SEE MY FUTURE:
FUTURE THINKING OF ADOLESCENTS WITH
A PROGRESSIVE LIFE-THREATENING NEURODEGENERATIVE ILLNESS

by

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Abstract

The construction of meaningful future self-representations is an important part of identity development. For adolescents living with a progressive life-threatening neurodegenerative illness, the projection of self into the future requires the movement into the unknown and uncertain realm of an illness trajectory. The purpose of this study was to examine how adolescents who are living with a progressive life-threatening neurodegenerative illness construct meaningful future self-representations. A narrative approach was utilized as the method of inquiry. Ten adolescents between the ages of 12 and 20 who had been diagnosed with a progressive life-threatening neurodegenerative illness participated in a semi-structured narrative interview. Within the interviews three lines of inquiry were followed, which explored future thinking, possible selves, and continuity in the stories of the selves over time. Data analysis occurred across four readings of the narrative transcripts. The analysis included a stepping-in and stepping-back process, allowing for individual stories to remain contextualized and for collective themes to emerge across the narratives. Major findings confirm future thinking as a contextually based activity, a construction of a range of possible selves both with and without the illness, and an ability to oscillate between these two versions of future selves. As well, the adolescents demonstrated personal continuity in the selves of the past, present, and the future. As an overarching theme, future thinking emerges as a required activity for reasons of coping, personhood, and decision-making. This research makes contributions to developmental science as well as pediatric palliative care as it extends current literature pertaining to future thinking and possible selves, thereby adding to the conceptual and theoretical knowledge base. As well, the findings highlight the importance of developing a healthcare practice that is responsive to the developmental need to create a future self and to explore all aspects of what is possible, as well as impossible.
Preface

Ethics approval for this research study was received from the University of British Columbia Behavioural Research Ethics Board (BREB): BREB number: H09-01518.
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Dedication

To Jane and Halle—find something that inspires and challenges you. Jump over the hurdles, duck and cover when you need to, and always know that “digging deep” is a part of life. This is for you.
Chapter 1. Introduction

The adolescent period of the life span is marked by substantial physical, social, emotional and psychological changes (Lerner & Steinberg, 2004). The increase in opportunities for socialization coincides with the changes in thought patterns, thereby placing the adolescent in a unique circumstance of change and growth (Eccles, 2004; Nurmi, 2004). As the adolescent navigates through this novel and unfamiliar territory, the questions of “who am I?” (Erikson, 1968) and “where am I going?” (Nurmi, 1991) become more prominent. From a developmental perspective, the adolescent, armed with more advanced reasoning skills and cognitive capacities, confronts an expanded opportunity space for exploration of the relationship of self to others across various settings and with the added dimension of an orientation to the future (Nurmi, 2004).

Importantly, not all developmental trajectories are equal. An inclination toward the future has been established as a common occurrence during adolescence (Nurmi, 1991; 2004; Poole & Cooney, 1987); however, what is unknown is how the process of future thinking transpires in adolescents who are navigating this phase of the life course outside of the expected pattern. What if the signposts and maps available do not account for a detour from the typical adolescent developmental trajectory? How do adolescents who have been charged with the task of balancing growth amidst loss manage the future thinking required for identity development? This dissertation examines future thinking under the special circumstance of illness, an area that has thus far remained unexamined in the scientific and practice literature. As a way of entering into this study, what follows is the amalgamation of several clinical anecdotes into a single case vignette.

It Starts With a Boy

Josh is 16. He attends a school that is a ten-minute drive from his home. He likes to sleep, eat, and play video games. He plays on a soccer team that has a great winning record this season and is on track to compete at the national competition. His body is changing and he has become more interested in the clothes he wears and the image he is putting out to the world. He spends a lot of time dreaming about big things like scholarships, graduation, and the freedom that comes with age. School is okay but it is a struggle to keep up and he worries
about graduating on time. He is really preoccupied with the girl down the street who waves at him but he doesn’t even know her name. Recently, it feels like it takes a lot of energy to get through each day. He wishes life wasn’t so complicated.

But his life is complicated. The movement in his body is limited to the neck up and two of the fingers on his right hand. His primary mode of transportation is a power wheelchair. It takes him 45 minutes to coordinate the transportation for the ten-minute drive to school. He has to ask for help to go to the bathroom. His caregivers choose his clothes—even the color of his socks. Last night he received an email from one of his teammates on the wheelchair soccer team and their leading scorer is in the hospital with pneumonia. He is all too familiar with what pneumonia can mean. All aspects of his care are at the will of others. Privacy is non-existent and the changes that have occurred in his body make it awkward when his parents are helping him with his daily personal care. He wishes this life wasn’t so complicated.

Unquestionably, the experience of living with a progressive life-threatening neurodegenerative illness presents a significant challenge. Parachuting the illness experience into adolescence, a life phase typically associated with growth and development, exacerbates these difficulties. The rendering above reveals the nuances of a daily struggle when a disease has taken hold of a growing body. Josh has been diagnosed with a progressive life-threatening neurodegenerative illness that affects approximately one in 3,500 live-born males (Emery, 1991). The illness trajectory involves diagnosis in childhood after observations of muscular weakness (Reisman, 2003; Weidner, 2003), and somewhere between the ages of three and five, the pattern of physical development starts to diverge from peers. The degenerative nature of this illness translates into a cascade of losses; the disease is fatal, and although presented with periods of plateaus, there is an inevitable decline in functioning (Steele, 2000). Typically, those diagnosed have transitioned into a wheelchair between the ages of seven and twelve (McMillan, Campbell, & Mah, 2010).

The progression of this disorder results in an increase in dependence on parents and caregivers at precisely the age peers are gaining independence (Stevens, Dunsmore, Bennett & Young, 2009). Yet the desire for autonomy mirrors that of a healthy adolescent (Knapp, Quinn, Murphy, Brown, & Madden, 2010). Oftentimes profoundly affected by the loss of peer interaction resulting from the complications of illness (Knapp et al., 2010), and by
physical limitations causing further removal from opportunities for social interaction, the accompanying social withdrawal (Bushby et al, 2010a) potentially leads to an increased susceptibility to depression (Weidner, 2005). The emerging sexuality of the adolescent also parallels closely that of their healthy peers (Knapp et al., 2010), and as has been established through observations in clinical practice with this population, the drive and desire for romantic relationships exists.

Recognized both intuitively as well as through the scientific examination of patterns of time use during adolescence, as one progresses in age from childhood to adolescence there is a gradual pull away from time spent with family, and a shift toward activities outside of the home such as peer relationships and school involvement (Larson & Richards, 1991; Larson, Richards, Monetar, Holmbeck, & Duckett, 1996). Adolescence is typically cited as the period of time when a prominent shift in the use of time is noted with a wider range of opportunities available through an expansion of the social world (Shanahan & Flaherty, 2001). Indicating a deeper significance to this shift, Shanahan and Flaherty (2001) describe patterns of time use as “tangible representations of individual identity and the meaning of age groups in the life course” (p. 385). As well, the parental promotion of autonomy is widely recognized and accepted as a central task for parents of adolescents (Manzi, Regalia, Pelucchi & Fincham, 2011). With adolescents’ access to the new freedoms granted by parents (Barker & Galambos, 2005; Feldman & Quatman, 1988), the high school years in particular are characterized by a continuing decline in the amount of family time. Further to this, a study conducted by Barker and Galambos (2005) suggests that when adolescents think about growing up and becoming adults, the implicit theories of maturity that include living independently, autonomous decision-making, and financial independence are used as markers of maturity to inform their own expectations of the transition to adulthood.

Importantly, the variables associated with the increased time spent outside of the home that include having a car, employment, and permission from parents to extend time away from home (Larson et al., 1996) starkly contrast the experience of the adolescent introduced in the opening vignette. Caught in a contradiction, adolescents living with a progressive neurodegenerative illness have difficulty venturing into this new arena of independence as disease progression prevents them from acquiring a driver’s license, landing a part-time job, and participating freely in activities outside of the home.
As a less than familiar path, a progressive disease interrupts the anticipated transition through the developmental phases of a life course. More specifically, for adolescents living with a progressive life-threatening neurodegenerative illness, the significant physical losses run parallel to what would otherwise be an anticipated time of launching into the new freedoms commonly associated with adolescence. Currently, little is known of how the progressive nature of the illness intertwines with the theories of adolescent development that are often held at the forefront during this life phase. As the processes of development and disease progression collide, a space is created for a new dimension of healthcare practice.

A balancing act

What does living with a progressive life-threatening neurodegenerative illness entail? For most people it is difficult to imagine adolescent development amidst life-threatening illness. Several tensions are at play during this experience. As the social worker in a pediatric hospice I first noticed the tension from a practice perspective as concerns from healthcare professionals began to emerge during interdisciplinary rounds. How do healthcare professionals respond to the teen who expresses a desire to attend a high school party? Is it appropriate to provide transportation to and from an appointment for body piercing or a tattoo? How might a practice of care sensitively handle the emerging sexuality of the adolescent? In what came to known to our healthcare team as a need to “balance polarities” that are inherent in pediatric palliative care (Stephanson, Nicholson, & Fletcher Johnston, 2006), over time it became clear that what we were struggling with was the delicate balancing act of witnessing growth amidst loss. By virtue of our role in the care of these adolescents living with a progressive life-threatening illness, we had been issued a reluctant invitation by the adolescents into the processes of development that would normally occur in private or with peers (Larson et al., 1996). It became increasingly apparent that as the adolescents in the program began to develop in a typical pattern of wanting independence and autonomy, the practice of care needed to respond.

Recognized across clinical settings and within the existing medical literature, the care of the developing adolescent within the context of pediatric palliative care presents both a challenge and an opportunity (Knapp et al., 2010). Further to this, the advances in medicine foretell that the lives of a growing number of adolescents with progressive illness will extend
over longer periods of time (Blum, 1992; Boice, 1998; Eagle, Baudouin, Chandler, Giddings, Bullock, & Bushby, 2002; Gravelle, 1997). The interventions that aim to prolong life consequently require the family and the adolescent to face an increasingly severe burden of disease (Birnkrant & Noritz, 2008). With the anticipation of a growing number of adolescents living with a progressive life-threatening neurodegenerative illness, and with an increase in the complexity of care associated with the advances in medicine, ascertaining how this population “fits” within a pediatric infrastructure needed to be established. The challenge healthcare providers face is determining how to respond to the developmental process within the constraints of a progressively weakening body. Ultimately, they face the paradox of promoting independence in the context of an increasingly dependent adolescent.

My curiosity regarding future thinking emerged slowly from the clinical work with the research population wherein transition planning required an engagement in conversations about the future. Despite the recognition that a degree of future planning was necessary, I noted discomfort among healthcare practitioners and parents when the conversations moved off the course and into aspirations and goals that appeared to stretch beyond what could be expected. Oftentimes I felt challenged from various directions by an apparent reluctance to assign value to ventures into the future of these adolescents. Concerns from stakeholders ranged from a belief that these aspirations are merely a function of denial, and that perhaps the role of healthcare providers should be to provide more “information” about disease progression, to a relegation of these thoughts as simply wishful thinking. Regrettably, I recall one such family team meeting that was driven by an agenda to help the adolescent “understand” the inevitable progression of illness:

Jeremy sits in the circle alongside his parents, a grandmother, and four members of his healthcare team. The “clinic” asked for a consult with the team as it appeared as though Jeremy didn’t “understand” the severity of his disease. Despite the provision of an accurate and detailed rendering of the progressive and irreversible nature of his muscle weakening, Jeremy talked about his plan to keep “getting stronger” by going to the gym and lifting weights. From his wheelchair he makes the motion of a bicep curl, his arm moving slowly and his body swaying to the side and willing the arm upright. As he does this he smiles broadly and his grandmother cheers him on. He
flexes both his arms, looking directly at his grandma who sees him exactly as he needs her to. The rest of us sit watching, unsure of what to say next.

Are excursions into the future like Jeremy’s a practice of wishful thinking, denial, or a function of coping? Importantly, in the absence of scientific evidence, all explanations are plausible, and one is left to hypothesize about the occurrence of future projections. What is the value of future thinking when the future holds little promise of stability? Currently the anecdotes from practice stand in isolation from empirical evidence. A glimpse into the occurrence of future thinking has swung open the door to a new conceptual space that requires close examination.

The Research Purpose and Organization of the Dissertation

The overall purpose of this dissertation is to examine the future thinking activities of adolescents who are living at the intersection of disease and development. This first chapter was intended to provide an overview of the identified research problem. In chapter two, I start by reviewing the literature on the three concepts that are central to this research study: identity, future thinking and possible selves. Extending from these concepts I present the features of a progressive life-threatening neurodegenerative illness that factor most prominently into the processes of adolescent development. Next, I explore how the illness trajectory intersects with the anticipated developmental process and in doing so I look to the research that has examined adolescent development and chronic illness. The literature review concludes with the identification of the research questions.

In the third chapter, I review the selected analytical approach and offer a detailed description of the entire research process. The findings of this study are presented across three chapters. In chapter four an overview of the future thinking activities in the research sample is provided; in chapter five the data concerning the relational and contextual factors that influence future thinking is presented; and in chapter six the experience of past, present, and future selves is explored. In chapter seven I present a summary and discussion of the findings, consider the strengths and limitations of the study, identify the implications for practice, and suggest areas for further investigation.
Chapter 2. A Review of the Literature

This study is concerned with the future thinking activities of adolescents living with a progressive life-threatening neurodegenerative illness. Accordingly, the conceptualization requires an awareness of concepts that are broadly associated with the life phase of adolescence, such as identity, future thinking, and possible selves, as well as an understanding of the key features of this specific illness trajectory. Thus, the presentation of the literature begins by drawing upon the adolescent development literature and extends to consider development within a context of both chronic illness and progressive life-threatening neurodegenerative illness. Navigation through these literatures results in the arrival at what is described as the intersection of development and disease, and it is here that momentum builds as the prospective lines of inquiry become known. Substantially rooted within, and extending from, the existing knowledge base that lengthens across various areas of study, the culmination of this chapter is the identification of the three specific research questions that direct this study.

Conceptual Convergence: Identity, Future Thinking and Possible Selves

Identity as the fundamental frame

As one of the features of the self that gains prominence during adolescence, identity serves as a fundamental frame and houses the related constructs of future thinking and possible selves. Accordingly, the conceptual framework for this study assumes that the processes of identity development serves a central function during adolescence, and that the activities of future thinking through a projection of possible selves is an important feature in the construction of identity (Dunkel & Anthis, 2001; Kerpelman & Pittman, 2001; Seginer, 2008). To add another layer of conceptual specificity, this study examines identity through the narrative self. Therefore, this first section is comprised of four parts. In the first part, a conceptual definition of identity is provided followed by a synthesis of the pertinent research considering identity during adolescence with a specific focus on self-continuity and narrative identity. The second and third parts follow in a similar fashion by first providing a conceptual definition of future thinking and possible selves, respectively followed by a
synthesis of existing studies. To conclude, the theoretical relationships between narrative identity, future thinking and possible selves will be discussed.

By definition, identity refers to the self-structures of an individual (Nurmi, 2004). As a synthesis of the past, the present, and the future (Erikson, 1968), identity can be viewed as the way one perceives the ‘self’ across time and space (Baumeister & Muraven, 1996) and serves ultimately as an interpretation of the self (Baumeister, 1986). It is during adolescence that identity becomes especially important (Erikson 1968; McAdams, 1985, 2001). This is predominantly due to the combined effect of a “physiological revolution” (Erikson, 1968, p. 128), cognitive maturation (Inhelder & Piaget, 1958) and sociocultural influences (Erikson, 1968; McAdams, 1993).

An optimal sense of identity prompts a feeling of psychosocial well-being. Erikson (1968) describes the concomitants as “a feeling of being at home in one’s body, a sense of ‘knowing where one is going,’ and an inner assuredness of anticipated recognition from those who count” (p. 165). Identity helps one select from the available choices by recognizing potential based on possible goals, alternative choices, and potential futures (Adams & Marshall, 1996). Identity also furnishes one with a sense of strength and resilience (Baumeister, 1986). For the purpose of this study, identity will refer to a quality of self-understanding, to the way in which the self can be arranged or configured (McAdams, 2001) across time.

As an integrative framework for understanding “self in the world,” the discussion that follows aims to elucidate the intricacies of identity formation during adolescence. Both theoretical and empirical literature (Chandler, LaLonde, Sokol, & Hallet, 2003; Erikson, 1968) indicate that constructing explanations of selves as continuous across time that are different from others is an imperative activity for adolescents. These explanations are manifestations of how an individual represents her or his life course (Negele & Habermas, 2010), a course that contains various roles and elements that are separated in time (McAdams, 2001).

Several dialectics are at play in identity. Expressed in different ways, authors have identified the concurrent need for a sense of uniqueness and belonging (Adams & Marshall, 1996), for personhood and selfhood (Guidano, 1991), and for individuality and connectedness (Grotevant & Cooper, 1985). Terminology aside, these concepts point
ultimately to a balance between interpersonal differentiation and integration (Erikson, 1968). The work of the adolescent is to establish a sense of self as unique and differentiated, and to integrate oneself within existing social structures such as the peer group, the family, and society. Historically, development during adolescence was understood as the movement from merger to separation (Blos, 1962). Contemporary theorists, however, suggest that the process involves increasingly complex relationships and connections to others (Josselson, Lieblich, & McAdams, 2007) that include processes of both disengagement and transformation (Larson et al., 1996), wherein a shift occurs resulting in a deepening of relationships with peers and subsequently an individuation from parents. Importantly, rather than assuming a longstanding “severing of ties,” there is evidence of a transformation of the parent-child relationship (Larson et al., 1996).

Identity is both personal and relational. Identity is constructed through individual and social functions of socialization with the underlying processes of differentiation and integration, respectively (Adams & Marshall, 1996). Importantly, a view of development that appreciates connectedness renders various aspects of “development” as significant concepts to investigate in adolescents who remain necessarily dependent on others for care. For the adolescents in this study, disengagement from parents and caregivers is not a feasible expectation and, in reality, could be compromising to their health. Therefore this exploration of identity development specifically focuses on the relational and contextual nature of this developmental process.

The contextual nature of identity has been emphasized elsewhere in the literature (e.g., Adams & Marshall, 1996; Bosma & Kunnen, 2001; Markus & Nurius, 1986; Nurmi, 1991, 2004), and the role of society as a core component of identity construction to establish definition and organizational structure (Baumeister, 1986) is not commonly disputed. Valsiner, Branco, and Dantas (1997) describe a co-constructionist stance as a view of human development that includes the preservation of the uniqueness of the individual as well as the interdependence within the culture. Accordingly, identity construction as a developmental process is influenced by sociocultural factors that prescribe an “opportunity space for the adolescent” (Nurmi, 2004, p. 87) and provide the parameters within which the exploration can unfold. Drawing from Nurmi, the current study seeks to explore whether the social
context surrounding adolescents with progressive life-threatening neurodegenerative illnesses serves as a channel to shape future thinking.

**The continuity of selves across time**

Sameness and continuity are integral components of identity (Erikson, 1950, 1968) as the individual is aware of, and receives recognition for, qualities of the self that remain unchanged (or are constructed as such in the person’s mind) and continuous across time. It is suggested across various literatures that claims of identity require a sense of personal continuity (Chandler et al., 2003; Negele & Habermas, 2010). The concept of personal persistence, or sameness across time, is described as effectively constituting the self (Chandler et al., 2003). This sense of personal persistence requires a resolution of the central paradox of sameness within change. In other words, any conceptualization of self as temporally persistent requires an appreciation that characteristics and qualities can remain the same within various systems of change. Both theoretical and empirical literature (Chandler et al., 2003; Erikson, 1968; Erikson & Erikson, 1997) indicate that constructing explanations of selves as continuous across time and different from others is an imperative activity for adolescents. Further highlighting the salience of self-continuity during adolescence, Negele and Habermas (2010) recognize that during times of biologically and socially determined change, such as adolescence, discontinuities arise as the central problem of life narratives.

Achieving an identity furnishes the individual with an awareness and acceptance of personal continuity with the past and a more stable orientation toward the future (Chandler et al., 2003; Erikson, 1968). The capacity to conceive of oneself as consistent across space and time is an important task of identity construction during adolescence. Inclined towards the future and with the images of future selves in tow, the challenge for the adolescent is to integrate the various elements of the self. Juxtaposing uniqueness and belonging, sameness and change, and an abundance of selves across social settings and relationships, the task for the adolescent appears to be considerable.
Narrative identity and the life story

In concert with various researchers (Guidano, 1991; McAdams, 1985, 1993, 1996, 1999; McLean, 2008; Neimeyer, 2004; Nurmi, 2004; Pratt, Arnold, & McKay, 2001), I believe that story telling is a means through which one comes to know oneself, a process of constructing an identity. From this stance, identity is viewed as a narrative achievement, a sense of self established through the story telling process. Riessman (1993) concurs with the philosophy that individuals construct the past events and actions of their life into their own narratives as a way of claiming their identity. This involves the stories we tell, the stories relevant others tell about us, and the stories we enact (Neimeyer, 2004). As well, this process is embedded within a cultural and temporal context. Bruner (1991) described narrative as a natural way through which humans make sense of lives in time. Importantly, the activity of sharing stories has been attributed to increases in self-cohesiveness, positive self-concept, self-esteem, and an ability to relate one’s identity to significant others (Nurmi, 2004). In what could be described as a universal effort after meaning, the resulting self-narrative is an overarching macro-narrative that organizes the many micro-narratives into a consolidated self-understanding (Neimeyer, 2004).

A narrative identity is described by McAdams, Josselson and Lieblich (2006) as referring to “the stories people construct and tell about themselves to define who they are for themselves and for others” (p.4). Effectively, it is believed that meaning and purpose in life can be ultimately found through the construction, internalization, and constant revision of life narratives (McAdams & Logan, 2006). The current study is based on the premise that the activity of identity construction is fuelled by human beings’ quest for self-unity and purpose, and that the concept of identity becomes especially important during the adolescent years. It is proposed that the life-story theory of identity (McAdams, 1985, 1993), which assumes that individuals construct more-or-less integrative narratives of the self to provide their life with a sense of unity and purpose, is a promising approach to understanding the construction of identity for adolescents coping with a progressive life-threatening neurodegenerative illness.

The life story is a psychosocial construction, an internalized and ever-changing narrative of the self that incorporates the reconstructed past, perceived present and anticipated future (McAdams, 1996). Importantly, a life story is based partially on empirical
fact but also on imaginative renderings helping to translate the past, present, and future into a meaningful and cohesive narrative (McAdams, 1996). The narrative integration of objective reality and subjective imagining is key to identity development and the substance of this research. Specifically, individuals are challenged to construct a narrative that synthesizes diverse elements of a life. Essentially, the task at hand is to construct a “telling” of the story suggestive of coherence among disparate self-elements, and confirmation of elements of self from the past in the present, and continuity of these into the future (McAdams, 1993). This task illustrates a nice conceptual tie between the narrative self, self-continuity, and identity. That is to say, that through the construction of a life story, one is able to weave together elements from the past into the present and the future in a way that denotes a sense of unity and purpose. McLean (2008) refers to a storying of the self as an essential mechanism in creating this temporal continuity. Similarly, McAdams (1999) describes the main function of the life story as integration. This process involves a binding together of disparate elements of the “me” into a broader narrative frame; this selfing process makes a patterned identity (McAdams, 1996).

The motivation for self-definition and the construction of the life story becomes increasingly important during the adolescent period (McLean, 2008; and for a comprehensive review see Habermas & Bluck, 2000). Mirroring much of the literature concerning adolescent identity development previously discussed, the literature surrounding the emerging narrative self during adolescence credits both social and cognitive functions of the era. Age-graded norms infer that it is during adolescence that one will begin to shape his or her life into a pattern or design (McAdams, 1996). Habermas and Bluck (2000) suggest that due to an age period characterized by the greatest normative personal discontinuity, adolescence is the time when the life story is first constructed and ultimately most intensively rehearsed. Evidently, for adolescents, the role of narrative is central in the construction of self, and the formulation (and reformulation) of the life story is the crux of an emerging sense of identity (Pratt et al., 2001).

**Future thinking**

According to Erikson (1950, 1968), identity is constructed by a process of reviewing old beliefs and views of oneself and by exploring various possible identities (Habermas &
Bluck, 2000). The exploration of these identities involves a process of looking back with hindsight at the past selves, considering the current self, and subsequently considering the selves of the future. Importantly, future thinking is an activity embedded within a general orientation to the future and although levels of engagement and inclinations towards the future vary, the literatures surrounding these terms refer to them as complementary processes. Seginer (2009) reflects upon the multiple definitions of future orientation and provides the general description as “individuals’ tendency to engage in future thinking” (p. 3).

As a way of understanding the selected approach to a study of future thinking, it is beneficial to trace back to the initial stages of a concept. As one of the first psychologists to contribute to a growing interest in future orientation, Kurt Lewin ventured into what he described as the “psychological future” (Lewin, 1997, p. 80). Several aspects of his work are particularly relevant in the conceptualization of this research study. First, he maintained a special interest in the transitional period associated with adolescence and the opportunity for a broadening in life-space afforded within this life phase. Lewin (1997) describes one view of adolescence as a “change in group-belongingness” (p. 266) rendering certain activities possible that were previously not accessible. Next and widely recognized as his foremost contribution, Lewin conceptualized future orientation as a joint product of person and environmental factors. Thirdly, he suggested that the picture one holds of his or her future will seldom correspond with what actually happens later in life and that regardless of the accuracy of these images of oneself, the picture can profoundly affect both the mood and action of the individual. All three points have a significant bearing on this research study and provide a rationale for both the selection of this age group for a study on future thinking, as well as the focus on the contextual and relational structures influencing this process.

Of key importance to this study, and as affirmed in the literature surrounding future orientation and possible selves, future thinking comprises a variety of images that include both the probable and improbable. Even at the early stages of conceptualization Lewin (1942/1948) described mood as affected by the construction of future images; poignantly, he emphasized the importance of hope in the psychological future:
Only when the person gives up hope does he stop ‘actively reaching out’; he loses his energy, he ceases planning, and finally, he even stops wishing for a better future. Only then does he shrink to a primitive and passive life. (Lewin, 1997, p. 80)

Thus, even from the earliest conceptions, future thinking was understood to contribute toward self-enhancement as well as serve the more commonly cited function of self-regulation associated with motivation and goals. Similarly, as will be explored further in the description of the possible selves construct, not all future images are accompanied by strategies for achievement, and in these cases, the function of these images is merely self-enhancement (Seginer, 2009) and feeling good about oneself (Oyserman, Bybee, Terry & Hart-Johnson, 2004). Thus, what is expected among a repertoire of future images is a clustering of images that promote goal-directed behaviour and those that prompt a sense of enhancement.

Seginer (2008) narrowly defines future orientation as the images an individual has about his or her future. Additionally, Nurmi (1991) describes one of the major features of human thinking and actions as involving an orientation toward future events and outcomes. Taken together, future thinking in the context of this study is approached as the projection of oneself into the future and the construction of images of “future selves.” The conceptual link between future projection and identity is also supported in the literature concerning possible selves (Markus & Nurius, 1986) and future thinking processes (Nurmi, 1991). Indeed, exploring future opportunities, the setting and achieving of goals are all processes that contribute towards identity construction (Nurmi). Commonly occurring during adolescence, an orientation to the future helps adolescents establish future goals for the transition to adulthood (Poole & Cooney, 1987).

Nurmi (2004) describes channeling, selection, adjustment, and reflection as the key mechanisms that support the formation of identity. In applying this framework, the adolescent is presented with an opportunity space that channels motivation, thinking, and behaviour. The adolescent actively selects from the available options, adjusts goals based on the feedback from others, and engages in an active reflection on his or her life. Relevant to this research study, the notion of an opportunity space directs our attention to the context within which selection occurs, thereby permitting a consideration of how these spaces of
opportunities might be limited within the context of a progressive life-threatening neurodegenerative illness. Importantly, reflection, the fourth mechanism, involves a process of constructing a self-concept and identity. In this activity, the adolescent bridges the past and the present, and can project with greater coherence into the future by constructing and sharing the personal life story (McAdams, 2001).

In the service of offering a solid foundation, and building upon the conceptual convergence between identity development and adolescence, the literature clearly situates an orientation to the future, as demonstrated by future thinking activities, as a key activity during adolescence. Seginer and Lilach (2004) associate a preparation for adulthood as a recognizable developmental task of adolescence, which accounts for the focus on adolescence within the future-orientation research. As well, Poole and Cooney (1987) concur that adolescence can, at one level, be considered as a period of orientation to future goals as one prepares for the transition to adulthood. Upon review of a considerable number of studies related to adolescence and future orientation, Nurmi (1991) draws attention to the importance of future thinking in adolescence for reasons associated with the normative age-specific tasks expected during adolescence, that decisions about the future have influence on adult life, and that this activity plays an important role in identity formation. Thus, the construct of future thinking is aptly positioned as an approach to understanding the experience of adolescent development amidst a progressive life-threatening neurodegenerative illness.

**Possible selves**

Projection of self into the future and within various roles is argued to be an integral part of the identity construction process (Kerpelman & Pittman, 2001; Markus & Nurius, 1986). Extending from the work of William James (1842-1910) and the conception of envisioned future selves, the idea of possible selves has been explored in psychological research (Comello, 2009). Falling under the rubric of “self-knowledge,” possible selves are conceptualized by Markus and Nurius (1986) as the part of the self-concept with a focus on the thoughts people have about themselves, their potential, and their future. Importantly, these selves are diverse and represent an individual’s ideas of what he or she might become, what they aspire to become, and what they are afraid of becoming (Markus & Nurius).
Representing aspirations such as general happiness, satisfying work, and meaningful relationships, as well as concerns for illness, loneliness, and poverty, the range and number of possible selves differs between individuals (Dunkel & Anthis, 2001).

Examinations of possible selves are well situated within studies of adolescence, as all conceptualizations of oneself in the future are intrinsic to the social role of the future (Oyserman et al., 2004). Accordingly, possible selves contribute toward the identity formation process (Dunkel, 2000). In a study aimed at replicating and extending what was currently known about the link between identity and possible selves, Dunkel and Anthis (2001) found a positive relationship between identity exploration and the number of possible selves. Their findings suggest that the generation of possible selves is one of the mechanisms used in the exploration process, and thus possible selves play an important role in the identity formation process.

A consideration of possible selves calls to attention the features of ‘how’ individuals think about their future, thereby providing some of the ‘content’ to this activity. Several specific features of the possible-selves construct formed the basis for inclusion in this study. First, a diverse range of possible selves is expected that include hoped-for and feared-for selves, and the future images of the self serve the function of incentives for behaviour as well as an evaluative or interpretive context for the current view of the self (Markus & Nurius, 1986). Thus, possible selves provide an important conceptual link between cognition and motivation (Markus & Nurius). Most commonly viewed as incentives for behaviour, these cognitive manifestations of goals, motives, and fears are grounded in the sociocultural and historical context (Markus & Nurius; Poole & Cooney, 1987). Second, possible selves help in the understanding of changes in self-concept associated with transitional periods across the life span (Hooker, Fiese, Jenkins, & Morfei, 1996). Integral to identity construction, it is the perception of oneself in particular roles that helps the individual construct an authentic identity (Baumeister & Muraven, 1991).

Markus and Nurius (1986) describe an important function of possible selves as “providing a context of additional meaning for the individual’s current behaviour” (p. 955). Thus, possible selves are presented as key components of the exploration and commitment process of identity construction, and serve the important function of providing motivation for goal construction (Nurmi, 2004) and evaluation of behaviour (Markus & Nurius, 1986).
Third, possible selves provide the link from the past to the future. And finally, possible selves are derived from the categories made available in the particular sociocultural and historical context, and therefore are both contextually based and drawn from social experiences (Markus & Nurius).

Adding to the structure of the conceptual framework, the possible selves construct is embedded within the self theories approach to the study of future orientation. Drawing from the psychological roots of James (1910) who distinguished between what he described as an “immediate present-me” and the “potential social-me”, exploring possible selves permits access to the details of how one perceives their potential future self (Markus & Nurius, 1986).

Branching out from this conceptualization and theoretical orientation, there are various assumptions about the self. First, the nature of the self is viewed as a multifaceted phenomenon, originally described by James (1950) as a multiplicity of selves and these include self-representations that extend across the past, present, and into the future, and the self has motivational features that can serve to initiate movement toward goals (Seginer, 2009). In addition, by continuing to draw from Lewin, the possible selves, as a function of future thinking, are contextually based and learned in social interactions with the environment and in social interaction with other people (Seginer, 2009). Overall, the literatures reviewed concerning identity, future thinking, and possible selves place great emphasis on the contextual nature of the activities. Therefore, to understand development under circumstances that deviate from the typical context, it is necessary to closely examine the features of that context that mark it as different. And so, for the purpose of this study it is time to venture onto the landscape of the illness experience.

**Contextual Considerations: Exploring Adolescent Development and Illness**

**The landscape of progressive life-threatening neurodegenerative illness**

Invariably, basic knowledge of a disease is required in order to conceptualize what it might be like to live with the diagnosis and progression of a particular illness. The following review is meant to provide what I am referring to as the ‘landscape’ of the illnesses that were included in the research sample. Specifically, all participants had been diagnosed with muscular disorders that fall under the broad umbrella of progressive neurodegenerative
illnesses, with the majority of participants living with one of two of the muscular dystrophies: Duchenne muscular dystrophy (DMD) or spinal muscular atrophy (SMA). As will be discussed further in the methods section, the inclusion criteria did not require specificity related to a particular type of neurodegenerative illness but rather a progressive trajectory, and characteristics of the disorder were the determining factors of inclusion in the research study. Accordingly, the aim of the initial stage of the literature review is to provide a clear rationale for a study that intentionally narrows to a specific disease category and to a designated phase of life.

Importantly, a comprehensive medical summary of neurodegenerative illnesses is not the intention, but rather the purpose of this overview is to provide the key information about the disease trajectory that is most relevant for the concepts that are being investigated within the research population. As such, what follows is an integration of observations from clinical practice with the available medical evidence. In an attempt to weave clinical wisdom and science, this rendering of the landscape attends to what has presented in practice and in science as the most challenging aspects of adolescent development amidst a progressive life-threatening neurodegenerative illness.

