions regarding hospital staff's communication with you.

It is important that you answer each question honestly. Anything you share with me will be kept private. You do not have to answer any question that makes you uncomfortable.

You do not have to be in this research study. If you decide to be in the study, you can change your mind later and your child will still receive care at The Children's Hospital.

The sponsor of the research is the Hematology/Oncology Department at The Children's Hospital. If you have additional questions about the study, please feel free to call me. My phone number is 970-988-0871. If you have a complaint or concern about the study, you can also contact the Colorado Multiple Institutional Review Board. Their phone number is 303-724-0155.

Thank you for your time. I look forward to speaking with you.

Sincerely,

Natalie Volz

Appendix B
Consent Form

COMIRB Approval Date: 9-22-08
Valid for Use Through: 9-22-09

**Study Title: Effective and Compassionate Communication between Hospital Staff
and Parents of Children with Newly Diagnosed Cancer**

Principal Investigator: Kerry Moss, MD

COMIRB No: 08-0796

Version Date: July 29, 2008

Version No: 1

You are being asked to be in a research study. This form provides you with information about the study. A member of the research team will describe this study to you and answer all of your questions. Please read the information below and ask questions about anything you don't understand before deciding whether or not to take part.

Why is this study being done?

This study plans to learn more about effective and compassionate communication modes that hospital staff can use when addressing parents of children with cancer.

You are being asked to be in this research study because your child has been recently diagnosed with cancer.

Other people in this study

Up to fifteen people from your area will participate in the study.

What happens if I join this study?

If you join the study, you will be asked a series of eleven open-ended questions regarding parent-provider communication.

The interview will last 30 minutes.

What are the possible discomforts or risks?

Discomforts you may experience while in this study include the possibility of emotions regarding this sensitive topic to resurface.

What are the possible benefits of the study?

This study is designed for the researcher to learn more about effective and compassionate communication between hospital staff and parents of children with cancer.

Will I be paid for being in the study?

You will not be paid to be in the study.

Will I have to pay for anything?

It will not cost you anything to be in the study.

Is my participation voluntary?

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you choose to take part, you have the right to stop at any time. If you refuse or decide to withdraw later, you will not lose any benefits or rights to which you are entitled.

Can I be removed from this study?

The study doctor may decide to stop your participation without your permission if the study doctor thinks that being in the study may cause you harm, or for any other reason.

Who do I call if I have questions?

The researcher carrying out this study is Natalie Volz. You may ask any questions you have now. If you have questions later, you may call Natalie Volz at 970-988-0871. You will be given a copy of this form to keep.

You may have questions about your rights as someone in this study. You can call Natalie Volz with questions. You can also call the Colorado Multiple Institutional Review Board (COMIRB). You can call them at 303-724-1055.

Who will see my research information?

We will do everything we can to keep your records a secret. It cannot be guaranteed. Both the records that identify you and the consent form signed by you may be looked at by others. They are:

- People at the Colorado Multiple Institutional Review Board (COMIRB).
- The study doctor and his/her team of researchers.
- The Food and Drug Administration.
- The Officials at the University of Colorado Denver.

We might talk about this research study at meetings. We might also print the results of this research study in relevant journals. But we will always keep the names of the research subjects, like you, private.

Agreement to be in this study

I have read this paper about the study or it was read to me. I understand the possible risks and benefits of this study. I know that being in this study is voluntary. I choose to be in this study. I will get a copy of this consent form.

Signature: _____

Date: _____

Print Name: _____

Consent form explained by: _____

Date: _____

Print Name: _____

Investigator: _____

Date: _____

Appendix C
Interview Questions

- 1) Tell me three things about your child (use name if provided).
- 2) What was the date of his/her diagnosis?
- 3) Was your child first diagnosed here at The Children's Hospital or elsewhere?
- 4) Did this news come as a surprise?
- 5) How did hospital staff deliver the news of your child's diagnosis?
- 6) How did these words and the method of their delivery make you feel?
- 7) Do you have any recommendations on how the news of your child's diagnosis could have been delivered more effectively?
- 8) Has the information you've received since your child's diagnosis been relayed clearly? Why or why not?
- 9) Has hospital staff met your needs regarding listening to your feelings and your questions? If yes, how? If no, how has hospital staff failed to meet these needs?
- 10) Has hospital staff been available for you when needed? If yes, how? If no, how has hospital staff been unavailable?
- 11) Do you have anonymous suggestions you would like to convey to hospital staff?