

2015

Behavioral Adjustment in Children with Life Threatening Illness A Qualitative Study

E. Joseph Becher Jr.

Antioch University - Santa Barbara

Follow this and additional works at: <http://aura.antioch.edu/etds>



Part of the [Clinical Psychology Commons](#), and the [Psychiatry and Psychology Commons](#)

Recommended Citation

Becher, E. Joseph Jr., "Behavioral Adjustment in Children with Life Threatening Illness A Qualitative Study" (2015). *Dissertations & Theses*. 205.

<http://aura.antioch.edu/etds/205>

This Dissertation is brought to you for free and open access by the Student & Alumni Scholarship, including Dissertations & Theses at AURA - Antioch University Repository and Archive. It has been accepted for inclusion in Dissertations & Theses by an authorized administrator of AURA - Antioch University Repository and Archive. For more information, please contact dpenrose@antioch.edu, wmcgrath@antioch.edu.

BEHAVIORAL ADJUSTMENT IN CHILDREN
WITH LIFE THREATENING ILLNESS
A QUALITATIVE STUDY

A dissertation submitted to the Faculty of

ANTIOCH UNIVERSITY SANTA BARBARA

in partial fulfillment of
the requirements for the
degree of

DOCTOR OF PSYCHOLOGY
in
CLINICAL PSYCHOLOGY

By

E. JOSEPH BECHER, JR. MA, MSW
APRIL 2015

BEHAVIORAL ADJUSTMENT IN CHILDREN
WITH LIFE THREATENING ILLNESS
A QUALITATIVE STUDY

This dissertation, by E. Joseph Becher, Jr., has been approved by the committee members signed below who recommend that it be accepted by the faculty of Antioch University Santa Barbara in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

Dissertation Committee

Steven Kadin, Ph.D.
Chair

Juliet Rohde-Brown, Ph.D.
Second Faculty

Joseph P. Bush, Ph.D.
External Expert

Abstract

Behavioral Adjustment of Children with Life Threatening Illness

By

E. Joseph Becher, Jr.

This study investigated factors that affect adjustment in children with life-threatening illness from the viewpoint of the parents/caregivers. The data were collected from parents/caregivers whose children have a life threatening diagnosis. Parents/caregivers were interviewed and asked to complete the Parent Request Questionnaire (PRQ) which was given to them after the in-person interview. This newly developed PRQ was utilized into prior research to predict the levels of adjustment in children. It includes age, whether the child has been informed of the diagnosis, whether the child engages in age-appropriate activities, the child's prior experience with death, the child's family's involvement in treatment, and the child's belief in an after-life. Prior literature suggests associations between these factors and the child's ability to adjust to the diagnosis. This study examined these factors revealed by the parents/caregivers and any similarities were noted. There has been limited research conducted on behavioral adjustment in children with life threatening illness. This qualitative study utilized an open-ended interview process to gather information about the factors that promote behavioral adjustment and whether or not the factors already researched in quantitative studies applied. The interviewees were participants in independent support groups benefiting the caregivers/parents of the children with life threatening illness. Participants were also recruited by word-of-mouth after calling such groups and individuals in California. The PRQ was distributed after the interview as an additional measure. The interview revealed factors as noted by the caregivers and indicated the emergent themes of: isolation, fear, inquisitiveness, age-appropriate activities, diagnoses shared, and support systems. The interview and the PRQ were used to analyze child adjustment reported during the interview sessions. The participants in this study were all parents/caregivers. Instrumentation was a structured interview and a demographic questionnaire (PRQ). The texts were transcribed and analyzed using Thematic Analysis. Narratives of their life experience with the child having life-threatening illness were examined. Emergent themes, previously mentioned, were elicited from the interview material in hopes of providing additional support services needed as voiced by the parents/caregivers. "The electronic version of the dissertation is accessible at the Ohiolink ETD center <http://www.ohiolink.edu/etd/> "

Keywords: adjustment, death, hospice, palliative care, pediatric, life threatening illness

DEDICATION

I would like to dedicate this dissertation to The Etonian, Swansea, Duncan, Amanda, and Emily. As I lived in the Palm Springs, CA area and drove weekly to school in Santa Barbara, CA, I was able to spend very little time with my four-legged friends. I promised them that if I ever finished, I would dedicate this dissertation to them. Well, here is that dedication. Amanda is the only surviving dog. Since that time, I also had the support of Claude, Shaba, Angie, Beatrice, Barnaby, and Kitty. Angie, Beatrice, Barnaby, and Kitty are still with me. As we all know, research has proven that we have a longer life span when we have a pet. They have taught me the meaning of unconditional love.

ACKNOWLEDGMENTS

I have several people to acknowledge in this very long journey. First, I would like to thank my Dissertation Committee for *pulling me* through this process. I thank Dr. Steve Kadin, my chair, for all of the negotiations and suggestions as well as Dr. Juliet Rohde-Brown for remaining on my committee, being of tremendous help, even though no longer at Antioch University. Finally, Dr. Joe Bush, I thank you for always being available and for not giving up on me. I would not even be in school if it were not for Dr. Ray Hwang who helped me in every way imaginable. I thank you for the advisement and all of the knowledge you imparted.

I wish to thank Dr. Ron Pilato, our new chair, for “taking the bull by the horns” and helping me arrange my dissertation to be a workable project. I wish to thank Dr. Barbara Lipinski for allowing me to finish during some challenging times. Then, there is Dr. Katherine Burrelsman, also known as Xena, warrior woman who defeats all odds. I thank you, Xena, for all of the tutorials as I changed from quantitative to qualitative. I thank you for the constant texts and support. I would like to thank Donna Mathes and Paul Luciano for helping me meet this finish line. I wish to thank Drs. Michele Harway and Cheryll Smith, for the profound knowledge imparted in this process and maintaining my interest in school. Finally, I want to thank Stephanie Holland for all of the administrative work while assisting me in preparation for my presentation and graduation.

I thank Elizabeth Sandozequi, my graphic artist, for her assistance with this project and constant support into all hours of the night. I wish to thank five very important individuals who helped me while I have been unemployed and attempting to finish this project: Pam and Rachel Miller, and Dr. LeAnn Matlin. I wish to thank Maxine Weksler for allowing me to sleep in her spare bedroom instead of driving all the way home to Palm Springs and also the great gourmet dinners! I thank Dr. Clemencia Moore for her support, interest, and kindness in enabling me to always attend events with our peers while not taking no for an answer.

I cannot forget my boss while at Antioch University. Christine Forte, I thank you for all of the assistance, setting up this dissertation, the articles, and the ideas. I also have a constant support system that has been with me every step of the way for the last 18 years: Dr. Angie DeMartines, Eadie Siegel, Judy Rosenson, and Lois Edgerton, my fellow teachers. I thank you.

I must thank my friends who have been with me on a daily basis to offer love and support: Timothy Mitchell, Helen Mitchell, Pat Goehe, Teresa St. John, Delores Martin, William Heath, Wendy Arnold, Lauri Alexander, Linda Robbins, Dr. Carole Hatch, Scott Hoxby, Jamie Cunningham, Dr. Mary Ruth Ivan, James Kottwinkel, Charlotte Leslie, Ellen McHugh, Kate Porter, Alex Hunter, Maxine Sands, Betty Twombly, Dr. Manuel Tajon, Irene Gabelsberger, Adele McMahon,

and Julie Ames. I certainly hope that I did not forget anyone but apologize if it happened!

Last, I would like to thank my late parents, Edith and Earl Becher, for always helping me and being supportive of my educational goals. I thank St. Jude, the patron Saint of the hopeless, because many times that is how I viewed this project (and that is who my mom prayed to about me)! With all of the support of the above mentioned individuals, it was necessary that I finish. I thank God for allowing this to happen with Mary interceding. Finally, “I want to tell you one more thing.” as Dr. Clemencia Moore would like to say, “*No longer shall I be subjected to, ‘and how is the dissertation going?’*”

Thanks for the memories.

TABLE OF CONTENTS

| | |
|---|-----|
| CHAPTER ONE: INTRODUCTION..... | 1 |
| Definition of terms..... | 7 |
| CHAPTER TWO: REVIEW OF LITERATURE..... | 12 |
| Age..... | 12 |
| Whether or Not the Patient Was Informed of Diagnosis/Prognosis..... | 18 |
| Experience With Death..... | 24 |
| Family Involvement in Treatment..... | 25 |
| Engaged in Age-Appropriate Activities..... | 27 |
| Belief in an After-Life..... | 29 |
| Age of the Patient as it Relates to Stages..... | 31 |
| Gender, Ethnicity, Time Since Diagnosis, Socio-Economic, Being the Only Child..... | 32 |
| Behavioral Adjustment..... | 33 |
| CHAPTER THREE: METHODS..... | 37 |
| Background and Rationale for the Study..... | 37 |
| Basic Research Question..... | 37 |
| Procedures for the Study..... | 39 |
| Data Processing Techniques..... | 41 |
| Methodological Assumptions and Limitations..... | 43 |
| Table 1..... | 45 |
| CHAPTER FOUR: RESULTS..... | 47 |
| Description of Sample..... | 47 |
| Participant Profiles..... | 48 |
| Theme 1: Isolation..... | 51 |
| Theme 2: Fear..... | 56 |
| Theme 3: Inquisitiveness..... | 61 |
| Theme 4: Age-Appropriate Activities..... | 67 |
| Theme 5: Diagnosis(es) Shared..... | 74 |
| Theme 6: Support Systems..... | 80 |
| CHAPTER FIVE: DISCUSSION..... | 86 |
| Introduction..... | 86 |
| Conclusion..... | 104 |
| Clinical Implications and Future Research..... | 105 |
| Limitations..... | 108 |
| REFERENCES..... | 112 |
| APPENDIX A..... | 116 |
| APPENDIX B..... | 117 |
| APPENDIX C..... | 119 |
| APPENDIX D..... | 120 |

| | |
|------------------|-----|
| APPENDIX E | 122 |
| APPENDIX F..... | 130 |
| APPENDIX G..... | 134 |

List of Tables

| | |
|---------|-------------------------------------|
| Table 1 | Participant Demographic Information |
|---------|-------------------------------------|

List of Figures

| | |
|----------|----------------------------|
| Figure 1 | Isolation |
| Figure 2 | Fear |
| Figure 3 | Inquisitiveness |
| Figure 4 | Age Appropriate Activities |
| Figure 5 | Diagnosis(es) Shared |
| Figure 6 | Support Systems |

List of Appendices

- Appendix A Letter of Introduction
- Appendix B Recruitment Letter 1
- Appendix C Recruitment Flyer
- Appendix D Recruitment Letter 2 with Consent Form
- Appendix E Parent Response Questionnaire (PRQ)
Behavioral Adjustment of Children
- Appendix F Form B
- Appendix G 1:1 Interview Questions

CHAPTER ONE: INTRODUCTION

Researchers began focusing on dying children in the 1950s. Concerns and questions focusing on the children's conceptual understanding of death and dying were raised (Martinson & Papadatou, 1994). Feifel (1977), a leading researcher, discovered in his work with terminally ill children (3- to 9-years old) that young children were aware that they were dying and also that this process was not reversible and was indeed final. Feifel believed that children conceive of death just as adults conceive of death. Waechter (1971), as she explored children's awareness of fatal illness, acknowledged that her own review, as well as others, indicated that more quantitative studies in this area were needed in addition to the qualitative studies being conducted.

Armstrong-Dailey and Zarbock (2001) suggested that caregivers of dying children underestimate the child's awareness of death because of the caregivers' own anxieties. They felt that in order for adults to be able to help these children, these adults must first become aware of their own feelings about life, sickness, death, and grieving. This could be a limitation due to the caregiver's own perceptions and reports of the child. Armstrong-Dailey and Zarbock (2001) felt that children are generally quite ready to talk about anything in their own experiences.

The well-known Elisabeth Kubler-Ross worked with small children since the 1980's until shortly before her death in 2004. During her work, she discovered

that even three-year-olds were aware of death and could talk about it (Kubler-Ross, 1969). Adults, at times, deny children the right to know their diagnoses and prognoses. When this information is concealed or minimized, the child is denied the experience of truth. Communication is impeded and the focus of the concern reverts back to the adults in the form of a defense mechanism to cope with their own anxiety. The child is left out in the dark.

It is the premise of the study that when parents, caregivers, and medical staff involve the child in the treatment planning, the behavioral adjustment will be less traumatic to the child with life-threatening illness. Through the interview process, parents/caregivers can reveal the factors they observed to impact the treatment planning of the child. The process will then establish certain themes which have now been conveyed.

Most of the current literature on children with life-threatening illness involves case studies. Zebach, Zeltzer, Whitton, Merting, Odom, and Berkow (2002) discovered that the two major areas of palliative care research involve psychosocial support and quality of life and pain/symptom control; both of these areas are relatively new and warrant further research. There has been little research in this area involving children. In addition, much of the research was conducted to benefit pediatric oncology. Zebach et al. (2002) noted that the many constraints of institutional review boards, along with the small number of patients at any given facility, impose many problems for research on the children with a

life-threatening illness. An informed approach to understanding how the diagnosis/prognosis impacts behavioral adjustment can indeed help families. Psychological services provide additional services, if warranted, and develop knowledge on how to help children help themselves. This is a question that parents/caregivers might attempt to answer during the interview.

Martinson and Papadatou (1994) found no comprehensive studies examining whether families had a more comfortable experience in a hospice setting or allowing their children to die at home. They argued that research should be centered on the experience of the child. The focus of this study is to be child-centered with the family being only one component in the examination of factors that impact the adjustment of the child with life-threatening illness as conveyed during the interview process. Research exists from Kubler-Ross (1969), Martinson and Papadatou (1994), and Feifel (1977), reporting children being aware of death at a very young age. This level of awareness may be dependent on the child's cognitive stage and level of functioning as outlined by Erikson and Piaget.

This study will examine the factors in which the parents/caregivers deem important promoting their children's behavioral adjustment. Hagey (1999), in a developmental study having to do with the cognitive evaluation of death in children, found that despite efforts of both family members and physician to conceal information the child still somehow had an awareness of their prognosis.

Children can be quite astute in reading nonverbal facial expressions, gestures, and tone of voice. Children are frequently able to sense when something is wrong by how adults respond to them.

This study will examine socio-economic status (SES) factors to determine if SES plays a role in the adjustment of dying children. If a family has high SES, this may mean that educational resources are more readily available. This information will have to be conveyed by the parent/caregiver during the interview process. The child may have started school earlier and learned to read at an earlier age, thus being able to verbalize feelings and attitudes at an earlier age than those of lower SES.

Kane (1979) and Kubler-Ross (1983) believed that children who have experienced the death of someone close to them would have a better comprehension of all aspects of death. Therefore, they would raise a different order of questions than those lacking such experience.

This study will also examine the factors possibly causing any such maladjustment as relayed by the parent/caregiver. This is useful in the field of psychology in an attempt to stimulate further research in hopes that meaningful social support can be offered to any child with life-threatening illness and appropriate assistance given.

Kubler-Ross (1983) suggested that when the child can engage in age-appropriate activities such as handicrafts, visiting with the family pet, playing

music, drawing, or molding clay, this can help build the child's self-worth. Adults may need to stop for a moment and try to imagine what it would be like for a child who was quite active to experience a life-threatening illness/prognosis. Hopefully, the parent/caregiver will be able to shed light on their child's interests, activities, and talents.

Before we got sick we could run fast, play hard, and we were happy. Before we got sick, we didn't use words like "hope" and didn't talk about God very much. We thought our parents could make anything bad going away. (Jampolsky, 1979, p.6).

There is a Rainbow Behind Every Dark Cloud (Jampolsky, 1979), a book written from eleven children sharing their experience of dying. The children revealed that it was much easier to talk about death with other children than it was to discuss it with adults. This could be the result of the family's response and effective adaptation to this event. In an inpatient setting it would be possible to discuss it with adults. This could also be the result of the family's response to facilitate a group of children as they share their feelings. It may not be so easy if the child remains at home.

In Jampolsky's (1979) book as well as in the book *On Children and Death* (Kubler-Ross, 1983), a predominant theme of sadness was turned into resolve in helping the child adjust to having a life-threatening illness. This sense of spirituality strengthened as the child looked forward to being re-united with loved ones. According to Kubler-Ross (1983), it was suggested that adults must at least

give the child 1% hope to help them move forward. Listening to the parents/caregivers during the interview may answer whether or not hope was actually instilled

Children may have an easier time adjusting because caregivers would be aware of different factors impacting the child's emotions and behaviors. There may develop a greater understanding about the psychological issues and the process of children with life-threatening illness. Children have been found to verbalize emotions at a very young age. This study will determine if this will be a salient theme as revealed by the parent/caregiver.

According to Armstrong-Dailey and Zarbock (2001), a standardized interview is the most frequently used way to elicit information from children regarding death. They noted that when children under the age of eighteen did not know the investigator, they had difficulty in understanding the questions. It was more effective when parents were involved in the interview process. Some investigated using nonverbal communication such as pictures or drawings, but there was little consistency in their results (Armstrong-Dailey & Zarbock, 2001). The interview for the purpose of this study will be conducted with the parent/caregiver.

Efforts to develop a global theory have been impeded due to large numbers of independent variables in the quantitative research that relate to children's understanding of death. They continued to state that, from the list of independent

variables, cognitive development has been most linked with age. This study will focus on the qualitative perspective as revealed by the parents/caregivers.

Chapter 2 is a scholarly review of the literature appropriate to behavioral adjustment in children with life-threatening illness. Earlier work has been incomplete in attempting to validate an understanding of death in younger children and the impact on their behavior. Chapter 3 describes the proposed methodology while Chapter 4 will present the results of the study.

Definition of terms

Behavioral Adjustment—absence of significant problem behaviors.

Stages of Cognitive Development—as defined by Piaget, who theorized four stages: sensorimotor, preoperational, concrete operational, and formal development. The "preoperational" (2- to 7-years old) is the second stage, in which the child's ability to use words, draw, and relate symbolic thought is heightened (Piaget, 1952). Chronological age will be used as a proxy for cognitive development.

Components of a Death Concept—(a) irreversibility—once people die they do not return (b) universality—everyone will die (c) nonfunctionality—body ceases life as do bodily functions (f) causality—reasons people die (g) noncorporeal continuation—some form of personal existence after death (Waechter, 1971).

Culture—a way of life; especially, general customs and beliefs of a particular group of people at a particular time (Ferrante, 2000).

Death—permanent cessation of physical and mental processes in an organism. Irreversible loss of cerebral functioning (American Psychological Association, 2007).

Diagnosis—to determine the nature of a disease (American Psychological Association, 2007).

Emotions—the fundamental way in which the mind assigns value to external and internal events and directs attention to further processing observed in behavior (Siegel, 1999).

Ethnicity—classifying people according to any number of attributes, including national origin, ancestry, cultural traits, religious practices, languages, or socially important physical characteristics (Ferrante, 2000).

Feelings—a term used to describe the conscious awareness of either an emotion or an affect (Siegel, 1999).

Hospice—a special form of comprehensive care provided to individuals who have a serious progressive illness, as well as to their families, that has its roots in the Middle Ages. Today this concept means that the patient is within the final six months of life as determined by physicians and foregoing care other than palliative. In 1977 Children's Hospital International found no programs for children and by 1983 there were only four programs accepting children, out of

1,400 hospices throughout the United States (Armstrong-Dailey & Zarbock, 2001).

Levels of Expression—messages communicated by verbal (words) and symbols (nonverbal expressions). Symbolic messages harder to comprehend may be perceptual (Kubler-Ross, 1983).

Palliative Care—active total care of patients whose disease is not responsive to curative treatment and control of pain, psychological, social, and spiritual care are the focus. The goal is to achieve the best possible life for the patient and family. Some definitions include the time when active, aggressive medical treatment is terminated (World Health Organization, 1990). A broader view: prevent, relieve, reduce or soothe the symptoms produced by serious medical conditions to maintain the patient's quality of life (Medicine, 2001).

Pediatric Psychology—an interdisciplinary field of research and practice that addresses the interaction of physical, behavioral, and emotional development (American Psychological Association, 2007).

Personal Mortality—human beings will die (Hasazi, Bond, & Reilly, 1983).

Prognosis—a prediction of the future course of disease or disorder (American Psychological Association, 2007).

Psychosocial Stages of Development—Erikson (1963) emphasized eight psychosocial stages of development: (1) trust vs. mistrust; (2) autonomy vs. shame and doubt; (3) initiative vs. guilt; (4) industry vs. inferiority; (5) identity

vs. identity confusion; (6) intimacy vs. isolation; (7) generativity vs. stagnation; and (8) integrity vs. despair. (Erickson, 1963).

Socioeconomic Status—the position of an individual or group on the socio-economic scale determined by factors, such as income, amount, and kind of education (American Psychological Association, 2007).

Spirituality—a sense of a power outside of oneself and greater than one's self (Armstrong-Dailey & Zarbock, 2001).

