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Living With Muscular Dystrophy: Sexual Education

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Walden University
2018

Abstract

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MA, Montana State University-Billings, 2007

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Dissertation Submitted in Partial Fulfillment

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Abstract

Sexual pleasure and intimacy are fundamental and innate human needs. Individuals with physical disabilities often find it difficult to meet these needs because of such factors as impaired mobility and lack of knowledge about sexual health. People with physical disabilities are often seen as asexual and not capable of having sex, and sexuality is often not considered a concern among this population. These misconceptions can result in individuals with physical disabilities not receiving basic sex education or advice and guidance when issues arise. Not receiving this attention may impede disabled individuals' sexual potential and personal relationships. This study's focus was on the unique challenges individuals with muscular dystrophy (MD) face regarding sexual pleasure and intimacy. Humanistic psychology and the human rights theory provided the theoretical framework for this study. Using a qualitative multiple case study approach, 4 individuals with MD were asked what sexual education, if any, they received, and if they did receive sexual education, whether it met their needs. Data were analyzed using open and axial coding. Key findings were that there is an overarching theme of sexual silence and lack of sex education for people with MD. These findings can help inform efforts to provide more inclusive education for people with MD and individuals with other types of physical disabilities. Study findings contribute to social change by showing the importance of the need for more inclusive sexual education. Providing such education will better meet the basic human needs of an often underserved and stigmatized population and end the silence that individuals with physical disabilities have regarding sexual health and intimacy.

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Dedication

I dedicate this dissertation to my husband, Steve, our children, Jessica and Thomas, and my parents, Tom and Brenda Beers, for all your unconditional love, support, and encouragement through my doctoral journey. I thank you so much for your understanding when I was frustrated, your love and encouragement through all of the ups and downs, cheering me on every step of the way, and accepting me for who I am and standing by me every step of the way. Mom and Dad, you are my guiding light and helped me become the individual I am today, someone who treats people equally and accepts them for who they are. You have encouraged me and supported me through the years to empower myself and believe in myself, and for this I am forever grateful. Jessica and Thomas, you inspire me each and every day to be the best mom and individual I can. I give thanks each and every day that you are both in my life and cannot be more proud of each of you and all of your accomplishments. You are the meaning of good in this world. Through your generosity and kind hearts, the future is yours. Steve, you are truly my best friend, my support system, confidant, and soulmate. From the first time we met, I knew we would be together forever. You have listened to never-ending conversations regarding this dissertation, but never once did you ask me to quit. Instead, you pushed me forward and offered unconditional support. Words will never be able to express the love and respect I have for all of you. I thank each of you for supporting me in this endeavor and helping make my lifelong dream come true.

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Chapter 1: Introduction to the Study

Sexual pleasure and intimacy are fundamental and innate human needs. However, meeting these needs can be problematic for individuals with physical disabilities (O'Dea, Shuttleworth, & Wedgewood, 2012). Not only can various factors such as impaired mobility cause people with physical disabilities to resist intimacy, many disabled individuals avoid intimacy because they lack the knowledge about sexual health that is routinely provided to individuals without physical disabilities (Schairer et al., 2014).

Historically, men and women living with a physical disability have been seen as asexual and may also have been seen as not capable of having sex (Kim, 2011; O'Dea et al., 2012). As such, health care professionals, educators, family, and friends often do not consider sexuality a concern for individuals with physical disabilities (Schairer et al., 2014). These misconceptions and lack of consideration can result in individuals with physical disabilities not receiving basic sex education as well as advice and guidance when issues arise such as sexual dysfunction or the need to adapt one's sex life due to changes related to disease progression (Areskoug-Josefsson, 2013; Rowen, Stein, & Tepper, 2015). Not receiving this attention may impede sexual potential and personal relationships for disabled individuals.

Although there are many types of physical disabilities, individuals with muscular dystrophy (MD), a group of hereditary neuromuscular diseases, face unique challenges when it comes to sexual pleasure and intimacy and are the focus of the present study. MD is characterized by progressive weakness and degeneration of the skeletal muscles that control movement and may include cardiac muscles. Furthermore, MD encompasses a continual wasting, weakness, and irreversible degeneration of muscle strength as the disorder progresses, resulting in diminution of ambulatory capacity, increased fatigue, chronic pain, sleep disorders, and depression, which can contribute to a loss of self-esteem and increased societal isolation (O'Dea et al., 2012). Some of the unique challenges individuals with MD face can develop at different stages of life. Depending on the type of MD and age of onset, there are symptoms that may affect sexual health. According to Areskoug-Josefsson (2013), health care professionals are often reluctant to discuss issues concerning sexual health due to embarrassment, lack of knowledge, fear of offending the patient, lack of skills, and beliefs that patients are too ill.

Although some researchers have identified the need for and value of addressing issues related to sexual pleasure and health for people with physical disabilities (e.g., Kedde, Van De Wiel, Schultz, Vanwesenbeek, & Bender, 2010; Kim, 2011; O'Dea et al., 2012), I did not find literature concerning these issues specifically for individuals with MD. In a search on the literature on MD and sexual health, Areskoug-Josefsson (2013) noted a similar lack of information. As such, educational needs regarding the sexual health of individuals with physical disabilities, specifically, adults with MD, were the focus of this study. I believe results from this study will have important social implications for improving the sexual health for individuals with physical disabilities, which can also improve their overall physical health as well as their emotional and social health. The study results may also help lawmakers, health care providers, and communities meet demands for greater equality for people with disabilities and help diminish the negative perceptions and stigmas people with disabilities often suffer.

In the following chapter, I address the topic of sexual education needs among disabled individuals, specifically for individuals with MD. Also provided are a description of the gap in knowledge I addressed in this study, the problem statement driving the study, the study’s purpose, and the specific research questions. I present the theoretical framework for the study, a summary of the methodology, and study assumptions, limitations, and delimitations. A discussion of the study’s significance and a summary conclude the chapter.

Background

Over 650,000,000 individuals worldwide live with disabilities (World Health Organization [WHO], 2012). These individuals face prejudice and stigma throughout their daily lives (WHO, 2012). One of the areas in which disabled individuals face prejudice and stigma is sexuality. People with physical disabilities have the same sexual behaviors and desires as individuals without disabilities (WHO, 2012). However, much of the sexual education they receive has primarily focused on reproduction or sexual abstinence (WHO, 2012) and not on issues of sexual well-being. People with disabilities have normal desires for relationships and intimacy and, while they need to know about reproduction, fertility, and sexual behaviors (Higgins et al., 2012), they also need to know how they can meet their intimacy needs in the context of their physical disabilities. Higgins et al. (2012) explored the experiences of people with a physical disability.

Participants stated that their impaired bodily functions complicated their social and sexual life. Furthermore, according to Higgins et al. (2012) a physical disability can diminish self-esteem, one's sense of attractiveness, relationships, and sexual functioning. Many participants in Higgins et al. (2012) reported challenges meeting partners and worries about being isolated and abandoned to a world without affection, touch, or intimacy. Study participants also reported receiving little to education on human sexuality.

People with physical impairments can benefit from sexual therapy and education. Kedde et al. (2010) examined the feasibility and efficacy of six-session structured psychosexual therapy designed for people with diverse disabilities (*N* = 47) who reported experiencing sexual or intimacy problems. The results demonstrated psychosexual therapy and sexual education's positive effects on several areas of sexual well-being. Participants reported less relational stress and sexual stress, an increase in sexual satisfaction, sexual esteem, and sexual interaction competence, and a higher frequency of sexual contact. O'Dea et al. (2012) explored how living with neuromuscular disorders can affect sexual behavior and personal relationships. These authors also noted that the lack of information and sexual education provided to individuals with MD regarding sexual and personal relationships can cause distress and anguish in life.

Believing people with physical disabilities are asexual can prevent them from receiving adequate sexual education. Kim (2011) researched relationships, intimacy, and sexual education among persons with disabilities to gain more knowledge about how sexual behavior relates to societal views regarding the asexuality of disabled individuals. According to Kim (2011), “Disability does not eliminate basic drives or the desire for love, affection, and intimacy” (p. 482). However, Kim argued that an individual’s disability will impact his or her physical ability to engage in sexual activity. Therefore, adaptations and accommodations must be sought to help individuals fulfill their desire for intimacy and relationships.

The WHO (2013) released a manual promoting sexual health and reproductive health for persons with disabilities. The manual authors recognized the rights of persons with disabilities to receive sexual education and noted that such rights are often overlooked. According to the WHO, key actions are needed to prevent the prejudice and stigma regarding persons with disabilities being sexually active and having intimate relationships. Figure 1 illustrates the WHO’s key actions for promoting sexual reproductive health and rights for individuals with disabilities.

Since the first social movement of deinstitutionalization followed by the civil rights movement of the 1950s and 1960s, advocacy and grassroots organizations have played a large role in developing opportunities for greater equality for people with disabilities by increasing awareness through legislation, advancing research, and educating health care professionals and community members on a range of issues. However, lesser attention has been paid to the inequities between sexual education provided to disabled and nondisabled individuals. Knowing more about the education physically disabled individuals receive and their perceptions of their sexual health education needs could help advance greater equality in this area as well.

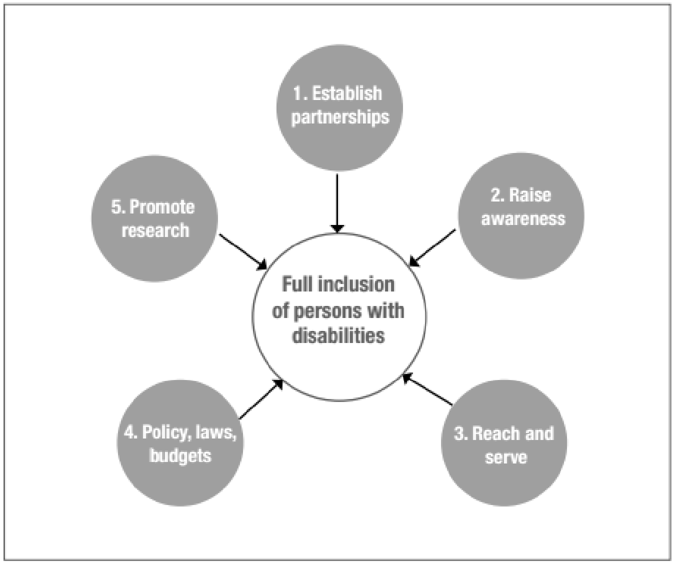

Figure 1. Actions toward full inclusion of the sexual health of persons with a disability. Adapted from *Promoting Sexual and Reproductive Health for Persons With Disabilities*, by the World Health Organization, 2012, p. 15. Copyright 2012 by the World Health Organization.

Problem Statement

People with physical disabilities have the same sexual behaviors and desires as individuals without physical disabilities (WHO, 2012) but they typically are not provided the same sexual education as individuals without disabilities. As such, they may not know how to address and fulfill their desires in the context of their disability. Some may have never received basic human sexuality education. Others may have received basic sex education that only focused on reproduction or sexual abstinence and not on issues of sexual well-being. That health care providers are often reluctant to address sexual health issues with their physically disabled patients because of embarrassment, lack of skills and knowledge, and fear of offending physically disabled patients also adds to the problem (Higgins et al., 2012). Because these issues are commonly ignored, men and women with disabilities may face difficulties regarding their intimacy and sexuality (Porat, Heruti, Navon-Porat, & Hardoff, 2012). However, without knowing more about the education the physically disabled do receive as well as the type of education they believe will best meet their needs, efforts to provide this education can be considered stabs in the dark at best. There is a lack of understanding, knowledge, and awareness of sexual health and sexual health education needs among the disabled (WHO, 2013). What is known is that “the challenges in sexual health are not just part of having a disability but instead often reflect stigma and discrimination, lack of social attention, legal protection, accessibility of services, understanding and support” (WHO, 2013, p. 1).

Purpose of the Study

In this qualitative multiple case study, I explored the experiences associated with human sexuality education among individuals with MD. By using an in-depth narrative interview approach, I discovered and identified what type of sex education individuals with MD have received and what they perceive to be their sexual educational needs. Findings from this multiple case study may be used to better inform greater inclusion of disabled individuals in sexual education provided at various life stages as well as sexual education that better reflects the needs and desires for individuals with MD.

Research Questions

Two questions were developed to guide this investigation: What sexual education, if any, have individuals with MD received, and if sexual education was provided, did it meet the individual’s needs? Based on these research questions, I used guided inquiry to ask participants to describe what kind of sexual education they have received, if any. I also asked them to describe how the education they have received influenced their experiences in terms of their body responding or not responding to physical and emotional sexual desires and discuss how sexual education or the lack of it may have influenced or affected their experiences with sexual anxieties and dysfunctions. Focusing on these key topics invited the participants to express their feelings and emotions and allowed me to ask additional questions and prompt for more detail as needed.

Theoretical Framework

This study’s focus was on the core of basic human needs and desires and on how sex education can impact the quality of life of disabled individuals. I used the research developed by Kim (2011) that built on the theoretical frameworks of the humanistic psychology theory and the human rights theory while she examined the basic human drive for intimacy and how disabled individuals desire sexual fulfillment but are often excluded from sexual education due to their disabilities. As Kim explained, when there is a disconnection from an intimate relationship, an individual may begin to have feelings of emptiness and negative emotions. More details on the humanistic psychology theory and the human rights theory and how Kim used these frameworks in her research are in Chapter 2.

Nature of the Study

A qualitative approach was chosen for this study as it is best for studying data based on participants' categories of meaning. It is also useful for studying a limited number of cases in depth as well as describing complex phenomena, which also provides individual case information to the researcher (Yin, 2014). Other strengths of taking a qualitative approach is that the documentation, even though broad, can be specific, stable, and unobtrusive; archival records are precise; interviews are targeted and remain focused directly on the case study topic; there is direct access to participant insights, explanations, and personal views; and direct observation is immediate. Qualitative research can determine how participants interpret constructs such as self-esteem. Further, data are collected in naturalistic settings, and researchers may also determine ideographic causation of a particular event (Patton, 2002). See Chapter 3 for more detail on the strengths and weaknesses of qualitative approaches and why a qualitative approach was chosen for this study.

