# “This is me. I like who I am”: A Qualitative Descriptive Study Using Photo Elicitation to Examine the World of the School-Age Child With Cystic Fibrosis

A Dissertation Presented for the
Doctor of Philosophy
Degree
The University of Tennessee, Knoxville

Renée Carol Burk
December 2011

Copyright © 2011 by Renée C. Burk

All rights reserved.

## Dedication

I dedicate this work to a man whose presence left this world too early, Dr. Iley "Tripp" B. Browning III. Tripp introduced me to cystic fibrosis (CF), a genetic childhood disease, when I was a still a novice nurse practitioner working in Corpus Christi, Texas. During the two years we worked together he was my teacher, mentor, role model, and friend. To this day, I continuously strive to reach and live up to the standards he set before me. Tripp was a servant dedicated to improving the lives of his patients and their families through excellence. He was a man of high moral and ethical standards who possessed a brilliant mind, a compassionate heart, and a caring spirit. He was also a loving husband and devoted father, but the quality that stood out beyond all others was Tripp's ability to listen to his pediatric patients and acknowledge their presence. The smallest voices often have the least power in society, but Tripp paid attention when children expressed their needs and became their advocate. Although he no longer walks among us here on earth the light of his life's' mission will continue through the works of the professionals he has educated, trained, and mentored.

## Acknowledgements

First, I desire to acknowledge my husband Randy for the years of support, patience, and confidence as I worked towards my PhD. He allowed me to lean on him through the difficult moments, rejoiced along side of me when I reached crucial milestones, and never stopped loving me. We made it my love!

Next, I would like to thank my dissertation chairperson, Dr Susan Speraw who voluntarily joined me on this journey into the world of school-age children with CF, as well as my other wonderful and supportive dissertation team members Dr. Tami Wyatt, Dr. Nan Gaylord, and Dr. Marsha Spence.

I want extend my appreciation to all my friends and colleagues for their help and support throughout the duration of this study including Polly, Felecia, Mary, Jacque, Tammy, Jennifer, PJ, John, Eduard, Margie, Casey, Vivian, and Janice. Fourthly, to all the children and parents who participated in this study. Without your help and commitment, this research would not have been possible.

I also wish to thank Sigma Theta Tau – Gamma Chi Chapter for awarding me a research grant, which went towards the purchase of equipment for this study. Not only was the money greatly appreciated, it was also an honor to have received it.

Finally, I give praise to my savior Jesus Christ who was my strength throughout this entire dissertation journey. I asked for wisdom and he showed me patience, faithfulness, and love.

## Abstract

School-age children with Cystic Fibrosis (CF) possess valuable knowledge about themselves. They have experience and ability to offer insight about living with CF. Previous studies, exploring the perceptions of CF children, give little attention to eliciting and listening to their voices. Also, traditional data collection methods limit children from participating in research. The purpose of this study was to explore and describe how school-age children with CF see themselves in the world they live.

The study utilized qualitative description methodology. Symbolic Interactionism served as the researcher's philosophical lens. It is a perspective that seeks to understand the social world of others, as they perceive it. Photo elicitation was used as the primary data collection method. Each participant was asked to take photographs about "What it is like to be you". Photographs were then used to stimulate and guide an audio-recorded interview and make a photo book for the child to keep. Data were analyzed using Boyatzis method of inductive thematic content analysis. Sixteen children with CF between the ages of 8 to 11 were purposively recruited from the Southeastern United States. Data saturation was achieved after 13 interviews. Rigor was maintained by a variety of ways including bracketing, peer evaluation, and member checking.

Five themes emerged from the data *Me Being Me*, *My Medicine and Treatments*, *My Family*, *My Friends and Other Key Relationships*, and *My World.* Findings revealed that life does not revolve around CF, but instead centers on "me being me" and living a normal life. Additionally, photo elicitation empowered participants to be authors of their own stories, and promoted communication between them and the researcher.

In knowing the reality of children, nurses and other multidisciplinary CF team members are better equipped to design and plan interventions that are meaningful, beneficial, and satisfying to the child and his or her parent. The results of this study demonstrate children can be active participants in research and provides opportunities to transform nursing care by developing and evaluating strategies for the delivery of care to children with CF.

Recommendations for future research include expanding this study to other CF centers and including the perceptions of parents, nurses, and other CF health care providers. Additionally, because perceptions a person holds about them selves and the world change overtime, a follow-up study when participants reach adolescence and adulthood is suggested.

**Table of Contents**

CHAPTER PAGE

I. INTRODUCTION ..... 1

Background on Cystic Fibrosis ..... 2
Stance of Researcher ..... 5
Foundational Research ..... 6
Statement of the Problem ..... 8
Purpose of the Study ..... 9
Philosophical Lens ..... 10
Research Question ..... 12
Assumptions ..... 13
Operational Definitions ..... 13
Delimitations ..... 15
Limitations ..... 15
Summary ..... 15

II. REVIEW OF LITERATURE ..... 17

Existence ..... 19
Defining Existence ..... 19
Existentialism ..... 21
Non-Existence ..... 23
Summary ..... 24
World ..... 25
Symbolic Interactionism ..... 25
Defining the World ..... 27
Summary ..... 38
Family ..... 39
The Family as a System ..... 40
Qualities of Strong Families ..... 45
CF and Family Relationships ..... 47
Self ..... 53
Conceptual Definition of Self Used in this Research ..... 57
Development of the Self ..... 58
Chronic Illness and the Self ..... 66
Perceptions of Growing up with Cystic Fibrosis ..... 70
Historical Context of Children and CF in Research ..... 71
Adult Perceptions of Growing-up with CF ..... 76
Adolescent Perceptions of Growing-up with CF ..... 80
Perceptions of the School-Aged Child with CF ..... 86
Gaps in the Literature ..... 94

Summary....95

III. METHODOLOGY....97

Method....97
Design....97
History of Photographic Methods....99
Types of Photographic Methods....100
Photographic Method Used in this Study....103
Procedures....103
Sampling....103
Inclusion/Exclusion Criteria....104
Recruitment....105
Setting....108
Specific Information Concerning Visits and Data Collection Procedure....109
Protection of Human Subjects....120
Equipment Used in this Study....122
Data Management During the Interview Process....123
Data Analysis....124
Theme Development....127
Threats to Effective Thematic Analysis....128
Methods to Maintain Rigor....129
Summary....130

IV. FINDINGS....132

Participant Demographics....132
Photographs....135
Developmental Aspects of Methodology....135
Thematic Structure....137
Contextual Ground....138
Themes and Exemplars....139
Theme # 1: Me Being Me....139
Theme # 2: My Medicine and Treatments....152
Theme # 3: My Family....166
Theme # 4: My Friends and Other Key Relationships....183
Theme # 5: My World....200
Conclusion....214

V. DISCUSSION....218

Comparing Models....218
Contextual Ground: Developmental Stage....222
Theme # 1: Me Being Me....225
Life Biography....225
Existential Elements of "Me Being Me"....228
Theme # 2: My Medicine and Treatments....231
Theme # 3: My Family....234
Uncertainty....239
Normalization....239
Theme # 4: My Friends and Other Key Relationships....240
Theme # 5: My World....244
Summary....247
Implications for Nursing Practice....249
Patient and Family Education....249
Clinical Practice....250
Nursing Research....253
Implications for Health Care Industry....253
Ideas for Future Nursing Research....254
Conclusion....257

REFERENCES....259

APPENDICES

Appendix A Empirical of Literature....279
Appendix B Photograph Release Statement....281
Appendix C Flyer....285
Appendix D Schedule of Study Visits....286
Appendix E Participant Information Form....288
Appendix F Child Assent....289
Appendix G Picture taking Instructions....291
Appendix H Transcribers Pledge of Confidentiality....293
Appendix I Research Team Members Pledge of Confidentiality....294
Appendix J Examples of Memos....295

VITA....296

## LIST OF TABLES

Table 2.1 Piaget's Stages of Cognitive-Developmental ..... 60
Table 2.2 Erikson's Eight Stages of Development ..... 62
Table 3.1 Example of Collapsing Data Into Themes ..... 126
Table 4.1. Participant Demographics ..... 133
Table 4.2. Participant Characteristics ..... 134
Table 4.3. Medications Taken by Participants ..... 135
Table 4.4. Comparison of Two Participants and Their Connections in the World ..... 215
Figure 5.1 Models of the CF child's world ..... 219
Figure 5.2. Colors favored by girls ..... 223
Figure 5.3. Colors favored by boys ..... 223

## LIST OF FIGURES


Figure 2.1 The World of the Child with Cystic Fibrosis....18
Figure 2.2 Bronfenbrenner's Ecological Systems Model....64
Figure 3.0 Adam's picture book....119
Figure 4.1 Thematic Structure of *Me Being Me*138....138
Figure 4.2 David....140
Figure 4.3 Anna....141
Figure 4.4 (a) Hilary, (b) Hilary and her stocking....141
Figure 4.5 Emily....142
Figure 4.6 Molly....142
Figure 4.7 Hilary's drawing of Foxy....143
Figure 4.8 Mary playing her violin....144
Figure 4.9 Andrew playing the drums....144
Figure 4.10 Children's activities:....145
Figure 4.11 Tyra painting....145
Figure 4.12 David's favorite Chinese meal....146
Figure 4.13 Lauren and her cat....147
Figure 4.14 Ashley and her Santa present....148
Figure 4.15 Hilary's CF bracelet....151
Figure 4.16 Mary's medications....153
Figure 4.17 Adam's pills....153
Figure 4.18 Faith's pills....154
Figure 4.19 Anna's medicine....154
Figure 4.20 Daniel doing his treatments....155
Figure 4.21 Faith taking her treatments....155
Figure 4.22 Adam using his vest....156
Figure 4.23 Emily taking a treatment....156
Figure 4.24 Molly's Vest®....157
Figure 4.25 Emily's Vest®....157
Figure 4.26 Mary doing treatment and using the Wii™....158
Figure 4.27 Anna's medication:....159
Figure 4.28 Tyra waking up....160
Figure 4.29 Lauren in the hospital....161
Figure 4.30 Santa and his reindeer visiting Lauren....162
Figure 4.31 Tyra in the hospital....162
Figure 4.32 Hilary's Foxy....164
Figure 4.33 Andrew's family....166
Figure 4.34 Hilary's grandparents....167
Figure 4.35 Mary's family....168
Figure 4.36 Julia's family Christmas stockings....169
Figure 4.37 Hilary's toy Scamps®....169
Figure 4.38 Children and their dads:....170

Figure 4.39 Children and their mothers:....170
Figure 4.40 Andrew with his dad....173
Figure 4.41 Faith's dad....173
Figure 4.42 Hilary, her dad, and her brother....173
Figure 4.43 Adam's mom....174
Figure 4.44 Mary and her mom in the snow....175
Figure 4.45 Adam's older brother shooting arrows with a bow....177
Figure 4.46 Jacob and his brother....177
Figure 4.47 Emily and her sister....178
Figure 4.48 Adam's grandparents:....180
Figure 4.49 Mary's popcorn balls....180
Figure 4.50 Julia's heirloom doll....181
Figure 4.51 Adam's family game night....181
Figure 4.52 Emily topping the tree with the angel....182
Figure 4.53 Bethany's Christmas tree....182
Figure 4.54 Emily's friend....184
Figure 4.55 Molly and her best friend....185
Figure 4.56 Andrew and his girlfriend....187
Figure 4.57 Mary, her sister, and friends....188
Figure 4.58 Julia's dog....189
Figure 4.59 Joseph and his dog....189
Figure 4.60 Ashley's dog....190
Figure 4.61 Faith's dog....191
Figure 4.62 Julia's horse....191
Figure 4.63 Hillary's kitty....192
Figure 4.64 Emily's teacher....193
Figure 4.65 Mary's Pastor....194
Figure 4. 66 Molly's Pastor....194
Figure 4.67 Molly's Nurse in CF Clinic....196
Figure 4.68 Emily's nurse....197
Figure 4.69 Molly's Respiratory Therapist in the respiratory clinic....197
Figure 4.70 Faith with the CF Research Coordinator....198
Figure 4.71 Emily with her physician and her nurse practitioner....198
Figure 4.72 Adam and his Legos®....201
Figure 4.73 Bethany's bedroom....202
Figure 4.74 Ashley's favorite picture....202
Figure 4.75 Mary and her favorite baby....203
Figure 4.76 Emily's favorite hospital room with the panda wallpaper....204
Figure 4.77 Hilary's pictures depicting beauty....205
Figure 4.78 Ashley's back yard after a snowfall....206
Figure 4.79 Looking at the sky from Faith's back porch....207
Figure 4.80 Jacob on his motorbike....207

Figure 4.81 Daniel's front yard....207
Figure 4.82 Adam's Monkey Land....208
Figure 4.83 Andrew's beach vacation with his family....209
Figure 4.84. Mary's family vacation....209
Figure 4.85 Julia playing games at a community sponsored event....210
Figure 4.86 Daniel riding in a parade....210
Figure 4.87 Adam's police station....211
Figure 5.1 Models of the CF child's world....220
Figure 5.2 Colors Favored by Girls....224
Figure 5.3 Colors Favored by Boys....224

# CHAPTER 1

## Introduction

> The child shall have the right to freedom of expression; this right shall include freedom to seek, receive, and impart information and ideas of all kinds, regardless of frontiers, orally, either in writing or print, in the form of art, or through any other media of the child's choice (Office of the United Nations High Commissioner of Human Rights, 2002, Article 13.1).

Children with have the ability to offer insights into their health condition and may express these insights through stories, art, photographs, and music. Children with CF possess valuable knowledge about their disease. However, research studies dedicated to exploring knowledge and perceptions of children with CF give little attention to eliciting and listening to children's voices. Instead, studies have involved primarily parents, families, and the memories of adolescents and adults with CF (e.g. Admi, 1996; Christian & D'Auria, 1997; Dickinson, Smythe, & Spence, 2006). Researcher's who have evaluated the CF child's social position during health care visits report children of school-age and younger are marginalized (Dickinson, 2004-2005; Savage & Callery, 2007). In other words, the presence of the child is not recognized while health care providers (HCPs) engage in dialog with the parent leaving the child out. While these studies add to the nurse's knowledge about CF, they provide little information from the perspective of the school-age child with CF.

The lack of information in the academic literature about the child's perspective of living with CF lead me to ask the following two questions (1) "How can nurses know what children with CF think and feel if children's voices are not heard during health care visits?"

and (2) "How can nurses adequately support and care for children and families with CF when nurses do not know how children perceive themselves or the world in which they live?"

In this study, photo elicitation (using participant-authored photographs to elicit conversation during an interview) was used to collect data (Oliffe & Bottorff, 2007). First, each child participant was given a Kodak digital camera and asked to photograph the world in which he/she lives. Next, I interviewed each participant face-to-face. The participant guided the interview by using his or her photographs. The photographs were then used to construct a photo book about the child's social world for his or her to keep.

This chapter begins with an overview of the disease of cystic fibrosis. Next, the researchers' stance is presented followed by a description of the philosophical lens that guided this study. The chapter will continue with the presentation of research questions, research assumptions, and key definitions and then closes with study delimitations and limitations.

## Background on Cystic Fibrosis

Cystic Fibrosis is one of the most common inherited life limiting diseases in the United States. According to the Cystic Fibrosis Foundation (2011) one of every 2,500 live babies is born with CF. Approximately, one in 31 Americans carries the CF gene and about 1,000 individuals are diagnosed with CF in the United States each year. The majority (70%) of the newly diagnosed individuals are less than two years of age. Currently, 30,000 of the 70,000 diagnosed children and adults with CF live in the United States; 60 percent of these

individuals are under 18 years of age. CF is most prevalent among the Caucasian population of Northern European descent.

Cystic Fibrosis was first described as a disease by Dr. Dorothy H. Anderson, a physician, in the late 1930s, when malnutrition and pulmonary infections claimed the lives of most CF children during infancy (National Library of Medicine, n.d.). Cystic Fibrosis is a disease of the mucus secreting glands of the body. There are varying degrees of CF disease depending upon an individual's genetic make-up. The primary cellular defect in CF is located within the electrolyte transport system in a protein known as the Cystic Fibrosis conductance Transmembrane Regulator (CFTR) (Strausebaugh & Davis, 2007). The purpose of the CFTR is to control the movement of ions, including sodium and chloride, across the cell membrane. In CF, the CFTR is defective resulting in the production of thick mucus. The abnormally thick mucus plugs the airways in the lungs and obstructs passageways between and within organ systems.

Cystic fibrosis affects any bodily organ and system where mucus is produced including the respiratory system (lungs and sinuses), digestive system (intestines, liver and pancreas), and reproductive system (Orenstein, Spahr, & Weiner, 2011). Common CF symptoms include poor growth, persistent cough, frequent and prolonged respiratory illnesses, flatulence, malodorous bulky stools or constipation, and salty tasting skin. Complications of CF include bronchiectasis, chronic obstructive pulmonary disease (COPD), chronic bronchitis, chronic sinusitis, diabetes, intestinal malabsorption, gastroesophageal reflux, intestinal obstruction, liver cirrhosis, gallstones, pancreatitis, and lack of seminal sperm in males.

Two goals of current CF treatment regimens are to promote (a) healthy lung development by minimizing airway inflammation and preventing bacterial lung infections and (b) normal growth and development through good nutrition and by reducing intestinal fat malabsorption (Cystic Fibrosis Foundation, n.d.; Orenstein et al., 2011). To compensate for intestinal malabsorption and the extra energy required to breathe, most children with CF require a high calorie, high fat diet; once to twice daily A, D, E, and K vitamins; and oral pancreatic enzymes with meals and snacks.

Daily treatments for CF are numerous and time consuming. On average, CF children spend 74.6 minutes a day taking aerosol treatments and performing airway clearance maneuvers (Ziaian et al., 2006). To prevent lung infections, children need to clear their airways of thick mucus at least once a day, and sometimes as often as four times a day. Each airway clearance session lasts approximately 20 to 30 minutes and involves one or more of the following techniques (a) chest percussion therapy with a mechanical vibrating vest, mechanical percussor, or the patting of caregiver hands on a child's chest, (b) cough, (c) huffing, (d) flutter, and (e) active cycle breathing. Then children inhale specially prepared aerosolized medications to thin airway mucus, kill pathogenic bacteria in the airways, and minimize airway inflammation. Each aerosol medication treatment can take from 2 minutes to 10 minutes. Children with CF related liver disease must ingest additional pills and those with chronic sinusitis are advised to irrigate their sinuses with hypertonic saline on a daily basis. Additionally, children with CF related diabetes must also perform finger sticks four times a day to check blood glucose levels and then administer insulin to keep blood glucose levels under control.

Maintaining the health of children with CF places significant demands on the daily life. Medications and treatments must be done before school requiring CF children to wake much earlier than their siblings and peers. Then in the evening, treatments need to be done before going to bed. Time-consuming treatments can also disrupt activities with family and friends. When hospitalized with CF related illnesses, children are often separated from family, friends, and school for up to two to three weeks while they receive numerous respiratory treatments and intravenous antibiotics. The burdens of CF are numerous and the perspective from children who live with it day in and day out need to be communicated.

## Stance of Researcher

The voice of the school-aged child with CF is often silent during health care visits. It is traditional for the parent to speak for the child, particularly for the child with a chronic disease. There is an old saying, "It is better for a child to be seen than heard". In the healthcare settings this has become the rule or norm. Yet, on the contrary, health care professionals need to hear from children with CF because parents do not always know what their children are thinking or how they are feeling. Children possess valuable information and the ability to offer insights into their health condition, but without including the child, it is difficult for health care providers to know what the child has to say about his or her chronic disease.

During the first 15 years of my nursing career, I cared for adults. However, due to a strong desire to work with children and adolescents, I switched roles and became a pulmonary nurse practitioner in a children's hospital. Immediately, I noticed a striking difference between adult and child health care visits. Health care providers, including

myself, primarily engaged in dialog with the parent when eliciting health information about the child, thereby leaving the child marginalized, whereas in adult health HCPs conversed with the patient. In comparison to adult health care, where the patient is engaged often to the exclusion of the family, the marginalization of school-aged children with a chronic condition such as CF seemed even more pronounced. During routine and illness related CF visits, I noticed that children either sat quietly off to the side or engaged in art activities provided by a child life specialist, while the parent spoke to the health care provider. Since the inception of my career with children, I have learned that it is a misconception to think the parent has total knowledge about what their child, thinks, feels, and experiences. Many times, it was only through eliciting the child's thoughts and opinion that I was able to arrive at a correct diagnosis. Curiosity on my part about this phenomenon of exclusion prompted a search of scholarly literature.

## Foundational Research

Reports from nurse and non-nurse researchers, who have examined the position of the child with a chronic disease during interviews with parents and health care providers, have supported my observation that children with chronic conditions have little voice. Dickinson, Smythe, and Spence (2006) reported that when interviewing family members of children with a chronic disease for their study, it was "challenging to ensure that the children's [*sic*] voice was heard" (p. 313). Parents interrupted as their child told his or her story. Because of parental interference, researchers diplomatically guided the conversation to encourage child participation. Savage and Callery (2007) observed during CF dietary consultation visits the position of the child was passive. Conversation occurred primarily

between health care providers and parent(s). Although participants age 10 and older tended to be included more in conversations, for the most part, children adhered to the custom of sitting quietly unless spoken to or risked reprimand for interrupting.

Listening to the parent and not to the child with CF informs health care providers only about the perspective of the parent. As a result, health care providers acquire limited knowledge about what a child knows, understands, or has to say concerning his or her CF. Some adults judge school-age children and younger as being unreliable, immature, and incompetent in regards to discussing health information and in making health care decisions (Dickinson, 2004-2005; Savage & Callery, 2007; Thomas & O'Kane, 2000). However, recent studies portray children as possessing valuable knowledge and experience and the ability to offer insights into their health condition (e.g. Alderson, Sutcliffe, & Curtis, 2006; Sarvey, 2008; Thomas & O'Kane, 2000).

For example, a qualitative study by Alderson et al. (2006) about young children with diabetes revealed children possess more knowledge about their diabetes than previously thought. Children as young as age four were able to understand principles of diabetes and make appropriate, responsible decisions in managing their diabetes. The authors findings led them to question a common assumption, which is also an ethical principle, that the more serious a disease the less the younger child can or should be involved in treatments and decision-making.

In another study, Sarvey (2008) interviewed 11 ventilator dependent children between the ages of 7 to 12 for the purpose of obtaining their experience of living with a machine. Sarvey reported the children were, "quick to demonstrate what they knew about

themselves and their experience" (p. 192). The participants communicated in a clear and forthright manner. The children in Sarvey's study were described as being composed and poised as they spoke and provided vivid details about their life experiences without appearing "bored or fatigued" (p. 194).

Children around the world are perceptive to their marginalized status. A child who presented at the May 2002 Children's Forum said, "We are children whose voices are not being heard. It is time we are taken into account" (United Nations Children's Fund, 2009). Dickinson (2004-2005), an Australian pediatric nurse researcher, asserts children possess sophisticated knowledge about their chronic condition, and although their perspective is different from the nurse's, it is no less valuable. Furthermore, children admit to feeling angry and frustrated when adults do not listen to them.

## Statement of the Problem

In the late 1980s, a new paradigm for understanding child development emerged within the social science disciplines. Prior to that time, children were viewed through the cognitive theories of development; however more recent social scientists take a constructivist stance in which children are seen as active participants, interacting within the culture where they are situated, striving to make sense of their social world (Sartain, Clarke, & Heyman, 2000). The Office of the United Nations High Commissioner of Human Rights (2002) published the United Nations Convention on the Rights of the Child in 1989. This document recognized and supported the human rights of children around the world. Article 12 gave children, capable of forming an opinion, the right to express their view in all matters, which affect them according to their age and level of maturity.

When examining the literature I noticed that, since the early 1990s, research studies have increasingly included children as participants. Instead of seeing children as poor informants whose judgments and perceptions could not be trusted, researchers now express confidence in children's abilities when participating in research (e.g. Miller, 1999; Sharples, Davison, Thomas, & Rudman, 2003). However, there is a paucity of published nursing research that elicits the perspective of the school-age child with CF. The majority of research with CF children follows the positivist research tradition using disease specific theories and quantitative methods. Fewer studies have used naturalistic methods. The problem is that researchers and providers alike do not know and understand how children with chronic illness perceive their physical, social, and inner worlds. Additional qualitative research is needed that elicits the perspective of school-age children with CF using child friendly methods.

## Purpose of the Study

The purpose of this qualitative study was to explore and describe how children with CF view themselves in the world they live. The child's world was viewed through the lens of *symbolic interactionism* (Blumer, 1969). Qualitative description (Sandelowski, 2000) was utilized as the research design. The study focused on the participants' perspective of what it is like to be themselves by incorporating participant-authored photography and photo elicitation as data collection methods. Participants for the study were recruited from one CF center located in the Southeastern United States.

## Philosophical Lens

According to Charon (2007), an emeritus professor of sociology at Minnesota State University at Moorhead and renowned writer, human beings see reality through filters called perspectives. Perspectives develop out of a person's social life. Because it takes more than one angle to understand an object, a person's perspective is "limited and biased" (Charon, p. 10). Perspectives can help researchers to understand phenomena or they can hinder one's understanding of phenomena. For my dissertation research, I chose symbolic interactionism as the lens to assist me in defining reality from the child participant's viewpoint. A human quality recognized by symbolic interactionism is "taking the role of the other" (Charon, 2007, p. 106). Taking the role of the other allows the researcher to move beyond his or her perspective and visualize the world from the perspective of the research participant.

Symbolic interactionism is a unique perspective found within the discipline of sociological social psychology. Sociologic social psychology focuses on the ongoing social interaction between groups and individuals. Early twentieth century philosopher George Herbert Mead heavily influenced the development of symbolic interactionism (Charon, 2007; Stryker, 1987). Mead was a pragmatist influenced by Darwinism and Behaviorism. Other American scholars who contributed to the development of symbolic interactionism include William James, John Dewey, Charles Cooley, and Louis Worth. However, Stryker (2002) credits Herbert Blumer, a student of Mead, as the inventor of symbolic interactionism.

Symbolic interactionism emphasizes the subjective meaning of human behavior and social interaction. Human beings interpret the actions of others and attach meaning to them as they interact with others (Blumer, 1969; Charon, 2007). Symbolic interactionism consists of five main ideas including (a) human beings are social beings, they interact with others; (b) human beings think when acting; (c) humans define the situation they are in through ongoing social situations and thinking; (d) human action is the result of what is presently occurring in an individual's social interaction, thinking, and definition; and (e) human beings do not just respond to their environment, they are actively involved (Charon, 2007).

Three concepts addressed by symbolic interactionism include *environment* (also referred to as the social world), *communication,* and *self* (Blumer, 1969; Charon, 2007). Central to symbolic interactionism is the environment. Human beings do not just respond to the environment nor are they shaped or controlled by the environment. Humans define, use, and act with their environment according to "…ongoing definitions arising from perspectives that are themselves dynamic" (Charon, 2007, p. 42). Additionally humans have the freedom to do, act, make, and direct self within the situational parameters of the environment.

People communicate through symbols (e.g. spoke and written language, drawings, and mathematical equations), which are essential to human society. Symbols are societal created objects and include anything that can be observed, touched, measured, referred to, or named. They are intentional, meaningful and used to represent and communicate feelings, thoughts, goals, and experiences (Charon, 2007). Symbols are unique to the

society and culture in which a person resides and are exchanged within one's environment. Because of symbols, people are able to interpret and attach meaning to their experiences (Stryker, 2002).

Important to symbolic interactionism is the self. The self is complex and unique to each person (Blumer, 1969; Charon, 2007). According to Charon it is "the internal environment toward which we act" (p. 73). It is an object of a person's own actions, which develops out of an individual's interaction with his or her environment (Blumer; Charon). The self begins in childhood and is social. Development of the self is a process; it is continuously being defined and redefined during social interaction. People learn about their self and their existence by interacting with other people. Because human being's possess a self, they are able to reflect on situations and imagine being in them.

Symbolic interactionism is an appropriate lens for studying children with CF because it is a perspective that seeks to understand the social world of others, as they perceive it. Additionally, symbolic interactionism is a perspective that supports naturalistic inquiry into the domain of children (Charon, 2007). Data collection methods such as interview, participant observation, audiotaping, and journaling are appropriate methods within the philosophical stance derived from symbolic interactionism.

## Research Question

The question this study sought to answer is, "What is it like to be a school-age child with CF?"

## Assumptions

Assumptions about school-aged children living with CF developed out of my clinical expertise as an advanced practice nurse who has cared for school-aged children with CF for 12 years, and by reading scholarly healthcare literature concerning care giving experiences with children.

1. School-age children with CF desire to have similar life experiences as their same-age peers.
2. School-age children with CF are knowledgeable about their chronic disease and have something to say about it.
3. School-age children with CF are willing to share stories and photographs about their world, which includes having CF.
4. The elements of a child's daily life can be captured using photographs.
5. School-age children are capable of learning to use a simple camera and taking photos that accurately represent their world.

## Operational Definitions

1. Cystic Fibrosis - Cystic fibrosis is a common inherited childhood disease of the body's mucus producing glands that primarily affect the respiratory and digestive systems and often results in an early death. The diagnosis of CF is typically confirmed by either a positive sweat test and/or two identifiable genetic mutations for CF. In this study, the presence of CF was measured by parental report of a positive sweat test or two genetic CF mutations.

2. School-age Child – For the purpose of this study, a school-age child is defined as a child between the ages of 8 and 11. In this study, age was determined by parental report.
3. Existence - For the school-age child, existence means to have life and to be perceptible by others. Life can be viewed from the past, present, or future. Existence addresses the existential concern of "who am I" and the human desire to have a meaningful life in the world. Existence is uncertain and human beings must confront four existential concerns including death, freedom, isolation, and meaninglessness. The child's perception of existence was based on the description of his or her photographs and accompanying narratives.
4. World - The world consists of the physical, social, and subjective domains and is the sphere of the child's actions, interests, and pursuits. It is a place of earthly existence comprised of social objects situated in human society and cultures with which children experience, interact, interpret, and respond too. As a result of social interaction children form perceptions of their inner and outer worlds, which they take with them into other experiences. The child's perception of the world was based on the description of his or her photographs and accompanying narratives.
5. Family – The family is a holistic structure, comprised of interlocking relationships, that works as a system to support the child's emotional, physical, and social well-being and is influential in the child's differentiation of self. The child's perception of family was based on the description of his or her photographs and accompanying narratives.
6. Self - Constitutes the child. The self is comprised of perceptions, which arise out of the child's daily social interaction, self-beliefs, and his or her personal experience with

cystic fibrosis. The child's perception of self was based on the description of his or her photographs and accompanying narratives.

## Delimitations

This study confined itself to interviewing school-aged children with CF from one CF center located in the Southeastern United States. The criteria for inclusion was limited to school-aged children with CF, between the ages of 8 and 11, who were interested and willing to assent to the study, take photographs, and had parental permission.

## Limitations

Children with CF live in many cultures around the world and models of care among CF treatment centers differ. Because this study involved children from one geographical area, results these results may not transfer to other settings and cultures. Recruiting reliable key informants maximized participant reliability. There is a risk within naturalistic studies for researchers to get too involved in the culture they are studying and possibly compromise the validity of study results. Therefore, a bracketing interview, peer debriefing, and self-reflection journal were employed to ensure the accuracy of findings. All participants in this study wanted to participate. Additionally, all of the parents supported their child's interest in being in it. The results of study may not represent the perceptions of children who either did not want to be in the study or whose parents would not allow them to participate.

## Summary

Even though the United Nations Convention on the Rights of the Child delineates the rights of children around the world, children still are not recognized in the United States as having value. School-age children with CF possess the experience and the ability to provide

health care professionals insight into their world. School-age children with CF must be recognized and heard by those who care for them. Nurses need to provide opportunities to listen to children with CF and allow them to express their knowledge, opinions, concerns, feelings, and emotions. When attempting to elicit the childhood experience of living with CF previous researchers have used CF parents and families as proxies and the memories of adolescents and adults with cystic fibrosis (e.g. Admi, 1996; Christian & D'Auria, 1997; Dickinson et al., 2006). Few studies have focused on the perceptions of children. Many have used adult oriented methods and steered participants towards the interests of the researchers. Nurse researchers who have engaged school-age children as research participants have either collected data through structured and guided interviews (Shannon, 1979), asked children to describe memories or critical events (D'Auria, Christian, & Richardson, 1997), or utilized instruments such as health related quality of life surveys (e.g. Havermans, Vreys, Proesmans, & De Boech, 2006; Ziaian et al., 2006).

This study differs from previous research because recent child-authored photographs, depicting children's perceptions of being themselves in their environment, guided the interviews. Using children's own photographs to guide the interviews empowered each child participant to be the author of his or her own story. This study gives nurses, parents, and other health care providers, insight into the world of school-age children living with CF as perceived by them in the here and now. In knowing the reality of children with CF, I believe nurses are better equipped to offer care and plan interventions that are meaningful, beneficial, and satisfying to the child and his or her parent(s).

# CHAPTER 2

## Review of Literature

This integrated literature review represents what I learned while exploring the phenomenon of the world of the child with CF. My search of the empirical, opinion, and theoretical literature encompassed the disciplines of nursing, developmental psychology, sociology, sociologic social psychiatry, philosophy, theology, anthropology, social work, medicine, biology, education, and art. The chapter begins with a presentation of theory applicable to the childhood experience of CF. This literature review starts by defining and discussing the concepts of existence, world, family, and self. The chapter concludes with a review of empirical peer reviewed literature regarding perceptions of the childhood experience of CF.

Below is a model (Figure 2.1) constructed after the literature review was completed, which represents the world of the CF child from an academic viewpoint. I will use the model as a reference point when guiding the reader through this review working from the outside of the model inward. The things which comprise the child's world include the perceptions the child holds about his or her existence, world, family, self, and CF. The red outer most ring signifies the concept of *Existence*. Next is a blue circle representing the *World*, followed by *Family*, which is a green loop. After that is an orange circle depicting the concept of *Self,* followed by a purple ring titled *Chronic Illness* representing CF. The inner yellow rings symbolize the *Child* of whom this study is about. The child along with his or her perceptions sits in the center of the world. These perceptions are influenced by the child's level of development. They arise out of the child's daily social interaction, self-

beliefs, and his or her personal experience with CF all of which influence the development of the self. I will now begin by defining and discussing the concept of Existence.

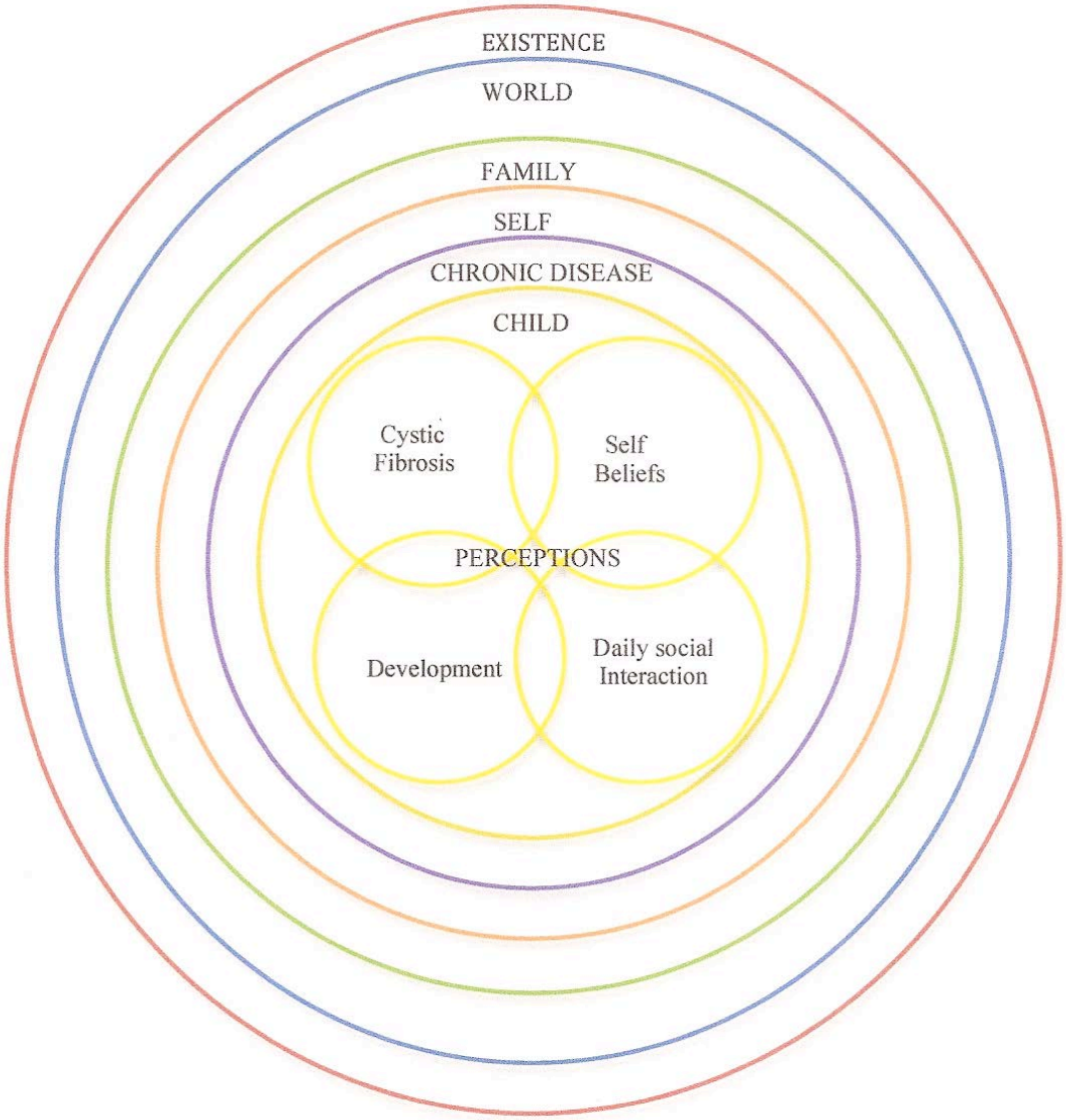



Figure 2.1.The World of the Child With CF

## Existence

The model's outer most red ring signifies the concept of *Existence*, which addresses the existential concern "of who am I" and the human desire to have a meaningful life. For thousands of years humans have pondered the concept of existence, even the ancient Greek philosopher Socrates (Plato, 1996) contemplated issues relating to the presence and power of humanness. According to Socrates, "an unexamined life was not worth living" (Plato, n.d.). Socrates reasoned that to discover the truth about others and one's self one should "know thyself" (Plato, 1996). Descartes, a 17th century French philosopher, concluded that only conscious thinking could be esteemed as evidence of one's true existence (Descartes, n.d.; Nores, 1999). He regarded the body, feelings, memories, sensory perceptions, motions, and time with suspicion and considered them fictions of the mind. In other words, Socrates thought existence involves personal reflection and examination of how one has lived his or her life up until a particular point in time and Descartes believed it is only through active conscious thought that a person can be assured of his or her existence. Socrates and Descartes' ideas about existence are abstract and philosophical; above and beyond the level of how a typical school-age child would describe their own existence. To obtain a tangible and applicable definition of existence it is better to look in contemporary writings, beginning with the dictionary.

### Defining Existence

Both of the terms *being* and *existence* have been used over the past five centuries when addressing the idea of human earthly presence. However, during the past century and a half, *existence* has been increasingly used in place of *being* (Leclerc, 1984). Leclerc believed

this trend developed partially out of confusion with defining the verb *be.* The term, *being,* originated around the 14th century. The Oxford English Dictionary (being, 1989) defines being as (a) life, physical existence, (b) existence in some relation of place or condition, (c) that which exists or is conceived of existing; a person, and (d) essential substance, essence.

The term *existence* originated during the 15th century. The Oxford English Dictionary (existence, 1989) provides several, yet similar, modern day usages of the word *existence* including (a) all that exists; the aggregate of being, (b) something that exists, such as a being or an entity, and (c) being; the fact or state of existing, 'actual possession of being'. These definitions imply *existence* involves something of substance, for example a child that resides in the world is present, real, and living. Dictionary.com (existence, n.d.) augments the idea of existence as the "essence of being, perception, consciousness". Existence is a static term (noun) thus applied in reference to things or persons capable of perceiving and thinking. Nevertheless, what does it mean *to exist?* The English word *exist* is an action word derived from the Latin verb *ex(s)isto* meaning: to appear, come forward, come into being (exist, 1996; Leclerc, 1984). The contemporary definition of *exist* is to have life, to be perceptible, and to "have place in the domain of reality" (exist, 1989). Defining and understanding human existence extends beyond the dictionary. During the early to mid 19th century a philosophic movement began (Mounier, 1948) dedicated to understanding man[1] and exploring concerns related to human existence (May, 1959b; Yalom, 1980). This movement, called existentialism, was popularized in the 20th century.

---

[1] For the purposes of writing, the term *man* is used to reference humankind and does not imply gender or the superiority of one gender of the other

**Existentialism**

Existentialism is a philosophy that ponders the unending tensions of human circumstances that all humans share (Breisach, 1962). The ancestral roots of existential thought can be traced to Socrates, the Stoics, Pascal, St. Augustine, and St. Bernard (Mounier, 1948). Central to existentialism is the idea that human beings struggle to make meaning in a meaningless world. Humans are conscious entities who interact with themselves, other beings, and objects in the world and their decisions in life determine who they are and what they become. Although, the most influential and quoted existentialists include Søren Kierkegaard, Martin Heidegger, and Jean-Paul Sartre this literature review will focus on the theoretical orientation of Irvin Yalom because it is less philosophical, more concrete, and applicable to the school-age child.

Yalom (n.d.) is a United States born author and Professor Emeritus of psychology at Stanford University. His viewpoint is applicable to this study because he addresses issues involving living and death, both of which children with CF encounter. According to Yalom (1980) the person as more than just a perceiving being. The person is conscious and actively participates in constructing his or her own reality. For all, existence is uncertain. Varying degrees of "conscious and unconscious forces" along with motives and fears are at work within each person (Yalom, 1980, p. 6). Yalom identifies four dynamic concerns that human beings inescapably confront by being present in the world. These concerns include death, freedom, isolation and meaninglessness.

A person's attitude towards death effects how he or she lives and mature (Yalom, 1980). Humans fear obliteration and helplessness, but at some point everyone will face the

death of a loved one and/or one's own death. Death is a source of anxiety; people either consciously or unconsciously avoid thinking about it. Yet, it is through confronting death that people see the value and immediacy of life. Facing death intensifies human desire to continue to exist and heightens awareness of others and the world (May, 1959a; Yalom, 1980). While adults avoid the subject of death children think often and deeply about it. Yalom reports that his five-year-old son commented that he never stopped thinking about death (Yalom, 1980). Children's thoughts of death influence how they experience the world. They fear death and link growing old with death.

Freedom is a deep existential concern that has "broad, personal, social, moral, and political implications" (Yalom, 1980, p. 216). People are the authors of their own destiny. Freedom involves accepting personal responsibility for one's actions or inactions, predicaments, sufferings, and feelings. The absence of social structure forces humans to confront freedom. For example, college students are often confronted with the choice of studying for an exam or attending an all night party. When making a decision, students typically feel anxiety over what they want to do and what they should do; either way they have the freedom to decide. Failure to accept responsibility results in displacement of responsibility (blaming someone else), compulsivity, avoiding situations, and denial of responsibility (innocent victim).

Another existential concern is isolation. Existential isolation pertains to an unbridgeable physical and emotional separation of the person from others and the world (Yalom, 1980). Existential isolation is the sense of nothingness outside of one's own consciousness resulting in feelings of helplessness, aloneness, and groundlessness. As one

of Yalom's patients describes it "there's no one else there but me" (p. 355). In order to create meaningful relationships people must confront existential loneliness.

The final human concern is meaninglessness. Man is a "meaning seeking creature" thrown into a meaningless universe (Yalom, 1980, p. 9). Yalom posits that humans need a meaningful life in order to survive. A life without goals, values, ideals, or purpose provokes dissatisfaction, discomfort, helplessness, and distress. Sources of meaning develop out of one's spiritual beliefs, altruism, dedication to a cause, creative productivity, realizing one's potential, and self-transcendence. Life is fulfilling for those who find meaning. However, some individuals find no meaning in life.

**Non-existence**

Death is the most obvious threat to existence. Physical death is tangible evidence that a person is no longer present in the objective world. Without an awareness of non-existence (death), existence is unreal and "characterized by lack of concrete self-awareness" (May, 1959a, p. 48). Physical death is not the only means by which people experience non-existence. As depicted in the lyrics of a song by The Sisters of Mercy (1990), "I don't exist when you don't see me", for some the feeling of not existing can arise out of disregard and lack of recognition by other human beings in the world. Another writer (anonymous, n.d.) describes non-existence as a desperate emptiness arising out of a tortured and restless mind searching for something that cannot be found:

I must rest to forget

What I am

What I will be

I am tired of searching for answers

Visions of past and future

Silently my mind fades into nothingness

Maybe I will sleep forever

In reference to the anonymous writer's stance on non-existence Sartre (Sartre, 1965) would say that non-being is not a passive emptiness but the non-being of being.

Existential concerns exist not only in the hearts and minds of adults, but also the young. Vallino and Maccio (2004) assert that it is through parents that children come to know and experience their existence. The simple act of a parent picking up and comforting their crying infant symbolizes to the child that he or she is recognized and loved. An awareness of love is important for a human being's sense of existence (Yalom, 1980). Maslow identified love and belonging as a basic human need for overcoming loneliness and isolation (Eggan & Kauchak, 2001). When denied parental affection children risk "drifting into a sense of non-existence" (Vallino & Maccio, 2004, p. 74) and perceiving themselves as being unwanted, forgotten, or even annihilated.

**Summary**

In summary, a sense of existence is vital for the survival of the child. Humans are purpose-seeking creatures thrown into the world without consent. Each person is responsible for creating meaning and for his or her destiny. Without goals or a purpose, life is not meaningful. To fully understand existence one must also consider non-existence. The lack of human acknowledgement and affection results in a deep sense of loneliness and

feelings of rejection. The next portion of this paper will discuss the world, a place where all human beings, including children with CF, exist.

## The World

The next inner ring of the model is a blue circle representing the concept of the *World*. The world is the realm of earthly existence comprised of social objects situated in human society and culture where children experience and develop perceptions of their inner and external worlds.

One of the oldest sources providing a definition of the term *world* is in the book of Genesis found within the Old Testament of the Bible. Genesis provides a description of a physical world that consists of "all the earth" (New King James Version, 1982, Gen 2:7), the sky above, and the heavens beyond the sky. On the earth are living creatures, vegetation, water, and land, which are affected by day, night, and seasonal changes. However, the world is more than just a physical domain, it is also a place where human beings develop and experience that which is in the world. Whereas the first chapter of Genesis identifies a world that is concrete, the sociologic perspective of Symbolic Interactionism (SI) exposes a social world constructed and maintained through human interaction (Blumer, 1969; Charon, 2007).

### Symbolic Interactionism

Symbolic Interactionism emphasizes the micro level connections between "the subjective consciousness, interpersonal interaction, and identity formation" (Johnson, 2008, p. 111) as well as the nature of a socially constructed larger world. Human beings are completely (Heidegger, 1996) and dynamically (Charon, 2007) immersed in a physical,

objective and subjective world. People actively participate in and respond to the environment around them (Blumer, 1969; Charon, 2007). Through interaction with others and the self, people come to learn, understand, and define their world. The environment is comprised of objects, which possess social significance and value. People indicate, isolate, categorize, interpret, and ascribe meaning to objects in their environment. The concept of social objects is broad and includes the self and all places, people, natural and man made things, societal places, laws, symbols, traditions, and emotions. Although objects are socially created and typically understood by other members of a society, the meaning of an object can differ among individuals and groups. It is also subject to change or abandonment through the passage of time or as situations change.