As a grouping of hereditary and progressive intrinsic muscle disorders, the muscular dystrophies are characterized by a destruction of muscle tissue leading to a progressive weakness resulting from a degeneration of skeletal muscle that is replaced by fatty connective tissue (Amato, 2003; Weidner, 2005). With variations in the age of onset as well as the nature of clinical manifestations such as the distribution of weakening muscles and the presence of cardiac and neuronal involvement (Weidner 2005), for each individual there are wide variances in the rate of progression. Not surprisingly, one of the most pressing questions that patients and families living with disorders such as DMD focus on is the prognosis and survival (Eagle et al., 2002).

The population prevalence and birth incidences of the more frequently inherited neuromuscular diseases such as those included in this study were reported in a survey of the world literature. Emery (1991) provides the “conservative” estimate that one in 3,500 of the live-born male population may be expected to be diagnosed with a disabling inherited neuromuscular disease that presents in childhood or later in life. As the most common of the muscular dystrophies, DMD is frequently reported as having an incidence in live-born male
births ranging from one in 3,500 (Eagle et al., 2002, 2007; Fraser et al., 2011; Weidner, 2005); one in 3,500 – 5,600 (Amato, 2003); and one in 3,600 – 6,000 (Bushby et al., 2010).

Combined, existing clinical anecdotes and the medical literature reveal distinct variations in how the illness manifests among individuals inflicted with these disorders. The differences are most prominently displayed in the range of physical functioning within the research population. Despite differences in the rate of progression the common features of muscular weakness, a delay or lack in motor development, and poor muscle tone are clinical manifestations of the muscular dystrophies (Russman, 2003; Weidner, 2005). Importantly, at birth an individual with a progressive neuromuscular disorder such as DMD often develops normally and the motor milestones of sitting, standing, and walking are achieved at a rate similar to, or slightly slower than peers (Amato, 2003). Subsequently, a proclivity toward frequent falls, and generalized “clumsiness” emerges between the ages of two and five, and the affected boys begin to experience challenges in walking, running and jumping and are noted to be slower than their peers (Amato, 2003). A typical presentation includes abnormalities in gait (i.e., toe-walking, falls, delays and intolerance), again noted as occurring between the ages of three and five (McMillan et al., 2010). In her interviews with families, Steele (2000) reports that parents of children diagnosed with a progressive neurodegenerative disease articulated a range of onset patterns that began with their own observations of an unusual behaviour or symptom. The diagnosis often occurs around the age of five, when these children diverge from the typical developmental path demonstrated by their peers (Bushby et al., 2010).

The child with a progressive neuromuscular disorder experiences continued loss of muscle strength, and by eight years of age often has trouble climbing stairs (Amato, 2003), with the loss of independent ambulation noted as occurring between the ages of seven and twelve (McMillan et al., 2010). Reliance on a wheelchair is expected to occur before such children reach their teenage years (Bushby et al., 2010). Although significant progress has been made in the therapeutic and technological support of muscular dystrophy, a cure has not been established (Weidner, 2005), and these disorders are fatal. The reported life expectancy for those with the disorders and diseases included in the research sample is identified as ranging from the early twenties (Amato, 2003) to late twenties (McMillan et al., 2010), and
sometimes even into the thirties (Russman, 2003), with 19 years the reported mean age of
death (Bushby et al., 2010a; Eagle et al., 2007).

Importantly, the muscle weakening observed in the motor functioning is not limited
to affecting only mobility; there is also significant weakening in the muscles responsible for
the functions of the heart and breath. Accordingly, long-term mechanical ventilation has
become a common end point of individuals living with muscular dystrophy, and the
combined effect of a progressive illness and dependence on mechanical ventilation results in
a heightening in uncertainty about the future (Briscoe & Woodgate, 2010). Amato (2003)
describes a gradual decline in respiratory functioning where the risk of a minor cold can be a
significant life-threatening event. It is this combination of pulmonary insufficiency and
chronic infections that eventually leads toward an end-of-life transition (Amato, 2003).
Collectively, the medical literature concludes that death is the result of emerging respiratory
or cardiac complications (McMillan et al., 2010), as weakness produces respiratory
insufficiency, difficulties in swallowing, nutritional concerns and cardiac abnormalities
(Bushby et al., 2010b; Weidner, 2005). Eagle et al. (2007) summarize the trajectory of DMD:
“without intervention, the progression of the disease causes loss of independent ambulation
by the age of 13 years, followed by the development of scoliosis, respiratory failure and
cardiomyopathy, with a mean age of death of 19 years” (p. 470).

Living on the landscape: The adolescent and the family

Importantly, adolescents living with a progressive life-threatening neurodegenerative
illness are not alone on this landscape. Rather, as a result of their ongoing care needs their
lives are commonly intertwined closely with their families. A review of the literature reveals
that within the small pool of recent research concerning the experience of a progressive life-
threatening neurodegenerative illness the focus has remained primarily on the family
describes the experience that was conveyed to her during interviews with families:

Although the children were diagnosed with NLTI’s (Neurodegenerative Life-
Threatening Illnesses) that would lead to their eventual death, the families remained
uncertain about how the child would respond to medical treatments, how long the
child could be expected to live, and how their ability to manage would be altered as the child’s disease progressed” (p. 57).

Similarly, Rallison (2009) describes this experience as a “living in the in-between” (p.2).

Clinical work with families who are living with this diagnosis reveals the intricacy associated with living the first several years of life as a parent to a healthy child, and then having to integrate loss into what had thus far been a story of health and growth. The achievement of an infant sitting up and expanding the repertoire from crawling to walking are celebrated accomplishments firmly embedded within the collective experience of parenting a developing child. For the families of affected children, the diagnosis marks a significant departure from their anticipated life course. Embedded within a family context, living with a progressive life-threatening neurodegenerative illness has implications for the family system surrounding the adolescent. In particular, disruptions have been noted to extend from the individual living with the illness to the “emotional, psychological, and spiritual fabric of the entire family” (Weidner, 2005, p. 550), resulting in adaptations to the family structure and to the patterns of interaction oftentimes resulting in an ongoing family reorganization of roles (Steele, 2000).

So what does this landscape offer to understand this research population? A feature of this illness trajectory that must remain at the forefront of our awareness is that despite the aforementioned variance in trajectory there is an observable adherence to a pattern. It is apparent that adolescents who are diagnosed with a progressive neurodegenerative illness are charged with the task of moving forward toward independence amidst an increasingly dependent body. That in the face of uncertainty and variance of disease progression there is certainty that life is not unfolding in a normative pattern.

**At the intersection of disease and development**

As evidenced by the gradual decline in functioning, the nature and progression of the disorders included in the research sample in this study present a dilemma for the developing adolescent. Following the described trajectory, by the time adolescence is reached the individual requires assistance with all activities of daily living including feeding, changes of position, and toileting (Birnkrant & Noritz, 2008). Importantly, the complexity of managing
these losses during adolescence has been noted in the literature. Researchers note that for adolescents living with a progressive neurodegenerative disorder, the increase in dependence on families and caregivers parallels a time when peers are experiencing an increase in autonomy and independence from the family (Fraser et al., 2011). Weidner (2005) highlights the contrasting experience for these adolescents:

Normally adolescence is a time for developing self-esteem and independence as one gradually moves away from parental ties and masters opportunities that exist outside the family. However, by adolescence, the child with DMD often has lost ambulation and experienced a significant decline in his physical capabilities (p. 550).

This domain of the experience appears to be the most commonly cited consequence of the adolescent illness experience, wherein the onset of limitations during the ages of 12 – 18 is noted as making it difficult for adolescents to move toward an appropriate level of independence from parents and caregivers (Stevens et al., 2009).

Weidner (2005) calls for what he describes as an “interaction of multiple disciplines” (p. 548) to address the psychosocial and emotional consequences that accompany the disturbances to development. As well, Bushby et al. (2010a) describe the medical care of these patients as incomplete in the absence of support for their psychosocial well-being. Highlighting the importance of understanding the psychosocial needs of this population, Weidner (2005) continues to explain that oftentimes as the illness progresses, treatment options become limited and psychosocial and emotional support gain salience.

It is during this shift in the balance of care that the specialized practice of hospice palliative care services can become central features in the care of the adolescent and the family. Importantly, a research study examining the provision and usefulness of hospice care among young people with neuromuscular disease concluded that this population forms a large proportion of the caseload at children’s hospices (Fraser et al., 2011). As well, Steele (2000) noted that children living with neurodegenerative life-threatening illnesses account for a large portion of the population receiving pediatric palliative care. Of key relevance to the development of this study is the finding that within the patterns of hospice usage, the age distribution of neuromuscular patients peaks at an age range of 12 – 16, this trend is
speculated to be the result of an increase in both physical and emotional needs (Fraser et al., 2011). Importantly, this finding lends empirical support to the clinical observations of an increase in the need for the provision of psychosocial support at precisely this intersection of development and disease progression.

Although unable to locate evidence of research with a specific focus on the exploration of future thinking activities in adolescents with a progressive life-threatening or chronic illness, the results of several studies exploring adolescent illness experiences suggest that aspects of the future are important considerations for adolescents living with various illnesses. Within this literature a few studies aimed at examining the individual and family experience of adolescent development with a chronic illness venture into brief explanations of future thinking activities. Extrapolating from these studies, future thinking activities within the context of chronic illness is commonly occurring. For instance, upon examining how children ‘grow up’ with various health conditions, it becomes evident that upon looking across the broad generalization of chronic illnesses (Taylor, Gibson, & Franck, 2008) to the more specific identification of illnesses such as cystic fibrosis (Admi, 1996) and spina bifida (Wollenhaupt, Rodgers, & Sawin, 2012), young people are coping with these illnesses by continuing to plan for their future. Collectively the findings from these studies provide a preliminary understanding of the occurrence of future thinking in adolescents living with chronic illness. The results of these studies provide the impetus for further inquiries into future thinking amidst illness; however, the transferability of these findings to the research population may be limited due to the difference in illness trajectories and experiences. Therefore, a precise research focus on future thinking activities is needed to explore how adolescents with a progressive life-threatening neurodegenerative illness think about the future, and contribute to our understanding of this specific developmental process.

Accordingly, as a way of conceptualizing this research study, it was necessary to extend the search and to consider the literature on adolescence and various chronic illnesses. The applicability of the chronic illness literature to a progressive life-threatening neurodegenerative illness is conceivable due to the chronicity of symptoms associated with the progressive nature of these illnesses (Rallison, 2009). As I navigated through this body of literature, the transferability of knowledge between a population of adolescents coping with chronic illness and those coping with a progressive life-threatening neurodegenerative
illness became increasingly apparent. Currently, it is estimated that 20 – 30\% of adolescents in Western countries are living with a chronic illness, with 10 – 13\% experiencing significant limitations to their daily functioning (Yeo & Sawyer, 2005). Further to this, in North America, it is estimated that up to 98\% of children diagnosed with a chronic health condition may now reach the age of 20 (Coupey, Neinstein, & Aelter, 2002). It is noted within this research field that the “ongoing management of chronic illness can impose physical, emotional, and financial dependence at a time when increasing autonomy is the developmental goal” (Sansom–Daly, Peate, Wakefield, Bryant, & Cohn, 2012, p. 380). As well, the adolescent coping with chronic illness grapples with the same developmental issues as their healthy peers with the added complication of disruptions due to treatments, illness, and oftentimes repeated hospitalizations (Taylor et al., 2008). Although much has been established to understand the physical consequences of chronic illness within this population, very little is known of the subjective personal experience (Taylor et al., 2008).

Researchers concerned with pediatric chronic illness (Boice, 1998; Drew, 2003; Gortmaker, Perrin, Weitzman, Homer, & Sobel, 1993; Lock, 1998; Seiffge-Krenke, 1998; Stam, Hartman, Deurloss, Groothof & Grootenhuis, 2006; Steele, 2000, 2002) acknowledge that there is a lack of research concerning the subjective experience of the illness experience. As an exception, a study conducted by Woodgate (1998) focused primarily on the subjective experience of chronic illness and involved interviews with 23 adolescents living with chronic illness, and established eight important themes regarding the care of this population. The results of this study reveal that much can be learned about practice when time is taken to explore the individual experience. Unfortunately, studies of chronically ill adolescents managing the developmental tasks of adolescence are fairly scarce (Seiffge-Krenke, 1998); therefore, only a provisional understanding can be gleaned from existing literature. The existing reports of data are contradictory with several researchers emphasizing the challenge and detriment illness poses to development (Carroll, Massarelli, & Opzoomer, 1983; Gortmaker, Walker, Weitzman, & Sobel, 1990; Stam et al., 2006; Wallander & Varni, 1995), while others report the possibilities of positive development (Capelli et al., 1989; Drew, 2003; Seiffge-Krenke, 1998; Zani, DiPalma, & Vullo, 1995). Importantly, these contradictions highlight the paradoxical nature of this developmental process and indicate that for adolescents living with chronic illness, challenge and opportunity coexist.
Owing to advances in medicine, the prevalence of chronic illness is rising. Individuals are surviving longer with conditions that previously caused death in infancy or childhood (Blum, 1992; Boice, 1998; Gravelle, 1997). Consequently, the number of adolescents living with chronic conditions has increased significantly, resulting in more adolescents than ever before facing the unforeseen challenges of living with chronic illness (DiNapoli & Murphy, 2002) and reaching adulthood (Stam et al., 2006). Families are faced with ambiguous trajectories and complex care needs for extended periods of time. Evidently, medicine has progressed to the point where it is necessary to find ways to enable chronically ill adolescents to surmount the normal stresses of adolescence and prepare for productive adult lives (Boice, 1998).

Current research indicates that coping with chronic illness alongside the multiple changes occurring in adolescence adds yet another dimension to an individual’s experience (Boice, 1998). Presented with a dual challenge (Woodgate, 1998) the adolescent must face the changes particular to their phase of development as well as those resulting from the disease itself (Carroll et al., 1983). Adolescents with chronic illness face variations in pubertal timing, decreased socialization and friendship opportunities, and a necessarily dependent relationship on family, all of which are factors contributing to a potentially altered developmental trajectory from that experienced by adolescents without a chronic illness (Canadian Paediatric Society, 2008). The research pertaining to adolescent development and chronic illness clearly points to specific features of the illness trajectory that present developmental challenges and highlight the need for specialized health care practices for adolescents.

**Future thinking has important implications for adolescents living with a progressive life-threatening neurodegenerative illness**

Advances in pediatric and adolescent medicine have resulted in a rising number of adolescents living with long-term illness. Eagle and colleagues (2002) conducted a systematic review of survival rates comprising 197 patients with Duchenne muscular dystrophy cared for between 1967 and 2002; analyses showed significant improvement across decades with the mean age of death in the 1960s as 14.4 years compared to those ventilated since 1990 when the mean age of death extended to 25.3 years. More specifically,
the proactive management of complications from the progression of neuromuscular disorders has led to improvements in quality of life and survival (Eagle et al., 2007). Interventions such as the use of nocturnal ventilation and spinal surgery have resulted in the rise in life expectancy (Eagle et al., 2002; Eagle et al., 2007). However, research is beginning to highlight a significant lack of planning and preparation for this group (Abbott, 2012). Families are faced with ongoing medical decisions as they navigate through this process and the complexity of the care needs have increased significantly and extend over longer periods of time (Rallison 2009; Gravelle, 1997; Steele 2000, 2002). As the population of adolescents coping with chronic and life-threatening conditions continues to grow, the healthcare system has a responsibility to respond holistically to the needs of these adolescents and their families.

Studies concerned with adolescence and disability have become well established within the social sciences (Abbott, 2012). As well, research concerning pediatric palliative care has demonstrated a trend toward increasing (Steele & Davies, 2006; Steele et al., 2008). Interestingly, within the field of pediatric palliative care, various models and frameworks that can be used to direct practice have been developed under the guidance of experienced clinicians (Rallison, 2009), yet within a growing body of published articles, few of these are reports of empirical research (Steele et al., 2008). Further to this, very little is known about the specific intersection between a progressive neurodegenerative illness and adolescent development. When narrowing the literature search specifically to adolescent development and life-threatening illness, a small amount of literature is referenced. The majority of this literature focuses on the pediatric experience of cancer (Woodgate & Degener, 2003; Woodgate, 2005; Woodgate 2006), or on how families manage pediatric life-threatening illnesses (Bousso, Misko, Mendes-Castillo, & Rossato, 2012; West, 2011; Woodgate 2003). Knapp, Quinn, Murphy, Brown and Madden (2010) contend that despite an awareness of the immense difficulties a life-threatening illness poses to adolescence, areas such as self-esteem and body image, relationships with parents, and the range of social consequences of developing within an illness context have not been well explored for adolescents with life-threatening illness other than in pediatric oncology, or if they have occurred, the available evidence is limited.

In a position statement concerning adolescent healthcare practice, the Canadian Paediatric Society places emphasis on developmentally appropriate care and the necessary
integration of this care into all healthcare practices (AH 2007-01). Indeed, Taylor et al. (2008) assert that the strategies of care developed for use during early adolescence will not necessarily translate into effective approaches to care for young people in late adolescence. The work of supporting adolescents in pediatric palliative care presents an opportunity to develop a practice that responds to the unique challenges that become apparent as illness and development collide (Knapp et al., 2010; Stevens, Dunsmore, Bennet, & Young, 2009). Few clinicians would argue this point, however expertise is required in territory that has thus far been largely uncharted. Rallison and Moules (2004) suggest that the “unspeakability of pediatric palliative care” might inadvertently contribute to a process of silencing related to this experience (p. 290). Despite this, there is an open acknowledgement of the unique features of adolescent chronic and progressive illness and subsequently an acceptance of the need to develop a responsive practice. This degree of consensus has resulted in a call for care that responds to the unique nuances and needs of this population. To develop developmentally appropriate care, practices must be linked to research evidence that is firmly rooted in the experience of the adolescents.

The knowledge that will be gained by exploring the concept of future thinking in the context of life-threatening illness has direct implications for the psychosocial care of the research population. Delving into processes of forward thinking for adolescents living with a life-threatening illness is a conceptually interesting venture. Importantly, the value of this knowledge extends beyond the interest in a seemingly out-of-the ordinary developmental process. Specifically, understanding future projection has both practice and policy implications in the context of adolescent healthcare, a field that is requiring rapid development of expert knowledge and skills. From a procedural standpoint, an orientation to the future and the ability to project a stable set of self-structures across time (to see oneself in the future) is an important component of decision-making and planning (Nurmi, 2004, 1991).

As practitioners seek the engagement of adolescents in their healthcare decisions, they are assuming that an active projection of self in the future is occurring and thereby informing the decisions that are taking place at the current time. Although an inclusive practice pertaining to decision-making is hypothetically a good idea, it is important to determine whether active decision-making is a reasonable expectation for adolescents with a progressive life-threatening neurodegenerative illness. With potential bearing on the policies
and practices of inclusion in conversations about future healthcare decisions, the results of this study will contribute towards an understanding of whether adolescents are actively engaging in future thinking regarding the management of their illness.

Extant research reveals that current understanding of adolescent development in the context of a progressive life-threatening neurodegenerative illness is preliminary. Despite the commonly agreed upon assertions that the construction of an identity is a core part of adolescent development, that future thinking is a process that contributes to identity development, and that this future space is populated by a range of diverse possible selves, current understanding of how these interplay within the context of progressive life-threatening neurodegenerative illness is based only on theoretical and conceptual linkages. Oftentimes, these links can be partnered with anecdotal clinical evidence and although the value of clinical wisdom is not being disputed, one must acknowledge that these observations are being made from outside the arena of the experience and consequently the current understanding is rudimentary at best. Adding to this, studies aimed at the personal and subjective illness experience are scarce, and therefore capturing the voice of the adolescent experience of development amidst a progressive life-threatening neurodegenerative illness will make a significant contribution to this existing literature base.

Pulling the Concepts and Context Together: A Summary

By looking across the concepts of identity, future thinking and possible selves, several prominent features converge. Notably, the development of identity, a proclivity to project into the future, and the construction of possible selves are contextually based activities that increase in frequency and importance during the adolescent phase of the life course. As well, the constructing of an identity, a future, and a collection of possible selves facilitates an integration of self across time. By turning the focus to a specific context of an illness trajectory, the literature revealed that little is currently known about the intersection of disease and development. Importantly, the implications of this study extend beyond a contribution to healthcare practice. The current study advances the research on identity, future thinking and possible selves by making further contributions to the existing conceptual understanding of these developmental processes.
The research questions

The purpose of this research is to examine how adolescents who are living with a progressive life-threatening neurodegenerative illness construct meaningful future self-representations. Conceptualizing identity development as a contextually based process comprised of a past, present, and a future, this program of research involves three interconnected research questions:

1. Do adolescents who are living with a progressive life-threatening neurodegenerative illness construct an orientation to the future? How far does future orientation extend? Is there an imagined orientation (i.e., with versus without illness) to the future that does not include the history, diagnosis, or progression of the illness?

2. How are the possible selves of adolescents with a progressive life-threatening neurodegenerative illness explored, enacted, maintained, and/or silenced across various contexts?

3. How do adolescents living with a progressive life-threatening neurodegenerative illness experience their various stories of selves across time?
Chapter 3. Methodology

My role in coming to know the questions guiding this research is an important part of situating myself within the research process. Without hesitation I bring to this research a collection of images and clinical experiences that serve as both a touchstone and a compass. The experiences I have had working with the adolescents and their families in palliative care are an integral part of what I can offer this research inquiry. The observations from practice and clinical anecdotes served as a reference point in the initial formulation and construction of the research questions. I cannot separate that experience of social work practice from this position as a researcher, as I cannot separate the fact that I am a white female who was five months pregnant during the time of the interviews. Goodall (2008) reminds writers of narrative non-fiction that we learn to see things in one way and not another because we are born into a particular context and our views extend from our position in the world. The way we interpret the world is a product of both where we come from and who we are. Providing an explicit statement of self is a way of assisting readers in understanding and evaluating the interpretations I have made more fully. I bring this collection of experiences to the research inquiry and through this I acknowledge that what I will be presenting is a series of findings embedded within a joint construction of narratives.

The Analytic Approach

This program of research lends itself to a qualitative narrative approach. Stemming from my clinical experience, I wanted to construct a research study that would provide an initial understanding of future thinking activities of adolescents living with progressive a life-threatening neurodegenerative illness. In staying true to the clinical environment within which the questions emerged I felt it was necessary to structure the research in a manner that encouraged the telling of a story. Therefore, the study was exploratory in nature and the understandings gained through the research method aimed to provide an in-depth and detailed view of the phenomenon. As the word implies, “qualitative” places emphasis on the qualities of processes and meanings (Denzin & Lincoln, 2005). Importantly, the research questions are in areas largely unexplored, and therefore an inductive, flexible research design was employed.
By drawing from the established literature pertaining to adolescence and chronic illness, identity, future thinking, and possible selves, specific concepts were identified for their potential relevance in this study and were used in the conceptualization of this investigation (i.e., forming interview protocols based on social theories). These concepts reflect current theoretical ideas, and in addition to providing a conceptual anchor in the development of the research project, as the research progressed through to analysis they proved to be an important part of an ongoing dialogue between ideas and evidence (Ragin, 1994).

Recognizing that little is currently known about the experience of future thinking with a progressive life-threatening neurodegenerative illness, and that a highly structured and static research design would not address the anticipated complexity of this developmental process, it was determined that the initial forays into this topic area were well suited to this explorative and inductive method. A narrative research approach is especially appropriate for a population of adolescents living with a progressive life-threatening neurodegenerative illness, as a central goal is to give voice to the experience of living outside of the cultural mainstream and to situate the findings within the practice of care that surrounds these individuals.

**A contemporary framework: A narrative approach**

As a contemporary framework, a narrative approach to the collection and analysis of data permits an examination of how the stories an individual constructs effectively carry that person across time and space (Pasupathi & Hoyt, 2009). As one approach to identity, a narrative approach draws from the related fields of sociology and psychology and is founded upon the converging belief that personal narratives are people’s identities (Bruner, 1991; Gergen, 1991; McAdams, 1993, Polkinghorne, 1990; Rosenthal, 1993). As described by Lieblich, Tuval-Mashiach, and Zilber (1998), “the story is one’s identity, a story created, told, revised, and retold throughout life. We know or discover ourselves, and reveal ourselves to others, by the stories we tell” (p.7).

At its core, narrative research differs significantly from the positivistic stance, and rather than expecting a single or absolute truth, there is adherence to notions of pluralism, relativism and subjectivity (Lieblich et al., 1998) and an expectation of a plurality of truths.
Importantly, Fraser (2004) contends that narratives allow one to consider both the actions of the individual and the implications of any social structures that influence the narratives. Therefore researchers employing this method are able to strike a balance between what she refers to as the ‘witless relativist,’ that is, someone who erases the impact of social structures and cultural-political contexts; or a ‘social determinant,’ that is, someone who focuses so much on social structures and cultural contexts that individual agency is denied” (Fraser, 2004, p. 182). Echoing a similar stance, Lieblich and colleagues (1998) describe their position as narrative researchers as being “middle course” wherein they do not subscribe to the notion of relativism and assume all narratives as purely fiction, and are also aware that narratives cannot be taken at face value as fact.

Recognizing these key features, narrative researchers do not seek to establish a “correct” reading or interpretation of the text (Lieblich et al., 1998), the “right knowledge” or the “truth” (Fraser, 2004); rather, through the art of narrative research they aim to understand how individuals interpret events and experiences. Ultimately this requires a steering away from an analysis that becomes constitutive of an evaluation of how the interpretations offered by the narrator mirror, or line up with the researchers’ “interpretive construct of ‘objective reality’” (Mishler, 1990, p. 427).

All stories have a context within which the characters and plot evolve. A narrative approach to research offers the opportunity to consider the “context” thereby drawing necessary awareness and consideration to the various social and cultural structures in which the story is embedded (Fraser, 2004; Hole, 2007; Lieblich et al., 1998). Hole (2007) describes, “our understandings of who we are, our identities, are constructed by drawing on the prevailing discourses – the available images, representations, meanings, and so on – available to us in our historical, cultural, and social worlds” (p. 261). Importantly, the narrative approach opens the door to explore the “systems of meaning” the teller relates to the culture and social world (Lieblich et al., 1998) thereby permitting the exploration to extend from the individual to the surrounding context.

To summarize, a narrative approach to the study of the future thinking activities of adolescents with a progressive life-threatening neurodegenerative illness was selected for various reasons. First, studying a unique developmental trajectory requires a scientific approach such as narrative that encourages a complex and textured scientific account
and narrative accounts have proven to be one of the clearest channels of learning about an individual’s inner world and experienced reality (Lieblich et al., 1998). Second, a theoretical framework of development that includes a stance of co-constructionism, and contextualism, compels one to consider a method wherein the phenomenon of interest is examined within a framework of individual agency and social context (McAdams et al., 2006). In essence, the narrative approach acknowledges that individuals construct their identities and self-narratives from the “building blocks” that have been available in their culture as well as in their individual experience (Lieblich, et al., 1998).

The Research Process

Ethics approval

I received ethics approval from the Behavioural Research Ethics Board at the University of British Columbia. Based on this ethics approval, I also received ethics approval from the practice setting within which the participant recruitment occurred.

Participant selection

The goal of this research study was to examine and understand the nature and extent of future thinking processes for adolescents coping with a progressive life-threatening neurodegenerative illness. There were several criteria established in the recruitment process. In the literature, adolescence is a term broadly used to refer to individuals in the second decade of life. Accordingly, the first criterion for inclusion in these studies was that participants were between the age of 10 and 20. The second criterion narrowed the eligibility to individuals with a life-threatening disease that falls within the category of progressive neurodegenerative conditions. Specificity of the diagnosis was not required but rather the general characteristics of the progressive nature of the disease wherein the individual had experienced a gradual decline in functioning occurring during the adolescent years determined eligibility. Thirdly, the progression of the disease was considered with respect to cognitive and communicative abilities. To clarify, adolescents between the ages of 10 to 20 who were living with a progressive life-threatening neurodegenerative condition that has not
significantly affected cognitive ability and who were able to communicate in an interview were deemed eligible for this project. The selection criteria were discussed in detail with the recruitment team and the researcher relied primarily on their assessment of eligibility of participants for recruitment. In the end, all of the participants suggested by this team were included in the study.

**Recruiting participants**

A sample of ten participants was drawn from a healthcare setting. The core recruitment strategy engaged a well-established pediatric setting wherein the researcher had previously been employed, and where existing relationships and familiarity with the environment and the team would facilitate successful recruitment and data generation. Riessman (2005) explores the complex relationships involved in narrative research and the ethics involved when working in narrative traditions where the act of storytelling really pivots on relationships. Recognizing the complexity and sensitivity of this research study for all involved, it was deemed most appropriate to initiate recruitment in a setting where relationships between the healthcare professionals and the researcher had previously been established and therefore the likelihood of gaining access to a sample would be greater. As part of this core recruitment strategy, a letter of introduction (see Appendix 1) was provided to the social worker and the research committee at the healthcare setting. The personal contact information of the researcher was included in the letter and the participants were asked to notify me if they would like more information about potential involvement in this study. As a second option, the potential participants could give permission to the referring professional to forward their names and contact information to me to contact them. The second option was selected by all of the participants thereby granting me the opportunity to engage in a conversation with parents and the potential participants prior to meeting in person, which afforded further description of the study as well as a confirmation of the eligibility and suitability of the participants for this study.
Sample description

Ten research individuals participated in the study. As a way of ensuring that confidentiality is maintained, pseudonyms have been used to identify each of the participants. As well, the specifics of gender, age and diagnosis of each participant will not be offered as combined together these characteristics could lead to some speculation regarding the identity of the participants in this study. Rather, a general statement of the characteristics of the sample is provided. As determined by the eligibility criteria, all participants were between the ages of 12 and 20 and had been diagnosed with a progressive life-threatening illness falling under the broad category of neurodegenerative diseases. The progression of each disorder varied with all participants having experienced the loss of ambulation, and the majority demonstrated additional limitations in the upper body functioning with range of motion limited to the movement of fingers. As well, some of the participants had undergone surgery for a tracheotomy and were dependent on a ventilator for breathing. All of the participants lived at home with a parent or parents. The number of siblings ranged from one to six. The sample was drawn from one healthcare setting and therefore the participants were receiving care from a common team with access to similar support groups and conversations with professionals regarding future thinking.

Limiting the size of the sample was purposeful. Contemporary qualitative researchers do not adhere to the necessity of generalizability, and therefore they do not believe that the small number of narratives presented must be generalizable to a certain population (Chase, 2005). Given that the research pertains to a rather complex phenomenon involving a small population of adolescents, as well as the intent to provide a thick narrative description of the experience, the small sample size fits well with the overall approach.

Data Generation

The narrative interview

A narrative interview served as the primary source of data for this study. This process of generating data is viewed as a contextually bound and mutually created story (Denzin & Lincoln, 2005). A weaving of the knowledge drawn from the narrative literature
as well as from clinical practice confirms that storytelling has been proven to be a fruitful way of organizing life experience into meaningful episodes. Founded upon my own clinical experience, it was my strong belief that this type of collaborative interview was a required action to foster the exploration of a sensitive matter in the lives of these adolescents. Fraser (2004) views the interview as an opportunity to engage with participants in “relatively informal and friendly ways” (p. 185), two features of particular importance when working with this age group.

The clinical anecdotes and observations that had fuelled my curiosity about this particular experience continued to serve as a touchstone as I embarked on the development of the interview protocol. As the interview questions were developed I was cognizant of wanting to strike a balance between offering an opportunity for exploration in a manner that closely mirrored clinical practice, and yet also needing to be clear about the line between a therapeutic interview and a research interview. As part of this process I consulted with three colleagues who had worked very closely with me in the clinical work with these adolescents. Through a series of conversations it became known to me that my approach with the adolescents who had shared stories with me in the past was one of “openness” and that the space that I had provided permitted the expression of experience that was followed by interventions aimed at a deeper exploration of the emotion. It was essentially a non-directive approach.

Understanding my clinical approach armed me with the awareness of where to place the “line” between therapy and research. I felt that the most important way to mitigate the risk of moving into a therapeutic realm would be to establish a clear structure as a way of remaining aware of my role and intentions in each of the interviews. Commonly known as an interview protocol, researchers use these as tools to formulate a structure for inquiry but are not governed by them. Therefore, drawing from the available literatures three interview protocols were developed as way of providing a frame and a guide for the interviews. Each of the protocols addressed a specific line of inquiry. The first protocol explored future thinking and possible selves, the second protocol extended to the contextual nature of future thinking and possible selves, and the third prompted an exploration into the selves of the past, present and the future. The intention of each protocol was to provide an overarching structure to the collection of data with the inherent understanding that strict adherence to the
interview protocol was not the intention, but rather the questions provided a container within which the exploration would take place. In addition, I recorded research memos after each interview as way of debriefing the interviews with a focus on my own reaction and clinical hunches associated with the data that emerged. These memos proved to be an effective means of tracking my experience of the interviews and of recognizing the difference between my prior work in this area and the generation of data through the narrative interview.

The initial ten interviews took place within a five-day period in March of 2009. A second interview was offered to all participants and three agreed to be interviewed a second time. This interview took place a month later and was used as an opportunity for the participants to recall the interview and to “add” any information that they felt necessary. Importantly, the intention of this interview was not to review or validate my interpretation of the interviews, but rather to provide an opportunity to elaborate on the ideas that had been expressed. Consent forms were signed by the participants who were of age to determine this for themselves; in all other cases a parent/guardian signed the consent form (see Appendix 2) and participants signed assent forms (see Appendix 3). Seven of the ten interviews took place in the participant’s home and three took place at a health care setting. All interviews were digitally recorded with the participants’ permission. The length of interviews ranged from 40 to 80 minutes and the length of time I spent with each participant was between two and three hours. Immediately following the first interview I transcribed the interview, the research memo, and the recorded field notes in full. All subsequent interviews were transcribed by a professional transcriber referred to me through Alberta Health Services. I met with this individual for an hour prior to hiring and reviewed the research study, outlined expectations, and had her sign a confidentiality agreement.

