Abstract

Progressive Neuromuscular Diseases (PNDs) are relentless, debilitating, incurable diseases that cause nerves and muscles to atrophy. A large portion of the population who experience PNDs are adolescents. These adolescents progressively lose physical abilities and increasingly rely on caregivers at a time in their life when, paradoxically, normative adolescent development prescribes a move towards independence and autonomy. There is little research examining this experience from the adolescents’ perspectives.

The purpose of this interpretive phenomenology study was to understand the experience of adolescents with PNDs when making decisions in relation to their health. Data collection consisted of 10 semi-structured interviews with 5 adolescents, 16-19 years of age, who were living with a PND (two interviews with each of the 5 participants). These interviews lasted an average of 60 minutes.

Data were analysed using interpretive strategies, including the development of themes using exemplars, and paradigm cases. Findings revealed that the adolescents separated health decisions into two distinct categories, Big and Small, based upon level of perceived risk and physician involvement. Big referred to high-risk decisions, included physicians, and involved a medical/surgical procedure or intervention. Small referred to lower risk decisions, did not include physicians, and involved personal care. An expert emerged with each category of decision. In Big Decisions, the physician was perceived as the expert who made recommendations, provided information, and introduced the decision. In Small Decisions, the adolescent perceived himself as the expert. With Big Decisions, the physician expertise was typically respected, and the recommendations were followed. With Small Decisions, parents typically respected adolescent expertise.
However, the adolescents commonly experienced not having their expertise respected by health professionals.

In the context of Big and Small decisions, the theme Joint Ownership captured the sense that with the progressive loss of abilities and resulting dependence, the physical disability and illness were not experienced solely by the adolescent but by the adolescent and his parent(s). As the parent(s) and adolescent shared these experiences, the decisions, ownership of the physical body, and the responsibility for the care of the body also became shared.

The findings suggest that health care professionals need to include the adolescents in the Small Decisions, and also acknowledge that adolescents may desire parental involvement in Big Decisions.
# TABLE OF CONTENTS

Abstract ......................................................................................................................... ii
Table of Contents ......................................................................................................... iv
Acknowledgements ....................................................................................................... vi
Chapter 1 Introduction ................................................................................................. 1
  Study Significance ....................................................................................................... 2
  Definitions .................................................................................................................... 4
    Defining ‘Adolescence’ .............................................................................................. 4
    Defining ‘Progressive Neuromuscular Diseases’ ...................................................... 5
  Research Questions ..................................................................................................... 5
  Summary ...................................................................................................................... 5
Chapter 2 Literature Review ......................................................................................... 7
  Stages of Adolescence ............................................................................................... 7
  Normative Development ............................................................................................ 9
    Puberty ....................................................................................................................... 9
    Social Changes ......................................................................................................... 10
      Quest for Identity .................................................................................................. 10
      Puberty .................................................................................................................... 10
    Social Cognitive Development ............................................................................... 11
    Social Structural Changes ....................................................................................... 11
  Cognitive Changes ..................................................................................................... 11
  Identity Development ................................................................................................. 14
    Identity Formation With a Disability or Chronic Illness ........................................ 16
  Transition from Pediatric to Adult Care ................................................................... 17
  Importance of Obtaining Adolescents’ Perspectives ................................................. 20
    Autonomy Versus Dependence .............................................................................. 21
    Preferences Related to Involvement in Healthcare ................................................ 24
  Decision-Making ........................................................................................................ 26
    Decision-Making for Adults .................................................................................... 26
    Decision-Making for Healthy Adolescents .............................................................. 28
    Decision-Making for Adolescents With Disabilities or Chronic Illnesses ............ 29
  Progressive Neuromuscular Disease ...................................................................... 29
  Conclusion .................................................................................................................. 31
Chapter 3 Research and Design Implementation ....................................................... 32
  Sample ....................................................................................................................... 33
    Sample Characteristics .......................................................................................... 34
  Recruitment ............................................................................................................... 36
  Setting ......................................................................................................................... 38
  Data Collection ......................................................................................................... 38
  Data Management ..................................................................................................... 40
  Data Analysis ............................................................................................................ 40
  Scientific Rigor .......................................................................................................... 43
    Philosophical Rigor ................................................................................................. 44
    Practicality and Criteria .......................................................................................... 45
    Methods to Increase the Worth of the Findings ....................................................... 45
  Confidentiality and Ethical Considerations ............................................................... 47
Acknowledgements

I wish to thank Dr. Rose Steele and Dr. Alison Phinney for their patience, encouragement, guidance and fantastic editing. As well, I wish to thank the New Emerging Team: Transitions in Pediatric Palliative and End-of-Life Care for providing funding that helped make this research possible.

This research would not have been possible without the adolescents who willingly shared their stories and experiences with me – Thank You!
CHAPTER ONE

INTRODUCTION

Progressive Neuromuscular Diseases (PNDs), such as muscular dystrophy, spinal muscular atrophy, and Friedrich’s ataxia are relentless, debilitating, incurable diseases that cause nerves and muscles to atrophy. The actual prevalence of PNDs is debated in the literature, varying significantly between study and country (Darin & Tulinius, 1999). This variance seems to be primarily linked to the exact diseases and the particular country included in the epidemiological studies. It is agreed, however, that worldwide millions of people are affected with PNDs. In Sweden, Ahlstrom, Gunnarsson, Leissner, and Sjoden (1993) reported an overall incidence rate of 66/100,000 for all neuromuscular diseases. Comparatively, also examining data from Sweden, Darin and Tulinius reported a prevalence rate of 1/1300 for all neuromuscular diseases for children age 6 to 15 years of age. A group of researchers from Italy (Merlini, Stagni, Marri, & Granata, 1992) reported a similar prevalence of progressive neuromuscular diseases in the younger populations, finding that PNDs were one and a half times more prevalent in people 19 years and younger in comparison to the rest of the population. Thus, while a PND can occur at any age, a large portion of people living with a PND are adolescents.

In addition, while some of the PNDs, Duchenne muscular dystrophy (DMD) in particular, have historically been thought of as pediatric illnesses and typically not seen in the adult health care system, increasing technological and pharmaceutical support has changed the trajectory. People living with these diseases are now surviving into young adulthood, requiring that both pediatric and adult health professionals be involved with providing health services to this population. These advances in care and lengthened life
expectancy also mean that the adolescents must transition from pediatric to adult based health care, which often operate as two completely distinct entities. In addition there is some concern that current practices in the pediatric systems, such as arranging numerous specialist appointments through one clinic, may actually enable a dependency rather than foster independence (Hauser & Dorn, 1999; Rosen, Blum, Britto, Sawyer, & Siegel, 2003).

Health professionals face the challenge of supporting adolescents and their families throughout many years of hospitalizations, clinic visits, home care, and community care. An important part of the challenge of supporting adolescents with PNDs is that they progressively lose physical abilities and increasingly rely on caregivers at a time in their life when, paradoxically, normative adolescent development prescribes a move towards independence and autonomy. These tensions are likely to emerge with particular force when decisions need to be made about their health care. However, research in this area is very limited. In particular, it is not known how the adolescents themselves experience decision-making in relation to their health care. This perspective needs to be better understood for health professionals to provide the most effective support to these adolescents and their families. Therefore, the purpose of this qualitative study was to conduct an in-depth examination of the experiences of adolescents with progressive neuromuscular diseases, in regards to making personal medical decisions.

Study Significance

The goal of this study was to understand the experience of adolescents with PNDs when making personal medical decisions. This understanding is important to nurses and all health professionals who work with adolescents with PNDs for numerous reasons.
Firstly, health professionals who are involved in medical decision-making encounters with these adolescents need an awareness of what the adolescents themselves are experiencing to know how to best approach various discussions in a way that is supportive to the adolescents and their families.

Secondly, knowledge is needed regarding the experience of personal medical decision-making for adolescents during this time of transition to adult care. There is the expressed fear that the current pediatric models of care may in fact be creating dependent adolescents. Yet currently, there is no research reported that considers the adolescents’ perspectives in regards to this issue.

Additionally, there are multiple assumptions throughout the healthcare literature about what adolescents experience, as they make this transfer of healthcare from pediatric to adult services. It is assumed that adults are capable of decision-making and they are expected to be involved in their health care. It is also assumed that in order for a youth to make a successful transition from pediatric to adult services, s/he must learn the skill of personal medical decision-making. Another key assumption is that as the adolescent leaves pediatric care s/he will now become solely responsible for his/her health. In addition, family involvement will be minimal or non-existent. However, there is very little research about what adolescents actually experience as they make personal medical decisions, especially in relation to the time of transition.

These assumptions indicate a lack of knowledge and understanding and depict a significant gap in the literature. This lack of knowledge and research into this area of personal medical decision-making, particularly at the time of transition, means that guidelines, recommendations for clinical practice, and transition plans are being designed
without an understanding of the experiences of chronically ill adolescents. Therefore, an understanding of adolescent experience would add new information, potential insight into the process of transition, and knowledge on how to best support these adolescents. It is important to first understand the experience of this unique population before assuming what is needed to support them through transition.

Definitions

For the purpose of this study, personal medical decision-making was defined as any situation that involves at least one health professional and involves the opportunity to make a decision.

Defining ‘Adolescence’

Adolescence is an important developmental stage in life that includes biological, psychological, and social growth and development. However, the term ‘adolescent’ is used to describe a broad range of ages in the research literature. For example, Sawin and colleagues (Sawin et al., 2006) described people 10-21 years of age as adolescents, whereas Hokkanen, Eriksson, Ahonen, and Salantera (2004) classified adolescents as 13-18 years of age. Adolescence is medically defined as beginning with the onset of physiologically normal puberty and ending when adult identity and behaviour are accepted (Canadian Pediatric Society, 2004). This period of development typically falls between the ages of 10 and 19 years and is consistent with the World Health Organization’s (WHO) definition of adolescence, which has been adopted for the purpose of this study (WHO, 2004).
Defining ‘Progressive Neuromuscular Diseases’ (PNDs)

It is important to clarify the definition of progressive neuromuscular diseases (PNDs). PNDs are a group of incurable complex diseases that affect any part of the muscle and nerve and lead to an overall weakened state and eventual death (Carter, 2006). They include motor neuron diseases and peripheral neuropathies. The actual rate of progression varies among the specific diseases and between individuals afflicted with these diseases. The focus of this current study was on the most severe forms of PNDs that typically affect the majority of the muscles, including skeletal, respiratory, and cardiac, and progress to a state of significant overall weakness or limited mobility by adolescence, with death typically occurring in the early adult years.

Research Questions

The purpose of this study was to understand the experiences of adolescents with a PND in regards to personal medical decision-making. Two specific research questions were posed to aid in understanding this phenomenon:

1) How do adolescents with PNDs perceive their involvement in medical decision-making and what does their involvement in medical decision-making mean to them?

2) What factors influence (both negatively and positively) the adolescents’ perceived experiences of decision-making?

Summary

The experience of health care decision making for adolescents with a PND has not been explored in the literature. These progressive diseases cause debilitating damage to nerves and muscles that result in lost abilities and decreased physical independence
during a stage of life that normally involves an increase of abilities and independence. In addition, as the diseases progress, these adolescents are faced with health situations that potentially involve decision-making, such as discussions regarding possible medications, surgeries, or other interventions. As little is known about how these adolescents experience these situations, the purpose of this study was to understand the experiences of adolescents with a PND in regards to medical decision-making.
CHAPTER TWO
LITERATURE REVIEW

Adolescence is often termed a transitional stage that involves changing from child to adult. It is a time when many and varied changes occur for the adolescent (Suris, Michaud, & Viner, 2004). Biological changes, such as puberty, begin and last for a number of years. Social changes, such as a developing or engaging with a new peer group, may occur frequently. Students graduate from high school and enter workplace or post-secondary educational settings. Changes in social responsibilities, including becoming eligible to vote and to drive, also occur during this developmental stage. What is key is that these changes occur in a variety of facets of life and are not simple linear changes, but transactional complex changes that often occur simultaneously. While the focus of this current study was not specifically on adolescent development, it was focused on a population that was developmentally experiencing adolescence. It is necessary in the exploration of adolescents with Progressive Neuromuscular Diseases (PNDs) and medical decision-making to examine the context of these experiences. One central contextual element is adolescent development. Therefore, a review of the normative adolescent developmental literature formed an important background to this study. This developmental literature is briefly discussed in this literature review, prior to delving into more specific literature that relates to the experience of adolescences with PNDs and medical decision-making.

Stages of Adolescence

Complex, interacting changes and the relatively wide age gap, from the onset of puberty to the debated end of adolescence which is often thought of as anywhere from 19
to 25 years of age, has resulted in an inherent heterogeneity that leads to challenges in conducting research with this population. Categorizing adolescent development into stages enables the creation of some homogeneity and a concomitant ease of discussion in the literature. Many researchers, and psychologists, have subdivided this stage of life into useful age groups: Early adolescence, from the onset of puberty through age 14; Middle adolescence, from age 15 to 17; and Late adolescence, from age 18 through to the end of adolescence (Elliot & Feldman, 1990; Kroger, 2007a; Whitmire, 2000).

Early adolescence is typically when puberty starts, when there is increasing interest in social relationships outside of family and in interactions with members of the opposite sex (Kroger, 2007a). This increasing interest in the opposite sex is not specifically about sexual orientation, but about expanding the peer group. Sexual orientation and experimenting with sexual interests typically occurs during mid-adolescence for both heterosexual and homosexual adolescents. This is also a time of increasing complexity of thought processes, changing roles and relationships within the family, increasing importance of peer relationships, and, often, a time of adaptation to junior high or middle school (Elliot & Feldman, 1990).

Middle adolescence is typically when the puberty related biological change is slowing, and it is often seen as the time when the tension or struggle with developing a sense of self–identity typically is at its peak (see later discussion titled Identity Development) (Elliot & Feldman, 1990; Erickson, 1968; Kroger, 2007a; Whitmire, 2000). During this time there is an increasing desire for independence, and a continuing shift of focus from family relationships to peer relations (Kroger). It is also a time when more focused one on one love relationships develop, and a more clearly defined sexual
orientation emerges (Elliot & Feldman).

Late adolescence is typically when adolescents gain a firmer sense of identity, have begun to define themselves in the larger community, have greater cognitive skills, and have developed an awareness of and concern for others (Elliot & Feldman, 1990; Whitmire, 2000). Additionally, it is at this stage that adolescents often make decisions that some describe as “identity defining decisions” (Kroger, 2007a, p. 88). These include decisions to move away from home, attend university, seek a specific career, or further develop romantic relationships.

Normative Development

Puberty

Puberty, often used to define the onset of adolescence, is the most visible of the developmental changes. While puberty is often thought of as the physical changes and sexual maturation, it is not purely a physical event, but also has psychological, emotional, and social implications (Brooks-Gunn & Reiter, 1990). Physically, it is a time of growth and development of secondary sexual characteristics. This development begins with the increased production of adrenal sex steroids and the eventual maturation of the hypothalamic-pituitary-gonadal axis (Joffe, 2006). Throughout the puberty process, pituitary hormones, and testosterone in boys, estrogens in girls, control the sexual maturation process. This process typically lasts 3 to 4 years (Joffe), but can be incredibly variable, depending on genetics, nutrition, and environment.

Psychologically, these hormonal and structural neurological changes relate to changes in thinking and cognition. Emotionally, the increasing testosterone in boys and estrogens in girls can lead to mood swings and varying emotions, in addition to the
emotional implications of having a changing body. Socially, adolescents must begin to incorporate the physical changes into their identity and also deal with others’ responses to their bodies (Brooks-Gunn & Reiter, 1990).

Social Changes

Beyond the social implications of puberty, there are many social changes during adolescence, such as the movement from family dependent relationships to more independent social functioning with peers (Savin-Williams & Berndt, 1990). Brown (1990) examined and summarized these changes as relating to 4 categories: quest for identity; puberty; social cognitive development; and social structural changes.

Quest for identity.

Through peer groups, adolescents “try on” new traits, and new personality characteristics, in an attempt to understand and clarify who they are (Harter, 1990). This quest for identity is often a large part of what occurs in peer group formations. It is common for adolescents to look to peers and others experiencing similar events in an attempt to see where they “fit in the world.” Through peers groups, and trying out different groups or cliques, adolescents are attempting to build and develop an identity separate from their family (Brown, 1990).

Puberty.

Changes during puberty lead to increasing sexual identity and interest in sex and development of sexual orientation (Brown, 1990). Also, development of opposite sex friends, initiation of romantic relationships, and gaining a greater understanding of one’s own sexual orientation typically all occur within the context of friendships and peer groups (Savin-Williams & Berndt, 1990).
Social cognitive development.

In addition to the increased importance of peers and friendships, adolescents also develop new social skills and the ability to evaluate social groups and individuals' skills on a basis of normative values and styles of interactions (Brown, 1990). This evaluation allows the adolescent to begin to look at how they fit into the context of the larger community and society (Brown).

Social structural changes.

Peer influence increases and adult influence decreases, as adolescents begin to spend substantially more time with peers and less with their parents (Brown, 1990). There are practical structural changes that influence these social changes of adolescence. For example, parents will often now let teens stay at home alone or go out without adult supervision.

Cognitive Changes

The area of adolescent development and its implication for cognition is a growing field that encompasses two parts: 1) the psychological processes and development of learning, thinking, and memory; and 2) the physical changes that are thought to underlie these processes. Building on theories first proposed by Jean Piaget, researchers have identified that formal operational thinking begins to develop around 12 years of age and continues throughout adolescence (Ginsburg & Opper, 1988). During this period, thinking becomes flexible and effective. Adolescents begin to deal with complex problems of reasoning and shift from the childhood realm of only concrete possibilities to being able to imagine many possibilities and deal with hypothetical situations (Ginsburg & Opper). This shift and development of cognitive abilities allows for increasing problem
solving ability and the ability to consider multiple options with variables of multiple weightings, often considered an important part of decision-making. Additionally, at this time adolescents begin to think about their own thinking and become more self-aware (Erikson, 1968). While this self-awareness allows increasing cognitive development, it also can lead to an occupation with inner thoughts and hypersensitivity that others are aware of personal thoughts or continually observing behaviour, a concept referred to as an imaginary audience (Erikson, 1968; Ginsburg & Opper).

Recently emerging areas of study related to adolescent development are related to structural brain development and changing cognitive abilities. With the development of new technologies and techniques to obtain information, such as the functional MRI, researchers are now able to actually view what is structurally and functionally occurring in the adolescent brain. While this area has exploded with many new explorations and findings, two observations are key to understand adolescent development. As summarized by Steinberg (2005), these key observations are: 1) brain development continues during adolescence and into young adulthood, and the development during these times occurs in brain regions that are responsible for the regulation of behaviour, emotion, and the evaluation of risks and rewards; and 2) arousal and motivation change with puberty, and these changes precede the full development of the regulatory competence, which may explain or help with understanding the impulsivity often observed in adolescence.

