

## ABSTRACT

### Identity and Meaning in an Unimagined Future: The Effects of Life-Altering Physical Disability Acquired During Emerging Adulthood

Katherine McCullough

Director: William G. Hoy, DMin, FT

Emerging Adulthood is the term that developmental psychologists use to describe the stage of life in between adolescence and adulthood. During these years, individuals determine their core values and find their place of belonging in the world. These years are typically viewed as those with individual's highest level of beauty, physicality, and opportunity. Young adults do not imagine what their current lives would look like if they had a physical disability, something that seems to belong in a different category than youth. There is, however, a space where disability interacts with young adulthood that has yet to be fully investigated. I conducted a Grounded Theory study in order to explore ways that individuals cope, learn, and achieve with physical disabilities when they are developed during emerging adulthood. Through a series of semi-structured interviews, I gathered data directly from thirteen individuals who developed a life-altering physical disability between the ages of seventeen and twenty-nine. Through the use of constant comparison between my field notes and current literature, three major themes emerged: How does this experience change me? How does this experience change others? and How do I find meaning in this? In this thesis, I explain how these themes relate to this particular experience of disability, and I offer a unique lens with which to view the interaction of disability and young adulthood.

APPROVED BY DIRECTOR OF HONORS THESIS

---

Dr. Bill Hoy, Department of Medical Humanities

APPROVED BY THE HONORS PROGRAM

---

Dr. Elizabeth Corey, Director

DATE: \_\_\_\_\_

IDENTITY AND MEANING IN AN UNIMAGINED FUTURE: THE EFFECTS OF  
LIFE-ALTERING PHYSICAL DISABILITY ACQUIRED DURING EMERGING  
ADULTHOOD

A Thesis Submitted to the Faculty of  
Baylor University  
In Partial Fulfillment of the Requirements for the  
Honors Program

By  
Katherine McCullough

Waco, Texas

May 2020

## TABLE OF CONTENTS

List of Tables .....	iii
Acknowledgments .....	iv
Dedication .....	vi
Introduction .....	1
Chapter One: Grounded Theory .....	6
Chapter Two: How Does This Experience Change Me? .....	18
Chapter Three: How Do Others Respond To This Experience? .....	38
Chapter Four: How Do I Find Meaning In This? .....	55
Chapter Five: Conclusion .....	68
Appendices .....	76
Appendix A: Notice of Exemption from IRB Review .....	77
Appendix B: Consent Form for Research .....	78
Appendix C: Confidentiality Procedures .....	80
Appendix D: Semi-Structured Interview Guide .....	81
References .....	82

## LIST OF TABLES

<b>Table 1.1.</b> Profiles of study participants .....	15
--	----

## ACKNOWLEDGMENTS

I would like to thank the following people whose support was paramount to my completion of this study.

To Dr. Hoy, thank you for guiding me through my study and the thesis process. Without you, I would not have been able to learn the things I did and hear the stories of many incredible people. Your encouragement, steadfastness, and positivity brought me to the finish. I am grateful for your time, your effort, and your trust.

To Dr. Whitt, thank you for sharing your wisdom with me as I was grieving my own loss. Your intentional advice gave me courage to tell my own story and use my experiences to explore this unique topic.

To Dr. Nuner, thank you for being a part of my committee and giving me your thoughts and advice. Having you as an ally gave me motivation and guidance.

To Dr. Beck, thank you for being a constant encourager of every single honors student. Your overflowing support gave me strength to persist and work hard.

To my parents, thank you for creating a space for me to finish my thesis. You let me take over the dining room and eat all your snacks, and I could not have done this without you.

To my friends, thank you for going through this process with me. You showed me that I was not alone and loved me for being me. I am so proud of us and blessed to have you in my life.

To my study participants, thank you for trusting me with your stories. Your hardships, joys, losses, and gains have taught me about goodness and purpose in life. You have shown me how to live well and own my experience, and I am forever changed.

## DEDICATION

To all those whose lives are upended by disability – there is a future for you full of love,  
joy, and meaning.

## INTRODUCTION

When someone says the word “disability,” certain images are more likely to appear than others; an image of an elderly person in a wheelchair at the end of life, a friend who has Down Syndrome, or a relative who has gone blind from diabetes. Another image that might appear is that of a child in a power wheelchair or confined to bed. Without a personal experience with disability, these images are probably the extent to which one’s mind would venture when asked about the topic; this is true of myself. It is easy to explain the elderly having disabilities because they have lived long lives, for bodies wear out over time. It is more difficult to explain children and infants having disabilities because they have neither lived long lives nor worn out their bodies by use, but for those who are removed from disability, these explanations and justifications probably do not cause lasting concern.

A different category of disability that does not garner great attention in the minds of those who are unaffected is that which develops during young adulthood. In this case, individuals grow up believing their physical abilities to be stable and plan their futures on this belief, for why would this not be the case? Then the unimaginable occurs: a test result from the doctor, or an unexplainable accident, and futures and dreams seem to evaporate in thin air. The process of adjustment is necessary whenever one makes a life change, whether an intentional or unintentional change; people move between economic class, faith systems, occupations, and levels of ability every day. The development of a disability during young adulthood is a lot more difficult to discuss than getting a new job. Where there is a widespread acceptance for disability of the elderly and helplessness

regarding disability in children, there is a profound pity for disability of young adults. The themes of lost potential, lost beauty, lost wealth stand out in the few places where this subject typically arises: promotions campaigning against texting and driving or drinking and driving, news stories about traumatic accidents, or the occasional inspirational story parroting an individual who overcame the odds and learned how to walk again. Society and culture place an incredibly high value on youth, beauty, and physicality. When those things are ripped away, it leaves us with few words to say other than a remark on tragedy and loss incurred. It is a space that is rarely visited, if only to say a quick prayer in thanks that the victim was someone else. It is easy to live this way because disability seems far removed from youth, and youth that offers no space for it. This is how I saw myself in relation to disability until I realized that I had one.

Through an unfortunate set of circumstances, I did not receive my diagnosis of limb-girdle muscular dystrophy until I was a sophomore in college. Symptoms of muscle weakness began in middle school and progressed steadily onward. After seven years of receiving treatment for an autoimmune disease and pursuing second and third opinions, I submitted a blood test looking for gene mutations known to cause muscular dystrophy, and I was entirely convinced that they would come back negative. I knew that I had undesirable health problems but clung to the possibility that they would spontaneously remiss at a convenient time. The category of health issues that muscular dystrophy fit in was not one in which I wanted to belong. Needless to say, the shock was great when I received the phone call that changed my world. The positive changes such as stopping medications and infusions seemed to be worthless in comparison to the doomed life that lay ahead of me. I experienced much confusion and worry amidst deep identity issues

that plagued my thoughts and dreams. I sought advice and guidance from several mentors and searched for the answers to my questions of identity, how to cope with loss, how to accept myself, and how to pursue my dream of becoming a physician as a person with a disability. Life kept moving on, and I kept asking, searching, and reflecting.

One of my major sources of complaint was that of my youth; I was twenty years old and enrolled in college. Tough times can surely come at any time, but I was distraught because this diagnosis came too soon. I was too young to deal with such grief and loss of future; weakness and fragility were problems that belonged to the elderly, not to me. I found myself spending time in this uncomfortable place where disability interacts with young adulthood, a place where no one goes unless they have to. It dawned on me that there must be others who have had similar experiences and come through on the other side. I found the names of multiple people who had developed disabilities in young adulthood and currently lead the country in various political, humanitarian, and medical contexts, and this intersection of disability and youth no longer seemed as uncomfortable. I wanted to hear the stories of individuals like these and learn how others feel when they enter the world of disability as young adults. By turning my search outward, I would be able to seek personal instruction and, more importantly, find practical knowledge about disability that would benefit others.

Through the guidance of my mentors, I developed a grounded theory study that would let me explore this. While there have been studies concerned with life satisfaction before and after onset disability (Boyce & Wood, 2011; Hernandez et. al, 2014; Pagan-Rodriguez, 2010; Powdthavee, 2009), the effects of disability onset across the adult life span (Ifurna & Wiest, 2016), and the role of self-concept in adaptation to congenital and

acquired disability (Bogart, 2014), I was unable to find a study that described the experience of acquiring a life-altering physical disability during emerging adulthood. Most of the current studies are quantitative and focus on measures of life satisfaction and happiness or on a specific disability population such as those with spinal cord injuries. For this study, I conducted thirteen semi-structured interviews using a classic grounded theory approach to explore the way that life-altering physical disability acquired during emerging adulthood affects sense of self, pursuit of achievement, social relationships, and worldview. Individuals who fit into this population subset were interviewed because they have lived through the experience of interest.

By conducting a qualitative study of this complex and uncommon experience, I was able to discern three different lenses through which this population views the effects that life-altering physical disability has on their lives: the individual (how has this experience changed them), others (how this experience has others), and purpose of disability (how do they find meaning in this experience). These combine to form each individual's narrative about their disability and its role in their lives. In this thesis, I begin by discussing the background of the study and the methodology of grounded theory (Chapter One). I then discuss the three principles that characterize the data from this study: this experience changes the individual (Chapter Two), this experience changes relationships with others (Chapter Three), and this experience changes how meaning is found in life (Chapter Four). I conclude by addressing limitations of the study, summarizing the findings, and offering a practical way to approach this experience as someone who acquires a physical disability or a loved of someone who does (Chapter Five). The findings of this study offer components of this experience that can be studied

further both qualitatively and quantitatively to learn more about the ways that disability interacts with emerging adulthood.

## CHAPTER ONE

### Grounded Theory

In this chapter, I will explain the processes through which I conducted a grounded theory study to better understand the experience of acquiring a life-altering disability during the years of emerging adulthood. I will first address the gap in current disability research and then explain my study criteria. This is followed by an overview of grounded theory and an account of my study procedures.

#### *Background*

The published research about disability is substantial but incomplete. These studies are not difficult to find, but the focus of many is not concerned with individuals who have acquired disabilities during the years of emerging adulthood. There are some studies similar to the one proposed here as mentioned in the introduction; in addition, there is much interest in the literature about the transition into adulthood of children with disabilities (Mannino, 2015; Guo et. al., 2019; Stewart, 2009). Great effort has been spent on researching both children with disabilities and adults who acquire disabilities during old age; however, young adults who lived an otherwise “normal” childhood until young adulthood are under-represented in the literature. Interestingly, out of the 12.8% of the United States population that report having a disability, 7.3% percent of individuals between ages 5-17 have a disability (Kraus, 2018). 51% are between the ages of 18-64, and 41.4% are older than 65 (2018). No doubt the emotional significance of children with

disabilities contributes to interest in academia and research efforts; however, there is a compelling case for the relevance of acquiring a disability during the years of later youth. The differences between the experiences of individuals who grow up knowing their lives would be affected by disability and those of individuals who grow up not knowing their lives would be affected by disability could reveal much about the experience of adversity and the development of resilience. This study focuses on those whose lives began to be affected by disability in emerging adulthood, and the findings will likely contribute to existing literature about disability and broaden the depths of current understanding of disability.

### *Purpose*

The purpose of this study is to understand how the diagnosis of a life-altering disability affects emerging adults and how such individuals carry their burdens while pursuing success in a society of the able-bodied. Disabilities often have visible physical effects on individuals, but my intent has not been to limit my exploration of disability to physical challenges but to explore the experience of disability for the whole person. This includes both long-term and short-term effects on the body, spirituality, identity, worldview, community, emotionality, and sense of purpose.

There are several reasons why this research will be useful and relevant. This study will provide a healthy way to discuss disabilities with individuals who have them and those who do not. Discerning the positive and negative methods of communicating about disabilities will demonstrate the most effective handling of disabilities by medical professionals, families, and friends. This study will also offer explanations of the

resilience of human nature by hearing from those whose lives are drastically altered during a formative period of life. As this study discovers qualitatively how human beings overcome trauma and tragedy to not only find healing and identity but also serve and inspire the community, stigmas about disabilities can be disbanded in favor of common humanity in the midst of disability. Finally, other individuals who find themselves in similar situations will be able to grasp onto methods of coping, healing, and pursuing goals by finding their new normal and truly living.

### *Emerging Adulthood*

This study investigates the effects life-altering disability has on individuals when the disability is developed or diagnosed during the years of emerging adulthood because of the foundational nature of this stage of development. Emerging adulthood is a relatively new term in developmental psychology. The cause of this is likely due to demographic trends in the ages of people marrying and having children (Arnett, 2000). These life changes are postponed and create a gap between adolescence and young adulthood in which people have much freedom and flexibility to explore different directions of life. Demographic characteristics of people in their late teens and early twenties are difficult to predict, whereas there is little variation in demographic trends before and after this age range (Arnett, 2000). Varied demographics, as well as identity explorations are two of the key characteristics of emerging adulthood. Identity, goals, relationships, and belief systems are in flux the most during emerging adulthood (Arnett, 2000). Opportunities and experiences that occur during emerging adulthood greatly affect the trajectory of life into young adulthood (Wood et al., 2017). This makes emerging

adulthood a critical stage in development, and adversity during emerging adulthood will affect life directions and self-concept.