Stages of Death and Dying—defined by Dr. Elisabeth Kubler-Ross (1983): (a) denial and isolation—disbelief that there is truth in the diagnosis and individual begins to withdraw; (b) anger—at everyone and everything, including a higher power; (c) bargaining—requesting deals from others, including a higher power; (d) depression—deep sadness over the diagnosis and the impending separation from family and friends; and (e) acceptance—resolve of the situation (Kubler-Ross, 1983).

Life threatening Illness—possibly terminal but there is an existing life threatening diagnosis (Zebach, Zeltzer, Whitton, Merten, Odom, & Berkow, 2002).

Thanatology—the study of death and dying (Kubler-Ross, 1983).

Emergent theme—an abstract entity that brings meaning and identity to a current experience which develops from the data (Polit & Beck, 2008).

Narratives—The story in qualitative research which is the object of the inquiry (Polit & Beck, 2008).

Thematic Analysis—This is a method for analyzing, identifying, and reporting patterns (themes) within data (Braun & Clarke, 2006).

CHAPTER TWO: REVIEW OF LITERATURE

Literature has suggested that the child's age, whether or not he/she was informed of his diagnosis/prognosis, any previous experience with death, any family involvement in treatment, his/her own involvement in age-appropriate activities, his/her belief in an after-life, gender, ethnicity, socioeconomic factors all contribute to the behavioral adjustment of the terminally ill child. Through interviewing the parents/ caregivers, this qualitative study will investigate what factors were observed by the parents/caregivers to contribute to this behavioral adjustment.

Age

Age affects a child's stage of cognitive development, which plays an important role in the grieving process (Kaplan, 1997). Piaget (1952) theorized that as we attempt to understand the world, we develop through four age-related stages. The stages are: Sensorimotor (birth to 2 years); Preoperational (2- to 7-years old); Concrete Operational (7- to 11-years); and finally Formal Operational (11-years old through adulthood) represented in words, drawings, and images. Simple connection of physical action and sensory information has already been experienced in symbolic thought and now there exists heightened awareness approaching the next stage in which the child begins to reason. The child in the preoperational stage still lacks the ability to construct in his/her mind previous

physical activities, which is why it is called "preoperational" (Piaget, 1952). This is a stage at which children typically ask a lot of questions. The next stage, concrete operations (7- to 11-years old), focuses on the child beginning to replace intuitive thought with logical reasoning. The child becomes able to perform operations. Recently, children have been shown to pass quickly through the preoperational phase into the concrete operational stage; Piaget's age restrictions are only estimates. If indeed this is the case, the preschooler who is in the high end of the spectrum within this stage, may begin to think and reason logically. This child would be able to then apply specific or concrete examples.

Feldman (2004) challenged Piaget's theory and revised the preoperational stages to delete an ordinary sequence for preoperational thought development, making it difficult to find any pattern that would work for all individuals. To suggest that the child with life-threatening illness could not understand a prognosis would be unfair to the child.

Erikson (1963) developed a theory emphasizing eight psychosocial stages of development that may parallel the stages of Piaget. The stages are: infancy (1st year)—trust vs. mistrust; infancy (ages 1- to 3-years old)—autonomy vs. shame and doubt; early childhood (preschool ages of 3- to 5-years old)—initiative vs. guilt; middle and late childhood (elementary school years, ages 6 to puberty)—industry vs. inferiority; adolescence (10- to 20-years old)—identity vs. identity confusion; early adulthood (20's & 30's)—intimacy vs. isolation; middle adulthood (40's &

50's)—generativity vs. stagnation; and late adulthood (60's +)—integrity vs. despair. Behavior increases initiative, which is often lowered in a child with a life-threatening diagnosis.

The child in the initiative vs. guilt stage may blame him or herself for the illness because that notion that the illness was a punishment for some wrongdoing (Kubler-Ross, 1983). Logical thinking (Piaget 1896-1980) is not yet intact or this belief would not be likely to be entertained in this stage (Piaget, 1952).

Some children in the 3- to 7-year old range have moved forward to the fourth developmental stage, industry vs. inferiority. This stage occurs in the elementary school years as children attempt to master knowledge and become very enthusiastic about learning. These children at the upper end of the continuum (6- to 7-years old) may be quite capable of learning limited information about the ramifications of their disease. The child may begin to feel inferior to other children when he or she, for example, has no energy to play due to chemotherapy treatments. Again, children may move from stage to stage at slightly different ages from their peers.

Eiser (2004) claimed that children 3- to 4-years old cannot understand much about their diseases. Waechter (1971) believes that children view death as just going to sleep. Waechter stated that researchers typically divide the concept of death into components of irreversibility, universality, nonfunctionality, and noncorporeal continuum (which refers to some type of existence after death).

Eiser (2004) also suggested that by 4-years old, children have developed an intuitive theory of mind and that between 4- and 6-years old, a biological theory of life. It is in this period that the child starts to use the abstract concept of life. This contradicts Piaget's Stages of Development Theory, which does not posit a move from concrete to abstract until around 11-years old. This elicits more of a question as to the age that a child can understand the meaning and consequences of death. Eiser (2004) indicates a lack of current measures assessing that childhood understanding of death. Additional research could be valuable to develop test measurements.

Kubler-Ross (1983) observed, in her studies, several examples of children expressing knowledge in either symbolic nonverbal language, or symbolic verbal language. Siegel (1999) reported a 2-year-old during his final hospitalization telling his mother, "I want to be a little bird and fly off. I wish you could come with me, but you can't" (p.232). This certainly could indicate an awareness that his human form was now ready to change and he would be going on this journey alone. It could be interpreted as an understanding of the permanence of death as mom was unable to accompany him. Kubler-Ross (1983) wrote "small children, even 3- or 4-years old, can talk about their dying and are aware of their impending death" (p. 51). This was written as she reportedly observed a 4-year-old communicating not only verbally, but nonverbally while expressing feelings. Kubler-Ross said that the problem and controversy really revolved around the fact

that the child may not be able to express him/herself in adult terms, so credit was not given as to the understanding and awareness. She mentioned that children, not only adults, experience the stages of death and dying. These stages include denial and isolation, anger, bargaining, depression, and finally acceptance.

Armstrong-Dailey and Zarbock (2001) reported that, during their work with dying children, it was the more intelligent children who appeared to grasp the meaning of death at younger ages. This research was supported by Gross, Glaubman, Berman, and Orbach (1986). Gross et al. (1986) acknowledged that as intelligence increases, so does the child's organized comprehension of the dying process. The more children are aware of themselves, others, and their environment, the less difficulty in adjustment. Gross et al. (1986) discovered between the 3rd and 5th grades, there was an increase in comprehension of the finality of death. One explanation offered could be derived from Piaget's theory, that a young child sees disappearance as final. More research in this area would be helpful to clarify inconsistencies and apparent biases in currently available findings.

Brown and DuPaul (1999), while examining school success in children with chronic illness, discovered the level of cognitive development did influence conceptualization of the illness. They believed that children of all ages could differ within age groups in their conceptualizations. It would be therefore unfair to assume that all children in any particular psychosocial or developmental stage

cannot comprehend information regarding the potential outcomes of their illnesses.

Bertoia (1990) referred to Susan Bach, who had for decades been working with children, and who had noted that their drawings revealed psychological understanding of what was happening to them. She noted that even before children are consciously aware of their prognoses, they reveal preconscious awareness of this in symbolic verbal language. Kubler-Ross (1983) wrote that these drawings reveal preconscious contents, similar to dreams.

As is clear from the above, there is disagreement about the age at which children develop the ability to understand death. Kubler-Ross (1983) believed that children develop this understanding at 3- to 5-years old. Nagy (1948), one of the first researchers to outline death concept formation, believed that children 3- to 5-years old just see death as a departure that the person goes to live somewhere else. Nagy (1948) called this Stage 1. When a child is 5- to 9-years old, she/he believes that death can be avoided. This was termed Stage 2. When a child is between 9- to 10-years old, she/he reaches an understanding that death is permanent. Nagy (1948) also analyzed drawings and compositions of 378 Hungarian children who ranged in age from 3- to 10-years and observed their progression, on which he based much of his theory.

Demmin (1986) believed that it was very possible that a child's concern about death is more of a function of cognitive level and age than of emotional

response. Most of the research regarding children and death concept formation used surveys, interviews, and questionnaires. Demmin (1986) argued that there are problems with this methodology but did not elaborate on that, leaving his critique of past methodology quite vague.

Kubler-Ross (1983) believed that children in a hospital setting usually mature faster and develop a greater depth of understanding than those outside of this setting. This maturity has been revealed within many of the drawings collected by Kubler-Ross. Thanatology incorporates the use of drawings made by children in hospital or palliative care facilities. Questioning also provides information. Hasazi et al. (1983) assessed 5- to 10-year old children by asking the questions, "Can dead people come back to life?" and "Do you think someday you will die?" After listening to the children's responses, the authors decided that children as young as age six and all of the children by age eight could understand personal mortality. This was contrary to some reports in the literature stating the need for further research.

Whether or Not the Patient Was Informed of Diagnosis/Prognosis

No peer-reviewed literature reviewed in this area of psychology advocated withholding the diagnosis or prognosis from the child with a life-threatening illness. Withholding information was perhaps the norm twenty years ago, but not in this age. Although the adult may be reluctant to inform due to the painful undertaking, most do inform (Zebach et al., 2002; Paris, Barbarin & Chesler,

1986). The task at hand appears rather, to be *what, when and how*. Most children will have already picked up many cues from family members and their physicians.

When the child believes that adults do not openly discuss the diagnosis/prognosis, she/he is likely to feel isolated and alienated (Zebach et al., 2002). Paris et al. (1986) revealed that very few studies actually can relate exactly what parents tell their children. Twenty years ago, protection advocates argued against telling the child with a life-threatening illness the diagnosis/prognosis because these children were thought to be concrete thinkers rather than abstract thinkers (Paris et al., 1986). This was thought to prevent hope from being lost. Paris et al. (1986) argued that it is the parent's responsibility to share with the child important study information and details of the diagnosis/prognosis and treatment options. Their study dealt with families who had a child with cancer. Information was obtained by using open-ended questions and resources. Measures of medical status and demographics were obtained. In this 1985 study, not much, if anything was told to the children and several reasons were offered by the parents as excuses (not detailed). Seventy-three parents with children at a university hospital and children's center were surveyed. Twelve parents self-reported their knowledge about illness and treatment. The age of the child at the diagnosis was related to the sharing of the diagnosis and prognosis, as predicted by the researcher. Parents focused on the age of the child instead of his/her cognitive or

psychosocial development stages or individual maturation level. Therefore, the parents determined what they thought the child could handle in terms of his/her age. This may not have been an accurate estimation of the child's ability to comprehend their individual diagnosis and prognosis.

Kubler-Ross (1983) argued, throughout her work, that if parents talk openly about death, their 4- to 5-year olds would begin to talk about it as if it were temporary. She told a story about a little boy wanting his mother dead because he was angry at her. We can all probably remember similar personal stories. After a few hours, when he was hungry, he wanted her to re-appear and make a peanut-butter and jelly sandwich.

Demmin (1986) suggested that future research include some measure of childhood self-identity with self-consciousness to help determine the level of a discussion the parent might take with the child. Glover, Beliveau, and Miller-Thiel (1993) felt it important for the family members to realize that just because the child is not asking questions does not mean that there are none. Processing this information may have to occur before questions can be formulated. There must be a safe place for the child to do this along with a parent who is willing to have the discussion with the child.

Grollman (1996) constructed guidelines for speaking with children having life-threatening illness. These guidelines suggest talking with the child in a language that he or she can understand, trying to confirm in one's own mind

whether the child understands, explaining what caused the illness and how it started, allowing time for the children to express their own feelings, encouraging a positive approach, and reassuring children that even though they have an illness they are still loved. These guidelines can help create a safe environment for open communication.

Bertoia (1990) discovered that in Western culture there is a tendency not to tell children or adults the truth about their illnesses. She feels that it is quite important for caregivers to listen carefully, because in some cases the patient may not wish to know. This could mean that the patient is not ready to deal with this information. Bertoia maintained that when patients are told that, in any case, the information must always include a message of hope. Kubler-Ross (1983) maintained specifically that one must always communicate that there is at least a one-percent ray of hope.

Armstrong-Dailey and Zarbock (2001) stated that many children want to be included in the decision-making process, but that they are not afforded that opportunity if not informed. They suggested that children respond remarkably well to straightforward communication. Caregivers need to optimize the setting, find out what the child already knows, and what the child wants to know. They suggested giving information in small chunks. If death has been associated with going to sleep, the child senses she/he is dying. If informed, the child has the opportunity to ask questions about the illness and what might occur in the future.

Anxiety levels may decrease as information is assimilated by the children. There would not be the need for aggressive or acting-out behaviors and delinquency would be decreased. Armstrong-Dailey and Zarbock (2001) concluded that children were very ready to talk about their own experiences. The well-known children's book, *There is a Rainbow Behind Every Dark Cloud* (Jampolsky, 1979), followed eleven children who were ready and willing to talk about their feelings of dying. They were given a chance to ask questions. Some of these children did express fears of no longer being with their moms and other children wanted to know more details.

Kane (1979) revealed that children who have experienced the death of someone close to them have a better understanding of all aspects of death. Feifel (1997) concluded that children who had experienced such a loss were more likely to believe in personal mortality. The children exposed have some type of frame of reference upon which to draw as they use that experience to anticipate what may occur in the future.

A main stressor for hospitalized children may be separation from the mother figure. This would certainly seem to be relevant for children residing in hospice and palliative care facilities. When the family is involved, the child may be more likely to continue to feel like a member of the family. The child with a life-threatening illness, who has family involvement in their treatment, may show less signs of isolation, fewer complaints about physical symptoms, and may be more

focused. If additional attention is focused on the child, less need to act-out may occur. Thoughts may no longer be overwhelming as there is someone else to talk to in the course of treatment.

Adams-Greenly (1984) also believed that family members can help the children share feelings and emotions and to help them put those feelings and emotions into perspective. According to Kubler-Ross (1983), there is a question about society's ambivalence about whether or not death is a punishment. When children do not believe this punishment exists, there is a there is a greater likelihood that belief in an after-life may exist.

The children revealed in *There is a Rainbow Behind Every Dark Cloud* (Jampolsky, 1979) that praying had helped them. Beliefs that cause worry about having an after-life could cause problems in the level of adjustment by causing anxiety (Armstrong-Dailey & Zarbock, 2001). When anxiety occurs, acting-out behaviors are more prevalent. Also, she/he may not want to fall asleep (Armstrong-Dailey & Zarbock, 2001).

Fitzgerald (2005) determined that it is still not unlikely that families and medical staff tend to withhold information based on a motive to protect the child. They also maintain that the child can usually discover the diagnosis and prognosis by eavesdropping, examining his/her parent's nonverbal communication, and by talking to other patients. Parents, at times, do not reveal information regarding the diagnosis and prognosis because they do not want to deal with the associated

negative feeling and fear of upsetting the child (Brown, 2006). In reality, however, the uninformed child is likely to become lonelier and isolated because others have information that appears to be privileged knowledge.

Some anxiety within the child can indicate well-being and stability (Gross et al., 1986). Armstrong-Dailey and Zarbock (2001) discovered that the children who had been informed of their diagnosis and prognosis had greater anxiety levels than those children not having an illness. The mental as well as physical symptoms need to be addressed. Assistance must be given in terms of support to the child with life-threatening illness so she/he might adjust to the recent diagnosis/ prognosis and also prepare for any changes that may occur in his/her lifestyle.

Experience With Death

Kane (1979) reported that children who have experienced the death of someone close to them have a better understanding of all aspects of death, including the sequence of dying. Kane (1978) also assessed for anxiety and used the General Anxiety Scale for Children (GASC) along with a parental questionnaire to determine the above finding since there was no death anxiety scale for children. This finding supported the idea that certain life experiences, such as death of a loved one, can definitely impact a child's understanding of death.

Feifel (1997) reported that children who had experienced a loss of someone close were also more likely to believe in personal mortality. Willis (2002) stated that this experience does not happen very often because most children have not lived long enough to encounter this experience. She maintained that the degree to which children realize finality is still controversial.

Additional studies are clearly needed because not much research has been conducted in this area and the current state of knowledge is incomplete. The proposed study could be quite valuable in the future if it promotes greater understanding of children's experience of death by parents, teachers, and health professionals. Additional training for those involved with these children could be quite beneficial. It is hoped that this increased knowledge will lead to increased abilities to provide support to these children.

Family Involvement in Treatment

DeSpelder and Strickland (1996) stated that one of the main stressors for hospitalized children is separation from the mother figure. Kubler-Ross (1983) was an advocate of, whenever possible, bringing the child home from the hospice or palliative care facility so that the child might be in the familiar environment of home and around family and loved ones.

Kubler-Ross (1978) designed a place to go to learn how to live until death. It was called Shanti Nilaya, which means Final Home of Peace, not just for the dying but also for their families.

Parents and family members can help the child share thoughts and emotions so that the child can learn how to put these emotions into perspective in order to be able to control them (Adams-Greenly, 1984). The author reported that parents can be helpful in encouraging the child to interact with others and continue friendships. Parents are thus the spokespeople for this often silent minority. Bertoia (1990) and Kubler-Ross (1983) both state that parents can be a major vehicle for communicating help to their children. Children desperately rely on their parents for their voice.

It goes without saying that parents ultimately decide on the course of treatment along with the physician, including when to turn to hospice and palliative care. Children can benefit from the contact they have with siblings so they do not withdraw and isolate. Families can help create a safe space, an environment where the child can trust and feel comfortable to ask questions (Medicine, 2001).

Kubler-Ross (1983) stated that children are not so much afraid of dying as they are of abandonment. She maintained that they hold on to an environment of love. When continued parent-child communication occurs, positive coping mechanisms are displayed (Armstrong-Dailey & Zarbock (2001). Encouragement is derived from the parents at this very sensitive time in the child's life.

Waechter (1971) believed that when the parents are not available to discuss the child's impending death, the parents are allowing their child to die

psychologically alone. Parents can help the child grieve the loss of a normal life (Brown, 2006). Fitzgerald (2005) supports family therapy to help deal with this devastation. Kubler-Ross (1969), in her wisdom, stated:

Those who have the strength and the love to sit with a dying patient in the silence that goes beyond words will know that this moment is neither frightening, nor painful, but a peaceful cessation of the functioning of the body. Watching a peaceful death of a human reminds us of a falling star. One of a million lights in the vast sky that flares up for a brief moment only to disappear into the endless night forever. (p.276).

Engaged in Age-Appropriate Activities

Hospice and palliative care facilities have encouraged the children to continue age-appropriate activities that are enjoyed. Continuing in school whenever possible to avoid withdrawal has proven helpful.

Bertoia (1990) gave children some drawings and from this was able to determine how the children were feeling at the moment of drawing. This gives the child something easy to accomplish and assesses feelings and emotions in the process. A dual purpose is achieved.

Jampolsky (1979) verbalized that it was easier to talk with other children than to adults about sensitive topics such as being afraid of dying. Being at similar cognitive stages of development may make conversation fluid.

Feifel (1977) stated that investigators have explored communication in the context of directed play, drawings, and death-related pictures. While interviewing, the impact of activities on adjustment levels may be revealed. This information

could prove useful in the future for a hospice or palliative care facility team when designing activities.

Grollman (1996) found some activities useful when working with the child. Depending on the child's age level, stuffed animals can elicit expressions connoting feelings. The child might pick the animal whose facial expression reflects how the child is feeling in the moment. Drawing proves useful and fun and frequently a theme emerges. This is what occurs in qualitative research. Playing with puppets or working with clay and playing with dolls create outlets for safe expression that could lead to useful dialogue. Grollman (1996) believes that just being there with the child is important. Stevens (1993) promoted music therapy as a way to uncover predominant themes in children, using a Jungian approach.

Drawings can reveal an underlying, spiritual, and even unconscious awareness of death (Bertoia, 1990). This could provide an avenue for discussion and also serve as an assessment of the child's information. Writing poetry (Kubler-Ross, 1983) has been an outlet for the child to share thoughts and feelings. Journals can be kept to record those thoughts and feelings as the child chooses to reveal them.

Kubler-Ross (1983) mentioned creative visualization. In this technique, the child visualizes the hurt under a pink light which symbolizes healing. She encourages the child to read *There is a Rainbow Behind Every Dark Cloud*

(Jampolsky, 1979) to help with the visualizations. This may stimulate the child to draw or even write a poem.

Eiser (2004) referred to The Platt Report of 1959, which revealed that distraction activities involving inter-active play were valuable in helping the children adjust. Continuing in school has also been found to be positively associated with emotional well-being.

Many of these ideas can help show the child with life-threatening illness that enjoyment can still be experienced at times. Interaction with people can be facilitated through various media. Satisfaction can be found in completing puzzles, drawings, or molding a piece of clay.

Belief in an After-Life

Kubler-Ross (1983) believed that when the religious beliefs of children have been found to exert some influence over their understanding of death, it has been in the areas of causation and the concept of a life after death. Many confuse this with affiliation to a particular organized religion. It is not the organized religion but the beliefs acquired. These beliefs may be shared by many religious denominations. There are also children showing signs of ambivalence about whether or not death is a punishment for some wrong doing as opposed to a natural event. This concept may play an impact on the child's behavioral adjustment.