Multiple studies have begun to explore specific higher cognitive abilities thought to develop throughout adolescence and the physical changes in the developing brain. Findings from these studies indicate that specific areas of brain maturation are related to
inhibition, attention, memory, and decision-making. For example, Rubia et al. (2006) used functional MRI to examine motor response inhibition, cognitive interference inhibition, and attention. They found that with increasing age through adolescence and into young adulthood, there was an increase in brain activation in the prefrontal cortex and areas of the parietal lobe during various tasks. With this activation there was a corresponding improvement on task performance. This is thought to be indicating the continued physical maturation of the brain through adolescence into adulthood. Similarly Luciana, Conklin, Hooper, and Yarger (2005) found that memory and executive control processes continued to develop through adolescence, with increasing abilities noted up to late adolescence, at which point they seem to plateau. Again these changes are believed to be related to prefrontal cortex and ventrolateral frontal cortex development.

Additional studies (Eshel, Nelson, Blair, Pine, & Ernst, 2007; Hooper, Luciana, Conklin, & Yarger, 2004; Luna, Garver, Uban, Lazar, & Sweeney, 2004) demonstrated similar development through adolescence with improvements in decision-making, memory, behavioural inhibitions, and processing speed, relating these changes to structural changes in the prefrontal cortex. The specific structural changes that occur in the prefrontal cortex are synaptic pruning and mylenation. Synaptic pruning is the removing of synapses not used and mylenation is the insulating of the synapses with fatty myelin sheaths. These two processes lead to faster more efficient firing of synapses, resulting in more efficient processing of information. This process of pruning appears to begin around the same time as puberty and continues through the end of adolescence into early adulthood (see Blakemore & Choudhury, 2006 for review of development of adolescent brain).
Identity Development

At each of the varying stages of life there are tasks or challenges that one is expected to accomplish. There are a variety of tasks for adolescents as they transition from child to adult. One of the key tasks identified by numerous psychologists and development experts is the consolidation and acceptance of an emerging self-identity. This development task, often referred to as identity maturation, identity development, or even second individuation process, encompasses many other components or tasks. Identity is defined as a subjective personal understanding of and consolidation of beliefs about oneself (Erikson, 1968). There are multiple components expected to contribute to identity, including biology, individual psychology, and social environment.

The task of consolidating an identity of who one is from childhood and who one will become in adulthood emerges during adolescence (Erikson, 1968). Adolescents experience movement from a diffuse state of identities that have not really been acknowledged or accepted as one’s own, to a mature formation of a constant understanding of one’s identity (Erikson).

Building upon some of Erickson’s earlier work regarding psychosocial development, James Marcia (1966), a developmental psychologist, focused on the stage of adolescence and explored how identity formation occurs. Marcia described the process of identity formation as when “the individual is required to synthesize childhood identifications in such a way that he can both establish a reciprocal relationship with his society and maintain a feeling of continuity within himself” (p. 551). This process involves the individual reviewing options and making decisions about who s/he is and wants to be (Marcia). These decisions are thought to take into account parental input, and
societal, cultural, and environmental influences, but are made on one's own terms and may differ from parental wishes (Marcia).

Although he used a different term, "second individuation process," Peter Blos (1979) is often cited as a key theorist in the literature regarding adolescent identity development. In his theory on the adolescent passage, he described the second individuation process as beginning at puberty and compared it to what he termed the first individuation stage that occurs during infancy and early childhood. He compared the initial realization that one is an individual separate from the parent and the initial physical exploration of the world with the changes that occur during adolescence. The adolescent period is about shedding family dependencies, becoming a member of the larger society, and sorting out how as an individual one fits into the adult world. Blos described this stage as when one develops stable and constant boundaries of who they are and are not, and emotionally disengage from what he termed infantile dependencies upon parents. While other scholars do not use the term second individuation process, the tasks of this process and identity formation are the same. For example:

Identity development involves making sense of, and coming to terms with, the personal and social worlds one inhabits, recognizing choices and making decisions within contexts, and finding a sense of unity within one's self while claiming a place in the world. (Ferrer-Wreder, Palchuk, Poyrazli, Small, & Domitrovich, 2008, p. 95)

The achievement of a sense of identity, or completing the task of identity formation, seems to correlate with many benefits. Briefly, these benefits can be grouped into six key areas: cognitive capacities; ego development; moral reasoning; relationships; family relationships; and personality characteristics (Kroger, 2007b). While all areas of benefit are important, the adaptive features that occur with identity achievement in the
area of cognitive capacities are of particular importance to health care decision-making. Specifically, individuals who achieve identity formation typically function better under stress and implement more planned, rational, and logical decision-making techniques compared with those who do not achieve identity formation (Bluestein & Phillips, 1990 as cited in Kroger, 2007b; Boyes & Chandler, 1992 as cited in Kroger, 2007b; Marcia, 1966).

Identity formation with a disability or chronic illness.

Little research has been published regarding identity formation when an adolescent has a disability or chronic illness. There is some literature that addresses new identity formation in adults with acquired disabilities or illness, such as multiple sclerosis (Grytten & Maseide, 2006) or a spinal cord injury (DeSanto-Madeya, 2006), but little that addresses a population that is developmentally facing adolescent identity formation while also managing a severely disabling chronic illness. Some literature has examined adolescent development in the presence of an illness, but it is primarily related to very specific areas of development. Findings include restricted social interactions in adolescents with chronic conditions (Gortmaker et al., 1990 as cited in Seiffge-Krenke, 1998), decreased academic performance related to absenteeism, fewer peer relationships than non chronically ill peers, and perceived dependence on parents (Connolly, White, Stevens, & Burnstein, 1987; Sinnema, 1986). One study examined the psychosocial aspects of a traumatic spinal cord injury during adolescence through interviews with adults averaging 10 years post accident (Augutis, Levi, Asplund, & Berg-Kelly, 2007). While themes of family, peers, sexuality, and school emerged, identity formation and how the disability related to this was not addressed.
In a recent study (Kinavey, 2006), late stage adolescents with spina bifida were interviewed regarding how their physical disability shaped their identity and self-understanding. The themes that emerged in the study included: “identity as overcoming disability”; “identity as objectifying disability”; and “identity as integrating disability.” In addition, it was found that identity relating to the disability was not static, but changing and evolving, similar to identity formation in non-disabled youth. However, bifida is a static disability that is not terminal. It is possible the adolescents with a progressive life threatening illness such as a PND would experience identity formation differently. Moreover, while this study does capture the experience of youth with a disability, from the perspective of the youth, it does not address decision-making or health choices.

In fact, there may be an important relationship between decision-making and identity formation in adolescents. It has been argued that identity formation involves gaining the ability to make what have been called “identity-defining” (Kroger, 2007b) decisions or commitments. However, exactly what is identity defining, and the impact of physical abilities and changes on these kinds of decisions, remains contentious (Edwards, 1998, 2007). It might be that this depends on how individuals perceive their abilities or limitations and how they define their own identity. However, there is virtually no research exploring these specific issues.

Transition From Pediatric to Adult Care

The final developmental change in adolescence is of course moving into adulthood. For adolescents with disabilities or chronic illnesses, becoming an adult developmentally also means that their health care shifts from pediatric to adult care. This transition of adolescents to adult care is an important and much discussed issue in the
literature and clinical area. While this current study was not focused on transition to adult care, it constitutes an important context. The transition from pediatric to adult care was expected to have some influence on the participants’ experiences of medical-decision making and so warrants examination of existing literature in this area.

There is some concern in the current transition literature that adolescents with chronic conditions are at high risk of becoming dependent on others (Hauser & Dorn, 1999; Rosen, Blum, Britto, Sawyer, & Siegel, 2003) and that the current pediatric systems may actually enable dependency rather than foster independence. The position paper for the Society of Adolescent Medicine (Blum, Britto, Sawyer, & Siegel, 2003) states:

Many adolescents with chronic conditions are at higher risk than peers for unnecessary dependency, developmental difficulties, and psychosocial delay. A successful transition to adult healthcare may help prevent this by enhancing autonomy, increasing a sense of personal responsibility, and facilitating self-reliance. (p. 309)

Dependency is fostered through various systems that preclude adolescents taking responsibility for their own care because clinic staff plan and schedule appointments for the adolescent, and healthcare providers communicate through an adolescent’s parents rather than directly with the adolescent (Hauser & Dorn, 1999). This dependency is of concern for two reasons. Firstly, dependency, or excessive reliance on others during adolescence, is seen as being counter to the developmental tasks and norms of that stage. For example, a common societal expectation is that entering adulthood involves increasing independence and less reliance upon parents (Crittenden, 1990). Secondly, this dependency is crucial to understanding decision-making. While independence has been described in some literature as separation from one’s parents, there is now a focus on
independence in relation to decision-making capacities and self-responsibility (Crittenden).

In regards to transitioning to adult care, independence is viewed as important with adolescents predicting that their future care will involve attending appointments without their parents and communicating directly with their physicians (Hauser & Dorn, 1999). Reiss, Gibson, and Walker (2005) developed a three-stage model from their exploration of parental, adolescent, and health care provider views of the transition from pediatric to adult care. While all three stages were necessary for successful transition, the first stage, the age of responsibility, specifically was described as foundational to the transition. This stage involved family members and health providers encouraging independence and self-care in activities such as talking with health professionals, developing own routines, and taking medications. While decision-making was not directly mentioned in this study, it is quite plausible that decision-making is a subset of these self-care activities and it could be argued that decision-making would actually be a prerequisite for some of these activities.

Many current initiatives (American Academy of Pediatrics, 2002; NAPNP, 2002; Rosen et al., 2003) call for youth centered approaches to aid chronically ill adolescents in effectively transitioning from pediatric to adult care. These initiatives have been summarized by Betz (2004) into three key components: 1) “youth as the decision makers”; 2) “family support to assist parents in letting go of their developing adolescents”, and 3) “emphasis on self-advocacy and self-determination skill building” (p. 180).

While not directly stated in the literature, there are multiple assumptions underlying much of the adolescent transition literature. It is assumed that adults are
capable of decision-making and they are expected to be involved in their health care. It is also assumed that in order for a youth to make a successful transition from pediatric to adult services, s/he must learn the skill of personal medical decision-making. Another key assumption is that as the adolescent leaves pediatric care s/he will now become solely responsible for his/her health. In addition, family involvement will be minimal or nonexistent. However, there is very little research about what adolescents actually experience as they make personal medical decisions, especially in relation to the time of transition.

Importance of Obtaining Adolescents’ Perspectives

A significant challenge in understanding adolescents’ medical decision-making is that the majority of the existing literature is not from the perspective of the adolescents. It was only about 10 years ago that the perspectives of adolescents began to be included in the literature, and the majority of studies still report health care provider, parental, or teacher perspectives. This reliance on proxy reports is most evident in the disability literature.

Although it is known that family is important to adolescents with chronic illnesses, parental and adolescent perspectives on health issues can and do differ (Eiser & Berrenber, 1995; Farrant & Watson, 2004; Thomas & O’Kane, 1998). For example, in one study, adolescents with neurofibromatosis type 1 perceived the disease to be less severe than their parents did, and they found the most burdensome part of this disease to be daily interventions, while the parents spoke of possible medical complications (Sebold, Lovell, Hopkin, Noll, & Schorry, 2004). Similarly, Law (2002) found that adolescents with diabetes mellitus and their mothers had significantly divergent beliefs related to the amount one could control the disease. Because parental and adolescent
views differ, it is important to actually seek out the adolescents' perspectives on issues relevant to their health.

Not only do parental and adolescent perspectives differ, but also the perspectives of adolescents with chronic illnesses or disabilities differ from the views of healthy adolescents. For example Klostermann, Slap, Nebrig, Tivorsak, and Britto (2005) found that chronically ill adolescents desired more parental involvement in meetings with physicians compared with a control group of healthy adolescents. The findings of this study demonstrate the importance of research that focuses on the actual population experiencing a phenomenon rather than relying on a proxy group for information.

As researchers and clinicians acknowledged that parental and adolescent views differ, there has been increasing discussion in the literature regarding the importance of including children and adolescents as participants in research (Garth & Aroni, 2003). Of concern is that there may be disenfranchised, under researched, or excluded populations, such as children and adolescents with disabilities (Weir & Peter, 1997). While the aim of research that focuses on the perceptions of parents and caregivers is often an attempt to not burden a vulnerable population, the result has been limited adolescent voices, particularly those with disabilities, in the literature (Garth & Aroni).

However, a shift towards searching out adolescents' perceptions is occurring, with some studies including the perspectives and experiences of young people with a variety of chronic illnesses and disabilities. This literature has focused on two key areas: (1) autonomy versus dependence and (2) preferences related to involvement in healthcare.

Autonomy Versus Dependence

Autonomy is defined as “responsible independence” (Dashiff & Bartolucci, 2002,
p. 97) and is negotiated throughout adolescence and as one transition into adulthood (Crittenden, 1990). Spear and Kulbok (2004) succinctly summarized autonomy in their concept analysis of autonomy and adolescence as “the ability to make prudent decisions and to govern self in light of individual, family and societal needs” (p. 148). Therefore, decision-making and the experience of this decision-making is a subset of the concept of autonomy.

As with other areas of research, the majority of the adolescent autonomy literature is focused on healthy adolescents; however, a few studies are specifically focused on autonomy development in the chronically ill or disabled adolescent. In one such longitudinal, prospective quantitative study focusing on adolescents with spina bifida, Davis, Shurtleff, Walker, Seidel, and Duguay (2006) found that adolescents with a disability had delayed development of autonomy when compared with developmental norms. Additionally, those who had a higher spinal motor lesion, i.e., those who had a more significant level of disability, were the most delayed in autonomy development. However, McEwan, Espie, Metcalfe, Brodie, and Wilson (2004) found that although autonomy was delayed, the adolescents desired greater autonomy and concerns about being overprotected, restricted from activities, and lack of privacy were of significance.

The concepts of independence and self-responsibility are linked to autonomy. Independence, acting independently, and taking responsibility for one’s actions are part of achieving the state of autonomy (Spear & Kulbok, 2004). Sinnema (1986), in a cross-sectional study focusing on adolescents with cystic fibrosis and asthma, found that independence and activities that represented independence occurred at significantly later ages compared to the control group of healthy adolescents. Davis and colleagues (2006)
examined self-responsibility and reported that this adoption of responsibility for self-care did occur, albeit slower than the developmental norm. Additionally, in a qualitative study that focused on adolescents with diabetes and explored the experience of being chronically ill and the development of self-responsibility in regards to personal health care, Christian and D'Auria (1999) found that during the process of transitioning from parental dependence to independence the adolescents experienced a central phenomenon that they termed "gaining freedom." Of interest to the proposed study, the transition was gradual, involved the adolescents and parents sharing responsibility, and provided opportunities to practice this self-responsibility. Additionally, Christian and D'Auria noted that as the adolescents had opportunities to practice decision-making related to their health care, their confidence in their ability increased and they expressed a desire to become more involved in their future health care.

In a cross-sectional, descriptive study with a stratified purposive sample of 162 adolescents with either spina bifida or cerebral palsy, Blum, Resnick, Nelson, and St. Germaine (1991) examined relationships relating to family and peers. Of the many reported findings, those most relevant to the current proposed study relate to the high level of physical dependence reported by the adolescents and the close relationships with parents. Of those with spina bifida, almost 50% reported being dependent upon a parent in one way or another regarding bowel care and 98% of the respondents reported having a close relationship with their parents, with little conflict. Additionally, 30% and 25% respectively of the youth with spina bifida and cerebral palsy reported feeling overprotected and infantilized. The authors commented on a noticeable absence of the adolescent-parental conflict which frequently characterizes most adolescent-parental
relationships. They hypothesized that this absence of conflict, the feelings of being infantilized, the forced physical dependency, and the close relationships with parents potentially all interact and delay adolescent development.

Dependence in the literature is often related to behaviour or physical reliance on others and independence is discussed in regards to being able to carry out self-care activities. Decision-making, comparatively, is primarily described as a cognitive process involving choices and options (Crittenden, 1990). Although these concepts may seem unrelated, a significant relationship between physical independence and decision-making was reported by Hanna and Guthrie (2003). In their small quantitative study with a convenience sample of 34 adolescents with diabetes, the relationship between independent functioning and decision-making was significantly positive (r=0.72, p =.000). Additionally, the adolescents were separated into three groups according to developmental stages of early (11-14 years), middle (15-16 years), and late (17-19 years) adolescence, with reported findings suggesting that the early adolescents had much less independent functioning and decision-making than the older ones and that these skills developed with age.

Preferences Related to Involvement in Healthcare

Another important area of research, with a few studies reporting the perspectives of chronically ill and disabled adolescents, is adolescents' preferences in healthcare. In one such study, adolescents with cancer demonstrated a high desire to be involved in discussions and they wanted up to date information (Decker, Phillips, & Haase, 2004). Additionally, in a qualitative study, Garth and Aroni (2003) interviewed 6 to 12 year old children with cerebral palsy to gain their perspectives on being included and informed in
regards to their personal health issues. One finding was that the children felt quite strongly about being included and informed. While this study did not directly explore decision-making and the sample was children, it does show that even at a young age there is an interest in personal health and a desire to be informed.

Other research has focused on adolescents’ preferences in health care and management, specifically in relation to health care professionals and preferred communication styles. While some of these studies take into account the chronically ill adolescents’ experiences and perceptions, focus was on the communication and relationship with health professionals and not on the actual experience of decision-making. Relevant findings from these studies included clear age differences in how much communication and involvement the adolescents wanted with the physician (Beresford & Sloper, 2003), a preference for direct communication with the physician, a desire for respect of privacy (Britto et al., 2004), and that the presence of a parent was both inhibitive and supportive (Carroll & Marrero, 2006). Additionally, Woodgate (1998) investigated adolescents with diabetes, asthma, arthritis, or Crohn’s disease about their perspectives on health professionals and reported multiple themes, including “give me options.” This theme highlighted that adolescents wanted choices and options and wanted to be actively involved in the decision-making process related to their health.

In a study that explored nurse and adolescent perceptions of positive or distressing experiences during treatment, it is interesting that Hedstrom, Skolin, and von Essen, (2004) found contradictory perceptions. Nurses reported that adolescent involvement in decision-making was a positive experience, yet the adolescents did not identify their involvement as being an important positive experience, and some did not even discuss it...
at all. These results again exemplify how important it is to seek information from the actual adolescent experiencing the situation, not just from others.

While this emerging literature on the perspective of adolescents with chronic illness is an important contribution, few of these studies have included any adolescents with PNDs and none have focused exclusively on adolescents with this group of diseases. In addition, none of the research on adolescents with a chronic illness or disability has directly examined the experience of personal medical decision-making.

Decision-Making

While the adolescent literature provides some background, another key area that needs to be understood is decision-making. The literature regarding decision-making and its process is growing, but currently there is a paucity of literature regarding the experiential aspect, specifically for disabled adolescents.

Decision-making, and the literature about it, is very value laden, with terms such as good or bad decision-making evident in multiple studies (Ubel, Loewenstein, Schwarz, & Smith, 2005). Terms such as compliance and competency often are used to express that an individual followed or did not follow medical advice. Some of the literature addresses concerns about competency or uses the terms good and bad decision-making without actually defining the concepts. The gold standard that most research relies on is that the typical adult is competent and capable of making “good” decisions (Halpern-Felsher & Cauffman, 2001). Therefore, most of the studies of adolescent decision-making are comparisons with adult decision-making being the standard to measure up to.

