

The Experience of Emerging Adulthood in Men with Acquired Impairment

by

Ginelle Giacomini

A Thesis Submitted to the Faculty of Graduate Studies of

The University of Manitoba

In partial fulfillment of the requirements of the degree of

MASTER OF SCIENCE

Department of Family Social Sciences

University of Manitoba

Winnipeg

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## **Abstract**

This thesis explores the experiences of emerging adulthood for men with an acquired impairment. Qualitative semi-structured interviews were conducted with four men with acquired impairments in an urban center of Canada. Through thematic analysis, three themes emerged: internal perceptions, dynamics of social relationships, and barriers and opportunities. Their stories illustrate many common emerging adult experiences as well as some divergent experiences, which may potentially be due to their acquired impairment. The main findings include the importance of friends and family and the fact that the timing for some of the developmental tasks of emerging adulthood may be delayed. Implications for professionals and researchers are presented, focusing on ways to best support men in emerging adulthood with acquired impairments.

## **Acknowledgements**

I would like to thank my thesis advisor, Dr. Deborah Stienstra, for her on-going support throughout my thesis-writing process. Her patience and encouragement were invaluable. I also am very grateful to the members of my committee, Dr. Karen Duncan and Dr. Jacquie Ripat for their time and guidance.

I also appreciate the financial assistance I received during this project. Thank you to the University of Manitoba Faculty of Graduate Studies as well as the Social Sciences and Humanities Research Council for their financial assistance.

I must also thank my family, for their unending patience and unconditional love and support during my academic career and throughout my entire life, as well as my lovely friends, for always making me laugh and reminding me of what really matters. My rants and declarations of quitting were numerous, laughable, and necessary, and my family and friends got me through each freak-out with grace, humour and the occasional kick in the behind.

Finally, I must thank the four men who participated in this study. The personal experiences that you shared with me were of great importance and will hopefully help other individuals in similar situations.

## **Dedication**

This paper is dedicated to my mother, who has constantly supported and encouraged me with incredible tolerance and love. You taught me at an early age that “books are our friends” and I took that to heart. There are not enough words (even all of the ones that I’ve made up over the years) that can begin to describe the amount of gratitude, love and respect I have for you, Charlie.

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# **The Experience of Emerging Adulthood in Men with Acquired Impairment**

## **CHAPTER 1**

### **Introduction**

The life stage known as emerging adulthood (Arnett, 2000, 2004, 2007) reflects the unique characteristics and life experiences of young adults, aged eighteen to thirty. During this time, individuals are working to establish independence and redefine their identities as adults. When these developmental tasks are placed within the context of a newly acquired impairment, the situation can become exponentially more complex. This thesis examines the intersection of emerging adulthood and acquired impairment to better understand the experience of emerging adulthood for men with an acquired impairment.

This exploration is guided by one central research question: “How do men with an acquired impairment experience emerging adulthood?” In order to gain a comprehensive understanding of the lived experiences of emerging adulthood for men with an acquired impairment, qualitative semi-structured interviews were conducted with four participants who have an acquired impairment. These in-depth interviews focused on many of the themes of emerging adulthood, including identity formation, relationships with parents and family, the importance of friends, and potentially starting post-secondary education and/or a career, along with issues of masculinity. I used thematic analysis to generate common themes as well as identify unique experiences from the interview data, in order to better understand the experiences of the participants as a whole.

There appears to be a lack of research examining the impact of an acquired impairment on men in emerging adulthood. Due to the fact that men in emerging adulthood are at higher risk for acquiring an impairment, such as a spinal cord injury

(Dreher, 1996; Kessler & Walters, 1998; O'Connor et al., 2011; Shulman, Feldman, Blatt, Cohen, & Mahler, 2005), Crohn's disease (Mackner & Crandall, 2006; MacPhee, Hoffenberg, & Feranchack, 1998; Panes, Gomollon, Taxonera, Hinojosa, Clofent, & Nos, 2007) or schizophrenia (Gioia, 2006; Goeree, O'Brian, Goering, Blackhouse, Agro, Rhodes, & Watson, 1999; Schultz & Andreasen, 1999), it is necessary to explore the effects of an acquired impairment on men in this life stage. While men in emerging adulthood are not at a high risk of acquiring an amputation (Murray & Fox, 2002), for those men who do experience this type of loss, there is minimal research on them; and therefore, the need for this research exists.

Men in emerging adulthood are undergoing many transitions and, when compounded with an acquired impairment, these individuals may experience barriers and opportunities that are unique to the period of emerging adulthood. They may also pioneer or innovate as they adapt to their newly acquired impairment.

The purpose of this thesis is to examine the experiences of emerging adulthood for men with an acquired impairment through a qualitative study of four men's experiences. Chapter 1 provides a brief introduction to the thesis topic as well as an explanation of the two theoretical perspectives used. Chapter 2 examines the literature that exists on both the topic of emerging adulthood and various acquired impairments. Chapter 3 details the methodology used to explore this research question. Chapter 4 examines the findings of the data collected, organized into three overarching themes. The first theme is one's internal perceptions of one's impairment. The second theme explores the dynamics of the participant's social relationships. The third theme examines barriers and opportunities that the participants have faced. Chapter 5 discusses the

findings within the context of the current literature as well as detailing the limitations of the study and the implications of the findings.

This research is important for numerous reasons. To begin, there is a lack of Canadian research on emerging adulthood as a whole. By conducting this study, I am adding to the repertoire of Canadian research on the topic of emerging adulthood. This study also serves to address numerous gaps in current research including individual experiences of acquired impairment during emerging adulthood, focused research on emerging adult men who acquire an impairment, and the complexities of forming one's adult identity during emerging adulthood within the context of a newly acquired impairment. Aside from the importance of conducting academic research, it is also very important to understand the experiences of emerging adult men with acquired impairments in order to provide effective supports and services.

One potential outcome of this study is to bring awareness to service providers, individuals with acquired impairments and to researchers, by acknowledging the intersection of emerging adulthood and acquired impairment. This study will provide insight into some of the unique experiences of emerging adulthood for men with acquired impairments thus allowing the individuals to move through this stage of life with increased ease.

### **Personal Location**

Though I identify myself as an able-bodied woman, I have always been interested in the experience of disability. Long before I was aware of the social model of disability, it informed my perceptions. How individuals navigate their environment and the barriers imposed on them by society is something that intrigues me. While I am interested in all

types of disability, and have worked extensively in the developmental disability field, acquired impairment has always been a particular interest. I want to better understand what it is like for individuals to have lived their life in a society which works for them, a fact that most take for granted, and then to have to cope with the same society, suddenly full of barriers. As well, I was dissatisfied with the gap evident around the time of young adulthood. The focus was on children, and there was a definitive line between childhood (including adolescence) and adulthood, with very little grey area. The theory of emerging adulthood is fascinating. The changing dynamic of the parent-child relationship, as the child begins to develop a need and a desire for independence, while at the same time still needing a great deal of support from his or her parents is an exceptional dichotomy. As well, the significant role that friends play at this time, possibly more important than at any other developmental stage, is intriguing as they play such a large role in one's formation of attitudes and behaviours. As I studied this topic, I realized that I have experienced emerging adulthood first-hand and am able to identify with many of these experiences.

My lifelong interest in physical disability, my need to further investigate emerging adulthood and my desire to explore the human experience have come together to fuel my passion for understanding the experience of an acquired impairment in emerging adulthood and the affect that this has on the individual and the family. It is my intention to act as an ally (Bishop, 2002) for individuals and families experiencing an acquired impairment. As an ally, I seek to better understand this experience, examining the effect that society has on emerging adult men with an acquired impairment. It is my hope that this experiential knowledge will lead to the creation of more effective support

for this specific cohort of men as I believe, due to this particular life stage, they have unique needs as they concurrently adjust to multiple new identities.

### **Theoretical Framework**

Two theoretical perspectives guide this research project in an attempt to develop a better understanding of the potential barriers, opportunities and innovations that a man with an acquired impairment may experience during emerging adulthood. The social model of disability acknowledges that a disability is not medically based, but is instead socially constructed. Within this perspective, one is disabled by societal barriers as opposed to his or her individual impairment. Emerging adulthood, the second theoretical perspective, explores the transitions and experiences of many individuals, aged eighteen to thirty, who live in Western industrialized cultures. By combining these perspectives, this project will develop a unique understanding of the experiences of young men with an acquired impairment.

#### **Social Model of Disability**

The social model of disability examines disability within the context of society, seeing disability not as a medical issue but as “all of the things that impose a restriction on a disabled person; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable transport systems, from segregated education to excluding work arrangements, and so on” (Oliver, 2009, p. 21). By examining the experience of having an acquired impairment within the context of the social model of disability, the focus is shifted from the medical model, which emphasizes issues such as suffering, searching for a cure, or seeking rehabilitation to return to what is perceived as “normal” (Shakespeare, 2010), to a model which emphasizes society and the

lived experience. According to Shakespeare (2010), the priority of the social model of disability is to “accept impairment and to remove disability” (p. 268). This is an important distinction for this project as my focus is on men’s experiences in society during a particular part of life, as they adjust to life with a recently acquired impairment, as opposed to their quest to be cured.

Another aspect of the social model of disability is the psycho-emotional dimension (Reeve, 2004), which focuses on the internal aspects of a disability. The concept of internalized oppression must be addressed for young men with an acquired impairment. Internalized oppression occurs when “individuals within a marginalized group in society internalize the prejudices held by the dominant group” (Reeve, 2004, p. 87). How individuals cope with the potentially negative reactions of others to their disability in society can have lasting effects on their entire lives. If they begin to internalize the oppressions and prejudices of society, this will affect their self-esteem, actions, and thoughts. They may begin to accept the negative stereotypes of disability imposed on them by society, and consequently this acceptance may affect how they experience emerging adulthood.

### **Emerging Adulthood**

Emerging adulthood is a theory of development that describes the period of time when young people, aged eighteen to thirty, are considered by society to be adults despite the fact that they do not feel like they have reached adulthood (Arnett, 2007). In Western society, many of the traditional markers of adulthood, such as home-leaving, marriage, and childbearing, are delayed. The concept of emerging adulthood as a separate life course event was developed to address this time. The term acknowledges that during this

period many people in this cohort feel that they are no longer an adolescent but in many ways cannot yet be considered an adult (Arnett, 2007).

In past decades, many people in this age range were having families and establishing careers immediately following high school (Kins & Beyers, 2010). Some may have continued their education into college or university, but marriage and children were not far behind. However, in North America, the increased need for post-secondary education in order to secure well paying, professional employment has meant that home-leaving, marriage and childbearing, which have traditionally been seen as markers of adulthood, have been postponed (Arnett, 2000; Kins & Beyers, 2010). This deferral has resulted in a shift towards more individualistic criteria as a way of determining entry into adulthood (Kins & Beyers, 2010).

This project will use emerging adulthood as a framework in an attempt to understand the experiences of men with an acquired impairment in Canada within this specific age range. It should be noted that this framework is generalized and focuses on the Western industrialized cultures (Hawkins, et al., 2011; Nelson & Berry, 2005). As the idea of emerging adulthood has developed due to cultural changes in Western society, this framework may not be applicable to other cultures in other parts of the world or in minority cultures in Canada (Arnett, 2007; 2000; Nelson & Berry, 2005). Existing research “reflects the individualistic values of the American majority culture” (Nelson & Berry, 2005, p. 259); therefore, characteristics of emerging adulthood may differ in a collectivist culture (Shulman et al., 2005).

Schlegel and Barry (1991) examined 186 traditional non-Western cultures and found that while a period of adolescence appeared to be universal, a period between

adolescence and adulthood existed in only 20% of the cultures studied. The research which currently exists on emerging adulthood is generally either European (Chisholm, 1999; Dubas & Peterson, 1996; Kins & Beyers, 2010; Kins, Beyers, Soenens, & Vansteenkiste, 2009; O'Connor, Allen, Bell, & Hauser, 1996; Seiffge-Krenke, 2009; 2010) or American (Arnett, 2000, 2004, 2007; Barry, Padilla-Walker, Madsen, & Nelson, 2007; Birditt, Fingerman, Lefkowitz, & Dush, 2008; Lamborn & Groh, 2009; Nelson & Berry, 2005; Nelson, Padilla-Walker, Carrol, Madsen, Barry & Badger, 2007; Slicker, Picklesimer, Guzak, & Fuller, 2005; Thorton, Orbuch, & Axinn, 1995). For the purposes of this project, I have assumed that this literature can be extrapolated to include Canadians, as this population holds many of the same individualistic characteristics as its American or European counterparts. There appears to be little known about the emerging adulthood experience within the context of the Canadian Indigenous population or in recent immigrant communities.

Arnett (2000) also suggests that within industrialized and post-industrialized Western societies, there may be discrepancies in the existence or length of emerging adulthood. Certain minority cultures may have a shorter or non-existent emerging adulthood phase. Those that have few educational opportunities or are in a lower economic status group may also be less likely to experience emerging adulthood. Arnett (2000) points out that social class may be more important than ethnicity, as those who are in the middle class or above are far more likely to experience an extended emerging adulthood, regardless of ethnic background, which suggests that there are economic limitations to emerging adulthood. Also, those who live in urban areas are more likely to



experience an extended emerging adulthood, compared with people who live in a rural setting (Arnett, 2000).