Multiple case study was the specific qualitative approach chosen for this study. This methodology allows for exploring differences between each participant (Baxter & Jack, 2008). The goal of a multiple case study is to replicate findings in which the researcher can either predict similar results or contrasting results (Baxter & Jack, 2008; Yin, 2015). Baxter and Jack (2008) noted that while multiple case studies can be time consuming, the evidence created from multiple case studies is considered robust and reliable. According to Turner (2010), a case study approach allows exploring a phenomenon in real-life context. As such, case study was appropriate for the present study. A case study can be used to study single or multiple participants while including valuable insights (Turner, 2010). When using a case study, one can take a complex concept and simplify it through conducting open-ended discussions with participants (Yin, 2014).

The inclusion criteria for participation in this study were men and women over 18 years of age with MD who are English proficient. Potential participants were asked a series of questions to determine if they fit the inclusion criteria established for this study. These questions included when the diagnosis was made.

Data were collected through semistructured interviews using an interview guide I developed based on the literature review conducted for this study. This review underscored the need for further intimacy and human sexuality education among health care professionals, education professionals, students, and specifically individuals with a physical disability. Analysis was carried out through open and axial coding. Open coding is used to identify, name, categorize, and describe findings from the data that are collected. It calls for reading every word while seeking to determine what the data are about and what they reference (Strauss & Corbin, 1990). Holton (2010) noted that the conceptual abstraction of data and its reintegration as theory takes places through coding. Axial coding is then used to determine how the various codes, or themes, relate to each other (Strauss & Corbin, 1990). It goes beyond descriptive coding and reflects interpretation and reflection on meaning (Merriam & Tisdell, 2016). Chapter 3 includes further details on the methodology and the research design for the present study.

Definition of Terms

For this study's purposes, key terms were defined as follows:

Asexuality: Asexuality is defined as lacking sexual attraction to people of any gender (Lund & Johnson, 2014). Asexuality can also be defined as a lifelong lack of sexual desire that does not cause distress for the individual lacking this desire (Lund & Johnson, 2014).

Desexualization: Kim (2011) defined desexualization as acts or thoughts that cause a separation from sexuality for people with disabilities. Desexualization reflects beliefs that disabled people are undesirable and that disability results in sexual incapacity (Kim, 2011).

Intimacy: Intimacy is extreme interpersonal closeness that allows people to be comfortable about entering each other's personal space. Intimacy can also be described as loving and affectionate personal relationships that reflect a deep understanding of each person in the relationship ("Intimacy," 2016).

Sex: For the purposes of this study and to distinguish between intimacy and sex, sex is defined as sexual activity, including sexual intercourse ("Sex," 2016).

Assumptions

Assumptions in a study are things considered somewhat out of the researcher’s control (Simon, 2011). As Leedy and Ormrod (2010, p. 62) stated, “Assumptions are so basic that, without them, the research problem itself could not exist.” A key assumption in the present study was that participants would complete a semistructured interview. However, if any participants chose to withdraw from the study at any time, their anonymity would be maintained, and they were advised there would be no ramifications for withdrawing from the study. It was also assumed study participants would understand the questions I asked and provide honest and complete answers. Identifying enough individuals who would meet this study’s eligibility requirements for participation was also assumed.

Scope and Delimitations

This study’s specific scope related to exploring the sexual education needs of adults with MD. As such, the sexual education needs of youth with physical disabilities or adults and youth with other types of disabilities, such as developmental disabilities, were not included in this study. Participants were 18 years of age or older, and both men and women were recruited and included. As I live in a rural area of the United States, it was difficult to find participants for in-person interviews. As such, I interviewed most participants remotely using a smart phone or Skype. Finally, the sensitivity of the topic, the in-depth discussions that occurred during the interviews, and the methodology employed (multiple case study) made it impractical to have a large sample. Therefore, the small sample size was a study delimitation.

Limitations

Limitations are occurrences that may arise during the study that are out of the researcher's control (Simon & Goes, 2013). The key limitation in this study related to my role as researcher as I have MD and have been through different situations regarding human sexuality education, relationships, and sexual esteem. Bracketing, which calls for identifying the ideas, values, and beliefs that one holds (Jones & Metz, 2016), was one of the controls I used to address and alleviate the potential effects of preconceptions. These controls also included keeping a journal of my thoughts prior to and after each interview to ensure my awareness of my own thoughts so as to not put them on to the participant. Keeping the journal allowed me to confront my own opinions and prejudices so they did not bear any weight on my interpretation as I compiled the data. I followed the words of Rajendran (2001), "The researcher's primary goal is to add knowledge, not to pass judgment" (p. 3).

Significance

Amid calls for greater equality and inclusion of people of all cultural backgrounds, races, and sexual orientations, individuals with physical disabilities still experience prejudice and stigma in many areas, including human sexuality. Determining the sexual education needs of individuals with MD and whether these needs have been met was my attempt to make a positive change for individuals with this physical disability. Human contact, touch, intimacy, and desire for sex should in no way be diminished because of a physical disability. Inclusive human sexuality education would promote confidence and social abilities and encourage a positive self-image for men and women with MD. However, providing this education cannot be effectively done without knowing how much education individuals with MD receive and whether it meets the needs of these individuals when provided. Asking these questions directly of men and women with MD not only provided knowledge that can fill this information gap and can also help inform efforts to provide more inclusive education for people with MD and for individuals with other types of physical disabilities. Results may also be used to promote further studies and educate health care professionals, educators, and the disabled community on the need for human sexual education among the disabled population.

Summary

Although men and women with physical disabilities have often been considered asexual, their sexual behaviors and desires are not different than those in individuals without physical disabilities. Still, many individuals with disabilities receive no sex education at all. Others receive very rudimentary education or education that does not meet their needs. I found very little information on the sexual education needs of physically disabled individuals from the individuals' perspectives, and specifically from the perspectives of individuals with MD. As such, my focus in this study was on employing multiple case study methodology to explore what sexual education has been provided to individuals with MD and whether it has met their needs.

Chapter 1 provided an overview of the problem that was addressed in this study. I also presented the research questions, a brief discussion of the chosen methodology, the underlying theory, and study assumptions, scope, limitations, and delimitations. In Chapter 2, I present a review of current literature on sexual esteem, intimacy, human sexuality education, and skepticism regarding sexuality in individuals with MD.

Chapter 2: Literature Review

People with physical disabilities have the same sexual behaviors and desires as individuals without disabilities (WHO, 2012). However, meeting these needs can be problematic (O’Dea et al., 2012). Physical and emotional factors can both play a role. So too can the fact that physically disabled individuals often lack the knowledge about sexual health that individuals without physical disabilities routinely receive (Schairer et al., 2014). Sexual behavior among individuals with disabilities has often been difficult to address as it has been considered taboo. Further, individuals with disabilities are sometimes viewed as asexual due to preconceived notions of sex and what is considered natural. There is a general lack of information and education regarding disability and sexuality, which contributes to why society holds a stigma regarding disability and sexuality (Esmail, Darry, Walter, & Knupp, 2010).

Although some researchers have shown the need for education that addresses issues related to sexual pleasure and health for people with physical disabilities, I did not find any studies that specifically focused on addressing these issues for individuals with MD. As such, my focus in this study was on exploring the experiences associated with human sexuality education among individuals with MD. A better understanding of the sex education individuals with MD have received and what they perceive as their sex education needs may inform more inclusive sex education provided at various life stages. A better understanding may also inform sex education efforts that better reflect and meet the needs and desires of individuals with MD.

I begin this chapter with a discussion of this study's theoretical framework. Following this are sections on living with MD, intimacy issues for individuals with physical disabilities, barriers to education for individuals with physical disabilities, existing educational efforts, and what is needed for sexual education for individuals with physical disabilities. The chapter ends with a summary.

Literature Search Strategy

Most of the studies in this literature review were found in databases accessed through Walden University's library. These databases included the Thoreau multidatabase, SocINDEX with full database, ProQuest Central, and SAGE Journals. Google Scholar was also searched. Keywords and phrases searched were the following: *intimacy*, *sex*, *sexual health care*, *physical disability*, *sexuality*, *sexual knowledge among adults with a neuromuscular disorder*, *relationships*, *access to human sexuality information*, *body image*, *questions people may have about sex who have a physical disability*, *sexual esteem*, *sex education*, *marriage*, *neuromuscular disease*, *neuromuscular disorder*, *sexual rights*, *trust*, *communication*, and *rehabilitation*. All were accompanied by the phrases *physical disability*, *neuromuscular disease*, or *neuromuscular disorder*. These searches resulted in a number of articles, yet very few related specifically to neuromuscular disease or physical disability that did not involve a spinal cord injury. I added some of these studies as they touched on similar aspects of sexual needs and basic human rights. Although it is customary to obtain research and information that is within 5 years of study defense, I had to expand my inclusion criteria to gather enough material due to the shortage of information.

Another issue that became apparent when searching for literature to review for this study is that many researchers have only focused on intercourse when exploring sexual activity among individuals with physical disabilities (Esmail et al., 2010). Not enough research has been done on other topics such as sexual behavior, intimacy, sexual esteem, and sexual anxieties among individuals with physical disabilities (O'Dea et al., 2012). Very few studies have been done on sexual education needs for individuals with physical disabilities, let alone individuals with MD.

Theoretical Framework

The present study's topic reflects the core of basic human needs and desires—the fundamental human drive for intimacy, which can include the desire for sexual fulfillment (Kim, 2011). Most humans have basic needs for survival, belonging, love, power, freedom, and fun (Nucci, 2010). With these basic needs comes the urgent desire to eat, sleep, have financial security, and have the ability to engage in intimate and sexual behaviors. Individuals with disabilities have the same desire for intimacy as individuals without disabilities, but they can be disconnected from intimate relationships due to a lack of sexual education. When this disconnection exists, individuals with disabilities may have feelings of emptiness and other negative feelings (Kim, 2011).

The theories of humanistic psychology and human rights are relevant to the issues in the present study. Humanistic psychology focuses on each individual's potential and stresses the importance of growth and self-actualization (McLeod, 2015). Maslow described the humanistic psychological theory by using a pyramid model to show that humans are motivated to fulfill basic needs. Starting at the bottom of the pyramid, these needs are (a) physiological (water, air, food, breathing, and sleep), (b) safety (security, stability, freedom from fear), (c) love/belonging (family, friendship, and sexual intimacy), (d) esteem (personal worth, social recognition, and accomplishment), and (e) self-actualization (achieving individual potential; McLeod, 2015).

Regarding the present study, the humanistic psychological theory is especially applicable to the topic of physical disability and sex/intimacy as it emphasizes the role of the individual. Among individuals with physical disabilities, many struggle with life's ups and downs. Some of these individuals can find themselves on two different levels of Maslow's pyramid as they are trying to reach the next step without falling backwards and losing what they have accomplished. Humanistic psychological theory is a guide for these individuals to realize that despite the fact that they may go three steps forward and then two steps back, they are still making progress.

Human rights theory encompasses the concept that human rights are needed for a life of dignity and a life worth living. Human rights include significant and influential social and economic freedoms that relate to the individual's expression of survival (Blau & Moncada, 2015). Humans have wants, desires, and needs. Among these humans are individuals with neuromuscular disabilities who want to express their sexual needs and desires for intimacy but have been restricted from doing so (East & Orchard, 2014a).

According to Humans Rights Watch (2012), individuals have the right to be equal in terms of freedom, dignity, personal integrity, and self-determination. These human rights can encompass a number of things such as rehabilitation, curiosity, and a supportive framework as well as practical and social intelligence. However, basic human rights are often denied to many individuals with physical disabilities as they are seen as asexual creatures and are left out of discussions and educational processes regarding relationships and sex/intimacy (Human Rights Watch, 2012).

Living With Muscular Dystrophy

To understand the intimacy issues individuals with MD face, one must first have an understanding of the aspects of living with MD. MD is a group of hereditary muscular disorders that are characterized by progressive muscular weakness (Areskoug-Josefsson, 2013). MD symptoms include pain, fatigue, and physical and psychological impairment (Areskoug-Josefsson, 2013). According to the Muscular Dystrophy Association (MDA, 2017c), MD is one of seven categories of neuromuscular diseases, and there are 13 diseases that fall under the MD umbrella. Research on what causes MD and on aspects such as MD symptoms, age of onset, and life expectancy for those affected is ongoing. At the time the present study was conducted, there were no cures for any type of MD.

Each type of MD has its own characteristic symptoms. These symptoms always include loss of muscle mass and muscle weakness not related to any other disease or trauma (Areskoug-Josefsson, 2013). Another common characteristic among all types of MD is the breakdown of muscular cells, which are replaced with connective tissue (i.e., fat; Areskoug-Josefsson, 2013). MD has been diagnosed at its earliest onset at age 2 or 3 years but on rare occasions does not become apparent until age 25 years or older. The disease worsens over time. Its course depends on the specific MD form the individual is diagnosed with. MD can also lead to cognitive issues, respiratory failure, heart problems, digestion and swallowing impairments, and many other issues (Mayo Clinic, 2018).

MD can affect sexual health in different ways (Areskoug-Josefsson, 2013). Biological changes such as chronic pain, fatigue, and impotence can affect the desire to engage in sexual activities and the ability to do so. Changes in muscle mass and muscle weakness can lead to body image issues, depression, and fear of not being sexually desirable (Areskoug-Josefsson, 2013). However, although neuromuscular diseases such as MD may cause an individual to have limitations with fine and gross motor functioning, they do not necessarily affect a person’s desire for intimacy and affection (East & Orchard, 2014a; Milligan & Neufeldt, 2001). Some individuals with MD may not be able to move in a way in which society would consider a normal fashion, meaning individuals with the disease may have to use assistive devices to help them walk, eat, talk, and even modify sexual activities and intimacy. From a social perspective, these factors can impede sexual activities such as intercourse. However, according to Esmail et al. (2010), “It is becoming more recognized that sexuality is not based on physical performance but also on emotional closeness and pleasure” (p. 1151). Hence, living with MD can and should include expressing the desire for intimacy and embracing one’s uniqueness.

Intimacy Issues for Individuals With Physical Disabilities

Individuals with disabilities are often desexualized in today's society, yet they have the same need for intimacy, self-worth, and social belonging as people without disabilities (Esmail et al., 2010). Having a physical disability does not necessarily affect a person's desire for intimacy and affection, but it can affect how people approach sexuality as they may be facing barriers and challenges stemming from the physical disability (East & Orchard, 2014b; Milligan & Neufeldt, 2001). Having a physical disability may necessitate experimenting or perhaps readjusting notions and expectations of what sexuality and intimacy mean. That said, individuals can still achieve intimacy, sexual closeness, and pleasures regardless of a physical disability (Tepper, 2015).