Data generation in stage one:

The life line technique

As described, a semi-structure narrative interview was employed to generate data (see Appendix 4). Closely aligned to and informed by the Life-Story Interview (McAdams, 1993), in the initial stage of the interview the adolescents were prompted to reflect on the past, the present, and the future. Each interview began by asking participants to think about their life as if they were writing a book. Questions were then posed to develop the chapters: Where
does your story begin? What are the important things that have happened along the way? Can you identify high points, low points, and turning points? Are the chapters of the “future” written? If so, what kinds of things do you hope for? Fear for? This opening sequence of questions was intended to draw the participants into the stories of their lives as a way of establishing the movement from the past to the present and into the future.

This initial stage of the interview was framed as a “life line” and involved the construction of a visual representation of a timeline encompassing past, present, and the future. As a point of clarification, the notion of “time” within this research study referred to what Paul Ricouer (1984) described as “human time” rather than clock time. This is time whose significance is given by the meaning assigned to the events within its compass. To create this lifeline the participants were invited to use various creative supplies (i.e., pencil crayons, markers, paint, collage materials, clay, etc.). Depending on the fine motor skills and functionality of the adolescents, they were also given the option of “directing” the construction of the lifeline and using the researcher as a tool to actively construct the visual representation. Alternatively, participants could opt to speak their story. The use of diverse methods of data collection was intended to facilitate the narration and has been supported in the literature surrounding the life story method. Specifically, Habermas and Bluck (2000) encourage the use of diverse methods such as written or graphic representations of parts of life that can be arranged and manipulated physically as a form of narration. It is believed that a combination of methods helps to rule out low levels of performance in narration by reducing the demands for combinatorial reasoning and memory tasks (Habermas & Bluck).

All ten of the participants chose to narrate their story while observing the mapping out of the information, the construction of the visual representation acting as a reference point as well as a space in which I was able to verify what it was that I was hearing. At several points across interviews the participants used the visual as a reference to make points of clarification, to make revisions, or to request that I move data from one space to another, thereby demonstrating the usefulness of this form of data collection and mapping.

As a concrete anchor for time, the interview questions prompted participants to identify the major events or milestones of their life story. Questions were posed to determine if projection beyond the present was occurring; as well, participants were encouraged to construct more than one storyline (real vs. imagined). In a movement toward the “content”
of their future space, the range of possible selves was explored by asking each participant to list both their “feared-for” and “hoped-for” self. As well, participants were encouraged to share whether they have constructed a range of possible selves that do not include the diagnosis of the illness. Once the possible selves had been identified, questions were posed to explore whether the adolescents valued particular possible selves over others.

**Data generation in stage two:**

**Contextualizing the possible selves within relationships**

Next, adolescents were asked to develop a “self portrait” and a “map” that included all of their “possible selves” and the relevant people with whom they interact (see Appendix 5). The interview data from the first stage wherein the adolescents identified their various selves, including the real and imagined future self, was used in this stage of the interview. Secondly, as way of venturing outward from the adolescent, each participant was prompted to consider the people with whom they might share their future selves. Prompted first to add their parents, followed by any other people they consider to be relevant and important in their lives, the participants were encouraged to develop a map of the individuals that could include peers, family members, and any other individuals of significance to them. As the adolescent listed the individuals, these people were added as circles and names. Through a purposeful line of questioning, emphasis was first placed on the exploration of possible selves with parents. Finally, adolescents were asked to consider whom else they share each of their possible selves with (recognizing that some of the selves may be kept private or avoided), and the feelings associated with this sharing. In the service of understanding the relational aspect of future thinking, this line of questioning aimed at gathering information regarding the exploration, enactment, and maintenance of both the real and imagined possible selves.

**Data generation in stage three:**

**The experience of self across time**

The final area of exploration was concerned with understanding whether the adolescents were able to weave the selves of the past with the present and future selves. Recalling what was reviewed in the literature pertaining to the narrative self, the ability to
weave together various elements of the self across time is believed to be of key importance in the development of identity (Bruner, 1990; Negele & Habermas, 2010; Nurmi, 2004; Riessman, 1993). As well, the act of linking the various stories of the self across time and establishing what Neimeyer (2004) describes as a macro-narrative constitutes an important process of self-consolidation. As way of “getting-to” these stories and prompting a reflection of how they weave together, an interview protocol developed by Chandler et al. (2003) was reviewed. In recognizing aspects of the self as both fluid and persistent one is directed toward the classic paradox of sameness within change that is described by Chandler et al. (2003) as constituting an essential feature of self or personhood. The interview protocol (see Appendix 6) was influenced by a protocol developed by Chandler and colleagues (2003) that has been used to determine the strategies used to warrant self-continuity. Importantly, the identification of specific warranting strategies was not the intention of this line of inquiry, but rather the use of this established line of questioning permitted the exploration of a continuity of selves across time. Thus the adaptations of the protocol were derived from this concept of self-continuity in life narratives (McAdams, 1985; Negele & Habermas 2010), and the interview questions were aimed at prompting a consideration of the selves of the past, present, and the future and the identification of changes that have occurred. Accordingly, participants were asked to provide several self-descriptions beginning with a retrospective question taking the adolescents back three to five years. Next, the adolescents were asked to describe the sort of person they see themselves as being today and who they might anticipate being in five more years. Finally, as a way of exploring aspects of self-continuity amidst change, adolescents were asked to consider the important changes that have taken place over the years and to describe whether, when accounting for all that has changed, some elements of the self have remained the same.

**Flexibility in the design: Adaptations to the interview protocols**

To respond to the need for both structure and flexibility within the research design, each of the ten interviews followed a semi-structured approach. Congruent with the insights offered by Daly (2007), who suggests a semi-structured approach as an interview style that provides the necessary structure and openness to maintain an overarching focus for the collection and analysis of data, my experience as the interviewer quickly revealed this as a
required approach. On the one hand, the questions provided me with a structure to guide the interview and have proven helpful during data analysis by generating data within specific domains of experience. On the other hand, keeping in line with an emergent design, it was indeed evident that as the researcher I could not have expected to know all the questions beforehand, and therefore the freedom and ability to expand and explore relevant stories facilitated the collection of data in a manner that resulted in a rich and somewhat diverse series of stories. As Chase (2005) suggests, “the very idea of a particular story is that it cannot be known, predicted, or prepared for in advance” (p. 663). Therefore, in line with Kerlinger’s (1986) assertion that “design is data discipline,” adherence to an overall research design through the employment of a semi-structured approach was maintained with an emphasis on an open and flexible process, and the interview protocols facilitated the collection of data and the organization and structure of the research interview (Creswell, 2007).

As expected, the three protocols that had been developed were adapted during the interview process. The research proposal was originally constructed as a series of three interconnected lines of inquiry that could be distinguished by the specific focus of the questions contained in the interview protocol. It was originally anticipated that each line of inquiry might require a separate interview and the interviews were approached with this in mind. However, it was evident within the first interview that the questions were so closely related to one another that separating interviews would impede the flow of narration, and that the questions were not as discrete as originally expected. Therefore, after consulting with my supervisor we determined that each interview would include consideration of all three of the specified research areas and subsequently within each of the interviews I would proceed through all of the research protocols. I also altered the sequence of the interview protocols. Once in the interview setting, it became apparent that the future thinking and possible selves questions flowed more directly into the questions that focus on the relational and contextual features. Therefore, as a way of promoting a smoother narrative dialogue, I determined it was necessary to address self-continuity at the end of the interview. This logical progression of exploration was followed for all of the ten research participants.

After the first two interviews I consulted with my supervisor and seven of my PhD colleagues. As I was discussing the process of interviewing, my sense was that I needed to
come up with a way to encourage what narrative researchers would describe as a “more storied” account of this experience. Although the language of the interview questions was drawn from the life-story approach, an attempt was made to also encourage a more detailed rendering of an anticipated high point or milestone life experience, and the following question was added: *I want you to imagine that it is your best day in the future; tell me a story about what is happening.* Consequently, the first two interviews did not include this question because the change in interview schedule occurred at this point in the data collection process.

In addition, questions were added to explore “future thinking” from various perspectives and angles. The decision to add these questions occurred during the second interview when an apparent defensiveness regarding consideration of self without the illness prompted an in-the-moment examination of how to alter the questions to feel safer for the adolescents. The use of what may best be described as externalized questions were then added to the protocol. In subsequent interviews, the following two questions were added: *Some teens who are coping with an illness like you don’t want to think about the future...why do you think that might be?* And, *So you think it is possible that some teens who have an illness like yours might avoid talking about the future...and why do you think that might be?* By externalizing these questions, the adolescents seemed able to think about them more critically and provided significant insights into why avoidance of future thinking occurs. Again, the first interview was the exception, as an externalized version of the question was not posed.

A few basic exploratory questions were also built into the protocols in order to complement the data concerning future thinking processes. Once the occurrence of future thinking activities was established in all interviews, I decided to ask concrete questions to address the frequency of future thinking, the importance of future thinking from the adolescents’ perspective, as well as the relationship between future thinking and decision-making. Understanding the importance of this activity from the perspective of the adolescent provides clear rationale for future orientated discussions. Also, examining how adolescents experience the intersection of future thinking and decision-making gives concrete credence to the assertion that the ability to see oneself in the future is a necessary part of healthcare
decision-making. In some ways I was trying to explore whether the participant could essentially make a case for conversations about future thinking.

**Secondary sources of data**

Secondary sources of data included researcher memos that were verbally recorded immediately following the interview process in order to capture the variety of data represented in the interview. All ten of these memos were transcribed. In addition, field notes were written immediately following the interviews and included information regarding non-verbal behaviour, fluctuations in tone of voice or changes in the pacing of communication, environment, distractions, and the observed status of overall health. Field notes provide important contextual information and can include comments about the interview environment, the introduction of noises or distraction, as well as reflections on the interactive process of the interview (Creswell, 2007).

**Data Analysis and Interpretation**

**Methods of analysis**

Although often presented as separate entities, the process of data analysis and ensuring the credibility of the research process were intimately connected, and therefore, keeping in the form of how the analysis proceeded, it feels pertinent to present them concurrently. Through a consultation with the literature surrounding credibility in narrative research, decisions regarding data analysis were made, retracted and refined, in what turned out to be a 12-month continual iterative process that involved conceptual mapping, narrative summaries, and the development of several stories from the narratives. Rather than attempting to persuade readers by providing a summary paragraph of the actions taken to enhance the credibility of this study, I have selected to take the path of demonstrating this credibility through a clear articulation of the methods of analysis. I do this with an awareness that the true test stands in both the compatibility of my conclusions within the existing networks of beliefs (Seale, 2002), and ultimately, in whether there is reliance on the findings of this study as the basis for further work in the field, a measure of quality described
by Mishler (1990) as “trustworthiness.” In the end, this study’s credibility will be judged by the various audiences to whom the study is intended: the researchers, practitioners, and families who are living with a progressive life-threatening neurodegenerative illness.

I begin the description of analysis with a short detour away from the study and back into the discourses that surround science. Importantly, the indicators and criteria for what is described as “good narrative research” require attention to concepts that are somewhat “messier” or less concrete than those often cited in the quantitative fields. Certainly the most commonly known criteria include reliability, validity, objectivity and replicability, which are mainly quantitative (Lieblich et al., 1998), and contradict the very nature of this qualitative research approach. Arguments of the applicability of quantitative standards to qualitative studies have been well documented elsewhere (Lieblech et al., 1998; Mishler, 1990; Seale, 2002). In an interesting commentary on quality issues in qualitative inquiry, Seale (2002) describes this comparative tendency as resulting in a further divide between the qualitative and quantitative approaches. I tend to agree, and although unwilling to commit fully to his contention that good research can remain autonomous from philosophical and theoretical considerations, I am drawn to his conceptualizations of research as having “the character of a well crafted artifact” (p. 99), and his recognition that the quality we desire in qualitative research is “elusive, hard to pre-specify, but we often know it when we see it” (p. 102). In this respect, he described research to be more like art than science.

As I moved through all stages of analysis, I kept at the forefront the awareness that “narrative work requires self-awareness and self-discipline in the ongoing examination of text against interpretation, and vice versa” (Lieblich et al., 1998, p. 10). My hope is that, through a transparent process of describing the conceptualization and methods of analysis, readers have the opportunity to make a reasoned and informed assessment of my levels of self-awareness and discipline, and in how the dialogue between the interpretive viewpoints offered by existing literature (Lieblich et al.) offered theoretical sensitivity without limiting the ability to openly venture into new areas of discovery. This resulted in a constant movement described by Mishler (1990) as a process wherein theory and analysis are in a continual dialectic with each other and with the data. A detailed movement through the analysis process allows for a full uncovering of the iterative nature of analysis involved. By understanding the decisions made along the way and how they align with the philosophies
and intentions of this study, the overarching hope is that the quality of this study is known when it is seen.

The process of analysis was drawn from various exemplars of narrative research, resulting in a melding together of approaches that suited the character of the current study. Notably, the process of narrative research itself is often depicted through the use of metaphors, and the researchers likened to artists, craftspeople, and travelers, all with the common experience of trying to integrate information from various sources into a semblance of interpretations (Fraser 2004). Indeed, in reference to several studies that have undertaken to examine the process of science itself, Mishler (1990) describes a revealing of scientists as more commonly resembling craftspeople than logicians. The metaphor that resonates most closely with this study is that of the traveler. Fraser describes:

> We may be compared to travelers who embark on a journey and who try to use maps and compasses. Looking for signposts, but not always finding them, we are often challenged by the ‘forks in the road’ or the ‘crossroads’ that appear before us. (p. 183)

Remaining grounded in both clinical practice as well as the sensitivity to the relevant social theories within which the findings of this study might be situated, I began this process of discovery with a collection of vague and incomplete maps. Journeying through the data in this manner provided the opportunity to recognize familiar sights and venture into new places, as well it permitted the important process of getting “lost” and “found”. This approach to the analysis of data required degrees of craftsmanship and artistry. Maintaining conceptual coherence with the overall research design, the analysis proceeded in a structured yet flexible manner. Narrative researchers concur that although a systematic process for data analysis is necessarily developed, the analysis is not meant to be governed by formulas or recipes (Fraser, 2004). Approaches to the analysis of narrative data are diverse, and range from focusing on dimensions of holistic versus categorical approaches, to content versus form (for a full review of the model see Lieblich et al., 1998). This model for the classification and organization of the types of narrative analysis suggests that there are four “cells” within which narratives can be read. Upon review of the data I was challenged in an attempt to locate the potential narrative data from any one of the research questions within one of these
cells. I could not see how focusing on the global form of the narrative or the categorical content of the narrative would suffice. Subsequently, I conducted the analysis of these narratives along both dimensions, directing attention to the way the story is constructed as well as to the events and activities that are included in the story.

Drawing collectively from Fraser’s (2004) conceptualization of seven phases for narrative analysis, Hole’s (2007) offering of four interpretive readings, and Ragin’s (1994) model for constructing social research, I offer a detailed mapping of the iterative process of data analysis that occurred. As a reminder, the data set includes ten audiotaped transcripts, visual data, field notes and research memos. The analysis started with a process I referred to as “Preparing the Data” which involved listening to each audiotape while reviewing the prepared transcript. The purpose of this first step was twofold; first, to check the accuracy of each of the transcripts, and second, to identify the data-rich portions of each interview as related back to the research questions. Similar to what Hole (2007) describes as “reading for content,” significant areas were identified and highlighted in accordance with the research questions.

During this stage I added any content missed through the process of transcription, as well as details related to voice, such as fluctuations in tone and pacing. Subsequently I reviewed the visual data, written field notes as well as the debriefing summaries I had recorded following each of the interviews, all of which became a part of the data set. In listening to the stories I also noted any interruptions or incomplete statements. This was the first stage of re-engaging with the narratives, and upon listening through from beginning to end I approached the narrations in two ways. First, and drawing from Fraser’s (2004) initial phase of analysis, by hearing the stories again I allowed myself to reflect upon the emotion each interview evoked for both me as the researcher as well as any emotion apparent in the narrator. Second, I identified segments of the text that called for additional detail, thereby moving into a second stage of analysis.

The second stage of data analysis involved this process of re-transcription. According to Riessman (1993) the process of re-transcription involves identifying the key moments in the interview where a narrative form of expression is conveyed and essentially re-transcribing line for line what has been shared. This allows for the structure of the narrative to become “unpacked” and permits a closer textual analysis of specific storylines in the
narrative. Portions of the narrative interview were chosen for re-transcription based on whether the content could be directly related back to one of the research questions. A total of nine areas of re-transcription were identified and all subsequent readings of the transcripts included these re-transcribed portions of the narrative interview.

In an effort to maintain a focus on the research questions, I began the third stage by completing a “surface level mapping” of the concepts as they related directly to the research questions. In a lengthy process of engaging with the transcripts, a data map was drawn for each of the ten research participants as a way of having a one-page summary for each of the ten adolescents. In addition, an overarching data map was developed that summarized all ten of the research participants’ answers across eleven categories pulled from the data.

Table 1. Categories for Surface Level Map

<table>
<thead>
<tr>
<th>Categories for Surface Level Data Mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do adolescents with a progressive life-threatening neurodegenerative illness think about the future?</td>
</tr>
<tr>
<td>How far into the future does this projection extend?</td>
</tr>
<tr>
<td>Is there an imagined future that does not include the illness?</td>
</tr>
<tr>
<td>Do they value one of their future selves more than the others?</td>
</tr>
<tr>
<td>What is the range of “real” possible selves that they identify?</td>
</tr>
<tr>
<td>What is the range of “imagined” possible selves that they identify?</td>
</tr>
<tr>
<td>Who do they talk to about their real future and their imagined future?</td>
</tr>
<tr>
<td>Do they have a private self?</td>
</tr>
<tr>
<td>Do they avoid talking about the future?</td>
</tr>
<tr>
<td>Do they use future thinking to plan for their healthcare?</td>
</tr>
<tr>
<td>Do they think future thinking is important?</td>
</tr>
</tbody>
</table>

Subsequently, the movement of data into tables proved helpful in two ways. First, it served the purpose of organizing a vast amount of data into a manageable framework that could be used to launch into each narrative for a contextualized analysis. Secondly, it highlighted the consistencies and contradictions both within and across the narratives. Interestingly, despite my initial resistance to treating the data in this seemingly fragmented manner, this process of approaching the data permitted consideration from the distinct vantage point of almost descriptive quantification, and proved to be a helpful exercise in appreciating some of the trends in the data. However, what must be emphasized, and as will be demonstrated, during all phases of analysis the content presented in these maps was not
analyzed without again situating the data within the context of the narratives, thereby attending to the sequence and consequence of the narrative events.

**The readings**

Drawing from selected literature on narrative analysis (Fraser, 2004; Hole, 2007; Riessman & Quinney, 2005), several readings and steps were employed in the analysis of data. Extracting most significantly from the work of Fraser (2004) and Hole (2007), the analysis occurred across several readings of the text as well as through the process of circling back to the previously constructed data maps. A total of five readings occurred and are outlined, with the first four examining the stories within each case and the final reading extending across the ten cases. As described by Chase (2005), the narrative process often first involves listening to the voices and stories within each narrative before locating distinct themes across the interviews.

In the first of the series of readings, each transcript was read again with the intention of focusing on the specificity residing within each transcript. As a way of guarding against what Riessman and Quinney (2005) describe as a fragmenting into thematic categories, the categories and themes that emerged remained contextualized within the individual narratives wherein sets of ideas emerged but remained as part of an unfolding plot (Fraser, 2004). Again, this provided the opportunity for tensions and contradictions as well as degrees of consistencies and coherence to emerge within each narrative. As various ideas moved to the forefront, I began a process of charting and naming these as stories with the effect of establishing an ease of recall of the sets of ideas contained within the narratives (Fraser, 2004). As an additional level of detail, I mapped these stories onto a large sheet of paper hanging above my desk, and these stories became known to me as “stepping-in” stories, a title that would act as a constant reminder of the importance of maintaining each story as connected within the text of each narrative.

Following this, and drawing from the outline provided by Hole (2007), the second reading involved a close listening for “who” I was hearing within each narrator, which resulted in the identification of various “selves” emerging in the telling of the story. Aligned with the philosophical approach that encourages consideration of multiple voices as well as theoretical sensitivity to the multiplicity of the self, this reading offered the opportunity for
me to listen for the range of selves that appear within one narrative account. Following this, by integrating the stepping-in stories with the ‘voices’ of the narrator, I was able to write a narrative summary for each of the participants that included a list of ‘characters’ as well as ‘storylines’. The result was a ‘narrative summary’ for each of the ten adolescents. In addition to storylines and characters I added the contextual information that became known to me during the interview (i.e., notations of observed disease progression, family structure, cues taken from interview environment). This added level of detail permitted further contextualization of the narrative.

The third reading involved a process of reading each of the narrative summaries alongside each of the transcripts to note any contradictions and tensions that emerge. The intention was not to work towards elimination of these tensions, but rather to note the places of convergence and divergence between these two data sets. The occurrence of a storyline or character listed in the summary that appeared to not correspond with the tone of the narrative prompted a closer examination of the text. Importantly, through this process a macro-narrative emerged that revealed how this experience of living involves a life of paradox wherein various aspects of both health and illness coexist.

In the fourth reading, attention was drawn toward the cultural stories and discourses (Hole, 2007) in what Fraser (2004) refers to as a linking between the personal and the political. The analysis that occurs through this reading offers a lens of consideration toward social conventions and dominant discourses (Fraser) that can often be heard in the narrative activity. The focus during this phase of analysis was to begin to explore what the stories might be saying about the multiple experiences of the participants (Fraser). Importantly, during this analytic reading the “taking up” of a conventional cultural script reflective of what is commonly recognized as a normative pattern of development and movement through the life cycle was identified.

The final reading prompted the view to shift from within each narrative to across as I looked for commonalities and differences among the participants. Examining the transcripts collectively permitted the emergence of patterns that had thus far remained subdued within the individual context. Themes emerging across more than one narrative were coded and categorized. This approach is closely aligned with what is often described as the categorical-content approach or “content analysis” whereby categories are defined and data across all
transcripts are coded for these categories and extracted from the larger narrative into categorical groups (Lieblich et al., 1998). A clustering of plots, events and themes (Fraser, 2004) produced a connection between narratives that had to this point remained hidden. Essentially, a model for future thinking activities as strategies for living with a progressive life-threatening neurodegenerative illness emerged.

Importantly, within each reading, an interrogation of language occurred (Riessman & Quinney, 2005) wherein I considered the importance of the choice of words, focusing on not just the content of the narratives but also the intentionality in how they were told. This began during the interviews through a process of drawing attention to the use of certain words or phrases (i.e., “that was interesting when you said…”). Continued as well during the readings of each narrative, evocative words, such as “freedom”, references to “gained maturity” and phrases such as “one day at a time” were noted and then explored within the phrase and context of the narrative; subsequently many of these words were used as titles to the stepping-in stories.

I am fully aware that at this stage of the dissertation all claims of adherence to methodological procedures currently stands in the absence of any evidence of the finished product and therefore is difficult to assess. Mishler (1990) claimed that, “legitimacy cannot be legislated in advance. Neither abstract rules nor appeal to an idealized version of the scientific method will suffice. Rather, the defining features of exemplars are inferred by the actual practices of working scientists” (p. 423). Upon consideration of the range of studies that have received either applause for achieving high standards of narrative research, as well as those that have been criticized for claiming a narrative approach but upon closer examination followed procedures more closely suited to alternate approaches, I conclude this chapter by clearly identifying the features of this study that demonstrate methodological coherence with the narrative approach.

First, all interviews were audiotaped and transcribed in their full narrative form (Mishler, 1990), and the work of analysis extended from these detailed transcripts (Riessman & Quinney, 2005) that included notes of voice fluctuations, and aspects of the non-verbal telling of the stories. Secondly, repeated readings of each transcript occurred and the tape was reviewed when the full context required closer examination. Thirdly, as suggested by Lieblich et al. (1998), when utterances or single episodes stood out as significant the
resulting shift in focus toward a theme involved the identification of stories within narrative accounts that subsequently remained contextualized and read as part of the “whole” narrative. Fourthly, the discovery of parallels and commonalities across participants allowed for an interweaving of themes into a larger collective narrative. Importantly, during all stages of analysis careful consideration was given to the use of language and to how the participants, through their narrative accounts have taken up, or reveal cultural and social discourses.

In the service of ensuring the credibility of this study, a concerted effort has been put forth to present the results as a continual integration of direct quotations from the text and to add evidence of the context surrounding these quotes. The data is presented in this transparent manner, thereby permitting each reader to hear the words of the narratives and to draw conclusions about what Mishler (1990) describes as “the warrants for the claims” that are made during the presentation of findings.

In a final statement regarding the credibility of this study I wish to extend favor toward what Mishler (1990) describes as “trustworthiness”. The appeal of this dimension of credibility was immediately apparent to me as I considered the various ways in which this research might be evaluated. Trustworthiness is defined as the degree to which one can rely on the concepts included, methods used, and the inferences drawn, and ultimately whether the relevant scientific communities evaluate the reported findings as trustworthy enough to rely on for their own work (Mishler, 1990). Similarly, Lieblich et al. (1998) describe a process of consensual validation as a process of “namely, sharing one’s views and conclusions and making sense in the eyes of a community of researchers and interested, informed individuals” (p. 173). By being transparent I aim to allow readers an opportunity to make a reasoned and informed assessment of the steps taken to ensure credibility during all stages of the crafting of this research. I hope that the craftsmanship has been revealed and that the findings of this study might serve as a springboard for additional inquiry with the research population.
Chapter 4. Future Thinking Activities

If you don’t think about the future, it will just come and you won’t know what to do with it. What I find is you plan a future without even knowing you are. It just automatically happens. Your body memory puts some collage together and explains it in words. — Markus

This first chapter of findings will address future thinking by describing the occurrence of this activity within the research sample as well as considering how far into the future the thinking extends. Additionally, aspects of what is hoped-for and feared-for within this future space will be examined, followed by an exploration of possible selves. Within this first section of findings, the three research questions that are addressed include: Do adolescents who are living with a progressive life-threatening neurodegenerative illness construct an orientation to the future? How many years does this future projection extend? And finally, what are the hopes and fears surrounding the future? As a reminder, the term future orientation refers to where one wants to ‘get to’ in the future and consists of images of oneself that include both hopes and fears.

Drawing from a self-approach to the examination of future orientation, it is assumed that the constructed visions of the self are likely to be varied and may or may not lead to a specific plan. As such, the study voyages into a fourth and related domain of inquiry with the intention of acquiring a deeper understanding of the concept of possible selves as the chosen approach to study future orientation within this population. Thus, in the final section of this chapter a fourth question is addressed: Do adolescents with a progressive life-threatening neurodegenerative illness construct an orientation to the future that does not include the illness? Data are presented to reveal the myriad of possible selves imagined within the research sample.

Are They Future Thinking?

Logically, the presentation of findings begins with the concrete evidence of the future thinking activities that were conveyed through the narrative interview. The data offered in Table 2 offers a broad snapshot of this activity by capturing the participants’ responses to the
question of whether they think about the future, and subsequently, how far this projection extends. The data contained in this table was obtained within the first ten minutes of initiating the interview, and therefore the responses are embedded within this stage of an evolving exploration of the self through this narrative interview. Significantly, even at this early stage of the construction of the narratives, across all ten narratives an orientation to the future was demonstrated with variance occurring in the extent and distance of the projected future.

Table 2. The Occurrence and Extension of Future Thinking

<table>
<thead>
<tr>
<th>Age of Participant</th>
<th>Do you think about the future?</th>
<th>How far does this future extend?</th>
</tr>
</thead>
<tbody>
<tr>
<td>18</td>
<td>Yes</td>
<td>10 years</td>
</tr>
<tr>
<td>16</td>
<td>Yes</td>
<td>5-10 years</td>
</tr>
<tr>
<td>16</td>
<td>Yes</td>
<td>10 years</td>
</tr>
<tr>
<td>12</td>
<td>Yes</td>
<td>20 years</td>
</tr>
<tr>
<td>19</td>
<td>Not sure/maybe</td>
<td>1-2 years</td>
</tr>
<tr>
<td>19</td>
<td>Not much</td>
<td>Months</td>
</tr>
<tr>
<td>20</td>
<td>A little bit</td>
<td>Days to weeks</td>
</tr>
<tr>
<td>14</td>
<td>Yes</td>
<td>10 years</td>
</tr>
<tr>
<td>18</td>
<td>Yes</td>
<td>1 year</td>
</tr>
<tr>
<td>18</td>
<td>Yes</td>
<td>10 years</td>
</tr>
</tbody>
</table>

The data presented in Table 2 was obtained during the initial stage of the research interview, and therefore it feels pertinent to issue a caution related to the information. Certainly the evidence clearly supports the prevalence of future thinking and this is a significant starting point for the research. However, when these responses are situated within the broader narrative, a variation in levels of insight into this activity is revealed by the contradictions that emerged within particular narratives. Ultimately, an increase in self-understanding and insight was often evidenced by the demonstration of a heightened awareness that was seemingly gained through the narrative activity. Accordingly, the information in Table 2 captures the levels of awareness at the beginning of each narrative story. By situating these early responses into the full narrative account, several disparities
emerge between the stated activity and the developed story. For instance, Alan initially expressed uncertainty about an engagement in future thinking activities, yet after an hour of discussion he returned to his initial answer: “not much” and reflected, “I figure that is not really accurate. I do think about the future.” When asked how often he responded, “I guess once or twice a day.” Demonstrated in different ways across the narrative accounts, the interview appeared to have facilitated an increase in awareness of the activity, thereby revealing that it is only by venturing deeper into the full narrative accounts that we are able to pull back the layers of this experience.

Projections of a future self in the context of a progressive life-threatening neurodegenerative illness as presented through the construction of individual narratives, revealed the distinct nuances involved in the pursuit of an identity that can withstand a necessary integration of loss amidst growth. Efforts towards understanding this experience required a dance between recognizing that an engagement in future thinking within this population is a shared experience, and yet the character and nature of these activities are unique to the individual. Thus, an understanding is best achieved by moving between the individual and collective experience. The results are presented in this manner as a way of prompting the reader to visualize the stepping-in and stepping-back process that was involved in my discovery of findings.

The stepping-in process facilitated a more intimate relationship with each of the stories embedded within the narrative accounts and although the temptation for me to remain inside each of the stories was ever present, it proved to be an important part of the analysis process to also step back to examine and contextualize the narratives collectively, thereby prompting the consideration of how these stories converge and diverge from one another. Through this process of stepping-back an overarching finding emerged that will essentially serve as “bookends” to hold the results section of this dissertation together. Conveyed both directly and indirectly, the message that transcended across the stories is the existence of a drive that fuels the activity of future thinking within this complex life circumstance. Scribbled across iterations of data analysis and located across several narratives, the future projections of adolescents with a life-threatening illness are motivated by a desire to “come to know the unknown”, a model that will be presented and expanded upon across the next three chapters.
The emerging picture reveals that for the adolescents in this study the projection of self across time is a common occurrence. However, despite having a general idea that prospective thinking is happening, the picture remains vague. For instance, the term “future” is most commonly used as a reference to “a time that is yet to come”; however, what remains unstated within this conceptualization of future is whether there are parameters to establish whether a certain length of time from the present is required in order to deem it “the future”. Therefore, when I am referring to the future I might be referring to the “future” meeting that I am planning to attend this afternoon, or the “future” plans I have for the summer months, or the “future” ideas I have about the trajectory of my life over the next 20 years. Certainly, what constitutes the “future” depends on what I am talking about and therefore this concept is malleable across contexts. The fluidity of this concept bears significant importance on a research study examining a proclivity toward future thinking among adolescents living with a life-threatening illness, and therefore, as a starting point, it was deemed necessary to first explore precisely what was meant when these adolescents referred to the future.

Thinking “all the way”

To capture the concept of future thinking a visual timeline was used in each narrative interview as a prompt for a narrative of self across time. To encourage this exploration a large piece of paper was made available with a long line and the words past, present, and future underneath. Within this framework, I aimed for specificity by asking each of the participants how far into the future their projection extends. A quantification of years uncovers precisely what each of the participants is referring to as they describe a projection of self into the future. Importantly, as presented in Table 2 there was a vast range that included an engagement in thinking only days to weeks ahead, to a projection into the future as far as 20 years beyond the present. Interestingly, the range extends from a desire to think only very short-term to an ability to think well beyond what might be the life expectancy for a progressive life-threatening neurodegenerative illness. Notably, within this sample the youngest participant projects the greatest distance (a 12-year-old projecting 20 years), and the oldest participants’ future projections are limited to a range that extends from days up to two years. Although not considered a focus of this particular study, it would be interesting to explore the trends in the prospective time span and the association to disease progression or
life expectancy within a sample of adolescents with life-threatening illness. Certainly within this sample there is evidence that suggests that as the adolescents’ age increases and the conceptual space between “age” and “life expectancy” decreases the extension into the future may also decrease.

Recognizing the subjectivity of a concept such as “future”, the interview questions were grounded in the assumption that each participant is likely to conceptualize “future” differently. Interestingly, it was within moments of the first interview that it became apparent that in order to ensure a movement toward understanding what the participant was referring to when talking about “future thinking” activities, that the language used around future requires closer examination. An excerpt from the first interview conducted illustrates the importance of prompting a clarification of meanings:

Meaghen: How far into the future do you think about yourself?  
Riley: All the way.  
Meaghen: Okay, so if I were to ask you to think of yourself and your future in terms of weeks, years, decades…?  
Riley: Ten years. I’d probably say ten years.  
Meaghen: Ten years?  
Riley: Only ten years because that is as far as I want to look ahead.

As will be discussed later, the adolescents in this study have demonstrated consistent temporal extension when compared to the literature that examines this extension in typically developing adolescents. However, Riley’s reference to “all the way” may suggest that he is attempting to project fully through his life course. Under other circumstances, an 18-year-old making reference to thinking “all the way” into his future is likely to conjure up images of a progression through adulthood to old age and perhaps even to death. Although not directly stated as such, this particular reference serves as a reminder of the uniqueness of this life course as this participant demonstrates the delicate management of future thinking activities within the context of a progressive life-threatening neurodegenerative illness.
The Hoped-For Future

Finding a place for hopes and dreams when the future is uncertain is an important yet challenging undertaking. As described in the literature surrounding future orientation and possible selves, the destinations that are reached during this activity include aspects of the future that is hoped-for, as well as those that are feared. Accordingly, the narrative interview posed specific questions aimed at venturing into these specific dimensions of the future space. During one of the interviews, the answer to this question departed considerably from what had been a cautiously spoken and richly described narrative.