For this research project, emerging adulthood was used as a framework for recruiting participants as well as an analytical framework to examine the experiences of the participants. I will assume that when making generalizations about the experience of an acquired impairment during emerging adulthood, I am examining the experience of individuals in a Western culture and the findings may not be extrapolated to include those in a non-Western culture, with a low social-economic status, or Indigenous Canadians.

## CHAPTER 2

### **Literature review**

In order to develop a coherent understanding of the various aspects of this project, a comprehensive literature review has been conducted. The goals of emerging adulthood are explored. As well, the relationship between parents and the emerging adult is examined. A broad review of relevant literature on acquired impairments, focusing specifically on spinal cord injury, amputation, Crohn's Disease and schizophrenia is also presented. As well, the intersection of emerging adulthood and acquired impairment is discussed with a focus on masculinity. Finally, gaps in the above literature are highlighted in order to establish a basis for the development of this particular project.

### **Emerging Adulthood**

#### **Goals of Emerging Adulthood**

In his conceptual discussion of emerging adulthood, Arnett (2007) states that most people in their late teens and early twenties are now spending time trying out various roles in work, love, and school, as opposed to taking on traditional adult roles immediately after high school. People are no longer having children or establishing long-term careers in their early twenties, instead, many are in college or are working in introductory level positions. It is this lack of responsibility and permanency that allows young adults to devote a great deal of time toward introspection and identity exploration (Padilla-Walker, Barry, Carrol, Madsen, and Nelson, 2008). During this time, an individual experiences various changes in one's roles and explores different directions in life without having to commit to traditional adult roles and responsibilities (Kins et al., 2009; Padilla-Walker et al., 2008). The individual is free to explore his or her own

identity, questioning one's values, laws, beliefs, norms or standards (Padilla-Walker et al., 2008).

Barry et al. (2007) states that an emerging adult's main focus is on developing his or her own independence. This transitional time is marked by numerous characteristics, including identity exploration (in areas such as love, work, and world views), instability, possibilities, and a focus on the self (Arnett, 2007; Kins & Beyers, 2010; Padilla-Walker et al., 2008). Seiffge-Krenke (2009) suggests this time is "characterized by fluctuations, discontinuities, and reversals" (p. 238); that is to say emerging adults are attempting to figure out who they really are, what they want to do with their lives, and most importantly, what it means to be an adult.

Navigating life during emerging adulthood can be a highly anxious time. Arnett (2007) goes so far as to refer to some people in this cohort as experiencing a "quarter-life crisis" (p. 70), as they work to establish their own identity and develop a sense of autonomy that is characteristic of those in adulthood. Emerging adults are dealing with identity issues in all aspects of their lives. They are finishing formal education, establishing a career, and may be involved in their first serious romantic relationships (Arnett, 2007). They are also working to redefine their relationship with their parents into an adult relationship, which is no longer characterized by hierarchical dependence.

There are numerous developmental tasks that are salient during the period of emerging adulthood, including identity exploration (Arnett, 2000; Kins & Beyers, 2010), increased independence, formation of mature relationships, compliance with social norms (Nelson et al., 2007), and a redefinition of the parent-child relationship (Kins & Beyers, 2010). When examining the latter task, Birdditt et al. (2008) refer to the term "filial

maturity,” “whereby the offspring ends the rebellion of adolescence and perceives parents from the perspective of a mature adult rather than a child” (p. 2). Kins et al. (2009) report that having a positive relationship with one’s parents contributes to the emotional and psychological well-being of emerging adults. As the existing research highlights the continued importance of the parent-child relationship as the emerging adult moves into adulthood, it is necessary to examine the type and quality of this integral relationship.

### **The Emerging Adult/Parent Relationship**

While emerging adults attempt to navigate through the adult world and develop their own identity, their relationship with their parents generally continues to be important, extending beyond financial support and moving into a bi-directional social and emotional support network (Thorton et al., 1995). It is during this time that young adults are attempting to redefine and reshape their relationship with their parents (Barry et al., 2007).

Brofrenbrenner’s (1979) ecological systems model acknowledges the fact that a person does not experience the world individually. Rather, he or she interacts with various systems that affect his or her life on a daily basis. According to this model, the individual interacts with four ecological systems: (a) the microsystem, the immediate environment in which the individual lives, typically one’s family; (b) the mesosystem, which is the linkage between various microsystems in one’s life, such as workplace or school; (c) the exosystem, which are elements that affect the microsystem though they do not have direct contact with the individual, such as government policies or availability of social supports; and (d) the macrosystem, which is the individual’s culture and society as a whole. In their examination of the ecological systems model and special needs parenting,

Schweiger and O'Brien (2005) found that in order to successfully parent children who live with disabilities, people must be aware of the interlocking systems in their lives and recognize the need for extensive support from the exosystem and macrosystem. The ecological systems model acknowledges the fact that an individual does not exist alone in isolation (Darling, 2007) and that a crisis does not occur in a vacuum but is shaped by the social contexts and meaning in which it occurs (Myer & Moore, 2006). This model identifies key areas of interaction to consider when examining the experiences of men with an acquired impairment in emerging adulthood.

According to the ecological systems model (Bronfenbrenner, 1979), the parent-child relationship exists within the microsystem. Both the child and parent's characteristics and interactions affect and are affected by one other. As young people gain greater independence and take on more adult roles, there is increased mutual respect, affection, confidence, understanding, and enjoyment between the parent and the emerging adult (Thorton et al., 1995). Parents begin to accept that their children have their own opinions and values, and consequently the children begin to feel more comfortable expressing them. During this period, characteristics of a more egalitarian relationship between parent and child begin to develop.

Thorton et al. (1995) found that there is a general improvement in the parent-child dynamic as people move into emerging adulthood and that positive and supportive relationships exist between most parents and their children. Kins and Beyers (2010) found that the emerging adult leaving the parental home could be the catalyst for an increasingly mature parent-child relationship. The importance of the parent-child relationship during emerging adulthood within the context of a newly acquired

impairment has yet to be explored in current research, further illustrating the need for this research project.

### **Acquired Impairment**

In order to better understand the experience of an acquired impairment within the context of emerging adulthood, this project will focus on four possible impairments commonly acquired during this life stage: spinal cord injury, amputation, Crohn's disease, and schizophrenia. While Antonak and Liveneh (1995) make the distinction between impairment acquired by traumatic event, such as spinal cord injury or an amputation, versus a chronic illness, such as Crohn's disease and schizophrenia; for the scope of the project, under the theoretical perspective of the social model of disability, it is not the label of the impairment which is the focus, instead it is the lived experience of the individual (Shakespeare, 2010). No matter what impairment an individual may have, they all may experience disabling environments and social expectations.

#### **Spinal Cord Injury**

In the United States, there are approximately 250,000 individuals living with a spinal cord injury (Ellenbogen, Meada, Jackson, & Barrett, 2006; National Spinal Cord Injury Statistical Center, 2010), with 10,000 – 12,000 new injuries occurring each year (Gallaher & Hough, 2001; National Spinal Cord Injury Statistical Center, 2010). In Canada, it is estimated that 85,500 Canadians are living with a spinal cord injury; however, it is noted that there is no comprehensive data that clearly identifies the incidence and prevalence of spinal cord injury in Canada (Rick Hansen Institute, 2010). With respect to sex differences, there is a disproportionate incidence of spinal cord injury between the sexes, with men comprising 80% of all spinal cord injuries in North America

(Ellensbogan et al., 2006; Gallagher & Hough, 2001), which accounts for my focus on men.

In America, the most common causes of spinal cord injury are motor vehicle crashes (41.3%), falls (27.3%), acts of violence (15%), and recreational activities and sports (7.9%) (National Spinal Cord Injury Statistical Center, 2010). Due to the high risk behaviour which men in emerging adulthood are more likely to engage in (Dreher, 1996; Kessler & Walters, 1998; O'Connor et al., 2011; Shulman et al., 2005), the higher prevalence of spinal cord injury within this cohort is understandable (Rick Hansen Institute, 2010).

Spinal cord injuries occur suddenly and cause a drastic change in a person's life. People who sustain a spinal cord injury face multiple physical consequences (Chen & Boore, 2006; Lucke, Coccia, Goode, & Lucke, 2004), which could include the "loss of ability to walk, paralysis of the arms or legs, loss of bladder and bowel control, and loss of sexual function" (Lucke et al., 2004, p. 97). There may also be varied psychological consequences, such as depression, anxiety and stress (Boekamp, Overholser, & Schubert, 1996; Chen & Boore, 2006; Dryden, Saunders, Rowe, May, Yiannakoulis, Svenson, Schopflocher, & Voaklander, 2005; Scivolette, Petrelli, Di Lucente, & Castellano, 1997).

When one acquires a spinal cord injury, there is a period of identity adjustment as one reconceptualises him or herself within the context of the acquired impairment. There is existing literature about identity adjustments relating to spinal cord injuries, both in general (Webb & Emery, 2009; Yoshida, 1993) and specifically focused on sport (Smith & Sparkes, 2005; Sparkes & Smith, 2002; Tasiemski, Kennedy, Gardner, & Blaikley, 2004), sexuality (Burns, Hough, Boyd, & Hill, 2008), work (Fadyl & McPherson, 2010;

Krause, Saunders & Staten, 2009), and masculinity (Burns, Hough, Boyd, & Hill, 2010; Smith & Sparkes, 2005; Sparkes & Smith, 2002); however, research on identity formation, adjustment and redefinition for men with spinal cord injuries during emerging adulthood does not exist.

A spinal cord injury can be a life-altering event for both the individual who sustains the injury as well as his or her family and friends. It is well documented that spinal cord injuries not only affect the individual but also have a direct affect on the entire family unit (Alfano, Neilson, & Fink, 1994; Carnes & Quinn, 2005; Ellenbogen et al., 2006; Kennedy & Rogers, 2000; Kester, Rothblum, Lobato, & Milhouse, 1988; Meade, Taylor, Kreutzer, Marwitz, & Thomas, 2004; Ostrander, 2008; Pelletier, Alfano, & Fink, 1994; Shackelford, Farley, & Vines, 1998; Steinglass, Temple, Lisman, & Reiss, 1982). Whereas researchers have extensively investigated the impact of a child with a disability on the family (Aitken et al., 2009; Arroyos-Jurado, Paulsen, Ehly, & Max, 2006; Blomquist, 2007; Boyer, Hitelman, Knolls, & Kafjalas, 2003; Erikson, 2008; Hawley, Ward, Magnays, & Long, 2003; Kao & Stuijbergen, 2004; Souza, Braga, Filho, & Dellatolas, 2007; Tisdall, 2001), there appears to be minimal research examining individual experiences of spinal cord injury.

### **Amputation**

Due to an apparent gap in the literature on loss of limbs in Canada, it is unknown how many individuals experience an amputation. However, the literature that exists states that the majority of all amputations occur during older adulthood, most frequently due to complications of diabetes (Murray & Fox, 2002). In fact, people over the age of sixty account for approximately 85% of all amputations (Williamson & Walters, 1996).



Given that the emphasis in the current literature is on the majority - older adults who acquire an impairment - the need for literature exploring the experience of young adults with amputations is necessary.

Non-congenital amputation can be carried out for multiple reasons, such as diabetes, cancer and traumatic injury (Murray & Fox, 2009). There are multiple medical issues which one may experience following an amputation as well, including phantom limb pain (Bosmans, Suurmeijer, Hulsink, van der Schans, Geertzen, & Dijkstra, 2007; Senra, Oliveira, Leal, & Vieira, 2011), and residual limb pain (Hamill, Carson, & Dorahy, 2010). Following an amputation, one may also experience psychosocial adjustment issues such as depression and anxiety, as well as body image issues (Gallagher & MacLachlan, 2001; Hamill et al., 2010; Horgan & MacLachlan, 2004; Murray & Fox, 2002; Oaksford, Frude, & Cuddihy, 2005; Senra et al., 2001). There may also be potential impacts on sexual activity (Williamson & Walters, 1996). However, the literature that exists focuses on older adults and does not acknowledge the unique experiences of emerging adulthood.

In general, there appears to be minimal literature focusing on the non-medical aspects of lower limb amputation, with an even larger gap in the literature focusing on the experiences of young people. Only two studies were located that focused on younger adults; one which solely studied coping mechanisms of those who lost a limb due to trauma or tumour (Sjodahal, Gard & Jarnlo, 2004) and one which examined prosthesis use (Murray, 2009). It is evident that there is a lack of research that focuses on the individual's experience of emerging adulthood within the context of an amputation. As young men are at a higher risk for traumatic injury (Kessler & Walters, 1998; O'Connor et al., 2011; Shulman et al., 2005), possible amputations may occur, and it is necessary to

have a better understanding of the experience of emerging adult men within the context of an amputation.