Decision-Making for Adults

The desire to be involved in decision-making in a personal health care context is a
fairly new area of study. Researchers in one study investigated the amount of involvement adults wanted in clinical decisions. Almost all participants (98%) wanted to have their healthcare professional discuss options for treatment with them, whereas almost half (45%) wanted their physician to make the final decisions (Levinson, Kao, Kuby, & Thisted, 2005). An important finding in this study was the clear age effect, with a much higher percentage (compared with younger age groups) of people relying upon physician decision-making being older than 45 years.

Another study of adults explored patients' preferences about being involved in decision-making. The findings indicated that people who presented with minor complaints (i.e., generally were healthy) preferred more involvement and participation, whereas patients with chronic or severe diseases had lower preferences for involvement in decision-making. The conclusion was that not every situation warrants or necessitates involving the patient in decision-making (Schneider et al., 2006).

While literature is still quite limited on patient preferences regarding being involved in decision-making, it does seem that not everyone always wants to be involved. However, the current models of treatment that physicians and other health professionals are encouraged to use clearly involve the patients in decision-making. Terms such as shared medical decision-making and informed medical decision-making are found throughout the literature (Makoul & Clayman, 2006), encouraging physicians to include patients in decisions. While this encouragement to include patients is primarily in reference to adults, physicians are also advised to include adolescents in decisions. This is especially clear in a recent strong statement from the Canadian Paediatric Society (2004), which asserts "to deny decision-making to mature adolescents may be interpreted
as a violation of their fundamental rights” (Clinical decision-making and children and adolescents, para. 1).

Decision-Making for Healthy Adolescents

An interesting component of the literature, especially in relation to adolescents and decision-making, is the shift to assume that competency or involvement in decision-making has to do with age of majority. In Canada, this is not the case. The law recognizes that minors (those under age 19 years) may consent for treatment at any age if they are competent (Hesson, Bakal, & Dobson, 1993). The challenge is that competence is not an easily defined concept, and there is much variation across provinces and even within provinces as to how this is enacted in clinical practice. Additionally, the law is still unclear regarding adolescents’ abilities to refuse treatment, with numerous court cases struggling to deal with this issue over recent years.

In a cross-sectional study, students from grades 6, 8, 10, and 12 were compared with adults to ascertain the course of development of competency in decision-making (Halpern-Felsher & Cauffman, 2001). Adults were found to be statistically significantly more likely to explore options, discuss risks, and ask about long term outcomes than the students in grades 6 through 10; however, all groups were able to address the benefits and clearly state a preference.

In a similar, but earlier landmark study (Weithorn & Campbell, 1982), groups of children and adolescents age 9, 14, and 18 were compared to a group of adults age 21 years. Even the youngest group was capable of comprehending the basic elements of a scenario to be able to choose a treatment option. While again there were age differences and the younger groups did seek out fewer options, even at age nine there was the ability
to clearly express preferences and examine outcomes. It is important to note that both of these comparison studies included only healthy participants.

Decision-Making for Adolescents With Disabilities or Chronic Illnesses

Very little research has examined adolescents with a chronic illness or disability and their decision-making. What is known though is that these adolescents typically have low to moderate involvement (Sawin et al., 2006) and are less mature in their decision-making capacity compared to healthy adolescents (Buran, Sawin, Brei, & Fastenau, 2004). Neither of these studies included adolescents with PNDs in their sample and decision-making was broadly operationalized beyond decisions relating to medical or healthcare.

Progressive Neuromuscular Diseases

The majority of the literature on PNDs is medical and related to new treatments and outcomes, such as the effect of steroids on Duchenne Muscular Dystrophy (DMD) (Manzur, Kuntzer, Pike, & Swan, 2008), the benefits and risks of spinal fusion for adolescents with scoliosis (Mercado, Alman, & Wright, 2007), and the use of non-invasive home ventilation (Toussaint, Chatwin, & Soudon, 2007). There is very little literature that examines any part of the PND experience beyond the physical realm, and none that directly examines the experience of adolescents with a PND.

One study explored the wishes of young boys, 6 to 12 years of age, with DMD (Nereo & Hinton, 2003). After asking the children about their most desired three wishes, Nereo and Hinton categorized the wishes and compared them to healthy siblings and a healthy comparison group. Little difference was found between the groups. Of interest, only 16% of the DMD population wished for anything categorized as being related to
health. Another study that also investigated those with DMD examined the experiences of adults with DMD using a questionnaire format (Rahbek et al., 2005). Findings were reported in terms of describing the experiences of a typical adult with DMD. Additionally, the description included a list of typical activities and care required by the adults, and a brief discussion of the desires and struggles related to sexuality. Rahbek et al. also reported that the adults rated their quality of life high and did not worry about their disease or future. No information was reported regarding their experiences with health care or how decisions were made. Again none of these studies directly explored the experiences of adolescents with a PND, and more specifically their experiences with health care decision-making.

While, as described earlier, there is some literature related to adolescents’ experiences with other illnesses or disabilities, such as cancer, spina bifida or epilepsy, there is the need to focus on the unique population of adolescents with PNDs. Progressive neuromuscular diseases are a unique set of diagnoses that lead to the progressive loss of many physical abilities, particularly during the adolescent years, resulting in the young person becoming more and more physically dependent, while still maintaining normal cognitive development. Additionally, PNDs are typically diagnosed when the person is a young school age child, have no known curative treatments, are genetic which means that there may be a sibling or other extended family members who are affected with the same diagnosis, and are life limiting, with an average life expectancy into early adulthood. These diseases differ significantly from most other chronic illnesses or disabilities discussed in the adolescent literature. In a recent study, Patterson, Thorne, and Russell (2002) explored the nature of self-care decision-making in chronic illness in adults and
found that decision-making was very value-laden and unique to the specific chronic
disease and that the nature of the particular disease greatly influenced the participants’
decision making. Adults with type 2 diabetes, HIV/AIDS or multiple sclerosis recorded
their self care decisions over a 1 week period, and while there was some similarities, in
general, the experiences, the meanings and significance of the various decisions was
unique to the specific diseases. Therefore, the experience of adolescents with PNDs is
likely unique, especially in regards to personal decision-making and warrants further
investigation.

Conclusion

Adolescence is a transitional stage between childhood and adulthood that
encompasses many transactional changes. These changes include biological,
psychological, emotional, and social changes and involve the key developmental task of
identity development. In addition to experiencing adolescence development, adolescents
with PNDs also experience a chronic progressive disabling illness that is life-limiting. As
there are many important contextual factors to the experience of living with a PND as an
adolescent, it is important to gain the unique perspective of those living it, the
adolescents. In particular, the experience of these adolescents as they make decisions
related to their health care is needed to further the understanding of health professionals
directly working with this population and of policy makers who develop programs and
make recommendations regarding health services for this population.
CHAPTERTHREE
RESEARCH AND DESIGN IMPLEMENTATION

When researching a phenomenon that has yet to be researched and has little existing literature to build from, such as the experiences of adolescents with progressive neuromuscular diseases (PNDs) around medical decision-making, the use of a qualitative method is appropriate. As the objective of this study was to understand the phenomenon of personal medical decision-making, an everyday occurrence with many contextual influencing factors, interpretive phenomenology was employed. This methodology, with a philosophical background of hermeneutics drawing on the work of Martin Heidegger, focuses on understanding everyday events, the meaning behind these events, and the importance of the context of the experience (Annells, 1996; Cohen, Kahn, & Steves, 2000).

In addition, Heidegger emphasized the relativism of experience and understanding (Annells, 1996). Not only does relativism refer to contextual factors, but it also involves the researcher and the actual research situation. The understanding that is sought through research is the result of specific situations, such as interviews, that are contextual and situation dependent, and it is in these situations that meaning is generated (Annells).

A further key aspect of Heidegger’s beliefs on understanding is the hermeneutic circle. This theoretical circle represents the process of understanding. It is through interpretation and reinterpretation that one gains understanding (Plager, 1994). The circle depicts interpretation, as the process is never truly complete; interpretation will always continue (de Witt & Ploeg, 2006). The interpretive process is described as being circular in that it involves two key movements: ongoing movement between the whole and part.
and back to the whole again; and the ongoing movement between what one knows and what the data are revealing (Leonard, 1994). In essence, all are part of the hermeneutic circle. In order to have any understanding between people there must be some pre-knowledge or in Heidegger’s term, “fore-structures.” It is with this common ground or initial understanding that one enters the circle, allowing interaction, interpretation, and further understanding (Plager). From a research perspective, the researcher has fore-structures or pre-understanding that may be conscious (e.g., interests, perspectives, knowledge, and experiences) or unconscious (e.g., cultural or social values). These fore-structures have influenced the researcher to ask the particular questions and engage in the specific research she has conducted.

An advantage of using an interpretive phenomenological approach is that it “allows practical meanings and concerns to show up in their own terms” (Benner, 1994, p. 115). Interpretive phenomenology was specifically chosen as the methodology to allow what is important to the adolescents to be fully explored. The desire was not to create a theory or apply a decision-making model, but to gain understanding into authentic experience from the perspective of those who are experiencing the phenomenon, in this case, adolescents with PNDs. As the phenomenon of personal medical decision-making has not been explored, and it has many contextual factors, interpretive phenomenology was an appropriate method for this study.

Sample

The purpose of a phenomenological study is to understand a specific phenomenon and gain rich, in-depth information, rather than to generalize findings to a larger population (de Witt & Ploeg, 2006). Thus, information-rich participants who have lived
and are living the experience of personal medical decision-making as an adolescent with a PND were chosen. While the entire developmental stage of adolescence is of interest to the researcher, and she was keen to investigate groups of adolescents throughout the entire age period, this approach was not feasible due to existing time and financial constraints. This cross-sectional study was limited to adolescents between the ages of 16 and 19 years inclusively. Therefore the inclusion criteria for this study were being an adolescent between the ages of 16 and 19 years inclusively and having and being aware of a progressive neuromuscular diagnosis. The exclusion criteria were inability to participate in an interview due to cognitive limitations or requirement for translation services.

While the age range of the participants does include portions of both the middle and late stages of adolescence, this age range was chosen specifically. Given that the interest of this study was the experience of personal medical decision-making throughout adolescence, focusing on older adolescents who could tell stories of medical decision-making experiences from when they were younger allowed for the perspective of younger individuals to be accessed and included in the data. Additionally, as the transition to adulthood and adult health care is a process that typically occurs between the ages of 16 and 19, this sample was able to offer insight as to how this transition relates to the experience of medical decision-making.

Sample Characteristics

Anonymity is an issue for a number of reasons. All adolescents with PNDs in British Columbia and the Yukon receive health care primarily through only a couple of institutions. In addition, the population requiring frequent medical care is small and
typically well known by other adolescents, families, and health care providers. In addition, some of the diagnoses are less common than others, and simply linking age and diagnosis may allow a reader to suspect who the participant is. Moreover, the population of adolescents with PNDs has significantly more males than females, as the most common PND diagnosis, Duchenne’s Muscular Dystrophy (DMD), is a recessive X-linked disease. Therefore, the following steps were employed to protect the anonymity of the participants:

1) Demographic data are provided only as ranges or groupings.

2) Specific ages, diagnoses, and gender are not linked together or reported for specific quotes.

3) All references to participants use masculine or generic terms to protect the identity of the female participant.

4) All identifying information was removed from quotes, and in a few situations contextual data (such as location or specific timing of an event) were changed to obscure the identity of the participant. Care was taken to limit changes to the data, and it was done only when it was otherwise impossible to still ensure participant anonymity. In all cases, interviews were searched for other quotes or exemplars without identifiable contextual data, and if an alternative was available, then that quote was used rather than altering the data.

Five adolescents between the ages of 16 to 19 inclusive, representing 3 different diagnoses: spinal muscle atrophy; Friedrich’s ataxia; and Duchenne muscular dystrophy, were interviewed for this study. One adolescent was female. The sample included adolescents with married, divorced, and single parents. Both adolescents with siblings
and adolescents who were only children participated in the study. Participants came from a variety of locations throughout British Columbia and the Yukon. The researcher had hoped that adolescents from a variety of cultural backgrounds would participate, however all five of the adolescents who chose to participate in this study identified themselves as Caucasian.

Recruitment

The target population, adolescents age 16-19 years with a PND, was recruited through the neuromuscular clinic at British Columbia's Children's Hospital. The neuromuscular clinic is an outpatient program that follows and investigates children with a neuromuscular disease ranging from the prenatal period until 19 years of age. The children and adolescents, from British Columbia and the Yukon, attend clinic appointments annually or biannually depending upon the rate of disease progression and family needs. Because many of the adolescents have been attending clinic appointments since early childhood, they are typically familiar with the location and staff.

One nurse follows each adolescent, which involves scheduling future clinic visits and assessing the adolescents when they are at the clinic. This clinic nurse has worked at the neuromuscular clinic for over five years and is well known by the adolescents. As the nurse engaged in routine clinic interaction with adolescents and their parents, including in person, email, and via the telephone, she informed them that this study was occurring and provided them with contact information for the researcher. The clinic nurse informed potential participants and their parents that no one at the clinic would be aware of who chooses to contact the researcher and who does not, and that all involvement with this
study is confidential. Additionally, she reiterated that involvement or lack of involvement in this study would in no way affect the care the adolescent receives from the clinic.

In addition, the clinic nurse mailed out information packages to adolescents and parents who fit the inclusion criteria. The information package contained: a cover letter; an information sheet; an adolescent assent form; an adult consent form; and a parental consent form (see Appendix A) The researcher was not informed as to who received these packages nor was she provided with any other information from the neuromuscular clinic. The adolescents and parents were requested to contact the researcher directly themselves if interested in the study, negating further involvement with the neuromuscular clinic.

Further, a recruitment poster was posted around various parts of the hospital to encourage adolescents and parents interested in participating in the study to contact the researcher (see Appendix A). Common areas, such as by coffee shops, hallways, and outside the cafeteria, were chosen, in addition to specifically targeted areas that these adolescents would frequent, such as the cardiology clinic, respiratory clinic, and outside the neuromuscular clinic.

This passive recruitment, the requirement that the adolescent or parent contact the researcher directly, was employed due to concerns raised by the Behavioural Research Ethics Board (BREB) at the University of British Columbia. The following requirements by the BREB: mandatory parental awareness and consent prior to allowing the adolescent to participate in the study; no information was to be provided by the neuromuscular nurse to the researcher, even with adolescent and parental consent; and the researcher was not to meet the adolescents and parents in person, even with consent, at the neuromuscular
Clinic to further explain the study, were what led to the employment of passive recruitment. The resulting recruitment was very slow and the researcher suspects that some of this was due to the fact that a potential participant had to remember and choose to make that first contact, rather than having the ease of agreeing to potentially participate and then receiving a follow up phone call.

The recruitment resulted in five adolescents or parents contacting the researcher and all agreeing to participate in the study. In two of the cases, parents contacted the researcher after having recently attended a neuromuscular clinic where they received information regarding the study. In the third case, a parent contacted the researcher after receiving an information package in the mail, and in the fourth and fifth cases the adolescents themselves contacted the researcher after having received an email from the neuromuscular clinic nurse regarding the study. The researcher spoke with all parents of adolescents younger than 19 years of age and with all the adolescents to confirm interest in the study. Copies of consent letters were sent to those who had not yet received them. Consents were reviewed and signed at the first interview.

Setting

Informants had the option of being interviewed at their home or another location of their choice. Of the 10 interviews (2 interviews with each of the 5 participants), four occurred at the adolescent's place of residence, five occurred in a coffee shop chosen by the adolescent, and one occurred via telephone.

Data Collection

Data collection occurred through two in-depth open-ended interviews with each informant. The interviews ranged from 30 minutes to 90 minutes in length and were
audiotaped. As the purpose of interpretive phenomenological research is to understand and gain in-depth data, a second interview was important. This follow-up interview provided the researcher an opportunity to review the initial transcripts, and it enabled her to fill in any missing gaps and ensure understanding had occurred at the second interview (Benner, 1994). Additionally, the second interviews allowed the researcher to gain participants’ thoughts and reflections upon any interpretations already derived from previous interviews (Crist & Tanner, 2003). The second interviews were scheduled a minimum of two to three weeks after the initial interview to allow the researcher an opportunity to review the initial interview and begin to analyze the data.

A general interview guide was used to remind and focus the researcher (see Appendix B). The focus was on encouraging the informants to describe past experiences regarding medical decision-making, their perception of how they were involved, their most positive and negative experiences, and how they would like to participate in future decisions. The questions were broad and flexible to encourage an open dialogue with the adolescents and allow what was important to the adolescents to become clear. Narratives about situations that involved medical decision-making were sought. Through the narratives and accounts of previous events it was hoped that informants would share their concerns and knowledge in a way that allowed insight into their practical experiences (Benner, 1994). Additionally, a brief form pertaining to demographic information was completed with each participant at the beginning of the initial interview (see Appendix C). This form was used solely for the purpose of gathering background information to aid the researcher in asking questions.
During the interview the researcher kept brief notes to trigger key thoughts later. As soon as possible after the interview was completed, the researcher reviewed the brief notes and wrote up field notes. These field notes included observations, thoughts, or other information that the researcher gathered that were not captured on the tape. These field notes were included with the analysis to help clarify the context and add depth to the data.

Data Management

All of the interviews were tape-recorded, transcribed, and stripped of any identifying information. The researcher transcribed the interviews within the same week of the interview. Then the researcher listened to the tapes while reviewing the transcripts to ensure accuracy and used the field notes as a memory aid to add in non-verbal cues and contextual elements to the data. The audiotapes and transcriptions were given code numbers and were kept in a locked filing cabinet. The data on the computer were stored in an encrypted disk image and a backup file was stored on a portable hard drive that was locked in a filing cabinet. The names and contact information of the participants were kept separate from the collected data and remained securely locked in a filing cabinet in the researcher’s home office.

Data Analysis

The interviews and field notes were the primary source of data for analysis. The analysis began with the initial interview and continued throughout the entire research process. The transcripts were read and the tapes listened to for a global understanding of the phenomenon and the varying parts of the context (Mackey, 2005). Notes were made on contextual elements and global understandings and then written into an initial brief
summary of the interview. This brief summary incorporated field notes from the interview and any initial thoughts or hunches about the data. During this process of reviewing, an interpretive outline was developed. A meeting with the thesis co-supervisor helped to flush out what themes were emerging and aided in development and refinement of the interpretive outline. The outline was further developed and shared with the co-supervisors. After the interpretive plan was developed, each of the original interviews and all future interviews were examined from the view of the interpretive outline. As any further concepts were added to the interpretive outline, previous interviews were re-examined to incorporate these new additions (Leonard, 1994). This initial step resulted in all of the interviews having been reviewed and initially categorized as per the outline. The categorizing was purely a way to organize the data for analysis purposes and did not involve coding. This was achieved through cutting and pasting quotes into the interpretive outline, answering questions, and jotting notes throughout the text. Additionally, all of the interviews were printed to a hard copy and read and reread using a variety of colour highlighter pens to mark which part of the interpretive outline data fit and additional questions about the data were jotted in the margins of the text.

The next stage of analysis began with the systematic moving from parts back to whole text. This included checking for patterns, discrepancies, and agreements. As the researcher was reading and moving from whole to parts she began to employ three important strategies: paradigm cases, thematic analysis, and exemplars.

