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The Experiences of Medically Fragile Adolescents Who Require Respiratory Assistance

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Citation	Spratling, Regena. 2011. "The Experiences of Medically Fragile Adolescents Who Require Respiratory Assistance." PhD diss., Georgia State University. https://doi.org/10.57709/1872243
DOI	https://doi.org/10.57709/1872243
Download date	2026-03-09 02:45:39
Link to Item	https://hdl.handle.net/20.500.14694/11527

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ABSTRACT

THE EXPERIENCES OF MEDICALLY FRAGILE ADOLESCENTS WHO REQUIRE RESPIRATORY ASSISTANCE

by

REGENA SPRATLING

The population of medically fragile adolescents has grown in recent decades because of the sequelae of prematurity, injuries, and chronic or terminal illnesses. Medically fragile adolescents who require respiratory assistance are part of this unique population with challenges in their daily lives, yet as nurses, we know little about their experiences and the best approaches to use in caring for them. The purpose of this study was to explore the experiences of medically fragile adolescents who require respiratory assistance.

Interpretive phenomenology was used to describe and interpret the experience of 11 medically fragile adolescents who required respiratory assistance. The adolescents ranged in age from 13 to 18 years of age and required respiratory assistances of tracheostomies, ventilator support, and Bi-level positive airway pressure (BiPap). Audiotaped semi-structured interviews were conducted with the adolescents. Data analysis was completed using the steps delineated by Diekelmann and Allen (1989). Six themes and one pattern were identified from the interviews with the adolescents. The major themes were “Get to know me”, “Allow me to be myself”, “Being there for me”, “No matter what, technology helps”, “I am an independent person”, and “The only one I know of”.

This study explored medically fragile adolescents who required a specific technology, respiratory assistance, within a distinct developmental stage. These

adolescents have a clear view of who they are as a person. They want nurses to view them as a person, not just a patient. The adolescents felt that friends were there for them when they needed support. This was in contrast to those that they did not consider friends who were judgmental. Technology had meanings that encompassed enhanced daily living and existing as a part of their day, not their whole day. The adolescents viewed themselves as an independent person and were actively engaging in activities and strategies to achieve their goals of independence. This study contributes to nursing knowledge by helping nurses to understand what these adolescents experience in their daily lives and aiding nurses in providing better care for these adolescents. Recommendations for nursing practice, education, and research were identified in this study.

ACKNOWLEDGEMENTS

“...and proud we are of all of them.”- M. Lebowski

This dissertation is something that I will treasure. I have learned many things about myself and others in this process. In the end, I realize that this journey is just the beginning. I am proud of all of those who helped me in my journey.

I would like to thank Dr. Myra Carmon. This dissertation is the result of a long mentorship with Dr. Carmon. Thank you for inspiring me and encouraging me to expand my horizons as a nurse. I would also like to thank my committee members, Dr. Ptlene Minick and Dr. Karen Giesecker. Thank you for encouraging me to explore my possibilities and learn throughout the dissertation process. This study would have not been possible without their guidance.

I am thankful for my fellow students and colleagues. They remained a steady inspiration and source of support throughout the completion of this work. I am also grateful to the providers and staff at the clinic and office from which I recruited participants. Their vested interests in my work helped me to achieve this dissertation.

Thank you to the Epsilon Alpha chapter of Sigma Theta Tau International for financial support of this dissertation.

Thank you to my husband, Roy, and my son, Jacob, for their incredible support of my dissertation work. I could not have continued my education and career without their love, support, and encouragement. This dissertation would have not been possible without them. Thank you for being my biggest fans.

Thanks to all of the adolescents who shared their experiences with respiratory assistance. These adolescents were inspiring in their ability to reach for their goals and achieve to their fullest in their daily lives.

THE EXPERIENCES OF MEDICALLY FRAGILE ADOLESCENTS WHO REQUIRE
RESPIRATORY ASSISTANCE

by

REGENA SPRATLING

A DISSERTATION

Presented in Partial Fulfillment of Requirements for the
Degree of Doctor of Philosophy in Nursing in the Byrdine F. Lewis School of Nursing
in the College of Health and Human Sciences
Georgia State University

Atlanta, Georgia

2011

ix

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TABLE OF CONTENTS

	<u>Page</u>
List of Tables	xvi
List of Abbreviations	xvii
<u>Chapter</u>	<u>Page</u>
I. INTRODUCTION.....	1
Background.....	1
Terminology associated with medically fragile adolescents	2
Incidence and prevalence of medically fragile adolescents.....	3
Families caring for medically fragile adolescents	4
School attendance by medically fragile adolescents	4
Experiences of medically fragile adolescents.....	5
Significance to Nursing	6
Statement of Purpose	7
Theoretical Context	8
Assumptions	8
Interpretive Phenomenology.....	10
Interpretive Phenomenology as a Philosophy	11
Import Concepts of Interpretive Phenomenology	12
Taken for granted.....	12
World.....	12
Embodiment.....	12
Thrownness.....	13

<u>Chapter</u>	<u>Page</u>
Interpretive Phenomenology as a Methodology	13
Researcher background and interpretive foreground.....	13
Summary.....	14
Outline of the Study.....	15
II. REVIEW OF LITERATURE.....	16
Adolescence.....	16
Chronic Illness in Adolescence	18
Peer Relationships	18
Family.....	19
School attendance	19
Medically Fragile Children and Adolescents	20
Families of Medically Fragile Children and Adolescents	22
Family stressors	23
Normalization in families	24
Medically Fragile Children and Adolescents: Respiratory Assistance	26
Summary.....	28
III. METHODOLOGY	30
Research Design	30
Setting.....	30
Participants	31
Data Generation Strategies	33
Recruitment	33

<u>Chapter</u>	<u>Page</u>
Data Collection	34
Data Analysis.....	36
Trustworthiness	38
Researcher Bias	39
Protection of Human Subjects	39
Summary.....	40
IV. RESEARCH PROCESS	41
Research Design	41
Setting.....	41
Participants	42
Data Generation Strategies	45
Recruitment	45
Data Collection.....	48
Data Analysis.....	50
Trustworthiness	52
Researcher Bias	53
Protection of Human Subjects	53
Summary.....	54
V. FINDINGS AND DISCUSSION.....	55
Participant Characteristics	55
Themes.....	57
Theme: Get to know me	60

<u>Chapter</u>	<u>Page</u>
Subtheme: But don't be too nosy	64
Theme: Allow me to be myself	66
Theme: Being there for me	69
Subtheme: My friends see me as a person.....	71
Subtheme: Others judge me.....	73
Theme: No matter what, technology helps	75
Theme: I am an independent person.....	80
Subtheme: I see myself.....	83
Subtheme: Creating moments for myself	87
Theme: The only one I know of	89
Summary.....	93
VI. CONCLUSIONS AND RECOMMENDATIONS	96
Conclusions from the Themes	97
Theme: Get to know me	97
Theme: Allow me to be myself	99
Theme: Being there for me	100
Theme: No matter what, technology helps	101
Theme: I am an independent person.....	102
Theme: The only one I know of	104
Recommendations for Nursing Practice	105
Recommendations for Nursing Education.....	106
Recommendations for Nursing Research	107

<u>Chapter</u>	<u>Page</u>
Limitations.....	108
Summary.....	109
REFERENCES	110
APPENDICES	117
Appendix A: CONSENT FORM.....	117
Appendix B: ASSENT FORM	121
Appendix C: INTERVIEW QUESTIONS	124
Appendix D: DEMOGRAPHIC INFORMATION	126
Appendix E: DISSERTATION STUDY SUMMARY	128
Appendix F: RECRUITMENT FLYER	130
Appendix G: CODE BOOK	132
Appendix H: CATEGORIES.....	134

LIST OF TABLES

<u>Table</u>	<u>Page</u>
1. Themes and subthemes.....	60

LIST OF ABBREVIATIONS

OTA	Office of Technology Assessment
BiPap	Bi-level positive airway pressure
CSHCN	Children with Special Health Care Needs

CHAPTER I

Introduction

Adolescents who are dependent upon technology to help with vital body functions and require skilled nursing care are often described as medically fragile (Office of Technology Assessment [OTA], 1987). Medically fragile adolescents who are dependent upon, or require, respiratory assistance are a subset of the population of medically fragile adolescents. Respiratory assistance includes tracheostomies and ventilator support, mechanical ventilation via tracheostomy or positive airway pressure support via face mask (i.e. Bi-level positive airway pressure [BiPap]). Medically fragile adolescents who require respiratory assistance are a unique population with challenges in their daily lives, yet as nurses, we know little about their experiences and the best approaches to use in caring for them. Qualitative studies conducted to date, provide information about the adolescent's experience from their parents' or caregivers' perspective. At present, there is little known of the experience from the adolescent's point of view. The purpose of this study is to explore the experiences of medically fragile adolescents who require respiratory assistance using interpretive phenomenology.

Background

Adolescents who are medically fragile are a subset of children with special health care needs (CSHCN) who have complex chronic conditions and often depend on technology and specialty care (Buescher, Whitmire, Brunssen, & Kluttz-Hile, 2006; Gordon, Colby, Bartelt, Jablonski, Krauthoefer, & Havens, 2007). For this study, the term

medically fragile is used to indicate the special medical requirements of adolescents who are dependent upon technology for respiratory assistance and long-term nursing care (OTA, 1987).

Terminology associated with medically fragile adolescents. In the literature, various names are used to reflect children and adolescents who require assistance from medical technology. These terms include medically fragile (Haley & Ratliffe, 2006; Harrigan, Ratliffe, Patrinos, & Tse, 2002), technology-dependent (Cohen, 1999; Earle, Rennick, Carnevale, & Davis, 2006; Carnevale, Alexander, Davis, Rennick, & Troini, 2006; Heaton, Noyes, Sloper, & Shah, 2005; Montagnino & Mauricio, 2004), medically fragile/technology-dependent (Rehm & Rohr, 2002), medically fragile/developmentally delayed (Rehm & Bradley, 2006; Rehm & Bradley, 2005), children with complex chronic health conditions or complex continuing care needs (Carnevale, Rehm, Kirk, & McKeever, 2008), and medically complex and fragile (Gordon et al., 2007). For this study, the term medically fragile will be used to characterize adolescents who depend on respiratory technology to maintain their health. These adolescents have a wide range of illnesses, typically chronic along with acute exacerbations, and require a varying level of technology. Previous studies have included descriptions of the technology required by medically fragile children and adolescents. The technology requirements have varied from intermittent to continuous technology needs with nurse dependent care (Earle et al., 2006; Haley & Ratliffe, 2006; Harrigan et al., 2002; Heaton et al., 2005; Rehm & Bradley, 2005; Rehm & Rohr, 2002). Medically fragile adolescents who require respiratory assistance may require respiratory technologies in addition to several other technologies, reflecting a medically fragile population with multiple technology needs.

Incidence and prevalence of medically fragile adolescents. More recently, data from the larger population of children with special health care needs (CSHCN) are cited in the literature. Currently, an estimated 10.2 million (13.9%) of America's children and adolescents (birth to 17 years old) are considered to be medically fragile, meaning they have an ongoing health condition requiring more than routine health-care services (2005-2006 National Survey of Children with Special Health Care Needs, Child and Adolescent Health Measurement Initiative, 2007).

While the exact incidence and prevalence rates are unknown for the medically fragile pediatric population (Carnevale et al., 2008), an estimated 11,000 to 68,000 children and adolescents (birth to 21 years old) with technology needs live in the United States ([U. S.]; OTA, 1987). The OTA also estimated the monthly cost of a ventilator dependent adolescent (i.e., medically fragile adolescent who requires respiratory assistance) to be \$9,993 per month, or \$119,996 per year. The most recent data regarding incidence and prevalence of this population are greater than two decades old. Scholars have indicated that this is a growing pediatric population (Carnevale et al., 2008).

Recent prevalence data suggest the numbers of medically fragile children and adolescents have increased substantially since the national survey. Estimates for the medically fragile pediatric population are available for individual states in the U. S. and the United Kingdom [U. K.]. In North Carolina, Buescher et al. (2006) used state Medicaid data to estimate the prevalence of medically fragile children (birth to 18 years old), identifying 1914 medically fragile children and adolescents with a total cost of \$133.8 million, or \$69,906 per adolescent, per year. Glendinning, Kirk, Guiffrida, and Lawton (2001) estimated 6,000 technology-dependent children and adolescents (birth to

16 years) living at home in the U. K. with an estimated yearly cost of 150,000 pounds (over \$200,000 in current U. S. dollars). More studies are needed to provide an assessment of the population to plan adequate programs and services (Buescher et al., 2006; Glendinning et al., 2001). These studies suggest that medically fragile adolescents who require respiratory assistance are not a large percentage of the pediatric population, but they use a large portion of health care resources.

Families caring for medically fragile adolescents. Studies on medically fragile adolescents have focused on the needs of the parents and parents' perceptions of caring for the adolescent and child. In these studies, families expressed the physical, emotional, and social stress that comes from caring for those who are medically fragile (Carnevale et al., 2006; Haley & Ratliffe, 2006; Heaton et al., 2005), and the limitations on school, employment, and social life that influence their daily lives. Montagnino and Mauricio (2004) examined eighteen parents caring for a child with a tracheostomy and a gastrostomy in a descriptive, quantitative study and found parents were coping with the emotional and financial strain, but indicated a disruption of parents' social interactions associated with the child's care. Data from these studies are limited to a focus on parents' perceptions caring for medically fragile children and adolescents.

School attendance by medically fragile adolescents. School attendance by medically fragile adolescents has been found to be beneficial to the adolescent and their family, while being a concern for those caring for them (Earle et al., 2006; Heaton et al., 2005; Rehm & Bradley, 2005; Rehm & Rohr, 2002). School attendance by medically fragile adolescents was found helpful for the adolescent's socialization and the normalization of family's lives (Rehm & Bradley, 2005; Rehm & Rohr, 2002). School

attendance challenged both the parents and those responsible for caring for the adolescents at school (i.e. school nurses, educators, and trained aides) with safety and proper care being a primary concern (Rehm & Rohr). Ultimately, the risks and benefits of school attendance for each adolescent must be weighed (Rehm & Rohr). Despite concerns about school attendance from those caring for medically fragile adolescents, school has been described by the adolescents' themselves as a source of social contact with peers (Earle et al., 2006; Heaton et al., 2005). These studies were limited in their focus on parent and caregiver perceptions and the inclusion of medically fragile children and adolescents in family interviews.

Experiences of medically fragile children and adolescents. There is insight into the importance of school, peers, social interactions, and being normal from studies that combined the medically fragile child and adolescent's perspective. Earle et al. (2006) described the perspective of children and adolescents (ages 4.5 to 17 years old) on home mechanical ventilation, finding they desire to be a normal child and stressing the psychosocial needs of the child which included school attendance and peer relationships. School and peers contributed to their self-esteem and sense of being normal (Earle et al.). Heaton et al. (2005) explored experiences at home of technology-dependent children and adolescents (ages 4 to 19 years old) who also articulated the importance of school, social interactions and friends. These studies of medically fragile adolescents' experiences have provided some understanding; however, combined the child and adolescent perspectives despite differing developmental levels of the participants. Because investigators included data from children and adolescents, the information is not specific to the developmental needs of the adolescent.

Nurses need to understand the experiences of the medically fragile adolescent who requires respiratory assistance in order to individualize care for this unique group. Thus far, the literature lacks focus on specific technology needs of the adolescent. We have some understanding of the parents' experiences, but lack understanding of the adolescent experience. The adolescent experience thus far has been combined with the child's perspective, leaving the adolescent perspective unclear. This study will help nurses to better understand what medically fragile adolescents who require respiratory assistance experience in their daily lives.

Significance to Nursing

Adolescents who are dependent upon technology to help with vital body functions and require skilled nursing care are often described as medically fragile (OTA, 1987). In the last 20 years, the population of medically fragile adolescents has grown considerably because of the sequelae of prematurity, injuries, and chronic or terminal illnesses (Buescher et al., 2006; Glendinning et al., 2001; Rehm & Rohr, 2002). Advances in medical care and technology now allow adolescents with chronic and life-threatening illness to live full, productive lives. Other adolescents may recover from life-threatening illnesses and live full lives relying constantly on technology.

Medically fragile adolescents who require respiratory assistance are a unique population with challenges in their daily lives, yet as nurses, we know little about their experiences. Medically fragile children and adolescents' have described the importance of school, peers, social interactions, and being normal in their daily lives (Earle et al., 2006; Heaton et al., 2005). However, these studies included both children and adolescents with a variety of medical diagnoses and technology needs, leaving the

adolescent who requires respiratory assistance perspective unclear. Adolescents with chronic illnesses have described how peer relationships, family, and school are important, but these studies have not included adolescents who require technology. The majority of literature about medically fragile adolescents comes from the adolescents' family rather than directly from the adolescents. Thus, we know the parents' perspective, but not the adolescents' perspective. The experiences of medically fragile adolescents who require respiratory assistance have not been articulated in studies found to date.

Adolescence is a unique developmental stage characterized by questions such as, "Who am I? How do I fit with peers and family? Where am I going in life?" (Erikson, 1963). For medically fragile adolescents who require respiratory assistance, these questions remain unanswered. This study will explore their experiences with peers and family, and their future plans so nurses can aid them in living full, productive lives.

Knowledge about the experiences of medically fragile adolescents who require respiratory assistance can provide nurses with a better understanding of their needs. This understanding can aid nurses in using the best approaches in caring for them. In addition, the knowledge gained from this study will contribute to the development of interventions to enhance nursing care specific to medically fragile adolescents. This study is the first step in building the nursing science on medically fragile adolescents who require respiratory assistance.

Statement of Purpose

The purpose of this study was to explore the experiences of medically fragile adolescents who require respiratory assistance. This study will help nurses to better understand what these adolescents experience in their daily lives. The overall aim of the

study was to gain an understanding of how medically fragile adolescents who require respiratory assistance experience their world. Specific aims of this study were to gain an understanding of their perceptions of (a) the day to day life of a medically fragile adolescent who requires respiratory assistance, (b) how the adolescent with respiratory assistance experiences family, friends, and school, (c) how an adolescent perceives their future possibilities, and (d) how nurses may help.

Theoretical Context

The theoretical context of the study encompasses my assumptions as a researcher and a nurse caring for medically fragile adolescents who require respiratory assistance. The context also directs the study of their unique experiences in order to improve the care provided to them by nurses. Interpretive phenomenology allows for exploration of the medically fragile adolescent's experiences, who they think they are, how they walk through the world, how they relate to others, and how they experience the day to day life with respiratory assistance.

Assumptions

The assumptions of the researcher directs the approach to the study of the experiences of medically fragile adolescents who require respiratory assistance. Knowledge of these assumptions as a nurse caring for these adolescents is necessary to limit the projection of one's interpretation on the experiences of medically fragile adolescents who require respiratory assistance.

1. Medically fragile adolescents who require respiratory assistance are a subset of the population of adolescents who are medically fragile.