### **Crohn's Disease**

In 2008, a report by the Crohn's and Colitis Foundation of Canada (2008) found that about 112,000 Canadians have Crohn's disease. Most people are diagnosed with Crohn's during the time of emerging adulthood; however, 10-15% are diagnosed before reaching adulthood (Crohn's and Colitis Foundation of Canada, 2008; Panes, et al., 2007). There appears to be a peak diagnosis period between the ages of 16-25 (Panes et al., 2007), with approximately 56% of patients being diagnosed before the age of 22 (Garcia-Vega & Fernandez-Rodriguez, 2004). Further, studies suggest that the global incidence of Crohn's Disease is on the rise (Irvine, Farrokhyar, & Swarbrick, 2001; Sonnenberg, McCarty, & Jacobsen, 1991). Individuals in both North America and Europe are at a greater risk of developing Crohn's Disease (Crohn's and Colitis Foundation of Canada, 2008; Linfred, Saalman, Nilsson, Sparud-Lundin, & Lepp, 2012). Given that emerging adulthood has been understood primarily in a western context and the fact that there is a greater incidence of Crohn's Disease in the western world, it is even more important to study the experience of Crohn's disease for men in emerging adulthood. Furthermore, due to the fact that women are slightly more often diagnosed with this impairment (Crohn's and Colitis Foundation of Canada, 2008; Panes et al., 2007), there is a lack of in-depth examination of Crohn's Disease from the male perspective.

Crohn's Disease, one of two subtypes of life-long inflammatory bowel disease, "causes inflammation of any area of the GI tract from the mouth to the anus, although it

most commonly affects the small intestine and/or colon” (Crohn’s and Colitis Foundation of Canada, 2008, p. 17). It appears to be a multifactorial disease, wherein one’s environment, genetics, and immunology all play a role (Bianco et al., 2012) and it is fluctuating, wherein an individuals with Crohn’s Disease will likely go through periods of experiencing symptoms and then going through remissions (Crohn’s and Colitis Foundation of Canada, 2008; Lindfred et al., 2012). Common symptoms include flatulence, frequent diarrhea, and delayed puberty in children (MacPhee, et al., 1998), as well as weight loss or growth delay (Mackner & Crandall, 2006). As there is no cure for Crohn’s Disease, treatment focuses on alleviating the symptoms (Greenly et al., 2010; Lindfred, et al., 2012). People with Crohn’s Disease often struggle with minimal emotional support and a feeling of a lack of control over their disease, and subsequently, their lives. Even when not experiencing symptoms, people still have strong feelings of “stress, anxiety, fear about pain, and worry about the consequences of the disease” (Crohn’s and Colitis Foundation of Canada, 2008, p. 59).

The symptoms of Crohn’s can be considered embarrassing and socially taboo (Greenly et al., 2010; Lindfred et al., 2012; Mackner & Crandall, 2006; MacPhee et al., 1998). These feelings of embarrassment for individuals with Crohn’s disease may have far reaching effects, including effects on both peer and romantic relationships, choice of work or recreation, and identity formation, a point further supported by Mackner and Crandall (2006). Individuals who require ostomy bags may experience numerous post-surgical challenges, such as “diminished self-esteem, peer socialization, social stigma, sexual identity, independence, body image shifts, embarrassment, grief and loss of control” (Nicholas, Swan, Gerstle, Allan, & Griffiths, 2008, p. 115). These feelings of

embarrassment, low self esteem, and concern over body image and appearance may be further magnified when placed within the context of emerging adulthood.

A diagnosis of Crohn's Disease can have a profound effect on both the individual and his or her support network (MacPhee et al., 1998). Lindfred et al. (2012) acknowledge living with Crohn's Disease "can be particularly demanding... during adolescence, a critical period of physical, psychological and social development" (p. 256). While there is a great deal of research on the adolescent's experience of Crohn's Disease and its impacts on family, social life and psychosocial quality of life (Greenly et al., 2010; Lindfred et al., 2012; MacPhee et al., 1998; Mackner & Crandall, 2006; Nicholas et al., 2008; Sargent & Gross, 2011), very little research appears to exist which addresses the experience of Crohn's Disease within the specific context of emerging adulthood, a point highlighted by Nicholas et al. (2008). More specifically, there is currently a lack of research specifically looking at Crohn's Disease, emerging adulthood, identity formation, adjustment and redefinition for men.

### **Schizophrenia**

In much of the industrialized world, including Canada and the United States, prevalence of schizophrenia is approximately one percent of the population (Schultz & Andreasen, 1999), making it the seventh greatest cause of impairment worldwide (Frangou, 2008). Schizophrenia is usually diagnosed during emerging adulthood (Gioia, 2006; Goeree et al., 1999; Goff, Heckers, & Freudenreich, 2001; Schultz & Andreasen, 1999); however, it is important to note that men are generally diagnosed during emerging adulthood, while women are diagnosed about five years later than males, on average (Goff et al., 2001). Men with schizophrenia also have a less benign course of illness,

have less positive outcomes, exhibit more negative symptoms, and show more aggression when compared to their female counterparts (Brunette & Drake, 1997).

Schizophrenia has a wide range of impairments, most of which affect cognition (Schultz & Andreasen, 1999). Symptoms are split into “positive” and “negative” subcategories. Positive symptoms are considered to be abnormal by their presence and include delusions, disordered thought, and hallucinations, while the negative symptoms refer to an absence of normal behaviours, and include flat affect, apathetic social withdrawal, and poverty of speech (Frangou, 2008). Negative symptoms are considered to be “most debilitating for the patient, difficult for the family, and most detrimental to adjustment” (Wuerker, 2000) and are also the least likely to improve (Schultz & Andreasen, 1999). The suicide rate for individuals with schizophrenia is fifteen to twenty times higher than that in the general population (Goeree et al., 1999).

There appears to be a substantial collection of research on young adults who are living with schizophrenia, comparatively much more than spinal cord injury, amputation, or Crohn’s Disease. However, much of it appears to be medical in nature (Goff et al., 2001; Kayton, 1973; Lee, Kane, Sereika, Cho, & Jolley, 2011; McCann & Clark, 2004) or focused on specific issues, such as an increased involvement in the justice system (Baltodano, Mathur, & Rutherford, 2005; Davis, Banks, Fisher, & Grudzinskas, 2007; Grisso, 2004; Hartwell, Fisher, & Davis, 2010). There is minimal research which focuses on the individual experiences of emerging adults within the context of schizophrenia, specifically for men, in terms of identity, independence, and masculinity, despite the fact that the “transition from adolescence to young adulthood is a time of uncertainty and apprehension for families whose children struggle with mental health difficulties”

(Jivanjee, Kruzich and Gordon, 2009, p. 444). In order to improve the lives of the emerging adult men who acquire schizophrenia, as well as their families, further research is necessary.

As an emerging adult man with schizophrenia, the individual is at a high risk for substance abuse (Brunette & Drake, 1997; Jivanjee et al., 2009) and involvement in the justice system (Goeree et al., 1999; Hartwell et al., 2010; Jivanjee et al., 2009) as he negotiates his cognitive impairments while at the same time redefining his relationship with his parents, embarking on educational or vocational pursuits, and reconceptualising his identity as an adult.

### **Acquired Impairment and Masculinity**

An important piece of this research is focused on masculinity. Tepper (1999) states “dependency, diminished body image, impaired sexual function, and loss of earning potential may threaten a man’s gender identity or core sense of himself as a man and his ability to carry out established gender roles” (p. 44). For some, this loss of strength and self-reliance can feel like a loss of manhood; increased dependency can make a man feel childlike. During the time of emerging adulthood, where one is already struggling to adapt to an adult identity, this situation can become critical.

Identity reformation following an acquired impairment is both integral (Ostrander, 2008) and inevitable (Good, et al., 2006). As the emerging adult man tries to reconcile the dual identities of becoming an adult in addition to living with an acquired impairment, he also must renegotiate what he believes it means to be a man. He must redefine “masculinity in the face of a disease that challenges capacities usually associated with masculinity” (Riessman, 2003, p. 9). Younger men tend to experience more

masculine role conflict (Berger, Levant, McMillan, Kelleher, & Sellers, 2005), facing developmental challenges related to “perceived or real social limitations associated with dating relationships, sexuality, parenting and/or employment” (Good et al., 2008, p. 40), all of which are issues which young men in emerging adulthood, regardless of impairment, have to face.

Good et al. (2008) found that the way a man conceptualizes masculinity affects his behaviour in many ways and can be both negatively and positively associated with his ability to cope with an acquired impairment. Good et al. (2006) found that a man’s adherence to a traditional masculine identity can both impede and promote his adjustment to an acquired impairment. Some may try to maintain their original masculine ideal by continuing to engage in risk-taking behaviour, refusing help, and insisting on functioning as independently as possible. These men put themselves at an increased risk for depression once they realize that they cannot ignore their newfound impairment. Furthermore, the more one maintains a traditional masculine role, the more unfavourable their attitudes are toward psychological intervention (Good et al., 2006). There may also be benefits to maintaining a traditional masculine identity when faced with an acquired impairment, including the determination and the will to succeed and triumph over obstacles. Others may reformulate their definition of masculinity, shifting away from the traditional norms of masculinity, allowing for a more positive and successful identity reformation (Good et al., 2006).

### **Emerging Adulthood and Acquired Impairment**

Establishing one’s identity as an adult, autonomous from one’s family of origin, is the main task in emerging adulthood (Arnett, 2007; Padilla-Walker et al., 2008). Identity

refers to those aspects of self related to one's race/ethnicity, gender, ability status or other social characteristics (Ostrander, 2008). This can prove to be a very difficult undertaking for many individuals. Compounding this important life course event with an acquired impairment means that the individual is forced to reconcile several new identities during the same time period. When individuals are in their identity formation stage, they attempt to "reconcile the identity they have developed with the identity assigned to them by various social forces" (Ostrander, 2008, p. 585). When a person acquires an impairment that will affect his or her functioning in various ways, there is also a need to re-establish one's identity. Ostrander (2008) refers to identity formation as "the development of a cohesive identity that incorporates various aspects of self" (p. 585). He further suggests that following an acquired injury (in Ostrander's study, a spinal cord injury); individuals are faced with the task of redefining both their identity and their role in society.

The period of identity formation and redefinition for individuals with an acquired impairment is made even more complex, with a tension among need for care, the desire of family members to provide care, and the need and desire of the individual for independence from their parents. In his examination of acquired spinal cord injuries in men, Ostrander (2008) found that young men, within the age range of emerging adulthood, are characteristically "highly independent, sexually virile, and have the capability and duty to defend himself as well as his family and/or loved ones" (p. 594). Upon acquiring a spinal cord injury, men have reported "a loss of independence that resulted from the injury, an inability to engage in traditional sexual relations, a change in body image, and a feeling of vulnerability" (p. 594). This finding supports the suggestion



that an emerging adult with an acquired impairment may need to reconceptualise his identity in numerous ways.

Senra et al. (2001) acknowledge the need for “the renegotiation process of the new identity” (p. 181) when an individual acquires an amputation. When compounded with the typical identity redefinition period experienced by emerging adults, this may become a unique experience that must be examined further, as the current literature focuses on older adults who are already entrenched in their well-developed adult identity.

Peer support can be a positive moderator of coping in adolescents with Crohn’s disease (Nicholas et al., 2008); however, for individuals with Crohn’s Disease, the transition from familial dependence to supportive peer relationships may be delayed in adolescence due to increased dependence on parents (MacPhree et al., 1998). Therefore the emerging adult must work to develop an adult identity, independent of his or her parents. Reconceptualising multiple identities during an already complex life stage, as both Crohn’s Disease and life events common to emerging adulthood are very uncertain, can be very stressful. This is of concern for the individual as stressful life events have been correlated with exacerbation of Crohn’s Disease symptoms (Garcia-Vega & Fernandez-Rodriguez, 2004; Garrett, Brantley, Jones, & Tipton-McKnight, 1990); therefore, one must carefully work to develop independence and an adult identity.

Jivanjee et al. (2009) state that the transition into adulthood for people with schizophrenia is “a time of uncertainty and apprehension for families” (p. 444), with the challenges most emerging adults face exacerbated. For emerging adults with schizophrenia, this period is characterized by “low levels of educational attainment, high rates of involvement in criminal activities, high unemployment rates, high rates of

substance abuse and pregnancy, and low rates of independent living” (Jivanjee et al., 2009, p. 435). Most individuals desire more independence; however, they must negotiate the need for continued support from both family and community supports and services (Jivanjee et al., 2009). Crucial to the success of living autonomously is the development of independence and social functioning (Kuipers, 1991), both important factors in identity formation in emerging adults.

Independence is an important concept of this examination of emerging adults and acquired impairment. Young adults are both revelling in newfound independence while at the same time struggling with it (Arnett, 2007). One of the major hallmarks of this process is moving away from one’s parents, both physically and symbolically, which generally occurs during this time period. Following a spinal cord injury or loss of a limb, young men may become more dependent on others, which may increase the complexity of developing independence. For those with Crohn’s Disease, the same dichotomy may exist between an increased dependence on parents for support and care, while at the same time, the desire for independence as an adult.

Parents may fear that the nature of a cognitive impairment, such as schizophrenia, may affect one’s ability to make independent decisions (Jivanjee et al., 2009). For most individuals, “parents continue to be part of their life and young adults continue to rely on parental support and resources” (Jivanjee et al., 2009, p. 444), even as they make attempts at self-determination. Wuerker (2000) discussed the concept of “expressed emotion,” which measures parental attitudes toward the individual with schizophrenia. Individuals who have parents with higher expressed emotion, which is characterized mainly by emotional over-involvement, have a much higher chance for relapse. This

finding, supported by Kuipers (1991), indicates the need for emerging adults with schizophrenia to develop an autonomous identity, independent from one's parents.