Throughout the initial reading and listening process, the researcher searched for paradigm cases, i.e., situations that “stand out” or grab one’s attention. The researcher then examined and considered what it was about a particular paradigm case that caught
her attention, creating an opportunity for the researcher to begin to understand the situation in a new way (Benner, Tanner, & Chesla, 1996). Examining a specific experience or situation allowed for the richness of the context to be included in the analysis. This analysis of a whole paradigm case created an “opportunity to engage in the practical world of the participant and come closer to the lived experience, the understanding of the transition as it unfolds or a particular way of being in the world” (Benner, 1994, p. 114). Practically, this meant creating a word processing document on the computer and compiling quotes from various parts of interviews. Often teens would tell a story, move onto another topic, and then return to the story, or retell parts of the story in the second interview. To ensure that the researcher grasped the paradigm case, it was read in its entirety first. Then the quotes about the particular story were cut and pasted into one document to allow for reading and reviewing the story as a separate document. This allowed for a clearer story and showed some possible contradictions. Contradictions were then reviewed, looking back at the whole interview to see if context helped with the understanding. During second interviews, the contradictions were clarified.

Additionally, the researcher compared interviews and participants, employing thematic analysis and then returning to the individual case. Thematic analysis was used across all of the participants’ data to better understand and clarify differences and similarities in their experiences (Benner, 1994). It is important to note that thematic analysis is not coding as the comparisons involved larger parts of the data, such as meaningful events, happenings, or situations, rather than words or phrases (Benner). Throughout this process of analysis, patterns and incongruencies were explored.
Incongruencies were noted within participants and between participants. To further understand these incongruencies, the researcher reread interview texts in the whole and examined field notes to get an accurate picture of what the participant was saying. In some cases the incongruencies were noted prior to a second interview so the second interview allowed the researcher to ask questions about the discrepancies or differences noted. As the role of the researcher at this point was to attempt to make sense of the inconsistencies within participants and across participants without trying to simplify the analysis, questions emerged and additional insights developed through this process (Benner). As the themes become clearer and were revised with the addition of new data and insight, exemplars were sought.

Exemplars are textual examples that explain or demonstrate the themes identified throughout the analysis (Crist & Tanner, 2003). These examples are usually parts of stories or situations that will allow the reader to gain insight into what the themes actually represent. Used frequently to contrast or compare specific situations, exemplars add flavour or quality to the analysis (Benner, 1994).

After employing paradigm cases and thematic analysis with exemplars, the analysis involved reviewing the summaries, notes, and writing that was created throughout these steps. These were reviewed and an in-depth, holistic summary of the analysis was written.

Scientific Rigor

How to measure, describe, and ensure the rigor, quality, value, and worth of interpretive phenomenological research is much discussed in the literature. Two issues, as clearly synthesized by de Witt and Ploeg (2006), can be used to categorize most of the
recent literature regarding rigor and interpretive phenomenology: 1) concerns of a philosophical nature and 2) concerns related the practical application of measuring rigor.

Philosophical Rigor

There is often a desire to seek an account of the way things really are by using objective, interpretation free standards, but this desire is inconsistent with the philosophical nature of the method of interpretive phenomenology (Benner et al., 1996). Central to the understanding of interpretive phenomenology is that there is no right or even one interpretation and that the way things “really” are is contextual (Packer & Addison, 1989). It is this key concept that often is muddled in the attempt to apply inappropriate standards of rigor to this particular methodology. One example from the literature is the notion of findings being interpretation-free, and that the results are capable of being objectively true. As Leonard (1994) commented, this interpretation-free assumption has led to many researchers searching for a method or technique that will validate and ensure that the research is true while completely disregarding the underpinning philosophy of interpretive phenomenological research.

The challenge is to stay philosophically sound and yet be able to, at the same time, evaluate the research and know which work is of worth and which is not. The answer to this challenge is not to design a rigid checklist of standards, but to embrace the philosophy throughout the process of the study and let the findings speak for themselves. While “there is no one true meaning produced by any interpretive study… the meanings that are stated in the research findings must be logical and plausible within the study framework, and they must reflect the realities of the study participants” (Lopez & Willis, 2004, p. 730). In essence, the rigor of a study, in relation to the philosophical concerns, is
reflected in the extent to which the methods employed throughout the study are consistently based on the theoretical underpinnings of the stated methodology.

Practicality and Criteria

The second issue in the literature is the discussion of how rigor is actually measured: what exactly is one measuring and how does one know if this is research of any value? Packer and Addison (1989) discussed this process as evaluating interpretive accounts rather than validating, testing, or measuring. Some of the varying terms that are used to describe “good” interpretive accounts include consistency, relationship to other material, response of research participants, and communicability (Packer & Addison); and coherence, comprehensiveness, penetration, thoroughness, appropriateness contextuality, agreement, suggestiveness, and potential (Madison, 1988, as cited in de Witt & Ploeg, 2006). Others do not list specific qualities that the interpretive accounts require, but call for the need for reasoned, sound decisions that explicitly use the theoretical framework of interpretive phenomenology (Whitehead, 2004). Additionally, Benner et al. (1996) noted that an interpretive account is adequate when the practical concern that initiated the research in the first place is addressed.

Methods To Increase the Worth of the Findings

While ensuring the philosophical underpinnings of interpretive phenomenology were forefront in the researcher’s mind, the following methods were employed to increase the value of the findings. Some researchers believe that bracketing, or suspending one’s beliefs, is an essential skill that all phenomenologists must attain; however when employing interpretive phenomenology the researcher acknowledges that she is instrumental in the data analysis and such suspension is not feasible. Heidegger
proposed that pre-understanding, or shared background, is an essential part of all human beings existing in the world, although this understanding is for the most part not a component of our general awareness (Plager, 1994). This pre-understanding or fore-structure is inevitable; however, there are ways to work with this knowledge and improve the credibility of the research. To do so, the researcher explored her own assumptions, questioning why this topic interests her, what pre-knowledge and experience she has with the phenomenon, why she was asking particular questions, and if there were answers she was expecting (Plager). This reflection was accomplished through journaling. This journaling occurred in particular at the beginning of the study and focused around assumptions, questions, and the general topic.

As many of the participants were known to the researcher, it became important to set aside, as much as possible, the assumptions and pre-knowledge. To aid with this, the researcher wrote out three categories: assumptions; past observations; and additional information, on a sheet of paper. Prior to each interview the researcher jotted brief notes under each heading. These jottings helped the researcher to realize how much she thought she knew about the phenomenon of medical-decision making and about adolescents with PNDs in general. Through this jotting, assumptions quickly became apparent and allowed the researcher to listen to what the adolescent was saying, not what she thought the adolescent would say.

In addition to being a way of capturing personal assumptions and bringing to light hidden biases, journaling was used to track decisions and thoughts through the data analysis process. Thus, it created an audit trail of the research process.
An important part of interpretive phenomenology is ensuring the accuracy of the data. This researcher strove to achieve accuracy through immersing herself in the data, conducting the interviews, listening to the audio taped interviews, transcribing the interviews, re-listening to the interviews to ensure accuracy of the transcription, and then re-reading the transcriptions multiple times throughout the data analysis process. In addition, two in-depth interviews were conducted with each participant. The second interview allowed the researcher to clarify any information that may have been unclear or lacking depth in the original interviews. Moreover, as the study progressed the researcher was able to gain participant feedback about possible emerging understandings from previous interviews.

Confidentiality and Ethical Considerations

Ethics approval was obtained from the Behavioural Research Ethics Board of the University of British Columbia and the Research Review committee of Children’s and Women’s Health Centre of British Columbia (see Appendix D).

In the initial contact with the adolescents and parents, the researcher explained that the information shared during the interviews would be confidential. The adolescents were informed that the data would be shared with the researcher’s thesis committee, but that no names or identifying data would be included in this information. The informants were reassured in the initial contact and at the beginning of each interview that the information would remain confidential. In addition, the researcher spoke at length with each participant about how the information received from the data would be used and the possibility of using the information for clinical education. All adolescents were informed
that their participation would remain confidential and that any use of the data for educational purposes would involve general themes, with no identifying data being used.

Prior Relationship

From the beginning of the study, one issue of ethical concern was that in her ongoing role as a staff nurse at a pediatric hospice, the researcher had provided nursing care to many adolescents with PNDs. This created the possibility that she could have had a prior professional relationship with some of the potential research participants. Therefore to minimize any ethical dilemmas, the researcher refrained from providing nursing care to adolescents (age 16-19 years) with PNDs during the time the study was being conducted. Additionally, all recruitment occurred solely through the neuromuscular clinic where the researcher never had any affiliation or provided services. To further limit any role confusion, the researcher did not conduct any of the interviews at the hospice. In addition, the researcher clearly informed the adolescents that the study was being completed as part of a Master of Nursing educational requirement and not as a hospice project.

Consent

Adolescents who were younger than 19 years of age required parental or legal guardian consent and also were asked to provide assent to participate in this study. The one adolescent who was 19 years of age was asked to provide consent for himself. The researcher ensured at the beginning of the first interview that informed consent was obtained and all appropriate consent and assent forms were signed (see Appendixes C, D, and E). All adolescents and parents were informed at the initial contact and reminded
throughout the process that consent was voluntary and could be withdrawn at any point throughout the study.

Summary

This study used an interpretive phenomenological approach to understand the experiences of medical-decision making for adolescents with a PND aged 16 to 19 years. Through 10 semi-structured interviews, data were collected, transcribed, and analyzed with a focus on what five adolescents had to say about their experiences of medical decision-making. Thematic analysis was employed, with paradigm cases and exemplars being used to support the themes as they emerged from the data. The results from these analyses are presented in the next chapter.
CHAPTER FOUR

FINDINGS

The purpose of this study was to understand the experiences of adolescents with a progressive neuromuscular disease (PND) in regards to personal medical decision-making. However it became clear that the adolescents had information and experiences to share regarding decisions related to their health, beyond what was captured by the term medical. For this reason, the term health decision-making has replaced medical decision-making. The adolescents shared many examples, thoughts, comments, and advice about personal health decision-making. Through these data, it became evident that adolescents separated the decisions into two distinct categories, based upon level of perceived risk and physician involvement. These categories Big, referring to high risk decisions that involved physicians and typically occurred as a one time decision, and Small, referring to lower risk decisions that did not involve physicians and typically occurred as ongoing decisions, are described in the first half of this chapter as the backdrop to understanding the adolescents' experiences.

While each adolescent had unique experiences and told a variety of stories, one contextual theme emerged as central to the experiences of health decision-making: Joint Ownership. This theme, Joint Ownership, captures the sense that the physical disability and illness were not experienced solely by the adolescent but by the adolescent and his parent(s), and as the parent(s) and adolescent shared these experiences the decisions, ownership of the physical body, and the responsibility for the care of the body also became shared. Joint Ownership comprises five sub-themes: Shared body; Shared
decisions; Shared goals; Awareness of impact on parents; and Tensions with normal adolescent development. These are described in depth in the second half of this chapter.

Adolescents’ Descriptions of Making Big and Small Health Decisions

The adolescents described two distinct types of decisions related to their health, which have been termed Big and Small. Big Decisions occurred as onetime events and regarded specific medical or surgical procedures. In all situations when adolescents described Big Decisions a physician was involved. Yet, no nurses or other health care professionals were viewed as having a role in these decisions. In comparison, Small Decisions were ongoing in nature. They were made repeatedly each week or day, were not about a specific medical or surgical intervention, and did not typically involve a physician. In Small Decisions the health professionals involved were typically nurses, however in some cases occupational therapists and physiotherapists were described as involved as well.

Adolescent 4 explained his separation of decisions into the two categories as:

A big decision I would consider like surgery. Things like going on or off of the bipap. Things that would majorly affect the quality of my life, things like that I would classify as big. Where as small I would classify anything from deciding to take vitamins to ummm. Like probably the biggest small decision I would make up would be something like my care attendants.

In this quote, Adolescent 4 shared the clear distinction of Big and Small Decisions. In his words, Big Decisions “majorly affect the quality of my life.” Small Decisions were perceived not to affect his quality of life in the same way, thus having relatively little impact.

Another way of perceiving the Big and Small dichotomization of decisions is from the perception of risk. The adolescents used risk as a defining factor of Big
Decisions, with Small Decisions being perceived as being relatively low risk. Terms such as: “life threatening”; “risky”; and “chance I wouldn’t make it” were used to convey the risk of Big Decisions. In addition, the adolescents expressed fear and sometimes apprehension in regards to some of the procedures that resulted from the Big Decisions with terms such as: “this is scary”; “I [was] pretty scared”; “the anaesthetic I was worried about”; and “I was worried about going to sleep. Everything scared me.” Similar statements, reflecting fear or apprehension, were not present in relation to Small Decisions.

Also, adolescents desired different levels of personal and parental involvement for the two types of decisions. For example, Adolescent 3 stated how involved he would like to be in decision-making “just depends on the kind of decision it is.” Adolescent 4 explained further:

My parents had more say in the big decisions. I would seek their advice and their ideas more so if it was a big decision. Where as for small decisions it as my body, my personal care. I usually made up those.

These quotes show that the adolescents separated decisions into either Big or Small based upon the perceived potential long-term impact, and the possible risk associated with the decision. Additionally, the desire for parental involvement was more likely if the decision was perceived as Big as opposed to Small.

Big Decisions

When talking about Big Decisions, the adolescents used a variety of terms to convey the meaning of these decisions. These terms included: “big”; “life-threatening”; “speciality stuff”; “crucial”; “major operation”; and “significant.” Decisions that were labelled with these terms regarded making choices to have or not have a surgery; to start
or not start a new medication; and to start or not start home assisted non-invasive ventilation (bipap). All of these decisions were described as a single event, with the decision occurring at a specific time. The adolescents were able to recall the events surrounding the decision; where the decision took place; what information was shared; and who was involved in the decisions. All of the Big Decisions involved a physician, typically a specialist such as a neurologist or orthopaedic surgeon, and a parent or parents.

As the adolescents talked about “risky” or “significant” decisions, they also talked about the desire to have parents involved. This desire seems to be related to a fear of responsibility. In almost all of the Big Decisions, one real possible negative outcome was death. Two of the adolescents did not talk about the potential risk of death, with issues such as infection, long hospital stay, pain, or breathing complications being the only risks mentioned in relation to the decisions. Two other adolescents were quite open and talked about the risk “of passing away” and the risk that they “may not wake up from the anaesthetic” or die during the surgery. The fifth adolescent did not acknowledge that there were risks in relation to Big Decisions. It was this adolescent, Adolescent 1, who demonstrated the most fear of responsibility in Big Decisions.

Adolescent 1 described that if he took 100% responsibility for the Big Decisions then this would be “bad.” He chose not to elaborate as to why or how this would be “bad”, but he clearly expressed his desire for his mom’s input in his Big Decisions. Further, he expressed that he liked making some decisions and not others with the statement, “I can make those decisions [small personal care decisions] but health care decisions [referring to surgery] I don’t like.” He explained his desire to have his mom
primarily responsible for the Big Decisions as, “I just don’t like thinking.” He did not mind thinking about non-health related decisions such as entertainment choices, clothing, and friendships, but avoided thinking about Big Decisions.

This adolescent talked the least about his diagnosis, general health, and risks involved in Big Decisions compared to the other adolescents. In addition he purposely avoided talking about the future, his prognosis and disease trajectory, using humour, one-word answers, and redirection of the conversation to avoid the discussions. His avoidance was strikingly different from the other adolescents, all of who acknowledged their disease and progression throughout the interviews. The other striking aspect of his experience was his desire for his mom to be almost completely responsible for his health care, saying things such as, “I’d rather just have her do it,” in reference to making Big Decisions. It seemed he wanted his mom’s involvement in the decision-making of Big Decisions so as to not take on the responsibility and awareness of the potential risks involved. One way he managed not to assume the responsibility for his health was by ensuring that his mom always attended appointments so he could, “pretend I am listening,” and have his mom answer all the questions. He was, however, aware that this responsibility, while currently accepted by his mom, was not sought or desired by her. He described his mom as wanting him to, “talk for myself more and stuff,” but was “happy” with his current reliance on his mom, especially with Big Decisions, as he trusted her to make the “right decision[s].”

While Adolescent 1 was the most extreme example of this fear of responsibility, it was also evident in the experiences of other adolescents. For example Adolescent 4 shared:

I am finding it a little intimidating now because I am now actually doing it 100% most of the time. There are still times were I will be like “Mom help!” or “Can
In this quote, Adolescent 4 expressed that he was taking on increasing responsibility for
decision-making in relation to the Big Decisions. This does seem to be desired, but he
also acknowledged how “intimidating” this is. There are moments when he wanted help
and did not want to be solely responsible for his health care in general, and more
specifically he wanted his mom to assist with the Big Decisions. While in the above
quote he described himself as, “doing it 100% most of the time,” (referring to making Big
Decisions and being responsible for his health care), he also later stated that his mom had
about a 40% influence on his Big Decisions and that he still desired her input and
perspective.

Similarly Adolescent 5 stated:

I want them [parents] to be there with me. They probably don't have the final
decision. But I want them to be there because I know they care, that is part of it....
I still want them in the know how. I am not very good, I’ll be the first one to tell
you, I am not very good at remembering.... I am not the best at relaying stuff,
continuing on with stuff. I want them to hear what is being said, and for them to
nudge me on.

In this quote he expressed his desire that his parents be involved and present for the Big
Decisions. He was clear that he still wanted to make the “final decision”, but
acknowledged his limitations and did not desire sole responsibility for his health care
decisions and his general health care. These quotes reflect that the adolescents wanted
parental involvement in the Big Decisions. None of the adolescents actually desired full
responsibility for the Big Decisions, and all appreciated the support and help from their
parents.
This fear of Big Decisions was not limited to adolescence. One example by an adolescent, Mark\(^1\), demonstrated parental fear of responsibility. As Mark described it, when he was eight years old, his parents were approached by a surgeon who discussed the likelihood that Mark would require a back surgery. In Mark's words:

Dr. [orthopaedic surgeon] explained it to them [parents] and they kind of went this is scary and sat down and thought about it and things and then they came to me and told me they wanted me to talk to the doctor.

In the case of this surgery, the choice was not obvious. Mark shared quite openly that there was a known significant risk of death during the surgery, which he termed as a “25% chance I wouldn't make it.” In addition if he did not have the surgery, he would have future problems with pain, deformity, decreasing lung capacity, and breathing problems. His parents, aware of the risks, were scared and responded by choosing to engage Mark in the discussion, allowing him to influence the decision. Mark explained that he thought his parents had chosen to involve him because they did not want him to later be upset or blame them if they made a different choice from what he would have wanted. As he stated:

I guess they just felt that I was, I think that my parents, I am not them, but I think that what it was is that it ultimately was my life and so although I was really young, it was going to affect my life either way whatever decision they made, so they wanted [pause] I wouldn’t say the decision was 100% mine, but I definitely had a large amount of input in it, things like that. So they wanted to do that because they didn’t want to do something that they would then regret because I didn’t want, like that I would hold against them, things like that is what it was.