2. Adolescents who require respiratory assistance have unique experiences that differ from those who require other assistive devices.
3. Medically fragile adolescents' experiences are taken-for-granted as they experience medical technology on a daily basis without considering their world.
4. Respiratory technology, whether or not omnipresent in the daily life of an adolescent, is omnipresent in their experiences.
5. Medically fragile adolescents know their experiences better than anyone (i.e., nurses, family, friends, school).
6. Adolescents, including those who are medically fragile, are at a unique developmental stage with unique developmental needs and concerns.
7. Medically fragile adolescents are human beings with very different perspectives from adults and they are able to articulate their experiences.
8. Nurses caring for medically fragile adolescents provide holistic care from a developmental perspective.
9. Nursing care for medically fragile adolescents includes concern for social, developmental, physical, and spiritual well-being.
10. Concerns perceived by the medically fragile adolescent who requires respiratory assistance differ from the concerns of those involved in their care (i.e. parents, nurses).
11. The perceptions of medically fragile adolescents differ from the perceptions of medically fragile children.

As a researcher, the awareness of these assumptions allows me to understand the potential limitations on my interpretation of the experiences of medically fragile adolescents who require respiratory assistance. As a researcher, I strive to accurately present the voice of the participants in my interpretation as the meaning of their experiences lies in my interpretation of those experiences (Heidegger, 1962).

Interpretive Phenomenology

Interpretive phenomenology guides the understanding of experiences through description and interpretation to uncover the hidden meanings in those experiences (Heidegger, 1962). This method was chosen for study of medically fragile adolescents who require respiratory assistance as this is the best method to better understand their experiences and, with that understanding, nurses will be able to better care for them.

Interpretive phenomenology seeks to understand what it means to be a human being (Heidegger, 1962). For nurses, this understanding is a part of being able to provide the best care for patients, and the question is, “what are the experiences of those we care for from their perspective?” Interpretive phenomenology is the chosen method for study because the experiences of medically fragile adolescents who require respiratory assistance are conceptualized as taken for granted. Interpretive phenomenology is the best method to reveal the taken for granted meaning in everyday experiences. Understanding these meanings will help nurses to provide better care to medically fragile adolescents who require respiratory assistance.

Interpretive phenomenology speaks to me as a nurse caring for adolescents. I have reflected upon my own experiences caring for medically fragile adolescents who require respiratory assistance, yet I am unable to reflect on the experience of these adolescents in

my care from their perspective. Van Manen said, “We gather other’s experiences because they allow us to become more experienced ourselves” (1990, p. 62). I want to better understand how these adolescents live with respiratory assistance. The best method to better understand this is to ask the adolescents themselves as experiences are self-evident (Heidegger, 1962). Interpretive phenomenology can guide me in uncovering the experiences of these adolescents whom we know so little about.

Interpretive Phenomenology as a Philosophy

The founding of modern phenomenology has been credited to Husserl from which Heidegger adapted in his philosophy of phenomenology (Carman, 2008). Heidegger questioned the meaning of being in his book, *Being and Time* (1962). In essence, this is a discussion of human understanding and making sense of our world. Heidegger (1962) tells us that the description of our everyday understandings will take the form of an interpretation of questioning of who we are. The interpretation offers insight into the meaning of the experiences (Heidegger). It is this experience that is so hidden that no question arises about its meaning, thus, it becomes that which demands to become a phenomenon (Heidegger). Heidegger said that “the meaning of phenomenological description lies in the interpretation” (p. 61).

Phenomenology in its essence questions the meaning of being and our understanding of being (Heidegger, 1962). Nurses understand themselves and their existence through practice and the persons they care for (Heidegger). Interpretive phenomenology offers nurse researchers the opportunity for understanding the experiences of those in our care (Leonard, 1994). Medically fragile adolescents who

require respiratory assistance are adolescents cared for by nurses, yet little is known about their experiences from their perspective.

Import Concepts of Interpretive Phenomenology

Heidegger's view of phenomenology includes conceptualization of the relationships between human beings and the world in which they live in. Import concepts include taken-for-granted, world, embodiment, and thrownness. This is the essence of the world of medically fragile adolescents who require respiratory assistance.

Taken for granted. The common every-day experiences of adolescents who require respiratory technology are conceptualized to be taken-for-granted. Taken-for-granted experiences mean that the experiences are hidden to conscious thought (Heidegger, 1962). These experiences happen so frequently that the individual expects them to occur. While the experiences and their meanings are hidden to the adolescent, they are unique to others. Revealing these experiences will assist nurses in understanding what it is like to be an adolescent who requires respiratory technology.

World. World signifies the relationships that we have by being born (Heidegger, 1962). The world of the adolescent who depends on respiratory technology includes the full context and his or her relationships. The adolescent will be asked to describe situations in full including people, objects, and their relationships with one another.

Embodiment. Our awareness of the world comes to us through our body and is known as embodiment. The term embodiment also connects mind and body (Merleau-Ponty, 1962). Interpretive phenomenology includes a diverse view of the body, rather than having a body, we are embodied in our experiences (Merleau-Ponty). Our

experiences shape who we are as human beings. The participants are shaped by their bodily experience with technology, so this concept is essential in this particular study.

Thrownness. At birth, Heidegger (1962) perceived that we are thrown into to the world, called thrownness. Persons are thrown into their world without prior knowledge or experience, or a choice of their world (Heidegger). From this thrownness, persons have possibilities that exist for them for who they can become and who they cannot become in life (Heidegger). Our experiences and our future possibilities are based on the world in which we live, the world in which we are thrown into. The participants have been thrown into a world that includes daily need for technology.

These adolescents embody the experience of an adolescent who has been thrown into a world requiring technology assistance, an experience that is taken-for-granted. They have been thrown into this situation without knowing any other world.

Interpretive Phenomenology as a Methodology

From Heidegger's perspective of phenomenology, a methodology of how the study is conducted is signified along with the philosophical perspective of the study (Heidegger, 1962). As a methodology, phenomenology provides a guide for the exploration of a phenomenon of interest through understanding of participant's experiences (Benner, 1994a). The meaning of these experiences lies in the interpretation by the researcher (Heidegger). The interpretation of experiences from the individual's unique perception of that experience is critical to the strength of phenomenology as a methodology (Munhall, 2007).

Researcher background and interpretive foreground. In interpretive phenomenology, the researcher acts as an interpreter for the participants; however, the

interpreter can never escape his or her own taken-for-granted background that makes the interpretive foreground possible (Benner, 1994b). As a researcher, being reflective about self and the impact of background allows the articulation of practical, everyday understandings and knowledge of the adolescents (Benner, 1994b). The researcher must be self-reflective as he or she is the human instrument (Lincoln & Guba, 1985). The interpretive researcher's questions unconsciously form and forecast the possible answers to the questions and this should be considered by the researcher (Benner, 1994a). The researcher's own background is part of the interpretation as what the researcher finds significant may be different than that of the participants, and may have different significance for different participants (Van Manen, 1990). Therefore, the researcher must always keep the perspective of the participants in the interpretive foreground.

Summary

The experiences of medically fragile adolescents who require respiratory assistance are linked to the philosophical perspective of interpretive phenomenology, directing the questions that are asked, the interpretation of questions, the answers of the participants, and the interpretation of the answers (Van Manen, 1990). The purpose of this study was to explore the experiences of medically fragile adolescents who require respiratory assistance. The best information about the experiences of medically fragile adolescents who require respiratory assistance comes from the adolescents themselves, because they know more about their experiences than anyone. Adolescents know and are able to articulate what they do, what helps them, and the people and things in their world that have meaning. Understanding the day to day experiences of adolescents who require

respiratory assistance will help nurses provide the best nursing care possible for this unique group of adolescents.

Interpretive phenomenology offers me as a nurse a philosophy and a methodology from which to understand the world of those adolescents I care for, specifically medically fragile adolescents who require respiratory assistance. Interpretive phenomenology has been reviewed in the context of exploring the experiences of medically fragile adolescents who require respiratory assistance. Interpretive phenomenology is the best choice for understanding the experiences of medically fragile adolescents who require respiratory assistance in order to best understand their perception of the experience.

Outline of the Study

This chapter provided an introduction to medically fragile adolescents who require respiratory assistance and the need for study of their experiences. The purpose of this study was to explore the experiences of medically fragile adolescents who require respiratory assistance. The chapter introduced the theoretical context of the study, interpretive phenomenology, and presented the assumptions of the researcher. The second chapter will elaborate on the literature review for the study, what we know and do not know about medically fragile adolescents who require respiratory assistance. The third chapter will describe the research methodology using interpretive phenomenology. Subsequent chapters will present the research process (Chapter 4), findings and discussion (Chapter 5), and conclusion and recommendations (Chapter 6).

CHAPTER II

Review of Literature

The literature on medically fragile adolescents who require respiratory assistance is sparse. Therefore, the developmental stage of adolescence will be discussed as a critical developmental stage for transition to adulthood. The literature on adolescents with chronic illness will also be presented in the context of concepts of importance in adolescence. Medically fragile children and adolescents will be discussed in the few studies that have included them as participants. The literature on families of medically fragile children and adolescents will be reviewed in their descriptions of caregiver experiences. Finally, medically fragile children and adolescents who require respiratory assistance will be discussed as a focus on a specific technology need in the literature.

Adolescence

Adolescence is a time of the development of identity, independence, and a sense of individuality (Erikson, 1963). Erikson placed adolescents in the developmental stage of identity versus role confusion, a time characterized by the questioning of self. Questions that arise for the adolescent include, “Who am I? How do I fit with peers and family? Where am I going in life?” Adolescents who establish identity are able to identify with peers and develop relationships with others, while those who have role confusion are unable to conceive the future with themselves as productive members of society (Erikson). In addition, the adolescent is concerned with their appearance, sameness with others, and future educational and occupational plans (Erikson).

In the developmental stage of adolescence, youth strive for independence and begin to make decisions that impact their future (Spear & Kulbok, 2004). Freud (1969) said that from adolescence onward the individual's great task is freedom or independence from parents. This independence is primarily a shift from dependence on parents, but also signifies a time of independence in thoughts, feelings, and actions (Erikson, 1963). The adolescent moves from a dependent role in the family to a more independent role in society.

The adolescent also develops a sense of individuality in relation to others. A sense of individuality, or individualism, is defined as an encouragement to be yourself, develop your own talent, and be your best (So, 1990). Individuality is described by Erikson (1963) as an obligation to be your best and to succeed in the adult world. The adolescent's sense of individuality, along with their sense of identity and independence, contribute to their feelings of self and their future plans in adulthood.

The development of identity, independence, and a sense of individuality in adolescence is affected by their physical health (i.e., chronic illness). Thus, chronic illness can affect the social and emotional development of the adolescent (American Academy of Child and Adolescent Psychiatry [AACAP], 2002). Adolescents with chronic illness may be more dependent on their family at a time characterized by the development of independence (Erikson, 1963). The desire to fit in with peers may lead to attempts to conceal their illness from others and poor adherence to treatment of their illness (AACAP). The presence of chronic illness may also lead to isolation from peers (Berlin, Davies, Jastrowski, Hains, Parton, & Alemzadeh, 2006; Sankey, Hill, Brown, Quinn, & Fletcher, 2006) and decreased school attendance which in turn affects

relationships with peers (Taras & Potts-Datema, 2007). Adolescents with chronic illness have themselves described how chronic illness affects their identity, their emotional development, and causes interruption in developmental tasks (Wilson, Pistrang, Woodhouse, & Christie, 2007). For medically fragile adolescents specifically, the effects on social and emotional development are unclear, but may be similar to adolescents with chronic illness.

Chronic Illness in Adolescence

The experiences of medically fragile adolescents who require respiratory assistance also encompasses the experience of a chronic life-threatening illness. Studies on adolescents with chronic illness can provide insight into the developmental challenges present in adolescence. Chronic illness in adolescence affects relationships with peers and family, and the ability to attend school. The literature on chronic illness in adolescence is discussed as the effect on peer relationships, family, and school attendance have relevance for medically fragile adolescents who require respiratory assistance.

Peer relationships. In adolescents with chronic illness, peer relationships have been described as important to adolescents, however, affecting the adolescents' ability to provide appropriate self-care (Berlin et al., 2006). Technological advances in the treatment of diabetes (i.e., insulin pumps) have presented difficulties in the daily lives of adolescents and their families (Berlin et al.). A sample of twenty adolescents and their families described difficulties primarily in a social context, with adolescents citing the majority of insulin pump and self-management difficulties in the presence of peers (Berlin et al.). This study described the complex interactions among chronic illness, technology, and peers.

Family. In adolescents with chronic illness (asthma, epilepsy, juvenile rheumatoid arthritis, diabetes) (n = 40, ages 13 to 17 years), adolescents' perceptions of social support were examined by asking about their social network (Kyngas, 2004). The adolescents described parents, peers, health care providers, school, technology (internet, telephone, television), and pets as part of their social network, with parents being the most frequently discussed members of support. Also of note, peers were differentiated as "fellow sufferers" and "friends without a chronic disease". Other adolescents with chronic disease were viewed as understanding, caring, and supportive (Kyngas, 2004). These findings indicated that friends are important, but the family remains the primary support for adolescents with chronic illness.

School attendance. Chronic illness in adolescence affects school attendance. Higher rates of school absenteeism have been found in studies of adolescents with chronic illnesses (Taras & Potts-Datema, 2007). For example, children with sickle cell disease attended 148 days in a school year versus 173 days in a school year for healthy children (Taras & Potts-Datema).

School absences also affect relationships with peers. Sankey et al. (2006) examined the symptoms and school absenteeism of children and adolescents (n = 28, ages 7 to 17 years) with chronic fatigue syndrome, a chronic illness characterized by disabling symptoms. The majority of participants (64%) missed more than 50% of the school year. The low school attendance also affected peer relationships with 39% citing difficulties with maintaining friendships (Sankey et al., 2006). Missing 50% of a school year presents problems with academic performance and can play a role in maintaining peer

relationships. These studies exemplify the issues of school attendance for adolescents with chronic illness and the associated problems with peer relationships.

In summary, the studies on adolescents with chronic illness have found descriptions of peers, family, and school, but the meanings for medically fragile adolescents who require respiratory assistance is unknown. Benner (1994b) stated that specific illnesses have their own narratives based upon common bodily experiences. From the perspective of medically fragile adolescents who require respiratory assistance little is known, yet adolescents with chronic illness may provide insight for medically fragile adolescents.

Medically Fragile Children and Adolescents

The experiences of medically fragile children and adolescents have been explored as participants in a few qualitative studies. The samples of these studies, both medically fragile children and adolescents, have included a wide range of ages and developmental stages, leaving the adolescent perspective unclear.

The experiences of medically fragile adolescents have depicted the importance of being normal, school attendance, peer relationships, and family, similar to adolescents with chronic illness. Earle et al. (2006) described the perspective of children and adolescents (n = 5, ages 4.5 to 17 years old) on home mechanical ventilation. Themes identified were the desire to be a normal child, being able to regularly attend school, and having reciprocal peer relationships not affected by their medical condition (Earle et al.). In a study of families, Heaton et al. (2005) explored experiences at home of technology-dependent children and adolescents (n = 13, ages 4 to 19 years old). The adolescents described their everyday lives and the importance of school, social interactions and

friends. Another study by Noyes (2000) interviewed 18 ventilator dependent children and adolescents (ages 6 to 18 years old) in a hospital setting. The participants described the isolation from family and peers and their exclusion from school and social activities due to prolonged hospitalizations (Noyes, 2000). These studies identify the importance of school, friends, and family in the lives of medically fragile adolescents. The importance of “being normal” has emerged from this work as a salient concept. Being normal seemingly included attending school and having friends which is consistent with developmental needs of adolescents.

The peer relationships of children who are medically fragile were found to differ from those of their healthy peers in a study by Rehm and Bradley (2006). Social interactions at school of medically fragile children (n = 11, ages 5 to 12 years old) were observed in a typical school day. Limited interactions were noted with peers (16.5% of interactions were with other children). The children were able and willing to interact with peers, but limited by their physical and developmental disabilities (Rehm & Bradley, 2006). This study presented a need for interactions with peers and the development of friendships for medically fragile children, potentially similar for medically fragile adolescents.

School has been discussed as a source of social interactions for medically fragile children and adolescents. Rehm and Rohr (2002) investigated the consequences of medically fragile children’s school attendance with specific attention to caregiver perspectives on potential risks and benefits of school attendance. The participants included 11 parents, 8 educators, 9 nurse case managers, and 5 school nurses involved in the care of medically fragile children and adolescents (ages 5 to 18 years old,

technologies not specified). Ultimately, school attendance was described as beneficial to the medically fragile children and adolescents by providing socialization with their peers, and respite for families. Risks of attending school included the need for increased care and monitoring, less resistance to and ability to cope with infectious illnesses, and social risks such as stigma (Rehm & Rohr, 2002). While there are benefits to school attendance, any and all risks must be considered in the decision to attend school.

In summary, these studies provide a good beginning to understanding medically fragile children and adolescents. Peers, family, and school have emerged as meaningful to medically fragile children and adolescents, but how these are meaningful to medically fragile adolescents specifically is unknown.

These studies that have included adolescents' experiences have combined the adolescent perspective with the perspective of children, resulting in a wide age range (ages 4 to 19 years old) with multiple developmental stages (preschool, schoolage, and adolescence) (Earle et al., 2006; Heaton et al., 2005; Noyes, 2000). These studies exemplify the current state of the literature on medically fragile adolescents that combines adolescence with other developmental stages. A major limitation is the lack of recognition of adolescence as a unique developmental stage with its own challenges. As a result, little is known of the adolescent perspective.

Families of Medically Fragile Children and Adolescents

Studies have primarily focused on the families of medically fragile children and adolescents with the voices of the children and adolescents combined with the rest of the family. These explorations of family experiences have included parents and siblings, as

well as the medically fragile children and adolescents. Findings from these studies reveal the stressors of the family and how the family attempts to normalize their daily lives.

Family stressors. Stress has been identified in families caring for those who are medically fragile. Haley and Harrigan (2004) identified stressors and strengths of Pacific Island parents ($n = 6$) caring for medically fragile children and adolescents (less than 18 years of age). The perceived stressors were financial burdens, care burdens, role conflicts (i.e., conflicts with parenting and work roles), and lack of independence or isolation from friends and family. The families found strengths in spirituality, family, and social support (Haley & Harrigan). In a descriptive quantitative study by Montagnino and Mauricio (2004), stress and coping was examined in mothers ($n = 18$) caring for infants ($n = 14$, ages 2 weeks to 1 year old), children and adolescents ($n = 4$, ages 1 year old and greater) with a tracheostomy and gastrostomy. Mothers reported personal strain, a disruption in social relations with father and others, and less ability to cope with the stress of caregiving (Montagnino and Mauricio). These studies stress the challenges that caring for a medically fragile child or adolescent places on the entire family, but do not reveal any information about the experiences of the adolescents themselves. The studies also describe the impact of caring for a medically fragile child and adolescent on the families' relationships, both within and outside family relationships. This may provide insight into the relationships of medically fragile adolescents who require respiratory assistance.