Kubler-Ross (1983) related a story of a mean old woman who had died. In a study of 5-to 9-year old children, the children reportedly were inclined to view the lady's death as due to meanness as opposed to old age. This reflects, at times, attitudes and beliefs of adults in society according to which death is viewed as a punishment for an inappropriate lifestyle. This warrants further investigation. This knowledge would indeed help adults educate children, especially in the areas of causation of any possible guilt feelings. Waechter (1971) cited another component of the death concept, noncorporeal continuation. Children were found to question the truth about the soul/spirit departing from the body and entering some eternal life. This message may have been conveyed through organized religion and the family's belief system.

Jampolsky (1979) wrote about a child reporting prayer to be a great help to most of the children because prayer helped them find faith and hope. They reportedly felt safe when they prayed. It was not specified to whom or what the children prayed. Without saying so specifically, praying implies belief in some higher power that conveys a sense of safety for which the child feels a need.

A common aspect in most religious beliefs is some type of spirituality which endures after death, into an after-life. Belief in life after death or some re-uniting with loved ones seems to promote a sense of peacefulness.

Religion appeared to make a difference in the results of a study conducted by Paris et al. (1986). This study showed that Catholic parents told their children

more about the disease and its treatment, along with diagnosis/prognosis, than did parents of other religions. Previously, the researchers believed that this was because Catholics are known to have more children because birth-control is outlawed (any method but abstinence or rhythm) by the Pope. This belief no longer appears valid because Catholics are increasingly using contraception and having fewer children; thus, invalidating the Paris (1986) study reporting that Catholics are known to have more children, because they are deciding to use contraception and go against the teachings of the church.

Beliefs that cause worry about having an after-life should be discussed, because these very beliefs could cause problems in the level of adjustment by causing anxiety (Armstrong-Dailey & Zarbock, 2001). Armstrong-Dailey and Zarbock (2001) maintained that discussions about religion are the easiest spiritual concerns to recognize and children may express concerns or wishes in prayers that may not be expressed otherwise.

Age of the Patient as it Relates to Stages

Much of the research already reviewed here mentioned age as related to the levels and stages of development. Age, however, has also been found to be related to adjustment by O'Malley, Koocher, Foster, and Slavin (1982). These investigators have revealed that the older the age at diagnosis, the more positive the child's behavioral adjustment.

Gross et al. (1986) stated that age is indicative of knowledge, assimilation, maturation, and experiential exposure. Increasing age exposes children to various forms of death and expands their knowledge of self and environment.

Gender, Ethnicity, Time Since Diagnosis, Socio-Economic, Being the Only Child.

Armstrong-Dailey and Zarbock (2001) reported that children were supported by their family's cultural beliefs about death even if they differed from the caregiver. Attempts to change these beliefs were less than satisfactory in their outcomes; therefore, multi-cultural training could prove beneficial in this attempt.

There has been some attention in the research to socio-economic status. A more affluent child may have more readily available opportunities enabling a faster progression through developmental stages. Some guardians may have the money to purchase books, reside in an area having the best schools, and even have access to the best health care.

Hagey (1999) discovered that there was a strong correlation between family SES and death concern. Higher SES status was associated with higher death concern. Those with lower SES often have fewer educational opportunities due to lowered financial resources and perhaps the educational levels of other family members. The family's verbal skills would then be expected to be lower, and a strong relationship is expected between educational level and verbal ability. A child from a lower SES level may be thinking the same thoughts as a more

affluent child but may be less able to articulate these thoughts verbally. SES has also been associated with current environmental stressors.

Behavioral Adjustment

Being diagnosed with a life-threatening illness is shocking. It is even more shocking when the diagnosis is given to a child. Many feelings and emotions occur leading to a change in behavior. There must be a level of adapting, adjusting, while trying to cope with this new life experience.

Deasy-Spinetta (1981) published a study with school-aged children diagnosed with a variety of cancers at various stages. They found that cancer patients demonstrated substantially more inhibition in reaching out to others than the child who was not ill, and that they were less likely to try new activities or express feelings. They assumed more self-protective roles. Students who were depressed because of bad health were more anxious about future hospitalizations. Phases that can affect the level of adjustment include the initial diagnosis/prognosis, treatment initiation, illness stabilization, and end stage treatment (Brown, 2006). Each stage requires a new level of adjustment in order to deal with the situation.

Children have been known to be adaptable but certainly there is a limit to the amount of adjustment, before isolation or other forms of behavioral maladjustment develop. Recent studies have examined stress and coping responses in children with a wide age range but none have been found to examine

the behavioral adjustment in children having been diagnosed with a life-threatening illness. These studies were quantitatively conducted and were not the much needed qualitative studies in which the children are actually interviewed. Longitudinal studies would also be valuable in tracking the coping mechanisms of the child with life-threatening illness (Brown, 2006).

Children less than six years of age were most concerned with separation and children 6- to 10-years old were found to be fearful of physical injury and mutilation (Brown, 2006). This awareness has been beneficial to caregivers as the younger child may appear to be more clingy and act-out when parents are departing. Treatment planning could address these issues and actively help the child with adjustment.

Fitzgerald (2005) acknowledged many developing thoughts and emotions when the diagnosis/prognosis is revealed. This is why it is important for people close to the child to be willing to discuss and talk with him/her. If this does not happen, the child's anxiety typically may increase.

It is important for adults to realize that their uncomfortable feelings with the topic may indeed help the child to adjust if they begin a discussion and verbalize those feelings (Srivastave & Phipps, 1997). Yalom (1980) and Rochlin (1967) stated that this adjustment may entail coping strategies and defense mechanisms.

The school-age child has begun to increase independence. Self-esteem may be threatened as the child begins to make his/her own decisions. These decisions

may not always prove to be the right choice and this may affect self-esteem. A great deal of adjustment occurs (Armstrong-Dailey & Zarbock, 2001). The child needs support from a team of individuals involved with their care.

Bertoia (1990) stated that many times children with life-threatening diseases have a need to express anger and pain and may use swear words to release the tension so that they do not become overwhelmed. Caretakers need to understand and help the child release anger in an appropriate and beneficial way. This need not be a negative experience. This adjustment period can be discussed with involved adults. Kubler-Ross (1983) had parents use a hose piece to bang to express the anger. A child could do the same and be reassured that this is acceptable, and this can be made into a game that may even evoke humor.

Lubkin and Larsen (2002) found that child adjustment problems in this population included behavior difficulties, poor resolution of developmental tasks, and low self-esteem. Zebach et al. (2002) discovered that many studies over the years do not report increased depression or anxiety. Studies are needed to further investigate and test these hypotheses as researchers are in conflict as to the factors affecting behavioral adjustment. It will prove helpful to determine exactly what impacts children with life-threatening illness. Zebach et al., (2002) stated that children who know about their cancer have difficulty in adjusting behaviorally, contrary to Kubler-Ross (1983).

Further information gathered in this area can help awareness. Ideas as to what one might expect, when working with the child with life-threatening illness, would be helpful and supportive to assist in behavioral adjustment.

CHAPTER THREE: METHODS

Background and Rationale for the Study

Hospice and palliative care are finally becoming widely available as a much needed option for terminally ill children and families. The potential factors identified by the parents/caregivers that affect the adjustment of children with life threatening diagnoses with regard to behavioral adjustment after diagnosis/prognosis has been made by the medical staff could well be the first step in developing supportive interventions to help the child cope with present physical and emotional life changes whether the child is in a facility or at home. As more is learned about these important factors, further research can then be encouraged to determine appropriate treatment in the future.

This qualitative study required a structured interview with the parents/caregivers of the child with life-threatening illness. The parents/caregivers of the child with life-threatening illness completed a Parent Report Questionnaire (PRQ) after the structured interview.

Basic Research Question

This qualitative study's research question is: What factors are associated with the adjustment in children with life-threatening illness without brain impairment from the phenomenological perspective of the parents/caregivers.

The participants of this study were parents/caregivers of a child with life threatening illness without brain impairment. Some children may not have had parents actively involved so other caregivers were also sometimes involved.

The method of selection included recruitment from support groups and recruitment by word of mouth serving the population of individuals caring for a child with a life-threatening diagnosis. A letter of introduction was sent to various group homes, hospices, and hospitals soliciting participants and listing the criteria for inclusion.

Instrumentation used was a structured interview of 8 open-ended questions and a demographic questionnaire (PRQ). As individuals showed interest in participating in the study via emails or phone call, a recruitment letter and flyer and a consent form were sent. Each individual was then contacted via phone and scheduled a personal interview. All interviews were recorded via voice recorder for accuracy of the data collection and transcription. Brief memos were taken at the time of the interview to determine preliminary impressions of coding.

The participants were interviewed 1:1 by this researcher. The interview was a battery of 8 questions constructed in advance. They were open-ended questions to allow each participant to elaborate on each answer. Each question was designed by this researcher and approved by his committee members. Questions were designed to gather information to answer the main research question. One hour

was allowed to conduct the interview for each participant and then they completed the demographic questionnaire (PRQ) upon conclusion of the session.

Procedures for the Study

1. Announcing this study to potential participants via phone calls, word-of-mouth, letters, and flyers (see appendices).
2. The location of the interview site was nearby the participants to allow for convenience and provide a space to protect confidentiality.
3. Participants were required to complete a written consent form, 1:1 interview, and a demographic questionnaire.
4. After the initial phone call and the potential participant agreed to participate in the study, a recruitment letter explaining the study was sent. The time commitment expected was explained as was assurance for confidentiality. The recruitment flyer and consent form was included.
5. This researcher spoke by phone to potential participants prior to the interview and used email to communicate when necessary. U.S. Postal Service was used to send information about the study and also the consent form along with a flyer. The Demographic Questionnaire (PRQ) was completed after the interview so as not to lead the interviewee in any particular direction.

6. Interviews were conducted within the 60 minute data collection conducted by this researcher with each participant. There was a final optional interview for debriefing purposes conducted by this researcher.
7. The data collection interview was scheduled after paperwork received. The final optional interview was to be scheduled at a mutually agreed upon time but was declined by all participants.
8. The data was retrieved by this researcher during the one interview and by completion of the demographic questionnaire upon conclusion of the interview. Referrals for psychotherapy were available upon request. Participants either denied or had their own psychotherapist.
9. The data collection was interpreted via standard qualitative data analysis procedures using text-based thematic analysis. Codes were derived from the interviews, comments notated in the margins. Phrases, themes, patterns, sequences were identified; isolating similarities and differences.
10. The PRQ was completed upon the conclusion of the interview in order to examine factors supporting what was researched quantitatively. No generalizations were made. The parents/caregivers provided answers by completing the blanks and ranking on a Likert scale. This is a new measure developed by this researcher for the purpose of this study. Its psychometric properties are unknown at this time. The instrument was

designed to provide relational background information and demographics.

11. All information received pertaining to this study was and is kept in a secured lock box to protect confidentiality.

Data Processing Techniques

Rubin and Rubin (2005) define data analysis as a process. Data analysis moves from interviews to evidence-based interpretations. This researcher extracted meaning and interpretation along with comparing and classifying to reveal patterns. Themes and events were discovered by coding the interviews, such that concepts were retrieved in order to answer the research question.

In the interview the process of analysis began. A line-by-line analysis was conducted to explore relationships among various categories. Analysis of single words can explore relationships among various categories. Analysis of single words-to-phrases to-sentences was explored, looking descriptively at the details. During the interview, the researcher listened to not only what was disclosed but *how* it was said. Concepts, themes, and events were analyzed across different interviews for the purpose of discovering the emergence of possible meanings. Data were organized into categories and conceptualized into patterns. This was the process of coding.

Code structure comes about from the relationship between codes, thereby creating units and using the literature for suggestions as to possible meaning.

Codes required definitions which changed as the study progressed. Comparing interviews served the purpose of examining what each interviewee said about the same topic. Concepts were grouped together to examine implications. Data were physically coded by reviewing transcripts and placing a code next to the data. Analysis was conducted by using features of the word processor. The coded data were sorted and categorized for the purpose of supporting the effort of writing the narrative section of this study. An inductive approach was utilized which means the themes are linked to the data but may bear little relation to the specific interview questions. They would not be driven by this researcher's theoretical interest in the topic. The process does not attempt to *fit* the coding into a frame which already exists or by this researcher's preconceived ideas.

Thematic Analysis was the qualitative research protocol used for this study. Themes were discovered from the data. Patterns from the data were not theoretically bounded as in grounded theory. Unlike some other qualitative approaches, Thematic Analysis does not require detailed technological application in regards to analysis. It can be used to report the reality of the participants' lived experiences as they self-report regarding their meanings and experiences. This is essentialist method. The themes were identified at the semantic or explicit level, identifying the themes within explicit meanings of the data. This researcher was not looking for anything other than what the parent/caregiver said or wrote on the demographic questionnaire. The analytic process involved description to

interpretation. Thematic Analysis should therefore be viewed as a foundational method utilizing the core skills to conduct other types of qualitative analysis while providing flexibility and a detailed account of data (Braun & Clarke, 2006).

Methodological Assumptions and Limitations

Qualitative research constructs theory rather than testing it. Studying a population in a small area of California may limit the variability of the participants.

Parental/caregiver memory may result in limitation depending on length of time they are recollecting. There existed an outlier in age; one child was substantially younger than the rest. It was difficult to compare due to maturation and development. One might also say that a caregiver may not know the child as well as a natural parent, depending on the circumstance involved in the particular situation.

The results were derived from a sample of children with life-threatening illness and the narrative data was based on the parent/caregiver report. An assumption was made that the parent/ caregiver accurately interpreted the child's feelings, emotions, and thus, behavior. The researcher based the results of the study on children who have life-threatening illness. The parents/caregivers may not always have been clear to remember the distinction of the child's behavior both before diagnosis and after diagnosis.

Relationships between cognitive ability and levels of adjustment are important to consider. Kubler-Ross (1969, 1983, 1997) cited that children experience an awareness of life-threatening illness at a very young age. Capacity to adjust increases with age and with cognitive developmental level. This frequently is demonstrated by how the child will ask questions, engage in conversations with adults, and have the opportunity for verbal feedback. The parents/caregivers remember the conversations with the child to the best of their ability. Some children obviously have been more verbally expressive and forthcoming than others. Thus, there can be variation in the quantity of narratives about what the child has expressed according to the parents'/caregivers' memory.

Table 1
Participant Demographic Information

| | | | | | | |
|--|---|--|--|---------------------------------------|--|--------------------------------------|
| Participants: | Peter (12 y/o) Mother: Kathryn | Sebastian (17 y/o) Mother: Maya | Matthew (2 ½ y/o) Mother: Cindy | Brenda (14 y/o) Mother: Mary | Michael (6 y/o) Mother: Barbara | Ian (5 y/o) Mother: Janelle |
| Child Diagnosis | Cancer | Epilepsy (Seizures) | Microcephaly Lacks weight gain | Chronic Asthma | Brain Cancer | Chronic Asthma R/O Leukemia |
| Noticed Change in Behavior since Diagnosis | Yes | Yes | Yes | Yes | Yes | Yes |
| Belief in Afterlife | Yes | Yes | Unknown | Unknown | Yes | Yes |
| Family Involved in Treatment | Yes | Yes | Yes | Yes | Yes | Yes |
| Experience Death of a Relative, Friend, or Pet | Yes | No | No | Yes | No | Yes |
| Child Afraid of Dying | No | Yes | Unknown | Yes | No | No |
| Birth Order | Only Child | Youngest | Only Child | Youngest | Oldest | Only Child |
| Religion | Metaphysics | Christian | Catholic | Jewish | Jewish | Catholic |
| Parents Together | No | No | Yes | No | Yes | No |
| Health Insurance Covered | Yes | Yes | Yes | Yes | Yes | Yes |
| Yearly Income | \$25,000 To \$49,999 | \$25,000 To \$49,999 | 0 To \$24,999 | \$25,000 To \$49,999 | Over 100,000 | 75,000 To \$100,000 |

- Information acquired from Parent Report Questionnaire
- Ideas for possible future research as the above not included in interview.

CHAPTER FOUR: RESULTS

Description of Sample

Six adults (all women) from southern California were interviewed for this study to discover from a phenomenological perspective the factors associated with adjustment in children with life-threatening illness without brain impairment.

The oral interview consisted of eight open-ended questions lasting up to 30 minutes resulting in a total of 24 transcribed single-spaced pages. The analysis was guided by the themes that emerged from the interview and demographic questionnaire rather than by a particular model. This Researcher was interested in understanding individuals' everyday experience of reality to understand the factors associated with behavioral adjustment. There was no pre-existing theoretical framework. An inductive, semantic, and realist approach was executed.

The researcher reviewed and analyzed the interview texts which were then organized to identify "units of meaning" which were then categorized into themes, subordinate themes, and sub-themes. The themes discovered were: Isolation, Anger, Inquisitiveness, Age-Appropriate Activities, Diagnoses Shared, Support Systems. The information was relayed by the caregiver/parent of the child with life-threatening illness.

This analysis was data-driven and concerned with parental/caregiver perspectives. The analysis focused on sharing themes between the transcripts, looking for patterns in the semantic content. This researcher was interested in the parent/caregiver subjective view of factors associated with behavioral adjustment in the child with life-threatening illness. For this study, all caregivers were mothers of the child. Two mothers had husbands living with them and the other four were single mothers raising their child. See Table 1 for demographic information. The age of children ranged from two and one-half-years to 17-years of age. There were five males and one female in this study.

Participant Profiles

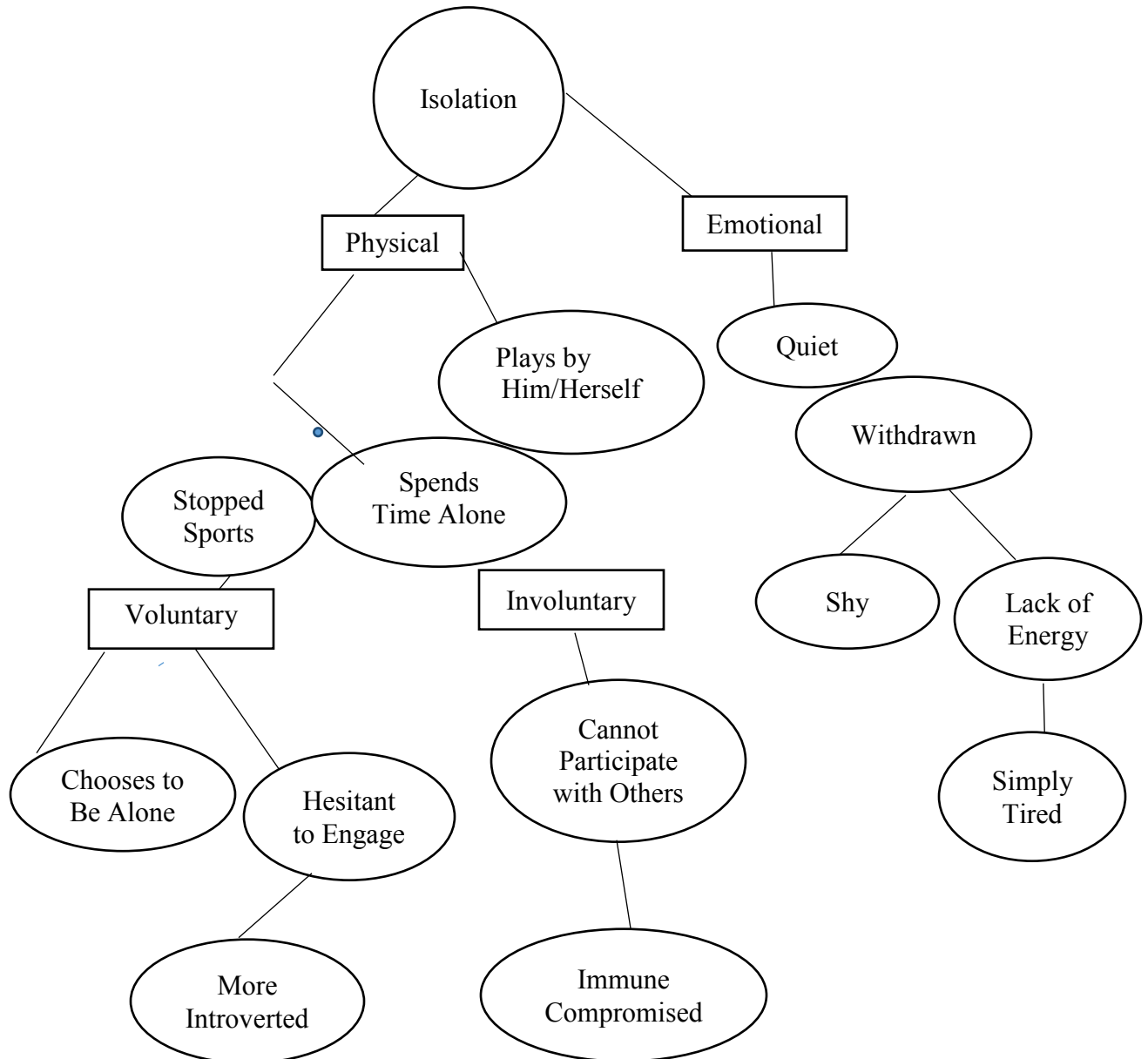
Each interview was comprised of eight pre-determined questions that were designed to elicit the experience of children as perceived by the caregivers observing behavioral adjustment of children with life-threatening illnesses. Pseudonyms were selected by the parent so that confidentiality would be ensured.