Central to the human essence is the use of symbols for communication. Symbols stand between the sensed world as it truly exists and a person's perspective of that world (Charon, 2007). Humans perceive and become aware of their environment through hearing, touch, sight, smell, taste, and kinesthesia (Charon, 2007; Tuan, 1977). Symbols and sensory perceptions aid individuals in understanding and defining their spatial and social orientation in the world and serve as perspectives for subjective reality. Perspectives then influence subsequent acts towards the environment (Blumer, 1969; Charon, 2007). Charon identifies three kinds of reality (a) the physical, objective reality; (b) social reality; and (c) the subjective reality created out of social reality. Since people handle and act towards their environment based on the meaning one assigns to objects, individuals residing in the same space may possess different realities and hence live in different worlds (Blumer, 1969; Charon, 2007).

**Defining The World**

When the average person wants to know and understand the meaning of a word they do not investigate theoretical perspectives; instead they go to the dictionary. In addition to defining the world as a physical place, the Oxford English Dictionary (world, 1989) also defines world as (a) the period of human earthly existence or this present life; (b) human society; and (c) sphere of one's actions, interests, and pursuits. The etymological root of the word world consists of *wer* (man) + *ald* (age) which means "age" or "life of man" (world, 2001). In this section, the world will be discussed in the context of three dimensions: a period of earthly existence, human society, and sphere of human actions, interests, and pursuits.

**A period of earthly existence.**

Corporeal existence on earth is limited. The average individual born today can expect to live 80 years (National Center for Health Statistics, 2010). There is a clear beginning and a definite end, beginning at birth when the infant is expelled from its mother's womb and ending with death of the body. Before 1966, when prenatal diagnostic procedures were limited, the account of one's existence, or biography, began at birth. However, since 1966 there has been an explosion of prenatal diagnostic procedures that permit health care clinicians to study an individual before birth (Woo, 2006).

Today, a CF child's health history may begin between conception and birth. When both parents are known CF gene carriers, prenatal testing can be performed to ascertain whether or not the fetus will be born with CF. Prenatal testing options include ultrasonography to look for CF markers (e.g. echogenic bowel) as well as amniocentesis

and sampling of the chorionic villus to determine CF genetic abnormalities (Goetzinger & Cahill, 2010).

Within minutes of birth, the infant's health biography continues to accumulate as health care professionals visually and audibly assess the newborn for abnormalities and assign an apgar score. Next, blood is drawn and analyzed for any genetic and metabolic diseases. To facilitate early diagnosis, newborn screening for CF is now standard in all states in the United States (US). Then, at approximately two to four days of age the infant is taken to the pediatrician's office for the first time. Infants who have a positive newborn screen go on to have a confirmatory sweat test[2] and are referred to a regional CF clinic. The CF child's health biography continues to expand with each subsequent encounter with the health care system as long as he or she corporally exists.

Birth also marks the beginning of the CF child's legal identity; footprints are obtained, a name is given, and gender is confirmed. An individual's idea of who they are and how they fit into society is shaped and developed over time (Shaffer & Kipp, 2010). Identity does not stabilize until late adolescence to early adulthood (McAdams, 2003; Shaffer & Kipp, 2010). Identity is also comprised of "thoughts, feelings, values, attitudes, and behaviors that define" one's self (Lerner & Ashman, 2006, p. 42). McAdams refers to one's identity as a life story, an integrated narrative of the self, comprised of reflections of the past, perceptions from the present, and expectations for the future. Through out life health and disease mark peoples lives.

---

[2] A sweat test involves the collection of sweat from an child's arm. The sweat is then measured and checked for an elevation of chloride ions.

The moment a person receives a medical diagnosis he or she is labeled. Individuals with CF will be always be "a person with CF" as long as they exist in the world. The label of CF follows upon entering school, with every clinic visit and hospitalization, and into adulthood when entering college and the workforce. People born with chronic health conditions such as CF have a shorter life expectancy than those born healthy (Cystic Fibrosis Foundation, 2011). Fortunately, modern technological and pharmaceutical advancements are contributing to increases in the period of existence for individuals with chronic life limiting conditions.

The median life expectancy for individuals with CF has risen from 13 years of age in 1978 (Fogarty, Hubbard, & Britton, 2000) to approximately 37.4 years as of 2008 (Cystic Fibrosis Foundation, 2009). Today more than 45% of people with CF are older than age 18 and 50% percent of all CF individuals are expected to live beyond age 30 (Cystic Fibrosis Foundation, 2011). According to the CF Foundation an early diagnosis lends to early treatment and results in a healthier childhood. In 2007, seventy percent of individuals with CF were diagnosed by age two (Cystic Fibrosis Foundation, 2007), but as of December 2009 all states required mandatory newborn screening for CF (Cystic Fibrosis Foundation, 2009). It is now hopeful that the vast majority of individuals with CF will be diagnosed in early infancy and that life expectancy will increase as a result of early identification and intervention.

**Human society.**

Berger and Luckmann assert (1966) a child is not born into society, but rather with a propensity towards sociability. Human society is defined as a distinct and unified group of

people, existing beyond the individual, who occupy a common territory and share common cultural patterns, traditions, interests, institutions, and history (Blumer, 1969; Charon, 2007; Park, 2010; Scott & Marshal, 2009). A child becomes a member of society through an internalization process called socialization. Socialization can be defined as the "comprehensive and consistent induction of an individual into the objective world of a society or sector of it" (Berger & Luckmann, 1966, p. 130) that shapes one's identity, thoughts, emotions, and the roles one assumes in society (Berger & Luckmann; Charon).

Symbolic interactionism conceptualizes society as a dynamic, but somewhat stable, structure comprised of people interacting with each other over time. Society defines, shapes, and directs the actions of others through symbolic communication (Charon, 2007). According to Charon three qualities must be present in order for a society to remain viable (1) cooperation and interdependence among members, (2) ongoing social interaction, and (3) culture.

***Cooperation and interdependence.***

A society can be long lasting such as the Australian Aborigines or it can be short lasting such as an old mining town. Charon (2007) asserts societies exist only as long as their members work together and put aside personal differences to achieve common or complementary goals. Whereas society and family are dependent upon children to carry on culture and civilization, children need the support of family and society to survive and achieve successful cognitive and psychosocial development.

***Ongoing social interaction.***

Social interaction is a mutual process between two or more people where individuals take into account the actions of others (Charon, 2007). Interaction occurs when people assume roles, communicate, interpret one another, adjust their acts to one another, direct and control their self, and share perspectives. In society, the actions of its members are intertwined; people fit their actions to the actions of others. In other words people act with the other person in mind. For example, children may confide to the nurse how they are feeling only if they sense that the nurse cares about them. The child's action of not speaking to the nurse in turn affects the nurse's subsequent actions towards the child.

A person's beliefs and perspectives are subject to change because interaction is an ongoing process that occurs with different people and groups. During early childhood the family is primarily in charge of the child's socialization (Berger & Luckmann, 1966). Reality is mediated by the parents and filtered to the child who then absorbs aspects of the social world he or she has been given access. For example, children from highly educated families may grow up planning on attending a university whereas children from a working class family may plan on attending a trade school or not school at all. When children enter school, classmates, friends, and teachers also become influential reference groups for socialization.

It is within the context of social interaction that identities are formed and lost. Individuals use their perceptions to define who they are according to each social group. Parents receive the identity of mother or father when interacting with their first child upon its birth. Through interactions with one's family, friends, teachers, and schoolmates a child

may be labeled or given a nickname. For example, the child with a caring disposition may be labeled as the good child where as a child with a mean disposition is labeled a bully. Sometimes a society may refuse to interact with certain individual's due to their outward appearance, unusual behavior, or disability thereby denying them societal recognition and social privileges. In Speraw's (2006) phenomenological study concerning parents and caregiver's experiences in seeking religious education for their child with special needs, parents reported difficulties in locating organized religious experiences for their disabled children. They anguished over their child's invisible presence to other members in their spiritual community. One mother reported congregational members looked over her child as if the child was not present. Other parents reported their child's special gift, such as musical ability, was discounted because the child was considered different and/or strange.

Understanding the perceptions behind the acts and interactions of others is crucial for human social interaction (Charon, 2007; Blumer, 1969). Charon calls this understanding "taking the role of the other" (p. 143). Taking the role of another is a necessary action nurses must utilize when caring for children and their families. Understanding how patients and their family perceive a particular situation or disease is essential for the delivery of quality patient centered care.

***Human culture.***

Over time, ongoing social interaction results in people developing and using similar perspectives and behavioral patterns (Charon, 2007). These ways of thinking, appraising, and acting form what is called culture. In turn, culture supplies the lens by which children view their social world (Charon, 2007; Lerner & Ashman, 2006). Culture encompasses the

total of all beliefs, values, morals, norms, customs, symbols (including language), institutions, and behaviors, which are shared and generationally transmitted within an identifiable group of people. For children culture is believed to guide their thoughts, decisions, emotions, roles, and behaviors and contributes to the differences between them (P. M. Cole, Bruschi, & Tamang, 2002).

Cultural beliefs influence how families and individuals view health and disease and affect their health care practices (Leininger, 2006). For example, some families believe disease such as CF, has a spiritual cause and think prayer will protect their child from the devastating effects of a disease (Jaye, 2003; Turner, 1996). Other families doubt the safety and effectiveness of traditional Western medicine. Instead, they rely on nontraditional practitioners and treatments such as home remedies, acupuncture, chiropractic, and special nutritional supplements to treat their child's CF.

**Sphere of human actions, interests, and pursuits.**

The previous segments of this section discussed the natural world, earthly existence, and the social world. The next section will present ways children engage with the world and express their experiences.

According to SI, symbols are central to human society because they make human reality possible (Charon, 2007). Symbols, especially language, provide the means by which people interact and communicate with each other and themselves. Symbols allow people to address the future, record the past, pursue goals, engage in activities, and convey knowledge. Language enables humans to learn about, adapt, respond, and interpret their natural and social worlds (Johnson, 2008).

Infants learn language by observing and imitating symbols communicated by their parents and other close family members, gradually incorporating the language of others into their own being (Charon, 2007; Meltzoff & Moore, 1989). Young children learn to use culturally learned symbols to express and share their thoughts, feelings, emotions, desires, worries, perceptions, and experiences. By age five, language development has stabilized and most children are viewed as competent speakers and communicators (Quigley, 2000).

Quigley (2000) and colleagues examined language differences among 36 Irish children in three age groups 5, 8, and 12 while having them construct autobiographical narratives. Researchers asked participants to bring photographs from home to promote conversation and discovered pictorial prompts helped younger children find a point of reference with which to begin their narrative. Although 5-year-olds spoke primarily of ownership, possessions, and present events and were less able to discuss the present with past and future time frames they could still reflect and construct a simple autobiography. Eight year-olds narratives were straightforward, more organized, and coherent. Stories had a definite beginning and end. Eight-year-olds narratives tended to be action oriented, conservative, and involved the past. The narratives of 12-year-old were more reflective, self-aware, and oriented towards the future. Additionally, older children possessed an awareness "of their image in the eyes of the other" (p. 188) and so they shaped events for the listener. Because this study involved children from only one culture, it may not be generalizable to children outside of the culture from which participants were recruited. It is possible that narratives from children in other cultures would differ from those described in this study.

Human expression arises from a world known only by the person who is in possession of it, the internal world. In Western society children are encouraged to express themselves in a variety of ways including through writing, talking, playing, dancing, painting, drawing, and singing. Three ways by which educators, clinicians, and researchers encourage children to express themselves are stories, drawing, and photography. These child friendly methods provide children with the means to voice thoughts, feelings, and experiences when they are not always able to state verbally.

***Stories.***

Discourse with children conveys cultural information as well as personal meaning. In all cultures, children enjoy hearing stories and telling stories (Egan, 1986). Children's narratives often reflect how they make sense of their world and their experiences. Schoolteachers often use stories as an education tool. Clinicians and researchers elicit stories from children through drawings and narratives as a means to get them to express their thoughts and feelings (R. Cole, 1986). Stories can also be used with children to promote health and socially desirable behavior.

One innovative nurse researcher used a technique called 'digital story' to assist school-age children with asthma in identifying and developing strategies to manage their asthma (Wyatt & Hauenstein, 2008). Wyatt created a computerized social world where children could receive stories about asthma and then construct their own asthma story. Other researchers have used "social stories" to help children with learning disabilities and autism to modify disruptive behavior (Crozier & Tincani, 2005; Moore, 2004). Social stories are simple stories constructed from the child's perspective designed to teach children socially

acceptable ways to interact and behave in their environment. Another mode of expression for children is art.

***Drawing.***

Since the 19th century, adults have been fascinated with children's artistic expression (Costall, 1995; Willats, n.d.). Although children draw for many reasons, children's drawings are believed to reflect their unique inner world (Malchiodi, 1998). Children use art to connect their experiences of the social world with their inner world and for integrating their inner thoughts and perceptions into the self. Drawing permits children to pictorially depict thoughts, feelings, and emotions in a way words cannot. To promote a sense of comfort and safety, psychologists, pediatricians, and social scientists often use drawing as a vehicle to enhance communication and encourage expression when working with children. Since adults can misinterpret children's drawings, it is important that adults realize the child is the expert of his or her experiences (Malchiodi, 1998) and when it comes to interpreting a child's drawing, the child is the authority. Malchiodi revealed an occasion when she interpreted a client's black spots as a sign that the child had been abused. However, in reality the black spots were the child's way of telling the therapist that she was experiencing physical pain from a stomach ulcer; in this case rather than focusing on a physical problem the therapist mistakenly assumed the child's problem was emotional.

***Photography.***

Photography is now becoming an increasingly popular approach for eliciting children's perceptions of their world. Teachers use photography to teach students how to write (Ewald & Lightfoot, 2001), with photographs serving as starting points for essays.

Researchers and journalists alike use photography as a vehicle for gaining access into peoples environments and lives that they, themselves cannot enter. Zana Briski, a New York photographer, moved to Calcutta in 1997 to document the lives of women and children living in the Indian brothels (Costall, 1995). On the side she taught photography to the children. The children's photos and their associated narratives depicted people and places unknown and inaccessible to Briski, which later added depth and richness to her award winning documentary film.

Ewald, a world-renowned photojournalist, says that photography gives children a voice for acknowledging and discussing their situations (Ewald & Lightfoot, 2001; Ewald, Weinberg, & Stahel, 2000). Children's photographs are taken at their own eye-level picking up scenes that go unnoticed by taller adults. At times she has been taken back by children's photos because they can be more complicated and even more disturbing than an even her own (Ewald & Lightfoot, 2001). One day while living on a reservation in Labrador, Canada she sent her young photography students out to take pictures. Along with pictures of inanimate objects, such as a teapot, they also returned with pictures of a drunken man and fighting couples. The children's photographs, in which nothing was posed, depicted the sharp reality of their environment.

Sharples, Davidson, Thomas, and Ruben (2003) examined children's photographic taking behaviors and abilities. Study participants were between the ages of 7 to 15. The authors report that children age 11 and under were typically accompanied by a parent when taking photographs. Seven year-olds tended to photograph their home environment, personal possessions (e.g. games and toys), and family members in posed positions. Eleven

year-olds took photographs of their external environment, posed animals, and silly scenes. The researchers learned that children were not immature photographers nor did they waste film as adults previously thought. Instead, children in all age groups were intentional in their picture taking actions and that their images represented reality rather than idealized images of their social world.

**Summary**

In summary, the world is a realm of human existence comprised of physical, social, and subjective domains. Corporeal existence in the world has a clear beginning and a definite end. Although, birth marks the beginning of an individual's legal identity, identity formation is a process that occurs through the process of socialization. Human society is a distinct group of cooperative and interdependent people who continually engage in social interaction (Blumer, 1969; Charon, 2007). Overtime, cultures are formed within society as clusters of people develop similar symbols, beliefs, and customs. Cultural beliefs affect how people view health and illness and their health care behaviors. However, little information was found in the literature concerning the effects of culture on the health care practices of families and individuals with CF.

People are not just shaped or controlled by their environment. They are also active participants who come to know and define their world by interacting with the objects in their environment (Blumer, 1969; Charon, 2007). Children interact with the world and express their experiences by hearing and telling stories, drawing, and taking pictures. Stories, drawings, and pictures are believed to reflect the child's innermost world by

depicting their thoughts, emotions, feelings and experiences. Today, researchers successfully use these methods to obtain children's perspectives about their world.

The next part of this literature review will define and discuss the concept of family as it relates to the child with CF.

## Family

In the model of The World of the Child With CF, family is depicted as the green line situated between the world and the self. The Family is a holistic unit, which supports the child's emotional, physical, spiritual, and social well-being and is influential in the child's differentiation of self from other members of the family. Families living with CF are faced with issues related to the child's chronic disease including uncertainty, normalization as well as the demands of living with a chronic illness, which in turn influence the child's perceptions about his or her self.

Today, families come in all forms. In its simplest and traditional form, the nuclear family consists of a mother, father, and child. Beyond the nuclear family is the extended family consisting of grandparents, aunts, uncles, nieces and nephews. With society's acceptance of same gendered parenting and increasing social pressures such as an elevated divorce rate, financial struggles, and high incidence of incarceration, the concept of family is being redefined as modern society acknowledges nontraditional family arrangements.

Shaffer and Kipp (2010) describe the family as a "holistic structure" comprised of interrelated parts, each influencing the other and contributing to the performance of the whole. Bowen (Kerr & Bowen, 1988) views the family as a complex emotional system comprised of a network of interlocking dynamic relationships. Family relationships are

reciprocal, not only do parents influence their children, children also affect the behavior their parents (Berk, 2010; Kerr & Bowen; Shaffer & Kipp). Families shape the beliefs, values, feelings, attitudes, and behaviors of their members, as well as create and maintain the roles that individuals occupy in the family system (Kerr & Bowen). Additionally, I personally believe that families serve to support the health and well-being of its members.

The following section will explore how families function as a unit according to Bowen's *Family Systems Theory.* Then six qualities of healthy families will be presented as outlined by DeFrain and Sinnett's *Family Strengths Model* (DeFrain, 1999).

**The Family as a System**

Bowen's family systems theory (FST) arose out of his observations of families in the 1950s while working at the National Institute of Mental Health (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). Through observation, Bowen came to believe that a person's behavior could not be understood outside the context of the functioning of other surrounding family members. This is because in family units, each person influences the physical, emotional, and social well-being of others (Kerr & Bowen, 1988). Bowen noticed that emotional relationships among family members were reciprocal. Extreme reciprocal relationships resulted in significant personality characteristics consisting of mirrored opposite (adequate and inadequate) behaviors. For example, if one person was excessively dominant another would be excessively submissive. Lastly, Bowen found that when the emotional connections among family members were stressed, one or more people would experience feelings of isolation, bewilderment, and loss of control (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988).

Bowen's FST consists of eight concepts that account for family functioning (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). The concepts include (1) triangles, (2) differentiation of self, (3) nuclear family emotional system, (4) family projection process, (5) multigenerational transmission process, (6) emotional cutoff, (7) sibling position, and (8) societal emotional process.

**Triangles.**

As previously mentioned it is not possible to explain a relationship between two or more people, such as a parent and child, without first examining their relationships with other people. (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). The process by which relationships become entwined with others is called triangulation. The triangle is a system that depicts the relationship between three people, such as a father, mother, and child. A single triangle is just one aspect of a larger emotional system of many more triangles. Within the triangle, anxiety is the predominant activity influencing the relationships. As anxiety increases between two individuals a third person is drawn in " creating a triangle" (135). For example, often when there is conflict between a child and one parent, the child will go to the other parent for support. Triangulation acts to lessen anxiety by diffusing the tension from two people to three people. However, during conflict one person in the triangle is pushed to the side and if pushed far enough the outsider such as the child will act out by rebelling, becoming depressed, or developing physical symptoms.

**Differentiation of self.**

Every child who comes into the world is dependent upon other human beings in the environment for survival (Kerr & Bowen, 1988). As children mature and separate from their parents, they begin to think and act for themselves. However, some people find it difficult to think and act separately from their family. The process by which a person is able to manage "individuality and togetherness" in a family system is called differentiation of self (p. 95). Bowen believed that the concept of differentiation explains why cohesiveness, altruism and cooperation vary among families (p.85). In a family whose members are differentiated, children are permitted to think and behave as individuals whereas in non-differentiated families, children's thoughts and behavior are dictated by the reactions of others. Bowen also used the term *fused* to describe an undifferentiated self. Level of differentiation is believed to affect a person's health, educational achievements, and length of life.

For example, families that support differentiation of self often encourage their children to participate in extra curricular activities, such as a sport, and stimulate thought about what their children would like to be when they grow up. Conversely, children with CF are often not allowed to participate in school sport activities out of parental and coach fears that too much activity could be harmful. Additionally, because parents of children with CF are often unsure about their child's future they may not discuss possible career opportunities with their child. Indeed, on a deeper level, some parents may be reluctant to have their child grow at all since the older the child becomes, very often the more tenuous

the child's life becomes. "Growing up" then becomes something that some CF families would prefer to avoid.

**Nuclear family emotional system.**

Anxiety among family members rises during times of prolonged or elevated stress (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). In the nuclear family emotional system there are four relationship patterns that may develop when family tension is heightened, including (a) marital conflict, (b) spousal dysfunction, (c) impairment of a child, and (d) emotional distance. These patterns are produced when members of a family are undifferentiation. Anxiety from family stress settles on either one person (e.g. child) or one relationship (e.g. mom and dad) resulting in physical, emotional, or mental symptoms. Families of children with CF often experience financial strain due to the cost of medications and hospitalizations resulting in marital conflict.

**Family projection process.**

The process by which parents transmit their anxieties on to their children is called the family projection process (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). The process involves three steps "scanning, diagnosing and treating" (2010, para 3). When scanning, an anxious parent looks for something wrong with a child's behavior. Once the parent perceives to have found what he or she is looking for, the child is labeled and treated as if he or she has a problem. For example, children with CF normally cough to expectorate lung secretions. However, if a parent is anxious, the cough may be overly interpreted as pneumonia prompting the parent to step up respiratory treatments and scheduling an unneeded health care appointment. Repetitive projection can affect the

growth and development of children who eventually come to embody their parent's perceptions as their own.

**Multigenerational transmission process.**

The root of every person's level of differentiation runs generations deep (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). Genetic and relational patterns that promote differentiation of self (e.g. moods, behaviors, and attitudes) are passed along from generation to generation. For example, people who grow up with anxiety about body functions may teach their children to be highly anxious about having CF. Transmission of these patterns occurs consciously and unconsciously. Within a multigenerational family there is a wide range of differentiation among its members. Nuclear families with highly differentiated members tend to be stable and are more apt to contribute to society, whereas families with poorly differentiated members tend to be chaotic, requiring support from society. Family patterns tend to be repeated in future generations, however with awareness, work and therapy it is possible to change dysfunctional patterns.

**Emotional cutoff.**

Emotional cutoff describes how people manage unresolved emotional issues with their family (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). Tension in the family is often reduced when the member assuming the majority of the burden moves away either physically or emotionally. People who are able to gain emotional objectivity tend to not cut themselves off and can remain in contact with their family.

**Sibling position.**

The concept of sibling position involves the premise that, within a family structure, order of birth predicts development of certain personality characteristics (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). In other words a person's personality is partially determined by his or her birth order. For example, the oldest child in the family tends to accept responsibility and endure hardship better than the youngest child. Middle children tend to possess characteristics of both the older and younger children in the family. In CF families, if the oldest child has CF, the burdens of being the oldest child are often taken care of by younger children who develop a deep sense of responsibility and feel as if they endure hardship at the expense of the older child.

**Social emotional process.**

The final concept, social emotional process, describes how prolonged periods of anxiety influence the manner in which a society functions (Bowen Center for the Study of the Family, 2010; Kerr & Bowen, 1988). For instance, progressive societies are typically calmer and less turbulent than regressive societies. This concept is important because it reminds health care providers that families are imbedded in and affected by a larger social system. The emotional processes of society appear to parallel the emotional processes of the human family. Case in point, in a society where school systems are sued for disciplining a child without parental permission, children from undifferentiated families are more apt to harass teachers and get away without punishment.

## Qualities of Strong Families

According to Lin (1994), healthy families are able to meet the needs of their members

while effectively managing stress and coping with the demands of daily life. Over the past 25 to 30 years DeFrain and Stinnett (DeFrain, 1999) have studied families around the world striving to understand why some families function better than others. They identified six qualities that strong families around the world have in common, including (1) commitment, (2) appreciation and affection, (3) positive communication, (4) togetherness, (5) spiritual wellbeing, and (6) the ability to cope with stress and crisis.

In strong families, one's spouse and children are of utmost importance. Parents and children are committed and faithful to the family unit. Family boundaries prevent work and hobbies from interfering with family interaction. At the same time, freedom and individuality is respected so that parents and children are still free to pursue individual ambitions. Family members are trustworthy and honest with each other and spouses value fidelity. Parents and children maintain a positive home environment by expressing how much they care, appreciate, and love one another.

People in strong families tend to possess good communication skills (DeFrain, 1999). They are respectful listeners and speak positively to one another instead of focusing on the negative. Additionally, humor is often used to express affection, disperse tension, and to entertain. Differences in opinion among family members are either resolved or they agree to disagree.

Strong families devote time and effort into being a family (DeFrain, 1999). Both quality and large quantities of time are important for building good family relationships. Happy families eat together, play together, and enjoy each other's presence. Inevitably, families will experience periods of crises and stress, but because strong families tend to plan for the

future, crises occur less often and are often viewed as challenges. These challenges provide opportunities for individual and family growth. Strong families possess confidence in their ability to meet life's challenges and are able to maintain a positive attitude during difficult situations, such as when dealing with an ill child.

Finally, strong families are bound together by their religious faith and/or spiritual beliefs (DeFrain, 1999). While some families in Defrain and Sinnett's research spoke of the importance of God others believed that love of family, family bonds, or "oneness with the world" (p. 11) is what keeps them together. Family spiritual well-being is all about having a common purpose and maintaining harmonious connections "to each other and…to that which is sacred to us in life" (p. 11).

**CF and Family Relationships**

According to Gregory (2005) the experience of chronic illness is an "on-going lived experience" that becomes a way of life (p. 373). In this next section I will present two concepts, uncertainty and normalization, both of which are relevant to families who have a child with CF. A discussion of the demands that chronic illness places on family functioning will follow.

**Uncertainty.**

Uncertainty is a cognitive state in which individuals are unable to determine the "meaning of illness related events" (Mishel, 1990). Uncertainty occurs when decisions must be made because they lack information or their knowledge is vague, ill defined, or lacking. As a result, individuals are either unable to assign definite value to objects and situations or are unable to predict an outcome . Uncertainty changes over time and can be assessed as

either a threat or an opportunity. Although I was unable to locate research that specifically explored the phenomenon of uncertainty in CF, researchers report evidence of uncertainty in their study results.

In CF families, uncertainty first arises just before or at the time of diagnosis. In Bluebond-Langer's (1991) ethnographic study of CF siblings, parents reported uncertainty before receiving the CF diagnosis when they were trying to find out what was wrong with their child. Then, when CF was finally diagnosed, parents became uncertain about their child's future, their own parenting skills, and how CF would affect family life. Gjengedal, Rusteen, Wahl, and Hanestad (2003) and Jessup and Parkinson (2010) reported similar findings from their qualitative studies with CF families and individuals with CF. Finding a diagnosis was a struggle filled with uncertainty (Gjengedal et al.). While parents knew something was wrong with their child, they did not feel as if health care professionals took them seriously particularly when their child did not appear ill. Parents also experienced uncertainty (a) when visions of intimate family relationship between them and their child are amended to include health care professionals, and (b) as they strive to assemble a normal life while facing an unknown future for their child (Jessup & Parkinson).

**Normalization.**

Even in the context of uncertainty, there is a desire among family members to maintain a sense of normality when managing a chronic illness (Gregory, 2005). The concept of normalization was articulated by two nurse scholars Knafl and Deatrick (Deatrick, Knafl, & Murphy-Moore, 1999) as a means for explaining how families respond and manage when a family member has either a disability or a chronic illness. Knafl and Deatrick define

normalization as "cognitive and behavioral strategies" (1999, p. 209) parents of children with a chronic disease use to help the family lead a normal life. Normalization is a process that occurs over time in which parents focus on the normal aspects of daily living (Admi, 1996; Gjengedal et al., 2003; Knafl & Deatrick, 1987; Tracy, 1997).

Characteristics of normalization include (a) family acknowledgment of the child's disease and its potential to threaten their way of life, (b) parents identify the child and their family as being normal within the context of the disease, (c) parents engage in behaviors and routines that support and sustain normal family functioning, (d) parents adapt treatment regimens that minimize disruption of child and family life, and (e) family interactions with others are based on a view that child and family are normal despite the disease (Deatrick et al., 1999; Knafl & Deatrick, 2002). Unfortunately, not all families are able to achieve normalization and the child's disease becomes an overwhelming and controlling presence. Parents who have difficult with normalization (a) reveal the disease is their primary focus, (b) see the disease as the family's major source of conflict, (c) see their child as being different from his or her peers, and (d) depict treatment regimens as being significantly burdensome (Knafl & Deatrick, 2002).

Robinson (1993) warns that while families benefit from the process of normalization there are also costs. From her qualitative research with families and individuals with chronic illness, Robinson learned that the process of normalization provides hope and carries individuals and families through adversity. Robinson argues that normalization also helps parents to love and accept their child by enabling them to see beyond their child's differences. However, parents in Gjengedal et al.'s (2003) study point out that living a

normal life is a struggle, which requires effort, planning, and compromise. For example, when encouraging their child to participate in organized sport activities parents must often choose between missing a treatment or leaving the activity early.

Unfortunately, some health care professionals see normalization practices as parental denial and attempt to educate parents on the reality of chronic illness thus hampering family normalization efforts (Robinson, 1993). One parent in Robinson's study felt health care providers were more interested in the pressing illness and as a result neglected those things that would help her child develop into a normal boy and prepare him for a future. However, Havermans and De Boeck (2007) assert normalization is a balancing act. Children with CF are "normal children with a serious illness" (p. 162) and health care providers must not compromise care by overbalancing on normality.

**Demands of a chronic illness.**

The demands of chronic illness can strain family relationships as parents strive to balance the needs of the CF child with normal family responsibilities (McCubbin, McCubbin, Mishler, & Svavarsdottir, 2001; Orenstein, 1997; Quittner, Espelage, Opipari, Carter, & Eid, 1998; Solomon & Breton, 1999). In addition to normal tasks, families with CF children deal with special dietary needs, a complex treatment and medication regimen, and many health care appointments. Maintaining adherence to medications, treatments, and appointments is multidimensional, dynamic, and requires a triadic partnership between parents, child, and members of the health care team (De Civita & Dobkin, 2004). Modi and Quittner (2006) examined the barriers to treatment adherence among children (age 6 to 13), who had either CF or asthma, and their parents. Primary barriers to CF treatments included

oppositional issues, bad taste, time management and forgetting. Researchers also found that the CF children and their parents possessed substantial knowledge deficits about CF. Children lacked knowledge primarily in regards to nutritional issues and timing of medications. Parents were least knowledgeable about nutritional issues such as the recommended daily caloric intake for children with CF.

Cystic fibrosis impacts family routines, leisure time, family activities, finances, insurance coverage, and family energy levels. However, researchers in the area of CF family functioning have produced conflicting and confusing results. Researchers from Great Britain, Blair, Cull, and Freeman (1994) used a mixed method design to examine the psychosocial functioning of families and young adults with CF, anorexia nervosa, and well families. The authors reported that while parents of young adults with CF tended to be over involved with their child, they still functioned just as well as the control group families in regards to level of criticism, communication skills, problem solving skills, handling of difficult issues, and ability to compromise. Psychological health of the CF young adults was indistinguishable from healthy peers.

Quittner, a psychologist, and her colleagues (1998) evaluated differences in parental and marital role strain between 33 parents with CF children to 33 parents with healthy children. Compared to the control group, parents of CF children were found to have higher levels of marital role strain, role frustration, daily child-care tasks, and child-rearing conflicts, as well as fewer exchanges of positive interactions with each other (i.e. affection). Couples with CF children also spent less time in recreational activities in and outside of the home. However, there was no significant difference between the two groups for marital

satisfaction and depression. Solomon and Breton (1999) suspect CF families may suppress marital and relationship problems. Although CF parents did not appear to be experiencing significant marital stress during the study, 18 months after study completion 30% of the CF parents had divorced compared to 6.8% of the control parents.

As children with CF grow up, responsibility for self-care is expected to shift from the parent to the child. Scotland researchers, Williams, Mukhopadhyay, Dowell, and Coyle (2007), explored the process of shifting responsibility for chest percussion therapy (CPT). Participants included 32 children with CF, ages 7 to 17, and their parents. Qualitative data were collected through interviews. Parents and children were interviewed separately. Mothers were primarily responsible for initiation of CPT. The experience of CPT transfer was accompanied by tension, uncertainty, mistrust, anxiety, and hope as the parental role progressed from one of complete directing to passive supervisor to noninvolvement. Factors influencing child and parental roles and shifting progression included family routines, episodes of illness, parental perceptions of the child's wellness, and parental doubt of child's performance and/or effectiveness in performing CPT.

Siblings of children with CF are also affected by chronic illness. Williams et al. (2009) explored the effects of CF on siblings age 8 to 14 based on parent perceptions. Parents reported both negative and positive effects. Negative effects included (a) jealousy and resentment because of the special attention bestowed on the child with CF, (b) fear and anxiety when CF sibling is ill, and (c) negative behaviors including not listening to parents and staying home from school with somatic symptoms. Positive effects included (a)

fondness for family closeness, (b) sensitivity towards the needs of the CF sibling, and (c) sensitivity to the difficulties of experienced by peers.

In summary, the family is holistic structure that functions as a system to encourage and support the emotional, physical, and social well-being of its members with the goals of producing individuals who can think and act for themselves as well as manage relationships with others and cope with daily demands. Family relational and genetic patterns are rooted in previous generations. A person's behavior is best understood within the context of the functioning of other members of the family. Many CF families strive to live a normal life amidst the uncertainty of CF, the extra tasks required by a chronic illness, and the issues surrounding society's acceptance of disability and chronic disease. Adhering to CF treatments can be a challenge plagued by barriers and parental and child knowledge deficits. Although some researchers have examined CF family functioning in regards to normalization and mealtime behaviors, very little research has addressed the concept of uncertainty among CF families beyond the time surrounding the diagnosis of CF. Additionally, research about how CF affects family functioning and family relationships is at times conflicting and confusing. In the next section I will define and discuss the concept of self.

## Self

After *Family*, the next concept on the model of the child's world is *Self*, which is represented by an orange ring. Development of the self is a progressive process of accommodation between the child and his or her environment, which begins after birth. Recent research now suggests that children who grow up with a chronic disease form their

identity around the disease (Speraw, 2009; B. Williams, Corlett, Dowell, Coyle, & Mukhopadhyay, 2009).

When striving to look at the world through the child's eyes, it is important to have a good understanding about what the self is and how it develops. In the section that follows, I will highlight aspects of five theoretical definitions of the self drawn from Mead, Blumer, and Charon, Roeper, Roy, and Tillich. These definitions represent the disciplines of social psychology, sociologic social psychology, education, nursing, and theology. I will then discuss the development of the self followed threats to self stemming from chronic illness.

Self is a common term. Every day people refer to and acknowledge the self with terms such as myself, yourself, self-esteem, self absorbed, and self care. But what is the self and how does the self come to be? In general, my review of the literature found the concept of self to be complex, unique to each person, and multidimensional. George H. Mead (1934), a social behaviorist and pragmatist, believed that the self is not present at birth but develops over time through social experience and worldly activity. The complete self is a reflection of an individual's participation in human society and of the social process as a whole.

Blumer and Charon (1969; 2007) emphasize the self as a social object. Just as an individual acts towards others in the external world, he or she also acts inwardly towards his or her internal world. People are constant thinkers striving to understand what is going on around them, reflecting upon current, recent, and past experience while planning a line of action (Blumer, 1969; Charon, 2007). Individuals also point things out to themselves. For example, in social situations a person can evaluate an event that has taken place and attach a label, such as anger, to their emotions. They judge themselves, take care of themselves,

set goals for themselves, as well as direct their actions and control their own behaviors. As individuals interact with others they develop a sense of who they are based on how others respond to them. Because of the self, people are able to actively respond and interpret what is going on in their environment.

Roeper (2007), a self educated child educator, provides a simple and concise definition of self. She presents the "I" as the self, which she labels the *beholder*. According to Roeper, the self is a unique and complex unit within everyone comprised of all bodily functions including "input from the brain" (p. xx). The self is the core of all human beings. It is the "inside that looks outside" (p. 1), the drive that keeps one going, and the source of all behavior. She believes the self originates in one's DNA as well as one's history, experiences, and from the deeper more mysterious side of existence.

Sister Callista Roy, a nurse theorist and author of Roy's Adaptation Model conceptualized the self as an entity focused on what she calls the self-concept and the relationship between the self-concept and a person's health (Roy & Andrews, 1999). Roy defines self-concept as "the composite of beliefs and feelings that a person holds about him or herself at a given time" (p. 49). Behavior and adaptation to health and illness are directed by the beliefs people have about themselves.

According to Roy, the self consists of two components a physical self and a personal self. The physical self contains both bodily sensations and body image and is the individual's assessment of one's own "physical attributes, functioning, sexuality, health and illness state, and appearance" (Roy & Andrews, 1999, p. 384). The personal self is the individual's appraisal of one's "own characteristics, expectations, values, and worth" (p.

381) and consists of self-consistency, self-ideal, and the moral-ethical-spiritual self. The personal self strives to keep ideas about the self in accord with one another and preserve equilibrium. Additionally, the personal self possesses a system of beliefs, ideas of one's capabilities, scheme for the future, and an idea of one's position in the universe.

Paul Tillich (1951), a German Christian theologian and philosopher, presents the self as an indistinct structure of self-centeredness. The self is unique: It includes a subconscious, unconscious, and self-consciousness (human thought). Having a self implies being separate and independent from all other things while at the same time possessing the ability to look and act on all of the other things opposite of oneself. Tillich writes it is difficult to discuss the self apart from existence and the world because the self, existence, and the world are interrelated. Without a world, the self would be empty; without a self, there would be no world. In other words the "self and environment determine each other" (p. 170). Without the self there would be no subjective reasoning, and without a world to be looked upon by the self there would not be objective comprehension. The self participates in its environment; it acts on and is acted upon by it. A person cannot exist without engaging with the world around them since humans discover themselves through encounters with other people. Additionally, it is through participation that individuals are able to develop relationships with other human beings.

In summary, all of the above theorists (Blumer, 1969; Charon, 2007; Mead, 1934; Roeper, 2007; Roy & Andrews, 1999; Tillich, 1951) concur that the self is unique to each person. They also agree that one's sense of self begins to develop shortly after birth. The

self is shaped by interaction in human society, particularly interaction with significant people in the environment where the self is situated.

**Conceptual Definition of Self Used in this Research**

Because this study will focus on the perceptions that children with CF have about themselves, it is necessary to define self. For the purpose of this study the self is conceptualized as the core of all human beings. It is complex, multidimensional, and unique to each person. The self develops following birth through a dynamic process of experience and social interaction with influential persons in the environment. It is comprised of unconsciousness, consciousness, and thought including beliefs, attitudes, values, emotions, reactions, and anxieties that an individual has towards his or her self and the world. Harmonious other selves such as the physical self, personal self, and spiritual self are integrated within the complete self. The self works to preserve equilibrium and adjusts with experience. The self is both subject and object; it looks and acts inwardly as well as outwardly. The perception an individual holds concerning the self influences his or her health related behaviors and adaptation to health and illness.

In this research it is necessary to have grounding in human development because this study seeks to understand the child from the child's point of view. How children see and make sense of the world and their ability to convey their experiences are influenced by cognitive, psychosocial, and biological factors of development. The next section will present three theories of development beginning with Jean Piaget's cognitive-development theory, followed by Erik Ericson's *psychosocial theory,* and then Uri Bronfenbrenner's ecological systems theory.

**Development of the Self**

The term development refers to the process of human growth and maturation (Shaffer & Kipp, 2010). The process of development is usually thought of as being orderly and patterned, beginning at conception and continuing until death. As previously mentioned, Mead asserts that the self begins to develop during infancy. Observations from Meltzoff and Moore 's 1989 study involving 40 healthy newborn infants less than 72 hours of age seem to support Mead's assertion. Researchers reported that infants' appear to form their motor movements by imitating and using adult acts as models (1989).

The theories of three 20th century scholars Piaget, Erikson, and Bronfenbrenner have had considerable impact on the study of child development. Piaget's cognitive-development theory and Erikson's psychosocial development theory both acknowledge that the formation of the self begins early in infancy. Bronfenbrenner's ecological systems theory highlights the importance of relationships between the child, biospychological events, and multilevel environmental systems.

**Piaget's cognitive–developmental theory.**

Jean Piaget was a Swiss psychologist who believed that children reason and perceive the world differently than adults. (Piaget & Inhelder, 1969). Piaget's theory arose out of his interest to understand and explain how children come to know and understand the world in which they live (Huitt & Hummel, 2003; P. K. Smith, Cowie, & Blades, 2003). His research explored how children think as well as their ability to judge and explain their world. He asserted that while adults impress the child, all adults begin as children (Piaget & Inhelder, 1969). Therefore, it is often the child that explains the man. Utilizing qualitative research

methods such as observation and interview, Piaget identified four primary stages of intellectual development occurring between the newborn period through age 12 (Table 2.1). His four stages of cognitive development include (a) sensori-motor - ages 0 to 2, (b) pre-operational - ages 2 to 7, (c) concrete operational - ages 7 to 11, and (d) formal operational - age 11 and on (Berk, 2010; Piaget & Inhelder, 1969; Shaffer & Kipp, 2010; P. K. Smith et al., 2003). These stages are arbitrary and theoretical because they reflect ideal cognitive development. It is possible for individuals to stray from or be hindered from achieving developmental milestones (Berk, 2010) or for gifted learners to move through stages at an accelerated pace (Carter & Ormrod, 1982).

The third stage of development of *concrete operations* occurs between the ages of 7 and 12, which encompasses the age of the study participants. The child is able to focus his or her attention on more than one aspect of a task (Piaget & Inhelder, 1969; P. K. Smith et al., 2003). Thought becomes more logical and organized although it is bound to that which is tangible and concrete. Thoughts are derived from the reality of experienced events, not on hypothetical situations or situations outside of the child's experience. The child is now able to mentally arrange, classify, and seriate objects as well as understand the idea of conservation of substance (Berk, 2010; Piaget & Inhelder, 1969). Children also become more aware of the perspectives of others (Shaffer & Kipp, 2010) and develop a better understanding of space (Berk, 2010; Parameswaran, 2003). According to Piaget (Piaget & Inhelder, 1969) "the formation of concrete operations is the functional unity…that binds cognitive, playful, affective, social, and moral reactions into a whole" (p. 128).

Table 2.1

Piaget's Stages of Cognitive Developmental.

| Stage | Age | Description |
|---|---|---|
| Sensori-motor | 0 to 2 years | Infants explore and get to know their world by physically interacting with the surrounding environment (Berk, 2010; Piaget & Inhelder, 1969; Shaffer & Kipp, 2010; P. K. Smith et al., 2003). Interaction is accomplished with the use of the sensory organs including the hands, eyes, nose, ears, and mouth and the appendages including the arms and legs. Infants develop the capacity for internal thought and the use of symbols for purposes of communication. |
| Pre-operational | 2 to 7 years | The pre-operational stage is divided into two periods the (a) preconceptual period, 2 to 4 years of age and (b) intuitive period, 4 to 7 years of age. Children tend to be egocentric assuming that the world revolves around them. Capacity for internal thought and the use of symbols (language) rapidly increases. Pretend activities are an example of how children symbolically construct sophisticated representations of their world.<br>Language, conceptual ability and symbolic thought grows (Eggan & Kauchak, 2001). Ability for ordering, classifying, and quantifying concrete objects begins to develop (P. K. Smith et al., 2003). There is also a decline in magical beliefs such as Santa Claus (Berk, 2010). |
| Concrete operational | 7 to 11 years | Children can attend to more than one aspect of a task (Piaget & Inhelder, 1969; P. K. Smith et al., 2003). Thought becomes more logical and organized and is concrete. Children can mentally arrange, classify, and seriate objects and understand the idea of conservation of substance (Berk, 2010; Piaget & Inhelder, 1969). Children also become more aware of the perspectives of others (Shaffer & Kipp, 2010) and develop a better understanding of space (Berk, 2010; Parameswaran, 2003). |
| Formal operational | 11 years and beyond | Children can begin to reason abstractly and think systematically (Berk, 2010; Inhelder & Piaget, 1958; Shaffer & Kipp, 2010). Thinking is not tied to facts or to what is observable. Reasoning about hypothetical situations becomes possible. Develops the ability to make predictions and then logically deduce or predict possible outcomes. Use of abstract symbols and scientific thinking becomes possible. |

Since the ages of the participants extend to age 11 it is possible that some children in the study will have reached Piaget's final stage of development, *formal operations*. At around age 11 to 12 children develop the ability to reason abstractly and to think systematically (Berk, 2010; Inhelder & Piaget, 1958; Shaffer & Kipp, 2010). Thinking is no longer simply tied to facts or to what is observable; instead, reasoning about hypothetical situations becomes possible. Within formal operations individuals develop the ability to make predictions and then logically deduce or predict possible outcomes. When a person has reached formal operations the use of abstract symbols, such as algebra, and scientific thinking become possible.

**Erikson's psychosocial theory of development.**

Erik Erikson, a contemporary of Piaget, was a renowned psychoanalyst and professor (Evans & Erikson, 1967). He believed that normal and altered development must be understood in the context of culture and technology (Erikson, 1968, 1979; Evans & Erikson, 1967). Erikson's theory of psychosocial development, which he called the "eight stages of man" (Evans & Erikson, 1967, p. 11), encompasses the entire life cycle from birth though adulthood. Table 2.2 presents each developmental stage, the approximate age each stage is encountered, and significant events surrounding each stage (Erikson, 1979; Evans & Erikson, 1967).

As people progress from stage to stage their intrapersonal and interpersonal perspectives change (Erikson, 1968, 1979). With each step individuals face a potential emotional crisis, which Erikson describes as "a crucial point of increased vulnerability and heightened potential" (1968, p. 96). Each stage builds upon the previous one with the later stages reaffirming emotional needs from previous stages. Participants in this study lie within Erikson's fourth stage of development *industry versus inferiority*, which encompasses the childhood years of 6 to 12. According to Erikson this is the point that the school-age child's sense of confidence emerges. Here children learn to complete and master tasks. Cognitive capacity increases along with their ability to socially interact with a wider range of people outside of the nuclear family, including peers and teachers. Children in this stage possess an enormous amount of curiosity and desire to learn about their world. They want to watch, be shown how to do things, and they ask many questions. The goals for this stage are to develop good interpersonal relationships and culturally appropriate technical

and cognitive skills. Adults are responsible for recognizing children's efforts and encouraging their talents.