Another study revealed the stressful experiences in caring for a technology-dependent child and performing clinical procedures on their own children (Kirk, Glendinning, & Callery, 2005). The parents ($n = 33$) were caregivers of 24 medically fragile children and adolescents (ages under 5 to 18 years old) requiring technologies that

included tracheostomy, oxygen therapy, mechanical ventilation, intravenous medications, enteral and parenteral nutrition, and peritoneal dialysis. A majority of the children and adolescents required two or more technologies. The parents described the alteration in home life, the added role of technological care to parenting roles, and the dual role of parental caregiver and professional nurse. (Kirk et al., 2005) These technological care responsibilities were added stressors for the parents and altered the meaning of parenting for families caring for medically fragile adolescents. The question remains, as medically fragile adolescents who require respiratory assistance move toward independence, do they perceive technology?

Normalization in families. The importance of normalization and developing normal family routines has been cited as a significant daily effort by families of medically fragile children and youth (Cohen, 1999; Carnevale et al., 2006; Earle et al., 2006; Rehm & Rohr, 2002). Carnevale et al. (2006) portrayed seeking normalcy and normalization as an important part of the moral experience of families (n = 12) caring for ventilator-assisted children and adolescents (ages 1.8 to 19 years old). Ventilator assisted was defined as ventilation via tracheostomy and ventilation via face mask. These families created routines to make their lives resemble those of normal families. The children and adolescents also desired not to be different and demonstrated behaviors to avoid being considered different or not normal. For example, they described not attending sleepovers, so schoolmates would not know about the “machine” (Carnevale et al.). In this study, both the family and the medically fragile children and adolescents desired normalcy in their daily lives.

Having a medically fragile adolescent at home affects the normal function of a family. Rehm and Bradley (2005) compared parents' perceptions of normal family life using the concept of normalization as described by Deatrick, Knafl, and Murphy-Moore's (1999) work describing families caring for children with chronic illnesses. Normalization means that families caring for children with chronic illnesses redefine normal in steps of 1) acknowledging the chronic illness and its potential threat to the family, 2) adopting a normalcy lens to define the family, 3) engaging in parenting behaviors consistent with the idea of normalcy, 4) developing treatment regimens consistent with normalcy, and 5) interacting with others based on a view of the child and family as normal (Deatrick et al., 1999). Normal was described by 26 families caring for 31 medically fragile children (ages and technologies not specified) due to prematurity, injury, or genetic conditions with concomitant developmental delays (Rehm & Bradley, 2005). The families did not consider themselves normal, but they did strive to attain normal family routines. These normal family routines included routine tasks of parenting, cooking, and cleaning along with the role of a skilled caregiver.

For medically fragile adolescents and their families, the role of being normal has been described as important in their daily lives. Having normal routines and normalizing daily lives has been revealed in their experiences. These experiences have been described by families caring for those who are medically fragile and medically fragile children and adolescents. The perception of normal by medically fragile adolescents remains unclear.

In summary, the literature has primarily focused on the family, parents and caregivers, of those who are medically fragile. The families of medically fragile children, not specifically adolescents, have been explored, and when child and adolescents are

included in the study, child participants are the focus. These studies have provided some insight into the daily lives of medically fragile adolescents, but the perspective of the medically fragile adolescents on these experiences has not been fully revealed.

Medically Fragile Children and Adolescents: Respiratory Assistance

Studies have focused on medically fragile children and adolescents who require a specific technology. The technology specific population studied thus far has been those who are ventilator dependent and technologies associated with ventilator use (i.e. tracheostomies, BiPAP). These studies have relevance for study of medically fragile adolescents in the context of a specific technology need.

The experiences of families caring for a ventilator assisted child at home were explored from the perspectives of the parents, children, and siblings (Carnevale et al., 2006). The study found that seeking normalcy was an important part of the moral experience of families. The ventilator assisted children (n = 12, ages 1.8 to 19 years old) required ventilation via face mask (n = 8) and via tracheostomies (n = 4) due a range of respiratory disorders, neuromuscular weakness, spina bifida, and craniofacial or airway abnormalities. Families described stressful parental responsibilities, seeking normalcy, conflicting social values, living in isolation, and questioning the moral order (Carnevale et al.). Another study examined the transition of a ventilator dependent child (ages not specified) from hospital to home care using grounded theory methods from the perspective of 4 families (Cohen, 1999). Inclusion criteria specified that technology required by the children include ventilator support due to the associated complexity and high cost of care. Families experienced moral distress and changes in family income, social relations, and self-esteem (Cohen). These studies are examples of a specific group

of technology dependent children and adolescents, those that are ventilator dependent. These studies captured a unique group that required similar technologies with similar perspectives; however, these studies were family-focused and reflected primarily a child sample. The adolescent perspective was not explored.

Ventilator dependent children and adolescents have been explored from their perspective. Home ventilation from a child's perspective was explored by Earle et al. (2006). The ventilator assisted children and adolescents (n = 5, ages 4.5 to 17 years old) described their desire to be a normal child, being able to regularly attend school, and having reciprocal peer relationships not affected by their medical condition. Having psychosocial needs met contributed to their self-esteem and sense of being normal (Earle et al., 2006). Noyes (2000) interviewed 18 ventilator dependent young people (ages 6 to 18 years old) in a hospital setting who described the isolation from family and peers and their exclusion from school and social activities due to prolonged hospitalizations. Ventilator dependency was defined as a child who was medically stable requiring ventilator assistance for breathing, with the majority of participants (72%) requiring ventilation via tracheostomy (Noyes, 2000). The sample focused on a specific technology use (i.e. ventilators), however, reflected both children and adolescent perspectives.

In a study of school-age children with a tracheostomy, Spratling, Minick, and Carmon (in press) explored children's perceptions of friends, family, school, and their perceptions of nurses. The children (n = 5, ages 7 to 11 years) expressed the importance of friends as helpful in their daily lives, the effect of telling others about their tracheostomy as a way of facilitating friendships at school, and feelings of isolation and loneliness in not knowing other children like them (i.e., children with a tracheostomy)

(Spratling et al.). Findings from this study support the significance of peer relationships, both friends with a tracheostomy and those without that existed primarily with schoolmates. The data also revealed the richness and depth of experiences by the older school-age child (age 11 years), and the limitations in eligible participants by sampling only those with a tracheostomy. Consequently, work on this study revealed the possibilities in research with medically fragile adolescents in a specific developmental stage beyond a specific technology need.

Technology specific populations studied have focused on ventilator and ventilator-associated technologies. These studies have isolated a narrow group of the medically fragile pediatric population, providing insight into the daily lives of children and adolescents who require a particular technology. However, these studies lack concerns specific to the adolescent. At this time, we know little about the perceptions of medically fragile adolescents who require respiratory assistance.

Summary

Adolescence is a developmental stage characterized by identity, independence, and a sense of individuality. For medically fragile adolescents, their identities may be affected by their limited interactions with peers, they require dependence on technology assistance and family support in a time of independence, and their sense of individuality may be affected by the need for technology. In addition, peer relationships, family support, and school attendance are developmentally important for these adolescents. These have been identified as concerns in the experiences of adolescents with chronic illness and those who are medically fragile. What we do not know from the literature is how development is affected, how peers, family, and school are perceived, how day-to-

day living is affected, and how future plans are shaped by the adolescent's need for respiratory assistance. Thus, little is known of the experiences of medically fragile adolescents who require respiratory assistance.

CHAPTER III

Methodology

The method of inquiry is guided by the theoretical context, interpretive phenomenology. In this chapter, I discuss the research plan, including research design, setting, and participants. Data generation strategies, including recruitment, data collection, and data analysis, will be described from a phenomenological perspective. The assurance of authenticity and trustworthiness of interpretive phenomenology as a method will be discussed in detail. Finally, protection of human subjects will be addressed to ensure the rights of participants in the study.

Research Design

Interpretive phenomenology will be used to describe and interpret the lived experiences of medically fragile adolescents who require respiratory assistance. The purpose of this study is to explore the experiences of medically fragile adolescents who require respiratory assistance, and the adolescent is the best source of this information. These experiences can only come from these adolescents using interpretive phenomenology.

Setting

The participants will be recruited from the outpatient Technology Dependent Pulmonary Clinic in a large pediatric hospital system and a private pediatric Pulmonology practice in the Southeastern United States. Both settings serve medically fragile adolescents who require respiratory assistance in urban and rural areas.

Eligible participants will be accessed through the outpatient clinic in a large pediatric hospital system and a private pulmonology practice that serves medically fragile adolescents in both urban and rural areas. The pulmonology practice has two permanent offices in the metropolitan area and offers satellite offices in outlying areas. Access to multiple sites is warranted to capture an adequate sample of eligible participants. The outpatient clinic and private office are organized based on the needs of the pediatric population served (i.e., technology dependent) with each serving medically fragile adolescents who require respiratory assistance with a variety of pulmonary problems (i.e., airway disorders, bronchopulmonary dysplasia, chronic lung disease, cystic fibrosis, respiratory insufficiency and respiratory failure due to neuromuscular disorders and neurological disorders).

Participants

Participants will be chosen based on their experiences with respiratory assistance within the adolescent developmental stage. Medically fragile adolescents who require respiratory assistance will be defined as those who are dependent upon respiratory assistance such as tracheostomies and ventilator support, mechanical ventilation via tracheostomy or positive airway pressure support via face mask (i.e., Bi-level positive airway pressure [BiPap]). The proposed purposive sample of medically fragile adolescents who require respiratory assistance will include adolescents 13 to 18 years of age, male or female gender of any race or ethnicity. Adolescents of this age group were chosen based on their similarity in developmental stage, secondary level of school, and being minors in the care of their parents. Their need for respiratory assistance is also considered similar despite differing severities of assistance (i.e., tracheostomy versus face

mask). The respiratory assistance is similar in the respect that if assistance is not provided, life-threatening problems will result.

Additional inclusion criteria are 1) adolescents using a minimum of one medical technology that provides respiratory assistance on a daily basis for the past twelve months or history of use of technology that provides respiratory assistance on a daily basis in the past two years. Medical technology that provides respiratory assistance will be defined as a technological device used to compensate for a vital respiratory function. The use of technology that provides respiratory assistance on a daily basis for the past 12 months will capture adolescents who have recently and routinely experienced the phenomenon of interest. Other inclusion criteria are 2) the ability to understand and read English, and 3) the cognitive ability to participate by answering questions without assistance from parents. The ability to speak with the researcher without interpretation by others will capture the experiences of the adolescents. Ideally, inclusion criteria would contain need for skilled nursing care on a regular basis to fit with definition of medically fragile, however, based on researcher's experience, actual hours of nursing care per week is a complex issue that may not relate well to the technology needs of the adolescent (i.e., relates to insurance, health care provider, and length of illness). Nursing care information will be obtained along with other individual and clinical characteristics.

Exclusion criteria include 1) adolescents with a diagnosis history of behavioral disorders and developmental disabilities limiting their inclusion in general classrooms will be excluded. The rationale for both these exclusion criterion is the potential impact on peer relationships and their ability to fully participate in the study. Additionally, 2) adolescents with a history of an extensive hospitalization, defined as greater than one

month, in the last 6 months will also be excluded. The rationale for this is the recent impact on need for technology and the potential impact on peer relationships and school attendance. These sampling criteria will be used to obtain a representative sample of medically fragile adolescents who require respiratory assistance (Brink & Wood, 1998).

The sample size will be determined by data saturation with a goal of 15 eligible participants. The clinic currently serves approximately 200 infants, children, and adolescents who require respiratory assistance. Of those, 75 are in the adolescent developmental stage with a conservative estimate of 30 being potential participants in the study. The practice serves approximately 25,000 patients with a conservative 0.1%, or 25, of those requiring respiratory assistance. Of those requiring respiratory assistance, approximately 10 are in the adolescent developmental stage. With these estimates, a total of 40 patients are potential participants in the study. In a previous study by Spratling et al. (in press), approximately half of potential participants were successfully recruited for the study.

Data Generation Strategies

Recruitment

An informational session will be offered to all providers working in the clinics and offices about the study, and written material will be provided to them. This will be done to aid in recruitment of potential participants and enhance the providers' knowledge of the study. For example, if possible participants expressed an interest or asked questions about the study, the practitioner would be able to provide information and recommend further contact with the principal investigator.

After Institutional Review approvals are obtained, potential participants who met eligibility criteria will be identified by nurse practitioners and physicians in the outpatient clinic and offices. The parents of potential participants will be mailed a recruitment form which includes information for both the parent and the adolescent about the study. Interested participants will be instructed to contact the principal investigator by email or telephone for an interview. If no response, a reminder form will be mailed to potential participants three weeks after the initial mailing. Flyers will also be posted in the clinic and offices in areas visible to the medically fragile adolescents and their families. The researcher will also make herself available for questions and interviews with potential participants in the clinic and offices during their time of visit in case they have any questions. In addition, if possible participants express an interest to a provider about the study; the provider would remind the parent the next time a routine call was provided of the investigators availability at the next scheduled clinic visit.

Prior to data collection, the purpose of the study, including risks and benefits, will be discussed with the parent(s) and the adolescent. Written informed consent (see Appendix A) from the parent and written assent (see Appendix B) from the adolescent will be obtained. The principal investigator will then proceed with data collection with the adolescent in a private, comfortable, quiet environment. The parent will be asked not to participate; however, they may remain at a location nearby.

Data Collection

In phenomenological studies, the data are the lived experiences of the participants (Van Manen, 1990). In this study, the data will be obtained from the

participants in a semi-structured interview. An in-depth interview with the adolescent will be conducted and audiotaped. In addition, field notes will be collected by the researcher.

The initial questions are developed specifically to establish rapport with the adolescent, encouraging them to discuss favorite things to do. The adolescents are asked initially, “Tell me about a time when you were doing something you really like to do. What are some of the other things you like to do? With friends? At home?” Subsequent questions explore the world of the adolescent, including daily life, school, future plans, and technology. For example, the adolescents are asked, “How do you see yourself in the future? College? Relationships?” The final questions inquire about advice for peers and nurses. For example, the adolescents are asked “What advice would you give to another adolescent with respiratory assistance? What advice can you give me to take care of an adolescent with respiratory assistance?” and “What can nurses do for you that is most helpful? What is not helpful?” These questions were asked in a previous phenomenological study by the researcher and revealed how nurses could better care for them (Spratling et al., in press). The interview guide can be found in Appendix C.

A demographic data form will be investigator-administered to the adolescents, including school attendance and grade level, medical diagnoses, hospitalizations, respiratory assistance required, any other technological supports needed by the adolescent, and nursing hours per week. The demographic information will be obtained in order to describe the sample and to guide understanding of their progression in school and the adolescent’s need for technology on a daily basis. The demographic form can be found in Appendix D.

Data collection will require approximately 30 minutes of the participants time with a maximum of one hour allotted for interview due to the limited attention span of the adolescents based on previous interview experience (Spratling et al., in press). Duration of study from initial recruitment to completion of data collection is anticipated to be six months, but will be extended as needed to recruit eligible participants. Participants will be compensated with a twenty dollar gift card upon completion of the study.

Data Analysis

The interviews will be audiotaped and transcribed verbatim. The interview transcripts will then be reviewed while listening to the audiotaped interview to ensure accuracy of the data. The field notes taken by the researcher will be incorporated into the interview transcript (Crist & Tanner, 2003). In addition, a reflective journal will be used by the researcher throughout the data analysis. The reflective journal will record personal feelings, ideas, and thoughts about the study. An audit trail will also be used by the researcher throughout the study. The audit trail will be kept to document the decisions made in the study and why the decisions were made. This will be presented in the write up of the study, so the reader can determine whether they agree with the decisions made. The audit trail will allow the researcher to clearly reference progress in understanding of the data and record changes in interpretation of the data (Lincoln & Guba, 1985).

Data analysis will be done by the researcher, a PhD in nursing student, and the research team, consisting of two PhD nursing students familiar with interpretive phenomenology and a recent PhD-nursing graduate who completed dissertation research in interpretive phenomenology. Further data analysis will be completed through peer debriefing with PhD dissertation committee, consisting of three faculty experienced with

research in interpretive phenomenology and adolescence. The research team serves as an aid in the interpretation of different meanings and also recognizes the researcher's assumptions as a nurse experienced in the care of these adolescents.

Data collection and data analysis will occur simultaneously. As a result of the simultaneous occurrence of data collection and analysis, initial interpretations can be validated with adolescents who participate in subsequent interviews. An example would be the interviewer says, "Some adolescents have told me that...Is that how it is for you or is it different?" Data analysis will begin with the completion of the first interview using the steps delineated by Diekelmann and Allen (1989). This data analysis method guides interpretations from the parts to the whole and whole to the parts and identifies shared meanings of the participants (Diekelmann & Allen).

In the first step of analysis, the interviews of the adolescent will be summarized by each member of the research team to gain an understanding of their experience and the interview as a whole (Diekelmann & Allen, 1989). The second step will consist of reading the transcripts line by line and coding everything the participant says in the interview. The codes of the second interview will be compared the codes of the first interview, and so on. This comparison of each interview to previous interviews is known as the constant comparison method. The third step will consist of identifying meaningful phrases and words coded from the interviews and grouping those that are examples of the experiences of the adolescent. These groupings of codes, called categories, will be compared with interviews of other adolescents in the third step as well, evaluating for similarities and differences among interviews. In the fourth step of analysis, the research team will identify similar and contradictory categories within the texts. When differences

arise, the team will reach consensus by returning to the transcript as a whole. In addition, themes will be identified from the categories. In the fifth level of analysis, the research team will identify emerging patterns which exist in all interviews that describe the relationship between the themes. In the final step of analysis, the themes will be reviewed by the research team, dissertation committee, and key participants to validate the interpretations (Diekelmann & Allen).

Trustworthiness

Trustworthiness in the study will be ensured in data collection and analysis. Lincoln and Guba (1985) cite credibility, transferability, dependability, and confirmability as criteria for trustworthiness in qualitative inquiry, as is interpretive phenomenology. Findings of the study will be validated with key participants; specifically, findings from adolescent participants will be validated later with key adolescent participants. This member checking will test data and interpretations with adolescent participants, a crucial technique for establishing credibility (Lincoln & Guba). Benner (1994b) concurred that it is good to clarify interpretations with the participants and can be done by paraphrasing what the participant has said, staying as close to the participant's account as possible. Findings from the adolescent participants will be presented using thick descriptions and quotes from the participants, allowing the reader to determine whether the findings are transferable to other adolescents (Lincoln & Guba). Dependability and confirmability of the data will be ensured through audiotaped interviews that are transcribed verbatim in addition to field notes and an audit trail will record observations by the researcher to adjunct the transcriptions (Benner, Tanner, & Chesla, 2009; Lincoln & Guba, 1985). The audit trail will record methodological

decisions and the reasoning behind them (Lincoln & Guba). Findings of the study will be validated with the research team as using a team approach will aid in obtaining multiple viewpoints and preventing over interpretation or under interpretation of the interview data (Lincoln & Guba).

Researcher Bias

In the interpretation of the experiences of others, the researcher respects differences and commonalities between themselves and the participants (Benner, 1994b). My experience is that of a white woman from the Southern United States who is considered educated and privileged in society. I am married with a child who has been blessed with good health. My familiarity with families and children experiencing life with respiratory assistance is in the dynamic relationship between the parents, the adolescent, and the health care provider.