As previously noted, research on intimacy issues among individuals with physical disabilities has been sparse. There is even less research specifically on intimacy issues among individuals with MD. Areskoug-Josefsson (2013) noted that research on symptoms that might decrease sexual health is lacking as well as research on what might improve sexual health. As such, the following discussion primarily reflects what is known about the topic in general among individuals with physical disabilities. Findings from the few studies on intimacy issues among individuals with MD are highlighted as they are discussed. To date, Areskoug-Josefsson's article is the most comprehensive scholarly investigation on muscular dystrophy and sexual health and informed much of the following discussion.

Physical Issues Related to Intimacy

Physical disability may alter a person's sexual or intimate behaviors, both when giving and receiving. As examples, in people with MD, difficulties closing the mouth or with mouth movements, which can be seen in myotonic dystrophy and fascioscapulohumeral muscular dystrophy, can result in difficulties kissing and performing oral sex (Areskoug-Josefsson, 2013). Difficulties lifting the arms, as can be the case in individuals with fascioscapulohumeral muscular dystrophy, can result in difficulties with hugging and kissing. Physical changes such as testicular atrophy and decreased lower limb muscles, the former seen with myotonic dystrophy, the latter with Becker's muscular dystrophy and Duchenne muscular dystrophy, can possibly result in negative body image and functional disabilities (Areskoug-Josefsson, 2013). Peric et al. (2013) found that among men with myotonic dystrophy type 1, the most common form of muscular dystrophy in adults, erectile dysfunction was prevalent in 72% of their male study sample. The same percentage (72%) had interstitial testicular failure, and 60% had tubular testicular failure. Erectile dysfunction was more common in men with interstitial impairment of the testicles (Peric et al., 2013). See Table 1 for more detail on symptoms for common forms of MD and their possible effects on sexual health.

Table 1

Symptoms of Muscular Dystrophy and Possible Negative Effects on Sexual Health

Type of muscular dystrophy	Symptom	Possible negative effects on sexual health
Myotonic dystrophy	Difficulties closing the mouth	Difficulties kissing and performing oral sex
	Delayed muscular relaxation, feeling of muscular stiffness	Difficulties with body position during sexual activities
	Testicular atrophy	Negative body image
	Pregnancy complications	Sexual and reproductive functions
	Unclear speech	Difficulties communicating with potential partners
	Mental symptoms such as apathy and inactivity	Difficulties finding a partner and performing sexual activities
Fascioscapulohumeral muscular dystrophy	Difficulties with mouth movements	Difficulties kissing and performing oral sex
	Difficulties lifting the arms	Difficulties with hugging and caressing
	Hearing impairment	Difficulties communicating with partner/potential partner
Becker's muscular dystrophy and Duchenne muscular dystrophy	Decreased lower limb muscles	Functional disability, negative body image

Note. Adapted from "Muscular Dystrophy and Sexual Health," by K. Areskoug-Josefsson, 2013, *OA Musculoskeletal Medicine, 2,* p. 3. Copyright 2013 by OA Publishing London.

Emotional Issues Related to Intimacy

Individuals with physical disabilities adapt to life as they know it and become aware of what limitations they may have. Regarding intimacy and sexual relations, individuals with physical disabilities may experience a number of emotional issues surrounding such concerns as whether they are lovable and if they will ever love in an intimate and sexual way (Rainey, 2011). Consequently, individuals with a physical disability must adjust to their doubts regarding entering into intimate relationships and increase their knowledge regarding the many ways to experience sexuality despite their physical limitations (Tepper, 2015). As a result of overprotection by health care professionals and family members, individuals with physical disabilities may be skeptical about intimate relationships and have negative self-esteem regarding their disability and how they can enter into an intimate relationship without feeling shame or disgust (Kim, 2011). These concerns and others are discussed next.

Skepticism of intimacy. Wondering whether one will have an intimate sexual relationship is common among both individuals without physical disabilities or limitations and individuals with physical disabilities. For people with physical disabilities, part of this skepticism may include wondering what others consider when they look for someone to date or marry. Do individuals’ attitudes change when they see someone in a wheelchair, or do they look past that and get to know the person with the physical disability regarding the person’s character, personality, intelligence, and humor (Marini, Chan, Feist, & Flores-Torres, 2011). Marini et al. (2011) asked this question and found that their study participants were more likely to engage in a friendship with a person with a disability and not as likely to date or marry an individual with a physical disability. Study participants further stated that they would not be interested in dating or marrying a person with a physical disability because they perceived that the person would be too much work or would require too much caregiving. Marini et al. (2011) stated this perception "likely stems somewhat not only from the model of disability, but also charity drives such as the annual Muscular Dystrophy Telethon as well as television and movie portrayals" (p. 22). Marini et al. (2011) found that participants' attitudes changed when they were presented with a picture and a small biography of the individual with the physical disability. Participants said they would feel more comfortable engaging in a relationship of intimacy with somebody with a physical disability if they were given more information on the individual and what the individual's needs would be.

Fear of intimacy. People with physical disabilities may fear intimacy due to perceptions of desexualization by others (Kim, 2011). Desexualization can occur during any stage of life among individuals with a physical disability, and it often causes health care professionals and family members to feel the need to protect these individuals from ridicule, therefore making it difficult for people with physical disabilities to obtain further knowledge on sexual relationships (Kim, 2011). According to Kim (2011),

> Desexualization is a process that separates sexuality from disabled bodies, making it irrelevant to and incompatible with them because disabled people are supposedly undesirable in society and because disability is believed to lead to

> sexual incapacity. In addition, desexualization refers to the ongoing process of creating distance between sexuality and people with disabilities through the fear of disability reproduction and contamination. (pp. 482–483)

Desexualization can take the form of close monitoring by health care professionals and parents when individuals with a physical disability are deemed incapable of making their own sexual choices. Because of desexualization, people with physical disabilities may find it difficult to lead sexual lives due to their distance from sexuality and the lack of ability to participate in sex education classes (Kim, 2011).

People with physical disabilities may experience feelings of sexual incompetence. They may believe they do not meet social standards or norms of physical attractiveness and therefore lack sex appeal (Cordes, Mona, Syme, Cameron, & Smith, 2013). Individuals with a physical disability have a heightened awareness of their body image and how it appears to others. This may adversely impact sexual activity and satisfaction (Kolzet et al., 2014). Researchers have identified sexual esteem, body image, and sexual satisfaction as strong predictors of self-esteem and depression among individuals who have a physical disability (Kolzet et al., 2014). Research results have shown that individuals with physical disabilities who had issues with sexuality and intimacy were at greater risk for depression (Kolzet et al., 2014).

Sexual self-esteem issues. Having a physical disability may result in individuals resisting entering into relationships due to low sexual esteem (Kim, 2011). Consequently, individuals with physical disabilities may feel self-defeated. This may be especially the case when the self-defeat has profound implications for social interactions and sexual relations due to the pain and lack of mobility caused by the individuals' altered physical status due to their limitations and disability (Schairer et al., 2014).

Damage to sexual self-esteem and sexual anxiety can occur through interactions with others (Mayers, Heller, & Heller, 2003). Name-calling and sexual insults can damage one's sexual self-esteem. Unsuccessful sexual interactions, sexual victimization, and one's own impulsivity and self-destructiveness in a sexual encounter can also affect sexual self-esteem (Mayers et al., 2003).

In their quantitative study on sex education for individuals with physical disabilities, including MD, East and Orchard (2014a) found that individuals with physical disabilities lacked sexual esteem due to the overall deficiency of disability-specific sex education. The results illustrated that the lack of disability-specific sex education left individuals with physical disabilities feeling tension about relationship desires. East and Orchard (2014a) concluded that well-balanced and comprehensive sex education for physically disabled individuals is important for promoting their self-assurance and self-esteem regarding intimate personal relationships.

The asexuality factor. Some of the most common misconceptions about people with disabilities are that they cannot have sex, do not want sex, or are not interested in sex (Rainey, 2011). People seem to think a disability neuters one sexually (East & Orchard, 2014a). This attitude can be found even among professionals who work with disabled people. Unfortunately, the way people are perceived often becomes the way they perceive themselves (Rainey, 2011).

People with physical impairments, including neuromuscular disorders, have historically been perceived as asexual (O’Dea et al., 2012). Individuals with physical disabilities are seen as asexual when it comes to discussions involving intimacy, relationships, and sexual behavior (Rowen, Stein, & Tepper, 2015). As such, individuals with disabilities often lack information about sexuality, and they experience distress and anguish about their sexual and personal relationships (O’Dea et al., 2012).

Another significant issue regarding sexuality for individuals with physical disabilities, and the key focus of this study, is the lack of education among many of these individuals. Some reasons for this lack are discussed next. They include a number of barriers to education for physically disabled individuals such as thinking these individuals are not capable of having sexual relations or that they simply are not entitled to this basic human right because of their disability.

Barriers to Education for Physically Disabled Individuals

Sexual rights and desires are a universal positive fulfillment of the fundamental law of humanity (Nucci, 2010). Continuing from this concept, individuals who are not disabled may have to overcome barriers to accepting and respecting sexuality among people with physical impairments (Cumurcu, Karlidag, & Almis, 2012). Believing people with physical disabilities are asexual can prevent individuals with disabilities from receiving adequate sexual education. Many individuals with disabilities face isolation and social stigmas partially due to society’s lack of education and knowledge regarding disabilities (UNICEF, 2013). Some of this lack of education and knowledge may stem from fear and the unknown of being around individuals with disabilities (UNICEF, 2013). As UNICEF (2013) put it,

> Disability is not the impairment itself, but rather attitudes and environmental barriers that result in disability. People with disabilities are often “invisible” and they are at greater risk of negative sexual esteem and violence than the non-disabled. (para. 3)

Even with increasing positive attitudes toward people with disabilities and more laws to protect and provide equal rights to these individuals, there are still barriers between nondisabled individuals and individuals with disabilities in everyday life (UNICEF, 2013).

People accumulate knowledge through beliefs, morals, and rules from family, society, and religion (Rowen et al., 2015). Hence, many individuals base most of their behaviors and feelings on that knowledge. The problem is not with sex; rather, the problem is how people manipulate the knowledge and make judgments regarding the issue (Rowen et al., 2015).

In the health care environment, resistance and barriers affect individuals’ efforts to value themselves as sexual creatures (Rowen et al., 2015). Because of obstacles and resistance, physical disability may alter how a person may give or receive any sexual/intimate behaviors. Thus, individuals with disabilities may have to experiment or perhaps readjust some of their notions of what sexuality means to them. Sexual health needs can be a concern for men and women with physical disabilities and can cause a high rate of sexual distress if not properly addressed (Rowen et al., 2015). Some of the barriers consist of receiving education and knowledge regarding intimacy, relationships, and sexual health issues.

Attitudes About Sexuality and Intimacy

Sexuality and intimacy encompass sexual knowledge, values, beliefs, attitudes, identity, personality development, and individual thoughts as well as spiritual and moral concerns (Tepper, 2015). However, attitudes about sexual behavior and intimacy have brought about discussion and controversy as many people believe that sexual behavior and intimacy are inappropriate conversation topics (Kim, 2011). Furthermore, the topics of sexual behavior and intimacy as they relate to individuals with a physical disability become taboo because of perceptions that individuals with a physical disability are asexual (Kim, 2011).

Sex has traditionally been portrayed as the privilege of White, heterosexual, young, single, and nondisabled individuals. Sexuality as a source of pleasure and as an expression of love is not readily recognized for populations that have been traditionally marginalized in society (Tepper, 2015, p. 7). Society and individuals with physical disabilities should be provided accurate information regarding the joys of sex and the power of engaging in an intimate relationship. Enabling romance and intimacy is a reminder that the pursuit of sexual happiness, regardless of age, gender, shape, or condition of our bodies, belongs to everyone (Tepper, 2015).

Marginalization of Individuals With Disabilities

Another barrier related to sexual education for physically disabled individuals relates to the marginalization of these individuals, which can be seen as a restriction of human rights. Human rights include significant and influential social and economic freedoms that relate to the individual's expression of survival (Blau & Moncada, 2015). People have the right to be equal in freedom, dignity, personal integrity, and self-determination (Blau & Moncada, 2015).

Physical and cognitive activities can encompass a number of areas on a daily basis for a person with a physical disability such as rehabilitation, curiosity, and a supportive framework, along with practical and social intelligence (Blau & Moncada, 2015). Hence, researchers have found that many individuals with physical disabilities are left out of discussions and educational processes regarding relationships and sex/intimacy because they are seen as asexual creatures (Human Rights Watch, 2012). Education on sexuality and disability is lacking, and individuals with physical disabilities want to express their needs and desires for sexual intimacy. By combining the human rights theory and qualitative methodology in the present study, study results may help other researchers to further expand on these findings and also develop a baseline for what is needed regarding sexual education among people with physical disabilities.

Existing Educational Efforts

According to the WHO (2012), sexual education for individuals with disabilities has mostly focused on individuals with intellectual and developmental disabilities, not on individuals with physical abilities. These educational efforts have primarily focused on reproductive issues or sexual abstinence (WHO, 2012). This focus is due to the lack of information and the barriers to health promotion among people with physical disabilities (Smeltzer, 2010). Other researchers have discussed educational materials that are directed toward individuals with spinal cord injuries as opposed to other physical disabilities such as neuromuscular diseases, including MD.

There is a definite gap in the knowledge and education presented to individuals with physical disabilities (East & Orchard, 2014a). For example, Planned Parenthood reaches out to many individuals—men and women, youth and older adults, straight and LGBT individuals, and the developmentally disabled. Yet, the organization has no specific outreach criteria for individuals with physical disabilities. There is definite equality when talking about religious, cultural, and gender considerations (Planned Parenthood, 2017). However, Planned Parenthood provides no information for individuals with physical disabilities.

Some organizations have been shown to be willing and able to help individuals in their human sexuality transitional stages as they fulfill their fundamental human drive for intimacy and desire for sexual fulfillment. These organizations include Planned Parenthood and the Sexuality Information and Education Council of the United States

(SIECUS). These two organizations are pushing forward the concept that comprehensive sexuality education should be more inclusive (Planned Parenthood, 2017; SIECUS, 2017). However, neither of these organizations specifically educate or talk about individuals with disabilities in their educational materials for the public.

