

A Phenomenological Study Exploring Relationship Change through the Adjustment to  
Chronic Illness & Disability (CID) Journey

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This dissertation titled  
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### **Abstract**

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A Phenomenological Study Exploring Relationship Change through the Adjustment to Chronic Illness & Disability (CID) Journey

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The purpose of this qualitative phenomenological study was to explore the lived experiences of young adults' adjustment to life with chronic illness and disability (CID) journey. This research aimed to look at how individuals adjusting to life with CID experienced changes in their personal relationships. Three key personal relationships were examined in this research project: family, friends, and intimate partners.

An extensive literature review was conducted on the key components needed to adjustment to life with a CID and have the desired quality of life post diagnosis. The current literature was also reviewed on disability and sexuality and relationships. A gap was found during the literature review with limited resources available for review on how relationships with family, friends, and intimate partners change when one partner is learning to live with a CID.

This research study reviewed the lived experiences of seven participants who were in the adjustment process of learning to live life with a CID. Each of the participants was interviewed using a semi structured interview guide that first looked at how the person is adjusting to life with a CID. Then each of the seven participants were asked about any changes that had occurred post diagnosis with CID with their family,

friends, or intimate partners. The phenomenological research method provided rich, detailed information on the changes that happened in these relationships.

The research data collected were then analyzed for common themes from the adjustment to CID process. These themes were then compared to the current literature and discussed. Themes were also developed from the rich data about the relationship changes that occurred with family, friends, and intimate partners. These themes identified three key components (relationship status at diagnosis, communication, and adaptability in their relationship) of relationship change during the adjustment to CID journey.

The significance of this study was to look at how relationships change when young adults are adjusting to life with a CID diagnosis. This research provides a starting point for future research on each specific type of CID and how relationships may change with family, friends, and intimate partners.

## **Dedication**

*I dedicate this dissertation to my father, Bobby Lake Stevens. I could not have made it through this PhD program and my own adjustment to CID journey without your love and support. I love and miss you.*

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## Table of Contents

	Page
Abstract.....	3
Dedication.....	5
Acknowledgements.....	6
List of Tables.....	14
List of Figures.....	15
Chapter 1: Introduction.....	16
A Brief Overview of my Personal Journey with CID.....	16
Background of the Study.....	18
Adjustment to CID.....	18
Disability & Relationships.....	20
Problem Statement.....	23
Research Questions.....	24
Significance of the Study.....	24
Purpose of the Study.....	26
Methodological Approach.....	26
Limitations of the Study.....	30
Definition of Terms.....	30
Chapter 2: Literature Review.....	32
Introduction to the Chapter.....	32
Psychosocial Adjustment to CID.....	33

	8
Stress.....	34
Crisis/trauma.....	36
Loss & grief.....	36
Body image.....	36
Self-concept.....	38
Stigma.....	39
Uncertainty and unpredictability.....	39
Time.....	40
Hope.....	40
Resilience.....	41
Cultural factors.....	43
Quality of Life.....	44
Identity Development during CID.....	45
Erickson: Psychosocial Stages of Development.....	46
Bishop: The Disability Centrality Model.....	46
Gill: Disability Identity Develop Model.....	48
Relevant Qualitative Outcome Studies.....,,,	49
Disability & Relationships.....	53
Family.....	54
Friendships.....	55
Intimate partner.....	56
Conclusion.....	58



Chapter 3: Methodology.....	59
Introduction to the Chapter.....	59
Problem Statement.....	59
Research Questions.....	60
Theoretical Approach.....	60
Phenomenology.....	62
Intentionality.....	64
Openness.....	65
Embodied listening.....	66
Phenomenological attitude.....	67
Phenomenological Reduction.....	68
Bracketing/bridling.....	68
Reflexivity.....	70
Epoche.....	70
Data Collection.....	71
Gaining access.....	72
Sample technique/size.....	73
Interviewing.....	74
Semi-structured interview guide.....	75
Documentation.....	77
Self as the Researcher.....	78
Data Analysis.....	79

	10
Limitations of the Study.....	83
Ethical & Legal Considerations.....	84
Informed consent.....	84
Confidentiality.....	84
Conclusion.....	85
Chapter 4: The Participants & Their Personal Journeys through CID.....	86
Introduction to the Chapter.....	86
Interview A: Jack.....	87
Interview B: Will.....	89
Interview C: Dorothy.....	91
Interview D: Karen.....	93
Interview E: Grace.....	95
Interview F: Sophia.....	97
Interview G: Rose.....	99
Summary.....	101
Demographic Trends.....	103
Current age.....	103
Diagnosis of CID.....	104
Relationship status.....	104
Educational status.....	105
Employment status.....	106
Data vs. Theory.....	106

	11
Conclusion.....	110
Chapter 5: Data Analysis.....	111
The Journey Thus Far with Adjustment to Life with CID.....	111
Psychosocial Adjustment Factor to CID.....	111
Stage 1.....	112
Crisis/trauma.....	112
Stress.....	113
Uncertainty and unpredictability.....	114
Stage 2.....	117
Loss/grief.....	118
Stigma.....	120
Stage 3.....	123
Time.....	123
Self-concept.....	125
Hope/resilience.....	127
Conclusion.....	130
Chapter 6: Relationships and Adjustment to Life with a CID.....	132
Introduction to the Chapter.....	132
Family.....	132
Discussion of Family Relationship after Diagnosis of CID.....	141
Friendships.....	144
Discussion of Friendships after Diagnosis of CID.....	150

	12
Intimate Partner.....	151
Single at time of interview.....	151
Dating relationships at the time of interview.....	153
Married/partnered at time of interview.....	157
Discussion of Relationship Change Themes.....	162
Theme 1: Relationship status in the early stages of the introduction of CID.....	163
Theme 2: Open communication.....	164
Theme 3: Adaptability.....	166
Conclusion.....	169
Chapter 7: Final Thoughts, Discussion, & Future Recommendations.....	170
Introduction to the Chapter.....	170
Implications for Counselors & Counselor Educators.....	171
Participant Recommendations for Counselors & other Healthcare providers.....	173
Limitations & Recommendations for Future Research.....	178
Limitations.....	179
Recommendations.....	180
Researcher's Observations and Final Thoughts.....	182
Conclusion.....	183
References.....	185
Appendix A: Recruitment Flyer.....	194
Appendix B: Semi-Structured Interview Guide.....	195
Appendix C: IRB Approval Letter.....	197

Appendix D: Approved Informed Consent with Adult Signature.....	198
Appendix E: Approved Informed Consent without Signature.....	202

**List of Tables**

	Page
Table 3.1. Data Analysis Process.....	83
Table 4.1. Demographic Information from the Participants of the Study.....	102

## List of Figures

	Page
Figure 5.1. First Stage of Psychosocial Factors of Adjustment to Life with CID.....	112
Figure 5.2. Second Stage of Psychosocial Factors of Adjustment to Life with CID.....	117
Figure 5.3. Third Stage of Psychosocial Factors of Adjustment to Life with CID.....	123
Figure 6.1. Family Relationship Themes.....	145
Figure 6.2. Close Friendships through the Adjustment to CID Process.....	151
Figure 6.3. Themes from Participants who were Single at the Time of the Interviews.....	153
Figure 6.4. Themes from Dating Relationships during Adjustment to CID Process.....	157
Figure 6.5. Married/Partnered Relationship during the Adjustment to CID Experience.....	162
Figure 6.6. Themes from Factors of Relationship Change during the Adjustment to CID Process.....	168

## **Chapter 1: Introduction**

People in society can become ill or injured at a moment's notice. This can be due to unexpected medical conditions or accidents such as a motor vehicle crash. According to the Centers for Disease Control & Prevention (CDC) 2012 statistics, it is estimated that 117 million people are currently living with one or more chronic illnesses. The National Health Council reported in 2014 that 40% of Americans (133 million) are living with a chronic health condition. The NHC estimates that by the year 2020 the number of Americans living with chronic illness is projected to be 157 million, with 81 million Americans living with multiple chronic conditions. These numbers are significant as more and more people acquire a chronic illness or disability (CID).

When people are diagnosed with a CID, they can feel as if their world is falling apart. My own lived experience is an example of how developing and adjusting to a CID can be a difficult journey.

### **A Brief Overview of My Personal Journey with CID**

In January 2010, I became extremely ill and was rushed from my doctoral classroom at Ohio University to the local emergency room. I do not have much memory of the time between January 6, 2010 and May 6, 2010 due to being in a medically induced coma while a team of doctors worked to save my life. I had been misdiagnosed with mononucleosis when in all actuality, what I had was atypical gallbladder disease with quarter-sized stones blocking the duct that allowed fluid to be excreted. The duct ruptured that day in class and sent gallstones into my pancreas, large intestine, and abdominal wall, which caused me to start to internally bleed to death. I was airlifted in a



snowstorm to a major medical hospital in Columbus, OH where doctors performed 12 surgeries over the three-month period that I was in the ICU.

Once I was stable, I was transferred to a rehabilitation hospital where I had to be weaned off the feeding tube and ventilator. I spent the next four months in physical, occupational, and speech therapy where I learned how to walk, swallow, and understand how to complete other daily living skills again as a person with a CID.

Because I have been a rehabilitation counselor since 2003, one thing that surprised me was the lack of information that is given to the client/patient in regards to how to manage changes in life such as interpersonal relationships. Not once did any medical or social services professional ever talk to me about relationships or sexuality changes once I was living with a CID. In fact, several times when I asked specific questions, the subject was avoided or I was referred to another professional. In one instance, a nurse whom I had gotten to know told me that I probably knew better than she did because I had studied about people with all different types of disabilities. I was never offered counseling of any sort throughout my entire eight-month stay in the three different hospitals. I was left to my own devices to educate myself about the lived experiences I was having as I adjusted to my CID.

Throughout my journey with diabetes and chronic pain, I have had medical professionals, family, friends, and colleagues treat me differently than they did before I acquired these medical disabilities. It really upset me greatly when a doctor or nurse would speak to my father instead of directly to me about my health and/or care. Since my discharge from the rehabilitation hospital in August of 2010, I have not only had to

transition from a person who was able-bodied to a person with a chronic illness/disability but I have also had to set boundaries and educate family, friends, colleagues, and potential intimate partner as to how I prefer to be treated as a person with medical CIDs. For these reasons, I have chosen to explore the lived experiences of people who are in the process of adjusting to CID to see if their intrapersonal relationships have changed.

### **Background of the Study**

A chronic illness can persist over time and may not have a definite start or ending point (Kralik, van Loon, & Visentin, 2006). Bury (1991) defined CID as a long-term, perhaps permanent, event in a person's life. Technology and medicine advancements have allowed people with CID to have longer life expectancies (Shahar & Lerman, 2013) and have better quality of life post CID diagnosis.

Traumatic events are part of the human experience and are highly personal and specific to each individual that they happens to (Buse, Burkner, & Bernacchio, 2013). CID may have a sudden onset and can be very traumatic (Livneh & Antonak, 2005). It is vital that a person with CID seeks support and/or counseling during the intensity of the crisis/trauma to avoid negative long-term effects such as depression or post-traumatic stress disorder (PTSD). Even with clients that develop a CID over time, the support assistance of a professional counselor can still be an essential component to ease their adjustment to CID.

### **Adjustment to CID**

Livneh & Antonak (2005) identified the six most common responses to being diagnosed with a CID as found in the literature, which are shock, anxiety, denial,

depression, anger/hostility, and adjustment. Not all clients with CID will go through all six stages, while some clients may ebb and flow through these stages as they adjust to their individualized diagnosis. They also identified some basic concepts of CID, including stress, crisis, loss and grief, body image, self-concept, stigma, uncertainty and unpredictability, and quality of life. The focus of this dissertation research endeavor was intended to focus on the quality of life factors as a person adjusts to life with a CID.

Quality of life is considered to be the overall level of satisfaction that people with a disability have about their daily activities. Livneh and Antonak's (2005) description of the quality of life included several functional domains, including intrapersonal (general health, life satisfaction, and well-being); interpersonal (family life, social activities); and extra personal (work activities, housing). People with CID have to find ways to adapt to their new found diagnosis and incorporate it into their life plan. Quality of life is considered positive if clients with CID are managing their symptoms well and have a positive self-concept and body image. Negative quality of life happens when a person with CID has an extended stressful period and has constant feelings of loss and grief.

Social support has been noted as an important component during the adjustment to the CID journey (Bury, 1991). Social support allows the person adjusting to life with a CID to discuss openly with others how he or she is feeling and what his or her symptoms are on a particular day. Practicing open communication allows people with CID to express their wants and needs. This open communication allows accommodations to be accomplished for themselves as well as people in their social circle. This open dialog

creates a jointly agreed upon presentation of symptoms and goals to be achieved to reduce stress caused by the adjustment to CID process.

Relationships are a significant part of a person's quality of life (Charmaz, 1995). R. Carter and C. Carter (1994) explored marital adjustment with 46 married pairs with chronic physical illness. The study found that couples that had tight bonds had higher levels of marital satisfaction. This closeness assists clients with CID to cope with their disability. The spouse provides support, empathy, and, in some cases, care giving for the spouse with CID. In cases where both spouses had some type of illness, there were higher levels of anxiety and a higher reliance on support from family, medical professionals, and support groups, and the quality of life was much lower. The level of support available for someone with CID is an indicator of how they will cope with disability, and it can have a direct result on their quality of life.

### **Disability & Relationships**

Sexuality is a natural expression of our quality of life (Juergens & Smedema, 2009). While "sexuality" is often associated with sexual acts, this is not always the case. According to Muzacz and Akinsulure-Smith (2013), our sexuality is displayed through the physical, emotional, social, and psychological aspects that make us our own sexual beings. Medlar (1998) viewed sexuality as including biological, psychosocial, ethical, emotional, religious, and cultural factors. Sexuality is one of the essential parts of human beings that make a person most vulnerable in the areas of intimacy, family life, self-esteem, and self-acceptance (Grey, Cummins, Johnson, & Mason, 1989). Therefore,

sexuality is of great concern to all people, including those with disabilities (Juergens & Smedema, 2009).

Due to negative social attitudes and stigma, people with disabilities may develop both real and self-imposed limitations in regards to dating, romance, and sexual intimacy (Juergens & Smedema, 2009). This can cause people who acquire a disability to stay in denial about their diagnosis for quite some time (Hingsburger & Tough, 2003). This opens the possibility for people with disabilities to discriminate against other people with disabilities as a way of coping with their own life situation.

Di Giulio (2003) discussed how people with acquired disabilities have to adapt their physical, psychological, and emotional aspects of their self, which includes their sexuality. Issues with self-image may develop, and as a result, a person's self-confidence may be affected. Psychological and sociocultural barriers may be even more of an obstacle for the person with an acquired disability than the actual documented impairment (Juergens & Smedema, 2009). This can cause a major challenge when trying to date or continue a relationship with a significant other. Partners may have to become caregivers, which can cause strain and stress on the relationship (Juergens & Smedema, 2009).

Kedde and van Berlo (2006) conducted a study about sexual esteem, which they defined as a person's ability to relate sexually with another person. They considered the age of onset of disability to be a major factor in how sexual self-image develops. Their study found that men who acquired a disability later in life had a much harder time adjusting to differences in their sexual relationship than did women in similar situations.

Women who acquired a disability later in life put more effort into developing the interpersonal aspects of sexuality, whereas men placed the psychological aspects of sexual esteem and body esteem as the higher priority.

Taleporos and McCabe (2003) conducted a study that compared relationships of people with a physical disability with those of their able-bodied peers. This study looked at sexual esteem and well-being as it relates to human sexuality, and found that being seen as a friend by a potential mate can leave a person with a disability feeling unwanted sexually. This may result in the person giving up on finding companionship all together.

Taleporos and McCabe (2003) also found that the level of severity of disability was directly related to the likelihood of people with disabilities being single. They established from their research that people with disabilities who required more assistance with daily living skills (bathing, dressing, cooking, etc.) were more likely to be single and less satisfied with their sexual needs. The research team discovered that people who were disabled and single reported higher levels of depression and lower levels of sexual esteem as compared to their able-bodied peer group. The overall conclusion of the study was that people who have a physical disability are less likely to be in a sexually intimate relationship.

While studies have been conducted on the psychosocial aspects of adjustment and coping with CID, and separate studies have looked at sexuality and disability, few studies have combined chronic illness and disability with relationship issues/concerns of the person adjusting/coping to a new diagnosis of CID. This study specifically focuses on the lived experiences of how relationships change for people who are adjusting to and

coping with a CID. The findings in this study provide the counseling field an opportunity to expand and gain resources to assist their clients with CID. This study combines the adjustment to the CID process with relationship changes and concerns to accomplish the following goals:

1. Increase counselors' knowledge base of how relationships are affected when a person acquires a CID.
2. Assist counselors in understanding the lived experiences of the psychosocial aspects of adjustment to the CID process.

Studies such as these will enable counselors and other medical professionals to better assist clients to have the opportunity to have a successful quality of life adjustment in their significant relationships.

### **Problem Statement**

The purpose of this study is to understand the lived experience of people who have acquired a chronic illness and disability (CID) diagnosis and how the diagnosis/es have/had affected their relationships with their family members, close friendships, and intimate partner.

An explanation of these terms follows. In this study, *family members* are the people in the participants' immediate families whom they consider to be the person(s) that raised them growing up. This could include biological parents, stepparents, grandparents, adopted parents, and so on. A couple of the participants chose to also talk to the researcher about their siblings and children. While relationship change with siblings and children were not part of the researcher's plan to include in this study, I

decided that the siblings and children data should be documented in this research endeavor.

*Close friendships* are defined for this research project as friends whom the participant considers to be people with whom they spend quality time. These are people that the participants see as close friends, and they may even consider them to be like extended family members.

*Intimate partners* are the people in the participant's lives that they had a romantic connection with at the time of the interviews. This could be a spouse, boyfriend/girlfriend, or same-sex partner.

### **Research Questions**

RQ1: What are the lived experiences of people in young adulthood as they adjust to life with a diagnosis of CID?

RQ2: What types of relationship changes did the person with the newly diagnosed CID experience with family members, close friendships, and intimate partner(s)?

### **Significance of the Study**

Most clinical mental health and rehabilitation counseling master's programs do not require a course on human sexuality in their programs of study. This is due to the fact that state licensing boards do not require a specific course in human sexuality. However, there have been researchers in the helping professions literature for 40 years who have advocated adding human sexuality to the education of future counseling professionals (Fyfe, 1980; Tanner, 1974). Tanner (1974) found that one of the largest barriers to teaching a class on human sexuality was objections from the administration at



the college level. Fyfe (1980) wanted to present counselors with the knowledge base to be able to provide a comfortable, knowledgeable space for clients to be able to talk about sexuality and relationship issues openly and honestly. Burling, Tarvydas, and Maki (1994) found that clients will most likely not bring up issues of relationship/sexuality if they do not feel comfortable that the counselor is willing to discuss it and knowledgeable about their specific problem.

In the counseling profession, we advocate for our current and future counselors to be able to take a holistic outlook on assisting our clients in working through their problems in a therapeutic environment. If we are not training our counselors on issues of disability and sexuality, then they will not have the specific tools to be able to discuss human sexuality and relationship issues with their clients. As counselors, we must listen to the needs of our clients so we can better prepare ourselves to not only assist the current clients, but to have the necessary knowledge and skill set to assist clients in the future as well.

Allowing clients to tell their stories of how they have adjusted to/coped with a chronic illness and disabilities (CID) diagnosis and how it affected their sexuality/personal relationships has provided a new vantage point of our profession to better educate our current and future counselors. The purpose of this research study is to understand the lived experience of people who have acquired a chronic illness and disability (CID) diagnosis and how said diagnosis affected their relationships with their family members, close friendships, and intimate partner. The results of this study allow counselors and counselor educators to have an insider's look into the key components of

how relationships are affected with a diagnosis of CID. This study provides a baseline of what additional information about disability and relationships needs to be added to the current curriculum for future clinical mental health and rehabilitation counselors.

### **Purpose of the Study**

The purpose of this study is to add to the professional literature for medical and social services professionals by providing information from the lived experiences of people adjusting to CID and how this adjustment process changed significant intrapersonal relationships in the clients' lives (family members, close friendships, and intimate partner). This study enables medical and social service workers to be more prepared in assisting clients with the adjustment to CID process, as well as helping fill gaps in the literature on the adjustment to CID for both the people adjusting to life with a CID as well as their family members, friends, and intimate partner.

### **Methodological Approach**

This dissertation takes a qualitative approach, with an emphasis on interviews. Patton (2002) defined qualitative interviewing as a process of learning about people, places, and things that we cannot directly observe. Interviewing allows the researcher to delve into another person's journey/truths and learn from his or her individualistic experiences. Patton goes on to state that the quality of the information we obtain is dependent on the interviewer; qualitative researchers must be prepared when they start to collect the data that would be most beneficial. In order to do this, an interview guide is one of the most valuable instruments for qualitative research (Patton, 2002). An interview guide can be used as the road map for the researcher as the interview

progresses. However, Patton cautions the reader that there are no perfect interview tools, because not every interview style will be the best fit for the person and the information you are trying to obtain.

Patton (2002) discussed the different types of questions you can develop and ask of your interviewees, including opinion-based, knowledge-based, and background informational questions. Patton advised that you carefully word your questions and pay attention to the order of the questions you ask the interviewee when conducting your interview. It is vital that you build up rapport with your interviewees so they will feel comfortable disclosing data that could become essential to your research.

Both Patton (2002) and Glesne (2011) discussed the importance of recording the interview data and the transcription process. Qualitative researchers should not go into an interview with their ears as their only source of documentation. It is essential that the interviewer take good field notes during the interview. In addition, consent must be obtained to record the interview, so it can be reviewed later to ensure no data was missed during the interview process. It is essential to make time the same day of the interview to review both your field notes and the recording while the interview is fresh in your mind. This technique allows for the interviewer to document the interview as clearly and precisely as possible.

Glesne (2011) also pointed out that it is important for the interviewer to not influence the interviewee with leading questions or presumptive questioning. It is best to allow the interviewees to understand that they are the knowledgeable resource that the interviewer is seeking information from. It is up to the researcher to keep the interview

flowing and keep the interviewee on subject and task. The interviewer directs the interviewee through the process without influencing the data output.

Rubin and Rubin (2012) identified the key elements of a qualitative interview. The first area is detail. When conducting qualitative interviews, you want to identify every potentially valuable aspect of what you are investigating. Next, the researcher should think about depth. When conducting interviews, the interviewer wants the interviewee to talk about multiple layers of the topic being researched. Depth allows the interviewee to go further than the superficial answers that most people give in a conversation with peers. Next, the researchers should evoke vividness as a key element. Having an interviewee paint you a metaphorical picture so that the interviewer feels like he or she is experiencing what is being discussed is key for qualitative research. Nuance is the next identified key element. By asking precise probing questions, the researcher is able to get a better grasp on what exactly the interviewee means by his or her statements. The last key element identified is richness. Richness allows the interviewer to identify multiple themes that can be explored more in depth to get a more holistic picture of what the interviewee is speaking about. Richness is achieved by listening intently and asking clarifying questions when the interviewer is unsure of what the interviewee is trying to say.

Semi-structured interviewing enables qualitative researchers to ask the identical questions to a selection of interviewees in order to show accurate comparisons or quantify results (Stake, 2010). This allows interviewees to tell their stories, but also allows the interviewer to collect the same data from each participant. One way to

accomplish this is by asking what is referred to as an exhibit question (Stake, 2010), in which the interviewer asks the interviewee to respond to a specific statement or quote. This may also allow the researcher to follow up with an opinion question or a feeling question to record the interviewee's immediate reaction to the exhibit question.

Phenomenological research allows the researcher to identify and describe the common meaning for a group of research participants who have experienced common phenomena (Creswell, 2013). These lived experiences that the interviewees discuss with the researcher allow for common themes to be identified and documented. This collective data-gathering technique allows the researcher to form a description of what the interviewees experienced and how they experienced the phenomena (Moustakas, 1994).

This study used phenomenology as its research methodology, which allowed the researcher to document the lived experiences of people who were adjusting to life with a CID. A semi-structured interview guide was developed to allow the researcher to find common themes of information provided directly by the people adjusting to life with a CID. This semi-structured guide allowed the researcher to find common themes among the interviewees on how their relationships changed with the three identified groups of people found in the research questions: family members, close friendships, and intimate partner. Gathering this qualitative data/themes provided future counselors to have a knowledge base of how they can be better prepared for possible concerns of clientele who are going through the many stages of adjustment to CID.

**Limitations of the Study**

As with all research, several limitations should be considered:

1. Relationship concerns may not be an easy topic for some participants to be willing to speak about openly and honestly with a researcher that they have just met.
2. It is essential to ensure that participants understand that the information they shared with the researcher will be kept confidential to allow participants to feel comfortable speaking openly about personal relationships concerns as they relate to disability and relationships.
3. This study focuses on people in early adulthood who were adjusting to CID between the ages of 18-40. The data may not be relatable to people adjusting to CID before the age of 18 or after the age of 40

**Definition of Terms**

For the purpose of this study, the following terms are defined as:

Chronic Illness and Disability (CID): a diagnosis of a disease or disability that the person was not born with that is not easily cured. The CID diagnosis has had or has the potential to have significant changes in the person's lifestyle in areas such as daily medical care, physical limitations, social limitation, and work limitations (researcher's definition).

Acquired Disability: a disabling condition, which has been acquired after the age of 18 (researcher's definition).

Counselor: a clinical mental health or rehabilitation counselor who has a master's degree in the counseling profession and is licensed and/or certified to practice with clients with physical, intellectual, or mental health diagnoses (researcher's definition).

Intimate Partner: a dating/romantic partner for a person with a CID. This could be a wife, husband, boyfriend, girlfriend, or same-sex partner (researcher's definition).

Sexuality: how we display our relationships with a chosen partner through means of physical, emotional, social, and psychological aspects that make us our own sexual beings (researcher's definition).

## **Chapter 2: Literature Review**

### **Introduction to Chapter**

Chronic illness and disability can bring a person's life to a complete halt when one is first diagnosed. I can attest to this with my own adjustment to CID, because I had to put my education on hold for a year and a half while I recovered and adjusted to living a life with CID. I was not given a lot of information while in the early stages of recovery on how my life would change not only medically but psychosocially. The goal of this chapter is to review the current literature on the adjustment to CID process (Bishop, 2005; Chan, Cardoso, & Chronister, 2009; Falvo, 2009; Kralik, van Loon, & Visentin, 2006; Livneh & Antonak, 2005).

While disability identity development has been focused on by many researchers (Baily-Lewis, 2007; Bishop, 2012; Frank, 2002; Galvin, 2005; Gill, 1997; Schneider, 2013), a gap was identified in regards to research that focuses on the lived experiences of how the personal relationships of people adjusting to CID changed after their initial diagnosis.

Current research on sexuality and disability (Burling, Tarvydas, & Maki, 1994; DiGiulio, 2003; Juergens & Smedema, 2009; Kedde & van Berlo, 2006) generally focuses on people that were born with CID, and in most cases, does not report on any relationship changes that happened during the adjustment to CID process, which further shows a gap in the literature.

Due to the gap identified by this literature review, a qualitative phenomenological study was proposed to learn about the lived experiences of changes in personal



relationships of people who are in the process of adjusting to a CID. The focus of this study looked at three primary interpersonal relationships: family members, close friendships, and dating/partners. The chapter begins with a review of psychosocial adjustment to CID.

### **Psychosocial Adjustment to CID**

According to Falvo (2009) rehabilitation professionals are moving away from a sole focus on the medical model and are now looking at adjustment to CID as an biopsychosocial experience. The medical model emphasized pathology as the root cause of CID and has a standard code of practice of how to deal with the symptoms of each CID. Falvo (2009) suggests that counselors and other rehabilitation practitioners look at CID as an experience where the person with CID combines “body, behavior, and society” into the lived daily experiences (p. 2). Falvo (2009) goes on to state that many factors affect the person with CID’s daily lived experiences, such as gender, race, social and family relationships, socioeconomic status, culture, environmental factors, and activities of daily living.

Livneh and Antonak (2005) expanded the discussion on psychosocial factors with the six most common reactions to being diagnosed with a CID found in the literature: shock, anxiety, denial, depression, anger/hostility, and adjustment. It should be noted that not all clients with CID go through all six stages, and clients may ebb and flow through the reaction stages as they adjust to their diagnosis.

Coping is a psychological strategy that is used by clients with CID to reduce stress associated with their diagnosis (Livneh & Antonak, 2005). There are two major

coping strategies that Livneh and Antonak (2005) identified: disengagement coping strategies and engagement coping strategies. When clients with CID are using disengagement coping strategies, they may avoid gathering information about how to cope with their CID. Examples of disengaged coping methods are denial, self-blaming, blaming others, and substance abuse.