Protection of Human Participants

Study participants will not incur any costs. There are not any foreseeable risks to participation in this study. After Institutional Review Board (IRB) approvals from the hospital system and other related organizations, written consent will be obtained from the parent and written assent will be obtained from the adolescent. Consent and assent will be obtained after details of the study are discussed with both the parent and the adolescent, including confidentiality, and risks and benefits (Shadish, Cook, & Campbell, 2002). A copy of the assent and consent form will be provided to the parent and the adolescent. Confidentiality will be maintained through identification numbers on questionnaires for each participant. A roster of participant names and corresponding number will be available to the research team. The participant roster and their assigned numbers will be

kept in another locked file cabinet separately from the data. The participant roster and their assigned number, and all audiotapes will be destroyed one year after study completion. The consideration of human subjects is important as phenomenological research touches the participants, and such consideration hopes to minimize any untoward effects (Van Manen, 1990).

Summary

In this chapter, an overview of the proposed research methods of interpretive phenomenology has been presented as the basis for study. The setting, participants, and data generation strategies have been presented. Data collection and data analysis will be completed using rigorous methods consistent with interpretive phenomenology. Authenticity and researcher bias are also discussed. In addition, protection of human participants is discussed as an essential part of the research methods.

CHAPTER IV

Research Process

In this chapter, I discuss the research process, including research design, setting, and recruitment of participants. A phenomenological perspective was maintained throughout the data generation process, from data collection through data analysis. Trustworthiness was assured in the research process. Protection of human subjects was also ensured for the participants.

Research Design

Interpretive phenomenology was used to describe and interpret the lived experiences of medically fragile adolescents who require respiratory assistance. The purpose of this study was to explore the experiences of medically fragile adolescents who require respiratory assistance. The adolescent is the best source of the information about their experiences with respiratory assistance. Interpretive phenomenology can aid to reveal the unique experiences of these adolescents.

Setting

Eligible participants were recruited from the outpatient Technology Dependent Pulmonary Clinic in a large pediatric hospital system and a private pediatric Pulmonology practice in the Southeastern United States. The pulmonology practice had two permanent offices in the metropolitan area and offered satellite offices in outlying areas. Both the clinic and office settings served medically fragile adolescents who require

respiratory assistance in urban and rural areas. Access to multiple sites was warranted to capture an adequate sample of eligible participants.

The outpatient clinic and private office were organized based on the needs of the pediatric population, serving a variety of pediatric patients with pulmonary problems (i.e., airway disorders, bronchopulmonary dysplasia, chronic lung disease, respiratory insufficiency and respiratory failure due to neuromuscular disorders and neurological disorders) from birth to 21 years of age. The outpatient clinic cared for those with respiratory assistance of a tracheostomy and other respiratory assistance associated with a tracheostomy. The private offices cared for those who require respiratory assistance not associated with a tracheostomy (i.e., BiPap).

Participants

Participants were chosen based on their experiences with respiratory assistance within the adolescent developmental stage. Medically fragile adolescents who require respiratory assistance were defined as those who were dependent upon respiratory assistance such as tracheostomies and ventilator support, mechanical ventilation via tracheostomy, or positive airway pressure support via face mask (i.e., Bi-level positive airway pressure [BiPap]). The purposive sample of medically fragile adolescents who require respiratory assistance included adolescents 13 to 18 years of age, male or female gender of any race or ethnicity. All participants met these inclusion criteria. Adolescents of this age group were chosen based on their similarity in developmental stage, secondary level of school, and being minors in the care of their parents. All participants were of similar developmental stage, attended high school, and were in the care of their parents, although two were not legally considered minors at 18 years of age. Their need for

respiratory assistance was also considered similar in the respect that if assistance was not provided, life-threatening problems would result. The participants of the study required respiratory assistance that if not used would be emergently detrimental to their health and potentially life-threatening. The single exception was one participant who had been decannulated (i.e., tracheostomy removed) recently.

Additional inclusion criteria were 1) adolescents using a minimum of one medical technology that provided respiratory assistance on a daily basis for the past twelve months or history of use of technology that provides respiratory assistance on a daily basis in the past two years. Medical technology that provides respiratory assistance was defined as a technological device used to compensate for a vital respiratory function such as a tracheostomy, mechanical ventilation, or BiPap. Participants were currently using medical technology on a daily basis, often more than one technology, with the exception of one participant who had been decannulated with tracheostomy stoma closure in the past 12 months. This participant had used technology on a daily basis prior to this time. All of the participants had recently and routinely experienced the phenomenon of interest.

Other inclusion criteria were 2) the ability to understand and read English, and 3) the cognitive ability to participate by answering questions without assistance from parents. All participants met these criteria, demonstrating the ability to understand the interview process and articulate their experiences. The adolescents' ability to speak with the researcher without interpretation by others captured the experiences of the adolescents.

Exclusion criteria included those 1) adolescents with a diagnosis history of behavioral disorders and developmental disabilities limiting their inclusion in general

classrooms. The rationale for both these exclusion criterion was the potential impact on peer relationships and their ability to fully participate in the study. All participants met these criteria, although some adolescents noted that they had “tutored” or independent study class sessions in their class schedules as a result of illness and missed class days in the past. All participants verbalized friendships and were able to discuss their experiences in the study interviews. Additionally, 2) adolescents with a history of an extensive hospitalization, defined as greater than one month, in the last 6 months were excluded. The rationale for this was the recent impact on need for technology (i.e., greater need for technology post hospitalization) and the potential impact on peer relationships and school attendance (i.e., decreased contact with friends and missed days from school). All participants met these criteria with no participants reporting an extensive hospitalization in the last six months. Many participants had not experienced an extensive hospitalization since their infant and toddler years. These sampling criteria successfully obtained a representative sample of medically fragile adolescents who require respiratory assistance in their daily lives.

The sample size was determined by data saturation with a goal of 15 eligible participants. Eleven participants were recruited for the study. Initial estimates for potential participants in the clinic and office were a total of 40. The clinic and office identified 18 eligible participants who currently required respiratory assistance who were 13 to 18 years of age and were able to participate in interviews without assistance. Many adolescents were not eligible due to developmental delays, behavioral disorders, and communication limitations. The conservative estimate of eligible participants vastly overestimated the number of participants who were developmentally appropriate and able

to communicate. Based on the number of 18 identified eligible participants and the number of participants in the study as eleven, the study recruitment was greater than half of the number of identified eligible participants.

Data Generation Strategies

Recruitment

After Institutional Review approvals were obtained, potential participants who met eligibility criteria were identified by providers, nurse practitioners and physicians, in the outpatient clinic and offices. In addition, nurses and respiratory therapists at the clinic and office were also helpful in identification of participants.

Information was offered to providers working in the clinics and offices about the study, and written material was provided to them. An informational session at the office included a brief overview of the study presented by the principal investigator and the presentation of a handout that summarized the study during a provider meeting (see Appendix E). At the clinic, providers, including the nurse practitioner, and the clinic staff were met with individually to discuss the study. During this time, the majority of eligible participants were identified for recruitment in the study.

The parents of potential participants were mailed a recruitment form which included information for both the parent and the adolescent about the study. Interested participants were instructed to contact the principal investigator by email or telephone for an interview. If no response, a reminder form was mailed to potential participants three weeks after the initial mailing. Four participants were recruited using this approach, including two participants who immediately called or emailed upon receiving the initial

recruitment mailing and two participants who emailed or telephoned months after the initial and reminder mailings.

In addition, flyers were posted in provider-only accessible areas in the office as a reminder at the time they were seeing patients that might be eligible (see Appendix F). Each nurse in the office was also given a flyer to post at her desk as a reminder when speaking to parents of eligible participants over the phone. The providers and nurses were instructed to contact the principal investigator of eligible participants who then contacted potential participants by mail.

Flyers were not posted in the clinic and offices in areas visible to the medically fragile adolescents and their families. The clinic and office providers felt that this approach would not capture any additional potential participants. The clinic also presented limitations of multiple clinics being held based on the date and time, necessitating the need to post and remove flyers on a constant basis. Flyers aimed toward providers were deemed a better approach to identify eligible participants and to remind providers of information about the study to discuss with eligible participants and their families. Few participants were identified using this approach, however, three participants contacted the principal investigator by phone after reviewing the mailings and subsequently speaking with their provider about the study.

The researcher made herself available for questions and interviews with potential participants in the clinic and offices during their time of visit. In addition, if possible participants expressed an interest to a provider about the study; the provider or staff would remind the parent when a routine call was provided of the investigators availability at the next scheduled clinic visit. This approach was found to be effective in making

contact with eligible participants and their families. Often, the adolescent and parent would agree to participation in the study and would request the interview be completed at the visit. Four participants were recruited at the clinic using this approach. The parents and adolescents verbalized that they had received the mailings and reviewed the information about the study, but had not had time to call or plan an interview time. Conducting the interview at the clinic was stated by parents and the adolescent participants as a convenient time and location for the interview.

Prior to data collection, the purpose of the study, including risks and benefits, was discussed with the parent(s) and the adolescent. A thorough discussion of the study was found to enhance the adolescents' active participation in the interview. Written informed consent (see Appendix A) from the parent and written assent (see Appendix B) from the adolescent was obtained. The principal investigator then proceeded with data collection with the adolescent. The parents were asked not to participate, but remained at a location nearby such as a nearby room in the home or the waiting room. The majority of the interviews ($n = 9$) occurred without the presence of the parents. When present during the interview, parents felt the need to assist with clarification of speech for adolescents with a tracheostomy who did not use a speaking valve ($n = 2$). This was not necessary as the researcher was able to communicate with the adolescents without assistance except for the occasional need to have the adolescent restate words. These parents did not answer questions or impose their thoughts during the interview, but did periodically restate the words of the adolescent.

Data Collection

In this phenomenological study, the data were the lived experiences of the participants (Van Manen, 1990). The data were obtained from the participants in an audiotaped semi-structured interview with the adolescent. In addition, field notes were collected by the researcher.

Data collection occurred at the adolescent's home, the clinic, and other settings familiar to the adolescent. Six interviews took place at the adolescent's home in the living spaces common to the family. Four interviews were conducted at the clinic with three interviews in a private exam room and one interview in a secluded area of the clinic waiting room. One interview occurred at the mall food court prior to the opening of restaurants in that area. All interviews were conducted in a private and comfortable environment. The interview setting was reasonably quiet in respects to hallway noise at the clinic and noise in the home such as a television in the distance.

The initial questions were developed specifically to establish rapport with the adolescent, encouraging them to discuss favorite things to do. The adolescents were asked initially, "Tell me about a time when you were doing something you really like to do. What are some of the other things you like to do? With friends? At home?" These questions seemed to be easy to answer and opened up the discussion, making the interview less of an interrogation or a test for the adolescent.

Subsequent questions explored the world of the adolescent, including daily life, school, future plans, and technology. For example, the adolescents were asked, "How do you see yourself in the future? College? Relationships?" The majority of adolescents

readily talked about plans for the future which included college, career, family, and children without a need for further prompting about college and relationships.

The final questions inquired about advice for peers and nurses. For example, the adolescents were asked “What advice would you give to another adolescent with respiratory assistance? What advice can you give me to take care of an adolescent with respiratory assistance?” and “What can nurses do for you that is most helpful? What is not helpful?” With these questions, the adolescents’ often needed help to focus their ideas with “If you could give advice to another teenager like yourself, what would you tell them?” The interview guide can be found in Appendix C.

A demographic data form was investigator-administered to the adolescents. The demographic data included school attendance and grade level, medical diagnoses, hospitalizations, respiratory assistance required, any other technological supports needed by the adolescent, and nursing hours per week as described by the adolescents. The adolescents described multiple technologies in addition to their primary technology of respiratory assistance. Their description of their medical diagnoses was typically a global description of “lung problems” as opposed to a specific diagnosis such as chronic lung disease or muscular dystrophy. The demographic information described the sample and guided understanding of the adolescents’ progression in school and need for technology on a daily basis. The demographic form can be found in Appendix D.

Data collection required approximately 30 minutes of the participants time with a maximum of one hour allotted for interview due to the limited attention span of the adolescents based on previous interview experience (Spratling et al., in press). Interviews were typically 30 minutes in length with two interviews of approximately 45 minutes.

The adolescents were attentive during the interview, but often concluded topics when they felt there was no more to discuss in the interview.

Duration of study from initial recruitment to completion of data collection was anticipated to be six months. After six months, there had not been any new eligible participants identified in the previous three months. In addition, all recruitment efforts of identified potential participants had been exhausted using mailings, being available at office and clinic visits, and with participants having discussed the study with providers without contacting the principal investigator.

Participants were compensated with a twenty dollar gift card. The adolescent was allowed to choose from a variety of gift cards for stores with items of interest for the adolescent such as electronics, music, and clothing. The gift card was given to the adolescent in the presence of the parent after the study was discussed and the assent and consent forms were signed.

Data Analysis

The interviews were audiotaped and transcribed verbatim. The interview transcripts were reviewed while listening to the audiotaped interview to ensure accuracy of the data. The field notes taken by the researcher were incorporated into the interview transcript (Crist & Tanner, 2003). In addition, a reflective journal was used by the researcher throughout the data analysis which recorded personal feelings, ideas, and thoughts about the study. An audit trail was used by the researcher throughout the study to document the decisions made in the study and why the decisions were made. This is presented in the write up of the study, so the reader can determine whether they agree with the decisions made. The audit trail allowed the researcher to clearly reference

progress in understanding of the data and record changes in interpretation of the data (Lincoln & Guba, 1985).

Data analysis was completed by the researcher, a PhD in nursing student, and the research team, consisting of a PhD nursing student familiar with interpretive phenomenology. Further data analysis was completed through peer debriefing with PhD dissertation committee, consisting of three faculty experienced with research in interpretive phenomenology and adolescence. The research team aided in the interpretation of different meanings and recognized the assumptions of the researcher as a nurse experienced in the care of these adolescents.

Data collection and data analysis occurred simultaneously. As a result of the simultaneous occurrence of data collection and analysis, initial interpretations were validated with adolescents who participated in subsequent interviews. For example, the interviewer said, "Some adolescents have told me that...Is that how it is for you or is it different?" For one adolescent participant who was reluctant to talk and extremely shy, these member checks served to open up the discussion for the adolescent. Data analysis began with the completion of the first interview using the steps delineated by Diekelmann and Allen (1989), a method which guided the interpretations from the parts to the whole and whole to the parts and identified shared meanings of the participants.

In the first step of analysis, the interviews of the adolescent were summarized by each member of the research team to gain an understanding of their experience and the interview as a whole (Diekelmann & Allen, 1989). The second step consisted of reading the transcripts line by line and coding everything the participant says in the interview. The codes of the second interview were compared the codes of the first interview, and so

on, using the constant comparison method. The third step consisted of identifying meaningful phrases and words coded from the interviews and grouping those that are examples of the experiences of the adolescent. The code book can be found in Appendix G. These groupings of codes, called categories, were compared with interviews of other adolescents in the third step as well, evaluating for similarities and differences among interviews. The categories can be found in Appendix F. In the fourth step of analysis, the research team identified similar and contradictory categories within the texts. In addition, themes were identified from the categories. In the fifth level of analysis, the research team identified emerging patterns existing in all interviews that describe the relationship between the themes. In the final step of analysis, the themes were reviewed by the research team, dissertation committee, and key participants to validate the interpretations (Diekelmann & Allen). Data analysis with the research team occurred in routinely scheduled sessions focusing on specific interviews while also revisiting interviews that had been previously discussed by the team.

Trustworthiness

Trustworthiness in the study was ensured in data collection and analysis. Lincoln and Guba (1985) cited credibility, transferability, dependability, and confirmability as criteria for trustworthiness in qualitative inquiry, as is interpretive phenomenology. Findings of the study were validated with key participants; specifically, findings from adolescent participants were validated later with key adolescent participants. This member checking tested data and interpretations with adolescent participants, a crucial technique for establishing credibility (Lincoln & Guba). Benner (1994b) concurred that it is good to clarify interpretations with the participants and can be done by paraphrasing

what the participant has said, staying as close to the participant's account as possible. Findings from the adolescent participants were presented using thick descriptions and quotes from the participants, allowing the reader to determine whether the findings are transferable to other adolescents (Lincoln & Guba, 1985). Dependability and confirmability of the data was ensured through audiotaped interviews that were transcribed verbatim in addition to field notes and an audit trail recorded observations by the researcher to adjunct the transcriptions (Benner et al., 2009; Lincoln & Guba, 1985). The audit trail recorded methodological decisions and the reasoning behind them (Lincoln & Guba). Findings of the study were validated with the research team as using a team approach. This validation of findings aided in obtaining multiple viewpoints and prevented over interpretation or under interpretation of the interview data (Lincoln & Guba).

Researcher Bias

In the interpretation of the experiences of others, the researcher respected differences and commonalities between herself and the participants (Benner, 1994b). My experience is that of a white woman from the Southern United States who is considered educated and privileged in society. I am married with a child who has been blessed with good health. My familiarity with families and adolescents experiencing life with respiratory assistance is in the dynamic relationship as a pediatric nurse practitioner and nurse caring for these adolescents and their families.

Protection of Human Participants

Study participants did not incur any costs. There were not any noted risks to participation in this study. After Institutional Review Board (IRB) approvals from the

hospital system and other related organizations, written consent was obtained from the parent and written assent was obtained from the adolescent. The consent and assent were obtained after details of the study were discussed with both the parent and the adolescent, including confidentiality, and risks and benefits (Shadish et al., 2002). A copy of the assent and consent form was provided to the parent and the adolescent. Confidentiality was maintained through identification numbers on questionnaires for each participant. A roster of participant names and corresponding number was available to the research team. The participant roster and their assigned numbers was kept in another locked file cabinet separately from the data. The participant roster and their assigned number, and all audiotapes will be destroyed one year after study completion.

Summary

In this chapter, an overview of the research process using interpretive phenomenology has been presented for the study. The setting, participants, and data generation strategies have been presented. Data collection and data analysis were completed using rigorous methods.

CHAPTER V

Findings and Discussion

This chapter will discuss the findings of the study, including participant characteristics and themes. The information on participant characteristics was obtained from the adolescent participants, allowing them to describe themselves in their own words. Themes emerged from the interpretation of interviews with eleven adolescents who required respiratory assistance. The adolescents' words are included to illustrate the themes.

Participant Characteristics

The participants of this study were eleven adolescents who required respiratory assistance. All of the participants lived in the Southeastern United States in both urban and rural areas. Five participants were male and six participants were female. Two participants were African-American, seven were Caucasian, one was Hispanic, and one was both African-American and Caucasian. The adolescents ranged in age from 13 to 18 years of age with a mean age of 15 years 8 months.

All of the adolescents had recent experience with respiratory assistance. Seven of the adolescents currently had a tracheostomy with four of these adolescents also requiring respiratory support at night. Two adolescents did not have a tracheostomy, but had experienced a tracheostomy; one adolescent had been decannulated with tracheostomy stoma closure in the past year and one adolescent had been decannulated in the past three years with continued need for nightly BiPap with sleep. Three adolescents were using

BiPap on a nightly basis, including the two adolescents without history of a tracheostomy.