Changing attitudes about people with disabilities is a process that may occur through advocacy. Kim (2011) noted that advocacy for positive sexual esteem among individuals with physical disabilities has been driven by the desire for more education and knowledge among individuals with a physical disability who want to increase their sexual esteem. One advocacy strategy is to promote both the recognition of all individuals with disabilities as full members of society and the respect for all of their rights without any discrimination (UNICEF, 2013). Stimulating changes in attitudes and practices of the general public and service providers toward people with disabilities could occur by collaborating with partners such as health care professionals, sex education organizations, and classroom teachers to promote the inclusion of individuals with disabilities into society (UNICEF, 2013). Leadership and advocacy may promote positive social change among individuals with physical disabilities by spurring the development of programs for educating them on their own human sexuality. The major stakeholders can help engage and promote these efforts through various organizations and support systems such as family and friends (East & Orchard, 2014a).

What Is Needed for Sexual Education

Information on sex, sexual health, and sexuality is essential for providing basic knowledge that all sexual beings should have, regardless of whether or not they have a disability. Such information not only addresses basic needs, it can provide the reassurance and guidance individuals need for rediscovering themselves, setting boundaries, and experimenting with their sexual desires (East & Orchard, 2014b). A well-balanced, comprehensive sex education for physically disabled individuals will influence an essential part of their knowledge and self-esteem, especially when promoting self-assurance and intimate personal relationships (East & Orchard, 2014b). Various suggestions for better efforts and approaches for addressing sexual education for individuals with physical disabilities have been made. They range from knowledge and understanding of disabilities among providers and educators to disability-specific sexual education.

Knowledge and Understanding of Disabilities Among Providers and Educators

East and Orchard (2014a) conducted a qualitative study regarding sex education among health care professionals, parents, and individuals with different physical disabilities, including participants with MD. Their consensus was that health care professionals, parents, and individuals with physical disabilities need a greater understanding of the misconceptions about sexuality and disability. This study highlighted that parents, educators, and health care professionals pass the responsibility of sex education to other individuals they believe are more qualified to deliver sex education to individuals with a physical disability. Because of this concept, people with physical disabilities do not always receive comprehensive sex education (East & Orchard, 2014a). Furthermore, without comprehensive sex education consisting of knowledge acquired through family, friends, classroom teachers, or health professionals, individuals with physical disabilities may not be able to attain the skills and knowledge necessary for understanding their own sexual capabilities and making informed decisions regarding their sexual health and intimate relationships (East & Orchard, 2014a).

Esmail et al. (2010) studied perceptions in society and attitudes toward sexuality and disability to explore how social stigma may differ among individuals living with a visible disability compared to an invisible disability. A qualitative approach was used to focus on service providers, people with visible disabilities, persons with invisible disabilities, and the general public. Esmail et al. knew from previous research that the sexual lives of individuals with disabilities are disregarded among society as many in this group are viewed as asexual due to preconceived notions of sex and what is considered natural. Esmail et al. also noted a lack of education and information regarding disability and sexuality among the general public and service providers and recommended further research focused on educating and informing society.

Higgins et al. (2012) used a mixed methods evaluation including pretest and posttest questionnaires and interviews to analyze if a 1-day interdisciplinary human sexuality education program would benefit staff members who worked with individuals with physical disabilities. The study’s focus was on the notion that individuals with physical disabilities have diminished self-esteem, sense of attractiveness, relationships, and sexual functioning (Higgins et al., 2012). The focus also reflected the belief that people with physical disabilities are not satisfied with the quality or quantity of information they receive regarding sexuality from those around them (Higgins et al., 2012). Analysis consisted of comparing the pretest and posttest measures based on questionnaires and interviews, which showed that the 1-day education program significantly increased staff members' knowledge, skills, and comfort level working with people with physical disabilities. Participants in the 1-day program stated they felt more enthusiastic and comfortable about creating a more supportive environment for the individuals they worked with regarding sexual concerns (Higgins et al., 2012).

Some of the articles previously discussed noted individuals with physical disabilities being viewed as childlike. As such, health care professionals and educators often miss the opportunity to provide sexual education because of the childlike perceptions. Many individuals, including parents and health care professionals, often find it difficult to communicate sexuality and intimacy issues with individuals with physical disabilities (East & Orchard, 2014a). Not having this communication can leave individuals with a physical disability lacking awareness regarding intimate relationships, which can result in their engaging in certain sexual practices and experimenting with intimacy without fully understanding their human rights (Kim, 2011). Therefore, it is important to remember to see the individual as a person before becoming focused on the disability. The spotlight should be on what can be achieved opposed to what cannot be achieved in terms of intimacy in relationships (UNICEF, 2013).

Disability-Specific Sexual Education

In their qualitative study on sex education among health care professionals, parents, and individuals with different physical disabilities, East and Orchard (2014a) found that their focus group participants lacked sexual esteem due to the overall deficiency of disability-specific sex education. As previously noted, health care professionals, parents, and educators often find it challenging to address sexual issues with individuals with physical disabilities due to inadequate knowledge or feeling uncomfortable discussing the topic (East & Orchard, 2014a). Because of the misconception that people with physical disabilities are incapable or uninterested in any type of sexual expression, sex education becomes focused on emphasizing safety and sexual abuse prevention, and aspects of healthy sexual development and sexual exploration in relationships are disregarded (East & Orchard, 2014a).

According to McMillan (2012), when offering information and support to an individual with a physical disability regarding relationships and intimacy it is important to remember the following:

- People with disabilities have the same sexual needs of anyone else and may need more time to discuss the issues;
- When giving guidance, check that the person has understood the language you use;

- Avoid making assumptions and being overprotective; and
- Remember every individual has the right to form intimate relationships. (p. 25)

Intimacy Versus Intercourse

Intimacy includes sexuality and sex, but the fulfillment of sex is directly related to the quality of sexual esteem that precedes physical contact. It is the fundamental nature of the caring touch that satisfies when giving and receiving (Rainey, 2011). Unfortunately, many professionals do not recognize that all patients have the same needs and desires for the simple pleasures of touch, intimacy, and sexual expression (East & Orchard, 2014a). As such, individuals with MD may not receive information regarding their emotions associated with relationships, intimacy, and sexual esteem.

The WHO (2015) recognizes that sexual rights are human rights and that sexual health is a core element of general health. Sexual esteem and intimacy require full sensual development. This developmental process usually begins in early childhood and has the potential for continued development throughout life. People’s senses include sight, sound, touch, taste, smell, feelings, and intuition. Intimacy and sexual behavior can be considered an individual’s rights and desires, which are considered fundamental truths but are simple and often ignored when involving people with physical disabilities.

Many researchers have limited their inquiries to exploring sexual activity through intercourse only (Esmail et al, 2010). There is inadequate research regarding sexual behavior, intimacy, sexual esteem, and sexual anxieties among individuals with physical disabilities (O’Dea et al., 2012). People with disabilities desire to be sexually expressive despite the difficulties they may encounter due to disability-related impairments, low sexual esteem, or sexual anxieties (Baylor College of Medicine, 2017). Their negative feelings of sexual inferiority can be conditioned and counseled through proper communication and education regarding sexuality and awareness (Baylor College of Medicine, 2017). Society and individuals with physical disabilities should be provided accurate information regarding the joys of sex and the power of engaging in an intimate relationship. Enabling romance and intimacy can remind people that the pursuit of sexual happiness, regardless of age, gender, shape, or bodily condition, belongs to them.

Summary

In Chapter 2, I provided a review of the literature on sexual esteem, intimacy, human sexuality education, and skepticism regarding sexuality in individuals with MD. In general, researchers have found that the sexual education provided to individuals with disabilities is sorely lacking and that there are a number of reasons for this, including stigma, social mores, and simple lack of knowledge regarding sexuality among disabled individuals in general. Assumptions that sexual education is not needed because disabled individuals are either not capable of sexual activity or have no interest in it are also prevalent. In Chapter 3, I provide a discussion of the study methodology, the rationale for the specific research approach chosen, and detail on participant recruitment, data collection, and data analysis.

Chapter 3: Research Method

Introduction

The experiences associated with human sexuality education among individuals with MD were the focus of this study. An in-depth narrative interview approach was used to explore, discover, and identify what type of sex education experiences and information individuals with MD have received and what they perceive to be their sexual education needs. Two research questions were developed to guide this investigation: What sexual education, if any, have individuals with MD received, and if sexual education was provided, how, if at all, did it meet the individual’s needs? Focusing on these key topics, I invited the participants to share their beliefs, perceptions, and experiences. I asked additional supporting questions and prompted for more detail as needed to achieve the quality of data needed for analysis.

In this chapter, I present the methodology for this study. I begin with discussing the research design and rationale. I also cover my role as researcher, study methodology and instrumentation, data collection and analysis, and issues of trustworthiness. A section on ethical considerations concludes the chapter.

Research Design and Rationale

The central concept of interest in this study was individuals with MD’s experiences regarding the type of sex education they receive and their perceptions of their sexual education needs. As such, a qualitative approach, specifically, a multiple case study approach, was employed for this study as it provides the tools for in-depth investigations of the life experiences of a sample of a particular population (Yin, 2014). By using a multiple case study approach, I focused on both unique and shared experiences of a sample of people with MD regarding a topic that is rarely discussed.

As I considered the design for this study, I determined the research approach that would appropriately address the research questions. In doing so, I identified the strengths and weaknesses of various methodologies and how they related to the research questions. A key strength of qualitative research is that it can be used to determine how participants interpret intangible concepts such as self-esteem. Data are collected in naturalistic settings, and researchers may also determine ideographic causation of a particular event (Ritchie & Ormston, 2013). Qualitative research is useful for studying a limited number of cases in more depth (Yin, 2014), as was the case in present study, and for describing complex phenomena and providing individual case information, which were important aspects of this study.

However, with the qualitative approach’s strengths also come some weaknesses. As they pertained to the present study, possible weaknesses were biased interview responses because of poorly articulated questions and inaccuracies due to poor data collection. Another factor I had to consider in choosing a qualitative approach is that this research method can be time consuming, especially regarding data collection and analysis, as it typically yields a large amount of data. Also, my personal biases and idiosyncrasies could possibly influence the results. Even with these weaknesses, I felt a qualitative approach was the most appropriate for this study as I could address possible weaknesses by having well-articulated questions, formulating a well-planned data gathering and analysis approach, and taking steps such as bracketing and journaling to address possible biases and idiosyncrasies.

My primary objective in using a multiple case study was to investigate and explore information received from participants regarding their perceptions of the sexual education they have received and their sexual education needs. Another reason for choosing a case study design is that a case study can provide detailed qualitative information that may offer insights for future research (Yin, 2014). Furthermore, case studies provide descriptive data that focus on the participants' personal experiences (Hsieh, 2004).

Role of the Researcher

The researcher takes on many roles during a study, including planning, design, development, data collection and analysis, and discussing and sharing study results (Yin, 2014). For this study, I conducted semistructured interviews with the study participants. According to Yin (2014), "Interviews are an essential source of case study evidence because most case studies are about human affairs or actions" (p.113). There are two objectives in interviews: to follow one's own line of inquiry as reflected by the research study's protocol and ask conversational questions of study participants in an unbiased manner (Yin, 2014). In following these objectives, I interviewed study participants by asking friendly and nonthreatening questions throughout the interview process and allowed the participants to respond to the questions in their words, which gave them the opportunity to express their personal perspectives and provide rich, thick data that went beyond the original question.

It was essential that I followed certain guidelines and procedures in these interviews. These guidelines include being a good listener (Yin, 2014). Being a good listener is not only about hearing the participant's words but also listening for how the participant uses the words in different contexts. Being a good listener also means being open minded and adaptive to the situation. Staying adaptive is important because a case study does not always begin or end as anticipated. It was important I kept in mind that changes may come up unexpectedly and that I must adapt for these unanticipated events. These may have included participants canceling, being late, inadvertently stopping the interview, deciding at the last moment that they no longer wished to participate, or adding additional data that was not originally thought to be part of the study but reflected the participants' true experiences. I remembered to stay in tune with my participants as I conducted the interviews and listened for keywords or uncomfortable pauses. This also prompted me to ensure that participants were still comfortable and to take breaks if needed (Yin, 2014).

Using interviews to collect data presumes that participants will provide as much information as possible for the study (Merriam & Tisdell, 2016). I helped to assure sufficient data collection by establishing a level of rapport and trust with study participants and making participants feel as comfortable as possible without being coerced. Interviewing takes time and practice as well as observation and interpretation skills, all of which help to establish adequate trust for participants (Merriam & Tisdell, 2016). Using reliable and efficient strategies to engage participants during the interviews will provide clear and useful quality data for analysis. Without practice, researchers may have weak interviewing skills and procedures, which may cause study participants confusion, anxiety, and discomfort (Merriam & Tisdell, 2016).

The interview process can be demanding and present unexpected challenges (Yin, 2014). Some of these challenges can include unexpected behaviors or responses from participants (Yin, 2014). I addressed these challenges by rephrasing questions as needed. I also employed flexibility regarding the order in which I asked the questions. These approaches allowed me to respond to situations by acknowledging the respondents' emerging worldviews and new ideas on the topic (Merriam & Tisdell, 2016). Asking the interview questions was one aspect of data gathering about which I was extremely careful as the study focus was sensitive, and some aspects may have been difficult for participants to discuss.

I followed an interview guide (see Appendix A) when asking questions of participants, but I was not restricted to asking only the set questions. This approach requires careful wording of the interview questions, putting the questions in a specific order, and also being open to allow participants to add more information or vary their response (Yin, 2014). Using an interview guide also allows for additional probing questions if necessary (Yin, 2014). Participants' time is used efficiently because the interview is highly focused. Finally, using an interview guide simplifies analysis as it is easier to find and compare participant responses (Merriam & Tisdell, 2016).

Avoiding bias is also important as a researcher (Yin, 2014). As I have MD and have had various experiences related to human sexuality education, relationships, and sexual esteem, controlling for biases I might have was essential. These controls included keeping a journal of my thoughts prior to and after all interviews so as to not impart them on participants. I also used bracketing, or identifying my ideas, values, and beliefs and temporarily putting them aside (Merriam & Tisdell, 2016) to address possible biases.