Table 1 offers a concise description of demographic characteristics as conveyed by the caregivers who completed the questionnaire after the interview. This verified that all participants noticed some kind of change in behavior since the child had been diagnosed. The questionnaire was constructed based on information gathered by this researcher from existing quantitative research. Although not part of the interview process, this researcher believed the questions

in the demographic questionnaire prove valuable for future research as similarities have been discovered.

Matrix 1

Theme: Isolation



- Rectangles indicate subordinate themes, while ovals indicate the sub-themes

Theme 1: Isolation.

Isolation was a salient theme which emerged in all eight interviews conducted by this researcher with the parents of children having life-threatening illnesses. Isolation ranged from physical to emotional, from voluntary to involuntary. All children experienced isolation. For instance, some children were too fatigued and weak due to chemotherapy or radiation and chose to remain alone as they no longer felt energy to play. Other children were actually kept away from individuals who might possibly be contagious and infect them.

Barbara, mother of Michael (6 yrs.) with brain cancer, described this required isolation:

Most of the time he was either in the hospital or the house, because he couldn't be around people very much because he was immune-compromised. Um-hum, It's like the hospital. He couldn't go into the room with other kids. He has to do things in his own room.

Michael experienced involuntary and physical isolation. Consequently, Michael had to play alone and became frustrated and angry at times. The subordinate themes of voluntary and involuntary isolation and emotional and physical isolation may be experienced separately or together. There exists a need to determine whether or not the isolation is physical, emotional, or both, if the child is to be accurately understood. Life was reportedly dull and boring being alone.

Kathryn, mother of Peter (12 yrs.) with brain cancer, stated:

Well, the diagnosis was a year ago. I didn't notice differences in behavior at first. As he got sicker, I've noticed him becoming more introverted. My son is one of those kids that loves sports. Now, he don't [sic] even go out and toss the basketball into the hoop anymore. He's just not quite as enthusiastic about anything...He used to romp with the dog. So, yeah, it's like he's slowing down.

Peter already had the tumor removed and is undergoing chemotherapy. His chemotherapy is responsible for much of the lethargy, but this may also have caused Peter to be depressed while withdrawing from others and the activities he has enjoyed. It was unclear whether Peter stopped playing sports because he felt he no longer was strong enough to participate nor did the recent chemotherapy cause him to be tired and fatigued.

Maya, mother of Sebastian (17yrs.) with epilepsy and seizures, reported that her son stopped physical activities:

Interestingly enough, at the onset of his illness, he had stopped doing sports. He was very active throughout childhood, junior high, high school. From lacrosse, soccer, the police explorer program, karate, jujitsu...Upon getting diagnosed, he had stopped doing all the physical activity. Was more kind of going into part of organizations [sic].

As reported in the interviews, physical activity, such as a sport, was frequently stopped by the child after hearing the diagnosis.

Cindy, mother of Matthew (2 1/2yrs.) with microcephaly (brain swollen) and weight loss, reported that her son became very sensitive to noises so he chooses to play by himself where it is not so loud rather than to play with the

other children. When a group of children get together, quite frequently it is noisy and this is what he wants to avoid:

His sensory problems. He was five months and he had that and they all went away. They recently came back. That stopped for a good while and came back right now. Before, it was just loud noises. It's also if you're talking, or the T.V. is on. He wants it off. You're talking or he wants to put his hand on your mouth like can you not talk? [sic] Before, it wasn't like that.

Interestingly, Matthew is only two and one-half-years old. He lacks the thought process of the older children. He withdraws and requires quiet according to his mother. He does not wish to be around anyone who is making any kind of noise such as merely talking. Matthew receives services through a Resource Center and has professionals working with him. He reportedly is very shy. Matthew does not eat which is causing problems to his health as he is not gaining weight. Cindy, mother of Matthew, reported that noise makes him withdraw. It was not discussed whether or not noise plays a part in his not eating and continuing to lose weight.

Mary. Mother of Brenda (14yrs.) with chronic asthma was concerned about her daughter's constant worry about her health. She mentioned that Brenda "lost her exuberance of life." "She doesn't get to participate in a lot of things and she doesn't think that's fair...I guess She feels like she can't fully participate so that kind of antagonizes her."

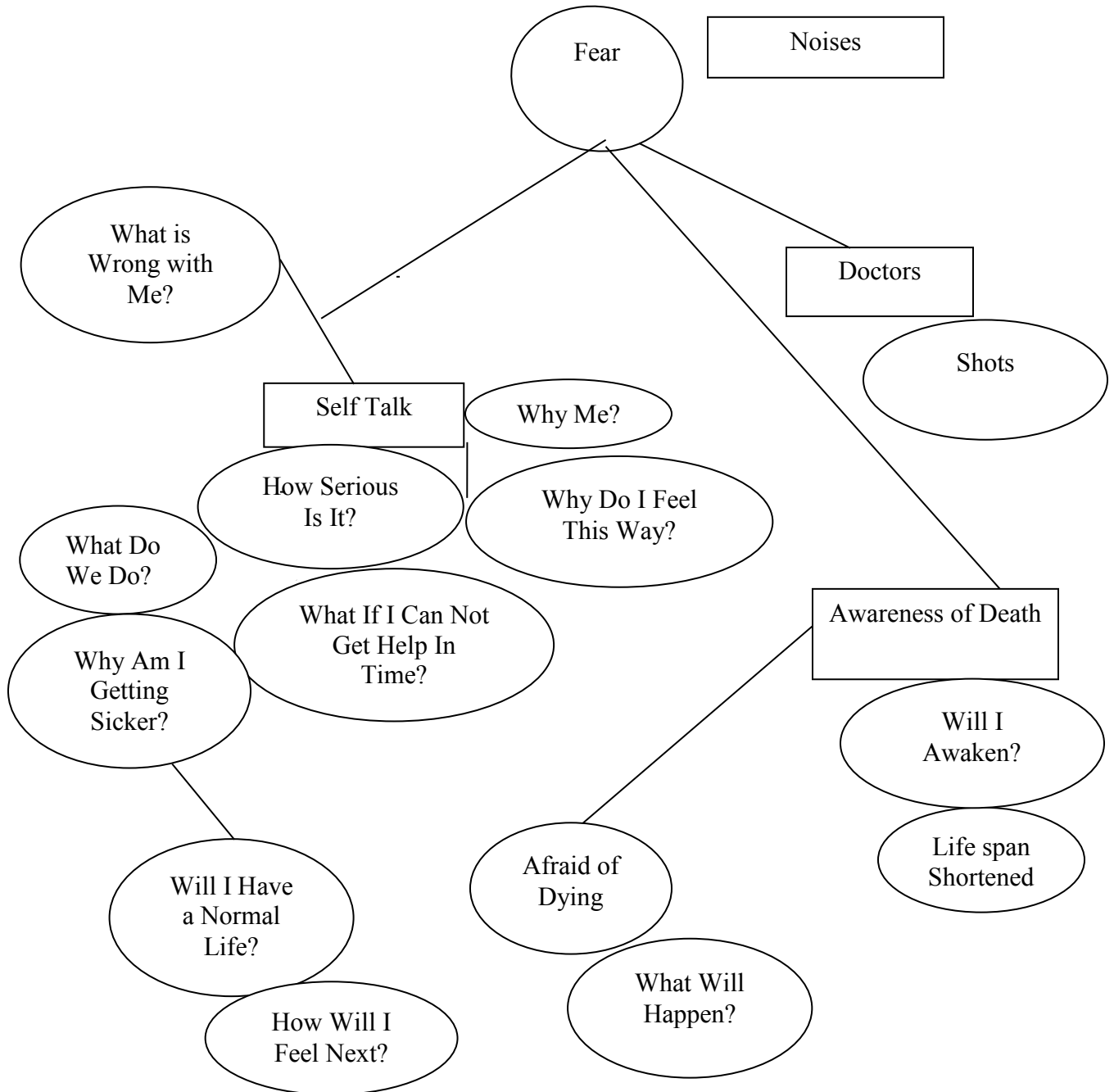
There may be a limit to the amount of adjustment before isolation develops. Some isolation should not be avoided if deemed a medical necessity. As the

illness progressed, Kathryn revealed that Peter withdrew from others. It may be important to assess whether there is a physical problem causing the isolation or an emotional one as the caregiver attempts to help the child.

The children may have voluntarily chosen to remain alone, watch TV, or play computer games. In the case of Michael (6 yrs.), there was little choice to remain in isolation so he would not get an infection. In the case of Peter (12 yrs.), his chemotherapy has been making him weak and fatigued and he was not interested in playing sports or participating in physical activities. With some of the other children, choices appeared to be initiated by the child. This voluntary isolation may certainly be due to fear.

Matrix 2

Theme: Fear



Theme 2: Fear

A second salient theme that emerged from the thematic analysis was fear. Fear included subordinate themes of self-talk, awareness of death, and doctors. There existed uncertainty as to feelings, health issues, seriousness of illness, normality of life, and what will happen in the future. These are all sub-themes.

There became an awareness of death provoking the fear of actually going to sleep and what would happen if one did not awaken. This was in the case of Sebastian (17yrs.) as reported by his mother, Maya. Most of the older children were reportedly afraid that their life-spans would be shortened. Since the two and one-half-year-old, Matthew, was too young to internalize much of the above, he became afraid of noises. He also had this fear of going to the doctor as did the others.

Kathryn, mother of Peter (12 yrs.) revealed that she had always been honest with her child. She does not have any concrete answers for him which makes him frightened of the unknown. “We’ve always been honest with each other. I think there’s fear in what you don’t know...I don’t want him to be fearful of anything.”

Kathryn verbalized that Peter asked: “How am I going to feel? How am I going to feel next week? Why do I feel this way”? That is how Kathryn knew he was afraid.

Maya, mother of Sebastian, (17yrs.), stated that her son was afraid of dying. He wanted to know if illness was a life-long thing and what would be the plan of

action. Sebastian has epilepsy with seizures that frequently occur nocturnally. Maya reported that this makes him fearful when it is time to go to bed as he is always afraid there may be another seizure. Maya reported that Sebastian could not understand why this was happening to him and was unclear as to the seriousness of the illness. He looked towards his mother for help but was afraid that she may not always get him in time. Sebastian was afraid that he might not experience a normal life and showed fear in the unknown regarding what might the illness cause for him in the future.

Similarly, Mary, mother of Brenda (14yrs.), reported the same concern. “Well, she’s fearful about her health and well-being.” Both of these children are teenagers and the fear apparently relates to retaining present abilities in everyday life and in physical activities such as sports. They both were concerned about the longevity of their lives and how this illness may impact a normal life. Bailey and Zarbock (2001) suggested that anxiety levels may decrease as information is assimilated by the children. Fear has been associated with the lack of knowledge. In the children’s book *There is a Rainbow Behind Every Dark Cloud*, some children did express fears of no longer being with their moms and other children. Like Brenda and Sebastian, they wanted to know more details about their illnesses and how they might proceed in life.

In particular, the two youngest children were afraid of going to doctors because they recognized it was the nurses who actually came in and gave the

shots for the doctors. Fear commenced upon having the knowledge that their mother had made a doctor's appointment.

Six year-old Michael was also in denial as his parents went one step further and informed him of the prognosis (not in any detail). Michael still believed he was going to "grow up and have four professions and a set of twins." Two-and-one-half-year-old Matthew was also afraid of going to the doctor and possessed the attitude "out of sight, out of mind," according to mother, Cindy. Cindy reported that Matthew would eventually say, "Doctor again? Why again"?

Matthew would have to have a feeding tube inserted at times if he would not eat. He was quite aware that the doctor was in charge of this procedure but still would not want to eat. He was afraid. It appears that there are additional fears.

Similarly, Janelle, mother of Ian (5yrs.) with a rule out leukemia diagnosis, reported that her son, too, is fearful:

I know he is very fearful of going to the doctor and getting any type of injection or anything of that sort...having the doctor examine him or the nurses come in. He's smart enough to realize that the doctor doesn't draw blood or doesn't give injections...but that doctor steps out and it's the nurse or an assistant who does that.

The younger children reportedly demonstrated a fear of going to the doctor while the older children appeared to fear the unknown. Kubler-Ross, in her wisdom spoke of strength and love.

Those who have the strength and the love to sit with a dying patient in the silence that goes beyond words will know that this moment is neither

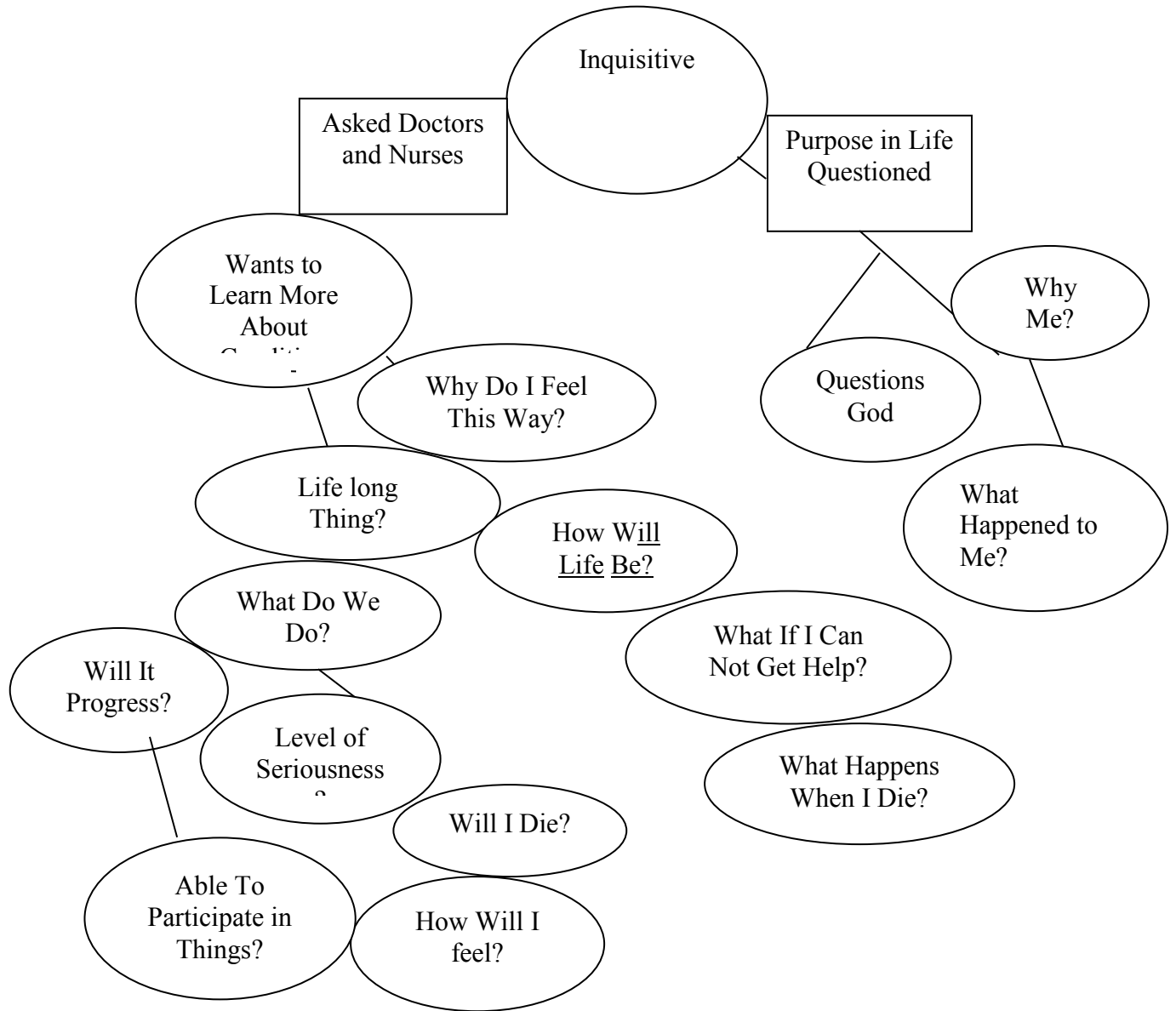
frightening nor painful, but a peaceful cessation of the functioning of the body.

Finally, the age and maturation level of the child as reported by the parents should be considered as to how their child dealt with fear. The older children were reportedly dealing with the unknown while the younger children were worried about appointments with the doctors and nurses. The younger children were worried they would receive a shot from the nurse.

Fear remains a factor associated with adjustment in children with life-threatening illness. Quite often fear is displayed in various forms of acting-out behavior from yelling to screaming, to withdrawing, crying, swearing, etc. There may always be some fear present but if it can be diminished, behavioral adjustment may prove to be less of a struggle and more rewarding to all involved.

Matrix 3

Theme: Inquisitiveness



Theme 3: Inquisitiveness

Five out of six children displayed inquisitiveness by asking questions about their illness.

Barbara, mother of Michael (6yrs.), revealed that her son with brain cancer “never asked a single question.” She went on to say, “We were straight-forward the whole way through and talked to him. He was sort of wise beyond his years. So that is who he is.” Michael has been in and out of the hospital with multiple surgeries and was finishing chemotherapy.

The level of awareness in order to ask questions may be dependent on the child’s cognitive stage and level of functioning as outlined by Erikson and Piaget. Kane (1979) and Kubler-Ross (1983) thought that children who have experienced the death of someone close to them would raise a different order of questions than those lacking such an experience (see Table 1). Michael (6yrs.) did not have that experience and did not ask any questions. This proved out of the ordinary as the other children had some question to ask. Barbara, mother of Michael, reported that her son “never asked a single question.” Glover, Beliveau, and Miller-Thiel (1993) felt it important for family members to realize that just because the child is not asking questions, does not mean that they have none. Processing the information may have to occur before questions can be formulated. Michael was in and out of the hospital so frequently it may have been difficult to finally create a safe place to ask the question.

Kathryn, mother of Peter (12yrs.), stated that her son asked more about his diagnosis the first time he went to the doctor. He asked, “What’s wrong with me”? Instead, he asked more questions when he returned from the doctor indicating the safe space may not have been at the physician’s office. The next questions, according to Kathryn, “How am I going to feel? How am I going to feel, next? Why do I feel this way”? These, of course, were questions that Kathryn was unable to answer at the time. Now, Michael could have misconstrued Kathryn’s answer at the time as she did not know.

Sebastian (17yrs.) reportedly became more inquisitive; thus, altering his behavior in asking more questions. Maya, his mother, reported his questions as: “Is it life-long? What do we do”? He was reportedly still withdrawn and had a hard time accepting the diagnosis as he verbalized how his life may change forever. He questioned God: “Why him”? Maya recalled him saying “I’ve done good in this world [sic]. Why is it that I have this? Why me?” According to the demographic questionnaire completed by Maya, Sebastian (17yrs.) does indeed believe in an after-life and does not believe God is punishing him with this illness (see Table 1). According to Kubler-Ross (1983), this is all about society’s ambivalence about whether or not death is a punishment.

Waechter (1971) discovered that children were found to question the truth about the soul/spirit departing from the body and entering some eternal life. This

message may have been conveyed through organized religion or the family's belief system. Maya, mother of Sebastian (17yrs.), stated:

I remember at the time, as a mom, I was like, you know, I need to be strong for him even though I felt like crying. I said, "Sweety, why not you"? Maybe because I'm religious and spiritual and maybe because God put this on us so we can advocate to help others.

Maya expressed that God had something to do with her son, Sebastian, receiving this illness as if it were a bad gift. Unknowingly, this relates to God choosing for some reason that Sebastian will bear this burden and the family must discover what to do with it. Maya did report on the demographic questionnaire that her son, Sebastian (17yrs.), did believe in an after-life.

Similarly, Barbara, mother of Michael (6yrs.), reported that her son was "an extremely spiritual child" who had these "spiritual relationships." She acknowledged on the demographic questionnaire (see Table 1) that her son is Jewish and believes in an after-life.

He's different than most boys of that age. He's had a personal relationship with God for many years. We are not a family where that's an element. That's just he had out of body experiences before he got sick. He had all these God things going on before he got sick. One time, he was sick and he had stopped talking about God and I said, "You know, you just don't talk about God anymore. Is God still with you? He's like [sic], "Of course, how stupid can you be"?"

Barbara has also referred to Michael as an "old soul." His question appeared rather atypical of a six year old boy. The demographic questionnaire revealed that he, too, believed in an after-life. There may exist a correlation between

inquisitiveness and belief in an after-life. There is nothing to ask if one believes in the will of God. Barbara continued to share:

He turned to my husband. We were eating an apple and he says to my husband, Blaine, "What in the person is like the seed of an apple"? Which is not a traditional four-year-old question. My husband, being a very smart man said, "I don't know, what is it"? He said, "It's the heart". He said, "How do you know that"? He said, "God told me and God's heart turns on and off the hearts of everyone in the world."