Of note, emerging adulthood is not a developmental period that is experienced by people universally, but “exists only in cultures that postpone the entry into adult roles and responsibilities until well past the late teens” (Arnett, 2000, p. 478). This indicates it is most likely to be experienced in countries that are postindustrial or highly industrialized (Arnett, 2000). Higher levels of education are expected in such countries, and education is usually completed before marriage and parenthood. This postponement allows for the exploration of identity, worldview, and relationships and contributes greatly to sense of self upon entering adulthood. The characteristics that contribute to emerging adulthood are not specific ages but rather the life events that occur most frequently at a point in life. As a result, there is some disagreement about the age range of emerging adulthood. Some consider it to be from eighteen to twenty-five (Arnett, 2000), while other consider it to be from seventeen to twenty-nine (Wood et al., 2017). I adopted the latter view of emerging adulthood because this afforded me a larger sample size.

The critical nature of emerging adulthood makes it an attractive population to study when isolating individuals who acquired a disability during it. The recent recognition of this developmental stage contributes to the small sample of literature on this topic. Any individual who developed a life-altering disability between the ages of seventeen and twenty-nine was considered appropriate to interview in this study. The age of the participant at the time of the interview did not influence their eligibility to participate because all participants were over the age of eighteen at the time of the

interview. People with disabilities of all types were welcome to participate in this study: any disability that was considered “life-altering” to the individual fit this criterion.

### *Grounded Theory Method*

#### *Overview*

Barney G. Glaser and Anselm L. Strauss developed the grounded theory method of qualitative research and first published a description of this methodology, *The Discovery of Grounded Theory*, in 1967 (Glaser & Strauss, 2017). Grounded theory is now the predominant method of qualitative data analysis in many disciplines and subjects (Bryant & Charmaz, 2007). Glaser and Strauss define grounded theory as “the discovery of theory from data” and, at its inception, knew grounded theory had great potential to benefit sociological research (Glaser & Strauss, 2017, p. 1). They believed that the adequacy of a sociological theory could not be separated from the methodology from which it was produced. In discussing the historical movement from qualitative methods of research to quantitative methods and from the generation of theory to the verification of theory, they hold the following:

*In many instances, both forms of data are necessary—not quantitative used to test qualitative, but both used as supplements, as mutual verification and, most important for us, as different forms of data on the same subject, which, when compared, will each generate theory (Glaser & Strauss, 2017, p. 18).*

There was previously not a standard method that allowed for both qualitative and quantitative research to positively interact and contribute to theory, and Glaser and Strauss believed that there should be a place for this to happen.

Grounded theory is well-suited for exploring social movements and phenomena that have not previously been studied thoroughly because it develops a theory from data rather than verifying a previous theory. The primary sources of data in grounded theory studies are people, and the data is collected through a series of semi-structured interviews in which the participant shares their experience about the topic of interest. Secondary sources can include academic literature, texts, websites, blogs, videos, newspapers, among other things: “Glaser’s constant refrain has always been ‘all is data’” (Bryant & Charmaz, 2007, p. 44). Glaser and Strauss call for analysts to enter their studies without extensively reviewing literature to prohibit preconceived notions from distorting the developing theory (Glaser & Strauss, 2017). While acknowledging this is sound, Bryant and Charmaz admit the practical inability of researchers to do this: “An open mind does not imply an empty head...A researcher can account for these [preconceived] ideas in some way, but certainly should not simply ignore them” (Bryant & Charmaz, 2007, p. 20). Rather than trying to empty her head of all relevant experience and knowledge, the researcher should postpone reviewing relevant literature until the theoretical framework of the study has been built (Stern, 2007). This “completes and enriches the research. Rather than verification, your job is to demonstrate how your work *adds* a new dimension, an element that heretofore was unknown” (Stern, 2007, p. 123).

Glaser and Strauss had disagreements about grounded theory methodology in the 1980s which led to them splitting in their methods of grounded theory (Bryant & Charmaz, 2007). This study adheres to the classic approach to grounded theory as outlined in *The Discovery of Grounded Theory* (Glaser & Strauss, 2017). Jane C. Hood

describes the seven major principles of Grounded Theory as established in *The Discovery of Grounded Theory* as follows:

- 1) A spiral of cycles of data collection, coding, analysis, writing, design, theoretical categorization, and data collection.
- 2) The constant comparative analysis of cases with each other and to *theoretical categories* throughout each cycle.
- 3) *A theoretical sampling process based upon categories developed from ongoing data analysis.*
- 4) The size of sample is determined by the ‘theoretical saturation’ of categories rather than by the need for demographic ‘representativeness,’ or simply lack of ‘additional information’ from new cases.
- 5) The resulting *theory* is developed inductively from data rather than tested by data, although the developing theory is continuously refined and checked by data.
- 6) Codes ‘*emerge*’ from data and are not imposed *a priori* upon it.
- 7) The substantive and/or formal theory outlined in the final report takes into account all the variations in the data and conditions associated with these variations. The report is an *analytical product rather than a purely descriptive account. Theory development is the goal* (2007).

### *Choosing Grounded Theory*

Grounded Theory was deemed to be the most appropriate method of research to study the set of experiences I was interested in exploring. First, grounded theory is

suitable for researching areas where little research has yet been conducted. In my preliminary work, I found that there was not substantial work in the topic of onset disability in emerging adulthood. Rather than looking toward existing literature as the primary source of information, grounded theory looks toward people who have experience in the area of interest. This was another benefit to using grounded theory; it allowed me to directly hear the stories of those from whom I wished to learn. Additionally, grounded theory allows the incorporation of relevant sources of any type, whether biographies, studies, textbooks, videos, poetry, etc.; widening the pool of contributing information strengthens the developed theory and enriches conversations with participants. Grounded theory allows interviews to be conducted via phone calls, so I was able to gather data from a geographically diverse set of participants as a full-time college student. The most appealing characteristic of grounded theory to me, however, is that it provides practical and relevant theories about people and their experiences due to the unique methods of collecting data. Stern says,

One essential quality of true grounded theory is that it makes sense; put simply, the reader will have an immediate recognition that this theory, derived from a given social situation, is about real people or objects to which they can relate (Stern, 2007, p. 114).

The process by which grounded theory was used to develop theory in this study is outlined in the following section.

### *Methodology*

In this section, I describe the methods I used to recruit participants, collect data, and synthesize data according to the classical grounded theory approach.

### *Recruitment*

This study had a sample size of thirteen participants. Due to the well-known status of some of these individuals, some details are omitted (such as cities of residence). Subjects were recruited to this study through various means, including direct email invitation and snowball sampling. To recruit potential participants to this study, I composed an email describing the study objectives and methods with an opportunity for response. I contacted personal acquaintances first and recruited additional respondents by asking participants for recommendations to other eligible individuals. Other subjects were recruited using the snowball effect, or word of mouth recommendation. I asked colleagues and professors to share my email with their colleagues and personal acquaintances. Additionally, people of celebrity status with well-known disabilities were contacted. Contact persons were informed that they may personally participate or choose to decline an interview. Each of the individuals who participated were contacted using the methods described above. Participant characteristics are described in Table 1.1.

### *Data Collection*

The interviews were conducted between January 2020 and April 2020. This study was ruled exempt by the Baylor University Institutional Review Board (IRB) (Appendix A). Each participant signed a consent form (Appendix B) prior to the interview and were read the confidentiality procedures at the beginning of the interview (Appendix C). All of the interviews were held via phone call, and the interviews were not recorded. Interviews last between forty and seventy-five minutes, and participants were asked to share

information about their experience with disability. I asked broad questions in order to allows the participants to simply tell their story and asked re-directing questions as needed to adhere to the study objectives. An interview guide was prepared for reference (Appendix D). In accordance with classic grounded theory methodology, interviews were not the only source of data (Glaser & Strauss, 2017). In this study, relevant academic literature, texts, videos, and websites were also used to collect data. Grounded theory incorporates both objective and subjective data in exploration of a specific experience in order to better understand it.

Table 1.1. Profiles of study participants

Sample size (participants)	13
Current home (state)	CA CO CT FL MA MI NC TX VA
Current age range (years)	23-76
Age range at time of onset disability (years)	17-29
Sex (respondents)	7 – Female 6 – Male
Disability	2 – Below-the-knee and arm amputations 1 – Dysautonomia/POTS 1 – Limb-girdle muscular dystrophy 2 – Lupus 1 – Lyme Disease 1 – Multiple sclerosis 2 – Paraplegia 3 – Quadriplegia

### *Constant Comparison: Coding and Memoing*

Throughout the interview process, I coded my field notes in accordance with the constant comparative method of classic grounded theory. This allowed me to learn phrases and terminology that were useful in further interviews, modify several questions to better convey my intentions, and add questions about different issues my participants raised. The process of coding involves examining and annotating field notes to discern categories observed and comparisons between them (Glaser & Strauss, p. 106). Eventually, categories are coded for multiple times and the analyst should write a memo of her ideas. Stern says, “Making memos is a process the analyst uses to keep track of what they think about the data” (Stern, 2007, p. 119). By memoing, I discovered patterns describing similar incidents (events, emotions, and changes) in the experience of my participants.

As the interview process progresses, incidents from interviews are then compared to memos and categories from prior interviews, and “the diverse properties themselves start to become integrated” (Glaser & Strauss, 2017, p. 109). Memos fill categories, and categories become the major themes of the developed theory. As this process continued, I approached the point of theoretical saturation:

After an analyst has coded incidents for the same category a number of times, he learns to see quickly whether or not the next applicable incident points to a new aspect. If yes, then the incident is coded and compared. If no, the incident is not coded, since it only adds bulk to the coded data and nothing to the theory (Glaser & Strauss, 2017, p. 111).

At this point, new interviews do not create new categories. They supplement existing categories and provide further support, but when the analyst reaches theoretical

saturation, the interview process is complete. The remainder of this thesis describes the developed theory from my interviews.

### *Conclusion*

In this chapter I outlined the purpose of my research and specified the subset population of interest. I gave an account of grounded study research and demonstrated that I followed the classical grounded theory approach in coding my data, memoing, and developing theory. The theory that emerged through this process is discussed in the subsequent chapters.

## CHAPTER TWO

### How Does This Experience Change Me?

There are many obvious changes that occur to individuals of any age when they develop a disability. Amputation, paralysis, degenerative disease, and neurological disease affect methods of transportation, mobility, eating, talking, working, exercising, and socializing, among other things. Throughout my interviews, different types of change were discussed at length. While several participants referenced specific things that changed about their bodies and the things they do, I also heard several ways their identity changed after acquiring a disability. Acquiring a disability during the years of emerging adulthood changes one's perspective of the world for a variety of reasons that I will explain in this chapter.

According to Elizabeth C. Salick and Carl F. Auerbach, "researchers have suggested that posttraumatic growth is produced by processes of cognitive reframing, including reevaluation of negative self-perceptions related to disability, developing a future orientation, and developing perceived control over one's illness or disability" (2006, p. 1022). Many of my study participants described these processes occurring in the years following the onset of their disability. The patterns of change that I discovered during the interview process include a grieving process during which the disability is manifested and recognized, a new perspective of identity, a determination to live in the present, a relinquishment of control, and a transformation of goals and purpose.

### *Grieving Process*

Although the most common experience grief is associated with is the loss of a loved one, grief is something experienced by a wide variety of individuals. As I inquired into the circumstances of accidents and diagnoses, I was reminded multiple times of the loss that follows the inception of disability. I spoke with participants who grew up wanting to be doctors, businessmen, and architects and with participants who were not quite sure who they wanted to be. They enjoyed physical activities such as rock climbing, hiking, dancing, traveling, and running. Freedom is newly actualized in young adulthood, and disability can take this away in several respects. Recognizing the potential loss of future milestones because of a disability causes grief. A qualitative study of the experience of individuals' after a spinal cord injury recognized that a core experience of a spinal cord injury is "finding a way to cope" and outlined a grieving process that several participants followed (Chuang, 2015). It is important to note, however, that grief affects people differently, and its trajectory often depends on the circumstances surrounding the loss.

### *Timing*

The timing of grief as I learned from my participants can be greatly affected by the specific type of loss and illness. Some told me that they were so sick or sedated at the onset of disability that they did not understand what was happening to them. When this was the case, family members were greatly affected by the loss. One participant who had broken his back in a rock-climbing accident kept telling his visitors about the great bouldering spot he had just discovered, not realizing what had happened there. This

caused his family so much distress that his mother demanded that one of his surgeons to come explain his injury to him. This participant had no emotional response to the news that he would never walk again until several weeks later in rehabilitation. An occupational therapist was guiding him through moving from his wheelchair to a shower bench, and he burst into tears as he truly recognized the ramifications of his paralysis. In a qualitative study examining the experience of young people following a major injury, Rebekah Ogilvie et al. noted a similar onset of the reality of injury by doing simple, daily tasks: “I was ok, and then it hit me!” (2015, p. 1843).

One participant told me that the constant stream of visitors and support during his rehabilitation period did not allow him to have a grieving process at the onset of his disability. He did not mind the attention and was grateful for the support. Twenty years later, as his new wife took on the responsibilities of caregiving, he fully recognized the reality of his disability because of the hardship his wife was experiencing. He finally allowed himself to grieve his losses and spent much time wrestling with his decision to get married; he loved his wife, and consequently, did not want to put her in a situation that was more than she could handle. As he and his wife went through this together, they discovered an online community of couples in similar situations and learned that they were not alone in their grief. This community gave them tangible ways to heal and cope with their losses.