Methodology

Participant Selection

The population for this study was adults with MD. The sample from this population was chosen using a purposive sampling strategy. Purposive sampling was used as it is one of the most cost- and time-effective sampling methods (Research Methodology, 2016). In studies where there are limited numbers of participants and limited resources, it is also the most effective approach for identifying and selecting individuals who meet the research criteria and who are available and willing to participate in communicating their experiences and opinions in a reflective manner (Palinkas et al., 2015).

Participants selected for this study had to meet specific criteria. These criteria were the following: over 18 years of age, diagnosis of a form of MD at the time of the interview, and English proficient. I only interviewed individuals over 18 years of age per my decision. I did not cap the age range, which eliminated age discrimination. Furthermore, it was important to have individuals of various ages discuss their sexual experiences as sexual activity and function are not confined or limited to a specific age (Kalra, Subramanyam, & Pinto, 2011). After careful consideration and review of everything involved pertaining to research with human subjects, I believed it was better to conduct this study on individuals over 18 years of age, especially due to the potentially sensitive subject matter that may be discussed. I only included English-proficient participants because I was the interviewer, and English is my primary language. Furthermore, to narrow the research scope, I decided to focus primarily on individuals with MD as opposed to individuals with cognitive and developmental disabilities or spinal cord disabilities due to the already extensive amount of research on these populations.

There were four study participants. The number of participants was based on other research that has been conducted as well as the ability to assess an appropriate amount of variation represented in the population (Nastasi, Moore, & Varjas, 2004). Furthermore, the sampling strategy for this study supported a smaller sample size (Research Methodology, 2016).

Procedures for Identifying, Contacting, and Recruiting Participants

To recruit participants, I contacted organizations near where I live such as Summit Independent Living Center, Living with Muscular Dystrophy, and the Alliance for Disability and Students at the University of Montana. These are organizations that regularly work with the study's target population and could help locate individuals who were willing to participate in this study. These organizations assisted with participant recruitment by posting flyers in their offices, emailing clients, and posting notices on their Facebook pages. Individuals who responded to these recruitment efforts were given my contact information and advised to contact me if they were interested in participating in the study. When I talked with potential participants, I asked them a series of questions to determine if they fit the study criteria, such as their age, if they have a form of MD, and if they speak English. All potential participants I spoke with met the study criteria.

I provided a detailed description of what the study would entail so potential participants could make informed decisions about participation. I advised them that the study results will be presented to such organizations as Planned Parenthood of Montana and rehabilitation centers, among others, with the hope of providing better information on the sexual education needs of individuals with MD so that programs can be developed to better meet these needs. I also discussed informed consent and advised potential participants that I would provide this form to them prior to commencing the interviews. A letter of informed consent was provided to all participants involved, stating the study was voluntary and confidential.

Instrumentation

I conducted interviews as my primary tool for collecting data for descriptive and explanatory analysis. Using an interview process allowed me to compile and present a description of the situation in its context while explaining cause–effect relationships to discover a common thread or theory. Furthermore, by collecting data through the interview process, I was able to speak with the participants one-on-one using open-ended questions, which allowed the participants to expand on their responses if needed. Finally, using open-ended questions allowed for engaging further with the participants and probing them for further explanations of specific situations. Data sources for case studies also include documentation and archival records, which study participants may have had in the form of sexual education materials they have been provided or instructions from health care providers regarding various aspects of sexual health and functioning. Prior to conducting the interviews, I asked study participants if they had any documents or records along these lines that they would like to share. They did not. Finally, observations are another standard data source for case studies. My observations of study participants during the interviews, which were documented in my interview notes, were also part of the data that I gathered and analyzed.

I used a semistructured interview guide consisting of open-ended questions that I developed. The interview guide was developed based on this study’s literature review, which highlighted the need for further intimacy and human sexuality education among health care professionals, education professionals, students, and specifically those with a physical disability. The interview guide consisted of open-ended questions, which gave me the ability to probe further into participants’ responses. I allowed sufficient time to conduct the interview without overburdening the participants. I estimated spending approximately 60 to 90 min on each interview. Three interviews took just under 1 hr each. The fourth interview lasted a total of 4 hr as it was conducted via text messaging, and the participant had to take numerous breaks due to health fatigue and nursing care.

All interviews were electronically recorded. I also took notes throughout the interviews to remind myself of specifics in such areas as voice and tone. If the interview was face to face, either in person or via Skype, I also jotted quick notes on body language. The exact type of recording depended on where the participants were located. Although my preference was to conduct face-to-face interviews, this was not possible with all participants as they did not live near me and our ability to meet was impeded because of mobility and transportation issues. When in-person interviews were not possible, I conducted interviews via phone and webcam (Skype). Of importance here was ensuring that the interview felt comfortable for the participants and for me. Emphasizing having a safe and comfortable area for the interviews helped participants be more at ease as well as more open with their responses. Interview locations were determined with each participant depending on mobility and transportation issues. The locations determined were private and free of disturbances. All interviews were completed in 3 weeks.

Interview Procedure

As noted, interviews were conducted face to face or electronically via Skype, phone call, or text messaging. Whether in person or remote, it was important that the interviews were conducted in places that were accessible and safe. The participants chose to be interviewed in their homes. One interview was in person; the others were conducted electronically.

Upon determining if the participant would be interviewed face to face or electronically, I then informed the participant of his or her rights as a participant and that he or she could stop the interview at any time and withdraw from the study without any ramifications or questions asked as to why. For interviews that were conducted electronically, I sent the participants a consent form for their signature prior to the interview via email or regular mail, and they returned the form to me prior to the interview. For the one in-person interview, I emailed a consent form for the participant to review, and I brought a consent form for her to sign before moving forward with the interview. Upon receiving the signed consent forms, I again explained to participants that the interview would be recorded and asked if they have any questions or concerns before beginning the interview. I again informed the participants that if at any time during the interview for any reason they wanted to stop the interview and discontinue participation they could without any explanation. I reiterated that we could stop at any time they needed a break for fatigue or emotional issues. Finally, I had emailed each participant a list of resources that they could use after the interview if they felt they needed to. These resources were of various counseling and health care resources that would be little to no cost to the participant. When the participants were ready to begin and had no questions, I began the interviews. At the end of the interviews, I thanked the participants for their time and advised them that they would have the opportunity to review my results before submission to ensure I had adequately represented what they had said. I asked if they had any questions before finally shutting off the recording device. I again thanked them for their time and participation and then exited the interview.

Data Analysis Plan

After all interviews were completed, I compiled the material gathered through the recorded interviews and my notes. All interview recordings were transcribed by a professional transcriptionist who has experience transcribing interviews for research purposes. This individual was asked to review and sign a confidentiality agreement (see Appendix B). Once transcription was complete, I began the coding process. Saldaña defined a code as “a word or short phrase that symbolically assigns a supportive, salient, essence capturing, and evocative attribute for a portion of language-based or visual data” (Miles, Huberman, & Saldaña, 2013, p. 72). Codes are used to categorize similar data that have been collected and enhances the ability to find and cluster related information. This facilitates reflecting on the data’s meaning by using codes as prompts (Howitt & Cramer, 2010; Miles et al., 2013). I used open and axial coding to discover common themes among the participants regarding their sexual education experiences. As noted in Chapter 1, open coding is used to identify, name, categorize, and describe findings from the data that are collected. It calls for reading every word while determining what the data are about and what they reference (Strauss & Corbin, 1990). Holton (2010) noted that the conceptual abstraction of data and its reintegration as theory takes places through coding. Axial coding is then used to determine how the various codes, or themes, relate to each other (Strauss & Corbin, 1990). Axial coding goes beyond descriptive coding and reflects interpretation and reflection on meaning (Merriam & Tisdell, 2016).

This coding approach allowed me to prepare a written structure to make sense of the data, concepts, and themes that were present, as suggested by Janesick (2011). Through this process, I looked for empirical assertions and narrative vignettes to support claims, connect all data collected to my analysis and interpretation while including interpretive commentary as it related to the data, and form a complete write-up that detailed the data and the results (Janesick, 2011). Data gathered from each study participant were analyzed both by the individual case (within-case analysis) and between cases (cross-case analysis or synthesis; Vohra, 2014). This approach is the heart of multiple case study research as it is a comparative approach (Goodrick, 2014). Thematic analysis was used for within-case analysis. The themes generated during within-case analysis were then used for thematic analysis across the cases.

Issues of Trustworthiness

Issues of trustworthiness in qualitative studies include credibility, transferability, dependability, and confirmability (Merriam & Tisdell, 2016). I addressed credibility and dependability by having more than one possible data source (interviews and observations during the interviews) and by member checking the data with study participants. As noted, participants had the opportunity to review my analysis of the findings and make any changes or corrections they deemed necessary so that their views were correctly reflected. Transferability was addressed by providing thick, rich descriptions of the participants’ experiences and by having some variation in participant selection such as age, marital status, etc. I addressed confirmability by being attentive to any bias regarding data analysis, interpretation, and participant selection. To be aware of my own bias, I kept a reflective journal before and after conducting the interviews. Using reflective journaling “enables the researcher to re-assess (if necessary) his/her behavior, attitude, question wording, or other aspects of data collection for the purpose of mitigating distortions in the data” (Roller, 2017, para. 3). As previously noted, I also used bracketing to identify and set aside my personal beliefs and biases.

Ethical Considerations

When conducting research, ethical considerations are a top priority not only to protect the researcher but also the participants. Ethical guidelines are followed for the benefit of all involved. These guidelines protect the participants’ rights and the researcher as well as anyone else who may assist in the study (National Organization of Human Services, 2015).

Treatment of Human Participants

My primary function as the researcher was to be honest, respectful, and ethical when interacting with study participants or others involved in the study such as administrators of the organizations I contacted or perhaps personal care attendants who may help participants set up for the interview process. A key element in protecting participant privacy and confidentiality is having them review and sign informed consent forms. This form detailed this study’s intent and nature and the interview procedure. It also stated that the study was voluntary in nature and the participant could withdraw from participation at any time. Details on study risks and benefits and privacy and confidentiality were also provided. I received formal approval from Walden's institutional review board (IRB) regarding the participation of human subjects in research and the guidelines and protocols I established for this study.

Anonymity and confidentiality of study participants were further ensured by how the data were handled during analysis. Individual identities were separated from the information provided by deleting all identifiers from the data. All participants were given pseudonyms. I was the only person involved with this study to know the participants' identities. I used a transcriptionist for transcribing the interviews, and this individual signed a confidentiality agreement.

Participant comfort during the interviews was a primary concern. I worked with the participants to identify interview locations they could easily access and that afforded them the privacy necessary for responding freely to interview questions. During the interviews, I asked participants if they felt comfortable in the interview setting and, if not, what I could do to make them feel more comfortable. I gave participants ample opportunities to stop the interviews if they needed a break or felt they needed time to collect their thoughts. At no time did I encourage them to continue with the interview until they stated they were ready to continue.

Some of the interview questions prompted undesirable memories in study participants that could have led to further emotional distress. None of these memories resulted in any participants discontinuing the interview. When asked, all participants stated that they were doing okay. We also took breaks when needed. I did have to remind one participant that it was okay to not answer a question that was asked and that she could discontinue the interview if she wanted. She stated that she was okay and that the topic was just hard to talk about. We then took a break. I asked her again if she wanted to continue and gave her the option of stopping. She wanted to continue. I had referral resources on hand that I could offer and provide to participants. Some of these referral resources consisted of names and numbers of counselors and organizations specializing in disability and sexual health. These resources were also emailed to all participants along with the consent form. I reminded all participants about these resources before and after the interviews and advised them that they could self-refer to these resources.

Participants experiencing emotional distress could have led to ethical concerns for which I had to be prepared. The primary objective is to continually have respect for the individuals involved, which would include following the codes and regulations detailed by the National Institute of Health (NIH; 2013). These consist of three main aspects: respect for persons; beneficence, which includes doing no harm and maximizing possible benefits and minimizing possible harms to the participant; and justice, which requires that I treat all individuals fairly and equally (NIH, 2013). I followed all of this guidance in conducting this study.

Treatment of Data

As previously noted, all identifiers were removed from the data to protect participant anonymity and confidentiality, and pseudonyms were used instead of real names when writing the study results and conclusions. A password-protected laptop computer was used for data analysis, and only I knew the password. All data gathered, both written and electronic, will be kept in a locked file cabinet in my office. I am the only person with access to the file cabinet. All data will be destroyed after 5 years in keeping with Walden IRB requirements.

Summary

Chapter 3 was a discussion of the methodology for the present study. I provided details on the research design and rationale and discussed my role as researcher. I also covered study methodology and instrumentation and data collection and analysis plans. This was followed by a section on issues of trustworthiness. I concluded with a discussion on ethical considerations. In Chapter 4, I present the results from data collection and analysis.

Chapter 4: Results

The purpose of this qualitative multiple case study was to explore the unique challenges that people with MD face regarding education about sexual pleasure and intimacy. Data were drawn from interviews with four participants with MD, two men and two women, about their perceptions of their sexual education needs and the adequacy of their sexual education. There were two research questions: What sexual education, if any, have individuals with MD received, and if sexual education was provided, how, if at all, did it meet the individual’s needs?

This chapter contains eight main sections and several subsections. The sections that present results are organized by research question. The first section describes the setting of data collection. The second section details participant demographics. Data collection is explained in the third section, following by a section detailing data analysis. The fifth section provides evidence of trustworthiness and authenticity.

The sixth section presents the results. Results are organized in three subsections. A theme summary is presented in the first subsection. In the second subsection, results for RQ1 are presented. The third subsection presents results for RQ2. The seventh section presents the participants’ final thoughts. The eighth section is a summary.

Setting

I conducted this study from Missoula, Montana. Because of the logistical issues related to my being able to travel and participants’ inability to travel due to distance and health care needs, I only interviewed one participant face to face. The other three participant interviews were conducted via Skype, phone, and text messaging. All interviews were conducted at a time determined by the study participants. All participants were in their homes at the time of their interview, which were quiet and private settings in which the participants felt comfortable and safe.

Demographics

Participant demographics are presented in two parts. The first part is an introduction to the participants via their psychological and emotional perspectives on intimacy and healthy relationships. I believe their perspectives on these fundamental human needs is the most accurate way to introduce each of the individuals who made this study possible. The second part is an introduction to each participant's physical experiences living with MD. The demographic characteristics of the four study participants are listed in Table 2 by pseudonym.