It seemed that his parents did not wish the full responsibility of the Big Decision and chose to share this with Mark. While this sharing of information, “openness” of his parents, and the way they included him in the decision-making was perceived by Mark as

\[^1\text{More detailed examples have been assigned pseudonyms to further protect the adolescents' confidentiality.}\]
an important positive experience that enabled him, now an adolescent, to be involved in his health care and decisions, it also resulted in Mark being aware of the risks associated with the decision.

Although the adolescents for the most part desired parental input and involvement with Big Decisions, the decisions were never discussed in terms of making a choice based solely upon the parents’ opinions. In all but one case, Big Decisions were made by the adolescent and parent(s) agreeing with the physician’s recommendations. Agreeing with physician recommendations, and much of the language used regarding Big Decisions, depicts an important component of Big Decisions; the physician was perceived an expert.

Physician as expert.

The physician was viewed as an expert by all of the adolescents, although no adolescent used the term expert. However comments like the following quote from Adolescent 3, as he talked about making a Big Decision, conveyed the sentiment that the physician was an expert:

I would talk with my parents and if I knew someone that was in the same situation, I would ask for their opinion, but their opinion wouldn’t be the first and foremost. The physician opinion would be first, people who actually know.

As this quote demonstrates, physicians were viewed as the key people to provide information related to Big Decisions. All of the adolescents identified that the majority of their health information came from physicians. Again Adolescent 3 stated, “I would ask a doctor I know or someone who has an idea what this is. That would most likely be Dr. [neurologist] or whoever is the doctor who knows my disability the best.” Additionally,

---

2 This case is described in depth later in the chapter, in the section “When expertise is contested.”
all of the adolescents expressed that if they had questions about a procedure or medication they would ask a physician. Occasionally adolescents would use the Internet or talk with other adolescents who had had similar procedures or been on similar medication, but in the end it was the physician who was perceived to know the most and have the most accurate knowledge.

When making a Big Decision, the adolescents typically would choose to follow what the physician recommended. For example Adolescent 1 was very succinct in his response to how he would know what choice to make and how he chose to have a surgery. The surgeon presented the information, it made sense to the teen, and he chose to follow it. As he summed it up, “I trust my doctor.” Adolescent 3 described choosing to have his back surgery as “He [surgeon] just kind of said that it was a good idea to take it and I don’t really not listen to the doctors. It is just whatever the doctor says, pretty much.”

Even in situations where it was not necessarily what the adolescent wanted, because of fear or uncertainty, the adolescent still believed that the physician was the expert and knew best. Adolescent 5 had had heel cord surgery and described how he was fearful of the anaesthetic, the surgery, being hospitalized, and being in pain. This fear led him to express that, “I really did not want to have this [surgery].” Yet he still agreed to have the surgery. He explained, “I didn’t disagree with it. I didn’t know much but I knew it would help.” This knowing that it would help was based upon the information that the physician had provided about the benefits of the surgery. Therefore, even when fearful and genuinely not wanting a procedure, the physician was still perceived as the expert, and the medical recommendations were followed.
Although the adolescents viewed the physician as expert, and typically went along with the physician recommendation, they still considered that they had a choice and had to make a decision. Adolescent 5 captured the way the adolescents addressed this sense that even with physician recommendations, it was still a choice when he said:

> It was presented as this is what we [physicians] think is best, but it is your choice in the end. You know the difference, what is going to happen. So they gave us the date when the surgery was going to be held. They always told me that if you ever want to not do it you have the choice, but we strongly recommend that you do. The doctors were all like, “yup you should get it done.”

While it was clear that the surgery was what the physicians recommended and ultimately the adolescent did have the surgery, from the adolescent perspective he did believe he had a choice. So although the adolescents felt that they made choices in regards to Big Decisions, only in one situation\(^3\) did an adolescent actually choose to not take the physician recommendation.

In summary, with Big Decisions, the physician was involved and typically was perceived as the expert, sharing information about the procedure or medication and potential risks and benefits. The adolescents considered that they had choices and were involved in decision-making with the Big Decisions and were almost always likely to follow what the physician recommends. In addition, Big Decisions were considered to have risk associated with them, and the adolescents desired parental involvement.

Small Decisions

While the adolescents had multiple phrases and words to convey what a Big Decision was there were very few words used to describe Small Decisions. These decisions were classified as what they were not, rather than what they were. Small

\(^3\) This situation is described in depth later in the chapter, in the section “When expertise is contested.”
Decisions were not: “life-threatening”; “speciality stuff”; “crucial”; “major operation”; and “significant.” “If it doesn’t affect me either way,” and “something smaller” were two terms used to convey the idea that Small Decisions had less impact. Small Decisions were typically about personal care with decisions about bedtime; when to wear bipap; when to bath or shower; if and when to do chest physiotherapy, or if and how to do leg exercises. These decisions were ongoing, repetitive decisions being made typically on a daily basis. The decisions were not described in the same detail as Big Decisions, but talked about more generally. Risk was not discussed in relation to Small Decisions, and there was no evidence of fear of responsibility. In addition, those involved with Small Decisions were the parents, adolescents, and in some cases health professionals, but never physicians.

Adolescents were clear that Small Decisions were theirs to make. There may have been parental input, but ultimately Small Decisions, were up to the adolescents. For example, “Whether I wanted to do my lung exercises or not. If I didn’t do my lung exercises it was up to me,” stated Adolescent 2. Similarly Adolescent 3 described how, “Most of the decisions are like are you going to go to bed now or later, shower now or later. Most of it is my decision.” In the same way, Adolescent 5 described how, “For small decisions it was my body, my personal care. I usually made up those.” Clearly from these quotes, the adolescents believed that they should choose and have the final say as to what happened in regards to Small Decisions.

This sentiment that Small Decisions were to be made by the adolescent was respected and encouraged by the parents. For example Adolescent 4 reported that his parents, “would say your choice, your body. With the bipap I have the final decision,” in
regards to what nights he wore the bipap. Additionally, even when the parent(s) may have wished for the adolescent to make a different decision, the adolescent’s choice was still respected. Adolescent 3 describes his parents’ input and the Small Decision of leg exercises as:

I know that my parents would like me to do more, they push me to do more, but at the end of the day it is my decision. Like for physio I do it sometimes when I am at school, but I don’t really care to do it lots. And that is something that I know my parents want me to do more, but it is my decision.

As these quotes depict, Small Decisions were determined by the adolescents’ choices and the parents respected these decisions. The adolescents perceived themselves as experts in regards to their bodies, and therefore desired and expected to be able to make the Small Decisions.

Adolescent as expert.

While with Big Decisions the physician was the expert, with Small Decisions the adolescent was the expert. He was the one who initiated the discussion about the decision, provided all the background and contextual data, and had the expertise of how his body felt. He viewed himself as the one who knew his own health best in relation to the Small Decisions. Adolescent 5 described his expertise in the following statement about why he chose not to read about his illness:

No I really don’t. It is right there, but I never look at it. I know how everything goes on and why it is doing this. I realize I live with it everyday; I don’t want to go read about it.

While he did not directly refer to himself as an expert, there was a sense that he knew about his disease. Because of this sense that he knew about his body, he already knew it and did not need to seek out more general information. In regards to Big Decisions about specific medication or procedures, he was much more interested in reading or
seeking out further information. The sense that he already knew it all was only in regards to general day-to-day living with his disease, not the specific Big Decisions.

The most common expression of expertise by the adolescents was the ability to know what their bodies needed based upon how they were feeling. For example, the adolescents frequently talked about basing Small Decisions on how they were feeling. Adolescent 4 commented that he decided to wear his bipap based upon, “Just on how I was feeling. If I was feeling well, if I was feeling energized, things like that would be my judge if I was going to wear it.”

Similarly Adolescent 2 shared about how he knew his body well enough to know how difficult it was for him to fight off a cold and how it could easily lead to pneumonia. He shared about how he would take steps that he knew would keep him well, such as chest physiotherapy. He increased the frequency of the physiotherapy, as he stated “[Be]cause I wanted to prevent getting colds as often, even though I wasn’t really getting any colds, but just to prevent them.” So even though he had not been told to keep completing the increased exercises he still “thought that I might as well always do it, so it won’t get bad.”

Adolescent 5 had similar experiences regarding Small Decisions and talked about how he knew his body and would know how he was feeling.

I feel very tired in the morning if I don ‘t [wear the bipap]. Don’t have it on I will get a cough. I mean my parents will tell me what they think, if they think I should be on. If I say I don’t want it on tonight, they wouldn’t say no you can’t. They wouldn’t force it on me, but they would highly suggest that maybe tonight [adolescent’s name] you better put it on.
This text also demonstrates that, in this case, his parents would have input, but did not force the final decision. There was a respect for him and his expertise, even with the suggestion and opinion of the parent.

Being respected as an expert was about more than just the Small Decisions, it was about being respected as a unique individual of value. One of the very real challenges for these adolescents as they lost physical abilities was that they sometimes were treated as objects, rather than people. Adolescent 4 captured this objectification when he talked about how he was treated by some nurses when in hospital. He described the care as “cold” and “insensitive.” Further describing that, “a lot of them [nurses] treated you more as, hmm the word patient does not really work, more like a number, like you just were in there.” This experience of being a “number” not a patient implied that he was made to feel unimportant. He perceived that he was just one of many, not an individual, but merely one more object. His example provided the sense that while he was physically involved in the care (as the object of care he had no choice), he was not actually involved in the care in any other way.

When Expertise Is Contested

For both Big and Small Decisions, typically the expert made recommendations about a choice and that choice was followed. Challenges occurred when the expertise was contested. There were two ways that this expertise was contested: first when there was more than one expert and second when an adolescent was not acknowledged as an expert.

The perception of more than one expert occurred when there was a Big Decision, and the physician was not viewed as the only expert. The only Big Decision described by an adolescent when the physician recommendation was not chosen is an example of a
situation with more than one expert. In this particular case the adolescent, John, chose not
to accept a physician recommendation of restarting a medication. While the actual event
was clearly a Big Decision, as it was a onetime event described in detail and involved a
physician prescribing a medication, the physician was not described by the adolescent as
an expert or as having any great wealth of information or knowledge about the
medication. What John did describe was his own expertise. He shared at length about
why he chose not to take this medication:

Because there were more negative effects than positive effects. Gaining weight. I
felt bad about myself. I didn’t like myself. The positive, I would be a little bit
stronger. But also one disadvantage to the deflazacourt is that it makes your bones
very weak. It helps the muscles better. It takes the good from the bones and brings
it too the muscles. My bones were getting really weak.

As John had previously been on the medication, he was well aware of the side effects he
had previously experienced, weight gain and bone weakness. In addition, he was aware of
other adolescents who had taken, or were currently taking, the medication, and issues
they had with the medication. This knowledge and experience led him to perceive himself
as an expert in regards to his body and this particular medication. While John did not
describe the physician as an expert, it is evident that the physician took on the role of
expert in this Big Decision. For example the doctor initiated the discussion about
restarting the medication, she provided information, and she recommended that John
restart the medication. With two people, the physician and the adolescent, both
perceiving themselves as experts tension and uncertainty emerged. With all other Big
Decisions, there was only one expert, therefore the adolescent and parent “knew” what
decision to make. In this case, to choose one option would be to choose to go against one
of the experts, either a trusted doctor or against John’s own experiences. John was
adamant about not taking the medication stating, “And I was completely against it. I said
No I don’t want to do that!” His parents were less decisive. They were aware of the side
effects, but also thought the physician may have been right about the potential benefit of
the medication. John’s parents chose to acquiesce to their son’s expertise, and John did
not restart the medication. This example of decision-making was ended by John sharing
some recent findings that highlighted the more negative effects of this drug. He
concluded by saying, “So I made the right decision we realize now,” and, “now that was
a good decision.” None of the other discussions about Big Decisions ended with the
adolescent justifying or trying to prove that the decision was “good.” There seemed this
sense that although he was the expert and chose to follow his own choice, he still needed
further evidence that deciding against the physician was the “right decision.”

In the case of Small Decisions, there were never multiple experts. Rather the
disagreements occurred when the expertise of the adolescent was not acknowledged.
Small Decisions were discussed as occurring in two distinct contexts, at home and in
institutions. At home, the Small Decisions did not typically involve health professionals,
although some adolescents would occasionally have a personal care aide assist them at
home. When the Small Decisions occurred in an institution, they almost always involved
a health care professional, typically a nurse. Whether the person involved with the Small
Decision was a health care professional or a parent, the adolescent viewed himself as an
expert of his own body and care and expected that he would be able to make the Small
Decisions. This expertise was typically acknowledged by parents, but was often not
acknowledged by health professionals in the institutional settings.
The adolescents shared multiple examples of their expertise not being acknowledged. For example, Adolescent 4 shared about a time when he was in hospital and his expertise about his own physical comfort was not acknowledged. In this situation, the nurses wanted to turn the adolescent, most likely for a specific health reason such as preventing pneumonia, or bedsores, however the adolescent was not aware of what motivated the nurses’ desire to turn him. From his perspective he had finally gotten comfortable (which he described as no small feat as he was in the intensive care unit, in a hospital bed, and had recently had surgery), and now the nurses wanted to turn him. The nurses began the discussion of turning with the adolescent, but once he refused, they then spoke with his parents. It was his parents who enforced the turning, or in his words “forced” the decision upon him. From the adolescent perspective, he was “forced” to be turned, and he lost the argument. He stated, “My parents won.” There is the sense that there was a victor and a loser. It is possible that the nurses and parents did consider the adolescent’s input about his comfort and weighed it against other risks, such as pneumonia and bedsores, and chose that he still needed to be turned. However, from the adolescent’s perspective, his expertise was not acknowledged. His input, that he was comfortable, was not considered and he lost; the decision was forced upon him. In this example, there was also the unusual occurrence of the parents colluding with the nurses. This type of collusion was rarely reported by any of the adolescents. In fact Adolescent 5 also provided examples about how his parents would encourage health professionals to speak directly to him and encourage nurses to, “Ask him.”

Adolescent 3 also used the term “force” to express what happened when health professionals did not respect his expertise. He stated:
Just before my back surgery, there was a lot of seating arrangements that were being made and it was just, yah. They [occupational therapists] didn’t really ask for input. They just kind of did it. It seems more force fed.... It seems to be that they want to do it their way more than anything.

He talked about being frustrated that he was not listened to. From his perspective it did not seem to matter to the occupational therapists that his seat was not comfortable. He understood the interaction to be that the occupational therapists believed “their way” was the right way and it did not matter what he had to say.

Another adolescent, Adolescent 4 shared this perspective, that health professionals did things “their way.” He shared his frustration when his expertise was not respected at a pediatric hospice:

That was actually one of my struggles when I was younger, was the bipap because there would be times when I didn’t want to wear it and it would be in my healthcare plan that I had to and ummmm that was a big struggle.... The health care plans were very rigid, and I found that they [nurses and care aides] didn’t allow the kids to make up their own minds some time. Like ummm I remember certain times like bath day would be written in there and I wouldn’t want to have a bath and people [nurses] would end up calling my mom to ask my mom, and things like that. It was just ... it was too rigid I guess.

In this example, Adolescent 4 described that the set way of doing things, the standard use of the care plan and the reliance on the plans rather than allowing the adolescent to make decisions, was being “too rigid.” The adolescent was not perceived as an expert in his own care, and instead the decisions that the adolescent was used to making when at home were now being made based upon a care plan or based upon the “expertise” of the parent. The nurses in this example did not acknowledge the expertise of the adolescent and instead perceived the parent as the expert, as they sought out parental approval to make changes to the care plan. However, this parental expertise was neither sought nor desired by the parents. Adolescent 4 shared how nurses requesting parental involvement in Small
Decisions frustrated his mom. He stated his mom felt, “It was like the independence that they (parents) had given me was taken away when I went to (hospice).”

Similarly, Adolescent 5 experienced the lack of acknowledgement of his expertise and “going by the parents.” As he stated, “That is the one down side to [hospice]. It is very limited that way, I find. They [nurses] go by my parents. They don’t go by me.”

All of the adolescents believed that as experts of their own body and own care that they should make the Small Decisions. In the home environment, this expertise was respected. In institutional settings this was typically not acknowledged and led to feelings of frustration, and a sense that decisions were being “forced”. Not being acknowledged as experts was shared as a negative experience, with the adolescents feeling frustrated and believing it impacted upon their independence.

Summary

Adolescents categorized decisions as Big or Small, depending upon perceived risk, physician involvement, and moment in time. With Big Decisions, the physician was perceived as the expert, and his/her recommendations were typically followed. With Small Decisions, the adolescents perceived themselves as the experts and expected their expertise to be acknowledged. Disagreements and frustration occurred whenever expertise was contested, either because there were multiple experts or because health professionals did not acknowledge the adolescent’s expertise. As the adolescents spoke of Big and Small Decisions, one contextual theme emerged, Joint Ownership. This theme is discussed in detail in the next section.
Contextual Theme: Joint Ownership

Progressive neuromuscular diseases cause a progressive loss of muscles, primarily affecting voluntary muscles, thus creating an increased reliance on assistance from others to complete many normal daily tasks. All of the adolescents in this study had a disease that had progressed to the point of having significant physical limitations and, therefore, relied on their parent or parents to provide the majority of their physical care. It is this paradoxical dynamic of moving toward independence (normal adolescent development) yet becoming increasingly physically dependent on others that exists as these adolescents experience adolescent development, live as middle or late stage adolescents, and rely on parental help for daily physical care. In the context of this dynamic, these adolescents experienced healthcare decision-making.

The theme Joint Ownership captures the sense that the physical disability and illness was not experienced solely by the adolescent but by the adolescent and his parent(s), and as the parent(s) and adolescent shared these experiences the decisions, ownership of the physical body, and the responsibility for the care of the body also became shared. As Joint Ownership is a contextual theme, this finding is examined first and then the five subthemes are explored through the presentation of a paradigm case and further exemplars.

Joint Ownership as Context

A central part of these adolescents' lives was their family, and in particular their parents. All of the adolescents who participated in this study shared at length about their parents, and the important roles their parents played in their lives. The main role that was described was that of primary care giver. While at school the adolescents had non-
parental care providers who assisted them and two of the adolescents had hired care assistants who provided a few hours of support at home, the majority of all physical care was under the direct responsibility of and primarily completed by the parents or parent. This physical reliance upon parents led to the adolescent and parent(s) working together to jointly care for the body. In the words of one of the adolescents, the decisions about the physical care and the daily enacting of the care was “joint.” As he needed physical help to get into bed, this action of “going to bed” became a “joint” venture. The physical act became joint, but the actual decision, a Small decision, was still under the expertise of the adolescent. He made the choice of when to go to bed, but considered the impact his decision would have upon his parents.

It is kind of joint. If my parents need to go to bed, then sometimes I will go to bed just because I can’t really [pause] because if they are tired I will just go to bed, but sometimes if I am busy doing stuff, then they will go to bed and I will wake them up later. (Adolescent 3)

As depicted in this quote, the care had taken on a routine and the parents and the adolescent worked together to accommodate each other and complete the physical task of getting the adolescent into bed. Additionally, the quote demonstrates the adolescent’s awareness of the impact his disability had on his parents and how he made decisions to accommodate his parents. This quote powerfully shows the compromise and “joint” work of the adolescent and parent(s) to sort out daily physical care.