### *Action-Orientation*

A common way to regain control in the wake of disability is to distract oneself from worrying about the future, and this is relatively easy to do by focusing on the needs

of one's body. Learning how to manage symptoms and absorbing oneself in rehabilitation were ways that my participants were "action-oriented." Rehabilitation is a time and place full of goals and people encouraging patients to do things. Figuring out a new normal and exploring bodily capabilities help individuals heal and adjust. For someone who has been told by health care professionals of many things he cannot do, it is encouraging to spend time in rehabilitation with others who help teach him how much he can do. This shifts the focus to the present and has significant effects on healing and processing the situation; the same phenomenon of distraction as a coping mechanism to avoid feeling overwhelmed has been recognized elsewhere (Ogilvie et al., 2015). Boredom is often described as painful and isolating, especially because it is more difficult for this population to go out and find things to do when they are still hospitalized. Service dogs are another helpful tool in healing. One participant shared that it was incredibly empowering to him to have a responsibility over another creature. It turned his focus outward instead of inward, and the constant presence of a friend who does not look at him differently because of his disability is comforting.

### *Accepting the Body, not Denying It*

Another part of the grieving process following the development of a disability is learning to accept one's body. Denial was not a significant part of the grieving process for the individuals I interviewed, which may be due in part to the visible manifestations of their disabilities. One participant said "It was easy to accept. I could just look down and see that my legs were gone." Some qualitative studies, however, have found that denial is a part of the grieving process after acquiring a physical disability (Chuang et al.,

2015). Accepting one's body is useful because it allows individuals to move towards their next step, whether that was rehabilitation or symptom management. Another participant said, "The goal [of rehabilitation] wasn't to overcome my body" and explained that he spent that time exploring and practicing the things he could do. Acceptance does not always come easily, and some can experience cognitive dissonance when trying to accept this new reality. One participant grew up on a farm and was accustomed to seeing dear and beloved animals euthanized when they became injured. She had a difficult time understanding why others were spending so much effort in keeping her alive when her body was broken. This participant struggled to accept her body until she survived a case of pneumonia that she did not expect to; when she realized that she would live through the illness, she decided she needed to "work on living and not on dying" and learn to love herself.

The processes of grief, healing, and accepting oneself follow no specific timeline or order, but each is affected by one's past experiences, family, and close community. Several participants told me how important their faith was during the uncertain time following the development of their disability. Trust in the sovereignty of God's will helped some find peace, comfort, and acceptance of their situations.

### *Regaining Confidence*

Finally, it became apparent that the growth of confidence occurred towards the end of the grieving process. It takes a significant amount of time to grow confidence, and it is a clear mark of accepting one's body and accepting the love and support of others. This idea is closely related to how individuals with acquired physical disabilities interact

with others following the onset of disability, which will be discussed in Chapter Three. Confidence, no matter its strength, is a big component of making new friends and re-integrating into society. Grief does not only come at the onset of disability but can also appear at important milestones in life. Although individuals come to terms with their disability and regain confidence, the process of grief impacts one's identity deeply. Disability becomes another attribute that makes individuals unique, and it affects how one makes meaning in life.

### *Identity*

There is great variation in the impact disability has on identity. Some reject labels, while others embrace them. The ways that disability shapes individuals are largely related to meaning making, which will be discussed in Chapter Four. Although my participants never used the word "resilient" to describe themselves as they transitioned into a life with disability, I believe that resilience is the trait that brings individuals to the acceptance and embracement of a life with disability, whether it is formally recognized or not. Resilience can be described as "an individual's capacity for adapting to change and to stressful events in healthy and flexible ways" (Catalano et al., 2004, p. 102). The following sections illuminate the many ways that individuals become resilient as they learn to adapt to acquiring a disability. The major patterns that arose from my interviews regarding identity include the claim that disability is not "other," an inclusion of disability in one's identity, and an understanding of the universal nature of suffering and adversity.

*Life with Disability is not “Other”*

Each of the individuals I interviewed grew up as a person without a disability. Their identities and sense of belonging in the world were in the midst of being formed when they developed a disability. As a result, the process of becoming an adult was transformed, and these individuals have a unique perspective on who they are in relation to the world. The tie between current identity and past identity became clear, and several participants vocalized that they were no different than people who do not have disabilities. Disability causes pain and hardship; so do other things in life. Relationships change with disability, but they also change without disability. People of all walks of life ask, “Why is this happening?” and experience periods of hopelessness. Several of the questions that people with disabilities ask about meaning, belonging, and purpose are not exclusive to this population. Comparing themselves with others is not helpful or meaningful, but, rather, finding solidarity with all kinds of people is. One participant said, “Everyone has to take their body into account,” meaning that everyone has to plan ahead for the things they do. Some people have restricted diets, others have allergies. There is a great desire to not be placed in separate box from colleagues and friends, and, furthermore, many participants expressed a keen dislike of pity. Pity makes one feel bad about being “other,” and it certainly does not empower an individual who is trying to accept their body and its limitations.

Another realization that surfaced was that one who acquires a disability becomes more aware of how many people in the world have problems. Rather than diminishing one’s disability, this helps dissipate the feeling of being “other.” When asked about

completing a medical residency while in a wheelchair, one participant said that it was a difficult training, but he was “surrounded by people with problems...The wheelchair wasn’t the hard part.” Another participant, also a practicing physician, echoed this by describing how unhelpful and unfair it would be to compare his experience in training to those who did not have disabilities. This kind of comparison shifts the focus to an unnecessary place and does not make anything easier. To “own your experience,” one must allow oneself to use personal experience with disability to become more receptive and observant of the pain and trials of others while refusing to allow the disability to isolate oneself from others. Disability allows individuals to have a unique perspective on life and the body, but it does not cast individuals to a separate category of people. Participants mentioned how they developed a true sense of empathy that they were able to use when interacting with others. Individuals who look different and do not want to be classified as “other” report that they accept people more easily and do not assume to understand of the sufferings of strangers.

### *Resilience*

Different people adapt in different ways to disability, and there are several healthy ways to view oneself with respect to disability. Resilience, the capacity to adapt, can be measured both internally and externally (Wood et al., 2017). In this section I discuss the changes to self-concept, a measure of internal adaptation that my participants described. I frequently heard phrases such as “I am the same person I was before” and “This is part of who I am but not everything I am.” Christopher Reeve, a prominent figure who became paralyzed at the age of forty-three, titled his autobiography, *Still Me* (Reeve, 1999). One

participant said, “Life is not better or worse [now],” life is just different. People with acquired physical disabilities do not want others to view them as completely different people because this is isolated and misrepresentative of identity after disability.

The idea of “disability concept” comes easier to those with congenital disabilities, but it is still important for those with acquired disabilities to adapt their sense of self to include disability (Bogart, 2014, p. 14). A different study examining identities of cancer patients diagnosed during late adolescence and young adulthood affirms the positive effects identity can have on adaptation. Patients who viewed themselves as a “survivor” and part of the cancer community were correlated with more positive adjustments (Cho, 2014, p. 602). This is similar to the concept of disability identity; being a “survivor” does not ignore the reality of the disability, nor does it focus on victimhood. Instead, it draws on experience and enforces the ability to persist.

No one gets to decide what one’s identity ought to be other than the affected individual, and the process of discovering this may take a long time. One participant hates the word “disability” and prefers to be seen as “someone who sits rather than stands.” This is not a statement of denial but rather one where an individual is declaring a right to determine his identity. There is much to be said about word usage in the world of disability and connotations that come with verbiage, but that will not be discussed here. Another participant used art as a method to figure out “how to belong when you look different.” By spending time with the concepts of visual effects, raw materials, and human perception, he was able to apply these concepts to himself. A prominent pattern I discovered was that once an individual adopted disability into his or her identity, it was

then utilized as a tool to help others, which is an incident that is closely related to meaning making.

### *Living in the present*

Another prominent pattern that surfaced during my interviews was the necessity of living in the present. Human lives are ever focused on the future; children are sent to school to learn so that they might attend higher education. Students attend university so that they might get good jobs. People work so that they might earn money to support a family, perhaps enough money to send children to go to school, and it starts from the beginning. Developing a disability during emerging adulthood stops this cycle, at least momentarily. Many questions arise about the feasibility of continuing education, whether high school, under-graduate school, or graduate school, not to mention questions about getting married, having a family, and earning money. These questions tend to lead to fear and worry about the unknown, and this does not provide a positive coping strategy. It became clear in my interviews that living in the present requires individuals to not dwell on the future, focus on concrete steps, and accept one's circumstances.

### *Shifting the Frame*

Rather than dwell on the past or the future, shifting the frame to focus on the present is the healthiest way to live. There is no determined path that all disabilities follow; even degenerative diseases vary in how they affect individuals. Dwelling on the future leads to fear and doubt, and the better one is able to cope with loss and develop identity in a meaningful way, the more one's attitude moves from the fear of the future to a

determination to live in the present. One participant shared how she no longer focuses on what she may be able to do in the coming days but focuses on the present day: “And I will do what I can right now.”

### *Concrete Steps*

An effective way to change one’s perspective to the present is to focus on concrete steps. Humans are excellent at adapting to circumstances and have been for a long time. Acquiring a disability is an event that grows resilience, and rehabilitation guides many people towards this. Many people find that they can do a lot of the things they could do before their disability, even if it looks a lot different. For instance, one of my participants who practiced medicine figured out that she could conduct a physical examination of patients by sitting on the table beside them. Another participant continued working after being diagnosed with multiple sclerosis; she was the breadwinner of her family and had to keep working, and because of this necessity, she discovered that she could still work. Other participants found ways to go back to school and utilize the available accommodations. The importance of self-advocating becomes very clear in the education system. Schools may not have perfect accommodations, but using what is available and requesting necessary assistance opens access to public places, often for multiple people.

### *Engineering Solutions*

In addition, people who develop disabilities can still help others. Being a receiver of help does not prohibit someone from being a giver of help, and all of my participants figured out ways to do this. There is much room for creativity in this world to help

individuals adjust and adapt to disability. One participant loved to travel before his legs were amputated and discovered that being a wheelchair user did not prohibit him from going around the world. Although it became more difficult, he was able to offer advice and assistance to other wheelchair users who wished to travel. Fear can be debilitating, but the future for people with disabilities can be full of the things once hoped for. One participant attained her bachelor's, master's, and doctorate degree after acquiring a disability, and at the onset of her disease, she never imagined how much she would end up doing. When explaining the need to live in the present, she said, "Don't assume [you can't do something]. Try." Accepting one's circumstances is requisite to living in the present. Take each day by itself with respect to one's body, regardless of ability, and try new things.

### *Control*

Another pattern of change that surfaced from my interviews was viewing disability through a lens that recognizes the lack of control humans have. People generally like to have control, whether it is over their bodies or their situations. As emerging adults grapple with the loss of control over their bodies after developing a disability, many find a rather theological meaning through this. Humans have never really been in control, and everyone is dependent upon others to certain degrees. One participant referred to this as the "interdependence" of humans. It is of great comfort to know that God, who is sovereign, good, and gracious, has ultimate control over the universe. Another participant drew an analogy from our dependence on God to her newly realized dependence on others. Relying on others because of a disability ought not be humiliating or

embarrassing: everyone on this earth is dependent on its creator, whether they know it or not. Being more dependent in the flesh than others does not lower you amongst them. The three major lessons that come from the understanding of this include a focus on the things one can control, surrendering the things one cannot control, and having patience with one's body.

### *Letting Go of Control in a Big World*

Focusing on things that one can control is very similar to living in the present by making small steps, but it adds the recognition that each person on this planet is just a tiny piece of a bigger picture. Although small in comparison to the whole world, each person merits value and support and contributes necessary gifts to others. One participant, as he was explaining the importance of each person's gift, said to do the best you can, "That's all you can do." A person who wins a Nobel peace prize for discovering a sustainable way to grow food in Sub-Saharan Africa and thereby improves nutrition opportunities for millions of people is not of more value than the man who sits at the ticket office of the local museum. Another participant said, "We are not all meant to be superheroes. It is dangerous to think otherwise." Humans are limited and do not have the control that many think they have. If everyone believed that their only way to have value and give to the world is to win the Nobel peace prize, then no one would sell tickets at the museum. Furthermore, if the standard for success is to be a superhero with ultimate control, those who lose some of their control, such as those who develop disabilities, will become useless in both their own eyes and the eyes of others. Through my interviews I heard several times over that those who develop disabilities are not, in fact, useless, but

rather have incredible and meaningful gifts to offer to others. So, the standard cannot be ultimate control.

### *Surrendering*

When one is able to recognize that control is largely an illusion whether one has a disability or not, it becomes easier to surrender things. Surrendering physical ability is a part of the grieving process but also leads to a surrendering over the control of one's future. A participant in a similar study said, "I kind of wish that the accident was my fault, like if I'd done it deliberately I could kind of think that I had some control over that, but now I'm like, that can just happen" (Ogilvie, 2015, p. 1843). No one knows the future, and no one can control everything that will happen. One of my participants said that "Disability is inevitable," and another said that "Life is degenerative." Once someone surrenders control, he can open his mind to learn from circumstances with a perspective not hindered by a false idea of control. It is then possible to learn what true grace and freedom are.

One participant described how she used her faith to surrender control and explained how the grace of God has the power to endure insurmountable pain and persist through tumultuous waters. It gives strength to those who have none and possesses the control that people believe they alone possess. One of my participants told me how free she felt after being diagnosed with lupus. She discovered the relationships that were worthy and good, and she relinquished herself from the high expectations of others. Others responded that they developed a newfound sense of freedom, a rather surprising finding because of

the noted lack of freedom associated with disability. For some, the fog is lifted as the truly important things in life are revealed.