Emerging adult men with an acquired impairment must also work to develop and maintain appropriate social networks and supportive peer relationships. In a study examining children and teens with spinal cord injury, Vogel, Hickey, Klaas, and Anderson (2004) stressed the need for young people who sustain spinal cord injuries and are dependant on care from their parents to continue to develop autonomy and do things with their peers in order to re-establish their identities as an emerging adults. One can extrapolate from this study the finding that peers and autonomy are as important for emerging adults as they are for teens, if not more so. Li and Moore (1998) point to the importance of social support when adapting to a newly acquired impairment, a finding which has also been confirmed for schizophrenia to prevent both isolation and loneliness (Kuipers, 1991). Social support has also been found to be a protective factor for young people with Crohn's Disease (Nicholas et al., 2008).

Dunn and Brody (2008) state that the balance between agency (a person's sense of choice or autonomy) and communion (a person's need to relate and interact with others) is the key to having "a good life" following an acquired impairment. That is to say, the emerging adult has to find a balance between his need for continued support and his need to develop into an independent adult. Throughout the literature, it is evident that young men with an acquired impairment must work to develop an identity centred on independence, both as an adult and as a person with a disability (Vogel et al., 2004).

## **Gaps in Literature**

Despite the vast amount of literature on the subject of acquired impairment and the recent interest and growing body of research on emerging adulthood, there does not appear to be any research that directly focuses on impairment acquired during emerging adulthood. Following an extensive review of the relevant literature, the following gaps exist:

- There appears to be a lack of research focused on the individual experience of acquired impairment during emerging adulthood.
- There is a lack of research that is focused on young men who acquire an impairment during emerging adulthood. This gap is significant because young men in emerging adulthood are at high risk for acquiring impairment resulting from a traumatic event or condition.
- Research on identity formation has not explored the complexities of developing several new identities during one time period. Specifically, the intersection between forming one's adult identity during emerging adulthood within the context of a newly acquired impairment has yet to be studied.

This research project begins to address these gaps in the literature. I use two theoretical frameworks: the social model of disability to explore the effect that society has on creating disability and emerging adulthood to understand the complex transitions that one goes through during this transition period, as I attempt to better understand the experiences of men with acquired impairments during the time of emerging adulthood.

## CHAPTER 3

### **Methodology**

#### **Study Design**

I used a qualitative approach to address the central research question: “How do men with an acquired impairment experience emerging adulthood?” I conducted semi-structured interviews in Winnipeg, Manitoba with four participants, between the ages of 26-35, who have an acquired impairment. I then used thematic analysis (Braun & Clarke, 2006) to generate common themes as well as unique experiences from the interview data, in order to gain a comprehensive understanding of the lived experience of emerging adulthood for men with an acquired impairment.

#### **Ethics Protocol**

The University of Manitoba Joint-Faculty Research Ethics Board approved the ethics protocol for study with human participants (See Appendix A). Before starting the interviews, I had each participant review and sign the consent form, outlining the study’s purpose and detailing the confidentiality protocols. If a research participant became distressed during the interview, I provided a list of community services as well as a phone number for counselling services.

As part of the commitment to ensuring confidentiality, the analysis of data gathered does not include any identifying characteristics of the participants. I ensured the individuals were aware that I would share the transcripts with them and with my supervisor if necessary. I also informed participants that they would be able to receive a copy of the study upon completion. I used pseudonyms and changed all identifying information, password protected all computer files, and kept all anonymized data in a

locked cabinet in a secured location in order to protect the privacy of the research participants. I will keep all transcripts, audio recordings, codes, and backup files in a secure location, known only to me, until one year following publication of this data. After one year, any data that identifies a participant will be destroyed.

### **Participant Recruitment**

I recruited participants for this research in a variety of ways. First, I reached out to various community support agencies including, but not limited to, the Canadian Paraplegic Association and Society for Manitobans with Disabilities, which shared my recruitment notice with their members. I also reached out to occupational therapists throughout Winnipeg who passed along my information to their clients. I obtained permission to post a recruitment notice in the Occupational Therapy Department of the Health Sciences Centre. Finally, other potential participants were informed of my study through word of mouth.

The target population for this study was men who experienced emerging adulthood within the context of an acquired impairment. Individuals were eligible to participate in this study if they had acquired an impairment during or before emerging adulthood and had, therefore, experienced emerging adulthood with some type of impairment. I asked the individuals to discuss their experience of emerging adulthood, either as it is happening or retrospectively.

If individuals were interested in participating in this study, they contacted me via email or telephone. An initial brief screening occurred at the point of first contact in order to ensure the individuals fit the basic parameter of this study. I informed each participant of the purpose of the study beforehand. I distributed the interview questions to each

participant before the interview to allow him to reflect on his answers as well as to increase his comfort level with the research topics. I also informed each participant beforehand that he had the right to refuse to answer any question or to withdraw from the study at any time. At the beginning of each interview, I reiterated the purpose of the study, thanked the participant for his participation, and asked that he review and sign the consent form.

### **Participants**

Participants ranged in age from 26 to 38. All participants were English speaking Canadian citizens.

Table 1		
<i>Study Participants</i>		
<u>Pseudonym</u>	<u>Current Age</u>	<u>Age of Acquired Impairment</u>
David	26	18
Richard	27	15
Brad	28	9
Sam	35	22

### **Research Questions**

The central research question for this study was: How do men with an acquired impairment experience emerging adulthood? Specific questions were asked to capture the experience of emerging adulthood for men with an acquired impairment:

- a) Have there been any important changes in your life with regards to your impairment?
- b) During your late teens/early twenties, how did having an acquired impairment impact your daily life? Have you experienced any barriers or challenges?

- c) Have there been any unique opportunities that you have experienced, when compared to your friends who do not have an acquired impairment?
- d) What sorts of innovations have you, your family, and/or your friends created or developed in order to adapt to your impairment?
- e) Can you tell me a bit about how you think your friends and family are dealing with the changes in your life?
- f) What sort of dreams and goals do you have? Have your dreams and plans for your future changed since your impairment? If so, why/what has caused this?
- g) What does “being a man” mean to you and does your acquired impairment impact your sense of being a man?

### **Data Collection**

I conducted four semi-structured interviews with participants in order to collect data from the research participants. An interview is defined as a method of data collection in which one person (an interviewer) asks questions of another person (a respondent) (Polit & Beck, 2006). I utilized semi-structured interviews, in which “open, direct, verbal questions are used to elicit detailed narratives and stories” (DiCicco-Bloom & Crabtree, 2006, p. 40). This type of interview is best suited for this research project as it allowed the interviewer to ask questions while at the same time allowed the participant to share his own story.

A short series of questions was developed which served as a guideline for the interview process. I utilized open-ended questions as well as follow-up or probing questions to ensure that all information was included or to encourage the participant to continue to tell his story. The series of questions focused on the participant’s experiences



following an acquired impairment within the context of emerging adulthood. Despite having a prepared list of interview questions, I used caution not to control the interview by allowing each participant to take their answers in whatever direction they felt was appropriate, as I wanted to respect the participants and their experiences, as opposed to treating them as data producers (Whiting, 2008). I audio-taped and transcribed all interviews.

Once each interview was transcribed, I engaged in member-checking in order to give research participants “an opportunity to check (approve) particular aspects of the interpretation of the data they provided” (Carlson, 2010, p. 1105). Each participant was sent a transcript of their interview in order for them to verify accuracy.

While the path of the interview was determined by the participant, the focus of the interviews was broadly based on the five characteristics of one’s environment and society, as detailed by Brown (2001): (a) accessibility, can you get where you want to go?, (b) accommodation, can you do what you want to do?, (c) resource availability, are your unique needs met?, (d) social support, are you accepted by those around you?, and (e) equality, are you treated equally by others? These questions reflect Bronfenbrenner’s (1986, 1979) ecological model as well as the social model of disability by acknowledging that disability is a socially constructed concept. While I did not directly address these questions in a specific manner, they were used as a guide when interviewing participants.

A potential issue when utilizing semi-structured interviews is that it may be difficult to separate the researcher’s own knowledge and bias from the data (Braun & Clark, 2006; Whiting, 2008). Throughout the interview process, I engaged in reflexive self-examination, acknowledging my own values, assumptions, prejudices, and personal

influences as a researcher, as suggested by Hand (2003). I engaged in journaling, or keeping a methodological log (Peterson, 2006), as a way to examine my own thoughts on the research process. This reflexive approach aided in the auditability of this qualitative research project. By acknowledging that, within qualitative research “the researcher and the research cannot be meaningfully separated, and that neutrality is impossible” (Peterson, 2006, p. 18), instead of being a source of bias, this reflexive approach can be thought of as a resource that may generate new insights. Journaling allowed me, as the researcher, to reflect on common barriers and opportunities presented by the participants that emerged as the interviews progressed.

### **Data Analysis**

Thematic analysis is the most appropriate approach to data analysis to better understand how a man with an acquired impairment experiences emerging adulthood. According to Braun and Clarke (2006), “thematic analysis is a method for identifying, analysing and reporting patterns (themes) within data” (p. 79). Thematic analysis, which aims to reflect reality (Braun & Clarke, 2006) and explore the understanding of an issue (Attride-Stirling, 2001), allowed me to search across the data for themes that emerge based on the participant’s experiences (Daly, Kellehear, & Gliksman, 1997). By identifying codes, which are categories in relation to the data, I was able to find repeated patterns of meaning (Braun & Clark, 2006) in order to develop themes, which “captures something in relation to the research question” (Braun & Clark, 2006, p. 82). I then analysed the themes in relation to the two theoretical frameworks used in this project (Attride-Stirling, 2001). Braun & Clark (2006) state that thematic analysis is not associated with any specific theoretical framework or perspective; therefore, as this

project utilizes two different theoretical frameworks, the flexibility of this type of analysis is beneficial.

I analysed the data in two stages: repeated readings of the transcribed interview to identify themes followed by in-depth coding of the transcripts using the identified themes. I identified three themes: internal perceptions, dynamics of social relationships, and barriers and opportunities.

During this stage, I withheld any judgement and let the participants' words tell the story. This narrative approach to developing codes and themes ensures the participants' stories are reflected. Smith & Sparkes (2008a; 2008b; 2005) suggest that a narrative is useful when studying disability as it offers insight into the experience of living with disability as well as an individual's socio-cultural life. Isakson and Prellwitz (2010) point out that narrative reasoning is especially useful when providing coherence to the confusion and chaos that an acquired disability can create. The narrative approach was most beneficial for this project as it ensured the research participants were able to tell their own stories.

The second stage of analysis encompassed both the themes that emerged from the interviews as well as current literature on emerging adulthood, in order to provide a comparison of the two. The entire process was recursive, as I moved through the data in order to develop a clear thematic overview of the experiences of the participants. By following the steps of data analysis outlined in Creswell (2009), I was able to move from the coding process to theme generation to interpreting the data within the context of existing emerging adult literature.

Braun and Clarke (2006) examined the advantages and disadvantages of thematic analysis. The advantages of thematic analysis are numerous, and include flexibility, accessibility for both novice researchers and for the public, an ability to provide a full description of the data set, including both the similarities and differences in data, and an ability to generate unanticipated insights when analysing the data. The disadvantages of thematic analysis appear to depend on the skill of the researcher herself. If the analysis is poorly conducted or inappropriate research questions are used, this can hamper the method in its entirety. The flexibility of the method, which is also one of its main benefits, may also prove to be a disadvantage if the researcher is unable to focus his or her work within particular theoretical frameworks. Both of these issues were avoided in this research project as I have ensured that I have strong research questions, conducted a clear analysis of the themes, and focused my final analysis within the context of the two theoretical frameworks.

Due to the fact that this is an exploratory study, merely beginning the conversation of an acquired impairment's impact on emerging adulthood, only a small sample was interviewed. I anticipate that due to the scope of this paper, as well as the potential population of young men with an acquired impairment within the Winnipeg area, this research project will likely not reach saturation.

## **Conclusion**

As disability is experienced within society, the impact which society has on an individual and family experiencing a disability is undeniable. Both the social model of disability and the ecological systems model acknowledge the role that society and one's environment has on the individual. By sharing their experiences and stories of emerging

adulthood, men with an acquired impairment will enlighten others to their unique experiences. This approach to acquired impairment and emerging adulthood will provide a rich and unique understanding of the experience in order to give meaning to the experience and to provide more appropriate supports for this cohort.

## CHAPTER 4

### **Findings**

I was able to determine three overarching themes using thematic analysis. These themes are: a) internal perceptions, b) dynamics of social relationships during emerging adulthood, and c) barriers and opportunities encountered during emerging adulthood. This chapter, focusing on these three themes as well as multiple subthemes, provides a detailed description of the data collected.

#### **Internal Perceptions**

All four participants shared their internal thoughts and feelings about their acquired impairment to varying degrees. The three main subthemes which emerged are their perspective on their impairment, issues with body image, and their perceptions on “being a man” along with the effect that their impairment has on their personal feelings of masculinity.