Table 2

Demographic Characteristics

Pseudonym	Gender	Age	State of residence	Heard about study
Zoe	Female	26	Maryland	Facebook
Molly	Female	32	Montana	Flyer by email
Jim	Male	43	Montana	From a friend
Randy	Male	46	Kansas	Wife read about study on Facebook

Psychological and Emotional Introductions: Participants' Descriptions of Intimacy and Healthy Relationships

All of the participants had well-developed views of intimacy and healthy relationships. They saw the two as closely related in that they practically addressed them in the same breath. In keeping with participants' views of intimacy and relationships as linked, this section presents comments on the two topics together.

For example, Jim described his views of intimacy and healthy relationships in parallel terms. For Jim, intimacy means "Being close with someone, human contact, trust, and feeling a spiritual connection with someone. Physical pleasure." Along the same lines, Jim believes that a healthy relationship involves "Trust, honesty, understanding, commitment, hard work, and forgiveness. Love."

Molly also saw intimacy and healthy relationships in a similar light, but she realized one was possible without the other.

> Intimacy is being close to somebody and holding and touching, just being together. Yeah, I guess, yeah, I think [intimacy is the same as having a sexual relationship]. No, I guess not. I think you can be intimate but not have sex. A healthy relationship is a relationship that makes you happy, and you're supportive of each other, and have good communication, not controlling, just letting each other be who you are.

Randy echoed Molly’s point that people in healthy relationships do not try to control each other. They want what is best for each other. Randy’s description of intimacy reflected his deep love for his new wife, Cindy.

> To me, intimacy is when two people get to know each other deeply, to know how each other works and how they think. When you become truly intimate with someone, you start reading their mind. It’s not even that you’re trying or that the other person is trying. You just get so accustomed to one another and how you think and act, thoughts and mannerisms. It kind of becomes second nature. You just know when to expect.
>
> Then, you know, love this person. You love them because you choose to spend the time to get to know them that way. It doesn’t mean that you necessarily like every single thing about them. I believe in letting other people be, you know, who they are, including my wife. I want her to be able to be whatever person she wants to be. In my mind, when you choose to get to know someone and basically tie your lives together, it involves sex. But it’s much, much more than that.

When describing healthy relationships, Randy reiterated his views on wanting for the other person what the other person wants for himself or herself. His words again show that most of the participants did not separate intimacy from healthy relationships.

> I kind of don’t know what to say. In a healthy relationship, you love the other person very much and you want them to be who they want to be, and want them to be able to realize whatever dreams. You know, I can’t . . . I can’t make Cindy’s

> dreams come true. She can’t make my dreams come true. But I can be there and be her support. I can . . . I can help in certain ways, everything from what we can do physically or financially to just emotionally to support it with a whole range of support. But, the whole idea is that [in] healthy relationships, you want the other person to be happy. If you can’t make them happy, but you want them to be happy—if it’s possible.

In contrast, and reflecting the only discrepant case on this topic, Zoe, the most physically able and sexually active of the participants, did not see intimacy as something distinctive.

> Yeah, so, I think intimacy is not something really special. Maybe it’s a generational thing. I don’t know. I think of intimacy more as closeness. Personally, I don’t see intimacy outside the context of love. I mean, I have had plenty of one-night stands.

However, Zoe had the same views as Randy and Molly that partners in healthy relationships are free to be themselves.

> Oh gosh. Something that is so typical, where people can be honest and committed and devoted to each other, where one person is not being ignored or restricted. Yeah, I think it can look plenty of different ways. I don’t think there is necessarily a speed with which your relationship should develop or certain outlines you should get to at [certain] times. I think it is just really when two people can develop on the same page.

Physical Experiences Living with Muscular Dystrophy

The participants shared the common experiences of living with MD. MD is a progressive disease. This section introduces the participants in terms of two inextricable features of their lives, then and now: their age when their symptoms first emerged and the nature of those symptoms and the adult lives they lead today. These data are summarized on Table 3. Zoe has Charcot-Marie-Tooth (CMT) MD. Molly and Randy both have spinal muscular atrophy type 2 (SMA2). Jim has Duchenne MD.

Table 3

Disease Characteristics

Pseudonym	Type of muscular dystrophy	Age at onset	Age at diagnosis
Zoe	Charcot-Marie-Tooth	5 years	5 years
Molly	Spinal muscular atrophy type 2	Birth	10 years
Jim	Duchenne	3 years	5 years
Randy	Spinal muscular atrophy type 2	Unknown	18 months

This section expands on the psychological and emotional introductions presented earlier to help readers get to know the person behind the diagnosis. As is argued in this chapter, each participant is not a disease first and a name second. Instead, each participant is first a person who has a disease. The following is also included to give greater depth to later sections on the nature of participants’ sexual education and subsequent sexual lives. Zoe and Randy lead rich sexual lives. Molly and Jim do not.

Zoe was diagnosed with CMT. CMT is a degenerative nerve disease that develops from a group of hereditary disorders that damage nerves in the appendages (MDA, 2017a). Symptoms include hammertoes and high arches, decreased muscle size and strength, and diminished sensation. (The latter symptom of diminished sensation emerged as a major role in Zoe's sex life.) CMT usually appears in adolescence or early adulthood. Primary approaches to treatment include physical and occupational therapies. Medications may reduce pain.

Zoe described her experience with CMT as a gradual decline. However, unlike the other three participants, she does not use a wheelchair or a walker. As to when her symptoms started to emerge, Zoe was a little vague:

> My best guess, probably I started showing symptoms at age 5. My whole family, well, a lot of family members, have it. So, I imagine they would have brought me to a doctor at that point. So, I walked normally and had normal function until age 5. And then—I don't really remember it—I started losing muscles in my calf. So, I started to drop foot more and more. It really only affected my feet at the beginning, you know, my leg to my foot. I ended up going to [unnamed children's hospital] and getting braces when I was in elementary school. My feet started turning to the exterior side and I was hopping on that side, which was painful. I had surgery at age 11, but that didn't work. It just got worse. I was 13 [when I] stopped wearing braces and got my ankles fused.

> My hands were not affected until the last couple of years. I’ve lost some muscle, like, dexterity. I can’t—I don’t know how to explain it—because the rest of my family, their hands are very different. They can’t extend their fingers out. They can only flex them. I can extend my fingers, although it’s just above the muscle and between my thumbs and my fingers. I don’t exactly know, medically, what’s on with that, but it makes fingertip buttoning difficult. Last year I tried to pick up small things, like coins and paperclips, [or] turning light switches and that kind of stuff. I couldn’t do that.

Molly and Jim both have SMA2. There are four types of SMA (1–4), with symptoms varying along a continuum from mild to severe. Atrophy is related to the presence and amount of survival of motor neuron (SMN) protein in nerve cells associated with motor activity (MDA, 2017d). Higher levels of SMN protein are associated with later onset and milder symptoms. In type 2 or intermediate SMA, symptoms typically emerge in babies ages 7 to 18 months. They learn to sit up by themselves but cannot stand or walk without assistance. Respiratory complications are a continuous threat.

Despite sharing the same disease and being similarly bound to wheelchairs, Molly and Randy lead very different lives. Molly said her MD was present from birth. But her two primary symptoms did not emerge right away. One, she did not crawl. “I just lied on my bottom, and I never walked when I was a baby.” Two, she had many respiratory issues as a baby. She mentioned frequent bouts of respiratory syncytial virus and pneumonia when she was older. “But mostly not crawling. I think I sat up all right. I don’t know when I rolled over.” Molly described her SMA2 as a “progressive neuromuscular disease.”

> So, my muscle strength has gotten worse over time. It also affects my breathing because the muscles around the lungs are really weak. So that’s why I had a lot of cases of pneumonia, so I’ve got to be put on oxygen 24/7 for 2 years now. So, it has mostly affected my breathing. I’ve been in a power wheelchair since probably kindergarten. No, excuse me, just a push chair when I was in kindergarten. So, I’ve been in a wheelchair since the age of 6.

Although Molly had several symptoms, she was not diagnosed until about age 10 years. Although she has sensation in her legs, they cannot bear her weight. She has good motor skills with her hands. “I have good hand function. I can write and type. I can do some self-care. I can feed myself. I can wash my face and brush my teeth. That’s really about it. I need help with everything else.”

Randy was diagnosed with SMA2 at age 18 months. He described what happened after doctors thought they had misdiagnosed him.

> The doctors actually got it right. They diagnosed me with SMA, basically type 2. But at the time they believed that I was more or less [dead], so they told my parents that I would probably die somewhere around the age 2, maybe 3, or something. When I didn’t die, ironically, the doctors figured they got the diagnosis wrong and changed it around. They thought it was a muscular

> dystrophy but a different type. Anyway, it eventually came back to the fact that I did have SMA like they thought.

Randy marveled how advances in modern medicine keep people from dying from "things that they used to die from." He gave the example of surviving double pneumonia when he was just 5 years old, although he "very nearly died. It was only the medical technology at that time that saved my life. You know, if I'd been born even 10, 20 years earlier, I probably wouldn't have survived." Randy described his MD as follows:

> For a person that is not familiar with it, SMA basically just means I have very weak muscles, particularly as it goes to my extremities. So, I never walked. I did crawl as a baby. But I didn't walk. I was always, you know, quite weak. My lungs are somewhat weaker than the average person, so things like respiratory infections and what not can be more difficult.
>
> So, for a person with SMA, I'd actually say I am quite fortunate. I don't have as many problems as a number of people at my age. In fact, there are a lot of people my age who are on some sort of ventilator at this point. I'm not. I'm . . . I'm really happy about that. But I do require assistance going to and from a chair, getting dressed, bathing. I do eat on my own but yet still with some difficulty. I have to, you know, get the table at just the right height, get the chair kind of just the right way and everything. I work. I'm a software engineer. I write software. I work for [company name deleted].

As a software engineer, Randy has a lot of independence and has been very successful. Technology lets him, as he put it, do the jobs anybody else can do. “It’s been great. I work. I have my own house. I drive a car. I use a joy stick to control the steering and gas. I do things just like anyone else.”

However, there are things Randy does not do like everyone else. For example, he is in a wheelchair. He cannot stand to do transfers between his wheelchair and his bed. He said he is small enough for most of his health care providers to pick him up and physically move him from place to place for transfers.

> I weigh about 70 pounds. I do actually have a lift. It’s not the floor lift. It’s the one that has the bar. I haven’t had many occasions where I had somebody that really wasn’t able or comfortable lifting. For the most part, I’ve had people just lift me. But I am basically dead weight. I don’t have any way of really providing any assistance to do anything.

Another reality is getting comfortable in bed. Randy needs help to roll over in bed, which means:

> I really can’t move when I’m in bed, generally. I try to lay and get into a reasonably comfortable position so that I won’t have to move. I had better be pretty comfortable because that’s where I am going to stay all night long. There have definitely been times in my life where there was nobody else around and I would have an aide come to my house, which now, because of my job, I pay for on my own. I have no assistance from the government or anyone else.

The final participant, Jim, has Duchenne MD. This is an inherited disorder that typically involves progressive muscular weakness in boys, although girls can be carriers and mildly affected. Symptoms of Duchenne include a waddling gait, big calves, falling down frequently, trouble getting up, trouble running, and learning disabilities. There is no cure. However, medications like corticosteroids and physical therapy can mitigate symptoms and improve the quality of life (MDA, 2017b).

Jim said his symptoms emerged around age 3 years and that he was diagnosed around age 5 years. He is in a wheelchair and described how his disability affects his daily life as "a gradual decline. I can't be left alone for more than 10 min and I'm ventilator dependent. I'm tube fed through a G-tube, and I need home nursing care. I'm basically a quad."

Data Collection

Two men and two women participated in this study. The participants were provided a detailed description of what the study would entail and an informed consent form. I reviewed the study details and consent form with the participants. I advised them that their participation was voluntary and that they could withdraw at any time before or during the research process. After this review, I provided the participants a list of organizations that can provide more information on sexual education needs of individuals with MD.

Each interview was conducted in a private, quiet, safe, and mutually agreed upon location. An interview guide consisting of open-ended questions was used during each interview. All interviews lasted 60 to 90 min. How the interviews were conducted depended on each participant’s physical ability. As an example, one interview was face to face; another was conducted via texts. The interview conducted through texting took longer than the others due to fatigue and the study participant needing nursing care during the interview. Throughout the interviews, I continually checked in with the participants regarding their physical fatigue and emotions, and I reminded the participants they could take a break if needed.

All participants granted consent for audio recording their interviews. Before starting each interview, I again reviewed what to expect during the interview process, informed the participants that their participation was voluntary, and reminded them that they could terminate their participation at any time. Finally, before starting the interviews, I also reminded the participants that they could take a break at any time and if at any time they felt overwhelmed or anything triggered a memory I would give them a list of organizations that could provide free- to minimal-charge services regarding varied MD issues, including counseling. All interviews went well, and all participants completed the interview process.

Data Analysis

I followed eight steps in analyzing the interview data. In the first step, I conducted the interviews and had the recordings professionally transcribed. In the second step, I read the transcripts repeatedly to thoroughly familiarize myself with the context and content of the material and begin coding. In the third step, I coded the data. In open coding, I assigned categorical labels until every passage was coded as either pertinent to answering a research question or an emergent theme. I repeated Steps 2 and 3 until the data were saturated with codes. In the fourth step, I organized the open codes in the process of axial coding by drawing connections between the open codes and further fleshing out themes. In the fifth step, I organized emergent themes further by using induction to label them as the overarching theme or a main theme. In the sixth step, I used selective coding to identify representative excerpts. In the seventh step, I reduced the data to a summary text. In the eighth step, I labeled passages as confirming or discrepant.

All of the study participants used verbal crutches to varying degrees during their interviews. However, two participants used verbal crutches excessively, primarily the crutches of “right” and “you know.” Verbal crutches were inserted from one to several times per sentence; instances of the latter tended to obscure the point the participant was trying to make. Therefore, crutches were removed from most of the direct quotes used in this chapter in the interests of clarity, except when including them gave meaning to the comment (e.g., by illustrating a rising anxiety level).