Engagement coping strategies are used to eliminate stressful events through goal-orientated activities (Livneh & Antonak, 2005). Examples of engagement coping strategies are problem-solving skills, information seeking to diffuse stressful situations, seeking assistance from family and friends, and making plans for the next occurrence of symptoms of CID. People with CID who use engaged coping strategies are usually viewed as having successfully adapted to a life with CID, having higher levels of general well-being, and having accepted that their diagnosis is not going to go away.

Livneh and Antonak (2005) also identified some basic concepts of CID: stress, crisis, loss and grief, body image, self-concept, stigma, uncertainty and unpredictability, and quality of life. Each of these seven areas will be described below with quality of life being explored further in a separate section of this literature review. In addition, time, hope, resilience, and cultural influences will be discussed, as they are important factors in psychosocial adjustment to disability.

**Stress.** Felton, Revenson, and Hinrichsen (1984) claim that clients with CID will be more prone to cope and adjust during high periods of stress. Coping behaviors are viewed as goal-directed as the client responds to stressful situations. How a client is able

to cope with a stressful situation is a predictor of the level of coping the client will most likely be able to achieve.

Felton et al. (1984) studied how adults with four types of CID (hypertension, diabetes, rheumatoid arthritis, and systemic blood cancers) compare when coping with stressful situations related to their CID. The sample consisted of 170 participants evenly spread over the four CID identified. Results of the study found that specific diseases are not exclusively linked with styles of coping to alleviate stressful situations. Emotion-based coping was seen as a weaker approach to adjustment to stressful situations as compared to clients that used problem-focused coping strategies. Social support from medical professionals as well as family/friends was an indicator of clients being able to stay more focused on coping with stressful life events.

People with CID experience tension due to needing to cope with many different types of daily stressors. Some examples of daily stress include the loss of a degree of independence, meeting the needs of family and job responsibilities, potential loss of income, loss of body functions, and altered future goals and plans (Livneh & Antonak, 2005).

Shahar and Lerman (2013) proposed the term *illness personification*. Illness personification is defined as how the individual with CID lives with, under, and outside of their chronic illness. They developed this term to assist clients to understand how to deal with chronic stress (persistent and continuous) that happens when a person with CID is adjusting to the symptoms of his or her newfound disability. The clients must find ways to change their attitude to reduce the stressful situation. To alleviate stress, the

client with CID needs to use goal-directed actions. These goal-directed actions will be used to eliminate stress on both short and long-term scales. Accepting the diagnosis as part of the self allows the person to personalize it and incorporate it into one's transformation of one's new identity as a person with CID. This provides the client with a sense of meaning of the stressful events associated with the symptoms of CID. It also allows clients to form a plan of action for reoccurrences of the stressful situations/symptoms.

**Crisis/trauma.** Traumatic events are part of the human experience. Traumatic events are highly personal and specific to each individual that they happen to (Buse, Burkner, & Bernacchio, 2013). CID may have a sudden onset and can be very traumatic (Livneh & Antonak, 2005). Therefore, it is vital that the person with CID seeks support and/or counseling during the most intense part of the crisis/trauma to avoid negative long-term effects such as depression or post-traumatic stress disorder (PTSD).

**Loss & grief.** The experience of a sudden onset of CID will most likely result in the client having feelings of loss and grief (Livneh & Antonak, 2005). This may be due to a loss of a body part or to the realization that the diagnosis of a chronic illness will end up shortening their life span. Depression needs to be monitored, as it is common for people with CID to develop depressive symptoms. Clients may also suffer from anxiety and high levels of stress during a period of loss and grief.

**Body image.** The experience of loss of body functions or part, pain, and changes in the physical appearance may cause the individual with CID to have issues with body image (Livneh & Antonak, 2005). As people with CID adjust to CID, they should be

encouraged to incorporate their new found body image into their self-perception and daily living (Charmaz, 1995).

Charmaz (1995) viewed chronic illness as an attack on the body that threatens our self-integrity. A person's sense of wholeness may be significantly damaged. The client must be able to reassess the meaning of wholeness and integrate this new body image and functions into a sense of self. This process can be extremely difficult for people with CID. This can be due to the fact that the illness may progress and regress with little to no warning. This makes it difficult for a person to know what the next day will bring. Some CID progressively gets worse and the person will have to continue to adjust and cope with further loss of function of body parts.

In her qualitative work with people with chronic illness, Charmaz (1995) discussed the difference between struggling *against* illness versus struggling *with* illness. Client who struggle against illness see their CID as something that they must continually fight and conquer. They hope to regain their old self again. Clients who struggle with illness focus on maintaining the aspects of their body that are still functioning properly and integrating a new body image into their lives as something that is here to stay. As a result, the patients are able to attend to their symptoms of health and take control over their lives again. The person with CID stops wishing for the old body image and adopts the new one into his or her sense of self.

Galvin (2005) identified in her qualitative study that people adjusting to CID had issues with appearance and sexuality. The participants felt limited by stereotypes and stigma about being a person with a disability and wanted to continue or start new intimate

relationships. Participants had to overcome such societal norms and redevelop their sense of being sexually attractive. Learning how to be able to continue sexual intimacy was a challenge, but some participants reported better lovemaking due to the lack of focus on traditional penetrative sex. Instead, the participants learned to develop more intimacy with their partners in non-traditional ways.

**Self-concept.** A person with CID may have issues with sense of self due to the negative reactions he or she may experience in social places (Livneh & Antonak, 2005). Being referred to as disabled can be a very difficult process for the individual with new found CID to adjust to and be comfortable with. CID not only creates changes in the person's physical self, but also affects the person's identity and self-worth (Bury, 1991). Loss of function of the body leads clients to lose confidence in themselves, which may lead to fewer social interactions.

Bury (1991) identified two stages of meaning when a person is diagnosed with CID. The first stage is what the consequences are for the individual. The client must review how the symptoms of the newly diagnosed CID affect daily living skills, work ability, and other social factors. The second stage is for the client to realize how significant the changes are to activities of daily living and their impact on the self and others around them. Coping behaviors can assist clients with CID to maintain their feelings of personal worth.

People who are chronically ill may have changes in their identity over the course of adjustment to CID (Charmaz, 1995). Clients must constantly be cognizant of the cost certain behaviors will have on their health. At times, it is in the person's best interests to

make difficult decisions such as to stop working at a particular job or to stop a favorite activity (jogging, drinking alcohol, etc.). When this activity is stopped, the person has to reassess how this change will be beneficial and what activity can be added to fill the void. Clients must find ways to redefine their self-concept as changes happen over the course of a life with CID. Adapting allows people with CID to take responsibility for themselves and gives them a renewed sense of meaning and self-confidence.

**Stigma.** The person with CID will have to deal with stereotypes and stigma from people in their social circles (family, friends, coworkers, strangers, etc.) and community (Livneh & Antonak, 2005). This can increase stress in the person with CID, reduce self-esteem, and make the person with CID withdraw from social environments, if not carefully monitored by medical professionals and counselors. Charmaz (1995) discussed how visible disability leads to much more stigmatized reactions from general society and even friends and family. Clients may find that they are treated as incompetent or childlike due to the societal stereotypes that exist about people with disabilities.

Stereotypes and stigma can hinder not only psychosocial adjustment to disability and coping efforts for the client, but it can also damage the counseling relationship. Rehabilitation counselors must get to know the client on an individual level and not make assumptions from work with previous clients with a similar CID. The perceptions of self and others of people with CID may lead the patient to have a sense of urgency to reduce the negative symptoms and conceal his or her diagnosis.

**Uncertainty and unpredictability.** CID symptoms can vary greatly depending on the actual diagnosis (Livneh & Antonak, 2005). For example, people may have days

with little to no symptoms and the next morning wake up in great amounts of pain or have other negative symptoms of CID. The unknown of CID can be very stressful for clients. Bury (1991) identified uncertainty as one of the key aspects of the disruptive experience of CID for the individual and the family unit. Changes will continue to happen over time for the individual with CID. It is important for patients to stay fluid in their approach to coping with the symptoms of CID.

**Time.** Time has been linked to the process of adapting and coping with the symptoms of chronic illness and disability (Livneh, 2012; Livneh, 2013). Adaptation to disability most likely will not follow an orderly standard of time, but instead evolve at difference paces for different clients. Time is influenced by both past memories and future expectations.

Time plays a major role depending on the individual diagnosis of CID (Livneh, 2012). For example, a person who has a life-threatening/acute CID diagnosis (i.e., terminal cancer) will be more cognizant of how much time is left as opposed to someone who was diagnosed with a non-life threatening/chronic diagnosis (i.e., diabetes). Life-threatening/acute CID diagnosis makes the patient focus more on the time limits of planning for the future. The onset of CID in some cases will promote the fear of death and each passing day will be of great importance and significance (Livneh, 2013).

**Hope.** The absence of hope can be a significant factor in the emotional health of a client adjusting to CID (Worthen & Isakson, 2010). Feelings of hope lead the client to having more motivation for change, developing clear goals, building confidence, and seeking out social support, all of which are key aspects to positive change with coping



and adjusting to disability. Hope lets the client have a vision of the desired future.

Having reasonable, attainable expectations will lead the client to having more feelings of hope for positive change.

Yalom (1995) identified the instillation of hope as his first curative factor in effective group therapy. Hope is built with clients by meeting their psychological needs during times of adjustment and coping to CID. Building the belief that clients are capable of meeting their needs and desires builds hopefulness. Clients must learn to set future-oriented goals as opposed to focusing on the negative events of the past, and they can build hope when they are able to hear success stories from other people who have been through similar situations. Hearing these stories instills hopefulness and allows clients the opportunity to set and achieve their goals.

Worthern and Isakson (2010) identified research that shows that clients with low hope may use avoidance coping strategies and become passive. This can lead to the development of mental health diagnoses such as depression or anxiety. On the other hand, clients with high levels of hope have a more optimistic outlook and purpose for moving on with life and making the best of it.

**Resilience.** People who can develop a good quality of life and start to move forward from the crisis of being diagnosed with a CID are considered to be resilient (Kralik et al., 2006). Kralik et al. (2006) discussed how important it is for the counselor to help facilitate resilience in their clients. Resilience allows clients to stop focusing on their deficits and problems and instead to work with their strengths and abilities. The clients are able to incorporate their CID into their lifestyle and treat it almost as if it were

a normal part of their self. This is a time of growth because they have come to the realization that they are survivors. They start to integrate themselves back into their social lives, focus on a healthy lifestyle, and may even be able to return to the work force at this point in their psychosocial adaptation journey to CID. While the clients will have good and bad days depending on their diagnosis, keeping a positive, goal-directed attitude and coping style will assist them in staying in a state of resiliency. However, resilience is not a stationary characteristic, and the person with CID will have to adjust depending on what life stresses are presented.

Kralik et al. (2006) conducted email discussion groups with men and women who were adjusting to CID. They used a participatory action approach as their data gathering methodology, which places the interviewer and interviewee planning and working closely together as the research is gathered. These email discussion groups allowed the participants to openly discuss their journey to adjustment to CID. The results of this study identified how people adjusting to disability defined resiliency. Some of the key factors that were identified were having a strong sense of self and to be able to use others' success stories for their own benefit. The participants described feeling that personal worth was more vital to survival than their physical restrictions. Self-esteem and confidence should be encouraged so that a person with CID can develop their own resiliencies. The counselor assist the person with CID to shift their focus from being different from others and not being able to do some activities that they used to be able to do, to being an individual who is self-confident and will adapt to new ways of doing tasks

in life. Resiliency is a process of reflection, learning, and taking action in the process of adapting to a new way of living life.

**Cultural factors.** Counselors must be cognizant of how CID affects each individual on many different levels, including culturally (Buse, Burkner, & Bernacchio, 2013). The counselor must be aware of the differences between clients that come from an individualist (focus on self) or a collectivistic culture (focus on family/community). If the client comes from a collectivistic culture, then the counselor must be aware of the cultural practices and traditions common to that culture in order to assist the client with adjustment to disability. Clients from a collectivistic society can be resistant to talking about personal feelings for fear of being disloyal to their family/community. In other cases, social support in a collectivistic society is a large portion of how resilience develops. The community may support the person experiencing adjustment to disability, or, in some cases, the community may view the person as damaged and a lost cause. It is imperative that the rehabilitation counselor knows as much about the client's culture as possible when working through adjustment to disability issues.

Another key area is religion and spirituality (Buse, et al., 2013). Religion and spirituality may influence values and beliefs that will inform how clients adapt and develop resiliency towards their newfound diagnosis of CID. Healthy individuals in some cultures may take the view that the body, mind, and spirit have to be in perfect harmony with each other for healing to take place, but this may not be possible when a person is first adjusting to CID. Clients from cultures that have a specific focus on

spirituality and the relationship of the body and mind may find it harder to have counselors assist them with traditional counseling methods/theory.

### **Quality of Life**

Quality of life is considered to be the overall outlook of the person with CID on a day-to-day function. Livneh and Antonak (2005) describe quality of life to include several functional domains, which include: intrapersonal (general health, life satisfaction, and well-being); interpersonal (family life, social activities); and extrapersonal (work activities, housing). Quality of life is considered positive if clients with CID are managing their symptoms well and have a positive self-concept and body image, while negative quality of life happens when a person with CID is stuck in a stressful time and has constant feelings of loss and grief.

Bury (1991) discussed the importance of social support during adjustment to CID. This allows patients to discuss openly with others how they are feeling and what their symptoms are like on a particular day, since communicating wants and needs is an important part of quality of life. Accommodation is accomplished when clients with CID can communicate well with their social circle and form an understanding of jointly agreed-upon presentation of symptoms are now part of their daily life.

Relationships are a significant part of a person's quality of life (Charmaz, 1995). R. Carter and C. Carter (1994) explored marital adjustment with 46 married pairs with chronic physical illness. The study found that couples where only one partner had a CID had tight bonds and had higher levels of marital satisfaction. This closeness assists clients with CID to cope with their disability, as their spouse provides support, empathy,

and, in some cases, caregiving for the spouse with CID. In cases where both spouses had some type of illness, there were higher levels of anxiety and a higher reliance on support from other family members, medical professionals, and support groups. In these cases, the ability to cope with disability and quality of life was much lower. Level of support is an indicator of how someone with CID will cope with disability and can have a direct result on their quality of life.

Quality of life can also be threatened when CID affects people's ability to work (Angel et al., 2012). Being unable to work can cause a ripple effect on the person's social life (family, friends), financial life, and mental health (depression, stress, anxiety). Social attitudes can lead to negative self-appraisal and negative worker self-concept (Kosciulek, 2010).

### **Identity Development during CID**

Powers and Dell Orto (2004) noted in their research that the life stage of the person who develops a CID could have a major impact on how he or she is able to cope and adjust to life with a CID. A lot of people develop a CID in the "prime of their lifetime" when they are focused on careers and starting a family (p. 52). The severity of the emotional reaction of the person just diagnosed may depend on the life goals that they were currently working on. It is therefore important to review research on identity development during adjustment to CID. Three identity development models will be discussed: (a) Psychosocial Stages of Development (Erickson, 1950/1963), (b) the Disability Centrality Model (Bishop, Bishop, 2005a; Bishop, 2005b; Bishop, 2012; Bishop, Smedema, & Lee, 2009), and (c) the Disability Identity Model (Gill, 1997).

**Erickson: Psychosocial Stages of Development.** First and foremost, the work of Erik Erickson (1950/1963) on psychosocial stages of development is of importance in working with people adjusting to CID. The stage during which the person develops a diagnosis of CID will affect the “developmental task or crisis” that the individual is already dealing with (Broaderick & Blewitt, 2010, p. 9). This is especially true with people who are adjusting to CID during what Erickson (1950/1963) refers to as the intimacy versus isolation stage of psychosocial development. Different textbooks have slightly different age ranges for this stage, with Broaderick and Blewitt (2010) just referring to this age range as “young adulthood” (p. 10). Erickson (1950/1963) list the ages in young adulthood as between 18-40 years. In this stage of identity development, people are more willing to share their identity with others as they try to develop strong bonds with friends and attempt to build relationships with a significant other. This is also the time that the person develops his or her own family and really gets started in a career.

**Bishop: Disability Centrality Model.** The Disability Centrality Model developed by Bishop (Bishop, 2005a; Bishop, 2005b; Bishop, 2012; Bishop, Smedema, & Lee, 2009) is a model for counselors to use when trying to understand the psychosocial adjustment to disability as it relates to the quality of life of the individual with CID. The model has four conceptual tenets: (a) an individual’s quality of life is dependent on the wellbeing of his or her domains and the order in which those life domains are organized by the individual; (b) onset of CID reduces the quality of life of the individuals life domains and satisfaction; (c) the client starts to work to close the gap between the present status of his or her life domains and desired quality of life; and (d) the client has three

potential responses to improving life domains and quality of life: importance changes, control changes, or neither change occurs (Bishop, 2005a; Bishop 2005b; Bishop, 2012).

Importance changes happen when the client moves life domains to different priority levels (Bishop, 2012). Life domains that no longer can be achieved and provide satisfaction for the client may be moved down or removed from the top priorities of the client's life domains, while other life domains that do provide satisfaction and are attainable by the client with CID will then be put in their place. With control domains the client seeks out way to gain control over one's own body and life. The client may focus on primary controls (efforts to change the surrounding environment) or on secondary controls (efforts to change internal psychological processes). Primary control can be achieved by seeking help from friends/family or obtaining accommodations (wheelchair, changes in job responsibilities, etc.) so that the person can regain his or her desired level of quality of life. Secondary control can be achieved by seeking treatment from medical or counseling professionals that can assist the client in learning techniques to regain control. If the client does not seek out important or control changes, then his or her quality of life will remain at a lower level of satisfaction.

It is important for the counselor to pay specific attention to individuals' differences in how they put their life domains in order of importance (Bishop, 2012). Every individual will have different life domains ranked in the order as they see best to their overall quality of life. The disability centrality model allows the counselor to view the experience and importance of how life domains are affected by the diagnosis and adjustment to CID. This gives the counselor a significant tool to be able to aid clients in

reorganizing their life domains so quality of life can be improved to the desired satisfaction level.

**Gill: Disability Identity Model.** Gill (1997) identified four types of integration in disability identity development. These four are as follows: (a) coming to feel we belong (integrating into society); (b) coming home (integrating with the disability community); (c) coming together (internally integrating our sameness and differentness); and (d) coming out (integrating how we feel with how we present ourselves).

As people with CID are adjusting to this new way of living, their roles in life may all have to be modified due to their CID diagnosis. Time spent away from society in a rehabilitation hospital may have isolated them from the general society, but afterwards, they start to understand that life has changed and they must learn how to cope with it so they can move forward with their new identity. Family, friends, and intimate partner can help facilitate this stage by being supportive as the person with CID develops a new identity and ventures back into society at large.

Next, the person comes home and learns more about what it will be like to live daily life in society with this CID identity (Gill, 1997). This is a time when counselors can play a vital part in assisting people with CID in networking with other people who have been through or are currently on a similar adjustment journey; these individuals can help the client learn how to take care of oneself and live life to the fullest. Ideally, these new relationships become supportive of the person's adjustment journey. Some people with CID may be resistant to this step due to the stage of adjustment that they are in



(denial, anger, etc.) so it is important to have family, friends, and intimate partner be supportive at this time.

Gill's (1997) third step of coming together is when people with CID attempt to bridge the gap between what their family and society views as their strengths and weaknesses as opposed to what they themselves believe they are capable of, while at the same time they adjust and cope to their CID. By focusing on what can be done instead of on the limitations that the CID imposes upon them, they can start to develop self-esteem and set new, achievable life goals. This in turn makes people with CID focus on their positive abilities instead of only focusing on their limitations.

Finally, yet importantly, Gill (1997) discussed the fourth step, coming out, in which the person with CID presents to others his or her new identity as a person with CID in society. This can be a challenging step for people who have a visual impairment (wheelchair, cane, amputee, etc.) due to the fact that they cannot hide their disability from the general public easily. Other people who have CIDs such as diabetes, HIV, or heart disease have a choice of who and when to disclose their identity as a person with CID. Not all people with CID move through these stages at the same pace, but with the proper support from families, friends, and intimate partner, this process can be achieved so the person with CID can adjust to and cope with his or her newfound identity.

### **Relevant Qualitative Outcome Studies**

One type of qualitative methodology that the literature has shown to be useful in qualitative studies with people with CID is the use of narratives. Personal narratives, family stories, and life histories allow researchers using qualitative methodology to

investigate social and cultural patterns (Patton, 2002). A narrative allows the researcher to start with broad, open-ended questions. Then the researcher allows the interviewee to tell his or her story with little to no interruptions (Glesne, 2011). Narratives allow researchers to learn about the human experience and people's psychosocial processes (Lal, Suto, & Ungar, 2012).

Lal, Suto, and Ungar (2012) discuss narratives as having become popular with qualitative researchers interested in studying illness experience and life altering events. Narrative analysis allows the researcher to focus on the inner world of the participant and the influences of his or her environment (physical, social, cultural, etc.). In using narrative analysis, it is essential to build rapport in order to ensure that the participant is comfortable with sharing intimate and sometimes private information with the researcher.

Salick and Auerbach (2006) investigated the adjustment and growth of clients after medical trauma using qualitative interviewing techniques. They focused on looking for themes of resilience and posttraumatic growth, and their goal was to develop a theoretical narrative about the process of trauma and recovery. The researchers chose qualitative interviewing techniques because they wanted to investigate the participants' personal experiences and their process of adjustment to disability. They used a grounded theory approach for data analysis. Grounded theory, which is described by Patton (2002) as a focus on the process of generating theory rather than a particular theoretical content. The results of their study identified five constructs: apprehension (sensing something is wrong), diagnoses and devastation, choosing to go on, building a way to live, and integrating disability into self (Salick & Auerbach, 2006).

Galvin (2005) investigated identity transformations towards developing a disabled identity. Galvin viewed identity as a narrative that is constantly under construction. Using purposeful sampling and snowball techniques from agencies that provided services and support groups to people with disabilities, she collected 92 narratives from four different countries via telephone interviews, written stories, and email communication. In the data analysis, grounded theory techniques were used to analyze the narratives to find common themes. The three identified themes were independence, work, and appearance/sexuality. The author also made note that nearly all of the narratives made mention of stigma from social circles after participants had obtained their CID. Galvin found that the use of analyzing the narratives of the participants allowed her to understand how new values were developed by the participants as they settled into their new identity as a person with CID.

Lynch, Keasler, Reaves, Channer, and Bukowski (2007) conducted a narrative analysis on stories of resilience of participants who were in early recovery from trauma. This study had 18 survivors of interpersonal trauma, all of whom were recruited through an urban outpatient counseling clinic. Narratives of the qualitative interviews were transcribed of the audio-recorded interviews, and a thematic analysis was conducted by the first three authors (Lynch et al., 2007). Coding was derived from the grounded theory approach to identify the experiences of resiliency. Fifty-four codes were identified and they were grouped into the following categories: self, connections with others, actions/coping, affect, type of violence, health, structure, and quality of the narrative. Participants had a desire to develop coping strategies so they could move on with their

lives and deal with the past so they could focus on the present. They desired to be free of the past trauma so they could focus on the connections with others, career aspirations, and to develop decision-making skills to ensure their future.

Persson and Ryden (2006) studied the effective coping of 26 individuals with a physical disability. Data was collected through interviewing the participants about their coping strategies. The interviews were audio taped and transcribed in order to use the constant comparative method of grounded theory data analysis. Two core concepts with five descriptive categories were generated from the data collected (p. 357). The core concepts were as follows: acknowledgement of reality versus creation of hope, and trust in oneself versus trust in others. The five descriptive categories were as follows: self-trust, problem-reducing actions, change of values, social trust, and minimization. The researchers suggested that their findings showed a holistic view of coping with people with CID.

Angel, et al. (2012) used a narrative analysis to look at how counseling interventions were used to assist participants to commit to the plan developed to obtain their goal of adjustment at work and to avoid low back pain. The data was collected from a previously completed randomized clinical controlled trial on assisting clients with low back pain to overcome workplace barriers and increase their physical activity. Out of the 150 participants who received counselor intervention, 20 of the narratives from the semi-structured interviews were selected for narrative analysis. A common theme found in the data analysis was that the counseling intervention had assisted the sample participants with developing strategies to be able to return to work and be more physically active

(Angel et al., 2012). Three themes developed out of this study: interpreting experiences from the intervention that evoked positive changes in behavior and attitude, integrating explanations into daily life, and generating resources. The counseling intervention instilled hope and set new goals for returning to work and being productive in the workplace. The participants reported they were able to focus less on their limitations and pain levels and focus more on physical wellness and ability. The participants were able to move from the passive victim role into a role of being active and in control of their own futures.

O'Donnell, et al. (2013) used narrative analysis to evaluate essays written by first year medical students who had gone on a supervised geriatrics home visit. The study included 165 medical students who were put into pairs to jointly write the essay after they had completed the home visit. The students were given a checklist of things to observe and take notes on, including how the physician interacted with the elderly patient. Eighty-four essays were collected and analyzed. In the analysis, medical faculty developed a key word list based on the checklist of important concepts they were investigating. The study found that the narrative analysis enabled the medical faculty to not only identify what the students learned during the home visits, but also to see how the home visits made them feel about geriatric work and home visits.

### **Disability & Relationships**

According to Chan, Cardoso, and Chronister (2009), it is necessary for the counselor and rehabilitation professions to conduct more social support research because the current literature lacks evidence-based practical support of how social support

impacts health outcomes. In their literature review of over 100 social support studies, Hogan, Wolfgang, and Najarian (2002) found that support from family, friends, and intimate partner has benefits to overall well-being. Chan et al. (2009) likewise stated that social relationships are “critical to the health and well-being of persons with disabilities and chronic illness” (p. 170).

Falvo (2009) talked about how a diagnosis of CID can impact a person in young adulthood, including how physical limitation may “inhibit individual’s efforts to build intimate relationships or to maintain relationships that they have already established” (p. 19). Development of a CID can lead some individuals into intentional or unintentional isolation as they adjust to life with a CID, as in Frank (2002), who wrote about how some days he would be open to letting people close to him during his battle with cancer while other days, he would push people away and be very distant.

**Family.** Powers and Dell Orto (2004) state that the family plays a major role in how individuals diagnosed and adjusting to disability react and cope to their new way of living. Confusing role changes, economic uncertainty, and the role of temporary or permanent caregiver may all play large factors in the reaction family members display towards the person adjusting to life with a CID.

Chan et al. (2009) discuss how research on how family supports play a role in the adjustment to disability process is needed in the literature. This will not only allow counselors and other rehabilitation professionals to understand how the relationship between family members and the person diagnosed with CID affects each other but also better prepare the counselor for the adjustment process of all members of the family.

This will assist counselors to help the individual diagnosed/adjusting to life with a CID and the family through times of crisis. Families must look at areas such as role changes, sibling relationships, and learning to cope with other family stressors (Chan et al., 2009).

Falvo (2009) assisted to fill a gap in the literature on how family relationships changed due to CID. Focusing on the psychosocial impact of the adjustment to CID, Falvo (2009) discussed how the family is impacted when a family member is diagnosed and adjusts to life with a CID, since the family is where identity is developed and relationship building begins. CID can impact families both emotionally and economically, and family members may go through some of the same stages of adjustment to disability (shock, anger, guilt, etc.) as the individual who was diagnosed and is adjusting to life with a CID.

**Friendships.** McDaniel, Hepworth, and Doherty (1999) posited that CID reaches into our family lives and friendship circles and is a prominent factor in our everyday lives. When a person is diagnosed and/or adjusting to life with CID the person may for some length of time be socially isolated. This may either be by choice or be due to being in a hospital or rehabilitation center where friends cannot visit on a regular basis. Powers and Dell Orto (2004) refer to this as the “recovery period,” where the individual with CID is coping with and problem solving his or her diagnosis (p. 58). During the early stages of adjustment to CID, someone adjusting to CID may only stay in contact with long-term established friends whom they are most comfortable with. While social isolation can be a sign of depression, this may not always be the case; counselors should be cognizant that each person with CID will cope with their association with friends on their own terms.

Frank (2002) and Baily-Lewis (2007) discussed the importance of friendships during the adjustment to CID process. Frank (2002) discussed how pain and illness start within one's body and then "move out" until they affect relationships with others (p. 36). During the weeks that he was getting bad medical reports, he found himself distancing himself from his friends by not taking on responsibilities and commitments that he might not be able to keep. As a result of feeling that his future was uncertain due to his cancer diagnosis, Frank distanced himself from his friends. Later in his adjustment to CID journey, he received letters from other people who were survivors of cancer that assisted him to reestablish old friendships and begin new ones, although other past friendships were lost, most likely due to the fact that those people could not deal for whatever reason with Frank's diagnosis of cancer.

Baily-Lewis (2007) discussed in her own dissertation how important visits and support from friends were when she was in rehabilitation and adjusting to life with a CID helped her through some of her darkest days. She noticed a difference between her progress in treatment and that of other people adjusting to their CID who did not have friends visit them.

**Intimate partner.** Chan et al. (2009) pointed out that both negative societal values and attitudes towards people with CID mixed with what others may perceive as their limitations may lead people diagnosed with CID to have a disadvantage when looking to date or maintain an existing relationship.