These are a few examples of the levels of questioning asked by this six-year-old boy who apparently asked no questions of his mother. It should be remembered that one can ask questions without verbalizing them. Barbara reported that he "never asked a single question." Nothing may be important to question if God oversees it all.

Janelle, mother of Ian (5yrs.), reported that her son asked questions about his physical appearance as his face reportedly gets flushed and red. Ian calls that problem "hot cheeks." Janelle stated that Ian asked about going to the doctor to find out about this problem. He does not appear to have all of the information and that concerns him because his mother does not have the answers now.

Mary, mother of Brenda (14yrs.), also stated her daughter has questions. She said:

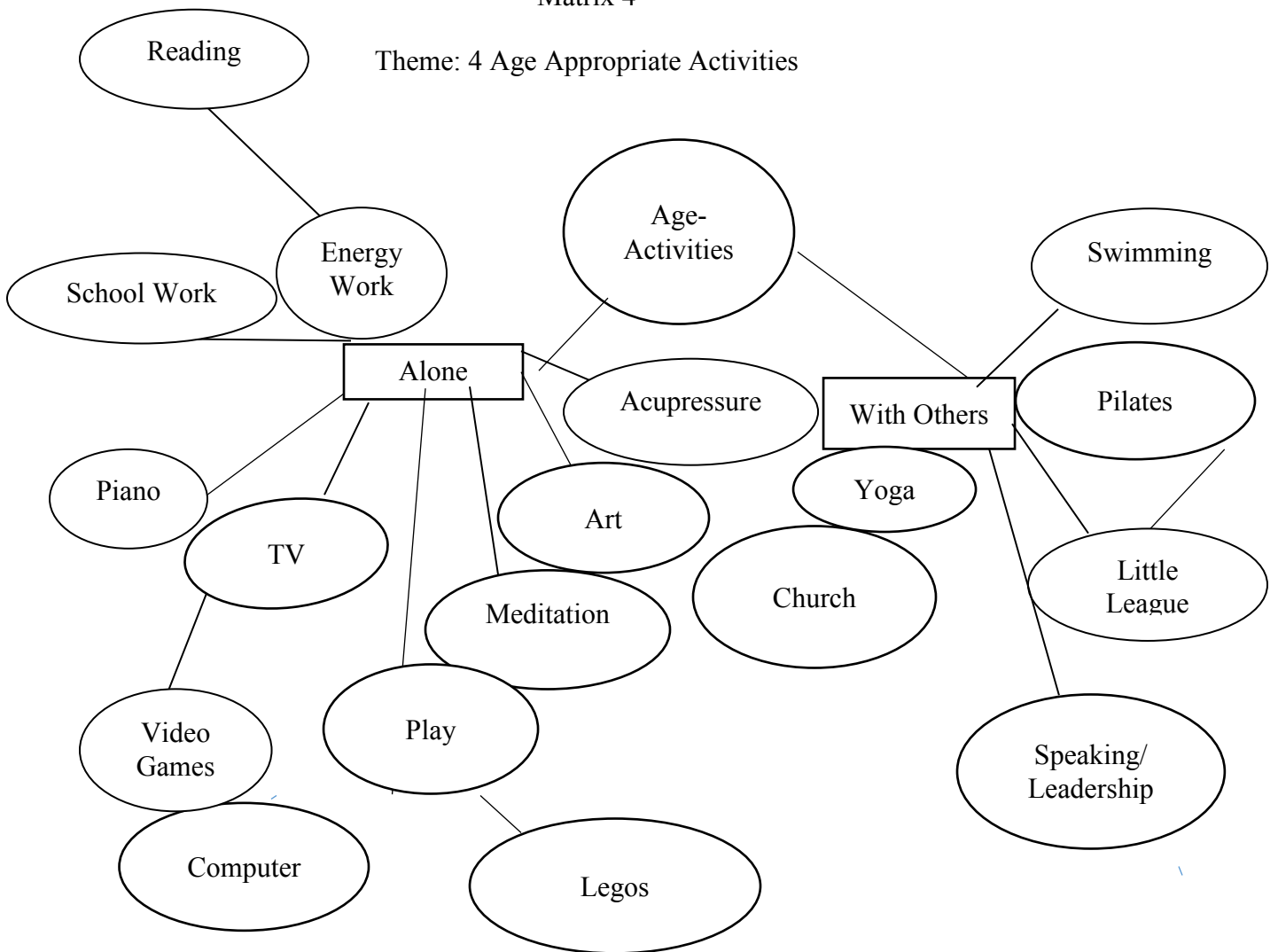
Well, she's had a lot of questions. She's very intelligent. I'm kind of a straight-forward person. So I believe in sharing what I know. I mean, I don't put a bad spin on it. I do come out and tell her the truth as I know it. She wants to know how serious it is. Is she going to die from this? If she dies, what's gonna happen [sic]? What happens when you do? What if she can't get help in time? She is full of questions about it.

The children have been given the straight-forward answers by their mother. Brenda wonders, “Is she going to die from this? Is she gonna [sic] make it through and have a normal life? This displayed a different level of behavior than the younger children.

Finally, the children displayed inquisitiveness in various ways involving behavior adjustment. Cindy, mother of Matthew (2 1/2yrs.), reported that Matthew has not asked any questions about his illness but has asked about the doctor. He said, “Doctor again?” He does realize that he must go see the doctor more often because he does not eat. Specifically, the children illustrated their use of inquisitiveness by asking questions about their illnesses. The level of questioning varied with age as did the content of the questions. This was also due to straight-forwardness exhibited by the parent. Behavior appeared to have adjusted accordingly.

Matrix 4

Theme: 4 Age Appropriate Activities



Theme 4: Age-Appropriate Activities

All of the six children were engaged in age-appropriate activities. Some engaged in activities alone while some shared the activities. These were the subordinate themes with sub-themes following. Although all were engaged in age appropriate activities, some proved much more educational, while being beneficial, than did others. Interestingly, Michael (6 yrs.) with brain cancer did not have an opportunity to engage with others. He was forced to entertain himself by himself so he did not contract any virus or other illness from other children or adults. His mother, Barbara, proved to be creative in an attempt to challenge him. “We brought in an energy worker. We brought in an acupressurist. So he worked with them. He worked with an art therapist.” Kubler-Ross (1983) suggested that when the child can engage in age-appropriate activities such as handicrafts, visiting with the family pet, playing music, drawing or molding clay, to build the child’s self-worth.

Barbara and her husband, Blaine, were financially able to bring in various additional resources to facilitate some rewarding and stimulating activity. Obviously, not everyone has been able to do this and many had to rely on their own innovations to provide activities for the child. Some parents appeared to allow T.V. watching if it was entertaining to their children. No indication was given as to particular shows watched other than Michael. His mother mentioned that he liked video games and America’s Funniest Home Videos. He also liked

the Marco Brothers. Michael could not be around people very much as he was immune-compromised.

Barbara, mother of Michael, wanted to ensure he was challenged so she bought him some Legos. “He loves Lego. He’s a Lego king...the number of people who brought Lego to the house, the hospital, etc. because he was the Lego king.” If you can’t bring the child to the activity, bring the activity to the child.

Michael (6 yrs.) was frequently in the hospital setting due to surgery and chemotherapy. Kubler-Ross (1983) believed that the children in a hospital setting usually mature faster and develop a greater depth of understanding. His mother, Barbara, commented “and they would just talk and do art projects together and talk.” This is a way the child can express his feelings in a safe environment. She continued to say that Michael is “different than most boys his age. He’s an old soul.”

Similarly, Peter (12yrs.) has cancer. Kathryn, his mother, stated that he loves sports. Now that he can no longer play due to his weakness, Kathryn informed this researcher that he can “pet the dog a little bit. He used to romp with the dog.” His behavior had to be adjusted as he had little energy. Peter could be encouraged to make a dog house out of Legos and paint or draw a dog park with himself and the dog. He may choose to share some emotion during the activity to help understand how he is feeling.

Maya, mother of Sebastian (17yrs.), also reported that her son had stopped doing sports after he had his second seizure and received the diagnosis from the physician in the emergency room.

Maya informed:

He was very active throughout childhood, junior high, high school. From lacrosse, soccer, the police explorer program, karate, jujitsu. Upon getting diagnosed, he had stopped doing all physical activity.

This was his choice stemming from fear. He reportedly was afraid to continue sports because that might provoke a seizure. Maya reported that he started getting involved in organizations instead:

Being the Vice President of the Political Science Club, the President of the political Science Club, the President of his class... So more or less he stopped the physical stuff and got involved more with, I guess, [sic] the speaking, leadership type [sic]. He's involved with the clubs, kind of [sic] making awareness to the school and other places that there are illnesses like this.

Jampolsky (1979) reported that it may be easier for children to talk with other children than with adults. Peter was at a similar cognitive stage of development as Brenda (14yrs.). Erikson (1963) believed that girls mature faster than boys; however, Brenda left sports and went to the piano. Sebastian reportedly engaged in meditation, yoga, and Pilates. Kubler-Ross (1983) even mentioned creative visualization activities such as visualizing the hurt under a pink light symbolizing healing.

Matthew, (2 ½ yrs), plays by himself, not with the other children. Cindy, his mother, mentioned that he plays with a word game but does not like activities that produce noise as he is sensitive to the noise. This may be physical as well as emotional and may have something to do with microcephaly. This creates a problem with the socialization process in learning to play with other children.

Mary, mother of Brenda (14yrs.), has been a teacher for many years and likes to use various modalities to help her daughter engage in age-appropriate activities. Mary revealed that Brenda did engage in age-appropriate activities. Mary revealed that Brenda did engage in sports but had to change her behavior when diagnosed with chronic asthma:

She can't do any kind of sports which would cause her trouble catching her breath. She does the piano and of course work {sic}...She reads a lot and watches T.V. and plays the video games like any other 14-year-old child.

Similarly, most of her activities were by herself. Mary may have been watching T.V. at times but there did not appear to be any engagement with others while watching the T.V. Mary never revealed that she thought Brenda watched too much T.V. Sometimes it is necessary to understand the belief and attitude of the parent/caregiver in order to comprehend what actually occurs. Similar to Sebastian (17yrs.), both are teenagers and both altered their behavior from physical activities to groups or events in his case, and piano and reading in the case of Brenda. Sebastian still continued the socialization process at some level. Mary shared this about Brenda: "We do have a few groups that we go to meetings

of major organizations that have activities. They have picnics and different events that we go to [sic].

Mary, when speaking about Brenda, usually uses the pronoun “we.” This implies that she accompanies her daughter, Brenda (14yrs.) to activities. This does leave little time for Brenda to be alone with her friends. Grollman (1996) believes that just being there with the child is important.

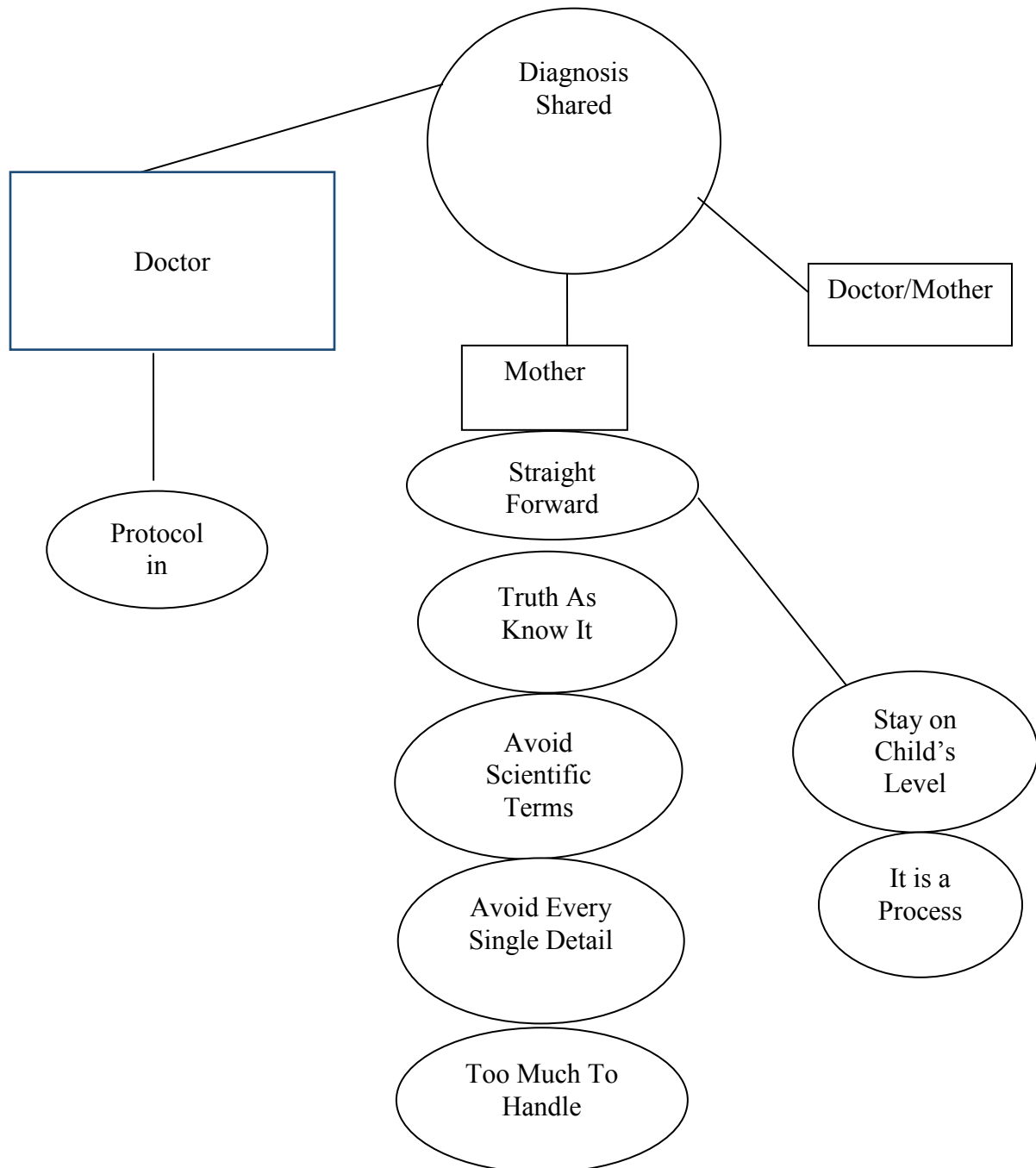
Janelle, mother of Ian (5yrs.), reported that since her child “passed out” on the playground, he has been quite reluctant to engage in physical play. “He’s less likely to get rambunctious than he normally would do [sic].” Janelle has instilled hope in her son, Ian, who is being examined for childhood leukemia. “We’re looking forward to the spring, hopefully, that he would be signed up for Little League. In the summertime, he does take swimming lessons because they are good for his asthma.”

Kubler-Ross (1983) suggests that adults must instill even a small amount of hope in children. Most of the change in behavior began after the diagnoses were suspected and gradually shared with the children. Other parents in this study also revealed that they saw a big change in behavior, too. There was a shift from the physical activities to activities that could be accomplished alone. The shift in behavior also included the teenagers, Brenda and Sebastian, joining groups, organizations, and attending events to replace time spent in physical activities

such as sports. Sharing the diagnosis (even without the prognosis), did cause behavioral adjustment to be initiated.

Matrix 5

Theme: Diagnoses Shared



Theme 5: Diagnosis(es) Shared

Of the six children, there was an attempt to share the diagnoses with each, depending on their maturity and what each was able to understand. Either the doctor, the mother, or both shared the diagnosis. These are the subordinate themes followed by the sub-themes. Cindy, mother of Matthew (2 1/2yrs.) shared part of the diagnoses with her child. She shared what she thought he could understand; failure to gain weight. This reportedly became too complicated to explain microcephaly to Matthew. Another parent, Janelle, mother of Ian (5yrs.), explained the diagnosis of chronic asthma to him but did not reveal the possibility of leukemia as she felt the results were inconclusive and decided to wait.

The parents wanted and needed the help of the doctor and/or nurse to explain the situation to the child and help the child understand the diagnosis. Michael (6yrs.) personally informed his parents when he went out of remission and believed he would grow up having four professions and a set of twins. There may exist a very fine line between denial and hope which may need to be considered. Kathryn, mother of Peter (12yrs.) stated:

We talk to a doctor and a nurse on a couple occasions. Then he came in and started asking a few more questions at a time...I remember the first time we talked to the doctor he asked me more about his diagnosis or "what's wrong with me"? So when he did that, we went online.

An informed approach to understanding how the diagnosis/prognosis impacts behavioral adjustment can indeed help families. No caregiver in this

study revealed to their children that they indeed could die from their illnesses. Obviously, the older children did have questions regarding the possibility of death but not much discussion ever took place about this during the questioning. Barbara, mother of Michael (6yrs.), reported that Michael always told her what was going on with his body. He appears to be quite an extraordinary child at six-years-old. When he was in a coma, Barbara was unsure if she told him of the diagnosis/prognosis. This is when the parents were informed and she wanted to be straightforward with her son. Barbara stated:

He knew he had cancer. In fact, when he relapsed, he was the one who told us that he relapsed. He knew his body very well, He is an extremely spiritual child. They put him in a medically induced coma. So he basically is in a coma right now. So we don't know what he knows. We tell him but we don't know what he hears.

Barbara never mentioned how she was initially informed of Michael's cancer diagnosis other than the fact that he informed her himself. "We were straightforward the whole way through and talked to him. He was sort of wise beyond his years. So that's who he is [sic]. He has got these spiritual relationships.

Kubler-Ross (1983) suggested that this sense of spirituality strengthens as the child looks forward to being reunited with loved ones. According to the demographic questionnaire completed by his mother, Barbara, Michael had never experienced the death of a loved one. He had no experience of death (see table 1).

Perhaps Michael's sense of spirituality strengthened while experiencing all of the medical problems. Spirituality did change as it apparently grew stronger and his parents were confused as Michael stopped talking about God, another behavior change. Michael was also the child who never asked a question. He was the child that was regarded as highly intelligent by his mother.

Maya, mother of Sebastian (17yrs.), revealed that she had nothing to do with sharing the diagnosis with Sebastian. She reports:

Actually, it was at the ER visits...after his second seizure. It's protocol. The doctor said that they identified him as having epilepsy. So it was at his second visit to the ER that they diagnosed him and they told him right then and there...He had no response either way. It was more processing when he got home. I spoke to him about it.

Maya shared that Sebastian was concerned and withdrawn still [sic]. "He had a hard time accepting it." It appeared that when she was present or was informing her child, the child's behavioral adjustment was not as negatively impacted. Perhaps this results from the level of trust between the child and his mother. This level of trust has a history. There was no level of trust established at this time among Sebastian and the doctor and nurse. It would be unfair to assume that all children in any particular psychosocial or developmental stage cannot comprehend information regarding the potential outcome of their illnesses. Maya and Sebastian reportedly had conversations about a possible shortened lifespan for Sebastian.

Cindy, mother of Matthew (2 1/2yrs.), was able to make an impression on her son that he has not been gaining weight because he was not eating. He is smaller than other children his age and it is very serious when he does not eat his food. She helped Matthew to remember the feeding tube that had recently been inserted because he was not eating his food. It was removed but he is still not gaining weight. Matthew reportedly understood this component of his illness and diagnosis. Cindy reported that when she gets ready to take him to the doctor, he expresses fear just knowing he has an appointment. He says, "Doctor again"? She reminds him again of the reason and Matthew replies, "Okay." It doesn't end with that statement. He questions, "Why again"?

Matthew has occupational therapy which involves eating so sometimes he eats and other times he does not eat his food. Cindy discovered that she may not have an accurate estimate as to whether or not her son understands the situation leading to his diagnosis. At times she simply feels lost.