The adolescent participants were able to communicate their experiences. The participants with a tracheostomy either used a speaking valve (n =3), did not use a speaking valve (n = 2), or had the tracheostomy capped (n = 2). Those participants who did not use the speaking valve or tracheostomy cap had a soft voice and were difficult to understand at times, resulting in intermittent clarification of speech from parents despite the researcher's experience in communicating with tracheostomy patients. In addition, some of the participants requiring a tracheostomy who used the speaking valve or requiring BiPap were noted to have a soft voice that was sometimes difficult to understand associated with their respiratory problems. The researcher would restate the adolescents' words or ask them to restate their words to ensure that they were heard correctly by the researcher.

All of the participants attended school regularly and none had experienced an extensive hospitalization in several years affecting school attendance. Typically, the adolescents described their last hospitalization as being in infancy or childhood. Ten of the adolescents attended public school. One adolescent attended private school. Eight of the adolescents were at expected grade level. Three adolescents were one to two years below expected grade level.

The participants were asked to tell the researcher about their medical diagnoses in their own words. The medical diagnoses described by the adolescents included "lung problems", "hard-time breathing", "upper respiratory history", and "back is curved, so

hard to breathe” in addition to musculoskeletal problems of “muscle weakness”, “hard-time walking”. Medical diagnoses included neurofibromatosis (n = 2), spina bifida (n = 1), muscular dystrophy or atrophy (n = 4), congenital abnormalities (n = 3), and quadriplegia due to injury (n = 1).

The participants required respiratory assistance of tracheostomies, ventilators, including positive airway support via ventilator, and BiPap. In addition, they required multiple technologies associated with their need for respiratory assistance, including oxygen concentrators, humidifiers, vest therapy (i.e., chest physiotherapy), cough assist, pulse oximeter, and suction equipment. Nine of the participants used some or all of these technologies on a daily basis. One participant verbalized having equipment associated with the tracheostomy, but the technologies were not in use on a daily basis. Only the participant who had been decannulated with stoma closure in the past year did not currently require any respiratory assistance, but did require daily technology when she had the tracheostomy.

Some of the participants also required other technologies in their daily lives not associated with their need for respiratory assistance. Other technologies required by the adolescents included wheelchairs (n = 5), leg braces (n = 4), gastrostomy tube and feeding pump (n = 3), and colostomy (n = 2). Thus, the participants reflected a group of medically fragile adolescents who required multiple technologies in addition to their need for respiratory assistance.

Themes

Interviews with the adolescent participants revealed their experiences with respiratory assistance and their ability to reflect on their experiences. Themes emerged

from the description and interpretation of the experiences of adolescents who require respiratory assistance. The adolescents were maintaining a sense of self beyond their need for respiratory assistance; medically fragile adolescents who require respiratory assistance had the courage to be themselves. Pseudonyms were used to protect the identity of the adolescent participants.

“Get to know me” and “Allow me to be myself” are themes about how the adolescents how the adolescents view themselves and how they want nurses to both view them and interact with them; “Get to know me” is also a pattern overarching all interviews. Relationships with nurses and being treated with respect by nurses are important for these adolescents. The adolescents do caution nurses to maintain boundaries for getting to know them in the subtheme “But don’t be too nosy”. The adolescent view themselves as individuals, recognizing their own individuality and self. They desire nurses to recognize them as individuals, reflecting a strong sense of self.

The theme, “Being there for me” refers to the support that friends provide for the adolescents. Friends are a supportive presence for these adolescents and help them to identify with others and have the courage to be themselves. These adolescents recognize who their friends are and appreciate their friends as liking them for who they are without concern for their need for respiratory assistance in the subtheme “My friends see me as a person”. Some peers who are not considered friends are deemed as judging them in the subtheme “Others judge me”.

Respiratory assistance emerged in themes of how medical technology helped the adolescents. Technology was considered beneficial to them and others in the theme “No matter what, technology helps”. The adolescents spoke of technology dependence as an

individual perception. There was an overwhelmingly positive outlook among these adolescents regarding their respiratory assistance.

The adolescents spoke about themselves, who they were and who they wanted to be in life as a successful, independent person. The theme, “I am an independent person”, presents their current activities and future plans in life. The adolescents strived for independence in their daily lives and were moving forward in their lives, transitioning to adulthood and independent living in the subtheme “I see myself”. They recognized the positive aspects in their lives and how they were able to achieve their goals in different ways in the subtheme “Creating moments for myself”.

The adolescents existed themselves as the only person that they knew or knew of who required respiratory assistance. “The only one I know of” is a subtheme that demonstrates their connecting with friends and identifying with peers like them in other ways.

These themes demonstrate the strength and courage that medically fragile adolescents who require respiratory assistance have in their daily lives. These adolescents maintain a sense of self without dwelling on their need for technology and the health problems associated with their technology.

Table 1

Themes and subthemes

Get to know me

 But don't be too nosy

Allow me to be myself

Being there for me

 My friends see me as a person

 Others judge me

No matter what, technology helps

I am an independent person

 I see myself

 Creating moments for myself

The only one I know of

“Get to know me”

The theme “Get to know me” symbolizes the adolescent’s desire to be seen for who they are by nurses, not the respiratory assistance that they require in their daily lives. They want nurses to ask them about themselves and get to know them as individuals. This may also signify the adolescents focus on other aspects of their lives, not their respiratory assistance, on a day-to-day basis. They also want nurses to focus on them, not their respiratory assistance when providing nursing care. Within this theme, there existed a notion that encompassed what the adolescents thought nurses should know about them.

A few adolescents did express concerns with nurses knowing too much about them in the subtheme “but don’t be too nosy”. Ultimately, the adolescents described the importance of getting to know them as an individual.

Stephanie felt that nurses should know about what her and other teenagers like to do. She suggested that nurses “...be like, more open to you. Like, some nurses they just come and they just take your, you know, information down and they just kinda leave. But if they’re actually engaging a conversation with you and they kinda get to know you a little bit better, instead of just the basic information, I think it helps you get a little bit more comfortable around them.” Stephanie revealed that when nurses get to know her, she becomes more comfortable with them. She described nurses going beyond the basic care and procedures in order to get to know her. What she does is important to her and she feels that it should also be important to the nurses who care for her.

Randy suggested that nurses “...Just learn what you’re supposed to do and make sure you know *their* interests.” He continued with “Just keep me entertained.” and elaborated “...bring in some news that’ll keep me interested...or be able to play video games.” He summarized that nurses should get to know “What are my interests, basically...what I like...” Randy wanted nurses to get to know his interests and be able to do things that he liked to do. This signified getting to know him by knowing about his life other than a patient and his uniqueness as an individual.

Brad recognized the need for nurses to be involved in his care, but felt that adolescents should also be able to talk about how they felt about things. He said “...try to allow the kids to have some sort of self...like by themselves...let them tell you how they’re feeling...” His suggestion was for nurses to get to know adolescents who require

respiratory assistance by allowing them to be themselves and talk to nurses about themselves. Brad wanted to be able to discuss his thoughts and express himself. He wanted nurses to respect his feelings and existence as a person.

Michael agreed that nurses were helpful when they talked to him and tried to get to know him better. He provided the example of "...I guess my most favorite [nurse] we had.....I just remember I used to always, um, talk to him for like, maybe an hour sometimes, you know, talking about, like, all the Superheroes and stuff like that. It was just really cool to talk to him about that." The nurse talked to Michael, spent time with him, and was successful in getting to know him as a person. Michael remembered the nurse caring for him as a person, not just his respiratory problems.

Several of the adolescents spoke of nurses that asked them about themselves. In speaking about how nurses were helpful, Ciara talked about nurses and stated "They just ask me how my day's been...and how I'm doing in school and stuff." Ciara described nurses asking about her day and how she is doing. Having the nurses ask about her and get to know her was what was most important to Ciara. When nurses asked about her, she felt that they got to know her better and that they recognized what she does as important.

Isabelle stated that it was helpful when nurses get to know teens and get to know about things that teens like to do. She provided examples of questions that nurses could ask teens "...ask them questions like, "What do you like? What do you like to do for fun?" and just, you know, just that type of things." She considered nurses helpful when they "Mostly do medical stuff...but they can also have fun with you too and taking us to, you know, play games and, you know, something to bond with the patient." She agreed that this was a way to summarize getting to know her as an individual. Nurses attended to

her needs along with spending time with her and getting to know her. When nurses asked Isabelle about herself, she felt they were better able to get to know her and spend time with her doing the things that she liked to do.

Crystal described being in the hospital with nurses who tried to get to know her as a person. She stated "...Well like, when I was in the hospital, I had like [movie] pictures, posters like everywhere in my room, so I mean, you could obviously tell I like the [movie] series, so like, you know, like, if you know, say, if you don't know about whatever, but like, you know, I just love nurses like, playing games with me." The nurses observed her likes of a particular movie series and talked to her about this. She felt that nurses did not have to know about her likes, but nurses' recognizing her likes and her uniqueness as a person was a way of getting to know her.

David described talking to his doctors and nurses and how lately they have been asking him how he feels, in turn getting to know him. He stated his nurse has "...been asking me a lot of questions about how I feel about how I feel about this thing [the tracheostomy]...I feel fine..." Nurses were described as asking him about himself and giving him the opportunity to discuss what is important to him. In this way, the nurses are getting to know him and his needs. By asking him about his feelings, the nurses recognized feelings that were important to him. They also recognized his importance as a person.

Each of these adolescents focused on the aspects of their lives not associated with their respiratory assistance, even in the presence of nurses caring for them. The nurses that took the time to get to know them were remembered as their favorite nurses, fun nurses, and nurses whom they were comfortable being around. The adolescent provided

examples of their experiences in which nurses had gotten to know them by asking them about themselves. Nurses asked them questions about their day, what they liked to do and their favorite things, and what their feelings were about their respiratory assistance. These adolescents had experienced nurses who asked them how they were doing in addition to questions about their need for respiratory assistance. For adolescents requiring respiratory assistance, “get to know me” was important for nurses. Adolescents perceived that these actions meant that nurses recognized the adolescents as individuals.

“But don’t be too nosy”. The adolescents did recognize that nurses had the potential to get to know too much about them. At this developmental stage, the adolescents may recognize professional boundaries of health care providers and the potential for inappropriately close relationships between the nurse and their adolescent patients. These adolescents warned that nurses should get to know them “but don’t be too nosy”.

Crystal described the nurses getting to know her as important, but also advised not to get to know too much. She described nurses getting to know her “...I mean getting to know someone is really, like important as being a nurse, I think and you just, yeah, try to, I mean, don’t be too nosy...” Crystal equated getting to know her as being as important as being a nurse, an essential part of nursing care. She did warn nurses of being nosy and getting to know her too much as a person.

Brad felt that nurses’ getting to know him was helpful, but expressed concerns for nurses knowing everything about an adolescent and being too involved with their patients. He presented the example “I mean, here’s the way I look at it...I love my mom. She helps me a lot. But, if I were to have another mom, which is basically what the nurse

would have to be...I don't think I'd like it...Honestly. Serious, one mom, I think that's as many as I could handle." Brad was opposed to too much involvement with the nurses and nurses getting to know too much about him as a person.

These adolescents thought it was important for nurses to "get to know me", however, they warned nurses "but don't be too nosy". These adolescents desired nurses to get to know them, but wanted nurses to avoid getting to know too much and becoming too close to the adolescents. Adolescents who require respiratory assistance want boundaries in their relationships with nurses while being recognized as an individual.

In the process of data collection and analysis, the theme of "get to know me" surfaced and was discussed with later participants. Other adolescents did not have specific stories about nurses getting to know them, but they agreed that nurses should attempt to "get to know me". Rose did not have any specific advice for nurses, but agreed that nurses were helpful when they helped her with her trach and tried to get to know her as a person. Maya suggested that nurses help adolescents when they get to know her daily needs. "Give them treatments...get me ready in the morning...fix my food." She agreed that it was helpful when nurses get to know you and know about the things that you like to do. Being attentive to her daily needs was a way that nurses would get to know her. Jack advised "Um, keep doing what you're doing (laughs)." He agreed that it was helpful when nurses got to know him. These responses from adolescents in later interviews confirmed the importance of nurses getting to know the adolescents as individuals in the care of their respiratory assistance.

Summary. The adolescents' wanted to be seen for who they were as a person, not simply the respiratory assistance that they required in their daily lives. This is how

medically fragile adolescents who require respiratory assistance see themselves. They want nurses to get to know them as a person, not just knowing about their respiratory problems. This includes nurses taking the opportunity to ask them about themselves, reflecting the adolescents' view of themselves as a person and their sense of self. The adolescents themselves focus on multiple aspects of their daily lives beyond their need for technology. They need nurses to know about more than their respiratory assistance as respiratory assistance is a small part of their overall day-to-day living. The adolescents felt that they were important enough, their daily lives were important, and that nurses should spend time with them and make the effort to get to know them as an individual.

“Allow me to be myself”

The adolescents described receiving special treatment or being treated differently because of their need for respiratory assistance. They expressed feelings of annoyance and questioned why they were experiencing these thoughts and feelings. They wanted to be treated like an individual in their interactions with nurses. The adolescents wanted to be treated as a person, as they viewed themselves, not for their need for respiratory assistance. “Allow me to be myself” is a theme that reflects the adolescents' sense of self and their desire for nurses to respect their needs.

Stephanie made the statement that nurses should treat adolescent who require respiratory assistance “like you would want to be treated”. She said to nurses “...don't treat me like I'm, you know, some little fragile thing. I wanna be normal. Wanna be treated normal...treat them normal. Like, you know, like yourself, like you would want to be treated.” She included “...I can walk, run, talk, and do everything that you can do. I just have a hole in my neck...I'm still able to do things...when you're able and people

treat you differently, and you just like get special treatment when you don't need it kinda makes you feel low in a way. So, I mean, I didn't like that feeling..." Her statement exemplifies the adolescents desire to be treated as a person and experience life as if they were any other adolescent.

Michael described nurses attending school with him, limiting his freedom to be himself at school. He stated that nurses "...used to go to school with me and that that was kinda annoying...it was like back in Elementary school but they would like ride the bus with me...like sit in the classroom with me and it was just annoying... 'cus they like, wouldn't be able to go like a hundred feet away from me, or something, not really, but I mean, they basically couldn't let me out of their sight." The nurse's constant presence with him at school diminished his ability to be his own person, to be himself at school.

David also described having nurses with him at school in the past. He stated "...I really don't prefer to have like a nurse at my side at all times 'cus sort of it makes me feel like I'm being like watched..." David wished to be like the other adolescents and not have close monitoring by the nurse at school. He wanted to be treated like his schoolmates and have the freedom to be his own person.

Crystal described multiple experiences that she had with nurses in a past hospitalization. She stated "...a lot of times I love them when they give me baths and stuff. 'Cus like, I shave, you know, and I was like hairy as a, you know, a tiger or whatever and I was just like disgusted and like, just icky and everything and like when they clean me, I just feel so great, like. And also I love sitting like at the edge of my bed, you know, 'cus all day, I just hate lying in bed and stuff and it's just really hard, you know to lay in bed. And I also like it, you know, when they like check up on me regularly

and, you know, talk and stuff...especially if you're going to do something, like take a temperature. Like if it's in the middle of the night...just come over there and say, "Hey, I'm going to take your temperature," and just like talk to them while doing it..." Crystal noted those special touches that nurses included in her care. These things, shaving and bathing, being able to sit up instead of laying in bed, and being talked to and informed about care, were important to her. The nurses addressing these things in her care allowed her to be herself, even when sick in the hospital. The nurses allowed her to maintain her sense of self, her identity as a person.

David did appreciate nurses being there for him at the hospital. He stated "...in the hospital...a friend of mine visited and his family visited...most of my family visited too, but that's not really enough social interaction...I had a bell or something, but...I never used it much 'cus people were always like, it felt kinda like a restaurant where people always bring you more drinks and stuff...people always checking up on you every now and then, but not staying around...just kind of being available...being there." David, like Crystal, appreciated the little things that nurses did during the hospitalization. This can be interpreted as nurses allowing medically fragile adolescents who require respiratory assistance to be themselves.

Summary. The adolescents emphasized their desire to be treated as normal adolescents. They desired for nurses to "Allow me to be myself". They recognized their own need for respiratory assistance and how it affected their need for nursing care and close monitoring from nurses both at school and in the hospital. In allowing them to be themselves, the nurses recognized their uniqueness as a person.

“Being there for me”

Friends were described as a supportive presence by the adolescent participants. Friendships are important to these adolescents and strengthen their sense of self. Two subthemes also emerged. The adolescents felt that their friends did not care about their respiratory assistance in the subtheme “My friends see me as a person”; however, they felt judged by those who were not their friends in the subtheme “Others judge me”. The overall theme relates to the adolescents’ feeling that their genuine friends are there for them, whereas those that are not their true friends are not there for them.

Friendships, notably at school, are important for medically fragile adolescents who require respiratory assistance. School is a source of friendships. Crystal described friends at school being there for her. She noted “...it’s getting close to school, you know, finishing and like all your friends. You know, you know who your friends are..... all my friends were just in a good mood and like, I remember just like they would all like say hi to me in the hallways, you know, and just like that feeling like you have a lot of good friends what would be out there for you...” Her statement “you know who your friends are” relates to later in the school year when friendships are established and new friends have become good friends. These established friends are there for her at school.

Crystal told a story about her friends at schoolmates in which her friends helped her to make new friends. She stated “it was last year at lunch and my friend...she sat next to me and she, like, um emailed her friend and was like would you sit next to this girl who’s like really funny and stuff in a wheelchair to the popular people...” Crystal described her friends as encouraging others to get to know her and being there for her in times when others did not demonstrate friendly behaviors towards her. She described

having a good feeling knowing that friends would be there for her in times like these. Friends supported her in the development of new friendships and helped her to connect with others.

Isabelle was appreciative of her friends being there for her. She profoundly stated “My friends, I really appreciate... appreciate them because without them I wouldn’t be myself today.” She later talked about how her friends help her, stating “...my friend Stella she, um, just helps me about to do anything and so does Emily too...and my friend Amy (name changed)...when I go to her house, you know, she walks me home, opens the door for me, um, like sometimes I eat ice cream over there, she help me feeds it to me...I got good friends. And that’s what friends are for and so whenever, you know, if they don’t help you or be there if they’re not your true friend.” Isabelle considered friends as those that would be there for her. Being there meant true friendship for her and distinguished friends from those that were not her true friends.

Randy stated “Just hanging out with my friends,” was what made school good for him. He continued his discussion with school that he and his friends were “talking when we can...” He also described “My cell phone just being around...sitting around bored, calling my friends.” Friends simply being there to talk to were important for him.

Several of the adolescents discussed friends primarily in the context of school. These friends were a supportive presence at school and helped the adolescents to be themselves. Ciara said “When I am with my friends, we have a lot of fun...in class...and when I get to school I normally hang out with my friends before school starts.” School was a time to be with friends. David described being with others at school as “...I like going to school ‘cus I can see my friends and stuff...” Attending school meant that he

could see his friends and be with friends at school. Maya noted school as a place to spend time with her friends, noting "...going to school" as something she liked to do because "...I got to play with all my friends and see all my friends and do...and be with people that I don't get to be with at home." Being with friends at school was important to these adolescents. An important part of the day was hanging out with friends. Hanging out with friends may signify just being there, being present, being around friends. Friends also support medically fragile adolescents who require respiratory assistance in being themselves.