In this context of “joint” work and parents providing physical care, there was the possibility of shared ownership of the physical body. As the adolescents lost voluntary agency and relied more upon parental assistance, the sense of body ownership became blurred.
The story “Working Together” is presented as a paradigm case of Joint Ownership and is used as a basis for further exploration of the five subthemes, drawing on exemplars from the other adolescents.

**Working Together**

One adolescent shared an example of his and his family’s experience when he was faced with an acute illness that resulted in hospitalization and a surgical decision. His story is shared to provide an example of how the various sub themes of Joint Ownership were present in the adolescents’ examples and this story is used as the basis for the discussion of Joint Ownership.

Paul, who was in the middle stage of adolescence when this situation occurred, told of his experience when he developed an acute illness that eventually required hospitalization and an unexpected surgery. To understand his experience with an acute illness, it is important to first understand the baseline experience of his disability within his family. For this adolescent, his parents were his primary care givers and provided all of his physical care when at home. This care included toileting, bathing, transferring him to and from his wheelchair, putting him into bed at night, getting him up in the morning, turning him at night, brushing his teeth, feeding him, moving his hands to enable him to use a computer, cell phone, television remote control, joystick for video games, or any other implement so he could enjoy a recreational activity, his joystick for his wheelchair so he could move about as desired, putting on his bipap every night, and any other physical assistance as he needed.

When he developed an acute respiratory illness his parents took on increased physical tasks to help him deal with the illness. They provided chest physiotherapy,
suctioning, increased turning, increased monitoring, and assistance with increased wearing of the bipap. His parents provided the intense physical care, sometimes every hour, and the adolescent provided his expertise as to how he felt his body was doing. Paul and his parents worked together to try to help him regain his baseline health status.

Together, Paul and his parents had decided that they did not want him to be hospitalized. He felt more comfortable at home with sleeping in his own bed, eating food he was used to, and not wanting to be in the noisy environment of the intensive care unit. He felt there was no benefit for him to be hospitalized as, “we could do everything they were doing at home…. and the environment was too loud. Not going to get better if you can’t sleep.” From Paul’s perspective, his parents desired him not to be hospitalized due to the lengthy commute to the hospital and care giving responsibilities for his younger brother. However, after five days his condition was not improving, and Paul saw how tired his parents were. He thought it was too much for them to be working 24 hours a day to try to get him better, so he asked to go to the hospital. He described this decision to be hospitalized as something he did, “for my parents’ sake. I was worried about them. They were really tired.” Initially his parents wanted to keep him at home, but as his health was not improving, they changed their opinion. As he tells the story of this decision, his words convey the sense that his physical body is shared. He stated, “So we [italics added] get major coughing attacks, I was really scared and we went to the hospital.”

Once hospitalized, Paul discovered he was sicker than either he or his parents had originally thought, and the physicians presented the potential need for an unforeseen surgery. Paul described his parents’ reactions to this and how he tried to stay calm to support them. He first told how his dad reacted by, “getting worried and interrogating
everyone,” and then how his mom reacted by, “taking it hard” and being upset about “her
[italics added] surgery.” He spoke in depth about how his dad needed as much
information as possible and, “wanted answers NOW,” and how his mom was crying and
“took it pretty badly.” Paul did not react emotionally to the news of the surgery. He
commented that, “I took it as something good because it needed to be done,” and he felt
that by staying calm he helped his parents realize, “what needed to be done.” As this was
a Big Decision, Paul and his parents eventually agreed with the physicians’ expertise and
decided to go ahead with the surgery.

Multiple facets of the theme Joint Ownership were present in Paul’s story and are
explored in further detail under each of the subheadings: Shared body; Shared decisions;
Shared goals; Awareness of impact on parents; and Tensions with normal adolescent
development.

Shared Body

Paul was physically reliant upon his parents. He was able to do very little without
physical assistance, and when at home his parents provided care. In this sense he was not
unlike the other adolescents in the study. All of the adolescents physically relied on their
parents. This ranged from an adolescent who was able to transfer himself, but needed
assistance with dressing and picking up dropped items, to an adolescent who needed
complete assistance including turning his head, positioning his arms and hands, and
needing to be fed. Adolescent 3 described his physical reliance on his parents as:

I need my parents or I need an assistant to do almost everything. I can brush my
teeth; I can do little things. I can feed myself. But to get changed, to use toiletry
(sic) I need my parents or an assistant.
When Paul became acutely ill, his level of need and reliance upon his parents increased significantly. In this context of a huge workload, of providing intense care sometimes on an hourly basis, the sense that the physical body was not solely Paul’s emerged. With his statement, “So we [italics added] get major coughing attacks,” Paul used the plural pronoun “we” in an unusual way; he described a solo physical body function, coughing, as a corporeal family event. From a purely physiological perspective, it is Paul’s body that was coughing. It was his lungs, his diaphragm, and his accessory muscles that were forcing mucous and air out of his body, clearing his airway, yet Paul used the pronoun we. Somehow this coughing attack was not just experienced by Paul. It was not just Paul’s coughing attack, and it was not just Paul’s body. There were others, his parents, who witnessed this attack, who worried about this attack, who had to take actions to assist with this attack, such as suctioning, wiping his mouth, repositioning him if the cough moved his body, or providing chest physiotherapy if the coughing did not clear the airway well enough. What typically, for those who are not severely disabled, would have been a solo personal event (coughing), became a shared event.

Paul was not the only adolescent to use plural pronouns to describe what is usually thought of as a solo or personal physical event. Other adolescents expressed similar statements. Adolescent 5, when describing a recent back surgery, referred to himself and his parents when he said “We realized yah we’re [italics added] having it. No going back.” In this statement he used the term “we’re”, conveying that he alone was not having the surgery, but he and his parents were having the surgery. Again, while from a physical perspective he was the only one who was to be anesthetized and operated on, the adolescent conveyed that the surgery was an event that was happening to him and his
parents. The underlying message was that perhaps his body was not his own, that perhaps his body was owned by him and his parents, thus indicating a shared ownership of the body.

Similarly, Adolescent 1 stated that he and his mom had been told, “that in the long term if we [italics added] didn’t get [the back surgery], it might be bad.” Again, the adolescent used the plural pronoun demonstrating that this was not the adolescent alone experiencing the surgery, but he and his mom. The plural pronouns showed the sense that experiences of the physical body, surgery or coughing for example, were in a very real sense shared by the adolescent and the parent(s).

Adolescent 4 also used a plural pronoun regarding a personal physical experience. His statement, “Like we [italics added] got an oxygen machine at home and we also [italics added], going through it [pneumonia] 30 times got really good of seeing the early signs” did not seem to imply the same sharing of ownership as the previous example. However, this example does show that the adolescent was aware that the experience of having pneumonia was a corporeal, shared experience.

Events that would normally be physically experienced privately by the sole owner of the body in the case of PNDs were experienced by the adolescent and his parent(s). Additionally, as the parents shared in these experiences and took on responsibility for the physical care of the body and movement of the body, the sense of ownership became contested. What emerged, even from the perspective of the adolescent, was that the body was not their own, that the body was on some level shared.

Adolescent 5 who repeatedly spoke of the physical care his parents provided and used plural pronouns as described above, also repeatedly stated, “It is my body.” He
seemed to need to clarify the ownership of his physical body. Repeated examples of
decision-making that he shared had the climax of it being his body. Perhaps this paradox
of him repeating “it is my body” and the actions being deemed corporeal with plural
pronouns was his way of demonstrating the tensions that existed as these adolescents
were trying to sort out how to be an individual agent when living through a body that
cannot fully perform voluntary actions.

It is important to note that the shared body reflected the sharing of the physical
body between the adolescent and the parent(s), not the entire family. While there was
some discussion and awareness of siblings and the impact the illness had on the siblings,
the body was never thought of as being owned or shared with the siblings. There were no
reports of siblings helping or taking any responsibility for the physical care, and no
request or expressed desire for this. So the sense of the body being shared seemed to
emerge from the parental-adolescent relationship, a relationship that was dominated
largely by the parents providing physical care to the adolescent. There was no evidence
of the body being shared with other care providers. However, none of the adolescents
experienced long standing daily relationships with any non-parent care providers.

Shared Decisions

In the case of Joint Ownership of the body, decisions about the body were
perceived to be shared between the adolescent and the parent(s). However it is important
to note that it is only the Big Decisions, those decisions with perceived risk and
considered to have long term impact, that were shared.

In Paul’s story the shared decisions included the decision to not be hospitalized at
the beginning, the decision to eventually go the hospital, and the decision to have the
surgery. All three of these decisions involved Paul and his parents. In the telling of all three decisions Paul told of what he wanted and additionally he told of what his parents wanted. There is this sense that the decisions were joint, that they were shared; that parental and adolescent perspectives were considered and resulted in the decision together.

Similarly, Adolescent 5 shared how when deciding about a surgery, “We [adolescent and parents] were all involved. Not directly to me. Not just directly to me” and how his parents’ involvement was desired. As he stated:

Like for the one [neuromuscular clinic appointment] right before my back surgery, the one where we [italics added] were making the final decision about the back surgery they were both there. I want them both there if it is significant.

Again the use of the plural pronoun we implies that the decision was shared, that the adolescent and his parents jointly decided to have the surgery. Adolescent 1 also used the plural pronoun in regards to the decision about a back surgery when he commented, “I think we [italics added] were given like…. so we [italics added] got a bit of choice.” In this comment he is referring to how he and his mom were provided with information and then had the opportunity to jointly make a decision about the surgery.

Similar to the sense of the shared body, not all decisions were clearly defined as shared. There remains a tension regarding the decisions and who owns them. For example, when describing the decision regarding a back surgery Adolescent 4 stated, “He [surgeon] explained the risks, the chances of passing away, all of that and the decision was mine to make.” Yet later, when describing the decision-making in greater detail, for this same surgery, he stated, “Although it was my parents’ decision, I was completely informed and I knew everything going into [it].” This switching of ownership of the
decision in the telling of the story suggests a tension, a blurring of the ownership of that decision. However this tension did not seem to have any emotional impact, with little emotion expressed or demonstrated related to the ownership of this decision. In addition, Adolescent 4 repeatedly expressed how involved he and his parents had been in the Big Decisions.

Shared Goals

Another component of Joint Ownership evident in Paul’s example was the sharing of goals. In his story, he and his parents worked together to achieve their initial goal of keeping him out of the hospital. Additionally, they had the health goal of returning him to his pre-acute illness state, and they worked together to achieve this. Paul summed up this working together in his comment “I would know if I needed more physio (chest physiotherapy) by how I felt. If I needed to cough or if it felt stuck. … Then my parents would turn me or do physio and suction me.” So shared goals were evident when the parent(s) and the adolescent worked together to achieve the same desired outcome. The examples the adolescents gave regarding the sharing of goals created a real sense that the parent(s) and adolescent have become a small team working jointly to achieve an end result.

Similarly, another adolescent shared about how he and his parents worked together to care for him when he developed pneumonia. He also did not like having to go to the hospital and preferred when possible to have his care provided at home. As he has had pneumonia many times, he and his parents had developed a routine of how they work together to keep him at home. They had a prescription for the “usual antibiotic” that could be filled if it was a weekend or night. Also, they had oxygen, bipap, and a suction
machine at home. The parents and adolescents had developed a real expertise in caring for him with pneumonia, as captured in this quote:

We also have a stethoscope at home so my parents will, cause they spent many years with me with pneumonia and the doctors kind of showed them how to listen and tell when it sounds like I'm crackly things like that. So if I am feeling off I'll say to them can you listen to my lungs and they will listen to my lungs and then I'll go okay well, and they will say yah they are really crackly, well okay I think I should [have chest physiotherapy], things like that.

Over the years of experiencing pneumonia repeatedly, the adolescent and his parents had developed an expertise and routine of dealing with this illness. They worked jointly as a team to achieve the shared goal of returning him to his pre-pneumonia health, without needing hospitalization.

Awareness of Impact on Parents

All the adolescents expressed awareness that their disability and illness affected their parent(s) as well as themselves. This awareness of the impact of their illness on their parents is a component of Joint Ownership for two reasons. Firstly, the extreme awareness, almost hypersensitivity, of the adolescents to their parents' needs and emotions depicts an extremely close relationship. This close relationship may in part be due to the blurring of conventional familial boundaries. The physical care that the parents must provide for the adolescents is beyond the normal boundaries of typical adolescent-parent relationships. With the intensive physical care being provided by parents, a sense that the physical body was shared had emerged. This concern for the parents suggests that there is further sharing and merging in the adolescent-parent relationships. Secondly, this concern for parents and making decisions with the parents in mind is a logical result of the shared body. When one shares ownership, one would consult with the other owner and consider the other owner when making decisions. In addition, the adolescents'
The second way this awareness of parents manifested itself was in how adolescents talked about the emotional impact of the illness. In the interviews, the teens shared very limited personal emotions about the disease progression and decision-making. Emotions that were shared were typically limited to frustration about not being involved with Small Decisions, or fear of the risks and responsibilities of Big Decisions. However, all of the adolescents talked about the emotions and reactions of their parents. In Paul’s example this is quite evident. When describing his experience of discovering that he was significantly sicker than he had thought and that there was the recommendation for an unforeseen surgery, Paul talked about his parents’ reactions. He shared how his mom cried and became emotional and how his dad became angry and impatient and sought out information. It was not until directly questioned that Paul shared any of his own reactions or emotions. Even with questioning though, Paul described his reactions as limited to “being calm” and “realizing that the surgery had to be done.” The focus of his example from an emotional perspective implied that the surgery and changes resulting from it had more impact on his parents than him. He implied that it did not affect him that much and that the losses associated with the surgery were not really a “big deal.” Similarly, Adolescent 4, when discussing his frustration with his expertise not being acknowledged in regards to Small Decisions, shared more about his mom’s reaction than his own. He made statements such as, “She [mom] found it really hard,” and, “My mom found it really difficult.” The example Adolescent 4 shared involved an experience, when his mom was not present, in which his expertise was not respected by nurses. Yet it was his mom’s response and her feelings that he shared, not his own.
awareness of their disease’s impact on their parents further indicates the high level of dependency and physical care requirements in this population.

This awareness of the impact on parents seemed to manifest itself in three different ways. First, it was the considering of how certain decisions would affect parents. These decisions were primarily Small Decisions that took place at home and the adolescent required parental physical help. In these situations, the adolescents talked about deciding to do or not do something based on their knowledge of how it would impact their parent(s). In Paul’s story, this is evident when he chooses to eventually be admitted into the hospital. He based his decision upon his awareness of how much physical work and time was required of his parents to keep him at home. His statement, “I was worried about them. They were really tired.” shows his concern and awareness of his parents needs. While he would have preferred to not be hospitalized, he was aware that this desire to stay at home was a lot of work for his parents and resulted in them getting very little sleep. Therefore, “For [his] parents’ sake,” he decided to go to the hospital.

Even at times with no acute illness, this concern and awareness of parental workload was evident. The most common example was in regards to going to bed. As none of the adolescents could settle themselves into bed, going to bed was not a solo event, but one that involved a parent. The adolescents talked about how they would base their bedtime on their parents’ needs, such as choosing to go to bed earlier if they knew that their parent was tired or had an early morning planned. Adolescent 4 described the decision regarding bedtime as, “If it was like staying up later I would always take into consideration if my dad had to go to work the next day, things like that.”
The third way this awareness of parents was evident was that the adolescents frequently expressed worry for their parents' well being, particularly in regards to emotional health. For example, Adolescent 4 shared about his experience of staying in the ICU and how he wanted parental supports:

"Someone for them [parents] to talk to, somewhere for them to go. Somewhere. Not saying that the hospital should be like a hotel, because I don’t agree with that at all. You are in the hospital, but just somewhere to make it a little more cosier I guess, because it can be a frightening time for the parents too, not just for the kids. It would be nice to see something."

None of the adolescents expressed a need or desire for personal support. While none of the adolescents expressed that they liked being in the hospital, the most common concern about hospitalization was the challenges for the parents, such as needing to commute, worrying about siblings, or the emotional impact.

Tensions With Normal Adolescent Development

An important component of the theme Joint Ownership is that it occurred in the context of adolescence. As normal adolescent development involves a move towards increasing independence and less reliance upon parents, Joint Ownership seem to be counter-intuitive. The developmental tasks of increasing independence and separation from parents seem at odds with the experience of sharing one's physical body, sharing goals, sharing decisions, and basing decisions upon the impact on parents. As one lives these two contradictory experiences, normal adolescent development and Joint Ownership, it would be expected that tensions would emerge. However very little tension was evident in the data.
The adolescents seemed aware that some of the limits or rules they experienced had nothing to do with their disability or illness, that these were "normal" for adolescents with or without a disability. For example, Adolescent 5 stated:

Most of the decisions are like are you going to go to bed now or later, shower now or later. Most of it is my decision. The odd decision is the stuff that they [parents] know is right versus me not, me being lazy and not wanting to do it. "Are you taking your medication?" "No" "Will you?" "Maybe." No one else [parents] can tell me what to do. I am a teenager come on.

In this quote, Adolescent 5 shared that he made most of the Small Decisions, however there were situations where he acknowledged that he was just being "lazy" or did not want to do something even though he knew he should. In these cases, he knew his parents would tell him what to do, and that he would follow through and do it. He also knew that his parents wanted the best for him and were vigilant about some things, such as taking medication to ensure that he stayed as healthy as possible.

Similarly, Adolescent 3 explained, "Well if I have to go somewhere, like a family thing, it is not my decision but I will go. Like a family dinner." Although not health related, it does demonstrate that the adolescents had a sense that they still followed parental wishes, but most were considered "normal" limitations or expectations that all adolescents typically have to accept. Another example of these "normal" limitations was present when Adolescent 5 shared about expectations while staying at a pediatric hospice facility saying, "It was pretty much just like you know typical teenage curfew, other than the list of friends that my mom had to okay." The use of the word "typical" implies that he realized that kind of limitation was "normal"; that all or most adolescents would be expected to have a curfew. However, the next part of his comment regarding his mom "okaying" a list of friends is not described as typical. The sense is that this requirement
was not “normal”, that in other situations “normal” adolescents would not have to list their friends and get parental permission to have them visit.

Adolescent 4 shares further about how he had made decisions based upon his parents’ needs, but began to realize that other adolescents do not do this. He describes this as:

If it was like staying up later I would always take into consideration if my dad had to go to work the next day, things like that, but as I got older I started to realize that you know, these are things [staying up late, choosing to go out late] that everyone else does, so I guess I started to do them more anyways to a degree. But still, I have always been the kind of person to take into consideration how it is going to affect people around me.

In his statement, “things that everyone else does,” he conveyed that basing his decision on when to go to bed upon his dad’s schedule was not “normal”; that other adolescents were able to determine their bedtime without considering their parents’ schedules. In response to this realization that, “these are things everyone else does,” he chose to stay up later and based fewer of his decisions upon parental impact. What allowed this to happen without tension was his parents’ awareness of normal adolescent development.