Meaghen: Is there a particular future that you hope for?
Rodney: (immediate response) …a good future and a good life.

Up to this point Rodney had shared his story in a reserved manner, evidenced by the silences noted throughout the transcript and especially common when venturing into new areas of discovery. Rodney would often pause after questions and proceed with an answer that would be accompanied with a descriptive account that resulted in a rich and vivid narrative. Through further exploration of this statement it was revealed to me that for Rodney, a good future and life would include “a nice home, lots of money, and one kid to spoil.” This type of an interweaving of aspirations was clearly demonstrated across the various expressions of hope. In Table 3 a sampling of the narratives is provided and the data is organized into categories and themes.
Table 3. Extensions of a Hoped-For Future

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
<th>Sample Narratives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>Practical</td>
<td>I would like to continue my education…maybe like social sciences.</td>
</tr>
<tr>
<td>Education/Occupation</td>
<td>Practical</td>
<td>Like finish school, go to university, stuff like that. Get a good job. Stuff like that.</td>
</tr>
<tr>
<td>Education</td>
<td>Practical</td>
<td>Once I am done school then I can register for university of college or something if I can get into there. Whether it be computer or photography.</td>
</tr>
<tr>
<td>Education/Occupation</td>
<td>Practical</td>
<td>I want to be out of school. Finish school. Then I guess get a good job—that would be cool. Probably...I don’t know what. Just hang out, I guess if I can.</td>
</tr>
<tr>
<td>Relationships</td>
<td>Relational</td>
<td>Stay connected, stay in touch with people.</td>
</tr>
<tr>
<td>Relationships</td>
<td>Relational</td>
<td>Having a family or something like that.</td>
</tr>
<tr>
<td>Relationships</td>
<td>Relational</td>
<td>Lots of good people around me—relationships.</td>
</tr>
<tr>
<td>Moving/Occupation</td>
<td>Practical</td>
<td>I hope to move out of Canada, either to England or into the States. Developing my career in the industry.</td>
</tr>
<tr>
<td>Occupation/Health</td>
<td>Practical/Health Related</td>
<td>That I get a good job, that I am healthy as best as I can be.</td>
</tr>
<tr>
<td>Regard</td>
<td>Relational</td>
<td>Be respected. Not that I am not now but continue to be respected.</td>
</tr>
<tr>
<td>Regard</td>
<td>Relational/Health Related</td>
<td>Be just the right size—somebody who looks fit—like just the right size.</td>
</tr>
<tr>
<td>Function</td>
<td>Health Related</td>
<td>To keep walking. Playing wheelchair soccer. Improving on skiing…sit-skiing. I learned how to do it this year for the first time. It was fun.</td>
</tr>
<tr>
<td>Health</td>
<td>Health Related</td>
<td>I want my health to stay the same and not get worse.</td>
</tr>
<tr>
<td>Function</td>
<td>Health Related</td>
<td>To walk and to feel my hands…that is what I hope for.</td>
</tr>
</tbody>
</table>

Important, when looking across narrative accounts to consider the themes that surfaced among individual accounts, the aspirations that emerged could be located within three life domains identified as: 1) practical: “Like finish school, go to university, stuff like that. Get a good job, stuff like that”; 2) relational: “Make sure I stay in touch with friends, friends really help me out in situations”; and 3) health related: “No visits to the hospital - that is what I want.”
Mirroring much of what is known in the literature as the “prospective life course”, the participants in this study reveal consistent patterns of hopes across the core domains of higher education, work and career, marriage and family, and self-concerns (Lewin 1942). More specifically within the research sample, expressions of hope included the pursuit of a range of careers (i.e., fashion design, writing, architect, nurse); the quest for financial stability (i.e., high wage, nice house, lots of money); the desire for meaningful relationships that included friendships, marriage and parenthood; and an appreciation for stability within the illness experience.

Sharpening the focus to examine the aspects of this experience that mark it as different from a typically developing adolescent, in five of the narratives the domain of “self concerns” centers upon matters of physical health related to the progression of the disease. Across these five narratives a range of hopes can be heard. There is a desire for stability within the illness: “[I] just want my health to stay the same”; a primary focus on the physical aspects of disease progression: “[I want to] keep walking, play power soccer, improve on sit-skiing”; an appreciation for the present condition and an expression of hopefulness: “Right now I do feel well, I am hoping I will be okay” and “[I hope to have] no visits to the hospital”; and finally a tone of acceptance for a life that contains a constant threat of illness: “[I hope] that I am as healthy as I can be.”

The interconnectedness of aspirations was revealed within the narrative accounts, and through a process of stepping in closer to the text and reading the full account I witnessed how a hope can be anchored in a desire for financial security as well as to have a relationship with a child: “Nice house with lots of money and one kid to spoil.” I hear the greatest wish as attaining work, maintaining health, and focusing on happiness: “Get a good job, that I’m healthy, the best I can be – and obviously that I’m happy too because that plays a big role. I believe that it affects your whole life – being happy keeps me motivated and I think it helps my health too.” As well, through the process of stepping back the stories speak to an ability to swim through the complexity as it becomes apparent that this life experience does not preclude a commonly shared desire to achieve fulfillment in various domains of life: to have a purpose, to find meaning, to establish security, to protect, to gain status, and to experience love.
One of the purposes of this research was to explore the experience of future thinking activities through an exploration of the range of possible future selves that are developed. Accordingly, moving into the narrative text allowed me to witness a forecasting of aspirations beyond the present time. As the hopes were expressed in each narrative I found myself intrigued by the familiarity of what was being described. If not for the visual reminder of this uncommon experience of adolescence, I could be easily convinced that I was interviewing a healthy adolescent about future goals. Wishing to complete high school “on time” and to continue on with post-secondary education, striving to maintain relationships, and finding a career that is fulfilling are all commonly shared goals among individuals in this particular stage of life. A few of the narratives provide a more detailed conviction of career aspirations. Congruent with the idea that individuals draw from the structures that are available to them, the stories shared demonstrate an inherent interplay between the individuals’ needs and the socio-cultural setting. This important finding confirms that even within the exceptional circumstance of developing amidst a progressive life-threatening neurodegenerative illness the stories of these adolescents are firmly embedded within a cultural script of normative developmental processes.

Notably, upon reviewing the narratives, and as described in Table 2, the first major theme to emerge within the “practical” domain was the importance of identifying a career path and pursuing the education and skills necessary to succeed. Interestingly, for some, the pursuit of education was not so much a means to an end but rather a goal in and of itself. A few of the participants described interest in “continuing education” due to an interest in learning and a desire to be engaged in an intellectual activity. Riley described: “I would like to continue my education” and when asked if there was a specific direction or area of study he appeared unsure: “No [specific focus]…well…maybe social sciences.” As well, after identifying education broadly as a hoped-for future Julian described: “Not really [specific area of interest]. Hopefully would take some classes online…with friends…occupy time.” Finally, Alan projected a hoped-for future self that involved a graduation from high school, he explained: “then I can register for university or college or something if I can get into there…whether it be computer stuff or photography.”

The majority of respondents were able to describe a quest for ongoing education that was clearly linked to specific interests in career paths. Several of the participants had many
ideas of the careers they might like to pursue. Interestingly, Logan’s narrative contained the paradox of clarity (i.e., “I have images of future professional selves in a career”) and ambiguity (i.e., “it’s hard to commit to just one of those future images”). I explored this further with him and encountered a hesitance to choose just one career path. He described his future hopes as: “Like finish school, go to University, stuff like that. Get a good job, stuff like that”; when asked to specify further he conveyed his desire: “to be successful, get a good job…something like a journalist. Something like that. It is not set in stone.” All participants were given the opportunity to refine their answers to include greater detail. Rodney described his future self as: “That I get a good job, that I am healthy as best I can be,” and when asked what a “good job” looks like he considers the question for a few brief moments and responds, “I think an accountant, I think I might be an accountant when I get older.” Markus includes the attainment of a good job, money, a house and a family as the core features of his hoped-for self. He explained his desire to “get a really good job, like an architect, that is what I want to be. Or a nurse…or something.”

The hoped-for future selves ranged from vague to concrete with all of them sharing the common theme of progressing through education toward a career. Jim was the least specific regarding his hoped-for future self: “I want to be out of school. Finish school. Then I guess get a job – that would be cool…probably. I don’t know what. Just hang out, I guess, if I can.” At a later point in the interview he expanded his aspirations to a specific area of life from which he draws great pleasure. He explained: “I want to work at a movie theatre…then I would get in free. That would be a good job. Probably…nothing else. I could work in a movie, like act and work at the other place.” One participant expressed a wish to “continue education and publish a book” and had already been in contact with a few authors and shared this plan with friends and family. Victory’s hopes for the future rang the clearest across all narratives as she had evidently spent a great deal of time thinking about this aspect of her future self: “I hope to move out of Canada, either to England or to the States. Probably get more fashion work, like more direct to my career and stuff. Developing my career in the industry…to move, moving out of Canada is what I really hope for.” Hearing some of these more specific goals furthers our understanding of the nature of future thinking activities by supporting the notion that not only are the adolescents considering their future in a broad or
general sense, but also they are developing plans with specific goals and well-defined career aspirations.

The relational domain is particularly interesting as the quest for meaningful relationships is authentically revealed. There was a common acknowledgement that establishing and maintaining close relationships was of the utmost importance: “Make sure I stay in touch with friends. Friends really help me out in situations.” As well, another participant described hoping to always have “good people around [me].” Poignantly, Riley took this opportunity to honor a specific relationship by emphasizing the importance of a common connection:

Riley: Stay in touch with people, watch hockey games together. I am having friends over tonight. I talk to friends. I stay in touch with [states name] we have very similar things with our health – completely different but very similar.

Meaghen: So you find that you have built a relationship on that?
Riley: Not really talking—we talk—but we kind of “feel each other” like we can just say to each other “life really sucks.”

Markedly, the connections to social support were looked upon as essential for both emotional and practical reasons. An attunement to a necessary dependence on others for care and support was evident and in some cases the adolescents were transparent about how this serves as an incentive to establishing and maintaining relationships, a concept that will be expanded upon in chapter six.

Expectedly, the expression of hope extended to aspects of personal health. The third domain involves the matters of health and serves again as a reminder that despite the appearance of a hoped-for future that closely mirrors that of a typically developing adolescent, there is the awareness that a focus on health is a required part of future hopes. As an interviewer I found it interesting that the conversation moved with ease from what might be described as “familiar territory” to the reality of how different this experience really is. Billy responded to the question of hope without hesitation: “To keep walking. Playing wheelchair soccer. Improving my power soccer. Improving on skiing…sit-skiing. I learned
how to do it this year for the first time. I want to continue doing that. It was fun.” In an excerpt from a field note following this interview I am reminded that these moments of what I called “grounding” indicated that the adolescents were able to manage the task of investing in a future that includes the typical milestones and hopes of adolescence and young adulthood to the harshness of knowing that there is a backdrop to this story that complicates matters significantly.

Ostensibly this backdrop alters the parameters of expressed hope. Interestingly, the hope for a cure was not a significant theme as we ventured for the first time into a hoped-for future. It was mentioned by two of the participants but it was mentioned in the context of “if anything was possible” this is what I would hope for. As well, one of the participants expressed a wish “to walk and to feel my hands” as the progression of the disease had taken away mobility as well as any sensation or functioning in both hands. Across all narratives it was evident that the stories were being constructed to include not only the diagnosis but also ultimately the progression of the disease. In an apparent adjustment of hope, wherein the disease is firmly integrated into the future projection, the expressed wishes included stability in the progression of the illness and an avoidance of hospitalizations. Appreciating the tenuous nature of the illness experience, Riley tentatively described his current health status, “right now I do feel well, I am hoping I will be okay.” Understanding that a cascade of losses is likely to ensue there is a general recognition that periods of plateaus offer a reprieve from the inevitable progression of disease.

The Feared-For Future

Expectedly, when this population engages in future thinking they feel fearful of both what is known, as well as what is not known. Surrendering oneself to the ambiguity of the future can be a daunting task for anyone. The additional layer of a life history that includes a body that has oftentimes betrayed all intentions complicates matters tremendously. Not surprisingly, all but one of the narratives included specific fears about the anticipated real future as well as the acknowledgement that as a result of this complicated life trajectory, engaging in future thinking was difficult. It was during the fourth interview that I came face to face with the harsh awareness of the obvious. Sitting alongside Markus whose overall
narrative reveals a transparency I had not yet experienced in prior interviews, perhaps I should have been prepared for his answer when asked the question of a feared-for future:

Meaghen: Is there a particular part of the future you are fearful of?
Markus: Yes, the one with muscular dystrophy...like whoa.

Making direct eye contact and with cheeks flushed due partially to the warmth in the small room, Markus answers this question honestly and precisely. His response is not spoken harshly, but rather in a matter-of-fact manner. The silence of reflection is held and after a few moments he continues, speaking softly he says, “the fact that I have MD...like whoa.”

As presented in Table 4, the participants have specific fears about their health and more broadly, a fear of what the future holds. Pronounced clearly across the narratives is an all-encompassing fear of the unknown that is riddled with the uncertainty of a variable disease progression, which for some translates into an ominous fear of unmet expectations.
Table 4. Extensions of a Feared-For Future

<table>
<thead>
<tr>
<th>Category</th>
<th>Theme</th>
<th>Sample Narratives</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health</td>
<td>Illness Progression</td>
<td>I think about health worsening</td>
</tr>
<tr>
<td>Health</td>
<td>Illness Progression</td>
<td>Like, I guess, any health problems. Something I worry about</td>
</tr>
<tr>
<td>Health</td>
<td>Illness Progression</td>
<td>I don’t know. I guess worried about when I have to use a trach¹</td>
</tr>
<tr>
<td>Health</td>
<td>Illness Progression</td>
<td>Getting worse</td>
</tr>
<tr>
<td>Health</td>
<td>Illness Progression</td>
<td>I guess like maybe like making decisions about wheelchairs…there will probably be new ones out there</td>
</tr>
<tr>
<td>Future</td>
<td>Uncertainty</td>
<td>Yeah, I do not know that the future will hold</td>
</tr>
<tr>
<td>Future</td>
<td>Uncertainty/Unmet Expectations</td>
<td>I am just worried that everything will not go as planned</td>
</tr>
<tr>
<td>Future</td>
<td>Unmet Expectations</td>
<td>I worry about getting to where I want to be. Succeeding to where I want to be in the industry</td>
</tr>
<tr>
<td>Future/Health</td>
<td>Uncertainty/Illness Progression</td>
<td>I am worried about getting into the adult program and what it’s like to go from care I am used to and off to new care</td>
</tr>
<tr>
<td>Future/Losses</td>
<td>Uncertainty/Losses</td>
<td>Spiders. I don’t know. My mom and dad and my papa. I worry about my family and dogs. I guess I worry about my mom passing away</td>
</tr>
<tr>
<td>Future</td>
<td>Uncertainty/Illness Progression/Unmet Expectations</td>
<td>That is what I am most scared about because I do not want to end up on the street especially with MD, that would be terrible</td>
</tr>
<tr>
<td>Nothing</td>
<td>Nothing</td>
<td>No…nothing really</td>
</tr>
</tbody>
</table>

Although distinct in their character, an interweaving of fears emerges from, and are connected to, the experience of living with a progressive life-threatening neurodegenerative illness. The sample narratives provided in Table 4 illustrate the arduous task of maintaining a vision of oneself in the future that encompasses the wide variances in this particular illness trajectory, bringing to the surface stories with tones of both uncertainty and paradox. Not surprisingly, the most commonly expressed fear of the future is firmly anchored in an awareness of the inevitable losses that will be scattered variably across the years ahead: “I know when I get older I will become more dependent but I want to be a more independent person. So that might bother me – I know I will be more dependent…that frustrates me.”

¹ The participant is referring to a tracheotomy
The feared-for future self was predominantly tied to disease progression. Statements ranged from a general concern for “health worsening” and worry about “my appearance” to the more specific fear of “getting pneumonia” and “not being able to walk anymore”, and finally to the fear of a specific intervention: “uncertainty, like maybe getting at trach [referring to a tracheotomy].”

In addition to recognizing the impending losses the participants also conveyed that living in the space of “not knowing” resulted in a general sense of insecurity. For instance, the uncertainty of the future was identified as a fear: “I just don’t really know what the future will hold” and “the future is scary because of uncertainty.” Even during healthy periods the apprehension surrounding uncertainties regarding health status appear to be ever present as described here: “my health I guess. I am pretty healthy but sometimes I worry about getting pneumonia, it just scares me. Like being in the hospital for months…that makes me worry.”

A few respondents were specific and concrete in their description of fears that included being concerned about the potential of requiring a tracheotomy and ventilation and the uncertainty of what it will be like to transition from pediatric to adult care. The consequence of living in this space of not knowing was revealed poignantly within one of the narrative accounts as the illness rendered one of the participants as feeling vulnerable to a life of insecurity. His story conveys a distressing concern that he would be homeless and unable to provide for himself or a family. When asked if there was a specific fear he had about the future Markus replied instantly: “…to end up on the streets with muscular dystrophy…that would be terrible.” This vulnerable self was revealed at several points in the interview as many of his aspirations were tied first and foremost to obtaining a status that would afford a life of security that could then be extended to a partner and a child.

Meaghen: Can you tell me a story about your “best” future?
Markus: Twenty years. Have a nice house, have lots of money. A good life.
That is what I plan. I want to live in a nice place.

Meaghen: Are you living with anyone?
Markus: I would be living with someone.

Meaghen: Would that be someone to have a family with?
Markus: (Smiling) Yes (emphasized with certainty).
Meaghen: So 20 years from now, you are hoping that you are in a relationship?
Markus: Mmmhmmmm.
Meaghen: I wonder what else...
Markus: Yes. One kid because then I could spoil it.
Meaghen: You have a nice house, a partner and a child.
Markus: Bigger than most ordinary houses...I have a good job and I get a high wage. Like not the minimum.
Meaghen: You hoped you would have a good future and a good life.
Markus: One that is not on the street.
Meaghen: You have said that a few times; you are really worried about that.
Markus: It does bother me. As long as I live in a house, have a vehicle and all that stuff. Food on your table. Electricity and water and that kind of stuff, that is all that I would need.

As the exploration of fears continued it became clear that for some participants “fear” presents as a counterargument for hope. Essentially, the narrative tone across several interviews includes the idea that an engagement and investment in specific hopes poses the significant risk of unmet expectations, dissatisfaction with accomplishments, and may act as a measurement of failure. Undeniably, it is considerably less risky to establish specific goals and hopes for one’s self when life is moving along in a seemingly unobstructed manner. However, for adolescents in this circumstance a movement into the years ahead does not occur in a clear and direct manner; hence, a specificity of wishes and expectations could potentially lead to disappointment.

This theme emerged with prominence in the narratives containing clearly constructed hopes and goals. The second line of Markus’ transcript reads, “Yeah, I do not know what the future is to hold.” He revisits this uncertainty again only a few moments into the interview: “I am just worried that everything might not go as planned,” and follows moments later, “Quite a bit [thinking about the future] just wondering. I don’t know, I don’t want things not to go the way that I planned out, the way I expected them to be, I am just worried that the plan does not go as I thought.” Alan describes one of his hoped-for selves as being able to ride his wheelchair across Canada, and in a notably sad tone he described: “That is just a pipe dream.
I told my Mom...like you just don’t know what life can hold. Like you might just for some reason do it. But I don’t know. Like it is like if it is going to happen, it will happen. Life is not predictable. You don’t think in advance...it just happens.” Finally, Victory’s narrative reveals that voyages outside of her home country in pursuit of a career in the fashion industry is accompanied by a feared future self. She described: “A future me that is scary is not being happy with what I have accomplished. Not being happy with what I have done.” By virtue of having concrete and defined goals these participants describe the fear that everything will not go as planned and where a future self falls short of their own expectations.

Victory’s full narrative account reveals much about each of the aspects of future thinking that has thus far been explored. Selected for the manner in which she speaks about her well-constructed future, I was drawn back into her narrative account by one of the “stories” I had identified and tracked during the analysis. Named for the clarity with which she spoke of her anticipated future self, and pulling from various places across her narrative account, “it’s the day my collection comes out” captures her experience of managing the connected nature of her hoped-for and feared-for future selves.

**It’s the day my collection comes out**

Victory arrives at the interview full of energy and excitement. Within minutes of arriving she asks for me to pull a shopping bag from the back of her wheelchair. I find a bright colored bag and pull it out as her eyes light up and she smiles. “Those are the shoes for my prom dress,” she explains. “I looked all day and just found them, they are the perfect color for my dress.” The excited anticipation of this event is evident by the manner in which she describes what appeared to be a month-long process of choosing just the “right shoes.”

Anchored by this opening dialogue, the voyage into the questions about the future seemed like a natural extension of what was in the forefront of Victory’s mind. Accordingly, within a minute of starting she described a turning point in her life: “Probably (a turning point occurred) this past year, high school, thinking about things about the future and the possibilities about it. Thinking about it because it is getting close. The future became closer for me and I got a new perspective on it.” She continues to confirm that she likes to think about the future. She explained: “Probably. I think ahead a long time ten years, yeah. Fifteen years. So thinking goes quite far. I like to plan ahead…I don’t know.”
describes her hopes for the next five years: “Hopefully go to school next year for fashion
design and probably live in (states city) and work, I would live with my best friend and work.”

She continues by projecting ten years into her future and explained: “I hope to move
out of Canada, either to England or into the States. Probably get more fashion work, like
more direct to my career and stuff. Developing my career in the industry.” Aware of some
of the challenges she might encounter along the way such as “the practicalities of moving,
how to set up in a different country,” she offered an alternate storyline that includes a subtle
variation or adjustment to the initial dream: “My backup plan would be still in fashion but
working in the magazines and writing. I think that is all I want, all being in
fashion…definitely in the same field, fashion.”

As the interview entered into the exploration of possible selves, Victory responded
with ease and familiarity to the idea of a “future self without the illness.” She described the
“imagined” self as a risk-taker who is afforded the freedom of travelling anywhere in the
world without having to “plan ahead.” During the exploration of this future self I asked what
might be possible for this self without the illness and in an immediate response, a story
spilled out of her in a clear and concise manner suggesting the familiarity of this prospective
space. Smiling, Victory shared the specifics of this dream:

It would be like the day, the collection I was working on came out and it was the
runway show. Sitting watching our collection that I have designed on display at a
fashion show. I would have everybody I know with me.

I selected this as a “stepping-in” story as within this narrative account there is a
strong commitment to a future self, accompanied by undercurrent of fear associated with not
reaching her expectations. In what appears as almost a battle between her hopes and fears,
she describes: “A future me that is scary is not being happy with what I have accomplished.”
As the narrative with the strongest theme of fear associated with unmet expectations and with
the most well developed snapshot into a hoped-for future self, this story exemplifies the
notion described previously that the fear of unmet expectations can present as a
counterargument for a well developed hoped-for future.
On a final note regarding a “feared-for” future, in only one of the narratives it was revealed that there was nothing to fear. This participant was extremely guarded in the interviews and it is reasonable that an exploration of fears was beyond consideration at this point. Given the complexity of the experience of living with a progressive life-threatening neurodegenerative illness, it is difficult to imagine that the fears of the future do not exist or had not been explored or considered. It is of course quite plausible that the research interview did not provide the safety required for this kind of an exploration.

**Possible Selves: A Future With and Without this Illness**

Applying the concept of possible selves was used to explore whether the adolescents in this study constructed an imagined orientation to the future that does not include the diagnosis of the disease or the likely progression of illness and related losses. A projection of possible selves entails an individual’s ideas of what he or she might become, aspire to become, and is afraid of becoming (Kerpelman & Pittman, 2001; Markus & Nurius, 1986; O’Brien McElwee & Haugh, 2010). Vitally important to this research study, the possible self construct is rooted in the understanding that the thoughts we have about ourselves are not necessarily grounded in reality, and thus permit a freedom to dream about all aspects of our future selves, those that are likely and unlikely to be realized. Seginer (2009) explains the function of possible selves as being the bridge between the present and the future. She describes, “Their main advantage is that they are relatively free from reality and hence may prompt coping with stresses and challenges whose successes seem improbable to the outside observer” (Seginer, 2009, p. 23). As such, this concept is integral as it affirms that the cognitions of self across time may not only serve as self-regulatory but also as self-enhancing. As well, future thinking is conceptualized as a means to cope with the difficult life circumstance of a progressive life-threatening neurodegenerative illness. Taking this into account, a direct exploration into a future that does not include the diagnosis is warranted.

At this stage of the interviews, aspects of the hoped-for and feared-for future have been explored within the context of future thinking, and within this many of the participants have ventured into describing aspects of possible selves. For instance, upon considering one of the most commonly cited “hoped” for futures as the self who graduates, is accepted to university, and ultimately finds a successful career, one can picture a possible self that is the
“educated professional.” On the flip side, when one considers the frequently described “health worsening” and “uncertain” feared-for future self, the image that comes to mind is the “ill patient who is venturing into the unknown.” Thus, the data presents the reminder that this construct of possible selves will include the future selves with both positive and negative connotations.

The interview prompted a movement into a more textured account of the range of possible selves that had been constructed, and each participant was asked to write a new version of their story where “anything is possible.” The question was initially asked in this broad manner in order to determine whether a self without the illness emerged without framing the question in this direction specifically. During this activity nine of the participants immediately confirmed that one of their possible selves includes a version of future devoid of illness and disease and the remaining participant was unsure. The voyage to these possible selves revealed three important findings. First, that this destination, the story of self without the illness exists; second, that visits are frequent; and third, that it appears to be a nurturing space. Notably, one of the participants described thinking about it “all the time” and another participant conveyed that this line of thinking is “a daily occurrence” and something that he “likes to do.” Rodney shares:

Like dreams, like walking and doing all that. I like that. Kind of makes me feel like I have two sides, like reality and dreams. Dreams that make me feel like I am normal. In reality I am in a wheelchair. I have dreams about the stuff I would do if I was walking.

He continues to explain that in his dreams at night he is not in his wheelchair. It is during this part of the narrative that he appears most calm and at ease. Interestingly, at this point in the investigation I observed a “shift” in energy across the majority of interviews that was documented in the field notes. Apparent in the facial expressions, posture and tone of voice, I noted a movement toward excitement or calmness. I described what I was observing to one of the respondents and received confirmation that “dreaming” about a different version of the same story evoked an emotional response described as “butterflies” and “excitement.” Observing the reactions of the adolescents I was inclined to conclude that this
A kind of a conversation was a positive experience and indeed this was validated in a statement that “[it] just feels good to talk about it.”

**The importance of the impossible bubble**

By stepping in and getting up close to the full textual account within Markus’ narrative, a vivid image of a range of possible selves is created. Again, the movement into one narrative allows for the story to unfold in a contextualized manner. This story was chosen as it provides concrete evidence of how Markus manages the discovery of his various selves. The ability to construct a variety of possible selves (i.e., with and without the illness) was evident across the vast majority of the narrative accounts. For Markus, the moment I began to describe the concept of “possible selves” he responded:

Markus: Like popping out of your body [possible selves]. You look at them in theory. When a person has something done to another thing – like the future does not go sometimes the way they want it to do…they add another one to their…bubble and then another one. Some bubbles may pop, some get bigger or smaller. There are some bubbles that are impossible and they just pop!

Meaghen: Do you think it is important to have those impossible bubbles?

Markus: Yeah, possibilities because it could become possible. Except flying without any machinery or anything, that is impossible. Unless you free-fall but then again you need something to stop you so you can not fall.

Meaghen: What are the possibilities for you when you do not have MD?

Markus: Lots (closes eyes and smiling). Like construction worker, those kinds of things, logger, truck driver… I thought I could drive a truck. Contractor or something like that (pauses as he looks up above his head and continues) Automobile industry, like you know, build a car. Be an architect to make cars instead of buildings. I have always been fascinated with cars since I was little.
Meaghan: Are there more bubbles around you without your illness compared to with your illness?

Markus: Yes, feels like a whole bunch floating in the air (looking up calmly)…I have so many bubbles that my head feels heavy (drops head and sighs).

This story reveals several important points. First, that Markus is able to understand the importance of constructing alternative storylines and that the images of what life would look like without the illness surrounding him daily provide a sense of comfort and enjoyment. As well, he uses the construction of these “impossible bubbles” as an anchor for hopefulness reflected in the statement that what feels impossible might just become possible. In reading the full narrative it is evident that these possible selves serve both self-regulating and self-enhancing purposes.

The self-enhancement is evident in both the description of the range of possible and impossible bubbles, as well as in the “dream-like” affect that accompanied the telling; it was as if for this moment in the interview he had been transported into a comforting and familiar space. The suggestion of the self-regulating feature of his possible selves is a little more detailed and requires a weaving together of a part of the story that occurs at a later point in the interview. During a reflection of his “selves” across time, Markus reflected upon how he had changed his behaviour towards others as he felt that in the past he made significant mistakes. He said: “I think I was a jerk to everyone to be honest. Now I just feel like I did really rude things to people…I regret it. I sort of lost my reputation in a way and tried to bring it back now.” Significantly, by situating this story alongside his possible-self exploration wherein a series of bubbles pertaining to relationships (i.e., to have a partner and a child) emerged, it is plausible to speculate that some of his introspection and related behaviour changes with regards to how he treats others may be motivated by the image of the possible self as a partner and a father.

Another significant point is how Markus proceeds to clearly describe his management of the possible selves that he finds threatening or scary. Further along in his narrative account he referred to the distressing possible selves that emerge and how he responds to them: “It pops into my head and I go wow, where did this one come from, is that actually what I think? So I go shoo, go away, I do not want to think about you, like SLAP.”
reveals that a strategy for coping with some of the difficult images that might appear during forward-thinking activities has been developed. By stepping back from Markus’ narrative and looking across participants, it is apparent that although other participants had also developed strategies for navigating future thinking. The ability to “manage” the future-thinking activities and subsequently the range of possible selves that this activity calls into awareness was demonstrated by the majority of participants through the intentional actions of “when” future thinking occurs and foreshadows several of the important themes that will be explored fully in chapter five.

As demonstrated above, the iterative movement of "stepping into” and then “across” narratives proved as an effective strategy in locating the “stepping-in” stories wherein one of the threads that is woven across various narratives is most clearly articulated. Next, through a process of stepping back it becomes possible to see how the stories of the self both with and without the illness reveal a range of possibilities. Table 5 provides an overview of both the possible selves that are grounded in the reality of living with an illness as well as the imagined possible selves without the illness. Gaining an understanding of the content of these stories provides a full collection of snapshots into a projected future and grants admittance into a space that is infused with the vulnerability of allowing oneself to be fully known. In this sense, vulnerability is demonstrated as the courage to allow oneself to discover the parts of the self that one wishes were different, and to build and expand these stories.
Table 5. Changes in the Sharing of Possible Selves

<table>
<thead>
<tr>
<th>Participant</th>
<th>Possible Self (Reality)</th>
<th>Possible Self (Imagined/Without Illness)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Riley</td>
<td>Connected to friends</td>
<td>Chef</td>
</tr>
<tr>
<td></td>
<td>In a relationship</td>
<td>Driving a car</td>
</tr>
<tr>
<td></td>
<td>Olympic Power Soccer</td>
<td>Helping out at home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Travelling</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Friends and a relationship</td>
</tr>
<tr>
<td>Logan</td>
<td>Be successful</td>
<td>I don’t think my plans would change.</td>
</tr>
<tr>
<td></td>
<td>A good job</td>
<td>It makes sense for them to be the same.</td>
</tr>
<tr>
<td></td>
<td>Journalist/Movies</td>
<td>It does not need to change,</td>
</tr>
<tr>
<td></td>
<td>Have a family</td>
<td>does not need to change.</td>
</tr>
<tr>
<td></td>
<td>Be respected</td>
<td>I try to keep things more realistic</td>
</tr>
<tr>
<td></td>
<td></td>
<td>as it just makes more sense.</td>
</tr>
<tr>
<td>Rodney</td>
<td>Accountant</td>
<td>Help my neighbors</td>
</tr>
<tr>
<td></td>
<td>Have a family</td>
<td>Mow the lawn</td>
</tr>
<tr>
<td></td>
<td>Be happy</td>
<td>More independence</td>
</tr>
<tr>
<td></td>
<td>One child</td>
<td>Police officer</td>
</tr>
<tr>
<td></td>
<td></td>
<td>More privacy and trust</td>
</tr>
<tr>
<td>Markus</td>
<td>Architect</td>
<td>Construction worker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Logger/trucker</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Architect</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Automobile industry</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Family and a child</td>
</tr>
<tr>
<td>Alan</td>
<td>Graduating</td>
<td>Play more sports</td>
</tr>
<tr>
<td></td>
<td>Web design</td>
<td>Tradesman</td>
</tr>
<tr>
<td></td>
<td>Store detective</td>
<td>Helicopter pilot</td>
</tr>
<tr>
<td></td>
<td>Maybe a relationship</td>
<td>Electrician</td>
</tr>
<tr>
<td></td>
<td>Drive power chair across Canada</td>
<td>Live independently</td>
</tr>
<tr>
<td>Bryce</td>
<td>Drawing decals for cars</td>
<td>Race car driver</td>
</tr>
<tr>
<td></td>
<td>Artist</td>
<td>Skateboarder</td>
</tr>
<tr>
<td></td>
<td>Woodworking</td>
<td>Hockey player</td>
</tr>
<tr>
<td></td>
<td>Relationship</td>
<td>Taller</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>Rich with more friends</td>
</tr>
<tr>
<td>Julian</td>
<td>I don’t know</td>
<td>Travel by plane</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Drive a car</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Have a family</td>
</tr>
<tr>
<td>James</td>
<td>Have a house</td>
<td>Walking and running</td>
</tr>
<tr>
<td></td>
<td>Have a car</td>
<td>Playing sports</td>
</tr>
<tr>
<td></td>
<td>Work at a theatre</td>
<td>Professional athlete</td>
</tr>
<tr>
<td></td>
<td>Have a family</td>
<td>Have freedom</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Have a family</td>
</tr>
<tr>
<td>Jill</td>
<td>Author</td>
<td>Dancer</td>
</tr>
<tr>
<td></td>
<td>Continue education</td>
<td>Ballerina</td>
</tr>
<tr>
<td></td>
<td>Graduate</td>
<td>Perform on a stage</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Have a family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Travel</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Have independence</td>
</tr>
<tr>
<td>Victory</td>
<td>Finish school</td>
<td>Fashion designer</td>
</tr>
<tr>
<td></td>
<td>Continue education in fashion design</td>
<td>Travel more</td>
</tr>
<tr>
<td></td>
<td>Move to (names city)</td>
<td>Be more outgoing</td>
</tr>
<tr>
<td></td>
<td>Develop career outside of Canada</td>
<td>Take more risks</td>
</tr>
<tr>
<td></td>
<td>Get married</td>
<td>Be not so plan ahead</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Maybe have a family</td>
</tr>
</tbody>
</table>
This dissertation includes a cast of characters that are embedded within a collection of stories. Finally, I have arrived at the place where further exploration into the content of these stories is both timely and appropriate. As presented in Table 5, when “anything is possible” the ten participants in this study transform into a ballerina, a construction worker, a pilot and the professional athlete, to name just a few. They enter realms of possibility that include the capacity to contribute, to own a house, to drive a car. They venture unrestricted to those “hard to get to” places, they take risks, they explore. They no longer fall victim to unfair judgment. It is easier to “find someone” to love. They become parents, they feel secure.