For these adolescents who require respiratory assistance, attending school meant having a place to develop and maintain friendships. Having friends at school resulted in feelings of having someone there for them, someone to support them at school emotionally. Their friends were there for them. In being there for them, friends supported the adolescents' sense of self as an individual.

"My friends see me as a person". The adolescents felt that their friends, their true friends, were not concerned about their need for respiratory assistance. Their friends were able to see them as a person and did not have worry or be concerned about the respiratory assistance. Their friends supported them in being their own person and maintaining a sense of self.

Ciara stated that her friends did not care that she had a tracheostomy. She emphatically stated "...I'm just a normal person who just has a trach. I think I'm just like everybody else...everybody else...you know...and so like cause all my friends they don't care that I have a trach...cause they just see me as a normal person." Ciara thought of herself as being just like any other adolescent. She felt that her friends felt the same way,

seeing her as another adolescent. She and her friends were not focused on her tracheostomy.

Stephanie felt that her relationships with friends had not changed from when she had the tracheostomy to now that she no longer has it. She said that her relationships were "...not really any different because I have the same exact friends that I started with and that I had after so...I'm surrounded by the same people so. It hasn't really changed any..." Stephanie felt that she had friends and had remained the same person, regardless of the tracheostomy. She felt that her friends saw her as a person whether or not she required respiratory assistance.

David described interacting with friends online, stating "...I really enjoy playing though, online...my friend Andy (name changed) was nice to me and he's from Britain...we know what each other looks like, we talk to each other a lot...I think he's a real best friend now, even though we're far away..." David noted that his friend online had seen him, meaning that he had seen his tracheostomy, and were friends. This friend was there for him, even if online, and did not care that he required respiratory assistance. His friend saw him as a person.

Brad described a difference in the way friends reacted to his respiratory assistance. He described "...usually my friends are very open and receptive. It doesn't bother them. Like...I had my best friend over a few weeks ago and it was the first time he had saw my feeding tube and it didn't bother him at all...Friends stay by you even when stuff is rough...they're there when you need to lean on someone." He described his friends as understanding his need for respiratory assistance and other technologies. They were accepting of his need for assistance. He also stated "they're there", symbolizing

how important that friends being there are for adolescents who require respiratory assistance.

The adolescents felt that their friends were not concerned about their respiratory assistance. In discussing how their friends saw them, medically fragile adolescents who required respiratory assistance referred to themselves in their narratives, ultimately demonstrating their recognition of their own sense of self. These friends saw them for who they were, not their respiratory assistance. This is how these adolescents viewed themselves. Their friends were described as “open and receptive” to their need for medical technology, which seems to differ from the sentiment from those not considered friends.

“Others judge me”. The adolescents described feelings of being judged by others and being uncomfortable in situations with people that they did not know well. A common thread among these experiences was that they occurred with schoolmates who were not designated as friends to adolescents who required respiratory assistance. They were also not supportive of the adolescents. This was interpreted in the subtheme “Others judge me” as an example of those that were not there for them when they needed a friend.

Crystal described a presentation in front of the class at school and feeling that she was judged by schoolmates. She stated “...I don’t like speaking in front of class ‘cus they just judge you more...like when I have to present a poster like I did today, I didn’t like it...like people in the school just like, judge you more and just like, it’s just more awkward. I don’t know I feel more comfortable with older people.” Crystal recognized some schoolmates as not being friends and judging her appearance and behavior. Friends

were not included with these schoolmates. She also presented a notion that older people were more accepting, potentially more mature and understanding of her situation.

Ciara described her favorite time as "...Halloween...because that's like the one day that you can be someone else and not get judged on it..." This was a time when she was not judged by others, judged based on her need for respiratory assistance, a visible presence for her that could be concealed with a Halloween costume. Ciara felt that others judged her, a contrast to previous statements that her friends do not care about her need for respiratory assistance.

Stephanie contrasted living with the tracheostomy previously to currently not living with a tracheostomy. She noted "...there's not as many questions. Like, you know, when something's sticking out of your neck people are gonna notice and they're going to ask you about it. But now it's just like, "Why, where did you get the scar", you know?" and continued with "And it's a different question. Not, "What is that for?" It's, "What happened?" You know?" She described schoolmates as having questions about her tracheostomy and now her tracheostomy scar. These schoolmates were not designated as friends, but as people that she was in contact with in her daily life. There was also a notion of judgment and questioning of their respiratory assistance by those who do not know her well.

David described what he would like to be able to do as talking to others at school, even debating on a team at school. He spoke softly with muffled quality to his voice. He expressed desire "...to be able to like, uh, I want to be able like to talk better 'cus people have trouble understanding me at school and stuff..." He described people at school as

having difficulties understanding his speech. David may have also felt that schoolmates judged his ability to communicate with them.

The adolescents conveyed experiences in which they felt judged by others, primarily schoolmates who were not considered friends. The subtheme “Others judge me” emphasizes their feelings of being uncomfortable around people that they do not know well and who do not understand the need for respiratory assistance. This is in contrast to friends who support them and are there for them without concerns about their need for respiratory assistance. The schoolmates who judged them did not know them as a person and see them as a person; they remained focused on their need for technology.

Summary. Being with friends expanded the possibilities for adolescents who require respiratory assistance whereas otherwise they felt limited in what they could do. Friends simply being there empowered them to engage in activities and be themselves. Friends were not judgmental and did not question the adolescents’ need for respiratory assistance. Friends were the people who would “be there” for adolescents who require respiratory assistance and saw them as an individual.

“No matter what, technology helps”

Technology was a part of the daily lives of the adolescents; however, this was not the focus of their day-to-day existence. Their focus was on everyday adolescent activities, such as school, friends, and family. For adolescents who require respiratory assistance, technology has different meanings. The adolescents recognized technology as helpful to them in their daily lives; technology also helps others. The assistance that technology provides also depends on the person and the situation.

Crystal described her use of multiple technologies as helpful. She stated "...I have a chair lift, well, like a stair lift thing for the stairs so, cause like one time I broke my leg and mom broke, like her back or something and when she was carrying me down the stairs and like slipped on a ball and dropped me down the stairs...I use that every day and one time it broke and I had a cast on and it was just crazy like, it was just insane to get up the stairs, you know, I use that, like I'm really dependent on that....sometimes I use the [patient] lift you know, I have to get used to it 'cus I know one day I'll have to use it..." She recognized the technology that helped her in her daily life and the need for technology to make the most of her daily living. She had experienced a bad event in which both she and her mother suffered injuries prior to having the stair lift. This technology in her daily life was a necessity that she viewed as beneficial to her quality of life.

Brad presented multiple benefits of technology, describing his wheelchair and his use of respiratory assistance. He presented "Well, first of all, I mean, I'd be stuck in one place if I didn't have my chair. I mean, that's my legs, right there." He continued with discussion of his respiratory assistance "So, I mean, the Bi-Pap it helps me sleep, helps me breathe easy. Um, my chair drives me around..." Brad felt that his wheelchair was his mobility and a technology that helped him in his daily life. He also described his respiratory assistance as helping him.

Several of the adolescents noted specific times that technology was helpful. Maya emphatically described "My vent!" that "...helps me sleep at night." She also paused and noted "Hmm...my concentrators [that] don't give me dry air." To her, technology positively affected her ability to breathe and sleep at night. Jack described a particular

time when he used technology. Jack mentioned "...having a battery pack for my ventilator...Like on the highway and take a nap at night when the power went out..." The technology associated with his respiratory technology helped him travel. David recognized his tracheostomy as helpful technology, stating "...Yeah, yeah, and lets me breathe...it helps me like, after my surgery..." He remembered his respiratory assistance being helpful in breathing and after surgery. The adolescent viewed technology as helpful in particular times and situations. Participants' statements did not reflect a constant awareness of the need for respiratory assistance. Instead, the need for respiratory assistance was taken for granted in their daily lives.

The adolescents felt that technology did not just help them as a human being; technology helped people in general, humankind. They reflected on technology and found a deeper meaning in benefits to people in the world. Stephanie commented that "...people who need it, you know, it helps and technology helps people, you know..." Stephanie recognized the technology that she had previously required in her daily life as being helpful on a larger scale to people in general. Michael described technology in a global, general sense, and used a time when technology helped him as an example of how technology helps people. He referred to the "...technology that they use in hospitals and...how it's used to save lives and stuff like that. Um, like when they had to do, like my emergency surgery or whatever...it's cool to know like, they can do..." Technology was helpful to him and others.

In keeping with their thoughts of technology being helpful, the adolescents provided examples of how technology was helpful and depicted technology as having different meanings depending on the person. Brad's morning routine included his

respiratory assistance; his plans for the day affected his use of respiratory assistance in some way. He stated that "...during the summer...I wake up. I have the Bi-Pap on...Um, after that I get dressed, take the Bi-Pap off, or I might leave it on. It depends. If I play video games, I leave it on. If I'm going somewhere, [I] take it off and leave..." He used his BiPap nightly and the decision to use his respiratory assistance during the day in the summer was affected by his plans of staying home or leaving the house.

Brad presented another example of his feelings that use of technology depended on the person, even if they were dependent on the same technologies. He noted that "...everyone is different. I mean, there might be someone who's on the tra... I don't know how to say it... [tracheostomy] ...And has a feeding tube and that's all he eats through it and, uh, has a wheelchair that he doesn't drive. And me, I drive my, um, I eat normally and supplement with a feeding tube and I have the Bi-Pap and we might both depend on technology a little bit but we're a lot different... You know what I mean?..." Brad felt that use of technology depended on the person. His use of respiratory assistance and other technologies may be different than other adolescents who require the same technologies.

Crystal described technology as part of her typical school day routine "...a school day...It depends on if I, like need to go in early...I wake up, go into my shower chair, and uh, brush my teeth, go to the restroom, and then I change. I do my breathing treatments...and it depends on if I'm in the Fall time is when I usually have upper respiratory stuff. So I usually have more, um, medication down in the Nebulizer and the vest..." Technology was a significant part of her morning routine and part of her

preparation for school each day, but her use of respiratory assistance depended on the situation. She described her use depending on the day and the season of the year.

Stephanie contrasted her experience with technology against the hypothetical experiences of others. She stated “I guess it depends on the person that has it. You know? Like, some people handle it differently... Well, for me, like I like to be with my friends and like to go off and have fun and listen to music and do normal teenager things and I understand that when you have a trach you can’t necessarily do just about everything that a normal teenager does and that they normal, like, tracheostomy patients do need extra care... I didn’t always have to be suctioned or being checked, or changing the trach. Well, I did, because, you know, it’d get dirty and you need to do that... but I wasn’t always in need of constant care and some actually are...” Stephanie noted that adolescents who required respiratory assistance had similarities and differences that depended on the person. She saw herself and others who required respiratory assistance as unique individuals regardless of whether they both had a tracheostomy.

Summary. Adolescents who require respiratory assistance recognize their need for multiple technologies in their daily lives. These technologies are seen as helpful by them. Their need for daily technology is a part of their lives, not their whole life. Their narratives reveal a notion of technology being taken for granted and something that they are not constantly aware of on a day-to-day basis. Technology existed as a beneficial presence. Their use of respiratory assistance was just one example among the many examples of technology and the many people in the world who benefited from technology.

These adolescents recognized the uniqueness of the individual in their experiences with respiratory assistance. They had contemplated their experience and inferred their experiences toward other adolescents who required respiratory assistance. They saw themselves as a person. The respiratory assistance was a part of their experience; the respiratory assistance did not define who they were and how they viewed themselves as a person. The experience with respiratory assistance depended on the person. There was appreciation of the uniqueness of themselves as individuals and respect for the individual among the adolescents interviewed who required respiratory assistance. Technology has different meanings for different persons, but “No matter what, technology helps”.

“I am an independent person”

In their daily lives, independence was a notion that was revealed in the interviews; This existed as a current concern and as a hope for the future. The adolescents depended on their respiratory assistance on a daily basis while also actively striving for independence in their lives. Adolescents can take care of themselves now independently and see themselves as living independently in the future. This encompasses the theme “I am an independent person”. Two subthemes emerged, including “I see myself” which relates to their future independence. The adolescents also recognize their need to adapt to situations in the subtheme “Creating moments for myself”.

The adolescents’ spoke of their current situation and desire for independence at school. The adolescents described being able to take care of themselves at school with little need for help from nurses and others trained to aid them in caring for their respiratory assistance. However, adolescents who require respiratory assistance did not feel that they needed constant care from nurses or other health care providers at school.

David stated that help was available from the nurse at school and emphasized that he can take care of himself. He stated "...I don't have any help with my trach...we always like contact the school nurse and inform them about the trach. ..we took a bag up there with a copy of all, um, equipment...but I really don't need...I can take care of myself..." He recognized that the nurse had information about his respiratory assistance and equipment to aid in management of his care. He also felt that this was not necessary and that he was able to independently care for his own needs.

Stephanie described having equipment available for management of her respiratory assistance. She noted in the context of school "...they, I had a, a suction machine but, I left that in the nurse's office so I, and I never used it so I've never really had any extra help." She alluded to being independent in her care at school, but a school nurse was available with equipment to aid her in caring for her respiratory assistance.

Jack responded "None anymore." when asked about any help that he received at school. He noted that he previously had a nurse at school with him, but now does not have a nurse with him at school. He explained "...I used to have a nurse that went to school with me, so, I don't have that this year. I wanted to be more independent, so I don't really have any help now...Yea. I feel like I do well, not having anybody." Jack continued with "...I'm very independent...And I can do a lot of it on my own." Jack was optimistic about not having someone assist him with his respiratory assistance. He proclaimed his independence in caring for himself. He felt that he was functioning successfully, independently, at school with respiratory assistance.

Ciara told a story about a time when she needed help from a caregiver at school, but helped herself. Ciara stated "...there was one time...in the eighth grade...that my

trach accidentally came out but I put it back in myself...they almost called the ambulance but...they didn't have to..." There was not a need for additional help from her caregiver or emergency services as she was able to manage the situation independently.

Brad stated that he had help at school that was primarily school work related. He described "...I'm not too good with the [test forms] so they'll bubble in for me. Um, other than that they help me with the bathroom, obviously. They help me get my food out at lunch. Other than that I'm pretty much by myself. I roam through the hallway by myself. Um, eat lunch by myself, other than that, that's it." He recognized his need for assistance, but also noted his ability to do things independently.

At school, Crystal described "I have a Parapro who's with me all the time and she just, you know, takes me to the bathroom, just gets my book out. She doesn't really, like, help me with schoolwork unless...I don't understand something 'cus it's nice to have her, you know, 'cus she's in the classroom with me...she just helps me..." Her statement that is it "nice to have her" suggests a notion of nice to have, but not necessarily needs to have assistance from caregivers at school. Crystal's depiction of her daily assistance also includes a notion of independence.

The statement by Randy, "if I need it", exemplifies his need to maintain independence in his daily life. Randy described having help at school from teachers and a nurse "...if I need it." He continued with the statement "Which, most of the time I don't." His statement reflects having assistance from a nurse and others at school, but feeling that he does not need assistance often and can function independently at school.

Independence is something of great concern for adolescents, but may be even more so for adolescents who require respiratory assistance. They see themselves as being

able to take care of themselves without assistance, despite their need for respiratory assistance. They are functioning independently and striving for further gains in independence in their daily lives.

“I see myself”. When asked about the future, the adolescents had plans for the future that included college, careers, and family. These were interpreted as “I see myself”. These plans did not reflect dependence on others, but reflected independent living. They had possibilities for the future that included independent living with respiratory assistance.

Both Ciara and Randy had basic ideas about their future that included the transition to college and career. Ciara had plans to go to college and said “I want to go to college...like I want to go there for something that goes with art...or music.” Randy mentioned thinking about college with “College-wise, I still think about it.” and expressed a desire in “...designing video games.” Both of their statements reflect a desire to go to college and have a career that reflects their interests.

In addition to college and career plans, Maya had plans for a family. She said that she wanted to be “A doctor...a trauma doctor” and had even chosen the university that she planned to attend. In addition, Maya expressed her desire in “having [a] child...adopting children.” Her desire to have a family also revealed that she had considered her physical limitations in having a child. She had made plans to have children by adopting, revealing her independence in the future.

Michael also described having a family and a career. He said “...a family, um, normal job...maybe even like a job that I like, like maybe something along the medical line.” He noted the importance of a normal job, possibly a job independent of his

requirement for respiratory assistance. He continued with describing other career options as "...maybe even something in sports. I don't know but my main two, uh, likes in majors, I guess, are things are medical and sports." This statement alluded to his recognition of completing college as part of his career plans that reflect his interests and plans for living independently.

Stephanie described her plans as broad in regards to career and college; however, she had considered future plans of living in another state. She said "I went to Daytona in July. It was fun. I loved Daytona. Think I wanna move to Florida...". For college and career, she stated "...I just hope that I'm gotta good job and college...I can see myself being an Elementary school teacher or a co-teacher in high school ...or like a day care type thing, 'cus, either way, I think I'd be good..." Her statement indicates a reflective process that Stephanie has experienced in which she has thought about her current strengths and weaknesses and made plans for the future. Her career plans reflect her interests and independent living.

Stephanie stated that it was hard to imagine the future as she had recently been decannulated, changing how she saw herself. She said "I see myself, well, it's kinda hard to say now, 'cus I never saw myself how I am now. So, I couldn't really tell you 'cus I didn't really picture myself being like this." With her recent change in need for respiratory assistance, her vision of herself had changed in regards to her future possibilities and ability to function independently. This notes a developmental transition to thought of the future and independence for these adolescents.

Isabelle made strong statements about herself and who she saw herself as being in the future. She stated "I see myself as a proud strong girl who wants to own her bakery

business. That's what I want to be when I grow up.", noting a deeper existence beyond career. She continued with "And I see myself working hard, earning money, um just, living by myself...I hope." and designating a tentative plan. She stated "...I see myself as me...I try nobody to let me down or put me down... some people, they may think, "oh you're in a wheelchair, you can do this", I can do this." She stated "I want to go to college...That's my biggest wish ever. I want to go to culinary school." Isabelle's vision for herself included living her dreams of being independent and achieving her goals of school and career.

Brad called himself a dreamer, recognizing his changing plans for the future. He stated "...I'm a dreamer. I think of a lot of different stuff. Honestly my goals change with the seasons...Um, I want to definitely go to college...I'm a very creative person...when I grow up I kinda wanna design video games. But if that doesn't work out, I mean, I have tons of other ideas. I could be a lawyer or something like that...my goals are so broad, if you will, that I don't honestly know exactly what I want to do when I grow up." His career plans were that of independent activities not limited by his need for respiratory assistance.