Table 2.2

Erikson's Eight Stages of Development

| Stage | Age | Description |
|---|---|---|
| **Trust versus Mistrust** | Infancy 0 to 1 year | The task of infancy involves learning to trust others and the world for one's basic needs as well as balancing an amount of readiness for approaching danger and discomfort (Erikson, 1968, 1979). Social interaction occurs primarily with the child's caregivers including parents/guardians (P. K. Smith et al., 2003). |
| **Autonomy versus Shame and Doubt** | 1 to 3 years | Toddlerhood to early childhood tasks involve freedom of self-expression by learning to do things for oneself such as ambulating, eating, and toileting, while being guided by parental and societal boundaries (Erikson, 1968, 1979). Social interaction occurs primarily with members of the family (P. K. Smith et al., 2003). |
| **Initiative versus Guilt** | Early Childhood 3 to 6 years | Movement and language increase. Children set out to explore their surroundings through language, play, and imagination (Erikson, 1968, 1979). Children begin to formulate goals for their actions and attempt to see themselves as grownups by identifying and wanting to be like their parents or other influential adults. Developmental tasks involve learning to work for things while balancing fantasies and the rights of others. Social interaction occurs primarily with family members (P. K. Smith et al., 2003). |
| **Industry versus Inferiority** | Childhood 6 to 12 years | The goals for this stage are to develop good relationships with others and culturally appropriate technical and cognitive skills (Erikson, 1968, 1979). Children develop a sense of confidence as they learn to complete and master tasks. Cognitive capacity increases along with their ability to socially interact with a wider range of people. Children in this stage are curios and want to learn about their world. Social interaction extends to others outside the family including peers and teachers (P. K. Smith et al., 2003). |
| **Identity versus Identity Confusion** | Adolescence 12 to 18 years | The goal of this stage is to develop the capacity to perceive and live by societal values (Erikson, 1968, 1979). Adolescents ask and seek to answer the question, "Who am I". They learn about themselves and how to fit into their culture by reaching the limits of experience. Doubt about one's self can lead to identity confusion. Social interaction involves mainly peers (P. K. Smith et al., 2003). |
| **Intimacy versus Isolation** | Young Adulthood | In this stage young adults strive to establish a career and form meaningful, intimate relationships with other people without losing oneself (Erikson, 1968, 1979). Isolation and loneliness can result if one's identity is not stable. |
| **Generativity versus Stagnation** | Middle Adulthood | The goal of this stage is growth of a health personality (Erikson, 1968, 1979). The adult is now firmly placed in society and accepts responsibility creating and directing the next generation. Individuals who do not reach developmental goals stagnate and become personally impoverished. |
| **Integrity versus Despair** | Mature Adulthood | At this point of development, the adult is able to look back and either appreciated life's experiences or anguishes over them, desiring that life would have been different (Erikson, 1968, 1979). |

Similar to Piaget's theory Erikson's stages are broad, arbitrary, and theoretical. However, Erikson's theory acknowledges that development is not always ideal and that an array of positive and negative healthy and maladaptive outcomes may result.

Another influential conceptualization of human development is Bronfenbrenner's ecological systems theory (EST). The EST addresses the mutual relationship between human beings and the environment as it relates to human development.

**Bronfenbrenner's ecological systems theory.**

Bronfenbrenner (1917 to 2005) was a Russian born American psychologist and cofounder of the Head Start program (Lang, 2005). He asserted that human beings "create the environments that shape the course of human development" (Bronfenbrenner, 2005c, p. xxvii). Bronfenbrenner's ecological approach (Figure 2.2) defines development as "…the phenomenon of continuity and change in the biopsychological characteristics of human beings both as individuals and as groups. The phenomenon extends over the life course across successive generations and through historical time, both present and past" (Bronfenbrenner, 2005a, p. 3).

According to EST, neither the environment nor a person's biopsychological status controls development. Instead, development is a progressive shared accommodation between the child and the environments the child is situated (Bronfenbrenner, 2005a, 2005c). Developmental outcomes vary due to person, context, process, and time.
The ecological environment is comprised of a hierarchy of nested systems; each system is encompassed by the next (Bronfenbrenner, 1977). These systems include the microsystem, mesosystem, exosystem, and macrosystem. Situated in the middle of the environment is the

child. Encompassing the child and environment is the temporal aspect of Bronfenbrenner's model called the chronosystem. The inner most environmental system surrounding the child is the *microsystem* (Berk, 2010; Bronfenbrenner, 1977, 2005a; Shaffer & Kipp, 2010; P. K. Smith et al., 2003). The microsystem involves the relationships and patterns of activity between the child and his or her immediate surroundings including the particular physical features of the environment (e.g. home or classroom) and the roles located within a given environment (e.g. teacher, student). Relationships between the child and those around the child are not only bidirectional, but third parties, such as a sibling or parent, can enhance or undermine relationships in the microsystem as well (Berk, 2010). Additionally, a child's interaction with the environment is influenced by his or her personal characteristics including genetic makeup, temperament, and physical characteristics.

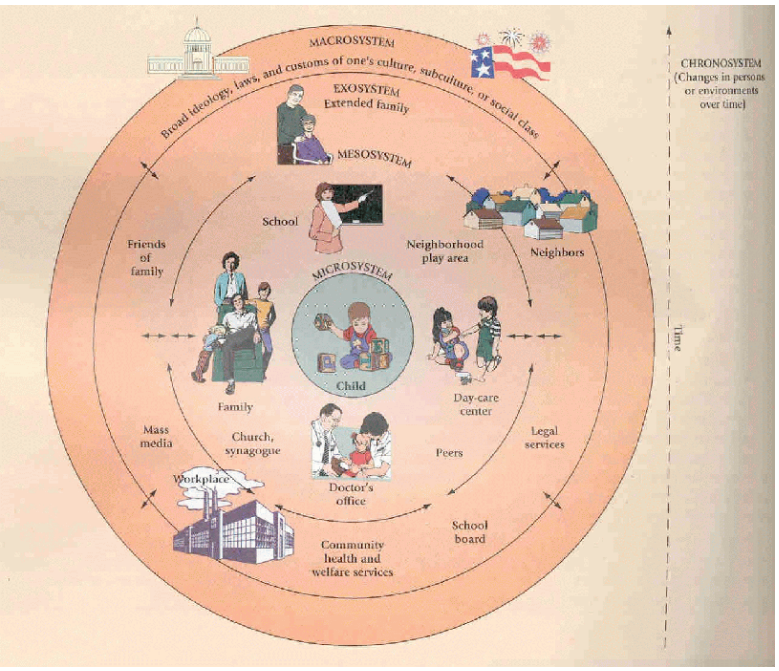



Figure 2.2. Bronfenbrenner's Ecological Systems Model.

From "Ecological theory: Sociocultural view of development," by U. Bronfenbrenner, Retrieved April 22, 2010, from http://www.des.emory.edu/mfp/302/302bron.PDF. Reprinted for educational purposes.

The second level is the *mesosystem*. The mesosystem links the relationships and processes occurring among the child's microsystems (Berk, 2010; Bronfenbrenner, 1977, 2005a; Shaffer & Kipp, 2010; P. K. Smith et al., 2003). Strong and supportive links are thought to enhance child development while nonsupportive links undermine development (Berk, 2010; Shaffer & Kipp, 2010). For example, cooperative parent-teacher communication may have a positive effect on school accomplishments whereas parent marital conflict may negatively impact school performance.

The *exosystem* is the third environmental structure. The child does not participate directly in the exosystem (Berk, 2010; Bronfenbrenner, 1977, 2005a; Shaffer & Kipp, 2010; P. K. Smith et al., 2003). The exosystem encompasses the formal and informal social structures that impact and determined the child's immediate surroundings and as a result influence childhood experience. These social structures include mass media, governmental agencies, religious institutions, community health services, and parental employment conditions.

The fourth and largest environmental structure is the *macrosystem* (Berk, 2010; Bronfenbrenner, 1977, 2005a; Shaffer & Kipp, 2010; P. K. Smith et al., 2003). Imbedded in the *macrosystem* are the patterns of the micro, exo, and meso systems. The macrosystem can be visualized as a blueprint carried in the minds of people living in a particular community, culture, or subculture (Bronfenbrenner, 1977, 2005a). This blueprint includes societal customs, values, beliefs, resources, lifestyles, laws, hazards, and patterns of communication. The level of priority the macrosystem places on children influences how children and their caretakers interact and how society treats children and their caretakers.

Finally, framing the child and the environment is Bronfenbrenner's temporal dimension called the chronosystem. The factor of time is believed to impact "…life events and experiences, singly or sequentially, on subsequent development" (Bronfenbrenner, 2005b, p. 85). The experience of time can originate in the external environment (e.g. the birth or death of a sibling) or within the individual (e.g. cognitive and biologic changes during puberty).

In summary, while none of the above theories comprehensively explain the process of child development, together the theories of Piaget, Erikson, and Bronfenbrenner encompass cognitive development, psychosocial development, and the idea that person, context, process, and time all contribute to child development.

Scholars and researchers describe chronic disease as a phenomenon of disruption and change (Bury, 1982; Charmaz, 1983, 1999; Kelly & Field, 1996; S. Williams, 2000). The next section presents the results of several research studies that have examined the experience of living with a chronic disease.

**Chronic Illness and the Self**

Adults report that having a chronic disease affects one's bodily performance, biography, self-concept, and social sphere. Corbin and Strauss's qualitative research with chronically ill adults during the mid 1980's revealed that chronic illness interferes with individuals' daily routines and alters a person's biography (Corbin & Strauss, 1985). With the onset and or exacerbation of a chronic disease, life revolves around the illness and new routines must be established. As disease progresses, individuals must devise new ways of

performing tasks such as walking up the stairs and either relinquishing or delegating tasks and responsibilities.

Charmaz contends that the primary form of suffering among individuals with a chronic disease is the "loss of self" (Charmaz, 1983, p. 168). Drawing upon the perspective of symbolic interactionism, Charmaz utilized a grounded theory approach to investigate the effects of chronic illness on the self-concept. Data were obtained via 73 in-depth interviews from 57 adults, aged 20 to 86 years. Participants reported experiencing a progressive deterioration of their once held positive self-image without generating a new and equally valued self-image. Participants suffering arose out of daily life due to (a) a restricted life, (b) social isolation, (c) discrediting by others, and (d) being a burden to others. Participants rarely spoke of gaining new insight, self-discovery, or a heightened awareness of the world as a result of their illness.

Bury (1982) describes chronic illness as a major "disruptive experience". The world of chronic illness consists of fluctuating symptoms, disability, and uncertainty where the "structures of everyday life and the forms of knowledge that underpin them are disrupted" (p. 169). In Bury's study of 30 adults newly diagnosed with rheumatoid arthritis (RA), disease was seen as an invading outside force that one must learn to live with. Individuals faced a world of pain and suffering where disease was held at a distance, and preservation of the self became a struggle as they compared the present with the past. As RA progressed, disruptions in friendships and social contacts increased resulting in social isolation, dependency upon others, and invalidity. For participants in this study, development of a

chronic disease interrupted the patterns of normal life and altered their identity and biography.

As just noted, the experience of chronic disease during adulthood results in alterations in self, body, and social interaction. But children diagnosed with a chronic disease early in life may have no recollection of ever not having a disease. For them, there is no before or after to compare.

In a qualitative research study involving 32 children with CF, age 7 to 18, Williams, Corllett, Dowell, Coyle, and Mukhopadhyay (2009) found that participants built their world and identity around CF. While treatments and medications were at times an inconvenience the regimen was not seen as abnormal. Symptoms such as coughing typically did not cause an interruption in daily functioning, goal formation, or aspirations unless such symptoms became severe enough to prevent participants from participating in normal daily activities. Disruptions such as a hospitalization did not prompt children with CF to question the self. Children were able to maintain control by reappraising their personal values and the constraints placed on them by the situation. Participants in this study also described two types of normality. The first was what is normal for them and the other was what is normal for society. One of the limitations of the reported research is that the voices of children age 7 to 9 were silent. This age group was not represented in any of the exemplars even though they comprised 38% of the sample.

A case analysis of a 16-year-old girl disfigured, blinded, and partially deaf from life long cancer, provides another example of how children incorporate the trajectory of life long illness into their being (Speraw, 2009). Speraw's case analysis was taken from a larger

phenomenological study that examined the lived experience of children with disabilities or special needs. Despite years of pain, suffering, and numerous disabilities Speraw found her participant to be a developmentally normal, intelligent human being. Her sense of self was one of confidence. She displayed humor, drive, curiosity, and an orientation towards serving others. There was no mention by the participant of what she had lost or what could have been. Instead, she strived for normalcy and possessed a positive vision for her future.

One illustration of just how much the self constructs itself around a childhood onset chronic disease is Orfali and Anderson-Shaw's (2005) case study about two adults whose health improved following organ transplants. As a result of their transplant, both of the participants experienced suffering as they transitioned from a state of chronic disease to a state of healthiness. According to the authors, the process of becoming cured impacts a person's identity leaving them to reconstruct a self outside of the technology and medical staff that was once needed to sustain their lives. For example, one participant had a rare kidney disease since age six and at age 30 had a kidney transplant. She cried for surgeons to remove her new kidney because without dialysis life no longer seemed normal. The other participant had a bone marrow transplant to cure sickle cell disease. After the transplant, the individual spoke negatively about the experience saying she no longer felt as if she existed.

In summary, it is only within in the last decade or two that researchers have critically examined the development of the self and self-perception among children with chronic disease, including CF. In the just mention studies, adults and children provided differing perceptions concerning how chronic disease impacts the self. Yet, few researchers have

looked at how perceptions of chronic disease differ among children and adults with a chronic disease and even fewer researchers have examined how a medical cure affects the self.

The next portion of this literature review will present how perceptions of the childhood experience of living with CF have been represented in the research literature.

**Perceptions of Growing up with CF**

The purple ring on the model of the child's world represents Chronic Disease, which in this study is Cystic Fibrosis. Chronic disease is defined as a pathologic condition of a bodily system or organ that is identifiable by a group of signs or symptoms as a result of a genetic defect, infection or environmental stressor. As noted previously, cystic fibrosis is the result of a genetic defect.

This final section of this chapter provides an overview of the reviewed empirical literature related to the growing up experience of having CF. Appendix A gives details for each of the discussed studies including sample size, age of participants, methods, location of research, and theoretical perspective or framework Appendix A. Eleven of the research articles reported using qualitative designs and four reported using quantitative designs. Reviewed research studies were performed in Australia (2), Brazil (1), England (1), Norway (1), Sweden (1), and United States (US) (9). Researchers utilized a variety of theoretical perspectives and frameworks including phenomenology, developmental theory, and biological theory. Four studies included children with CF and children with other chronic diseases (Angst & Deatrick, 1996; Fereday, MacDougall, Spizzo, Darbyshire, & Schiller, 2009; Janse, Sinnema, Uiterwaal, Kimpen, & Gemke, 2008; Sartain et al., 2000).

**Historical Context of Children and CF in Research**

Three early studies were included in this review because of their historical significance in regards to the social position of the school-age child (Korsch, Gozzi, & Francis, 1968), the perceptions of school-age children living with CF (Shannon, 1979) and the perceptions of CF siblings (Bluebond-Langer, 1991). The first is a landmark study performed by a pediatrician and two masters prepared, public health nurses (Korsch et al., 1968). Changes in medical practice sparked this study. The study took place when specialty care was increasing, and the patient relationship with one's personal physician was disturbed by visits to specialty providers. The researchers hypothesized that verbal communication between physician and patient affected patient satisfaction and reaction to provider recommendations. In this study, the patient was defined as the child's parent. Sixty-four pediatricians and 800 children along with their parent(s) participated. Data were collected in an emergency department (ED) during and following each ED visit using three or more the following methods (a) audio-taped interview of visit, (b) post-visit semi-structured interview, (c) chart review, and (d) follow-up interview. Patients were randomly assigned to one of three groups. In Group 1, data were collected by all methods. In Group 2, the post-visit interview was omitted, and in Group 3, audiotaping of the clinic visits did not occur. Then the data were analyzed for content concerning the parent's perception and satisfaction of the ED encounter with the physician.

The results of the data analysis identified several barriers to communication during health care visits including prolonged wait times and lack of introduction by the healthcare practitioners. However, the value of Korsch et el.'s (1968) study was not that it illuminated

barriers to patient care, but because it drew the attention of other pediatric researchers. These researchers (e.g. Tates & Meeuwesen, 2001) recognized the marginalized position of the child in the pediatric visit. Subsequently, researchers began to look at the relationships and communication patterns of the provider-parent-child triad (van Dulmen, 1998; Wissow et al., 1998) and the parent was no longer identified as the patient during pediatric encounters.

In 1979, Shannon, an education major, conducted a quantitative study, involving children with CF, for her PhD dissertation. The purpose of her study was to (a) describe participants' perceptions of the school environment, (b) examine the severity of illness in relation to demographic variables (e.g. age, gender) and sub-scores on the child questionnaire, and (c) to look for relationships between children's perceptions and their teachers' awareness of and involvement in the child's care. Eighty-five children, in grades 1 thru 12, participated. Participants were from a single CF center in the Southeastern United States. The author did not specify the ages of the participants. Seventy-three percent of the participants were Caucasian and 27 percent were Hispanic. Data collection methods included pulmonary function testing and two researcher developed questionnaires, one for children, and one for teachers.

Shannon (1979) devised an open-ended questionnaire for the child participant by examining three instruments and holding interviews with three CF health care providers (a physician, a nurse, and the director of a pulmonary function lab) from the site where her participants were recruited. The examined scales included (a) Gordon's, "How I see Myself" Scale, (b) Piers-Harris Children's Self-concept Scale, and (c) Sarason's General Anxiety Scale

for Children. The concepts Shannon sought to measure included self-concept, academic adjustment, medical orientation, and emotional/social development. A psychology professor then reviewed the questionnaire and reconfigured the questions into binary items. Criterion-related validity was measured against the Gordon's, "How I See Myself" Scale. Shannon then administered the 85 item questionnaire face-to-face to children and adolescents with CF. The participant's teachers were mailed a 16 item questionnaire designed to capture teacher awareness of and involvement in the child's CF care needs.

There are several limitations with Shannon's study. First, the dissertation was difficult to read and follow. The title does accurately depict the quantitative nature of the study and the eight hypotheses are unclear. Second, Shannon failed to elicit the experience of the child with CF when designing her research questionnaire. Without input from the child during instrument development, questions are most likely biased towards the perspectives of the adults who developed them. Third, validity of both questionnaires is lacking. Fourth, the interpretation of research findings does reflect instrument content. For example, Shannon discussed findings about male children feeling compelled to compete physically with healthy children even though their illness made it difficult to compete (1979); however, no item on the questionnaire specifically addressed physical activity. Finally, when reporting the questionnaire subscale score results, quotes from children participants were intermingled with the statistics. Reporting of the qualitative data over shadowed the quantitative results. Shannon's reporting of qualitative information was confusing considering she did not mention collecting qualitative data.

Despite the limitations, her research has value. The importance of Shannon's research is that it occurred at a time when researchers were developing an interest in exploring the childhood experience of CF; individuals with CF were beginning to live long enough to attend and complete grade school. Secondly, Shannon (1979) learned that (a) as the severity of illness increased the teacher's awareness and involvement in the child's care increased, (b) as severity of illness increased, self-concept scores decreased, and (c) female scores and male scores differed with severity of disease. Finally, Shannon discovered that children were able to convey their perceptions about living with CF.

Bluebond-Langer (1991) published a notable ethnographic study examining the experience of living with CF from the perspective of the well sibling and their parents. Bluebond-Langner observed and interviewed 40 families, who had at least one child with CF. Interviews occurred during clinic visits, hospital rounds, and in participant's homes. The author did not delineate the ages of the participants. The 10 themes followed the CF disease trajectory. Well siblings described the time around the diagnosis phase as being difficult particularly with regard to receiving information about CF from their parents. Well-siblings sensed their parents' concerns about the possibility of the CF child dying.

After the diagnosis when the symptoms of CF were under control, the health of the child with CF improved and, except for treatments, life appeared normal (Bluebond-Langer, 1991). The well siblings received little information about CF during this period. Well siblings played down the CF sibling's disease and portrayed the normalcy of the CF sibling to others. The CF sibling's first major pulmonary exacerbation changed the well sibling's view of CF as a condition "one does things for" (p, 140) to a frightening disease that is only

present when the CF sibling is sick. As pulmonary exacerbations and hospitalizations increased, the well siblings become aware of the differences between the CF sibling and healthy peers. Well siblings found it difficult to express views to their parents and learned that other people did not wish to talk about the CF sibling's prognosis. Siblings became protective of their CF sibling and watched out for them, yet they also consider the CF sibling as being spoiled and moody. They resented the attention and special privileges given to the CF sibling. The terminal phase was one of turmoil where well siblings questioned what they should or should not do. As the CF sibling's health deteriorated, the disease of CF became more of an everyday focus for the family. Hope for a cure or the possibility of controlling the disease departed and there was a full awareness of imminent death.

Bluebond-Langner's (1991) study is the first known cultural study that elicited perceptions of living with CF from the siblings' perspective and an inside view into parental and family issues. However, Bluebond-Langer portrayed the child with CF as a passive family participant whom the family members took care of. Additionally the only reported source of CF information came from the parents. There was no evidence that well siblings received information from the CF sibling.

In summary, the above three studies provide valuable information about the historical context of children in research. Korsch et al.'s (1968) study brought to light the marginalized position of children in research and during health care visits, Shannon's (1979) dissertation research allowed children with CF to voice their perceptions about

having CF and attending school, and finally, Bluebond-Langer (1991) allowed outsiders to experience the trajectory of CF disease according to the perspective of the well sibling.

Eighteen to 41 years have passed since the researchers published these studies. Technological and pharmaceutical advancements have contributed to an increase in the median life expectancy for individuals with CF from 13 years of age in 1978 (Fogarty et al., 2000) to 36.5 years in 2005 (Cystic Fibrosis Foundation, 2007). The next section of this paper will review literature from the past 15 years illuminating the childhood experience of CF as expressed by adults with CF and CF parents, adolescents with CF, and the family and child with CF.

**Adult Perceptions of Growing-up with CF**

The next three qualitative studies depict the growing up experience of adults with CF. Two of the studies included both adults with CF and parents who have children with CF. One study also included spouses of the adult CF participants.

In 1996, Admi published an article from her dissertation research. Twenty-one informants participated in the study including adults with CF, their spouses and parents with young children with CF. Admi used a grounded theory approach with theoretical sampling. Four theoretical views of chronic disease served as the lens for the research. Data sources include repeated interviews, theoretical memos, and field journal notes. Constant comparative method was used to generate a theory about the growing up experience of living with CF.

From the data, four major categories emerged (a) Perceiving the self and the centrality of the disease, (b) Constructing the view of others' perceptions of people with CF, (c)

Managing information about the disease, and (d) Managing medical regimes (Admi, 1996). Admi reported that the participants with CF experienced an active childhood and their lives followed a normal psychosocial pattern of development. Except for medications and daily treatments, they did not view themselves as being handicapped, ill, victims, or different from their peers. Despite being aware of their disease, participants were future oriented and ambitious. However, the management of stigmatizing information was a complex process. Participants resented other individuals' negative attitudes towards them in regards their competence, independence, and strength of their relationships. Disclosure of disease information depended upon timing and the ability to establish a safe and trusting relationship. As participants grew up, they attached different meanings to their treatments and clinical symptoms. Participants did not understand the necessity of their treatments until adolescence when they understood their disease better and realized the positive implications of their treatments. By late adolescence, they had modified and incorporated treatments into a daily routine.

Although Admi's (1996) research provides insight into the process of incorporation and normalization of CF into individuals lives, she only involved adults in her study. The perspectives of younger adolescents and school-age children were not included when developing her theoretical framework of growing up with CF.

Tracy (1997) conducted a hermeneutic phenomenological study to investigate the lived experience of growing up with CF. Participants were asked about what it was like to grow up with CF. M. van Manen's technique guided the thematic analysis. Three themes

emerged from the data (a) being different, (b) “Don’t call me terminal”, and (c) will power and faith.

The first theme, being different, encompassed characteristics the participants felt differentiated them from people without CF such as cough, dietary habits, delayed growth, hospitalizations, and disease progression (Tracy, 1997). The second theme, “Don’t call me terminal” highlighted the continuing awareness of medical statistics regarding life expectancy in CF. Prognosis statements were not welcomed. Participants wished to be recognized as individuals and not treated as statistics. The final theme, will power and faith, encompassed incremental goal setting and holding on until a better treatment comes along.

The strength of this study lies in its capacity to enlighten nurses regarding the thoughts and feelings of adult CF patient. Participants in this study felt health care providers place too much emphasis on statistics (Tracy, 1997). Adults felt that they already had beaten the odds. Yet despite the difficulties of CF they set incremental goals and possessed hope for the future. Knowledge gained from this study can be used to enhance nurse-patient relationships. A major limitation of this study is that the question asked at the beginning of the interview (“How has it been to grow up with CF?”) does not correlate with the stated purpose for the study, which was to “discover the participants’ vision of the phenomenon of living with a chronic illness” (p. 3). The term *vision* implies anticipating or looking ahead, which conflicts with the term *growing up* which implies looking at the past. Another limitation is that the discussion of the themes portrayed recent adult CF experiences and

the participant's reflective thoughts concerning these experiences. The authors provided little information about the growing up experience of CF.

A more recent qualitative study exploring the experience of growing up with CF was performed by Norwegian nurse researchers Gjengedal, Rusteen, Wahl, and Hanestad (2003). Data were collected via four focus group interviews. Researchers interviewed parents of children with CF and adults with CF in separate focus groups. Gjengedal et al. reported using a method of thematic analysis inspired by Knodel for analyzing the data.

Gjengedal et al. (2003) discerned three main themes during their data analysis including (a) From uncertainty to certainty, (b) A demanding but normal life, and (c) A wish for continuity, stability, and respect. The parents of children with CF identified uncertainty as a difficult time when they were trying to find a diagnosis for their ill child. The majority of participants with CF did not remember anything about the time around the diagnosis except stories told by their parents. Participants reported that even though they took medications and that there were hassles with eating and respiratory illnesses, their childhood and present lives were normal. However, the parents reported being well aware that their lives differed from other families.

Participants with CF remembered the time of adolescence best because of increasing respiratory illnesses and increasing disease awareness (Gjengedal et al., 2003). During adolescence, they became more serious about having a chronic disease, took more control of administering their treatments, and became more aware of infection control issues. As adults, they hoped that medical science would find a solution for CF yet they were not afraid of dying.

Similar to Admi (1996), Gjengedal et al.(2003) identified strategies for the process of normalization. Unfortunately, at times it was difficult to distinguish parent perceptions from the perceptions of adults with CF. The childhood experience of living with CF was not depicted in this study primarily because of vague memories possessed by the adults with CF. Instead, parental perceptions filled the void of absent childhood memories.

In summary, adult participants with CF viewed growing up with CF as a normal life experience (Admi, 1996; Gjengedal et al., 2003; Tracy, 1997). Normalization appears to be a process that families who have a child with CF begin to follow at the time of diagnosis. Although daily treatments and occasional illnesses were the norm, participants noticed differences between themselves and peers. Childhood memories of the CF experience were vague. On the other hand the period of adolescence, when they became more aware of their CF, stood out for most. Participants also resented the negative attitudes of others (Admi, 1996) and disclosed personal information to trusted individuals. In adulthood, participants possessed goals and hope for the future.

**Adolescent Perceptions of Growing-up with CF**

The next four studies depict the growing up experience from the perspective of adolescents with CF. One study involved only adolescents (Christian & D'Auria, 1997), two studies involved adolescents and school-age children (Pizzignacco & Lima, 2006; Sawyer et al., 2004), and one study included school-age children, adolescents, and adults (Dallenbach, Speraw, Davis, & Ledbetter, 1995, May). Only the perspectives of the children and adolescents will be presented.

Christian and D'Auria (1997) explored the memories of adolescents growing up with CF using a grounded theory approach. Researchers purposively recruited participants from a CF center in the Southeastern United States until saturation was achieved. At the beginning of each interview, participants were told to go back in time to their earliest memory of CF. They were asked to describe their memory by telling the researcher what happened, when it occurred and why the memory was important to them. Next, each participant drew a timeline depicting important CF events.

Participant's memories of CF behaviors (e.g. coughing, taking their medications) were vague before the age of five (Christian & D'Auria, 1997). Awareness about their CF began between the ages of 6 to 8 years during a CF related illness. Researchers identified three strategies that participants used to hide their differences from their peers (a) keeping secrets, (b) hiding visible differences, and (c) discovering a new baseline.

According to Christian & D'Auria (1997), the process of hiding differences began upon entering grade school. Because of their cough, thin stature, lower energy levels, and the need to take medications, participants learned that others viewed them as being different. As a result, they hid their medications, suppressed their cough, wore concealing clothes, and paced their physical activity. Participants also revealed that they avoided telling teachers and other students about having CF due to concern of being teased. Their secret of having CF was disclosed only to trusted friends. In later childhood and during adolescence, meeting other individuals with CF and sharing similar experiences reduced the sense of difference.

The focus of Christian and D'Auria's (1997) study was limited to eliciting participant memories of growing up with CF. It is possible that maturation and adolescent experiences altered the memories of past experiences. The strength of this study is that the researchers were able to describe strategies children and adolescents use to hide their disease and portray themselves as being normal. In the next article, researchers used quantitative methodology, to compare perceptions of health-related quality of life (HRQoL) among adolescents with three different chronic diseases.

Sawyer et al. (2004), a multidiscipline research team, performed a non-experimental, two-year prospective study comparing perceptions of HRQoL among Southern Australian adolescents with asthma, CF, and diabetes. All participants completed the 87-item Child Health Questionnaire (CHQ). The CHQ consists of 11 subscales covering behavior problems, family health, perceptions of physical activities, interference in peer and school activities, emotional and behavioral problems, and pain and discomfort. Questionnaires were completed at baseline and at 6, 12, 18, and 24 months. Participants' scores were compared to scores from a community sample of 1245 children who participated in another study.

Sawyer, et al., (2004) reported participants with CF, diabetes, and asthma all scored significantly lower than the control group in perceptions in the following areas: general health, behavior problems, family activities, physical activities, and perceived interference in peer/school activities. Scores for general health perceptions and emotional problems were higher for children with CF than for children with asthma. The authors theorized that children with CF adjusted to their chronic condition and perceived their HRQoL as being better than what health care professionals and parents would expect. Over the 24 months,

physical health scores for individuals with CF decreased while those with asthma and diabetes remained stable. However, Sawyer et al. did not say whether the decrease was statistically significant.

A strength of this study is that the researchers did not elicit past memories. Instead, data were collected prospectively over a 2-year period. Another strength is that the authors identified and discussed the theoretical foundation for their research. However, several limitations exist. First, participants came from one hospital. Therefore, the results are not necessarily generalizable to other CF populations. Second, the results of the statistical analysis were difficult to decipher. The findings section would have been more effective if the numerous statistics (e.g. p-values) were arranged in a table. Third, the authors did not provide information about the reliability (including Cronbach's alpha) and validity of their instrument. In the following study, researchers compared perceptions among children, parents, and pediatricians.

Medical researchers from the Netherlands Janse, Sinnema, Uiterwaal, Kimpen, and Gemke (2008), examined differences in perceptions of health and wellbeing among children with a chronic illness (asthma, juvenile idiopathic arthritis, CF, or acute lymphoblastic leukemia) and their parents and pediatricians. Researchers used the Health Utilities Index mark 3 [sic] (HUI3) instrument to measure health and wellbeing one week after hospital admission and after the first follow-up visit. Sixty parent-child dyads completed the baseline questionnaire and 41 dyads completed the questionnaire at follow-up.

Researchers identified significant differences in perceptions among parents, pediatricians, and children (Janse et al., 2008). Differences were most notable in the subjective domains as compared to the objective domains. One limitation of this study is that parents completed the questionnaires for children age 10 and younger. It is possible then, that the child's perception of wellbeing may be more reflective of the parent's perception. Another limitation is that the authors were unclear as to how many pediatricians participated in the study and how many questionnaires pediatricians completed at baseline and at follow-up.

In a Brazilian study, reported by Pizzignacco and Lima (2006), researchers utilized a descriptive and exploratory qualitative design to investigate the socialization process of children and adolescents with CF. Data were collected via audio-recorded interviews. Each participant was asked two questions (a) Tell me what you know about your disease, and (b) Do you think you are different from your friends/acquaintances who do not have cystic fibrosis?

Four themes were identified (a) Mistaken knowledge about the illness, (b) Concern about self-image, (c) Search for self-care, and (d) Hope for improvements for the future (Pizzignacco & Lima, 2006). Researchers learned younger participants (ages 7 and 10) lacked an understanding of CF terminology. Adolescents expressed frustration concerning the lack of knowledge about CF among acquaintances. Concern about self-image began during grade school when peers noticed differences in their physical characteristics and physical abilities. Increased awareness of the disease process and benefits of medications occurred during the adolescent years. The frequency of self-care behaviors was alleged to

increase over time, particularly when participants desired more independence. Adolescents expressed hope for the discovery of better medications to treat CF and improving the public's knowledge about CF.

A limitation of this study is that researchers failed to accomplish the aim of their study, which was to investigate the "socialization process of children and adolescents with CF" (Pizzignacco & Lima, 2006, p. 51). Instead, interview questions focused on eliciting participant's own knowledge about CF, their perceptions about what other people know and understand about CF, and perceived differences between themselves and their peers.

The final study in this section was a qualitative study by Dallenbach, Speraw, Davis, and Ledbetter. The purpose of the study was to explore the lived experience of families living with CF. There were 51 participants including 16 CF patients ages 8 to 38 as well as parents, siblings, and one grandparent. All participants were enrolled from one CF clinic located in the Southeastern United States. Data were collected using an open-ended sentence completion questionnaire distributed by either mail or by hand. A major strength of this study is that the perceptions of all nuclear family members were represented, including those of the school-age children with CF.

Researchers found that families and persons with CF are able to successfully live with CF. Family members found meaning in life through supportive relationships and hope for the future. For children and adolescents with CF, hope for the future included having access to good CF medications and finding a cure, even if it meant becoming a physician and finding the cure him or herself. However, things that threatened hope including not being

able to keep up with peers during physical education exercises, getting up early to take medications, and negative reactions from peers concerning their chronic cough.

In summary, adolescents' memories about CF were vague before age five (Christian & D'Auria, 1997). Awareness about CF began after entering grade-school when peers and adults in the school environment brought attention to their differences (Christian & D'Auria, 1997; Pizzignacco & Lima, 2006). Adolescents revealed CF information only to trusted friends and disguised their differences from other peers and teachers (Christian & D'Auria, 1997; Pizzignacco & Lima, 2006). Older children and adolescents with CF perceived aspects of their HRQoL as being lower than their peers without chronic disease, yet their perceptions of HRQoL remained stable over time. Researchers also reported perceptions of children's health and well-being differed among children, parents, and health care providers (Janse et al., 2008). Importantly though children, adolescents, and their families find hope in life despite CF and manage to live meaningful lives. The final section of this review will examine the growing-up experience from the perspective of children with CF.

**Perceptions of the School-Aged Child with CF**

The next six studies include three that involved CF children and those with other chronic diseases (Angst & Deatrick, 1996; Fereday et al., 2009; Sartain et al., 2000) and three that only included children with CF (D'Auria et al., 1997; Havermans et al., 2006; Wennström, Berg, Kornfält, & Rydén, 2005). Angst and Deatrick (1996) reported on a secondary analysis of interviews from two larger qualitative studies. The purpose of the secondary analysis was to examine the perceived involvement of parents and children

when making health care decisions for the child. The study involved children with CF and their parents, and children undergoing surgery for scoliosis and their parents. In the CF group, parents reported satisfaction with their own involvement in making health care decisions. Furthermore, at times parents felt there was no need to include their child when making health care decisions because the decision was not negotiable. The children reported that they were dissatisfied with their involvement and desired more verbal input and information concerning changes in their treatment plan.

Participants in the scoliosis group were fewer and older (Angst & Deatrick, 1996). Parents and children both reported satisfaction with their level of involvement when making decisions surrounding a single surgery for scoliosis and during discussions concerning the progression of their scoliosis. The decision for surgery was either jointly made with their parents and health care provider or left totally up to the child.

The importance of this article is that the authors suggest that children with CF perceive a lack of involvement in health care decision-making. However, it is important to consider that the differences between the two groups may have occurred not because of the type of chronic illness but rather because of the context of the health care decisions and age of participants.

Nurse researchers D'Auria, Christian, and Richardson (1997) utilized a grounded theory approach when examining the growing up experience of children from one CF center in the Southeastern United States. Researchers used the same approach in a previously reported study with CF adolescents (i.e. Christian & D'Auria, 1997). Similar to the adolescent study, children reflected on their earliest memory of CF and informed the

interviewer about what happened, the importance of the memory, and what feelings the memory elicited. Towards the end of the interview, researchers asked participants about what advice they would give to children newly diagnosed with CF.

The results of this study were clearly presented and comparable to Christian and D'Auria's (1997) adolescent study. The central phenomenon described by the participants was "Discovering a sense of differences" (p. 103). The process for discovering differences was identified by the following themes (a) puzzling out the differences, (b) being teased and picked on, (c) telling others, and (d) keeping up.

Participants remembered their parents informing them about having CF around age five (D'Auria et al., 1997). They were puzzled about the meaning of CF and surprised to learn that they were different from other children. Because of a limited understanding of CF, participants under the age of 10 experienced difficulty explaining their disease to peers. Teasing from peers about their differences prompted participants to withdraw from activities or pace their level of activity to avoid notice. They also hid their CF by concealing physical differences and visible symptoms (e.g. suppressing a cough) when around peers. Participants struggled for approval by keeping their CF a secret and telling only trustworthy friends about having CF.

D'Auria et al.'s (1997) study with school-age children and Christian and D'Auria's (1997) adolescent study both focused on notable memories about having CF. It does not appear that the researchers addressed memories outside the context of CF. Also, the authors did not discuss their methods for maintaining rigor and reliability or provide study limitations.

The next study took place within the National Health Service Trusts located in Northeast England (Sartain et al., 2000). Children with chronic disease, their parents, and nurses were interviewed about a recent hospitalization. Although not all participants in this study had CF, children with CF represented most of the sample. The purpose of the study was to explore the phenomenon of chronic illness from a biographical perspective among children hospitalized with a chronic disease, their parents, and their nurses and to develop a theoretical framework depicting the formation of perceptions among parents, chronically ill children, and professional nurses. Participants included seven children (three with CF), their parents and nurses. Nurses who had contact with the child participant during the hospitalization or at discharge were invited to participate.

In this article, Sartain et al. (2000) focused on the perceptions of the child participants' in regards to their chronic illness and a recent hospital experience. Interview data from parents and nurses were not represented in the research findings. The authors presented a contrast between children who experienced familiarity with the hospitalization process versus alienation experienced by others. Two children coped with the hospitalization by creating their own special space in the hospital. One child found hospitalization disrupting to her social routine while another minimized disruptions in routine by bringing equipment from home. Another participant described hospitalization as being boring because there was little to do, but other said she would rather be in the hospital because there were people around to play with her.

The primary strength of the Sartain et al.'s (2000) study is that it provides the child's perspective about the experience of living with a chronic childhood disease and of repeated

hospitalizations. However, the presentation of the study results and discussion sections of the paper were confusing. Themes from the research were not presented and the authors did not depict or mention development of a theoretical framework as mentioned in their purpose statement. Generalizability is limited to the population of children with CF and with other chronic diseases because of the small sample size, too broad representation of chronic illnesses, and the lack of representation from different ethnic groups.

A Swedish study by Wennström, Berg, Kornfält, and Rydén (2005), sought to explore the perceptions of self-esteem among children with CF, their healthy siblings, and healthy children. Fifty-five pairs of siblings were purposively recruited from four CF centers in Sweden. Researchers used the "I think I am" self-evaluation questionnaire (SEQ) designed for children ages 7 to 14, for measuring self-esteem. Subscales of the instrument included (a) mental well-being, (b) relation to others, (c) relations to parents and family, (d) physical characteristics, and (e) skills and talents. Wennström et al. (2005) did not discuss the reliability and validity of the instrument.

Wennström et al. (2005) reported that there were no significant differences in total scores between the healthy sibling, the CF sibling, and the reference group of healthy children. However, when comparing gender differences, researchers reported that healthy sibling girls and CF sibling girls scored significantly lower than the boys did in mental well-being and in relations to parents and family when compared to reference group scores. The importance of this study is that it suggests that there is no difference in self-esteem between children with CF and their peers. It also implies that CF may negatively affect both CF sibling girls and healthy sibling girls.

The study has several limitations. First, the authors were unclear about the concept they were measuring. In the abstract and discussion, the authors referred to *self-concept* as the concept they desired to measure, however when presenting the measurement instrument in the methods section, the authors said the SEQ measured *self-esteem*. Second, sample size consisted of less than 30 participants in each of the healthy sibling and CF sibling gender groups, therefore interpretation of the results must be viewed cautiously. Third, the authors did not clearly define their reference group. Lastly, the authors did not provide information about the reliability and validity of the SEQ.

Havermans, Vreys, Proesmans, & De Boech (2006) evaluated agreement between parents and children on health related quality of life (HRQoL) issues. The validated revised 43 item Cystic Fibrosis Quality of Life Scale (CFQ) was self administered by the parents. Researchers administered a 33-item child version to the children. Higher scores on the CFQ indicated better HRQoL. Children rated the subjective domains of treatment burden, body image, and emotional functioning higher than their parents did. They rated the objective domains of respiratory symptoms and digestive symptoms lower than their parents did. However, children and parents agreed in the objective domains of physical symptoms and eating disturbances. Havermans et al.'s (2006) study illuminates differences between parents and children about their views of quality of life related to CF and demonstrates the importance of obtaining both the parent's and the child's perspective. A weakness of the study was failure to integrate quality of life theory into the study design or results. Researchers superficially applied the concept of health related quality of life by just using

the CFQ instrument and failed to provide information about the reliability and validity of the CFQ instrument.

The final study in this review is also the most recent. A multidisciplinary team carried out the study including two nurse researchers, a physician with expertise in public health, and a professor of early childhood education. Australian researchers Fereday, MacDougall, Spizzo, Darbyshire, and Schiller (2009), conducted an exploratory study to investigate the "perceptions and experiences of physical activity" (p. 2) among children living with chronic disease. In stage 1 of the study, participants with CF, diabetes, and asthma were recruited from a large hospital in Australia. Researchers utilized several qualitative data collection methods including photography, mapping, parent and child focus group interviews, 'mapping', and 'traffic light' posters.

In their findings, the authors report that the participants did not perceive themselves as being different from their healthy peers when engaging in physical activities or report peer teasing. Except during an acute illness, chronic disease was not seen as a barrier for participating in sporting and recreational activities (e.g. judo, canoeing, dancing). Fereday, et al. (2009), note that the parents of the child participants facilitated and encouraged their child's physical activity. When data analysis was completed for part 1 of the study, additional focus groups with a new sample of children were conducted to check and validate research findings.

Although the authors report using interpretive phenomenology for their theoretical framework they did not effectively substantiate the relationship between phenomenology and the various methods used to collect the data. Additionally, Fereday, et al. (2009) did

not provide a clear description of the procedure used for integrating and analyzing the different types of data. Although the findings section was informative and well written, the themes were not consistent with phenomenology. Fereday, et al. presented only two themes: One theme from the parent interviews and another from the child interviews. The authors also failed to mention their methods for maintaining validity and rigor and provided only one limitation for their study.

In summary, similar to the adolescent studies, children under the age of 12 report that awareness of their disease begins between the ages of 6 to 8 years (D'Auria et al., 1997). Children notice their differences through interactions with peers and others in the school environment and experience difficulty when discussing their CF with others. They desire acceptance by peers and hide the visible aspects of their disease. HRQoL measures are quantitative means by which researchers and clinicians can obtain children's perspectives of their health and well-being (Quittner, Davis, & Modi, 2003). When asked children and their parents differed in their perceptions of the child's HRQoL (Havermans et al., 2006) and over time the school-age child's perception of HRQoL remains stable (Wennström et al., 2005). Children with CF feel marginalized when parents and healthcare providers make decisions about their care (Angst & Deatrick, 1996). Lastly, recent research with children with chronic conditions suggests that when parents are supportive of their child's participation in physical activities children do not express concerns of peer teasing and marginalization as described in earlier studies (Fereday et al., 2009).

## Gaps in the Literature

All of the reviewed literature was valuable in extending the boundaries of knowledge about the childhood experience of living with CF nevertheless several gaps in the literature exist. First, there is a paucity of published nursing research eliciting the childhood experience of CF from the perspective of the school-aged child with CF. More than half of the studies acquired the childhood experience of CF from parent proxies, or adults and adolescents with CF, only a few elicited the life experience of CF from the perspective of the school-age child.

Second, several authors of the above studies said research participants with CF perceived themselves as having normal lives (Admi, 1996; Gjengedal et al., 2003; Tracy, 1997), yet the majority of the authors focused on the perceived differences of having CF. There is little information about what individuals with CF perceive as being normal about their lives. Interestingly, the most recent of the reviewed studies by Fereday, et al., (2009) revealed that children with CF and other chronic diseases may not perceive themselves as different from other children as previous researchers have suggested.

Third, parents and nurses often serve as proxies for reporting the health and wellbeing of the child in the hospital and clinic settings. Nevertheless, few researchers have explored or compared nurses and parents perceptions of the CF child's health and wellbeing to the child's own perceptions. Current researchers suggest that health care providers and parents perceptions of the health and well-being of the child with CF differs from the child's perceptions of their own health and well-being.

Fourth, children with CF report feeling marginalized by parents and health care providers and that they desire more involvement and information during health care conversations. Little is known about the antecedents of such marginalization, how to best promote child involvement during health care visits, or the long and short-term effects when children do and do not participate in their healthcare.

Fifth, it appears that perceptions and experiences differ between individuals with adult onset chronic disease compared to early childhood onset chronic disease. Although researchers have examined the impact of chronic disease on the self, hardly any have compared the differences between adult onset chronic disease and childhood chronic disease and how a medical cure affects the self.

## Summary

The purpose of this literature review was to examine the theoretical, opinion, and empirical literature to gain a comprehensive understanding about the world of the school-age child with CF. The literature for this review was drawn from numerous disciplines including nursing, psychology, sociology, education, and the esthetic arts. This review found a large gap of knowledge concerning what researchers know and understand about the child's perspective of living with CF. In order for healthcare professionals to appreciate the school-age child's experiences and perceptions of health and illness, children require a larger voice in research and in the health care environment. Therefore, additional qualitative and quantitative research is needed which elicits the perspective of school-aged children living with CF in regards to how they perceive themselves and the world in which they live. This study captures the perspective of the school-age children with CF by

allowing them to tell their stories in a developmentally appropriate manner. The inner most yellow rings in the center of the model of the child's world (see page 18) represent the child with CF. Those things that influence the child and help form their perceptions of the world include development, beliefs, daily social interaction, and CF. In the next chapter, I will show the reader how I measured the inner most perceptions of the child.

# CHAPTER 3

## Methodology

The purpose of this qualitative study was to explore and describe how school-age children with CF view themselves in the world they live. As revealed in Chapter 1, symbolic interactionism served as the lens for this study. For the study design, I used the methodology of *qualitative description* as described by Sandelowski (2000). The method of photo elicitation was employed to collect data. In this chapter, I will present my rationale for choosing qualitative description as the design and for using photography as a means for collecting data and conducting interviews. The chapter will continue with an explanation of the study procedures including sample selection, setting, protection of human subjects, data collection, data analysis, and assuring rigor and validity.

## Design

A qualitative design was chosen for this study because little is known about how school-age children with CF perceive the world in which they live. Qualitative description is a naturalistic form of inquiry, which seeks to investigate phenomena in its natural context. Researchers do not commit to a priori theoretical view (Sandelowski, 2000). The tradition of naturalistic inquiry is based on the epistemologic viewpoint that humans are holistic beings and that human experience is multidimensional (Depoy & Gitlin, 2005). Reality depends on how an individual perceives and understands his or her life experiences. Individuals subjectively and objectively construct reality through social interaction within the environment where they are situated (Berger & Luckmann, 1966; Depoy & Gitlin,

2005). Individuals possessing the experience of a phenomenon transmit their knowledge through actions and verbalization (Depoy & Gitlin).