### *Patience*

Finally, as one learns to surrender control over their body and accept their present circumstances, one also learns how to be patient with one's body. Physical ability is not a measure of value even though popular culture, media, and sports culture indicate that it is. Character is a far better measure of value, and it is sharpened and developed by adversity. No one is excluded from value by virtue of physical ability. One participant told me that she has realized that "health is not an end," no matter how much modern medicine treats it so. Those who make health an end are likely closer to vanity than to virtue. Health is a means to achieve certain ends, but, many times, similar ends can be achieved by different means, as discussed earlier. Without certain physical abilities, individuals can still become doctors, teachers, counselors, travelers, parents, and politicians, to name a few things. It may not look the same, but that does not mean it has less value. Having patience with one's body, abilities, and lifestyle allows one to turn one's focus outward.

### *Transformation of goals*

This section discusses the ways that individuals adapt externally to acquiring a disability. Measuring resilience in this way reflects "how well a person navigates and achieves the developmental tasks presented by the external world" (Wood et al. 2004, p. 8). This includes development in education, relationships, and careers. One of my

participants who recently retired from practicing medicine told me of the assumptions people frequently make about her and people with disabilities in general. Among these assumptions were “poor” and “unemployed.” Perhaps, the root of the assumption that people with disabilities are unemployed comes from “disability insurance,” or Medicaid; regardless, it is important to support those who cannot work because of disabilities, but it is also important to recognize that many people who have disabilities can, and in fact do, work, volunteer, and give their time to others. Participants in my population of interest were either in high school, college, graduate school, or the workforce when their disability developed. After the onset of disability, many of them continued along the same paths on which they had started. Some modified their career pursuits because of symptoms and physical needs, while others changed their goals because of the things they experienced and saw in the world as a person with a disability. Patterns that emerged from the transformation of goals include using personal experience as a strength, modification of career, and reacting to the needs of the disability community.

### *Disability as Strength*

After individuals who develop a disability process the changes in their bodies and find a new normal, many become determined to use their experience with disability as a strength. One participant said that his disability re-oriented his value system so that his focus turned outward. He not only uses his medical training but also works with health-technology companies to research virtual care and the ways in which it might benefit certain medical populations. Another participant, whose career goal changed completely, shared with me how “All the aspects of the past lead to the future.” The experience of

navigating the world in a wheelchair, combined with a love for learning and a passion for leading, led him to his future. It was often said, through various phrases, that “I would never have done these things if I never had a disability.” Rather than discussing how much they wish this had never happened to them, each talked about all the things that they have learned through their experience with disability and, in turn, been able to use to help others. It may not have been the future of which they desired or dreamed, but it is one that does offer joy and purpose. One participant who works as a counselor said that she was able to help others “own their experience” in a way that she was not able to at the onset of her disability. Her interactions with the healthcare system showed her the importance of receiving others’ stories as truthful and has been able to guide her patients in a unique way because of this.

### *Approaching the Future*

Developing a disability does not necessarily end one’s career, ability to make money, or worth. People experience change every day, and these changes can affect dreams and goals. Functional limitations can affect what kind of job one can perform, but, as mentioned earlier, modern technology and creative thinking can help people of all abilities do many things. Some of my participants changed their majors in college, while others did not; however, disability was not the only reported reason. One participant had wanted to go into the priesthood before his accident, and the his religious mentors supported his continuation into seminary after the onset of his disability; however, after becoming a part of the disability community and seeing the needs that he could fill there,

he realized his calling changed. It was not his disability but his perspective that affected his decision.

Another participant decided not to pursue a doctorate in the present because of the demands of symptom management, but she did not lose hope. She said, “Maybe I can come back and do this in my future” without remorse or bitterness but with an acknowledgment of the demands of her body and recognition that her youth offered her future opportunities. Each of my study participants who were in the middle of their education finished their programs, whether it was high school, college, graduate school, or medical school. Many had to take a gap year because of the length of time that needed to be spent in rehabilitation, but their education systems remained loyal to the students and welcomed them back. There were certain difficulties along the way related to inaccessible buildings and pathways, but they could be navigated with certain adjustments and help from others.

### *Living in an Inaccessible World*

The recognition of the needs within the disability community opens one’s eyes to many problems that those in it face on a daily basis. The world remains largely inaccessible, even in the wake of the Americans with Disabilities Act. Healthcare structures are ill-suited to meet people with disabilities where they are, and the medical model of disability so widely used in medicine leaves doctors poorly equipped to support and accept their patients with disabilities. Medicaid laws make it difficult for some people with disabilities to work. When someone with a disability starts working, they often lose eligibility for Medicaid. Then, the cost of home health is too high.

One of my participants expressed his frustration with the inaccessibility of society and said he was lucky because his family had enough resources to help him navigate the world, but many do not have such opportunities. Public transport is helpful but not widespread enough. People with disabilities who do not have resources are “trapped” at home and shut out from the rest of the world. Another participant expressed how grateful she was to have a family member who was a physician because he helped her navigate the healthcare system as she was sent to specialist after specialist. Without his help, she would have had to wait inordinate amounts of time to see the necessary doctors and get the proper testing. Trying to meet with the right doctors in the appropriate amount of time would have been very difficult without the help of someone in the healthcare system, but not everyone has that help. Furthermore, many people do not have paid time off and other necessary resources to spend the time it takes to receive a correct diagnosis and treatment.

A study examining positive experiences with disability of people with spinal cord injuries reports that participants were eager to use “their disability positively for the benefit of the larger disability community and the nondisabled public” by means of “systemic advocacy,” “public education,” and “organizational membership” (Weitzner et al., 2011, p. 1462-3). Seeing the world from the perspective of a person with a disability gives insight to needs in the disability community and grows a desire to meet those needs. I spoke with individuals who strive to help those in the disability community every day, and they are able to give the gifts that they do because of their disabilities.

## *Conclusion*

Developing a disability changes people. Individuals grieve for lost dreams and futures while learning to use and accept their changed bodies. Identity is transformed as one realizes their changed place in the world, and creative methods of fulfilling goals and meeting needs are utilized to help others. Living in the present becomes the only way to live, and, through this, one discovers a newfound belonging in this big, wide world. Relinquishing control gives the freedom to live well and find rest. It is not easy to face such change, and few would risk it if asked. Even so, such choices are rarely given, and humans must accept present realities as they come. Adversity transforms goals and provides context and experience with which people use to advocate for others.

It is interesting to note that developmental psychologists consider the years of emerging adulthood to be particularly significant for the understanding of resilience “because the important changes in functional capacity, educational achievement, and social roles are large and varied and have a significant influence on life course outcomes” (Wood et al., 2017, p.8). This suggests that individuals who develop resilience in adapting to adverse circumstances become better equipped to respond to adversity in the future, which has been confirmed elsewhere (Manning et al., 2014). It became clear throughout my interview process that the characteristics that these individuals adopted in the early part of their journey with disability remained useful in life. Whether a challenging event was related to their disability or not, they were equipped to process change by engaging with the aforementioned practices such as living in the present, making small steps, and relinquishing control.

## CHAPTER THREE

### How Do Others Respond to This Experience?

Developing a disability not only changes an individual but also affects his interactions with others. Family members and loved ones of those who acquire disabilities can experience trauma and shock at the onset of the disability, for the futures that people plan together are changed by disability just as an individual's plan for the future. The presence of one's family, friends, and community provides needed support and encouragement while individuals adapt to their bodies and learn how to accept their disabilities. They often give functional and emotional help and work to create a place of belonging. The following chapter discussing the social effects of acquiring a physical disability during emerging adulthood contains four sections as follows: social isolation, changes in relationships, support in relationships, and professional relationships.

#### *Social Isolation*

Disability can change access to several different social spheres, especially those popular among young adults. Individuals whose social circles revolved around sports, exercise, and physically demanding activities find themselves separated from the camaraderie and fellowship in those groups. Time spent in intensive care units and rehabilitation can be lonely and isolating, and companionship during time spent in these places becomes the responsibility of family and friends. From the interview data, three major patterns emerged about the experience of social isolation: time spent in intensive

care and rehabilitation is isolating, the presence of community largely alleviates feelings of isolation, and social reintegration is an important part of the healing process.

### *ICU and Rehabilitation*

Not all people who acquire a disability in emerging adulthood spend time in an intensive care unit or a rehabilitation hospital. Those with late-onset disease processes usually do not, and those with severe spinal cord injury or burns often do. For good reasons, visitor hours in intensive care units are quite limited. This protects patients but can also cause great loneliness and fear. In her autobiography, Joni Eareckson Tada called fear and frustration her “twin companions during those early hospital days” (2012, p. 29). Fear comes from different uncertainties, and many people do not fully understand what has happened to them at the beginning of their hospital stay. One can experience frustration from perceived helplessness and lack of sensation or ability to move. Eareckson Tada spent months in the hospital after her accident and remembers most of this time, but some of my participants were highly sedated and medicated and do not remember the days following their accidents and surgeries.

Accidents that cause disability can happen far from one’s home, and this creates a geographic barrier for friends and family to be present. Sometimes it takes months of rehabilitation before someone can be transferred to a center closer to home. Whether or not individuals spend time in intensive care, feeling isolated is the result of being separated from previous daily activities, routines, and friends. This happens in hospitals, in rehabilitation facilities, or even in one’s home. Diagnoses such as Lyme disease, lupus, dysautonomia, and multiple sclerosis can have exacerbations or flare-ups that require

extensive management. Individuals with these diseases often obtain their diagnoses because the symptoms have become unmanageable, and learning how to manage these diseases can require taking months or years off from previous activities. The presence of one's community alleviates the loneliness and fear of isolation.

### *Community Solutions to Isolation*

The burden of fear, pain, and grief after an individual acquires a disability can be shared with family, friends, and mentors. When someone is in a critical condition or is severely sick, the responsibility of companionship falls on this community. Family members do not hesitate to travel far distances to be with a son, daughter, or sibling, but distance makes visits from others challenging. Dedicated friends and mentors often make great efforts to be present, and they are the greatest source of emotional support. Several participants explained how their parents helped them a majority of the time, but most of this help was functional help with physical problems. Conversation and companionship with peers, mentors, and significant others provided more emotional help, and one participant describes the difficulty she had without friends her own age. She had just started graduate school when she developed a disability, and she was closest with her old college friends; however, none of them made an effort to be present with her. It is easier for many to vocalize difficult feelings and fears to people of the same age, and the absence of this type of support deepens the experience of isolation. Two of my participants who were actively involved in their church communities described how dedicated their friends and mentors were in visiting them in the hospital. One's college pastor drove across several states to visit. The other described how his youth group

treated visits with him like a social event: “Everyone needed to know that I was going to be okay.” As people learn to live with their disabilities and manage symptoms, they become freer to pursue community on their own.

### *Social Reintegration*

Social reintegration is a significant point in the journey to come to terms with disability and establish a new normal. This looks different for each person but is often described with an event: returning to work, taking a flight, going to church, or returning to school. It marks the beginning of yet another learning process: How do I interact with others now that my body has changed? The various ways that relationships with others change is discussed in the next section, but it is vital to recognize the importance of the word “still” here. Social reintegration proves to people that they can “still” do things: they can “still” attend a football game, they can “still” make a living, and they can “still” interact with their friends. The places people go and the methods they use to get there may change, and there are some communities in which someone may never feel a sense of belonging in again, usually those centered around sporting activities or certain types of exercise; however, the focus shifts from the things that one cannot do to the things one can do and to those who will come with. The discovery of “still” being able to do these things enlightens individuals to the possibilities of the future. They find that they are no longer stuck inside but free to determine their future.

### *Relationships with Friends and Family*

The social effects of disability are particularly interesting among those who develop a physical disability during emerging adulthood. Disability becomes something that changes relationships between friends, family members, and significant others. Some people grow closer, and others grow apart. Meeting strangers and making new friends can be quite difficult for individuals who acquire a disability because much of their former confidence is gone, and many are self-conscious about their disability for several years. Telling one's story and controlling the narrative becomes important in the journey towards confidence. In the following section I will discuss the ways that relationships between friends, parents, and spouses change; the concept of controlling the narrative; and the challenges in making new friends.

### *Eras of Friends*

One of my participants said that life is full of "eras of friends," meaning that people generally have different groups of friends throughout different phases of life. When someone acquires a disability, a new "era of friends" begins. In my interviews, it was common to hear phrases such as "some friends are betting at adapting" and "my circle of friends shrunk" in the months following the onset of disability. An Australian study about onset disability found that a majority of participants experienced a "modest immediate reduction in [social] support followed by a rebound back to initial levels" (Emerson et al., 2014, p. 454). Rather than being unique to people who acquire disabilities, participants said that changes in friendships are merely byproducts of life events, similar to getting a new job or losing a loved one. Friendships built around activities such as hiking or yoga

often disappeared, but one participant said that her most marginal friends prior to her accident afterwards became her closest friends. These changes vary for different people but frequently depend upon the nature of the friendship prior to the disability.