Even Janelle, mother of Ian (6yrs.), stated, "Well, I think he's a little bit young to realize what a diagnosis might mean. He's not aware of what a diagnosis means." She apparently has talked herself into this belief for lack of any other understanding of the situation. Cindy and Janelle, mother of Ian (5yrs) reported:

You share as much as you can on that level. They're little. They're five. You share with them that we're still in the process of finding out what's wrong. I don't share with him scientifically any medical things or anything about the test. We're going to find out if it is leukemia...I just briefly am saying, we are going to find out what's wrong and if we can fix it. I'm not going to get

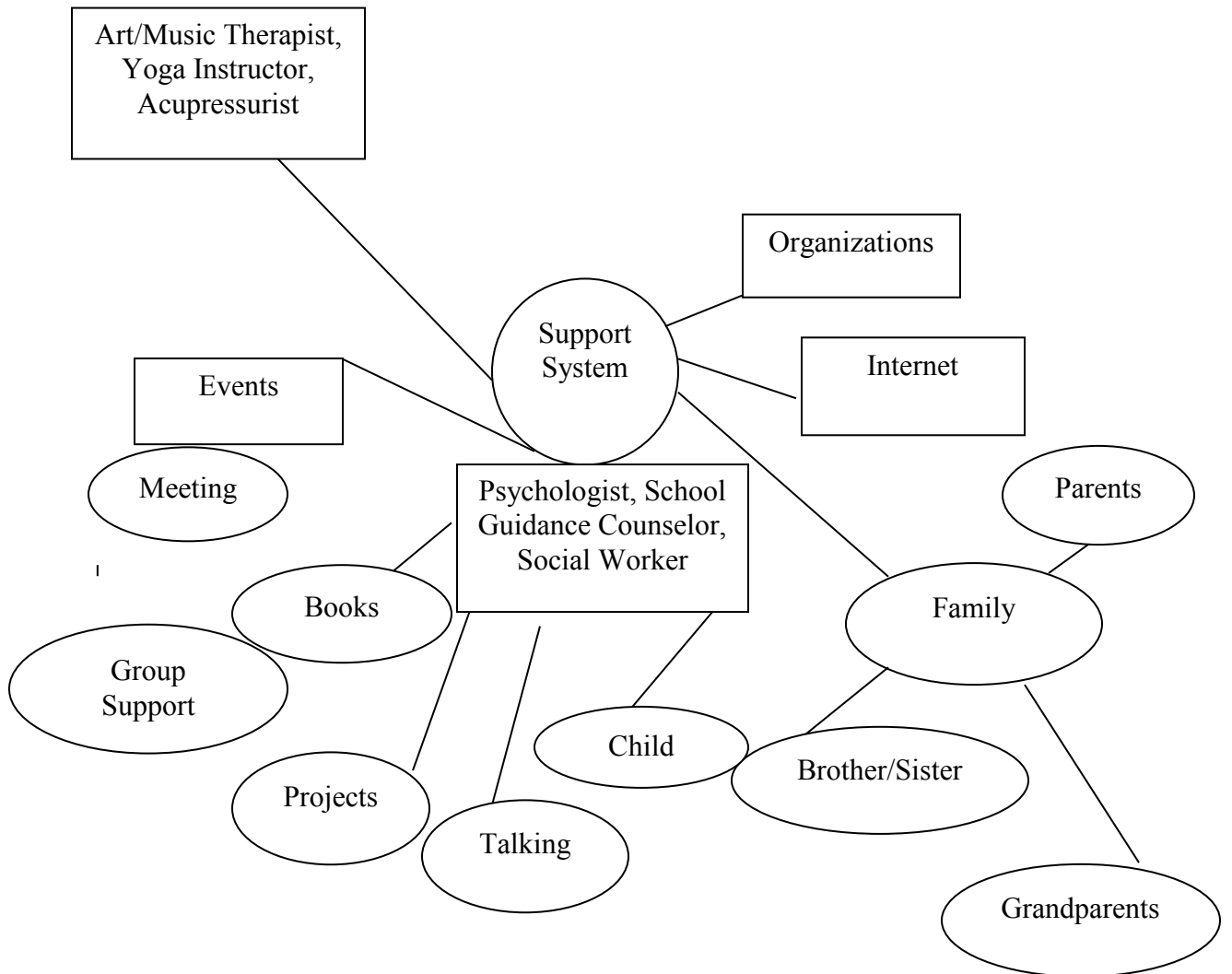
involved in every detail with him exactly what it is because it's too much for him to handle at that age [sic].

Finally, each parent involved in this study reportedly feels they "know" their own children. "How" and "what" was shared depends on the parental value system, truth, sensitivity, and their own level of anxiety. When the doctor, nurse, and parent were present, it provided the children an opportunity to ask questions while getting reassurance from the mother so it may have been a safe environment at the time. When the child is informed without the mother present, as in the case of Sebastian (17yrs.), it proves difficult for the mother to know exactly what and how something was said and what questions he asked about this information.

Prognosis was not included in this theme after the researcher coded the interviews. It does not appear that most parents shared any prognoses as the diagnoses were difficult enough to handle and to share, some not in entirety. All parents reported an attempt to put the information on a level that could be understood by the child, excluding Sebastian who was informed during his second ER visit. Specifically, until something was verbalized by the child or the ER physician, it was unclear if and how anything would be communicated to the child. Simply by hearing a diagnosis, the behavior of all the children changed.

Matrix 6

Theme: Support Systems



Theme 6: Support Systems

All mothers revealed support systems to be in place. This researcher discovered some children had more beneficial support systems depending on their treatment goals, accessibility, insurance restrictions, duration of time, and personal values of the families. Subordinate themes were based on services provided (see Matrix 6).

Barbara, mother of Michael (6yrs.), reported that her son received support through the school system. A teacher was brought in to the home. Barbara commented that her son really did not want to work with her but did not reveal what ultimately happened in this situation. As Michael had brain cancer, he was in and out of the hospital with multiple surgeries and chemotherapy. She stated:

Brought in a therapist and we had him working with an energy worker and acupressurist. He doesn't like to be called a healer. He would work on his auras when we had to switch ventilators. He was the one who guided the ventilator so Michael's energy would be smooth. We hired a child psychologist who did art therapy. Who worked with him because we thought that it was important to have him work with somebody other than just his parents [sic] They did art projects together...books and talking about a lot of things.

It appears that "talking about a lot of things" may have been the most beneficial component because Michael spent most of his time in isolation due to immune-compromised status. Barbara and her husband, Blaine, were able to financially secure this extra help with specialists. They attempted to take advantage of everything possible to help their child and were able to pay for these

services. Of all the children in this study, Michael was most critical in his medical condition. He eventually was placed in a medically induced coma which is where he was at the time of the interview. Socio-economic status did benefit Michael (see Table 1).

Michael may have had an easier time adjusting because his parents were aware of different factors impacting his emotions and behaviors because he informed them. His parents even discussed how they could help him when he became angry. He turned around and stated, “Remind me to think about the golden sun and the beautiful blue sky.” He also commented, “God’s heart turns on and off the hearts of everyone in the world.” Michael apparently has such a deep sense of spirituality that he was able to somehow face all of his challenges as each one came in his direction. Michael is Jewish but his mother reported that religion was not “an element for their family.”

Cindy, mother of Matthew (2 1/2yrs.), reported MediCal insurance which provided the special needs for her son. These special needs included speech therapy, occupational therapy, and Regional Center. Cindy stated:

Occupational therapy...they help him with motor skills and his mouth. They help him eat. His speech...they teach him words. They see how he interacts with others. His school I guess, just how he reacts with kids, learning social skills [sic]. I’ve seen improvement in speech. He puts three words together. He says his own little sentences. He says a little bit more words [sic]. Occupational therapy...it’s the same. It’s involving his eating. It’s still the same. He’s good. Sometimes he doesn’t eat.

Cindy reported that was happy with the services but due to socio-economic status, the services were short-lived with minimal visits. Matthew apparently was not receiving counseling or psychological services independent from the Regional Center. He was getting a teacher to come to the house and “just play with him and teach him words. It was like a mix for an hour. That was once a week but that stopped.” Cindy regarded it as two separate things which were playing and teaching of some words.

Matthew reportedly receives Optima through Regional. The mother only knows that this service “helps kids.” “It’s like therapy” was the only explanation given about this service. That reportedly stopped when Matthew was put in school. He reportedly “is around other kids... That helped him a lot.”

Cindy mentioned no other forms of support. Her mother, grandparents, sisters, and aunts reportedly have been a constant support to her according to her aunt who was nearby for the interview. Matthew reportedly is showered with love and was only one of two children having both parents at home with him.

Grollman (1996) constructed guidelines for speaking with children having life-threatening illness. These guidelines suggest talking with the child in a language he or she can understand. Matthew is learning both Spanish and English which may be a reason why he has trouble putting words together in a sentence. Other guidelines from Grollman (1996) include trying to confirm in one’s own mind whether the child understands, explaining what caused the illness and how it

started, allowing time for the children to express their own feelings, encouraging a positive approach, and reassuring children that even though they have an illness, they are still loved.

Maya, mother of Sebastian (17yrs.), reported that Sebastian found an epilepsy network by going on the internet and trying to learn more about his illness. He and his mother did that together so a joint effort existed. This was reportedly his idea as he wanted to become more educated about his illness and learning triggers to avoid. Maya reported excellent health insurance for her son. Sebastian, however, was reluctant to attend counseling services even though his mother is a social worker. He did not want to see a psychiatrist because that would mean “crazy.” There still exists that stigma. Sebastian needed to do so to be prescribed some medication for his anxiety. He did go to see a neurologist who currently is treating him. He did stop seeing the psychiatrist after three months of occasional sessions. Sebastian reportedly employs stress management by taking yoga on occasion, doing Pilates, and engaging in a lot of meditation. He reportedly has a section in his backyard and has planted plants to enable him to have a garden. Horticulture reportedly is his interest, too, and has been a great way to work outside in nature and forget about stressful events. This was once recommended by a social worker.

Sebastian reportedly went through a denial phase but gradually worked his way to acceptance. He reportedly has support from his mother, brothers, father,

grandparents and aunt. He enjoys learning about his disease and attends events and meetings on a regular basis.

Kathryn, mother of Peter (12yrs.), reported that he will be meeting with a social worker. His other support has been with health-care professionals from the hospital where he had surgery and chemotherapy. Kathryn reported that he has little family support as they have few relatives. She stated that the doctors and the nurses have been quite supportive while explaining the process and trying to meet their needs. She does feel much more can be done to help her son, however. This evokes anger and frustration at times because there needs to be more services for the children.

I really am still appalled. I just don't feel like there's enough support systems out there. Maybe this is a government thing. You probably can't do anything about it. I feel like children and adults, as well, with these kinds of diseases need more support, even financial support...I wish there was more support.

Mary, mother of Brenda (14yrs.), placed emphasis on the family and how much everyone loved Brenda. She stated:

We do have a few groups that we go to, meetings of major organizations that have activities. They have picnics and different events that we go to [sic]. She makes friends and sees lots of people with the same problem.

Similarly, Janelle acknowledges her family such as grandparents, aunts and uncles, and friends being a big support to Ian (5yrs.). Janelle mentions that they utilize the guidance counselor at school and the social worker at the hospital. She and her son found an asthma support group meeting in Ian's school, also. Janelle

has shown that she is quite resourceful. She, like Mary, mother of Brenda (14yrs.), is heavily involved in her socialization and does many activities with her daughter.

Teachers, school guidance counselors, and social workers at the hospital appear to be utilized to some extent. None of the parents mentioned, were reportedly involved in their own therapeutic sessions. The focus of this study was child-centered with the family being only one component in the examination of factors impacting the adjustment of children with life-threatening illness.

CHAPTER FIVE: DISCUSSION

Introduction

This study explored the research question: What factors are associated with adjustment in children with life threatening illness without brain impairment from the perspective of the parent/caregiver. The subjects of the thematic analysis were five boys and one girl all under eighteen years-of-age. The information was obtained during an interview with each mother sharing their perspectives about their children having life-threatening illnesses. Resulting themes that emerged were organized and categorized. Similarities were observed and analyzed in the search for factors the children shared with each other that affected their behavioral adjustment.

Themes that emerged from the interviews were isolation, fear, inquisitiveness, age-appropriate activities, sharing diagnoses, and support systems. Subordinate themes emerged from each of the above themes. At the conclusion of the interview, the mothers completed a demographic questionnaire (PRQ). The questionnaire, illustrated in Table 1, contained a few salient themes which could be addressed and used for future research.

A goal of this Researcher was to gain a qualitative sense of what the parents/caregivers viewed as factors affecting behavioral adjustment in their child

with life-threatening illness. The qualitative results focused on main themes emerging from the data.

For children newly diagnosed, this information may be overwhelming and may affect behavioral adjustment. It should be noted that this adjustment may have a positive or negative affect on the child. The purpose of this study was to find out from the parents/ caregivers which factors were associated with adjustment so there would be a better understanding and additional assistance could be given to the child.

After the coding process was completed, a matrix for each theme was developed to help visualize and determine subordinate and sub-themes. The ages of the children ranged from two-and-one-half years-old to seventeen-years-old. The caregiver of each child for this study was the mother in all six cases.

Isolation was the first theme that emerged from the interview. Isolation ranged from being voluntary to involuntary. It also ranged from being emotional to physical. For example, one six-year-old child was physically placed in isolation at the local hospital. Any close relative wishing to visit or any medical staff had to dress in a gown and mask to protect the child from outside infection. This child had no say as to how the treatment was being handled by staff. On the other hand, one fourteen-year-old child immediately stopped playing sports upon hearing the diagnosis. That child voluntarily stopped the activity and went home. She then resorted to reading and playing the piano. This was a choice she made while not

being advised to do so by the physician or by her mother. This choice was completely voluntary.

Isolation can be emotional. For example, one child had undergone brain surgery and had just finished chemotherapy. He reportedly did not have a lot of energy. He just did not want to be around anyone because he did not think he was “normal.” Reportedly, he stayed at home engaging in activities in his room. Another child reportedly would get “hot cheeks,” according to his mother, while playing on the playground at school. This child was being tested for childhood leukemia. His mother reported that he simply stopped playing those sports on the playground and resorted to doing activities in his room instead. He physically isolated himself because he did not like his peers seeing the “hot cheeks” while engaged in physical activity.

Isolation may be voluntary and emotional, or involuntary and physical along with other combinations. It depends on the child and what that child may be experiencing. It should be noted that many emotions may be surfacing concurrently. These factors affect behavioral adjustment and changes in behavior, be they emotional or physical. All six mothers noticed that their children’s behavior changed after the diagnosis was revealed. Most children were hesitant to engage and their behavior became more introverted. These children may have recognized such a sense of lack of control over their diagnoses that they just needed to be alone. Indications of the change in behavior were illustrated by the

child dropping out of sports, choosing activities to engage in at home, and playing alone. Changing activities, in itself, does not indicate negative adjustment. For example, one girl stopped playing sports and went to the piano. Another boy stopped playing sports and eventually joined clubs and organizations. The common thread appeared to be an issue with their self-esteem being threatened. They were afraid of what would happen to them in the future. The children did not know if they would ever be “normal” again, as reported by their mothers. The two and one-half-year-old became sensitive to noises and went to whatever place was quiet. The child could not even tolerate someone talking. He just played alone. Again, most of the children became hesitant to engage.

The effects of isolation may not initially be shown, may not be shown at once, or may never be shown. Isolation being experienced in the hospital for safety reasons is very important for the child; however, the emotions that may result may impact behavior negatively if it results in acting-out or withdrawal. With these children, assessing behavior could be difficult. For example, it may be hard to distinguish between lethargy due to recent chemotherapy treatments and depression. It may be difficult to determine if the child is isolating because he/she does not feel well or isolating due to diminished self-esteem. These children can become “lost souls” if there is not a support system in place.

Of equal importance, is the caregiver’s sense of self. This refers to taking note of one’s own fears and anxieties and how this may impact the child. Children

are often very perceptive and quite often read the nonverbal communication expressed by their caregivers. This study illustrated the close bond that has been established between the children and their mothers. Mothers who were interviewed expressed a deep concern about the well-being of their children and had been physically present and available to them.

Fear was shown to be manifested in various forms. The youngest child became afraid of noise. When he heard noise, he went to some place quiet as he was afraid. He was also afraid of doctors. Due to his level of development as expressed by Erikson and Piaget, his issues became more concrete and less abstract.

The teenagers in this study expressed fear of the unknown. They were afraid of poor health in the future and wondered what course of treatment would be available for them. There appeared to be self-talk. For instance, one child wondered what was wrong with him, why this was happening to him, and what if he could not get help in time. Another questioned why she was getting sicker and wondered the seriousness of the illness. Most of the children questioned the possibility of having a normal life in the future and how they would feel next. Reportedly, they lacked control over their own destinies as it all seemed to revolve around health issues. There existed a lot of questions about their health and quite often, their mothers were unable to answer their questions because they did not know the answers. Zebach et al. (2002) believed that children are likely to

isolate and feel alienated when adults do not openly engage in discussions with them. The children had no way of knowing if their mothers just were not telling them the truth or simply did not have the answer. Isolation may have caused fear and fear may have also caused isolation.

Through the interview process, the mothers, excluding the youngest child's mother, reported that their children had an awareness of death and some even expressed fear of dying. One child wanted to know what would happen next after death. The children all reportedly were aware that there was a possibility of a shortened life-span. This apparently was the ultimate fear associated with feelings of helplessness. As children mature, they become more aware of death. This relates to their illness causing behavior to change when they become more fearful and anxious.

Most mothers in this study commented that they have been quite straightforward with their children. The lack of having definite answers from the mother did evoke fear in the child. Individual behaviors reportedly changed in order to cope with fear. Some children chose isolation as a defense mechanism to cope with fear. Armstrong-Dailey and Zarbach (2001) suggested that anxiety levels may decrease as information is assimilated by the children. Fear has been associated with lack of knowledge. Mothers in this study shared that the diagnosis was relayed to the child by the doctor, by themselves, or by both. No mother communicated that there was any discussion by healthcare professionals

following presentation of diagnosis. The child appeared to have been “left in the dark” which can cause negative behavioral adjustment due to fear and anxiety.

The two youngest children were found to be fearful when the actual doctor appointments were made by their mothers. Mothers did not appear to be aware that this act alone evoked fear in their children. Children reportedly were afraid of the doctor largely due to their past experience of getting shots. They remembered that when the doctor finished his exam, the nurse came in and this was when they received the injection. This was assimilated due to past experience. When the parent is aware of the fear occurring, the parent can then engage in a discussion about the purpose of the appointment and what will likely happen while in the Doctor’s office. This may help relieve some of the fear that appears to manifest until the actual appointment.

Kubler-Ross (1983) stated that children are not so much afraid of dying as they are of abandonment. De Spelder and Strickland (1996) went on to include separation from the mother figure as another fear. This certainly is indicative of attachment theory and the anxiety and fear caused within the child if he/she feels abandoned. Reassurance that the parent still loves the child may be helpful during this difficult time (Bertoia, 1990). The child may be experiencing a myriad of emotions and may just need this reassurance.

The maturation level of the child certainly contributes to determining how the child may express emotions in terms of behavior. Children require a sense of

security and this may be supported if the parents promote an open-door policy with their children. Again, parents in this study reported little acting-out behavior even though the children felt anxious or fearful. This may have occurred because the parents were physically present and straightforward with their children.

Most parents reported that the children received a one or two word diagnosis and the doctor really was too busy to go in to much of an explanation at the time. Piaget and Erikson both agreed that the cognitive stage of cognitive functioning is important for the level of awareness in a child. Consequently, an age-appropriate explanation of a diagnosis by the physician with the mother present may be appropriate and very much needed by the child. This would be the time that the child could express his/her inquisitiveness and ask desired questions. Frequently, the child and parent may be in shock and unable to think about questions other than, "Will he/she live?" Kubler-Ross (1983) thought that children who have experienced death by someone close to them would raise a different order of questions. This is the justification in including this above question on the demographic questionnaire. This did prove accurate for one of the children in this study. Only about half of the children in this present study have experienced death in someone close to them. This could be a result of their young ages.

When children ask questions, the parents become more aware of what is on their minds. Perhaps one of the greatest realizations is the understanding that just because a child does not ask a question, does not mean he/she does not have a

question. Frequently, we may wish to assume that children tell us what is on their minds (Glover, Beliveau, and Miller-Thiel, 1993). However, the youngest child in this study has only been able to put two or three words together. Yet, we know that child said, “Doctor again”? The parent reported that she always needed more time asking the child if there was an understanding of what she just said to this child. It would also appear that a safe space for the child is needed for the child to formulate and ask the question. This may not occur if people are around, in a hospital room, or other places.

It seems important to realize that all children do not ask questions at the same time. Some may ask right away, while others may need some time to think about it. Children, as adults, ask some questions that have no immediate answers. It is part of that unknown area that adults may be hesitant to discuss. Mothers did report that the children in this study were found to ask more thought-provoking questions while they inquired about their illnesses. It appeared that the inquisitiveness helped them feel more comfortable. The level of questioning, of course, varied with age as did the content of the questions. This also may have resulted in the straight-forwardness of the parent when talking about the diagnosis.

It was reported that the older children questioned their purpose in life after hearing the diagnosis. One child questioned God while another had a very close spiritual connection to Him. For a brief moment, it seemed as if they were

wondering if the illness was a punishment for some wrong doing but no child reported this as a factor either in the interview or the demographic questionnaire.

All of the children in this study were reported to be engaged in age-appropriate activities, some more advanced than others. It was reported that frequently before diagnoses, the children were engaged in sports or other physical activities. Once the diagnoses were revealed, the behavior changed and they began engaging in more activities that could be completed alone. This may have been a result of isolation leading to fear. The behavior changed and the child became withdrawn.

One parent in this study had the financial resources to bring in various forms of support such as an energy healer, an art therapist, a teacher, and an accupressurist. This was an exceptional opportunity while in isolation at the hospital. These forms of support were helping the six-year-old with brain cancer.

Many of the children did continue to visit with the family pet, play music such as the piano, draw, and do handicrafts: these are consistent with the recommendations of Kubler-Ross (1983), who suggested that such activities can help build a child's self-worth. These various activities may be more readily available if a child is hospitalized as various departments have been organized to take care of the needs of the patient. This may prove more of a challenge should the child be at home and if resources there are limited. The caregiver would be responsible to provide these extra services as well as maintain dressing the child,

cooking, administering medications, and the like. This could all prove quite challenging for the caregiver.