#### **Perspectives on Impairment**

Three out of the four participants shared their thoughts on acquiring an impairment; what they have learned both about themselves and the world around them. The three men all had different feelings about their impairment.

David shared: “What I’ve learned is life is a whole lot more difficult when you feel that you are mentally ill, when you feel that you have a burden . . . I still feel I am different from people but now that I have my language back, I can explore my connection to all of those factors.” During his emerging adulthood, he has come to view his impairment as both a gift and a curse, but he currently feels that he is more focused and therefore it is a gift. In finding this balance, David has learned to “combine the mentally

ill mind with the healthy mind,” which has had a direct effect on his creative side and his work – “I feel more complete and more aware in knowing what I am talking about and what my creative flow is and where I am writing.” In allowing himself to accept his impairment and embrace the creative flow it inspires, he feels he has become a better artist.

Brad does not view his impairment as a barrier in most aspects of life, choosing to focus instead on what he can do. He does not worry about what he cannot do and chooses to adapt and learn about what he can do. He also states he tries to do things as if he does not have an impairment. His perspective on life has also shifted: “I’ve learned to always be positive. You can’t be negative about anything. For me, when I got cancer and had everything happen, it was the worst thing that could happen in someone’s life, so since then, everything is a positive. It’s one thing that I’ve learned, having a disability. Have a positive perspective on things”.

Sam has taken a positive approach, learning to become more open and accepting of others: “You don’t worry about the small things in life because there’s always somebody worse off than you”.

### **Body Image**

The three participants with physical impairments all briefly discussed their struggles with body image. Richard had lost a great deal of weight during his initial impairment, and he seemed uncomfortable with the extra attention he received during emerging adulthood. Brad gave the example of having to go to the beach: “People would go to the beach and I’d be self conscious about doing it... I’d have to have my prosthetic out”. Sam focused on his wheelchair and the impact going from standing and walking to

someone who was in a chair had on his dating life. He found himself wondering what girls would think, stating: “It shatters your confidence a little bit”.

### **Masculinity**

All four men initially struggled when asked what “being a man” meant to them. After some consideration, only one individual, Brad, prescribed to the stereotypical gender and masculinity roles: “I think you want to show your masculinity. You want to be a provider, be able to do things, the traditional man things. Be involved in physical activities... a hunter gatherer role”. Sam believes that being a man “means being strong and I don’t mean machismo strong but it means being responsible in all aspects of your life”. He also mentioned the fallacy that real men do not cry and stressed the importance of being sensitive as a man. These two participants felt that having a physical impairment negatively affected their sense of being a man. Sam felt less confident as a man during emerging adulthood, struggling with sexuality and dating, but these insecurities have passed as he has reached his thirties. Brad, also in his thirties, still feels the effect of his impairment on his masculinity: “Sometimes you don’t feel like you’re a complete person. With a disability, you don’t have a sense that you’re a full man”.

David and Richard held broader views on the definition of being a man. Richard believes “being a man... [is] simply having masculine and feminine sides in check”, while David feels that the idea of being a man is just a stereotype forced upon people and he chooses not to identify or stereotype. Instead, he believes “a man is just a person”. It should be noted that both of these participants also held positive perceptions of the impact of their impairment on their masculinity. David states: “I’m more of a man because I’ve been through the ritual of dealing with my sexual identity, even though it



may have been the wrong thing to do. Everything you do is necessary. And that's how I feel about being a man." Richard believes having an impairment as a man "makes you stronger... you get knocked down, but you get up again. So if anything were to happen again, I can deal with it better and have that motivation to overcome any challenges".

### **Dynamics of Social Relationships**

An important part of one's life during emerging adulthood is relationships, specifically redefining one's relationship with family and an increased importance of friends and romantic partners. The subthemes that emerged with regards to relationships are family, friends, girls/romance, personal support, work, school and sports. These are all important areas in the life of an emerging adult.

#### **Family**

All four participants spoke of a great deal of support and concern from their family. Although David struggled at times to communicate and relate with his mother due to his impairment, he shared, "My mom has always cared about me. Even when I wasn't able to understand." Both Richard and Brad stated that they could remember their parents being very concerned at the time of their initial impairment. Before a diagnosis of Crohn's disease, Richard's parents feared that their son was experiencing symptoms of colon cancer. However, after his initial flare up, when his health was back under control, Richard stated that "You just kind of forget...", pointing to the fact that both he and his family have accepted his impairment and it is no longer a defining issue in their lives. Having both experienced cancer at a young age, the families of Brad and Sam had to cope with both an acquired impairment as well as an illness at a young age. These families viewed the acquired impairment as a blessing, when compared to the potential

loss of life associated with childhood cancer. The two participants with mobility impairments also mentioned the accommodations and adjustments that their families assisted with, such as removing structural barriers throughout the home.

### **Friends**

David stated that he was abandoned by his friends when he acquired his impairment. “All the friends I had before my illness... They all left me. Every single last one of them”. He felt that they were unable to cope with his impaired communication abilities. However, David has met a new group of friends through his work at a local mental health art program. He believes that people are either very attracted to him or very put off – he refers to it as a “polarized experience.... That has drawn people to me but also pushed away”. It is important to note that David feels that this polarized experience is not due to his impairment: “I’m thankful that that is not because of my mental illness but it’s because of my life, my interests and my thinking”.

Richard had feelings of isolation and uncertainty at the onset of his impairment. Before his health was under control, he did not know when he was going to become ill and that had a direct effect on his social life in early emerging adulthood.

A supportive group of friends throughout emerging adulthood characterized the experience of both Brad and Sam. Both men stated that their strong support network of friends was integral while navigating through social experiences of emerging adulthood. Brad’s friends would encourage him to engage in all of the social outings that they attended. Brad shared an example: “People would go to the beach, and I’d be self conscious about doing it... I’d have to have my prosthetic out. My friends were a good support group so they’d encourage me to come out anyway, and once I came out and

hung out, it was fine. It wasn't an issue like I thought it was." The encouragement of his friends allowed him to move past fears and barriers that he held in his mind. Friends also played a large role in Sam's social life, assisting in accessibility when on social outings: "They just helped out wherever was needed – if I needed to go up the stairs to the bar, one person threw me over their shoulder and the other picked up my chair and we were there." Sam also mentioned the initial surprise that his friends experienced when he first became impaired at the age of 22, as he went into the hospital for seemingly minor surgery and emerged paraplegic. However, he felt there was never any discord, just acceptance.

### **Intimate Relationships**

All four men felt that their acquired impairment had a negative effect on personal relationships with women during emerging adulthood. Currently, two of the participants are living in common-law marriages. The other two men are single. All identified as heterosexual.

Richard appears to have felt the least impact. He felt that while it may have delayed his romantic life somewhat, it has not been an issue since first acquiring his impairment during high school. Richard currently lives with his girlfriend.

David's experience with women is unique compared with the other participants. A strong sexual side characterizes his acquired impairment and his feelings towards women are very complicated. He also acknowledged that as he is currently working to stabilize his mental health, coping with a romantic relationship is not ideal at the moment. He expressed concern at the prospect and uncertainty of a future romantic relationship: "I don't know what it would have to be, what formula it would have to take, for it to be part

of my life again. But ya, it is something I am going to have to deal with in my life, but I know that it has to happen. That makes me feel a little worried inside, actually.”

Both Sam and Brad, who have mobility impairments, struggled with confidence issues during emerging adulthood. Brad was self-conscious about his impairment, struggling with how to bring it up to women he was dating. He believes that he continues to use his impairment as a barrier, despite his friends assuring him that it is not a “big deal”. Sam, on the other hand, struggled during his early twenties, but has since moved past it and is now living with his partner of five years. During emerging adulthood, however, his confidence around women was greatly affected. His comments on being in a wheelchair reflect this: “It made a big difference. It shatters your confidence a little bit. Being someone who is standing and walking to someone who is in a chair, you never know what a girl is going to think... Obviously dating life became a barrier and a challenge because again, confidence shattered, you don’t know what girls are going to think. They had questions about whether you could do this, things like that. That was a barrier in things like that”. Sam struggled with what to tell women who had questions about his impairment: “You don’t want to let them know about everything – there’s a lot of issues that go on with a spinal cord injury, whether it’s incontinence or bowel movements or stuff like that. You let them know but you keep a little behind the curtain as well”. Towards the end of emerging adulthood, Sam let go of these concerns and began to date again. He approached dating in an honest way – “I was like screw it, I’m going to try and if a girl doesn’t like me because of that, that’s just gonna happen.”

## **Personal Support**

Three of the four participants spoke of the benefits of personal support when it came to speaking with other people with similar impairments. Richard connected on the internet, via a message board, with other participants with Crohn's and Colitis and they spent some time together. While they did not always focus on their impairments, he felt kinship with them due to their shared experiences: "Someone who quietly knew what it was like. Was going through the same stuff as you did. We just kind of have this connection". Both Sam and Brad participate in a local sledge hockey league and have found this connection with other participants with mobility impairments to be invaluable. Brad enjoyed the opportunity to mentor and support other participants with newly acquired impairments. Sam has learned to be more accepting of other people. He further expanded on this important support network: "It's just those friends that you could really confide in and they understand what you are going through... Not only just about hanging out with guys, but having guys with disabilities similar to yours so they understand... With us we can joke around and be stupid about our disabilities, rib each other and not have to worry about it."

## **Work**

Only one of the four participants worked during emerging adulthood. When Sam returned to work after acquiring his impairment, his employer was very accommodating. They renovated his workspace, including the washroom, as well as his duties. The other two participants who were completing post-secondary education did not work during this time, instead relying on financial support from their parents. David struggled with employment when his impairment was at crisis level, stating "I haven't worked... The

reason that I went... [he trails off]. I lost my sanity doing 9-5 work... At one point, I just snapped and left. Took my break and left.” Instead, David relied on a series of financial grants for his art.

### **School**

All four participants completed high school and attempted post-secondary education. David only completed one university course, as he felt the university experience conflicted with his unique way of doing things. The other three participants completed their university educations. Richard experienced interruptions during high school, but his impairment had little to no effect on his university experience. Brad attended university in Manitoba and encountered very few issues with accessibility. He had a disability parking pass which allowed him to park close to his classes. He also utilized the underground tunnels, linking various buildings on campus, allowing him to avoid poor weather and icy conditions, which presented a falling hazard. He also found that university presented a new social experience where people were more open. While Sam did not have any social issues at university, he did struggle with accessibility issues. Sam attended an out-of-province university which had poor accessibility infrastructure. He explained: “I had to scramble around and try and find classes that were on the bottom floor... Getting around campus is hard, particularly in the winter time because you have to go class to class to class.” While on campus disability services did attempt to provide assistance, Sam shared one example wherein he had to go down a flight of stairs backwards in his wheelchair in order to reach a final exam. There were also no tunnels at Sam’s university, therefore he had to cope with snow and ice as barriers every winter.

## **Sports**

Two out of the four participants did not mention participating in sports, while the other two mentioned it frequently. Both Sam and Brad struggled to accept the fact that they could no longer participate in the many sports they used to engage in prior to acquiring their impairments. However, both quickly adapted and found new ways to be physically active. For example, Brad started to play goal in soccer instead of playing a running position. He also took up new sports, such as golf and pool. However, hockey was an important part of both men's lives and they both expressed disappointment that they were not able to skate anymore. Joining the sledge hockey team has proved to be invaluable for both Sam and Brad. Brad found that the use of sports, specifically sledge hockey, allows him to be aggressive in a way that is only acceptable within the boundaries of the rink. "With sledge hockey, it's good to be involved in as a male because you can enact on ice, that you can't do anywhere else in society. You can be aggressive, trash talk, and you leave it all on the ice. Once you leave that environment, you have to be yourself again, you have to conform to society. You have to leave it on the ice. You can't exude that behaviour off the ice." Sam felt that his participation in sledge hockey has helped him rebuild his confidence and increase his motivation as he was able to participate in the sport he has always loved. Both participants also felt that they were free to engage in potentially inappropriate banter with their teammates, where quite often their impairments are the center of the joke.

## **Barriers and opportunities**

During emerging adulthood, these four participants had the opportunity to have unique experiences as a direct result of their acquired impairment. Conversely, they also

encountered both physical and social barriers as they navigated their environments. The subthemes that emerged were participation, accessibility, social barriers, innovations, and opportunities.

### **Participation**

Three participants felt that their participation in everyday life during emerging adulthood was somewhat affected by their impairment. Richard was on a restricted diet during the time that his illness flared up, but has felt few other effects. He continues to take daily medication to maintain his remission but feels that there is otherwise no effect. Brad spoke of having to adjust the way he interacted with classmates and his participation in sports shifted from the sports he could no longer play to other ones where he could still participate. Sam felt that there was little impact on his daily life. He adjusted when he needed to but “other than that, nothing really changed, I still had the same goals, the same plan. And just followed through with it”.

### **Accessibility**

The two participants with mobility impairments discussed accessibility issues, with regards to work, school and social environments. When Sam returned to his part-time job following the acquisition of his impairment, his employer made every effort to accommodate him: “Anything I needed, they’d help out. They renovated the bathroom inside, did lots of accommodation for me. I was working in the back area, helping to fold and collate things and stuff like that, and then they just transitioned me up to the front to do computer and data entry”. Both Sam and Brad mentioned accessibility at school, but these men had very different experiences. Brad felt there were few accessibility issues at his university, while Sam struggled with navigating his campus. Sam also addressed



accessibility issues in social settings such as bars. He never encountered accessibility issues when out with a group of friends as they provided assistance whenever necessary, as previously mentioned.