Families can be opposed to a nondisabled person being in a relationship with a person with a CID (Schneider, 2013). Schneider (2013) wrote an auto ethnography about



growing up with a disability. He was born with cerebral palsy and walks with arm crutches. Schneider described how he was treated no different from his siblings growing up. However, when he was old enough to date he found it challenging. In fact, when he first started dating the woman who is now his wife, both she and her family had concerns about their relationship, due to his disability. Schneider had to do a lot of psychoeducation for both his wife and her family to make them understand that he was looking for a partner to share life with instead of someone to be his caregiver.

Chan et al. (2009) discussed how the significant other of the person diagnosed/adjusting to CID could have added stress. Partners may have higher “levels of emotional distress” and dissatisfaction in the relationship (p. 195) due to several factors such as intimacy, finances, and caregiver burnout, just to name a few.

In her auto ethnographic dissertation, Bailey-Lewis (2007) discusses how adjustment to life with a CID was made easier by the support of her family, friends, and husband. A key turning point in her adjustment journey was the death of her husband, who had been her primary support as she was recovering and adjusting to her new life using a wheelchair for mobility after surviving spinal cord cancer. The loss of a loved one who also serves as a caregiver can create many stressful barriers for the person with CID.

Frank (2002) and his wife Cathie found that it was important through his adjustment to life surviving both a heart attack and cancer for them to have open communication about how life with a CID was affecting both of them. Through open communication, they were able to navigate the twists and challenges that life with a CID

presented to their relationship and family. Frank (2002) states that illness did “not just happen to me, it happened to us” (p. 3). He goes on to state that being able to share losses with his partner was a way that he was able to cope with his CID.

CID can bring partners closer together and push them to the point of breaking apart (Frank, 2002). Frank (2002) documented this point during his battle through cancer; while he and his wife Cathie became closer than ever, another colleague and his wife divorced after going through his own battle with cancer. This is yet another example of how everyone’s journey through adjustment to life with a diagnosis of CID is individualized and personal.

## **Conclusion**

This chapter has provided an overview of the current literature as it pertains to adjustment to CID and how it affects relationships with family, friends, and intimate partner, focusing on psychosocial adjustment to CID, quality of life, identity development during CID, relevant qualitative outcome studies, and disability and relationships. The key areas discussed in this chapter were as follows: 1) Psychosocial Adjustment to CID, 2) Quality of Life, 3) Identity Development during CID, 4) Relevant Qualitative Outcome Studies, and 5) Disability & Relationships. Next, the proposed methodology will be discussed in chapter 3 of how this research will be conducted and analyzed. The next chapter will focus on the methodology used to conduct and analyze this study.

## **Chapter 3: Methodology**

### **Introduction to the Chapter**

The intention of this research was to fill in an identified gap in the counseling literature of how interviewees adjusting to a diagnosis of a chronic illness and disability (CID) experienced interpersonal relationship changes. Using qualitative methodology, the researcher inquired into the identified participants as to what their lived experience was like from the diagnosis of a CID to the present. This study allowed the researcher to understand how the adjustment to CID process has been for the interviewee thus far, focusing on the specific relationships of the person with CID with family members, close friendships, and intimate partner.

The researcher's intent was to gather data of how relationships have changed and in what manner new relationships were developed after the person has adjusted to having a diagnosis of CID. A semi-structured interview guide was developed to assist the researcher to have consistency in the interviews. The guide also gave the researcher the ability to adjust probing questions as the research was gathered.

This chapter will discuss the methodology that was used in this study. The following subsections will be discussed in this chapter: (a) problem statement, (b) research questions, (c) theoretical approach, (d) data collection, (e) data analysis, (f) limitations of the study, (g) self as the researcher, and (h) legal and ethical concerns in qualitative research.

### **Problem Statement**

The purpose of this study was to understand the lived experience of people who have acquired a chronic illness and disability (CID) diagnosis and how the diagnosis(es)

have affected their relationships with their family members, close friendships, and intimate partner.

### **Research Questions**

- RQ1: What are lived experiences of people in young adulthood as they adjusted to life with a diagnosis of CID?
- RQ2: What types of relationship changes did the person with the newly diagnosed CID experience with family members, close friendships, and intimate partner?

### **Theoretical Approach**

People collect data on a daily basis, even when they are not thinking about what they are doing. Glesne (2011) stated that “research is conducted when people deliberately set out to collect data for a specific purpose” (p.3 ) and that as a research topic is developed, the researcher is able to decide if quantitative, qualitative, or mixed methodology will be the best way to proceed. Thus, with this research project, qualitative methodology was identified as the best research method to investigate relationship change as a person adjusts to a diagnosis of CID. I wanted to hear the lived experiences of how relationships changed with family members, close friendships, and intimate partner as the person adjusted to life with a CID and started to cope with the daily requirements to manage their CID.

Creswell (2014) stated that qualitative research is an approach for “exploring and understanding the meaning individuals or groups ascribe to a social or human problem” (p. 4). Qualitative data is collected in the field from the interviewees who have

experienced the research topic that is being investigated. Patton (2002) identified three different ways that a qualitative researcher can collect data: in-depth interviews, participant observation, and reviewing documentation. Interviewing allows the researcher the opportunity to hear the interviewee's direct lived experiences as they relate to the research topic. The researcher is not only able to document the real lifeworld experiences, but also able to hear how the interviewee experienced emotions such as pain, joy, sadness, and so on. Qualitative methodology allowed me to gather and learn firsthand information direct from the interviewees on how they coped and adjusted to changes in their lifeworld after being diagnosed with CID. The interviewees were able to share with me about how significant relationships changed as they adjusted to living as a person with CID.

Qualitative research allows the researcher to enter the environment where the interviewees live their life (Creswell, 2014; Glesne, 2011). The familiar surroundings provide the interviewees the chance to feel more comfortable in their surroundings, which may help them share important data with the researcher. This also allows the researcher to conduct participant observations of the interviewees in their preferred environment as opposed to a laboratory setting. As the researcher, I was able to go to the participants and interview them in their desired environment, which allowed me to gain rapport with the interviewees in a space they are comfortable with. This rapport permitted me to get rich, detailed data about how the interviewees coped and adjusted to life as a person with a CID and what direct effect that had on relationship changes with their family members, close friendships, and potential/established partners.

Qualitative research methods allowed me as a researcher with a CID to interview other people with CID from a different perspective. By having CID in common, it is my observation that I gained trust with the interviewees and they were more willing to share with me their adjustment to CID journeys. By being relatable as someone that continues to adjust to life with a CID. I am confident that this permitted the interviewee to be more open with their lifeworld story that they shared with me during the interviews. Through qualitative research methodology, I gained a better understanding of how my interviewee's relationships have changed with family members, close friendships, and intimate partner. I chose phenomenology as my qualitative method for this research endeavor. The following section will explain why phenomenology was the best fit for my research questions.

### **Phenomenology**

Van Manen (2001) described phenomenology as a way to gain a deeper understanding of the nature or meaning of our everyday experiences. Vagle (2014) viewed researchers who use phenomenology as interested in their interviewees' life experiences as they make decisions, and felt that "the phenomenologist is studying how a particular phenomenon manifests and appears in the lifeworld as opposed to researching the individual interviewee" (p. 23). Phenomenologists have a goal of understanding the meaning of a phenomenon and then analyzing, synthesizing, and presenting the meaning as accurately as possible (Dahlberg, Dahlberg, & Nystrom, 2008).

Phenomenology allows researchers to gain insight into the human condition (Findley, 2011). Findley (2011) stated that phenomenology allows the researcher the

ability to deepen our understanding of therapeutic practice. This in turn allows counselors to grow both professionally and personally. Findley goes on to state that “phenomenological research is potentially transformative for both the researcher and the participant” (p. 10). The interviewees are given the opportunity to voice how the phenomenon has impacted their lives, and this voicing is witnessed by the researcher. This was what I was able to do in this research endeavor.

Van Manen (2014) claimed that a phenomenological question may arise when a researcher has had a certain experience that makes us stop and think deeper about a phenomenon. Van Manen explained the phenomenological process as follows: “When we stop and reflect on such a phenomenon we think of the immediate now (how we live and experiences of our daily lives) and the reflective presence of the now mediated” (p. 34). By writing down experiences and reflecting over them, we can start to gain an even deeper understanding of the lived experience. By reflecting on what lived experiences are, the researcher can start to craft phenomenological questions that can explain the lived experiences shared by a group of people. This allows others to gain a better understanding of the phenomenon in question. Dahlberg, Dahlberg, and Nystrom (2008) describe the overall aim of lifeworld research as describing and elucidating the lived world in such a way that expands our understanding of human beings and human existence.

Vagle (2014) referenced the idea of the lifeworld as originating from Husserl (1998) who first described the lifeworld and phenomenology in the early 1900s. “The lifeworld is the world as it is lived as opposed to the world as it is measured, compared,

etc.” (p. 22). Husserl’s new philosophy gave researchers a new way to experience the world (Dahlberg, Dahlberg, & Nystrom, 2008). Dahlberg, Dahlberg, and Nystrom (2008) discuss how every lifeworld is “unique” even when we have much in common with our interviewees, it is the duty of the researcher to have “a careful curiosity about elements of uncertainty” (p. 63). As researchers, we go to the things that we want to study in their natural environment so that we can observe how they function.

Phenomenology focuses on how phenomena are being and becoming (Vagle, 2014). The individual is interacting with other people, places, and things and with each new experience he or she takes what is needed to move forward and leaves what is not needed for his or her specific journey. This in turn allows the researcher to focus on the phenomenon and how it has changed due to the intentional and intersubjective influences at play, which leads into a discussion about intentionality.

**Intentionality.** Vagle (2014) describes intentionality to show how we are “meaningfully connected to the world” (p. 27). Husserl spoke of a natural attitude, which means that we do not always consciously think about what we experience (1970a; as cited in Vagle, 2014). Dahlberg, Dahlberg, and Nystrom (2008) defined intentionality as the relationship between a person and his or her direct awareness of an object or event. This in turn allows researchers to gain meaning from the lived experiences/phenomena of the interviewee. This meaning of the phenomena is the core of what lifeworld researchers are trying to find and describe. Researchers can help to not limit meaning by being open and ready to the phenomenon when it presents itself (Dahlberg, Dahlberg, & Nystrom, 2008).



Gadamer (1996) talked about how it is not people's health but their illness that decides how they interact with the lifeworld. When we are ill, some of our interactions with the world are muted or completely taken away from us. This impedes us from achieving some of the goals that we are striving towards, as if our bodies become obstacles that limit our interactions with our lifeworld. According to Gadamer (1996), bodily dissonance limits a person with CID in some way from obtaining what is needed from his or her lifeworld. As researchers, we must be connected to the lifeworld and open to learning new ways of looking at it and understanding it.

**Openness.** According to Gadamer (1995; as cited in Dahlberg, Dahlberg, & Nystrom, 2008), researchers must have an open mind in order to learn new things from their interviewees, which is referred to as seeing the otherness of a phenomenon. Gadamer goes on to write that openness is a "wish to see, a wish to understand something in a new way" (1995, p. 111; as cited in Dahlberg, Dahlberg, & Nystrom, 2008). Dahlberg, Dahlberg, and Nystrom (2008) define openness as a researcher's ability to listen, see, and understand the phenomenon from the interviewee's perspective, and suggest that being open requires "respect, sensitivity, and flexibility" on the researcher's behalf towards the phenomenon being studied (p. 98).

Merleau-Ponty (1968) suggested that our conversations with other people allows us to be able to gather information and thoughts that we might not have come up with on our own. By being open to hearing other people's perspectives, we can gain valuable information that we might have otherwise missed. Lifeworld research has been called an open design or open approach due to the fact that there are not many set methods or rules,

so that the researcher can follow the phenomenon as it presents itself (Dahlberg, Dahlberg, & Nystrom, 2008).

Openness allows the lifeworld researcher to be able to hear what might otherwise be silent (Dahlberg, Dahlberg, & Nystrom, 2008). Another way to explain this concept is that being open to the interviewees allows the researcher to see and hear the personal experiences that the interviewee has experienced, since the interviewee has experienced the world in a different way than the researcher. Interviewing people who have adjusted to CID allows the researcher to gain knowledge of the lived experience of someone that is in the process of adjusting to life with a CID and how it has changed their personal relationships. It gives the researcher an insider's view of the journey the interviewee has been through.

**Embodied listening.** As a researcher who interviewed people with CID, I found it important to use embodied listening (Dahlberg, Dahlberg, & Nystrom, 2008). Embodied listening happens when the researcher listens in a manner to understand illness and the suffering of others, which allows the researcher to gain a heightened sense of one's own "mortality and vulnerability" (Dahlberg, Dahlberg, & Nystrom, 2008, p. 109). I believe that this was needed and helpful in my research in order to truly grasp what my interviewees' adjustment to their CID journeys has been like and what kind of changes have happened with their close relationships. I was able to hear the lived experiences of how the participants adjusted to life with a CID as well as how their personal relationships with family, close friendships, and intimate partner had changed as they

adjusted to life with a CID. I was able to better understand how their CID had changed their lives in both positive and negative ways.

**Phenomenological attitude.** According to Dahlberg, Dahlberg, and Nystrom (2008), a phenomenological attitude is defined as how a researcher can describe the world in the way that his or her interviewees experience it. The phenomenology attitude allows us to show what the world means to humans, both how they relate to their world and how they relate to each other, as well as allowing researchers to show how different situations are experienced.

Conducting lifeworld research allows the researcher to create a phenomenological attitude by seeing the “visible and invisible aspects” of an interviewee’s life (Dahlberg, Dahlberg, and Nystrom, 2008, p. 91). By conducting interviews and observing phenomenon, lifeworld researchers are able to make discoveries of parts of their interviewee’s lifeworld that may have never been shared publicly. The goal of lifeworld research is to clarify meaning as it is given (Dahlberg, Dahlberg, & Nystrom, 2008), which in turn that allows the lifeworld researcher to be able to contribute to the literature so others can learn what it is like to experience the phenomenon first hand. In my research, I am confident that I was able to identify information that counselors and other social and medical professionals can use to have a better understanding of where some of the gaps are with assisting clients who are adjusting to life with CID, such as struggles with changes in relationships.

## Phenomenological Reduction

Phenomenological reduction, which was developed by Van Manen (2001, 2014), is described by Dowling (2007) as the researcher allowing the interviewee to describe the phenomenon with the researcher documenting the details exactly how it was described, which is achieved by the researcher trying to avoid any personal previous knowledge or understanding in order not to influence what is documented.

Polkinghorne (1983) recommends a two-step process to achieve phenomenological reduction. To be able to find the true essence of the phenomena, the researcher has to use free variation to describe the interviewee's description of the phenomenon. Then the researcher looks at the concrete facts by using a technique called intentional analysis of the phenomenon that has been described. Dahlberg, Dahlberg, and Nystrom (2008) discuss eidetic reduction, in which the researcher allows the "essential components of a phenomenon" to present themselves (p.54).

**Bracketing/bridling.** Bracketing is part of the phenomenological reduction strategy where we as researchers put our pre-understandings, such as beliefs, assumptions, and theories, in check so that we do not influence the meaning that we gain from our subjects (Husserl, 1998; Giorgi, 1997, Dahlberg, Dahlberg, & Nystrom, 2008). Bracketing assists researchers in evaluating their pre-knowledge about what is being studied in order to focus on the lived experienced of their research participants (Dowling, 2007).

Dahlberg, Dahlberg, and Nystrom (2008), however, prefer the term *bridling* instead of the term *bracketing*. Bridling is explained as a tool that researchers use in

order to be “open and alert” when studying a phenomenon so that the phenomena will “present itself” to the researcher as he or she gains knowledge of the meaning (Dahlberg, Dahlberg, & Nystrom, 2008, p. 130). The researcher must be open and respectful so that the interviewee will feel comfortable sharing as much detail about the phenomena as possible. While it is necessary to be aware of one's pre-understandings of a phenomena, in all reality, it would be impossible to completely block it out when researching.

Dahlberg (2006, as cited in Vagle, 2014) stated that bridling takes in the essence of bracketing in the sense that the researcher must be aware of his or her pre-understanding of the phenomena being studied in order to remain open to hearing the lived experiences about the phenomena. Bridling goes beyond bracketing by allowing the researcher to stay aware and focus on the phenomenon as a whole throughout the research study. Dahlberg, Dahlberg, and Nystrom (2008) also noted that bridling allows the researcher to stay focused on the forward movement of the phenomena in real life, while bracketing tends to focus on how the phenomena has worked in the past, which could limit the research's pre-understanding of the phenomena.

Gadamer (1995) suggests that if we are aware of our own bias, we are more likely able to report the phenomena as it was presented to us. Gadamer goes on to say that phenomenologists must “distinguish true prejudices from which we understand from the false ones that we do not understand” (p. 299). Bridling allows researchers to be aware and reflect on our pre-understanding so that we do not allow it to affect our research.

As researchers, we must set aside our own beliefs and theories so that we can be open to hear what our interviewees disclose to us, especially the otherness of life

experiences that do not match our own (Dahlberg, Dahlberg, & Nystrom, 2008). I found in this project that as a person who continues to adjust to living a life with CID, I have to be consciously aware that I do not let my own journey interfere with the reports from my interviewees' journeys. Using a bridled approach allowed me to be aware of my own personal pre-understanding and increase my knowledge base.

The effects of this bridled approach gave my interviewees the opportunity to speak freely. Gendlin (1978) discussed the emotional aspect of pre-understanding as a "felt self" (p. 150; as cited in Dahlberg, Dahlberg, & Nystrom, 2008). This is the bodily experience or meaning of the phenomena that may not have ever been put into words. Likewise, Klein (1998) claimed that our internal world influences our understanding of our external world. It is my hope that by conducting this research it provided a relief for some of my interviewees to be able to speak about their journey of adjustment to CID and how relationships have changed over that period of time.

**Reflexivity.** Reflexivity is another way for qualitative researchers to ensure they are in tune with the lived experience. Dowling (2007) explained reflexivity as a tool of self-critique and self-appraisal, going on to state that reflexivity allows researchers to look at how their own experiences may have influenced the research. Being reflective allows the researcher to evaluate the natural attitude that ties us to the specific phenomenon (Dahlberg, Dahlberg, & Nystrom, 2008).

**Epoche.** Epoche is a key phenomenological principle and is described as the researcher refraining from judgment or assigning commonplace meaning to a phenomenon until all information is gathered and reflected on (Moustakas, 1994). It

comes from the Greek, where it means to refrain from judgment (Patton, 2002).

Likewise, in this usage, the researcher must not pass judgment and must stay away from the everyday way of interpreting things (Patton, 2002). By using epoche, the researcher is able to identify personal bias or preunderstanding of a phenomena, document it, and set it aside so that the phenomena are accurately documented in their natural environment.

Patton (2002) states that this is a continual process as the phenomena is studied and analyzed.

With this research endeavor I had to use epoche and bridle all of my own adjustment to CID so that none of my own experiences influenced my interviewees' lived experiences. I also was required to be open and use my embodied listening skill to make sure that I received the richest, accurate data possible from each of my participants. I had to use my phenomenological reduction skills of bridling my own experiences as I documented each interviewee's personal story of relationship changes throughout their adjustment to their CID life story. I also accurately documented information I received, and I was reflexive to ensure that I did not influence the data being collected.

### **Data Collection**

Dahlberg, Dahlberg, and Nystrom (2008) define data collection as an activity that "allows researchers to seek detailed descriptions, utterances, characterizations, narrations, depictions, and other possible expressions of the studied phenomena" (p. 172). Finlay (2011) describes gathering data as engaging an interviewee, listening reflectively, and being accepting of the data that is presented. In order to collect research for this dissertation, I used a combination of qualitative data collection. One benefit of

qualitative research is that there are very few limitations as to the data collection methods that are acceptable for human science/lifeworld research (Dahlberg, Dahlberg, & Nystrom, 2008). I conducted seven in-person interviews with people who were adjusting to life with CIDs. I also used observations and took field notes to document the interview experiences. The following paragraphs will provide more detailed information about how data collection was completed during this research project.

**Gaining access.** Access to participants for this study was gained through existing professional connections with rehabilitation counselors, mental health counselors, people with CID, and directors of disability services at Ohio University in Athens and the Chillicothe regional campus. More information on this will be provided in the following section.

One advantage I had in gaining access is that I myself am a person with a CID. However, Dahlberg, Dahlberg, and Nystrom (2008) caution researchers who are studying their own culture and state that researchers who have contextual knowledge may need to bridle it in order to gain specific knowledge about a certain area (phenomenon) that is lacking in the literature. Likewise, Finlay (2005) wrote about an intersubjective process where counselors can use empathy that goes past the felt experience but goes into a reflexive encounter with the lived experience of the interviewee, interviewer, and the intersubjective relationship between the two. Again, the researchers must have a bridled outlook to avoid having their own pre-understanding influence the data that is presented by the interviewee.



Finlay and Evans (2009) reported that counselors and therapists have an advantage when it comes to phenomenological research, since they know the importance of rapport between interviewee/interviewer due to their similarities with the client/counselor roles. The more rapport that is built with an interviewee, the higher quality narrative is available from the lived experiences/phenomenon. However, it is important to separate the roles of counselor and researcher to ensure that researchers are not counseling their interviewees instead of conducting phenomenological interviews.

**Sample technique/size.** In my data collection, I used purposeful sampling, which is defined by Creswell (2013) as the researcher selecting interviewees due to their experience with the phenomenon under study because of their lived experiences. After I sought and received IRB approval, flyers (see Appendix A) were displayed in the libraries and classroom building bulletin boards at both the Ohio University Athens campus and the Ohio University Chillicothe campus in order to recruit potential participants.

Participants were also recruited through the snowball technique of asking rehabilitation, clinical mental health, and medical professionals from both campuses to make referrals for potential interviewees, which involved contacting existing professional members of the Ohio University community such as doctors, professors, rehabilitation counselors, clinical mental health counselors, Ohio University counseling cohort students, and people with disabilities. Flyers were distributed to these individuals. This allowed the potential research participants the opportunity to reach me by email or phone so as to avoid any issues with privacy/HIPPA. A second recruitment strategy was used

by having these professionals contact potential participants via listservs in counseling and the medical school at Ohio University, in case the potential participants had not seen any flyers.

Criterion sampling techniques were also used. Creswell (2013) claimed that criterion sampling is useful in phenomenological research because this ensures that all participants have experiences with the phenomenon being studied. Likewise, Dahlberg, Dahlberg, and Nystrom (2008) argued that the phenomenon should direct the data gathering process. Therefore, the desired requirements to participate in this study were as follows: (a) having acquired a CID diagnosis between the ages of 18-40 years of age, (b) a minimum of one-year post injury/diagnoses of CID, and (c) a willingness to discuss adjustment to CID and their relationships with the interviewer. The final sample size was seven, due to the researcher feeling confident that saturation had occurred.

After participants were located and determined that they qualified for the study, they were asked to sign an informed consent form to participate in the research project. After the informed consent form was collected, the interview process was scheduled and completed.

### **Interviewing**

Interviews allow the research to enter into the lifeworld of our interviewees' lives and explore a phenomenon of shared interests (Dahlberg, Dahlberg, & Nystrom, 2008; Gadamer, 1995). Interviews allow the researcher a chance to facilitate a conversation that encourages the interviewee to get closer to his or her own experiences, which in turn may expand both the interviewee and researcher's awareness and understanding of the

phenomenon itself (Dahlberg, Dahlberg, & Nystrom, 2008). Kvale (2006) stated that an interview is a continual sharing and discussion of the different views of two people towards a common topic. As researchers we strive to have the interviewees' lived experiences articulated clearly and accurately (Dahlberg, Dahlberg, & Nystrom, 2008). Giorgi (1997) asked researchers to ensure that interviews are precisely documented with "a minimum number of generalizations or abstractions" (p. 243).

One of the main goals of a phenomenological interview is to have the interviewee reflect directly on the phenomenon under study (Dahlberg, Dahlberg, & Nystrom, 2008). For instance, in this study I asked the interviewees to focus on relationship changes with their family members, close friendships, and intimate partner as they have adjusted to living a life with a CID. The phenomena that I am focused on is the actual relationship change that has happened as the interviewee has moved from his or her diagnosis to present life.

Dahlberg, Dahlberg, and Nystrom (2008) cautioned that the researcher must "find a balance between being unstructured and structured" during the interview process (p. 187). While acknowledging that researchers are in search of rich data, they pointed out that during the interview process the interviewer cannot ask too many follow-up questions/prompts due to the need to understand the phenomenon as accurately as possible from the interviewee's perspective.

**Semi-structured interview guide.** A semi-structured interview protocol (found in Appendix B) was used for this project. Finlay (2011) described semi-structured interviews as "questions loosely prepared in advance to guide researchers and help them

focus on the phenomenon under study. Kvale and Brinkman (2009) defined semi-structured lifeworld interviews as having a purpose of learning about the lived experiences of the interviewee so that the research can define the meaning of the phenomena under study. Kvale and Brinkman also stated that this type of interview allows the researcher to gain knowledge of the themes of the lived experiences from the participant's daily perspectives. Rubin and Rubin (2012) stated that in semi-structured interviews, the researcher has planned specific questions that are related to the phenomenon in order to gain knowledge about it. Semi-structured interview guides contain a limited number of questions in order to help researchers identify key points they want to learn more about. Probing questions and follow-up questions may also be included in the interview guide. These questions are open-ended and encourage the interviewee to respond in as much detail as possible.

Patton (2002) stated that an interview guide allows the researcher to ensure that the "same basic lines of inquiry" are discussed with each interviewee (p. 343). This allows the researcher to maximize the time allocated to each interviewee. My semi-structured interview guide assisted me to keep a common foundation of questions to be asked of each participant. It also gave me some structure as I attempted to keep my interviewees focused on specifics about their relationship changes. This type of interview guide provided me the flexibility that I needed in instances when a key point came up that I did not expect, and it also allowed me to document rich lived experiences of my interviewees' adjustment to the CID process.

## **Documentation**

Each interview was digitally recorded with permission from each interviewee. These recordings allowed me to go back and listen to the interviews so as not to miss any of the rich data of the lived experiences of my interviewees. The recordings also enabled me to transcribe each interview for the data analysis process to follow. My original goal was to transcribe each interview within two days of collecting the data, which would have kept the interviews fresh in my mind and made it easier to deal with challenging or unclear data so that it would not be completely forgotten or lost. However, this goal was not achieved, due to how quickly participants wanted to participate in my research study. I also had not taken into consideration how long each interview would take to transcribe.

I asked my interviewees for permission to have follow-up phone calls/emails in order to clarify any of the data, which provided me the opportunity to ask further questions that might be needed to strengthen the data analysis process. I only needed to do this with the final interview, because my recorder malfunctioned during part of the interview. I was able to obtain permission from this interviewee to send the transcribed interview to her via email. She took the time to review it and fill in the missing information. I was very thankful to this interviewee for taking the time to make sure vital data was not lost due to a technological issue.

My original plan was to use a personal research journal as I collected my interview data, as suggested by Dahlberg, Dahlberg, and Nystrom (2008). This would assist me to document my own reactions to interviewees' stories so I could bridle my influence on the data and keep it as true to the phenomenon as possible. It would also

allow me to note any nonverbal communication from my interviewees as we went through the interview questions. I did well with my personal research journal with the first couple of interviews, but due to time constraints was not able to continue with it.

### **Self as a Researcher**

In qualitative research, the researchers themselves are the most important data-gathering tool (Dahlberg, Dahlberg, & Nystrom, 2008). As already stated, it is important for the researcher to bridle any pre-understanding of the phenomenon since he or she is the main tool to gather the data about the phenomenon. Merleu-Ponty (1995) discussed how since the researcher documents the words that the interviewee has experienced, these words should accurately represent what the interviewee has lived and experienced and not be influenced by the researcher's own life experiences. This is critical to qualitative research.

As a person who has experienced the adjustment to CID process and how my own personal relationships with family, close friendships, and intimate partner have changed, I had to bridle my own experiences. I needed to constantly be cognizant of my own experiences so that I did not influence the data. I also relied on Dr. Mona Robinson, my advisor, and Dr. Krisanna Machtmes, my methodologist, to assist me when I was struggling with the data collection and data analysis processes. They functioned as vital supports throughout this research endeavor. Dahlberg, Dahlberg, and Nystrom (2008) stress the importance of having a gatekeeper. A gatekeeper is a person who will be there to help support and guide you as you conduct your research in the field and as you

analyses, synthesize, and document the results of your data. Dr. Robinson and Dr. Machtmes served this role for me.