All of the children in the study reportedly watched television. Some may watch educational shows and others cartoons. One liked videos while all enjoyed video games. All of the above activities have been known to facilitate behavior change. While fear and anxiety may be present for a short time, the child might be engaged in laughter and fantasy. Children, as adults do, often get lost in the fantasy of all the television shows. Television can be thought-provoking and stimulate creative energies in the spirit of make-believe. Television can evoke laughter which has been proven to be very beneficial.

As previously mentioned, one set of parents sent in an energy healer, art therapist, and acupressurist to assist their son with activities. One teenager who withdrew from all sports joined clubs, continued to practice meditation, took a yoga class, and occasionally did Pilates. Both teenagers in the study started to attend events sponsored by organizations involving their particular illness. These would certainly appear to be examples of positive behavioral adjustment.

Age-appropriate activities are frequently engaged in with others but some may be enjoyed alone. Perhaps a balance of the two is desirable if the opportunity exists. In this current study, this opportunity did not exist for all of the children as one child was in isolation. Sometimes in medical isolation, it is not always possible to have a healthcare professional or parent in the room. Kubler-Ross

(1983) believed that children in a hospital setting usually mature faster than children home-based and have a greater sense of understanding than children at home. Perhaps this is due to the amount of time the individual spends with healthcare professionals and there exists so much of an opportunity to learn from them. The mother of the boy in isolation reported that he was an “old soul” and also “so intelligent.” That same mother also reported that her son’s questions were not those of a six-year-old boy. According to Kubler-Ross (1983), she believed that children in a hospital setting had higher levels of intelligence than ill children living at home.

Jampolsky (1979) reported that it was easier to talk with other children than with adults if you are a child. Children frequently say what is on their mind and share their feelings openly. They have been known to understand each other at a different level than that of an adult. When the child is only around an adult and does not have the opportunity to talk with peers, that child may become quiet.

Many younger children have to be taught how to play with other children. They may need encouragement and socialization skills. One of the mothers of the two and-one-half-year-old child reported this process. Her child did not know how to relate to other children; perhaps, because he was an only child and lacked playmates. Being the only child or birth order was not discussed in the interview. After reviewing the demographic questionnaire, birth order did not appear to be significant as reported by the parents.

Parents of children in this study appeared to all be physically present for their child. This certainly helped with positive behavioral adjustment. They attempted to instill hope which is extremely important as noted by Kubler-Ross (1983). One mother spoke of enrolling her son in Little League and also swimming for this summer. Her son may have hoped that he would be healthy by summer and may have become less fearful and less anxious as a result.

All mothers were involved in sharing the diagnoses with their children, excluding the one mother who did not have that initial opportunity as her seventeen-year-old son was informed by the ER physician. This may not be the most appropriate way to handle the sharing of diagnoses. At least, the other mothers were physically present, providing their children some sense of security. The seventeen-year-old boy who was informed of his diagnoses in the ER, reportedly did become emotional and apparently was quite fearful at the time the diagnoses were revealed. He was informed he had epilepsy and a seizure disorder. It may prove more beneficial for either the mother or the mother and doctor to share the diagnosis with the child as a greater level of trust is likely to exist when the mother is present. Also, questions could be asked with the doctor present and a discussion could ensue. There may need to be a special appointment scheduled for an additional discussion regarding the treatment plan and prognosis. Some parents revealed that they were informed of the diagnosis in passing with little time to even ask a question.

The mothers in my study stated a need to look towards the future. When the diagnosis was released, it appeared that both the mother and the child began the various Stages of Grief: denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1983). The mothers and the children did not exhibit anger or bargaining while in contact with this Researcher. Only one child was recently diagnosed, so it appeared that they may have already had the time for anger and bargaining. The parents of the six-year-old boy had reported acceptance of the situation but the child was still in the denial stage. He spoke of having four professions and a set of twins when he “grows up.”

When conducting this interview, a question was asked about sharing diagnosis/prognosis. This researcher had to separate the two questions when analyzing similarities because parents reported that they did not share a prognosis. The parents of the six-year-old boy were unsure if they shared the prognosis as they continued to talk to their child when he was in the medically induced coma. According to prior research, caregivers of children with life-threatening illness frequently underestimate the child’s awareness of death. This child, presently in a medically induced coma, was the child who actually reported to the parents that he came out of remission from the cancer. His mother reported that he was highly aware of his body. It was hard to assess his level of awareness as he remained in a medically induced coma.

Kubler-Ross (1983) suggested that the sense of spirituality strengthens as children look forward to be re-united with loved ones. This same six-year-old boy was reported by the mother to have a special relationship with God, as he was reportedly quite spiritual. The mother implied that this may have been the reason her son had such a positive behavioral adjustment since the diagnosis. It appears to this researcher that the parents also tried to make the adjustment as positive an experience as possible with the advanced therapeutic interventions sent to the hospital when the six-year-old child was in isolation.

The mother of the seventeen-year-old boy who was informed of his diagnosis by the ER physician reported that he really had a hard time accepting the diagnosis of epilepsy/seizures. She wished she had been present. She also reported that she worked at the hospital and stated that sharing a diagnosis or diagnoses in the ER was hospital protocol. Her son reportedly was negatively impacted by this experience and this did cause him to have many questions, be fearful, and to isolate for a time. It also caused him to be fearful when going to bed as his seizures were reportedly nocturnal and he was afraid of not awakening due to a seizure. He never returned to any sports. The manner in which the diagnoses were presented may have negatively impacted the child's behavioral adjustment. His mother mentioned that her son felt safer when she was around due to the level of trust. The more children are aware of themselves, others, and their environment, perhaps the less likely they are to have difficulty in behavioral

adjustment. Demmin (1986) believed that it was very possible that a child's concern over death is more of a function of cognitive level and age than of an emotional response.

It proved difficult for the mother of one small child to ascertain whether her child understood his diagnosis. When a child does not really talk, he leaves the parent to guess. Even Kubler-Ross (1983) stated that children three to four years-old can understand and that adults often underestimate them. Bertoia (1990) believed that we as adults feel they should not or can not handle the news. This researcher believes that this attitude does not show respect for the child if information is concealed. Even small children should be allowed the opportunity to ask questions to avoid acting-out behaviors.

Feifel (1997) reported that children who have experienced the loss of someone close to them are also more likely to believe in personal mortality (see Table 1). Understanding the permanence of death may depend on cognitive developmental stages. A child might know someone is dead in the evening but wait to see them again in the morning because it is a new day.

Finally, in this study, the teenagers showed many commonalities. The six-year-old boy with brain cancer in the hospital was an outlier. He asked no questions, had many special services, went into a medically induced coma, and expressed having a special relationship with God. Reportedly, the child showed signs of advanced cognitive development.

Each parent involved in this study felt they “knew” their children. All parents reportedly attempted to share the diagnoses on a level that would be understood by their children. Many were straightforward with their children; especially, with those children ages twelve through seventeen years. Just being informed of their diagnoses in this way appeared to change their behavioral adjustment.

All mothers revealed that support systems were in place. This researcher discovered, through the interview process, that some support systems were considered more beneficial than others depending on their treatment goals (see Table 1), accessibility, insurance restrictions, duration of time allowed, and personal values of the family system.

Support systems included psychologists, school guidance counselors, and social workers. The duration of time allowed for these services depended on the insurance provider. One mother reported to have MediCal as the insurance provider. She reported several services but then revealed her son was only allowed four or five sessions. It appeared that insurances may offer similar services but may be different due to the limitations and duration of service. The children reportedly benefited the most from services which were private insurances, comprehensive HMO's, or private pay.

After listening to the mothers in this study, it appears important that the caregivers be aware of the support teams working with their child so they may

reinforce desired behavior. Mothers reported that having family members, extended family members, and friends assist in the treatment proved beneficial. The six year-old-boy with brain cancer and the twelve-year-old boy with brain cancer were reported by their mothers to have no say or involvement in treatment goals. These decisions were formulated by the medical staff. Once parents agreed to the surgery, the medical staff presented when and how the process would progress. This, of course, was shared as the mothers perceived it. This seems understandable in terms of the medical necessity, but perhaps there is room to include the child and family in treatment goal planning, such as what may be offered during rehabilitation, what activities might be presented, and the type of psychological support to be offered. This may help the child and the parents feel their input and presence are worthwhile and even necessary for recuperation.

Interestingly, the older children were resourceful enough to go on the internet and continue to update themselves on the illness, what to expect, side effects from treatment, duration of treatment, and the like. This empowered them and gave them something constructive to do and opened communication between them and their parents. This paved the way for discussion. This behavioral adjustment proves to be quite beneficial. The older children were also able to go to yoga, Pilates, and meditation. A child with a life- threatening illness who has family involved in treatment, seems to show less signs of isolation, less

complaints about physical symptoms, and may even be more focused onto getting healthy.

One of the mothers reported that she was quite upset about the lack of support systems offered to her. She wanted to talk with other parents in hopes of finding more resources. This seems to be exactly what is needed. Parents must advocate for the help they need to assist their children in dealing with this life-threatening illness. The possibility of making new friends would be helpful, too. Children, too, can use each other for support when needed. Going to events together can be quite helpful for the parent, who in turn, can be physically present and show their love and concern to their children. Just as we advocate for children to stay engaged with friends, this also seems to apply to the caregiver. Support is vital. Support may prove to promote a positive behavioral adjustment in the children by helping them feel more comfortable and in developing stronger levels of trust with their parents.

The demographic questionnaire (PRQ) will be briefly addressed. (Some of the questionnaire items were included to see if commonalities existed amongst the children and/or parents while supporting the interview questions. Some questionnaire items were included as a possibility for future research).

Conclusion

Six mothers of children with life-threatening illness were interviewed regarding their perceptions of their children's behavioral adjustment. Results of

this study indicated that isolation, fear, inquisitiveness, age-appropriate activities, shared diagnoses, and support systems were all factors affecting behavioral adjustment in children with life-threatening illness.

This research was designed to utilize interviews with caregivers of children with life-threatening illnesses to explore their perceptions as to what positive and negative changes in behavior were exhibited in their children since diagnosis. There has been limited research in this area and this study was designed to provide more qualitative research speaking directly to the parent/caregiver of the child with a life-threatening illness. Families confronted with such a challenge deal with several different factors and frequently may feel that adequate support does not exist. At times, there is a sense of desperation, but somehow they manage to continue in order to help their children.

Caregivers and children may feel helpless while attempting to deal with this situation responsibly. Children require support from a range of sources such as professionals, family, and friends in order to gain maximum benefit. It is hoped that this research will be used to further investigate factors associated with behavioral adjustment in children with life-threatening illnesses.

Clinical Implications and Future Research

The findings from this study provide some important considerations for clinical practice. The findings of qualitative research are typically considered in the context of transferability of concepts. For any healthcare professional or

facility that deal with children having life-threatening illnesses, this study could provide further insight into the factors that affect behavioral adjustment, both positively and negatively. This study provides matrices for the six themes illustrating subordinate themes and sub-themes.

This study could assist clinicians in understanding how the themes of isolation, fear, inquisitiveness, age-appropriate activities, shared diagnoses, and support systems affect how the child behaves since the time of diagnosis. Psychological support in the above areas appears to be of particular value, especially in helping children deal with isolation. Whether a facility or a psychotherapist, possessing a better understanding of the ramifications involved would be of particular value. It could also apply to a facility involving palliative care or rehabilitation for children with life-threatening illnesses.

All caregivers noticed changes in behavior. All families were involved in their child's treatment. All caregivers who knew the answer to the question of belief in an after-life, answered in the affirmative on the questionnaire. It could prove interesting to examine behavioral adjustment in the child with life-threatening illness and belief in an after-life, even relating it to religion. It may be beneficial to study behavioral adjustment of children following diagnosis with the families being an integral component in the treatment plan compared to families not involved in the treatment plans. Furthermore, Elisabeth-Kubler-Ross (1983) sees a connection in children between the belief in an after-life and acceptance of

their mortality. This is of high interest to this researcher. It could prove to be a very interesting study. It would also prove interesting to examine socio-economic factors and their involvement in treatment of the child with a life-threatening illness residing in a hospice or palliative care facility.

In this present study, all children received some form of support services but there existed different factors and stipulations regarding the lower income children. Since the demographic questionnaire was optional and not part of the interview questions, these topics were not verbally discussed and would need to be an area for future research.

This current study could help explain attachment issues; especially, as related to the predominant themes of isolation and fear. Children with life-threatening illness who are hospitalized or in a hospice or palliative care facility may have attachment issues which could be contrasted with those children residing at home. This current study not only examined behavior but some of the feelings and emotions causing that behavior. It examined both positive and negative behaviors resulting from the identified factors which could prove beneficial for any clinician working with this targeted population. Further research may prove interesting to examine the two major areas of palliative care: psychosocial support and quality of life/pain control.

Measurements developed to assess childhood understanding of death would be helpful for further research. It could prove interesting to explore a longitudinal

study tracking coping mechanisms of children with life-threatening illness. This current study revealed several coping mechanisms, one being isolation. This study has shown that isolation can be both either voluntary or involuntary and also physical or emotional. Analyzing what could prove to be a coping mechanism in greater depth could be valuable. Additionally, for further research, constructing a measure of childhood self-identity with self-consciousness to help determine the level of discussion the parent might take with the child would have helped this current study and be valuable for future research (Demmin, 1986). Researchers may wish to further explore the 1991 death-anxiety scale for children to examine the impact of the age-appropriate activities and those activities proving most promising for the child.

In summary, hospitals are beginning to have separate buildings or wings for children with cancer or other life-threatening illnesses. It has taken quite some time to have these facilities provide services for this targeted population. Much research has been devoted to pediatric oncology which, of course, is needed. This Researcher would like to see the programs expand to include hospice and palliative care along with services that could be transferred to the home should the child remain home.

Limitations

Qualitative studies are not designed to be generalized to the population at large. This was a difficult population from which to secure a sample as these

children are obviously very sensitive and vulnerable. Even though the information was obtained from adults, the subjects of the study were children. The sample was small consisting of five boys and one girl, so generalizability really is not possible. All subjects were either Latino or Caucasian. Thematic Analysis is less focused on limitations and generalizations but on themes emerging from analysis of data. All participants resided in Southern California which is in itself, limiting. Only one subject was a patient in a facility. This particular study used caregivers, all being the children since time of diagnosis. It must be remembered that the caregiver's perceptions as adults about their children are fallible. Their own feelings and emotions may have entered into these perceptions (Armstrong-Dailey, & Zarbock, 2001). It is also important to realize that the caregivers' recall of the events and behavior prior to diagnosis may also be inaccurate.

Previous studies have acknowledged limitations involving the constraints of institutional review boards. This limitation made it very difficult to secure the sample due to stringent requirements involving confidentiality issues. Recruiting adult participants appeared just as difficult because the child was the subject of this study. Fifty-six facilities dealing with palliative care or life-threatening illnesses in children were contacted. Most would not entertain the notion of helping with this study because of confidentiality issues. It proved difficult to even have a flyer posted.

One facility in San Diego, California was very helpful in trying to help this researcher locate subjects. Upon locating two families appropriate for this study, the family members determined that they would not feel comfortable talking to “a total stranger” about such personal matters. The issue of trusting a stranger with personal family information was evident. Furthermore, there existed a small number of patients at any particular facility which impacted the research.

Only one interview resulted from contacting a support group. The mother was in a grief support group in the Los Angeles area. This researcher was not even allowed to attend a meeting due to confidentiality.

The issue of confidentiality and research may need to be readdressed if research is to be conducted involving children. It appears that a researcher would have to be involved in a grant or internship under a physician in order to have access to the possibility of conducting any research involving children. The participants in this study, excluding one, were all secured through word-of-mouth.

It is important to realize that the six themes were presented from this researcher’s own interpretation of the data, subjective to one’s own experience called double hermeneutic. This subjective interpretation may have been interpreted differently by another researcher. That researcher may have chosen different themes and subordinate themes. Also, there were subordinate themes. There was no attempt to secure any participants from various socio-economic groups, religions, race, or gender which may have changed the results of

participants. All subjects were under eighteen-years-of age residing in the Southern California area.

Finally, adults conveying information in this study may have been unaware of their own feelings about life, sickness, death, and grieving which could have influenced their perception. Once again, the results of this study were determined by analyzing the perceptions, reports of the caregiver, and one's feelings which were all drawn from the memory to report information. Shakti Gawain wrote about feelings and life:

There are no such things as negative or positive feelings. We make them negative or positive by our rejection or acceptance of them. All feelings are part of the wonderful, ever-changing sensation of being alive. If we love all the different feelings, they become so many rainbow colors of life (p. 213).

We create our own color wheel. We determine if the glass is half-empty or half-full. We impart who we are to our children. We share our values of life and of death. Life can be a struggle to survive or it can be a journey among those you love.

REFERENCES

- Achenbach, T. (1991). *Manual for Child Behavior Checklist 4-18*. Department of Psychiatry, University of Vermont. Burlington, VT.
- Adams-Greenly, M. (1984). Helping children communicate about serious illness and death. *Journal of Psychosocial Oncology*, 2, 61-72.
- American Psychological Association (2001). *Publication Manual of the American Psychological Association* (5th ed.). American Psychological Association.
- American Psychological Association. (2007). *APA Dictionary of Psychology* (1st ed.). Washington, DC: American Psychological Association.
- Armstrong-Dailey, A., & Zarbock, S. (2001). *Hospice care for children* (2nd ed.). New York: Oxford University Press.
- Bertoia, J. (April, 1990). Drawings from a dying child: A case study approach. University of British Columbia, British Columbia.
- Brown, R. (2006). *Comprehensive handbook of childhood cancer and sickle cell disease: A biopsychosocial approach*. New York, NY: Oxford University Press.
- Brown, R., & DuPaul, G., (1999). Introduction to the mini-series: Promoting school success in children with chronic medical conditions. *School Psychology Review*, 28(2), 175-181.
- Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3, 77-101.
- Deasy-Spinetta, P. (1981). *Living with childhood cancer*. Paper presented for WorldCat database, St. Louis: C.V. Mosby, 153-168.
- Demmin, H. (1986). Death concept formation. *Dissertation Abstracts International*, 47(6-B), 2610.
- DeSpelder, L., & Strickland, A. (1992). *The last dance encountering death and dying* (3rd ed). Vancouver, BC: Mayfield Publishing.

- Eiser, C. (2004). *Children with cancer: The quality of life*. Mahwey, NJ: Lawrence Erlbaum Associates.
- Erikson, E. (1963). *Childhood and society* (2nd ed.). New York: Norton Press.
- Feifel, H. (1977). *New meanings of death*. New York, NY: McGraw-Hill.
- Feldman, D. (204). Piaget's stages: The unfinished symphony of cognitive development. *New Ideas in Psychology*, 22(3), 175-231.
- Ferrante, J. (2000). *Sociology: A global perspective*. Belmont, CA: Wadsworth.
- Fitzgerald, C. (2005). The needs of children at the end of life: A case synthesis (*Doctoral dissertation, State University of New York at Buffalo, 2005*)
Publication No. AAT 3185299.
- Gawain, S. (1988). *Reflections in the light*. San Rafael, CA: New World Library.
- Glover, J., Beliveau, E., & Miller-Thiel, J. (1993). Caring for the dying child. *Hospice Journal*, 9(2-3), 55-72.
- Grollman, A. (1996). *Bereaved children and teens: A support guide for parents and professionals*. Boston, MA: Beacon Press.
- Gross, Y., Glaubman, H., Berman, D., & Orbach, I. (1986). Children's perception of various determinants of the death concept as a function of intelligence, age, and anxiety. *Journal of Clinical Child Psychology*, 15(2), 120-126.
- Hagey, S. (Aug. 1999). A developmental study of terminally-ill chronically-ill and physically-healthy children's concern with and cognitive evaluation of death. (*Doctoral dissertation, University of Texas at Austin, 1999*).
Publication No. AAT 9105561.
- Hanks, G & MacDonald, N.. *Oxford textbook of palliative medicine*. New York: Oxford University Press, Inc., pp. 699-717.
- Hasazi, J., Bond, L., & Reilly, T. (1983). Children's conceptions of death and personal mortality. *Journal of Pediatric Psychology*, 8(1), 21-31.
- Jampolsky, G. (1979). *There is a rainbow behind every dark cloud*. The Center for Attitudinal Healing. Millbrae, CA: Celestial Arts.