### **Social Barriers**

David encountered the most social barriers and stigma compared to the other participants. He struggled with “other people’s inability to cope with someone who isn’t able to talk in the same way” in addition to “the way in which society deals with people who have a different perspective... as if every divergent perspective were incorrect”. Furthermore, he felt as though he was suddenly defined by his impairment, a perception that he felt affected his work as well. “Before my illness... one thing that upset me about my illness is before my illness I used to be a person who was creative, someone who imagined and spoke. Suddenly, I don’t know if it was my perspective or others or both. Suddenly I was a mentally ill person who wrote poetry. No longer simply an artist but someone who was doing this because he was mentally ill”.

### **Innovations**

Two of the men spoke of innovations, new ways to cope with their acquired impairments. David coped with his struggles to communicate and learned he is at times better able to express himself through his work, especially his poetry. When Sam first acquired his impairment, he chose not to go to a rehabilitation hospital, located over an hour away from his home, and instead taught himself how to live in a wheelchair with the help of his family and friends. He did not want to be away from his support network for an extended period of time, believing that “you heal better at home... I think I healed faster. I got back to university and did the things that I wanted to do. Back to talking

with friends and things like that. Not being isolated. Rather than being in a hospital, lying in bed and having to go through all that”.

### **Opportunities**

All four men have encountered unique opportunities as a result of their acquired impairment. David received numerous funding grants for his artwork. On a personal level, he revelled in having no boundaries and having an unending source of creativity without restraint. Richard is currently participating in a one-of-a-kind study on Crohn’s and Colitis taking place in Manitoba. Brad and Sam have both had the opportunity to participate in a sport that they love. They have had the chance to travel, meet new people and play in tournaments. Brad has also had the chance to go and speak to children in schools about his experiences.

### **Conclusion**

These findings present a clear picture of the lives of these four men with acquired impairments as they experience emerging adulthood. I have a better understanding of how having an acquired impairment may impact the life of a man as he transitions into adulthood through the candid interviews with the participants in this study. Following an extensive examination of the data, I was able to begin thematic analysis.

## CHAPTER 5

### **Discussion**

The research question “How do men with an acquired impairment experience emerging adulthood?” is better understood by examining the experiences of the participants in this project within the context of current literature. Three main themes emerged from the data collected from the four participants who participated in this project: internal reactions to impairment; the dynamics of social relationships during emerging adulthood; and barriers and opportunities encountered during emerging adulthood. These findings demonstrate the experiences of emerging adulthood for four men with acquired impairments. Comparing the participants in this study to those in the current literature on emerging adults, it appears that their experiences are quite similar, however, their sources of support and timing of transitions may be affected by their experiences of disability and impairment.

#### **Shared Emerging Adult Experiences**

The first theme, internal reactions to impairment, focused on each individual’s perspective on his acquired impairment during emerging adulthood. The experiences of these men illustrate key features of emerging adulthood evident in the literature, including demographic information as well as identity redefinition.

#### **Demographics**

The participants involved in this project shared many characteristics with emerging adults in general. Demographically, the men in this project all identified as Caucasian and of a middle-class background. As Nelson and Berry (2005) state, typical emerging adult experience is focused on the Western majority. Arnett (2000) found that

emerging adulthood is extended for those who come from middle-class or upper-class backgrounds. Further, all four men did not get married or have children during emerging adulthood. This is a hallmark characteristic of emerging adulthood (Arnett, 2000; Kins & Beyers, 2010; Willoughby, 2012). They also all attempted post-secondary education in some form or another (Arnett, 2000; Kins & Beyers, 2010). All four men also lived in an urban environment, where individuals are more likely to experience an extended emerging adulthood period (Arnett, 2000). From this, I can confirm that the participants illustrated characteristics commonly associated with emerging adulthood found in the current literature.

### **Identity Development**

Defining one's identity as an adult is a salient developmental task of emerging adulthood identified in the literature (Arnett, 2000; Barry et al., 2007; Kins & Beyers, 2010). The participants did not directly address issues of identity definition. While their words did not speak of these issues, their experiences of redefining their identities as adults were implicit in their life stories, as they moved towards completing post-secondary education, gaining greater independence, and renegotiating important relationships in their lives.

While these participants moved through the task of identity redefinition, they also had to redefine their identity within the context of an acquired impairment. It appears their adult identity was significantly altered/shaped by their acquired impairment, suggesting that they negotiated their disability identity at the same time as defining and redefining their adult identity. Again, while none of the participants in this study spoke directly of identity redefinition issues within the context of an acquired impairment, they

did provide numerous examples of identity reformation, specifically focused on sexuality, sports, and artistry, which were affected by their acquired impairment.

One individual had to reform his sexual identity after acquiring his impairment at the age of 22, in the midst of emerging adulthood. As he transitioned from walking to using a wheelchair, he struggled with dating and how to discuss his impairment with women. It took him a few years to negotiate this new identity and become more confident with women again.

Two participants had to redefine their identity as athletes. Both men identified as athletes before they acquired their impairments. Initially, following their impairment, they no longer knew how to reconcile their athlete identity with their inability to participate in sports as they once did. However, both were soon able to reform their athletic identity to allow them to continue playing sports.

One individual struggled with his identity as an artist. Before his diagnosis, he was just seen as an “artist”. Following diagnosis, his identity as an artist shifted to being known as an “artist with a mental illness”. This caused him to question his talents as an artist, wondering whether people actually appreciated his work or if he was viewed as talented only within the context of his impairment.

While Burt and Paysnick (2012) found that emerging adults with medical conditions “can face great challenges in establishing independence, autonomy, and adult identity” (p. 500), this does not appear to be the case with respect to the participants in this project. The men in this project, when faced with identity development issues, appeared to have utilized their multiple bonadaptive resources, such as the support of

their friends and family, to assist them in developing a positive, autonomous, adult identity.

While the demographic profile and the developmental task of adult identity definition of these participants were similar to that of many men in emerging adulthood, the participants also experienced divergent emerging adulthood experiences.

### **Unique Emerging Adulthood Experiences**

Despite displaying evidence of certain characteristics of emerging adulthood, there were also characteristics associated with typical emerging adult experiences that were not directly addressed by the four men involved in this project, including anxiety, pursuing independence and relationships with family.

#### **Anxiety**

Arnett (2007) found that due to the multiple identity issues salient during emerging adulthood, this could be a highly anxious time for many individuals. However, none of the participants interviewed shared that they felt atypically anxious during emerging adulthood, even while juggling the tasks of finishing their education, establishing careers, and beginning intimate relationships. The absence of increased anxiety during this time may be due to the increased support of both family and friends for these four participants, a point that will be addressed in an upcoming section. Their positive outlook on life, which they believed was a direct result of their acquired impairment, may also play a role in their decreased anxiety. By choosing to view their impairments in a positive light, they hold a unique perspective on life that may have mitigated any increased feelings of anxiety.

## **Independence**

One of the main tasks of emerging adulthood is establishing one's own independence (Barry et al., 2007). None of the men spoke of a struggle or an overt desire to gain independence in a variety of aspects in their lives. The three participants who completed post-secondary education lived at home during this time, which is characteristic of many emerging adults (Kins et al., 2009; Smart, 2012). None of the men appeared to feel a need, or were able, to break away from their familial home in order to attain increased independence. The experiences of the participants in their continued positive relationships between the individuals and their parents offer a different perspective than that found in the literature. For example, Dubas & Peterson (1996) found that emerging adults who have the most contact with parents, namely those living at home, tend to have the least close relationship to their parents. While it is difficult to generalize on the basis of a small sample, the cases of these four men suggest that the need for continued support as a result of an acquired impairment affects the relationships between parents and the emerging adult and proximity of parents may be less detrimental to the individual's adjustment as they move into adulthood.

In addition, the emerging adult literature suggests that attempting financial independence is a common developmental task of emerging adulthood (Thorton, et al., 1995). The participants in this project accepted financial support from their parents (a point which will be further addressed in another section). Only one individual worked part-time during post-secondary education. All three continued to be supported financially by their parents into their twenties.

To my surprise, there was no frustration expressed by the four participants with regard to attaining physical independence. Coming from my able-bodied perspective, I expected the participants to emphasize a desire for physical independence. However, none of the participants appeared frustrated with needing assistance to cope with any structural barriers they encountered. Instead, they seemed to face this need for infrequent intervention and assistance with a positive attitude, as opposed to potentially expressing frustration and a desire for increased independence.

### **Body Image**

Emerging adulthood is a period of time where individuals have increased body image issues. Bucchianeri, Arikian, Hannan, Eisenberg and Neumark-Sztainer (2013) completed a ten-year longitudinal study examining body dissatisfaction from adolescence to young adulthood and found that men report the most body dissatisfaction as they reach young adulthood. Proving that negative body image is not just a woman's issue, Gillen and Lefkowitz (2009) found that over 65% of male college undergraduates report being dissatisfied with their bodies. It should be noted that this study did not acknowledge the experiences of young people with disabilities. The authors appear to make universal claims with little evidence of universality. This further highlights the invisibility of the experiences of young people who have impairments within current literature.

For one participant, typical body image issues were compounded by the visibility of his impairments. Brad expressed concern when having to show off his prosthetic when going to the beach. For individuals with amputations, body image distortion and body image anxiety issues are pervasive (Horgan & MacLachlan, 2004), which can have a direct impact on one's well-being, quality of life and autonomy (Senra et al., 2011). As



well, Murray and Fox (2002) state there is a significant correlation between body image and life satisfaction “indicating the more negative an amputee feels about his or her body image, the less satisfied her or she is with his or her life” (p. 925). In Brad’s case, his friends assisted him in overcoming these body image issues, which provided further evidence that social support is helpful for individuals with amputations (Sjodahl et al., 2004). By having encouraging, supportive friends, one may be able to overcome or at least address body image issues related to impairment.

### **Substance Abuse**

The men in this study did not fit the image portrayed in the literature on alcohol and substance abuse. For many men in emerging adulthood, dangerous recreational activities, including the abuse of substances, such as alcohol and drugs, are more likely (Arnett, 2000). Smart (2012) found that for all age groups, people with impairments have a higher rate of alcohol and substance abuse when compared with the general population. The participants in this project did not mention the use or abuse of alcohol or substances at all. It is important to note that their silence on this topic could be interpreted in a number of ways, only one of which is that they did not abuse substances. They may have not felt comfortable sharing, or they may not have a memory of it. However, based on the experiences shared by the participants, it appears that alcohol and substances did not play a major role in their lives. This is noteworthy as the literature suggests that men in emerging adulthood with an impairment are at a much higher risk of abusing alcohol and/or substances (Smart, 2012).

## **Masculinity**

As the literature suggests, perceptions of masculinity shaped the experiences of the participants, although not in the manner anticipated. I expected more of a focus on traditional masculinity norms and on a perceived negative impact of impairment upon one's sense of "being a man", however, this was not the case.

My initial hypothesis supports the findings of Shuttleworth, Wedgwood, and Wilson (2012), who stated that most disabled men "tend to identify on both personal and political levels with hegemonic notions of masculinity such as independence and bravado" (p. 175). One participant prescribed to these hegemonic norms of masculinity and thereby felt that his impairment made him feel like less of a man. Another individual shared that although he had a more open definition of masculinity, during emerging adulthood he still felt the impact of his impairment on his sense of "being a man" when it came to talking to women, a feeling that he has since overcome. Interestingly, these two participants are the two who participate in sports, which Berger et al. (2005), Lindermann and Cherney (2008) and Shuttleworth et al. (2012) found is a way for some physically impaired men to "construct or recuperate a hegemonic masculinity" (Shuttleworth et al., 2012). The two men who participated in sports are the two who prescribed to more traditional or hegemonic views of masculinity.

The other two participants had broader, more inclusive visions of masculinity and felt that their impairments had little to no effect on their personal feelings of "being a man". In fact, they felt that having an impairment positively affected their masculinity, a seemingly unique finding within the current literature, as the majority of the focus is on

negative impacts of impairment on masculinity. These two participants felt that having experienced an impairment made them stronger and more resilient in their lives.

An important gap in the literature is addressed by speaking with individuals with a variety of impairments about masculinity. Shuttleworth et al. (2012) state that differences in impairment among disabled men were not discussed nor given importance within the current literature examining the intersection of disability and masculinity. They suggest “failing to differentiate between impairments implies that differences in type and degree of impairment do not articulate and interact differently with masculine expectations” (p. 179). Therefore, the importance of this particular project is supported by the need to examine masculinity within the context of a variety of impairments as each individual’s experiences are unique.

While this project begins to examine masculinity within the context of different impairments, further research is still necessary in order to better understand this unique finding of positive feelings of impairment and masculinity. The variable, degree of or type of impairment, may directly affect one’s feelings of masculinity and manhood. None of the participants shared any experiences with sexual dysfunction or need for assistance with performing sexual activities as a result of their impairment. While this silence may be due to an unwillingness to share with an interviewer, I assumed, due to their candid nature of the rest of their interviews, that sexual dysfunction was not an issue for these participants. It is possible that there may be different perceptions of masculinity when a man experiences sexual performance issues as a result of impairment such as quadriplegia.