### **Data Analysis**

Moustakas (1994) and van Manen (2014) discussed how a phenomenological study's data is analyzed, while Creswell (2013) described these steps in an easy-to-understand manner for first time phenomenological researchers. The following are the steps described by Moustakas (1994), van Manen (2014), and Creswell (2013):

1. The researcher must document any personal experiences with the phenomenon in order to bracket/bridle as much as possible his or her personal or pre-understanding of the lived experience.
2. Significant statements are identified from the transcripts from each interview. Each of these statements are of equal worth. The researcher is responsible for not having duplicate significant statements.
3. The significant statements are then grouped together into what Moustakas (1994) calls meaning units or themes. Meaning units are central themes that are identified in multiple transcripts.
4. From the meaning units, detailed descriptions that focus on two elements are formulated. The first element is what the interviewees have experienced in common, which Moustakas (1994) referred to as textural description of the experience. This includes experiences of what happened with the phenomenon as described by the interviewees.

5. The second element is how the interviewees have experienced the common phenomena, which is also called structural description (Creswell, 2013; Moustakas, 1994). This is verbatim information from the interviewees as to how they experienced the phenomenon. For example, in my study, this would be how relationships have changed as the person has adjusted to living with a CID.
6. The final part of a phenomenological analysis of the data is to write a composite description of the data (Creswell, 2013). Moustakas (1994) called this the essence of the phenomenon. The essence is a descriptive passage that brings the *what* and the *how* together in a culminating statement.

Smith, Flowers, and Larkin (2009) also have a guideline of steps for data analysis of their Interpretative Phenomenological Analysis (IPA). The following are the steps of analysis of IPA:

1. Reading and re-reading the data: the researcher reads each interview transcript and takes notes of what stood out through the first reading. Then, the transcript is re-read with more notes taken to ensure that the researcher has a good grasp of the lived experience of the participant. This also allows the researcher a chance to think about key words or observations from the interview that may be important details to document. The researcher can also note and bridge any personal



emotions/reactions to ensure they do not interfere with the true lived experience of the interviewee.

2. Initial noting: the researcher starts to note specific and key terms/statements that were used by the participant. The researcher's goal is to note things as they were said in order to accurately document the meaning the interviewee stated in the interview. This allows the researcher to "immerse yourself in the participant's lifeworld" and gain understanding of the phenomenon being studied (Smith et al., 2009, p. 84). Smith et al (2009) suggested underlining specific statements in the transcripts and then write in the margins why these statements feel significant, so that upon rereading the transcript, the researcher will be prompted to analyze this statement again. It will also help in future steps when looking for meaning/themes across the data set.
3. Developing emergent themes: the researcher takes the data set of the interview transcripts and the notes that they have taken from reading and re-reading said transcripts and develops emergent themes about the phenomenon. These themes are the "psychological essence" (Smith et al., 2009, p. 92) of the phenomenon under study.
4. Searching for connections across emergent themes: the researcher looks at the themes in a chronological order and decides which of them stand out as the most significant as it relates to the phenomenon under study. Some themes may be abandoned at this stage of the analysis due to not relating

to the research question/focus. Themes that relate to each other are grouped together and renamed with a broader title to start to condense the data.

5. Moving to the next case: each interview transcript follows steps 1-4 mentioned above. It is up to the researcher to bridle the pre-understanding gained from each previous transcript to ensure that he or she is being true to each participant's lived experience with the phenomenon.
6. Looking for patterns across cases: this allows the researcher to identify similar themes across all of the interview transcripts. These shared themes become the essence of the lived experience of the phenomenon of the research participants. At this stage, some of the themes may once again need to be renamed or combined to accurately represent the data set.

In this study, the data analysis process was conducted through detailed reading and rereading of data that was collected. I looked for key statements that I could pull out from each interview transcript in order to develop key themes. As more research data was collected, these key statements gathered more information. From these initial key statements, broader key themes were grouped together to demonstrate how relationship change has happened with family members, close friendships, and dating/partners. The following figure describes the steps that I took in the data analysis process of this research endeavor.

Table 3.1

*Data Analysis Process*

Step 1	Transcribe individual interviews
Step 2	Read and reread each transcript
Step 3	Note significant statements in each transcript
Step 4	Compare significant statements in each transcript
Step 5	Form common themes from each relationship type (family, friends, dating/significant other)
Step 6	Develop common themes from each of the transcripts

**Limitations of the Study**

As with any research study, this particular project has several limitations. First, relationships concerns may not be an easy topic for some participants to be willing to speak about openly and honestly with a researcher that they have just met. In addition, it was essential to ensure that participants understood that the information they shared with the researcher would be kept confidential in order to allow participants to have a high enough comfort level to speak openly about personal relationships concerns as it related to disability and relationship. Finally, the study focused on people who adjusted to CID between the ages of 18-40, based on Erickson's psychosocial stage of intimacy versus isolation (Erickson, 1950; Erickson, 1963), and therefore it may not be relatable to people adjusting to CID before the age of 18 or after the age of 40.

## **Ethical and Legal Considerations**

Dahlberg, Dahlberg, and Nystrom (2008) stated that conducting lifeworld/qualitative research has the potential to “stir up emotions and memories” that interviewees did not even realize that they had (p. 203). They also discussed how the interview process may be the interviewees’ first time that they have openly spoke about the phenomenon in question. Therefore, I had to remain sensitive and be prepared for interviewees who got emotional as we talked about their journey of adjustment to disability together during the interviews.

**Informed consent.** Each interviewee was given an informed consent form to sign and a copy to take home. Finlay (2011) stated that some of the things that the informed consent form must include are: (a) an explanation of the project; (b) what the research will involve; (c) the participant’s expectations and limits of time spent on the project; (d) any risks that the participants might encounter; and (e) a statement that the participant has the right to stop participation in the study at any time. (Appendix D; Appendix E).

**Confidentiality.** Confidentiality must also be ensured for all participants (Finlay, 2011). Due to the narrative/personal stories of some interviewees, this can become challenging, since some people’s stories may be so unique that others may be able to identify them. This needs to be explained to all participants during the informed consent process, and participants should be informed that every effort will be taken to protect confidential information and that no identifying information (name, city where they reside, etc.) will be included in their interview transcripts.

As a qualitative researcher, Finlay (2011) stated that researchers must make sure that they practice due care, which is an awareness and sensitivity to respect the well-being of the interviewees. I was aware I asked a lot of my interviewees. This research asked my participants to recall and talk about some difficult times of adjustment that may have been painful for them. I had to use my skills as both a counselor and a researcher to make sure I did not cause undue harm to my clients in gaining the data that I sought. Findlay (2011) also talked about the importance of boundaries and roles when the researcher is also a counselor. I believe that I was able to avoid this ethical dilemma due to the fact that my goal with this research project was to interview participants that I did not already have a previous professional or personal relationship with. While I did encounter a situation where a participant was someone with whom I already had an established connection, I used my bridling techniques to avoid this relationship affecting the true lived world experience of the interviewee.

## **Conclusion**

This chapter demonstrated how this phenomenology dissertation study was conducted, focusing on the problem statement, research questions, theoretical approach, data collection, data analysis, limitations of the study, self as the researcher, and legal and ethical concerns in qualitative research. Having explained the methodology, the next chapter will introduce the study participants and their stories.

## **Chapter 4: The Participants and Their Personal Journeys through CID**

### **Introduction to the Chapter**

The purpose of this study was to add to the professional literature for medical & social services professionals' information from the lived experiences of people adjusting to life with CID and how this adjustment process changed significant intrapersonal relationships in the participants' life (family members, close friendships, & intimate partner). This study contributes to the current research to inform medical and social service workers to be prepared in assisting clients with the adjustment to CID process. This study provides information to help fill in a gap in the literature that is an important part of the adjustment to CID process for not only the clients but also the client's family members, friends, and intimate partner.

As mentioned in chapter two, there is already established research on adjustment to chronic illness and disability, as well as on disability and sexuality concerns. However, there a gap in the literature reviewed was identified that ties both of these topics together, namely how relationships may change as a young adult adjusts to life with a CID. It is estimated that up to 40% of Americans (133 million) currently are living with a chronic health condition (National Health Council, 2014). The NHC estimates that by the year 2020, the number of Americans who will be living with chronic illness is projected to be 157 million, with 81 million Americans living with multiple chronic conditions. These numbers are significant, and as counselors and social health professionals, we must educate ourselves to be able to assist our future clients when or if they are diagnosed with a CID.

This chapter will provide demographic information about the seven participants that chose to be a part of this study. The goal of this chapter is to provide a rich biographical sketch of how each of the research participants has adjusted to CID thus far in their personal journeys. This chapter will also review how the participants fit into the theories presented in chapter 2: Erickson's stages of psychosocial development, Bishop's disability centrality model, and Gill's disability identity development model.

There were seven participants in this research study. Five other potential participants responded to the recruitment flyers but were excluded for not meeting the requirements to participate in this study, which were as follows: (a) acquired an CID diagnosis between the ages of 18-40 years of age, (b) a minimum of one-year post-injury/diagnosis of CID, and (c) a willingness to discuss their adjustment to CID and relationships with the interviewer. Each of the seven participants were given a pseudonym to protect their confidentiality. Specific cities, college or university names, and employers are also not given in order to protect the interviewees' identities.

**Interview A: Jack.** Jack is a 35-year-old Caucasian male who identifies as bisexual. He lives in southern Ohio. Jack is currently an undergraduate student working on a bachelor's degree in the social sciences at a regional university. He is also currently employed in the social services field. Jack was diagnosed with Human Immunodeficiency Virus (HIV) at the age of 30 years old. Jack is married with two stepchildren and a biological daughter.

Jack described his initial diagnosis as a shocking and stressful time. He had only been married for about a year and was scared of how his wife would react. Jack was also

fearful that he might have exposed his wife to HIV, but she remains HIV free to this day, due to Jack's ongoing education and medical checkups to ensure he is taking the best care of his CID. The couple has had many struggles but has managed to stay together.

Jack reported that one of the biggest challenges he had when he was first diagnosed was deciding whom he should disclose his HIV status to. He and his wife have told some of their closest family members, but have made the choice not to inform the children at this time. Jack explained that he felt like this would only cause them to worry about something that he is doing the best to keep under control. Jack exercises three to five times a week; quit smoking, drinking, and using other drugs; and follows a precise medication regiment that his doctor has prescribed. Jack stated that his doctor has been one of his biggest role models, and he wants to show people that there is life after an HIV diagnosis. At the time of the interview, Jack's HIV levels were at an undetectable state, according to his last checkup.

Jack stated that at this time, he is very open about his HIV diagnosis. He has been a guest speaker for groups of men and women on how to practice safe sex as well as explaining how HIV is and is not spread to others. Jack also said that he does not let his CID diagnosis define him.

According to Jack, the biggest concern he has for living a life with a CID is the unpredictability of things. He has to be very careful, because just catching a stomach bug or the common cold can make him become extremely ill. He also has to be very careful not to miss any of his medications and to manage his stress level in a healthy way. Jack



reports that he copes with life with a CID by exercising, spending time with family, and helping others to meet their own goals and objectives in his chosen field of employment.

Jack was very open during the interview and was eager to be a part of this project. He was the first person to contact me to be a participant and wanted to be my first interview. I was fortunate to be able to sit down with him in person at my office with permission from my employer, which allowed for a quiet, private space to conduct this interview.

**Interview B: Will.** Will is a 25-year-old Caucasian heterosexual male. He is originally from Michigan, but is currently living in southern Ohio. Will is currently working on his PhD in a social service field at a major university in Ohio. He currently works on the campus that he is attending, also in a social service field. Will was diagnosed with Crohn's disease at the age of 18. Will is married with no children.

Will stated that for him, the hardest part of adjusting to life with Crohn's disease was the stress of not knowing when he might be sick. He also had to learn what foods he could continue to eat and what he would have to limit to avoid getting sick. Will stated that he had to adjust to planning out his food to match what he needed to do or get accomplished that day.

Will stated that he has been fortunate to have all the supports that he needs to be successful with managing his Crohn's disease and being a PhD student. His wife works and is understanding when he does not feel good or does not think it would be in his best interests to do certain things. One example he gave was going out for dinner and a movie. If he is going to go somewhere with rich foods, there is a chance he will be sick

during the movie, so the couple has to go to a movie first and then out to dinner. Will also has to check out places to see if they have a private bathroom when his stomach is upset. For example, Will reports that a lot of college town bars may not have a stall with a door that can be locked for privacy. This limits the places where Will feels comfortable going with friends in case he starts to feel ill.

Will also discussed with me how he does not get home often to see his family in Michigan, and this has been hard on him at times. It is a more than six-hour drive home to Michigan through a lot of rural areas where bathroom access is limited. When he does make the trip, he has to plan out what he eats before he leaves and where clean restroom facilities options are along his route. Will knows that his symptoms are worse in the mornings, so he plans his travels not to start until after lunch if he knows he has to travel a long distance.

Will stated that he copes with his Crohn's disease mainly by eating a healthy diet, working out, taking medications, and trying to keep his stress level down. He chooses not to disclose his CID to a lot of people because, as he put it, "who wants to hear about your bathroom routine." However, he does disclose his CID to professors, and his employer, and his family and close friends all know. One of his close friends in Michigan will text or call to tell him about a new restaurant or bar that has really nice bathroom stalls. He feels like he has the needed support at this time.

Will's interview was one of the longer interviews that I had. We met via Skype due to conflicts in our schedules and his desire to complete the interview before his final

exams. Will was very open with me and we seemed to build rapport quickly, so the rich, detailed data that he provided was very much appreciated.

**Interview C: Dorothy.** Dorothy is a 39-year-old Caucasian heterosexual female who just recently completed her master's degree in a social services field from a university in southern Ohio. She is currently unemployed and seeking employment in her field. Dorothy was diagnosed with Fibromyalgia at the age of 25. She is married with no children.

Dorothy reported that the hardest part of being diagnosed with Fibromyalgia was not having any information given to her about what it was and how to live a life with it. She remembers leaving the doctor's office after finally having an answer as to what had been wrong with her for months, but having more questions than before she was given her diagnosis. She recalled getting on the computer and reading about it that evening and feeling like her world was caving in. Dorothy remembers being in a depression for many months afterwards and being very sick.

Dorothy stated that the more she read up on her CID, the more she realized that she had to learn her limits. She could not be a full-time student or work full-time any more. If she pushed herself too far, by the end of the day she was in so much pain that she could barely move. She said, "I learned to listen to my body and when it is telling me something I cannot ignore it." Dorothy had to learn to adjust everything that she did in order to still accomplish her goals of obtaining a master's degree and working in the social services field, so she took one or two classes per semester and held down a part-

time job, accomplishing her goals on a little longer path than she would have initially preferred.

Dorothy stated that she does not disclose her CID diagnosis unless she has to. She is thankful for this because she dislikes it when people treat her with special privileges or pity. In fact, Dorothy stated that people who show forced concern is one of her biggest pet peeves in life, so she is thankful that most days the people she interacts with in her community have no clue about her Fibromyalgia. Dorothy stated that she gets all the needed support she needs from her husband, family, and a few close friends.

Dorothy was asked what coping skills she had to learn to use to manage life with a CID, and she reported that she had to learn that it was okay to ask for help when she needed it. This was very hard for her, because she considered herself to be a very independent woman. Dorothy also stated that she had to learn that the goals and objectives of the day need to be flexible, and if she needs to take a break, it is okay. She knows that if she does not take a break, then she may not be able to finish what she has started or be able to function later in the day or even the next day. She also copes by watching what she eats and keeping her stress level down. She realized early on that when her stress is high, her symptoms of Fibromyalgia are high, so she uses meditation and resting in bed with her husband watching television or reading as ways to reduce stress. She also follows her doctor's advice in regards to medication management and not lifting over twenty pounds.

Dorothy was a pleasure to meet and interview. She was very open from the beginning of the interview, and being in a related field, she was eager to be a participant

in this research. Dorothy and I met on a cold day at a college library in a study room to conduct this interview. Dorothy had many interesting stories about her journey with adjustment to disability, but there is not space to include them all here.

**Interview D: Karen.** Karen is a 38-year-old Caucasian heterosexual female who was referred to this study by a student who saw the flyer at a regional university in southern Ohio. Karen was diagnosed with a degenerative hearing disability at the age of 29 after several years of going to doctors in order to figure out why she was having trouble hearing things. Karen has a high school diploma and is employed as a counselor for a rural substance abuse agency in rural southern Ohio. She is recently married and has one child.

Karen stated that one of the hardest things about adjusting to life with a hearing impairment is not being able to participate in all the activities she would like to be a part of. Karen talked to me about how technology has assisted her with her hearing disability:

My hearing loss has affected my communication with others. Examples would be talking on the phone because I cannot see their lips. Text has taken over and that kind of saved me and it really really helped so it's kind of balanced out a little bit now. It still can be frustrating when I have to ask people to repeat themselves and they get frustrated and that makes me frustrated. I have to stay away from noisy restaurants because I cannot hear people that I'm with. I cannot attend concerts or anything like that.

Karen has learned to adapt her communication style so that she can comprehend what is going on in social situations. She relies on text messaging and apps like

Facebook Messenger for communicating with her family or peers when she is not face to face with them. Karen has taught herself to be a good lip reader and is annoyed when someone does not make eye contact with her while she is trying to have a conversation.

Karen stated that to avoid confusion or miscommunication, she does not have a choice in most situations about telling people she has just met that she has a hearing problem. She states that this is awkward at times, because some people overcompensate and speak too loudly or very slowly. Because of this, she limits the amount of time she is around people she does not know. Karen told me that she easily gets frustrated and tends to isolate herself or just stand and be quiet if she has trouble communicating with someone that she does not know very well, which sometimes gives people the wrong impression of her.

Karen stated that one of her biggest coping skills is to have a few close family members or her young son with her to help her communicate. Her son will tell people, “Mommy’s ears are broken,” when someone is trying to get her attention and she does not hear them. Karen also has a couple of very close friends that take it upon themselves to repeat things that she misses or, in noisy places, get close to her ear to let her know what was just said. Karen reported that adjusting to life with a hearing impairment has also taught her to advocate for her needs when she needs something. Before her diagnosis, she felt completely independent and relied on no one but herself. Over time, however, she has had to let her pride go and rely on others for some guidance when she has no other choice.

Karen was a bit of a challenge in the interview process. She was short, sweet, and to the point with many of her answers. In some areas of her life, she was very guarded and did not appear to feel comfortable with giving great detail to me as the interviewer. For example, I asked her to tell me more about when she was first diagnosed with her hearing impairment and if the doctors thought it was genetic. She said that the doctors were not entirely sure why this was happening to her, but that it could have been due to some trauma. When I asked as a follow-up if she had been in an accident, she replied, “No physical trauma.” Due to the tone of her voice and her facial expression, I did not feel comfortable asking for more information. Overall, I thanked Karen for her time and feel that she provided me with some new perspectives of adjusting to life with a hearing impairment.

**Interview E: Grace.** Grace is a 24-year-old Caucasian heterosexual female who is from eastern Ohio but is currently working on her PhD in the health sciences field at a university in southern Ohio. At the age of 21, Grace was diagnosed with Bilateral Vestibular Hypo- Functioning, which is a condition that scars the middle and inner canals of the ears. Grace is preparing to start her final year of her degree and complete her clinical rotation. She is currently in a dating relationship and has no children.

Grace reported that the most difficult part of learning about her diagnosis was coming to terms with the fact that that this is a progressive CID where her hearing, vision, and control of her balance are all affected. There is no cure for her diagnosis, and no doctors can give her a set timeline of how this CID will progress. She has learned how to adjust in many areas of her life and attempts to stay as independent as possible.

Grace stated that she continues to stay physically active. One of her doctors told her that her age is one factor that she has to her advantage, because people are usually in middle adulthood when they receive a diagnosis like this. In high school, she was a cross-country runner and also played basketball. Now, however, due to the fact that her vision gets blurry when she is moving at a rapid pace, she has to be extra careful when she runs out in nature. She always carries her cell phone with her and lets someone know when she is going out for a run in case she has problems with her vision. Grace is still able to drive, but she relies on a GPS to tell her where to make turns because she cannot read street signs when the car is moving. She also has more trouble driving at night due to cars' headlights, so she does most of her travel during the day or relies on family or friends for nighttime events. One of Grace's biggest fears is the day that she will be told that she is no longer allowed to drive, and she is hopeful that this day will be far into the future.

Grace stated that she rarely tells people she does not know about her condition. Since it is an invisible disability, she usually does not have to disclose. This poses challenges for Grace, since as she says, "It's difficult at times, I guess, because I'll pass someone on the street and they will wave to me and I can't see them. So then it's like I worry that some people think I'm rude." Losing her balance in public is embarrassing for her, but she tries to blame it on being clumsy.

One way that Grace has started to cope with her ever-changing CID is to start attending counseling at her university counseling center. She has found this to be helpful, even though her counselor did not know anything about her diagnosis when she first



started seeing him. She took it upon herself to educate her counselor and was impressed when her counselor took the time to read up further on her condition. Grace stated that she is learning how to be okay with asking for help and not being ashamed of having a CID. She is also fortunate to have been introduced to a professor who researches vestibular disorders at her local university. This professor has become a mentor to Grace, who is very thankful for this opportunity.

Grace and I met in the library of her university in a study room to conduct the interview on a cold Saturday in December 2015. She was getting ready to pack up and go home for the Christmas break within the next day or so. Grace went into a lot of detail in our interview and I was very thankful for her willingness to be so open and honest with me for my research.

**Interview F: Sophia.** Sophia is a 39-year-old Caucasian heterosexual female who lives in a rural city in southern Ohio. A graduate student whom I was teaching at a regional campus referred Sophia to me. After Sophia and I had spoken on the phone, I realized that she would be an excellent candidate for my research study. Sophia was diagnosed with Crohn's disease after being extremely ill and having emergency surgery to remove a bowel obstruction when she was 36 years old. Sophia is currently unemployed but is seeking employment. She is single and has two children, one of whom still lives at home.

Sophia reported that she had a hard time adjusting to her diagnosis of Crohn's disease due to the circumstances under which it happened. For years, she had been having symptoms of upset stomach and frequent bathroom trips, but had never sought

medical attention because she thought it was due to the stress of owning and operating two different businesses with her ex-husband. Sophia reported that she “really lost it” when the doctors told her that she might only have a few years left to live unless she changed her lifestyle. She eventually sold her businesses and decided to travel in case the doctors were right, spending some time in Arizona and Illinois before returning home to Ohio.

Sophia chooses not to tell anyone about her diagnosis of Crohn’s disease. If people ask her if she is okay when she is having many symptoms, she tells them that she is under the weather and has a weak immune system. Sophia reported to me that only her son and her best friend actually know everything that is going on with her and her health. Sophia feels like it is really no one else’s business and she will deal with it on her own. She reports that she chooses to have no social life, because she has no desire to date or go out due to not feeling well most days.

When asked how she copes with her CID, Sophia stated that she turns to prayer, asking God to watch over her and guide her in making good decisions for her health. She has learned what she can and cannot eat. She plans her day around doing things more after lunch because she feels the worst in the mornings. She stated that she has good days and other days where she can barely get herself out of bed. She was very concerned about a job interview she had coming up, because the job is located over an hour away from where she lives. She was concerned about where to stop and use the bathroom if she felt ill on her commute.

Sophia's interview was one of the most challenging that I conducted for this research project. She was very guarded at first and asked me a couple of times who would be able to hear the recording, and how I would protect her confidentiality, and said that she wanted no one to know her real name. I tried to reassure her that no one would find out who she was from this interview project. When I told her I would need an email address so I could send her a copy of the transcript for her to review, she informed me that she would rather that I not do that in case I accidentally sent the transcript to the wrong email address. She did agree to let me call her if I had any follow up questions during the data analysis process. Overall, I got some useful information about adjusting to Crohn's disease from this interview.

**Interview G: Rose.** Rose is a 26-year-old Caucasian pansexual female who lives in southern Ohio. She has completed a master's degree in the social sciences field but is currently unemployed. Rose was diagnosed with a brain tumor at the age of 22, during the time she was working on her master's degree. She is currently single and has no children.

The tumor was discovered during the treatment process for severe migraine headaches. Due to the location of the tumor, it could not be fully removed, but Rose's surgery at age 23 removed some of the pressure that was built up around the tumor and created a new pathway for her cerebral fluid to continue to flow around it. Thankfully, the tumor was benign, and she has periodic checkups to check on the status.

Rose stated that the biggest challenge with being diagnosed and preparing for her brain surgery was choosing to isolate herself and not tell her family and friends what was

going on with her for several months. Rose says that looking back at it now; she is not sure why she did that, other than because of the initial shock and denial that she experienced when she was first told. Rose stated that she was scared about the surgery and not knowing whether the surgery would be successful in reducing her migraines. Rose reflected that this was what she needed to do to emotionally prepare for the surgery and life with a chronic illness.

Rose finally decided that she needed a nonbiased person to speak to about all the emotions and thoughts that were going on with her. She started attending counseling and now feels that this was the best decision that she made through her entire adjustment process to life with a CID. She and her counselor talked about how she was feeling and how scared she was to tell her family and friends. Her counselor enabled her to process through what she wanted to say to her family and friends and helped her practice saying the words aloud before meeting individually with several family members and close friends. Finally, with only a few weeks before her surgery, she told her family and friends and had their support and assistance through her surgery and recovery process.

Rose had to be out of school for six months, from the time she had her surgery until she had recovered enough to be released to go back to school. She coped with being out of school that long by doing lots of reading, watching some of her favorite shows, and spending quality time with her family and close friends. Rose reported that she had feelings of uselessness, but with the support of her mother and her determination to return to school to finish her master's degree, she got through the process. Rose stated that she

became really close with her mother during this process, and she was very thankful for her love and support.

Rose and I met via Skype because Rose did not feel comfortable with me coming to her house, since she still lives with her parents. We also could not figure out a private space to meet up in her community or mine. The Skype interview format worked well for this interview, except for one point when the recorder malfunctioned. I ended up having to ask Rose to review my transcript and assist me to fill in some blanks that had not been captured. She was happy to help and I was very appreciative of her taking the time to make sure my research was accurate.

### **Summary**

The purpose of this section was to give an introductory sketch of each participant in this research study. Each participant's general demographic information was provided. I also wanted to paint a picture of what some of the challenges of the adjustment process have been thus far. The coping techniques used by each of the participants were also discussed. I decided to include how each participant identified their sexual orientation to provide a better idea of who I interviewed in this study. Table 4.1 on the next page reviews the demographic information discussed above.

Table 4.1

*Demographic Information from the Participants of this Study*

<b>Participants Name</b>	<b>CID Diagnosis</b>	<b>Age of Diagnosis</b>	<b>Current Age</b>	<b>Relationship Status at Diagnosis</b>	<b>Education</b>	<b>Employment</b>
<b>Jack</b>	HIV	30	35	Married	Bachelor's	Medical SW
<b>Will</b>	Crohn's Disease	18	25	Married	Master's	PhD Student
<b>Dorothy</b>	Fibromyalgia	25	39	Married	Master's	Unemployed
<b>Karen</b>	Hearing Disorder	29	38	Dating	HS Diploma	Substance Abuse Counselor
<b>Grace</b>	Hearing Disorder	21	24	Dating	Master's	PhD Student
<b>Sophia</b>	Crohn's Disease	36	39	Divorced	Bachelor's	Unemployed
<b>Rose</b>	Brain Tumor	22	26	Single	Master's	Unemployed

## Demographic Trends

The participants of this study were selected through my recruitment process of hanging flyers on three different college campuses in the southern region of the state of Ohio. I also emailed the flyers to professors and former students that I knew in hopes that they would share the flyer with potential participants. This study aimed to not only hear the lived experiences of people adjusting to life with a chronic illness and disability but to also look and see if personal relationships changed during the adjustment process. I looked at three specific types of relationships: 1) family, 2) close friendships, and 3) intimate partner. The following section includes the demographic data analysis collected from Research Question 1 of my study and will review the following information for all seven participants: (a) current age, (b) age of diagnosis of CID, (c) current relationship status, (d) education level, and (e) current employment status.

**Current age.** I asked each of my participants to identify their current age in the recruitment emails before setting up an in-person or Skype interview. The current sample ranged from age 24-39, with a mean average age of 32 years of age. The two male participants were age 25 and 35, for a mean average of 30 years of age. The five female participants ranged from age 24-39, with a mean average of 33. As mentioned previously, in order to take part in the study, individuals had to be between the ages of 18-40, based on Erik Erickson's psychosocial stages theory, which states that the basic conflict at this life stage is intimacy versus isolation, and that the important life event that people in this age range strive for is to find a partner to share their lives with.

**Diagnosis of CID.** Before the interviews, I also inquired what age each participant was diagnosed with their CID, confirming that each participant was diagnosed between the ages of 18-40. Participants' age at their diagnosis of CID ranged from age 18-36, with a mean average of 26 years of age (25.85). The two male participants were 18 and 30 at their time of diagnosis for a mean average of 24, while the five female participants were 21-36 for a mean age of 27 (26.6). The shortest life experience with living with a diagnosis of CID was 3 years, while the longest was 14 years. All told, the participants had experienced a combined 45 years of life lived with a CID; with the mean average of life experience of living with a CID was 6 years. Each of the participants in the study has lived with their CID long enough to be able to discuss not only how they have adjusted to life with a CID, but also how their relationships may have changed during that process.