Like all good stories, by listening closely it is possible to attend to the unique nuances that make each story distinctive. As well, overarching themes are beginning to emerge. By listening on both levels I became aware of several storylines—of independence, of freedom, of taking risks, of experiencing new places, of non-judgment, of security, of relationships, and of contribution. Rodney describes:

Sometimes I do [imagine self without illness]. Like I dream of having my own house and I guess walking and being able to do a lot of other things…like driving and I guess I just see myself as a lot more independent.

The awareness that the illness is restrictive extends across all narratives. Tones of restriction can be heard in Victory’s expressed desire for freedom and spontaneity: “[If I didn’t have this illness] I just wouldn’t be limited in what I would do” she continues “[I would] move around more, not be so plan ahead and take more risks.” As well, Julian explores the ease with which he might travel, “yes, to travel more – get to places that are hard for me to get to right now.” The word freedom was mentioned across several narratives, and in regards to going to new places and in the case of several of the participants—the ability to drive. With eyes cast upwards toward the sky Riley considers his options in a life without his illness and says:

I would help out a lot more around the house…drive…driving is a big one. In my state now it is impossible. It’s another form of freedom – another step up. Maybe I’d like to cook some stuff too. Make dinner. I like helping out in the kitchen. Give my
mom a break sometimes. (Long pause). Probably do more sports and more contact…no, no, forget I said that.

In two cases, the future self without the illness is free from being judged by appearances. In the first instance, Markus compares the future self without the illness to the current self and explains that without the illness he could be “just the right size, somebody who looks fit…like, just the right size.” Consequently, in both cases as the stories of self without the illness develop, a heightened degree of confidence materializes. Rodney explains:

I see myself independent and confident, more confident in the way I look because my appearance – sometimes people judge me because of the way I look in a wheelchair. If I was walking in they wouldn’t make those judgments – they probably think that my brain is kind of screwed up- like they assume that I am not normal and that really bothers me…so if I was walking they wouldn’t think those things. If I was walking I would be a more confident person.

One of the common renderings of this imagined future self is the expressed future self that is married, and parenting a child. In addition to being identified earlier within the general sense of a “hoped-for” future, imagining oneself in a significant relationship was indeed a central storyline related to this specific exploration of a possible self without an illness. Being in a committed relationship surfaced as a common projection among six of the participants and when I explored what was meant by a “relationship” it was confirmed that they had thought about marriage and the potential of having children. Interestingly, two of the adolescents spontaneously offered that they only wanted to have one child and when I asked them to suggest why this might be one of them described wanting to be able to “spoil” a child and the other adolescent linked this directly to the ability to “protect.”

The confusing nature of this particular expression of hope for the future was evident as several of the participants were tentative in “where” they would locate this version of their future self – is it located in a hoped-for future that includes the disease? Or is it only written into the possible self wherein the illness is non-existent? A future self in relationship with
others is certainly not an impossible future for these adolescents. However, there was a shared appreciation that the disease makes this more complex:

It [a relationship] would be easier if I was walking...its hard – people judge me...it is still possible but it is harder for people to understand. That’s what I think. Like they probably think ‘I’ll have to take care of this guy and we will have to go to places at certain times” so I guess I think having a relationship if I was walking would be easier.

To provide a visual snapshot into the research interview, at this time the participant and I were working on a large piece of paper with the words “real” and “imagined” in the middle of each side of the page, and large branches coming out of the circles with space for the participants to list the possible selves. For clarification purposes and for ease of discussion, “real” referred to the possible selves that include the illness and “imagined” referred to the possible selves without the illness. As one would expect, the discovery of possible selves was not linear, but rather was a conversation that included the exploration of “real” and “imagined” concurrently as the mention of one often prompted the mention of another. Due to the limited functioning of the adolescents I was asked to take the lead in mapping out the interview and oftentimes found it difficult to navigate “where” on the visual map I should write this aspect of the future as I sensed the ambivalence. Jake made a request that really underscores the complex nature of this aspect of the experience. As we were mapping out the “imagined” and “real” possible selves he said: “Maybe what might happen [if I didn’t have this illness]. A family maybe. You could write that. I would put that in imagined [thoughtful pause]...and um can we put it in both?”

Thus far the narrative accounts, by virtue of exploring the self without the illness, have revealed a fairly obvious array of losses associated with being restricted due to an illness. Conveyed clearly in the wishes for freedom, for the ease of sliding into relationships without the risk of judgment, and for the ability to take risks and travel to new places, the familiar tone of these losses echoed much of what I had heard in clinical practice. However, two of the narratives revealed something unexpected. In constructing a story of self that does not include the illness, both Riley and Rodney disclosed that what they imagine for
themselves when they consider this different version of self is the capacity to help others. Expressed first by Riley who would like to be able to help his mom out in the kitchen, and secondly by Rodney whose future without the illness translates into a greater capacity to help others. Through a consideration of his two versions of the self he shared:

I’d like to be able to cut my lawn – like I want to work and like I’m independent – like cutting the lawn – helping the neighbors – I won’t be able to do that from the wheelchair but I could do that if I was walking.

For me, this was a hallmark moment in each of the interviews and I found myself called back several times to think about these statements. A limited ability to contribute to others was a powerful reminder that the experience of feeling restricted involves losses related to aspects of life that do not come to our awareness as readily. Simply stated, it was through this process of discovery that I have come to appreciate a bigger message. This experience of adolescent development amidst a progressive life-threatening neurodegenerative illness is so multifaceted and dense that several of the losses are likely to be hidden aspects of this life circumstance.

Calling attention now to some of the variance that occurred within the sample, I turn to a description of how three of the narrative accounts shared a common stance of pragmatism. To recall, data analysis occurred over several iterations of readings. The second reading involved a process of listening to the narrative and identifying "names” to describe the narrator. Importantly, it was within this process that three “selves”, embedded within three different narratives, were identified as the “pragmatists”. In all three cases, the character was revealed first when these participants were asked to consider if they had ever thought of themselves without the illness. Within their “pragmatic stance” these individuals shared a strong investment in keeping their lives anchored in reality as was first indicated by the resistance I encountered upon asking for consideration of how a future without the illness might look.

Although each of these accounts differs slightly, they all fall under a common storyline and are highlighted in this presentation of findings as their distinctive nature offers important insight into the diverse nature of future thinking activities within this population.
The first quotation reveals that despite what was demonstrated in the majority of narratives, depictions of self in the future without the illness do not necessarily require a departure from what is constructed as the “real” future self with the illness:

Meaghen: Have you ever thought about yourself without the illness?
Logan: Quite a few times…it wouldn’t make sense for it [future self] to change. I just mean it shouldn’t really change. It just doesn’t need to change – like sure it could change but if you are interested in that already it doesn’t need to. I try to keep things more realistic because it just makes sense that way.

Meaghen: Hmmm.
Logan: I guess I would be pretty much the same…a little different.
Meaghen: Do you think you avoid thinking about yourself without the illness?
Logan: I haven’t really thought about it, it would just be different. I don’t enjoy it, but it is not terrible.

As well, Julian’s response reveals a similar notion of alignment between what “is” right now and what might be possible in the “imagined” future without the illness. After describing a desire to “try to go to places that right now are hard for me to get to go” and to have a family he explains, “its hard [considering self without the illness] to know without actually doing it. [I think about not having my illness] a little bit. But, then I think I might be exactly the same as now.”

An additional dimension of this pragmatic stance is uncovered as Alan initially resists the idea of thinking about a self without the illness. Upon being asked the question of a future self without the illness he immediately shook his head, looked down and said: “I don’t really think that way,” and he continued, “that is not something I really expect.” Interestingly, as the story unfolded and he began an “in the moment” exploration of possible future selves he became more engaged, and explained that on more than one occasion he considered what it would be like to play more sports, to be a tradesman like his father, to live independently and to fly a helicopter, a clearly impossible task given his physical limitations. His ability to move through his initial resistance to a space that is populated with various
future selves demonstrates that he has engaged in some projection of self without the illness but that because it did not seem logical to spend much time considering this further he did not feel motivated to expend time or energy on this future self.

**The valued possible self**

The narrative interview continued to explore whether the participants valued one of the constructions of the self over the others. Within this exploration an array of valued “future” possible selves emerged. Prior to discussing the specific findings related to the future selves that are held as most “valuable” it is important to mention the inherent challenge of answering this question. Most often conveyed in a reluctance to assign value to only one future self or a wavering once one had been selected, the interconnectedness of the future selves was apparent. In what appeared to be akin to asking a parent to choose a “favorite child,” the participants’ demonstrated resistance to the request to concretely assign value to just one, as was astutely conveyed in the following quotation:

> Okay, they are all very important. I’m not too sure. I don’t have one specific. They come aside each other. Successful and a good job come together. If you are not successful you won’t have a job. Respected is important. They are all connected, that makes sense.

The future self that was most commonly identified as being of greatest value is to be in “relationship” with others. As an almost all-encompassing theme, the responses ranged from the general statement of wanting to be in various “relationships” to the more specific “having my own family” as the most valued future self. As mentioned earlier, a theme of wanting to be able to contribute was also prevalent in two of the narratives, and although initially considered a distinct theme, upon further consideration of the context and the story surrounding this valued future self, it became clear that this also ties into a valuing of relationships as the contributions that these individuals aspire toward are in relation to a parent and to a neighbor.
Summary

An intentional progression of questions beginning with a broad exploration into the future inclusive of hopes and fears, and finally, a discovery of the range of possible selves has led to the important finding that the participants in this study can identify both hopes and fears about the future, as well as the ability to juggle a collection of future images of self. Figure 1 is the first stage of a three-stage model that will be used to summarize the findings. In this initial stage, the model provides a visual map of what has been revealed regarding the hopes and fears that are encapsulated within future thinking activities, as well as the range of possible selves that were shared.

At this juncture a portrait is emerging that demonstrates the capacity of adolescents living with a progressive life-threatening neurodegenerative illness to launch into a future that includes the illness as well as a future without the disease. Significantly, this oscillation between a future self that is grounded in the harsh reality of their illness, as well as a possible self where the illness does not exist was apparent in all ten of the narratives. Importantly, for clinicians and others who support the health and development of this population, it is essential to recognize that engagement in a hoped-for future that includes aspects that appear to be unrealistic does not necessarily preclude the adolescent from understanding the reality of a future that indeed includes an illness trajectory. What may be categorized as “false hopes” or “denial” may actually be a part of a healthy conceptualization of self that includes the formation of both possible and impossible future selves. Notably, in an effort to extend oneself across time, the participants in this study have demonstrated the ability to cope with the emotions related to future thinking. This dimension of the model becomes further elaborated as the map evolves into its entirety.
Figure 1. Stage One in the Evolution of a Map
Chapter 5. Sharing this Space with Others

Recognizing that the experience of future thinking and the construction of possible selves involves an interplay between the individual and his or her context, this next chapter of findings examines both the internal and external processes involved in the projection of selves across time. Extending from the exploration into future thinking activities and the construction of possible selves, the overarching question that is addressed in this chapter is: How are the possible selves of adolescents coping with a progressive life-threatening neurodegenerative illness explored, enacted, maintained or silenced? In the first section, the frequency of future thinking activities is considered both internally and externally by exploring the nature of this activity to determine whether the participants in this study discern any difference in the level of engagement in future thinking activities when compared to peers. The second section examines how an engagement in future thinking occurs along a continuum that encompasses both approach and avoidance tactics. Next, the direct link to practice is explored as the participants explain the importance of promoting or encouraging an orientation to the future through purposeful conversations. And in the concluding section, the relational aspect of this experience is considered as I examine the complex nuances involved in how the adolescents share this space with others as the intentionality and discretion involved in the strategic sharing of information is revealed.

My Story is Different: Perspectives on Peer Comparisons

Building upon the exploration of the occurrence of future thinking and the subsequent extension of the projection of selves across time, the narrative interview launched into the frequency of future thinking activities. Although originally intended to focus primarily on the external factors (i.e., how do the adolescents “do” future thinking with others), it was challenging to extrapolate explorations that focused solely on future thinking in relation to external factors, as the participants demonstrated the close relationship of their internal process related to thinking about the future and the external processes of opportunities to engage in future-oriented conversations. Therefore, based on an assumption of a mutual influence between internal and external processes, in this chapter the reference to future thinking activities includes both internal thoughts and external conversations. In the first
stage of this exploration participants were asked to consider whether future thinking activities have varied in frequency at different times in their lives. It was hoped that the data gleaned from these questions would help to determine whether there are “peaks and valleys” in the future thinking activities, and whether these are related to a specific age or life circumstance that are occurring at that time.

Six out of the ten research participants were either approaching or had recently experienced a graduation from high school. Accordingly, for these adolescents the discussion of the future became more frequent as the perceived salience of these conversations increased due to the anticipation of this life milestone. “Because of the past year, university scholarships…all get you thinking about it [the future].” Consequently, the examination of these specific aspects of future appear to be embedded within a collective dialogue with peers that include questions about graduation and what to do next, where to go, and how life will feel. Riley explains, “[I] talk about it [the future] with other kids, about grad, what’s it gonna be like to be not in school. How weird it is going to be.” As one might expect, the narratives of the older participants reveal that discussions and decisions about “what to do next” became more relevant as they approached the milestone of graduation, thereby prompting an increase in future thinking activities. Importantly, Riley described this experience in greater detail:

Riley: [I think about the future] more often than average – above average. Always thinking, probably yeah – I always think about it.

Meaghen: Are there people you talk to about it?
Riley: Mostly self-thought, independent thought…like what’s it gonna be like in five years when I am doing this and that.

Meaghen: So trying to picture yourself...
Riley: And…mostly not bad things.
Meaghen: Okay, what’s it like to think about it [the future]?
Riley: Ahh – it scares me a little bit – but not in a negative way – in a positive way – kind of makes me look forward to it – hard to explain.

Meaghen: So it [the future] is something you look forward to and it scares you in a positive way?
Riley: Yes, it makes no sense…but yes.

Understanding whether the participants felt they engaged in future thinking more or less than their peers, revealed yet another diverse experience as responses to this line of inquiry varied. The majority of the responses indicated that the adolescents in this study felt their future thinking activity was occurring at a rate similar to, or above average when compared to their peers. Indeed, for some of the adolescents there was a tone of preoccupation. “[I am] always thinking, I always think about it.” Certainly the focus on the future was understood partially by the salience of future in the context of graduation and decisions regarding “next steps,” and yet there was also an appreciation for the paradox of projecting into a future that contains the ambiguity of disease. As I read through the narratives the image that comes to mind as the participants describe this process is a percolation of “what-ifs.” Described previously as a counterargument for hope and conveyed again across several narratives, a circular pattern of thinking emerges whereby the adolescent projects and subsequently worries that the projection will not be accurate. As described in the following quote: “quite a bit [thinking about the future], just wondering. I don’t know—I don’t want everything to go the way I don’t want.”

In a poignant reflection Rodney considered the difference in his story and subsequently the complexity of exploring a future alongside peers who have a more common story to tell. During my data analysis this story was ascribed the title: “My Story is Different”, as this portion of Rodney’s narrative account distinguished his experience as unique from others. Within this rendering he makes the important point that regardless of the frequency of future thinking when compared to his peers, his experience of the activity differs, as his future does not project with the same clarity as his peers. Akin to having different puzzle pieces to the same puzzle he explains, “About the same [consideration of future compared to peers] I guess. Some kids like to dream about the same amount of time. Some have the same story to tell, like walking, makes it easier to connect.”

To contrast, three of the participants perceived their future thinking activity to be occurring less frequently when compared to friends. For Jake this was confusing and during his interview he shared, “it seems other kids my age would do it a lot more but [I am] not sure why.” By stepping back, the theme that emerged across these narratives was a choice to
“live in the moment” and a necessary focus on coping with the “here and now,” consequently resulting in a shift in focus away from the future. These adolescents report thinking about the future less than their peers: “I try to take one day at a time, I just try to take things as they come” and “not much [future thinking] I just go along day by day, less than other teens.” Finally, one of the participants explained, “I just…I care about my life right now – I just don’t care about the future …that much.”

Dancing with Engagement: If I Go There I Can’t be Here

A paradox is at play within this experience, as even within an engagement in future thinking activities there is a dance between going “there” (i.e., yes I think about the future) and staying “here” (i.e., I focus on the present). Evidently, in some cases a strategy of avoidance has been employed. The analysis thus far reveals that this is essentially adopted as a means of navigating an unpredictable life course. Importantly, future thinking activities appear to fall on a continuum that includes both engagement and avoidance. Subsequently this exploration of avoidance proved relevant for all participants as each adolescent was given the opportunity to explore whether they have avoided future thinking and if so, what the reasons for avoidance might have been. The most common response to this question falls once again under the theme of living in the present. Conveyed in various ways and at different points throughout and across the narratives, but most notably within this exploration of potential avoidance, the participants portray an image of avoidance fuelled by a necessary grounding of “in the moment” living. Reflections such as, “I guess [I avoid future thinking] because it is not worth talking about the future until you are almost there,” and, “I don’t like to plan that far…I guess…I don’t like to plan that far,” suggest that oftentimes a focus on the present takes priority. As previously expressed, there is an inherent fear related to the uncertainty of disease progression and ultimately a lack of control over how the future will unfold. As well, by threading in one of the previously mentioned findings—that the consequence of building a well constructed and specific future is a heightened awareness when things do not go as planned—avoidance might be best understood as a protection from the feelings associated with a variable and uncertain disease progression. Further to this, avoiding the future permits a detachment from “hope,” thereby protecting oneself from the seemingly inevitable experience of disappointment.
In the few cases where the adolescents were unable to think of a time when they had avoided thinking about the future, I found the strategy of “externalizing” the question prompted a deeper exploration into the rationale or motivation for avoidance. By moving the question outward from the individual experience of the adolescent being interviewed, more broadly to “a teen with a progressive life-threatening neurodegenerative illness,” the responses became more clearly detailed. Again, the unique features of this experience emerge; a fear of facing the reality of disease progression, a fear of unmet expectations and hopes, and the uncertainty attached to living with the unknown. A participant explains, “I am not sure. They [adolescents with progressive life-limiting illness] might just avoid it because they don’t like what it will turn out to be. I don’t know.” In addition, “I guess they [adolescents with progressive life-limiting illness] don’t want to deal with it themselves. They might think of something that might not come true I guess. They think they are afraid to think about it. They are afraid it might not happen.” And profoundly, one of the adolescents explains, “they avoid talking about it [future] because they might think it is a silly idea.” Across all explorations there was an acknowledgement that fear is the motivation for avoidance. One of the participants reflects on his own experience of avoidance, “[it is] kind of hard to think about it [future]…like it is scary because I don’t know,” and, “maybe [other adolescents avoid] because they are scared.”

Undoubtedly, activities of future thinking can be emotionally taxing. Therefore avoidance is also a strategy employed to manage the difficult feelings related to the experience. Revealed in several ways across the narratives, exploration into the years ahead prompts an emotional response ranging from excitement through to fear, sadness and anxiety. Clearly and simply stated, one of the participants reflected on times he has avoided: “talking about the future makes me sad sometimes.” Adding to this, Rodney describes strategic excursions into the future with a focus on what is described as the “normal things” like “jobs and stuff,” but that exploring the spaces of uncertainty is something he avoids. He described, “I try not to think about the what-ifs because they can make you feel anxious.” Importantly, the power of this kind of thinking to evoke an emotional response provides, in some cases, the motivation to avoid or at least to tailor the nature of future explorations.

Not surprisingly, the willingness to expend energy and emotion on future thinking activities depends also on the emotional state or mood of the adolescent. In the cases where
this was identified as a factor contributing to the avoidance of future thinking, each participant was asked to consider the time or circumstance when they had avoided future thinking as a result of their mood. Responses ranged from the general message of, “hit me on a sunny day and I’ll be happy to talk about it,” to a more specific account related to a change in health status. In this second case, the adolescent explored a specific time when his mood was “low” and he spoke about a long hospitalization that extended over several months. He reflected upon this experience as a specific time when he would not want to have these conversations. “[When I am] in the hospital, definitely in the hospital [avoids conversations about the future].” This evidence presents somewhat of a dilemma that will be expanded upon in the discussion of findings. Based upon my observations in practice, changes in health status and hospitalizations are oftentimes the contexts that prompt an engagement in these conversations. However, this may not, from the perspective of this participant, be the optimal place or time for exploration of future wishes.

For a few of the participants the avoidance of future thinking was experienced as very much external to the adolescent. In these cases a notable lack of opportunity is apparent. One of the participants reflects, “people don’t ask me,” and another explains, “I never talk about that [future] because they [people] never ask.” Devoid of the opportunity to talk about oneself in the future, the speculation as to why this avoidance might be occurring resulted in a state of confusion and uncertainty.

Other participants were able to conclude that the uncertainty of their life circumstance caused others to feel “nervous” about talking about the future. Within this group there appeared to be a growing recognition that it is easier to avoid this altogether than it is to embark on an exploration of the unknown. As described, “I am not sure [why others avoid talking about my future]...[maybe it is] because they do not know what is going to happen?” Interestingly, Victory suggested that avoidance might be the easiest route, as an exploration is likely to threaten the commonly held beliefs about persons with disabilities. In her own words she explains, “maybe because they [people who do not want to ask her about her future] think about…like they do not want to talk about it or they are scared to hear the answers because they have their own beliefs or whatever.”

The nature of a relationship was recognized as an important component in the decision to avoid conversations about the future. Not at all surprisingly, participants
described avoidance as occurring with “people you don’t like” and “people you don’t trust.” Logan explained: “No I wouldn’t say [that I avoid talking about the future], I am pretty open about it…most of it. Well, maybe [would avoid] with people you don’t trust…or maybe if you were not getting along with them.” Jake described avoidance as stemming from a fear of the reaction the future projections might produce; notably, Jake responded: “they [teens with a life-threatening illness] don’t want people to know [their future selves] because they might think it is a silly idea.” In addition to affirming what is already known about communication and relationships, this evidence needs to be considered as once again the data leads to an important discussion point that will be further expanded upon in the discussion of findings. Despite the rather conventional assertion that exploring personal matters is best facilitated through the development of relationship and trust, the topic needs to be considered further to understand what this means for practice. Understanding that avoidance might be occurring as a result of a relationship not yet fully formed (i.e., new healthcare team), or an experience of mistrust (i.e., healthcare system), these aspects point to important considerations for healthcare professionals when formulating a plan for conversations about the future with adolescents living with a progressive life-threatening neurodegenerative illness. Accordingly, it is conceivable that the individuals primed and professionally trained to prompt these conversations might not be the best choice to facilitate explorations into the future, as the success of these conversations are dependent upon past experiences both with healthcare professionals and with the healthcare system in general.

**Trust me enough to connect me to my future**

Meaghen: Do people see you as a person with a future?
Rodney: Some people do and some don’t…just the way they look at me sometimes…jeez it must suck to be like that…but it doesn’t. Not as bad as some people think.

The narratives highlight the inherent importance of acknowledging a future space for adolescents with a life-threatening illness. Articulated clearly in the quote above and echoed across several accounts, the participants in this study have a strong desire to be seen as persons with futures that are worthy of exploration. Linking back to what has been learned
about the prevalence and content of future thinking activities as well as the approach and avoidance continuum, it is time to consider how to interweave these into an approach to practice. The title of this section, “Dancing with engagement: If I go there I can’t be here,” came to me as I listened several times to the narratives with the clear descriptions of the oscillation between a real and imagined future self. Further analysis affirmed that the participants in this study have the capacity to navigate future thinking activities and that this navigation encompasses the ability to chart the course as well as to deal with the emotions that arise as a result of the exploration.

Confirming the value of future thinking activities, the vast majority of participants wish to be asked about their future, with eight adolescents agreeing that future thinking activities should be promoted. Ultimately these conversations about the future provide the opportunity for adolescents to connect with others regarding goals, purpose, and identity. “I guess it [talking about the future] feels good. It is sharing a goal you have.” Significantly, talking about the future is experienced as both an opportunity to express aspirations, and also serves as evidence that others have an investment in the adolescents as living and growing beings: “I don’t want people to think I am in a wheelchair and I am miserable. That I will grow up to be somebody; it makes me happy when they say stuff…”

The inherent value of conversations about the future is further supported by the feelings of hopefulness and positivity occurring as a result of these discussions. One of the participants was adamant that a vision of his future is not approached as something to be avoided. He described his experience of thinking and talking about the future as, “feeling hopeful—nothing bad, you are hoping—I guess you are hoping for something.” As well, recalling what has previously been discovered within this narrative activity, the projection of possible selves both with and without the illness effectively prompts feelings of excitement and hopefulness for many of the participants.

Handle with care

In the service of painting the full picture, a caution has been issued that must be called to our attention. Two of the participants expressed uncertainty about encouraging future thinking in the context of a progressive life-threatening neurodegenerative illness. When asked to give voice to the argument “for or against” encouraging future thinking
conversations, Alan explains, “[I] sort of agree with both [sides] in a way because they [people avoiding future thinking conversations] might think that the kids might get mad instead of more happy in talking about it. Then I would say with the other person [encouraging future thinking conversations] that it does help. So I would agree with them both.” Consistent with what has been learned about the continuum of approach and avoidance, this type of activity has both positive and negative effects, and subsequently the adolescents have essentially issued a “handle with care” warning associated with all conversations into the future.

**Managing My(selves): Preservation of a Private Space**

To reiterate an important finding, for the participants in this study there appears to be a steady vacillation between a future projection that is realistic and one that is fictional (i.e., does not include the illness). Subsequently, the study moved into an exploration of how the adolescents “manage” the alternative future stories of self that have been developed. The term “manage” has been intentionally selected to encapsulate the distinctively deliberate action of sharing specific parts of one’s future in specific contexts. A finding that will be further explored in this section concerning information management, the adolescents demonstrated a strategic preservation of one or more “private selves” that they hold tightly as their own.

All participants were asked to consider whether they have a private future self that they have not shared with anyone. The non-verbal reactions to this question were captured in field notes during the interview as several of the responses included a knowing look and a smile, communicating to me that perhaps the answer is obvious. As well, there was hesitation to answer the question and in several interviews it was helpful to provide the reassurance that they would not be asked to divulge the content of the private self but rather that the question was meant to determine “if” a private future self is maintained.

The importance of preserving a private self was evident in several of the responses, “yes there is [a future self I keep private], but again, I don’t want to talk about it.” As well, the emotion surrounding the protection of this private self became apparent in both the subtle hesitance to acknowledge the existence of a future private self and more overtly, in an
unwavering commitment to maintain this aspect of privacy, “Yes, [I have] one [private future self] I would not tell anyone – not even family.”

Unprompted by the research interview, in some cases, aspects of this private self were revealed. Within these cases the theme that emerged was that the future self that was most often withheld from others was a version of self without the illness. Revealing that these images of a self that is free from disease are kept hidden or protected, a participant describes, “[the] imagined self is kept pretty private.” Through an exploration of the motivation around maintaining privacy related to this specific future, it was clearly stated that maintaining this boundary of privacy is a way of protecting oneself and others from the feelings connected to an expression of hope associated with the future self without the illness. This ultimately suggests that giving voice to a version of a future self without the illness is comparable to speaking the unspeakable.

Within the sample there was a much-less prominent theme of not maintaining a distinctively private future self. The participants who described not having a private future self were also the ones who have previously been described as the “pragmatists,” and as the interview ventured into new areas of exploration it appeared that these adolescents became even more firmly anchored in this pragmatic stance. Drawing from the pattern of thinking that has thus far emerged it is plausible to discern that the projection of a future self that may be seen as a far stretch from reality (i.e., the imagined self) is not a self that has been fully developed. Accordingly, as revealed in the statement, “No, I wouldn’t see the need to have one [private self],” for the pragmatist, any desire to have a “private self” seems somewhat illogical or unnecessary.

**Managing my(selves): Self-determination in exploring and sharing**

Recognizing that the majority of participants maintained a private self, the analysis considered the communication patterns related to both the “real” and “imagined” possible selves. In this next series of findings the focus is on how this process is embedded within a larger social context. More specifically, consideration is given to how the possible selves of the adolescents are explored within relationships. In this portion of the narrative, the interview moved through a series of questions aimed at exploring how the adolescents communicate about their future selves with a parental figure and also with other people in
their life. A visual map was constructed starting with asking the participants to identify the “people in your life that help you or support you.” During this activity each participant was permitted to identify more than one person and oftentimes the range of significant people included siblings, extended family, and friends. Following this, the words “real” and “imagined” (referring to the imagined self without the illness) were added to the page and the participants were asked to consider who they talk to about each of these future selves.

The data presented in Table 6 establishes that across all ten narratives, either a “mom” or “parents” were identified as the persons that participants were most likely to talk to about their “real” future self. Notably, siblings were identified four times. As well, the broad term “family” was selected by two of the participants and when asked, they did not want to identify the individuals specifically. A grandmother and a cousin were also listed.

Table 6. Communication Patterns of Possible Selves

<table>
<thead>
<tr>
<th>Participant No.</th>
<th>Sharing of real possible self</th>
<th>Sharing of imagined possible self</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Parents and sister</td>
<td>“Maybe” parents and sister</td>
</tr>
<tr>
<td>2</td>
<td>Mom, dad, siblings, friends</td>
<td>Nobody</td>
</tr>
<tr>
<td>3</td>
<td>Mom, cousin, grandmother, friends</td>
<td>Mom, cousin, grandmother, friends &amp; sibling</td>
</tr>
<tr>
<td>4</td>
<td>Parents, family, friends</td>
<td>Parents</td>
</tr>
<tr>
<td>5</td>
<td>Mom and sister</td>
<td>Nobody</td>
</tr>
<tr>
<td>6</td>
<td>Mom, family</td>
<td>Nobody</td>
</tr>
<tr>
<td>7</td>
<td>Mom</td>
<td>Mom</td>
</tr>
<tr>
<td>8</td>
<td>Friends followed by parents</td>
<td>Parents followed by friends</td>
</tr>
<tr>
<td>9</td>
<td>Nurses, mom, God</td>
<td>Mom, God</td>
</tr>
<tr>
<td>10</td>
<td>Parents, brother, friend</td>
<td>Friend, brother</td>
</tr>
</tbody>
</table>

Overall a family member was identified 19 times across the ten narratives, indicating that the majority of the time the adolescent would have conversations about their real future self with family. This lends credence to the importance of supporting families in the development of effective communication patterns related to illness in the family context. Following this strong theme of communicating with families, friends were the next most commonly cited confidants with four of the participants identifying a close friend as someone with whom they would share their “real” future selves.
In a research memo I express both my surprise and concern after hearing for the fourth time that a sibling is the person to whom the adolescent confides. I wrote:

I find it interesting that the adolescents are talking to their siblings—as in many cases the siblings are of similar age or even younger. Are these sibs equipped with the knowledge and the skills to support these conversations and what might their own experience of this be? Are they supported emotionally and how does it feel to discuss these very real and difficult matters?

Upon further reflection, in the absence of data regarding the nature of these conversations, it is difficult to know how this relationship might be being used. For instance, is the sibling relationship, by virtue of its accessibility and continuity over time, the place where these adolescents are “trying on” various selves? How many of these selves are being revealed, and to what extent is the exploration occurring? As one of the “unexpected” findings, specific data was not gathered regarding the extent of these conversations. Due to the limitations of the available data, it is not possible to draw further conclusions, but this does open up an interesting area for future research.

**Preservation of my(selves): Intentionality and discretion**

Perhaps the most interesting finding is not with “whom” the adolescent shares but rather how the sharing changes when they are referring to the imagined future self. Table 6 captures the nature of these changes by including the verbatim responses from all the participants. Significantly, in all cases but one (see participant 7), there is a change in either the sequence in sharing (see participants 8 and 10), or by the addition (see participant 3) or removal (see participants 2, 4, 5, 6, 9, and 10) of an individual. This highlights one of the main findings of this research study— that all information regarding future self is managed or shared in a purposeful or strategic manner.

In a related research memo I write: “I am surprised at how they are able to clearly differentiate between whom they share their “real” and “imagined” future selves.” For instance, after describing that he would share his “real” future self with his friends first and then his parents, one of the participants explained: “maybe, probably share [imagined future
Determining the patterns of interaction was the initial step in exploring the relationship context or external factors related to the development of future selves. This exploration was based on the premise that conversations about self are an integral part of developing a future self and are at the core of identity development. Therefore, if conversations were being either promoted or avoided it would be helpful to understand why this might be occurring.

One of the themes emerging from the analysis is that the adolescents make decisions not only about which version of the future self (i.e., real or imagined) they share, but also discretion is used in relation to the specific selves they choose to reveal within each of these categories. For instance, in the short dialogue below, Jake effortlessly identified a parent as the person with whom he would discuss his “imagined” future self, yet when I gestured to the lengthy list of “imagined” possible selves he had developed and asked if all of these would be shared, he demonstrated discretion in his sharing:

Meaghen: Would you share all of these [imagined possible selves] with your parents?
Jake: Probably [lengthy pause]. Not the sports and the running though. But I would do the rest okay. I would keep the walking and the freedom [to myself] but I would share the rest.