Qualitative description is the design of choice when a straightforward description of a phenomenon is desired (Sandelowski, 2000; Sullivan-Bolyai, Bova, & Harper, 2005). According to Sandelowski, the goal of qualitative description methodology is to discover the "…who, what, and where of events or experiences, or their basic nature and shape" (p. 338). It is a method which seeks to obtain a rich description of an experience by (a) allowing for collection of data from multiple sources, (b) purposive sampling for obtaining information-rich cases pertaining to the phenomenon being studied, (c) staying close to the data, and (d) using low inference interpretation (Sandelowski; Sullivan-Bolyai et al., 2005). Researchers conducting qualitative descriptive studies use everyday language to present the facts of an experience or event and the meaning the participants attach to the facts (Sandelowski).

When children are consulted about their preferences in regards to research data collection methods, they suggest activities deemed interesting and fun for them, such as photography, interviewing each other, video taping their environment and drawing pictures (F. Smith & Barker, 2000). Qualitative description allows for active participation of the child in the research project. In this study, children with CF were key informants in relaying information about their world.

Because adults were once children, adults may assume they know what it is like to be a child and thus feel they are adept at relating to the child. However, children not only communicate differently than adults, their understanding and experiences of the world

also differ (Thomas & O'Kane, 2000). For the researcher, it is important to gain information through application of techniques that allow full freedom to communicate in ways comfortable for the child.

## History of Photographic Methods in Research

Photography is not a new method for collecting research data. According to Prosser (1998) anthropologists used photography during the 19th century to record field data such as artifacts, and rituals, and environment of the people they were studying. However, by the 1920's fieldwork became popular and photography was no longer used as the primary method for data collection. Two anthropologists, Margaret Mead and Gregory Bateson, saw value in adding photographs to their research analyses and attempted to revive visual methodology in the mid 1940's, but their attempts did not succeed (Harper, 1998).

Early sociologists began using photography about the same time as ethnographers, but visual sociology did not emerge as a substantial sub-discipline until the late 1960's (Harper, 1998; Prossler, 1998). From the 1960's until the early1980's, conservative positivist researchers and visual researchers debated over the validity of photographic images in research (Pink, 2007). According to Pink, opponents familiar with scientific methods argued that photographic images "…lacked objectivity and scientific rigor…" and that the "…specificity of the photographed moment rendered it scientifically invalid" (p. 9). Collier and Collier (1986) argued photographs are tools, which provide "…pathways for strangers to gain access into unfamiliar and unforeseen environments and subjects" (p. 99).

Around the mid 1980s postmodern sociologists began to redefine the relationship between researcher and participant (Harper, 1998). Gathering data became a collaborative

process between researcher and participant. Researchers were allowing research participants to photograph their lived environments. Postmodern documentary photography supports the idea that the "…meaning of a photograph is constructed by its maker and the viewer, both of whom carry social positions and interests to the photographic act" (Harper, p. 32).

**Types of Photographic Methods**

Next, four photographic methods currently used by researchers will be highlighted including documentary photography, auto-photography, photovoice, and the method I used for this study photo elicitation.

**Documentary Photography.**

Documentary photography (DP) involves the recording of real life circumstances involving people, places, and events (McCredie, n.d.). The origins of DP go back to 1839 when photography served as a means for reporting news about war. During the 1930s, photography became a tool for social reform when Walker Evans explored the extent of poverty in rural southern America (Ewald et al., 2000; McCredie, n.d.). Since then DP has been increasingly used by photojournalists around the world to enlighten people concerning the social issues of hidden and marginalized individuals and groups. Wendy Ewald is one well-known photojournalist who, over the past 30 years, has given cameras to children and taught them to photograph their everyday world. Through photography Ewald has encouraged children to explore their environment, family, and selves and to express their dreams and fantasies.

**Auto-photography.**

Auto-photography is a research communication tool used to understand and evaluate a person's perceptions of self in the context of others and their social environment (Ziller & Lewis, 1981; Ziller & Smith, 1977). Ziller coined the term auto-photography during the mid 1970s by combining photography and autobiography. Zeller's research method utilizes both an experimental and a control group. For example, in one study he compared the perceptions of college students from a university psychology clinic with a control group of students from an introductory psychology class (Ziller & Lewis). Photo-autobiography involves giving participants a camera and instructing them to take pictures that "describe who you are as you see yourself " (Ziller & Lewis, p. 452). In analyzing data, Ziller categorized participant's photographs according to environment, self, and social constructs and then analyzed the content of the photos. Photographs from the experimental group are then quantitatively compared to the control group using chi-square and Fisher's exact test. In the more recent literature, Armstrong (2005) identifies auto-photography as a process where individuals critically reflect on and interpret photographs of people and places they have either taken themselves or have been given.

**Photovoice.**

Photovoice is a participatory action research strategy developed by Wang in the mid 1990s, as a means for helping people bring light to silent or hidden issues (Wang & Pies, 2004). Theoretical underpinnings of the photovoice method include feminist theory, documentary photography, and Freire's education for critical consciousness. Photography gives voice to people who normally would not be able to express themselves to others in

the world. Wang's method empowers individuals by entrusting cameras to research participants. In this manner, they are able to convey what is important to them and express concerns they have about their social environment. Both the researcher(s) and participants then engage in dialogue about the photographs; identify themes, issues, or theories; and present their insights to the community through forums such as the newspaper and photo exhibitions. Researchers, community leaders, and/or policy makers utilize participant's recommendations as catalyst for change.

**Photo Elicitation.**

Photo elicitation is a process of viewing and discussing photographic images during individual interviews (Oliffe & Bottorff, 2007). Participants are either interviewed with photographs they have either taken themselves or photographs that researchers have taken (Harper, 2002). Photo elicitation is thought to have its origins in anthropologic research. The first anthropologist to write about using photographs during interviews was John Collier in 1957. Photographs add dimension to the interview process in two ways (Collier & Collier, 1986; Pink, 2007). First, photographs take the researcher into places where it would be difficult for the researcher to enter or participate, such as a child's special place. Second, photographs allow participants to tell their personal story and encourage the sharing of information about artifacts, processes, and places.

Collier and Collier (1986) report photographs serve as "…starting and reference points during discussions" (p. 99). Additionally, the use of photographs during interviews may sharpen participant's memories and provide richness to the data not obtained during a regular interview (Epstein, Stevens, McKeever, & Baruchel, 2006). Epstein et al. discovered

photograph guided interviews with children helped to build rapport and trust between researcher and participant, triggered memory, and permitted children to participate more fully in the interview process. Close (2007) reported that photo elicitation with children improved data generation and provided her with deeper insight and understanding of participants' reality.

### Photographic Method Used in this Study

The strategy of photo elicitation was chosen as the best method for this study because it allows children to become active members in the research process and interpreters of their own world (Darbyshire, MacDougall, & Schiller, 2005). According to Pink, social anthropologist, photographs have two key values. First, photographs are taken at a moment that is meaningful to the photographer and "within a particular narrative of events" (p. 91). Second, new narratives are formed and new meaning is bestowed on the photos when participants discuss their photographs.

In this study, photography was employed as a means for collecting observational data from the participant's environment. Then the participants took their own photographs depicting what was important to them such as people, places, and activities. The photographs were then used to stimulate and guide conversation when obtaining verbal data during one to one interviews with the child participants.

## Procedures

### Sampling

I chose to study school-age children with CF because the review of literature revealed that this age group is under-represented in the CF research literature. My study population

was limited to include children ages 8 to 11 because children in this age range are at the same developmental stages of Piaget's concrete operational stage and Erickson's stage of industry versus inferiority.

According to Polit and Beck (2004) a guiding principle when determining sample size during qualitative inquiry is data saturation. Data saturation is the point at which "no new information is obtained and redundancy is achieved" (p. 308). In a study by Guest, Bunce, and Johnson (2006) researchers interviewed 60 women in West Africa. They achieved data saturation after 12 interviews. Kuzel (1999) recommends 12 to 20 participants if trying to achieve maximum variation. Therefore, my goal was to recruit a minimum of 15 children. Recruitment resulted in 17 participants of which 16 completed the study. Data saturation and redundancy was obtained after 13 interviews.

**Inclusion/Exclusion Criteria**

The following are the inclusion and exclusion criteria used for this study.

Inclusion criteria**:**

1. Participant must be 8, 9, 10, or 11 years of age at time of enrollment.
2. Confirmed CF diagnosis as reported by parent/guardian based on the following criteria:
    a. One or more clinical features consistent with the CF phenotype and either b or c.
    b. Positive sweat chloride >60 by pilocarpine iontophoresis.
    c. A genotype with two identifiable mutations consistent with CF.
3. Written informed consent from one parent or guardian.

4. Written assent from the child participant.
5. Child and parent/guardian are willing to and able to comply with requirements of the study.

Exclusion criteria:

1. Child is unable to take photographs.
2. Child does not like to or is unwilling to take photographs.
3. Child unwilling to participate in an interview with researcher.
4. Unstable emotional or physical health status as reported by the parent at the time of enrollment. For example, a child is being hospitalized for severe depression or for a severe CF exacerbation.
5. Parent or guardian refuses to sign a photographic release statement (Appendix B).

**Recruitment**

Originally, I had planned to recruit from two CF centers located in two cities in the Southeastern United States, but the timing for this study did not work out for one of the centers. As a result, all participants were purposively recruited from one CF center. While designing the study, I obtained verbal and written permission from the physician director of the CF center where my recruitment efforts were focused. I also obtained permission from the CF clinic nurse manager and elicited support from the (a) CF clinic nurses, (b) CF clinic social worker, and (c) CF clinic clinical nurse specialist (CNS). Then before recruitment commenced, two start-up meetings were held for members of the CF clinic team. All CF team members were asked to participate in at least one of the meetings including physicians, nurse practitioners, staff nurses, respiratory therapists, dieticians, the

physical therapist, and the social worker. The purposes of the meetings were to (a) introduce and explain the study, (b) provide instructions for recruitment, and (c) answer any questions put forth by team members.

The methods for recruitment reflected suggestions made by the CF team members at the site from which the participants were recruited and were based on past research recruitment experiences with the CF population in that particular clinic. Methods used to recruit participants included (a) sending an introductory letter about the study to parents[3] of potential participants, (b) placing an announcement in the CF clinic newsletter, (c) offering verbal reminders by CF staff during CF visits, and (d) being available to clinic staff during CF clinic days.

Upon approval of both IRBs, parents of children ages 8 to 11, who regularly attended the CF clinic, were sent a letter and flyer informing them of the study and inviting their child to participate. A designated CF staff member identified potential participants from the clinic CF registry, created mailing labels, and attached the labels to envelopes. Then, letters and flyers were placed in the envelopes and sent. Parents of children interested in participating in the study were invited to contact me either confidentially via cell phone on a number specifically secured for this study or via my university email address.

While letters and an announcement in the CF newsletter were helpful for alerting and familiarizing CF parents and children about the study, these two methods only elicited two parental inquiries via the telephone. No one made contact by email. Since this type of a

[3] For the ease of reading, from this point forward the term parent(s) will be inclusive of both parent and guardian.

response was expected, flyers (Appendix C) were also placed in strategic locations in the CF clinic (e.g. on exam room doors) and staff nurses provided verbal reminders.

On the morning of each CF clinic day, I called the clinic to enquire if any patients met the inclusion criteria. By this time, the clinic nurses had already looked through the day's list of patients and identified potential participants based on age. On days when potential participants were identified, I drove to the hospital clinic and waited in a room away and out of sight from all CF clinic patients and families. As children were brought into the exam rooms, clinic nurses handed the parent the same flyer that was sent to them in the mail. The nurse then briefly explained the study and informed them that the researcher was available to meet with them after the completion of their visit, if the child was interested.

The clinic nurse would then notify me when a child and parent desired more information about the study. I would receive the names of the child and parent, their room number, and an approximate time when I could meet with them in their clinic room. At no point did I ever approach a child or family on my own. Additionally, the CNS indentified and approached possible participants who where being hospitalized. She then notified me if a child wanted to participate. All participants recruited from the clinic and hospital were of good physical and emotional health at the time of enrollment.

Participants were recruited over an 11-week time period beginning in mid November until the first week in February. Recruitment progressed faster than originally expected because not only were the children interested in taking photographs with their own camera, but they also had control over what pictures they took. Eliciting input from key clinic stakeholders including the CF clinic nurse manager, staff nurses, CNS, and social

worker guided the researcher in adjusting to the clinic culture and in the development of appropriate and specific recruitment techniques. Additionally, the presence and availability of the researcher (PI) for the clinic staff on CF Clinic days and input from clinic personnel when enrolling participants into the study was crucial for recruitment success. Keeping CF nursing staff appraised of the study progress via email and weekly phone calls kept clinic staff motivated and thinking about recruitment.

**Setting**

To participate in the study, each child participant and at least one parent were asked to meet with the researcher face to face three to four times throughout the study (Appendix D). Study visits were labeled as follows: Screening Visit, Visit 1, Visit 2, Visit 3, and Visit 4. The screening visit took place in one of three ways (a) over the phone, (b) the CF nurses notified me and I visited the family at the CF center, or (c) the CNS notified me and I visited the family in the hospital.

Visit 1 took place in one of two ways. It occurred (a) immediately following screening visit if face-to-face or (b) if the screening occurred over the phone, I completed the screening and then scheduled a face-to-face visit at the parent's convenience. The second scenario occurred only twice. One family asked to meet at a fast food restaurant and I met with the other family when the child was in the hospital for a scheduled course of IV antibiotics. Visits 2, 3, and 4 all occurred in the family home or a place chosen by the participant's parent. More specific details about each of these visits will now be presented.

**Specific Information Concerning Visits and Data Collection Procedure**

When meeting the child for the first time I either sat or bent down to eye level of the child and introduced myself, "Hello, My name is Renée Burk. I am a nurse who has cared for children with CF for a long time. I go to school just like you. I am doing a project for school about children who have CF. The project is called a study. For the study, I am going to ask children to take pictures about what it is like to be you." Because some children become leery and or fearful of adults dressed in white lab coats or in formal business attire, I wore nice coordinated casual clothing that was loose enough to allow me to move around with the child.

**Screening visit.**

Initial contact with all participants occurred at the Screening Visit. During the screening visit, the child and his or her parent were informed about the details of the study and I assessed whether or not the child met study criteria.

First an overall explanation of the study was provided including the (a) purpose of the study, (b) inclusion/exclusion criteria, (c) methods and procedures, (d) benefits, risks and protection measures, (e) the use of peoples' images for professional and educational purposes, and (f) rights to the child-authored photographs. Then I completed the Participant Information Form (PIF) (Appendix E) to verify that the child met the study requirements. All information for the PIF was collected from the parent and child. The PIF included demographic information including name of child, age, date of birth, gender, verification of CF, and contact information including the parent(s) name, contact number, address, and name of CF Center.

Then, if the child met study criteria and both child and parent wanted to participate additional information was collected including (a) FEV1, (b) activity limitations, (c) members of the family system, (d) number of CF exacerbations and hospitalizations in the past year, (e) exercise limitations, and (f) names of treatments and medications. In all cases the child met study criteria, however on a few occasions either the child or parent decided not to participate. The reasons for not wanting to participate varied from non-interest on the child's part to the parent being too busy to commit. The screening visit took approximately 5 to 10 minutes.

**Visit 1: Enrollment.**

During Visit 1, I reiterated the specifics of the study in detail as specified above in the screening visit (unless the screening visit had just occurred). Then an informed consent and a Photograph Release Statement (PRS) (Appendix B) were obtained from at least one parent and an assent (Appendix F) was obtained from the child prior to enrollment into the study. The PRS is a form that gives the researcher permission to use the child's pictures and the child's and his or her parent's image for educational and professional purposes. The PRS is further explained under Protection of Human Subjects.

Consent forms and PRSs were verbally explained to the parent(s) of the participants. Children were given a simplified written explanation of the study as well as a verbal explanation with additional dialog as needed. Once the consent, PRS, and assent were signed each child was handed a point and shoot Kodak EasyShare C143 digital camera, camera manual, and picture taking instruction sheet (Appendix G). The parent(s) were

clearly informed, verbally and in the informed consent, that the camera was on loan only for the purpose of the study and that it needed to be returned in working condition.

To assure participants knew and understood how to use the camera, I then showed each child how to use the camera and asked for a return demonstration. Several participants owned similar camera's of their own and already knew the workings of the camera. The other children caught on very quickly. All children knew the basic workings of the camera by the end of the visit including how to (a) turn the camera on and off, (b) zoom in and out, (c) use the flash feature, (d) view photographs, (e) delete unwanted photographs, and (f) frame a picture.

I then discussed picture-taking instructions. Participants were given the following instruction, "With your camera, take pictures that show other people (like me, your parents, friends, nurses, doctors, or teachers) what it is like to be you. Take pictures about everything in your life that you want people to know about, including the good stuff, the bad stuff, and everything in between. Take pictures about the people you know; things that you do; things that happen to you; things that are important to you such as people, pets, and places you go; stuff you do; and pictures of when you are happy, sad, scared, sleepy, or hurting. I would like you to take pictures of your inside world and your outside world". Each child was then asked if they knew what made up their inside and outside worlds. Most of them did not, so I went on to explain that the outside world consisted of everything outside of their body (e.g. people, places, and things) and their inside world was everything inside their body and inside their head (e.g. thoughts, feelings, bodily sensations, tastes, smells). I then asked the children to give examples of their inside world and outside world. The children quickly realized that there were some things that could be experienced inside and outside of their body, such as food. They could see food when it

outside their body, but smell, taste, and swallowing of food was something that happened inside their body.

Next, we talked about how to take photographs of their inside world. At this point, the children often did not know what to say, so I gave them some ideas such as drawing a picture and taking a photograph of it. Lastly, each child was advised to ask permission before taking pictures of other people and to not take embarrassing photographs of themselves or anyone else. To assure the participants understood what an embarrassing photograph meant, I asked them to give an example. Children reported that it would be embarrassing for other people if they took pictures of them crying, sleeping, getting mad, or taking a shower.

At the end of the visit, each child was handed a two-pocket folder which included (a) copies of the informed consent and child assent, (b) picture taking instructions, (c) a camera manual, and (d) additional PRSs for family, friends, and neighbors whose images appeared in child's pictures. The camera was dispensed in a zippered, padded camera case with an attached shoulder strap along with two extra batteries. A card with my name and contact information was placed inside the camera case along with a condensed version of camera instructions.

Participants were then informed that they had 2 weeks to take photographs. In reality participants kept their cameras for 2 two 4 weeks. Extensions beyond 2 weeks were given because (a) some children wanted to keep their cameras to take pictures over the Christmas holiday and (b) snowstorms delayed parents returning the camera. In case the parent and or child had any questions about the workings of the camera, a manual was included with the camera. Families were also informed that they could contact me if they

had any questions on the cell phone number secured for this study. The first visit lasted between 45 and 60 minutes. The next visit was supposed to occur when the participants were done taking pictures.

**Visit 2: Camera retrieval.**

The purpose of Visit 2 was to pick up the study equipment either at the participant's home or in the CF clinic and review the photographs on the camera in case the child wished to delete any unwanted photographs before the interview. However, because of severe weather conditions and extreme distances between the participants and researcher, Visit 2 occurred as planned with nine out of 16 participants. When Visit 2 went as planned, the children and I reviewed the pictures together, however, none of them wanted to remove any pictures because they had already deleted all of the pictures beforehand. Most of the deleted pictures they had taken themselves. These pictures were eliminated because either the picture did not turn out as expected (e.g. picture was out of focus) or the picture was a duplicate. They deleted pictures other people had taken when the picture was taken without their permission. For example two children reported that another child had gotten a hold of their camera and taken pictures they did not like and another child's mother took a photograph that was embarrassing to the child.

Up to 10 digital cameras were in use at one time. All cameras were returned in working order except for one. One camera malfunctioned after the participant had the camera for 3 weeks and taken 53 pictures.

The second visit took approximately 15 to 20 minutes, when it took place. A one to two week waiting period followed the second visit so the photographs could be developed.

When Visit 2 was not possible, one of two scenarios occurred (a) the study equipment was sent via mail to the researcher in a self-addressed stamped box provided by the researcher or (b) Visit 2 occurred along with Visit 3.

**Visit 3: The interview with photo elicitation.**

At Visit 3, I interviewed the child with his or her pictures and helped him or her make a picture book. To preserve participant recall, I tried to schedule the interviews no later than two weeks from the date the camera was returned. Visit 3 occurred within two weeks for 13 of the 16 participants and within 3.5 weeks for all other participants. The time between when the camera was returned and when the interview occurred did not affect the length or the quality of the interviews.

All interviews were conducted face-to-face and digitally audio-recorded. Before beginning the formal interview, I spent time building rapport with the child and his or her parent. Then I brought out the child's pictures and laid them out. For two participants I was unable to collect the camera beforehand, so for these interviews the pictures were downloaded to my 13" MacBook® laptop computer and onto iPhoto®. The children were then allowed to scroll through and look at their pictures on the computer. When they wanted to talk about a particular picture I had them click on the picture to bring it up and when they were done with the picture they pressed escape. When I was three quarters of the way through the interviews I realized that the children liked using the computer. At this point in the study, the last four participants were given a choice between using their pictures or the computer. Three of the four chose the computer because it was fun for them.

When presented with his or her pictures each child was encouraged to look through them and choose the one he or she wanted to talk about first. When the child was ready, I asked him or her to "Tell me about this first picture". The participant's answers and photographs guided the next questions. For example, "What is going on in this picture?" and "How does this picture make you feel?" Discussion surrounding each photograph continued until the participant indicated he or she wanted to move to the next choice.

Thompson et al. (2008) found that restricting the number of photographs stifled the interview process. Therefore, participants were not restricted to discussing a predetermined number of photographs. When the child tired during the interview, I either (a) stopped the interview and took a break (e.g. stretched or had a snack) and resumed when the child was ready or (b) scheduled another visit and returned to finish the interview at another time as soon as possible. Only once did I need to stop and resume the interview on another day. That particular interview occurred in the evening on a school night and the child got sleepy. As a result, the parent and I decided to complete the interview the following weekend.

The children talked about all of the pictures that they themselves had taken. But since Visit 2 did not occur with everyone some participants had not reviewed their pictures before turning in their cameras. During the interviews, several of these children came across pictures that someone else such as a parent, friend, or sibling had taken that they did not like. The majority of the time when this happened the child did not wish to talk about it and so the picture was eliminated from the study. Participants were not pushed to

speak about any picture they did not want to talk about; instead, the child was allowed to go on to the next picture.

Fifteen interviews took place in the participant's home and one occurred in a private room around a table in a hospital library. Of the interviews occurring in the participant's home, one was on the floor in the child's bedroom, two were on the living room floor, one was in the living room around a table, and 11 interviews took place around the family dining table. The interview that happened outside the child's home had the most interruptions. The child found it difficult to focus during the interview and requested numerous breaks so she could get up and move around. The most awkward experiences for me were the two interviews that took place on the participant's living room floor. Although it was winter, the air-conditioning was on in one house. As a result, both the participant and I were uncomfortably cold. In the other home, the available floor space was restricted to a cramped 3x4 foot space making it difficult to spread out the pictures and the recording equipment.

To minimize interruptions and parental interference. I preferred children be interviewed alone and in a location where interruptions by others would be limited and where the child's stories could be confidential. However, some children were more comfortable talking to an adult with a parent present. These parents were asked to sit off to the side and not in direct line of eye contact with their child. Five children were interviewed out of earshot from their parents, five other children's parents sat in an adjoining room, and a parent was in the room for most or part of the interview for the other six children. In one of the cases, where a parent was in the room, the parent got in the

way of the child telling his or her stories. Instead of the child directing the interview, the parent interfered by suggesting that the child choose a specific picture and tell a particular story about the picture.

Towards the end of the interview I asked the child, "Is there anything or anybody that you wanted to take a picture of but couldn't?" If the child responded with a "yes", he or she was asked to tell me what or whom would that picture have been about. Their answers varied: Some would have liked a picture of another person, such as a friend, while others wanted a picture of some activity they partook in or a place they visited. At the conclusion of the interview, I assisted each child in constructing a 6 x 8 inch photo book with his or her photographs. The picture books were created in iPhoto® on my laptop computer (see Figure 3). The book was given to the child to keep as compensation for participating in the study after it was developed, hardbound, and linen covered.

The average interview took 96 minutes. The shortest interview took 45 minutes and the longest interview lasted 148 minutes. The interview with the child who took the most photographs was the longest, and the interview with the participant who took the least amount was the shortest. However, for the rest of the participants the length of the interviews did not correlate with the number of pictures taken by the child.

Parents were notified in the informed consent, during Visit 1, and again when scheduling the interviews to allow 2 hours for the interview. However, 30 minutes into two separate interviews, a participant's mother announced that the family would be leaving soon. In the first case, the participant's mother asked her child to get up and put her coat on because she had errands to run and in the second case another participant's mother

informed the me that the family was going out to eat. During the first situation I was able to negotiate an additional 15 minutes so the child could finish talking about the pictures and start making the picture book. Unfortunately, the child was unable to complete the picture book and asked the researcher to complete it for her. In the second situation, the participant's parents were willing to schedule a second visit so the child could make his picture book.

At the end of Visit 3, if they had not already done so, children were encouraged to give their thoughts about being in the study. All of them liked being in the study and thought it was fun. Fourteen had never participated in research before. What they liked about their involvement included taking, being in, and talking about their pictures, as well as making the picture book. However, the two "best things" they reported about being in the study were (a) they were in charge of taking all their pictures, and (b) they were able to make their own picture book on a computer. Making the picture book required some guidance on my part but overall the children directed the project. It was during the making of the picture book that the researcher and child connected the most. Children sat on my lap, leaned on my shoulder, and placed their head against mine as we worked on the picture book.

When the book was completed, each child typically celebrated by running to ask his or her family to look at the book. The family then gathered around the child to look and listen. I turned the pages on the computer while either the child or myself read the words. Children typically wore a big smile during their presentation. Afterwards, everyone else

clapped and or congratulated the child on a job well done. The following figure is an example of a child's picture book.

Figure 3. Adam's picture book.

Then before leaving I inquired whether or not the child and parent would be amenable to participating in Visit 4. All who lived within close proximity to the CF clinic were agreeable to a fourth visit. Picture books were typically sent to the participants within 4 to 6 weeks of the interview.

**Visit 4: Validation of results.**

The fourth visit was not necessary but was appreciated so that I could validate the findings from the study, with the participants, to assure accuracy of the study results. Visit 4 occurred after data had all been analyzed, themes were finalized, and a thematic structure was drawn (see Figure 4.1, p. 138). Only participants who expressed interest in a fourth visit were contacted. Parents were called via the telephone and I made an appointment to meet with the participant and his or her parent(s). All final visits occurred in the child's home. During the fourth visit I presented the findings of the study in a language understandable to the child and his or her parent. Children were handed a picture

of the schematic structure to look at. I explained each theme, how it was developed, how each theme was named, and what each theme was about. In all cases, the children liked the thematic structure saying that it represented their world and agreed with my findings. The fourth visit lasted between 30 to 60 minutes.

## Protection of Human Subjects

Prior to recruitment a completed Form B was submitted to the Institutional Review Boards (IRB) at the University of Tennessee, Knoxville (UTK) and the hospital where participants were enrolled. Once IRB approval was obtained from both institutions recruitment commenced. An informed consent was obtained from at least one parent and assent was acquired from the child prior to enrollment into the study. The consent form was verbally explained to the parent(s) of the participants. Children were given a simplified written explanation of the study as well as a verbal explanation with additional dialog as needed. Child and parent were permitted to withdraw from the study or stop the interview at anytime. All data were destroyed for anyone choosing to withdraw from the study.

A separate form called the Photograph Release Statement (PRS) was presented and discussed during enrollment (Appendix B). The PRS asked parents to grant the researcher permission to use the child's photographs and any photographic images of the child for professional and educational purposes including publications, printed materials, exhibits, and presentations. I also requested that any family members (e.g. mom, dad, siblings, grandparents) or friends (e.g. a best friend) whose images appeared in the photographs to also sign a PRS. Additional PRS forms were given to parent(s) so that signatures could be gathered during the period the children took their photographs. Parent(s) were asked to

sign the PRS for any minor children (under the age of 18). The identity of participants and persons in the photographs are to be kept confidential. If photographs were taken of any persons who did not (or if under age 18 a parent) sign a PRS and their image was identifiable, then the faces of those persons will be either electronically blurred or not used in any report, publication, or presentation.

The real names of all participants were kept confidential. Before transcribing any transcripts the transcriptionists were asked to sign a Transcribers Pledge of Confidentiality (Appendix H). During transcription, names and places were removed from the interview and replaced with pseudonyms. Information identifying the participants was removed before documents were shared with my dissertation committee. When assuring the validity and accuracy of the study findings during peer examination, colleagues and professors were asked to sign the Research Team Member's Pledge of Confidentiality (Appendix I).

Potential risks of participating in the study were minimal. Risks included possible emotional discomfort, which could arise when children talked about their world. Building rapport before and during the interviews as well as allowing the children to guide their interviews diminished anxiety and discomfort.

There were several benefits for the participants. Children were given opportunity to freely express themselves verbally and with photography. Knowing that others value their perceptions and experiences were reassuring, affirming and supported their sense of worth. Also, parents gained important knowledge about their child's ability to (a) commit and participate in qualitative research project and (b) take good (and sometimes excellent), creative, and meaningful pictures.

## Equipment Used in This Study

Equipment required for this study included (a) 10 point and shoot digital cameras including camera manuals and cases, (b) 50 AA batteries for the cameras, (C) one Sony® ICD-UX200 digital recorder to record interviews, (d) one 4GB Livescribe™ Echo smartpen to audio record interviews and a Livescribe™ notebook to record photographs as they were discussed by the participants, (e) an iMac® with 2.8GHx Intel Core i5 processor and 8GB of memory, (f) a 13" MacBook® laptop computer, (g) a 500GB external hard drive to backup and store data, (h) Atlas.ti© computer software to assist in organizing and analyzing data, and (i) iPhoto Mac® software to manage and organize photographic data.

Electronic data including audio-recordings, transcribed interview files, digital photographs, reflective journal, field notes, and data analysis were all stored on the iMac® computer while the study was being conducted, analyzed, and the results were written. Files were backed up on an external hard drive while the computer was in operation every two hours. Electronic storage devices, enrollment forms, and hand written notes taken during the interviews were kept in a locked cabinet in my home when not in use. Except for myself and members of the dissertation committee, no one else had access to the photographs, transcripts, and field notes.

A nationally recognized photo processing company, RitzPix, was used to print photographs and photo books because (a) they offered a password protected file to upload

photographs and photo books, (b) the products were of good quality and prices were affordable, and (c) a print shop was locally available.

## Data Management During the Interview Process

Upon return of the camera digital images were transferred from the camera memory disc to the iMac® computer and into iPhoto®. The. A back-up copy of all photographs was stored on my laptop computer. To prevent unauthorized access to study data, both computers were protected with a password known only to me. Then all photographs were erased from the camera memory discs to assure children's photographs would not be passed on to the next participant. All of the uploaded pictures were then numbered in the order that they were taken so that they could be matched to the text later on. Photographs were uploaded to a password protected file on the RitzPix.com website (http://www.ritzpix.com/net/Default.aspx?) and electronically sent off for printing. They were developed and picked up within 24 hours and then numbered in the same order as in iPhoto®.

All interviews were recorded on a digital voice recorder and a smartpen. The smartpen allowed me to synchronize my notes with the recorded audio. Later, during data analysis, when I wished to review a photograph in iPhoto© with the text I found the picture number in my notes, pressed the tip of the pen on the picture number that I had previously written down, and the audio recording that correlated with that particular picture played.

Photo books were constructed by myself digitally on the RitzPix.com website using the child constructed iPhoto® book as a template. Each book took 2 to 4 hours to complete

depending upon the number of pictures the child wanted in his or her book. When the book was completed, it was sent electronically to a local Ritz affiliate print shop where it was constructed and ready within 24 hours. The majority of photo books were sent to the participants; only three were delivered by hand.

## Data Analysis

Sandelowski (2000) recommends that for qualitative description, data be analyzed using qualitative content analysis. There were several aspects to consider when analyzing data from photo elicitation (a) the volume of photographs and text collected during the study, (b) context, and (c) the individual photographer's perspective represented in the photograph, (Collier & Collier, 1986; Kolb, 2008).

To handle the vast amount of textual data I utilized Atlas.ti©, a computer software package, which helped me (a) organize all textual data, then (b) label, code and later thematize data during analysis. I had originally planned on using Atlas.ti© to manage the photographic data as well, but I found that iPhoto© was simpler and easier to use. The primary benefit of iPhoto© was that multiple photographs could be viewed at once whereas with Atlas.ti© only one photograph could be viewed at a time.

To fully understand the context of the child's perceptions and to help me connect with the participants' stories each transcript was read along with the photographs and audio recording before coding and thematizing began. I repeated this practice throughout the analysis process to keep myself grounded and immersed in the data. The goal of my analysis was to stay as close to the data as possible so that a rich description of the phenomenon of CF children's perceptions of the world emerges.

Interviews and photographs were analyzed using a modified version of Boyatzis (1998) method of inductive thematic analysis. Thematic analysis is a process for coding qualitative data and an appropriate method to use when a rich description of a phenomenon is desired. Boyatzis, thematic analysis moves the researcher through three phases of inquiry (a) seeing, (b) seeing it as something, and (c) interpretation. *Seeing* involves perception of a notable pattern occurring among photographs and text. Once the pattern is recognized it is classified or described. This encoding of a pattern is called *seeing as*. Developing the ability to use thematic analysis involves four stages:

1. Sensing themes – recognizing codable patterns.
2. Doing it reliably – recognizing a codable pattern and coding it consistently.
3. Developing codes (or themes).
4. Interpreting the information and themes in the context of a theoretical lens or framework (contributing to knowledge development).

The process used to analyze the data will now be explained.

Each transcript was coded separately. *Sensing* began when first reading and listening to a particular transcript text with the child's photographs. Next, I returned to the transcript text and photographs and began to apply broad labels to the text where patterns were sensed. During this process of encoding Boyatzis named *seeing as,* labels were inductively constructed from the raw data with either the actual words of the participants or a word that identified the concept of what the child was communicating. Often a piece of

text was labeled with two codes. Table 3 is an example of how textual data were condensed into labels then into codes and then finally a theme.

Table 3.1

Example of Collapsing Data into Themes

| Text | Labels | Codes | Theme |
|---|---|---|---|
| • I like to be an artist or doctor pediatrician, cuz I like babies. | • What I want to be<br>• The future | • When I grow up | |
| • I want to be a lot of things. I aspire to be a fashion designer be cause I like to make clothes. | • The future | | |
| • I'm into crafts and art. I'm into some stuff like coloring, designing rooms. I love art and I like drawing. I made up an invention. It's a chair and you take this chair and it has storage under the chair and it has a cushion on it like a built in cushion. | • My abilities<br>• Things I like to do. | • Being me | • Me Being Me |
| • This is me playing the violin. This violin is very special to me because I made it into the orchestra. | • My abilities | | |
| • She makes me feel happy. She loves me | • Feeling happy<br>• Being loved | • My Feelings | |
| • She loves me. She takes me to school and she don't work because she takes care of me when we go in the hospital. | • Being loved<br>• My mom | | |

As each piece of text was labeled the photographs were connected to the text and labels within Atlas.ti© by using memo's. Labels from each transcript were used to label the next transcript. Additional labels were developed as textual and photographic data introduced new patterns. While labeling the data I also wrote memos in Atlas.ti©. Memos were reflective notes for recording my ideas, observations, any insights and when noticing patterns or suspected patterns in the data. For examples see Appendix J.

After going through all of the transcripts and seeing codable patterns I had applied over 400 labels. I then reviewed the coded text, labels and photographs from all of the transcripts. I was able to collapse the data into 207 labels after combining labels with similar wording. For example, initial labels for the pattern *Doing my treatments* also included *taking nebulizer* treatments, *taking Cayston©,* and *using my vest.* I repeated this process again until the data were compressed into 155 labels. I reviewed the data again searching for recognizable broader patterns and relationships among the data. Again trying to stay as close to the data by using either the actual words of the participants or similar words that described what was being conveyed in the data, I was able to collapse the textual and photographic data further and attach broad codes. For example, in referring to Table 3, the labels *What I want to be*, *My abilities*, and *Things I like to do* are all related to stories that children told when talking about how they perceived themselves. These labels were subsequently coded as *Being me*.

After all of the data were coded, I began to look for themes, which were even broader and more comprehensive than codes. I sweepingly reviewed the data again including the coded text, photographs, and memos. Boyatzis (1998) recommends no more than seven (plus or minus two) codes. With much thought and reflection the codes were condensed into five overall themes. The themes will be presented and described in Chapter 4 and interpretation of the themes will be discussed later in Chapter 5.

**Theme Development**

Boyatzis asserts that a good theme "is usable in the analysis, interpretation, and presentation of the research" (1989, p. 31). The elements of the themes for this study included:

1. A label (e.g. *Me Being Me*).
2. A definition of what the theme concerns (e.g. In this theme participants convey the perceptions they hold about themselves and the feelings evoked when looking at their image and the context of those images in the pictures).
3. A description of how to identify a theme when it occurs (indicators) (e.g. Indicators for identifying the theme *Me Being Me* included references to the self including the terms *me*, and *I*).
4. A description of qualifications and exclusions for identifying the theme (e.g. The theme *Me Being Me* refers specifically to the child's self including his or her feelings, likes and dislikes, and aspirations; not to other people, places, or things).
5. Positive and negative examples to help eliminate confusion when looking for a theme (e.g. Positive examples include: "I feel sad", "That's me". Negative examples: "That's my doll", " This is my friend").

**Threats to Effective Thematic Analysis**

Boyatzis (1998) identified three threats to effective thematic analysis, researcher (a) projection, (b) sampling, and (c) mood and style. Projection is temptation on the part of the researcher to impose his or her characteristics, attitudes, values, or emotions onto the research participants. Projection was lessened by (a) developing reliable codes and using them consistently, (b) continuously returning to look at and listen to the data and using the

words of the participants during the analysis, and (c) obtaining the perspectives of others by asking committee members and members of the university's qualitative research group to examine and help with coding the raw data.

The mood and cognitive style of the researcher can influence the collection of data, processing of information, and data analysis (Boyatzis, 1998). As suggested by Boyatzis, to limit distractions and errors during data analysis I (a) worked to suspend my personal beliefs and judgments and go with the data by constantly immersing myself in the data; (b) developed clear and simple labels, codes, and themes; (c) avoided distractions when performing thematic analysis by constructing a quiet and calm office space in my home; and (d) backed off of thematic analysis when preoccupied or fatigued.

**Methods to Maintain Rigor**

Qualitative validity is the accuracy and truthfulness of findings (Borkan, 1999). To assure valid results the following strategies were employed:

1. A clear outline of the data analysis method – An outline delineating my method for data analysis was developed when preparing the proposal for this study.
2. Bracketing - - I participated in an exploratory interview before commencement of data collection for the purposes of identifying, exploring, and clarifying any personal biases regarding school-age children with CF. A transcript of the interview was also brought to the university's interdisciplinary qualitative research group where it was read and examined by professors and peer colleagues who in turn gave verbal feedback.

3. Reflexive journal – A record of my thoughts, feelings, and experiences were kept in a journal during the processes of data collection and data analysis.
4. Transcripts were checked and rechecked for any errors made during transcription.
5. Triangulation - Data were examined from different sources (interviews, photographs, and field notes) to provide justification for my findings.
6. Peer examination - Neutral experienced nurse researchers were asked to review and question the research study once it was developed to help uncover any investigator bias or assumptions. Selected interview transcripts were also brought to the university's interdisciplinary qualitative research group for examination. Members of the group read the interview transcripts aloud. Together group members detected meaning units and identified preliminary themes. When all of the transcripts from a study were analyzed, an experience nurse researcher reviewed the final themes.
7. Member checking – To assure the accuracy of my findings a summary of the themes and the thematic structure was taken back to several participants to validate findings.
8. Audit trail - A record was kept to document meetings, strategies, any methodological changes, and progression of data analysis.

Additionally, there is a risk within naturalistic studies for researchers to get too involved in the culture they are studying and possibly compromise the validity of study results (Creswell, 2003). Debriefing with peer colleagues and committee members as well as

ongoing self-reflection outside of journaling was employed to monitor the accuracy of findings.

## Summary

In summary, the purpose of this study was to examine how school-age children with CF perceive themselves and the world in which they live using a naturalistic qualitative design. This study employed qualitative description as the methodology and photo elicitation as the primary means for collecting data. Textual and photographic data were analyzed by using a method of inductive thematic analysis by Boyatzis, which was modified for this study. The next chapter will discuss the results of the data analysis.

# CHAPTER 4

## Findings

The purpose of this study was to obtain an understanding about how school-age children with CF view themselves in the world they live. This chapter will present the research findings beginning with participant demographics. Next, the themes that emerged from the participants' stories will be introduced along with the contextual ground upon, which the child's perceives his or her world. A pictorial thematic structure of the child's world will follow. Then the contextual ground will be addressed and each theme presented in detail along with supporting exemplars. The chapter ends with a summary of the research findings.

## Participant Demographics

Seventeen participants were enrolled, and 16 participants completed the study. One participant was unable to complete the study because the child's mother was unable find time for the interview. The average age of the participants was 9.24 years (Table 4.1). Ten (62.5%) children were female, and six were male (37.5%). The majority of participants (75%) lived with their mother and father and two (13%) participants had no siblings. Information about socio-economic status was not collected from the participant's family, but there were environmental indicators observed when visiting the homes. Participants lived in a wide variety of situations ranging from a rented apartment in a small town to a 4000 square foot stone and brick home in an upscale neighborhood. The following table gives key details about each participant.

Table 4.1.

Participant Demographics

| Child Number | Pseudonym | Gender | Age | Living Situation | Number of Siblings | Number of Pictures |
|---|---|---|---|---|---|---|
| 1 | Tyra | F | 8 | Mother and Stepfather | 2 | 81 |
| 2 | Adam | M | 9 | Parents | 2 | 51 |
| 3 | Julia | F | 9 | Parents | 1 | 42 |
| 4 | Did not complete study | | | | | |
| 5 | Molly | F | 10 | Parents | 1 | 53 |
| 6 | Bethany | F | 9 | Parents | 1 | 17 |
| 7 | Daniel | M | 9 | Parents | 0 | 93 |
| 8 | Emily | F | 11 | Parents | 1 | 71 |
| 9 | Jacob | M | 11 | Parents | 7 | 64 |
| 10 | Mary | F | 10 | Parents | 2 | 154 |
| 11 | Hilary | F | 9 | Paternal Grandparents | 1 | 72 |
| 12 | Ashley | F | 10 | Maternal Grandmother | 0 | 44 |
| 13 | Lauren | F | 11 | Parents | 2 | 22 |
| 14 | David | M | 8 | Parents | 1 | 97 |
| 15 | Faith | F | 8 | Parents | 2 | 90 |
| 16 | Anna | F | 8 | Mother and Stepfather | 2 | 104 |
| 17 | Andrew | M | 8 | Parents | 2 | 39 |

The gold standard for monitoring respiratory function and disease severity in CF is pulmonary function testing. In CF research, the Forced Expiratory Volume in One Second (FEV1) percent predicted is the primary indicator of lung function. It is a measure for determining the amount of airway obstructive. Knudson's (2008) prediction equations for weight, age, and gender are used to determine PFT values. Established ranges are (a) FEV1 ≥ 70% mild disease, (b) FEV1 40% – 60% moderate disease, and (c) FEV1 ≤ 39% severe disease (Modi & Quittner, 2003). The participants' percent FEV1 ranged from 59% (moderate disease) to 122% (mild disease) with the average being 93% (Table 4.2).

Seven participants (44%) did not require any IV antibiotics for their CF in the past year, whereas 9 (56%) participants required 1 to 5 courses of IV antibiotics for lung related CF symptoms.

All participants reported using a vest percussion device for airway clearance at least once a day. Participants took 9 to 14 different medications each day including a pancreatic enzyme, ADEK vitamin, proton pump inhibitor, dornase alfa, bronchodilator, and inhaled hypertonic saline. The number of pills per pancreatic enzyme dose ranged from 0 to 6. Pancreatic enzymes were taken before each meal and before consumption of snacks containing any amount of fat. Table 4.3 shows the types of medications taken by participants and the number of participants that took them.

Table 4.2.

Participant Characteristics

| Child Number | Pseudonym | Number of Daily Medications | FEV1 | FEV1% | Courses of IV Antibiotics in Past Year |
|---|---|---|---|---|---|
| 1 | Tyra | 9 | 0.98 | 81 | 1 |
| 2 | Adam | 10 | 1.89 | 83 | 1 |
| 3 | Julia | 11 | 1.29 | 72 | 0 |
| 4 | Did not complete study | | | | |
| 5 | Molly | 13 | 1.85 | 122 | 1 |
| 6 | Bethany | 13 | 1.36 | 75 | 2 |
| 7 | Daniel | 12 | 0.91 | 104 | 0 |
| 8 | Emily | 14 | 1.10 | 59 | 5 |
| 9 | Jacob | 12 | 2.25 | 109 | 0 |
| 10 | Mary | 9 | 2.06 | 96 | 2 |
| 11 | Hilary | 14 | 1.64 | 101 | 0 |
| 12 | Ashley | 14 | 1.73 | 94 | 1 |
| 13 | Lauren | 14 | 2.01 | 97 | 1 |
| 14 | David | 11 | 1.84 | 120 | 0 |
| 15 | Faith | 11 | 1.16 | 78 | 0 |
| 16 | Anna | 14 | 1.42 | 95 | 1 |
| 17 | Andrew | 9 | 1.40 | 103 | 0 |

Table 4.3.

Medications Taken by Participants

| Oral Medications | # of Participants Taking Medication | Inhaled Medications | # of Participants Taking Medication |
|---|---|---|---|
| Pancreatic Enzyme | 5 (94%) | Pulmozyme® | 16 (100%) |
| ADEK Vitamin | 15 (94%) | Bronchodilator | 15 (94%) |
| Proton Pump Inhibitor | 4 (87.5%) | Hypertonic Saline | 14 (87.5%) |
| Laxative | 12 (75%) | Corticosteroid | 12 (75%) |
| Montelukast | 11 (69%) | Nasal Steroid Spray | 10 (62.5%) |
| Azithromycin | 10 (62.5%) | TOBI® | 9 (56%) |
| Antihistamine | 6 (37.5%) | Cayston® | 2 (12.5%) |
| Probiotic | 3 (19%) | | |
| Vitamin D | 3 (19%) | | |
| H2Blocker | 2 (12.5%) | | |
| Bile Acid Sequestrant | 2 (12.5%) | | |
| Vitamin A | 2 (12.5%) | | |
| Vitamin K | 1 (6%) | | |
| Insulin | 1 (6%) | | |

## Photographs

A total of 1094 photographs were taken for this study (Table 4.1). The least number of pictures submitted by a participant was 17, and the most pictures submitted was 154 with the average being 68 pictures per participant. One participant and his mother unexpectedly added an additional 37 pictures from the family digital photo album because the pictures depicted parts of his life that he was unable to photograph during the study period. Since the participant did not take many of these photographs, they were not included in the total number of pictures taken for the study. They were, however included in the data analysis.

## Developmental Aspects of Methodology

To verify if the participants understood the enrollment instructions about what they were to take photographs of, I asked each child at the beginning of the interview the following questions: “Do you remember when I gave you the camera? What did I ask you to take pictures of?” Even though I did not ask any of the participants to take pictures of CF,

two children Adam (age 9) and Jacob (age 11) said "My CF Life." The other participants gave a short paraphrased response including: "Pictures of my family and my life" (age 11), "Of things I like and what I do" (age 10), "Of things that make me sad or happy" (age 9), "Pictures of my life and the people I love and stuff" (age 8), and "Something that's important in your life that you really want to take pictures of" (age 8). Interestingly, the two participants who said, "My CF Life" one (age 11) did not have any pictures related to CF and the other child (age 9) had only one picture that was about taking a treatment.