**Relationship status.** Jack and Sophia were each married at the time they were diagnosed with their respective CIDs, although after her diagnosis, Sophia separated from her husband and shortly thereafter divorced. Will and Dorothy both married after their diagnoses with CID. Grace ended a relationship that she had been in shortly after she was diagnosed, but recently started a new relationship with her current boyfriend. At the time of her interview, Karen was dating her boyfriend, and they have since married. Rose was the only participant in the study whose experience with adjustment to CID has not included a significant relationship. Sophia and Rose both stated that dating/relationships are not a top priority for them at this point in their life as they continue to learn how to live with their CID.



Three of the participants, Will, Karen, and Sophia, had children at the time of the interviews. Will had two stepchildren and a biological daughter living in the home with him and his wife. Karen's young son lives with her. Sophia had a teenage son living in with her and an adult daughter who lived independently.

Exploring their relationship status with each participant allowed the researcher to get an in-depth look into how significant relationships may have changed as the person adjusted to life with a disability, as well as what it was like to begin new relationships post-diagnosis. The rich data from the interview transcripts also provided information as to how it has been for the participants to start new relationships since the diagnosis of CID. This particular data will be further explored in Chapter 5.

**Educational status.** All seven of my participants have a high school diploma. Jack, Will, and Grace are all current graduate students at their respective college/universities. Two of the participants, Dorothy and Rose, have finished their master's degrees in the social science field. Karen works full time in the social services field and is responsible for keeping up with continuing education credits to keep her chemical dependency license active. All of the participants appeared to be educated about their CIDs and active in making sure they are following their physician's care plans to maximize their quality of life.

This data showed that none of the participants in this particular study have let their diagnosis of CID get in the way of achieving their educational goals. Rose, for example, had to take six months off from her master's degree while she recovered from her brain surgery, but she set a pre-surgery goal that she would go back to school once

she recovered, which is exactly what she did. This example of hope and resiliency will be discussed further in chapter 5.

**Employment status.** Jack and Karen were employed fulltime at the time of their interviews. Will was employed by his university as a graduate student working in student services on a part-time basis, which was part of his PhD program requirements and provided him with practical experience in his chosen field of study. Grace was not employed at the time of the interview but was getting ready to start her clinical rotations in January 2016. Dorothy, Sophia, and Rose were all unemployed at the time of their interviews, but all three women were exploring opportunities for at least part-time employment.

The data showed that employment is one of the largest challenges for the participants in this study, since of the participants were not employed at the time of the interviews. As stated above, all three were actively looking for employment, but careful consideration was being taken to ensure that they could manage their life with CID while being successful at a job. This can be a difficult feat for people who are adjusting to CID, especially when living in a rural part of the country where jobs may be limited.

### **Data versus Theory**

After the data set was collected, it was compared to the two theories presented in Chapter 2: Bishop's disability centrality model and Gill's disability identity development model.

Bishop's disability centrality model discusses how people adjusting to life with a CID have to adjust their life domains in order to meet the desired quality of life

standards. Jack, Will, and Grace felt that they have taken the necessary steps to meet the needs of their CID as well as meet their desired quality of life goals. All three participants are following their doctor's recommendations for daily care (secondary controls) and have adjusted their primary controls (support from family, attending school) to obtain their personal goals to further improve their quality of life.

Karen has learned which primary controls (such as texting as a means of communication with others or, having trusted friends to help her comprehend in noisy environments) she needed to modify to be successful in her adjustment to life with a hearing disorder. However, she is still working to change other primary controls (support and understanding from her parents) that are a current concern in her life.

The other three participants are still working on improving their quality of life as they continued to adjust to life with a CID. As stated above, Sophia, Dorothy, and Rose all were looking for employment at the time the data was collected. Sophia had to take into consideration what type of work she would be able to be successful, at since her doctor's advice (secondary control) was for her to have a job that does not cause her high levels of stress, as it could agitate her symptoms of her Crohn's disease. She had already taken care of one area of primary control, a divorce from her husband, who had created a great deal of stress in her life. Having finished their master's degrees in the social sciences, Dorothy and Rose were looking for job opportunities in their chosen fields. Dorothy is aware of her recommendations for both her primary control (not working fulltime) as well as her secondary control (paying attention to her pain level and state of fatigue). Rose continues to monitor her symptoms and follow her doctor's advice

(secondary control) to avoid getting migraine headaches. She is able to live at home with her parents, which allows her to have an acceptable quality of life (primary control) until she is able to find employment and eventually find her own place.

Gill's research focused on four areas of disability identity development:

1. Coming to feel we belong,
2. Coming home,
3. Coming together, and
4. Coming out.

Step 1 discusses how people reintegrate back into society after diagnosis with CID and how some people have to be in rehabilitation hospitals for extended amounts of time as they adjust to their life with CID. However, only two of my participants (Sophia and Rose) had spent any significant time in hospitals due to their CID diagnosis. All the other participants have been fortunate to have CIDs that have allowed them to adjust and cope at home with their family, friends, and intimate partner.

Step 2 discusses how people adjusting to life with a CID integrate into the disability community. Due to the fact that all of my participants were diagnosed with invisible disabilities, it did not appear that the majority of them have sought out connections with other people with the same diagnosis. Jack was the only person in this study who stated that he occasionally goes to support meetings for people diagnosed with HIV/AIDS. In future studies, this factor should be looked at further to understand the reasoning for participants not seeking out support from people who are going through the same adjustment process.

Step 3, which looks at the process that the person with CID goes through to bridge the gap between what family and society views as strengths and weaknesses, appeared to be a work in progress for all of the participants in this study. As mentioned previously, only one participant, Jack, readily shares with his CID diagnosis with other people he comes in contact with. However, Jack and his wife have chosen not to disclose his HIV status to their children to avoid them worrying about his health. The other participants are selective as to whom they disclose their CID identity. Dorothy reported that she does not like to be “labeled,” so she prefers not to disclose her fibromyalgia to others. Sophia made it clear that her CID diagnosis is shared with no one because she considers it to be her private business, and has even chosen to not disclose her diagnosis to her own adult daughter. Overall, it was unclear how the participants in this study related to Step 3 of Gill’s model.

Finally, Step 4 of this disability identity model discusses how people with CID present their new identity to society. As mentioned above, only Jack prefers to disclose his diagnosis to people outside of his immediately family. While he is selective as to whom he discloses this, he said, “Disclosing my HIV status allows me to feel like it has less power over me.” Will, Dorothy, Karen, and Rose have all disclosed their CID identities to close family and friends, but for the most part, they do not openly share their diagnosis with others. Grace and Karen both have disclosed their CID identity to their family and friends, but both struggle at times with close family really understanding what is going on with their respective hearing disabilities. Sophia only really talks about her

Crohn's disease with her doctor, with one close friend and her teenage son knowing more about her daily struggle than anyone else in her life does at this point.

While each of the participants has been diagnosed with a CID, a review of the transcripts shows that there are a variety of differences in how they have chosen to live their lives with their respective CID. Since all the participants have invisible disabilities, they have the choice to not be noticed or feel the need to disclose their CID when interacting with society, and they need to advocate for themselves for the level of support that they need from the people in their lives whom they choose to disclose to and receive support from. No one theory or model will be a perfect fit, but more research is needed on the adjustment to CID process.

## **Conclusion**

This chapter provided an overview of the demographic information of the seven participants of this study and provided a view into the lived experiences of each participant's adjustment to CID with a specific focus on challenges and coping skills that each participant has used in his or her adjustment journey. In addition, the theories that were used in the literature review were reviewed to show how each participant has adjusted to his or her CID status. Even though each of these participants live individual lives, some of the common bonds that the study of adjustment to CID process uncovers were made apparent. Chapter Six will include a discussion of the overall themes of relationship change during the adjustment to CID process.

## **Chapter 5: Data Analysis:**

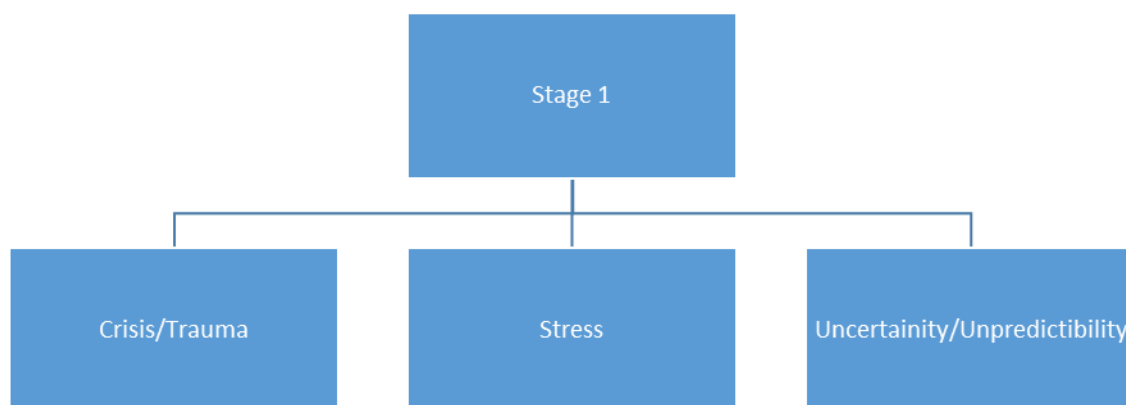
### **The Journey Thus Far with Adjustment to Life with CID**

This chapter reviews the data that were collected from the seven participants discussed in the previous chapter, focusing on their lived experiences in order to show current themes in the psychosocial adjustment to CID experience. Each interview was transcribed and then analyzed following the data analysis process of Smith, Flowers, and Larkin (2009), as previously described in more detail in Chapter 3. The six steps of the data analysis process were as follows:

1. Reading and re-reading the data,
2. Initial noting,
3. Developing emergent themes,
4. Searching for the connection across emergent themes,
5. Moving to the next case, and,
6. Looking for patterns across cases.

### **Psychosocial Adjustment Factors to CID**

During data analysis, one theme that emerged was the psychosocial adjustment factors to CID, which have been reorganized and condensed here into three stages of adjustment to life with a CID. The factors that will be discussed in this part of the chapter are as follows: Stage 1: crisis/trauma, stress, and uncertainty/unpredictability; Stage 2: loss and grief, and stigma; and Stage 3: time, self-concept, and hope/resilience.



*Figure 5.1.* First Stage of Psychosocial Factors of Adjustment to life with CID

### Stage 1

The key psychosocial factors from this research study that were identified as ones which are experienced early in the adjustment to CID process are as follows: a) crisis/trauma, b) stress, and c) uncertainty/unpredictability.

**Crisis/trauma.** Two of the participants talked about how they received their CID diagnosis without warning. Sophia explained that she had had no idea that she had Crohn's disease until she had to go to the emergency room:

I found out that I had Crohn's Disease due to a bowel blockage so it was a surprise that I even had this illness... it just kind of took affect after the major surgery. My life kind of stopped to tell you the truth.

This is a perfect example of how adjustment to CID can affect every part of a person's outlook on life and the way it changes one's daily life.



Karen was very guarded in her interview but appeared to feel emotional when discussing the origin of her CID: “My hearing impairment may have been caused by trauma, physical trauma.” I asked a follow-up question, but Karen appeared to be physically upset by talking about this part of her adjustment to CID journey, so I did not press her for more details, nor did she give any more information in reference to this statement throughout the rest of the interview. It was obvious by her emotional reaction that she had been triggered by some painful memories from her past. Karen’s statement also shows how things outside of our control can affect our health and quality of life.

**Stress.** Stress was identified in three participants’ transcripts as a key factor of their adjustment to CID process. All three participants were diagnosed with their CID while they were college students, and each of them talked about how stressful that time had already been for them prior to their diagnosis. Will talked to me about how the stress affected his freshman year experience: “I was diagnosed with Crohn’s disease my freshman year. I was already having so much change and then this was dropped on my lap as well. It was a lot to take and I had to miss a lot of class time due to my stomach issues.” Will found it difficult to manage all his responsibilities as a freshman in college due to this newfound medical concern.

Dorothy also talked about how the stress of her diagnosis affected her college experience:

I only tried one semester where I took four classes and it got to the point where I was just shutting down. Then emotionally and physical I just wanted to crawl up in a ball. Since then I have only been able to work and go to school part time. I

realized the more stress I was in the more physical pain I had with my fibromyalgia.

Dorothy had to learn and impose personal boundaries so that her stress level did not impact her daily functioning in life.

Rose said that her symptoms started as a college student:

I started having really bad headaches in my undergraduate work. I just thought ok I'm just stressed out. This went on for two years so in grad school I finally got it checked out and come to find out I had a brain tumor. This was added stress on me because of something new to have to deal with on top of all my other responsibilities as a graduate student.

During Rose's interview, the stress was evident in her voice as she remembered this difficult time in her life.

Stress played a key part in these three participants' lives because the introduction of a diagnosis of their CID added a new life stressor to all their other current responsibilities. This lead into the next category of discussion in Stage 1: uncertainty and unpredictability.

**Uncertainty and unpredictability.** A lot of rich life experience was collected from the data on how unpredictably a CID diagnosis can progress and how uncertain people adjusting to a CID will feel when presented with the need to cope with new or recurring symptoms. Karen shared a brief but powerful statement with me during her interview: "My hearing loss is going to progress and I'm not really sure how far it will go. I can possibly become deaf at some point in my life." Doctors and other medical

professionals can only provide people with CID estimates of the progression of their CID diagnosis, because each person's progression with a given CID differs from that of others.

Sophia discussed how her Crohn's disease affects her daily life: "There are times when it (Crohn's) peaks and it's really, really bad, and then there's times when it's just normal life. On average, it (Crohn's) takes away a few days a week for me." Having a CID like Crohn's makes it hard for people like Sophia to plan their lives out in advance, due to never knowing when they may feel too sick to even get out of bed. This poses a challenge with trying to hold down a job and complete other activities of daily living.

Rose talked to me about the unknowns of how life would be before and after surgery:

I was kind of trying to emotionally prepare myself for anything that might happen after my brain surgery. I lost focus of school and work and stuff like that so it was just kind of it, it was a really rough few months for me.

Rose was not sure how to prepare for the adjustment process after her brain surgery. She did the best she could to prepare herself but still struggled with the unknown, since the doctors could not give her many definite answers. Rose also discussed how she adjusted to life after her brain surgery: "After I had my brain surgery, the adjustment was pretty intense because I, I honestly didn't know what to do. This was really scary for me." Rose had a lengthy recovery time after her brain surgery where she could not be in school or work. This was very hard for her to deal with because of the lack of things she was able to do for herself and to keep her motivated to follow the doctor's orders so she could get

back to the things she wanted most in life, finishing school and finding a job in the social service field.

During her interview, Grace shared about her unique hearing impairment, which also affects her balance and vision at times. First, Grace talked about the uncertainty in just getting the initial diagnosis:

No one could really figure out what was going on. And then I when I got the diagnosis the doctors didn't had never seen it in someone as young as me. They said they couldn't help me. So I kind of gave up from there and just decided I would try and adjust the best I could.

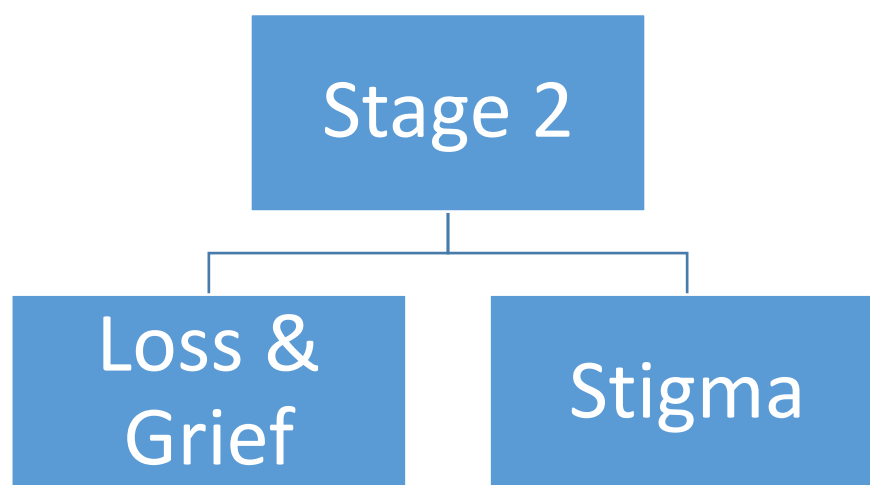
Grace struggled to get the information she needed about her diagnosis and did not know how to even start adjusting to her hearing impairment. However, this was not her only ongoing challenge: "It's very difficult for me to explain my diagnosis to others which I think is one of the most frustrating things for me. Uhm because people don't know what it is and my symptoms change so frequently."

Next, Grace explained how her hearing disorder's uncertain progression makes it hard for her to adjust and cope.

The main adjustments for me were just realizing the things that I need to pay more attention to [days where vision and balance are affected]. The thing that's hardest for me is no one can tell me how far it's going to progress. Or if it will ever stop or really where I'm going because as far as the doctors that I've seen no one really has seen this before. So they don't know how to help me and they said they couldn't do any sort of surgery because it's so small in your ear that it'd be

risky to uhm to hit the acoustic area and then I'd be deaf. One of my fears is that what if it continues to get worse then I wouldn't be able to drive which is a big component of my independence.

Grace, Rose, Sophia, and Karen all discussed how their CID has many unknowns, which makes their daily lives hard to predict and plan. This was the overall theme from Stage 1: the fear and stress of the unknown.



*Figure 5.2.* Second Stage of Psychosocial Factors of Adjustment to life with CID

### **Stage 2**

In the second stage of factors that are experienced in the adjustment to CID process, the transcripts showed examples of loss and grief, and also stigma. Based on the data collected, it seemed like this was the middle step of factors that the participants experienced as they adjusted to their CID diagnosis. While body image was also

considered and would be appropriate to include here, due to the lack of participants referencing problems with body image it was excluded from this discussion.

**Loss/grief.** There were many examples of how loss and grief were experienced in the interview transcripts. Karen discussed how she tries to cope with her hearing loss:

Often times I try to have at least one person with me that will repeat things for me and when that fails I tend to just be quiet and isolate because there is really no point if I cannot hear. There's certain tones that I can pick up better than others. Uhm Women and children not really good and uhm then the lower voice tones are difficult for me to pick up on. And I've lost 11 letters out of the alphabet so far. The only positive is that my hearing loss has progressed slower than I feared it would.

Karen is missing out on potentially important information due to her hearing impairment and her reservations about asking people whom she does not know well to repeat communication that she did not hear. This isolating behavior was also evident in Sophia's story.

After her diagnosis of Crohn's disease, Sophia's life changed dramatically: "My whole life fell apart. My business failed, my marriage ended, and my doctor told me I had five years to live if I wanted to continue my current lifestyle [e.g., high stress, little sleep, unhealthy diet, etc.]." Sophia experienced a great deal of loss immediately following her diagnosis of Crohn's disease. She had a lack of support during this very trying time period when she did not feel like she could reach out to others for support.

Dorothy also discussed her loss and grief after her diagnosis of fibromyalgia: “I spent about three months just moping. I even dropped out of school. The doctors gave me very little information and when I researched my diagnosis and saw there was no cure it really got me down.” Again, there is an evident theme of a lack of information provided by a medical doctor causing the person who is adjusting to life with a CID to struggle to cope in a healthy way.

Rose shared how she struggled with grief and loss while she recovered from her brain surgery:

Things went pretty well but those first few months were kind of rough too just because I, I knew I wasn’t going to be able to get back into things right afterwards uhm but it was just I kind of had to basically sit around for about six months. I couldn’t do anything so I kind of felt useless so it was like what I would imagine some people go through during postpartum depression or something. I think it was just that part of me that I couldn’t get back into school and finish things that bothered me the most.

This feeling of loss of purpose, even though it was temporary, was difficult for Rose to deal with during her recovery from her brain surgery.

One final example of grief and loss was Grace’s explanation of the physical losses she has experienced with her unique hearing/vestibular disorder:

Finally, a doctor found that my canals in my ears were totally sclerotic [scarred] so that’s why therapy doesn’t help. That’s why I can’t get better is because uhm usually vestibular therapy is used to train the canals to kick back in and work

again. But mine are basically dead. Some of my symptoms have got a lot worse this past year. Mostly the vision has. My balance has got a little worse but uhm like I said before like trying to stay fit and work you know uhm kind of helps me maintain balance a little bit if I just keep up my muscular control and reactions.

While Grace has found a way to manage and adjust her balance control via exercise and staying healthy, she has yet to find ways to cope with how her vision problems are getting more noticeable and problematic for her daily living. All of the participants in this section discussed how the loss of function or ability has affected major aspects of their lives (school, work, etc.).

**Stigma.** The participants' reactions to the possibility of stigma from others varied significantly. One interviewee, Jack, talked about how he has turned the stigma of his diagnosis into something positive: "I don't let my HIV status define me as a person. By disclosing my status, I can dispel a lot of fear and provide knowledge to others about HIV." Not only does Jack empower himself by sharing about his HIV status, he also is able to break through some of the stigma associated with people who are diagnosed with HIV. Jack is a healthy, successful, and social person, and he feels confident to educate his fellow peers on HIV.

Karen's philosophy about disclosing her hearing disability in hopes of avoiding stigma from peers was similar to Jack's:

I know uh for me if I tell people in the beginning it kind of nips it in the bud because they're going to be more apt to speak up and to let me see them you know let me see them talking and things like that so...



By initially Karen telling people that she has trouble hearing, she can avoid awkward conversations later on. She can also hopefully dispel any stigma that might come with people assuming she has other disabilities by disclosing up front.

For the rest of the participants, stigma was not as positive of an aspect of their daily lives. Dorothy explained how her diagnosis made her feel:

I had to learn how to live with the new label of fibromyalgia. I don't really like talking about it because if I did not tell you I had fibromyalgia most of the time you would not know because I am really good at covering it up.

Dorothy felt like this "label" was something that she had to wear, describing it as if she had a label printed on her clothing or tattooed on her. She felt afraid of how people would treat her differently when they noticed this new label, but since she has an invisible CID, she can choose to not disclose it to others. This theme of non-disclosure due to stigma was also apparent with Grace and Sophia.

Grace discussed why she chooses not to disclose her hearing/vestibular disability:

When I lose my balance uhm in public I get embarrassed a lot and so. And I worry a lot being young especially in our generation has the stigma of using drugs and alcohol. And so uhm I do get embarrassed about that and you know if someone makes a comment or joke I just try and shrug it off and not worry about it. I don't want people to judge me and make assumptions of what [my CID] is because I fear what they could assume.

Grace fears what others assume and think about her, yet she chooses not to tell people about her CID diagnosis because it is so hard for her to explain what is medically going on with her.

Sophia also talked about how she feels other people would not understand or care even if she did disclose her Crohn's disease:

I am probably not the personality that would ask anybody for help anyways.

Most people are not aware of [my CID]. If you tell somebody hey I feel like I got the flu every day they're going to be like oh yeah that stinks for you. And then they go about on their own life so no, I mean for the most part I can keep it

together and most people don't know or think that I'm hurting and as sick as I am.

Sophia has decided to limit who knows about her Crohn's disease, because she feels like no one would care or able to help her. As a result of this personal stigma that Sophia has developed, she has only disclosed her health status to her teenage son and a close friend. As a result, Sophia is coping and adjusting to her life with a CID mostly on her own.

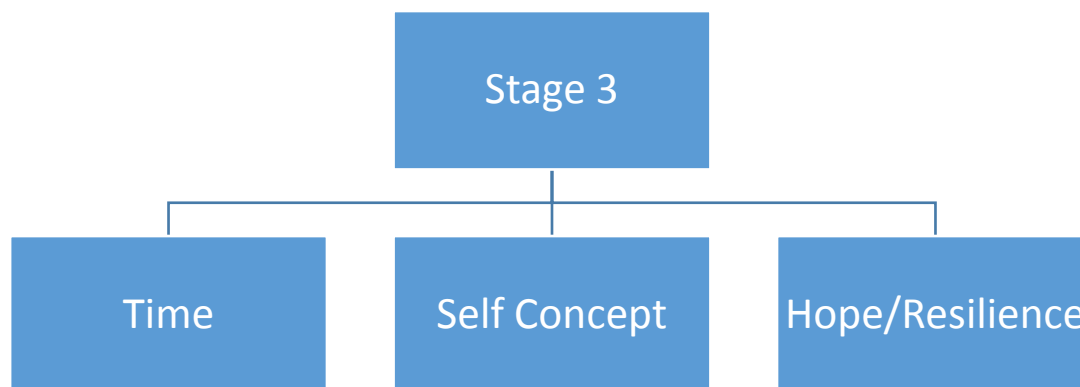
Sophia also made a statement that referenced both the potential of stigma and issues of body image. She said:

If I ended up with a bag [colostomy] hanging out of my side I'm sure I would never leave my house. I know me and I would be too vain to do it. I would also be afraid people would find out and then want to ask too many questions.

Sophia is so scared that others will find out about her Crohn's disease that she would be willing to stay at home all the time if her disease progressed to the point of needing to have a colostomy bag. Her quality of life is already guarded with whom she tells about

her CID, and she has already predicted the future of what she would do if a colostomy became medically necessary.

In Stage 2, the participants identified that they have worked through feelings of loss and grief and have dealt with internal and external stigma. In the final stage of this data analysis, three more adjustment factors will be discussed: time, self-concept, and hope/resilience.



*Figure 5.3.* Third Stage of Psychosocial Factors of Adjustment to Life with CID

### **Stage 3**

In Stage 3 of the adjustment to disability factors that were found in this research, the participants talked about how they are using time, self-concept, and hope/resilience to give them the strength to make the most out of each day that they have.

**Time.** Two of my participants discussed how they have to pay attention to their physical needs by organizing their day around their CID, Crohn's disease. Sophia explained that she knows she will have more stomach issues earlier in the day:

I know I will be sick a couple of times in the mornings. It's guaranteed. I will be sick a couple of times in the morning on the way to work because the nausea does not stop until 12 or 1p.m.

She went on to voice concerns as to how she will manage this when she tries to go back to work. Sophia was actively looking for employment at the time of the interview but was having trouble finding a position that paid well but that did not start until after 1p.m. This is a major challenge, but Sophia knows the timing that she needs to work with in order to obtain and be successful with employment.

Will also talked to me about how he has used his Crohn's disease to his advantage to help himself be more organized:

My CID helped me become more organized and set schedules for myself. It is harder to do things on a whim because what if my stomach's not feeling well.

Really having to plan things out is one of the biggest adjustments for me I think.

Planning food out is just normal for me now.

Will has to think about all he needs to get done each day, and then pick foods that he knows will not make him feel nauseous in order to be more productive and enjoy his day.

Will went on to talk about timing issues in relation to his CID:

I know that my stomach issues are worse in the mornings so if I know I need to travel I will plan on not leaving until 11a.m. or noon to let my stomach calm down some. I also have to plan my trips ahead of time to look for places that I can stop and use the restroom.

This was a major adjustment for Will, as he said that he used to just be “a do what I want when I want to kind of person” before he was diagnosed with his CID. When Will organizes his time and plans out his day and food choices, he is more successful in avoiding getting sick and not getting all his tasks completed that day.

The data here shows the adjustment factor of time as a way some of the participants organized/planned out their day due to the symptoms of their CID. The more participants learned about their CID diagnosis and their bodies’ way of displaying symptoms, the more they have learned to adjust their way of life to meet their daily needs and achieve their desired tasks.

**Self-concept.** Several participants, including Karen, Jack, Will, and Rose, talked to me about how the adjustment to CID process has built up their self-concept. Karen was brief in many of her responses to the interview questions; when asked how she copes with meeting new people and having to tell them about her hearing disability she said,

I have decided I just need to be pretty out with it. Uhm I mean I’m not ashamed or anything like that and then I can actually communicate better with people. If I disclose my hearing impairment right off the bat its better in hopes that maybe people will kind of be understanding and maybe talk a little louder/clearer.

Karen really seemed to go back and forth with how comfortable she is disclosing that she has a hearing disability, but in regards to it building up her self-concept, she has found that disclosing builds up her confidence and communication with others.

Jack had a similar stance about his HIV diagnosis:

It has not hindered me in any way. I tell everybody that wants to know or doesn't know a lot of the times when I think it's appropriate because that way I feel is that uhmm the more people that know about it the less power it has over me. By disclosing my status, I can dispel a lot of fear and I can share knowledge.

Jack is building his self-concept by not letting his HIV diagnosis stop him from achieving his goals in life. By feeling that he can disclose his status in appropriate situations, he has control of what people know about him and his diagnosis.

Will discussed how until he discloses, some people may get the wrong idea about him:

If I eat too much then I'm very uncomfortable which makes me look unsocial because I am sitting there thinking oh my god I have a stomachache. I am always so self-conscious around friends that do not know about my CID. Until I disclose I fear that people think I am antisocial or that I do not like them when in reality it's just that I do not like the establishment they are going because of the lack of privacy of the bathroom or that I am really not feeling well that day. It isn't that I am embarrassed but no one really wants to hear about your bathroom issues. So it is hard to share about my Crohn's disease sometimes. But after I have disclosed it the awkwardness goes away and people understand why I do not want to participate in some activities I am invited to.