- Kane, B. (1979). Children's concept of death. *Journal of Genetic Psychology*, 134, 141-153.
- Kaplan, J. (1997). The emotional experiences of treating dying children: Nurses speak out. (*Doctoral dissertation, Massachusetts School of Professional Psychology, 1997*). Publication No. AAT 9832069.
- Kubler-Ross, E. (1969). *On death and dying*. New York, NY: Simon & Schuster, Inc.
- Kubler-Ross, E. (1983). *On children and death*. New York, NY: Simon & Schuster, Inc.
- Kubler-Ross, E. (1997). *To live until we say good bye*. New York, NY: Simon & Schuster, Inc.
- Lubkin, I., & Larsen, P. (2002). *Chronic illness: Impact and interventions*. Sudbury, MA: Jones & Bartlett.
- Martinson, I. & Papadatou, D. (1994). Care of the dying child and the bereaved. In Bearison, D., & Molhern, R., *Pediatric Psychooncology: Psychological Perspectives on Children with Cancer* (pp. 193-214). New York: Oxford University Press.
- Medicine, I. (2001). *Improving Palliative Care for Cancer*. Washington, DC: National Academy Press.
- Nagy, M. (1948). The child's theory concerning death. *Journal of Genetic Psychology*, 73, 3-27.
- O'Malley, J.E., Koocher, G.P., Foster, D.J., & Slavin, L.A. (1982). Communication of the cancer diagnosis to pediatric patients: Impact on long-term adjustment. *American Journal of Psychiatry*, 139(2), 179-183.
- Paris, J., Barbarin, O., & Chesler, M. (1986). "Telling" the child with cancer: Parental choices to share information with ill children. *Journal of Pediatric Psychology*, 11(4), 497-516.
- Piaget, J. (1952). *The origins of intelligence in children*. New York: International University Press.

- Polit, D. & Beck, C. (2008). *Nursing research: Generating and assessing evidence for nursing practice* (8th ed). Philadelphia: Lippincott, Williams, & Wilkins.
- Rochlin, G. (1967). Explaining death to children. In *How younger children view death and themselves*. Boston, MA: Beacon Publishing, 51-88.
- Rubin, H.J., & Rubin, I.S. (2005). *Qualitative interviewing: The art of hearing data* (2nd ed). Thousand Oaks, CA: Sage Publications.
- Siegel, D. (1999). *The developing mind: Toward a neurobiology of interpersonal experience*. The Guilford Press.
- Srivastava, D., & Phipps, S. (1997). Repressive adaptation in children with cancer. *Health Psychology, 16*(6), 521-528.
- Stevens, M. (1993). Psychological adaptation of the dying child. In *Oxford Textbook of Palliative Medicine*. New York: Oxford University Press.
- Waechter, E. (1971). Children's awareness of fatal illness. *American Journal of Nursing, 71*, 1168-1171.
- Willis, C. (2002). The grieving voices in children: Strategies for understanding, educating, and reconciling children's perceptions of death. *Early Childhood Education Journal, 29*(4), 221-226.
- World Health Organization. (1990). *Cancer pain relief and palliative care*. WHO Technical Report Series, 804.
- Yalom, I. (1980). *Existential psychotherapy*. Oshkosh, WI: Basic Books.
- Zebach, B., Zeltzer, L., Whitton, J., Mertens, A., Odom, L., Berkow, R., (2002). Psychological outcomes in long term survivors of childhood leukemia, Hodgkin's Disease, and Non-Hodgkin's Lymphoma: A report from the childhood cancer survivor study. *Pediatrics, 110*, 42-52.

APPENDIX ALetter of Introduction

To Whom It May Concern:

This will serve to introduce Joe Becher who is a doctoral candidate in psychology at Antioch University, Santa Barbara.

As part of the requirements for graduation, Joe is conducting a study entitled “Behavioral Adjustment of Children with Life Threatening Illness.” He will follow up this letter with a phone call to see if you would be willing to participate in this important research. His study involves a 1:1 taped interview with parents/caregivers and a brief demographic questionnaire. It is hoped that the outcome of the study will enable treatment facilities to better meet the needs of children and their families. As a participant facility, Joe will be happy to provide you with summary information about participants.

Thank you for being willing to consider participation in this study. Joe will be providing you with additional information on which you can base your decision.

Sincerely,

Ron Pilato, PsyD.
Department Chair
Doctoral Program, Clinical Psychology
Antioch University

APPENDIX BRecruitment Letter

Code _____

To Whom It May Concern:

I am a doctoral candidate in the Department of Clinical Psychology at Antioch University Santa Barbara. I am currently working on a study titled: *Behavioral Adjustment of Children with Life Threatening Illness.* This research is designed to look at the adjustment of children with life threatening illness before and after diagnosis.

In this study the participation of one or both parents/caregivers is needed. A structured, taped interview and The Parent Report Questionnaire (PRQ) will be completed for each child. The child's family will be one of several families participating. All materials/responses will be identified by number so that participant identity remains confidential. I will request that parents/caregivers complete the PRQ following the 1:1 interview. Your participation is a valuable contribution to health care professionals in the care and treatment of children with life threatening disease, particularly for increased knowledge of how these children cope with present physical and emotional life changes. Further research in determining appropriate treatment for this population in the future can be encouraged from the results of this study. It is my hope that additional funding and services will also be encouraged.

I will be contacting you in a week or so to ask if you know of anyone who may be interested in this study. I will be happy at that time to answer any questions you may have regarding the nature of the study or the consent forms. If at any time you would like to meet to clarify anything, I would be happy to comply with your wishes. I would also be happy to speak with any caregiver or parent participating in any support group dealing with children having life threatening illness.

No one will have access to the data from this research except me and my advisors. All materials/responses will be in a locked file cabinet in the researcher's office and the key will be kept in a locked combination safe. The 1:1 interview will take about one hour and the PRQ questionnaire about thirty minutes.

Thank you very much for considering participation in this important research. I look forward to speaking with you soon. Please feel free to contact me by phone, letter, or email. Any participant may withdraw from this study at any time without negative consequence.

Sincerely,

Joe Becher

Researcher

Joe Becher, M.A., M.S.W.

Department Chairperson

Ron Pilato, Psy.D.

Antioch University

602 Garden Street

Santa Barbara, CA 93101

(805) 962-8179

rpilato@antioch.edu

APPENDIX C

Each of us has a fire
in our hearts.
Through the eyes of a
child,
Please
keep it burning.

Contact: Joe Becher
Psy D. Candidate
760-778-4926

APPENDIX DRecruitment Letter

Code _____

Dear Parent/Caregiver,

I am a doctoral candidate in the Department of Clinical Psychology at Antioch University Santa Barbara. I am currently working on a study designed to explore the adjustment of children after diagnosis/prognosis (prediction of the probable course and outcome of the disease).

You will be one of several families participating in this study by completing a 1:1 interview and questionnaire. The participation of one or both parents/caregivers is necessary. My hope is to contribute to current understanding of how these children adjust to present physical and emotional life changes. Future research may then be encouraged for determining additional strategies in working with this population. Any valuable information derived from my research may also facilitate future funding and services.

The researcher will complete a structured interview with you, which will be recorded for comparison with other participant responses in this study. The interview regarding behavioral adjustment of your child will take approximately one hour. This researcher is very interested in your observations before and after the diagnosis/diagnoses. At the conclusion of the interview, you will be asked to complete a demographic questionnaire (PRQ) which will be used to compare your responses to the research that already exists.

All materials/responses will be confidential. These will be secured in a locked file cabinet in my office with the key kept in a locked combination safe. Your identity will be carefully protected.

I ask that you attempt to answer each question of the PRQ; but, you may omit if needed. At any time you are free to withdraw from the study and your information will not be used. It is also very important for you to initial the consent form I have provided for you. The PRQ asks that you fill in a few answers, circle others, and check some of the chosen answers based on your observations of the child. Please feel free to contact me by phone, email, or mail should you have any questions. Remember to initial and date the consent form.

Your prompt response to and participation in this study may contribute to the literature that explores the impact of disease on children's quality of life.

Sincerely,

Joe Becher, M.S.W., M.A.

Researcher

Joe Becher, M.A., M.S.W.

Dissertation Chairperson

Steve Kadin, Ph.D.

Antioch University
602 Garden Street
Santa Barbara, CA 93101
(805) 962-8179
skadin@antioch.edu

Please return after you detach, initial, list your relationship to the child, date, and list the name of the facility if any. A prepaid-addressed stamped envelope is provided for you to return all materials to the facility.

Parent/Caregiver Consent Form

Code _____

I (We) give Joe Becher, M.S.W., M.A. permission to use the information provided from the structured taped interview and the PRQ for his doctoral research study.

_____ (initials) _____ (relationship)

_____ (initials) _____ (relationship)

Date (mm/dd/2015)

Date (mm/dd/2015)

My (Our) child lives in _____ (my house or name of hospice/palliative care facility)

Joe Becher

Date Received

APPENDIX E

Code_____

Parent Report Questionnaire (PRQ)

Behavioral Adjustment of Children

Please complete the following questionnaire. Be completely honest in your responses as this information will be used for research purposes ONLY. Data will be used to assess which factors play an important role on the behavioral adjustment of the child. Please answer all questions if possible but feel no pressure to do so if any item makes you feel uncomfortable. Thank you.

General Background Questions:

1. What is your relationship to this child?

Father_____ Mother_____

Caregiver/guardian_____

Step-father_____ Step-mother_____ Other_____ (please specify)

2. Are you the primary caregiver?

Yes_____ No_____

3. For demographic purposes only (Provides more information about population of interest), please list your child's religion (if any).

Agnostic_____ Atheist_____ Protestant_____

Buddhist_____ Jewish_____ Pentecostal_____

Catholic_____ Baptist_____ Evangelical_____

Muslim_____ Other_____ None_____

4. Has your child been informed of the diagnosis?

Yes _____ No _____ I don't know _____

5. How long ago was your child informed of their diagnosis?

Under 1 month _____ 1 mo.–6 mo. ago _____ 7mo–1year _____

13 mo.–2 years _____ over 2 years ago _____ I don't know _____

Does not apply _____

6. Who informed your child of their diagnosis? (Please specify)

Doctor _____ Brother/sister _____ Step-father _____

Nurse _____ Caregiver _____ Grandparent _____

Mother _____ Clergy (religious) _____ Other (please specify) _____

Father _____ Step-mother _____

7. Do you think your child understands the nature of their illness?

Yes _____ No _____ I don't know _____

Please explain _____

8. Has your child been informed of their prognosis (a prediction of the probable course and outcome of the disease)?

Yes _____ No _____ I don't know _____

9. Was the prognosis explained along with the diagnosis to your child?

Yes _____ No _____ I don't know _____

Does not apply _____

10. If not, how long AFTER your child was informed of their diagnosis was the prognosis presented?

Less than 1 month after_____ 1–6 mos after_____

7 mos–1 yr after_____ 13 mos–2 yrs after_____

Over 2 yrs after_____ I don't know_____

Does not apply_____

11. Do you think your child understands the prognosis?

Yes_____ No_____ I don't know_____

Does not apply_____

12. Does your child attend formal schooling in community or at a facility?

Yes_____ No_____ I don't know_____

Does not attend school _____

13. Does your child have home schooling or private tutoring at the facility instead of formal schooling?

Yes_____ No_____ I don't know_____

Does not apply_____

14. If you answered yes, how often does this schooling occur? Please check all that apply. If your answer was not yes, please feel free to comment.

Once weekly_____ 2x weekly_____ 3x times weekly_____

4x times weekly_____ five times each week_____

I don't know_____ Does not apply_____

15. Do you think that your child engages in age-appropriate activities while at the hospice/palliative care facility?

Yes_____ No_____ I don't know_____

N/A_____

16. If you answered yes, how often?

Once weekly_____ 2-3x weekly_____ 4-5x weekly_____

6-7x weekly_____ I don't know_____ Does not apply_____

17. What activities? Check all that apply.

Spiritual group_____ TV/movie watching_____

Singing/dancing/musical instruments_____ Sports_____

Video/board games_____ Pet therapy_____ Arts/crafts_____

I don't know_____ Does not apply_____ Other_____ (Specify)

19 Has your child ever experienced the death of a relative, friend, or pet?

Yes_____ No_____ I don't know_____

20. If you answered yes to #18, who was the deceased?

Parent_____ Brother or Sister_____ Friend_____

Both parents_____ Grandparent_____ Pet_____

Caregiver_____ Step-parent_____ Other (Please specify)

21. Do you think that your child is afraid of dying?

Yes_____ No_____ I don't know_____

Please explain_____

22. Does your child believe in any after-life?

Yes _____ No _____ I don't know _____

23. Have you ever had a discussion about death with your child?

Yes _____ No _____

Please explain _____

24. Have you ever thought that your child regarded the illness as a punishment?

Yes _____ No _____ I don't know _____

Please explain _____

25. If your child is seen by a counselor, social worker, or psychologist, check all that apply.

Counselor _____ Social worker _____ Psychologist _____

Psychiatrist _____ Other _____

Please explain _____

26. How often is your child seen by a counselor, social worker, psychologist, or psychiatrist?

Once weekly _____ 2-3x weekly _____ 4-5x weekly _____

6-7x times weekly _____ Every other week _____ Once monthly _____

I don't know _____ Does not apply _____

27. Is your family actively involved with your child's treatment?

Yes _____ No _____ I don't know _____

28. If your child is in a facility, how frequently do you or the caregiver visit?
- Once weekly_____ 2-3x weekly_____ 4-5x weekly_____
- 6-7x times weekly_____ Every other week_____ Once monthly_____
- Does not apply_____ Other_____ (Please specify)
29. Please rank the birth order of your child.
- Only child_____ Middle child_____ Other (specify)_____
- Oldest_____ Youngest child_____
30. Are the child's birth parents residing together?
- Yes_____ No_____ I don't know_____
31. Does the child have contact with both of the birth parents?
- Yes_____ No_____ I don't know_____
32. Is the caregiver or guardian the sole person involved with the child instead?
- Yes_____ No_____ I don't know_____
33. How old was your child upon entering the hospice or palliative care facility if applies?
- _____yrs Does not apply_____
34. What is the primary language of the child?
- English_____ Other_____ (Please specify)
- Spanish_____
35. Please indicate the number of years of education for each parent or caregiver who lived with the child before the child was diagnosed. (Ex. high school, 12 yrs, junior college, 14 yrs, etc)
- Mother_____ Father_____ Caregiver_____ I don't know_____

36. Does your health insurance cover the child in this facility or at home? (Please specify)

Yes _____ No _____ I don't know _____

37. How immediate was hospice or palliative care services made available after your child was diagnosed with the illness?

Less than a month _____ 1-2 months _____ 3-6 months _____

7 mo-1 yr _____ Over 1 yr _____ I don't know _____

Does not apply _____

38. Does your child usually share feelings with you?

Yes _____ No _____ I don't know _____

39. Have you noticed a change in your child's behavior since the time of diagnosis?

Yes _____ No _____ I don't know _____

Please explain _____

40. How would you rate your child's quality of life at the moment?

Poor _____ Fair _____ Good _____

Very good _____ I don't know _____

Please explain _____

Optional: What is your yearly income? (Combined if both parents supporting the child).

\$.00-\$24,999 _____ \$25,000-\$49,999 _____ \$50,000-\$74,999 _____

\$75,000-\$100,000 _____ Over \$100,000 _____

Thank you for completing this questionnaire on your child.

APPENDIX F

Participant Code _____

Form B**THIS FORM IS TO BE COMPLETED BEFORE RESEARCH BEGINS****Insuring Informed Consent of Participants in Research:
Questions to be answered by AUSB Researchers**

The following questions are included in the research proposal.

1. Are your proposed participants capable of giving informed consent? Are the persons in your research population in a free-choice situation? Or are they constrained by age or other factors that limit their capacity to choose? For example, are they adults, or students who might be beholden to the institution in which they are enrolled or prisoners, or children, or mentally or emotionally disabled? How will they be recruited? Does the inducement to participate significantly reduce their ability to choose freely or not to participate?

Yes. The participants will be age eighteen and over. They will volunteer to participate in an interview and complete the PRQ if so desired. The participants may withdraw at any time from the study. Participation is strictly on a volunteer basis to share perceptions of their child. The recruitment process would commence through internet searches of support groups for parents/caregivers of children with life-threatening illness in California. These groups must not be affiliated with an institution such as a hospital. The contact number would be called by this researcher and after a brief introduction by this researcher, an introductory letter and study explanation would be sent by U.S. mail (and a copy by email if requested) to the group leader explaining the study and offering to speak before, during, or after their group session to explain the study and its purpose. The group leader will be asked if he/she could share this request with the members of the support group and that this researcher would make himself available to further explain the study in person. A flyer would be included in the mailing for possible posting. Other methods of recruitment would be from word of mouth and posting flyers. This

researcher would focus initially from San Bernardino County in California to Santa Barbara County.

2. How are your participants to be involved in the study?

The participants are the parents/caregivers of the child with life-threatening illness will be asked to complete the interview and share their perceptions of the child with life-threatening illness both before and after the diagnosis and complete the Parent Request Questionnaire should they choose to do so after the interview.

3. What are the potential risks—physical, psychological, social, legal, or other? If you feel your participants will experience “no known risks” of any kind indicate why you believe this to be so. If your methods do create potential risks, say why other methods you have considered were rejected in favor of the method chosen.

The topic of the interview may stir emotions. As with any research study, there is always the possibility of the unknown. This researcher will make every attempt to protect sensitivity. An interview will be conducted by phone or in person to discuss the study with the prospective participant and to assess their strength in terms of being a part of the interview. Special attention will be paid on display of negative emotions during the selection process. The parent/caregiver will be asked how he/she feels about participation and be informed that they may stop the interview at any time should feelings arise that were unexpected. A list of referrals to licensed therapists in their area will be given to participants should they need at the moment or in the future. This researcher wants to ensure that the participant is provided help if needed. This researcher will not be seeing or engaging in any way with the terminally ill child.

4. What procedures, including procedures to safeguard confidentiality, are you using to protect against or minimize potential risks, and how will you assess the effectiveness of those procedures?

The consent forms will be coded numerically starting with 01 as will the taped interview cassette. The identifying information with name and the coded number will be kept in a locked safe which I have already purchased located in my home. This researcher has a locked box to transport from the site of the interview to the researcher’s home. The recorded interview on cassette tape will be given to a professional

transcriptionist already used by two class members with only a numerical coding on the tape and the pseudonym within the actual tape. This researcher will have asked the participants to choose a different name and that name will match the number assigned. The true identity will not be listed on anything other than the signed consent form which will be locked in the safe. All study materials will be kept in said safe and the key hidden. The written transcript upon receipt from the transcriptionist will also go in to this locked safe as is already coded on cassette tape. The demographic information and questionnaire all coded will be secured in the safe with this researcher being the only person having access. At the conclusion of the study, the written information will be shredded and the tape will be erased and destroyed. The coded consent form, transcript, and demographic questionnaire will be kept in a locked safe. Potential risks may be minimized by allowing the participant to terminate the study at any time should negative emotions be displayed or felt by the participant. The participant will be given a referral list of licensed therapists in their area should any emotions be stirred and assistance needed in this area. An interview will first be conducted on the phone to determine if the parent/caregiver will be appropriate for the study and if that parent or caregiver feels they are emotionally ready to share their perceptions of the terminally ill child. There will be a follow-up phone call within 3 days of the interview to request feedback and inquire about the participant's feelings during and after the interview. Once again a referral list of licensed therapists will be given to the participant if help is needed.

5. Have you obtained (or will you obtain) consent from your participants in writing? (Attach a copy of the form.)

Yes. See Consent Form attached.

6. What are the benefits to society, and to your participants that will accrue from your investigation?

Society will benefit through an understanding of the needs of children with life-threatening illness. After this understanding, a future study could then evaluate the appropriateness of existing services to determine if the services meet the needs of the child with life-threatening illness. The child may benefit by receiving additional services to help in terms of meaningful social support and coping with present physical and emotional changes. The actual participants will benefit by receiving supportive services to assist in the care of their child with life-threatening illness.

They will benefit after having the above knowledge so they may choose to help the child adjust accordingly.

7. Do you judge that the benefits justify the risks in your proposed research? Indicate why.

As with any study, there may always be a possibility of risk but this researcher has outlined how he will attempt to minimize the possibility of risk. The benefits will hopefully justify this new study. This study may show how the illness of a child can impact the quality of life. This may be the first step to assess further needs of the child. No child will be contacted by the researcher and the parents/caregivers may choose to share perceptions through the use of an interview with this researcher. The participants have the chance to complete the Parent Report Questionnaire to provide additional demographic information. The parents/caregivers will be encouraged to answer each question but will always have the option not to answer a question or to withdraw at any time. The possible risk could include the display of negative emotions before, during, or after the interview. This researcher will provide a list of licensed therapists in their area to be contacted interview. This researcher will provide a list of licensed therapists in their area to be contacted.

Both the student and his/her Dissertation Chair must sign this form and submit it before any research begins. Signatures indicate that, after considering the questions above, both student and faculty person believe that the conditions necessary for informed consent have been satisfied.

Date: _____

Signed: _____

E. Joseph Becher, Jr. MA, MSW
Student

Date: _____

Signed: _____

Steven Kadin, Ph.D.
Chair

APPENDIX G

1:1 Interview Questions

1. What emotions/feelings has your child expressed to you since being diagnosed?
2. Have you noticed any difference in your child's behavior since diagnosis? If so, what are they?
3. Please tell me about the process involved in deciding to share or not to share your child's diagnosis/prognosis?
4. Has your child asked any questions about his/her illness? If so, what are the questions?
5. How has your child been involved in their own treatment planning?
6. What kind of activity is your child engaged in at this time?
7. What are any support systems your child may take advantage of since being diagnosed?
8. What does your child think will happen because of this illness?