Then I asked the children to pick the first picture they would like to talk about. The first picture chosen by 11 participants was either a person or a pet. The other five participants chose a picture depicting an activity that they were either involved in or attending. These five pictures included a set of drums, a basketball game scoreboard, playing a Wii™ game, tumbling on a mat, and a favorite soft drink. At face value, some pictures possess obvious meaning (e.g. Emily's picture of her favorite nurse with the nurse's arm around her) but others did not seem to say anything (David's picture of a yellow soft drink in a glass). However, pictures were laded with personal meaning much of which was elicited in the interview. All participants used positive words when talking about these first pictures including fun, nice, good, favorite, happy, pretty, and love. The two common threads among all of these pictures were that they evoked a pleasing memory and a pleasurable feeling within the participant. For example, David's picture of the soft drink elicited a story about the good feeling he experiences when drinking it.

The amount and richness of the data collected for this study validates the merits of the method I chose: Pictures without an interview and vice versa lacks definition. All of the

participants in this study could take photographs and or direct another person to take specific photographs for them. Combining participant authored photography with interview along with photo book construction proved to be an effective method to engage school-age children in the research process. Each element contributed data that was, in the end, essential to obtaining a full life description.

## Thematic Structure

Five themes emerged from the data during analysis: *Me Being Me*, *My Medicine and Treatments, My Family*, *My Friends and other Key Relationships*, and *My World*. Then a thematic structure using the themes was constructed. The thematic structure is a pictorial representation of the world of the school-age child with CF (see Figure 4.1). I have titled the thematic structure *Me Being Me*. *Me* is the child, represented by the blue figure in the middle. The contextual ground upon which *Me* sets is *Developmental Stage*. CF is not visible on the figure, yet it is an integral part of *Me*. It is in *Me's* DNA and where ever *Me* goes so goes CF. The ring around the child'*s* middle is a metaphorical hula-hoop symbolizing the motion by which *Me* comes in and out of contact with those things which exist outside of *Me*. At any given time, various elements of the child's existence (friends, family, medications, and the world) are in the forefront closest to the body where they are the focus of attention. The other aspects of life do not disappear at those moments; they just recede in relative importance. As *Me* moves through life *being Me*, he or she comes in contact with (a) CF treatments and medications, (b) family, (c) friends, and (d) all of the things in the world. *Me* does not come in contact with these things all at the same time nor is he or she in constant contact with any one of them.

**Contextual Ground**

In this study, the contextual ground against which participants perceive and experience their world is *Developmental Stage.* Although, all participants were in the same developmental stages of *concrete operations and industry versus inferiority* some participants' photographs and narratives were more detailed and reflected a higher level of thought while others pictures and stories were simpler and more concrete.

Figure 4.1 Thematic structure of *Me Being Me*.

## Themes and Exemplars

- Photograph Release Forms giving consent to use participants' pictures have been obtained from every child and his/her parent or guardian.
- Photograph Release Forms giving consent to publish a person's image have been obtained from every person who is pictured in this dissertation.
- The names of all child participants and names of people and pets mentioned by the participants have been replaced with pseudonyms.

As data were collapsed five distinct themes stood out. These themes are labeled according to the words of the participants *Me Being Me, My Medicine and Treatments, My Family, My Friends and other Key Relationships, and My World*.

### Theme #1: Me Being Me

When designing this study I strived to have no preconceived notions concerning what the participants would take photographs of or what they would talk about except, considering that the participants were asked to take pictures of what it is like to be them, I did believe that the pictures would most likely be centered around themselves. While much of what the children photographed were of people, pets, and things that exist in the environment around them, 23% (n=250) of the photographs depicted only the participants and the participants' image was in 49% (n=534) of all photographs.

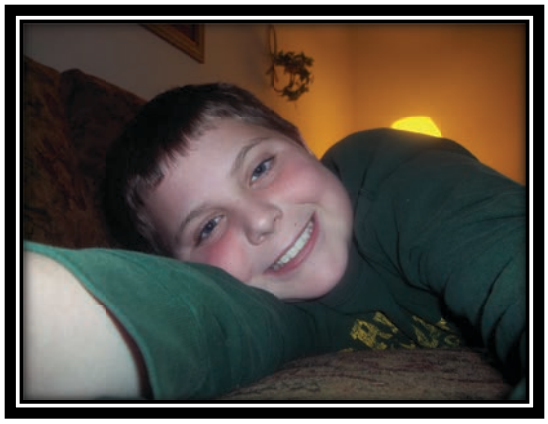
The first theme, *Me Being Me*, contained the most identified textual units from the interviews and is divided into four subthemes: *This is Me*, *My feelings*, *Secrets*, and *When I grow up*. In this theme, participants convey the perceptions they hold about themselves and the feelings evoked when looking at their image and the context of those images in the pictures. The children saw themselves as multidimensional and attractive.

#### This is me.

In general, people often avoid the camera because either they are embarrassed or

afraid of not liking what they may see when looking at their own image. However, when the participants of this study viewed images of themselves, they liked what they saw. For the most part, according to the narratives, the children made statements indicating they liked who they are. They saw in themselves beauty, humor, talent, ability, and human emotion. They also perceived a future for themselves beyond childhood.

When I asked Daniel, age 9, to tell me about the picture he chose first he said, "It makes me happy." I then asked him to convey what it was about the picture that made him happy. He said, "Me and really being in it." Daniel's reaction to seeing himself was typical of all the participants. During the interviews when participants came across their own image in a photograph they pointed at their portrait, smiled, and animatedly said, "that's me" or "that's me again." The next two pictures are self-portraits by the participants. Notice their happy and apparently effortlessness smiles.



David, age 8: "This is me. I like to lay on the couch and watch TV. I like who I am."

Figure 4.2. David.

Anna, age 8: "Me with my beautiful yellow shirt. All of the pictures of me are cute."

Figure 4.3. Anna.

The participants were content with various aspects of them self, including their appearance and traits that make them unique. Each photograph depicting a participant told a story about how the child perceived him/her self. Participants talked positively about their physical characteristics.

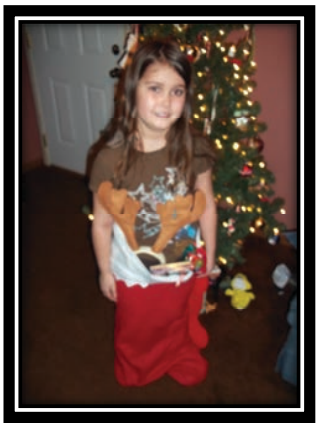
A B 

Figure 4.4. Hilary. (A) Hilary smiling, (B) Hilary and her stocking.

Hilary, age 9: "[That's] when I first got my camera and I looked pretty (Figure 4.4a). I have long eyelashes. I am fashionable. This is a stocking, [I'm holding] a big huge stocking (Figure 4.4b). My legs are inside. Its like I am inside a stocking. It looks like I'm a Christmas present. I would be a beautiful Christmas present."

Emily, age 11: "[That's] me. I have CF and I know how I got it. My mom and dad's cells got together, formed me, and I have CF. I have white skin and I got freckles. I got it from mama. And I've always wanted straight hair and then sometimes I want it curly."

Figure 4.5. Emily.

Emily acknowledged genetic qualities passed on to her by her parents. Like her light creamy complexion, freckles, and curly hair, CF is part of her personhood.

Figure 4.6. Molly.

Molly, age 10: "[These are] pictures of me being me."

The topic of CF typically arose when participants talked about doing treatments and taking medications and will be discussed as a separate theme, *My Medicines*, later in this chapter. Opinions about having CF, varied among participants. David, age 8, whispered that he "liked" CF because he is in a CF drug trial and he gets to play computer games when he goes to the clinic. Also, because of his CF he receives toys during special hospital events and

a family friend holds a CF fishing tournament each year in his honor. On the other end of the spectrum is Jacob, age 11, who stated:

> "[CF is] bad because sometimes you don't think you have CF and you're like 'I know I don't have CF. Just take me to get the test again. I promise you I don't have CF. Just take the test again' or 'find the cure really fast.'"

Participants also talked about their unique personal qualities, talents, and abilities. Mary, age 10, perceives herself as being creative and a leader, "I love crafts and I love pink. And I am very creative and I love to be a leader. I am good at being a leader because I have good ideas."

Several children took pictures of their artistic talents including playing musical instruments (e.g. violin, flute, and drums), drawing, and painting. These participants were serious about developing their talents and understand practice is necessary if they want to advance. Parents facilitate the children's abilities by providing them with private lessons and purchasing items to support their learning, such as how to books and musical instruments.

Hilary, age 9: "I love drawing. I mean I draw all the time."

Figure 4.7. Hilary's drawing of Foxy.

Figure 4.8. Mary playing her violin.

Mary, age 10: "This is me practicing the violin. My violin is very special to me because I [was selected to be in] the orchestra. I had been practicing and practicing and practicing and I made into the orchestra."

Figure 4.9. Andrew playing the drums.

Andrew, age 8: "My mom and dad had to pay a lot to get [my drums] so ... I don't [want them] to give it away by not playing. If I give up, I'm not gonna be able to play really good … Playing the drums are like, if I keep going, I'm gonna get better and I'm gonna get good."

Mary and Andrew provide factors that motivate them to practice their musical instruments. Mary's desire was to make it into the orchestra. Andrew not only wanted to improve his drum playing ability, but he also wanted to practice so that he would not have to give up his drum set or waste his parents' money. In addition highlighting their artistic talents, participants took pictures and talked about their physical abilities. Contrary to common belief that children with CF tend to be physically inactive or fragile, some are involved in organized high-energy athletic activities including tumbling, ballet, and basketball. Other participants, while not in any formal sport, engage in physical activity by riding a bicycle, riding a motorbike, bowling, jumping on a trampoline, running, and most

the most recently playing with the Wii Fit™.

A B C

Figure 4.10. Children's activities. (A) Julia doing a handspring, (B) Daniel bowling, (C) Faith playing basketball.

**My feelings.**

The participants possessed a high level of awareness of their inner experiences and feelings and found ways to reflect them in their photographs. When talking about their emotions, the children primarily chose to talk about being happy. "being happy" is a good feeling that participants want to feel everyday.

Tyra age 8: "I just feel like coloring, just using different colors. It makes me happy. I feel good doing it. Just getting to see those colors and coloring it."

Figure 4.11. Tyra painting.

Despite having an obvious permanent intravenous line in her right arm in many of her pictures, it was not the focus of her experience. Tyra never referred to either the IV line or

the discomfort associated with it when looking at her pictures. CF was not the totality of her world. Instead, her life experience was textured and included happiness. Similarly, David said that he did not take any sad pictures because he did not like to be sad. Jacob, age 11, also explained what happiness means to him: "It feels good, and so its like nothing can stop you from being happy."

According to the participants' happiness is a bodily experience involving the senses and is derived from something that is felt, tasted, seen, perceived, or accomplished. Some of the things that made the participants happy include running, playing in sand and snow, cuddling and hugging, playing with family and friends, watching and participating in sport activities, eating or drinking a favorite food, seeing colors, drawing, giving and receiving gifts, building with Lego's®, and helping others. David, age 8, talked about what he feels like when looking a picture of his favorite Chinese food and Lauren, age 11, explained how her cat makes her feel.

Figure 4.12. David's favorite Chinese meal.

David, age "8: It just fills my emotion inside ... and it's reaaally good. [It starts] inside [me and goes] all the way up [over my head]. That's how I like it so much."

Lauren, age 11: "[I feel] happy. Cuz he always comes up to you and he'll sit on your lap or something and he'll lay on you if you're laying down and he drools a lot."

Figure 4.13. Lauren and her cat.

While participants did not take pictures specifically reflecting unhappiness some pictures, apparently about other subjects, evoked memories of negative feelings such as sadness or fear. When Jacob, age 11, was asked to explain what it was about being sad he did not like to talk about he said, "I don't really like sad…. I don't know [it] just feels bad and you're just like real mad." When the participants did talk about feeling unhappy it usually resulted from disappointment. For example, when looking at his sister riding the family motorbike, Jacob conveyed that he and his sister did not have a close relationship. When asked how he felt about the situation he replied, "She could be more civil and stuff cuz we could be nicer. It makes me sad sometimes and that's something you don't want to talk about."

Below, Ashley, age 10, talks about her disappointment and negative emotion surrounding the time she discovered Santa Claus was not real. The photo itself was not an obvious depiction of anger or disappointment and a casual observer would not have identified it as such. Yet in her story, her disappointment emerged and was explained.

Ashley, age 10: "I found the wrapping paper for my presents [from Santa] and that got me down. And so that got me pretty mad. Cuz all that time I left out cookies and milk [for Santa] when I could have ate those cookies and milk."

Figure 4.14. Ashley and her Santa present.

There were several situations that evoked fear or apprehension in the participants. Julia, age 9, thought doing a standing back handstand by herself for the first time was scary. Mary, age 10, said, "surgeries and shots" made her scared. She also said, "I'm afraid of like going downstairs in the basement at night…. And I get scared of stuff that I know is not real, like ghosts." But scary situations can be overcome with determination on the part of the participant and physical and emotional support from trusted individuals including coaches, parents, and siblings. For example, Mary will go downstairs at night only if her younger brother goes before her, and Julia's fears are quieted when her coach assists her.

The notion of death also arose during the interviews. The children spoke about the death of past pets and some alluded to their own fragile existence. Death is unwanted: When the topic came up in the interviews participants tended to veer away from talking about it. Adam, age 9, found it difficult to talk about his grandmother, who had cancer, because it make him feel "bad". Unfortunately, his grandmother died a few weeks after the interview. When talking about a beloved pet, Tyra, age 8, conveyed that she was worried about her dog because it had a "big giant hole in his arm" that had not healed. When asked what she was worried about, the child put her head down and would not speak. Her mother

then explained that Tyra was afraid the dog might die. Tyra reported other family dogs had died and so she was happy when this dog came along. Even though she did not specifically say that she was worried about her dog dying her body language suggested she was thinking something sad and unspeakable might happen.

**Secrets.**

A few participants spoke about having secrets during the interviews. Some secrets were revealed in the stories and others were not. Secrets were kept from parents, siblings, and peers. One child's secret was that he did not tell his parent something because he did not want to hurt the parent's feelings. Another child's secret was a lie that she had previously told her mother. Her mother was present for the interview and thus found out the child's secret.

A few participants revealed that they are secretive about having CF and that they hide evidence of their disease when people visit. Tyra hides her equipment, including the treatment vest and nebulizer, behind doors and drawers in her bedroom. Anna, age 8, keeps her medications in a large chest at the foot of her bed:

> "I keep my medicine usually in this little thing with my toys and stuff. I know that's not right but like when my friends come over, I try to hide it because I don't like my friends knowing like everything about me and stuff so I try to keep it a little secrety."

Tyra and Anna each had an influential incident while in kindergarten when other children made fun of them because CF. Both recognized that the experience taught them to be careful as to whom they tell about having CF.

> Tyra, age 8: "I tell [nobody] or they will annoy me. One time I told A. That's when I didn't know that he was mean… One day he comed [sic] out and bugged me about it. And then he said he'd tell if I didn't want to be his friend. So he holded [sic] that

> against me for the whole kindergarten grade."

Anna, age 8, reported feeling sad when children in her class teased her about the intravenous line (IV) in her arm when she had to take IV medications:

> "I did have to go in once [to school] with the IV and then kids started making fun of me and stuff. I only went for about a couple of days. Then I asked my mom if I could stay home."

**When I grow up.**

Participants not only spoke about themselves in the here and now, they also talked about their future selves. Importantly, participants in this study expect to grow-up. They have a sense that life will endure and possess long-term plans for the future. Molly, age 10, loves horses and plans on having at least two when she grows up. Mary, age 10, talked about the kind of house she would like to have when she is older:

> "I really want a house of my own…. I don't really like huge houses because I get scared of some rooms. It would be like a one room cabin."

Ashley, age 10, has many interests and talents and is considering several career options:

> "I want to be a lot of things. I aspire to be a fashion designer because I like to make clothes. I draw clothes and stuff. And I'm also into drawing so probably an illustrator too. I draw a lot of pictures. I also want to be a photographer when I grow up too. I'm going to have to [go to] college [for] 16 years."

Other children talked about their hope for a cure for CF. Because of a groundbreaking clinical trial that was being conducted at the CF clinic where the participants were recruited, children in this study were well aware of the CF Foundation's goal of finding a cure. Hilary, age 9, had recently purchased two bracelets from the CF Foundation website; they express her hope for the future.

Figure 4.15. Hilary's CF bracelet.

> Hilary, age 9: "It's a bracelet, but it says Cystic Fibrosis with Breathe on the back and since I have cystic fibrosis I just thought it would be cool to take a picture of it. I want to get rid of it."

**Summary.**

The children in this study liked what they saw when viewing pictures of themselves. The images and perceptions participants' hold about themselves are positive including being attractive, possessing talents and abilities, and having a future. They preferred to take pictures that depicted pleasure and happiness and veered away from the negative, particularly those things that make them sad. Early childhood peer teasing experiences taught some participants to keep their CF a secret, which resulted in them hiding evidence of having CF. When looking towards the future the children in this study hope that a cure for CF will be found and expect that their life will endure.

The next theme *My Medicine and Treatments* is about taking medications, doing nebulizer treatments, and CF related hospitalizations.

**Theme #2: My Medicine and Treatments**

Photographs specifically targeting CF comprised 7% of all pictures taken by the participants. Five children did not take any pictures portraying CF and CF was not brought up in four of the interviews. CF related photographs most commonly contained images of nebulizer treatments, the airway clearance vest, and medications. Although few photographs portrayed hospital and CF clinic experiences, participants did talk about being in the hospital and at the clinic.

**Taking medications and doing treatments.**

The participants in this study spoke openly about their medications and, when given enough time, each could name or describe most of the medications they took. During enrollment children were asked to tell me the names of their oral and inhaled medications. Often when the child had difficulty remembering the parent would prompt the child. However, several parents interrupted and took over naming the medications for the child for the sake of saving time. When this happened, the child was essentially relegated to the margins of the conversation as the parent took over the conversation with the researcher and the child became a passive observer, until the conversation reached a point where the child could be brought back into the conversation.

As previously mentioned, participants took between 9 and 14 different oral and inhaled medications a day for their CF. The following exhibit is a portion of Mary's daily medications.

Figure 4.16. Mary's medications.

Mary, age 10: "This is a tiny portion of all my medicine. We have tons of medicine but that's just a little bit that I'm showing you. I wanted to show you my breathing treatments and medicines and boxes of stuff and lots of pills. There's a lot more under this and above that and in bags and in places."

Considering that the medications and equipment for treatments occupied a notable proportion of space, particularly in the smaller more modest residences, the reality of CF was spread throughout the home environment. When families were at home, there was no way to ignore or lose track of the prominence of CF in family life.

The next picture shows the number of pills Adam, age 9, takes prior to a meal followed by a picture of Faith, age 8, taking her pills. For Adam swallowing pills is not a problem but for Faith it is hard.

Figure 4.17. Adam's pills.

Adam, age 9: "It's just the pills I take. Well, I try to just take the three pills like that. And at breakfast I take a white pill and not the Prevacid®. That is my enzymes to help break up the fat. It's not really difficult. I just plop 'em all in my mouth and swallow."

Faith, age 8: "That's me taking my pill. I have to take it. And then - and then those are all the other pills I have to take, every single day. It's hard. I can't really swallow 'em."

Figure 4.18. Faith's pills.

The children talked about treatments and medications as being a part of their everyday life. Anna, age 8, explained why she took the following picture:

Anna, age 8: "Because it was just my medicine and it was like part of my life and stuff; medicine is."

Figure 4.19. Anna's medicine.

But, that did not mean taking treatments and medications were something that they wanted or liked to do. Participants complained about not liking to use their airway clearance vest. Vest treatments are taken one to two times a day and last between 20 to 30 minutes each; they hurt, and are boring. Additionally, when the treatment is in progress, the vest restricts movement and hinders the child's ability to play and interact with others.

Figure 4.20. Daniel doing his treatments.

Daniel, age 9: "I just don't like it. It vibrates my body. I don't like the vest, but I do like the breathing treatment cuz it gives me some salt[4]. Taking my treatments, now that's one thing I like … one thing I like to do, cuz then I can watch television."

A B

Figure 4.21. Faith's taking her treatments. (A) Faith and her vest, (B) Faith and her nebulizer.

Faith, age 8: "That's my [vest] treatment (a) and that's my breathing [nebulizer] treatment (b). I have to do both of those every day. [The nebulizer] for five minutes and [the vest] for thirty minutes. I'm used to [the nebulizer], but I don't like [the vest]. It's big and it shakes me. I have to do it for thirty minutes … it used to feel like a massage, but now I'm kind of sick of it. I don't like it."

---

[4] Child is referring to the taste of his nebulized hypertonic saline treatments, which he finds pleasing

Figure 4.22. Adam using his vest.

Adam, age 9: "It vibrates your stomach and it helps clear my lungs too. It's kind of boring. Cuz all you can do is sit around because it's a trick. You can't just like go. I would kind of like to move it downstairs so I can play Wii™."

Figure 4.23. Emily taking a treatment.

Emily, age 11: "[The vest is] fun sometimes and sometimes when I'm playing, you know, it gets in the way. Sometimes I have nothing to do and … I get to watch TV while I do it. [Sometimes] it hurts … and we switch [the pressure]."

Until recently airway clearance vests were manufactured in only black, dark blue, or dark green depending upon the manufacturer. One vest company has introduced two new color options, "cashmere pink" and "coastal blue", which appeal to child users. (Hill-Rom, 2011). Additionally, colorful skins can now be purchased allowing children to customize their vest machine. Several participants recently acquired one of the new style treatment vests. They spoke positively and excitedly about the colors of the newer vests and the skins

they can collect. The girls in the study perceived the new colored therapy vests as being prettier, more fashionable, and more comfortable.

Figure 4.24. Molly's Vest®.

Molly, age 10: "I got a new pink one. I used to have a black vest And I actually got a pink one, and I want to get one of the covers to put around the Vest® [machine]. It's flowery [and] you can put 'em on the Vest® [machine]. You can order them … I like it because it looks better. Cuz usually it's just a black vest. And I still have just the plain white machine."

Figure 4.25. Emily's Vest®.

Emily, age 11: "This is my new Vest® and it is hot pink and that's what I like. It is comfy. It's really comfy. The inside it has padded [sic] and it's soft."

Participants spoke more positively about taking nebulizer treatments particularly a newer medication named Cayston®. The drug is delivered through a unique nebulizer system and takes only one minute to administer. Other nebulized medications such as albuterol and Pulmozyme® can take upwards to 10 minutes each. The participants talked about the ways they have discovered to make treatment times more interactive and entertaining. For example, above in Figure 4.23, Emily is pictured with her handheld

Nintendo® DSi game console in her lap. Next, Mary age 10, talks about how she has incorporated the Wii™ into her treatment regimen.

Figure 4.26. Mary doing treatment and using the Wii™.

Mary, age 10: "When I am doing my treatments I can run [with the Wii™] and stuff instead of shaking [with the vest] and it does a lot better than the shaking. It keeps you from getting bored and stuff. See how I am running there … you have to run. You have to hula-hoop and stuff and it really gets you out of breath. It kind of takes your mind off [the treatment]… you get set on the goal… and then you keep trying like 'I'm going to make it' and then you get wore out, but you keep on going cuz you get your mind set on it."

Children admit that they do not always want to take their medications and treatments when ask by their parents. The two things they complained about the most were the treatment vest and medications that taste bad. They resist by running away, hiding, saying and shaking their head "no", pursing their lips, and not opening their mouth. Their refusal is temporary because they know the possible negative consequences of refusal. The children did not talk about the consequences, only that they ultimately do what they are asked.

A

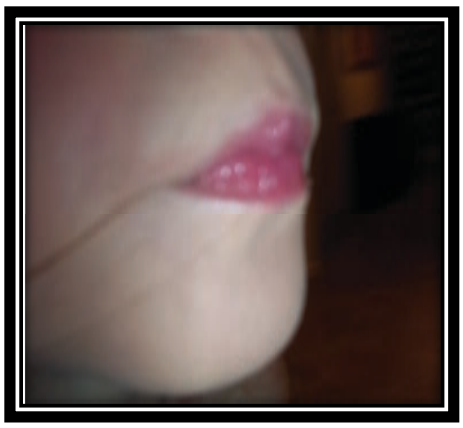
B 

Figure 4.27. Anna's medication. (A) mom giving medication, (B) Anna not wanting medication.

> Anna, age 8: (A) "That was when I got my liquid antibiotics … and my momma's giving it to me." (B) "She told me to go get my antibiotics out of the fridge so I can [sic] take it and I'm like 'No, Mommy'. And she's like 'Don't tell me no' and I went and got it.'"
>
> Bethany, age 9: "Sometimes I don't want to do my vest but I have to anyways. Sometimes I hide from my mom so I don't have to do my vest. I don't like to take my vest."

Hilary, age 9, spoke frankly about what would happen to her if she did not take her medications, "If I didn't have TOBI, the medicine, I could get really sick and I could get so sick I might get pseudomonas and it might be so bad that I might die. I could DIEeee." Mary, age 10, was aware of the terminal nature of CF, "I have a lot of CF friends that are older and they all have died…cuz they stopped doing their treatments." Mary is determined not to meet the same fate as her older CF friends. So, she religiously takes her treatments and does aerobic exercises to promote clearance of airway secretions.

Children want a say concerning when and where they take their treatments and the activities they involve themselves in during treatment time. Adam (age 9) previously mentioned that he would like to take his treatment vest downstairs so that he can play the

Wii™. Children with CF and their parents are often advised to take particular treatments including their vest, bronchodilator and Pulmozyme® in the morning to clear secretions, which have accumulated in their lungs during the night. In the next example, Tyra, age 8, says she gets upset when her mother wakes her up in the morning to take a treatment. She then offers her own opinion about what it will take for her to be mentally ready to face the treatment regimen.

Figure 4.28. Tyra waking up.

Tyra, age 8: "I was mad. As soon as I woke up I was tired. I [wanted] something to drink. [My mom] yells at me to go do my treatments. I'm like 'give me a few seconds'. That was one minute. What was I supposed to do? I didn't even get my hair or anything done. I didn't even change my clothes. So then what is it I'm supposed to say? Give me 5 minutes".

Lauren, age 11, who has an older sister with CF, manages her own medication schedule. She illuminates why taking treatments in the morning is difficult and instead does her treatments later in the day:

> "I can't take them in the morning cuz I have to go to school. I go back to sleep and I don't have time to do them, cuz I only [have] a few minutes. I would have to wake up early like at 5 or 4. We do [our treatments] after school and before we go to bed."

**Being in the hospital.**

Another thing the children found distressing was being hospitalized. The hospital is a piece of the child's world that exists outside the home environment and might have been presented under the theme *My World*. But because the hospital experience relates to CF

where administration of medications is a prominent feature, it will be discussed in this section.

Few pictures were taken depicting the participants' hospital experiences because only three participants were hospitalized during the study. But all participants had prior CF related hospital experiences and could speak authoritatively on the subject. The participants talked about what they did and did not like about being in the hospital. Hospitalization was described as being boring and scary.

Figure 4.29. Lauren in the hospital.

Lauren, age 11: It's boring. You have to stay in your room. You get hooked up [to IVs] and stuff and you can't really like go anywhere else. You can't leave the hospital so you have to wait till your two weeks[5] are over. You can't really like play with your friends or anything."

While in the hospital participants are separated from friends, family, and normal activities including school, music lessons, and outdoor play. If they are in the hospital over a holiday such as Christmas, children are unable to partake in family holiday traditions and instead rely on alternative traditions provided by hospital volunteers such as a visit from Santa Claus and gifts donated by a variety of local charities.

[5] Lauren stays in the hospital until her lung function improves and when she completes a full course of antibiotics, which for her is usually two weeks.

Figure 4.30. Santa and his reindeer visiting Lauren.

Lauren, age 11: "Santa came to the hospital and the reindeer. They came and gave us presents".

The scariest part of being hospitalized is going into the surgery suite and having a PICC line[6] inserted. A PICC line is not only a source of discomfort; it also violates the child's body integrity, which is very threatening to children in this developmental stage.

Figure 4.31. Tyra in the hospital.

Tyra, age 8: "I fall asleep and they cut me. They put in a PICC line. I hate it. It's just that it hurts even when I put a jacket on. It hurt me and I had to wear loose shirts. Yeah, I don't like em. I don't like going there. How would you feel if you were going to [get] cut open?"

Anna, age 8: "The scary part is when I go to sleep… Then when I get [the PICC line] … it feels so weird…. It's just oh freaky and when they put the medicine in it's really cold. How they flush [the PICC line] it just gives me a chill in my arm…. And nobody wants to go through that twice, but I had to last time because they didn't have in the right place."

[6] A PICC line is a long slender catheter inserted peripherally into a large vessel, usually the arm, when long lasting intravenous (IV) access is needed.

On the other hand, there are parts of the hospital experience that participants enjoy including playing games, pretending to be a princess, watching TV, making crafts with a representative from the Child Life staff, eating favorite foods, and receiving extra special attention from family, friends and hospital personnel.

> Lauren, age 11: "[A] good thing is like my mom will go to restaurants and get food for us so we[7] don't have to eat hospital food. I play board games and stuff and watch TV and play with my friends like whenever they come visit. Last year was better cuz a lot of people, more people, came to visit…."

> Anna, age 8: "The hospital I got to tell you it's kind of fun. I mean cuz you get a lot of attention but it's not really fun like "Yea, I want to just go crazy" but you can walk around and you can learn stuff from it and you can learn a lot of things. Your family'll come see you and stuff. Sometimes people [think it's] a dream to go to the hospital because it's [fun] like that sometime. As long as they don't hurt me that bad with the picker [PICC-line]."

Emily, age 11, compared the hospital where she currently visits to the hospital she went to when she was younger. She senses and values the long-term commitment hospital personnel have towards helping her manage CF:

> "I like [hospital #2] better than [hospital #1] ... Cuz they they're trying to cure me and they're funny and they like to talk to me and they're much nicer. I love [hospital #2]. I'm gonna stay there until I [grow] up. They say when you're 20 you got to go. I'm gonna miss it but that's a long time away."

Maintaining connections outside of the hospital with friends, family, school, and church is important for the participants. Contact is preserved when people telephone and visit the child during his or her hospitalization and when others, including classmates and church

[7] Lauren and her sister are usually hospitalized together.

members, send cards. Emily, age 11, said, "When I'm in the hospital they give me cards. 'Get Well Soon,' and stuff like that. I like them and I like to put em in my room."

The participants also like being connected to the nurses from their rooms, via the call light. The call system offers assurance that someone is nearby and that a nurse will come if they have a need. On the other hand, participants become upset and perceive others do not care when people, including family members, do not acknowledge their absence during a hospitalization. Tyra, age 8, talked about both of these situations:

> "Whenever anything goes on, when anything is done, or if I'm done with anything they [answer the call light]; they pick it right up. I just call them and they pick it right up. They say "Can I help you?" real fast and then come [to my room]….
> [My brothers], they don't even call. I mean the boys don't call. They don't care. When I came back what did I get? Nothing. I didn't even get a hug."

Participants also spoke about the objects of comfort they bring along with them to the hospital. These comfort objects, mostly dolls and stuffed animals, provide not only companionship but also hope and confidence that they will be all right when undergoing a hospital procedure, such as a bronchoscopy (bronch) or a PICC line insertion. Hilary, age 9, brings along a favored stuffed animal.

Figure 4.32. Hilary's Foxy.

Hilary, age 9: "This is Foxy…. And I just love her. She comes with me to my bronchs and everything. She makes me feel better when I'm in the hospital because I know she will help me sleep better and she gives me confidence that everything will be OK and that she like makes me feel like everything is going to be OK and nothing is going to go wrong during the bronch and stuff."

Emily, age 11, brings her favorite doll with red hair when she goes to the hospital. She likes it when hospital personnel care for her doll like a patient:

> "She goes into the surgeries with me…. Sometimes they have a bed for dolls in the surgery… and so they put her in it. They give me that medicine and they take her out of my bed and put her in a bed, in the other bed, and she has a blanket and a pillow. [After surgery] she goes in my cart and goes to my room."

**Summary.**

Doing treatments and taking medications are a part of everyday life for the study participants. Even so, children still find them difficult to take and tolerate at times, particularly the airway clearance vest because it takes time, it can hurt, and it's boring. Children would prefer (a) an option that would allow them to incorporate a more exciting activity in their treatment time or (b) a type of airway clearance activity that would be as effective as the vest but where they could also interact with their environment and be distracted from its discomforts. Evidence that even minor changes can alter perception is reflected in children's statements that colorful "pretty", softer vest covers made treatments more comfortable.

Being hospitalized can be frightening as well as fun. Having bronchoscopies and insertion of PICC lines are the scariest part of the hospital experience. To cope with the fear, children bring comfort objects along with them to the hospital. Heath care providers who engage with the children through play and humor as well as interactive computer games help make the hospital experience more enjoyable.

**Theme #3: My Family**

All participants' talked about family. Furthermore, they all spoke about it early in the interviews. The children discussed their nuclear family, including parents and siblings, and their grandparents. As much as the participants liked looking at images of themselves they were also fond of viewing pictures of their family, particularly when all members of the family were together in one picture. Four of the participants' first pictures depicted family. Viewing family photographs stimulated feelings of happiness and love and a sense of belonging. Below, Andrew talks about seeing a family picture and, in a profound manner that only a child can execute, explains what it means for him to be a member of a family. Theme three is divided into three subthemes: *My dad, my mom*, *My siblings*, and *My grandparents*.

Figure 4.33. Andrew's family.

Andrew, age 8: "I like to see my family in a nice picture like that. [Family] makes sure [that] I have friends around me and like I'm in a family, not like a hobo. A hobo is one that that doesn't have a family, doesn't have friends. When you have a family, you don't be a hobo so you don't have to like hunt for deer, for food, or clothes and it makes [life] much easier."

The participants' statements about family were about belonging; children are not on their own.

As previously noted, not all of the participants lived with both biological parents. In their stories, children articulated who constituted their nuclear family. This is meaningful because (1) they have a clear definition of who comprised their nuclear family and cared enough to inform the researcher, and (2) they wanted the researcher to understand the limits of their nuclear family.

Consequently, for the two participants who live with grandparents, the nuclear family was defined by the children to include the grandparent(s) in the primary care giving role, as well as siblings and anyone else living in the household fulltime. As for the two children who live with their mother and stepfather, the nuclear family consists of the mother, stepfather, siblings, and any stepsiblings. Hilary's grandparents are included in this section (and not later when discussing grandparents on page 184) because they serve as the primary caregivers in her nuclear family.

"Hilary, age 9: This is mamaw and papaw. They are important and … I love them. And they have always been there for me."

Figure 4.34. Hilary's grandparents.

In the following pictures what will be seen are traditional family units because few pictures of non-traditional family units could be included. Viewing family pictures always lead to a conversation about each person depicted in the photograph.

Figure 4.35. Mary's family.

- Mary, age 10: "That is my dad, my mom, me, my sister, and my brother."
- "This is my dad and he dances and he is always the center of the party."
- "My mom, I'm so proud of her."
- "My brother he'll play whatever I want to and he's really good at it. Like he helps me with my dolls and plays puppy."
- "My sister, she is very independent; she plays by herself. She is very very tough when she is hurting."

Not all children took pictures of their family. Some took pictures that represented family members because either (a) family members were not present when taking pictures or (b) family members did not want their picture taken and so the participant respected their privacy. For example, Julia, age 9, took pictures of family members Christmas stockings. Each stocking represents a family member; therefore, two pictures are presented. Omitting one picture would omit two members of the family.

Figure 4.36. Julia's family Christmas stockings.

One of the primary functions of a society is preparing children to be responsible citizens. The means by which families do this is by setting expectations, exercising discipline, and encouraging proper behavior. Even though children in this study are vulnerable to punishment laxity due to their health needs, this did not mean they were exempt from discipline. They are rewarded for good behavior and punished when they act up. Emily admitted that her mother teaches her "to mind" and sometimes her mother has to raise her voice to get her attention. But she also accepts and comprehends the value of parental discipline, "I like it because [without discipline] I would be in a mess." Conversely, Hilary, age 9, is rewarded when she achieves good grades in school.

Hilary, age 9: "I got Scamps® for my report card in the 3rd grade."

Figure 4.37. Hilary's toy Scamps®

**My dad, my mom.**

The children in this study spoke affectionately about their biological parents regardless of whether they lived with them or not. Parents provide emotional support as well as moral guidance. Pictures of the participants with their parents often illustrated the loving nature between parent and child. In these pictures, facial expressions and the significant physical closeness including hugging, cuddling, and sharing all signify an affective expression of happiness in the experience.

A B C

Figure 4.38. Children and their dads. (A) Daniel and his dad, (B) Mary and her dad, (C) Faith and her dad.

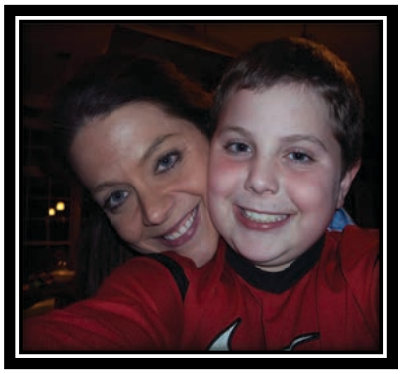
A B  C

Figure 4.39. Children and their mothers. (A) Tyra and her mom, (B) David and his mom, (C) Bethany and her mom.

The following quotes are some of the things participants said about their parents'. These quotes do not correlate with the pictures above.

- "He's always there when I need him."
- "Any time [I am] sad he'll just cuddle me up and make me happy…"
- "I love my mommy a lot so I took this picture. She loves me and she is kind to me."
- "Me and my [mom] were together to take a picture. It was good, [it] felt good."
- "I like being with him [daddy]."
- "She's fun, funny, nice, [and] pretty."

The children's stories about their fathers were heartfelt. They reflected a picture of fatherhood that was loving, devoted, and playful. Fathers were not portrayed as stern or disciplinarians. Instead, the children spoke about their fathers' admirable qualities including their fathers' interests (e.g. college football, fishing, and hunting), their fathers' devotion to family, and how their fathers' play with them.

> Anna, age 8: "He's always at work but he's always there when I need him so I guess that's good in one way and he comes and sees me every time I'm in the hospital. [He] will order food and he'll take me for a walk around the hospital because it's boring just sitting a room all day and he loves me."

> Molly, age 10: "He is the best dad in the world. He's really helpful, because his mom, she has a lot of stuff in her house. He said he wants to go up there and help clean [it] out … so she can move closer to us [and] we can help her. He loves me by playing with me. And if I get hurt, he comes back to help me up. He helps me buy medicines. He gets my food ready in the morning, and whenever … we have Toaster Strudels®, he puts a cool design on it with the icing."

> Mary, age 10: "My daddy is just awesome. He can make [me] be happy and brave and stuff like that…. Sometimes he takes me out on little dates. Like after I play in the orchestra…. He wakes up really early in the morning, like four in the morning … and he gets home at 6 or 7 or 8 so he could have some family time with us."

Even when her father cannot be physically with her during difficult situations, Mary, age 10, still imagines her fathers' voice calming her. Her father helps to push the "bad" stuff away by supporting her with memorized words and the remembrance of his encircling arms:

> "When I am scared he can make [up] funny [things] to think about. Like when I was scared for auditions for violin for orchestra he would say, "Think, I am the daughter of my father. I am strong, I can do this."

Children have a rounded view of their parent. Julia, age 9, likes it when her father plays tricks on her. At the same time, Julia also realizes that her father makes personal sacrifices to provide for his family:

> "Sometimes whenever we're in his old truck, he used to hold on the brakes and say we were out of gas, but we really weren't. One Christmas, he had to sell his old racecar because he wanted to get us some Christmas presents. I would rather have kept the racecar instead of getting new Christmas presents. I love going to the race track and watching him race."

The display of sacrifice made by Julia's father did not go unnoticed by the child. Her response to her father's actions demonstrates she in turn has felt the impact and learned the lesson of selflessness.

Children also appreciated the lighthearted aspects of their relationships with their father and were careful to include pictures that represented this. The next set of pictures depicts this element of pleasure. Many participants enjoy the opportunity to just spend time with their dad being silly and having fun.

Figure 4.40. Andrew (L) with his dad.

Andrew, age 8: "I like to play tennis with Daddy a lot and this summer we're gonna do it again…. I just like being with him."

Figure 4.41. Faith's dad.

Faith, age 8: "I was doing my breathing thing [at the CF clinic]. [My dad's] a Shrek™. He's funny. He acts like a kid."

Figure 4.42. Hilary, her dad, and her brother.

Hilary, age 9: "We are having a snowball fight. There is my dad right there. Here is where I'm throwing a glob of a snowman we made, at him. And then he grabbed a piece of it and threw it back at me. It was just fun."

Like fathers, mothers also made the children feel happy and loved. However, participants' mother stories differed from dad stories. Mothers not only meet the emotional needs of the children, they also provide for their physical needs and desires. In this study, it was typically the mother who assured the child took his/her medication, made him/her mind, helped with schoolwork, drove to and from child related activities, attended school events, and guided decision-making. An interesting side note: seven (44%) of the participants' mothers (or mother figure) worked outside of the home.

Generally, the youngest participants were brief and concrete when they talked about their mothers.

Figure 4.43. Adam's mom.

Adam, age 9: "[That's] my mom. I took a picture of her standing in the living room. She's a good cook. She is nice."

Older children gave more detail when describing their mothers. They spoke lovingly and sincerely about the deep affection and appreciation they have for them as well as their enduring characteristics. Although, Ashley, age 10, lives with her grandmother she still spoke about how much she loves her mother:

> "I love my mom deeply**.** I love her more than anything in the world cuz she's really special to me. I mean everyone's mom is the most specialist [sic] and everything. We only go get to see each other on weekends, and we get to talk to each other on the phone … cause she doesn't have a car. But when I see her I try to spend the most

> time I can with her and she's funny and I love being with her. I'm comfortable and I feel safe when I'm with her."

One mother was nearby in another room when her daughter began to talk about her. As the child spoke, she came over to the table where the interview was taking place. She then sat down in a nearby chair and began to quietly weep. She did not know how she was actually perceived by her daughter until that moment and was overcome with emotion when she realized the depth of her child's love for her. Below Mary, age 11, eloquently points out her mother's admirable qualities and the support she receives from her mother during treatment time.

Figure 4.44. Mary and her mom in the snow.

> Mary, age 11: "She almost knows how I feel, because she is the one who stays up and makes me do it [my treatments]…. I sit on her lap and we can talk or watch a video or read a book or do what ever we want to do. She just helps me get through it. Those are very good memories. She can just push on and on and on. She is a very good perseverer [sic]. She looks around and if someone needs help, whether she knows them or not she helps them. She's taught us a lot of really good lessons."

The participants are impressed with visual, tactile, and emotional images of their parents who serve as role models for their child's current and future behavior, which demonstrates how vital the parenting role is in regards to the development of the child's ability to love, feel secure, and function successfully in the world.

**My brother, my sister.**

Not all of the participants had siblings. Two were the only child in the family. Ten of the participants were the oldest, three were the youngest, and one was the 7th out of 8 children. In general, participants spoke positively and respectfully about their siblings. The bonds between them were typically strong and influential. Participants described their brothers and sisters as role models, playmates, and friends.

In addition to what the children said about their siblings, I also had the opportunity to observe them. These observations took place when I was in the homes doing the interviews. Siblings usually stayed in another room while the participants were with me being interviewed. Most siblings would eventually come into the room where the interview was taking place and stand by the participant to listen and watch. The child who was being interviewed was always respectful of the brother or sister's curiosity and spoke kindly and gently to him or her. Only once did a participant ask a sibling to leave and that was because of disruptive behavior. The opportunity to observe interaction between participants and their siblings added to my appreciation of the children's pictures, and in every case provided validation for what was shared in their stories.

Younger participants tended to look up to older brothers and sisters who served as role models for skills they wished to acquire and future privileges they would one day hope to achieve. Adam, age 9, admires his oldest brother who is skilled and old enough to hunt and enjoys watching him practice shooting his gun and compound bow, looking forward to the day when he can join him.

Adam, age 9: "That would be my brother shooting his bow, a compound bow. He likes to hunt. That's how he got his doe. I couldn't [go]. I would have wanted to take pictures of it but I couldn't."

Figure 4.45. Adam's older brother shooting arrows with a bow.

Participants with younger siblings talked about how they liked playing and being with them. They kept watch over younger siblings making sure they remained safe when parents were not close by. The protective nature of the relationship comes through in the photographs. In the following picture notice the how Jacob's arm surrounds his younger brother, holding him close.

Jacob, age 11: "He's my brother and he's cute and he's awesome. He has a little boy haircut and he's just fun to play with."

Figure 4.46. Jacob [L] and his brother [R].

The children also articulated the friendship and similarities shared between them and their sibling, particularly if they were close in age.

Emily, age 11: "My sister. She loves me; [she] hugs me. She goes to church with me and she gives me presents for Christmas…. We color together. She's the same foot size as me so ... we share [shoes]."

Figure 4.47. Emily [L] and her sister [R].

Although some sibling relationships were described as being close and enjoyable others were not. Participants recognized that they did not connect equally with all of their siblings. Relationships where the participant felt disconnected from a brother or sister were uncomfortable.

> Faith, age 8: "He [my brother] is kind of mean. He don't [sic] play with me."
> Jacob, age 11: "[My sister] we don't get along that much. Most of the time [we] just ignore each other if we can. Sometimes we are nice to each other. She could be more civil and stuff … we could be nicer. It makes me feel sad sometimes."
>
> Mary, age 10: "My brother brings a lot of joy to my life and a lot of aggravatedness [sic] to my life. He can be like, if something is wrong he [will] try to help, but sometimes he doesn't really help, but still it's a good effort. He's a really good little brother… [but] my sister, o'boy. Me and her are very extremely opposite … in like practically everything. Like there are about 100 things [different] for everything we are alike in. She is very independent [but] I need a partner. And she despises pink and I love pink."

The youngest participants expressed their disconnectedness in simplistic and sometimes derogatory terms (e.g. mean, lazy, brat) while the older children spoke about the disparity among sibling relationships. Importantly, from a developmental point of view, not only were the children able to describe gradations in "getting along" but they also

analyzed the fundamental reasons for the differences, demonstrating a more complex, higher order thought process

**My grandparents.**

Participants also took pictures and talked about relationships with their grandparents. Most commonly, participants lived in close proximity to at least one grandparent with whom they visited one or more times a week. When extended family lived out of town contact was less frequent. There were no instances where children described an estranged grandparent relationship. Instead, the relationship between grandparent and child was vital.

Two participants lived with their grandparents because their biological parents were unable to care for them. However, in functional terms, most grandparents performed the following roles (a) watching and caring for the participant and his/her sibling(s) when parents are gone and when the child just wants to stay the day or night with them, (b) looking after siblings when the participant is in the hospital, and (c) visiting the participant when he/she is in the hospital.

Grandparents also transmit family history, culture and traditions. They pass on their treasures be these skills, objects, or interests. Participants talked about how their grandfathers took them fishing and 4-wheeling and grandmothers helped them make treats to eat and do crafts (e.g. knitting). Adam, age 9, talked about the visit he and his brother had with his great-grandparents.

A B

Figure 4.48. Adam's grandparents: (A) Adam and great-grandfather, (B) Adam and great-grandmother.

> Adam, age 9: "That's my great-grandpa. He was in the air blue, the Air Force. We wanted to go over for a day since my brother liked airplanes, [grandfather] liked airplanes, and to talk about it and stuff. He's fun…. And [that's] my great-grandma. She gave us the [airplane] blanket."

Mary, age 10, took pictures her grandmother helping her and her siblings make popcorn balls (Figure 4.49) while Julia, age 9, took a picture of a treasured heirloom doll given to her by her grandmother (Figure 4.50).

Mary, age 10: "Me and mamaw making popcorn balls."

Figure 4.49. Mary's popcorn balls.

Julia, age 9: "That is a doll my great-grandma gave me…. She wanted me to have it cuz it was special…. it was [an] angel doll. She got two [of her] dolls out and put 'em in a bag. I had to stick my hand in there and pull one out, and I chose that one. It's very special."