When Will discloses his CID to people he is with, his self-concept improves. For example, the people he is with will understand that he prefers not to go to a particular bar or restaurant due to the fact that the bathroom stalls there have no doors. Will is able to

communicate his needs better to people that are knowledgeable about his CID diagnosis because he has less worry about them getting the wrong impression of him.

Rose felt that her self-concept improved during her adjustment to her CID diagnosis:

I became a lot closer to people in my life through this experience. I was not a very open person before so this experience allowed me to become an open more open person and I was able to become a lot closer to certain people. These people in my life have remained closer since I have recovered and adjusted to my life post-surgery.

The adjustment period after her brain surgery really enabled Rose to learn how to communicate and build her self-concept with the people in her life. This adjustment in her self-concept has continued to strengthen her personal relationships with others.

The participants represented self-concept in various ways. At some level, all the participants have found that being more open with the people in their lives has assisted in the adjustment process to life with a CID. The participants' self-concept has changed because of this new level of communication and advocacy for their needs in their lives.

**Hope/resilience.** For the purpose of this analysis, the concepts of hope and resilience have been combined due to the way that the participants talked about ways of coping with their adjustment to life with a CID. In this section, we will hear from Sophia, Dorothy, Jack, Grace, and Will.

Sophia explained how she uses her spirituality: "Prayer, nothing else to say but prayer lots of prayer is how I cope with all of this. It's what gets me through each day."

Sophia uses her spirituality to build hope and resilience as she continues to adjust to life with Crohn's disease. Since Sophia has chosen not to disclose her CID to many people, she has adjusted to relying on herself and using her spirituality to guide her through the ups and downs of the symptoms of her CID.

Dorothy discussed a major change she had to make to become resilient with her fibromyalgia diagnosis: "I had to learn to ask for help when I needed it. This continues to be difficult at times for me to do but I have gotten a lot better at it over time." When Dorothy asks for assistance, she can avoid symptoms such as pain and fatigue limiting her daily living tasks. Dorothy also talked about how she had to adjust to her doctor's orders: "I found a medication that helped with the symptoms and I started to come to terms with the fact that this was something that I was going to have to live with for the rest of my life. This was difficult for Dorothy, as evidenced by the emotion she showed on her face when she spoke about this. By having hope that a medication could help with some of her daily symptoms so that she could continue to do the daily things she wanted to do, Dorothy was able to adjust to life on life's terms.

Jack and Grace had some similarities in their respective discussions of hope and resilience. They both made references to how good medical care and exercise have helped them in these areas. Jack said:

I have hope because I have a great doctor that is supportive and keeps me motivated to take care of myself. As a result, I take really good care of myself and I do what I have to do to stay healthy.



Jack goes to the gym multiple times a week and appeared to be in very good physical condition. Jack's doctor had stressed the importance of him eating healthy; exercising; not using alcohol, drugs, or cigarettes; and trying to keep his stress level down. By following his doctor's advice, Jack's HIV status is undetectable and he has hope that he will be able to have a long and prosperous life.

Grace also talked about good medical care and exercise as ways that she copes with her vestibular disorder:

Probably the only reason I am doing so well with my diagnosis is that I am young and fit. One of the doctors had told me these were advantages for me. So I decided that I better stay active and fit then.

Grace has hope that by staying active and fit, she can slow down the progression of her vestibular disorder. Even though she has challenges with one of her passions, running, she is resilient to continue it in some capacity so she can stay healthy. She has hope that by staying active, her CID symptoms will not disrupt her desired life goals.

Will discussed what he uses to be able to stay resilient and not allow his Crohn's to keep him from going out with his peers: "I sometimes will go out to eat with friends and eat half the meal and then eat the other half when I get home to avoid having stomach aches that can cause me to be antisocial." By doing this, Will is still able to participate in activities that he enjoys but avoids having physical symptoms from his CID. Will went on to discuss what gives him hope:

I am fortunate because my chronic illness is a mild to moderate case and can be controlled with medications and good food choices. I drew a lot of strength also

from a friend of mine who had cancer in high school. He always kept a positive attitude so that inspired me to do the same with my CID,

By focusing on the positive things Will can pull from his adjustment to life with a CID, he has built hope and resilience in his own daily journey. He has learned how to adjust his food intake and take medication that helps him avoid being in great amounts of pain and/or discomfort that would keep him from being able to have an active social life.

Stage 3 factors of time, self-concept, and hope/resilience have provided some insight into what the participants in this research study have done to better their lives as they adjusted to life with a CID. All of these psychological factors of the adjustment to CID process have assisted the participants in this research study to learn what they have to change to make their quality of life the best it can be. As Sophia said:

I just decided I was going to try to change my life. If I wanted to live I was going to change it. So I have traveled a lot and checked off things on my bucket list because I really didn't think that that... I didn't know how much time I had left to enjoy these things.

## **Conclusion**

The participants in this study have done what they have to do to try to keep living the desired lives that they want to even with the roadblocks that their respective CIDs may provide along their way.

While this chapter has focused on the participants' internal adjustment, the next chapter will focus on how the participants felt that their personal relationships with their

parents, close friendships, and intimate partner have changed over the course of their adjustment to life with a CID.

## **Chapter 6: Relationships and Adjustment to Life with a CID**

### **Introduction to the Chapter**

This chapter will focus on the three research questions that specifically dealt with potential relationship changes during the adjustment to life with a CID process. The three types of personal relationships discussed in this study are as follows: relationships with family (parents, siblings, and children), relationships with close friends, and relationships with partners/dating life. Each of these relationship categories will be analyzed by exploring statements from each of the seven participants that were identified in the transcripts. The chapter then concludes with the overall themes found from relationship changes during the adjustment to CID process.

### **Family**

The data on how family relationships have been viewed by the participants was some of the most detailed information gained from this study. Not only did participants talk about relationship change with their parents, but several also opted to talk about their siblings and their own children. Even though this was not specifically part of the interview guide questions, I have elected to include brief snapshots of data provided about siblings and children in this family section of the data analysis in order to provide a more detailed picture of the adjustment process. While the participants had a wide variety of experiences on this topic, Jack, Dorothy, and Rose all felt that their adjustment to life with a CID has brought them closer to family members.

Jack reported that his parents had very different reactions when he told them he was HIV-positive: “Dad was very supportive, Mom wanted to pray it away.” Now that

they see how healthy he has been able to stay, Jack's parents rarely bring up his HIV status. Jack's parents are divorced, and he considers his grandmother to be the person that raised him. Unlike his parents, his grandmother and aunt do not avoid talking about his HIV status: "My grandma and aunt are always doing research and reading about HIV and giving me information they have found. They are probably my biggest family supports." Jack made it apparent that he is very thankful for the support that he gets from his grandmother and aunt.

Jack also talked to me about his children. He and his wife have one child together, but he has two stepchildren that he considers his own. Jack talked to me about deciding what to tell his kids about his CID:

My wife and I decided not to disclose my HIV status to our children until they are a bit older. I don't want to burden the kids with the fact that even though it's a small chance as healthy as I am that I might get sick and die someday.

Jack went on to say that they made this decision due to the fact that his stepchildren have had a lot of change and loss of father figures with their mother's past relationships. Jack's daughter is five years old, so he and his wife think she is too young and probably would not understand what HIV is. Jack and his wife have decided that when the kids are older, they will be informed, but since his health is good, it is not information that they need to be concerned with at this point. These sorts of decisions are difficult for the person with CID to make; later in this chapter there will be a discussion about how two other people, Karen and Sophia, have handled disclosing to their children.

Like Jack's aunt and grandmother, Dorothy's parents provided similar experiences of positive support:

My parents were very supportive when I told them I had been diagnosed with fibromyalgia. About three years after I was diagnosed my mom was also diagnosed with fibromyalgia. This gave me someone to talk to about everything that had been going on with me. Finally, I had someone that could understand and we were able to help each other.

Not only did Dorothy experience positive support from her parents, she also was able to lean on her mother due to their close, trusting relationship and shared similar experiences. After her own diagnosis, Dorothy's mother had personal, firsthand understanding of some of the symptoms and pain that Dorothy was experiencing.

Rose also was fortunate to have good support from her family, including her parents and her siblings, after her brain surgery:

My mom was one of my biggest inspirations through all of this. I had seen her go through illness when I was younger and she had persevered through that so it was I was just kind of like thinking of that to keep myself going.

Rose's mother's previous struggle with an illness inspired Rose to give herself the strength and courage to get through the adjustment to life with a brain tumor.

Rose further discussed the level of support she got from her parents during the hardest days of her recovery from brain surgery:

I had put a lot of thought into how I had felt about this whole situation, so I sat down with each of my family members to talk about all these different things and

I think that made our relationships stronger because we all felt so much closer to each other. I allowed myself to be open about things and my emotions and this has allowed my family and I to be much more open with each other. My mom was more of my caretaker and my dad was there for support and would help me get answers from the doctors when I had questions/concerns.

By planning what she wanted to say to her parents before her surgery and being so open with them, the experience brought Rose and her parents closer together. They were there for her during her recovery from her brain surgery and have remained close to her even after her recovery.

Rose also discussed the support that she felt she received from her sisters: “My sisters were just present kind of if I needed to talk about anything. They were part of my social support and if there was something bothering me about being back home I could talk to them about it.” Rose had always been close to her sisters, but she felt that they provided particularly vital support for her during her recovery from her surgery, including a level of social support that she did not feel like she received from her parents during that time.

Unlike the primarily positive examples shown above, Will and Grace’s stories provide examples of both positive and negative support from their parents and siblings.

Will reported that he has mostly had positive experiences with his family and the support they gave him, but that they also create various stressors for him as well:

My parents were really worried and were very protective over me when I first started having symptoms. They insisted to go with me to the doctor’s

appointments. Over time the amount of concern they had for me got to be overbearing because I had so much on my mind and then constantly hearing their worries and concerns was a lot to handle. When I moved to [my current city] for grad school my mom constantly asked how I was feeling so I had to set a boundary with her that I would let her know if I was not feeling well.

In Will's situation, his parents were so concerned about his newly diagnosed chronic illness that they became more of a hindrance than a support to his adjustment to life with a CID some days. Will had to set a boundary with his parents to reduce feelings of stress and being overwhelmed by letting them know that if he was really sick with his Crohn's, he would inform them.

Will provided another example of his parents causing him undue stress during his adjustment to life with Crohn's disease:

My parents told me that they struggle as much as I was with my chronic illness. This really upset me because they do not know what it is like to live like every day. This conversation I think helped my parents realize what I was going through and how their reactions affected me quite a lot.

While Will felt like his parents meant no harm in saying that they struggle as much as he does with his diagnosis, it really hurt him because they do not go through the daily struggles of the symptoms of Crohn's disease. By Will talking with his parents about how statements like that made him feel, he was able to help his parents to understand the emotional impact that family members can have on the person adjusting to life with a CID.



Will had only one brief statement about his siblings: “My siblings were/are always concerned, but it is just something that we do not discuss unless it is information that I think they really need to know.” Will went on to discuss how he has lost one sibling since his diagnosis and his other siblings are busy young professionals who, in his opinion, do not have the time to hear every private detail of his Crohn’s disease. Will made it clear that if his health took a turn for the worse he would inform his siblings, but other than that, when he gets time to speak with them the last thing he wants to discuss is his stomach issues.

Grace talked to me about how the amount of support from her parents has varied widely and has had both positive and negative effects on her adjustment process:

I feel like my dad would never bring [my CID] would never talk about it and if I talked about it I always felt like he shrugged it off and acted like it wasn’t a big deal or that it didn’t really exist. My mom was the other extreme and she just kept wanting to understand. She wanted me to send something to her so she could like learn about it and figure it out. And then uhm but at the same time she didn’t really know how to help me so then she stopped bringing it up.

Grace experienced two very different responses from her parents. Since she has an invisible CID, it is harder for her family to see the changes that are happening with her vision, balance, and hearing. Her father appeared to be in denial that she was even sick, while her mom grew frustrated when Grace could not find much information to share with her about her diagnosis and symptoms, since her vestibular disorder rarely happens in patients as young as she is.

Grace intends to change one aspect about how she handles her adjustment with CID with her family:

The hardest part for me is that my family and I do not bring up my CID and talk about it. So I have started in the past year to take every opportunity that something that would be difficult for me and they're talking about that I would try and say well I can't do that anymore or that would be really hard for me. And I think that and that was difficult because I still always felt like they shrugged it off. I do feel that this past year they do actually acknowledge it a little better. I think explaining what is going on with me to my family is always going to be challenging. I don't think that's ever going to go away. Especially because they don't get what it is really it's just so hard to explain. I feel like the emotional and support component was very slow to come from my family because of this.

Grace plans to be more open and honest with her family so that her family members can better understand what has and is continuing to change in her life due to her vestibular disorder. Grace was aware that since she had allowed her family to not talk about how her CID symptoms were progressing, they were not aware of what she now has trouble doing on a daily basis. While my original intent was that I would follow up with Grace after Christmas break, when she planned to sit down and have a long discussion with her family members about her CID, I did not hear from her at that time.

Grace also talked to me briefly about her younger brother and the level of support she receives from him:

I have one brother two years younger but he's just so caught up in his own life and uhm I never really brought [my CID] up with him at all. I rarely see him. It's just never been something that I thought to bring up and talk about in the short amount of time that I would see him.

Her brother lives in Wisconsin and is finishing up his college degree and in a relationship of his own. Grace did state that over the holiday season when they would be in the same place, she would like to sit down with him in person and explain what is happening with her adjustment to CID and her current symptoms. She made it very clear that she wanted to do this in person since she has such limited communication with her brother due to both of their hectic lives.

Grace decided that she had to advocate for herself, explaining to her family how her vestibular disorder was affecting her daily life and educating them about her increased difficulty in performing activities of daily living. By choosing to bring it up and talking about it openly with her parents, she hopes for increased support from them.

Unlike the above examples, Karen and Sophia receive little-to-no support from their parents or family members.

Karen chooses not to be around her family as much as she would actually like to be:

My family, they're frustrated with me a lot. At times my relationship with them is strained. They get angry and I just don't get the logic there. But I do understand that it is frustrating after I repeat myself you know like say that again huh you know. I get it, I get it.

Karen went on to explain further about her choices when it comes to spending time with her family:

I am absent a lot from my parents' events and they often complain about it. Every once in a while my mom will speak up on my behalf but overall I do not feel like I am supported by my family.

Karen has made the choice to remove herself from spending quality time with her parents because she feels like they do not support her and/or try to understand what is going on with her hearing loss. Therefore, it has become easier to simply not be around her parents to avoid feelings of frustration from their lack of support. As will be discussed later in the section on friendships, some of the participants have developed almost family-like relationships with their friends to build the missing support from family members that they may need during their adjustment to life with a CID.

While her parents are unsupportive, Karen does have a brother and her son who are both very supportive of her. Karen does not get to see her brother often but she said, laughing, "I have one brother that is pretty understanding and he's also pretty loud so I'm good with that." Karen also told me that her young son "tells people that [her] ears are broken [she laughs] when he notices [she] didn't hear someone say something." Karen has adapted to having support from her brother when she gets to see or speak to him as well as from her young son because they advocate for her when she is in noisy places or someone addresses her out of her sight and she does not hear what was said. Karen has adapted to life with the family that is supportive of her at this time.

Sophia talked about how she prefers to deal with her Crohn's disease on her own instead of relying on family:

I just do not tell my family what is going on with me. I was raised by my grandparents and my grandmother was the last to go and she died a few months ago. My son is pretty supportive. He's 16 and I have told him about my Crohn's disease. He knows more than I think he should know but he lives with me. My family was kind of hit or miss before I got ill. Like the ones who have always been around are still around. Plus, I just don't tell people that we just don't talk about that.

Sophia did mention that she has a sister, but she does not disclose anything to her because "she is in her own crisis." Sophia made it very clear throughout the interview process that she was a very private person and that she really does not speak to anyone, including her family, about her Crohn's disease. She prefers to only disclose about her health on a need-to-know basis. This choice has limited the amount of close family support that she receives.

### **Discussion of Family Relationships after Diagnosis of CID**

Having looked at the data, it is clear that family support is dependent on several factors, including how much information the participants provided their loved ones about their diagnosis. The participants that had more open communication with family members had more family support, as compared to the participants that chose not to disclose their adjustment to CID diagnosis to their family members.

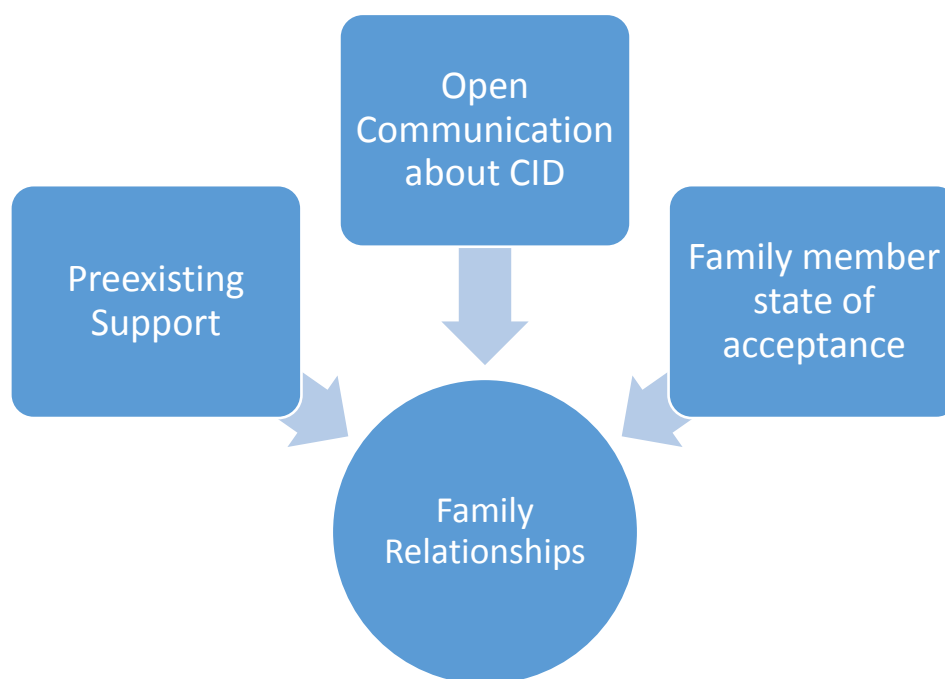
Another factor was how much support the family members offered, as well as how much support the participants were willing to receive. For the participants who already were close to their parents, siblings, and children before they were diagnosed, the research appeared to show that they were more likely to receive good-to-excellent family support. For the participants who already had strained relationships with their family members, the data showed that the introduction of the CID did not appear to have much change on the level of support that was given or received.

Family members go through the stages of adjustment to disability in their own ways and at their own pace (shock, depression, acceptance, etc.), as evidenced by the qualitative interviews as described above. Both Will and Grace had family members that really struggled with the fact that their child had been diagnosed with a CID, which added stress to Will and Grace's lives, as they were constantly questioned about how they were feeling and asked for more information about their condition. This led to the point when Will set a boundary for his family, requesting them to stop asking about his health every time he talked with them. On the other hand, other participants like Karen and Sophia became even more independent from their family members in order to reduce their stress from the lack of support that they received from their family members, leaving them to cope with the adjustment process on their own.

While not everyone spoke about their sibling relationships, the participants that did so showed that the same factors of preexisting support from siblings and open communication with them both affected how much support the person adjusting to CID was provided. Rose felt like she got social support from her siblings that her parents did

not provide, while Grace said that she does not get much support from her sibling, because he lives out of state and is not aware of everything that is going on with her situation.

Preexisting support and open communication were also relevant when looking at the support provided by the participants' children. Jack decided not to tell his children about his CID because of their ages. Karen did tell her young son, who is very supportive of his mother when she does not hear people speaking to her by telling them that her ears are broken. Sophia receives support from her 16-year-old son because he lives with her and sees her daily symptoms of Crohn's disease.



*Figure 6.1.* Family Relationship Themes

## Friendships

Next, the participants discussed their relationships with close friendships. The participants provided rich, detailed information about how friendships may change as a person adjusts to life with a CID. Each participant discussed how his or her close friendships were, for the most part, supportive and a vital part of the adjustment process.

Jack talked to me that he really limited past friendships before he was diagnosed with HIV, because he completely changed his lifestyle:

I was diagnosed with HIV when I was in residential drug treatment. Many of my previous friendships were people that I partied with so I had to cut unhealthy relationships out of my life so I could achieve my desired sobriety.

In regards to his current friendships, Jack said, “I feel like I have the right level of support from my friends at this time. I can probably count five people that I consider friends outside of my family unit.” Jack went on to say that between the significant support from his family and the busyness of his life with fulltime employment, his wife and kids, and graduate school, he has only a limited amount of time at this point in his life to spend with his friends. However, he does have several close friends that he stays in contact with and receives support from at this time.

Will talked to me about a unique friendship he made while he was at his undergraduate school:

One of my friends from undergrad also had Crohn’s disease. He had a very serious case. He was someone I could talk openly and honestly with and he



understood what I was going through. It was like we had our own little chronic illness support group.

Having a peer support as he went through the adjustment to life with a CID process was a positive experience for Will. He was able to feel comfortable to talk about detailed information regarding his Crohn's disease with this friend, since he knew he would be more likely to understand and relate to him, since he was going through a similar experience. Will went on to talk to me about other close friendships he has:

My other friends tried to be supportive and learn about what was going on with me. I like that my close friends can joke around with me about a lot of things and keep it light. Them being able to joke around with me about my chronic illness made me feel a little more normalized.

Will appreciates humor about his frequent trips to the bathroom from his close friends. His friends have accepted that this is something that he has to deal with, and through the use of humor, they can simply have fun and not make a big deal out of Will's need to watch what he eats and go to places that have a private restroom.

Will also shared about his best friend since high school: "One of my best friends always checks out the bathrooms in bars and restaurants and text me that he found a new place where I can go. He is just super, super supportive and understanding of me." Will went on to say that until he discloses his Crohn's disease to new people in his circle of friends, they sometimes think it is odd how much he and his best friend talk about restrooms at bars and restaurants. Will feels well-supported by this friend.

Dorothy felt that she really found out who her true friends were as she adjusted to her life with fibromyalgia:

I got a lot of pity from people and that just aggravated me. A few of my lifelong friends have been very supportive, but acquaintances have not been as helpful to be honest. One of my friends is a massage therapist and she has magical fingers. So when I am in a lot of pain she will massage me, which is so helpful. I do not have a lot of close friends but the ones that I do have are very supportive and attentive.

While some people that she considered friends started to fade into the background over time as she disclosed and adjusted to life with fibromyalgia, other friends that she had had for most of her life stood by her side and even provided services to assist her to cope with pain related to her CID.

Karen discussed how her close friendships have strengthened as she has adjusted to her hearing disorder progression:

If anything [my close friends and I have] gotten closer and they are very supportive. This [adjustment to hearing loss] has actually helped us get closer you know. They are amazing people. Uhm like there like I said there's some voice that I can't pick up on especially on the phone so they text me a lot and message me on social media. Uhm and they understand they're very understanding yeah so they're awesome.

Karen went on in this part of the interview to talk about how several of her close friends are more like adopted family members, now that she has adjusted to life with a hearing

disability. She is much closer to her friends and has more communication with them than with her own family.

Grace found that her friendships grew stronger once she was diagnosed:

I really feel like my friends understand me a lot more than my family does. My friends here at [the university] that are in my class because at least they've taken a vestibular class and they know somewhat. And they live with me uhm which I think is another big thing.

Grace has an advantage because she is working on her graduate degree in the medical field and her friends in her graduate program have taken a class about vestibular disorders. Therefore, Grace and her friends have more knowledge about what is going on with her vision, hearing, and balance, and her friends know ways to support her when her symptoms are painful or difficult.

Grace also explained how her friendships had supported her throughout her adjustment to CID journey:

My friendships were a big deal in my adjustment. I was diagnosed while in undergrad, and my friends were not in the medical field. They were very supportive of me and there for me. When I moved to a new university to start my graduate work, my roommates have been a huge support to me. In class my eyes fatigue after a few hours so my friends help me take notes, help me study, and offer to get me things when I am having a lot of symptoms.

Grace was fortunate to have good friendships that were understanding and supportive at her undergraduate school. Once she moved to her graduate school she became

roommates with other women who were in her same program of study, who also go above and beyond to support Grace as she deals with fulltime graduate school and her symptoms of her vestibular disorder.

Grace also talked to me about the strength of her close friendships:

I think my friendships have got closer and I've never felt like they were treating me differently. Which was always a good thing. I've never felt like I was really being a burden to them or anything. I've tried to maintain as much independence as possible... uhm... but I felt like they were really supportive and I don't think that it really changed our friendships in anyways so my friends are a huge support for me.

Due to the quality support that Grace receives from her friends, she is very appreciative of her friendships with them. Because she knows that her friends have more knowledge/understanding of her symptoms and possible progression of her vestibular disorder, Grace is much more open and honest about her symptoms of her CID than she might otherwise be. At this point in Grace's adjustment to life with a CID, she is closer to her friends than she is with her family.

Rose talked about how her friendships have changed over the course of her diagnosis:

I have a really close core group of about three friends that I met during college, and I became a little distant until I sat down with them and told them everything that was going on with me. They were super supportive and spent a lot of time with me during my recovery. I would talk to them daily or as much as they could

during my recovery process. I think just being able to be open with each other because I, there are times I have been closer to my friends about everything than with some of my family members and I think that is because I was with them constantly. My friendships have continued to get stronger through this process and we continue to make bonds with each other. My friends provide like the highest level of support for me.

Once Rose was able to be open with her friends about what was going on with her brain tumor, her friends were there for her unconditionally. Rose's friends provided her the highest level of support at times, because during her recovery she was constantly with her parents. Therefore, being able to spend time with her friends gave her a different level of support and someone different to speak with about her adjustment to CID process.

Sophia talked to me about having a friend to lean on:

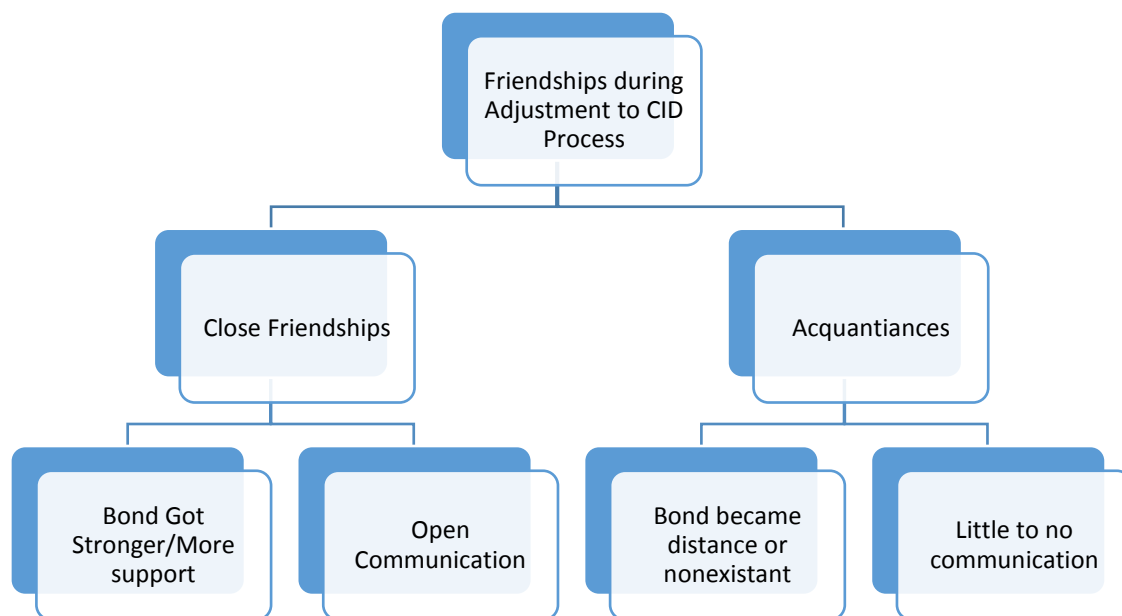
You don't want to get together with your friends and talk sickness. Maybe it's just my personality that I just don't get really close to people. I have one close friend and I check in with her every couple of weeks on average. That is probably the closest relationship that I have in my life other than the one I have with my child. She was one of my first calls when I was in the hospital. She has always been there when really needed her.

Sophia's eyes filled with tears when sharing about her friend, who was obviously a special person in her life. She stated that the reason she is not in closer contact with her friend is because not only does she likes her own privacy, she tries to give her friend privacy as well, since she is a single mother who both works and studies full time.