## **Relationships**

The experiences of these men are consistent with the literature, illustrating the importance of relationships during emerging adulthood, as discussed in the second theme of the findings. Specifically, familial relationships and peer relationships appear to be most important for these men. However, intimate relationships were not as significant for these participants when compared to the literature on emerging adults.

Burt and Paysnick (2012) state “close relationships, whether continuing relationships with parents or supportive romantic partners, close friends, and mentors, are prominent factors influencing resilient adaptation in the transition to adulthood” (p. 502). Also, the role that sports play in the lives of two of the participants featured prominently within the data. Interestingly, intimate relationships seemed to play a much smaller role, which the literature on emerging adulthood states is not generally the case (Halpern-Meekin, Manning, Giordano, & Longmore, 2013; Petit, Roberts, Lewingsogn, Seeley, & Yaroskavsky, 2011; Smart, 2012).

### **Familial Relationships**

When an emerging adult acquires an impairment, it is not just the individual who is affected. Instead, all of the systems in the individual’s life are affected and change and respond reciprocally. In their examination of Brofrenbrenner’s (1979) ecological systems model and a crisis event, Myer and Moore (2006) acknowledge, “primary and secondary relationships among individuals and systems are affected by the event” (p. 142). Brofrenbrenner’s (1979) model places familial relationships within the microsystem, which is the system closest to the individual. By acknowledging both the proximity of the microsystem to the individual and the fact that it is not just the individual who is

affected by an event (in this case, an acquired impairment), one can grasp the importance of familial relationships to these participants.

The beneficial role that family plays during emerging adulthood is supported throughout the literature (Galambos, Barker, & Krahn, 2006; Holahan, Valentiner, & Moos, 1994; O'Connor et al., 2011; Petit et al., 2011). Petit et al. (2011) directly links family support during emerging adulthood to increased well-being. O'Connor, et al. (2011) found that high positive development during emerging adulthood is predicated by strong relationships with one's parents (as well as peers), allowing individuals to positively develop their identity and trust, to explore their environment and adapt well to change as well as develop emotional control. This supports the experience of the four participants in this project. It appears that these four men all have very supportive families who have been integral in their development throughout emerging adulthood.

Based on both the data in this project and current literature on the topic, familial support is valuable to emerging adults who are experiencing an acquired impairment. This point is illustrated in various ways throughout the data, as families provided both tangible assistance navigating structural barriers in addition to emotional and financial support as necessary.

When needed, family members assisted the participants in navigating disabling structural barriers. Whether modifying the house or helping to make a car accessible, the parents of these participants provided immeasurable support. As previously discussed, all four families also provided a great deal of emotional support to the participants, a fact that all four men mentioned as a factor in both their acceptance of their impairment and in their adjustment to emerging adulthood in general.

The fact that the men in this project received considerable financial support from their parents during emerging adulthood is consistent with current literature on the topic. Of the three participants who completed their post-secondary education, only one participated in paid part-time work. The other two were encouraged by their parents to focus solely on school and were financially supported by their parents as they worked to finish their education. Despite the fact that financial independence is a goal of emerging adulthood (Nelson & Berry, 2005), monetary support from parents seemed welcomed and appreciated by the participants in this project. In a study on parent assistance of their college-aged children, Padilla-Walker, Nelson, and Carrol (2012) found that most emerging adults struggle to sustain an adequate income while attending college/university without some type of financial assistance, most likely from parents. Over fifty percent of parents surveyed provided substantial support (between \$5,000 and \$30,000 annually) in aspects such as tuition, housing and daily expenses.

### **Peer Relationships**

The experiences of these men supported the literature's contention (Roisman, Masten, Coatsworth, & Tellegen, 2004) that developing close relationships with peers is an important part of emerging adulthood, although the stigma of impairment adversely affected at least one of the participants in this area.

Two participants stressed the importance of their friends during emerging adulthood. Their friends provided support, companionship, and at times, assistance with accessibility. Their experiences were mirrored in the research on peer relationships during emerging adulthood. Perceived social support can act as a buffer for negative

mental health outcomes (Petit et al., 2011), a factor which one can assume played a role in the positive attitudes of the participants in this project.

Only one individual, who lives with mental illness, struggled with peer relationships, which he attributed directly to his impairment. He felt that the friends he had before his diagnosis abandoned him. He currently appears to struggle with peer relationships and may be somewhat socially isolated. Burt and Paysnick (2012) point to a lack of positive social and attachment relationships as a risk factor in successfully making the transition to adulthood, which may play a role in this particular case. Smart (2012) notes multiple examples of individuals with psychiatric impairments losing friends following their diagnosis. This appears to be a common occurrence and Smart (2012) suggests that when this occurs, the family “must assume more responsibility” (p. 347), which appears to be the case with this particular individual.

### **Intimate Relationships**

I was surprised that there was a minimal focus on establishing intimate relationships among the participants. Despite the literature stressing the importance of intimate relationships during emerging adulthood (Halpern-Meekin et al., 2013; Petit et al. 2011; Smart, 2012), none of the men discussed having specific intimate relationships during emerging adulthood. Their silence on this topic may be due to a number of factors, including a reluctance to share intimate details with a stranger; however, the participants did appear to speak candidly on this topic to what appears to be the full extent of their experiences.

One individual did note his lack of intimate relationships during this time of his life, a fact he directly attributed to his acquired impairment. While some of the men

noted a lack of confidence when dating, no one shared their dating or relationship experiences. As the interview questions within this project directly addressed intimate relationships, it may be possible that this finding points to delayed development of romantic relationships during emerging adulthood for men with acquired impairments. This research project supports Smart (2012) who found that, of all social relationships, many people with impairments say that dating is most difficult.

The experiences of these participants can be better understood within the context of the social model of disability. Intimate relationships and sexuality are “greatly impacted by social constructs within our society” (Esmail, Darry, Walter, & Knupp, 2010). People with disabilities are largely regarded as asexual, with ambiguous social norms regarding intimacy and disability. The social barriers which emerging adult men with acquired impairments face include overt resistance to their sexuality, socio-cultural barriers which may be more disabling than the impairment itself, and a “prevailing social myth that people with disabilities are asexual beings” (Esmail et al., 2010, p. 1151). The impact of these stigmas can lead to individuals internalizing these socio-cultural perceptions, which affect their “confidence, desire and ability to find a partner” (Esmail et al., 2010, p. 1151).

### **Sports**

The importance of the relationships developed within the context of team sports is a significant finding of this study and is supported by the current literature on the intersection of disability and sport. Being surrounded by others with similar impairments and experiences, the participants found there was little discomfort or censorship among friends. Two participants focused on the importance of sports as a way of finding social



support, camaraderie, and meaning within their impairment. By playing a team sport where the majority of individuals have impairments, they are able to share their experiences with other men with similar impairments. This appears to be a strong coping mechanism for both participants, a point which supports existing literature on the topic (Lindermann & Cherney, 2008). They are able to joke with each other in a unique way, which Lindermann and Cherney (2008) refer to as “locker room talk” (p. 111). The men are free to use “no holds barred” insider humor, which include taunting and teasing each other about their impairments. This type of male friendship relationship, full of posturing and mockery, is also commonplace for men without impairments who participate in team sports (Lindermann & Cherney, 2008). These relationships also allow the men to share their difficult experiences and mentor young men with newly acquired impairments (Lindermann and Cherney, 2008), a point which both participants stressed was important and fulfilling.

This research project supports the finding of Lindermann and Cherney (2008), who argue that participation in wheelchair sports generally results in an increase in self-esteem as well as a change in worldview and perspective. The two participants involved in sports acknowledged this finding. Both expressed a shift in their perspective on life as a direct result of their participation in sports. Additionally, Taub and Greer (1998) found that involvement in sports “may be one of the few avenues for men with physical disabilities to construct a masculine identity” (p. 298). In their discussions with nineteen men who have physical impairments, they found that participation in sports and physical activities “allows them an opportunity to increase masculine self perceptions (p. 298). This conclusion is supported by one participant’s experience within the current data, a

participant who felt that playing sports allowed him to be masculine and aggressive in a way that he felt is not appropriate in everyday society.

### **Innovations**

There is a significant gap in the literature regarding innovations of/by emerging adults with acquired impairments. Due to the unique developmental tasks of emerging adulthood, these individuals have unique needs, and I wondered to what extent the participants developed innovations to address their own changing needs. The participants talked about several innovations they initiated to address changing circumstances.

For example, when Sam was faced with living over an hour away from his support network in order to stay at a rehabilitation center, he chose to create his own rehabilitation program in his own home to stay in close proximity to family and friends. Sam recognized the importance of friends and family during adulthood, which was addressed in previous sections of this chapter, and innovated a plan so that he could continue to be close to them.

David's experience with communication issues provides another example of innovative thinking. Communication struggles are common for some individuals with schizophrenia (Titone, 2010). David found that using poetry was a successful way to meet his communication barriers. He also attended a local art program and found that he was able to better express himself through his art.

There is a need for further literature examining possible ideas and programs that support and share innovative thinking of young men with acquired impairments. While the participants were able to innovate things that worked for them, sharing these

innovations with others may allow for more emerging adult men with acquired impairments to address barriers in their lives with more ease.

## **Barriers**

When examining the experiences of the participants in this study, it appears that at one point or another during emerging adulthood each individual experienced society's negative stereotypes about disability. While the third theme focused on both barriers and opportunities, it is the structural and social barriers that must be examined within the context of the social model of disability.

None of the participants directly discussed their impairment within the context of the social model of disability. Instead, all four men focused on issues pervasive in the medical model of disability. They discussed their impaired bodies and what they felt their bodies prevented them from doing, as opposed to focusing on the structural and psycho-emotional barriers put in place by society that prevent them from fully interacting with the world. However, it is important to discuss their experiences within the context of the social model to better understand the disabling structures of society.

The two participants with mobility impairments faced structural barriers in their daily lives, specifically in school and work. While both felt accommodations were made to make their environments more accessible, one individual's university campus was extremely disabling. He struggled to find classes he could easily access. Examining this experience through the lens of the social model of disability, it is his university that disabled him by failing to create an accessible campus for all.

All four men were further disabled by society's beliefs surrounding disability, consistent with the literature. Smart (2012) states, "everyone gains a self-identity through

the opinions of other, or to state it more accurately, everyone gains a self-identity through his or her perceptions of others' opinions" (p. 355). Whether feeling self-conscious about their bodies or perceiving pity from others, individual prejudice and discrimination affected all of these men at one time or another. According to Reeve (2004), the psycho-emotional dimension of the social model focuses on the internal aspects of impairment. How an individual internalizes the beliefs held by society and how he copes with the potentially negative reactions of others to his impairment can have a large impact on his self-esteem and self-perception.

Reeve (2004) supports the ever-changing nature of the psycho-emotional dimension – some may experience it more intensely at certain times of their lives. Societal barriers may be more disabling than structural barriers, depending on the situation and point in life. Some participants feared that women might not be interested in dating a man with an impairment while another felt that his work was now being judged in a different light due to his impairment. These are examples of the psycho-emotional dimensions of disability waxing and waning over time, thus supporting Reeve's (2004) finding.

In summary, it is evident that while the experiences of men with acquired impairments in emerging adulthood are similar to those in the existing literature on emerging adulthood, there appear to be certain aspects which are potentially divergent, such as one's sources of support along with their timing of transitions.

## **Limitations**

This study has several limitations, including the number and composition of recruited participants as well as research methods used. Some of these limitations are a result of the population available while other limitations reflect choices made.

The data in this study is not generalizable as it reflects the experiences of only four individuals from middle-class socio-economic backgrounds who live in an urban area. These four participants do not represent all emerging adults with acquired impairments. The experiences of emerging adults with acquired impairments may be very different for individuals from different socio-economic backgrounds as well as those who live in rural areas. Given the small numbers and the range of acquired impairments among participants, this study simply provides a flavour of the complexities of impairment within emerging adulthood but does not explore any one aspect in depth.

The data also reflect constraints as a result of how close in time participants were to their experiences of both emerging adulthood and acquired impairment. Two out of the four participants shared their experiences of emerging adulthood historically. These two individuals were in their thirties and looked back on their emerging adulthood when sharing their experiences. This may also be a limitation; their recall may be affected and their perceptions may have shifted as they have reflected over time. However, there did not appear to be a significant difference between the reflections of the participants, in terms of whether they were looking back at emerging adulthood or not.

Several methodological factors also shaped the data and may be seen as limitations. I did not have multiple sources that confirmed the responses given by individuals. By talking to their parents, families, peers and support providers, I could

have increased the reliability of the data in this study. However, this is a pilot study, merely beginning the exploration of the intersection of emerging adulthood and acquired impairment.

Issues inherent with in-person interviews may also be considered a limitation. Participants may have tailored their answers due to social desirability, as they potentially wanted to appear favourably to a stranger. They may have also struggled with recall issues and experienced reluctance to share personal experiences with a stranger. Further, these individuals are a part of a more public discourse on disability and impairment. Their answers may reflect the fact that they do not want to be seen as tragic victims (one image of disability often publicly portrayed); therefore, they may have chosen to present their lives in a way that focuses on the positive outcomes and experiences. It is impossible for me to know exactly what the participants were thinking. In addition, I reviewed their experiences with my own interpretative lens. I attempted to let the participant's voices come through throughout this study, however certain nuances may have been lost.