Figure 4.50. Julia's heirloom doll.

**Playing with my family.**

Most children took pictures of family activities. Inside and outside of the home the families in this study do many things together. At home, activities include: playing board games, collecting baseball cards, wrestling, tickling, watching movies and TV, and holding garage sales. Activities that took place outside the home environment will be discussed later under the theme *My World*.

Adam's family sets aside one night a week to play board and card games.

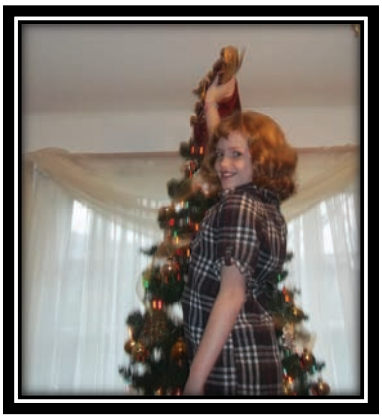
Adam age 9: "This one is the game UNO® Spin…. And then we have Red River®. We just got this new game, it's called Yahtzee® Hands Down. And we just got the Monopoly®."

Figure 4.51. Adam's family game night.

Since data collection for this study occurred during the month of December, most

participants took pictures during the holiday and talked about their family Christmas traditions including decorating the tree. The participants pictured no other holidays besides Christmas, Thanksgiving, and Easter.

> Molly, age 10: "We put the Christmas tree up. We always put the ornaments on. We have two stars cuz Daddy wanted to keep his, and Mama wanted to keep hers… so my sister gets to put up [Dad's], and I get to put up [Mom's]. We do that every Christmas and we all get to decorate the tree."



Emily, age 11. "I put I was putting the angel on top. Every year one of us does it and it was my turn. Next year it's my sister's."

Figure 4.52. Emily topping the tree with the angel.

All of the family Christmas trees seemed to be decorated with ornaments made by the participant when they were younger. The children pointed out their handmade ornaments in the pictures.

Bethany, age 9: "Well there's ornaments on the tree... I made [two] of those in second grade."

Figure 4.53. Bethany's Christmas tree.

**Summary.**

According to the children in this study, their family provides them with a sense of belonging and the feeling of being loved. It is also a place where their behavior is shaped through discipline. They perceive their fathers as being devoted, fun, and playful while mothers are seen as being nice, caring, understanding, protective, and the one who teaches and enforces family rules. Not all of the participants have siblings but those who did were respectful of their brothers and sisters and have strong bonds with them, even though they do not always emotionally connect equally. Participants with older look up to them and those with younger brothers and sisters are protective of them: The presence of CF does not change that dynamic. The majority of participants have grandparents who actively engage with them on a regular basis, stepping in when their parents are away. Finally, the participants perceive their families as doing things together. Be it playing a game or watching TV, being and engaging with family makes the child feel good inside. Parents are integral in helping children form relationships outside of the family unit.

**Theme #4: My Friends**

The participants in this study talked about their friendship experiences. They discussed being friends with other children, with their pets, and with influential non-parental adults. Friendships are usually formed over time through repeated positive interactions with another person or pet. Participants describe their friends as being nice to them and good people.

According to the participants, friendship is an interactive reciprocal process that involves playing and being together, mutual trust, acceptance, love, and support. Friends do

not share any of the participants' secrets with anyone else nor do they make fun of them. Interactions with valued friends make participants feel happy. Friends were categorized by the participants as "my best friend", "a good friend", and "my friend".

Not all relationships with others were positive and affirming. Negative peer experiences starting as early as kindergarten influence some participants' ability to trust people outside of their families. Children with CF learned early on that some people interact with them differently because of their condition. As a result, participants do not like it when friends tell others about their CF. Instead, the participants desire control over personal information shared with others, and are typically cautious about revealing their diagnosis. In general, sharing about CF is only done with true friends.

**Other children.**

The oldest friendships started very early in life as a result of interacting with children of their parent's friends. Other friendships were formed when the participants entered school and through community related activities such as the church, neighborhood play, and scouting. Below is a friend whom Emily, age 11, has known all her life.

Figure 4.54. Emily's friend.

Emily, age 11: "That's my friend. She was at church in the fellowship hall and I got [a] picture. We've [been] friends ever since we was born. Yeah, I was a year old when she was born. We growed [sic] up together really. We went to a movie last year, to 'Alvin and [the] Chipmunks.'"

Best friends are the most trusted friends. The children will reveal to them about having CF and allow them to be present during treatments. A best friend was described as one who is not fearful of or in any way put off by CF and willingly stays behind when the participant has to take time away from an activity to receive a treatment. According to Molly, age 10, what makes a friend a best friend is: "they're really nice to me. They make me feel comfortable around them for some reason." The emotional bond between the participants and their best friends is close and can be observed in pictures taken of them together. In those snapshots, children stand shoulder to shoulder with little space between them. The following are two exemplars, one from a boy and the other a girl, illustrating the qualities that make someone a best friend. First, David, age 8, talks about his best friend then Molly talks about hers.

> David, age 8: "We're best friends. We go to school together…. We'll never switch schools, cuz … he's my best friend. We play together. We're in the same grade cuz I skipped 1st and he was the in the 1st grade [when] I was in Kindergarten… You can play with him, [he] makes you happy. He eats organic food."

Figure 4.55. Molly and her best friend.

Molly, age 10: "This is me and my best friend. She always hangs out with me outside and on the playground. She plays with me a lot, and if I would be able to choose somebody to come over to my house and spend the night, I would choose (her)… she's just my best friend. She's really nice to me." [My friend] said that if she wants somebody to come over, she thinks, but she doesn't have to think for a long time

> because she always picks me. She knows a lot about it [CF] cuz I tell her a lot about it. And she's fine with it. Whenever we're playing inside, cuz I have to do the medicines, she wants to stay – I ask her to stay now with me, and she says, 'Okay, I'll stay here with you.'
>
> She has a sling because she … broke her arm from a horse. She actually has a cast on behind the vest, underneath her jacket. Her sling, it was kind of a little bit loose … And I said, 'I'll help you.' And then I tightened it up … I had to carry her lunch tray. Her mom actually asked me to help instead of anybody else. If I forget my water for PE, she'll think about it … but she doesn't say it to anybody. She goes back and grabs it and I'll say, 'Man, I forgot my water!' She has it behind her back."

In contrast to the intimate sharing that takes place with "best friends" participants also tell "good friends" about having CF, but they do not give out as much information. "Good friends" may or may not be allowed to see the participant doing treatments. Finally, a peer who is labeled as just a "friend" may or may not know the participant has CF and will not be privy to seeing the child take treatments. David, age 8, explained how he differentiates a best friend from just a friend:

> "My best friend is a lot nicer and Larry's my best friend like I have 2 best friends. I wouldn't say my cousin's my best friend cuz he fights me. [My best friends] are way nicer."

Good friends will remind the participant to take medication when he/she forgets.

> Lauren, age 11: "My friends sometimes [remind me]. I forget [to take my enzymes] at school, [so] they tell me. Cuz I've told them why I have to take medicines and so they just tell me, remind me, when to take it cuz I told them I have to take [my enzymes] like before or after lunch."

However, the qualities of friendships do not always turn out as the child expected. Tyra, age 8, eluded to this fact previously, under the theme *My Medicine and Treatments,* when she told a story about a friend who violated their friendship by telling others about

her CF. During the interview Jacob, age 11, reflected upon his previous relationship experiences and in the process gained a new perspective concerning initial impressions of a person and the resultant quality of friendship:

> "I mean at first you think that one person "ooo" … "I know they're going to be one of my best friends" and they turn up being your enemy and then the person you thought was going to be your enemy ends up turning to be your best friend so. Yeah, it's just really cool."

Through reflection, Jacob was able reframe his negative friendship experiences into a positive thereby demonstrating his awareness concerning the formation of friendships and his ability to cope with unpleasant interactions with his peers.

Children in this study talked about both their male and female friends. That is to say girls discussed friends of both genders, just as boys did.

Figure 4.56. Andrew and his girlfriend.

Andrew, age 8: "I wanted I wanted to keep this cuz I don't (see) this girl a lot … she actually lives in (another town). She … likes to play with me. She comes over. She gives me a hug if she misses me a lot. Sometime … she'll come over for a day or two."

Participants recognize and are drawn to their friends' unique characteristics. Earlier, David talked about his how his best friend eats organic food. Below Mary, age 10, acknowledges her admiration for her friend's ability to invent and build things.

Figure 4.57. Mary (2nd on the right), her sister (far left), and friends.

Mary, age 10: "These are very special friends. And he is coming over tomorrow. And that is my sister's best friend. And I would like to let you know that he is very funny. He is an inventor. He can make him a whole popcorn stand if he wants. He goes through things that his mom is going to throw away like boxes and stuff."

**Pets.**

The majority (81%) of the participants had at least one pet in their household. Six participants (38%) had three or more pets including dogs, cats, gerbils, sugar gliders[8], guppies, frogs, a bird, and a horse. Although pets comprised only 8% of the pictures the longest stories told were about pets, animals with which they have special, strong relationships. Favored pets accept the child unconditionally and are always there for them. Dogs and cats come running when a child calls them, cuddle, and even sleep with them.

Stories about pets typically began with information about how the child came to possess the pet. Daniel, age 9, ordered his African Clawed frogs through the mail; Molly, age 9, purchased her guppies at a local pet store; and Joseph and his family obtained their dogs from reputable breeders. On the other hand, many of the participants' pets were found seemingly abandoned by previous owners.

[8] A sugar glider is a small marsupial, often referred to as a gliding possum, indigenous to the forests of Australia, New Guinea and Indonesia (Sugar glider, 2008).

Figure 4.58. Julia's dog.

Julia, age 9: "That's my dog. She's a mixed breed, and when we got her, my aunt had drove by a burned-down house, and her mom and her brothers and sister were in the house. Nobody would claim 'em, so my aunt kept the [mother] dog, and my dog and all of her brothers and sisters. And I finally got to choose a puppy, and my dog was the one who was always goofing around. She follows me around and kind of protects me."

When talking about their pets the children mostly talked about the special and strong connection that they have with their cats and dogs. The relationship between the child and pet is a happy one because the animal listens and the child perceives that their pet loves them. The children talk to their pets and tell them secrets. In return their pet sits, listens, and does not argue or talk back.

Figure 4.59. Joseph and his dog.

Joseph, age 11: "Well he's my favorite and I'm his favorite and he follows me everywhere and he just he always sleeps with me at night and … he just like never lets go of me."

Figure 4.60. Ashley's dog.

Ashley, age 10: "She [has] a special place in my heart and I love her so much. I treat her like my sister. I mean, it's really weird. I'll get her up there [on my bed] and lay with her and just cuddle with her and we'll put the blanket over us and we'll just sit there and sleep and she takes care of me like all the time. I protect her and she protects me and we are best friends. Like I can tell her a secret and she won't tell. I just tell her [about] people I like and then I'll tell her how I feel sometimes and she just sits there. She stares at me like she's actually listening. It's kind of strange but I listen to her. I feel like she tells me stuff. It's kind of strange. It really is, but I love her and … she's just really special to me. She sleeps with me. There's not one night she's not been with me."

Not only do they love and protect their pets but the children also perceive that their pets love and protect them in return. Ashley continued her story about her dog, giving an example of how her dog protected her on one occasion:

> "My mom's ex-boyfriend, his friend had come over with [his] son [to] play. As soon as he started walking up to our door, [my dog] ran passed us and stood there and started [barking]. [My dog] kept barking and barking and barking at them. She would not let me go past em or anything. She growled and everything."

The children recognized each pet's unique character and features as well as the breed of the animal. Children love and care for their pets by feeding, watering, and grooming them, and assuring they have a warm and comfortable place to sleep.

Figure 4.61. Faith's dog.

Faith, age 8: "He's nice, and he plays. He loves to drink milk and water. He runs a lot. He has brown eyes; you can't see his eyes, and a moustache. He fetches. I love him… He treats me good."

Figure 4.62. Julia's horse.

Julia, age 9: "That's my horse… she's called a Haflinger. She's very gentle; she's not mean. Like if she sees someone new, she just lets 'em pet her and stuff. I feed her and give her water. And when I have the time, I brush her hair out."

Play with pets involved dressing them in costumes and bright colored collars, teaching them tricks, playing hide and seek, and petting them. The animals put up with what adults would consider bothersome and annoying antics, yet they always returned to the child when called. The connections between participants and their pets are different than those that they have with family and friends. Hilary's story below sums up the special relationship these children have with their pets.

Figure 4.63. Hillary's kitty.

Hilary, age 9: "Here I'm lovin on Kitty and Kitty lovin on me. He is my best friend and he sometimes gets on my nerves because he scratches on the door and wants in. And he loves to love on you and when he comes in the house he looks for ya. Even though I cannot understand nothing that he says or anything that he means when he meows, I still love him. Not like a person you know like when you have a relationship with your animal, but its like it's a strong one? Its like we love each other a lot because every time he sees me come home from school and he's out in the woods he tries to run over and tries to love on me and I love on him back and he just don't ever stop. And I teach him tricks. He can lie down, he can freeze and I'm still trying to teach him how to stand up. He's just my best friend and we have been with each other since he was born. Kitty sometimes runs off in the woods and plays, but when I holler for him he comes and plays and everything."

**Influential non-parental adults.**

Participants took pictures and talked about adults who have a positive influence on their lives, including teachers, pastors, family friends, and health care professionals. Adults who are perceived as taking a personal interest in the child appear to make the biggest impression. As described by the participants, these adults connect and engage them through humor, play, fantasy, talk, and loving touch. Teachers will be discussed first, followed by pastors, and other adult friends.

Not all of the participants were allowed to bring their cameras to school, but those who couldn't expressed that if it had been possible, they would have liked to have taken a picture of their teacher. Although most pictures were of their schoolteachers they also recognized Sunday school teachers, music teachers, and coaches. Participants seem to

connect with teachers who are nice, fun, playful, able to engage them in learning activities, and use the latest educational technology. They also appreciate it when teachers help them with school assignments and do not overwhelm them with homework.

The fact that schoolteachers work hard did not go unnoticed. Besides teaching, children appreciated the effort that went into keeping order in the classroom, grading papers, and disciplining students when they do not mind. Participants also realized that teachers have a life outside of the classroom and like it when teachers talk about their interests. Knowing some personal aspects of the teacher allows the child to draw similarities between the teacher's life and their own family and promotes bonding between student and teacher.

Emily identifies similarities between her teacher, her parents, and herself. Her teacher is interested in college sports, is an authoritative figure and a source of knowledge. At the same time Emily, age 11, recognizes that her teacher likes to have fun, which is what a child of Emily's age likes.

"She's very funny. She likes to make jokes all the time and she works hard for us. She has to grade all the papers and do all that teacher work. She likes the [college football team]. She is like daddy. And she makes you mind. She yells at us sometimes. Especially [at] some boys I know. And it works; they listen."

Figure 4.64. Emily's teacher.

Some relationships with teachers were also valued because they connect children to a world outside the home and school environment (e.g. field trips, class projects) resulting in

novel life experience and the formation of new knowledge. The focus concerning participant connection with the world via others will be discussed further on page 206 under the theme *My World*.

Some participants spoke highly of their church pastor who they described as providing spiritual direction and teaching spiritual beliefs. The pastor is a source of spiritual and emotional support when the participant and his/her family are hurting or in trouble, be it related to CF or something else. Pastors and church congregations are usually informed when the participant has an illness and/or enters the hospital so that members know to visit, send cards, and pray for them.

Figure 4.65. Mary's Pastor.

Mary, age 10: "This is my preacher and his wife. They are really good folks because when I am having some troubles or hurting or anytime of the day or anything, he doesn't mind to come over at 3:00 in the morning. Or you call him or something, he doesn't mind; he is never grouchy. He'll just come over whenever and help you and stuff. He's just a really big influence and help in my life."

Figure 4. 66. Molly's Pastor.

Molly, age 10: "I got a picture with him for two reasons. He's a really good pastor, and the other one was I was in confirmation class, he taught it, so I learned a lot about baptism. I can't say it very well, but I learned about the church and more about Jesus. He [usually]

> stands out[side the church] to shake our hands, but last Sunday he wasn't feeling good. He didn't want to get [anyone] sick so he stayed in[side]."

Of the four children who took pictures of their pastors, three participants had pastors that were racially different from them, yet children did not discuss these differences. Instead, the focus was on the common beliefs that united them.

The participants were impressed when unrelated adults took an exceptional interest in them. Andrew, age 8, talked about why he wanted a picture of one couple:

> "Mr. Indigo and Mrs. Indigo are moving away and so I just wanted to get a picture of [them] so I don't forget about em. He means a lot to me…. Mrs. Indigo is my teacher for drums. She's letting me [take lessons] for free cuz I'm so special to her."

Mary, age 11 talked about her relationship with a grandmotherly woman with whom she compares her mother and her life. This lady has taught Mary to appreciate her family and the things that she has:

> "There is one of our friends…. Well, her mom didn't teach her all the stuff that my mom teaches me. Her mom had left her when she was younger, but I can just tell that she didn't have all the stuff that we have. Even though her mom didn't teach her those things she is a very special lady because when mom has to go on errands or doctor appointments or something, she'll just spend the night or come over."

Mary also shared an example about another adult friend who uses a creative method to cheer her up when she has to go into the hospital for a bronchoscopy:

> "Patty will come every single year when I am in the hospital. There is some theme [she picks to cheer me up]. It could be cowboys or funky monkey or Hawaii or pets. And she always dresses my sister and brother and her kids up. Sometimes they may have on cardboard suits and paper mask plates or fairy costumes or dwarfs or little hula skirts and those hula thingies, leis. They just have crazy acts. She comes in when I come back [from my bronch]. I usually sleep and then I wake up and my room is all pretty. She always comes [to the hospital] and she can cheer me up."

David, age 8, talked about a woman who works with his grandmother and what she does to support him and his community's fundraising effort in finding a cure for CF:

> "I love her. I like her. I like her. I like her. I like her, like her. She comes to the CF Fishing Tournament that [another adult friend] throws me and we go fishing every summer."

**Health care providers.**

Participants were drawn to health care providers (HCPs) who engage them in talk and playful activity. Influential HCPs help make hospital and clinic visits fun and interesting, projecting humor and creativity into what can be a scary and boring experience. They also like assurance that they are loved, cared for, and that the HCP is trying to "cure" them. When HCPs engage with them and talk to their parents, participants feel a connection to that provider and feel that they care. Several participants took pictures of their favorite nurses.

Figure 4.67. Molly's Nurse in CF Clinic.

Molly, age 10: "She comes in every time I go to a CF appointment, and she talks to my mom. She's one of the CF nurses. She's very nice to us. That's for one thing. And she helps Mama and Daddy know what to do. And she is very good."

Figure 4.68. Emily's nurse.

Emily, age 11: "That was my nurse. She's fun. She played with me. She made me these snowflakes, big snowflakes. Sometimes she gives medicine to go to sleep for my bronch. She gives me shots. She loves me cuz she treats me well. She's my favorite. She makes me feel happy; it feels good."

The children photographed other HCPs as well. Other than the clinic and hospital staff nurses, participants called all other HCPs, "doctors". This included their physician, respiratory therapist, nurse practitioner, research coordinator, and operating room transport tech. While sometimes it seemed that the participants made a distinction based on attire or the kind of care received, there was no consistent information as to how or why non-nurses were labeled as "doctor". However, participants were always accurate in calling staff nurses "nurse".

Figure 4.69. Molly's Respiratory Therapist in the respiratory clinic.

Molly, age 10: "I've known her since I was like three. She's really nice to me. So I've known her for a pretty long time. And she's like one of my favorite doctors."

Figure 4.70. Faith with the CF Research Coordinator (a non-physician).

Faith, age 8: "She's my doctor.... She's nice and fun, and she makes me laugh."

Because certain HCPs stood out among the others, the participants mentioned them more often. It seems that these particular individuals used creative methods to capture the attention of their patients, including teasing, joking, drama, and dressing in unusual child-appealing clothing. Several children talked about a physician who wears a variety of specially designed lab coats with cartoon characters on them. Others mentioned an operating room transport person who wears outrageous hats and decorates his vehicle and parks it in front of the hospital on holidays. Below, Emily age 11, talks about a funny picture she had taken with a physician and a nurse practitioner from the CF clinic.

Figure 4.71. Emily with her physician (L) and her nurse practitioner (R).

Molly, Age 11: "I really want to show this one. My doctors … we took a picture. I was [making a] funny face and [the doctor] was doing one and [the NP made] one. They're crazy sometimes. They're trying to find a cure but they can be crazy. Sometimes Dr. Martin tickles me and then Dr. Paul he's funny…. He makes his self talk funny."

Although the participants acknowledged having favorite HCPs Mary, age 10, recognized that differences among her providers can complement and benefit the care she receives. However, sometimes she also wants more guidance in managing her CF:

> "My special doctors are Dr. Diaz and Dr. Hedges and they are my most special doctors…. And they are my bestest [*sic*] of the best doctors and they are so different but together they make a great team. [Dr. Diaz says to me]… "this has to be done." [Dr. Hedges] listens to me. [But] sometimes you kind of [think] 'OK [Dr. Hedges] you are a guide, but you have to say, "do this" so that I have something to lean on…. But together they make the most perfect team that I've ever seen. Well, they are just amazing."

Embedded in this quote was evidence of appraisal. Mary not only likes her doctors on a personal level, but was also making judgments about what kind of care works for her. Although, Dr. Hedges' less directive approach may at times be valued it also leaves her feeling adrift. The expressed need for specific concrete direction may be somewhat developmental, but it also reflects abstract thought consistent with a more mature development seen in adulthood where people want both "heart" and specific explicit guidance from their HCPs.

**Summary.**

Participants spoke about the friends who impact their lives including best friends, pets, teachers, pastors, and HCPs. Friends engage with the child through fun, humor, play, teaching, talking, hugging, and listening. They are perceived by the participants as being loving, nice, fun, funny, trustworthy, protective, and supportive. Relationships with others,

outside of the nuclear family, enlarges the child's world by giving him or her access to knowledge, places, and objects not available in the home environment. As a result, good friendships with peers, pets, and non-parental adults help make living in the world a rich and secure experience.

**My World**

In addition to showing awareness of their selves, treatments, family, and friends participants recognized and appreciated their place in the larger world. Their sense of place was shown in concrete things such as favorite objects, locations where they had visited, and community activities they participated. There were also more existential things they experienced in the world that stimulated their mind and senses, and these things were harder to depict. How children situated themselves in the grand scheme of the universe was reflected in photos of sunsets, the sky, the countryside, a flower in bloom, freshly fallen snow, pretty inside and outside lighting, and a burning fireplace. Children demonstrated great creativity in illustrating these more affective qualities of existence. This final them, *My World*, is divided into four subthemes: *The concrete: My things*, *The affective: Pretty and fun*, *Connecting to the world through others*, and *Children's place in the universe*.

**The concrete: my things.**

Both boys and girls chatted about their possessions. Favorite belongings included toys, games, animals, holidays, foods, movies, and posters. Girls mostly talked about their dolls, Nintendo DSis™, Precious Moment® and stuffed animal collections, jewelry, and books. Boys talked about Legos®, computer games, cars and trucks, spy equipment, guns, bicycles, 4-wheelers, and motorbikes. These possessions were objects that typically represented

favorite things participants have interacted with, heard about, or seen (either in person or in picture) in the world. When talking about favorite things participants told long and involved stories.

Several of the boys reported that they liked to build things. Creating and constructing toys gave them a sense of accomplishment.

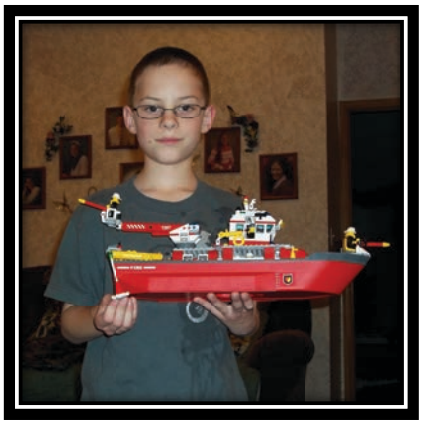
A B 

Figure 4.72. Adam and his Legos® (A) Adam building his Lego boat, (B) Adam after building his Lego® boat.

> Adam, age 9: "This picture, is when I got my [Lego] fireboat (Figure 4 a).... My grandma helped me get my Christmas present. I loved it. I like Legos®. It came with firemen and stuff like there's the boat and the firemen. There's a little yellow boat in the back to help to go out in the water and to help drowning people."

Most of the girls preferred the colors pick and or purple. As a result, many of the things that they possess including clothing, toys, electronic devices, treatment vests, and their bedrooms were all pink or purple. For them, living in a physical environment that reflected their tastes and preferences enhanced their sense of mood and comfort as well as their emotional well-being.

Figure 4.73. Bethany's bedroom.

Bethany, age 9: "That's my bedroom. I love, love pink like Barbie does. Pink is my favorite."

Figure 4.74. Ashley's favorite picture.

Ashley, age 10: "I asked [grandmother] to take a picture of me with … my favorite tree that I decorated myself and my new PJs and so this would have to be my favorite picture cuz all my favorite things were in there."

Often seeing a favorite color or being with a favorite object stimulated a good feeling inside them. Particular feelings or emotions associated with favorite objects included a sense of creativity, happiness, and comfort. Additionally, favorite objects often served as reminders of the people who had given them the object or as a proxy for special family members with whom they had limited contact (e.g. a grandmother or cousin).

Figure 4.75. Mary and her favorite baby doll.

> Mary, age 10: "That's me feeding my baby at the window. I got her when I was 8 and she is very special to me, and like sometimes when I am going through hard times she is one of my only hopes because she can understand everything. And so I take her into stores and embarrass my sister. I got a brand new cousin … she lives in another state [and is growing up] really fast and we don't get to see her much. And so [my doll] is like my real baby because she can move and cry, open and close her eyes and sleep and kind of snore and stuff. I take her everywhere and bundle her up and give her a bath."

Playing with favorite objects allowed participants to free their mind of the present and construct an imaginary world where they could be whatever they wanted to be, in a place and time they wanted to be. Their perceptions of the world influenced their imagination. Even though she did not take a picture of her bedroom, Ashley, age 10, talked about how her bedroom transforms into a place where she is free to play and imagine what her future might be:

> "I just go up to my room and imagine [that my room is] like a huge island … and I just do whatever I want in my room. I'll sing and I'll dance and I'll listen to music. I watch a lot of shows and draw and stuff. It's like I live in there because I do everything in my room. I only come out if I'm hungry or if I have to use the bathroom really. When I'm in my room, I feel comfortable and warm. I'll go through

> my closet and pick out what I wear at for school and then I'll play games in there, like how I want to be an actress. And I'll clear out one shelf and I'll put books and stuff in there. I like to play school a lot. I'll act like I'm 16 in high school and I have a locker and go to classes."

During data analysis it also became evident that children's interests and behaviors in the hospital reflected their larger world. In that way, they were able to link the larger world to the hospital. For example, Emily's favorite animal is a panda, so when she is hospitalized for exacerbations of CF she prefers to stay in the room with the panda wallpaper border.

Figure 4.76. Emily's favorite hospital room with the panda wallpaper.

As previously discussed under the theme *Taking Medicine and Treatments* children bring objects of comfort from home to the hospital (e.g. stuffed animals). They also bring their imagination as well. Below Tyra, age 8, talks about pretending to be a princess:

> "Sometimes, I feel like [a princess].... [I get to] go and eat icecream when ever. Remember those little tubs of ice-cream ... that cookie dough stuff? Well, I have em [hospital staff] bring em up. You know how people always eat icecream at movies? They have a robe on and slippers on and then they eat [ice-cream]? Well, that's exactly how I did it, except [I had] a little tub. Usually in the movies they're [big] tubs. Whenever anything goes on, when anything is done, or if I'm done with anything I just call [the front desk] and [the nurses] pick [the call] right up."

**The affective: Pretty and fun.**

In addition to favorite objects, participants also enjoyed showing and talking about the things they do in their environment and places they had been. Excursions out into the world exposed the participants to many exciting sights and adventures including beautiful lights at a theme park during the winter holidays, making snowmen and throwing snowballs with friends after a big snowfall, and climbing a wall of rock.

Differences between boys' and girls' outdoor photographs emerged during the interviews. In their narratives, girls explained that they took pictures of the outdoors because the sights were aesthetically pleasing and they appreciated the beauty of the natural world. Pictured were mostly vistas and scenes of the winter season.

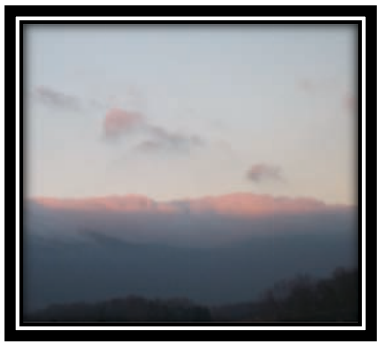
A B  C

Figure 4.77. Hilary's pictures depicting beauty. (A, B) sunsets,(C) snow on the mountain.

> Hilary, age 9: (A& B) "These [pictures are] about when the sun was about to set and the clouds looked all pink and pretty and I just thought they would make a pretty picture." (C) "[Here] we were driving and it was really pretty on the mountains so I thought we should take a picture of it. And it made me feel happy to know that I live in a place that has winter and stuff because there is some places that only have summer all year round or winter or not even have winter or fall."

Figure 4.78. Ashley's back yard after a snowfall.

Ashley, age10: "The reason I took this picture is because I love the snow so much and it just made all the trees beautiful. My favorite thing is snow and my favorite is season is winter cuz snow just make it look like a wonderland to me. That is actually how deep [the snow] was. I mean it was huge."

Figure 4.79. Looking at the sky from Faith's back porch.

Faith, age 8: "I'm out on my back porch. And it's pretty, and I like to sit there. I do my homework there and stuff. It's fun and pretty and nice."

In contrast to the girls' stories, which were mostly about seeing, the boys' stories of the outdoors involved doing and engaging with nature. Jacob, age 11, talked about his engagement with the natural world when riding motorbikes with his siblings.

Figure 4.80. Jacob on his motorbike.

> Jacob, age 11: "We are just like "vroom…." It's just really fun. You feel the wind just blowing back. You can … control how fast you go and we've figured out a way to make [the motorbike] go really fast like up to 20 miles per hour ... it's like the throttle but you can push down harder and go really fast."

Daniel, age 9, lives on a large farm. He spoke about his interactions with living things in his front yard.

Daniel, age 9: "Now that's just the cows. The cows are scared of me every time I come next to them. [They] run. That's a frozen catfish pond. We did have walleye there. [I feed the fish] bread and catfish food."

Figure 4.81. Daniel's front yard.

Adam, age 9, has a multi-generational connection to a place where he plays. During the interview, Adam's mother reminded him that when she was a child she played in the places where he now plays on his grandparents' land.

Figure 4.82. Adam's Monkey Land.

> "Adam, age 9: It's just a [sic] old fallen down tree. And we call it Monkey Land. And my brother, he made a sign. You can't see it, but he put it up and it says Monkey Land. That's me. I'm wearing the brown coveralls … we're climbing up on the rotten logs…. And there's me climbing… I'm just climbing towards them rocks. This picture is supposed to look like I'm rock climbing."

Not only does Adam perceive his grandfather's land as a fun place to play but he now understands that the land is part of him passed along from generation to generation.

**Connecting to the world through others.**

Most of the time it was the participants' parents who exposed them to the world outside the home environment. Planned family outings out into the community and beyond included a dinner theater, the symphony, restaurants, a hair stylist, a parent's work party, 4-wheeling, hockey and basketball games, church gatherings, extended family get-together, and a variety of vacations including going to the beach and a Caribbean cruise. Family outings such as vacations provided opportunities for children to connect with their parents and siblings. These outings exposed the children to new places and activities they rarely or never before encountered and generated positive memories of family fun.

Figure 4.83. Andrew's beach vacation with his family.

> Andrew, age 8: "We were at the beach for a while…. We had fun at the beach. I got to surf a little but some waves caught me on the back…. One huge [wave], knocked [me] over. Here's … where we're trying to make a sand castle. We played golf there. That was a pirate golf place. Me and my daddy got a hole in one."

Figure 4.84. Mary's family vacation.

> Mary, age 10: "This is at the hotel. And here is my dad when he was nana boobooing me and I had a snowball. This is me and my [family] at a restaurant."

Participants were also connected to the larger world through people other than their parents. Organizations including the school, Cub Scouts, and church as well as people outside of the family all planned and organized activities to which the participant was invited to attend. Parents often accompanied the children to these events, but not always. It

was during these outings that the children met and socialized with friends and other peers. These excursions included a visit to a nearby amusement park, parents night out, team games, parties, field trips, parades, and the Boy Scout Pinewood Derby®.

Figure 4.85. Julia playing games at a community sponsored event.

> Julia, age 9: "This [picture is] where I was playing … beanbags and throwing them. My high score was … 450 something, I think. This [other picture] is when we were playing limbo. I got as low as [I could]."

Figure 4.86. Daniel riding in a parade.

> Daniel, age 9: "That was in the parade when we had the parade in the Cub Scouts. It was really good. I got hit in the head with candy. [I saw] mamaw and granddad. I waved at them."

The participants appreciated teachers who involved them in learning activities that promote interaction with things in their environment. These learning experiences left lasting impressions on the children. Julia, age 9, spoke about the time her class raised butterflies:

> "I would have took a picture of my teacher, but I wasn't allowed to bring [the camera] into school. We raised butterflies once, and she knows a whole bunch about birds and butterflies. We raised Monarchs, and when one got ready, like after they were ready to fly, she put one of 'em on her hand, on her finger, and just let it fly out the window."

Adam's first grade teacher took his class on a field trip to the local police station. Since that experience, he has been fascinated with being a policeman. A large willow tree in his backyard serves as his imaginary police station.

Figure 4.87. Adam's police station.

Adam, age 9: "I pretend it's my police station. I pretend I have a computer and stuff up there. I'm a policeman. I don't really know much about [policemen]. All I know is when I went on that field trip to the police station. They go around catching bad guys and directing traffic."

**Children's place in the universe.**

Parents and other people are a means by which the school-age participants experience and connect to the larger world. Early childhood experiences and the perceptions formed by these experiences influence their actions (e.g. keeping secrets), interests (e.g.

butterflies), abilities (e.g. playing drums), and ideas for their future. As a result of caring for her elderly grandmother and working in the church nursery, Lauren, age 11, thinks she knows what her future career will be:

> "I want [to] be a nurse cuz I'm good at it cuz I take care of my grandmother. I like taking care of people and helping out people. It makes me feel happy. I like taking care of babies too. At church I go and help out [with] the little kids."

The participants in this study saw themselves connected to the future. Above, Adam age 9, is role-playing a future as a policeman in his back yard tree and Emily, age 11, is thinking about being a "nurse" and then a "doctor pediatrician" because of her interactions with the CF health care professionals. Other participants' plans for future were presented under the theme *Me Being Me* and included:

- Molly, age 10, plans to have two horses when she is older.
- Mary, age 10, would like a small house of her own.
- Ashley, age 10, aspires to be a fashion designer.

However, some children do not want a future that includes CF. When Hilary, age 9, was invited to talk about her CF bracelets she said: "I want to get rid of it [CF]". Jacob, age 11, not only made it clear that he does not want CF, but sometimes he cannot believe that he truly has CF:

> [Having CF] it's bad because sometimes you don't think you have CF and you're like "I know I don't have CF, just take me to get the test again. I promise you I don't have CF. Just take the test again" or "find the cure really fast."

Negative perceptions about their lives arose when their engagement with the world was restricted. Although he conceded that he had fun riding his motorbike, Jacob, age 11, explained how he saw his life, "I pretty much got no life. I eat, I play on the computer, I go

outside and ride bikes. That's me. Yeah, I go to school, but it's kind of bland."

At this point I can only speculate why Jacob felt isolated from the world outside his home environment, but other participants did talk about how boring it was to be in the hospital and when taking CF treatments (see Theme #1, *Me Being Me*). When in a room doing a treatment or in the hospital having procedures, treatments, or IVs, participants are socially cut off from others, leaving them no option but to interact with what is left in their immediate environment. This usually means the TV, computer games, a book or magazine, or a few toys.

**Summary.**

Participants in this study showed an appreciation for things that surround them in the world. Concretely, participants talked about the objects they own and play with. Be it a sense of accomplishment, happiness, or affection the children possess emotional attachment to the things they chose to show me through photographs. These objects allow them to be creative and encourage them to use their imagination. When taking pictures of the natural world, there were differences between genders. The girls took pictures of beautiful outdoor scenery where as the boys took pictures of their engagement with the outdoors. Parents are the primary means by which the participants are initially exposed to the world outside the home. However, friends, teachers and community organizations are also influential in exposing the children to objects and social activities in their community and the larger world. As a result of these experiences, children learn about themselves and develop ideas for their future. Unfortunately, children sometimes feel a lack of engagement with the world due to the isolating effects of CF related activities or for other unstated

reasons. As was so well illustrated by Jacob, age 11, feelings of isolation can lead to the child feeling that they are missing out on life.

**Conclusion**

Relationships between the parents and children were strong. For better or for worse their engagement with the world was largely encouraged by their family. Relationships with others outside the family provided another means by which children were able to socialize and interact with their environment. What follows is a comparison of two children and their connections in the world (Table 4.4). This comparison demonstrates the range of connections among the participants. Molly exists on one end of the spectrum while Bethany's life is on the other. All of the other participants fall somewhere in between, but the majority lie much closer to Molly, very much part of the world.

Molly's lives a life of connections. She can talk and play with her parents and knows her family loves her. Her family regularly leaves the home environment and interacts with others in the community and as a result, has numerous positive relationships with peers and influential adults. She does not always like doing her CF treatments, but accepts that she must do them. Molly also has interests, abilities and plans for her future. In contrast, Bethany's life is more constricted. Her relationship with her mother is strained at times and her father was not depicted in any of her pictures. Except for the CF clinic, Bethany did not identify any connections to the community. She mentioned only 2 meaningful relationships with people outside of her nuclear family. Bethany's interests are centered in the home, and not outside. She does not like doing her CF treatments and will sometimes hide from her

mother, knowing that there will be consequences. She did not talk about anything related to the future.

Table 4.4.

Comparison of Two Participants and Their Connections in the World

| | **Molly, age 10** | **Bethany, age 9** |
|---|---|---|
| **Me** | • Pointed out objects in the pictures. Able to remember why a picture was taken and who took it. Able to describe the activity taking place at the time the photograph was taken. Able to articulate feelings when looking at her photographs. | • Pointed out the objects in the pictures. Had difficulty remembering why the picture was taken and anything outside of the picture including other objects and activities going on at the time. In simplistic terms able to articulate what she was feeling when the picture was taken. |
| *Interests* | • Likes to help others, likes animals especially horses, dogs, and cats | • Likes anything to do with Barbie™ and playing with dolls. |
| *Abilities* | • Draws. | • Plays games on the Wii™ |
| *Feelings* | • Playing with family, friends, and her things are fun and they make her feel happy. | • It feels good when her mother holds her. |
| *Future* | • Wants to own 2 horses. | • No future identified. |
| **My Treatments and My Medications** | • Took several photographs about taking treatments.<br>• Does not mind doing treatments except when they interfere with playing with friends. Takes her treatments and medications when her mother asks her.<br>• Expressed happiness about getting a new pink treatment vest and possibly a skin for the Vest® machine. | • Did not take any pictures of her medications or treatments.<br>• Helps mother with preparing her treatments.<br>• Does not like doing the Vest® treatments. Hides from her mother at treatment time sometimes. |

Table 4.4 cont.

| | **Molly, age 10** | **Bethany, age 9** |
|---|---|---|
| **My Family** | • Lives with mother, father, and younger sister.<br>• Photographed and talked about her relationships with each of family member including her mother, father, sister, and grandfather. | • Lives with mother, father, and little brother.<br>• Photographs of family members including her mother, brother and a cousin. |
| *Father* | • Articulates that her father loves her. He helps her spirits when she is down, and he helps his own mother. | • Her father gave her a stuffed animal. No emotion attached or mentioned in relation to father. |
| *Mother* | • Actively prepares and assures treatments and medications are taken. Got her a much desired toy horse stable for her birthday, to keep her occupied. | • Expressed disappointment about how her mother would not let her play a game when she asked permission to play. |
| *Siblings* | • Has a younger sister (though close in age) with whom she plays and goes places. | • Has a little brother whom she watches and plays toys with. |
| *Grandparents* | • Grandfather visits every week. He teases and plays with her and her sister | • Grandfather moved away a couple of months ago. Grandfather had a pet name for her brother but not for her. Grandmother gave her a stuffed animal. |
| *Traditions* | • The whole family decorated the Christmas tree together. | • She and her little brother helped their mother decorate the Christmas tree. Christmas ornaments that she made are displayed on the tree. |
| **My Friends**<br>*Peers* | • Has at least two best friends and numerous school and neighborhood friends. | • Pictured one friend, her cousin. Did not talk about any other friends. |
| *Pets* | • Has 2 dogs and 3 cats. | • Has no pet. |
| *Adult Friends* | • Took pictures and talked about schoolteachers, friends, the church pastor, adopted grandparents, and the employees at her favorite restaurant. | • None depicted or discussed. |
| *Health Care Providers* | • Took photos and talked about her favorite CF nurse and respiratory therapist. | • Did not take photos or talk about any of her health care providers. |

Table 4.4 cont.

| | **Molly, age 10** | **Bethany, age 9** |
|---|---|---|
| **My World** | • Lives on the outskirts of a major city in a subdivision in a modest size home.<br>• Most photographs were about relationships with family, friends, and pets and the activities she does with them. | • Lives in a small rural town in a small brick house in a small subdivision.<br>• Most photographs were taken indoors and at home. The only photographs taken outside of the house were those taken at the CF clinic on the day of study enrollment. |
| *Favorite things* | • Santa Toy, the color hot pink, horses, miniature horse stable. DSi™ | • Barbie™ movie, the color pink, stuffed animals. |
| *Family activities* | • The family goes to church, has a favorite fast-food restaurant, and attends community-sponsored events including a yearly fundraiser for the local children's hospital.<br>• Travels with her family. | • Goes on errands with her mother frequently and to the CF clinic.<br>• No other activities photographed or discussed. |
| *Peer activities* | • Goes on sleepovers and to birthday parties. Made snowmen and went snow sledding with the neighborhood children. | • Plays in her room with her cousin or inside her house with her brother. |

# CHAPTER 5

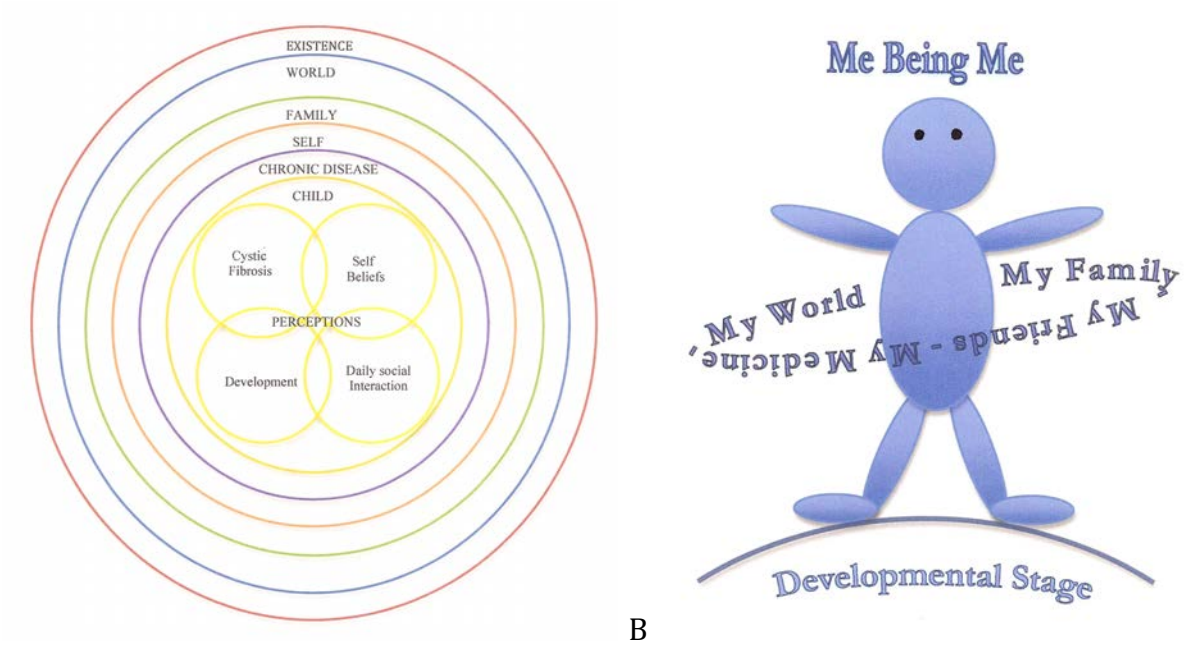
## Discussion

As disclosed in the first chapter, the purpose of this study was to explore and describe how school-age children with CF see themselves in the world. The question this study sought to answer was, "What is it like to be a school-age child with CF?" To answer this question school-age children with CF were given cameras and asked to take pictures of, "What it is like to be me". The second chapter reviewed the multidisciplinary theoretical, opinion, and empirical literature pertaining to the concepts, which comprise the world of the child with CF including existence, the world, family, self, and chronic disease. Then the third chapter presented the qualitative methods used to answer the research question and the fourth chapter presented the themes that emerged during the data analysis. This final chapter, Chapter 5, will discuss the research findings and how the findings relate to the current published literature. The chapter will begin by comparing the data derived thematic structure to the model of the child's world from the literature review. Then, the discussion will progress by first addressing the contextual ground and then each theme separately. The discussion will be followed by implications for nursing practice and end with ideas for future research.

### Comparing Models

When framing the literature review for this dissertation, the CF child's world was visualized as five concentric circles each representing the concepts of existence, world, family, self, and chronic disease with the child and his or her perceptions situated in the center (see Figure 2.1 on page 21). That first model was a scholarly product developed

from philosophical, theoretical, and empirical viewpoints by two nurse researchers including Susan Speraw, PhD, RN my dissertation chairperson, and myself. However, after data were analyzed and a thematic structure was constructed, an obvious visual discrepancy between the original model and the analysis-derived thematic structure was observed. In other words, the figure *Me Being Me* did not align with the figure from the literature review *The World of the Child With CF*.




A B

Figure 5.1. Models of the CF child's world. (A) Original academic model "The World of the Child with CF", (B) Data derived model "Me Being Me".

As the reader's eye can see, the original model is static and flat with each concentric ring separate from the other. There is nothing to suggest an overlap among the conceptual elements nor does it reflect movement or variation. Additionally, the dimension of personhood is missing. The child is merely represented by yellow intersecting circles, which possess no human features or individuality.

In contrast, the thematic structure of *Me Being Me* was derived from the photographs and stories of the study participants. Although children acknowledged the basic elements in the original model (existence, social world, family, CF disease, and self) the resultant thematic structure, representing the child's reality, is strikingly different from the first model where one theoretical concept is layered upon another.

Compared to the original scholarly model, the data derived thematic structure is not only simpler and more appealing to look at, but it also (a) reflects the perceptions of the children's world in their own words, (b) illustrates that children with CF actively participate in the world, (c) accentuates the importance of relationships by including both family and friends, (d) identifies the ground upon which children's perceptions are based, (e) reflects the notion that *being* involves constant change and interaction with the environment. The children saw themselves as multidimensional beings with human features. Life appears uncluttered by societal expectations and vast amounts of book knowledge. Even though the child is still centered in the middle of the world, the elements that frame a child's existence change as he or she moves through space and time.