This parental awareness of normal adolescent development appeared to be the reason for this lack of significant tension between normal adolescent development and Joint Ownership. The parents were aware of normal adolescent development and were aware of the needs of the adolescent, beyond purely physical needs. While the relationships between each adolescent and their parent(s) differed, each described their parents as being advocates and spoke of them favourably. It is possible that this favourable relationship, and parental awareness of normal adolescent development, is what mediated the expected tension between the theme of Joint Ownership and normal adolescent development.
An example of this parental respect was evident in Adolescent 5’s statement:

My parents are really good that way they aren’t going to say “_____ it is ten o’clock, when are you going to bed?” They will say, “I’m going to bed. Call me when you are ready.” They respect me. They understand that I am a teenager; I don’t want to go to bed at ten.

As evidenced in this quote, parents were aware of normal adolescent development and the independence and freedom desired by the adolescents. Although there is a sense of a shared body, shared decisions, shared goals, and awareness of the impact on parents, there is also parental awareness of normal adolescent development. This awareness seemed to be most evident by the respect the parents showed the adolescents by accepting the expertise of the adolescents in Small Decisions, thus mitigating much of the expected tension between Joint Ownership and normal adolescent development.

Summary

The adolescents shared many examples regarding health care decision-making and their experiences with health care professionals in hospital, clinic, hospice and rehabilitation settings. Throughout all of these examples, it was clear that decisions were categorized as “big” or “small”, and that with each category an expert emerged. Big Decisions typically had physician experts and the adolescents were the experts in Small Decisions. The experts’ opinions and recommendations were typically respected and followed. When expertise was contested, there was frustration and confusion. Throughout this process of decision-making, a key contextual theme, Joint Ownership, was central. For adolescents with PNDs, the desire for independence and inclusion in decisions occurred within the context of relying more and more upon others for physical assistance. With this increasing reliance, especially upon parents, there was the sense that the physical body became shared. This sharing of the physical body at a time when the
developmental norm is to strive for increasing independence could create tension
between the adolescents and parents. However, the parents’ awareness of adolescent
developmental needs and advocacy seemed to mitigate this tension. Unfortunately, health
professionals do not always seem as aware of adolescent development and the
adolescents’ desire for inclusion. In the next chapter is a discussion of these findings in
relation to current research, possible future research, and potential clinical implications.
CHAPTER FIVE

DISCUSSION

This final chapter provides a discussion of the findings in relation to the current literature and study research questions. The two specific research questions were:

1) How do adolescents with PNDs perceive their involvement in health decision-making and what does their involvement in health decision-making mean to them?

2) What factors influence (both negatively and positively) the adolescents’ perceived experiences of decision-making?

The original research questions used the term medical decision-making. However, it became clear that the adolescents had information and experiences to share regarding decisions related to their health, beyond what was captured by the term medical. For this reason, the term ‘health decision-making’ has replaced the term ‘medical decision-making’ in the research questions.

In answering the research questions, it became evident that the adolescents categorized health decisions. This categorization was relevant to the experience of decision-making as adolescents perceived their involvement in health decision-making based upon a system of categorizing the decisions as Big and Small. In addition, the theme Joint Ownership emerged as central to the adolescents’ experiences and provides understanding of the context.

Jurisdiction With Small Decisions

The process of characterising decisions as Big or Small allowed the adolescents to define the areas over which they believed they should have jurisdiction. The Small
Decisions were perceived by the adolescents as belonging to them alone. This process of dividing decisions into categories and determining areas of ownership is an important aspect of individual autonomy (Helwig, 2005), as is developing an understanding of what areas one may make decisions about without influence or guidance from authorities (Helwig). The development of individual autonomy during adolescence has been studied in depth (see Turiel 1998 for review), and personal issues or actions, such as choice of friendship, appearance, or leisure activities, are areas where adolescents typically claim ownership (Helwig).

Adolescents perceived personal actions and issues as "matters of privacy and individual preference" (Nuci & Webber, 1995, p. 1438) and "acts that did not affect others, were their own business, and should not be governed by rules" (Nucci, 1981, p115). Similarly, Smetana and Asquith (1994) discovered that adolescents and their parents typically agreed that personal actions or issues were under adolescent control. When these areas were not viewed as within adolescent control, the adolescents were likely to complain or argue in regards to the decisions being made.

The findings of this current study with adolescents who have PNDs concerning their desire for jurisdiction over Small Decisions are similar to those reported in the literature regarding personal issues and actions. However, none of the published studies examined adolescents with chronic illnesses or a disability. In addition, the literature does not directly discuss health issues or answer the question of who has jurisdiction in health related decisions.

The adolescents’ perception of their involvement in Small Decisions was that they should be, and they desired to be, the ones making the decisions. Their involvement
meant two key things to them: first, being respected as the expert of their own bodies; and second being acknowledged as a person. As experts of their own body, the adolescents believed that they had important information to provide to the health care professionals, especially in regards to Small Decisions. When this information was not received or ignored, the adolescents felt excluded from their care.

Similar findings were reported by Hassouneh-Phillips, McNeff, Powers, and Curry (2005) in a secondary analysis of data from three previous qualitative studies examining the experience of women with disabilities. While the focus of their study was specifically examining maltreatment in relation to health professionals, and the sample was adult women with a variety of physical disabilities, the findings were incredibly similar to those of the current study. Of the four major themes reported by Hassouneh-Phillips et al., three are present in the current study: Taking over, Discounting, and Objectifying. Taking over was when health professionals made decisions for the women; Discounting was when the women’s expertise was ignored, and Objectifying was when the women perceived treatment that demonstrated they were merely disease entities or objects to the health care providers, rather than individuals. All three of these themes were evident in the experience of adolescents with PNDs. Taking over and Discounting reflected how the adolescents experienced having their expertise disrespected in Small Decisions. Objectifying was most evident when Adolescent 4 shared the example of nurses turning him and physically involving him, but not involving him socially or psychologically or in any way connecting with him. Similarly, Bricher and Darbyshire (2004), in a study that examined the experiences of children and adolescents (8-20 years) with disabilities in relation to surgeries and treatment options, reported that some of the
older participants expressed frustration with health professionals who did not acknowledge their expertise or listen to their suggestions. All of the complaints regarding not being acknowledged or listened to in both of these studies were related to decisions that adolescents in this current study termed Small.

Jurisdiction With Big Decisions

In the current study, adolescents' perception of their involvement in health decision-making in regards to Big Decisions was typically very positive. All of the adolescents perceived that they were involved to the level that they wanted to be. Although the level of involvement varied, the adolescents never expressed a desire to be more involved. When it came to Big Decisions, the adolescents were included in discussions, provided with information, and spoken to directly. This involvement meant being included, yet it also meant hearing information about negative outcomes, disease progression, and prognosis. In addition, the Big Decisions often had some risk associated with the available choices. So while involvement in Big Decisions meant increased knowledge and awareness of what was occurring to their bodies and a sense of respect because they were being spoken to directly, it also meant receiving information that was not always desired.

As reported in chapter 4, two components of the fear of responsibility were receiving negative information and the risk involved in most of the Big Decisions. It was fear of responsibility that led to adolescents desiring parental involvement (and in one case the parents desiring child involvement), but it may be that fear of responsibility was also what led to perceiving the physician as expert. In some ways, trusting the physician and perceiving that s/he is an expert with all the information might make it easier to
choose a course of action when these are difficult decisions with no obvious correct answer. The adolescents and parents did not need to research or ask for more information; they could trust the physician and choose to follow the physician’s recommendations. Therefore, they would not need to take responsibility themselves.

Stegenga and Ward-Smith (2008) also reported in a pilot project involving adolescents with cancer that the physician was perceived as the expert. The adolescents with cancer also demonstrated a fear of responsibility and expressed their desire to not make the decisions, but to have the physicians who had the most information make the treatment decisions. In another study examining adolescents with a cancer diagnosis, Dunsmore and Quine (1995) reported that the majority of adolescents wanted to be involved in the decisions, but did not want sole responsibility, preferring parental and physician input. Thus, it is clear that the experience of not wanting sole responsibility in relation to Big Decisions is not limited to adolescents with PNDs.

Joint Ownership

The overarching contextual theme throughout the adolescents’ experiences of health decision-making is Joint Ownership, which has five sub-themes: Shared body; Shared decisions; Shared goals; Awareness of impact on parents; and Tensions with normal adolescent development. Adolescents experienced their involvement in health decision-making as part of a family. They spoke about being in a “joint” relationship and having shared aspects with their parents. Further, they expressed the belief that not only they, but also their parents experienced the illness and disability. This sharing of the experience of the disability and illness is also evident in the adult literature, but in a different form. It is not that families, typically adult children and spouses, perceived that
they were experiencing the physical solo events, such as surgeries or hospitalizations, but that the families also experience great distress, worries, and burdens in relation to the event. For example, Juarez, Ferrel, Uman, Podnos, and Wagman (2008) measured various aspects of quality of life in family caregivers of patients undergoing palliative surgery and discovered that family caregivers had disruptions similar to patients in physical, psychological, social, and spiritual dimensions. Thus, these researchers demonstrated that the surgery was “experienced” not only by the patient, but by the family also.

One striking component of the theme Joint Ownership was the adolescents’ use of plural pronouns when discussing personal health related events. Only one study was found that reported a similar phenomenon. When Seiffge-Krenke (1997) interviewed adolescents with juvenile onset (type 1) diabetes and their mothers, they discovered that mothers frequently used plural pronouns when discussing events that typically would be thought of as adolescent solo events. The majority of the plural pronouns were used in relation to health concerns, such as blood sugar levels or diet. Similar to the adolescents with PNDs, the mothers were not aware when they used the pronouns and referred to these incidents as “a slip of the tongue” (Seiffge-Krenke, p. 349). While both mothers and adolescents were interviewed by Seiffge-Krenke, no adolescents were reported to have used plural pronouns. All of the adolescents with diabetes theoretically had the ability to perform the tasks of diabetic care (no physical or cognitive limitations were reported), yet the mothers chose to provide the care and take on the responsibility. Comparatively, the adolescents with PNDs could not perform the tasks with which their parents assisted them. This distinction between required and chosen help is key. The mothers in Seiffge-
Krenke’s study were described as overprotective and potentially limiting the adolescents’ independence. However, none of the adolescents with PNDs described their parents in this way. In fact adolescents typically perceived their parents as assisting with improving their independence. It is important, therefore, to attend to whether or not care is required when exploring Joint Ownership with adolescents with PNDs.

Limitations

Recruitment for this study occurred through one site, the neuromuscular clinic at British Columbia’s Children’s Hospital. While this centre provides ongoing care to the population of interest for all of British Columbia and Yukon, the inclusion of only one site is a limitation, because all of the adolescents’ experiences involve the same institutions (hospital, hospice, and rehabilitative centre) and same health professionals, in particular the specialists (surgeons, neurologists). Adolescents who receive health care at different institutions with different health professionals may have significantly different experiences.

The second limitation in this study is related to sample. While qualitative studies are not focused on sample size, because depth of information and the importance of powerful informants are key, five participants was a fairly small sample size. A larger sample size was desired, however recruitment was very slow and data collection had to cease within a specific timeframe. As mentioned in chapter 3, the slow recruitment may have been due to the passive recruitment requirements. A second limitation with the sample was the lack of ethnic diversity. All of the adolescents described themselves as Caucasian and spoke English as their first language. Unfortunately, no adolescents of other ethnic backgrounds chose to contact the researcher in regards to this study.
A final limitation of this study was the requirement of parental consent for adolescents younger than 19 years of age. The researcher had hoped to interview adolescents with a variety of experiences regarding health decision-making and also suspected that parents influence the experience of decision-making, therefore an exemption from the requirement of parental consent for all participants younger than 19 years of age was requested from the BREB. Unfortunately, this exemption was not approved. Therefore, adolescents 18 years and younger were only able to participate with parental consent. The researcher did not have any adolescents contact her without parental consent, so it is not possible to know if the requirement of consent actually influenced the participation or lack of participation of teens. However, as all parents expressed appreciation for this study and an interest in how to support the adolescent in their family with health decision-making, it is quite possible that the experiences of the adolescents in this study are quite different from the experiences of adolescents who may not have been able to receive parental consent to participate in this study.

Implications and Recommendations

The implications and recommendations from this study are threefold. The first two are for direct care health professionals, and the other is for those involved in planning or assisting with transitioning adolescents to adult care.

The recommendations for health care providers are to (1) acknowledge the adolescent as a person and (2) recognize adolescent expertise. These are the key points that adolescents repeated throughout their experiences of decision-making and similar findings exist in the published literature. The adolescents want to be acknowledged by care providers who speak to them directly, ask them questions, engage them when
performing physical care, and listen to them. The most common complaint or concern in situations specifically related to decision-making was in regards to Small Decisions and how adolescents felt that health care providers demonstrated a lack of respect for their expertise. Adolescents want to be listened to and respected for the knowledge that they have.

When planning for or working with adolescents who are transitioning to adult care, two of the findings in this study are particularly relevant. First, adolescents expressed a fear of responsibility regarding Big Decisions and did not desire to be fully independent in their decision-making. The desire for and the ongoing attendance of parents at clinic appointments, doctors’ offices, and other meetings is important to note. This parental involvement may be wanted by and helpful to adolescents, at least to those with PNDs. While this finding cannot be generalized to state that all adolescents desire parental involvement, it should be recognized that the option of parental attendance needs to be offered to adolescents and each situation should be dealt with individually. Second, the theme of Joint Ownership is very relevant as adolescents are transitioning into adult care. Joint Ownership includes the sharing of decisions with parents, in addition to adolescents basing some decisions upon parental needs. If the involvement of parents is not acknowledged when developing transitional programs or when assisting adolescents in transitioning into adult care, there is the possibility of setting up unrealistic expectations, such as expecting adolescents to be solely responsible for their health even though they may not want to do so.
Future Research

While this study has begun to explore experiences of health decision-making in adolescents with PNDs, it has also raised issues that warrant examination in future research. For example, as parents and health professionals were very important in the adolescents' experiences, it would be beneficial to also examine parental and health professional perspectives regarding health decision-making.

A second area of interest would be to conduct a similar, but larger research study across the various stages of adolescence. Such a study would capture not only developmental changes, but also changes in physical ability and dependence as the PNDs progress. Additionally, further exploration of the theme of Joint Ownership and how it relates to various developmental tasks, in particular identity formation, would bring new knowledge and information that could be used by clinicians to improve quality of care to this population.

Conclusion

As an initial step to increasing understanding of the experience of adolescents with PNDs as they make health decision, this study employed interpretive phenomenology. The main findings in this study were: (1) the categorization of decisions and (2) the theme of Joint Ownership. In regards to the categorizing of decisions, the central concepts were expertise and fear of responsibility. When an adolescent perceived himself an expert, he desired to be heard and allowed to make the decision. When this was not allowed, he felt disrespected and sometimes even objectified. This lack of acknowledging expertise was unfortunately very prevalent in the adolescents' stories, with very few positive examples provided regarding health professionals. This highlights
the need for health professionals to listen to the adolescents and acknowledge the information and expertise they have. The concept of fear of responsibility is a finding that suggests that expecting adolescents to be fully responsible for their own health is unrealistic and not desired by the adolescents. This highlights the needs for health professionals to include parents on a case-by-case basis, based upon the desires of the adolescent.

In regards to the contextual theme Joint Ownership, this finding adds new insight into the experience of losing physical abilities and becoming increasingly dependant upon parents while in the developmental stage of adolescence. The relevance of this theme to decision-making is threefold. First, this is what the adolescents are experiencing as they are involved in decision-making. Second, it provides insight into how decisions are shared with parents, how they are made with awareness of parental impact, and how parents seem to mitigate the tensions by respecting normal adolescent development. Finally, this theme highlights the complex nature of these parent-adolescent relationships and the need to consider the level of parental involvement desired by the adolescent when involved in health decision-making.

In conclusion, adolescents shared many negative examples regarding their experiences with health professionals. Hopefully, these negative examples can be used to provide insight and improve clinical practice merely by “listening” directly to the adolescents as they say, “Respect me,” “Talk directly to me,” and, “I am unique.”
References


Appendix A Recruitment Materials

The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease

Principal Investigator: Dr. Alison Phinney, UBC School of Nursing

Co-Investigators: Mrs. Sarah Derman, RN, BSN, MSN student
Dr. Rose Steele, York University School of Nursing
Dr. Susan Dahinten, UBC School of Nursing

This study will form the thesis research for Sarah Derman, under the supervision of Dr. Phinney.

Dear Sir or Madam:

Please find enclosed information about a study that may be of interest to you or an adolescent in your family.

This study, "The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease" is being conducted out of UBC and the nurse researcher is recruiting through the neuromuscular clinic at BC Children’s Hospital. The focus is on exploring how adolescents, age 16-19 years, with a neuromuscular disease are involved with medical decision-making. All participation in this study will be kept completely confidential and your decision to participate or not in the study will in no way affect your care at the neuromuscular clinic.

Please find more information about this study in the enclosed package, including:

- An information sheet
- A consent form for parents/guardians
- A consent form for adolescents age 19 years
- An assent form for adolescents younger than 19 years.

The consent/assent forms are included so you may have a chance to review them, however these do not need to be signed at this time. If you choose to participate in the study, the consent and assent forms will be reviewed the first time we meet.

If you have any questions or wish to participate in this research, please contact Sarah Derman at [email protected] or [email protected]

Thank You,

Sarah Derman, RN, BSN
Information Sheet

The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease

Principal Investigator: Dr. Alison Phinney, UBC School of Nursing

Co-Investigators: Mrs. Sarah Derman, RN, BSN, MSN student
Dr. Rose Steele, York University School of Nursing
Dr. Susan Dahinteri, UBC School of Nursing

This study is being conducted as part of the requirements of Mrs. Derman’s Masters of Nursing degree at the University of British Columbia

What is the purpose of the research?
The purpose of this study is to understand what it is like to be involved in personal medical decision-making while having a progressive neuromuscular disease (PND). As you are transitioning or approaching the transition to adulthood and adult health care, we would like to learn more about your experience of medical decision-making as an adolescent. It is expected that this study will add new information and understanding that will guide health care professionals’ practice as they support adolescents with PNDs transitioning onto adult health services.

Who can participate?
We are inviting adolescents who have a progressive neuromuscular disease (such as muscular dystrophy, spinal muscle atrophy, or Charcot-Marie-Tooth disease) and are between the ages of 16 and 19 years of age.

What is required to participate?
Mrs. Derman will meet with you two separate times for about an hour each time. During this time, she will talk about your experiences with medical decisions. These interviews will be audio taped. The preference would be to meet in person (locations can be arranged for anywhere in the Lower Mainland or possibly Vancouver Island), however telephone interviews may also be a possibility.

Remuneration/Compensation:
As a small token to say thank you for participating in this study, the adolescent will receive $10 gift card at the beginning of the 1st interview.

How do I participate?
If an adolescent in your family would like to participate in this research please contact Sarah [contact information redacted] or [contact information redacted]
Assent Form
(Adolescent younger than 19 years)

The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease

Principal Investigator: Dr. Alison Phinney, UBC School of Nursing

Co-Investigators: Mrs. Sarah Derman, RN, BSN, MSN student
Dr. Rose Steele, York University School of Nursing
Dr. Susan Dahinten, UBC School of Nursing

This study will form the thesis research for Sarah Derman, under the supervision of Dr. Phinney.