The selectiveness in sharing that is conveyed in the above excerpt was prominently reflected across the narratives. Thus, an additional layer of intentionality emerges and a theme of strategic information sharing begins to take shape. In one of the narratives, the degree of scrutiny described regarding the sharing of future selves reveals intention in the sequence or order of sharing based on what the participant deems as the “most important” aspects of his future. As a way of providing context, within this particular narrative one of the prominent storylines was the quest for a secure future. Upon being asked which future selves he would share, he responded with:
Probably the real because the imagined has not happened yet. Probably do [share] the ones I think are most important. Probably the first would be house, family, car. These are the most important because actually and work because you have all those then you are okay.

Importantly, information sharing was not only purposeful and deliberate but also conditional. The participants in the study described several “conditions” that either promote or discourage them from talking to others about the future. The first condition that was described is rather logical and referred to the nature or quality of the relationship as a determinant for sharing:

I don’t usually talk about it [real future self], my parents are close and Grandparents come over once in awhile. Like I tell them when they come over. My grandmother comes over often. I could tell them if they know me…if I have a really good relationship with them, and we are close.

As well, this participant speaks to the motivation for sharing stories of what his future might be like without his illness and in his narrative he explores times when he finds it necessary to talk about this imagined future: “Sometimes [future self without the illness] makes me feel sad because I can’t do things. That is probably why I talk about it with people.” Poignantly, following his description he shares a major reason why he avoids talking about the future with those who are close to him: “Sometimes it [talking about the future] makes them feel more upset. Because if I get sick I could die – it could be deadly. I usually try not to say that to make them upset.”

This statement presents an important aspect of this experience as all participants identified a family member as the person they are most likely to engage in future thinking conversations and yet, it logically follows that those who are closest to them have an emotional investment in their well being and therefore conversations about the future in the context of a life-threatening illness can feel extremely difficult. In many ways, this participant is giving voice to a foreseeable paradox. The picture that is left is that those who are most available to the adolescents, and appear to be the preferred people to talk to, are also
those with whom the adolescents are aware of wanting to protect from exploring the reality of the future, which subsequently poses limitations to the exploration.

**Upholding a shield: Inhibiting the sharing of selves**

This notion of protection is a complex phenomenon, as it appears to be operating in several directions. As described above, this participant expresses an awareness of wanting to protect his family from having to explore the harsh reality of living a life of vulnerability associated with disease progression. The desire to protect others was indeed a theme interwoven throughout several of the narratives. As well, the adolescents spoke about “self protection” and a purposeful avoidance of the emotions associated with thinking about a future without the illness. In one of the interviews this idea of protection was elaborated upon more fully, as the initial assertion was that avoidance was likely due to a desire to protect others, but then through a dialogue the participant concluded that the reluctance to engage in conversations about the future was fuelled by a desire to preserve and protect herself: “It [avoiding conversations] probably would not be to protect them but to protect myself.”

Adding another layer of intentionality, mood was once again identified as a contributing factor to engaging in conversations about the future. The emerging picture reveals that in addition to proceeding with caution into any conversations about the future, one should wade carefully into the exploration of the future. As one participant was describing an obvious fluctuation between engagement and avoidance of future thinking, I asked him to consider how a person might determine whether or not they should ask about the future. He explained: “It is good to ask…sometimes like [on] a happy day. Mood affects it probably. If you are angry you might not want to do it. It takes energy and…when it is sunny and a nice day maybe.” Another participant described his desire for conversations as determined by where he is “at” in the moment and who he is with: “Sometimes [engage in conversations with] my sister. I do talk to people besides them [Mom, Dad, Sister] but you know…it all depends wherever I am at [mood], like [I] talk about different things to different people, yeah.”
Conveyed in various ways across the narratives, the intentionality and discretion exercised in the sharing of possible selves and future thinking is clearly influenced by various factors that can easily be taken into account in a practice to support the healthy development of adolescents living with a progressive life-threatening neurodegenerative illness.

**Managing my(selves): Privacy and control**

A very intriguing theme emerged from within this contextual exploration of future thinking activities. On the heels of establishing a clearly strategic engagement in the sharing of possible selves and an awareness of the “conditions” that influence sharing, came the awareness that the strategies employed in this activity are firmly rooted in an inherent need for privacy and control. Therefore, the theme of strategic information sharing can be conceptualized and understood as a function of preserving personal choice.

It is important to note that by the very nature of their physical limitations, the restrictions for personal freedom and choice are visibly evident. Indisputably, the nature of disease progression places great limits on the experience of maintaining control and securing a private world for oneself. Activities are often closely monitored and support is required for movement within and between environments. Subsequently, the ability to maintain a space that one can control may act as a safeguard against losing all aspects of privacy and control.

**Keys to the gate of my house**

Although most prominently featured in Rodney’s narrative, this “stepping-in” story presents itself as a central storyline in many of the narratives; a lack of self-governance and requisite control was clearly articulated as Rodney explained how basic choices have been taken away. During the interview he described:

like right now [I am keeping a private self]. Yes, sometimes I don’t feel like I have my privacy – they choose the clothes. I’d like to have more privacy...I lost a lot of my ability to open doors and stuff because – like I have a lot of siblings right and it’s frustrating because they can bust into my room without my permission and I can’t really say anything. So it makes me sad that I can’t do what I use to do in the past
like open doors and feeding myself and stuff…because sometimes I find that being in a wheelchair it is harder to have that control – some certain things you can’t do and you need people to help you do it.

The desire for privacy and control is evidently a strong motivation for the maintenance of the private self. In one of the most memorable moments during the interview process Rodney responds to the question of “why” it is important to keep a private self:

Rodney: You don’t want to tell somebody everything about you. Like it is giving them a key to a jail cell. You don’t want them to know everything about you right? I think it is important to keep something to yourself. You need to keep something to yourself and not everything.

Meaghen: So is it a way of keeping some control?

Rodney: Yeah.

Meaghen: It was interesting that you said giving them a key to a jail cell.

Rodney: Not just a jail cell – a key to the gate of your house.

Meaghen: So, that gives you a bit of motivation to keep a little something to yourself. It gives you a bit of control over who you are?

Rodney: That is exactly what it is.

Meaghen: Do you think that little piece of you that you keep to yourself, does it stay the same or does it change over time?

Rodney: I guess when you get older there are things you keep private. When you get older there are more things to keep private.

Summary

Understanding how adolescents with a progressive life-threatening neurodegenerative illness share their future thinking activities with others is of key importance to this study, as the results aim to contribute to progress in the provision of a developmentally appropriate practice of psychosocial support. Through this exploration it is apparent that the perceived frequency of future thinking activities when compared to peers is most commonly considered
to be at a rate similar to or higher than peers. As well, the participants in this study demonstrate the ability to situate these activities on a continuum that involves the movement towards, as well as away from, projections into the future. The importance of these conversations has been emphasized alongside a sensitivity to consider the context of sharing and the critical importance of handling the possible selves with care. Finally, the various strategies of information management and the significance of privacy and control is discovered. Building upon what was established in the previous chapter, Figure 2 provides a visual summary of what was learned regarding the contextual nature of the sharing of future thinking and possible selves, and the engagement of these activities as occurring on a continuum that includes an investment in living in the present as well as planning for the future.

**Figure 2. Stage Two in the Evolution of a Map**
Chapter 6. The Experience of Selves Across Time

Building upon the foundational understanding of both the internal and external processes involved in the projection of self into the future, this final chapter of findings addresses the question of how the adolescents experience continuity within a projection of self across time. Conceptualizing possible selves as the representations of self that exist along the life continuum, this chapter explores the final research question: How do adolescents with a progressive life-threatening neurodegenerative illness experience their various stories of the selves across time? This is an admittedly broad question within which two specific areas will be explored. In the first section I revisit the concept of “coming to know the unknown” that was first introduced in chapter four. By extending from what has been learned thus far about future thinking with respect to the stories of hopes, fears, engagement and avoidance, consideration is given to “why” this population might traverse into a projected future space. Secondly, and working from the assumption that future thinking involves a sense of self continuity from the past to the present and into the future, the analysis proceeds to examine how the participants reflect upon the changes in self over time, what they consider as accounting for change, and finally how they weave these different elements across time while being firmly anchored as the “same” person.

The Value of Knowing the Unknown

Referred to previously as the “binding” that holds the findings together, the concept of “coming to know the unknown” is now revisited and consideration moves from understanding the activity of future thinking to considering the value of this activity for adolescents living with a progressive life-threatening neurodegenerative illness. Within this is the discovery of “why” the projection of self into the future is part of an important developmental process to manage the experience of a life course altered by illness. Through the presentation of findings thus far, the extent and nature of future projections has been demonstrated alongside an intentional management of a range of possible selves. What will come to be understood now is how the participants in this study describe the value of future thinking as a way to strategically engage with the unknown elements of this uncommon life circumstance.
In one way, the results presented will be helpful in addressing some of the concern surrounding exploration of future within this population, and essentially helps to answer the important question of “what’s in it for me?” from the perspective of the adolescents. More precisely, through the narratives, entry is gained into the personal experience of managing future projection within the context of a progressive life-threatening neurodegenerative illness. Notably, despite the complexity and inherent ambiguity associated with these futures, the value of voyaging into a process of future thinking activities is revealed.

Building upon the stories shared, the findings presented in the first part of this chapter are intended to provide an answer to the question of “why” future thinking is important.

**This is a required activity**

Remaining attuned to the use of language, the analysis revealed two instances when the words chosen by the participants seemed to encapsulate much of what was being shared across the narrative accounts. Convincingly, within these narratives the words “needed” and “required” arose in an evocative way, serving to highlight the significant value the participants place on considerations of the future. Significantly, the initial theme that emerged when looking across the narratives was that the adolescents in this study did not see future thinking as optional but rather as a required activity. The implied “necessity” of this activity prompted further examination of the data. As a researcher I was drawn back to phrases shared first by Logan who described future thinking as, “I would say it’s just a needed activity,” and next by Markus who referred to his future thinking as “a required activity.” Extending from these narratives I was able to locate stories stretching across all three areas of inquiry as relevant and applicable to understanding the necessity of this activity.

Upon stepping back, the narratives reveal that future thinking is a necessary activity for three specific reasons: as a strategy for coping, as a strategy for personhood, and as a strategy for decision-making. The word “strategy” has been intentionally selected as the best representation of what I came to know as the active engagement in future thinking as a tactic in “coming to know the unknown.” In this sense, “knowing the unknown” refers to an engagement with the unknown aspects of the disease, the self, and how the disease and the self will be managed across time to inform healthcare decisions. Bound together by the common desire to know the unknown dimensions of their future, the stories of coping, of
personhood and of decision-making, contain the endowment of new understandings of why a projection of self across time is of fundamental importance for adolescents living with a progressive life-threatening neurodegenerative illness.

A strategy for coping: Knowing what might play out

Within the context of future thinking as a required activity, the most prevalent theme was the sense that anticipating the future gave the adolescents insight into their life circumstance and subsequently helped them to anticipate the changes ahead, and most importantly, what type of care they would require. Described by the participants as a way to approach “what might play out” in the days, weeks and years ahead, and the “what-ifs” associated with living with a disease, future thinking presents itself as a way of coping both practically and emotionally.

From a practical perspective, future thinking is used as way to plan. The importance of knowing what one’s care needs might be and the ability to convey it to others was echoed in many of the narratives. The adolescents are keenly aware of their reliance on those external to them, and in addition to knowing the importance of building relationships of support, the ability to project, anticipate and plan for their care also appears to be a high priority. Markus explained, “[we] should talk about the future because if you don’t talk about the future nobody is going to be able to help…nobody will know how to help you, that’s what I find.” Again this highlights the distinctiveness of this experience as the adolescents are clearly anticipating an increase in the complexity of care requirements over time. While reflecting on the importance of thinking about the future, Alan shared: “So you have some insight into some of the things that happen because you can’t just look at what is right now because anything can change.”

Having a version of “a plan” in place for the changes that are going to occur emerges as a coping strategy. The narratives serve as a reminder that the experience of development amidst a progressive disease places the adolescent in a challenging position of wanting to anticipate what they will need within a variable and uncertain illness trajectory that makes it difficult to plan. Within a discussion of coping with the constant changes associated with illness, one of the participants who despite being firmly anchored in a “living in the present” philosophy reconciled himself to the necessity of future thinking: “I think it is important to
think about other thing[s] happening, not just about now.” Indicating that despite the inclination for some of the participants to live predominantly in the “here and now,” there is a shared appreciation for the importance of projecting beyond the present. In the face of uncertainty, the value of future thinking is described:

Markus: But like I said you cannot predict the future so you never ever ever know what is going to happen. You know what? I could be completely 110% wrong about what I said in the future. I mean for all I know I could be a billionaire or somebody on the street or somebody with minimum wage or a high wage, or a good job, you never know.

Meaghen: Okay, so for you the future feels really uncertain.

Markus: Yes, I make plans. I am not 100% but I believe that I am going to have a good job and a good life.

Meaghen: So you still make plans for yourself.

Markus: Plans can affect the future.

Meaghen: Planning for the future is important.

Markus: So if you don’t plan for the future, it will just come and you won’t know what to do with it.

Moving closer to the unknown results in an engagement in the range of emotions attached to the progression of an illness. Subsequently, coping skills are required to combat the difficult feelings associated. During the analysis I entitled one of the stories, “anchor and release,” as the participant painted a clear picture of how future thinking is an important way to anchor him to the reality of his life experience. Aligned with the previous finding related to coping, he clearly illustrated the value in a process of taking himself into the unknown to think about his future with his illness, thereby prompting an emotional response and ultimately a cathartic release. He was adamant that future thinking was important and during his reflection he explained, “sometimes it [future thinking] makes me feel sad because I can’t do the things. That is probably why I talk about it with other people…it just feels good to let it out.” For this participant the value of future thinking was twofold as it led to an increased awareness of his illness experience and facilitated an integration and expression of emotions.
As I listened to this story I was reminded of how Markus previously described dealing with the feelings associated with his “possible and impossible bubbles.” These two concrete examples contribute to the evidence that adolescents with a progressive life-threatening neurodegenerative illness have the capacity for developing skills and strategies for coping with the emotional response related to future thinking.

**A strategy for personhood: Owning an identity**

It [future thinking] gives you insight…yeah, it tells you how to change. Yes, you start to think about who you might become. Helps you to understand your needs and whatnot. — Logan

Extending from the initial findings that situated future thinking as one of the strategies for coping, this opening quote reveals that engagement in future projection, in addition to facilitating an anticipation of care needs, is also used as a way to conceptualize identity. Resonating throughout this short quotation is a belief in the fluidity of the self over time, and the inherent capacity to comprehend the self and to adjust and make changes accordingly.

Further, future thinking and the sharing of thoughts about the future is presented as an opportunity to inform and educate the world about this life circumstance and to engage others in a way that they might see all that he has to offer:

Sometimes I say it because I want to let it out or I want people to realize my disease is not a super bad thing like I can still do things that normal people can do – I can still say things that normal people would be interested in. Like soccer for example, some people might not even know that there are sports for people in wheelchairs and I like to stay stuff like that – and then they might become more interested in me.

It became apparent that for the participants in this study an important function of future thinking is how it links to a sense of identity. The connection between these concepts was further evidenced by the frustration and confusion that surfaced within the exploration of the reasons others might not understand or appreciate the importance of talking about the
future. In a poignant reflection Rodney clearly articulates how the activity of thinking about the future and sharing it with others is intrinsically connected to his sense of self. He explained:

Thinking about myself and talking about myself in the future is helping other people see me as a person that has a future. I don’t want people to think I am in a wheelchair and that I am miserable. That I will grow up to be somebody, it makes me happy when they say stuff [about the future].

Logan also offered significant insight into the importance of thinking beyond the present and sharing this with others. With reverberations back to what had been previously heard from Rodney about needing to be seen as a person, Logan augments our understanding by sharing the feeling that future thinking for him is a way of establishing a sense of self apart from how others view him:

Logan:  Maybe thinking of yourself as you, as your own, not as everyone else.
Meaghen:  Getting to know yourself as you see yourself as opposed to how everyone else sees you.
Logan:  Not so much seeing yourself, but knowing or understanding yourself as before…
Meaghen:  If you can understand yourself…
Logan:  By understanding yourself they will understand you more.

Subsequently, future thinking also affords the opportunity to speculate about how things might improve relationally. The adolescents in this study foresee a transformation in how they will be perceived within relationships and consequently this appears to instill a sense of hopefulness. In a story dating back to elementary school, one of the participants described his experience: “I didn’t have any friends. I moved here in grade four – everyone saw me as the kid in the wheelchair…ate by myself…who liked to be by myself.” He continued to talk about how things have subtly changed and he now feels “sort of” more accepted in high school. He credits relationships and taking risks to helping others see him
differently. Other participants expressed a future hope of an identity wherein they are taken more seriously and are not being judged based on their disability. In a defiant tone, one of the participants stated: “In the future people will take me more seriously.” There is a tone of anticipation for a time when how one is perceived and treated in relationships might be different than the current experience. Rodney reflected:

I notice when you get older and when you go to college and stuff and people are less judgmental I guess. High school and elementary people assume I am not normal. But when you are older people will take you a little more seriously. Like they won’t judge you or anything. Like when I was younger I would not talk much, I have developed this ability and I think that will help a lot.

**Waiting for the call: The understudy**

A similar theme of wanting to be “seen” fully appeared in Jill’s narrative. In a story entitled, “waiting for the call,” Jill presents as confused and frustrated while experiencing a silencing of her future selves. She has been thinking about her future since she was ten years old and described thinking about the future as “the same, about the same,” as her peers. Aligned with the findings thus far, Jill’s future selves include a self that is grounded in a realistic image of herself as the author of a new book, describing her “best day” in the future as “the day when my book is published,” as well as an imagined version of a future self without the illness. Importantly, this imagined version of self is shared in the interview with enthusiasm and she responds promptly to all questions about this particular future self: “To be a dancer. To be on stage…a ballerina.” Despite having clearly developed future selves, she experiences an avoidance of discussing the future by others, and understands this to be a function of them wanting to protect her. She explained: “I don’t understand—it is hard for me to understand.” As a young woman with a well-developed future, she emerges in this story as an “understudy” in her own life as she awaits the call to reveal herself fully to others.
Strategy for decision-making: You have to know if it is worth it

The final area of exploration regarding future thinking as a “necessary” activity links back to one of the intended practical applications of this research study. As I moved through the narrative interviews and established first that future thinking was occurring, and second that there is an apparent fluctuation between engagement and avoidance, I decided to insert the question: “Does thinking about yourself in the future help you make healthcare decisions?” The rationale for such a straightforward question was to essentially consider whether the participants themselves would identify this cognitive activity as a helpful tool for decisions they will inevitably have to consider. The evidence gained gives further credence to the argument that traversing cautiously through the resistance and avoidance is a worthwhile effort as it may lead to a more thoughtful healthcare decision that is aligned closely with future wishes.

The vast majority of the participants described a process of decision-making that involved the consideration of short-term pain for long-term gain. Participants described a process of projecting into the future to weigh out the options of decisions like surgery or the introduction of a new medication: “I would imagine the different possibilities and which one would be better,” and, “I would um like – what medication will do in a couple years, thinking about the impact over the next several years. What life would look like and then make my decision based on that.” As well, one of the participants emphasized that there have been times that he has engaged in future thinking more often and that these are related to his health status. He said “Yes – [thought about the future] more during back surgery…you have to know if it is worth it.” Significantly, it was during this discussion that one of the participants placed emphasis on the salience of this activity, suggesting that given this life circumstance, future thinking is necessary: “if I was healthy I wouldn’t have to [future think] as much, but having an illness you need people to help you. I would be totally different.” In essence, this participant is suggesting that decisions made regarding health have other consequences such as an extension of care provision by others and therefore must be considered in the equation. In this important expression, the value of future thinking is once again validated as a way to anticipate and plan for care and support requirements.
Conversely, the question of future thinking as an important component in decision making presented a dilemma for two of the participants. In both cases the confusion was immediately apparent, as the adolescents could not recognize how future thinking might be related to, and helpful for, decision-making. In order to understand this further I asked each of them to consider a time when they were faced with a decision about their health. In response, one of the adolescents remarked, “nobody has asked me to do that [make decisions] and the other adolescent felt that it was always best to just “ask the doctor.” In these cases the participants were not confused about the idea of future thinking, but rather appeared puzzled by the idea of participating in the healthcare decision-making process.

**Tracking Myself Across Time: An Evolving Story of Maturing**

Understanding how the adolescents in this study experience themselves across time proved to be a valuable endeavor, as it led to important findings regarding the integration of elements of the self from the past to present, as well as extending into the future. In the initial stages of this exploration each participant was asked to reflect upon who they were five years ago compared to who they are in the present. As a way of capturing the overall tone of descriptions, the verbatim descriptors of self across time and the identification of what accounts for change are all summarized in Table 7. Upon reviewing this table it will become apparent that the overarching theme is one of acquired maturity. Six of the adolescents used the term ‘maturity’ to describe either the changes that have taken place, or as a contributing factor to the changes that had taken place. As well, in other narratives the concept of maturity was not stated overtly but rather alluded to, and made evident in the perspectives and attitudes towards life that were demonstrated in the narratives.
<table>
<thead>
<tr>
<th>Descriptors of Self 5 Years Ago</th>
<th>Descriptors of Present Self</th>
<th>Descriptors of What Accounts for Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shy, Ingoing vs. outgoing, Boring, Independent, Isolated, No friends, The kid in the wheelchair</td>
<td>Outgoing, Not boring, friends, enjoy making plans and doing things.</td>
<td>Maturity, Taking risks, Stepping outside of comfort zone</td>
</tr>
<tr>
<td>Shy, Harder because of transition to a wheelchair, Unsure of things, Didn’t go out alone, Less social, Less confident</td>
<td>Independent, Successful in school, Successful in sports, “Open” about things, More social, confident</td>
<td>Confidence, Knowing what you are comfortable with, Being more sure of yourself, Taking risks and trying more things, Push out of comfort zones, Getting to know yourself so others can understand you</td>
</tr>
<tr>
<td>Less mature, More worried, Could play other sports, Shy, Less motivated</td>
<td>Mature, Less worried, Found power soccer, Confident, More vocal, More calm</td>
<td>Maturity, Confidence, Attitude, Gained a voice</td>
</tr>
<tr>
<td>Energized, A jerk, Rude, Did stupid embarrassing things</td>
<td>Feel more relaxed, More polite, More mature, more confident</td>
<td>Medication change, Learning how to control “the beast” (referring to anger), Understands people better, Forgives people</td>
</tr>
<tr>
<td>Healthier, Easy-going</td>
<td>In more pain</td>
<td>Getting older</td>
</tr>
<tr>
<td>Always joking, Cheeky, Grumpy, Angry</td>
<td>Joking, More cheeky, Not as grumpy, Happy, Not as angry, More fun to be around</td>
<td>Maturity, Responsibility</td>
</tr>
<tr>
<td>Quiet, Shy</td>
<td>A little less quiet, A little less shy, Smart, Funny</td>
<td>Experiences, Getting older and gain experience, Maturity</td>
</tr>
<tr>
<td>More freedom, Independent</td>
<td>Less freedom, The same independence I think, Interesting, Happy</td>
<td>I don’t know</td>
</tr>
<tr>
<td>Friendly</td>
<td>Not very shy, Friendly, Good, Imaginative, Religious, Determined</td>
<td>Getting involved in youth groups</td>
</tr>
<tr>
<td>A bit naïve, More outgoing</td>
<td>More cautious, More mature, More humorous</td>
<td>Growing up and dealing with different people, Developing my own personality</td>
</tr>
</tbody>
</table>
The adolescents in this study most often referred to a sense of gained maturity as the difference between who they were five years ago and who they are today. A notion of increased maturity emerged in the vast majority of narrative accounts. Interestingly, in these cases where maturity emerged as a “change” that had occurred, the adolescent spoke about this with a great deal of ownership and pride. As well, not only was this described as “a change” but it was described by one participant as the “most important” change that has occurred across the five year time period:

Most important ones [changes], probably maturity and confidence. Just because maturity helps me and because I am older I think I am more mature. I noticed that as the years go by I am getting more and more mature. I’m going through that transaction of being an adult.

When referring to maturity as a significant change, several of the participants grouped this characteristic with other qualities that have changed over time. Statements such as, “I am more humorous, more mature,” and, “you act more mature and vocal and you can get more help,” demonstrate how this idea of maturity is quite versatile as it is seen here as a core part of personality changes, as well as an important aspect of ensuring participants can obtain the help they require. Echoing much of what had been described by others, Bryce summarizes: “[I am more] mature, confident, happy, what about the fact I play two sports? More calm. Don’t worry as much. That is about it I guess.” Interestingly, a feeling of increased confidence was commonly expressed among the participants. In addition, one participant conveys the notion that maturity is a natural consequence of age: “because I got older. I got more mature and more responsibility.”

Notably, several of the participants appeared to enjoy this retrospective activity, and my field note reflected that this activity provided an opportunity for the adolescents to identify some of their accomplishments and that the mood again lifted during this section of the interviews. For the majority of participants, this activity facilitated a sense of ownership of some of the changes that had taken place. Alternatively, a few of the participants identified their present self as less healthy, in more pain, and with less freedom than they had
five years ago. Despite the “heavy” tone of this retrospective activity, the participants who described themselves in this manner did not appear to be upset by this reflection.

As well, this activity set the stage for participants to reflect upon changes in how others may have perceived them. Riley began by sharing his experiences in elementary school:

Riley: I didn’t have many friends really. Ever since I moved here in grade four and I was the handicapped kid right? I was walking funny and in the wheelchair and it took a long time to get back into social…in my old school I was pretty popular but now – brand new school – brand new area and I don’t know a single person. It was just so different.

Meaghen: So you feel like people saw you as different?

Riley: Yes. They saw me as the kid in the wheelchair who likes to play by himself. I would try to be friendly…but…I made a friend. And now, high school is so much better.

For Markus, this segment of the interview served as an opportunity to integrate some of the parts of himself that he is less proud of, into who he is today, and who he expects to be in the future. As part of this critical reflection and in a regretful tone he shared:

I think I was a jerk to everyone to be honest. Now I just feel like I did really rude things to people. Like once I was going down a line-up and I pulled down my pants in front of everybody. It was stupid and I don’t know why I did it. I try not to think about that.

Highlighting the significance of this story for Markus, during the interview he returned on three different occasions to this story. Later in the interview he refers back, “yeah, that I really regret. I sort of lost my reputation in a way and tried to bring it back.” As he considers how he is different now he reveals:
The only thing that has really changed is my attitude on the inside. I’m nicer to people and I think that helps a lot and I always think I had that inside of me. I notice it helps me get more help…because I depend on a lot of people so it kind of helps… I feel a lot more relaxed. Like I feel a lot more polite to people in a way. Like I just look at myself in the past…I am more mature.

The practice of perspective

The capacity to nurture happiness and calmness within the context of a progressive life-threatening neurodegenerative illness was also a prevalent theme in half of the narratives. Although not always outwardly named as maturity by the adolescents, during the analysis these narratives collapsed intuitively within a maturity framework. In the first and clearest case, while exploring the changes that have occurred over time, one of the participants revealed an awareness of disease progression as well as an achieved level of maturity that is helping to cope with these losses: “A couple of things I have noticed is that I am getting weaker and I became more mature and I realized I have a disease and I have to live with it and be happy and calm.” In a closely related theme, four of the participants describe a focus on the present as a skill they have cultivated to counter or manage the emotions related to the uncertainty of disease progression. A focus on the “here and now” is evident in each of the following four quotations:

I know that my health is going to get worse in the future. I realize that it is going to get harder and that is why I try to living day to day. I try not to worry about the what-ifs, why this happens, just try to be calm and live day by day and see what happens. Yes, I try to be calm before anything big happens I usually just wait until the day comes and deal with it then.

I try to take one moment at a time because I don’t know what the next day is going to be like.
Like…it is like…if it is going to happen it will happen. Life is not predictable. You don’t think in advance it just happens.

I think that is what it takes [focus on present] and it helps to realize that I am going to get weaker than before and try not to worry about what will happen. When I was younger I was thinking ‘can’t do this and can’t do that’ and thinking all negative stuff. Trying to be positive that is what I believe.

The notion of a gained perspective reverberated through seven of the ten narratives, and was most often demonstrated in the context of learning to live with the diagnosis and the reality of the disease. In an open and honest reflection, Markus described how his attitude toward the illness transformed over time as he gained knowledge and experience:

Markus: Like when I first understood muscular dystrophy I wanted to kill myself. Sometimes I just felt like putting a bag over my head and killing myself but I just realized that it is not worth it.

Meaghen: And what do you think stopped you from doing that?

Markus: I met other people with muscular dystrophy and realized that it was not that bad. And I realized that there are some that are even worse than me and even as muscular dystrophy progresses, I might not even get as bad as they are anyways. It is just – be thankful for what you have or else you may lose it…I think.

In similarly powerful moments the adolescents provided evidence of a changed outlook on life and living. In some cases it was stated clearly; “when I got older I got a better understanding of life and life is about being positive.” Alternatively, the altered standpoint was presented in the form of a personal story or reflection. In one such case, the adolescent conveyed a significant learning about forgiveness and caring. In his narrative he referred to the importance of recognizing the difference between a person being “plain old mean” or “having a bad past.” Accordingly, his story speaks to the important lessons he has learned by living with an illness:
Markus: I really forgive people. I know what it is like to go through muscular dystrophy and it is not fun all the time. It is not fun and games.

Meaghen: So do you mean that your experience of going through muscular dystrophy helps you to understand people?

Markus: Yes, I do not make people hurt any more than they are already hurting.

A shared appreciation for the times in life when things are going “smoothly” was also conveyed across the narratives. In their own words, the adolescents describe appreciating the plateaus of illness as a period when everything “levels out” and when things are just going along “pretty steady.” Accordingly, one of the participants described the importance of recognizing and appreciating the simplicity that is offered by a “regular day.” Evidently, the perspective gained from the experience of living with an unpredictable illness includes a shared understanding that an important aspect of this experience is to appreciate the times that life offers a respite from the challenges of disease.

Reflections on change: Two incredibly different “me’s”

The ability to see the self as having undergone significant change was apparent across all ten interviews, thereby providing a foundation for further exploration into the concept of identity as a stable set of self-structures across time. The notion of continuity was described to the participants as the ability to see oneself as the same person across time. Accordingly, in the context of the significant changes that all of the participants eagerly revealed, each adolescent was asked to consider these differences and then to identify whether they are the “same” person.

Two of the participants felt that they had changed so dramatically that it was difficult to describe themselves as the “same person.” In the first case the adolescent responded:

No [not the same person], I feel like a whole entire different person. Like somewhere I must have turned a corner like you were saying. A turning point. Like I was one person and I just changed and everything just calmed down, so much easier. Just you know, more mellow.
The second adolescent reflected:

You know I don’t think this is the same [states own name] sitting here…I can’t answer that because there are two incredibly different “me’s.” I am the same person body-wise but my mind’s been tweaked a bit – it’s opened up a bit more.

In the remaining eight narratives the participants described being the “same” person. In these instances, once they revealed they were the same, they were asked to identify what it is that makes them the “same person” as they were five years ago. This sparked an interesting range of responses as the participants were charged with the task of sorting through the difficult question of what makes a person the same across time.

In some cases the participants used their physical self as their anchors to sameness and assigned the significant changes to their mental state or attitude. As one described, “Yes [I am the same person], you are in the same body – just mentally changed.” As well, in one of the narratives the structures of self that remained the same were firmly anchored in the concrete evidence of height and a name not changing, as well as some of the personality characteristics that have remained the same: “My shortness. I don’t care I like my size. I like being short. My weight goes up and down. Happy, cheeky, grumpy and joking…and…because my name hasn’t changed.”

Finally, one of the participants identified both self-perception and how others perceive you as what changes over time: “you are always the same; you just think about yourself differently I guess. And maybe what other people think of you as they notice change.” As well, participants described their “inner self” as remaining relatively stable and therefore providing a consistent sense of self across time. This aspect of the experience was described by three participants in the following different ways: “the inner self stays the same;” “I just think I will be the same happy person;” and “[I have] the same personality and I like the same things as I did before.” Within this group the descriptions of what makes them the same included the recognition of a congruent attitude, their personality, their preferences, and disposition.
Interestingly, one of the participants recognized herself as continuous across time through what might be considered a dual process involving both the external relationships surrounding her, and an internal consistent set of values and beliefs:

Probably [know I am the same person] like the people around me, my personality, my values, and my morals and stuff like that. Relationships are one thing that help define who I am over time and then my personality and values.

This was undoubtedly one of the most challenging portions of the interview as the question in and of itself presents a complex phenomenon that is not commonly explored within the general context of living. Despite this, all but one of the participants were able to respond to the question and in this exceptional case the adolescent was very thoughtful about the answer, and after several minutes of thinking replied: “I really know I am the same person…it’s weird.” Thereby confirming that despite the significant changes that had been articulated and explored that there is a strong sense of being the same person.

**Defining moments: Stepping further outside of the known**

The study continued to explore whether the participants were able to determine what might account for the changes that had taken place. Posed in plain language, each adolescent was prompted to consider how they would explain all the changes that had taken place in their life, and ultimately how it is that they have become the person they are right now. In response, the narratives indicated four themes that account for change: 1) taking risks and pushing outside the boundaries; 2) accessing strength through coping; 3) increased levels of confidence; and 4) the general life experience of growing up.

Certainly the most prominent theme emerging from the narratives was the importance of taking risks and pushing yourself beyond what is comfortable. One participant reflected on what he described as a protected childhood, “maturity, yeah, when you are a kid everything is just in a bubble. Stepping out of your comfort zone pops the bubble…I did that a few times.” He expands on this idea by sharing a story of a time when he pushed himself to take a risk:
Riley: I could never imagine how going to one small event could completely change my life. I didn’t want to go. I kind of encouraged myself. I decided I would go for five minutes, I thought, “five minutes won’t hurt.” I went for five minutes and stayed for two hours. The grad barbeque – I met two people who changed my life. Amazing how one event can make you change.

Meaghen: Is there a word to describe how it is you have changed?

Riley: I think it is taking risks. That is a really big thing. I’m glad I’ve taken them…that sums it up.

Meaghen: As soon as you say that sums it up your face gets light and happy. You are really glad you did it, pushing yourself out of your comfort zone.

Riley: Yes, very proud, I think it is about taking risks.