Just like a hula-hoop, life is in constant motion. At various points in life aspects of the child's world are closer, sharper in focus, and more prominent while other aspects,

although still present, are situated further away. For example, when a child with CF experiences a significant respiratory exacerbation *My Medicine* will most likely be closest to the body and prominent in the child's perceptual field while other aspects of life such as *My Friends* and *My World* are pushed back, particularly if the child is hospitalized. When the child is healthy, able to go places, and playing with friends then *My Friends* and *My World* are perhaps what stands out in life and *My Medicine* becomes distant and out of focus.

It is not just at various phases of life that these things change, but because life is in constant motion aspects of the child's world shift throughout the day. For example, if the child is at a birthday party roller-skating with friends then *The World* and *My Friends* are most likely in focus and what is important. During this time he or she is probably not thinking about CF. However, later when he or she must leave the party to go home and take treatments, the child comes face-to-face with *My Medicine* and his or her existence is narrowed to a typically boring place (e.g. the bedroom) separate from friends and family. It is at this time the child may be inclined to think about CF related issues and his or her vulnerability.

Because of the differences between the two models, the next section will not be aligned according to the concepts outlined in the literature review. Instead, the discussion will be presented according to the themes, which emerged from the data. The next part of this chapter will continue by comparing and discussing each thematic element of *Me Being Me* with the theoretical and empirical literature in the literature review, beginning first with the contextual ground of Developmental Stage.

**Contextual Ground: Developmental Stage**

Due to limited life experience and concrete patterns of thought, the participants' perceptions of the world differ from that of their parents, health care providers, and other adults. As they move along the spectrum of development they mature biopsychosocially and acquire new life experiences. Consequently, their perceptions and ability to interact in the world change.

As previously noted in the review of literature, the age-range of the children in this study lies within Erikson's developmental stage of *industry versus inferiority* and Piaget's *concrete operations*. In *industry versus inferiority* children's sense of confidence increases and they become more curious about the world, prompting them to explore the larger environment and develop relationships with people outside of the family (Erikson, 1968, 1979; P. K. Smith et al., 2003) and in *concrete operations* thought is concrete and tied to something tangible (Berk, 2010; Piaget & Inhelder, 1969).

The study results demonstrate that the participants are following normal cognitive psychosocial patterns of development. This finding aligns with previous research exploring the growing up experience with CF adolescents and adults where the participants expressed having a relatively normal childhood experience (Admi, 1996; Gjengedal et al., 2003). All participants photographed family members and belongings in and around the home. Additionally, the majority of them journeyed out of the family environment and into the larger community to take pictures concerning their social relationships with others and activities in which they were participants. The children took pictures of concrete things (e.g. people, toys, activities) and told their stories in ways that were developmentally

appropriate and gender typical. They did not take pictures of anything mystical. Even when children took pictures of things that were abstract, such as beauty or emotion, they chose concrete objects to illustrate it. For example, Hilary (age 9) took a picture to demonstrate the beauty of her outdoor surroundings and the emotion she felt when taking it, “”We were driving and it was really pretty on the mountains so I thought we should take a picture of it. And it made me feel happy to know I live in a place that has winter…”. Ashley (age 10) took a picture of the snow in her backyard and said, “ The reason I took this picture is because I love the snow…. That is actually how deep the snow was”.

Girls were interested in all things pink and purple, playing with dolls, looking at pretty outdoor scenery, tumbling with friends, and ponies. The boys liked building things with Legos®, playing in the woods on fallen trees, climbing over rocks, riding motorbikes, and preferred colors representing their favorite sports team. The following two diagrams (Figures 5.1 & 5.2) provide the reader with a concrete visual illustration of the children’s favorite colors. The children identified these colors when asked about background coloring for their photo book. Each block represents a color favored by a child. In general, this shows that little girls favored stereotypical colors that were soft and typically associated with the feminine and boys preferred bold and strong colors.

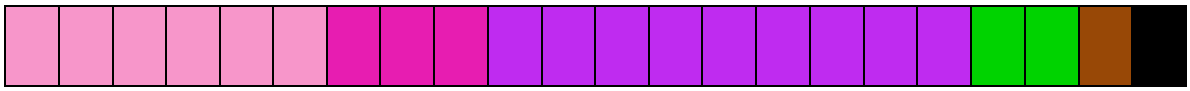


Figure 5.2. Colors favored by girls.

Figure 5.3. Colors favored by boys.

In the end, all children were drawn to the things in life that made them feel happy and good inside, which included some aspects of having CF. David, age 8, said that he liked having CF and for him this is appropriate considering he is in the concrete operational stage of development. At this point in his development, he notices the immediate benefits having CF brings including playing games and receiving gifts when he goes to the clinic and fishing with his friends at a yearly CF fundraiser held in his honor.

Ideas of how CF may impact the participants in the future rarely figured into their stories. Because of school-age children's limited experience and ability to think abstractly (including deductive reasoning), it is difficult for most of them to imagine the future implications of CF except for those things they have already experienced (e.g. clinic visits, treatments, and medications), except for one participant in this study, Mary.

Mary's ability to reason is more advanced and she is oriented more towards the future than the majority of the other participants. She has begun to analyze situations and identify the potential long-term consequences of her actions in regards to taking medications and making treatments more effective. Learning about the recent deaths of a few older CF clinic patients motivated her to learn more about CF and its continuing effects on her body. Through a process of inquiry and parental support, she has gained a better understanding of the progressive nature of CF and what it takes to continue to manage the disease. Mary's level of cognitive development is higher than what is typically expected at her age. However, the experience of chronic disease (CF) along with an emotionally and intellectually rich home environment, including frequent outings into the world adds to her life experience, all of which facilitate cognitive and social development.

Theoretically, all of the participants are in the same Erikson and Piaget developmental stages, but in reality they varied in their level of cognitive and social maturity within those stages. The children reflect a continuum of development. On one end of the spectrum are those who struggled to express their thoughts and were less precise in expressing emotion. At the other end of the spectrum are children who were able to articulate their thoughts and were future oriented. While some children have many friends and regularly engage in social activities outside the home, others have a few good friends and prefer to play at home and be with family. In general, the stories and pictures of 8 and 9 year old participants, were more simple, concrete, and involved the past and present. While 10 and 11 year old's pictures and stories demonstrated some evidence of reflection and thoughts about the future. However, no matter their age, all children were able to provided rich descriptions of their world.

## Theme #1: Me Being Me

Bury (1982) reported the development of a chronic illness is a major disruptive experience for adults, which affects their identity and biography. However, this is not how the children in this study view their chronic disease.

### Life Biography

Having been born with CF and lived with it all their lives the children know nothing else. CF is who they are; it is part of their DNA. CF has been assimilated into their "identity" and their social interactions with others from the time they were born. Although daily life routines are periodically interrupted with medications and treatments, visits to the CF clinic, and hospitalizations these things do not abruptly change the "self" or suddenly alter

their biography like the onset of disease during adulthood. Symptoms such as the cough associated with CF are ordinary occurrences that seem to go unnoticed by the child. Although the vast majority of the children could be heard coughing or clearing their throat throughout the interviews, the subject of "coughing" was never brought up during the interviews. This finding is in contrast to the previous literature (D'Auria et al., 1997) and challenges the reliability of research where children are prompted to address their symptoms by being asked to talk about having CF. Nevertheless, this study did not ask children to take pictures or talk about CF which says when children are not prompted, cough is not figural.

Because CF has been present since the beginning of their earthly existence, there is no before or after to compare and thus the routine activities and regular symptoms (e.g. cough) associated with CF are normal. These findings are supported by a study reported by Williams et al. (2009). Williams et al. found that although children and adolescents maybe inconvenienced by treatment and medication regimens, these things are not perceived as being abnormal nor do their CF symptoms interrupt daily functioning unless they become severe enough to disrupt daily life.

However, the notion of CF being a normal part of a child's existence may not hold true for all children with CF including those (a) who are diagnosed later in life and are able to remember a time without CF, (b) individuals, with mild symptoms, where CF treatments and medications are not incorporated into their daily routine unless a significant CF related illness occurs, and (c) whose nuclear family is unable to achieve a sense of normalcy.

The belief that children diagnosed with CF early in life psychosocially assimilate CF and the routines of CF into their identity and daily life, brings up a question of debate often heard among CF practitioners, and that is: When is the appropriate time to incorporate certain CF related treatments (e.g. chest percussion therapy) into the CF patient's routine? For example, some practitioners prefer to prescribe chest percussion therapy (CPT) only during pulmonary exacerbations out of fear that too many treatments may overwhelm the family schedule. Other practitioners feel that CPT should be initiated during infancy or as soon as the child receives the CF diagnoses so that a routine is established early on and CPT will not be seen as such an inconvenience later in life when it becomes a treatment priority. This study appears to support the idea that the earlier a treatment is practiced the more likely it is to be accepted, and possibly performed, by the child later in life.

**Existential Elements of "Me being Me".**

From an existential perspective, few studies have explored how children see their existence. Yalom (1980) identified four themes (or concerns) that people eventually face just by being present in the world: death, freedom, isolation and meaning. The participants addressed all of Yalom's themes in their pictures and stories, indicating that children also think about their existence and have existential concerns. However, there is very little in the literature that addresses existentialism from the child's perspective.

**Death versus life.**

Yalom (1980) said children think about death. Although the topic arose very briefly, the fact that it came up during the interviews indicates children in this study definitely think about it. Death was not depicted visually in any of the pictures, but it came up in the

participants' stories in roundabout and sometimes subtle ways. For example, when children described the death of a pet and an elderly grandparent. Not only do the children think about the death of their pets and other people, but the findings also demonstrate that the children think about their own existence in terms of life and death. Hilary (age 9) said she took a particular breathing treatment so she would not get pseudomonas and die, while Mary (age 10) wanted to manage her CF in the best way possible so she would continue to live. Other children alluded to the vulnerability of their existence by desiring a cure. In previous CF studies with adults (Gjengedal, 2003; Tracy, 1997), adolescents (Pizzignacco & Lima, 2006), and children (Dallenbach et al., 1995) participants report that while they did not fear death they still were waiting for either a cure and or better treatments, indicating that they too desire life.

**Freedom versus lack of freedom.**

According to Yalom (1980), freedom is about choosing ones own destiny, which involves personal and social implications. In this study, freedom was more about the child's desire to avoid constraint, to be given a choice in matters that concern them, and to be allowed to express themselves. The children lack freedom when (a) having to take particular medications, (b) using the vest (c) asked to take treatments when they are not ready, (d) undergoing a PICC-line insertion and a bronchoscopy, and (e) being hospitalized for prolonged periods of time. However, lacking freedom is not just about issues related to CF. Children also perceive a lack of freedom when parents set boundaries for behavior and when they wish to be more connected to the community outside of the nuclear family.

Yet, despite constraints children find ways to liberate themselves from confining situations and create their own sense of freedom via (a) creatively adapting and incorporating regular playful activities into treatment times, (b) acquiring fashionable CF accessories such as a colorful treatment vest, and (c) filling their environment (including the hospital room) with comforting personal objects. They also experience freedom through (a) artistic expression including drawing, painting, and playing a musical instrument; (b) moving freely through space when speeding on a motorbike, doing a back handspring, or when climbing trees and rocks; and (c) and by creating new worlds with their developmentally appropriate rich imagination (e.g. being a princess with servants).

However, parents are also trapped by CF. Parents must ensure that their child receives his or her medications and the necessary medical procedures or risk irreparable damage to the child's health. In this sense, parents are not only responsible for making the choice of life versus death for the child, but they also set a trajectory for the child to follow as they continue to mature. According to Rakowski (1986), the experiences of health and illness are important because overtime these encounters contribute to an individual's ability to assess their own health status. School-age children with CF are in the process of acquiring the skills needed to live and function successfully in society, including those needed to manage CF. and parents are key to helping them in this process.

**Isolation versus connections.**

Receiving recognition (Vallino & Maccio, 2004) and knowing that one is loved are important to a person's sense of existence (Yalom, 1980). Furthermore, Eggan and Kauchak (2001) identified love and belonging as two basic human needs required to defeat

loneliness and isolation. In this study, participants identified both love and belonging as being pivotal to their existence, using phrases such as “he loves me” and “I’m in a family, not like a hobo”. Positive connections with family, friends, and pets provide children with a sense that are not alone in the world and that someone cares about them. Knowing they are loved makes them feel special, safe, protected, supported, and happy; all of which are needed when overcoming the isolation they experience during periods of hospitalization and when doing their treatments.

The concern of isolation among school-age children with CF is one that has gone unrecognized in the CF literature until now. Nebulizer treatments, vest treatments, and hospitalizations were all identified in this study as situations that emotionally and physically separate CF children from people and the other social objects in their environment. For example, Lauren (age 11) discussed the isolation she experiences when in the hospital, “It’s boring. You have to stay in your room. You get hooked up [to IVs] and … can’t go like anywhere else”. Faith (age 8) complained about the amount of time her vest treatments took everyday, “I have to do it for 30 minutes”. Considering the amount of time they spend in the hospital and the length of their vest and nebulizer treatments, these children spend many hours of their life socially isolated from family, pets, friends, and school. This is time that could otherwise be spent learning and socializing.

As just mentioned, knowing that others love them and that they belong to a family helps participants to overcome isolation, but love and belonging are not enough. So to manage periods of isolation, the children engage in behaviors that allow them to connect to the objects and people within the environment. For example, when using the vest and

taking treatments they engage with objects within their reach (e.g. toys and games) and when in the hospital they form relationships with health care providers, use the call light, and engage with visitors.

**Meaning versus meaninglessness.**

Yalom (1980) asserts, in order to survive, life must have meaning. The children in this study described their life as meaningful. For them life is not fleeting. They have goals, values, talents, opinions, responsibilities, and friends and family with which to do things. It is through encountering the world that the participants' find meaning in life and they were able to express this through their photos and stories. Meaning was found in the things that they do, the places they go, and the relationships they have with others. For example, painting pottery and building things with Lego's gave children a sense of creativity and accomplishment, receiving affection from family and friends provided children with a sense of comfort, acceptance, and belonging, and meeting set goals such as being selected for the children's orchestra gave children a sense of accomplishment. Most importantly, these participants expect life to endure and they perceive a future for themselves despite CF. For example, Lauren (age 11) said, "I want [to] be a nurse cuz I'm good at it". Also, Ashley (age10) who aspires to have more than one career stated, "I'm going to have to [go to] college [for] 16 years".

## Theme # 2: My Medicine and Treatments

Perceptions about CF including medications, treatments, and hospitalizations comprised a small portion of the participants' photographs and stories. Unlike some previous research with adults and adolescents (Christian & D'Auria, 1997; Gjengedal, et al.,

2003; Tracy, 1997) the participants in this study focused less on CF and the negativity of CF and concentrated more on their positive relationships with people, the things that they like to do, and their favorite belongings. Several important findings were identified from this portion of the data including (a) the barriers and motivators CF children confront when taking medications and treatments and (b) the fears and boredom associated with hospitalization along with the coping methods employed by the participants.

The barriers found in this study are consistent with previous studies with children, adolescents, and adults (e.g. Williams et al., 2007), but new findings also surfaced in regard to motivating factors. Although, these barriers have also been identified and reported in previous CF related research, this is the first study in which these barriers and the factors, which facilitate taking treatments, have been explored and presented purely from the perspective of school-age children.

Barriers include (a) bad tasting medicines (e.g. TOBI®, antibiotics), (b) long boring treatments, (c) discomfort when using the vest, (d) taking treatments when not mentally prepared, and (e) getting up early to take treatments before leaving for school. Children have learned to creatively incorporate some of their normal play activities into their vest and nebulizer treatments to make them tolerable and less isolating. The most common activities mentioned were the Nintendo® DSi, Wii Fit™, and watching TV. These methods engage not only their mind and body, but they also seem to hasten the passage of time.

The factors I found, which motivate participants to take treatments and medications, include (a) good tasting medications (e.g. hypertonic saline), (b) short aerosol delivery methods (e.g. Cayston®), (c) colorful and softer feeling airway clearance Vests®, (e)

understanding the purpose and benefits of medications and treatments, and (f) a desire to live.

In her study with CF adults, Admi (1996) reported participants did not understand the importance of their medications until after reaching adolescence. Admi's findings are not inline with what I found in this study; participants knew most of their medications and the basic reasons why they took them. Additionally, children as young as 8 years old understood the health consequences (they get sick) of not taking medications and those as young as 10 understood they could die. One reason why many of the participants in this study knew and understood their medications could be because the CF clinic where they were attending was making a concerted effort to teach children about their medications. This finding could conceivably be a reflection of the CF team members' efforts, however additional investigation is warranted.

In this study, participants found the hospital experience of getting a PICC-line or a bronchoscopy to be threatening, scary, painful, and violating. Having to stay in a hospital room for prolonged periods of time was isolating, boring and yet sometimes fun. To cope with the emotional, physical, and social disruptions caused by procedures and hospitalizations the children brought favored comfort objects from home, imagined themselves in grand surroundings, played electronic games, watched TV, asked family to bring in favored foods, engaged and played with hospital staff, and were distracted by visitors.

Even though it is well known that the hospital environment can be frightening to children, the perceptions of school-age children with chronic illness and their hospital

experiences have received little attention in the empirical literature. One study (Sartain et al., 2000) did include children with CF and researchers reported similar findings. Researchers found children with chronic disease minimized disruptions by bringing in accessories from home to create a special place in their hospital room and by developing relationships with people in the hospital. PICC-line insertion and bronchoscopy are common procedures for CF children yet no recent literature has addressed the perceptions of school-age children in regard to their experiences with these procedures.

New findings from this study not mentioned or addressed in the previous empirical literature with children include (a) the amount of isolation children experience when having to take long nebulizer and vest treatments, (b) the dislike for and the amount of discomfort children experience when wearing the treatment vest, (c) basic knowledge and understanding of medications help motivate school-age children to take their medications, and (d) the extent to which children with CF experience fear, discomfort, and isolation during periods of hospitalization.

**Theme #3: My Family**

For the purpose of this dissertation, the family was defined as a holistic unit comprised of interlocking relationships that works as a system to support the emotional, physical, and social well-being of the child and the differentiation of self. The participants' stories support the definition of family as described in the literature review. The data from this study demonstrated children as young as 8 years old possessed the ability to understand, define, and articulate the purpose and benefits of family. The majority of children portrayed their family as a system where members are clothed and fed, loved, understood,

nurtured, and protected. The pictures supported their stories by demonstrating the reciprocal closeness, affection, humor, and playfulness between parent and child and among siblings. These findings meshed with several of DeFrain and Stinnett's (DeFrain, 1999) qualities of a strong family including commitment, appreciation and affection, and togetherness.

The majority of the participants lived in a traditional nuclear family with both biological parents and one or more siblings. Even when children did not live with one or more of their biological parents, the nuclear family still consisted of a mother and a father figure. In all families, the children were central and each member's role was defined.

Mothers typically, but not always, helped the child manage their treatment and medication regimen by reminding them to take medications and helped them to assemble and administer their treatments. Participants also perceived their mothers in the more traditional sense as being nurturing, nice, and the family cook. Similar to my findings, Williams et al. (2007) also found in their research that mothers were primarily responsible for initiating children's treatments, particularly CPT.

While mothers were portrayed in a conventional manner, fathers were not. The fathers of these children did not fit the stereotypical dad who sits in the background of the family. Even though parental roles differed, fathers were no less distant and removed than mothers. In fact, the fathers were quite involved in their children's lives, siblings and CF child alike. Participants portrayed them as loving, dedicated, supportive, playful, and funny. Few researchers have specifically examined CF fathers and their role in the family, but two previous studies support my findings about fathers. Dallenbach et al. (1995) reported that

fathers in their study were very involved in the child's CF care and were emotionally devoted to their families. More recently, Australian researchers Hayes and Savage (2007) learned that while fathers of CF children are emotionally invested and involved in the care of their child, they often feel as if they are not recognized. The results from this study show that the participants in this study identify a clear paternal role and recognize how much their fathers care for them and support their CF related needs.

Bowen (Kerr & Bowen,1988) believed that a person's behavior could not be understood outside of the functioning of the other surrounding family members. As noted previously in the review of literature (pp. 40-45), Bowen identified eight concepts that account for family functioning. Half of Bowen's concepts surfaced in the data. Because this study was not about family systems, it is reasonable to understand that not all of these concepts were identified. Those concepts not seen include triangles, family projection process, emotional cut off, and societal emotional process.

For the most part, the families of the children in this study appeared to be highly functional. Children typically portrayed their family in a positive manner and avoided discussing the bad. Their pictures and stories did not portray any significant family conflict, tension, or anxiety. Neither did they identify anyone in the family who was cut off, pushed aside, or any unusual alliances between a child and parent or between siblings. Quite the opposite was true. In one family the child lived with the grandparents because the mother did not have a job or money, yet the child spoke about the close relationship they shared.

Concepts that arose include differentiation of self, nuclear family emotional system, multigenerational emotional system, and sibling position. Children portrayed family

functioning in regards to these concepts in a positive light. Differentiation of self was foremost seen in the theme *Me Being Me*. The majority of participants thrived as individuals. They were able to articulate who they were by describing their interests and abilities, what they did and did not like in their lives, and what they wanted to do when they grew-up. These participants are permitted to be not only themselves, but also children. They are encouraged by their parents to engage in activities with peers, have hobbies, develop talents, and participate in community activities of their choice.

In regards to the concept of nuclear family emotional system, only one child gave the researcher a sense that the family was emotionally stressed. Otherwise, participants portrayed their families as emotionally stable with identifiable roles among family members. Parents acted as parents, and children were allowed to be children. Additionally, there was interplay between individuality and togetherness. Participants not only possess a sense of self, but they also spent time engaging and connecting with family members. Emotionally, the children appear to be secure in their relationships with their parents and know they are loved, supported, and protected.

Evidence of multigenerational emotional process surfaced when children spoke about family. The grandparent role was portrayed in a traditional sense as the passers on of family heritage via knowledge, stories, and personal or homemade objects. However, grandparents also stepped in to help parents when the nuclear family needed support, particularly when the CF child was hospitalized. Additionally, grandparents of today are increasingly being called upon to parent their grandchildren (Children's Defense Fund,

2011). This societal family trend was reflected in this sample in that two participants currently lived with their grandparents.

Sibling position was discussed when the children talked about their brothers and sisters. Previous research by Bluebond-Langer (1991) portrayed well siblings as protectors and caretakers of the CF sibling even when the child with CF was the eldest. Instead, photographs and stories demonstrated the opposite. Older CF children recognized the vulnerability of younger siblings and watched over them, protecting them from harm. Younger CF children looked up to the older siblings and viewed them as role models for future behaviors and privileges. Although some participants were particularly close to one sibling, they were disconnected from another. Considering Bluebond-Langer findings that siblings harbor resentment and consider the child with CF as being spoiled and moody it is possible to think that the disconnect is related to the CF. The disparity found among sibling relationships in this study is not an abnormal finding in any family. In fact, Howe, Ross and Rocchia (2011) report the quality of sibling relationships vary widely within families. While some brothers and sisters emotionally bond and spend much time together, others experience conflict, disagreements, and differences in personalities. However, what is a notable finding in this study is the depth of analysis a few of the children demonstrated when discussing the differences in their relationships. In particular, the thoughts of two children reflect higher order more abstract thinking, which at times was fairly advanced when considered in the context of their chronological age.

For example, when describing the differences between her and her younger sister Mary's descriptions went beyond the simple and concrete, physical characteristics that

would have been consistent with less developed cognitive reasoning by contrasting her personal characteristics with those of her sister. She described herself as content to be at home and needing a partner in life whereas her sister is someone who is extremely independent and a lover of glamour.

**Uncertainty**

The phenomenon of uncertainty (see page 47) as it relates to chronic disease did not surface in this study. Uncertainty is a phenomenon typically seen around the time a chronic disease is diagnosed (Bluebond-Langer, 1991; Gjengedal et al., 2003; Jessup & Parkinson, 2010). None of the participants had been recently diagnosed with CF or any of the other chronic conditions associated with CF (e.g. CF related diabetes).

**Normalization**

Normalization (see page 48) is a phenomenon often seen among families with children who with chronic illness, which serves to help families to live an "average" life. In this study, the data indicated normal family functioning and typical child rearing behaviors. The participants' parents appear to have accepted the fact that their children have CF. They demonstrate acceptance by taking them to regularly scheduled CF clinic visits and reliably providing them with medications and treatments. Additionally, parents discipline the children according to societal rules and allow them to engage in age appropriate activities at home and outside in the community. CF was never mentioned as a factor limiting family members use of humor, engagement in playful activities, and participation in planned family outings and vacations. Except for treatments, medications, and occasional hospitalizations the participants perceive and portray themselves as having a regular life.

This is a testament to how CF is viewed in the family system and reflects that CF has been incorporated into the patterns of normal daily life.

**Theme # 4: My Friends and Other Key Relationships**

Symbolic interactionism is about the nature and quality of the interaction that occurs between people (Blumer, 1969). Interacting with others helps to shape the child's identity, their actions, and how they in turn interact and communicate in society. Participants in this study sought out relationships with people (and pets) they could trust and who in turn trusted them. The value of trust was something they learned almost immediately upon entering the school system. Negative encounters with other children taught participants that friendship was more than just playing with someone; it also involved mutual trust and loyalty. To prevent teasing and unwanted attention from peers they had to keep their CF a secret and learn whom they could and could not trust with their secret. According to Woltering and Lewis (2011), the importance of mutual trust is typically not realized until middle childhood when a child's ability to conceptualize friendship is enhanced and group membership becomes important. In this study, participants described how they learned from direct peer encounters that sharing about their CF could result in negative attention. Thus, through experience they learned at an earlier-than-developmentally-typical age to define the true meaning of friendship. Keeping CF a secret and the process of establishing trusting relationships are findings also supported in previous research with children (D'Auria et al, 1997), CF adolescents (Christian & D'Auria, 1997), and adults (Admi, 1996).

The participants possess a clear and eloquent definition of friendship, which shows that the children in this age group are socially aware of what it takes to be a good friend

and are intellectually mature enough to convey such a definition. Although, their definition was provided in the results section, it bears repeating here: *Friendship is an interactive reciprocal process that involves playing and being together, mutual trust, acceptance, love, and support*.

The children desire friendships with peers where they are free to be themselves, and where CF does not get in the way. The relationships between the participants and their best friends are reciprocal and not one of dependence. Besides having fun and doing things together, positive relationships with peers provide happiness as well as opportunity to confide in someone else, share similar interests, and "watch their back". The children in this study do not consider themselves any different from peers in regard to interests, abilities, and physical features. This finding is consistent with Fereday et al.'s (2009) research involving exercise and children with a chronic illness and Wennström's (2005) research concerning self-esteem with CF children. Unlike the school-age participants in Christian & D'Auria's (1997) research, the children in my study did not report concealing CF symptoms, struggling for approval, or dropping out of activities to prevent others from noticing their CF.

In addition to peer relationships, they formed connections with non-parental adults including pastors, teachers, and health care providers. Interaction and the development of relationships with people outside of the family is developmentally appropriate for the school-age child and is in accordance with Erikson's stage of industry versus inferiority. The participants in this study are at the age where their ability to socially interact with people outside of the nuclear family increases significantly (P. K. Smith et al., 2003).

Friendships with influential adults have a positive impact on the participant's lives. Non-parental adult friends contribute to the children's development by teaching them skills and life lessons. They also provide emotional support during difficult and stressful times including hospitalizations and assurance that they are accepted and loved by others besides just family. Relationships between children and unrelated adults were facilitated and maintained when adults (a) demonstrated an exceptional interest in them, (b) acted respectfully towards them, (c) shared common beliefs and characteristics with them and their family, (d) engaged them with humor and creative playful activities, (e) listened to them, and (f) showed them love and affection. These facilitating and motivating factors are consistent with research done with youth in foster care. For example, when Ahrens et al. (2009) explored non-parental adult relationships with foster care youth they found relationships were facilitated when adults displayed emotion and attention, shared their own experiences, respected the youth, shared similar characteristics, maintained contact, and incorporated the youth's interest in activities.

Very little research has focused on CF children and their relationships outside of the family context, including their relationships with nurses and other health care providers. Previous research involving CF adults depict CF health care providers in a negative fashion citing adult providers view the CF patient as a statistic rather than an individual (Tracy, 1997). In contrast, the children in this study gave a positive image of their nurses and CF team members describing them as engaging, loving, and funny. This finding suggests children's bonds with members of their CF team members maybe qualitatively different than the bonds between CF adults and their providers.

One unexpected finding from this study is that participants classify all hospital personnel into two groups, nurses or doctors. While they seem to understand the role of the nurse, they do not seem to be able to differentiate between the roles of physicians and other health care personnel, such as respiratory therapists. Not enough information was obtained to learn why this is so, therefore I can only speculate about the reasons why children seem confused about who is a doctor and who is not. It may be related to the crossover in hospital attire as most hospital personnel wear either scrubs or lab coats. Also, it might be that personnel generally assume that children understand their role because they have seen them numerous times before and, as a result, fail to reinforce their title and role each time they see them. On the other hand, it could be that children truly do understand the differences in the various roles of hospital personnel, but that it is just easier for them to remember there are nurses and everyone else is a doctor.

Finally, the children are not only attentive to the people around them they also have deep and loving bonds with their pets[9]. All of the children who had pets spoke about them in kind and loving terms. Two participants, Hillary (age 9) and Ashley (age 11), considered their pets as confidants and best friends. A previous study by Bryant (1985) supports my findings. She found 7 to 10 year old children share confidential information with pets and consider them special friends. Melson (2010) is another researcher who has examined the child-pet relationship. He asserts pets contribute to children's social and emotional development. He has found children rank relationships with pets as one of their most intimate bonds.

---

9 In the more recent literature children's pets are now referred to as companion animals.

Extrapolating his views from his own as well as other people's research, Melson suggests children who have special pets obtain more accurate ideas about life and death, receive valuable support from pets when they are emotionally upset, and may be more empathetic towards others.

## My World

According to Symbolic Interactionism (Blumer, 1969; Charon, 2007) human beings are active participants in the world. The children in this study are no exception. The results showed that the school-age children in this study (who had moderate to mild CF disease) perceive themselves as actively engaged in the world around them. They took pictures and talked about going to birthday parties and amusement parks, taking fieldtrips, going fishing, and participating in a variety of physical activities including tumbling, riding bicycles, and climbing trees. Additionally, the children did not consider themselves as being different from their peers in regards to their ability to participate in any of their activities, even those related to sports. This finding is similar to what Fereday et al. (2009) concluded when exploring the phenomenon of physical activity among children with chronic illness. In their study, participants (including some who had CF) did not feel as if they performed any differently than other children their age during team sport and recreational activities.

Bronfenbrenner's ecological systems theory asserts connections with other people in their environment contribute to the child's development (Berk, 2010; Shaffer & Kipp, 2010). In support of Bronfenbrenner's theory, close relationships with peers and other non-parental adults contributed to the participants' social development and their ability to live a normal life. These connections are doorways into other worlds, which provide

opportunities to see and explore places outside the home environment. Relationships with others facilitate development by encouraging the children to partake in other types of activities, learn new skills and gain fresh knowledge about themselves, their environment, and society. For example, Daniel (age 9) learned how to bowl when attending a friend's birthday party; Julia (age 9), observed the lifecycle of the Monarch butterfly through her teacher's class project; and Adam (age 8) developed a passion for the law enforcement profession after visiting a police station on a field trip.

Looking and talking about their pictures brought forth some of the sensory and emotional aspects of the participants encounters in the world. This meshed with the beliefs of Charon (2007) and Tuan (1977) who assert human beings perceive and develop an awareness of the environment through their senses. For example, Jacob (age 11) reported feelings of exhilaration as he sped along on his motorbike up the long road like driveway at his family's country home. Even though the motorbike was only traveling about 20 miles an hour, the velocity of his motorbike and the touch of the air on his skin led him to perceive his experience as being fast and fun.

However, the findings from this study also show that not all participants were as engaged in the world as others. Cases in point, Bethany (age 9) and Jacob (age 11). As mentioned in the previous chapter, Bethany's pictures and narrative portrayed a narrow and constricted life with very few connections outside of her nuclear family. CF or not, some children's ability to engage and socially interact with others in society is limited by the boundaries set by their parents. If parents are too busy and interaction with others

outside of the nuclear family is not facilitated then the child's experience in the larger community is likely to be limited.

On the other hand, there is Jacob who perceived that he had "no life". His pictures portrayed him having fun engaging with his siblings and enjoying the freedom of riding his motorbike outdoors. However, Jacob wanted to be more socially connected to his local community. It is essential to understand that Jacob's reality is his own and it is created out of his perceptions obtained from his social experiences. Even if a parent, researcher, or health care professional may think otherwise, it is the child's reality that counts. As Charon (2010) points out, no person thinks like another or has the same experience even when participating in the same event. Therefore, a child's reality will differ even from his or her parent's, siblings, and everyone else with whom they are in a relationship. For this reason, it is important that children be included and engaged in their health care visits. It is only when the child is given a voice in matters that concern them that their reality can be made known.

It is vital to note that perceptions and engagement in the world can change over time. A major limitation of this study is that the data collection phase for taking pictures was restricted to a 2 to 3 week interval. The pictures the children took only represent a short time period of their life. Additionally, most photographs were taken over the Christmas and New Year holidays when community and school activities are down for school break. Because some participants took fewer pictures than others or spoke little about things in their community, it is easy to conclude that these children spend less time in the world outside of the family than the others. However, that may not be the case. Experiences and

perceptions may vary from time to time. If this study had been performed during a different time of the year, such as when school is in session or during the summer when children attend camp, participants may have taken a different set of pictures and held different perceptions about themselves and their place in the world.

## Summary

Two nurse scholars developed the original model of the CF child's world. This served as a launching place for the study, but it was not the end place. Participants' pictures and stories revealed the rich complexity and interrelatedness of the factors central to their existence. As a result, a new model was developed out of the data. The new model illustrates a child, who is engaged in constant interaction with elements in the world. The child is surrounded by these elements and grounded in their developmental stage. Although the new model provides a more accurate view of the CF child's reality, it required the perceptions of school-age children with CF to point out what two health care professionals with years of CF experience were unable to discover.

Since birth CF has been assimilated into the participants' identity and their social interactions with people and objects in the world. Since all of the participants were diagnosed with CF early in life and were symptomatically stable, they were not experiencing uncertainty, a concept often seen in adult onset chronic disease. Children with CF are active participants in the world who are following a normal path of psychosocial development, and similar to adults, they think about their existence and have existential concerns. The following results from this study are supported by previous literature and include:

- Daily treatments and chronic cough are a normal part of CF life
- Children experience barriers related when taking medications and treatments
- CF fathers are emotionally invested in the care of their children.
- Despite CF families can function normally and develop normal life patterns.
- Relationships with friends and other non-parental adults connect children to the community outside the nuclear family.
- Pets play an important role in the CF child's life.

New findings from this study include:

- Children as young as 8 years of age can possess a basic understanding of their medications and the consequences of not taking them.
- Motivating factors were identified that encourage children to take their medications and treatments.
- Hospitalization and prolonged treatments are factors that isolate CF children from family, friends, and community.
- CF children experience notable emotional and physical disruptions when undergoing PICC-line placement and bronchoscopies.
- Although children understand the role of the nurse they have difficulty distinguishing between the roles of the physician the other health care providers.

This study highlights the importance of getting the CF child's perspective. School-age children with Cystic Fibrosis (CF) possess valuable knowledge about themselves. They are also able to provide insight into the childhood experience of having CF.

## Implications for Nursing Practice

Implications for nursing practice were apparent in this study and are strongly suggested. The following recommendations focus on patient and family education as well as clinical practice and nursing research.

### Patient and Family Education

The findings of this study demonstrate that children as young as 8 years of age can possess a basic understanding of their medications including knowing the names and purpose of taking them. Additionally, knowing basic information about medications can be a motivating factor for children when taking medications. In light of this finding, nurses and other CF team members must begin teaching children about their medications in early childhood using developmentally appropriate methods.

Taking nebulizer treatments and using the treatment vest are sometimes an inconvenience that must be balanced amid activities with family, friends, and community. Treatments and the vest also isolate the children limiting their ability to engage in their environment and the people around them. Nurses are in the position to inform, educate, and assist parents and children when incorporating patterns of routine CF care into daily life. To promote adherence and ease family stress, nurses can help parents and children to explore barriers and motivators to treatments, identify ways to circumvent obstacles, and develop a treatment routine that is least disruptive to the family and child's life. Additionally, nurses can assist CF children and their families in identifying activities that can be incorporate into treatment times, which are beneficial to their health as well as their social and intellectual development.

The participants reported hospitalizations as boring and isolating. Parents and other family members need to be informed and reminded about how hospitalization limits the child's ability to socialize and maintain contact with the world outside the hospital. Nurses and other members of the CF team should (a) advise CF families that it is important to the hospitalized child that all members maintain some kind of contact with them and (b) help children and families identify ways to keep the CF child in contact with the world outside of the hospital environment. Hospitals can also facilitate the child's contact outside the hospital room by developing innovative means for socialization. For example, some hospitals have created computer based hospital chat rooms so that CF children can communicate with each other from their rooms.

An unexpected finding in this study was that the participants did not seem to know and understand the titles and roles of non-nursing hospital and clinic personnel. Nursing staff can help children understand the roles of other personnel by referring to non-nursing staff by their titles as well as using their names. Additionally, ancillary staff must affirm their title and position when communicating with children and their families.

**Clinical Practice**

The findings from this study confirm school-age children with CF, between the ages of 8 and 11, are active participants in the world. They possess much knowledge about themselves and their CF and can express that knowledge to others. However, sometimes children's voices are stifled or unheard due to the pressure of time restraints during health care visits. Children need to be given the opportunity to talk and fully participate throughout their entire health care visit and not just during the physical exam.

Since the nurse is typically the first provider to see the child in the exam room and each day in the hospital, her or she is in a key position to set the trajectory for the entire clinical experience. To fully involve the child in the visit, the nurse and all other CF team members must focus their voice, eyes, and ears towards the child and give him or her opportunity to respond to questions. Preferably, children should be asked for their input before their parents. Children are drawn to people who listen and engage with them. Interjecting humor and playfulness into conversations with children captures their attention and encourages interaction on their part. The child should be asked to name his or her medications, provide a reason for the visit, and voice any questions or concerns. From a developmental perspective, children also need to be rewarded for active participation. A system can be developed to reward children when they have learned or performed a desired behavior, such as naming or writing down their medications.

Participants reported that the airway clearance vest is uncomfortable and it hurts. Because children typically grow taller and gain weight as they mature, vest usage and settings should be evaluated at least once or twice a year as well as during hospitalizations to assure proper fit, comfort, and optimal settings. Additionally, some children may not want to use the vest. In this case, the nurse and respiratory therapist should then explore alternative means of CPT, such as flutter device or hand CPT. Again, the emphasis should be on respecting the child's input and wishes rather than always imposing the will of adults. So, while the necessity of CPT is non-negotiable, the child's preferences for the CPT method should be taken into count.

The children in this study also reported that having a bronchoscopy and getting a PICC-line can be frightening and violating hospital experiences. Children should be encouraged to bring a favored object, such as a stuffed animal, along with them each time they have a procedure. Objects that are special to the child can be a source of comfort as well as a distraction. However, these objects do not push away all of their fears, therefore hospital measures that limit the child's stress and anxiety during and leading up to these procedures should be identified and implemented. For example, children seemed to be more comfortable when the same person met them and took them to the procedure room.

Hospital personnel need to be cognizant of the fact that children requiring frequent hospitalized may have a favorite room. When possible allow CF children a choice of rooms, particularly if the admission is planned ahead of time and their stay is long. Also, it is important that administrators of children's hospitals understand that room décor influences the child's hospital experience. This finding lends support for including children in the process when redecorating and designing new child spaces.

Finally, although healthcare professionals and other adults may see concrete evidence that the child is out in the world, the child's perception may be different. Adults cannot presume that the child is happy and feels engaged. If a child such as Jacob says, "I got no life" then he must be taken seriously and allowed to discuss his feelings. While some issues may be easily addressed, such as a desire to participate in a particular school activity, others are not. In these cases the child and his family should be referred to a mental health care professional who specializes in children's issues. A plan of action can be negotiated for maximal quality of life.

**Nursing Research**

Because school-age children often lack language proficiency and their ability to conceptualize is limited, research methods originally designed for adults are not always developmentally appropriate for children. Nurse researchers must make every effort to develop and utilize methods that best obtain children's perceptions of phenomena and encourage their participation in research. The method of photo elicitation, as used in this study, is one such method that can be utilized.

## Implications for Health Care Industry

The participants in this study had several ideas that they felt would improve their quality of life. The most common suggestions were (1) make all nebulized medications so that they could be administered in 1 minute or less; (2) find faster, less boring, and more comfortable airway clearance methods; and (3) find ways to make being in the hospital less boring.

First, pharmaceutical companies should continue to develop inhaled nebulized medications that can be administered in 1 minute or less. The children reported nebulized medications with shorter administration times (e.g. Cayston®, metered dose inhalers) were less disruptive to their daily schedules and less conspicuous to outsiders.

Second, additional planning and research should go into finding more comfortable and effective airway clearance techniques. The treatment vest not only isolates CF children from family and friends it also "hurts". Softer and visually appealing treatment vests seem to improve comfort and acceptance of the treatments, but because participants are attached to a machine they are unable to interact with their environment. CF children have

personal experience with current devices and seem to know what works for them and what does not. Industry must consider involving these children when developing and designing new airway clearance methods and devices.

Finally, prolonged hospitalizations isolate CF children from family, friends, and their community. Hospitals and community organizations, including schools, must identify and develop innovative methods to meet the social and educational needs of these children. With assistance from the Internet, schools and hospital systems can work together to build virtual classrooms where children can access classroom teachings and class assignments so that they do not get behind in their schoolwork. The Internet can also be utilized to develop venues for children that connect them to other hospitalized CF children and their friends.

## Ideas for Future Nursing Research

Out of the findings from this study the following ideas for further research were recognized:

1. This study only involved children from one CF center therefore it cannot be generalized to other settings. This study should be expanded to involve school-age children from other parts of the US including other racial and cultural groups, and to other countries.
2. Perceptions of the CF child's quality of life vary among the child, parents, nurses and other health care providers. Therefore, this study should be expanded to include parents, and members of the CF team. Perceptions among parents, children, and providers could then be compared, contrasted, and assessed.

3. Additional research using the methods employed in this study should be done with different age groups and different chronic disease conditions. The findings from these studies, along with this research, should then be compared and assessed for differences and similarities in how participants see themselves.
4. Over time how a person interacts with the world and perceptions they have about the world change. Therefore, a follow-up study using the same group of participants should be done in 5 years after all of the participants have reached adolescence and then again after reaching adulthood. The purpose of such a study would be to identify and assess how perceptions of "What it is like to be me" change over time as individuals with CF mature cognitively and biopsychosocially.
5. Participants in this study talked about their fathers' admirable qualities and the important role fathers have in the CF family. However, the literature review revealed that very little research has focused on CF fathers. Therefore, additional research needs to be done to further examine the role of CF fathers as well as their perceptions of fatherhood.
6. In this study, participants portrayed good relationships with peers and non-parental adults as having a positive influence on their lives. Additional research should be done to further explore the impact peers and influential non-parental adults have in the lives of children with CF.
7. Previous research with individuals with CF and their connections with nurses and other providers of health care portray HCPs in a negative light. In this study, children spoke positively about their relationships with members of the CF team.

Additional research needs to be done to further explore and evaluate the relationships children have with nurses and other CF team members and compare them to the relationships of CF adults and adult CF team members.

8. Pets were an important source of social and emotional support for the children in this study. To obtain a better understanding the role companion pets have on the CF child's development, research exploring and evaluating the relationship between CF children and their pets should be performed.
9. Children do not like using the treatment vest and desire alternative methods for airway clearance. Additional research should be done to evaluate and assess airway clearance options that allow children to be more interactive in their environment. The participants suggested the following activities:
    a. Jumping on the trampoline
    b. Playing with Wii Fit™
    c. Running
    d. Yoga
10. Prolonged nebulizer treatments, CPT with the vest, and hospitalizations all socially isolate CF children from family, friends, and other objects in their environment. Further research should focus on identifying and developing effective interventions to help children and their families cope with these isolating experiences.
11. Participants in this study not only knew and understood their medications, but it also appears that knowing such information motivates them to take their treatments. Further investigation is warranted to determine why so many of the

participants, in this study, knew and understood as much as they did about their medications and the current and long term effects such knowledge has on medication adherence.

12. Several participants in this study expressed interest and involvement in drawing, painting, coloring, music, and designing. Involvement in these activities made them feel happy and good inside. Studies should be done to investigate the CF children's involvement in the expressive arts and the impact these activities have on their intellectual, emotional, and social development.
13. Participant interest in making a picture book with their photographs was an unexpected finding. A secondary analysis of the data from this study should be done to further explore and describe the picture book making process used in this study. Additional research could also be done to explore and evaluate the method of using participant constructed picture books in helping children tell their personal stories.
14. Hospitalization, bronchoscopy, and PICC-line insertion are disruptive events, which have rarely been explored from the perspective of the school-age child with CF. Additional research should be performed to further examine the perceptions children have about these experiences and evaluate the methods they use to cope when going through these situations.

## Conclusion

According to Bloomer (1969) and Charon (2010) when "taking the role of the other" it is important to understand the perceptions that motivate decisions and actions. The children in this study took pictures of their world and then told me their stories. As the

researcher it was my job to listen, understand, then analyze and describe what it is like to be a school-age child with CF from their perspective. In effect, the researcher becomes the instrument by which the voice of the child is heard.

The participants in this study depicted what is normal for them and that normal life is mingled with CF. The reality is that CF is in their DNA: It is integral to who they are and it is with them from the moment of conception. In terms of their life biography, there is no other way to be other than a child who has CF. The routines of taking medications and treatments are woven into daily life routines, and although they can be isolating and burdensome at times these things are a part of normal everyday activity.

CF has not robbed the participants of their childhood or of living a full life. Life is an interactive process. The children gave descriptions of experiences that were simple and uncluttered. Their social experiences and perceptions are developmentally appropriate and at times even more complex than what one would expect for their chronological age. The school-age child with CF has a life that is active. They are influenced by changes in the world, yet at the same time they are involved in activities, which alter their world. Most importantly, the school-age CF child has an optimistic attitude in that he or she possesses plans for the future and expects to live a long life.

References

Admi, H. (1996). Growing up with a chronic health condition: A model of an ordinary lifestyle. *Qualitative Health Research, 6*(2), 163-183.

Ahrens, R. K., Dubois, D. L., Garrison, M., Spencer, R., Richardson, L. P., & Lozano, P. (2009). Qualitative exporation of relationships with important non-parental adults in the lives of youth in foster care. *Children and Youth Services Review, 33*, 1012-1023.

Alderson, P., Sutcliffe, K., & Curtis, K. (2006). Children's competence to consent to medical treatment. *Hastings Center Report, 36*(6), 25-34.

Angst, D. B., & Deatrick, J. A. (1996). Involvement in health care decisions: Parents and children with chronic illness. *Journal of Family Nursing, 2*(2), 174-194.

anonymous. (n.d.). nonexistence. February 8, 2010, from http://www.nonexistence.de/

Armstrong, K. B. (2005). Autophotography in adult education: Building creative communities for social justice and democratic education. [Article]. *New Directions for Adult & Continuing Education*(107), 33-44.

being. (1989). Oxford English Dictionary (2nd ed.) Retrieved from http://dictionary.oed.com

Berger, P. L., & Luckmann, T. (1966). *The social construction of reality: A treatise in the sociology of knowledge*. New York, NY: Anchor Books.

Berk, L. E. (2010). *Development through the lifespan* (5th ed.). Boston, MA: Allyn & Bacon.

Blair, C., Cull, A., & Freeman, C. P. (1994). Psychosocial functioning of young adults with cystic fibrosis and their families. *Thorax, 49*, 798-802.