Crystal had well-defined plans in addition to college, career, and family. She responded "I see myself very clearly...what I want to do, I already know, like, I want to have a medium sized house, you know, all accessible and everything. I would like to be a writer...I want to adopt a daughter that's kinda older, not like a baby or anything, just, you know, it would be fun, I guess. And I want to take my family on a Hawaii cruise". She also noted that she "... really want[s] to visit New Zealand. That's just, I've always

wanted to go there...” She had a vision of herself that symbolized independent living while recognizing her physical limitations.

Crystal continued with discussion of other career options and college. She said “...I also kinda want to be a teacher, but I read in a magazine that like people, like, with Muscular Dystrophy and stuff, that one girl was like a teacher and she kept getting sick a lot and the doctor said, you know, “If you value, you know, your life and not getting sick, don’t be a teacher cause all the kids have like sickness and stuff”...so I’m kinda like second guessing that, like if I really should be a teacher or not. So, I don’t know.” When online teaching was presented as an option for college and career, she rebutted “...but I like interacting with people...I really want to go to [university] for college...” She had taken these things into consideration of whether or not she would be able to attend college independently in light of her need for respiratory assistance and other technologies.

Jack stated that he saw himself broadly as “...wealthy, having a lot of money...having a family...and having a new dog.” He stated that he wanted to attend a particular university and career-wise “...wanted to work with computers but I don’t know about that now. I might want to go into Sports Medicine.” Jack had definite plans for the future that included independence in life.

David, like Stephanie, noted a recent reflection on plans for college and career. He was exploring his options for colleges and careers at this time, stating “I’m not sure about college yet...” in reference to various local colleges that he was considering attending. He noted “...But I don’t know what I want to do really...I want to do something that I’m familiar with but is fun...I want to do something social, like maybe

work in, um, lab, lab or an office with a lot of people in it, maybe biology, uh, chemistry...” David was actively considering multiple college and career paths, revealing his strive for independence.

The adolescents did not feel limited in their future possibilities, even though they did take their need for respiratory assistance into consideration when making future plans. They also felt that they would be able to continue to care for themselves independently in the future. These adolescents were striving for independence and making decisions for the future, typical of adolescence (Spear & Kulbok, 2004).

“Creating moments for myself”. The adolescents’ need for daily respiratory assistance and the illnesses associated with their need for respiratory assistance often affected their participation in activities, however, the adolescents modified and created activities that they enjoyed and suited them best. Medically fragile adolescents who require respiratory assistance adapted to the situation and had the courage to create their own moments in the activity.

For the male participants, sports were an activity that they desired to participate in, but were not able to; they participated in sports in other ways, their own way. Michael expressed a desire to play sports with his friends. He stated that he would like to “...just play sports like a lot of my friends at school...I’d just like to be able to play basketball like them, be able to run up and down the court like they do...but I can’t because I only have like, thirty or thirty-five percent lung capacity and I get tired real easily...It’s not too fun. But, I mean, I love going to their games. Like, I love being a part of the student sections...and cheering and stuff...” Michael was able to participate by observing games, being present at the games and cheering for his friends, even if he was not able to

participate himself. This was his way of participating in sports and creating moments for himself.

Brad was a self-described sports fan, stating “Um, I love sports of all sorts. I like baseball, football, anything, even golf and tennis. I’m just a big fan of competition.” He stated that he would like to “...play sports because I absolute love everything to do with sports.” He proceeded to mention that he watched sports on television “constantly”. He recognized that he was not able to play sports and participated through observing sports and being a fan of sports. This was Brad’s way of being involved in sports.

David alluded to playing sports with his friends, but recognized that he would not play professionally or be able to play team sports at school. He stated “Um, I want to, um, I’m not going to be able to do this professionally, but I like playing sports and stuff like my friends. But, I wanted to get on a team at school...” He stated that he played sports “Like, maybe at a friend’s house or on a football field at school or...when we had a PE...” David’s outlook on being able to play sports at school was that it was a possibility for him. He viewed the times that he had with friends and at school as his own.

Jack described his activities as manager of the football team at his school. He also mentioned his like of “...basketball season.” When asked about helping with the basketball team as well as the football team, he replied “Not yet...I want to.” Jack was not able to play on the sports team due to his need for respiratory assistance; he was able to participate by assisting with the team, creating a way to participate for himself.

The adolescents were not able to participate in activities due to their need for respiratory assistance. For adolescent males, playing sports with friends and at school

was not a possibility due to their underlying respiratory problems, need for respiratory assistance to aid them in breathing, and for some, mobility problems. The adolescents were found to be participating in other ways such as observing and being present at events. The adolescents felt that they were still able to participate and enjoy these activities by creating their own way of participating, creating moments for themselves.

Summary. These adolescents had a strong sense of self; they knew who they were and who they wanted to be. The adolescents had visions of being independent now and in the future. The adolescents felt that they were able to provide care to themselves currently. When faced with situations that were affected by their need for respiratory assistance, they adapted to the situation and created ways to engage in activities in their own way.

“The only one I know of”

The adolescents described others who they considered like them in regards to their need for respiratory assistance and their daily living. The adolescents described a person that they knew or knew of who required respiratory assistance and also discussed those that required other medical technologies in their daily lives. These adolescents knew of others with similar needs for technology, however, few adolescents had friends and schoolmates that they interacted with on a regular basis. This theme was revealed in the participants’ sharing about a person that they knew who required respiratory assistance being “the only one that I know of”.

Stephanie described an adolescent like her who required respiratory assistance, an adolescent with a tracheostomy at her school. She stated “...I know this guy that goes to my school that has a trach....Mark (name changed)...and he’s in a wheelchair. And he

and I both had a trach at the same time. And I watched him, you know, rolling down the hallways having a trach...But he's the only one that I know of that has like breathing issues at our school..." She noted that this adolescent was the "only one that I know of" at school who required respiratory assistance like her, a tracheostomy. She referred to him as an acquaintance not someone that she was friends with at school. Stephanie also described him as having other needs for technology (i.e. wheelchair) in addition to the tracheostomy. She recognized the adolescent as similar, yet different than her, and as being normal prior to needing respiratory assistance and other assistive devices.

Ciara described an adolescent that she used to know at school who had a tracheostomy like her. She remembered "There was this one kid at school...but he doesn't go there anymore. He was like in a wheelchair...he had a trach. He was a normal kid but his body couldn't function at all...he has a trach and I know him but...I lost touch with him since he left school." She paused and stated "Umm...all I can remember is that his name is Steven (name changed)..." Ciara defined the schoolmate as being normal, but having bodily issues that affected his daily activities. The fact that he had a tracheostomy was an aside, a part of his being, not who he was as a person. Also of note, she knew of him in general terms, but did not identify him as a friend or someone she knew well. He was noted as being someone like her in having a tracheostomy. He was the only person that she knew of with a tracheostomy.

Michael described someone he knew or possibly knew about with a tracheostomy. He described another adolescent with a tracheostomy "...who we've known since I was little...he has a trach...Peter (name changed)...but he's like, I guess the only one I know." Like Stephanie, Michael acknowledged that this adolescent was the "only one I

know”. He continued with “...I’ve met him before but I think it was like...I don’t remember or I don’t remember him very well...but I know we’ve got like pretty much the exact same, um, medical issue...Like, he’s got a trach for, um, you know, like breathing issues like me. I think he’s got a G-Tube also, just kinda the exact same as me.” His final statements alluded to him knowing about Peter, but did not actually know him. He did identify with the other adolescents need for respiratory assistance and described the adolescent as being like him in needing respiratory assistance in addition to other medical technology.

Brad clarified the discussion of knowing any other adolescents who require respiratory assistance. He stated “...it depends on what you mean. Like, know of...? Like do I know of people?...Or do I have a...relationship with someone who has it?...like I know of people, like, who require respiratory assistance.” He recognized “I know of” other adolescents and provided the example of his interactions with other adolescents who need assistance. He continued with “Um, I know one kid that has Bi-Pap...To be honest, I haven’t seen them in two years...because last year camp was canceled...I mean, last time I went to camp I didn’t have Bi-Pap so I have no idea.” Brad was familiar and knew of other adolescents like him, those who required respiratory assistance. These adolescents were acquaintances or friends that he interacted with at camp only, not friends that he saw on a regular basis.

David described others that he knew with a tracheostomy, mentioning “...I know that there’s one friend I had that used to have some kind of, not a trach, but some kind of respiratory thing...a mask or something.” His description was general and not indicative

of a close relationship. This friend at school was the only person that David knew of who required respiratory assistance.

Isabelle described knowing another adolescent who required technology, not specifically respiratory assistance. She answered “no” that she did not know anyone with a tracheostomy, but did note that she knew other people that needed technology. She described a schoolmate as “Um, yes, I met this boy. He’s my friend. His name is Mark (name changed). His hands are like curved and his legs. So, he can’t write. He can’t straighten up his arms like me...He doesn’t have a tracheostomy but he is still alive and just...nothing can bring him down.” She clarified that he has a computer to assist him, but he does not have a tracheostomy. Isabelle felt that he was like her in respects to needing technology and considered him a friend.

Crystal knew others like her. She stated “Yes I do.” and continued with “I have a best friend named Jennifer and she has Muscular Dystrophy too. She’s the same age as me...And we’ve know each other since we were like five and we did dance together and she uses a BiPAP...she’s not paralyzed, but she can’t really move a lot and like she can barely move her head and her arms...she can’t cough, like at all, and she had a feeding tube and everything and they literally have to put all their weight on her chest and literally push on it to make her cough and she also has a cough assist...” She concluded with “So, it’s pretty extreme, her respiratory things.” She clarified that they had similar respiratory needs with “Yeah, we do. Like, when I started using it she’s like, I love the BiPAP...” Crystal had a close friend who required respiratory assistance. This friend was someone that she saw as like her and had been there to support her when she first began

using respiratory assistance. This friend who required the same respiratory assistance as her was the only one that she knew of who required respiratory assistance.

Several of the adolescents did not know anyone else who required respiratory assistance. Jack, Randy, Rose, and Maya stated that they did not know or know of any adolescents who required respiratory assistance. After the interview concluded, Rose asked “what did some of the other kids say?” She was interested in what they had to say. Maya did not know anyone else who required respiratory assistance and posed question whether anyone else existed. She asked the interviewer “Have you?” These questions reveal the notion of adolescents who require respiratory assistance not knowing or knowing of anyone else like them and may reveal that they may consider themselves the only adolescent in their situation. The other adolescents simply denied knowing anyone else who required respiratory assistance. These adolescents do not have anyone else like them in existence in their world. They were “the only one I know of” in their experiences.

Summary. The adolescents described other adolescents who required respiratory assistance and other medical technologies as being “the only one I know of”. These adolescent participants were limited in their knowledge of and interactions with other adolescents like them. Few adolescents had friends that they knew well and interacted with on a regular basis. Most of the adolescents had an acquaintance at school that they knew of, but had little interaction with on a day-to-day basis.

Summary

In this chapter, the themes and patterns found in the interviews with the adolescent participants were presented. The themes emerged from the description and interpretation of the experiences of adolescents who require respiratory assistance. All of

these adolescents have a strong sense of self. They know who they are, the obstacles they face, and who they want to be. They look past the technology and focus on the positive aspects of their lives. They are courageous, thankful, thoughtful, mature, and introspective. They have a sense of individuality and independence that is appropriate for their developmental stage of adolescence.

Nurses were the focus of the themes “Get to know me” and “Allow me to be myself”; “Get to know me” is also a pattern overarching all interviews. These present to nurses how the adolescents who require respiratory assistance view themselves and how they want nurses to view them and interact with them.

Friends are a supportive presence for adolescents in the theme, “Being there for me”. These adolescents know and appreciate their friends as liking them for who they are without concern for their need for respiratory assistance. Those who are not considered friends are felt to judge them.

Respiratory assistance emerged in the theme, “No matter what, technology helps”. The use of respiratory assistance is recognized as a part of their daily lives and the daily lives of others. Technology dependence has meanings that differ based on the person.

The adolescents spoke about themselves and their daily lives in the themes, “I am an independent person”. The adolescents had a positive outlook on their current and future situation, while recognizing the limitations that respiratory assistance presents in their daily lives. The adolescents had the strength to move past these challenges and create moments that they could participate in.

The adolescents described not knowing or knowing of few adolescent who required respiratory assistance in the theme, “The only one I know of”. The adolescents did not know others like them who required technology.

CHAPTER VI

Conclusions and Recommendations

The purpose of this study was to explore the experiences of medically fragile adolescents who require respiratory assistance. Eleven adolescents who required respiratory assistance were interviewed about their experiences. Interpretive phenomenology was used to describe and interpret the lived experiences of medically fragile adolescents who require respiratory assistance using data analysis steps delineated by Diekelmann and Allen (1989). The limitations of the study that emerged are discussed for consideration in the findings and conclusions.

Six themes and one pattern were identified from the interviews with the adolescents. “Get to know me” and “Allow me to be myself” are themes about how the adolescents want nurses to view them, being similar to how they view themselves as an individual; “Get to know me” is also a pattern overarching all interviews. The theme, “Being there for me” refers to friends being there for the adolescents. The adolescents spoke of technology as beneficial to them and others in the theme “No matter what, technology helps”. The theme, “I am an independent person”, presents their current activities and future plans in life, including how the adolescents have adapted to respiratory assistance in their daily lives. Finally, “The only one I know of”, is a theme that relates to their feelings of loneliness in not knowing other like them.

This study explored a unique population of medically fragile adolescents who required a specific technology, respiratory assistance, within a distinct developmental

stage, adolescence. In this chapter, conclusions from the findings will be discussed along with recommendations for nursing practice, education, and research.

Conclusion from the Themes

The themes that emerged from the data provided insights into the experiences of medically fragile adolescents who require respiratory assistance. Thus, the purpose of this study, to explore the experiences of medically fragile adolescents who require respiratory assistance, was fulfilled. The specific aims, exploring (a) the day to day life of a medically fragile adolescent who requires respiratory assistance, (b) how the adolescent with respiratory assistance experiences family, friends, and school, (c) how an adolescent perceives their future possibilities, and (d) how nurses may help, were also uncovered in the themes. The themes of “Get to know me” and “Allow me to be myself” address nurses caring for the adolescents. “Being there for me” relates to friends and school. Daily living with technology emerged in the theme “No matter what, technology helps”. The theme, “I am an independent person”, presents the adolescent future plans in life. Finally, “The only one I know of” also includes notions of technology. In discussing conclusions from these themes and later discussing recommendations, this study will help nurses to better understand what these adolescents experience in their daily lives and aid them in providing better care for them.

“Get to know me”

The adolescents wanted nurses to get to know them beyond their need for respiratory assistance in the theme “Get to know me”. The adolescents saw themselves as important, as a person, and wanted nurses to view them the same. However, in some

ways, they desire distance from nurses and a professional relationship; they wanted a nurse, not a friend or parent figure.

The adolescents wanted nurses to get to know them and talk to them about their lives without focusing on their need for respiratory assistance. Cantrell and Matula (2009) interviewed childhood cancer survivors who wanted nurses to engage in discussions with them that were not focused on the cancer. The adolescents and young adults wanted nurses to see them as individuals, not patients with cancer (Cantrell & Matula). This is how medically fragile adolescents who require respiratory assistance also feel. They want nurses to view them as individuals, not patients with respiratory assistance.

The adolescents also wanted nurses to ask them about themselves as a way of getting to know them. There was also a notion that the adolescents were comfortable with nurses getting to know them which may reflect their increased exposure to health care providers and their comfort with those providing their care. In a study of adolescents living with a long-term illness or disability (Berntsson, Berg, Brydolf, & Hellstrom, 2007), the adolescents stated that they felt more mature than their peers and were used to expressing their opinions and being responsible for their own treatment. This was interpreted as a feeling of personal growth (Berntsson et al.). Medically fragile adolescents who require respiratory assistance also were comfortable speaking with nurses and exhibited confidence and maturity greater than expected for their age.

The subtheme “But don’t be too nosy” is a new notion that emerged from these participants. Within the desire for nurse to get to know them as a person, the adolescents also wanted boundaries in the relationship. They warned nurses not to get to know too

much, presenting the notion that they recognize the nurse-patient relationship as separate from friendships and familial relationships. Ultimately, the current study supports nurses getting to know these adolescents as a person beyond their need for respiratory assistance. The adolescents wanted to be seen as individuals rather than objects. The study also presents that these adolescents have a strong sense of self, or self-esteem.

“Allow me to be myself”

The adolescents had strong feelings about how they wanted to be treated by nurses in the theme “Allow me to be myself”. They also had a strong sense of self and the courage to speak up and express their desires to be themselves. This again focuses on their desire to be seen as a person, not for their respiratory assistance.

The adolescents wanted to be themselves and treated as a person, not treated differently due to their need for respiratory assistance. Adolescents with Treacher Collins syndrome, a craniofacial difference, also expressed a challenge in balancing how they were the same and different to other adolescents (Beaune, Forrest, & Keith, 2004). They felt that they were treated differently, even though they did not wish to be treated differently (Beaune et al.). For nurses, medically fragile adolescents who require respiratory assistance want to be treated like themselves, like a person, an adolescent, not as a patient who requires respiratory assistance. Findings from this study support the notion that nurses should focus on the adolescent as a person instead of focusing on the patient who requires respiratory assistance. This also exhibits their strong self-esteem and sense of individuality.

“Being there for me”

The adolescents felt that friends were there for them when they needed support in the theme “Being there for me”. Friendships were important to them. Their friends saw them for who they really were as a person. This was in contrast to those that they did not consider friends who were judgmental. These adolescents were typical adolescents in every way with their need for respiratory assistance and other technologies as the thing that made them different. These adolescents focused on the similar interests that they had with friends. Their friends were there for them and recognized them as a unique person, not just someone who requires respiratory assistance.

Friends’ being there has been cited in the literature for adolescents. Spratling et al. (in press) found that friends were a significant source of companionship and simply someone to be there with them in a study of children with a tracheostomy. Berntsson et al. (2007) found that being with friends was important to adolescents living with a long-term illness or disability. This was equated with feelings of support, independence, and spontaneity (Berntsson et al.). In a study of adolescents with epilepsy, adolescents who had support from friends seemed to experience less strains associated with their illness (Eklund & Sivberg, 2003). The notion of being there for them encompasses support from friends for these adolescents.

Adolescence is a time when belonging is important and youth often exclude those who are different (Erikson, 1963). These adolescents focus on the things that make them similar to other adolescents, not the differences in requiring technology. This is contrasted in the subthemes “My friends see me as a person” and “Others judge me” in which the participants either felt accepted or judged. Beaune et al. (2004) found that

adolescents with Treacher Collins were “reconstructing perceptions of others” through developing a positive sense of self-worth and helping others get to know them. The adolescents formed friendships that aided them in overcoming negative judgments from others (Beaune et al.). Being judged by those not considered friends is a challenge for the adolescent who required respiratory assistance and adolescents who have chronic illness. Support from friends helps adolescents overcome these challenges and develop positive self-esteem (Earle et al., 2006; Tarrant, MacKenzie, & Hewitt, 2006).

The notion of friends as a supportive presence is found in this study and other studies on medically fragile children and adolescents and adolescents with chronic illness. Friendships are not a new concept in the adolescent literature, but how friends are important in adolescents who require respiratory assistance is emerging into the concept of support from friends or social support.