Evidence of Trustworthiness and Authenticity

Providing credible information about the status of sexual education for people with disabilities in a sensitive, rigorous, and transparent manner was a key focus of this study. Sensitivity was maintained during all contacts with study participants. For example, with respect to personal comfort during the interview, I asked all participants at least twice if they would like to stop and take a break from the discussion. Further, with respect to psychological and emotional comfort during the interview, I took particular care to focus my questions and prompts on the nature or adequacy of their sexual education in order to avoid asking potentially embarrassing questions about their sex lives. I purposely employed this indirect interview strategy in the interests of maximizing participant comfort and eliminating leading questions. The results showed that all four participants eagerly volunteered to share intimate details, although some were more willing to share than others. This suggested that my indirect interview strategy was an effective approach.

The four cornerstones of trustworthiness in qualitative research are credibility, dependability, transferability, and confirmability (Merriam & Tisdell, 2016). Each aspect is considered next as it pertained to the trustworthiness of the data and analysis. Credibility is the qualitative counterpart to internal validity; it was established in the current study with the strategies of extended contact with participants through in-depth interviews and subsequent member checking, data saturation, and ongoing reflexivity. Dependability is the qualitative counterpart to reliability; it was established in the current study through extended participant contact, data saturation, and reflexivity. Credibility and dependability were initially addressed during participant selection by ensuring that the participants represented a range of demographic characteristics (e.g., age, marital status, social life, type of MD, etc.). In addition, all participants were encouraged to provide any documents that could inform the study’s purpose; none were provided.

During the interviews, I managed reactivity by using a semistructured interview guide and remained aware of how I managed my potential influence on the participants. Using the interview guide and conducting interviews over Skype helped minimize leading nonverbal cues. During the interviews, I also often stopped to verify the participant's meaning, a form of immediate member checking. I did not interrupt participants when they were speaking. Once the interviews were complete and the data transcribed, formal member checking was also employed. That is, participants reviewed the transcriptions of their interviews and were invited to make any changes, additions, or retractions necessary to increase the veracity of the data. All four approved of the transcripts as accurate, and no changes were made. This step increased transparency. Using the indirect interview strategy and the resultant eagerness of all four participants to voluntarily share intimate details were further reflections of credibility.

My personal familiarity with MD and a sex life as a wife (and mother) made it critical that I identify my biases and bracket them during interviews and analysis to the greatest extent possible. Researchers cannot completely bracket their thoughts and ideas from qualitative data analysis (Gibbs, 2011). However, I practiced reflexivity throughout (i.e., during data collection and data analysis) to minimize faulty reasoning based on personal judgment, preconceptions, or biases. The aim of my efforts to be adequately reflexive and to minimize threats to the study's validity was a thorough understanding of my personal preconceived notions and assumptions about sexual education and people with disabilities. In effect, I did a self-study, and I documented the results of my self-study in a reflective journal. Regular review of my journal helped me reassess my behavior, attitudes, wording of interview questions, and other aspects of data handling in the interests of mitigating distortions in the data (Roller, 2017).

Transferability is the qualitative counterpart to external validity. It was established in the current study by ensuring variability among participants during the participant selection process. It was further addressed by presenting thick, rich descriptions as evidence.

Confirmability is the qualitative counterpart to objectivity. It was addressed by being attentive to bias in participant selection and data interpretation. Further, it was established through reflexivity.

Results

Results are presented in three subsections. First, a theme summary is presented. Second, results for RQ1, extent of sexual education, are presented. RQ1 results are presented in two parts (sex education class and sex education from health care providers). Third, results for RQ2, adequacy of sexual education, are presented. RQ2 results are presented in five parts (did sex education classes meet individuals' needs; sexual education class discussions of intimacy and relationships; first dates, relationships, and sexual experiences; impact of MD on relationships; and masturbation).

Theme Summary

Figure 2 shows emergent themes as a schematic, which illustrates their relationships to one another. The overarching theme was sexual silence. Figure 2 shows it as the central theme. This theme reflected the absence of participants’ discussions with parents, physicians, and health care providers about anything associated with sexual education or the role of sex in the lives of people with disabilities. Evidence for sexual silence underscored the majority of the participants’ comments, which revealed several forms of sexual silence. The gist was that the participants had to find out about sex for themselves. The evidence shows that some did. Others did not. But everyone wanted to.

The overarching theme was reinforced by five specific main themes (see Figure 2). One main theme referred to experiences with general sexual education (RQ1); the gist was that participants had a basic exposure to sex education with other students in the form of the essentials of reproductive biology. A second main theme pertained to the level of the adequacy of sexual education (RQ2); the gist was that the basic sexual education was inadequate.

The three other main themes were not conceptualized as occurring in any specific order. A third main theme was that the participants were on the outside looking in when it came to intimate relationships. Whereas all of the participants had strong opinions about the roles of intimacy and healthy relationships, their comments revealed a divergence of actual experience. Specifically, two participants, Zoe and Randy, have sex lives. Two participants, Molly and Jim, do not; they are on the outside looking in.

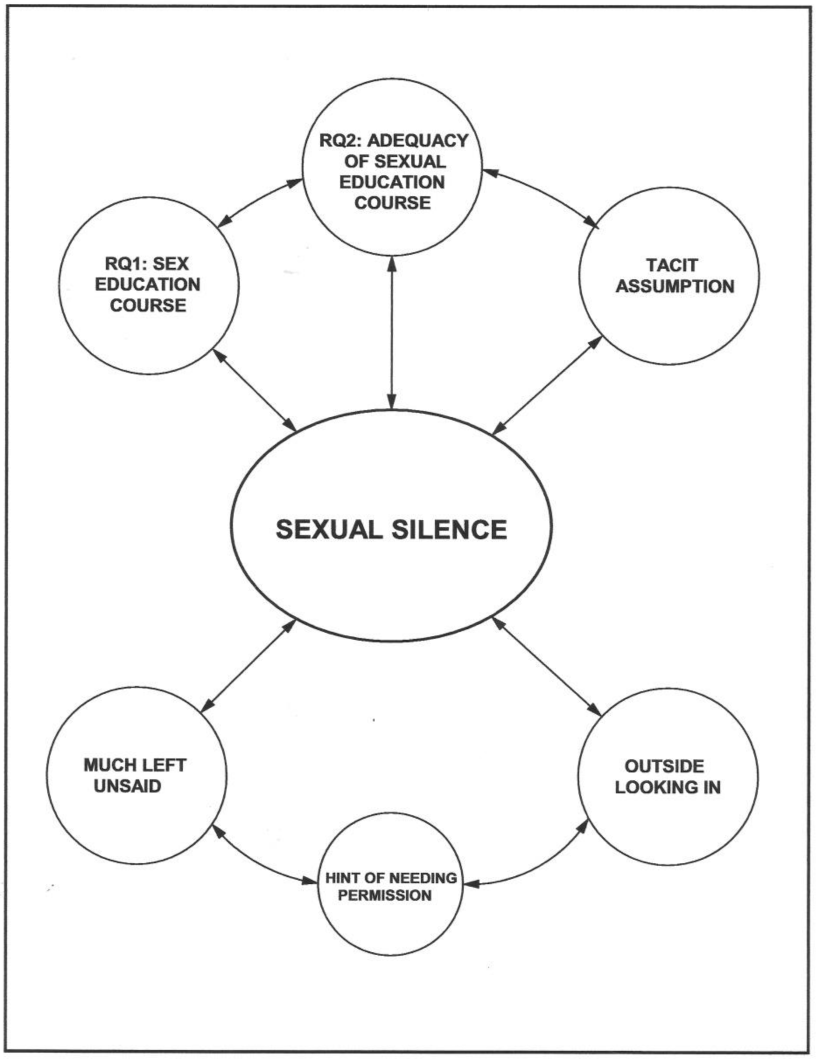

Figure 2. Schematic of themes.

A fourth main theme was labeled much left unsaid. Evidence from the narratives strongly suggested that most of the realities of sexuality remained unstated and unexplored. The fifth main theme pertained to the tacit assumption on the part of health care providers as well as parents that people with MD are disinterested in having sex, being in love, and having fulfilling relationships.

The smallest circle on the bottom of Figure 2 refers to the subtheme of a hint of needing permission to have (or consider having) a sex life or intimate relationships. This idea corresponded to the main themes of much left unsaid and being on the outside looking in. All participants expressed their feelings of inadequacy in terms of intimate relationships. They did not know who to go to for resources to get their questions answered, which resulted in their feeling alone and left out.

Research Question 1: Extent of Sexual Education

RQ1 asked what sexual education, if any, have individuals with MD received? The interview questions related to this question focused on discovering whether the participants received basic sex education as well as any guidance about sexuality or sexual dysfunction traced to their disease and/or changes in their sexual capacities based on the progression of their disease. A caveat was that participants were discussing sexual education classes they had attended 10 to 30 years ago, given their ages. Responses are divided into the class itself and information from health care providers.

Sex education class. The gist of the participants’ comments was that they had all attended a sex education class with the other students during middle or high school that covered basic reproductive anatomy and biology. Jim had a standard human sexuality education by attending “sex ed in health classes with regular students.” He recalled that the class covered biological reproduction, safe sex, and birth control.

Like Jim, Randy’s sex education class was in middle school and was the same one that the other students attended. It too covered the basics of anatomy and reproduction. “I think we had human health class [in] seventh grade. They [addressed] various things about health, you know, the right diet. But obviously there was the section on human sexuality when they talked about sex and reproduction.” Zoe estimated that she attended her sexual education class sometime in late elementary school or middle school because it was tied to teaching students about female menstruation. “Probably we started learning about periods and puberty when I was in fifth grade. I remember vaguely some sex in middle school and my parent talked to me about it.”

Molly’s sex education class experience was slightly different. She too received the standard education about human sexuality in high school in “just the health class,” with the “boys and girls together.” However, the primary difference was that the class Molly took touched on intimacy and relationships “a little bit,” making Molly the sole outlier whose sex education class included references to relationships and intimacy in addition to basic reproductive biology. But like the other participants, Molly recalled that “it was more about anatomy.”

> I remember talking about the menstrual cycle, the body parts of the male and the female. I think they talked about contraception (I can’t remember that). They covered things like birth control, and reproduction, and anatomy. They didn’t really talk about like [sexual] positions or anything.

Sex education from health care providers. Most students attend some type of sex education class. But unlike most students, the participants in this study were in regular contact with health care providers due to their disabilities. However, they received little if any sexual education from the countless providers with whom they had contact.

This conspicuous absence may have been evidence of a tacit assumption on the part of health care providers that people with MD are disinterested in having sex, being in love, or having fulfilling relationships. Behaviors and attitudes that reflected this tacit assumption suggested it as a main theme. The following section also contains evidence of the main theme of much left unsaid.

For example, Jim had never discussed his sexuality, intimacy, or relationships with any of his health care providers because they never broached the subject with him. This is evidence of the main theme of much left unsaid. Jim said he that would have appreciated his health care providers speaking more openly to him regarding his sexual health. However, Jim did not broach the subject of sexuality with his providers. It is hard to know if this was because he is characteristically succinct, uninterested in intimacy, or did not believe that intimacy or love could happen to him. In any case, Jim was terribly discouraged as he is optimistic about everything but relationships and has become very frustrated over time. Jim said, “I’ve always had a positive outlook. Self-esteem has never been a problem. But it’s been frustrating and difficult, and I do become depressed, so I guess my self-esteem goes down.” This is an example of the subtheme associated with the main theme of much left unsaid, that of a hint of needing permission. Persons with disabilities depend on help from others for some, most, or all of what they need. Because of some level of inescapable dependence, it may be that some people with disabilities also depend on being told and reassured that sex is natural, their feelings of sexual desire are normal, and that intimacy is a possibility, more so than people without disabilities because everyone needs some information and reassurance about the need and desire to be in an intimate relationship.

Why did Jim not broach the subject of his sexual needs with his health care providers? When prompted as to whether his reticence related to his own comfort discussing his sexual needs or because he did not have any questions, Jim admitted that it was “a little of both.” He conceded that if he were to open a discussion about his sexual needs with his health care providers, “I think one of them would answer me if I asked.” But he has never opened that discussion. Nor did he elaborate in this portion of his interview. This was evidence of the theme of much left unsaid, this time in the form of reciprocal sexual silence. It also may have been evidence of a tacit assumption on the part of health care providers that people with MD are disinterested in having sex, being in love, and having fulfilling relationships.

Molly’s doctors and other health care providers have also never talked to her about any type of sex education. She too experienced a type a sexual silence. “I’m trying to remember when I had a pediatrician. No, I don’t think he ever did [mention sex]. I just relied on my info from school. And then at the university, I took the human sexuality class."

Molly noted that her current physician assistant asked her if she had an active sex life at one point. But the context of the question was pertinent: At the time, Molly was seeking ob-gyn services to find out why she was hemorrhaging.

> Yeah, my PA, I think, did [ask if I had an active sexual life]. But they never really talked about [sex] because I told them I was not sexually active. I never really talked about contraceptives until I had issues with fibroid in my uterus. I saw an ob-gyn for the first time about it because I was bleeding all the time, heavy menstrual bleed. I did try a progesterone shot because they said that would slow down the bleeding and eventually stop, but I had to get that every 3 months. So I had three shots. But I was still having blood loss and blood clot sometimes. I ended up needing four transfusions of blood because I got too anemic. I had tried another form of progesterone—that didn't help either. I don't know why it didn't work on me. I don't know if the disability had anything to do with it or just the way I am [or how] my hormones work. I eventually decided to have a hysterectomy.

After Molly told her health care providers that she was not sexually active, they did not talk to her further about sexuality or any related topics. That was just the end of the discussion, evidence of the overarching theme of sexual silence. Molly's disclosure was also evidence of the main theme of much left unsaid. Failure to broach the topics of intimacy or relationships also may have been evidence of a tacit assumption on the part of health care providers that people with MD are disinterested in having sex, being in love, and having fulfilling relationships.

Zoe also denied getting any information from her health care providers, more evidence of the overarching theme of sexual silence and the main theme of much left unsaid. She said that no one had ever talked to her about relationships, intimacy, or the things that could happen to her body during sexual encounters, either in the sex education classroom or medically “outside the context of ‘Are you on birth control?’” Zoe did not complain about this in the interview, but her comments revealed the pain and confusion that sexual silence can create.

> I guess like they couldn’t have necessarily known. But I would have definitely appreciated finding out from a health care professional instead of just finding out on my own for a long time. It’s just been [only] the past year or so that I’ve come to be really comfortable with how disability affects us. So, I’ve been living with the whole active symptoms for like 7 years or so. It would have been nice to know about this.