### **Discussion of Friendships after Diagnosis of CID**

The data that was collected on friendships during the adjustment to CID journey was very powerful. Several of the participants got emotional when they talked about their close friendships. Many of them gave the impression that these close friendships are more like adopted family members in many situations, because they spend more quality time with their friends than they do their own families at times. Often, the friendships seemed to get stronger during the participants' adjustment process. Many of the participants felt that they were able to identify their true, lifelong friendships through this life-changing experience, because the friendships grew stronger and the participants received high level of support during their times where they were struggling with the symptoms of their respective CIDs.

Only a few of the participants reported that some of their friends did not come around as often or dropped out of their life after they were diagnosed with a CID. The participants mostly reported that those acquaintances turned out to not be a vital part of their adjustment to disability process, and while it was sad to not have them be as supportive as they would have liked, the participants still received the level of support that they needed from the friends with whom they had strong bonds. Dorothy talked about how it upset her when acquaintances would offer sympathy for her, versus the support that she would have preferred to have. This made her distance herself from those acquaintances and surround herself with the people that provided the support that she needed during her adjustment to CID process. Table 6.2 below gives a visual summary of the themes of close friendships during the adjustment to CID process.



*Figure 6.2.* Close Friendships through the Adjustment to CID Process

### **Intimate Partner**

The final section of this data analysis focuses on the relationship changes that the participants adjusting to life with a CID have with their significant other or dating life. This was probably the most challenging section of the interview for the participants, because some of them found the questions difficult to answer if they did not currently have a significant other. Even though two of the participants were single at the time of the interviews, each of the seven participants will be discussed, with the data analysis split into those who were (a) single at the time of the interview or (b) dating or partnered.

**Single at time of interview.** Two of the participants, Sophia and Rose, were single at the time of the interviews. Each discussed why they chose to be single at this point of their adjustment to life with a CID.

Sophia was direct when asked about dating/relationships:

I have no desire to date at this time. It's not even in my thoughts right now. I don't even care if it happens. I don't think about it much. I just don't even care. I really love my ex-husband and we live together right now with him also going through his own chronic illness, but he has his own room and we work out well as roommates at this time.

Sophia made it clear that dating and relationships were not a top priority in her life at the time of the interview, as she was focused on taking care of herself and her son at the time of the interview. She was also assisting with her ex-husband's needs, since he was going through his own battle with chronic illness.

Rose also was single and not looking for a partner at the time of the interviews.

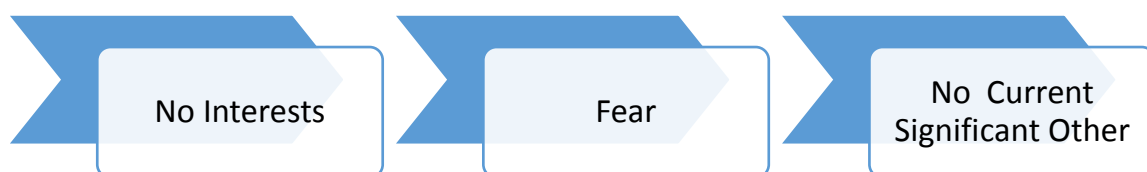
Her reasons for singleness were as follows:

I do not have a past or current relationship through this process. I feel like it made it harder for me to date after I was diagnosed because I didn't even like to think about it. It's like I'm not even going to talk about anything like that. I feel like it might even scare someone away. It's interesting because as soon as I've said anything about [my CID], it turns into kind of a like oh I pity you kind of thing and then it just completely turns me off to that person.

This interview was difficult for me, because Rose's experiences closely resembled my own. It is hard to decide when to disclose your CID to a potential partner. Rose was afraid that if she disclosed too early, the person would not be interested any more, but if she disclosed later in the development of the relationship, trust might be lost with a



potential partner by not having been honest in the beginning. Both scenarios provide added stress for the person who is adjusting to life with a CID. Figure 6.4 below shows the themes of not wanting to date from Sophia and Rose's lived experiences.



*Figure 6.3.* Themes from participants who were single at the time of the interviews

**Dating relationships at time of interview.** Grace and Karen were in new dating relationships at the time of the interviews and each discussed how their dating life had been since their diagnosis of CID, as well as how it was currently.

Grace talked at length about dating while she was adjusting to her CID, beginning with some of her first dates post-diagnosis:

I always feel awkward uhm just since I've tried dating uhm it's a little uncomfortable to bring up especially because uhm you know I always don't want people to judge me and make assumptions of what it is, because I fear what they could assume. Whether it's the first date or the third and I just haven't told him yet and it's just really awkward uhm because especially just because I can't just say I have some disorder that everyone's heard of and so if I say it they have no idea what I'm talking about and it turns into the entire dinner conversation

because it takes so long to explain and then they still usually don't understand.

[laughs] and then they will google it and who knows what they're going to come up with if they don't have a medical background [laughs] use Wikipedia and be so confused.

Grace used humor to explain how frustrating dating was for her right after she was diagnosed. Although she was coming to terms with her diagnosis, it was tiresome to have to tell new people in her life about what was going on with her health. In Grace's situation, the challenge was even larger, since her CID that is not very well known, especially for people in their 20s.

Prior to her diagnosis, Grace had been in a relationship, but it did not last:

I'm in a relationship currently and I had one other one before kind of when the diagnosis was forming. The guy I was dating when I was going to all the doctors just did not understand at all but also there was a host of other stuff going on as to why the relationship ended.

Grace went on to say that her relationship was already not doing well before she was diagnosed, and it was for the best that the couple parted ways. She was happier with less drama and had better support from her family and friends as she was adjusting to her new CID diagnosis.

Grace then transitioned into discussing her current relationship:

The one I'm in now has been really good and uhm I had a really great experience with my boyfriend right now because he is also in the same graduate program I am but he's not in my class. He is two years behind me. I don't remember how it

came up but I told him on one of our dates uhm and he just seemed really interested. He wanted to understand and figure out what was going on and I told him the whole story. He was engaged the whole time listening to me and then when I was finished he just... I remember he said oh thank you so much for telling me. He's been really supportive and you know takes my arm and then at night and uhm helps me if I need it and he's supportive and he will ask questions when he's confused about something so it's been really good.

Grace has been very fortunate to find a current partner that is knowledgeable and supportive of her health. Grace's current partner wants to understand what she is going through, so he can assist her when she needs it. The couple has good communication skills, and he is not afraid to ask questions. Grace smiled a lot when she talked about her current partner and her tone of voice showed that she really cares deeply for him.

Karen's story about her dating life had some similarities to Grace's. Karen started out by discussing her past experiences: "Dating life has been rough especially trying to meet people. The first date can be very stressful uhm especially if they want to go to like an example would be a noisy restaurant or something like that." Due to Karen's hearing impairment, she has to inform any potential dates before they go out if she wants to have a better opportunity to hear her date's conversation and get to know him.

Karen identified another area where dating has been challenging for her:

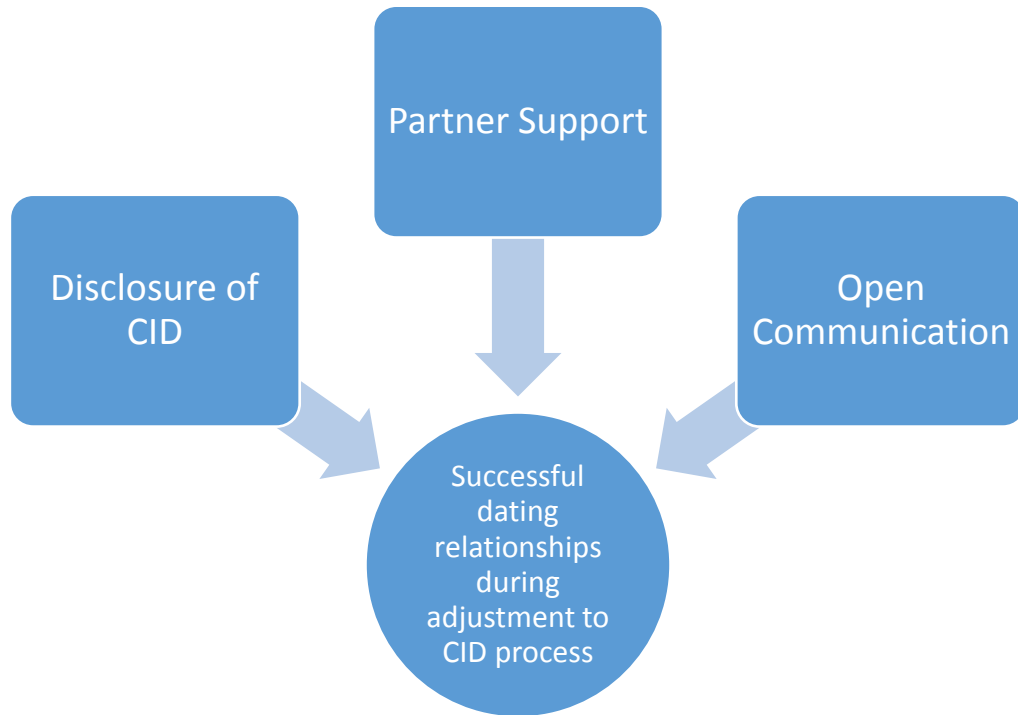
I actually at one point had gotten on an online dating site, and I was reluctant at giving my phone number out because that's the first thing people ask you for so

that was challenging. Dating was frustrating a lot. I actually have been accused of just having selective hearing and that is not the case at all.

Since Karen has trouble hearing conversations on the phone, online dating was a challenge unless she went ahead and disclosed her hearing disability online to her potential mate. Karen stated that she ended up getting rid of her online profile and relying on friends to try to introduce her to potential mates, due to the stress that online dating caused her.

Karen got a smile on her face when discussing more recent developments in her dating life: “I just recently started seeing somebody and he’s really awesome and so he makes sure I’m listening and he’s kind of loud too so that’s great [laughter].” Karen had only been dating her partner for a couple of weeks at the time of the interview, but the tone of her voice made it clear that she was excited about this potential mate. Her current partner has learned how to communicate with her, and this has made Karen’s dating experience enjoyable. In April 2016, Karen followed up via email, saying that she was now engaged to the man she had been dating at the time of the interview.

Grace and Karen showed that it is difficult to decide when in the dating process to should disclose one’s CID to a potential partner. Another challenge to dating was finding a potential partner that would be understanding and willing to learn about their personal experiences with their CID. Open communication and support were key factors to both Grace and Karen finding dating relationships that they were satisfied with. Figure 6.5 provides a summary of the themes identified with the dating relationships.



*Figure 6.4.* Themes from dating relationships during the adjustment to CID process

**Married/partnered at time of interview.** Three of my participants, Dorothy, Jack, and Will, were married at the time of the interviews. This section will focus on how adjusting to a CID may affect marriages or long-term partnerships.

Before discussing her marriage, Dorothy first talked about her previous relationship at the time she was first diagnosed: “I broke up with the boyfriend that was not supportive after I was diagnosed. I moved back in with my parents and I realized that my emotional wellbeing directly correlated to my physical wellbeing.” Dorothy explained that that relationship, both before and at the time of her diagnosis, was difficult and that her partner was not as supportive as she would have wanted for a long-term relationship. The stress of the relationship had a negative effect on her symptoms of her

fibromyalgia, but she was not aware of this until the relationship had ended. At several points during the interview, Dorothy mentioned how her emotional wellbeing has had a direct effect on her symptoms of her CID.

Dorothy then talked about her next relationship, which was a much more positive and permanent one:

I started dating a guy who has been my husband for ten years now. He became even more supportive after I got really sick about seven years into our relationship. He could finally see something as opposed to me just relating to him how I was feeling. He is so careful now not to cause me physical pain and I am so grateful for that. He is a very kind and gentle person.

Dorothy's whole body language changed when she talked about the man that is now her husband. It was easy to see during this part of the interview how much she loves this man, and it was apparent that he loves and supports her very much. As she talked about the highs and the lows of her CID journey and their relationship, it was clear how supportive Dorothy's husband is of her.

Dorothy told one story that shows how deeply her husband cares about her:

Sometimes I will come home after a long day and I'm like I really want to spend some time with you [referring to her husband] but I have to go lay down now. He usually looks at me and he is like ok do you want to hang out in bed. [giggles] So I mean yeah. We find ways to work around [my CID] if we can.

As Dorothy talked about her husband during the interview, it was apparent that she holds him in the highest regard due to the level of support that she has from him. As mentioned

before, Dorothy's emotional wellbeing is directly related to her physical wellbeing, so this high level of loving support from her husband enables her to manage the daily struggle with her CID symptoms.

Will talked about how his relationship with the same partner has developed since he was diagnosed with Crohn's disease: "I have been with my girlfriend and now wife since I was diagnosed. We had been together a year when I was officially diagnosed. My wife is very supportive and we try to have open communication to avoid stress/frustrations." Again, the importance of open communication about the adjustment to CID experience is evident. Will and his wife are able to talk openly about how he is feeling and what will be best for him to cope with his current symptoms related to his CID. Will stated that he feels like this has been one of the biggest successes of the length and survival of his relationship with his significant other.

Will gave an example of how he and his wife use open communication with each other in their relationship:

My wife has been there through the lows and the highs of my CID. We have learned how to compromise well together. We are both independent as well. If I do not want to do something because I'm afraid I will have stomach issues she will go and do some things without me and I do not get upset about it.

Will explained this further so I would understand this concept of how the couple does not let his Crohn's disease hold them back from the things they want to do in life. For example, if his wife wants to go to a nearby major city for the day for shopping, the movies, and going out to eat, Will may ask her to make plans with some of her female

friends while he stays at home and does other things the couple needs done, such as laundry, grocery shopping, and studying for his classes. This works well for the couple because both partners are getting their needs and wants accomplished without either of them getting upset or worried about the other partner's needs and wants.

Jack was married for approximately one year when he found out about his HIV diagnosis. Jack had concerns about disclosing his status to his wife: "I was afraid of what she would say when I disclosed my HIV status and I was scared that she would end our relationship." Jack's wife was supportive, even though it was stressful until she had been tested and found out that she was HIV negative. Jack stated that he has been appreciative of his wife for sticking by his side and taking a medication that provides a line of protection, as well as using safe sex practices in order for her not to also become HIV-positive.

Jack then brought up one of the struggles that he has with his wife: "It really bothers me when my wife says that she struggles more at times with my HIV status than I do. I just have a hard time understanding because she is not living with the virus inside her." Jack reported that this used to cause arguments, but he has learned from his doctor that his wife is going through an adjustment to his CID process, just as he is. She has worries and concerns for his health and wellbeing, just as he does. Jack has had to learn to assist his wife with coping with his CID diagnosis, just as she has to be there for him and support him on the days he is not feeling well. Jack is currently in great health and reports that someday he really does not even think about his HIV status, so when his wife struggles with his status, it catches him off guard at times.



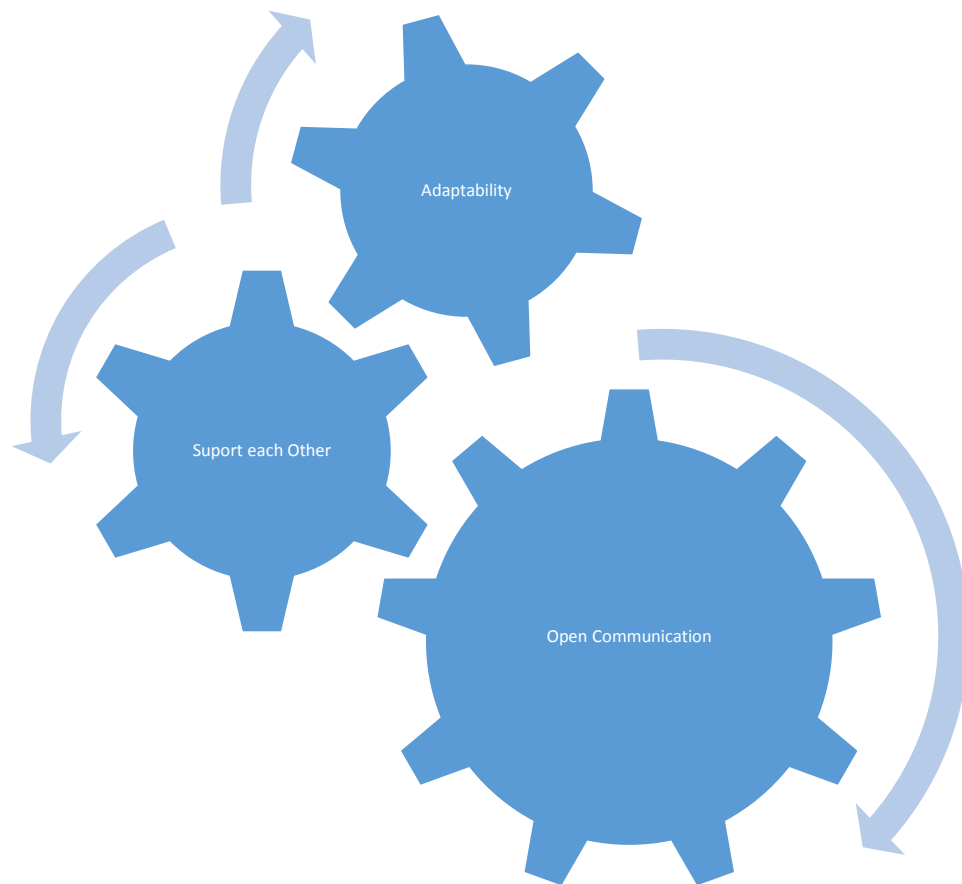
Jack got emotional during this part of the interview and shared a personal story about one struggle he is currently having in his marriage:

Our relationship has transitioned from when I was first diagnosed. I felt like my wife was the stable one who supported me. Now I feel like I am the stable one in the relationship. I believe that is because I don't want my disease uhm affecting who I am or my mentality or anything like that.

Jack had expressed earlier in the interview that he works fulltime, goes to school fulltime, and helps out around the house as much as he can with his wife and their three children. The stress on both the person with the CID diagnosis and his or her significant other can have some negative effects on the daily maintenance of the relationship. It is up to the partners in said relationship to figure out how to support each other and adapt to each other's needs during the times of high stress or anxiety.

These three married participants showed three common themes that appeared to assist them in having successful relationships with their partners during the adjustment to life with a CID. All three of the participants reported that they have moderate to high levels of support from their significant other. This allows them to have support on both the good and bad days of life with a CID. All three couples have learned to use open communication to ensure that their partners are aware of what their current needs are. Each couple has also had to learn how to adapt and compromise with each other when the partner with CID needs extra support. The participants have also demonstrated through the telling of their life experiences that they have also had to learn to adapt to providing support to their partners and compromising when their partners are having their own

struggles in the relationship. Figure 6.6 will provide an overview of the themes found from the married couples.



*Figure 6.5.* Married/partnered relationship themes through the adjustment to CID experience

### **Discussion of Relationship Change Themes**

Overall, the majority of the participants were in different stages of relationship status and felt satisfied with their current relationship status. Sophia and Rose were

single, and dating was not really an important factor in this part of their adjustment to CID journey. Grace and Karen were in the early stages of new dating relationships and both were receiving a level of support from their partners that met their current needs. The three participants that were married all reported that the majority of the time, they received good support from their partners. Dorothy and Will talked about how they had made adaptations to their relationships in order for both partners to be satisfied. On the other hand, Jack said that while overall his relationship is supportive, he sometimes feels like he has to be the stronger partner as his wife has days when she struggles with his CID diagnosis. Open communication and being honest with one's significant other seemed to be an overarching theme present in this data set.

Throughout the analysis of the participants' relationships with family, friends, and intimate partner, three themes emerged.

1. Relationship status before introduction of CID
2. Open communication
3. Adaptability
4. A discussion of each of these themes will be reviewed in greater detail.

**Theme 1: Relationship status in the early stages of the introduction of CID.**

The data showed that relationships with family, friends, and intimate partner all depended on the strength of the relationship during the early stages of the introduction of the CID diagnosis. In regards to families, the participants that had close relationships with their families (Jack, Will, Dorothy, and Rose) all received acceptable support from the family members that they were closest to before the introduction of their diagnosis.

When it came to close friendships, all seven of the participants identified at least one friend that they have a close bond with. In most of the cases, these friendships were established before the person was diagnosed with CID. Grace had made some close friendships post-diagnosis due to living with classmates during her graduate program of study, but she also had a couple of friends that she was close to before her CID diagnosis. The data suggested that often, friendships became even closer after the CID diagnosis.

Finally, the participants who were in relationships at the time of the interviews reported that they were receiving the amount of support from their intimate partner that they needed at this time. Rose and Sophia were single at the time of the interviews and reported that a relationship was not their primary focus of their life at this stage of their adjustment to life with CID. Karen and Grace were in new relationships that they felt provided the level of support that they needed from their significant other. The married couples (Jack, Will, and Dorothy) also stated that they were receiving the support that they needed from their significant other at the time of the interviews.

The majority of the people in this research study had developed new relationships after their diagnosis, which was of interest. They were able to find a suitable partner that accepted them as a person first and not just a diagnosis.

**Theme 2: Open communication.** The second theme identified in this study was that the strength of the relationships with family members, close friendships, and intimate partner was dependent on how much the person adjusting to the CID was willing to disclose about his or her diagnosis. All of the participants in this study had the option of to whom and when they disclosed their CID, due to the fact that they had invisible CIDs.

The data showed that the participants that disclosed more information to their families (Jack, Will, Dorothy, and Rose) received higher levels of support during their adjustment to disability process. Karen was an exception to this, because while she had disclosed her CID status to her family, they still were struggling to accept the fact that she had a hearing problem. Grace had limited the amount of information that she had provided her family members due to her rare diagnosis. This lack of disclosure and education had caused her family to be confused as to why she had problems and limitations with certain aspects of her daily living activities. Sophia chose not to inform any of her family because she was a private, independent person. Due to this decision, she had little to no support from her family members because they were unaware of her daily struggles living with Crohn's disease.

Similar experiences were identified when it came to close friendships and the amount of disclosure of the CID diagnosis that the participants had provided. All seven of the participants felt like they had at least one identified close friend with whom they could share in detail about their daily life experiences with CID. The close friendships in which the other person had more education about what was going on in the daily life of the person with the CID were more supportive and understood more about the daily struggles that the person with the CID goes through. For example, Rose was scared to disclose her brain tumor and upcoming surgery to her close friends. She prepared what she wanted to say with them, sat each one of them down, and talked with them. Due to the fact that she disclosed what was going on, her close friends were there for her daily

throughout her recovery from her surgery. She felt like this experience had brought her even closer to her friends.

When it came to intimate partner, the participants who were married or dating stated that they received a high enough level of support from their partner due to the fact that they had open communication about what was going on with their CID diagnosis. By keeping their significant other informed of their needs, the couples were able to support each other and make sure that the person with the CID's needs were met.

**Theme 3: Adaptability.** Adaptability in relationships appeared to be vital in order for the person with CID to receive the needed support from family members, close friends, and intimate partner. In regards to adaptability in family members, there were several examples that were apparent. Dorothy reported that she relied on her mother for a lot of support in the early days of her adjustment to life with fibromyalgia; then, when her mother was also diagnosed with fibromyalgia, they developed an even closer bond, because they had to learn how to support each other.

Karen explained how her six-year-old son has adapted to assist her when they are out in public. When Karen does not hear someone speaking to her, her son will tell them that his "mommy's ears are broken" and then direct Karen's attention to the person who is trying to communicate with her.

Will and Grace's lived experiences were good examples of friendships and adaptability. Will had several friends who would check out new restaurants and bars to see if the bathrooms would provide him enough privacy for him to enjoy spending time

in a social environment. This provided Will with great support so that he could have less stress if he needed to use the restroom in a public place.

Grace's classmates adapted to her vestibular disability by offering to assist her in tasks of daily living. When Grace got tired of taking notes in long, graduate-level classes, her roommates/friends would take the notes for her. If Grace needed something in the evening when she had more trouble driving, her friends/roommates would often offer to drive her or pick up the needed item for her. Grace did not even have to ask her roommates to do these things in most situations; her friends simply adapted to assisting her when she needed them to, due to the fact that she had informed them about her CID.

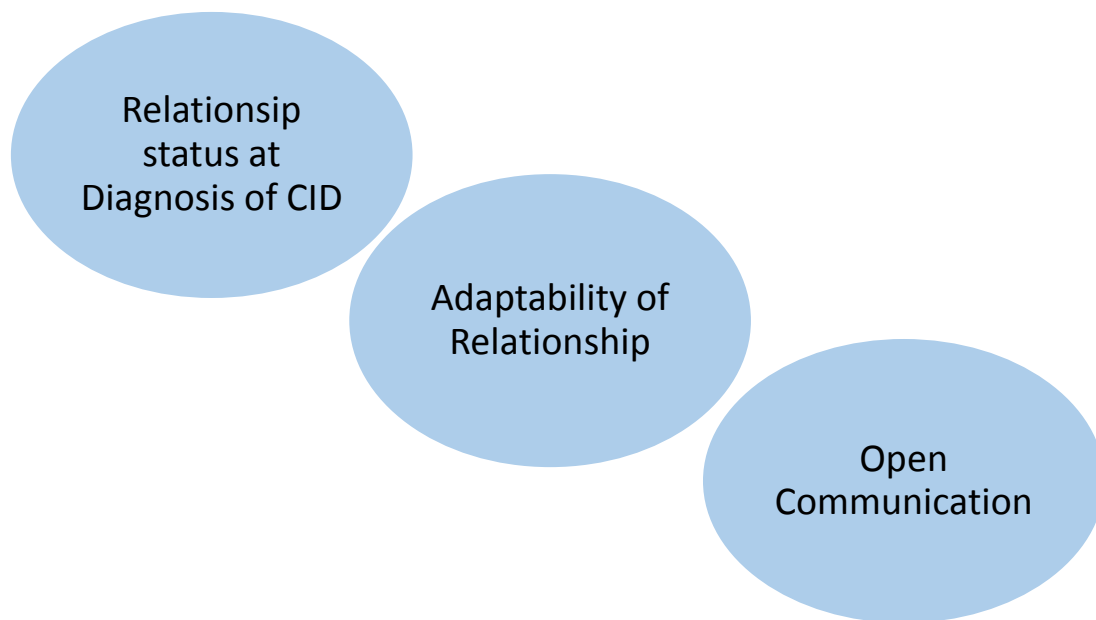
When it came to intimate partner, several of the participants described how they had made adaptations in their relationships during their adjustment to CID experience. Jack discussed how he and his wife have learned to provide extra support for the other when one of them is having a more stressful day. Sometimes Jack has to provide more support to his wife, and other days his wife has to provide more support to him.

Dorothy and her husband have adapted how they spend quality time together. If Dorothy is tired at the end of a long day and needs to lie down in bed, her husband will often lie down with her to spend quality time together. Dorothy's husband has also learned how to touch her so that he does not cause her any physical pain when she is having severe fibromyalgia symptoms.

One adaptation that Will and his wife have made is that she will do activities with other friends if Will thinks that the activity will cause him to have stomach problems. Will has adapted to this by doing other things that he and his wife need completed and

then spending quality time together with her after each partner's individual needs of the day have been met. The couple has found that this compromise works well for both of them and has strengthened their relationship.

This endeavor has allowed me to get an insider's view into the relationship status of each of my participants. The relationships with their family members, close friendships, and intimate partner have been explored to find three overall themes: (a) relationships status prior to diagnosis, (b) open communication, and (c) adaptability. Figure 6.7 below provides a visual representation of the themes represented in this section.



*Figure 6.6.* Themes from factors of relationship change during the adjustment to CID process



**Conclusion**

The participants in this research project have painted a lived experience perspective of how their relationships have changed throughout their adjustment to disability journey. The data has shown mostly positive relationship change, as based on the major themes identified above. This chapter has provided an in-depth look at how relationship with family members, close friends, and intimate partner may change through the adjustment to CID journey. The last and final chapter will discuss future implications, recommendations, and limitations of the findings in this research study.

## **Chapter 7: Final Thoughts, Discussion, & Future Recommendations**

### **Introduction to the Chapter**

This research study used a phenomenological research design to investigate the lived experiences of people adjusting to life with a CID. The major focus of this qualitative study was to learn about how relationships change as participants adjust to daily life with a diagnosis of CID. This study looked at three specific relationships: family members (parents, step-parents, grandparents, siblings, and children), close friendships (friends whom the participants spent significant time with that felt more like extended family members), and dating/significant other (spouses, partners, etc.). The seven participants of this study provided detailed personal accounts through in depth interviews and observations of how their relationships changed during the adjustment process. The goal of this study was to identify the lived experiences of the participant's adjustment to CID story and identify relationship change that happened during this adjustment journey.

This study identified additional rich data than the researcher had expected, which resulted in two separate chapters of data analysis. Research question one, which focused on the general adjustment and coping process, was presented in chapter 5. The results correlated with Livneh and Antonak's (2005) research on the six most common reactions to a diagnosis of CID, as well as the basic concepts of adjustment to life with a CID. Each of the seven participants' experiences through the early, middle, and late stages of adjustment was included in this chapter.