“No matter what, technology helps”

The adolescents had an overwhelmingly positive view of technology as helpful to both them and others in the theme “No matter what, technology helps”. Technology had meanings to them that encompassed enhanced daily living and existing as a part of their day, not their whole day. There is a notion that these adolescents use of technology is taken for granted unless others call attention to the technology. The adolescents did present that technology has different meanings that depend upon the individual’s perception of the technology.

Adolescents recognize the help that technology provides in their daily lives. In a study of quality of life of adolescents with cerebral palsy, Davis et al. (2009) found that the adolescents recognized the importance of their equipment in their mobility and their

ability to live as independently as possible. Heaton et al. (2005) also found that the medically fragile child and adolescent participants recognized technology as beneficial in their daily lives and as enabling them to do the things that they want to do each day. These studies and the current support equate technology with the ability to function independently.

The adolescent participants viewed technology as a benefit to others. Within this notion, technology was an individual perception that had different meanings depending on the person. This global view of technology is a unique finding in the current study, presenting the concept of technology dependence as an abstract thought versus a measurable number of technologies or hours of technology use per day.

“I am an independent person”

The adolescents voiced their views of themselves in themselves in the theme “I am an independent person”. This theme demonstrates their courage, inner strength, and self-esteem. They recognize the challenges that technology present in their daily lives, yet they push past the challenges and live their life to the fullest. They do their best in order to be the best person that they can be in life.

Independence is a goal for all adolescents, but may be even more so for those who require respiratory assistance. The process of becoming independent in the management of chronic illness, specifically diabetes, has been noted in the literature (Piana et al., 2010). The adolescent participants in the current study felt that they were functioning independently. They wanted to share this with others and they wished for others to recognize and respect their independence.

The subtheme of “I see myself” depicts their positive outlook on their future possibilities. There is also evidence of goals for independent living and the notion of transitioning to adulthood. Adolescents living with a long-term illness or disability had beliefs in the future that were positive (Berntsson et al., 2007), whereas adolescents with cerebral palsy and their parents expressed concerns and worries about the future (Davis et al., 2009). Future plans may be a dichotomy of hopefulness and worry for adolescents with chronic illness, however, for these adolescent participants, they see themselves with a future that includes independent living.

The adolescents adapted to situations in order to function independently in the subtheme “Creating moments for myself”. Previous studies have described the limitations in activities that having a chronic illness presents in adolescence (Beaune et al., 2004; Berntsson et al., 2007; Eklund & Sivberg, 2003), however, participants this study present that the adolescents participants adapt to situations in order to minimize the limitations and maximize their participation in activities. Adolescents with cerebral palsy also described different ways of participating (Davis et al., 2009). This creating ways of participating in activities demonstrates that adolescents actively strive to have independence in their lives.

In the current study, the adolescents viewed themselves as an independent person now and in the future. They were actively engaging in activities and strategies to achieve their goals of independence. These adolescents are resilient, demonstrating positive outcomes, including self-esteem, in the presence of technology, a presumed adversity. Resilience has been defined as positive adaptation in the presence of adversity (Luthar & Cicchetti, 2000), and has been used to describe children and adolescents who do well

despite the presence of risks for poor outcomes (Curtis & Cicchetti, 2003). The findings from the current study present resilience as a concept of interest for these adolescents.

“The only one I know of”

In this study, the adolescent participants had little connections with other adolescents like them. In the theme “The only one I know of”, the majority of the adolescents had little acquaintance, if any, of others who required respiratory assistance or other technologies. These adolescents did not know anyone like them with whom they could identify. This isolation and lack of connection to other like them was also found in a study of the experiences of children with a tracheostomy (Spratling et al., in press).

One adolescent, Crystal, did have a friend who required respiratory assistance and other technologies like her. This friend that she knew who required respiratory assistance was a source of support for her and someone that she could identify with as having similar experiences. Kyngas (2004) found that adolescents with chronic illnesses described peers who had chronic illnesses as “fellow sufferers” who were understanding, caring, and supportive to them. The current study had one example of knowing someone that the adolescent could identify with as being supportive and understanding the experience of requiring respiratory assistance.

Adolescents help one another by forming friendships and groups with others whom they identify with (Erikson, 1963). These adolescents do not have other adolescents like them in their need for respiratory assistance. Previous studies with medically fragile children and adolescents have suggested that knowing children with similar concerns may be associated with higher self-esteem (Earle et al., 2006; Heaton et al., 2005). Findings from this study supported the notion that having connections with

other adolescents who require respiratory assistance or other technologies was important for these adolescents.

Recommendations for Nursing Practice

The participants of the current study, medically fragile adolescents who required respiratory assistance among other technologies, expressed a desire for nurses to get to know them as a person and to allow them to be themselves. The adolescents also lacked connections with other medically fragile adolescents and schoolmates who did not understand them. Nurses are in a position to enhance care through connecting with these adolescents in their nursing care and fostering connections with other adolescents, including medically fragile adolescents. Nurses can facilitate connections via the internet and social networking websites.

Nurses can help to build connections with medically fragile adolescents who require respiratory assistance through getting to know these adolescents as persons. Asking about their daily lives and focusing on aspects of their lives not associated with their need for respiratory assistance is an important part of nursing care. Through these actions, nurses foster self-esteem in these adolescents and encourage independence in daily living for these adolescents. Nurses also increase the adolescent comfort and confidence in nursing care.

Future practice for nurses can include networking medically fragile adolescents who require respiratory assistance. Nurses can encourage use of a “buddy system” in classes to foster connections with schoolmates for adolescents who may be hesitant to make connections. There is also potential for development of online resources and “social network” for medically fragile adolescents within clinics, geographic areas, and on a

national and international level. Knowing other adolescents who require respiratory assistance and other technologies can help these adolescents find support and understanding from others like them.

Recommendations for Nursing Education

Medically fragile adolescents are a unique population of adolescents that nurses typically have little knowledge about unless they are directly involved in their care. Nursing education should focus on increased awareness of medically fragile adolescents in undergraduate and graduate nursing programs and learning resources for currently practicing nurses, including programs for school nurses. Also, nursing education could extend to educational programs for the community and peers at school.

Nurses who are not exposed to medically fragile adolescents who require respiratory assistance often do not have an awareness of this unique population. Including content on the medically fragile pediatric population in undergraduate and graduate curriculum would be beneficial. Also, including student clinical experiences at medically fragile day cares, technology dependent care units, and pediatric home care agencies would increase exposure to these adolescents.

For nurses in practice, the development of lectures and modules as learning resources for continuing nursing education would be helpful. These learning resources could also be directed towards school health nurses who are often responsible for care of these adolescents at school. Such resources could include information about their psychosocial and physical needs.

Within the community and schools, education should be directed towards increasing awareness of medically fragile adolescents and decreasing any myths or

concerns that others may have, including peers. There is often an association with physical and mental disabilities, which is not always the situation as demonstrated in the current study. As the adolescent participants noted, getting to know others and developing connections often alleviated their peers fears and concerns about their use of technology.

Recommendations for Nursing Research

This research was an initial step in the study of medically fragile adolescents who require respiratory assistance. Since there are few studies on the medically fragile pediatric population, studies similar to this exploring other technologies and age groups would be helpful in increasing nursing knowledge. Other areas of interest for future research include the exploration of resources to aid medically fragile adolescents in transition to adulthood and application of a theoretical framework such as resilience to a larger study on medically fragile adolescents. Also, the role of the nurse in the daily lives of these adolescents, including school nurses and home nurses, is an area for exploration. Future research may include specifically what adolescents think nurses need to know about them and to explore the boundaries of the nurse-patient relationship with adolescents who require respiratory assistance.

Independence and transitioning to adulthood were noted to be underlying notions in this study. Research is needed on how these adolescents achieve independence and how nurses can aid them in functioning independently. The transition to adulthood is a concept of interest in adolescents with chronic illness; research is needed for medically fragile adolescents on how they transition to adulthood and what resources are needed for the transition.

No studies have been found that use a theoretical framework and quantitative methods in the study of medically fragile adolescents. A larger multi-center or possible national study is needed on this population to advance nursing knowledge on this population. These adolescents are resilient in their ability to do well and maintain a positive attitude in the presence of the challenges of daily need for technology. Resilience is a potential theoretical framework for use in the study of this population.

The current study revealed some of the needs that medically fragile adolescents who require respiratory assistance have in their nursing care. Future studies could provide further data on the role of the nurse in caring for these adolescents and the dynamics of the nurse-patient relationship among the nurse and the adolescent. School nurse and home nurse who often interact with these adolescents on a routine basis would be an ideal beginning for this exploration. In a population where nursing knowledge is limited, continued study is warranted to learn about medically fragile adolescents and explore the best approaches to caring for them by nurses.

Limitations

Limitations for the study included 1) sample size, 2) sample selection, 3) geographic location 4) the adolescents' ability to articulate their experiences, and 5) the parents' willingness to allow their adolescent's participation in the study. All of these perceived limitations held true in the research process. The sample size was small and smaller than anticipated, however, typical for a qualitative study with a unique population. The sample was selected from a group of medically fragile adolescents who require respiratory assistance in a relatively small geographic location. This distinct group had similarities and differences based on their need for respiratory assistance and

their experiences of daily living in the Southeastern United States. Most notably, all were experiencing care from the same group of providers and similar resources at home and school within the governing bodies of the same state. They differed in their access to resources based on rural versus urban location. The adolescents recruited were able to articulate their experiences; however, the concomitant communication disorders and developmental delays associated with need for respiratory assistance severely limited the sample. Lastly, study of a minor population required great consideration by the parent whether or not to allow their adolescent's participation in the study. Parents were often hesitant to allow their adolescent to participate in the study until after they had thoroughly reviewed the mailings and spoke to the researcher and/or their provider about the study.

Summary

This study has contributed to the nursing knowledge of medically fragile adolescents who require respiratory assistance. Through the adolescent participants' description of their experiences, insights have emerged for nurses who provide care to them. These adolescents have a clear view of who they are as a person, and they want nurses to view them as a person, not a patient who requires respiratory assistance. Further inquiry is needed on medically fragile adolescents. In uncovering their strengths, there is an opportunity for enhancing nursing care for all adolescents.

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Appendix A
Consent Form

Children's Healthcare of Atlanta
Consent to be in a Research Study

Title: The Experiences of School-Age Children with a Tracheostomy

Principal Investigator: Dr. Myra Carmon, RN, CPNP

Student Principal Investigator: Regena Spratling RN, MS, CPNP

If this form is being read by the parent or legal guardian, the term "you" refers to "your child."

Your child is being asked to volunteer for participation in a research study. In order to decide whether or not you want your child to be a part of this study, it is important that you read and understand this form. It is also important that you ask any questions that you may have and that you understand all the information in this form. This process is called "informed consent."

Why is this study being done?

The purpose of this study is to explore the experiences of medically fragile adolescents who require respiratory assistance. The overall aim of the study is to gain an understanding of how medically fragile adolescents who require respiratory assistance experience their world. Specific aims of this study are to gain an understanding of their perceptions of (a) the day to day life of a medically fragile adolescent who requires respiratory assistance (b) how the adolescent with respiratory assistance experiences family, friends, and school (c) how an adolescent perceives their future possibilities and (d) how nurses may help.

What will happen to you in this study?

If you decide to participate, your child will be interviewed and audiotaped. You will be asked to complete a demographic information sheet. This interview will be done after your child's regularly scheduled clinic appointment at Children's Healthcare at Scottish Rite, or in your home, if you prefer. Participation in this study should take approximately 30 minutes for you and your child. Your child will be interviewed by the investigator without the presence of the parent, if possible. If not possible, as a parent you are asked not to answer questions for the child.

How long will you be in this study?

Participation will require approximately 30 minutes of you and your child's time.

What are the possible risks to being in this study?

In this study, your child will not have any more risks than you would in a normal day of life. There will be minimal risk to privacy. Your child's name will be replaced with a number and will not be associated with any study information.

What are the possible benefits of being in this study?

Taking part in this research study will not benefit you personally but we may learn new things that may help others in the future.

What are the alternatives to being in this study?

If you choose not to participate in this study your child's treatment will not be affected.

What is the cost of being in this study?

You will not incur any costs for this study or be compensated for your time. Your child will receive a twenty dollar gift card.

What if there is new information about this study

We may learn new things during the study that you may need to know. We may also learn about things that might make you want to stop participating in the study. We will tell you about any new information.

What if you have any questions or problems while in this study?

If you have any questions about this study call Regena Spratling at 404-307-2291 or Dr. Myra Carmon at 404-413-1154. If you have any questions about your rights as a participant in this study, you can call the Children's Healthcare of Atlanta Institutional Review Board (IRB) at (404) 785-7477 or Susan Vogtner in the Office of Research Integrity at Georgia State University at 404-413-3513 or svogtner1@gsu.edu. The IRB is a committee of people that approves all research in this hospital and follows all the rules and regulations made by government agencies about how research is done.

Who will be able to see your records of study participation?

Your child's records of participation in this study are not accessible to the general public and every effort will be made to maintain confidentiality. However, all records may be subject to subpoena by a court of law. Information that may be gained from this study will be used only for research and educational purposes. Information may be published in medical journals with permission of the Principal Investigator, Myra Carmon and Regena Spratling, but your identity will not be revealed or written in a way that you can be recognized. Additionally, identifying information will be available to people from the Children's Healthcare of Atlanta IRB and Georgia State University IRB.

What are your rights as a study participant?

Taking part in this study is completely voluntary. You may choose not to take part in this study. If you take part in this study, you may stop being in the study at any time. Your decision to not take part in the study or to stop being in the study will not in any way affect your child's current or future medical care at this hospital.

The study doctor may stop you from taking part in this study for any of the following reasons: (1) it would be dangerous for you to continue; (2) you do not follow study procedures.

Appendix B

Assent Form

**Children's Healthcare of Atlanta
Assent to be in a Research Study**

Study Title: The Experience of Having a Tracheostomy

Why am I being asked to do this?

We are trying to learn more about adolescents who require respiratory assistance. You are invited to be in the study because we want to know what you think.

Why is this study being done?

The study is being done to find more about adolescents who require respiratory assistance so that nurses and doctors can better take care of them.

What will happen to me?

I will be asked questions about me and my respiratory assistance. The interview will be recorded.

Will the study hurt?

The study will not hurt.

Will the study help me?

The study may not help, but nurses may learn how to help adolescents in the future.

What if I have any questions?

You can ask any questions that you have about the study. If you have any questions later, you can call me at 404-307-2291.

Do my parents know about this?

Yes, this study was explained to your parents and they said that you could be in it if you wish. You can talk this over with them before you decide.

Do I have to be in the study?

No, you do not have to be in the study. If you don't want to be in this study, just tell us. You can say yes now and change your mind later. It's up to you. It will not matter to your doctors or nurses if you want to be in the study or not.

Writing your name on this page means that you agree to be in the study, and you know what will happen to you. If you decide to quit the study, just tell the person in charge.

Printed Name of Research Subject Age _____ Date of Birth _____

Signature of Research Subject Date _____ Time _____

Signature of Person Obtaining Assent/Consent/Permission Date _____ Time _____

Signature of Witness Date _____ Time _____

Signature of Interpreter Date _____ Time _____

In my opinion, the child is not able to assent to participate in this research study for the following reason:

Signature of Person Obtaining Assent/Consent/Permission Date _____ Time _____

Appendix C

Interview Questions

Interview Questions

1. Tell me about a time when you were doing something you really like to do. What are some of the other things you like to do? With friends? At home?
2. Tell me about a typical day in your life.
3. Tell me about your favorite time of the year.
4. Tell me about school. Tell me about a time when you had a good day at school.
Tell me about a time when you had a bad day at school.
5. Tell me about any help you have at school? Who helps you and how do they help you?
6. How do you see yourself in the future? College? Relationships?
7. What would you like to do that you feel you are not able to do?
8. Tell me about a time when technology was helpful in your daily life. Computer? Internet? Cell phone?
9. Do you know any other adolescents who require respiratory assistance? What do you know about them?
10. What advice would you give to another adolescent with respiratory assistance?
What advice can you give me to take care of an adolescent with respiratory assistance?
11. What can nurses do for you that is most helpful? What is not helpful?
12. Is there anything that you can tell me that would help me to understand who you are and how you live that I have not asked you?

Appendix D
Demographic Information

Demographic Information

Age: _____ I.D# _____

Gender: Male _____ Female _____

School Attendance: Public _____ Private _____ Home _____

School Grade: _____

Race: Caucasian _____
 African American _____
 Hispanic _____
 Asian / Pacific Islander _____
 Other _____

Medical Diagnoses/Hospitalizations:

Respiratory support:

Tracheostomy: Since age _____

Passey-Muir Valve: No _____ Yes _____ If yes, Day _____ Night _____

Humidified Trach Collar or Humidivent:

No _____ Yes _____ If yes, Day _____ Night _____

CPAP: No _____ Yes _____ If yes, Day _____ Night _____

Ventilator: No _____ Yes _____ If yes, Day _____ Night _____

BiPap: No _____ Yes _____ If yes, Day _____ Night _____

Other technological supports:

Nursing hours per week: _____

Appendix E
Dissertation Study Summary

Dissertation Study Summary
Regena Spratling, MS, RN, CPNP

Research question: (1) What are the experiences of medically fragile adolescents who require respiratory assistance? Specific aims of this study are to gain an understanding of:

- (a) the day to day life of adolescents
- (b) how the adolescent experiences family, friends, and school
- (c) how an adolescent perceives their future possibilities and
- (d) how nurses may help

*Adolescents who require respiratory assistance are defined as those who are dependent upon tracheostomies and ventilator support, mechanical ventilation via tracheostomy or positive airway pressure support via face mask (i.e. Bi-level positive airway pressure [BiPap]).

Design: A qualitative methodology using interpretive phenomenology to describe and interpret the lived experiences of the adolescents.

Data collection: Audiotaped semi-structured interviews

Significance: Knowledge about the experiences of adolescents can provide nurses with a better understanding of their needs and can aid nurses in using the best approaches in caring for them. In addition, the knowledge gained from this study will contribute to the development of interventions to enhance nursing care specific to these adolescents. This study is the first step in building the nursing science on medically fragile adolescents who require respiratory assistance.

Findings from the study of school-age children with a tracheostomy:

The children (n = 5, ages 7 to 11 years) expressed the importance of friends as helpful in their daily lives, the effect of telling others about their tracheostomy as a way of facilitating friendships at school, and feelings of isolation and loneliness in not knowing other children like them (i.e. children with a tracheostomy).

Appendix F
Recruitment Flyer

Study participants needed!

I am looking for...

1. Adolescents 13 to 18 years old
2. Use of BiPap or CPAP
(or history of use in the last 2 years)
3. Able to answer questions in an interview

If you come across these patients, please contact me at
regenaspratling@hotmail.com or 404-307-2291.

Thank you,

Regena Spratling

Appendix G

Code Book

Code Book

Friends

-being there

-being connected

Not friends

Technology

Future/independence

Independence

Like me

Passive

Active

Sick

Work

Nurses

Appendix H

Categories

Categories

Friends

Get to know me

Technology

Beyond technology

Work of adolescence

Future/independence

Observing/Participating

Like me