### *Losing Friends*

Being “dropped” by one’s friends can be difficult for an individual because having support and encouragement from friends is crucial to processing this kind of change. The disappearance of friends can make an individual with a disability feel like a burden or a problem. Some friends can handle the change that disability brings, but some cannot. One of the hardest barriers for friends is communication: most people without disabilities do not know how to talk about disability. This does not change when a best friend acquires a disability. In a study investigating the experiences of athletes following spinal cord interviews, a participant said the following:

I mean it, [going back to high school] was very awkward. I mean very...I felt out of place. I didn’t feel like I should be there. I felt like everybody was staring at me. I didn’t know how to act. I didn’t know how to interact with people. I didn’t even know how to interact with my friends that have been my friends my whole life...They didn’t know what to say to me, and I kind of didn’t know what to say to them. So it’s kind of very uneasy for a while (Machida et al., 2013, p. 1059).

Friends can be taught how to talk about disability, but this requires vulnerability and communication between both parties. Although many people do not know how to communicate about things they are uncomfortable with, one of my participants said that most people in his experience are willing to be educated about disability and ways to talk about it. Vulnerability is also a tool that is useful in making new friends.

### *Making New Friends*

Many participants discussed the difficulties they experienced in making new friends. There are many insecurities that come with physical disabilities about self-image; strangers who meet someone with a disability do not have a concept about this person before they had a disability, and, unfortunately, there are several negative stereotypes that are applied to people who have physical disabilities. Furthermore, strangers often stare at people who look different, contributing to the insecurity and “othering” of those who are still figuring out how they can belong again. When meeting new people, my participants shared their struggles with what to talk about and whether or not to address their disability. They worried about over-sharing and being seen as someone who always complains, and one woman feared that she would not be able to become close to anyone again: “How could anyone else understand without having a similar experience?” It becomes clear that no one can begin to understand what it is like to live with a physical disability without someone who has one trying to explain.

### *Vulnerability*

Brené Brown shares her research findings about connection and vulnerability in a TED Talk titled “The Power of Vulnerability” (2010). She argues that the thing that holds people back from connection is the fear that they are not worthy of connection, and those who feel connected to others feel that they are worthy of connection. People can only find true connection to others when they overcome the fear that something about them deters others from wanting to connect with them; overcoming this fear and opening up to others allows connection to form. She says that vulnerability is necessary to connection with

others, and it is the “birthplace of love, of creativity, of belonging, and of love” (Brown, 2010). I found Brown’s argument largely echoes the accounts from my study participants about friendship.

Many of my participants explained how being vulnerable with others was key to forming new relationships and deepening old ones. Offering to share one’s story with disability and answer any questions about disability tells others that it is okay to be curious. Honesty makes people approachable, and it shows others sincerity. It is not necessary to hide the pain and difficulties that come with disability in order to make friends; most people can figure out that life with disability looks different than life without it. People will not be scandalized to learn that some things in life are difficult, but, rather, they will start to understand and accept those who are open about it. One participant said that “It felt lousy and horrible” to make new friends and be vulnerable with others in the beginning. It might seem that starting friendships by telling others about all of their differences would separate them, but, instead, disability becomes another thing that makes someone unique. I am not saying this to reduce the weight or difficulty in having a disability but to explain the way friendships form after someone acquires a disability.

This can be difficult for individuals who have an invisible disability because they have an “appearance of normalcy.” Opening up requires more self-disclosure since others do not have a visual context of their disability. Whereas prior friends of someone who acquires a disability bear a certain responsibility to maintain the friendship provide support, the responsibility of making new friends falls on the person who acquired the disability. One of my participants phrased it like this: “It is the onus of the patient to

make others comfortable you. Then they will include you.” This sounds a little odd and unfair, but strangers are generally uneducated about disability. Taking the initiative to be vulnerable not only undermines dominant stereotypes about people with disabilities but it also demonstrates a desire for friendship, something to which people are generally open.

### *Narrative*

Everyone has their own lens through which they see the world, and through these lenses every person creates narratives to explain various phenomena. Opening up with others helps others feel comfortable with talking about disability, but it also lets the person with a disability control the narrative. He gets to tell the story and, in doing so, establish the extent to which disability affects his identity. When someone does not get to tell his own story, the weight of others’ narratives can be harmful. People can assume that their friend with a disability is miserable and bitter and act miserable and bitter around him, thus projecting inaccurate emotions needlessly. Others, in trying to justify why an accident happened, will tell the person that acquired a disability that this happened because of a character flaw or poor decision. For instance, participants reported family members saying things such as, “This wouldn’t have happened if you believed in God” or “This is why you don’t wear mini-skirts.” Such comments seem ridiculous, but they can confuse people and negatively impact their adaptation of identity. These narratives also imply that the person who acquired a disability is the problem; this is harmful to hear for those whose dependence in life has just increased permanently.

I was surprised to learn how patient my participants are towards family members and strangers who create inaccurate narratives of them. Responding with grace is a practiced

behavior that takes time to develop. Someone without a disability does not know what it is like to view the world through the eyes of someone with a disability, so it is unreasonable to expect them to react contrary to their worldview. Sharing personal experience helps others see the world through a different lens, and it allows people to better represent the stories of others.

### *Parents*

The relationship between parents and their children changes much during the years of emerging adulthood, and developing a disability does not preclude this change. Participants described the onset of disability as traumatic for their parents, most of whom had no idea what their child's life would look like with a disability. One participant's mother survived polio and was deeply saddened by her son's disability because she intimately knew many of the troubles that came with living with a disability. Some participants also said that parents were not always in agreement about their needs. One man, in particular, suffered severe burns in a car accident, and he lived in misery for a year with skin grafts that did not take before he decided to amputate the affected limbs. His parents were against the procedure and had denied the amputations to their son right after the accident, unbeknownst to him.

The independent nature of people in young adulthood clashes with parents' natural inclination towards decision-making when their child is injured or sick. Many people move into their parents' houses before figuring out their next steps. Parents are eager to help their children and support them in the best ways they can, but sometimes they "over-help" and hinder their child's attempts to become more independent. Over-helping is not

empowering, but it is an understandable tendency. Parents provide much of the functional and physical help needed for those who are learning to live with a disability, but most emotional support comes from peers.

### *Significant Others*

Relationships between persons with acquired disabilities and their significant others change in similar ways to friendships. Some relationships grow stronger while others dissipate. Degenerative diseases that are diagnosed after a couple is married affect the spouse deeply, and one man told me how his wife “didn’t want to be involved with his deterioration.” Another woman told me her husband became so depressed that he turned to alcohol to cope with his feelings, not offering any support to her. Changes in caregiving needs, financial needs, and opportunities for hobbies affect changes in marital status (Burchardt, 2003). Disability, however, can provide a unique set of challenges in a marriage through which relationships can be strengthened. In her biography, Joni Eareckson Tada describes what it felt like to love someone and, at the same time, realize he could not handle her quadriplegia even though he loved her. Her friend, Dickie, explained:

I began to see Don questioning the relationship. Several times he confided to me that he wished he’d never let his feelings for you get so out of hand. I suppose he...saw what you saw with me: that many guys really can’t deal with the chair in the long run (p. 164).

Although there are many who “really can’t deal with the chair,” there are many who can. One participant, who re-married after her diagnosis, asked her husband what he would do if she got sick, to which he replied, “Then I can take care of you.” Based on my interview

responses, partners in relationships that stayed together focused more on the well-being of the other than of themselves and made clear commitments to stay with each other.

### *Relationships give support*

The presence of supporting figures through adversity and challenges of all kinds enables people to endure, and this is true with acquired disability, too. The loneliness and despair that isolation brings can be lifted by friends and loved ones. Research has demonstrated a strong connection between social support and increased resilience (Ifurna, & Wiest, 2018; Zautra et al., 2008), and some claim that “resilience is fundamentally social” (Castro & Zautra, 2018, p. 70). Although all relationships are affected by disability, those who come alongside someone who has developed a disability support, guide, encourage, and contribute to the growth and healing of this person. Machida et al. also found that social support was necessary in developing resilience (2013). Throughout my interview process, the patterns that emerged which relate to the positive effects of others include the importance of empowerment, accepting help, and having a mentor.

### *Empowering not Limiting*

Empowerment is the most useful tool that friends and family can offer to someone who is learning to live with a disability. Rather than over-helping, the act of empowering offers positive encouragement that focuses on things that can be done. One participant, who finished both her bachelor’s and master’s degree after being diagnosed with multiple sclerosis, wanted to work towards her doctorate degree. Her doctor advised against this and did not think her body could handle the extra commute, but her husband encouraged

her to try it. Empowering words turn the focus to things that are possible instead of limitations. Doubt turns the focus back to limitation and what someone is not able to do. Empowerment is a healthy way to encourage people to explore their bodies, capabilities, and place of belonging in the world without placing unrealistic expectations; it is a powerful way that friends and family can help individuals find their “new normal” and accept their changed bodies.

One man in my study said his graduate school friends held him in a “cocoon of support.” They held him up, kept him safe, and were always close by when he needed help. Others shared how their experience with disability helped them to appreciate authentic friendships. One participant shared how he came out the other side with a “clearer idea of good friends.” These friends empowered each other and constantly offered a listening ear. They learned how to take care of physical needs and helped willingly and joyfully. One man’s roommates were his caregivers for ten years after he graduated high school. The support and empowerment of community for those who acquire a disability contributes to well-being, healing, and meaning making.

### *Accepting Help*

Individuals with physical disabilities often need help with daily tasks or transportation. As contradictory as it seems, someone with an acquired physical disability must learn to accept help from others to function independently. Even after the Americans with Disabilities Act was passed, several public places remain inaccessible. Wheelchairs are not made to go upstairs, and stairs are everywhere. When a wheelchair user is traveling along and is confronted with stairs with no alternate routes, they either

leave without going where they wanted, or they wait for help. It can be awkward to ask a stranger for a boost, but it is often necessary if someone wants to be independent. One man who uses a wheelchair expressed a deep gratitude for the kindness of strangers and friends alike: “They lift me up, sometimes literally.” An observant passerby can provide timely assistance to someone whether it is holding open a door or lifting a wheelchair upstairs.

Another of my participants told me that although receiving help can be embarrassing, her friends accept the ways that she needs help, which, in turn, increases her comfort with interacting with her community. One woman I interviewed did not want to tell her parents about her disability because she did not want to worry them, and they lived far away. When her father died, her mother decided to move to live with her, and she found out about her diagnosis. Instead of being worried, her mother said, “Well good [that I am here], now I can help you.” Another man told me that he tries to be as independent as he can, but sometimes he decides that asking for help is more efficient. For instance, he could put on his own clothes in the morning, but this would take ten minutes and cost a great deal of energy. If he asks his wife to help him, it takes less than a minute. The cost of independence is not always worth the cost of energy, and he recognizes that it is okay to get help.

### *Mentor*

Finally, forming a relationship with a mentor figure can transform personal experience with disability. Many people have no experience with disability before becoming a part of the disability community or watching a loved one do so. If someone

acquires a disability and has no concept of disability co-existing with happiness, success, and meaning, there is no reason this person would not question whether or not a positive future is attainable. Rehabilitation hospitals often try to introduce people who are on different stages of a similar journey with disability. The previously mentioned study about sports and resilience also found that meeting others with similar disabilities was crucial to adapting to disabilities; participating in the wheelchair rugby club gave individuals easy access to peers and mentors (Machida et al., 2013). Seeing someone else who had to re-learn the same things and discover a “new normal” demonstrates that a future is possible. The image of a possible future is not only motivating but also encouraging. All of a sudden, the one who imagined himself a pioneer becomes a disciple. Someone else has carved a path and paved the way, which can make the process of acceptance easier to traverse. Learning to live with a disability is not easy, with or without a mentor, but there is strength and community with those who have similar experiences.

### *Professional Relationships*

One of the fears about living with a disability involves the possibility of a professional life. People with disabilities can go to school and work in a variety of settings but worry about how colleagues and co-workers will treat them. In the subsequent section I will discuss the effects of disability on professional relationships in school and at work.

### *Inclusion*

Returning to school and work are important in social reintegration and developing a community of friends. My participants said that teachers usually “bend over backwards” to include them and give them an equal learning experience. As a medical student, one woman described to me some of the clever ways her professors employed to include her in learning experiences, such as helping her onto a tall stool to observe surgery and lowering examination tables. Another participant’s graduate professors allowed her to attend class without taking notes and give an oral defense for class examinations since she could not write. Those with invisible disabilities had more trouble getting necessary help and spent more time asking administrations to encourage professors to be accommodating.

One participant, who attended graduate school for counseling, found a warm and accepting community of colleagues. She concentrated her studies in disability counseling, and her peers were interested in her experience and intentionally included her opinions. Another participant, a practicing physician, felt insecure as he began his residency because he was meeting colleagues who, for the first time, had never known him as a “person who stands.” He was glad to be welcomed by the medical community, one that is known to appreciate diversity of all forms. Fears of being cast out are not realized; most interactions with peers and colleagues are full of respect and inclusion. People learn to extend grace to those who are uncomfortable with disability, and being vulnerable allows a space to open for honesty and education.

### *Patient-Provider Relationship*

Interactions with patients are transformed by disability. Individuals who are clinical counselors say that they have “immediate street cred” with their patients because of their disability. Patients can see that their counselor also has experience with adversity and feeling out of place, and it allows for trust to form between patient and provider fairly quickly. Similar interactions occur between physicians and patients. One participant who practices medicine said that building relationships with patients and their families is easy for him. A type of solidarity forms among those who suffer and endure. Physicians do not have to self-disclose with patients, but patients notice when their doctor has a disability, and they appreciate it. Similar to the mentor’s role of support mentioned earlier, the person with a disability becomes a source of hope and a vision of a possible future for patients who are suffering. It is through experiences such as this that meaning is discovered through disability, the topic of Chapter Four.