Relationship changes as the participants adjusted to life with a CID were presented in chapter 6. Each participant shared how personal relationships with their family members, close friendships, and intimate partner had changed. As demonstrated by the data presented in this study, relationship change was dependent on three identified themes: (a) the relationship status at the time of the diagnosis/disclosure of CID, (b) open communication, and (c) the adaptability of the people in the relationship.

The concluding chapter of this phenomenological study will show how the information that has been presented in this study can contribute to the current literature on both the adjustment to CID as well as disability and relationships. The following sections will be addressed: (a) implications for counselors and counselor educators, (b) participant recommendations for counselors and other healthcare providers, (c) recommendations for integrated care between counselors and other healthcare providers, and (d) limitations and recommendations for future research.

### **Implications for Counselors and Counselor Educators**

Assisting people's adjustment to life on terms that are not their own is one of the primary responsibilities of a mental health or rehabilitation counselor. Both counselor trainees and seasoned professional counselors have a high probability of working with a person who is adjusting to life with a CID, with the numbers of people being diagnosed with CID projected to rise to 157 million people with 81 million Americans living with multiple chronic conditions by the year 2020 (National Health Council, 2014). Thus, it is vital that counselors and counselor educators receive more training on how to provide

counseling to people who are adjusting to life with a CID. This project was undertaken in order to help fill this gap in the current literature.

People who develop a CID already have established relationships with their family members, close friendships, and intimate partner. Previous research has noted that more research needs to be conducted on the social impact of the adjustment to the CID (Chan, Cardoso, & Chronister, 2009). This study shows that the seven participants had to make adjustments not only in their personal day to day activities of daily living, but they also had to have tough conversations with their families, close friendships, and intimate partner about what was going on with their health. Counselors and counselor educators need to have resources and educational materials available to them in order to be able to assist and support their clients through both aspects of this process. The people adjusting to CID have to inform the significant people in their lives how they may need different levels of support or assistance with care from time to time. This can be an overwhelming process, not only for the participant with the CID diagnosis, but also for the family member, close friend, or significant other. Therefore, counselors and counselor educators need to be educated on how to support clients who are struggling to inform and/or cope with the significant people in their lives. This research endeavor provides lived experiences of the relationship changes that happen during the adjustment to CID process that may prove beneficial as a resource to professionals in the field. The following section will further develop this idea.

### **Participant Recommendations for Counselors & other Healthcare Providers**

The final question on the semi-structured interview guide used in this study gave the participants an opportunity to recommend ways that counselors and other social/health related professionals could provide more education and support during the early stages of adjustment to life with a CID. The research participants were asked to provide any recommendations or feedback that they would have found beneficial from counselors or other healthcare professionals during their journey, and all seven participants provided helpful recommendations.

Jack was straight to the point with his answer: “Help the person to see their strengths. Being HIV+ is the least significant part of who I am today” (personal communication, 2015). Jack wanted counselors and other healthcare providers to provide him with the necessary education about what life would look like with a diagnosis of HIV, which would be vital to his survival. Jack also stressed the importance of focusing on the positive factors of staying healthy and following his medication regiment in order to have the quality of life that he wanted. These things motivated Jack in regards to health and daily life, and he believed that this type of information could benefit others adjusting to life with HIV as well.

Will talked about client/patient advocacy:

Help your client learn how to advocate for themselves. This will help them to relieve the stress and anxiety caused by worrying what other people think when you have to use the bathroom around them frequently. You are already dealing with a lot, so why not get your needs met by advocating for yourself.

Will stressed how important it is for counselors and other healthcare professionals to be knowledgeable about their clients' adjustment process to Crohn's disease in order to help them advocate for their needs and communicate openly with their families, close friendships, and intimate partner. By informing others about his health concern and advocating for his needs, he found a way to reduce one area of stress and anxiety in his life.

Dorothy discussed how counselors or other healthcare professionals must have the proper education about the specific CID that their clients are dealing with:

Learn about that CID as much as you can even if it means asking your clients about it. I think it is important for us to have as much information as we can... and showing that genuine positive regard is probably... yeah knowing as much as you can about the illness and you know if you don't feel competent to do it tell them.

Dorothy spoke not only as a person who has learned how to cope with the daily struggles of her fibromyalgia, but also as a professional in the counseling/healthcare world herself. Education about a client's CID is needed before the counselor or other healthcare provider can assist with the adjustment to CID process or any relationship changes that may occur during said process.

Karen said that counselors and healthcare providers should:

Be direct and follow up to make sure the client understood you. This will provoke a response from your client and you will be able to understand what the true needs are.

By being direct and asking follow-up questions, the counselor or healthcare provider ensures that the client's needs are being met. Karen stated that after her diagnosis of a hearing impairment, she was given little education on the issue, which resulted in her educating herself online with possibly unreliable resources.

Grace recommended understanding and research as vital to providing support for the person adjusting to life with a CID. She stated:

I think the biggest thing is understanding what your client has uhm so I think it's a lot easier to talk to someone who at least tried to research what your disability is so they at least have a baseline knowledge what your symptoms are and how it might affect you.

Grace had attended some counseling at her college after she had been diagnosed with her vestibular disorder, because she was really struggling with the lack of information that she had been provided by her healthcare providers. Like many others in this study, Grace had gone to online resources to educate herself more about what her CID diagnosis entailed. Grace was impressed that before the second session she had with her counselor, he had taken the time to research about what her vestibular disorder entailed so that he could relate to her symptoms and concerns. Grace felt like this helped her feel like someone cared and wanted to assist her in her adjustment to CID process. These counseling sessions also assisted Grace in preparing to speak with her family about her CID diagnosis to clear up confusion and hopefully build the needed support that Grace sought from them.

While Sophia had been very direct and to the point throughout the interview process, she went into detail about what would have helped her when she was first diagnosed with Crohn's disease. She said:

If I could if I had any support that I wish immediately after I was diagnosed somebody would have come in and said let me show you how to eat that probably would let me show you how to make this disease as affective like as, as good as we can get it. Let me show you that and let's change it now while it was while it was on my mind. Some education about how to manage feelings of depressed and to see a counselor if you have one. Someone to keep you on track to say alright don't even worry about this just focus on this one thing today.

Sophia did not feel like she received the needed education and support that she wanted when she was first diagnosed with her CID after an emergency surgery. Sophia made it clear throughout the interview process that she preferred to keep her business private and that she only has informed her 16-year-old son and one close friend about her CID diagnosis. Even with this desire for privacy, Sophia wanted more education about Crohn's disease from her doctors, nurses, and other healthcare providers. Sophia also made it clear that seeing a counselor at the time of her CID diagnosis would have been useful to her.

Rose also spoke at length, telling a personal story about how useful counseling had been to her adjustment to life with a CID. She said:

I actually was seeing a counselor before I was diagnosed with my CID. She was probably one of the best counselors I've ever seen. She is the main reason why I



became so open and wanted to talk to my family members and friends about certain things because she helped me realize that what I was particularly fearful of about talking about my brain tumor and the surgery that was upcoming. Uhm so she sat me down in her office whenever I met with her every week or two uhm trying to get me and sometimes she would use like certain techniques to get me to reflect on what precisely was bothering me about heading into surgery or talking to that particular friend about whatever it was. I was so thankful to have her at that moment because she talked to me like no one had talked to me before. I wish doctors in the hospital had someone like that one staff at that moment of diagnosis.

Rose had an already established counseling relationship at the time that she was diagnosed with her brain tumor, which gave her an advantage in her adjustment process by having a person to talk openly to about all the concerns she had, not only about life with a CID, but also about informing her family and close friendships about her brain tumor. Rose was able to discuss her identified fears about the process of speaking with her family and close friendships about her diagnosis and upcoming surgery, and she was able to continue this counselor/client relationship after she recovered from her brain surgery. This relationship proved to be a vital resource for Rose, as it gave her confidence to speak with her family and close friends about her health concerns, which in turn provided Rose with the critical support that she needed during this part of her adjustment to CID journey.

Rose went on to say that she now has plans to find a career where she will be able to work with children or adults who are adjusting to life with a CID. She has set a goal to work with people in the early stages of adjustment to CID and attempt to partner with doctors and other healthcare providers to work as an integrated team to provide education and support to individuals in this situation. She would also like to inform clients/patients about how to prepare to talk to their family members, close friends, and intimate partner about their diagnosis and adjustment process.

In summary, the data collected from the participants shows that there are several things that counselors and other medical professionals need to be prepared and educated to do, including providing more psychoeducation about CID symptoms, prognosis, and best care practices, not only when the patient is first diagnosed, but also during the adjustment process. This would allow patients to be more informed and proactive in taking care of their CID. In addition, counselors can provide support for patients who have to disclose their new diagnosis to their family, close friends, or intimate partner, since it may be very difficult to inform the important people in their lives that they have to make significant changes in their lives to take care of themselves. This can cause the patients' families, close friends, and/or intimate partner to go through their own adjustment process, and they may also need support from a counselor.

### **Limitations and Recommendations for Future Research**

This study identified some challenges and recommendations for future research on how relationships change throughout the adjustment to CID process, but first, there will be a brief discussion of the limitations of this study before concluding this section

with future recommendations as to how this line of research can be continued in order to add to the current literature.

**Limitations.** Several limitations were identified throughout this study. Besides the fact that this was the first time that this researcher had attempted a qualitative/phenomenology research study, three major limitations have been identified: (a) the research focus needed to be narrowed down more, (b) a lack of diversity in the research participants, and (c) the interview guide needed to have more specific questions.

The first limitation identified was that the research needed to focus more on specific types of CID. This research study allowed anyone that had been diagnosed with a CID between the ages of 18-40 years of age to participate. As a result, the participants that responded and qualified for the study had five different types of CID. While the main focus of this study was on relationship change through the adjustment to CID process, it should be noted that future studies conducted by this researcher will look at only one type of CID and how relationships change in that situation, as opposed to having so many different types of CID studied at once. This change in the requirements to participate in the study has the potential to strengthen and identify CID-specific types of relationship change.

The second limitation identified in this study was the fact that this study had a major lack of diversity in its participants, with six of the seven participants identifying as Caucasian. It is possible that since participants were only recruited through two Ohio University campuses (Athens and Chillicothe), that this created this limitation. In future research, more online interviewing maybe attempted in hopes of a more diverse sample,

which would enable the researcher to note any relevant diversity or cultural issues on the topic of CID adjustment.

The third and final limitation is that the interview guide had very broad, open-ended questions, which was suggested by most of the literature on qualitative research and phenomenology. While follow-up/probing questions were included, they were also broad and may have not challenged the participants to really delve deep into the issues being discussed.

More specific questions on the interview guide may have created the opportunity for even more psychosocial facts to surface in the research. For example, it should be noted that since there were no specific questions in regard to spirituality or the potential economic impact created after diagnosis with CID were briefly or not mentioned at all by the participants in this study. These factors could have led to deeper discussion on how adjustment to life with a CID influences relationships with family, friends, and intimate partners.

Another area that was not focused on in this research endeavor was the caregiver role of the family, friend, or intimate partner. While several participants did discuss how family, friends, and/or intimate partners did have to provide more assistance during the early stages of adjustment to life with a CID there were no specific probing questions in this research study. This missed opportunity will be included in future research studies.

**Recommendations.** There are two key recommendations to continue this discussion about how to identify relationship changes during the adjustment to CID processes a result of this study. The first recommendation is for future researchers to

focus on specific CID diagnoses as participants adjust to a CID (e.g., HIV/AIDS, diabetes, Crohn's disease). CID-specific research may help identify CID-specific issues of relationship change so that counselors can be prepared to assist their clients in this area. If counselors receive education about relationship changes during specific lived experiences of the CID adjustment process, they will be able to provide the most comprehensive counseling to their clients.

Clinical rehabilitation counseling, a relatively new field, can become a huge asset in this area, because counselor education programs with this degree have coursework on the medical and psychosocial aspects of CID that is necessary to educate future counselors.

The second recommendation for future research is the need to continue to bridge the gap between clinical mental/rehabilitation counselors and the rest of the medical field. By both groups working together as an integrated care team, participants adjusting to life with a CID will receive all the desired information for them to make informed choices in regards to life changes that have to be made during their adjustment process. Furthering this type of research will not only allow an integrated care team to inform the patients/clients about their diagnosis but also allow the integrated care team to inform the patient/client as to how to talk to their family, close friends, and intimate partner about their new diagnosis. This could make the adjustment to CID a much more informed process to assist clients in dealing with potential relationship changes. This research also has the potential to assist family members with their own adjustment to the news of their loved one having a CID diagnosis.

### **Research's Observations and Final Thoughts**

This research study provided me with the experience of starting my research agenda as a future counselor educator. The data that I was able to collect has me excited about the potential of developing future phenomenological research studies focusing on specific types of CIDs (diabetes, HIV/AIDS, traumatic brain injury, etc.). It is my hope that by focusing on specific CIDs I will be able to focus my research on the adjustment process and identify CID specific relationship changes with family, friends, and intimate partners.

While I found this research project enjoyable, I also discovered some personal challenges. A couple of the participant's stories really hit close to my own adjustment to CID experience. I found it to be challenging at times to use the bridling technique so I did not interject my own adjustment story into the interview. I did decide that it would be appropriate at the conclusion of the interview to tell Rose that her story had many similarities to my own. Rose told me that she noticed that I seemed to get slightly emotional and wondered if I was relating with her experiences but did not want to ask in the middle of the interview.

Another challenge that I found with this dissertation project was not switching for the role of researcher to the role of counselor. I remember that during Dorothy's interview she talked about having to deal with a new label and not liking the way that people focus on her cane when she has to use it on bad pain days. Being a person who walks with a cane I could really relate to what she was saying. I wanted to give her praise/encouragement or tell her that I understood where she was coming from but I had

to remember to keep my researcher hat on and stay focused on the interview at hand. At the conclusion of the interview, I talked with Dorothy about how I related to what she had said and we had a moment of bonding that I will always remember.

The connection that I developed to these seven participants was very rewarding and I am so blessed to have had the privilege of hearing these seven participants' personal journeys into adjustment to life with a CID. The rich data that I was able to collect has only fueled the fire in me to continue this type of research agenda so that people adjusting to life with CID as well as their family, friends, and intimate partners will have some idea of what their own journey with adjustment to CID may entail.

## **Conclusion**

This study used the qualitative research methodology of phenomenology to investigate how relationships change as a person adjusts to life with a CID. The research focused on four research questions:

1. How has the adjustment to life with CID been thus far?
2. How, if at all, has your relationships changed with family?
3. How, if at all, has your relationships changed with your close friendships?
4. How, if at all, has your relationships changed with your dating/significant other?

Seven research participants were recruited and interviewed to document their lived experiences with relationship change as they adjusted to life with a CID.

This study identified that relationships do change as a person adapts to life with a CID. Three themes were identified as a result of this research study. The first theme was

that the stronger the relationship was before the introduction of the CID, the more likely it was that the relationship would stay strong. The second theme was that the higher the levels of open communication between the person with the CID and the family member, close friend, or dating/significant other, the more likely it was that the relationship would stay the same or get stronger. The third theme identified showed that the person adjusting to life with a CID were more likely to continue a stable relationship if both parties were willing to be adaptable to adjusting activities together so both people could complete the task at hand.

This research was undertaken to fill a gap that in the current literature. It is my hope that further research will be conducted to assist people adjusting to life with a CID as well as their family members, close friendships, and intimate partner to adjust to changes in relationships.



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## Appendix A: Recruitment Flyer

Do you have a chronic illness or disability (CID)?

Have you experienced changes in your relationships with...

Family members (parents, siblings)

Close Friends

Intimate partner

My name is Rob Stevens and I am conducting a dissertation study exploring how relationships change as a person adjusts to life with a chronic illness and/or disability (CID). If you would be interesting in sitting down with me and discussing how your relationships have changed as you have adjusted to life with a CID then I look forward to speaking with you.

### Requirements of the study:

- 1) Between the age of 18-40 years of age
- 2) 1 year post diagnosis of a CID
- 3) Willingness to discuss adjustment to CID and current relationships with family members, close friendships, and intimate partner.

*To participate in this study please contact me at [rs190809@ohio.edu](mailto:rs190809@ohio.edu) or (870) 925-1122.*

*Interviews will be scheduled in person at your convenience and desired location. I look forward to speaking with you and learning about your journey.*

## **Appendix B: Semi-Structured Interview Guide**

### **Adjustment to CID & Relationship Change Interview Guide**

- Thank interviewee for agreeing to participate and sign informed consent
- Ask if interviewee has any questions/concerns then begin interview

### **Research Questions**

#### **RQ1: Tell me about your adjustment to life with a CID experience thus far.**

##### Possible probe questions:

P1: What has been some of the challenges during your adjustment experience?

P2: How have you coped through your adjustment journey?

P3: What/Who has been your inspiration through your adjustment experience?

#### **RQ2: Tell me about your relationship with your family members through your adjustment to CID experience.**

##### Possible probe questions:

P4: Tell me about your relationship with your parents through your adjustment experience

P5: Tell me about your relationship with your siblings through your adjustment experience

P6: Can you tell me more about your relationship with your family member as you have adjusted to life with a CID

P7: What level of support do you feel like your family members have provided during your adjustment experience?

**RQ3: Tell me about your relationships with your close friends through your adjustment experience.**

Possible Probe questions:

P7: Can you tell me more about this friendship?

P8: Have you noticed that your friendship has changed in any way on your adjustment experience?

P8: What level of support do you feel like your close friends have provided during your adjustment experience?

**RQ4: Tell me about your dating life or about your significant other.**

Possible probe questions:

P9: How has the dating process been during your adjustment experience?

P10: How has life been with your significant other during your adjustment experience?

P11: What level of support do you feel like you have received from people you have dated through your adjustment experience?

P12: What level of support do you feel like you have received from your significant other through your adjustment experience?

- Ask for any information that we may have left out during the interview process.
- Ask for permission to contact interviewee with any follow up questions during the data analysis process.
- Thank the interviewee for their time and participation in the study.

## Appendix C: IRB Approval Letter



**OHIO**  
UNIVERSITY

Office of the Vice President for  
Research

15X217

Office of Research Compliance

RTEC 117

Athens, OH 45701-2979

T: 740.593.0664

F: 740.593.9838

www.ohio.edu/research/compliance

The following research study has been reviewed and approved by the Institutional Review Board at Ohio University for the period listed below. This review was conducted through an expedited review procedure as defined in the federal regulations as Category(-ies):

7

**Project Title:** A Phenomenological Study Exploring Relationship Change through the Adjustment to Chronic Illness & Disability (CID) Journey

**Primary Investigator:** Robert Lake Stevens

**Co-Investigator(s):**

**Faculty Advisor:** Mona Robinson  
(if applicable)

**Department:** Counseling & Higher Education

*Shelly Rex*

Office of Research Compliance Staff

Rebecca Cale, AAB, CIP

Shelly Rex, BS

Robin Stack, CIP

11-6-15

**Approval Date**

11-5-16

**Expiration Date**

This approval is valid until the expiration date listed above. If you wish to continue beyond the expiration date, you must submit a periodic review application and obtain approval prior to continuation.

The approval remains in effect provided the study is conducted exactly as described in your approved application. Any additions or modifications to the project must be reviewed and approved by the IRB (as an amendment) prior to implementation.

IRB approval does not supersede other regulatory requirements, such as HIPAA, FERPA, PPRA, etc.

Adverse events/unanticipated problems must be reported to the IRB promptly.

S

## **Appendix D: Approved Informed Consent with Adult Signature**

### Ohio University Adult Consent Form with Signature

Title of Research: A Phenomenological Study Exploring Relationship Change through the Adjustment to Chronic Illness & Disability (CID) Journey

Researchers: Robert L. Stevens, ABD, LPC-CR, CRC, CDCA

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

### Explanation of Study

This study is being completed due to my current interest to understand the lived experiences of relationship change(s) that happened during your adjustment to life with a chronic illness or disability (CID). I am particularly interested in learning how significant relationships in your life (parents, siblings, close friendships, and intimate partner) may have changed since you were diagnosed with CID. Your personal experiences will assist me in educating myself and other counselors on how to support people adjusting to CID and the relationship changes that occur.

If you agree to participate, you will be asked to meet for an in person interview I will be asking you questions about your adjustment to CID journey as well as questions about relationships with your family members, close friendships, and intimate partner. Your participation in the study will last for a maximum of 60-90 minutes. I will be also asking for permission to contact you with any follow up questions after I document the interview. This will also provide you an opportunity to share with the researcher any additional experiences that you did not have the opportunity to share in the interview as well as to have an opportunity to debrief about your experience with participating in the study. You will be recorded during the interviews for the purpose of data analysis. Your recordings will be deleted upon completion of the project.

### Risks and Discomforts

There are no anticipated risks or discomforts expected throughout this interview process. Due to the content of the interview process, participants may experience negative

memories/emotions from their adjustment to chronic illness/disability experience. If you do feel overwhelmed at any time during the interview I ask you to let me know immediately. A break can be given for you to collect your thoughts and then we can move on with the interview when you feel you are able. You have the right to discontinue the interview at any time. I will provide you with my contact information if you have any questions/concerns after the interview process has been complete. Information for Ohio University Counseling & Psychological Services office will also be provided to you in case you need to speak to someone after the interview is completed.

### Benefits

Individually, you may benefit from this study by having the opportunity to share your adjustment to disability story for possibly the first time with a member outside of your immediately family/friends. No other potential personal benefits are identified at this time.

This study is important to science/society because there is not enough current research that documents individual's lived experiences with the adjustment to chronic illness & disability (CID) journey. Your story of how you have adjusted to life as a person with a disability and how you have navigated relationship changes with your family members, close friendships, and intimate partner will allow counselors at all levels (students, clinicians, & faculty members) to be able to assist future client's through similar adjustment journeys.

### Confidentiality and Records

Your study information will be kept confidential due to the fact that your identity will be concealed by the researcher and you will be assigned a code name i.e. participant # 1, participant # 2... in order to be identified for the purposes of data analyses. The only place that your name will appear is on this consent form. Your consent form and de identified data will be stored behind two locked doors. Your personal information will be stored at the primary researcher's apartment. Your consent form will be stored in a locked filing cabinet separate from your digital recorded interview and transcripts. The digital recorded interviews and transcripts will be stored on a password protected laptop computer at the primary researcher's apartment. The primary researcher's apartment is always locked by a deadbolt lock and he is the only person that has a key to the apartment. Any identifying information (master list, address, consent form signature pages, etc.) will be destroyed at the completion of the defense of my dissertation/graduation which is anticipated in May 2016. All transcripts with no identifying information will be kept for up to two years for future data analysis.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with my adviser Dr. Mona Robinson for clarification of how to accurately analyze the data

collected. Again your name will not be provided to Dr. Robinson only the transcripts that have been de identified of your personal information (name, etc.).

### Compensation

As compensation for your time/effort, you will receive a onetime offer of a \$25-dollar gift card. This is a given as an appreciation of you taking the time to share your personal experiences/journey with me. Participants that end the interview early or do not show up for a scheduled interview will not receive a \$25-dollar gift card.

### Contact Information

If you have any questions regarding this study, please contact the investigator Robert L Stevens @ rs190809@ohio.edu or (870) 925-1122.

My faculty advisor can also be contact at the following information:  
Dr. Mona Robinson @ robinsoh@ohio.edu or (740) 593-4461.

Ohio University Counseling & Psychological Services can be contacted at (740) 593-1616 in person at the Hudson Health Center 3rd floor on the Ohio University Athens, Campus.

Student Accessibility Services may also be a good resource for assistance with your educational goals and managing your CID. They can be reached at (740) 593-2620 or in person in the Baker Center, Suite 348 on the Ohio University Athens Campus.

If you have any questions regarding your rights as a research participant, please contact Dr. Chris Hayhow, Director of Research Compliance, Ohio University, (740)593-0664 or hayhow@ohio.edu.

By signing below, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered;
- you have been informed of potential risks and they have been explained to your satisfaction;
- you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study;
- you are 18 years of age or older;
- your participation in this research is completely voluntary;



- you may leave the study at any time; if you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Signature

Date

Printed Name

Version Date: 11/3/2015

## **Appendix E: Approved Informed Consent without Signature**

### Ohio University Adult Consent Form without Signature

Title of Research: A Phenomenological Study Exploring Relationship Change through the Adjustment to Chronic Illness & Disability (CID) Journey

Researchers: Robert L. Stevens, ABD, LPC-CR, CRC, CDCA

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to provide verbal consent to participation in this study. You should print out a copy of this consent document for your records.

### Explanation of Study

This study is being completed due to my current interest to understand the lived experiences of relationship change(s) that happened during your adjustment to life with a chronic illness or disability (CID). I am particularly interested in learning how significant relationships in your life (parents, siblings, close friendships, and intimate partner) may have changed since you were diagnosed with CID. Your personal experiences will assist me in educating myself and other counselors on how to support people adjusting to CID and the relationship changes that occur.

If you agree to participate, you will be asked to meet for an online Skype interview. I will be asking you questions about your adjustment to CID journey as well as questions about relationships with your family members, close friendships, and intimate partner. Your participation in the study will last for a maximum of 60-90 minutes. I will be also asking for permission to contact you with any follow up questions after I document the interview. This will also provide you an opportunity to share with the researcher any additional experiences that you did not have the opportunity to share in the interview as well as to have an opportunity to debrief about your experience with participating in the study. You will be recorded during the interviews for the purpose of data analysis. Your recordings will be deleted upon completion of the project.

### Risks and Discomforts

There are no anticipated risks or discomforts expected throughout this interview process. Due to the content of the interview process, participants may experience negative

memories/emotions from their adjustment to chronic illness/disability experience. If you do feel overwhelmed at any time during the interview I ask you to let me know immediately. A break can be given for you to collect your thoughts and then we can move on with the interview when you feel you are able. You have the right to discontinue the interview at any time. I will provide you with my contact information if you have any questions/concerns after the interview process has been complete. Information for Ohio University Counseling & Psychological Services office will also be provided to you in case you need to speak to someone after the interview is completed.

### Benefits

Individually, you may benefit from this study by having the opportunity to share your adjustment to disability story for possibly the first time with a member outside of your immediately family/friends. No other potential personal benefits are identified at this time.

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### Confidentiality and Records

Your study information will be kept confidential due to the fact that your identity will be concealed by the researcher and you will be assigned a code name i.e. participant # 1, participant # 2... in order to be identified for the purposes of data analyses. Your online Skype interview will be digitally recorded and the data will be stored behind two locked doors. Your personal information will be stored at the primary researcher's apartment. The digital recorded interviews and transcripts will be stored on a password protected laptop computer at the primary researcher's apartment. The primary researcher's apartment is always locked by a deadbolt lock and he is the only person that has a key to the apartment. Any identifying information (master list, address, etc.) will be destroyed at the completion of the defense of my dissertation/graduation which is anticipated in May 2016. All transcripts with no identifying information will be kept for up to two years for future data analysis.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with my adviser, Dr. Mona Robinson, for clarification of how to accurately analyze the data collected. Again your name will not be provided to Dr. Robinson with Dr. Robinson only

reviewing the transcripts that have been de identified of your personal information (name, etc.).

### Compensation

As compensation for your time/effort, you will receive a onetime offer of a \$25-dollar gift card. This is a given as an appreciation of you taking the time to share your personal experiences/journey with me. Participants that end the interview early or do not show up for an online scheduled interview will not receive a \$25-dollar gift card. In order for me to get the gift card to you I will have to have your name/address to be able to mail the gift card to you. Your address will only be used to mail the gift card and then destroyed. Your address will not be associated with your digital interview or your de identified interview transcript.

### Contact Information

If you have any questions regarding this study, please contact the investigator Robert L Stevens @ rs190809@ohio.edu or (870) 925-1122.

My faculty advisor can also be contact at the following information:  
Dr. Mona Robinson @ robinsoh@ohio.edu or (740) 593-4461.

Ohio University Counseling & Psychological Services can be contacted at (740) 593-1616 in person at the Hudson Health Center 3rd floor on the Ohio University Athens, Campus.

Student Accessibility Services may also be a good resource for assistance with your educational goals and managing your CID. They can be reached at (740) 593-2620 or in person in the Baker Center, Suite 348 on the Ohio University Athens Campus.

If you have any questions regarding your rights as a research participant, please contact Dr. Chris Hayhow, Director of Research Compliance, Ohio University, (740)593-0664 or hayhow@ohio.edu.

By agreeing to participate in this study, you are agreeing that:

- you have read this consent form (or it has been read to you) and have been given the opportunity to ask questions and have them answered;
- you have been informed of potential risks and they have been explained to your satisfaction;
- you understand Ohio University has no funds set aside for any injuries you might receive as a result of participating in this study;

- you are 18 years of age or older;
- your participation in this research is completely voluntary;
- you may leave the study at any time; if you decide to stop participating in the study, there will be no penalty to you and you will not lose any benefits to which you are otherwise entitled.

Version Date: 11/3/2015



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