Similarly, in another narrative the adolescent explains how change requires pushing through some resistance. When asked to comment on his experience of change he explains, “trying new things that pushes us [causes change]. I try to push myself out of my comfort zone. I just try as much as I can.”

Riley described the acquisition of strength through struggle. In this portion of the interview he reviews a time in his life when he was faced with what felt like an insurmountable struggle. Interestingly, it was within this struggle that he described experiencing the most change:

It [an eight-month hospitalization] changed me – it changed my outlook in life. It changed how I dealt with things and how I coped with things…showed that I can deal with a lot more than I thought I could. It is just that everything else has changed – a whole new way of living basically.

He continued: “Yeah, and maybe I took for granted the things I wasn’t doing or wanted to do. When I was in the hospital I was like, “why didn’t I do this, or this, or this, before?” Reflecting upon the changes that had occurred for him and the experiences that
contributed to those changes, this participant felt that the decisions he had to face in the hospital and subsequently the fear associated with these decisions, was more manageable than he had expected. He describes leaving the hospital as a “whole new person.”

The final two factors that were identified as accounting for change included increased an increased level of confidence and life experience. In one of the narratives, a sense of self-assuredness was deemed an important contributor to change:

Not sure [what accounts for change] but confidence might be a part of it. Know what you are comfortable with. Just more sure of yourself. So it is linked to confidence, so not being afraid of what others might think of you.

Finally, general life experience was described as a feature of change: “Probably just growing up, going to school, dealing with different types of people you learn to get your own personality.” The progression in age was also noted, that simply by getting “older” you gain more responsibility and maturity and this acts as a prompt for change. In addition to these more general life experiences, the uniqueness of living with a progressive life-threatening neurodegenerative illness was also described as accounting for change. In this particular narrative the participant is reflecting on the important change of becoming more “serious” as you get older. He says, “I think it is interesting taking yourself more seriously. Not everything. But like healthcare you have to be serious about health.”

**Summary**

The themes emerging from the exploration of the “selves” across time contribute greatly to an overall understanding of this unique life experience. Discovering the concept of “maturing” was unexpected as it revealed itself within the narrative accounts during the reflections of self in the past, exploration of self in the present, and expectation of self in the future. Within this discovery, several important storylines reappeared: an investment in maintaining a focus on the here and now, the importance of positivity and staying calm, and ultimately—a gained perspective.

At this stage of analysis many key features have been established and the findings in this chapter build upon this foundation. Accordingly, the following Figure 3 presents the
final stage in the evolution of the map that has extended across the three findings chapters. Contributing further to this model, future thinking is presented as a required activity that is intentionally managed by the adolescents. Importantly, the adolescents in this study have demonstrated that venturing into this future space is used as a strategy for coping, personhood, and decision-making.

Figure 3. Stage Three in the Evolution of a Map
Chapter 7. Discussion

In this study I examined how adolescents who are living with a progressive life-threatening neurodegenerative illness construct meaningful self-representations across time. The results of this study stretch widely across the topics of future thinking, identity, and possible selves. This final chapter begins by presenting a concise summary of the key findings that have been distilled from the presentation of results that occurred in chapters four, five, and six. Following this I provide an interpretation of how these results address the research questions, and consider the significance these results bear in light of previous research and the existing literature base. Next, the discussion moves to a broader level to examine the patterns and relationships among the findings. Also, the study itself will be discussed, wherein its limitations as well as its strengths will be identified.

In the second part of the chapter, the focus moves to the implications of the findings by relating them back to the goal of the study. Through an exercise in speculation, I will extend the knowledge gained through this research into implications for a practice of healthcare that seeks to support the research population. Through this speculative process I will also identify a few areas for potential future research as a way of considering how this inquiry might be used as a springboard into other related areas of research to advance our understanding further. The chapter concludes by coming back full circle to consider how the results and implications of this study might influence our knowledge about, as well as our practice with, adolescents living with a progressive life-threatening neurodegenerative illness.

Summary of Findings

As a reminder, the study explored the occurrence of future thinking and the construction of possible selves (with and without the illness), the contextual and relational aspects of future thinking, as well as the experience of selves across time. The key findings related to these questions are:

1. The adolescents demonstrate future thinking.
2. The possible selves include a range of selves with and without the illness.
3. There is an ability to oscillate between these two versions of self.
4. The stories of self include the typical "cultural anchors" associated with adolescent development and follow a sociocultural normative script of aging.

5. Silencing by others was not commonly reported, but rather the adolescents demonstrated an intentional and strategic information management.

6. The adolescents demonstrated personal continuity in the selves of the past, present and future.

This study addressed a series of questions beginning with the determination of whether adolescents with a progressive life-threatening neurodegenerative illness think about the future. Through an integration of my own practice experience and the scientific literature, at the outset of this study I anticipated that it was possible that projections were occurring; however, I had no expectation regarding the nature or extent of these activities. Importantly, all ten of the research participants described processes of future thinking. The results of this study thereby converge with existing practice wisdom as well as the theories of identity development that have emphasized the salience of future thinking during adolescence (Nurmi, 1991).

The second question considered whether a construction of possible selves both with and without the illness was occurring within the research sample. Again, and drawing solely from my clinical observations in practice, I was inclined to believe in the likelihood of the constructions of self without the illness. However I was skeptical as to whether a research interview (vs. a practice of counseling) would prompt a revealing of this range of possible selves. Again, surprisingly and convincingly, all ten of the research participants offered descriptions of possible selves that included the selves in the future living with the illness as well as a range of selves without the illness. Again, the results of this study concur with the possible-selves literature (Markus & Nurius, 1986) by demonstrating that the possible selves for adolescents with progressive life-threatening neurodegenerative illness, like those studied in typically developing adolescents (Kerpelman & Pittman, 2001), include both the destinations feared and hoped for, and that neither are necessarily grounded in reality.

A third line of inquiry shifted the focus of the study from the internal processes of future thinking and possible selves to external factors, focusing on the relational context of possible selves. By casting the gaze outward from the adolescent, the first unexpected
finding was encountered. Drawing from my clinical experience I had anticipated that the participants would describe a process of “silencing” wherein they would expose the failings of the contexts that surround them to support the projection of self across time. Apart from one of the narratives that included a sense of not feeling “seen” or “heard,” a common process of silencing was not identified within the narratives and instead, what was learned was an intentional and strategic process of information sharing that situated the adolescent as the active agent in the management of sharing information about their future.

The final question examined the ability of the adolescents to weave a sense of self-continuity across time, from the past to the present and into the future. This was an area that remained largely unexplored in my clinical practice, and therefore I drew upon the literature base of narrative identity during the conceptualization of the question. Extending from what is known about the importance of integrating diverse and distinct elements of the self across time I speculated that the adolescents in this study would be able to demonstrate a similar pattern. However, I was curious about whether the disease process would interrupt the flow of this narrative thereby rendering the composition of the story across time challenging. Through the act of telling stories, all of the participants were able to demonstrate an integration of various selves across time.

As identified in the sample description, the age range of the participants extended from 12 – 20 years old. Notably, six of the participants fall into the older age range extending from 18-20. Interestingly, the most prominent variance in how this group deals with future orientation is in relation to the content of the future thoughts (i.e., a focus on graduation) and the desire for an increase in privacy.

In isolation from one another these findings offer a degree of insight into the experience of adolescent development amidst a progressive life-threatening neurodegenerative illness. Assembled, a more dynamic understanding can be reached. I introduce the word “dynamic” intentionally as way of representing both what became known about the diverse range of possible selves that have found a home in the participants’ future thinking, as well as to highlight the relational and contextual dimension that was explored within this study. Certainly I began this research feeling curious about “what” would be found in the spaces of future thinking, but further to this, and most importantly in my mind, the knowledge I desired was first how the adolescents experienced the future-thinking
activities and second, how the social structures (i.e., parents, families, caregivers) influence this process either through hindering or facilitative means. Further to this, and with perhaps the most direct application to practice, I sought to understand whether future thinking held implications for a sense of identity and for decision-making among the participants.

**A merging of understandings: The collection of care**

The care of adolescents living with a progressive life-threatening disease requires a merging of the specialized care offered in pediatric palliative care and an advanced understanding of adolescent development processes within this population. Since the inception of this study in 2006 there has been a considerable increase in research that focuses on pediatric palliative care. Importantly, aspects of the family experiences of progressive neurodegenerative illness was examined by Steele (2000) and again by Rallison (2009) as through their practice as pediatric palliative care nurses, the unique features of this lengthy trajectory that often stretches across several years (Rallison, 2009) was called to their attention. Taken together these examinations provide a clear and vivid description of the family experience that involves navigation through uncharted territory (Steele, 2000), and a process of “living in the in-between” (Rallison, 2009). Eloquently, Rallison (2009) offers an interpretation:

> living between life and death; between the complexity of care and the joy that a child with complex care needs brings to a family; living in between sorrow and suffering, and courage, and resilience; living between today and tomorrow, not knowing which crises will result in death; living between decisions for cure and intervention, and easing of suffering; living between decisions to prolong and extend life, and the certainty of impending death (p.4).

Both of these studies highlight the character of this trajectory as including times of plateaus and stability that are interrupted by changes in health status and medical crises. The current study adds another level of understanding, and by narrowing the focus from the family experience to the experience of the adolescent living with the illness, contributions are made toward a new dimension of understanding that further complements what is already
known. The adolescents in this study are living in the space between adolescence and young adulthood, with a history of plateaus and crises that serve as a reference point and incentive for living in the moment and not allowing oneself to become consumed with a preoccupation with “what-ifs.” Extending across interdisciplinary fields the community of professionals that supports the care of this population, by bearing witness, have recognized the intricate balancing acts involved in the navigation of this unique experience. By merging an understanding of the family and individual experience with the existing knowledge base in pediatric palliative care, the picture of what is needed is becoming more detailed and leads to a weaving of skills and expertise to build a comprehensive collection of care.

Importantly, this study offers additional insight into an experience that is commonly known as requiring specialized practice. Despite an awareness of the need for specialized care, reports of variable and inconsistent health care practices are noted by the advocacy organization supporting this population (Bushby et al., 2010b), and an apparent absence of guidelines for the care or surveillance of this population within Canada (McMillan et al., 2010). Further to this, advances in medicine have extended life expectancy resulting in a larger number of adolescents navigating the space between childhood and adulthood. Often dismissed as “difficult to help and unlikely to reach adulthood anyway” (Abbott, 2012, p. 241), little is currently known about this influential period of life for those affected with progressive life-threatening neurodegenerative illness. The call to know more continues to ring loud and clear.

The results of this study contribute to a growing knowledge base in pediatric palliative care and the practice of adolescent medicine. Certainly the findings are consistent with much of the existing literature that is based in the “typically developing” adolescent population, thereby offering a contribution to further validate important concepts and trajectories of understanding within that large field through the extension of knowledge into this unique population. Although these areas of convergence will be noted during the discussion, my intention in this summative chapter is to examine the aspects of this experience within the research population that will serve to contribute to both knowledge and practice in the care of these individuals. For purposes of clarity and organization, the discussion moves sequentially through the key findings and situates the finding within the
related literature base, pointing to areas of convergence and divergence as way of offering an extension of knowledge.

Managing an Unwelcome Visitor: A Reason to Think about the Future

In the context of a progressive life-threatening neurodegenerative illness, movement into the years ahead inevitably leads to a progressively weakening body. Thus, “the future” could be conceptualized as an “unwelcome visitor.” Importantly, upon situating the character of this illness within the experience of adolescence—a time when a “gearing up” for the future is equally as inevitable—the convoluted nature of this experience is revealed. However, even within the ambiguous quality of a future space that includes ongoing physical losses, the participants revealed an ability to “manage” their future thinking activities by charting purposeful voyages into the future.

Amidst the findings related to future thinking a few points are particularly striking and warrant further discussion. First, all the participants revealed varying degrees of engagement in future thinking and it occurred to me as I was interviewing, and then again upon listening to the tapes, how readily accessible the future projections are for these adolescents. Second, the adolescents demonstrated a range of reasons for future thinking. Presented in the results as strategies for coping, decision-making, and personhood, the narratives in this study depict future thinking as a valued and purposeful activity.

The findings related to future thinking in the current study closely parallel the recently published study that involved 25 interviews with adolescents with spina bifida. In their study that examined the family management of a chronic health condition, Wollenhaupt et al., (2012) describe how participants envisioned a distant future life, and within these projections some of the participants felt concern about the years ahead, while others sounded eager to anticipate it. As I reviewed this study a second time in light of my own research findings, I was reminded of the contrast between the trepidation with which Markus initially approached the conversation about “future” and the eager anticipation evoked by Victory as she beamed with excitement referring to her plans for graduation and beyond. Taken together, these studies confirm the diverse nature of the activities of future thinking for adolescents dealing with chronic and life-threatening illness, as well as the experience of a range of emotions involved in this projection.
In a critical review examining the literature on the experience of living with a chronic illness during adolescence, Taylor et al., (2008) describe the developmental task of future thinking as compromised due to the uncertain outcomes for some chronic illnesses. In considering this statement alongside the results of this study, I would agree that the participants in this study demonstrated “degrees of compromise” in relation to the certainty with which they are able to project into a coherent future path. I can see some parallels in the study; however, it was not the case that the “engagement” in the activity itself appeared to be compromised significantly, but rather that the movement into a projection of the years ahead was effectively managed by the adolescents in a manner where they might learn about themselves, make decisions and plan for the future, and cope with the progression of the illness.

Confirming the occurrence of this activity within the research participants is not surprising. Future thinking is a major feature of human thinking (Nurmi, 1991) that takes centre stage during adolescence. Importantly, the knowledge gained from this study extends from the identification of an activity as occurring to an understanding of the subjective meanings assigned to the activity by the participants. Effectively, the participants in this study demonstrated a masterful navigation through the uncharted waters of disease progression and development. By situating these findings within both research and practice, there is an expansion of insight into how the future thinking activities of adolescents living with a progressive life-threatening neurodegenerative illness helps them to manage living life at the intersection of disease and development.

Much of what was learned in this study confirms in this population what has been previously known in the population of healthy adolescents. Within existing studies examining future thinking, the number of years adolescents look ahead is reported as ranging from a focus on the three to five years ahead (Poole & Cooney, 1987), and extending to the end of the second and beginning of the third decade of life (Nurmi, 1991). The results of the current study closely parallel what has already been established as typical projection patterns. For instance, taking into account the age of the participant and the number of years they report projecting ahead, the age range within which the projection extends is from 19 years old through to 32, a very similar range to what is suggested in the studies examining future thinking during adolescence. Importantly, this study suggests that there are several common
features of developmental processes and therefore various aspects of the knowledge pertaining to healthy adolescents appear to be transferable to adolescents living with a progressive life-threatening neurodegenerative illness.

Despite commonalities, there are important distinctions that serve as reminders of the unique features of living at this intersection of disease and development. For instance, within the exploration of future selves the participants were asked to consider aspects of the future they are fearful of. Interestingly, the results align somewhat closely with that of the typically developing population, with fears listed as unemployment and divorce; however, results depart in the articulation of specific fears. Healthy adolescents describe being fearful of non-normative life events such as death and divorce of parents and global threats such as nuclear war (Nurmi, 1991), whereas the adolescents in this study did not report these concerns but rather consistently added the dimension of fear for their “health.” Again, these findings concur with what Stevens et al., (2009) discuss in their consideration of adolescents living with life-threatening illnesses, as they describe the greatest concern being “the effects of the illness on their plans for career and relationships, and on their lifestyle” (p. 123).

**The Importance of the Impossible Bubble: I Need Both Possible Selves**

Perhaps one of the most intriguing findings was the ability of the participants to construct an array of possible selves that included what has been referred to in this study as the “real” and “imagined” future selves (i.e., with vs. without the illness). Similar to the discussion above, the occurrence of a range of possible selves that includes a focus on school, continuing education, and future occupations is not a new or novel finding. Oyserman et al., (2004) cite various studies that have observed this pattern of possible selves during adolescence.

Situating this study within the extensive literature on possible selves, the insight gained by listening to these narratives of future selves extends our knowledge with respect to the self-enhancing qualities of these cognitive constructions. Accordingly, the commentary that follows regarding possible selves is grounded in an understanding that an oscillation between the real and the imagined future self is occurring and that these selves appear to serve the important function of self-enhancement.
The contextual nature of possible selves has been established in the literature, and Markus and Nurius (1986) describe this clearly by suggesting that adolescents use social comparisons to contrast their characteristics and behaviours with those that surround them. It is within this comparative process that adolescents consider: “what others are now, I could become.” This also rings true in the current study, as the range of possible selves that were constructed are associated with the commonly presented images of building relationships, education, career and financial status.

In the full conceptualization of possible selves, a “balance” of hoped-for and feared-for possible selves is assumed to underlie augmentations that motivate behaviour (Seginer, 2008). This is perhaps most easily understood by taking a moment to think about the ease with which a balance of selves can be constructed. Take for example one of the most prevalent hoped-for future self revealed by the participants in this study: the self in relationship with others. It is not difficult to decipher that the opposite feared-for self in this regard is the self who is without relationships, alone and isolated. Therefore, the behaviour that is motivated is likely to be pro-social with the intention of building and maintaining relationships. Indeed, this balance of opposing possible selves revealed itself in several of the narratives when participants reflected on their dependence on others for care and the necessity of relationships.

This study aimed to explore whether an imagined self without the illness is included in the range of possible selves constructed. Consequently, to understand the function of the full range of possible selves it is necessary to shift out of the “motivation” paradigm and consider another function of possible selves, that of self-regulation. Importantly, this discussion does not assume that the range of possible selves do not serve a self-regulatory function; it is quite likely that these possible selves promote behaviours related to various dimensions of living. However, this is an area that requires further examination in order to engage in productive speculation. In the context of a life-threatening illness many of the possible selves constructed are unlikely to serve a self-regulatory function as achieving these selves (i.e., the helicopter pilot and ballerina) are not possible due to limitations in physical functioning. Therefore, this study offers additional evidence of the importance of the self-enhancing function of possible selves.
Although the concepts of self-enhancement and self-regulation have not been fully disentangled (Oyserman et al., 2008), there is awareness of both functions. Markus and Nurius (1986) situate possible selves alongside personal goals and strivings. They explain that the function of possible selves extends beyond regulation of behaviour, a function that was apparent in this study. The self-enhancing quality of the possible selves did reveal itself as the participants spoke of a range of positive emotions associated with the projection of selves. Essentially, when the projections of self are not equipped with strategies for achieving a hoped-for self, their value is not necessarily diminished. To tie this to a larger body of research, Gonzales, Burgess, and Mobilio (2001) contend that it is the act of constructing a self-improvement plan and the promise of a better future, that help individuals feel better in the present and closer to their best possible self. In their study they examined the “allure of bad plans” and the implications of plan quality for progress towards possible selves, and found that participants were more likely to report on the psychological benefits of planning (i.e., increased self esteem, enhanced self confidence, happiness and optimism) than the instrumental benefits associated with goal achievement. Taking into account the findings of the current study related to increased feelings of positivity and hopefulness when discussing the “imagined” possible selves, it is interesting to consider these findings as sharing a similar view that not “all plans” or all “possible selves” need to be feasible in order to serve a function.

As established in the review of the literature, possible selves were selected as a construct on the basis of being relatively free from reality, and for the suggestion that they might be used to enhance coping in stressful situations (Oyserman et al., 2004). Seginer (2008) describes: “while earlier researchers were concerned with the irreality of future orientation, the possible selves approach contends that, by being relatively free of reality, possible selves may prompt coping with stresses and challenges” (p. 27). The findings from this study lend additional credence to the assertion that possible selves may simply help adolescents feel good about themselves by serving the function of self-enhancement. Thus, the oscillation between a real and imagined future self that has been demonstrated in this study may be thought of as an approach to coping with living with an illness as well as a way to map out the selves in the future in order to make life decisions.
We Share the Same Script: Cultural Anchors and the Life Course

From the moment I first noted the emergence of “cultural anchors” found scattered throughout the narrative accounts, I have been eagerly anticipating the movement of this finding into a discussion. I recall clearly the intonation in the voice of one of the participants who when describing his activity of future thinking said, “some [kids] have the same story to tell, like walking. Making it easier to connect with other people.” The visual image that presents itself is an entrenchment in “different-from,” and the observation that there is a common experience that stands apart from his. Interestingly, this full narrative account reveals the common stories of relationships, parenthood, and career. Therefore, although he is aware of his difference, he continues to draw from the cultural script that is made available.

I have used the term cultural anchors to describe a category of findings wherein the participants’ narratives revealed many of the milestones and accomplishments that are commonly known and taken-for-granted expectations as an individual moves from adolescence through to adulthood. Examples of these include involvement in a relationship, continuing education, and developing a career. As Nurmi (1991) describes, an individual’s future-oriented goals and interests develop within the context of what is considered to be the normative life events and the related developmental tasks, and both are assigned to a timetable. He continues to describe these “tasks” as providing knowledge about expectations, models for how these might be successfully achieved, and normative standards and deadlines for the emergence of appropriate behaviours. The findings of this study reveal that even at the intersection of disease and development, there is an awareness of, and an active pursuit for, the adherence to these standards. For instance, in addition to the examples noted above, echoing clearly across the majority of narratives was the concern that the graduation from high school might not occur “on time,” indicating that in addition to wanting to follow in the expected path, one did not want to fall behind despite having a considerably different life experience from their healthy peers.

The results of the study conducted by Nurmi (1991) examining future thinking activities in adolescents point to a “cultural prototype” of the activities that are anticipated within development across the life-span. He describes: “Young people expect to finish their education first, then get a job, third to get married, and finally to build up a material basis for
their later life” (p. 27). The results of the current study offer further contributions to the influence of an established prototype of a typical future trajectory. Converging with what Nurmi (1991) describes, the processes of future orientation demonstrated in these narratives are associated with the established patterns of normative developmental expectations, and the selection of opportunities appear to be consistently drawn from the choices that are made available in the broader culture (Nurmi, 2004). Thus, the findings indicate that although the core story for each of these participants differs substantially from their healthy peers, they continue to draw from the cultural scripts that are made available. For the participants in this study, future thinking involved consideration of what researchers interested in future thinking have described as the “prospective life domains” that include social relations, marriage and family, higher education, and work and career (Seginer & Lilach, 2004). As well, Poole and Cooney (1987) drew comparisons between adolescents living in various contexts and concluded that future thinking, goals and plans, are directed toward an instrumental set of plans (i.e., education and work), and an expressive set of plans (i.e., marriage and family).

Extending an understanding of the strength of the cultural and social influences surrounding adolescence, the findings of this study reveal that even amidst a life course that departs considerably from the “norm,” the adolescents in this study, by virtue of drawing from a collective script, are constructing stories of self into the future that fall into the expected life domains thereby adhering to the sociocultural expectations.

This finding ties agreeably into what is broadly known about future thinking in the context of life-threatening (Stevens et al., 2009) and chronic illnesses (Taylor et al., 2008; Wollenhaupt et al., 2012). Wollenhaupt et al. (2012) described as occurring, in their sample of 25 adolescents with spina bifida, hopes for the future that included living independently, furthering education and engaging in a career, getting married and having children. Moving more broadly to a category of “chronic illness,” Taylor et al. (2008) found that the adolescents’ future thinking activities had a similar focus with concerns about employment, moving away from home, and having children. Additionally, and in close parallel with the adolescents in the current study, these young people acknowledged the limitations that may be imposed by the illness in the choice of career and in the opportunities presented.

The adolescents who participated in this study have clearly adopted this script as a means to write the future stories of the self. Although the self-enhancing qualities of
projecting into the future have already been explored in this study, it is necessary to critically examine the potential consequences of these projections. If adolescents with a progressive life-threatening neurodegenerative illness engage in consideration of what one “might be” or “should be” in comparison to others without taking into account the difference in life experience, it is not advantageous to speculate that this might result in negative self appraisals. Further to this, by situating this speculative process within the life stage of adolescence wherein the differences in patterns of autonomy and independence has been distinguished, adolescents with life-threatening illness are at risk of falling victim to the expectations within this script, which have not made provisions for development outside of the normative context. As discussed by Stevens et al., (2009):

A sense of worth in adolescence is linked to experiencing milestones along the journey to adulthood. If milestones and rites of passage such as examinations, graduations, school formals, and celebrations of significant birthdays are missed due to illness, a young person’s sense of worth may deteriorate (p. 120).

It is not uncommon for an adolescent living with a progressive neurodegenerative illness to experience deviations from the commonly travelled path. The findings from this study affirm that despite an awareness of living a life of being “different from” their healthy peers, the adolescents continue to use the cultural script made available.

**Keys to the Gate of My House: Strategies of Information Management**

As one of the key findings of this study, the intentional manner in which the research participants shared information about their future thinking activities was demonstrated across all ten narrative accounts. Perhaps best depicted as an effort to maintain jurisdiction regarding the personal information related to future thinking, the adolescents in this study demonstrated precision in how they managed these boundaries. One of the most profound statements regarding the ability to control what is shared and with whom it is shared was depicted as a way to maintain control and governance over a private space. For Rodney, allowing oneself to be fully known was akin to a surrendering of the “keys” to the gate of his house.
The need to negotiate the management of boundaries between families and adolescents coping with illness comes as little surprise. It is widely accepted that the boundaries between maintaining privacy over matters of the body become blurred in the giving and receiving of personal care. Wollenhaupt et al. (2012) explain that the adolescents with spina bifida in their study offered insight into issues of privacy and suggested that the overstepping of boundaries can result in familial conflict. Observing the privacy needs of adolescents when provisions of personal care are necessary is a balancing act that must be negotiated within the relationship. Interestingly, the results of this study clearly demonstrate a preservation of the boundaries related to information sharing, and suggest that this can be used as a strategy for maintaining governance and control over personal matters.

A vast body of literature offers insight into processes such as boundary management (Petronio, 1991), self-disclosure (Noller & Bagi, 1985), and topic avoidance (Guerrero & Afifi, 1995a, 1995b). Importantly, striking a balance of self-disclosure and topic avoidance is thought to be of high importance within the parent/child relationship during adolescence (Petronio, 2002) and the transition to young adulthood (Guerrero & Afifi, 1995a). It is during this transition that boundaries are renegotiated and new rules established to govern future communication patterns. As a strategy for maintaining privacy, topic avoidance occurs for reasons including: (1) self protection, (2) relationship protection, (3) partner unresponsiveness, and (4) social inappropriateness (Guerrero & Afifi, 1995a). Again, by the very nature of the progressive nature of the illness it is fairly evident that achieving this balance is difficult for adolescents and parents living with a progressive life-threatening neurodegenerative illness. Even in the absence of a concerted effort to gather data relating to these four reasons, the results of this study offer additional insight into these processes; the participants clearly described protection of self and others from the emotions related to future thinking and the reality of the future, as consequently altering the information they shared regarding their future projections.

Connecting back to a few of the previous findings related to possible selves and the cultural script, the self-concepts of adolescents are open to social feedback from peers, the media, parents, and other adults (Oyserman et al., 2004). As such, these future visions of the self are described by Kerpelman and Pittman (2001) as quite malleable and often shifting in response to feedback from others. A statement in one of the narrative accounts really hits
this on the mark as the participant explores the notion of “why” adolescents might not talk about their future with others. In his response to this question Jake suggests that the reason they might not share their visions for the future is because, “they [the listener] might think it is a silly idea.” Implied within this statement is the suggestion that the vulnerability associated with sharing a full spectrum of hopes and dreams may prevent adolescents with a life-threatening illness from sharing with others. In another poignant moment Victory turns the focus outward to the listener and suggests that she shares only with people she trusts and who express an interest in her future. She is aware that by sharing she will evoke a response in the listener and that the response might not be one that the listener is comfortable with. She explains that maybe people don’t ask her about her future because they don’t want to hear about how it “might” turn out.

In a study that focused on the experience of growing up with a chronic illness, Admi (1996) found that the management of disease-related information is an ongoing process that changes over time. Although the current study did not focus on disease-related information but rather on information about the future, one of the participant’s comments closely parallels this finding. While exploring how much of “himself” he keeps private, Rodney explained that he expected that as he got older there would be “more things to keep private.” As well, Admi (1996) found that the participants in his study carefully selected their “audience” for disclosing health-related information with the main criteria including a caring listener, a perceived capability to deal with the information, and the establishment of a relationship. Again, with the focus on future thinking, the results of this study indicate that the adolescents are selective in who they will share their future thoughts with, thus demonstrating a degree of alignment with these criteria.

Guerrero and Afifi (1995b) describe family communication as shaped by topic avoidance and self-disclosure, and the necessity of striking a balance between these processes increases in importance when children are moving into adulthood. Various theoretical perspectives focus on the management of information within a family, and call for a balancing act between the need to maintain control and privacy with the need to self-disclose and experience intimacy (Guerrero & Afifi, 1995a). Described from a dialectical perspective by Baxter and Erbert (1999), the interplay between expression and privacy as revealed by “informational candor” versus “informational discretion” occurs in relationships...
as individuals encounter the simultaneous need to be both open and closed. As well, Petronio (1991) recognizes the paradoxical demands associated with our concurrent needs for autonomy and intimacy and the effects of these demands that operate in decisions to disclose private information. Oftentimes individuals are pulled in two directions, toward both intimacy and autonomy as they make decisions about what to share. Conceptualized as dialectics, the push and pull between the opposing forces of connection and separation, expression and privacy influence the decisions one makes about self-disclosure. Importantly, these theoretical perspectives are founded upon various opposing forces such as openness-closedness, connectedness-autonomy, and ascribe to an overarching principle that some level of closedness or avoidance is characteristic of all relationships (Guerrero & Afifi, 1999a). Topic avoidance is presented in the literature (Guerrero & Afifi, 1999a) and confirmed in this study as serving important functions in close relationships such as the preservation of privacy and a sense of autonomy.

A few of the features of Petronio’s (1991) Communication Boundary Management Theory are relevant to this discussion of findings. In particular, the basic thesis underpinning this theory assumes that sharing private information reveals aspects of the self that lead potentially to feelings of vulnerability. As well, she describes the construction of a metaphoric boundary as a means of managing the flow of information in various relationships: “when boundaries are tightly controlled, access to information is limited, autonomy is achieved, and vulnerability is at a minimum” (Petronio, 1991, p. 314). Interlacing this with the demonstration of “protection” that occurred within the narratives, another dimension of understanding is added to the fold, as it is possible that the rigidity of boundaries and the selectiveness with which adolescents share information allows them to choose the individual with whom they feel they can be vulnerable.

**Tracking My(selves) Across Time: Looking Back to Look Ahead**

The results of this study confirm that the participants were able to map themselves into the future and also trace themselves back into the past. The value of future thinking was clearly articulated as the adolescents demonstrated the importance of moving towards a level of “knowing” what might lie ahead and in turn, the ability to develop coping strategies and to engage in decision-making that is aligned with their core values and beliefs. Within this
space of “unknowns” the adolescents are able to map out a range of future selves and through this, to become acquainted with dimensions of the self that may otherwise go unexplored. Essentially, by bridging the self of today with the self of the future the adolescents are constructing their identity. As well, the “looking back” that occurred offered a reference point for the “changes” that have taken place. Subsequently, through a process of “looking back to look ahead” the adolescents shared important reflections of the aspects of the “self” that remain the same, as well as the factors that contributed to the changes that have taken place.

As indicated in chapter six, an overarching theme of acquired maturity emerged across the narratives. In some cases the adolescents used the word “mature” to describe the changes that had taken place and in other narratives the maturity was made evident in descriptions of gained perspectives on life. With a view to the literature on maturity this study offers some preliminary insight into the subjective accounts of perceived maturity within this population. As a serendipitous finding it is intriguing to consider that even without prompting a line of questioning in this direction, this concept of maturity was prominently featured across the narratives in the descriptions of change over time.

Importantly, maturity is presented in the literature as a concept with many elements, and therefore what is meant by “being mature” will differ depending on the criteria used to measure maturity. Regarded as the formative period of the life span, adolescence marks a time of tremendous change towards maturity (Klimstra, Hale, Raaijmakers, & Wim, 2012). This is a time commonly associated with a progressive movement toward an “ideal of maturity typically associated with adulthood” (Tilton-Weaver, Vitunki & Galambos, 2001, p. 144). The frequently studied markers of maturity include chronological age, biological age, and subjective age (Galambos, Kolaric, Sears, Maggs, 1999). Extending the concept further, various milestones and markers are often used to establish a sense of maturity. Interestingly, in the study three participants mentioned the transition from childhood to adulthood, which lends additional support to the notion that there is an expectation of movement from one life stage to another. Arnett and Tabor (1994) suggest that in most non-Western cultures the social event of a marriage marks this as an official transition; however, in the contemporary West this entrance to adulthood emphasis independence and individualism. To tie these literatures together and situate them within the context of the present study, it is interesting to
speculate on the potential differences in perceptions of maturity. If a strict adherence to the
criteria of individualism, autonomy, and independence is occurring, would the participants in
this study so openly adopt the self-descriptor of mature? The inclination of the adolescents
involved in this study to describe themselves as mature provides further indication of the
subjectivity of this concept, and the necessity of turning to the adolescents themselves to
identify the criteria they use to establish a sense of maturity. As a way to situate this finding
within the larger body of research surrounding maturity in a manageable way, and to position
these findings in the literature to which it might contribute, the discussion that follows
considers the subjective experience of maturity from the perspective of adolescents.

A study conducted by Tilton-Weaver et al., (2001) contributes significantly to this
discussion as the researchers sought to explore the subjective meanings of maturity in
adolescence by asking adolescents to describe what it means to be “grown up.” Drawing
from literatures extending back to the work of Greenberger, Josselson, Knerr, and Knerr
(1974), it is evident that a level of consensus can be located in the literature regarding what it
means to be mature wherein the models of psychosocial maturity include autonomy,
interpersonal adequacy, and social responsibility. Understanding the existence of models
that are used predominantly in the evaluations of maturity is relevant to this study in the same
way as were the normative patterns of development referred to earlier. Thus far the stories of
self in the future have been punctuated with cultural anchors drawn from a collective script,
and therefore the influence of a social and cultural rendering has proven to be a reference
point within this population.