### *Conclusion*

Acquired disability affects the relationships between people. The basis of friendships may adapt to suit different abilities, and some friendships disappear. When friends and community travel alongside those who are learning to live with a disability, they can together find a “new normal” and learn how many possibilities there are. Relationships built around empowerment and focused outwardly contribute to the formation of identity and belonging. Reintegrating into society is healthy and important, and community helps this transition by offering physical, functional, and emotional support.

## CHAPTER FOUR

### How do I Find Meaning in This?

In his book, *Man's Search for Meaning*, Viktor Frankl argues that people's capacity to endure hardship is related to their capacity to discover meaning in adversity:

If there is a meaning in life at all, then there must be a meaning in suffering. Suffering is an ineradicable part of life, even as fate and death. Without suffering and death human life cannot be complete. The way in which a man accepts his fate and all the suffering it entails, the way in which he takes up his cross, gives him ample opportunity—even under the most difficult circumstances—to add a deeper meaning to his life (2006, p. 67).

People cope with loss, tragedy, and obstacles of all sizes by finding meaning, and the inability to find meaning often leads to an inability to cope and endure. A study measuring resilience among emerging adults with disabilities transitioning into adulthood found that these individuals have a “longing to create [their] own meaning” as they entered the adult world (Mannino, 2015, p. 137). In my interviews, I learned many different ways that people find meaning in their experiences with disability. I am not going to argue that meaning making is the only way that people adapt to loss because I do not think that is what my data show. Rather, meaning making is an important facet of learning to live with disability, just as several others which have already been discussed such as finding a new normal, reintegrating into society, and molding identity to include disability. The process of meaning making, however, is complex and diverse, and I will discuss the major ways that individuals with acquired physical disability explain their life circumstances in this chapter by discussing attitudes that orient one towards meaning

making, reconciliation of disability with God's will, and shaping disability into a strength with which to guide and assist others.

### *Attitude*

In the occurrence of unimaginable loss or adversity, people must choose the type of attitude they will possess. There are many types of attitudes to choose from, and these change with growth, influence, and circumstances. Progression in attitudes from bitterness, regret, desperation, hope, joy, or gratitude occur throughout periods of grief, growth, and stability. By adopting certain attitudes, people view the meaning of life and loss through different lenses. These are ultimately up to the wearer to decide, and trying one on is not a permanent decision. The adoption of certain attitudes requires intentional effort every day to create a habit of joy or a habit of hope. The discussion about the effect of attitude on meaning making will include the topics of owning one's experience, looking outside of oneself, and discovering the possibilities of life.

### *Own Your Experience*

The idea of "owning your experience" was mentioned earlier in the topic of social relationships, but it also has great impact on identity and meaning making. Losing the ability to walk or kick a soccer ball does not take away someone's ability to own his experience and put on his own metaphorical glasses. It is important to control the narrative of one's disability so that someone else does not control it, but it also allows someone to choose the lens with which one views the world. This does not mean that people with disabilities always have the right answers and are encouraged to ignore the

wisdom and guidance of others; it simply means that one must believe in their narrative in order to discern meaning from it.

One of my participants mentioned how significant Frankl's book was in her attitude towards living a life with a disability because she learned that she had the "freedom to choose how to react" (Frankl, 2006). One of her mentors at the time told her that her attitude towards her circumstances would greatly affect the trajectory of her life. She knew she had to adopt an attitude that would give her encouragement and hope to live the way that she wanted. Attitudes of determination and persistence do not exclude those of acceptance; when someone takes his body into account while pursuing a career or a relationship, he embodies one participant's statement: "And I will do what I can right now." Controlling the narrative of one's disability contributes to finding meaning, and it helps to establish a trajectory for one's life.

### *Ability not Disability*

Another component of attitude that contributes to meaning making is searching for meaning outside of oneself. Disability fits into identity in the place that someone with a disability puts it. Adopting an attitude that dwells not on the things one cannot do but on the things that one can do disallows a negative attitude to affect meaning making. One participant who has a spinal cord injury explained how he does not focus his life on overcoming his body; rather than obsessing over current experimental therapies and research about spinal cord injuries, he focuses on living in the present: "If someone finds a cure, I'm sure they'll let me know." Orienting attitude outside of his body allows him to experience life and find his new normal. Individuals focus on achieving and succeeding

at that which they endeavor, whether at practicing medicine, writing books, counselling others, getting a promotion, etc. Many people I spoke with find pride and satisfaction when they are self-sufficient. For some this is cleaning the house, for others it is working a full-time job. The map of success does not have to change for people with disabilities; there is no need to “lower the bar.” Meaning is found when attitude is shifted from the things one cannot do with a limited body to the joy found in friendships, educational pursuits, and careers.

### *Learning What Life Has to Offer*

Living a life with a disability is not something with which many people are familiar, and for this reason, assumptions are made about life with disability. One man explained the great worries and fears he and his family had when he became a paraplegic. They had never known anyone who was a paraplegic and, thus, had no concept of life this way. Could life be good with a disability? Can life still offer enjoyable things? Their questions were not shallow or discriminatory: they simply did not know, for how could they without having any experience with disability? As he went through rehabilitation, went back to work, and married his fiancée, he began to realize that life can, in fact, be good, and it does offer enjoyable things. Shifting one’s attitude to this realization offers hope and leads towards acceptance.

Another participant told me how important it is to hold onto hope and not fear loss. Attitude should not center on the impossibility of happiness nor on the fear of losing it: “The things we are most afraid of happening don’t usually happen...you can’t assume it will happen and live by this assumption.” Live in the present, and “do what you can while

you can.” When worries about the future arise, she advises others to “hold everything lightly,” meaning that the possibilities of loss in the future should not have control over actions in the present. People with disabilities find meaning in the same things in life as people without disabilities: love, family, and careers. Healthy attitudes orient one’s mind toward these things with determination and patience and help one find peace and hope in their circumstances.

There is some disagreement in current literature about the ability of individuals to adapt to disability in terms of happiness. Richard E. Lucas argues that there lasting changes in well-being caused by onset disability and that happiness following disability does not return to levels before the onset of disability (Lucas, 2007). Others, however, argue that individuals who develop a disability can experience high levels of recovery in well-being (Oswald & Powdthavee, 2008). In my study, individuals reported that they were happy and content with their lives. There was an expressed desire to focus on the present and pursue happiness and meaning in the context of their current state of being. Comparing levels of happiness between their lives with disability and their lives without disability was unhelpful and irrelevant to living in the present. One participant told me that he sometimes has dreams of his past, but he sees himself in a wheelchair in the dream even though he did not use one then. As mentioned in Chapter Two, healthy ways to adapt and accept life with disability do not include dwelling on the past. An individual’s ability to develop resilience is likely a strong indicator for his ability to be happy and find meaning in life with an acquired physical disability.

## *God's Will*

Many people who face hardships find comfort and peace from their faith system. Spirituality can be a useful tool through which meaning and purpose can be found, but this is not always an easy process. Some believe that God gave them a disability to work a certain purpose on earth, but others hesitate to attribute such causality to God. Some do not think about theodicy but choose to find peace in the steadfastness of God and the community found in the Church. This section will discuss the various ways people with acquired disabilities find meaning in their situations through the lens of faith.

### *Suffering as Opportunity for Growth*

A commonly held conviction in the Christian faith is that suffering causes growth and edifies the soul. Great good can come from tragedy and adversity, and this does not exclude developing a disability. Joni Eareckson Tada found great meaning in believing that God gave her a certain challenge in order to glorify Him and share His good news. In response to being asked if she was happy, Eareckson Tada made the following statement:

I really am. I wouldn't change my life for anything. I even feel privileged. God doesn't give such special attention to everyone and intervene that way in their lives. He allows most people to go right in their own ways. He doesn't interfere, even though He knows they are ultimately destroying their lives, health, or happiness, and it must grieve Him terribly. I'm really thankful He did something to get my attention and change me (2012, p. 186).

Eareckson Tada believed that God directly intervened in her life to give her a disability for the purpose of transforming her character and setting her on the correct path. Through this lens, she found immense strength to learn and succeed. Today, her ministry, Joni and Friends, has a global impact. Joni and Friends holds family retreats, teaches courses about

disability and theology, donates wheelchairs to developing nations, and provides radio and television broadcasts to share encouragement and hope to people in all walks of life (Eareckson Tada, 2012 p. 193). She would not have done these things if she had not been paralyzed, and she interprets this to mean that God gave her a disability so that she could help others in this way.

Not everyone of the Christian faith who has acquired a disability believes this, however. Renee Bondi broke her neck at the age of twenty-nine and, like Eareckson Tada, has encouraged and supported people around the world by sharing her story. When asked whether or not she would undo the accident that paralyzed her, Bondi replied as follows:

Absolutely, yes. I would love to undo the accident and learn everything that I've learned in some other way! However, if the price was to be ignorant of God's faithfulness, then no. I knew the Lord before my accident; I had a relationship with him, but I was not good at recognizing him in my family life. I have learned so much about God by being in this wheelchair...I have to be careful here, because in no way do I believe that God put in me in this chair. It was just a bizarre accident...God can use even a tragic injury to bring his children closer to himself (2002, p. 274).

Bondi did not believe that God moved directly to paralyze her but knew that in her suffering, she would find meaning and relationship with him.

### *Did God Cause my Disability?*

Several of my study participants brought up the difficulty they had navigating the topic of God's culpability in their disability. One woman said that while she was adapting to life with her disability and pursuing a career she had not previously considered, she thought God acted directly to cause her disability because the things that changed in her life ended up being so good. In reflection, she is no longer certain that this is the case.

She is no longer willing to attribute causality of disability to God: “Does God act so directly?” Of course, good can come from accidents and disease, but it feels wrong to some to think that God cares so much about the end that He will use this type of means.

Another participant said that she has grown to understand disease and disability as products of “corporal sin.” This removes agency of disability from God and places it on humankind’s state of sin, but it does not prohibit God from acting as an agent of good in the midst of disease and disability. Great meaning can come from the knowledge that God will transform loss and pain into strength and utility. She also mentioned that it is important for people to know that disability is not a punishment from God. Disability has been seen as such in the past, which has damaged the relationship between people with disabilities and the Church (Braddock & Parish, 2002). To this participant, considering disability to be a product the fall of humans and not the sin of individuals is critical for the Church’s acceptance of people with disabilities and, in return, the sense of belonging people with disabilities have in the Church.

In conclusion, people with acquired disabilities determine the place that disability fits into their worldview. Those of the Christian faith struggle with theodicy and the role God has in such a dramatic life change, especially during the years of emerging adulthood. Regardless of one’s view of the cause of suffering and purpose of disability, people of faith strongly believe that God works all things for good; disease and disability are not meaningless.

### *Disability as a Tool*

In this final section, I will discuss a final way that individuals with acquired disabilities find meaning through disability: using personal experience with disability to help others with disabilities. This is probably the most profound way that individuals find meaning with this experience because it gives an account for the purpose of disability. As explained in the previous section, those with a Christian faith often learn to accept their circumstances by believing that God can use them for good. This section will further explore the concept of using disability as a strength and advantage for the benefit and growth of others with the following concepts: disability uniquely equips one to relate to others with disability, disability provides a unique learning experience not found elsewhere, and re-framing one's identity to find belonging in the world can be useful for helping others to do the same in any circumstance of life.

### *Helping Others with Disabilities*

As one comes to terms with disability and learns to accept a new set of limitations and abilities, focus begins to turn outward instead of inward. Earlier in this chapter, I explained that part of shaping attitude toward finding meaning involves focusing outside of the body, and once someone does this, he begins to see others in a different view. One of the ways that acquired disability changes someone, as mentioned in Chapter Two, is nourishing a newfound understanding of empathy. Dealing with loss and pain while adjusting to a new life causes people to be more acutely aware that other people go through similar things. These two ideas combine when someone with a disability sees other people with disabilities and utilizes personal experience to encourage and support

them. The existence of the community of disability demonstrates that no one is alone in disability; there were people there before, and others will join after. Persons with disabilities find themselves in a unique situation in which they can affect positive change in the lives of others by virtue of their disabilities. The same finding arose in a study about individuals who grew up with disabilities. Jennifer E. Mannino says, “A number of the participants expressed the desire to use what they have learned from their past experiences to teach others. Having experience firsthand the difficulties related to having a disability, they longed to help others” (2015, p. 137).

Unsurprisingly, people with disabilities appreciate seeing others with disabilities in casual and professional settings. Weitzner et al. found that individuals with spinal cord injuries viewed their disability positively when they used it to help others with disabilities through peer support and peer encouragement (2011). The physicians I interviewed explained how interactions with patients are transformed because of the high level of understanding between provider and patient. One of them said, “My experience [in the hospital] would have been different if my doctor had a disability,” which was one of the reasons he decided to go to medical school after acquiring a disability. Another said that his disability “enhances clinical practice.” Patients feel understood when they know their provider can relate and empathize with them.