Bluebond-Langer, M. (1991). Living with Cystic Fibrosis: The Well Sibling's Perspective. *Medical Anthropology Quarterly, 5*(2), 133-152.

Blumer, H. (1969). *Symbolic Interactionism: Perspective and method* (9th ed.). Berkeley, CA: University of California Press.

Borkan, J. (1999). Immersion/crystallization. In B. F. Crabtree & M. L. Miller (Eds.), *Doing Qualitative Research* (2nd ed., pp. 179-194). Thousand Oaks, CA: SAGE Publications.

Bowen Center for the Study of the Family. (2010). Bowen theory. Retrieved April 23, 2010, from http://www.thebowencenter.org/pages/theory.html

Boyatzis, R. E. (1998). *Transforming qualitative information*. Thousand Oaks, CA: SAGE Publications.

Breisach, E. (1962). *Introduction to modern existentialism*. New York: Grove Press Inc.

Bronfenbrenner, U. (1977). Toward and experimental ecology of human development. *American Psychologist, 32*, 513-531.

Bronfenbrenner, U. (2005a). The bioecological theory of human development. In U. Bronfenbrenner (Ed.), *Making Human Beings Human: Bioecological Perspectives on Human Development*. Thousand Oaks, CA Sage Publications, Inc.

Bronfenbrenner, U. (2005b). Interacting systems in human development. Research paradigms: Present and future. In U. Bronfenbrenner (Ed.), *Making Human Beings Human: Bioecological Perspectives on Human Development*. Thousand Oaks, CA Sage Publications, Inc.

Bronfenbrenner, U. (2005c). Making human beings human: An introduction. In U. Bronfenbrenner (Ed.), *Making Human Beings Human: Bioecological Perspectives on Human Development*. Thousand Oaks, CA: Sage Publications, Inc.

Bryant, B. K. (1985). Sources of support derived from neighborhood walk. *Monographs of the Society for Research in Child Development, 50*(3), 34-55.

Bury, M. (1982). Chronic illness as a biographical disruption. *Sociology of Health & Illness, 4*(2), 168-182.

Carter, K. R., & Ormrod, J. E. (1982). Acquisition of Formal Operations by Intellectually Gifted Children. *Gifted Child Quarterly, 26*(3), 110-115. doi: 10.1177/001698628202600304

Charmaz, K. (1983). Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168-195.

Charmaz, K. (1999). Stories of Suffering: Subjective Tales and Research Narratives. *Qual Health Res, 9*(3), 362-382. doi: 10.1177/104973239900900306

Charon, J. M. (2007). *Symbolic Interactionism: An introduction, an interpretation, and integration* Upper Saddle River, NJ: Pearson Prentice Hall.

Children's Defense Fund. (2011). The state of America's children. Retrieved August 4, 2011, from http://www.childrensdefense.org/child-research-data-publications/state-of-americas-children-2011/

Christian, B. J., & D'Auria, J. P. (1997). The child's eye: Memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing, 12*(1), 3-12.

Close, H. (2007). The use of photography as a qualitative research tool. *Nurse Researcher, 15*(1), 27-36.

Cole, P. M., Bruschi, C. J., & Tamang, B. L. (2002). Cultural Differences in Children's Emotional Reactions to Difficult Situations. *Child Development, 73*(3), 983-996.

Cole, R. (1986). *The moral life of children*. New York, NY: The Atlantic Monthly Press.

Collier, J., & Collier, M. (1986). *Visual anthropology: Photography as a research method (Revised and expanded ed.)*. Albuquerque, NM: University of New Mexico Press.

Corbin, J., & Strauss, A. (1985). Managing Chronic Illness at Home: Three Lines of Work. [Article]. *Qualitative Sociology, 8*(3), 224-247.

Costall, A. (1995). The myth of the sensory core: The traditional versus the ecological approach to children's drawings. In C. Lange-Küttner & G. V. Thomas (Eds.), *Drawing and Looking*. New York, NY: Harvester Wheatsheaf.

Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches* (2nd ed.). Thousand Oaks, CA: SAGE Publications.

Crozier, S., & Tincani, M. J. (2005). Using a Modified Social Story to Decrease Disruptive Behavior of a Child With Autism. *Focus on Autism and Other Developmental Disabilities, 20*(3), 150-157. doi: 10.1177/10883576050200030301

Cystic Fibrosis Foundation. (2007). About cystic fibrosis: Frequently asked questions. *About Cystic Fibrosis* Retrieved February 15, 2009, from http://www.cff.org/AboutCF/Faqs/#How_do_people_get_cystic_fibrosis?

Cystic Fibrosis Foundation. (2009). About cystic fibrosis: Frequently asked questions. Retrieved March 21, 2010

Cystic Fibrosis Foundation. (2011). About cystic fibrosis: Frequently asked questions. Retrieved October 7, 2011, from http://www.cff.org/AboutCF/Faqs/#How_do_people_get_cystic_fibrosis?

Cystic Fibrosis Foundation. (n.d.). Living with cystic fibrosis: Staying healthy. Retrieved October 7, 2011, from http://www.cff.org/LivingWithCF/StayingHealthy/

D'Auria, J. P., Christian, B. J., & Richardson, L. E. (1997). Through the looking glass: Children's perceptions of growing up with cystic fibrosis. *Canadian Journal of Nursing Research, 29*(4), 99-112.

Dallenbach, J., Speraw, S., Davis, J., & Ledbetter, J. (1995, May). *The experience of cystic fibrosis in the family*. Paper presented at the Thirteenth Annual Robert C. Coddington, M.D. Resident Research Conference, University of Tennessee College of Medicine Chattanooga, TN.

Darbyshire, P., MacDougall, C., & Schiller, W. (2005). Multiple methods in qualitative research with children: More insight or just more? *Qualitative Research, 5*, 417-436.

De Civita, M., & Dobkin, P. L. (2004). Pediatric adherence as a multidimensional and dynamic construct, involving a triadic partnership. *Journal of Pediatric Psychology, 29*(3), 157-169.

Deatrick, J. A., Knafl, K. A., & Murphy-Moore, C. (1999). Clarifying the concept of normalization. *IMAGE: Journal of Nursing Scholarship, 31*(3), 209-214.

DeFrain, J. (1999). Strong families around the world. *Family Matters, 53*(Winter), 6-13.

Depoy, E., & Gitlin, L. N. (2005). *Introduction to research: Understanding and applying multiple strategies* (3rd ed.). Philadelphia, PA: Mosby.

Descartes, R. (n.d.). Meditation II: Of the nature of the human mind; And that it is more easily known than the body. *Meditations on First Philosophy*. Retrieved January 29, 2010, from http://www.archive.org/details/meditations_descartes_dew_librivox

Dickinson, A. (2004-2005). 'We are just kids': children within health care relationships. *Contemporary Nurse, 18*(1-2), 1-2.

Dickinson, A., Smythe, E., & Spence, D. (2006). Within the web: The family-practitioner relationship in the context of chronic childhood illness. *Journal of Child Health Care, 10*(4), 309-325.

Egan, K. (1986). *Teaching as stroy telling: An alternative approach to teaching and curriculum in the elementary school*. Chiicago, IL: The University of Chicago Press.

Eggan, P., & Kauchak, D. (2001). *Educational psychology: Windows on classrooms* (5th ed.). Upper Saddle River, NJ: Merrill Prentice Hall.

Epstein, I., Stevens, B., McKeever, P., & Baruchel, S. (2006). Photo Elicitation Interview (PEI): Using Photos to Elicit Children's Perspectives. *International Journal Of Qualitative Methods, 5*(3). Retrieved from https://ejournals.library.ualberta.ca/index.php/IJQM/article/view/4366/3496

Erikson, E. (1968). *Identity: Youth and crisis*. New York: W. W. Norton & Company.

Erikson, E. (1979). *Identy and the life cycle*. New York: W. W. Norton & Company.

Evans, R. L., & Erikson, E. (1967). *Dialogue with Erik Erikson*. New York Harper & Row.

Ewald, W., & Lightfoot, A. (2001). *I wanna take me a picture*. Boston, MA: Beacon Press.

Ewald, W., Weinberg, A. D., & Stahel, U. (2000). *Secret games*. New York, NY: Scalo.

exist. (1989). Oxford English DIctionary (2nd ed.). Retrieved from http://dictionary.oed.com

exist. (1996). The Concise Oxford Dictionary of English Etymology. T. F. Hoad (Ed.) Retrieved from http://www.oxfordreference.com

existence. (1989). Oxford English DIctionary (2nd ed.). January 15, 2010, from http://dictionary.oed.com./

existence. (n.d.). Dictionary.com Unabridged. Retrieved October 21, 2009, from http://dictionary.reference.com/browse/existence

Fereday, J., MacDougall, C., Spizzo, M., Darbyshire, P., & Schiller, W. (2009). "There's nothing I can't do: I just put my mind to it and I can do it": A qualitative analysis of how children with chronic disease and their parents account for and manage physical activity [Electronic Article]. *BMC Pediatrics, 9*(1), 1.

Fogarty, A., Hubbard, R., & Britton, J. (2000). International comparison of median age at death from cystic fibrosis. *Chest, 117*(6), 1656-1660.

Gjengedal, E., Rusteen, T., Wahl, A. K., & Hanestad, B. R. (2003). Growing Up and Living With Cystic Fibrosis. *Advances in Nursing Science, 26*, 149.

Goetzinger, K. R., & Cahill, A. G. (2010). An update on cystic fibrosis screening. *Clinics in laboratory medicine 30*(3), 533-543.

Gregory, S. (2005). Living with chronic illness in the family setting. *Sociology of Health & Illness, 27*(3), 372-392.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough?: An experiment with data saturation and variability. *Field Methods, 18*, 59-81.

Harper, D. (1998). An argument for visual sociology. In J. Prosser (Ed.), *Image-based research: A sourcebook for qualitative researchers* (pp. 24-41). Bristol, PA: Falmer Press, Taylor & Francis Inc.

Harper, D. (2002). Talking about pictures: A case for photo elicitation. *Visual Studies, 17*(1), 13-26.

Havermans, T., & De Boeck, C. (2007). Cystic fibrosis: A balancing act? *Journal of Cystic Fibrosis, 6*, 161-162.

Havermans, T., Vreys, M., Proesmans, M., & De Boech, C. (2006). Assessment of agreement between parents and children on health-related quality of life in children with cystic fibrosis. *Child: Care, Health & Development, 32*(1), 1-7.

Hayes, C. C., & Savage, E. (2007). Fathers' perspectives on the emotional impact of managing the care of their children with cystic fibrosis. *Journal of Pediatric Nursing, 23*(4), 250-256.

Heidegger, M. (1996). *Being and time*. (J. Stambaugh, Trans.). Albany, NY: State University of New Your Press (Original work published in 1927).

Howe, N., Ross, H. S., & Recchia, H. (2011). Sibling relations in Early and Middle Childhood. In P. K. Smith & C. H. Hart (Eds.), *The Wiley-Blackwell handbook of childhood social development* (2nd ed., pp. 356-369). Malden, MA: Wiley-Blackwell

Huitt, W., & Hummel, J. (2003). Piaget's theory of cognitive development. Educational psychology interactive. Retrieved April 7, 2010, from http://www.edpsycinteractive.org/topics/cogsys/piaget.html

Inhelder, B., & Piaget, J. (1958). *The growth of logical thinking from childhood to adolescence: An essay on the construction of formal operations*. (A. Parsons & S. Milgram, Tans). New York: Basic Books, Inc.

Janse, A. J., Sinnema, G., Uiterwaal, C. S., Kimpen, J. L., & Gemke, R. J. (2008). Quality of life in chronic illness: Children, parents, and paediatricians have different, but stable perceptions. *Acta Pædiatrica, 97*(8), 1118-1124.

Jaye, C. (2003). A matter of integrity? Affliction and healing in Christian Science. *Health 7*(1), 5-27.

Jessup, M., & Parkinson, C. (2010). "All at Sea": The experience of living with cystic fibrosis. *Qualitative Health Research, 20*(3), 352-364. doi: 10.1177/1049732309354277

Johnson, D. P. (2008). *Contemporary sociological theory: An integrated multi-level approach* New York: Springer.

Kelly, M. P., & Field, D. (1996). Medical sociology, chronic illness, and the body. *Sociology of Health & Illness, 18*(2), 241-257.

Kerr, M. E., & Bowen, M. (1988). *Family Evaluation: An approach based on Bowen theory*. New York: W. W. Norton & Company.

Knafl, K. A., & Deatrick, J. A. (1987). Conceptualizing family response to a child's chronic disease or disability. *Family Relations, 36*(3), 300-304.

Knafl, K. A., & Deatrick, J. A. (2002). The challenge of normalization for families of children with chronic conditions. *Pediatric Nursing, 28*(1), 49-53,56.

Kolb, B. (2008). Involving, sharing, analyzing - Potential of the participatory photo interview. *Forum: Qualitative Social Research, 9*(3). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1155/2574

Korsch, B. M., Gozzi, E. K., & Francis, V. (1968). Doctor-patient interaction and patient satisfaction. *Pediatrics, 42*, 855-871.

Kuzel, A. J. (1999). Sampling in qualitative inquiry. In B. F. Crabtree & M. L. Miller (Eds.), *Doing Qualitative Research* (2nd ed., pp. 33-46). Thousand Oaks, CA: SAGE Publications.

Lang, S. S. (2005, September 25). Urie Bronfenbrenner, father of Head Start program and pre-eminent 'human ecologist,' dies at age 88, *Cornell University News Service*. Retrieved from http://www.news.cornell.edu/stories/Sept05/Bronfenbrenner.ssl.html

Leclerc, I. (1984). God and the issue of being. *Religious Studies, 20*(1), 63-78.

Leininger, M. (2006). Cultural care diversity and universality theory and evolution of the ethnonursing method. In M. M. Leininger & M. R. McFarland (Eds.), *Cultural care diversity and universality: A worldwide perspective* (2nd ed.). Boston, MA: Jones and Bartlett.

Lerner, J., & Ashman, O. (2006). Culture and life span development. In K. M. Thies & J. F. Travers (Eds.), *Handbook of Human Development for Health Care Professionals*. Sudbury, MA: Jones and Barlett Publishers.

Lin, P. L. (1994). Characteristics of a healthy family (ERIC ED377097). Retrieved April 25, 2010, from http://www.eric.ed.gov:80/ERICWebPortal/custom/portlets/recordDetails/detailmin

i.jsp?_nfpb=true&_&ERICExtSearch_SearchValue_0=ED377097&ERICExtSearch_SearchType_0=no&accno=ED377097

Malchiodi, C. A. (1998). *Understanding children's drawings*. New York, NY: The Guilford Press.

May, R. (1959a). Contributions of existential psychotherapy. In R. May, E. Angel & H. F. Ellenberger (Eds.), *Existence: A New Dimension in Pyschiatry and Psychology* (pp. 37-91). New York: Basic Books Inc.

May, R. (1959b). Origins and the significance of the existential movement in psychology. In R. May, E. Angel & H. F. Ellenberger (Eds.), *Existence: A New Dimension in Pyschiatry and Psychology* (pp. 3-36). New York: Basic Books Inc.

McAdams, D. P. (2003). Autobiographical memory and the construction of a narrative self: Developmental and cultural perspectives. In R. Fivush & D. A. Haden (Eds.). Mahwah, NJ: Lawrence Erlbaum Associates, Publishers.

McCredie, A. (n.d.). History of documentary photography. Retrieved May 31, 2010, from http://www.tki.org.nz/r/arts/visarts/ans-westra/docs/history-docu-photo.doc

McCubbin, M. A., McCubbin, H. I., Mishler, D., & Svavarsdottir, E. (2001). Family relationships. In M. Bluebond-Langer, B. Lask & D. B. Angst (Eds.), *The Psychosocial Aspects of Cystic Fibrosis*. New Your: Oxford University Press Inc.

Mead, G. H. (1934). *Mind, self, & society: From the standpoint of a social behaviorist* (C. W. Morris, Ed.). Chicago, IL: The University of Chicago Press.

Melson, G. F. (2010). Child development and the human-companion animal bond. *American Behavioral Scientist, 47*(1), 31-39.

Meltzoff, A. N., & Moore, M. K. (1989). Imitation in newborn infants: Exploring the range of gestures imitated and the underlying mechanisms. *Developmental Psychology, 25*(6), 954-962.

Miller, S. (1999). Hearing from children who have diabetes. *Journal of Child Health Care, 3*(1), 5-12.

Mishel, M. H. (1990). Reconceptualization of the uncertainty in illness theory. *IMAGE: Journal of Nursing Scholarship, 22*(4), 256-263.

Modi, A. C., & Quittner, A. L. (2006). Barriers to treatment adherence for children with cystic fibrosis and asthma: What gets in the way? *Journal of Pediatric Psychology, 31*(8), 846-858. doi: 10.1093/jpepsy/jsj096

Moore, P. S. (2004). The use of social stories in a psychology service for children with learning disabilities: a case study of a sleep problem. *British Journal of Learning Disabilities, 32*(3), 133-138.

Mounier, E. (1948). *Existentialist philosophies: An introduction* (E. Blow, Trans.). London, England: Rockliff. (Original work published 1847).

National Center for Health Statistics. (2010). Health, United States, 2009: WIth special feature on medical technology (Library of Congress Catalog Number 76–641496). Washington, DC: U.S. Government Printing Office.

National Library of Medicine. (n.d.). Celebrating Americas physicians: Dr. Dorothy Hansine Anderson Retrieved April 14, 2009, from http://www.nlm.nih.gov/changingthefaceofmedicine/physicians/biography_8.html

New King James Version. (1982). *Genesis*. Nashville, TN: Thomas Nelson, Inc.

Nores, J. (1999). The philosophy of pain: New concepts. *Journal of Chronic Fatigue Syndrome, 5*(2), 99-105.

Office of the United Nations High Commissioner of Human Rights. (2002). Convention on the Rights of the Child. Retrieved February 12, 2009, from http://www.unhchr.ch/html/menu2/6/crc/treaties/crc.htm

Oliffe, J. L., & Bottorff, J. L. (2007). Further Than the Eye Can See? Photo elicitation and research with men. *Qualitative Health Research, 17*(6), 850-858.

Orenstein, D. M. (1997). *Cystic fibrosis: A guide for patient and family* (2 ed.). Philadelphia, PA: Lippincott-Raven Publishers.

Orenstein, D. M., Spahr, J. E., & Weiner, D. J. (2011). *Cystic fibrosis: A guide for patient and family* (4 ed.). Philadelphia, PA: Wolters Kluwer/Lippincott Williams & Wilkins.

Orfali, K., & Anderson-Shaw, L. (2005). When medical cure is not an unmitigated good. *Perspectives in BIology and Medicine, 48*(2), 282-292.

Parameswaran, G. (2003). Experimenter instructions as a mediator in the effects of culture on mapping one's neighborhood. [doi: DOI: 10.1016/S0272-4944(02)00104-4]. *Journal of Environmental Psychology, 23*(4), 409-417.

Park, C. (Ed.) (2010) A Dictionary of Environment and Conservation. Retrieved May 15, 2010 from Oxford Reference Online via http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t244.e7520.

Piaget, J., & Inhelder, B. (1969). *The psychology of the child*. New York: Basic Books, Inc.

Pink, S. (2007). *Doing visual ethnography* (2nd ed.). Thousand Oaks, CA: SAGE Publications.

Pizzignacco, T. M. P., & Lima, R. A. G. d. (2006). Socialization of children and adolescents with cystic fibrosis: support for nursing care. *Revista Latino-Americana de Enfermagem, 14*, 569-577.

Plato. (1996). *The plato reader* (T. D. J. Chappell, Trans.). Edinburgh, Scotland: Edinburgh University Press.

Plato. (n.d.). Apology (B. Jowett, Trans.). Retrieved February 20, 2010, from http://classics.mit.edu/Plato/apology.html

Polit, D. F., & Beck, C. T. (2004). *Nursing research: Principles and methods*. Philadelphia, PA: :Lippincott Williams & Wilkins.

Prossler, J. (1998). The status of image-based research. In J. Prossler (Ed.), *Image-based research: A sourcebook for qualitative researchers* (pp. 96-112). Bristol, PA: Falmer Press, Taylor & Francis Inc.

Quigley, J. (2000). *The grammar of autobiography: A developmental account*. Mahwah, NJ: Lawrence Erlbaum Associates.

Quittner, A. L., Davis, M. A., & Modi, A. C. (2003). Health-related quality of life in pediatric populations. In M. C. Roberts (Ed.), *Handbook of Pediatric Psychology* (3rd ed.). New York, NY: The Gullford Press.

Quittner, A. L., Espelage, D. L., Opipari, L., Carter, B., & Eid, N. (1998). Role strain in couples with and without a child with a chronic illness: Associations with marital satisfaction, intimacy, and daily mood. *Health Psychology, 17*(2), 112-124.

Robinson, C. A. (1993). Managing life with a chronic condition: The story of normalization. *Qualitative Health Research, 3*(1), 6-28. doi: 10.1177/104973239300300102

Roeper, A. (2007). *The "I" of the beholder: A guided journey to the essence of a child*. Scottsdale, AZ: Great Potential Press, Inc.

Roy, C., & Andrews, H. A. (1999). *The Roy Adaptation Model* (2nd ed.). Stamford, CT: Appleton & Lange.

Sandelowski, M. (2000). What ever happened to qualitative description? *Research in Nursing & Health, 23*(4), 334-340.

Sartain, S. A., Clarke, C. L., & Heyman, R. (2000). Hearing the voices of children with chronic illness. *Journal of Advanced Nursing, 32*, 913-921.

Sartre, J. P. (1965). *Being and nothingness: An essay in phenomenological ontology (3rd ed.), (H. Barnes, Trans)*. New York: The Citadel Press (Original work published in 1953).

Sarvey, S. I. (2008). Living with a machine: The experience of the child who is ventilator dependent. *Issues in Mental Health Nursing, 29*(2), 179 - 196.

Savage, E., & Callery, P. (2007). Clinic consultations with children and patients on the dietary management of cystic fibrosis. *Social Science & Medicine, 64*(363-74).

Sawyer, M. G., Reynolds, K. E., Couper, J. J., French, D. J., Kennedy, D., Martin, J., . . . Baghurst, P. A. (2004). Health-Related Quality of Life of Children and Adolescents with Chronic Illness: A Two Year Prospective Study. *Quality of Life Research, 13*(7), 1309-1319.

Scott, J., & Marshal, G. (Eds.). (2009) A Dictionary of Sociology. Retrieved May 15, 2010 from Oxford Reference Online via http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t88.e2187.

Shaffer, D. R., & Kipp, K. (2010). *Developmental psychology: Childhood and adolescence* (8th ed.). Belmont, CA: Wadsworth, Cengage Learning.

Shannon, A. T. (1979). *An analysis of the perceptions of school-age children with cystic fibrosis.* PhD Dissertation, University of Miami, Coral Gables, FL.

Sharples, M., Davison, L., Thomas, G. V., & Rudman, P. D. (2003). Children as photographers: An analysis of children's photographic behaviour and intentions at three age levels. *Visual Communication, 2*(3), 303-330.

Smith, F., & Barker, J. (2000). Contested Spaces: Children's Experiences of Out of School Care in England and Wales. *Childhood, 7*(3), 315-333. doi: 10.1177/0907568200007003005

Smith, P. K., Cowie, H., & Blades, M. (2003). *Understanding children's develoment* (4th ed.). Malden, MA: Blackwell Publishing.

Solomon, C. R., & Breton, J. J. (1999). Early warning signals in relationships between parents and young children with cystic fibrosis. *Children's Health Care, 28*(3), 221-240.

Speraw, S. (2006). Spiritual experiences of parents and caregivers who have children with disabilities or special needs. *Issues in Mental Health Nursing, 27*(2), 213-230.

Speraw, S. (2009). "Talk to Me--I'm Human": The Story of a Girl, Her Personhood, and the Failures of Health Care. *Qual Health Res, 19*(6), 732-743. doi: 10.1177/1049732309334517

Strausebaugh, S. D., & Davis, P. B. (2007). Cystic fibrosis: A review of epidemiology and pathobiology. *Clinics in Chest Medicine 28*(2), 279-288.

Stryker, S. (1987). The Vitalization of Symbolic Interactionism. *Social Psychology Quarterly, 50*(1), 83-94.

Stryker, S. (2002). *Symbolic Interactionism: A social structural version*. Caldwell, NJ: The Blackburn Press.

Sullivan-Bolyai, S., Bova, C., & Harper, D. (2005). Developing and refining interventions in persons with health disparities: The use of Qualitative Description. *Nursing Outlook, 53*(3), 127-133.

Tates, K., & Meeuwesen, L. (2001). Doctor-parent-child communication. A review of the literature. *Social Science and Medicine, 52*, 839-851.

The Sisters of Mercy. (1990). When You Don't See Me [song lyrics]. November 25, 2009, from http://www.the-sisters-of-mercy.com/lyrics/whenyoud.htm

Thomas, N., & O'Kane, C. (2000). Discovering what children think: Connections between research and practice. *British Journal of Social Work, 30*, 819-835.

Thompson, N. C., Hunter, E. E., Murray, L., Ninci, L., Rolfs, E. M., & Pallikkathayil, L. (2008). The experience of living with chronic mental illness: a photovoice study. *Perspectives in Psychiatric Care, 44*(1), 14-24.

Tillich, P. (1951). *Systematic theology: Volume one*. Chicago, IL: The University of Chicago Press.

Tracy, J. P. (1997). Growing up with chronic illness: The experience of growing up with cystic fibrosis. *Holistic Nursing Practice, 12*(1), 27-29.

Tuan, Y. (1977). *Space and place: The perspecitve of experience*. Minneapolis, MN: University of Minnesota Press.

Turner, D. C. (1996). The Role of Culture in Chronic Illness. *American Behavioral Scientist, 39*(6), 717-728. doi: 10.1177/0002764296039006008

United Nations Children's Fund (UNICEF). (2009). What young people want. *Voices of Youth*. Retrieved February 12, 2009, from http://www.unicef.org/voy/explore/rights/explore_153.html

Vallino, D., & Maccio, M. (2004). The child's sense of existence and the fatal attraction of identification. [Article]. *International Forum of Psychoanalysis, 13*(1/2), 71-77. doi: 10.1080/08037060410027859

van Dulmen, A. (1998). Children's contributions to pediatric outpatient encounters. *Pediatrics, 102*(3), 563-568.

Wang, C. C., & Pies, C. A. (2004). Family, maternal, and child health through photovoice. *Maternal & Child Health Journal, 8*(2), 95-102.

Wennström, I., Berg, U., Kornfält, R., & Rydén, O. (2005). Gender affects self-evaluation in children with cystic fibrosis and their healthy siblings. *Acta Paediatrica, 94*, 1320-1326.

Willats, J. (n.d.). Child art. *Grove Art Online.* Retrieved May 15, 2010, from http://www.oxfordartonline.com/subscriber/article/grove/art/T016465

Williams, B., Corlett, J., Dowell, J. S., Coyle, J., & Mukhopadhyay, S. (2009). "I've Never Not Had it So I Don't Really Know What it's Like Not to": Nondifference and Biographical Disruption Among Children and Young People With Cystic Fibrosis. *Qual Health Res, 19*(10), 1443-1455. doi: 10.1177/1049732309348363

Williams, B., Mukhopadhyay, S., Dowell, J., & Coyle, J. (2007). From child to adult: An exploration of shifting family roles and responsibilities in managing physiotherapy for cystic fibrosis. *Social Science & Medicine, 65*(10), 2135-2146.

Williams, P. D., Ridder, E. L., Setter, R. K., Liebergen, A., Curry, H., Piamjariyakul, U., & Williams, A. R. (2009). Pediatric chronic illness (cancer, cystic fibrosis) effects on well siblings: parents' voices. *Issues in Comprehensive Pediatric Nursing, 32*(2), 94-113.

Williams, S. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health and Illness, 22*(1), 40-67.

Wissow, L., Roter, D., Bauman, L. J., Crain, E., Kercsmar, C., Weiss, K., . . . Moher, B. (1998). Patient-provider communication during the emergency department care of children with asthma. *Medical Care, 65*(10), 2135-2146.

Woltering, S., & Lewis, M. D. (2011). Conceptual development and emotion: A neuropsychological perspective. In P. K. Smith & C. H. Hart (Eds.), *The Wiley-Blackwell handbook of childhood social development* (pp. 45-63). Malden, MA: Wiley-Blackwell

Woo, J. (2006). A short History of the development of Ultrasound in Obstetrics and Gynecology. March 17, 2010, from http://www.ob-ultrasound.net/history.html

world. (1989). Oxford English DIctionary (2nd ed.). February 10, 2010, from http://dictionary.oed.com./

world. (2001). Online etymology dictionary. February 16, 2010, from http://www.etymonline.com/index.php?search=world&searchmode=none

Wyatt, T. H., & Hauenstein, E. J. (2008). Pilot testing Okay With Asthma ™: An online asthma intervention for school-age children. *The Journal of School Nursing, 24*(3), 61-66.

Yalom, I. D. (1980). *Existential psychotherapy*. New York: Basic Books, Inc.

Yalom, I. D. (n.d.). Irvin D. Yalom. February 2, 2010, from http://www.yalom.com/index.html

Ziaian, T., Sawyer, M. G., Reynolds, K. E., Carbone, J. A., Clark, J. J., Baghurst, P. A., . . . French, D. J. (2006). Treatment burden and health-related quality of life of children with diabetes, cystic fibrosis and asthma. *Journal of Paediatrics & Child Health, 42*(10), 596-600.

Ziller, R. C., & Lewis, D. (1981). Orientations: Self, Social, and Environmental Percepts through Auto-Photography. *Pers Soc Psychol Bull, 7*(2), 338-343. doi: 10.1177/014616728172025

Ziller, R. C., & Smith, D. E. (1977). A phenomenological utilization of photographs. *Journal of Phenomenological Psychology, 7*, 172-182.

# Appendix A

## Table of Empirical Literature

| Author | Age of Participants with Chronic Disease and Number of Participants in Study | Design/Method | Country | Theoretical Perspective/ Theoretical Framework |
|---|---|---|---|---|
| Admi, H. (1996) | 16 to 25 years.<br>Adults with CF n=10<br>Family members n-11 | • Qualitative<br>• Grounded Theory<br>• Interview<br>• | United States | Life history |
| Angst, D. B., & Deatrick, J. A. (1996) | 7 to 11 years.<br>CF Children & Parents, n= 20<br><br>10 to 19 years.<br>Scoliosis children & parents, n=8 | • Qualitative<br>• Interview | United States | Not specified |
| Bluebond-Langer, M. (1991) | 6 to 24 years.<br>CF children and their families, n=40 | • Qualitative<br>• Ethnography | United States | Ethnography |
| Christian, B. J. & D'Auria, J. P. (1997) | 12 to 20.<br>Adolescents with CF, n=20 | • Qualitative<br>• Grounded Theory<br>• Interview | United States | Social ecologic theory |
| Dallenbach, J., et al. (1995, May) | 8 to 36 years;<br>Families, n=40<br>Persons with CF, n=16<br>Parents, n= 25<br>Siblings, n=9<br>Grandparent, n=1 | • Qualitative<br>• Sentence completion open-ended questionnaire. | United States | Lived experience<br>Hope<br>Development |
| D'Auria, J. P., et al. (1997) | 6 to 12;<br>Children with CF, n= 20 | • Qualitative<br>• Grounded Theory<br>Interview | United States | Social ecologic theory |
| Fereday, J., et al (2009) | 4 to 12 years.<br>Part 1: Children & their parents, n=25<br>Part 2: Children, n=12 | • Qualitative<br>• Phenomenology<br>• Interview | Australia | Interpretive phenomenology |

Table of Empirical Literature cont.

| Author | Age of Participants with Chronic Disease and Number of Participants in Study | Design/Method | Country | Theoretical Perspective/ Theoretical Framework |
|---|---|---|---|---|
| Gjengedal, E., et al. (2003) | 20 to 47 years.<br>Adults with CF, n=14<br>Parents of CF children, n=8 | • Qualitative<br>• Interview | Norway | Not Specified |
| Havermans, et al. (2006) | 6 to 12 years.<br>Children with CF, n=47 | • Quantitative<br>• Questionnaire | United States | Health-related quality of life |
| Janse, et al. (2008) | 10 to 17 years.<br>Children & Parents<br>CF, n= 22<br>ALL, n=8<br>JIA, n= 17<br>Asthma, n= 13<br>Pediatricians, n=19 | • Quantitative<br>• Questionnaire | Netherlands | Health-related quality of life |
| Korsch, B. M., et al. (1968) | 4 to 10 years.<br>Children, n=800<br>Pediatricians, n=64 | • Qualitative<br>• Interview | United States | Not Specified |
| Pizzignacco, T. & Lima, R. (2006) | 7 to 18 years.<br>Children and adolescents with CF, n=8 | • Qualitative<br>• Interview | Brazil | Developmental theories of Ericson and Piaget |
| Sartain, S. A., et al. (2000) | 8 to 14 years.<br>Children with chronic disease, n=7<br>Parents, n= 10<br>Nurses, n= 7 | • Qualitative<br>• Grounded theory | England | Biological |
| Sawyer, M. G. (2004) | 10 to 16 years.<br>CF, n=39<br>Asthma, n=40<br>Diabetes, n=44 | • Quantitative<br>• Questionnaire | Southern Australia | Health-related quality of life |
| Shannon, A. T. (1979) | Grades 1 to 12, n=85<br>Children with CF | • Quantitative<br>• Questionnaire | United States | Biological and developmental |
| Tracy, J. P. (1997) | 23 to 42 years<br>Adults with CF, n=12 | • Qualitative<br>• Phenomenology | United States | Hermeneutic phenomenology |

**Appendix B**

## Parent

### Photograph Release Statement

I _____, give Renée Burk unlimited permission to use, copy, edit, publish, or communicate any of the photographs taken by my child _____ for the purpose of this study. I also give Renée Burk permission to use any photograph that may include the image of me and/or my child as long as I and/or my child are not identified by name or by any other background information. I agree that these photographs may be used for (check all that you agree to):

☐ Defense and publication of dissertation manuscript

☐ Research presentations local, regional, national, and international

☐ Publication of research findings in scholarly peer reviewed journals

I agree to waive any right that I may have to inspect or approve the finished photographs, printed products, or electronic matter. I understand that I and my child will not receive any payment from anyone for these photographs and I agree to hold Renée Burk harmless from all claims (compensation or residuals) related to use of these photographs taken for the research study titled, The World of School-Aged Children with Cystic Fibrosis: A Qualitative Descriptive Study using Visual Methods. If I have any further questions, I can call Renée Burk at 865-806-7560.

By signing below, I acknowledge that I have read and fully understand this Photograph Release Statement.

_____ _____

Signature Parent/Guardian Date

_____

Street address, city, state, and zip

**Child**

**Photograph Release Assent Statement**

You may use any of the pictures that I took for your work. I can pick which pictures you can use, but I will have to choose the pictures when we talk about them. I want the pictures of me (pick one)

☐ to be shown without my face blurred (or)

☐ with my face blurred so people do not know it's me

_____ _____

Name of Child Date

_____

Child's Signature

## Family, Friends, and Neighbor

### Photograph Release Statement

I am and/or my child is in a photograph taken by _____. I _____, give Renée Burk unlimited permission to use and edit any photograph that may include the image of me and/or my child _____ as long as I and/or my child are not identified by name or by any other background information. I understand that the photographic images may be used for (check all that you agree to):

- ☐ Defense and publication of dissertation manuscript
- ☐ Research presentations local, regional, national, and international
- ☐ Publication of research findings in scholarly peer reviewed journals
- ☐ No presentations or publications (viewed by researcher and research team only)

I agree to waive any right that I may have to inspect or approve the finished photographs, printed products, or electronic matter. I understand that I will not receive any payment from anyone and I agree to hold Renée Burk harmless from all claims (compensation or residuals) related to use of these photographs taken for the research study titled, The World of School-Aged Children with Cystic Fibrosis: A Qualitative Descriptive Study using Visual Methods. If I have any further questions, I can call Renée Burk at 865-806-7560.

By signing below, I acknowledge that I have read and fully understand this Photograph Release Statement.

_____ _____
Name of person in photograph Relationship to photographer

_____ _____
Signature (Parent/Guardian if under age 18) Date

_____
Street address, city, state, and zip

**If the family, friend, or neighbor is a child**

You may use any of the pictures taken of me for your work. I want the pictures of me (pick one)

☐ to be shown without my face blurred (or)

☐ with my face blurred so people do not know it's me

_____ _____

Name of Child Date

**Appendix C**

# Do you like to take pictures?

## Information about participating in a fun research project

**"The World of the School-Aged Child with Cystic Fibrosis: A Qualitative Descriptive Study using Visual Methods"**

**WHAT:** A nursing research study seeking to learn and understand how children with CF see themselves and the world in which they live.

**BY WHOM:** A nurse with 25 years experience who has worked with children who have CF for 11 years and is now completing a PhD in nursing.

**WHY:** Children possess valuable knowledge about themselves. Yet, children with CF report they are excluded from health care conversations. By using child produced photographs and interview, the voices of children with CF will be heard through this research. This project will allow children with CF to talk about themselves and share their world as photographs. Knowledge gained from this study will be used to inform people who care for children with CF about what children with CF know and understand about their world and themselves.

**WHO CAN PARTICIPATE:**

- Children ages 8, 9, 10, and 11 with cystic fibrosis.
- Children who are willing and able to take photographs with a digital camera and then talk about their pictures with a nurse researcher.
- Children whose parents agree to let them participate.

**WHAT'S INVOLVED:** Three meetings with child and at least one parent (guardian). First meeting to meet with family and provide picture-taking instructions, second meeting to pick up camera, and third meeting for child to talk about his/her pictures with the nurse researcher.

**COMPENSATION:** Children will receive a hardbound photobook of their photographs.

**WHERE:** Children will be interviewed in a place chosen by the child and parent, either their home or another convenient location.

**WHEN:** Beginning November 2010

**HOW:** To discuss the study in more detail call the Principal Investigator Renée Burk, RN, MSN at **(865) XXX-XXXX** and leave a confidential message with your name and phone number for a return call or by email at rburk@utk.edu. The investigator will respond to your message as quickly as possible. Requesting information does not require participation in the study in any way.

# Appendix D

## Schedule of Study Visits

| SCREENING | VISIT 1 | VISIT 2 | VISIT 3 | VISIT 4 (optional) |
|---|---|---|---|---|
| May be done over phone or face-to-face | Study enrollment | To be completed within 1 to 2 weeks of Visit 1 | To be completed within 1 to 2 weeks of Visit 2 | To be completed at the end of data analysis. |
| 20 minutes<br>Explain details of study including inclusion/exclusion criteria, methods and procedures, benefits, and risks and protection measures, rights to photographs and use of images for professional and educational purposes. | 60 minutes<br>Review details of study (see screening). | 30 minutes<br>Review photographs with participant. | 30 minutes to 2 hours<br>Interview participant with photographs. | 30 to 60 minutes<br>Validate researcher-identified themes with participants. |
| Answer participant and parent questions. | Review and obtain parental informed consent. | Pick up camera and camera manual. | Assist participant in constructing a photobook. | Answer participant and parent questions. |
| Complete Participant Information Form and assess if child meets study criteria. | Review and obtain child assent. | Answer participant and parent questions. | If necessary, obtain additional photograph releases. | *After completion of the study (dissertation is written) participants will be sent a CD of his/her pictures.* |
| | Review and sign Parent and Child PRS.<br>Leave Family, Friend, and Neighbor PRS forms with family.<br>Dispense point and shoot digital camera and camera manual.<br>Review picture taking instructions with child and parent.<br>Answer participant and parent questions. | *Following visit: Develop photographs.* | Answer participant and parent questions.<br>*Following visit: Develop photobook and either send or deliver to participant.* | |
| | **Visit Date & Time** | **Visit Date & Time** | **Visit Date & Time** | **Visit Date & Time** |

# Appendix E

## Participant Information Form

The World of School-Aged Children with Cystic Fibrosis:
A Qualitative Descriptive Study Using Visual Methods

Name of Participant: _____

Gender: Male/Female

Date of Birth: _____/_____/_____

Grade at Time of Enrollment: 3rd_____ 4th_____ 5th_____

Confirmed CF Diagnosis: YES NO Clinical Symptoms/Sweat test/Genotype

Parent Name: _____

Contact Number: ( ) _____ ( ) _____

Address: _____

Name of CF Center: _____

Current FEV1: _____ Date of measurement: _____

How many serious CF exacerbations have they had in the past year? _____

Have any of them required a hospitalization? _____.

Are the child's activities limited in anyway? YES NO

If yes, how_____

Who is in the family system? _____

_____

Which organs are most affected by CF? _____

What treatments does the child take daily basis and how often? _____

_____

What kinds of medications does the child take?

_____

| Name of Med | Dose | Frequency | Route |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

# Appendix F

Participant #

## CHILD ASSENT

**The World of School-Aged Children with Cystic Fibrosis:**
**A Qualitative Descriptive Study using Visual Methods**

I have talked with Renée Burk MSN, RN, who is a nurse and goes to school at the University of Tennessee. She likes to care for children who have CF. I can call her Renee. She asked me to be in a study. The study is about children who have CF. She wants to know about what it is like to be me so she can tell other people who care for children with CF how to take better care of people like me.

If I say it is OK, Renee will give me a camera to borrow. Then I will take pictures about me and everything in my life. I will have to give the camera back after I am done taking pictures. When the pictures are made, she will come back to see me and we will talk about my pictures.

Our talk will be recorded on a voice recorder. If I do not like the questions she asks, I can tell her and we will stop talking about them. If I get tired, I can let her know and we will rest. If I do not understand something, Renee will explain it to me. She might be with me for 2 hours. If I decide I do not want to talk or do this study anymore, I know that I can stop. Renée will then destroy all of the pictures and information that I have given her.

After we talk, Renee will keep the pictures, but she will help me make a picture book with my pictures. The picture book is mine to keep after it is made at the store. When this study is done, Renee will write a report, she will not use my real name in the report.

Participant #

I want to be in this research study. I was told about the research study and had a chance to ask questions. I know I can ask questions anytime.

_____
Name of Child

_____ _____
Signature of person administering the assent Date

_____
Printed name of person administering the assent

**Parent/Guardian Documentation of Assent**
I have witnessed the assent administered to my child, and am satisfied that Renée Burk has discussed these procedures with my child in a manner and to an extent appropriate for his/her capacity to understand at the present time. My child's has voluntarily agreed to participate.

_____ _____
Signature of Parent/Legal Representative (Circle One) Date

_____
Printed Name of Parent/Legal Representative

_____ _____
Signature of Investigator (I have reviewed the study with the subject and parent/legal guardian, and have given them the opportunity to ask questions.) Date

_____
Printed Name of Investigator

## Appendix G

## Picture Taking Instructions

- "With your camera, take pictures that show other people (like me, your parents, friends, nurses, doctors, or teachers) what it is like to be you. Take pictures about everything in your life that you want people to know, including the good stuff, the bad stuff, and everything in between. Take pictures about the people you know; things that you do; things that happen to you; things that are important to you such as people, pets, and places you go; stuff you do; and pictures of when you are happy, sad, scared, sleepy, or hurting."
- The pictures you take should be your idea not someone else's.
- Respect other people's feelings when you take pictures with your camera.
    - Do not take a picture of anything that will embarrass someone or make someone feel bad.
    - If you can, ask permission from people before taking their picture.
- Be safe when taking pictures. Do not take any pictures when you are walking. Stop first then take the picture.
- Keep the camera strap around one of your wrists when carrying the camera.
- Keep both hands on the camera when taking a picture.

- Remember if you stand too close your picture will be blurry. If you stand too far away the details of the picture will be hard to see.
- When taking photographs outdoors do not face into the sun. Instead, put your back to the sun so that you are looking away from the sun.
- When inside, turn on the flash before taking a picture.
- Remember to put the camera in a safe place when you are not taking pictures.
- Do not download any pictures from the camera.

**Instructions to Parents/Guardians:**

Pictures must be taken by the child except if:

1. The child is the subject of the photograph.
2. The child asks you or other people to take a picture of him/her.
3. Do not allow your child or anyone else to download any of the pictures from the camera.

## Appendix H

## Transcriber's Pledge of Confidentiality

The World of School-Aged Children with Cystic Fibrosis:
A Qualitative Descriptive Study using Visual Methods

As a transcribing typist of this research project, I understand that I will be transcribing confidential audio digitally recorded interviews. The information in these audio recordings have been revealed by research participants who participated in this project in good faith that their data would remain strictly confidential. I understand that I have a responsibility to honor this confidentially agreement. I hereby agree not to share any information in these interviews with anyone except the primary researcher of this project. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

_____ _____

Transcribing Typist Date

# Appendix I

## Research Team Member's Pledge of Confidentiality

The World of School-Aged Children with Cystic Fibrosis:
A Qualitative Descriptive Study using Visual Methods

As a member of the phenomenology group, I understand that I will be reading transcriptions of confidential audio digitally recorded interviews. The information in these transcripts has been revealed by research participants who participated in this project in good faith that their data would remain confidential. I understand that I have a responsibility to honor this confidentiality agreement. I hereby agree not to share any information in these transcriptions with anyone except the primary researchers of this project, her doctoral chair, or other members of this research team. Any violation of this agreement would constitute a serious breach of ethical standards, and I pledge not to do so.

_____ _____

Research Team Member Date

## Appendix J

## Examples of Memos

- Some children seem exceptionally close to influential adults outside of family such as the school nurse and her family.

- Emily is close to her father. Look to see how many other girls talked about their special relationship to their dad.

- 01Tyra's first picture for was of her and a friend having fun in an activity. Look at the first pictures of all other participants and see what is special about them.

- Fieldtrips influence child's play and imagination. This field trip in the first grade definitely made an impression on the child.

- Children are aware of where they are situated in their environment.

- Families develop routines that become a tradition on holidays. These parents got up with their children and watched them open up presents. Also, this 9-year-old child still believed in Santa Clause. These parents kept the fantasy of Santa alive.

- Treatments are so normal for the family even the family pets have adjusted to child's routine.

- Taking treatments can be boring.

- CF has not robbed child of her childhood.

- The Vest is now a fashion accessory. This is also an example about how manufacturers are normalizing CF technology and making fashion accessories out of CF machinery.

**Vita**

Renée C. Burk was born on July 7th, 1960. She was raised with her three brothers by two loving parents in rural Minnesota. She attended Rochester Community College from 1979 to 1981 with the intention of becoming a medical technologist, but after about a year realized that the laboratory setting was not her passion nor was it her calling. She changed her major to nursing and a year later entered the Bachelor of Science Nursing program at the University of North Dakota located in Grandforks, ND.

Upon graduation in 1984, she moved to Beaumont TX and worked as a staff nurse at St Elizabeth's hospital in the Surgical Intensive Care Unit (SICU). Within a year, she returned to Minnesota and continued her career in the SICU at the University of Minnesota Hospital. In 1988, she left the hospital environment for a position as a clinical studies coordinator at the Minneapolis Heart Institute. Then in 1990 she accepted a 2-year position in the research department at a Minneapolis based startup medical device company as a coordinator for a national multicenter trial. When the job ended she relocated to Corpus Christi, Texas and attended Texas A & M University.

She graduated with a Masters of Science Degree in nursing in December of 1994 and became board certified as a Family Nurse Practitioner (FNP) in 1995. She began her FNP career in family medicine. However, a strong desire to work with children and adolescents prompted her to switch roles and enter the subspecialty field of pediatric pulmonary medicine. She was employed by Children's Physician Services of South Texas from 1998 to 2001. Then in 2001, she relocated to Knoxville, TN where she continued her FNP career in pediatric pulmonology at East Tennessee Children's Hospital. In 2006, she returned to the

academic environment to pursue a PhD in Nursing and a minor in Education. She currently holds a fulltime position as an Assistant Professor of Nursing at King College in Knoxville, TN and works part-time as a family nurse practitioner for Take Care Health Services.