Reflecting on this study, there are changes I could have made in order to improve reliability and validity. I could have reached out to various programs and organizations within the community very early on in my program in order to make connections and contacts, which may have allowed my recruitment to proceed faster.

Initially when proposing this research study, I chose to focus on the experiences of individuals who shared one specific impairment. In hindsight, earlier recruitment would have potentially allowed me to reach more individuals with a shared impairment. As I was unable to reach these potential participants in a timely manner, I had to broaden

my recruitment to include any type of acquired impairment. I may have been able to find a more homogeneous sample if I had focused on relationship building within the community earlier on.

A final limitation is the fact that I was unable to reach saturation, due to the small number of participants in the study. Despite these limitations, I believe I was successful in creating a novel study which is the first of its kind, thus beginning to include individuals with acquired impairments in research on emerging adulthood.

After considering the limitations of this study, both in terms of recruitment and research methods, I explore the implications that this research has on existing resources and supports in addition to potential avenues for future research.

## CHAPTER 6

### **Conclusion**

#### **Implications**

This study explores the experiences of emerging adulthood for four young men with acquired impairments. After reviewing the findings of this study, I began to explore the implications of the results of this study for both the current resources and supports available for young men with acquired impairment as well as for future research in this field. The data reveals that, in some cases, emerging adults experience unique developmental tasks, and within the context of an acquired impairment, these tasks can become even more complex. Based on these results, I have made recommendations both for individuals who support young men with acquired impairments along with researchers in the field.

#### **Implications for Service Providers**

One of the strongest findings in the data is the fact that social supports, including family, friends, and peers with similar impairments, are very important to young men experiencing an acquired impairment. It is important that these supports exist. Wide and encouraging support networks helped the participants in this study move through emerging adulthood with greater ease. Service providers must work to ensure that these supports are available and in place for an individual as soon as he acquires his impairment. If they are not already, service providers should be aware of the usefulness of these relationships and should remind families of the important role they can play in supporting an emerging adult with an acquired impairment. As well, young men should be encouraged to draw on their personal relationships as a means for support. If these



types of personal relationships are not naturally in place for an individual, the necessary steps should be put into place to create a community for an individual in order to assist in his transition through emerging adulthood.

Service providers should also ensure that programs and resources are readily available and easily accessible, via referrals and information transfer. Emerging adults with acquired impairments should not have to search for these resources. In many cases, the resources and programs that currently exist are for adults in general. As emerging adult experiences are unique and unlike those of someone twenty or forty years their senior, service providers should work to create a comprehensive list of programs, including in the arts and sports, that are tailored to young adults.

Support groups for these emerging adults would also be beneficial. Sharing common experiences is effective in easing the transition through emerging adulthood for men with an acquired impairment. The men in this project used their own resources and supports to produce innovative and successful outcomes when faced with both societal and structural barriers. Service providers need to find a way to enable these men to share their innovations and resources to allow for continued success for other emerging adult men with acquired impairments.

The provincial government may also play a role in creating useful supports for emerging adults with acquired impairments. Community service programs could create spaces that are more open and accessible to the diverse experiences of emerging adults, including those with acquired impairments. By allowing more inclusive spaces, individuals may feel more comfortable accessing supports.

Specific supports surrounding intimate relationships and sexual intimacy should be created, and where they do exist, be clearly advertised, more accessible and less stigmatized. Men of this age may feel uncomfortable talking to a doctor or service provider about these issues. Instead, mentorship programs could be created, possibly through rehabilitation centres, independent living centres, non-profit organizations and sport and art programs, which link men who have lived with an acquired impairment for a longer time with those who have a recently acquired impairment. As the participants who engaged in team sports found, having the ability to discuss issues with peers who have had similar experiences has been very beneficial.

### **Implications for Future Research**

This study focused on the experiences of four young men from middle-class backgrounds who lived in an urban area. The experiences of emerging adults who are in the minority – specifically, young men and women of an Aboriginal or minority background, those from a lower socio-economic background, as well as those who live in northern or rural regions of Canada require a deeper exploration. A more focused analysis of the general experiences of Canadian emerging adults is also necessary. As well, specific research examining the intersection of emerging adulthood and impairment in Canada is needed in order to increase understanding and provide better support for individuals.

Further, researchers need to better understand the unique experiences of individuals with similar impairments. This study examined the experiences of four men living with a variety of impairments. More specific research, where each participant shares a similar impairment, would allow for a more nuanced understanding of certain

experiences of emerging adulthood. While the impairment is certainly not the most defining characteristic of one's transition to adulthood, exploring the stories of multiple individuals with similar impairments may allow for a better understanding of some experiences which may be unique to one's impairment.

The unique finding of positive perceptions of masculinity within the context of an acquired impairment should be further explored. Current research focuses on hegemonic norms of masculinity and the negative impacts an acquired impairment has on a man's perception of his own manhood. Researchers need to further explore sports as a mitigating factor in improving one's internal perception of manhood. In addition, more inclusive definitions of masculinity and manhood need to be better understood within the context of an acquired impairment. While this project begins to examine masculinity within the context of different impairments, this unique finding of positive feelings of impairment and masculinity requires deeper analysis.

The current literature on emerging adulthood has gaps when it comes to impairment. Researchers are trying to create an inclusive, broad definition of this developmental period but the experiences of young people with impairments remain invisible in this. This research project offers an example of including young people with impairments and suggests extending the duration of emerging adulthood in definitions of emerging adulthood. While individuals with impairments may eventually complete the developmental tasks of emerging adulthood, they may accomplish this at a slower pace. For example, they may continue to live with their parents and accept financial support for a longer period of time. They may also maintain a closer relationship with their parents

throughout their twenties. Developing intimate relationships may also be delayed for individuals with an acquired impairment.

Based on this research, it was not possible to determine if other developmental tasks may possibly be accomplished at a faster pace. Regardless of a developing at a slower or faster pace, implying that these experiences are against the norm creates a social barrier as individuals may feel they are not keeping up with their peers, which may lead to increased stress and social ostracization.

### **Conclusion**

The central research question guiding this study was “How do men with an acquired impairment experience emerging adulthood?” By talking to four men in an urban center in Canada, I was able to gain an introductory understanding of how men with varied impairments experience emerging adulthood. I explored various aspects of their lives, including relationships with family and friends, intimacy, work and school, focusing on ways that they navigated social or structural barriers. I also explored the topic of masculinity in order to better understand how men with acquired impairments perceive masculinity during emerging adulthood.

Multiple findings within this study were consistent with current literature on emerging adulthood. Most importantly, the support of friends and family was integral to the well-being of the individual as he transitioned into adulthood. There were also findings that were somewhat divergent from the current literature. It is possible that there are some significant developmental tasks of emerging adulthood that may be slightly delayed when experienced in conjunction with an acquired impairment. These experiences challenge the standard understanding of emerging adulthood.

While the developmental tasks of emerging adulthood are common to young men with and without impairments, the timelines prescribed in the emerging adulthood literature are challenged when emerging adulthood is experienced within the context of disability. Individuals may take more time to complete various developmental tasks of emerging adulthood, including leaving the family home and starting an intimate relationship. As well, the literature on the level of family involvement is challenged by the findings in this study – individuals may continue to rely on the support of family members long into emerging adulthood.

The current literature on emerging adulthood continues to render individuals with impairments invisible by not considering their experiences. The underlying message is that their experiences are not important or valued, and because they are different from what is described as the norm, they are identified as abnormal. This has the effect of increasing pressure on emerging adults who live with an impairment and asserts universality without addressing these diverse experiences. As they move through the developmental tasks of emerging adulthood while coping with an acquired impairment, these individuals are faced with an additional stressor as they feel pressure to live up to social norms and to move through this developmental period independently within a prescribed timeline, based on the standard understanding of emerging adulthood. This study suggests there is an opening for researchers in this area to address the experiences of individuals with impairments and increase their understanding of diverse experiences of emerging adulthood.

By exploring this topic within the context of the social model of disability, we can better understand the role that society plays in disabling individuals. The social model of

disability states that a person is not disabled by their impairment, but instead is disabled by the barriers that they face in society. By addressing these barriers, whether structural or social, stairs or a stare, individuals everywhere can work to reduce barriers and make our world far more accessible and accepting.

It is my belief that this study begins a conversation. First, there needs to be more research that explores the multiple experiences of emerging adulthood. Men living with an acquired impairment are one example, but there are multiple unique populations in Canada in which a better understanding of their experiences of emerging adulthood is necessary. Second, by acknowledging that emerging adulthood is a unique developmental task, I implore service providers and programs to create well-tailored supports for especially for men with acquired impairments. Third, by recognizing the importance of family and friends during this time, I hope that men in emerging adulthood are able to ignore any societal pressure to move away from their support network before they are ready and to accept the love and support from their family as they move through this time in their lives.

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# Appendix A

## Consent Form



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### Consent Form

**Project:** The Experience of Emerging Adulthood in Males with an Acquired Impairment

**Researchers:** Ginelle Giacomini, Masters Student ([ginelle@live.ca](mailto:ginelle@live.ca)), Family Social Science,  
Human Ecology

**Approved by:** University of Manitoba Joint Faculty Research Ethics Board

**Complaints:** Human Ethics Secretariat, 474-7122 ([margaret\\_bowman@umanitoba.ca](mailto:margaret_bowman@umanitoba.ca))

**This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.**

I am doing an exploratory study, learning about the experiences of emerging adulthood for young men with an acquired impairment. Emerging adulthood is a term that describes a life stage, typically experienced by those between the ages of 18-25. The focus of this research is the potential barriers, opportunities and innovations that males with an acquired impairment may experience during emerging adulthood.

The interview should take between one to two hours. However, if you have a lot of information to share, it could take longer. I will ask you basic questions about your background, family, and your impairment. I will then ask you about any specific barriers, opportunities and/or innovations that you have encountered during emerging adulthood. I am also interested in the impact of your impairment on your friends and family as well as your use of services in the community.

You are volunteering to participate so you can stop the interview at any time and you are free to **not** answer any question you don't want to. All information will be kept confidential. Only my research supervisor and I will be able to see your responses related to your name.

The information you give will be combined with the information collected from other interviews. Once all of this information has been collected and analyzed, I will create a final report. After I transcribe your interview, I will send you a copy of the transcript, via email or mail, in order for you to verify its accuracy. As well, I will send you a copy of the themes that emerge, via email or mail, to allow you the opportunity to provide your comments on these themes. If you would like a copy of the final report, one can be sent directly to you following the completion of this project.

Your signature on this form indicates that you have understood the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. If you have any questions please contact Ginelle Giacomini ([ginelle@live.ca](mailto:ginelle@live.ca)) at any time.

This research has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-7122. A copy of this consent form has been given to you to keep for your records and reference.

I \_\_\_\_\_ (print name) understand what the study is about and what participation involves and the signature below means that I agree to participate.

\_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(date)

\_\_\_\_\_  
(Signature of Interviewer)

\_\_\_\_\_  
(date)

In order to verify accuracy of both the transcripts of our interview and the themes which may emerge, I would like to send you copies of both over the next few months. Would you like to review these documents and provide feedback if necessary.

YES  NO

I anticipate that the final report will be available at the end of August, 2013. Would you like a copy of the final report?

YES  NO

If yes for either question, please indicate how we can send the material to you:

E-mail: \_\_\_\_\_

or

Mailing Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## Appendix B

### Interview Guide

Name

Age

Date of Acquired Impairment/Diagnosis

Length of time since Acquired Impairment/Diagnosis?

Where are you currently living? Is this where you were living before you were impaired?

What is your relationship status? What was it before you were impaired?

Tell me a little about your support network – you family and close friends.

#### Research Questions

These questions are tools and guidelines to seek out your personal experience of going through emerging adult while living with an acquired impairment. Any information that you feel free to share that is not addressed in the questions, please do so. You are welcome to decline answering any question or end the interview at anytime without explanation.

→ Have there been any important changes in your life with regards to your impairment?

→ During your late teens/early twenties, how did having an acquired impairment impact your daily life?

-work?

-school?

-family?

-social life?

-romantic life?

*Probe:*

*Have you experienced any barriers or challenges, living with an acquired impairment?*

→ Have there been any unique opportunities that you have experienced when compared to your friends who do not have an acquired impairment?

→ Can you give me an example of anything that you have had the opportunity to learn or do since you have acquired an impairment?

→ I am interested in not only what causes problems and barriers, but also how these issues are creatively solved. What sorts of innovations have you, your family, and/or your friends created or developed in order to adapt to your impairment?

*Probe:*

*Have you or your loved ones adapted anything or have approached something, an activity, a daily task, going out with friends, or dating, or work and school in a new way?*

→ Can you tell me a bit about how you think your friends and family dealt with the changes in your life/your impairment?

→ What sort of dreams and goals do you have? Have your dreams and plans for your future changed since your impairment? If so, why/what has caused this?

→ What does “being a man” mean to you?

*Probe: Does your acquired impairment impact your sense of being a man?*