Most of my participants pursued a career in a field that helped people with disabilities of various kinds. Experiencing the healthcare system, traveling the world, going to school, or seeking mental health resources as a person with an acquired disability caused them to see a gap between the ways things are and the way things could be for people with disabilities. The very experience of disability provided an opportunity

to do certain things and become certain people that would never have been realized or achieved without disability. Opportunity is not the first word that comes to someone's mind when one thinks of disability, and yet, it can become such. One man shared how amazing it is to receive emails from people whose lives had been changed because of the work he does because he knows that his disability enabled him to affect their lives in this particular way. Shifting focus outward allows individuals to see others in similar situations and fill roles in which the experience of disability plays a crucial part in changing the lives of others.

### *Grateful for Learning Experience*

Several individuals expressed a gratitude for the learning experience that developing a disability offered because it changed the way they saw the world and their place in it. One participant said, "The future I have now is more beautiful than the future I imagined for myself." She realized that the trials and changes caused by her disability showed her an image of the world in which her place of belonging was something better than she had planned for herself. Being grateful for the things learned from disability is not the same thing as being grateful for disability itself. The question of whether someone would choose to have a disability if given a choice is not a very useful question in my opinion. People are not given this choice, and the thoughts that stem from this question are not likely to benefit the current problems and insecurities of people with disabilities. We can learn more from people with disabilities when we ask, instead, what their lives have been like because of their disabilities and what they want others to know about them. Of course, their lives would have looked different without a disability; of course,

many of their careers would have been different. My participants did not speak with bitterness or regret but with amazement that they have been able to touch the world as they are.

### *Belonging*

Finally, people who acquire disabilities during emerging adulthood are forced to learn how to re-frame their sense of self in order to belong and fit into the world as someone with a disability, something at which people are, generally, not very good. This unique experience of acquiring a physical disability during emerging adulthood equips individuals to guide others through the same process of finding belonging. Doing, belonging, and understanding are three ways that Gillian King et al. found in which people find meaning in life (2003). Disability is just one of many events in life that change one's sense of belonging in the world. Receiving a terminal diagnosis, losing a loved one, and developing a disability can cause one to feel disconnected with the surrounding world. Tragedy reminds humans that they are not in control, and this is devastating to many.

Through these interviews, I heard stories that destroy the hierarchy of control. Control does not bring happiness or belonging; it does not give one friendship or love. Those who find themselves with a lack of control because of a physical disability do not have a reason to be without hope. Everyone on this earth has a place where they can belong and find friendship, and developing a physical disability does not exclude someone from finding meaning, joy, and purpose. Individuals who have this experience find creative and influential ways to share this knowledge with others. Those who pave

the way for others with disabilities to follow do immense favor to those with disabilities and those without disabilities alike.

### *Conclusion*

In this chapter, I explained the final principle that emerged from this study and discussed the ways that acquiring a physical disability in emerging adulthood affects meaning making. Disability affects attitude toward the self and one's place in the world. It also causes many to wrestle with the role that God may or may not have had in causing disability. Knowledge that personal experience with hardship can positively affect the lives of others gives purpose and meaning to the efforts of many. Developing a disability is not a reason to be without hope, and individuals with this experience show that there is further work to be done for people with disabilities. Disability opens one's eyes to the needs of the disability community in the world at large, and it equips individuals with unique tools to approach challenges and advocate for others.

## CHAPTER FIVE

### Conclusion

In this chapter, I will describe the limitations in my study, summarize the developed theory of this study, and offer a parting thought about the potential use of these results in both a research and personal setting.

#### *Limitations*

There are some potential limitations to this study. First, I conducted the study as a person who acquired a disability during adolescence and thereby faced the potential problem of allowing my personal experience to interfere with my interpretation of the data. In response to this, I would argue that my closeness to the subject, so long as I adhered to the methodology of Grounded Theory, allowed me to perceive and communicate a deeper understanding from the stories of my study participants rather than distorting the data analysis. Glaser and Strauss say the following on this subject:

The theory that emerges from the researcher's collection and analysis of qualitative data is in one sense equivalent to what he *knows systematically* about his own data. Why does the researcher trust what he knows? ...he himself knows what he knows about what he has studied and lives through. They are his perceptions, his personal experiences, and his own hard-won analyses...What is more, if he has participated in the social life of his subject, then he has been living by his analyses, testing them not only by observation and interview but also by daily living (2017, p. 225).

The observations and experience of the investigator do not discredit the data barring misrepresentation of the data or ignoring inconsistencies between personal experience and collected data. As I explained in Chapter One, I conducted this

theory strictly using the classical methods described by Glaser and Straus. Unless expressly given as my personal opinion, the references to principles from the study come solely from participants and relevant theory. My experience allowed me to view and understand the data in a unique way but did not alter the data.

Second, there is a selection bias of the study participants who agreed to an interview. Although dozens of individuals were contacted to request an interview, many never responded. Those whom I had the privilege of interviewing were very self-possessed in telling their stories to me. They have reflected upon their life with disability and have largely come to terms with disability. This is not to say that they never have bad days where despair and hopelessness creeps in, only that they had the strength and patience to tell a complete stranger about a difficult time in a way that was, in many respects, positive. Not everyone who acquires a disability during emerging adulthood is in this place. Healing and adapting can take much time, and these individuals enter periods of grief at various stages of life following disability.

Additionally, most of the individuals in my study had either taken some graduate coursework or completed graduate degrees, and several of my participants are well-known in the disability community and regularly tell their stories in public. It seems likely that these characteristics affect the way that people reflect on their disability and place in the world. Many people with disabilities are not able to continue education or find community with others with disabilities. Most people with disabilities do not have a public platform from which they can control their narrative, and many would not be comfortable doing so. In light of these things, my study data likely has a bias towards individuals with acquired physical disabilities who have come to terms with their

disability and adapted their lives in ways where they find meaning and purpose. This does not represent every single person with an acquired physical disability during emerging adulthood, but that does not discard the value of the theories I developed. Rather, it shows that there is hope and a future for people with acquired physical disabilities.

The individuals I interviewed demonstrated that life with a physical disability in a world of the able-bodied does not exclude someone from finding happiness, meaning, and relationship with others. Wrestling with the ways that disability changes lifestyle, occupation, faith, and friendships brings people closer to acceptance. It is not an easy process, and it might not be what someone would have chosen for himself. Acquiring a physical disability during emerging adulthood is not something people imagine would happen, but through it, the lens through which one views the world changes to see beauty and purpose in powerful ways. Although this process is different for each person, the aforementioned themes show how living in the present, focusing on small steps, pursuing community, and looking outside of oneself lead individuals to live well, not in spite of their disability, but because of it.

Lastly, this study has a small sample size. The experiences of individuals with an acquired physical disability are in no way confined to the principles and themes discussed in this thesis. According to the classic grounded theory approach, interviews were not conducted after I discerned that theoretical saturation had been met (Glaser & Strauss, 2017). While knowing that every human life is unique, and no two experiences with disability are identical, I was no longer learning new information about the subject population. These results cannot predict the pattern of change and development in every

individual who acquires a physical disability during emerging adulthood. Due to the small sample size and nature of grounded theory, each response has equal value, and something expressed by seven participants does not receive more significance than something expressed by one participant. Continued research in these areas will more clearly ascertain incidence and depth of these patterns.

### *Summary of results*

Through the use of constant comparison, I located three principles that categorize the experience of acquiring a disability during emerging adulthood. The principles were different lenses through which individuals view this experience and included that of the self, others, and the purpose of disability. Using the lens of the self, participants expressed the various ways that they changed because of their disability. Through processes of grief, learning to live in the present, adapting identity, letting go of control, and transforming goals, individuals become resilient and find their “new normal.” Using the lens of others, participants described the various social changes that occurred after the onset of disability. This includes the experience of social isolation, changes in relationships, the contribution of support to resilience, and the development of professional relationships. With the final lens of meaning found in disability, participants shared the positive growth that resulted from their disability. By adopting a healthy attitude, reconciling disability with God’s will, and using disability as a strength with which to help others, great meaning is discovered and pursued.

These results show that acquiring a disability in emerging adulthood affects many parts of life. Although individuals with this experience do not grow up knowing the

future challenges they will face, they can adapt well to drastic changes. Acquiring a disability during a young and opportunistic season of life causes great insecurity because self-image is changed by disability; however, the elasticity and flexibility of individuals in emerging adulthood likely contribute to their ability to be resilient. Disability does not preclude life from offering joy, meaning, and good things. The effects are substantial, but empowering individuals with physical disabilities and allowing them to tell their own story creates a space for them to find meaning, contribute to society, and live well.

### *Potential Uses*

The theory that emerged from this study has much potential use in both academic and personal settings. In the former, it this research shows a possibility that emerging adulthood is connected to resilience in the onset of physical disability. Although there needs to be further research, the opportunity-filled nature of emerging adulthood may contribute to the individual's ability to adapt and cope with adversity such as disability. This study also isolates several ways that contribute positively to coping with disability, such as focusing on the present, making small steps, and allowing disability to become part of one's identity. It also reveals a trend of this population to pursue careers that help others with disabilities. Additionally, this research could be used to compare the ways that onset physical disability affects different age populations such as children, adolescents, middle-aged adults, and the elderly.

In personal settings, this research shows several helpful and unhelpful ways that people can support friends, family, loved ones, and patients with disabilities. Adopting attitudes of empowerment were the most useful to individuals with acquiring physical

disabilities. When others encouraged them to try things, participants were grateful and learned more about their potential than they did with attitudes of doubt and pessimism. Being vulnerable with others is the best way to form connections, for both people with disabilities and people without disabilities. Although both parties may be uncomfortable first meeting each other, being vulnerable breaks through discomfort and demonstrates the desire to become connected. I asked one participant to share what she would say to someone who just acquired a disability, and she replied, “Take it day by day, moment by moment if you have to. Don’t try to figure it out all at once. This moment isn’t forever. We are ever changing.” After hearing the stories of these thirteen individuals, I would respond in the same way. There is a hope and a future for everyone regardless of their physical ability. When someone acquires a disability, the doors of the world do not close. Allow time and the presence of others to guide you through change, and choose to view the world with a new lens that focuses on ability rather than disability. Use your unique perspective to see things where others cannot, and advocate for those who are unseen and unheard.

### *Final thoughts*

In the conclusion of a study comparing life satisfaction in individuals before and after developments of mild and severe disability, the author makes the following aside:

Are these observations made by outsiders completely wrong? Do we miss a large part of what disabled people are thinking about when they are asked to assess how happy they are with their life? Currently little is known about the impact of disability on different domain satisfactions and, in turn, overall judgment of life satisfaction (Powdthavee, 2009, p. 1843).

As someone who is a part of the disability community and someone who has heard the stories of many others in the disability community, I think that Powdthavee is asking important questions. Studies of life satisfaction and quality of life abound in disability literature, as if it is difficult to comprehend that idea that people with disabilities can be satisfied with life. It also reflects a small-mindedness: how could the experience of disability be explained by a quantification of happiness? I have learned that the challenges those who live with disabilities face are much deeper and diverse than people assume; people with disabilities are truly people. Their lives are as full, complex, and busy as those of people without disabilities. There are many differences that disability causes, but it is shallow and easy to limit explorations of disability to questions of life satisfaction or quality of life.

As an insider, I wanted to know what this particular experience with disability was like without making assumptions. Grounded theory is particularly useful for this because it mandates the investigator not make assumptions about findings before interviewing the population of interest. It is for this reason that I learned how deep the experience of disability can be. It affects change in several aspects of life, but it does not change everything people think it does. People who acquire disabilities still desire to achieve, make friends, see the world, and save the lives of others. People's priorities are not consumed by finding satisfaction in life but turn outwards towards helping others. People are resilient and transform apparent weaknesses into strengths, and they strive to succeed and thrive in a world that does not always make room for them. Being diagnosed with a disability is not a death sentence; it does not condemn someone to singleness, loneliness, or helplessness. Change is hard. Learning how to navigate the bathroom, the

stairs, or the store with legs that do not work is hard; however, there is hope. The road has been paved for people with acquired physical disabilities to adapt and live well. No one has to be alone in the experience of disability.

## APPENDICES

## APPENDIX A



**BAYLOR**  
UNIVERSITY

INSTITUTIONAL REVIEW BOARD – PROTECTION OF HUMAN SUBJECTS IN RESEARCH

### **NOTICE OF EXEMPTION FROM IRB REVIEW**

Principal Investigator: Katherine McCullough  
Study Title: The Effects of Life-Altering Disabilities in Emerging Adults

IRB Reference #: 1437431  
Date of Determination: 05/13/2019  
Exemption Category: 45 CFR 46.104(d)(2)

---

The above referenced human subjects research project has been determined to be EXEMPT from review by the Baylor University Institutional Review Board (IRB) according to federal regulation 45 CFR 46.104(d)(2): Research involving the use of educational tests, survey procedures, interview procedures or observation of public behavior.

The following documents were reviewed:

- IRB Application, submitted on 05/04/2019
- Protocol, dated 04/16/2019
- Consent Form, dated 04/16/2019

This exemption is limited to the activities described in the submitted materials. If the research is modified, you must contact this office to determine whether your research is still eligible for exemption prior to implementing the modifications.