Purpose:
The purpose of this study is to understand what it is like to be involved in personal medical decision-making while having a progressive neuromuscular disease (PNDs). As you are transitioning or approaching the transition to adulthood and adult health care, we would like to learn more about your experience of medical decision-making as an adolescent. It is hoped that this will add new information and understanding that will guide health care professionals' practice as they support adolescents with PNDs transitioning onto adult health services.

Study Procedures:
You will be asked to participate in two interviews that will last approximately one hour each. During the interviews you will be asked questions about your personal experiences about making decisions or being involved in decisions regarding your health care. The interviews will be conducted by a trained, sensitive interviewer and will take place at a location convenient to you. Your interview will be audio-taped and transcribed for research purposes only.

Risks:
This research project deals with a topics that some may find sensitive. The interviewer will monitor your distress level and will stop the interviewing process if you become upset. In addition the interviewer will then ensure that you are aware of your right not to answer any questions asked and your right to terminate the interview at any time. If you wish further support around subjects discussed, the interviewer will refer you to the social worker for B.C. Children's neuromuscular clinic.

Confidentiality:
Your identity will be kept strictly confidential. All identifying information will be removed and stored separately from the data. All documents and audio tapes will be identified only by code number and the information will be retained in a secured information system and locked filing cabinet. All documents that are kept on a computer will be password protected. Identifying information will not be emailed to anyone at any time. You will not be identified by name in any reports of the completed study.

Remuneration/Compensation:
For participating in this study you will receive $10 gift card at the beginning of the interview. If you withdraw from the study after this point, you will still receive the gift card.

**Contact for information about the study:**
If you have any questions or desire further information with respect to this study, you may contact Sarah Derman at [contact information] or [contact information].

**Contact for concerns about the rights of research subjects:**
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598.

**Assent:**
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time.

Your signature below indicates that you have received a copy of this assent form for your own records.

Your signature indicates that you agree to participate in this study.

_________________________________________________________________________

Participant Signature                  Date

_________________________________________________________________________

Printed Name of Participant Signing Above
Consent Form
(Adolescent age 19 years)

The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease

Principal Investigator: Dr. Alison Phinney, UBC School of Nursing

Co-Investigators: Mrs. Sarah Derman, RN, BSN, MSN student
Dr. Rose Steele, York University School of Nursing
Dr. Susan Dahinten, UBC School of Nursing

This study will form the thesis research for Sarah Derman, under the supervision of Dr. Phinney.

Purpose:
The purpose of this study is to understand what it is like to be involved in personal medical decision-making while having a progressive neuromuscular disease (PNDs). As you are transitioning or approaching the transition to adulthood and adult health care, we would like to learn more about your experience of medical decision-making as an adolescent. It is hoped that this will add new information and understanding that will guide health care professionals' practice as they support adolescents with PNDs transitioning onto adult health services.

Study Procedures:
You will be asked to participate in two interviews that will last approximately one hour each. During the interviews you will be asked questions about your personal experiences about making decisions or being involved in decisions regarding your health care. The interviews will be conducted by a trained, sensitive interviewer and will take place at a location convenient to you. Your interview will be audio-taped and transcribed for research purposes only.

Risks:
This research project deals with topics that some may find sensitive. The interviewer will monitor your distress level and will stop the interviewing process if you become upset. In addition the interviewer will then ensure that you are aware of your right not to answer any questions asked and your right to terminate the interview at any time. If you wish further support around subjects discussed, the interviewer will refer you to the social worker for B.C. Children's neuromuscular clinic.

Confidentiality:
Your identity will be kept strictly confidential. All identifying information will be removed and stored separately from the data. All documents and audio tapes will be identified only by code number and the information will be retained in a secured information system and locked filing cabinet. All documents that are kept on a computer will be password protected. Identifying information will not be emailed to anyone at any time. You will not be identified by name in any reports of the completed study.

Remuneration/Compensation:
For participating in this study you will receive $10 gift card at the beginning of the interview. If you withdraw from the study after this point, you will still receive the gift card.

**Contact for information about the study:**
If you have any questions or desire further information with respect to this study, you may contact Sarah Derman at [redacted] or [redacted].

**Contact for concerns about the rights of research subjects:**
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598.

**Consent:**
Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

__________________________________________  _______________________
Participant Signature                      Date

__________________________________________
Printed Name of Participant Signing Above
The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease

Principal Investigator: Dr. Alison Phinney, UBC School of Nursing

Co-Investigators: Mrs. Sarah Derman, RN, BSN, MSN student
Dr. Rose Steele, York University School of Nursing
Dr. Susan Dahinten, UBC School of Nursing

This study will form the thesis research for Sarah Derman, under the supervision of Dr. Phinney.

Purpose:
The purpose of this study is to understand what it is like for adolescents, who have a progressive neuromuscular disease (PNDs), to be involved in medical decision-making. As this population of adolescents is transitioning into adulthood and the adult health care system, little is known regarding their involvement in their medical decision-making and their experiences of this. It is expected that this study will add new information and understanding that will guide health care professionals' practice as they facilitate decisions and support adolescents with PNDs.

Study Procedures:
A researcher will meet with the adolescent on two occasions for about one hour each time. During this time the adolescent will be asked about his or her current, past and predicted future involvement in medical decision-making. The adolescent will be asked to reflect back over the years and answer questions regarding any changes in involvement, health care professional involvement and parental/guardian involvement. All of the interviews will be audio taped. The preference would be to meet in person (locations can be arranged for anywhere in the Lower Mainland or possibly Vancouver Island), however telephone interviews may also be a possibility.

Risks:
This research project deals with topics that some may find sensitive. The interviewer will monitor the adolescent’s distress level and will stop the interviewing process if he/she becomes upset. In addition, the interviewer will then ensure that the adolescent is aware of his/her right not to answer any questions asked and his/her right to terminate the interview at any time. If he/she should wish further support around subjects discussed, the interviewer will refer him/her to the social worker for B.C. Children's neuromuscular clinic.

Confidentiality:
The adolescent’s identity will be kept strictly confidential. All identifying information will be removed and stored separately from the data. All documents and audiotapes will be identified only by code number and the information will be retained in a secured information system and
locked filing cabinet. All documents that are kept on a computer will be password protected. Identifying information will not be emailed to or shared with anyone at any time.

**Remuneration/Compensation:**
For participating in this study, the adolescent will receive a $10 gift card at the beginning of the interview. If he/she withdraws from the study after this point, he/she will still receive the gift card.

**Contact for information about the study:**
If you have any questions or desire further information with respect to this study, you may contact Sarah Derman at [contact information] or [contact information].

**Contact for concerns about the rights of research subjects:**
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (604) 822-8598.

**Consent:**
Your consent to allow the adolescent in your family to participate in this study is voluntary. You may rescind your consent or withdraw the adolescent from the study at any time.

Your signature below indicates that you have received a copy of this consent form for your own records.

I consent/I do not consent (circle one) to my child's participation in this study.

__________________________________________  ______________________________________
Parent (Guardian) Signature                     Date

__________________________________________
Printed Name of the Parent (Guardian) Signing Above

__________________________________________
Name of Adolescent Participant
Are you between the ages of 16 and 19 years with a Neuromuscular Disease?

If so, we require adolescents who are willing to participate in a study about the experiences of making medical decisions.

The study involves a researcher meeting with you twice (for about an hour each time) to talk with you and ask questions about your experiences with medical decisions.

For more information, or if you are interested in participating in this study, please contact Sarah Derman:
Appendix B

Interview Guide

The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease

The interview process:

Adolescent informants will be asked to tell the researcher about their experiences with medical decision making. Both current and retrospective information will be sought. A conversational tone will be used throughout the interviews. As the interview progresses, questions will be asked that reflect back the interviewee’s own words. The interviews will begin with open-ended prompts. The following guide will be used to remind the interviewer and help focus the interview, however the questions will not necessarily be asked in order and additional questions/ prompts will be added as necessary. Additionally, in some of the interviews not all of the questions will be asked, but all of the same topic areas will be covered.

For the second interview I will use the same conversational tone, and use the interviewee’s own words in the wording of the questions when possible. The second interview will begin with any questions that we may not have had time to address during the first interview. For example, if during the first interview, the adolescent had much to say about current and past decision making, and the interview had already lasted 1 hour, I would not ask about the adolescent’s views/hopes on future decision making. Therefore at the second interview I would include this area that the first had missed. In addition to any topic area that was not covered during the first interview, the second interview will also include questions to clarify any area I may be unclear about, or if there are specific areas I wish to have expanded. For examples of possible second interview questions see below.

Interview Guide – INTERVIEW ONE

Introduction:
Thank you for agreeing to participate in this interview. Please remember that there are no right or wrong answers to the questions. What I am most interested in learning about is your viewpoint or perspectives about the topics. I want to hear about your experiences, your stories about the topics. It is important you know that you can stop the interview at any time or choose not to answer the questions, for any reason. Also, I will be tape recording the interview. Your name and personal information will not be included on the tape. Do you have any questions before we begin the interview?

Questions:
Tell me about being diagnosed with ___________ (the PND).

Probes: How old were you? Who was with you when you were told? Where were you told? What was this experience like for you?

When you were diagnosed with ___________ (the PND), were there any decisions that had to be made?
Probe: Any choices to be made regarding treatment (such as medications, physio, surgery)?
Follow up: Who made these decisions? How were these decisions made? Who decided? What was your involvement/role? Is this what you would have wanted to have happen?

Where do you currently receive most of your health care?
Probes: hospital? Dr.’s office? Canuck Place? Neuromuscular clinic? Follow up: How often do you attend this place?

Describe a typical visit at _________ (identified health care place or places)
Probes: can you think of an atypical visit, how was this visit different? What about the last visit? What happened? What do you usually do? What kind of things might you say? Can you give me an example?

When you attend _______ (neuromuscular clinic/ and or other identified health care place) who usually attends with you?
Probes: Who do you meet with? Has this changed over the years? Who does most of the talking? What kind of things are discussed - - can you give me an example

Has the visit and what you do/ who goes with you changed since you were younger?
Follow up: Think back to when you were younger and attended a clinic. Who went with you? Is that different from now?

When you were diagnosed with _______ (the PND), you talked about making a decision about _______. Have there been any recent decisions about your treatment?
Probes: decisions about taking medication? To have or not have surgery? To use or not use bipap? Trach/vent? Etc. Follow up: How have these decisions been made? Who is involved in the decision making? Can you give me an example of a time you made a decision about your health care?

Think back to a recent time when you had to make a medical decision. (Prompt with specifics – i.e. deflazacort/ or have surgery – rod surgery, heel cord release), how did it get decided what would happen?
Follow up: Who was involved in the discussion about _______? What was your role (what did you do)? What did you want to have happen? What happened?

Are there any decisions you might need to make in the future? Are there any medical treatments you might need in the future?
Prompts: heel cord release/ rod surgery/ trach/ bipap Follow up: How will you make these decisions? Who will be involved in the decision-making?

Who usually makes the decisions regarding medical situations (i.e. choosing to take a medicine, have surgery, to visit a specialist?
Follow up: Can you give me an example? What is each person’s involvement? What are each person’s typical roles? Who is most involved?

How are you involved in medical decisions?
Follow up: How does this look like? If you had to rate your involvement in percentage – 0 not at all, 100% meaning fully involved how involved are you?

What has happened when there is a disagreement when making a decision about the medical care?
Follow up: How are disagreements settled? Can you think of a specific example?
Who makes the final decision? How much input do you have in the final decision 0-100%? What about disagreements between yourself and your parents? Your parents and the doctors or other health professionals? Yourself and the doctors or other health professionals?

Think back to when you were younger. Has there been a change in how decisions are made?
Follow up: Has your involvement in decision-making changed? Can you give an example of decision making when you were younger and now?

Has there been any change in how health professionals relate to you or involve / not involve you?
Follow up: Can you give me an example? Also encourage teen to talk about ‘over the years’ and not just a specific point in time

Has there been any change in who is involved in the decision-making?
Follow up: What about your parents? How involved were they? Compare that to now?

Can you tell me about a time when you felt involved and listened to during a medical health meeting?
Follow up: A time when you did not feel involved? Can you tell me about the specific situation (example) How did you feel? What made the difference? Is this how you want it to be?

How do you think your involvement in decision making will differ in the future? Follow up: What about your parent’s / doctor’s involvement – how will their involvement differ? What are your hopes about your involvement in future medical decisions?

Is there anything else you wish to tell me about your experience with decision-making?
Prompt: anything I missed, or that you would like to tell me more about?

Conclusion:

Thank you for meeting with me and telling me about your experiences. I have found this time very helpful and really appreciate you being so open with me. Over the next few days I will listen to the tape, and review my notes to see if I have any questions. I will contact you sometime in the next two weeks, and we can arrange to meet again so I can make sure I got all the information correct and ask some more questions. If you have any questions at all, please do not hesitate to contact me (ensure teen has contact info on consent form). Thank you for all your time, and we will talk again in a couple of weeks.
Interview Guide – INTERVIEW TWO

Introduction:
Thank you for agreeing to meet with me again. The last time we met was very helpful, and you have provided me with lots of great information. I want to remind you that your involvement is completely voluntary. If you want to stop the interview or wish to not answer any question, please let me know. Also, I will tape record this interview, the same as last time. Do you have any questions/comments before we start?

Questions or areas that were not discussed in the last interview: (These questions would be specific to each interview, and I would develop them prior to each interview)

For example: “During the last talk, we talked about how you were involved in making medical decisions when you were younger, and how you are involved now, --- I am curious how do you see yourself involved in the future?
Probes: How would you like to be involved?

Questions to ensure clarity: (These questions would also need to be developed specifically for each interview)

For example: When we met last time, you mentioned about “they” --- “They always make the decisions.... They are always deciding for me.... They are always getting the final stay.” Could you clarify for me who they are?
For example: Last time we met, you talked about an upcoming surgery, and I realized later, that I didn’t find out what surgery is planned. Could you tell me a bit more about this surgery and how you decided to have this surgery?

Questions to get adolescent input on beginning data analysis: (These specific questions would need to be generated once analysis has started)

For example: After talking with you and a couple other adolescents, I noticed that you talked about feeling left out of decision-making. Would you consider that this “feeling left out” is an accurate way of describing your decision making experience?
Probes: Tell me more about that. What feeling would you use to describe your experience?

Questions to gain further adolescent input:

After the last time we met, were there any questions I asked that surprised you? Why?

Is there anything that you think I should have asked but didn’t?

Is there anything else that you wish to tell me about your experience with medical decision making?
Conclusion:

Thank you very much for all your time and help. Would you like me to contact you in the near future to provide you with an update about this study? I can provide you with a transcript of your interview if you would like, or a brief written summary of the themes from the interviews.

Please remember I will not be using your name or any identifying information about you in any material I present. If you have any further questions or concerns, please do not hesitate to contact me.

Thanks.
Appendix C
Demographic Questionnaire

The Experience of Medical Decision Making for Adolescents with a Progressive Neuromuscular Disease

Participant ID #___________

1) Please provide us with the following information about yourself:

Date of Birth: _____________

Your Gender: _______________

Your Diagnosis _____________________________________________

Your Ethnicity: (please tick one)

___ Arab
___ Black
___ Chinese
___ Filipino
___ Japanese
___ Korean
___ Latin American
___ Native
___ South Asian
___ Southeast Asian
___ West Asian
___ White
___ Other (specify): _______________________

Genogram
2) Please provide us with information about health professionals that are currently involved in your health care:

<table>
<thead>
<tr>
<th>Name of facility/provider</th>
<th>Reason for Involvement</th>
<th>Duration of Involvement</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix D Behavioural Ethics Approval Certificates
## Certificate of Approval

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR</th>
<th>DEPARTMENT</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selby, Kathryn</td>
<td>Pediatrics</td>
<td>CW07-0132 / H06-04067</td>
</tr>
</tbody>
</table>

**CO-INVESTIGATORS:**
Derman, Sarah;

**C&W DEPARTMENTS, PATIENT BASED PROGRAMS AND ADMINISTRATIVE JURISDICTIONS IMPACTED BY THIS STUDY:**
Acute and Critical Care;

**SPONSORING AGENCIES:**
Unfunded Research;

**TITLE**
The Experience of Medical Decision-Making for Adolescents with a Progressive Neuromuscular Disease

**APPROVAL DATE:**
Aug 16 2007

**TERMS OF APPROVAL:**

**CERTIFICATION:**
The protocol for the above-named project has been reviewed by the Research Review Committee and has been found to be appropriate with respect to ethics, methodology, patient impact and availability of C&W resources.

---

Approval of the C&W Research Review Committee
Dr. M. Levine, Chair
Dr. M. Bond, Associate Chair

This Certificate of Approval is valid for the above term provided there is no change in the research protocol.
Certificate of Approval
-- RENEWAL --

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR</th>
<th>DEPARTMENT</th>
<th>NUMBER</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selby, Kathryn</td>
<td>Pediatrics</td>
<td>CW07-0132 / H06-04067</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CO-INVESTIGATORS:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Derman, Sarah;</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C&amp;W DEPARTMENTS, PATIENT BASED PROGRAMS AND ADMINISTRATIVE JURISDICTIONS IMPACTED BY THIS STUDY:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acute and Critical Care;</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SPONSORING AGENCIES:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unfunded Research;</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TITLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Experience of Medical Decision-Making for Adolescents with a Progressive Neuromuscular Disease</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TERMS OF RENEWAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jul 04 2008 - Jun 29 2009</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CERTIFICATION:</th>
</tr>
</thead>
<tbody>
<tr>
<td>The protocol for the above-named project has been reviewed by the Research Review Committee and has been found to be appropriate with respect to ethics, methodology, patient impact and availability of C&amp;W resources</td>
</tr>
</tbody>
</table>

Approval of the C&W Research Review Committee
Dr. M. Levine, Chair
Dr. M. Bond, Associate Chair
This Certificate of Approval is valid for the above term provided there is no change in the research protocol
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.
CERTIFICATE OF APPROVAL - MINIMAL RISK RENEWAL

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR:</th>
<th>DEPARTMENT:</th>
<th>UBC BREB NUMBER:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alison Phinney</td>
<td>UBC/Applied Science/Nursing</td>
<td>H06-04067</td>
</tr>
</tbody>
</table>

**INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:**

<table>
<thead>
<tr>
<th>Institution</th>
<th>Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's and Women's Health Centre of BC (incl. Sunny Hill)</td>
<td>Children's and Women's Health Centre of BC (incl. Sunny Hill)</td>
</tr>
</tbody>
</table>

Other locations where the research will be conducted:
The interviews will be conducted in either the subjects' homes, or at the Children's and Women's Health Centre.

**CO-INVESTIGATOR(S):**

Sarah Derman

**SPONSORING AGENCIES:**

N/A

**PROJECT TITLE:**

The Experience of Medical Decision-Making for Adolescents with a Progressive Neuromuscular Disease

**EXPIRY DATE OF THIS APPROVAL:** June 30, 2009

**APPROVAL DATE:** June 30, 2008

The Annual Renewal for Study have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:

- Dr. M. Judith Lynam, Chair
- Dr. Ken Craig, Chair
- Dr. Jim Rupert, Associate Chair
- Dr. Laurie Ford, Associate Chair
- Dr. Daniel Salhani, Associate Chair
- Dr. Anita Ho, Associate Chair