In the study conducted by Tilton-Weaver et al. (2001), adolescents were asked to
describe what it means to be “grown-up.” The analysis of these qualitative descriptors
revealed four “hallmarks,” thus described: “These ‘hallmarks’ reflect variations in the extent
to which the descriptions focused on one or more aspects of independence, responsibility,
pride, or power” (p. 149). A cursory look at these indicators reveals a discrepancy
between what these healthy adolescents described as indicators of maturity, and what the
adolescents in the current study have experienced in their lives. However, upon looking
more closely at the first hallmark, recognized by the authors as “genuine maturity” and
characterized by the adolescents as “responsibly independent behaviour and thought” (p.
149), the commonalities between what the adolescents in this study have described, and this rendering of maturity became increasingly apparent.

Interestingly, without “unpacking” what was meant by “independent behaviour” it might easily be assumed that the adolescents in this study, due to the limitations of disease progression, are unable to enter into aspects of independent behaviour. And yet, within this study the process of independent thought was clearly demonstrated, as were degrees of independent behaviour. The independence in behaviour was most clearly demonstrated in how the adolescents managed the sharing of information about their possible selves and the precise construction of boundaries around the sharing of their future thinking.

Maturity is often conceptualized as being closely tied to autonomy and independence. Arnett (1994) explained that the criteria for adulthood that are most commonly cited among college students reflect independence and self-sufficiency. As a point of clarification, autonomy refers to both the behaviour and emotional aspects of an individual’s life. The characteristics of autonomy stretch across a wide spectrum and therefore the idea of “autonomy” should not be viewed as a static “all-or-nothing” process. These distinctions have implications for this study as the findings related to information-sharing revealed that the adolescents in this study have specific patterns of information-sharing that demonstrate autonomy. Upon completion of their study Tilton-Weaver et al., (2001) remarked: “It is good news, to hear from adolescents, that they are fully cognizant of what it means to be truly mature – being self-reliant, responsible, and concerned about the well-being of others as well as oneself” (p. 156). Curiously, the adolescents in this study have experienced maturity somewhat differently, as utter self-reliance is not reasonably attainable; however, responsibility and concern for others was evident in the narratives. Upon reviewing the literature surrounding maturity, these findings suggest that the adolescents in this study are not feeling bound by a notion of maturity that is unattainable due to the constraints of their illness, but rather have anchored their maturity in internal processes, such as the ability to cope with emotions, and a gained perspective on life where a philosophy of living in the moment is embraced.
What Has Been Learned?

There are a few patterns and relationships among the key findings of this study that warrant further discussion. The first is related to the intentionality participants demonstrated in the activities of future projection explored within this study. In reflecting upon the full scope of findings, one can feel optimistic about the ability of adolescents living with progressive life-threatening neurodegenerative illness to determine for themselves the scope and extent of future thinking. As well, one can anticipate that they will be able to steer the direction of conversations should one have the opportunity to engage in an exploration of the future. This is good news. It directs attention toward some of the more salutogenic features of this experience. The participants in this study choose for themselves the type of future images they construct, and they manage the emotions related to the occurrence of some of the more difficult future images. They intentionally move into areas of a future space that include hopes, fears, real and imagined future selves, and they manage the movement between these spaces. They select from this range of selves the ones they wish to share, and they maintain control over the ones they wish to keep.

From the completion of the interviews to the analysis, I experienced a disconcerting feeling that there was something being communicated across the narratives that I was unable to understand. After months of wondering I came to the admission that what I had expected to hear in the stories was a little more hesitation, resistance, fear, anger, and despair in the collective renderings about the future. This was an uncomfortable awakening for me.

As I thought more and more about the findings in this study, I came to a new understanding of the experience of living with a progressive life-threatening neurodegenerative illness. What began as an examination of how adolescents who are living with a progressive life-threatening neurodegenerative illness construct future self-representations, evolved into a new understanding of the qualities of this life experience. More specifically, this study highlighted that the experience of “silencing” was not at all what I had anticipated. I began this study anchored in a belief that “if” silencing was occurring, it was because the individuals surrounding the adolescents did not want to take the adolescents to a “painful” place and open them up to excess amounts of vulnerability and pain. Inherently implied within this supposition is the idea that these future spaces are
painful; one of the contributions of this study is that it allows an “unpacking” of this presumption.

**It’s not all fun and games but it isn’t terrible**

Through iterations of data analysis I came to understand that although the lives of the adolescents I interviewed were undeniably difficult, these lives are perhaps viewed from the outside as more difficult than they are experienced. During one of the interviews the adolescent explored how his life “looks” to other people. I drew the title of this section directly from his manuscript as he talked about this perception of life with muscular dystrophy. In a review of the literature I was able to locate one study that examined the self-perceived quality of life for adolescents with neurodegenerative diseases. In what was described as “surprising results”, when the quality of life was measured between two groups, the average score in the physically disabled adolescent were similar to those of the non-disabled group, with the vast majority reporting that their lives were worthwhile and rather enjoyable (Vuillerot et al., 2010). The ability to cope with illness by remaining focused on the present and not permitting the illness to consume daily life and future plans has also been demonstrated in other populations such as those with cystic fibrosis (Admi, 1996).

Adolescents with chronic and life-threatening illness are demonstrating that despite how it might look from the outside, the illness does not always take centre stage. Taylor et al. (2008) concur that young people with chronic illness have a general view of themselves that shares many common features with their healthy peers. Aligning with this assertion, the adolescents in this study have indicated that the illness does not always remain in the forefront, and rather than allowing the disease to define and steer the direction of their lives, the individuals within whom these illnesses reside find ways to masterfully manage the disease.

The “disability paradox” is a conceptually known phenomenon. Albrecht and Devlieger (1999) describe this paradox as the question of why it is common that people with serious and persistent disabilities report that they experience a good or excellent quality of life, when to most external observers these lives are undesired. As well, Payot and Barrington (2011) highlight the tendency for individuals who have not been in a situation of illness or disability to evaluate the quality of life much differently than the individuals living
with these challenges. The findings of the current study highlight the importance of not making assumptions about how adolescents living with a progressive life-threatening neurodegenerative illness might evaluate their overall quality of life, and rather to allow the subjective experience of each individual to guide our understanding of the experience of illness and disability. Linking the discussion back to the intention of this research study, it is plausible that the misinterpretations about the illness experience are preventing healthcare workers and others surrounding the adolescents from asking questions, as there is an assumption that the answers are perhaps more difficult than in actuality.

I want to emphasize that I am not suggesting that this experience occurs without pain, anguish and the range of emotions associated with the unfairness of a life-threatening illness. Rather I am suggesting the importance of stepping back and allowing each individual story to unfold, which might be done by simply creating the space for the telling of all stories. What has occurred to me is that perhaps our avoidance into this future space has been cloaked with a “concern” for the adolescents that is more appropriately assigned for ourselves. Thus, it may be possible that the people surrounding these adolescents are viewing life with a progressive life-threatening neurodegenerative illness as being of a much lower quality than it actually is for the adolescents, and subsequently are avoiding important aspects of development. This “aha” moment coming from a social worker who has planted herself firmly within the “strength-based paradigm” feels awkward to admit, as I realize now that much of what I was seeing as “strength” had to be firmly entrenched in pain and suffering before I would see it as so. Perhaps, the strength lies not in the overcoming but rather in the “being” with both sides of the story. The ability to venture into the real and imagined avenues of future thinking with the full awareness that the end result is beyond your control may be a demonstration of vulnerability to the fullest extent.

**Limitations and strengths of the study**

Although the results of this study provide novel insight into the future thinking activities of adolescents with a progressive life-threatening neurodegenerative disease, they must also be considered in light of the limitations of this study. Perhaps the most significant limitation is that by virtue of the recruitment process, all ten of the adolescents were involved in hospice and palliative care programs, and hence, it is plausible that the consistency with
which future thinking activities were described is partly a function of the provision of care within hospice and palliative care. It would be useful to branch out the study beyond adolescents who are a part of hospice and palliative care programs, and repeat the study as a way of considering areas of convergence and divergence.

A second limitation of this study is that the results are relevant to a rather small population of adolescents. It is important to note that within the broad diagnosis of progressive neurodegenerative illness there is a great deal of variance in disease progression and trajectory. This means that although the prevalence and incidence rates appear to be fairly substantial, the number of individuals who will experience what has been described as the intersection of disease and development is fewer than the reported number of individuals living with these illnesses.

The primary strength of this study is that it offers an exploration into an important topic that has thus far gone unexamined for this population. By virtue of the design, the study offers important insights into how adolescents who are living with a progressive life-threatening neurodegenerative illness are able to construct a narrative of self that extends from the past through to the future. This is an important finding as it confirms that the familiar processes of future thinking and identity development are indeed occurring for this population. In addition, the study offers important insight into the care of this population. Therefore, as I extend into a discussion of the implications of the findings for practice, I wish to identify the translation of findings into clinical practice to be a key strength of this study. Finally, the transparency offered in this study is also a key strength. In particular, a concerted effort was made to provide a detailed account of the analysis of data as a way of permitting readers to assess the trustworthiness of this study.

**Implications of Findings**

As a way of guarding against what might be viewed as merely a voyeuristic foray into the intimate details of an uncommon experience, from inception of the study to completion of this dissertation I found it necessary to remain continually anchored in the implications of this study. Even as I write this final chapter I wonder where the understandings gleaned from this study might find a home. I imagine them taking up residence among other scholarly work and can locate contributions to various fields. Certainly I would expect an easy appeal
to the research community concerned with pediatric palliative care as well as those examining adolescent development in the context of the narrative self, future thinking and possible selves. The results of this study make further contributions to a growing body of literature aimed at understanding the future thinking activities of adolescents and to the field of possible selves. As well, the study offers additional insight into the identity development of adolescents developing under special circumstances. The contributions and extensions into these scholarly bodies are somewhat intuitive and follow an expected course of a dissertation.

**Practice implications**

These results have important bearings on the development of a practice of care for this population. At the broadest level, the study has demonstrated both the occurrence and importance of future thinking as a manner in which adolescents manage this life experience. At the very basic level, armed with the knowledge that voyages into the future are both likely and valuable, the individuals and systems of care surrounding the adolescent can integrate explorations into the future into existing practices aimed at supporting the development of adolescents coping with a progressive life-threatening neurodegenerative illness. In doing so, and by drawing from the results of this study, the practices of support surrounding the adolescents can benefit from the awareness of the pattern that revealed itself in this study, whereby the participants were able to navigate into future spaces populated with selves both “real” (i.e., future selves with the illness) and “imagined” (i.e., future selves without the illness).

In my own clinical observations, the explorations into the future are the most palatable for individuals surrounding these adolescents when the hopes and dreams expressed fall somewhere within, or very close to, what might be reasonably expected. When the expressions of future push us to the outside corners of this experience, and beyond, many are able to accompany the adolescent while “in the moment” of exploration; however, this is followed by a somewhat critical examination of what might be occurring. Questions are raised about cognitive understandings, about the risks of venturing too far off a realistic trajectory, about false hopes and coping strategies.

Interestingly, as I ponder this finding and the implications for practice, I am reminded of a young boy who was part of a bereavement program I was involved with. A family was
receiving support after the death of an infant daughter, and regularly attended the grief support group. Each week this young boy, the sibling of the infant daughter, would arrive at the group in a superhero costume, complete with mask and cape. As part of the team of support that surrounded this family, we recognized this costume as part of his coping, and as such, the costume was viewed as an important part of his individual grief process. As I think about the range of “imagined” possible selves that were presented during the research process, I wonder how much they differ from the boy’s costume—from an attempt to slip into something different, to feel diverse parts of one’s experience, even those parts that fall outside of what is possible. All humans entertain ideas of a range of future selves that fall to different degrees “outside” of the realm of possibility. Why would one expect this to be any different for adolescents living with a progressive life-threatening neurodegenerative illness?

What I am suggesting is that “future thinking” is located as an expected, healthy, and important part of the developmental process for adolescents living with a progressive life-threatening neurodegenerative illness. Second, that the projections of self are likely to include both the possible and impossible aspects of future. Importantly, the results of this study indicate that the development of one future self does not preclude the development of the other. The imagined future self that is living a life far outside the parameters of what is expected is not of detriment to the real possible self. Understanding that the adolescents in this study experience an oscillation between these two futures may help to convince those surrounding these adolescents that the projection of self into the realm of possible and impossible may be in the service of their coping.

As well, the evidence of the self-enhancing qualities of future thinking that emerged in this study suggests that more could be learned about the association between future thinking and positive outcomes. Importantly, the encouragement of professionals and families in accompanying these adolescents on excursions into the future also requires the awareness that the possible selves of the future are not always going to “fit” with a realistic picture. Understanding that these images serve the important functions of self-enhancement and identity-development may help alleviate anxiety and mitigate the inclination to request more “realistic” pictures of future selves.

It has been suggested that palliative social workers have the unique set of skills required to address the psychosocial care of individuals coping with advanced illness.
(Higgins, 2011). As well, social workers can play an important role in the identification of strengths and the potential for positive outcomes for patients and families in palliative care (Cadell, Shermak & Johnston, 2011). The findings related to the contextual nature of future thinking activities drawn from this study support the notion that social workers, by virtue of their training related to relational and contextual theories, are well situated to support the processes of future thinking for adolescents living with a progressive life-threatening neurodegenerative illness.

Adolescents with such illnesses do think about their future. They do this as a way of coping, developing an identity, and considering the decisions related to their health care. Accordingly, as a system of support that aims to focus on the relief of physical, psychosocial, emotional, and existential suffering, the palliative care team with the interdisciplinary approach is of great importance to the care of this population (Weidner, 2005). Several of the conditions the adolescents identified as influencing whether or not they engage in future thinking conversations are closely aligned with the key features of practice associated with palliative care. For instance, participants talked about the necessity of a relationship and trust in order for conversations about the future to take place. The hospice and palliative care team, by virtue of their training, are attuned to the significance of the psychosocial care of patients facing death and remain sensitive to the importance of relationship. It was certainly my experience that the relational component of care was regarded to be of high importance in the care of families. Accordingly, the care teams surrounding adolescents coping with life-threatening illness can feel affirmed in this commitment to the establishment and development of relationships over time.

In addition to the relational component it is important to observe what has already been noted in the work of Steele (2000), particularly that healthcare provision needs to occur as much during the “plateaus” as it does during times of crisis. Weidner (2005) noted that parents of boys with neurodegenerative illnesses have reported frustration with fragmentation of care. Importantly, by shifting the focus of care to include the peaks and valleys of the illness experience, one can engage adolescents in conversations that are not always centered on a crisis or change in medical status. Taken together, the previous research and the current study offer a suggestion that hospice and palliative care programs consider optimal use of the stable times during the illness to offer support to the adolescents and families. Furthermore,
the plateaus may offer the opportunity for an exploration into the future; explorations during plateaus are perhaps less threatening than explorations during a health crisis.

This study also highlights the importance of opening the space for conversations about the future, but not pursuing this future space in a way that undermines the adolescents’ need for control in the management of information. Recognizing that the privacy of adolescents coping with a progressive life-threatening neurodegenerative illness comes under attack regularly, honoring their provision of information as a choice is of key importance. The information contained in this “space” should remain under the jurisdiction of the adolescents.

The results of this study confirm that the activity of reflecting back to the past and looking forward to the future is useful. In considering the psychosocial care of these adolescents as paramount in their overall care, the narratives included in this study suggest that this activity plays an important role in support of the developmental process, and it was both enjoyable and useful for the adolescents. In particular, it was within the reflecting back the adolescents articulated aspects of the changes in self over time that they held with great pride and ownership. It is therefore advisable to construct interventions that encourage a narrative sharing of the story as this can support and encourage the development of a narrative self.

One of the most significant implications for practice is the connection that has been drawn between future thinking and decision-making. This finding may be of greatest appeal to the palliative care community that supports the adolescent along the trajectory of the illness. The decisions adolescents with progressive life-threatening neurodegenerative illness have to make regarding their healthcare hold great bearing and consequence on their future selves. For the participants in the study who were able to recall inclusion in decision-making about their health, this process of projecting forward into the future was indeed described as a useful activity to inform the decisions. Participants explained that future thinking was helpful when deciding whether a surgery or the side effects of a medication are “worth” the long-term gain. This is of great relevance as without the “practice” of future thinking, adolescents who are faced with a major healthcare decision are doing so without having had the experience of exploring this future space. This could possibly result in the adolescent making a major decision around one specific medical event, rather than having constructed
various images of the self across time and being able to either choose from, or compare to, a series of familiar future images.

**New Directions for Future Research**

The results of this study hold the promise of acting as a springboard for continued research in related areas. I have identified a few areas that I hope to pursue as the next step in this research process.

**Future thinking and mindfulness-based practice**

Of particular interest to me is to consider how to support this process of future thinking and the related emotions. It is with some reservation that I present future thinking as a “useful” and important activity as I am concerned about how these findings might translate into a practice that also requires the skills of emotional support. From the perspective of both the adolescent as well as the person accompanying an exploration into the future, it is integral to also develop the skills to manage the associated range of emotions. As an intervention noted for its application to populations living with chronic health problems and disability, mindfulness-based stress reduction is thought to enhance coping with distress and disability in daily life (Grossman, Niemann, Schmidt, & Walach, 2004). Therefore, understanding now that the adolescents in this study experience a range of possible selves resulting in a range of accompanying emotions, it would be interesting to consider how a mindfulness-based stress reduction practice might serve to support the integration of the emotions related to the experience of future thinking.

Greenberg and Harris (2012) describe an explosion of interest in mindfulness-based strategies for the promotion of health. As well, they describe a growing interest in this type of intervention for enhancing coping and resilience in both the general population of children and youth, as well as in the treatment of disorders in clinical populations. Importantly, they also caution that the current enthusiasm for the promotion of these practices extends well beyond any evidence that supports the efficacy. The current study could extend to consider the effectiveness of employing a mindfulness-based intervention as way of building
emotional-regulation skills to cope with the emotions related to future thinking amidst a progressive life-threatening neurodegenerative illness.

**Systems of influence surrounding future thinking in adolescents with a progressive life-threatening neurodegenerative illness**

As a second line of research I would be greatly interested in understanding how the individuals involved in the care of these adolescents experience the activities of future thinking. For instance, how do healthcare professionals and family members feel about the idea of engaging in future thinking conversations with adolescents living with a progressive life-threatening neurodegenerative illness? Discovering our own assumptions around future thinking and our inclination to move towards or away from these conversations holds the promise of understanding how the systems of support surrounding these adolescents may be influencing processes of future thinking. Following a similar line of inquiry as Marshall, Young, Domene and Zaidman-Zait (2008), who studied adolescent possible selves as jointly constructed in parent-adolescent career conversations, research aimed at examining how possible selves of adolescents with a progressive life-threatening neurodegenerative illness are jointly co-constructed would contribute to both the practice literature surrounding the care of adolescents’ in pediatric palliative care, as well as more broadly to the possible selves literature.

**Conclusion**

If you want to know me, you must know my story, for my story defines who I am. If I want to know myself, to gain insight into meanings of my own life, then I, too must come to know my own story. — Dan McAdams, *The Stories We Live By: Personal Myths and the Making of the Self*

A ballerina, a construction worker, a journalist, a chef, and a helicopter pilot, have told you their stories. You heard a familiar script scattered with the milestones of celebrating a graduation and continuing with post-secondary education, of ultimately having a successful and fulfilling career. You were taken down the road of falling in love, of parenting, of
spoiling and of protecting a child. You heard about wanting to provide a good life to a family, of needing a sense of security, of attaining a status in life that affords a home and a car. You heard a longing for the ability to contribute, to simply “help a neighbor by mowing his lawn.” Perhaps these are not a surprising range of hopes and dreams for a group of adolescents. However, these stories have emerged through a harshness you also came to know well. The houses they spoke of, the futures they explored, have been built upon a landscape of progressive and life-threatening illness. These stories have survived the invasion of a progressive weakening in a body geared for growth.

A great deal has been learned about future thinking in the context of a life-threatening illness. In particular, I better understand this process as an intentional means to manage the uncertain landscape of a progressive illness. This management involves the pursuit of an identity that can withstand the intrusion of illness by integrating the selves of the past with the current and future selves. The possible selves take many forms; some are firmly anchored in reality and others are granted a freedom from the constraints of illness, thereby permitting access to sacred space where “anything becomes possible.”

By listening closely to these stories, it is clear that the provision of care for adolescents with progressive life-threatening neurodegenerative illness needs to respond to the developmental need to create a future self and to explore all aspects of what is possible, as well as impossible. The value of this activity is best understood as being in the service of coping, personhood and decision-making. Echoing loudly across this landscape is the call from the adolescents to trust them enough to ask them about the future, as it is in this act of asking that they feel “seen” as persons.
Bibliography


West, C. (2011). Addressing illness suffering in childhood cancer; exploring the beliefs of family members in therapeutic nursing conversations. (PhD Nursing, University of Calgary). (Dissertations University of Calgary Theses)


Exploring Meaningful Self-Understanding in Youth Coping With a Progressive Life-Limiting Illness

January 24, 2009

Hello

As per our earlier conversation, I wanted to follow up with you regarding the study that I am conducting for my PhD dissertation. The purpose of this study is to understand how youth who are coping with a progressive life-limiting illness construct meaningful future self-representations. This research is important because we know that self-understanding as a healthy part of adolescent development can influence health care decisions and experiences, but we do not know in what ways this occurs. I hope that the knowledge produced through this study can be used to inform health care practices and policy that will support relevant and appropriate care for adolescent patients and their families.

My intention is to interview youth who are coping with a progressive neuromuscular disease. I will be exploring self-continuity by asking questions about their past, present, and the possibilities they see for themselves in the future. I plan to interview participants in meetings that may last from 30 to 90 minutes. Participants will be asked to be interviewed three times but may choose to participate in one, two, or three interviews. All meetings will take place at a time and location of their choice – which can include their home.

I am wondering if you would help bring this study to the attention of parents and youth who might be interested in discussing their experiences with me. This could be done either by posting or distributing the enclosed notice, or by obtaining
permission for individuals to give their telephone number to me so that I could contact them directly and provide further information.

If you have more questions about this study, please don't hesitate to telephone me at XXX-XXX-XXXX or email me at XXXX@XXXX.ca. You are also welcome to contact my PhD supervisor, Dr. Sheila Marshall, at XXX-XXX-XXXX or email her at XXXX@XXXX.ca for further information. Also, if at any point, you are interested in discussing the emerging findings, I'd be happy to meet with you and would welcome your feedback. Copies of any reports or publications will be available to you upon request as well.

Your help with this project would be very much appreciated! Please call if you have any questions or would like to know more about it.

Thanks again for your interest and support.

Sincerely,

Meaghen Johnston MSW, RSW, PhD Candidate
Appendix 2: Parent/Guardian Consent Form

Exploring Meaningful Self-Understanding in Youth Coping with a Progressive Life-Limiting Illness

Parent/Guardian Consent

Principal Investigator: Dr. Sheila Marshall
School of Social Work
Telephone: XXX-XXX-XXXX

Co-Investigator: Meaghen Fletcher Johnston (PhD Candidate)
School of Social Work
Telephone: XXX-XXX-XXXX

The purpose of this study is to understand how youth who are coping with a progressive life-limiting illness see themselves across time. This research is important because we know that self-understanding is a healthy part of adolescent development and can influence health care decisions and experiences, but we do not know in what ways this occurs. We hope that the findings will help doctors, nurses and other health care workers develop practices and policies that support appropriate health care for adolescent patients and their families.

This study is being conducted for a dissertation and is part of the requirements toward a PhD for Meaghen Fletcher Johnston.

If you decide to consent to your child’s participation in this study, your child will meet with Meaghen Johnston to explore how he/she has come to understand him or herself and the potential for your child in the future. The study involves three separate interviews and your child can choose to participate in one, two, or all three
interviews. Through these interviews Meaghen will explore self-understanding by asking your child questions about the past, present, and the opportunities they see for themselves in the future. An interview is likely to last 60 to 90 minutes. All interviews will take place at a time and location of your choice – this could include your home. With your permission, the interviews will be audio-taped and transcribed; a copy of the interview transcript will be given to you upon your request.

Your child’s participation in this study is voluntary. Your child will have the right to refuse to answer any questions, to request that audio-recording be stopped at any time, and to withdraw any information he or she does not wish to have included in this study. You and your child are also free to withdraw from the study at any time. Should you withdraw, the information your child has provided up to the point of withdrawal will be used in the data analysis, unless you or your child state that you wish to have it removed. Your decision to withdraw or not participate in this study will in no way jeopardize your involvement with any programs or services that you are or will be using.

The information you and your child provide will be kept confidential unless you specify otherwise in writing. Consent and assent forms, transcripts and audiotapes of all interviews will be kept in a locked cabinet in the secured offices of the Principal Investigator and/or Co-Investigator. Your name and any other identifying information will be removed from all transcripts; pseudonyms will be used to reference your child. All electronic files will be kept on a password-protected computer in the secured offices of the Principal Investigator and the Co-Investigator. Access to these offices and files is strictly controlled and limited to the Principal and Co-Investigator.

We recognize that some aspects of self exploration may be distressing to some of the participants. Your child is not obliged to answer any questions that make them feel uncomfortable or that they do not wish to answer. We are prepared to stop the interview immediately upon their request. We are also prepared to help you locate appropriate support if participation in this study is unsettling for you, as well as provide a written list of support services to you.

Each participant will receive a $15.00 honorarium for agreeing to participate in the study. Importantly, some people find it beneficial to talk about their experiences and through this process gain a greater degree of self-understanding. Some people also appreciate the opportunity to share information about their experiences that may help to improve health care for others.

We will report the findings of this study in Meaghen Johnston’s dissertation, journals, conference presentations and workshops. All efforts will be made to insure that you
are not identified by others by changing or removing information that might otherwise readily identify you.

If you have any questions or desire further information about any aspect of this study, you are invited to contact Dr. Sheila Marshall at XXX-XXX-XXXX or XXXXXXX@XXX.ca or Meaghan Johnston at XXX-XXX-XXXX or XXXXXXX@XXX.ca. Furthermore, if you have any concerns about your treatment or rights as a research subject you may contact the Research Subject Information Line at the Office of Research Services at the University of British Columbia at 604-822-8598, or email to RSIL@ors.ubc.ca.

Thank you for considering involvement in this study. If you agree to your child’s participation, your signature is required below.

Sincerely,

Dr. Sheila Marshall, PhD           Meaghan Johnston, (PhD Candidate) RSW

_______________________________________________________________

I understand that my consent to my child’s participation in this study is entirely voluntary. He/She will be asked to participate in three interviews and will sign an assent form and may choose not to participate or may withdraw from the study at any time.

My signature below indicates that (1) I consent to my child’s participation in this study, and (2) I have received a copy of this consent form for my own records.

_______________________________________________________________

Parent/Guardian Signature              Printed name              Date
Appendix 3: Participant Assent Form

THE UNIVERSITY OF BRITISH COLUMBIA

School of Social Work
Faculty of Arts
2080 West Mall
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Tel: (604) 822-2255
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Exploring Meaningful Self-Understanding in Youth Coping with a Progressive Life-Limiting Illness

Participant Assent

Principal Investigator: Dr. Sheila Marshall
School of Social Work
Telephone: XXX-XXX-XXXX

Co-Investigator: Meaghen Fletcher Johnston (PhD Candidate)
School of Social Work
Telephone: XXX-XXX-XXXX

The purpose of this study is to understand how youth who are coping with a progressive life-limiting illness see themselves across time, or in the past, the present, and the future. This research is important because we know that self-understanding is healthy and gaining an understanding of yourself will help you make important future health care decisions. We are interested in hearing about your experience in your very own words, to hear “your story”. We hope that the findings will help doctors, nurses and other health care workers develop practices and policies that support your care.

This study is being conducted for a dissertation and is part of the requirements toward a PhD for Meaghen Fletcher Johnston.

If you agree to participate in the study, you will meet with Meaghen Johnston to explore how you have come to understand yourself and to tell her about the potential you see for yourself in the future. The study involves three separate interviews and it will be up to you whether you choose to participate in one, two, or all three.
interviews. Through these interviews Meaghen will explore self-understanding by asking you questions about the past, present, and the opportunities you see for yourself in the future. An interview is likely to last 60 to 90 minutes. Therefore, if you choose to participate in one interview the amount of time for the interview will be about an hour, if you choose to participate in two interviews the total time would increase to about two hours, and if you decide you would like to participate in all three interviews it will likely take up about three hours of your time. All interviews will take place at a time and location of your choice – this could include your home. With your permission, the interviews will be audio-taped and transcribed; a copy of the interview transcript will be given to you upon your request.

Your participation in this study is voluntary, completely your own decision. You will have the right to refuse to answer any questions, to request that audio-recording be stopped at any time, and to withdraw any information you do not wish to have included in this study. You are also free to withdraw from the study at any time. Should you withdraw the information you have provided up to the point of withdrawal will be used in the data analysis, unless you state that you wish to have it removed. Your decision to withdraw or not participate in this study will in no way jeopardize your involvement with any programs or services that you are or will be using.

The information you provide will be kept confidential unless you specify otherwise in writing. Consent and assent forms, transcripts and audiotapes of all interviews will be kept in a locked cabinet in the secured offices of the Principal Investigator and/or Co-Investigator. Your name and any other identifying information will be removed from all transcripts; pseudonyms will be used to reference you. All electronic files will be kept on a password-protected computer in the secured offices of the Principal Investigator and the Co-Investigator. Access to these offices and files is strictly controlled and limited to the Principal and Co-Investigator.

We recognize that some aspects of talking about yourself in the future might be emotional. You are not obliged to answer any questions that make you feel uncomfortable or that you do not wish to answer. We are prepared to stop the interview immediately upon your request. We are also prepared to help you locate appropriate support if participation in this study is unsettling for you, as well as provide a written list of support services to you.

Each participant will receive a $15.00 honorarium for agreeing to participate in the study. Importantly, some people find it beneficial to talk about their experiences and through this process gain a greater degree of self-understanding. Some people also
appreciate the opportunity to share information about their experiences that may help to improve health care for others.

We will report the findings of this study in Meaghen Johnston’s dissertation, journals, conference presentations and workshops. All efforts will be made to insure that you are not identified by others by changing or removing information that might otherwise readily identify you.

If you have any questions or desire further information about any aspect of this study, you are invited to contact Dr. Sheila Marshall at XXX-XXX-XXXX or XXXX@XXXX.ca or Meaghen Johnston at XXX-XXX-XXXX or XXXXXXXXX.ca. Furthermore, if you have any concerns about your treatment or rights as a research subject you may contact the Research Subject Information Line at the Office of Research Services at the University of British Columbia at 604-822-8598, or email to RSIL@ors.ubc.ca.

Thank you for considering involvement in this study. If you agree to participate, your signature is required below.

Sincerely,

Dr. Sheila Marshall, PhD  Meaghen Johnston, PhD (Candidate) RSW

I understand that my assent to participation in this study is entirely voluntary. I may choose not to participate or may withdraw from the study at any time.

My signature below indicates that (1) I assent to participate in this study, and (2) I have received a copy of this consent form for my own records.

________________________________________  ____________________________  ______________________________
Participant's Signature          Printed name            Date
Appendix 4: The Life Line Technique Interview Guide

Instructions

I. Every person’s life can be written as a book. I would like you to think about your life now as if you were writing a book. I’m going to ask you questions along the way to help you think about your life like the chapters of a book. I’d like to hear about the major events that have happened that divide up your story. I have paper and art supplies here to help you think about your life this way. The line on the paper represents your life from birth to the present day and into the future.

- Every story starts with an opening scene. When did your story begin?
- What has happened between that opening scene and today? Try to add three important things to your life line that will help to tell your story.
- Looking at your entire life, can you tell me about a high point?
- What about a low point?
- Has there been a turning point for you where things changed? What happened and what were the changes?
- Do you think about the future? How far? How often?
- What kinds of things do you hope for?
- What kinds of things do you fear?
- I want you to imagine that it is your best day in the future, tell me a story about what is happening.
- Do you think future thinking is important? If so, why?
- Should future thinking be something that is encouraged?
- Have you used future thinking to make decisions about your healthcare?

II. We all have different versions of our life story. We have what we call “possible selves.” Some of these are based in real life, others are fantasy. I’d like to hear about your possible selves. Now, imagine that anything is possible for you and rewrite your story in as many different ways as you’d like to.

- How is your story different?
- Is this a new story you are telling today or is this something you have thought about in the past?
- What kinds of things do you hope for?
- What kinds of things do you fear?
- Is there a “future you” that you keep private to yourself?

III. I wonder if you could tell me which one of these possible selves:
- Do you value the most?
Appendix 5: The Contextualization of Possible Selves Interview Guide

Introductory Comments

The purpose of this study is to better understand how you communicate about your future. The way we are going to do this is by drawing out a map that will include you, your family, and the people in your life that you talk to.

Adolescent Self-Portrait

Take some time to think about all of your different possible selves. These can include your real selves as well as those you imagine, fear, or hope for. These are the “you’s” of the future and encompass all the different ways you think about yourself in the future. Some of these might include your illness, and others might not. There is no right or wrong answer in this activity. Draw these as circles in the middle of this page and label them.

Next, locate your parents on this map. You can space them out all over the page however you like.

- Are there other people you talk to that you’d like to add?
- Now, draw a line between each possible self and the person you share this self with (you can share a possible self with more than one person)
- Is there a possible self that you don’t share with anyone?
- I’d like you to tell me about the feelings that occur when you share _____ with ______.
- Under what circumstances are you most likely to share?
- When you don’t share, is it because you want to protect yourself or the relationship?
- Have you ever felt that you shared something about one of these selves and the person did not listen?
- Has anyone ever made fun of one of these possible selves?
- Do you think it is possible that some teens who have an illness like yours might avoid talking about the future? Why do you think that might be?
Appendix 6: The Experience of Selves Across Time Interview Guide

Introductory Comments

The purpose of this study is to better understand the concept of self-continuity. Self-continuity is the ability to see oneself as continuous across time. One way that we do this is by finding things that stay the same about us. Stories are often a way that we weave parts of our selves across time. In this final series of questions I will prompt you to reflect on your past and present.

Self

First, I would like you to describe what sort of person you were five years ago.

If someone didn’t know you, what could you say to help them understand the sort of person you were then?

Next, I would like you to describe the sort of person you see yourself as being right now.

It sounds like you have changed in some important ways from the sort of person you were five years ago. What are some of the important changes that have taken place in your life in the last five years or so?

Do you think of yourself as the same person? What makes you the same person?

How would you explain all the changes that have taken place in your life?

How is it that you have become the person you are right now?