If you have any questions, please contact the office at (254) 710-3708 or [IRB@baylor.edu](mailto:IRB@baylor.edu)

Sincerely,

Deborah L. Holland, JD, MPH, CHRC, CHPC  
Assistant Vice Provost for Research  
Director of Compliance

---

OFFICE OF THE VICE PROVOST FOR RESEARCH

One Bear Place #97310 • Waco, TX 76798-7310 • (254) 710-3708 • FAX (254) 710-7309 • <http://www.baylor.edu/research/irb/>

## APPENDIX B

### Consent Form for Research

PROTOCOL TITLE:           The Effects of Life-Altering Disabilities on Emerging Adults

PRINCIPAL INVESTIGATOR:   Katherine McCullough, Dr. Bill Hoy (Faculty Advisor)

SUPPORTED BY:             Baylor University

**Purpose of the research:** The goal of this research project is to examine the effects that a disability has on an individual when the disability is acquired between the ages of eighteen and twenty-five.

**Study activities:** You will be asked to complete an interview. The interview will be either via telephone or in person and should last 30 to 45 minutes.

**Risks and Benefits:** You may feel emotional or upset when answering some of the questions. You do not have to answer any questions that make you feel upset. Tell the interviewer at any time if you want to take a break or stop the interview.

**Confidentiality:** All information will be kept completely confidential. Notes from your interview will be assigned a random case number and any identifying information will be kept separate from your responses. The only people with access to the interview information will be principal investigator and her faculty advisor. Nothing identifying you will be disclosed in published reports of this research.

Authorized staff of Baylor University may review the study records for purposes such as quality control or safety.

**Questions or concerns about this research study:** You can call the researcher(s) with any concerns or questions about the research.

Katherine McCullough  
Katie\_McCullough@baylor.edu

Dr. Bill Hoy  
Bill\_Hoy@baylor.edu

If you want to speak with someone not directly involved in this research study, you may contact the Baylor University IRB through the Office of the Vice Provost for Research at 254-710-1438. You can talk to them about:

- Your rights as a research subject

- Your concerns about the research
- A complaint about the research

Taking part in this study is your choice. You are free not to take part or to stop at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled. If you decide to withdraw from this study, the information that you have already provided will be kept confidential. Information already collected about you cannot be deleted.

By continuing with the research and completing the study activities, you are providing your consent.

By signing here, I acknowledge that I have read the above information and agree to proceed with the interview process as described.

Participant Name (Printed):

---

Participant Signature:

---

Date:

---

## APPENDIX C

### **Confidentiality Procedures**

(to be read to participants at start of interview)

Your confidentiality is of paramount concern in this study. All information will be kept completely confidential. Notes from your interview will be assigned a random case number and any identifying information will be kept separate from my notes on your responses. I will not be recording your voice or image in this interview and I will not disclose your name to other research participants. The only people with access to the interview information will be me. Nothing identifying you or your organization will be disclosed in published reports of this research.

You may decline to answer any question asked or discontinue the interview at any time; the interview will be completely controlled by your comfort level.

Do you have any questions about these procedures?

Are you satisfied with the procedures in place to protect your confidentiality?

Are you willing and ready to proceed with the interview?

## APPENDIX D

### **Semi-Structured Interview Guide**

#### **Background**

What were your biggest aspirations before your disability? How did you become aware about your disability?

Who diagnosed you with a disability?

In what manner did he/she explain your disability?

#### **Immediate Effect**

What were your initial thoughts after hearing your diagnosis? Did your physician suggest any type of counseling?

How did your family initially respond?

Who did you tell your diagnosis to?

Did you think that your aspirations were unfeasible?

Were you angry at the world/God for your diagnosis?

What kind of things did you have to change to accommodate your disability?

#### **Coming to Terms**

Have you ever considered your adjustment to your disability as a grieving process? Did you attend any kind of counseling or group therapy?

How did your life plans change?

What were your new plans? (If different)

What encouraged you the most in transitioning into the world of disability? What kind of support did your family and friends give you?

How long did it take you to find a new normal?

What is your new normal?

What is something you wish had been addressed at your initial diagnosis? What was the hardest part about adjusting to your disability? The easiest part?

#### **Following a New Path**

Do you think your disability has transformed you in a positive way? Do you use your disability as a tool?

How does your disability effect your daily life?

Is there anything that could support you more in your daily life?

Do you perceive a societal stigma about disability in your daily life?

Would you rather people ask you about your disability or offer the information on your own? What is the method you prefer of sharing information about your disability?

What kind of language do you think is the most supportive to use in the world of disability? What is something you wish everyone knew about having a disability?

What would you tell a young adult who was just diagnosed with a disability?

Are there other issues about living with a disability you would like to discuss or tell me about?

## REFERENCES

- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *The American Psychologist*, 55(5), 469–480. <https://doi.org/10.1037/0003-066X.55.5.469>
- Bogart, K. R. (2014). The role of disability self-concept in adaptation to congenital or acquired disability. *Rehabilitation Psychology*, 59(1), 107–115. <https://doi-org.ezproxy.baylor.edu/10.1037/a0035800>
- Bondi, R. (2002). *The last dance but not the last song* (2nd ed.). Grand Rapids, MI: Fleming H. Revell.
- Boyce, C. J., & Wood, A. M. (2011). Personality prior to disability determines adaptation: agreeable individuals recover lost life satisfaction faster and more completely. *Psychological Science*, 22(11), 1397–1402. <https://doi-org.ezproxy.baylor.edu/10.1177/0956797611421790>
- Braddock, D. & Parish, S. L. (2002). An institutional history of disability. In D. Braddock (Ed.), *Disability at the dawn of the 21st century and the state of the states* (1st ed., pp. 3-61). Washington, D.C: American Association on Mental Retardation.
- Brown, Brené. (2010, June). *The power of vulnerability* [Video file]. Retrieved from [https://www.ted.com/talks/brene\\_brown\\_the\\_power\\_of\\_vulnerability?language=en](https://www.ted.com/talks/brene_brown_the_power_of_vulnerability?language=en)
- Bryant, A., & Charmaz, K. (2007). Grounded theory in historical perspective: An epistemological account. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (1st ed., pp. 1-57). London: SAGE Publications.
- Burchardt, T. (2003). Being and becoming: Social exclusion and the onset of disability (Vol. 0101). *Centre for Analysis of Social Exclusion, LSE*.
- Castro, S., & Zautra, A. (2016). Humanization of social relations: Nourishing health and resilience through greater humanity. *Journal of Theoretical and Philosophical Psychology*, 36(2), 64–80. <https://doi.org/10.1037/teo0000040>
- Catalano, R., Berglund, M., Ryan, J., Lonczak, H., & Hawkins, J. (2004). Positive youth development in the United States: Research findings on evaluations of positive youth development programs. *The ANNALS of the American Academy of Political and Social Science*, 591(1), 98–124. <https://doi.org/10.1177/0002716203260102>

- Cho, D., & Park, C. L. (2015). Cancer-related identities in people diagnosed during late adolescence and young adulthood. *British Journal of Health Psychology*, 20(3), 594–612. <https://doi-org.ezproxy.baylor.edu/10.1111/bjhp.12110>
- Chuang, C. H., Yang, Y. O., & Kuo, L. T. (2015). Finding a way to cope: A qualitative study of the experiences of persons with spinal cord injury. *The Journal of Neuroscience Nursing: Journal of the American Association of Neuroscience Nurses*, 47(6), 313–319. <https://doi-org.ezproxy.baylor.edu/10.1097/JNN.000000000000169>
- Eareckson Tada, J. (2012). *Joni: An unforgettable story*. Grand Rapids, MI: Zondervan.
- Emerson, E., Kariuki, M., Honey, A., & Llewellyn, G. (2014). Becoming disabled: The association between disability onset in younger adults and subsequent changes in productive engagement, social support, financial hardship and subjective wellbeing. *Disability and Health Journal*, 7(4), 448–456. <https://doi-org.ezproxy.baylor.edu/10.1016/j.dhjo.2014.03.004>
- Frankl, V. E. (2006). *Man's search for meaning* (1st ed.). Boston, MA: Beacon Press.
- Glaser, B., & Strauss, A. (2007). *The discovery of grounded theory: Strategies for qualitative research*. New Brunswick, N.J: Aldine Transaction a division of Transaction Publishers.
- Guo, B., Huang, J., & Porterfield, S. L. (2019). Transition to adulthood: Dynamics of disability, food security, and SNAP participation. *Journal of Adolescence*, 73, 63–72. <https://doi-org.ezproxy.baylor.edu/10.1016/j.adolescence.2019.04.002>
- Hernandez, C. L., Elliott, T. R., Berry, J. W., Underhill, A. T., Fine, P. R., & Lai, M. H. (2014). Trajectories of life satisfaction five years after medical discharge for traumatically acquired disability. *Rehabilitation Psychology*, 59(2), 183–192. <https://doi-org.ezproxy.baylor.edu/10.1037/a0035887>
- Hood, J. C. (2007). Orthodoxy vs. power: The defining traits of grounded theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (1st ed., pp. 151-164). London: SAGE Publications.
- Infurna, F. J., & Wiest, M. (2018). The effect of disability onset across the adult life span. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 73(5), 755–766. <https://doi-org.ezproxy.baylor.edu/10.1093/geronb/gbw055>
- King, G., Cathers, T., Brown, E., Specht, J. A., Willoughby, C., Polgar, J. M., MacKinnon, E., Smith, L. K., & Havens, L. (2003). Turning points and protective processes in the lives of people with chronic disabilities. *Qualitative Health Research*, 13(2), 184–206. <https://doi-org.ezproxy.baylor.edu/10.1177/1049732302239598>

- Lucas, R. E. (2007). Long-term disability is associated with lasting changes in subjective well-being: evidence from two nationally representative longitudinal studies. *Journal of Personality and Social Psychology*, 92(4), 717–730. <https://doi-org.ezproxy.baylor.edu/10.1037/0022-3514.92.4.717>
- Machida, M., Irwin, B., & Feltz, D. (2013). Resilience in competitive athletes with spinal cord injury: the role of sport participation. *Qualitative Health Research*, 23(8), 1054–1065. <https://doi-org.ezproxy.baylor.edu/10.1177/1049732313493673>
- Manning, L. K., Carr, D. C., & Kail, B. L. (2016). Do higher levels of resilience buffer the deleterious impact of chronic illness on disability in later life?. *The Gerontologist*, 56(3), 514–524. <https://doi-org.ezproxy.baylor.edu/10.1093/geront/gnu068>
- Mannino, J. E. (2015). Resilience and transitioning to adulthood among emerging adults with disabilities. *Journal of Pediatric Nursing*, 30(5), e131–e145. <https://doi-org.ezproxy.baylor.edu/10.1016/j.pedn.2015.05.017>
- Ogilvie, R., Foster, K., McCloughen, A., & Curtis, K. (2015). Young peoples' experience and self-management in the six months following major injury: A qualitative study. *Injury*, 46(9), 1841–1847. <https://doi-org.ezproxy.baylor.edu/10.1016/j.injury.2015.05.036>
- Oswald, A., & Powdthavee, N. (2008). Does happiness adapt? A longitudinal study of disability with implications for economists and judges. *Journal of Public Economics*, 92(5-6), 1061–1077. <https://doi.org/10.1016/j.jpubeco.2008.01.002>
- Pagán-Rodríguez, R. (2010). Onset of disability and life satisfaction: evidence from the German Socio-Economic Panel. *The European Journal of Health Economics: HEPAC: Health Economics in Prevention and Care*, 11(5), 471–485. <https://doi-org.ezproxy.baylor.edu/10.1007/s10198-009-0184-z>
- Powdthavee, N. (2009). What happens to people before and after disability? Focusing effects, lead effects, and adaptation in different areas of life. *Social Science & Medicine*, 69(12), 1834–1844. <https://doi-org.ezproxy.baylor.edu/10.1016/j.socscimed.2009.09.023>
- Reeve, C. (1998). *Still me* (1st ed.). New York: Random House.
- Salick, E. C., & Auerbach, C. F. (2006). From devastation to integration: Adjusting to and growing from medical trauma. *Qualitative Health Research*, 16(8), 1021–1037. <https://doi-org.ezproxy.baylor.edu/10.1177/1049732306292166>
- Stern, P. N. (2007). On solid ground: Essential properties for growing grounded theory. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (1st ed., pp. 114–126). London: SAGE Publications.

- Stewart, D. (2009). Transition to adult services for young people with disabilities: current evidence to guide future research. *Developmental Medicine and Child Neurology*, 51 Suppl 4, 169–173. <https://doi-org.ezproxy.baylor.edu/10.1111/j.1469-8749.2009.03419.x>
- Weitzner, E., Surca, S., Wiese, S., Dion, A., Roussos, Z., Renwick, R., & Yoshida, K. (2011). Getting on with life: positive experiences of living with a spinal cord injury. *Qualitative Health Research*, 21(11), 1455–1468. <https://doi-org.ezproxy.baylor.edu/10.1177/1049732311417726>
- Wood, D., Crapnell, T., Lau, L., Bennett, A., Lotstein, D., Ferris, M., & Kuo, A. (2018). Emerging adulthood as a critical stage in the life course. In N. Halfon (Eds.) et. al., *Handbook of Life Course Health Development*. (pp. 123–143). New York, NY: Springer.
- Zautra, A., Hall, J., Murray, K., & the Resilience Solutions Group<sup>1</sup>. (2008). Resilience: A new integrative approach to health and mental health research. *Health Psychology Review*, 2(1), 41–64. <https://doi.org/10.1080/17437190802298568>