At another point in the interview, Zoe said she never wondered how her disability may have influenced her sexuality. Zoe approached her sexuality by embracing her family’s strong can-do attitude:

> Anything I found out, I found out on my own. I come from a family who, if you want to do something, you do it and you succeed, and if it’s something that I was unable to do, [it was] what I was not allowed to try.

Some minutes later, Zoe illustrated the main theme of sexual silence in stating that her family did not talk about sex. She described her mother’s candid approach to sexual education.

> It’s really funny actually—my Mom treating the subject. She came home when I was 11. She like threw me a paper bag full of condoms and threw one to my sister too (she doesn’t have muscular dystrophy). And I was so upset. I was, like, why are you giving this to me? And she was, like, “Oh well, the 11-year-old needs to know about sex so I figured that you will be safe.” I was so bewildered by it. I still remember.

Her mother’s candid tutorial in sexual education hit Zoe hard, and the memory stuck with her because it made her feel invalidated. “Like I was an object and she was already telling me that I would never have anybody who would want to be with me sexually, so I might as well get used to it at a young age.” This disclosure was more evidence of the theme of much left unsaid, including how to practice safe sex.

Research Question 2: Adequacy of Sexual Education

RQ2 asked if sexual education was provided, how, if at all, did it meet the individual’s needs? The following sections show that the answer to RQ2 is an emphatic no. Sex education did not meet the participants’ needs. It was woefully inadequate.

The first section presents excerpts from participants’ disclosures on how they tried to get their needs met despite the inadequacies of sex education. This section is followed by four sections that provide more detail related to RQ2: Sex Education Class Discussions of Intimacy and Relationships; First Dates, Relationships, and Sexual Experiences;, Impact of MD on Relationships; and Masturbation.

Did sex education classes meet individuals’ needs? The consensus was that the sex education classes did not meet individuals’ needs. All participants took their own paths to get these needs met. The basic sex education that Randy received in school did not meet his sexual needs and did nothing to launch his sex life. Instead, Randy launched his sex life on his own. Randy had an active sex life at the time of the interview, based on his can-do attitude. Randy had less to say than the other participants about his health care providers’ roles in discussing human sexuality, intimacy, and relationships with him for two reasons. One, his exposure to health care providers appeared to be limited compared to the other participants.

> I so rarely went to the doctor. Even today I go to the doctor once a year for a physical because they require me to do so to keep my driver’s license. Aside from that, I just don’t go to the doctor. As a younger person before, I used to go. But now I don’t have any reason to go.

It appeared that Randy did not get information about intimacy and healthy relationships from his health care providers, adequate or otherwise. This did not appear to frustrate him and perhaps reflects the other reason why Randy had less to say than the other participants about his health care providers' roles in discussing his sexuality. Randy's focus was on direct experience. "I suppose some of [intimacy and relationships] could be taught, but ultimately I was going to have to experiences anyways." Randy's direct experience approach to his sex education was similar to Zoe's can-do approach. However, Randy did not make the same beeline progress that Zoe did to her direct experience. (Randy's reference to "the shadows" in this passage relates to hiring a prostitute to finally have some sex.)

> In all of life—sex or whatever—a lot of joy is derived from exploring and experiencing new things. I certainly don't regret not being told something. I'm certainly thankful that I had the opportunity in so many ways to go out and experience new things, different things and just, yeah, that joy of discovery of whatever new experiences I had for the first time. You know, it is pretty cool. I didn't resent that I had to go into the shadows to get it done right. The idea of prostitutes . . . I definitely didn't like that somehow, I had to do something wrong to learn about an experience with something others just take for granted.

The basic sex education that Jim got in school did not meet his sexual needs. When asked about the adequacy of his sex education and how he felt about the fact that none of his health care providers had ever asked about his sexual side, Jim said, "Like, I'm different. My sexual needs don't matter because I'm disabled. I felt they overlooked me because I was disabled." When asked if he had been directly told that intimacy in relationships is possible despite a disability, Jim said he thought it would have made a big difference in his sex life. As to whether his MD had a negative impact on his intimate relationships, traced to inadequate sex education, Jim agreed and stated, “Yes, [my MD] has had a negative impact.” Jim’s disclosure was evidence of the main theme of much left unsaid and its subtheme of a hint of needing permission to be sexual. As such, Jim’s experience was further evidence of the theme of being on the outside looking in.

Molly’s basic sex education in school also did not meet her sexual needs, despite its fleeting references to intimacy and relationships. Her instructors did not address the topic of relationships among people with disabilities to the entire class or to Molly personally, another form of sexual silence. Molly claimed that this did not bother her. However, although Molly’s following comment hints that it did not bother her because she chose not to think about intimacy provides support for the theme of much left unsaid, it belies subsequent evidence that Molly did in fact put a great deal of thought into intimacy and relationships. Her disclosure was also evidence of the main theme of being on the outside looking in.

> I guess I really don’t care that much about the human sexuality side. Of course, I watch soap operas and things. It looks really nice and all that. But I never experienced it. I just didn’t really think of it. I think the problem with my family, we didn’t really talk about—I talk to my mom a little bit about my period and stuff. But we never talked about sex. I think part of that is being Catholic: You’re not supposed to sleep with somebody before you are married.

Molly’s and Jim’s responses reflect the fact that information transfer between people is a two-way street. For Molly and Jim, this lack of information transfer reflects a type of reciprocal sexual silence. Jim never asked his health care providers about love or sexuality. Neither did Molly. In Molly’s case, this seems reasonably related to her Catholic upbringing; note her comment that her mother never talked about love or sexuality. I asked Molly if she was also uncomfortable asking for information about love and sex. Perhaps she was before, but she is not now, as she replied, “Yeah, I think I would be comfortable now.” This was more evidence of the theme of much left unsaid in reference to the unaddressed question of why she was uncomfortable before.

Sex education class discussions of intimacy and relationships. The previous sections on RQ1 and RQ2 presented evidence that sex education classes included the basic facts of life, safe sex, and birth control. But for study participants, they failed to meet their need to know they are sexual beings and can enjoy fulfilling relationships. This section takes these omissions a step further by highlighting what sex education classes excluded, thereby providing further evidence of the overarching theme of sexual silence.

All study participants except Molly stated that their sex education classes excluded discussions of intimacy (there were brief references to intimacy in Molly’s class). However, their comments also either suggest or imply that this omission was unrelated to their disabilities. Evidently, sex education classes did not include discussions of intimacy or relationships for anybody. It was sexual silence on a large scale.

Randy said he was not treated differently than other students as no one heard presentations on intimacy or healthy relationships. “I don’t think they did that for any student. Not really.” He vaguely remembered some indirect consideration of it “when they start talking about sex and pregnancy and unwanted pregnancy and what not—when they were talking about relationships and sex and that sort of thing.” Randy thought he understood why there was little discussion of intimacy or even healthy relationships in sex education classes:

> It almost gets very, very political. In other words, they can’t hardly talk about what might constitute a good relationship at the private schools because there are your religious families [who] are going to object to the fact that religion is left out of discussion. And I am going to say, that’s just the pillar of a healthy relationship. [And] nonreligious [types are] certainly are going to object to any sort of implication that there’s some other external being deciding their morality or whatever. So anyway, I don’t remember anything about what really healthy relationships will be.

When prompted as to whether his sex education class ever included discussion about intimacy and relationships in general or for individuals with disability, Jim simply stated, “No, it was not covered with nondisabled or disabled students.” Molly reported a similar experience. Whereas intimacy and healthy relationships were referenced in Molly’s sex education class, these references were fleeting at best. At no point did course instructors talk to either the entire class or to Molly personally about relationships when someone has a disability. Again, Molly claimed that this did not bother her.

Randy did engage in discussions about intimacy and relationships as a student, but in an English class instead of a sex education class. During discussions in English class, he was surprised to discover that he recoiled from the thought of marrying someone different from himself.

> I had a pretty good English teacher in my freshman English class. I remember ideas about relationships started just coming up in that class. I mean, when you write about literature, that provides you with a good opportunity to talk about relationships. I remember talking about finding people who treat you right. If you are in a relationship where somebody isn't treating you right, you run, get out. It's like, you know, you don't need to be hanging around some relationship where you're not treated right.

Zoe's sex education class also excluded consideration of intimacy and relationships. But there were other sources for learning about intimacy in relationships, including some possible modifications due to her MD.

> One time I met somebody with CMT. For a couple of minutes we were like in a waiting room in [park name deleted], and it kind of like illuminated something about my family to me. I met this little girl who was about my age. She told me she went to disability camp and all this different kind of stuff, whereas my family was like, "Pull yourself up by [your] boot straps. We don't need the

> accommodations. We don’t need all this kind of adaptive thing, you know. We are going to do it and if we can’t do it and we just won’t.” So my parents never talked to me about that.

First dates, relationships, and sexual experiences. As the previous passages indicated, study participants did not feel that they were given an adequate education on sexuality or intimacy. As such, they learned on their own. This section provides glimpses into their first dates, other relationships, and sexual experiences.

Randy did not talk about his first date per se. His words echoed Jim’s statement about being different because he was disabled. He then divulged that his initial sexual experiences only occurred after decades of frustration.

> Sex lives weren’t really open to me, you know. I mean, that’s just that. In general, there are very limited opportunities for sex for a person with disability. That’s a fact. And that definitely comes with frustration. I spent a great portion of my 20s and 30s very frustrated. I had seen pornography on videotapes and stuff. Certainly, magazine still existed back then. You know, so that was that, right, and you know, so when I was, like, a teenager, I masturbated throughout forever. So that’s the sex side. I didn’t really have any opportunities beyond that.
>
> Way back in college I had been told by a girl to go see a prostitute and figure out, you know, basically what works, what doesn’t really, whatever. My frustration finally came to an end when I was almost 42. I had thought about it and finally did the research and learned a lot of things [about] how things work. I

> arranged to visit a prostitute. It just makes it a lot easier when you find someone to have sex with.

Randy closed by saying that the suggestion that he find out what worked physically and what did not work physically was a good idea. “Ironically, she was maybe right. In some respects, it did help as far as when I did finally have a real relationship, I already knew kind of what things worked, what didn’t. That was probably actually helpful.”

Jim first stated that he had never been on a date. Then he disclosed that his first intimate relationship was with one of his caregivers when he was 34 years old. He added, “I’m no longer in the relationship.” Jim claimed that he did not have sexual anxieties associated with his MD that kept him from pursuing an intimate relationship. “Being naked in front of someone never been a problem because of all of caregivers. I’m used to it.”

Molly’s first date was 4 years before her interview for this study. She met a man on a dating website for Catholics. He had a visual disability and traveled by bus to visit her. She recalled,

> I was very nervous because it was the first date I’d ever been on with a stranger. He was nervous too. He came to my parent’s house and picked me up. He gave me white lilies, which I thought was nice. It was kind of late. [So] the next day, we decided what we wanted to do. I said ‘Let’s go bowling. Have you bowled before?’ He said ‘Yes, I have.’ So we went to [unnamed bowling alley]. It was

> awful because he just could not bowl. I think he has bowled, but having this visual impairment, he couldn’t bowl very good. And I needed help because I had to use the ramp. So he had to help me put the bowl on the ramp and I had to guide him through. It was kind of embarrassing. We did go out to dinner that night. That was really nice. We went to the art museum. There was a class, and we did some painting because he liked art and stuff.
>
> So it was a good date but it was a little embarrassing. We had just no connection. It was more of friendship. I just wasn’t feeling the chemistry with him. I think he liked me more than I liked him. We never kissed.

Despite some awkward moments, Molly enjoyed herself: “My self-esteem was up. I had a good time bowling even though it was hard for him and kind of embarrassing. I guess part of it was that he couldn’t see very good. So I wasn’t quite as nervous with him because that was one of the reasons.”

Zoe recalled her first date as the first time an older male friend she really liked came over and took her out. Like Molly, she said felt elated, although her reliance on verbal crutches in the following excerpt suggested that the memory was somewhat unnerving.

> My first date, Oh gosh. I didn’t have like a real date until, gosh, I don’t know, I really don’t know. The only thing I can remember, I don’t know if it was a date or not, was when I was . . . There is this guy I was like totally smitten with—I thought I loved him, which is not true. I was 13 and probably in third grade. He

> and I would talk on the phone for hours every day. He was older so he didn't feel, like, it was the appropriate to kind of like have a relationship. [Yet] one day he and his friend picked me up and took me out. I thought it was a date. I don't know what it was. But I felt like I was somebody.

Impact of MD on relationships. The participants had different views of MD's impact on their relationships. Zoe said her MD was unrelated to her first date, when she felt elated about being taken out by her older male friend with whom she was smitten. Then she launched into a discussion of her intimate experiences. When asked if she had ever been in a relationship and her age at her first intimate relationship, Zoe sought to clarify the question by asking, "Do you mean a relationship where you had sex or do you mean a loving relationship?" She then stated,

> I had sex the first time when I was 13. It wasn't anything, like, emotional. We weren't in a relationship. It was fun, I guess. But I guess my first relationship where I had sexy times was a little bit about fooling around. I guess the real one was when I was 15. I went off to school, like, long distance. There was a girl at school. That was probably the best, like, my best relationship with intimacy.

I prompted Zoe to consider the positive and negative impacts of her disability on her intimate relationships. Zoe responded by saying her disability "absolutely, definitely" impacted her relationships.

> You can't separate it from yourself. I think that it's a huge part of who I am, and it really affected my thinking. I think I really had to prove a lot when I was younger

> because I had to be like sexy, cool, and handsome in other ways because having disability almost definitely set me apart. So, I think it has probably [played a part] in every relationship but it's not necessarily a bad thing either. It has mostly been bad. But I don't think it has to be bad.

Sex does not have to be bad for individuals with MD. But parts of it can be bad, or at least a turn-off to most people. Zoe first apologized to me during the interview as if asking permission, and then gave a graphic example:

> When I was younger, I thought that I was orgasming when I had sex. But, actually I was pissing myself. For a while I was trying to figure out what was going on there. I was, "All right, like, you know, it is part of the deal and, you know, it's okay." I figured this is normal.

Zoe said she would have liked having any of her doctors tell her beforehand about some of the things that could or likely would occur when she became sexually active, further evidence of the overarching theme of sexual silence. But she was sidetracked about her presumed orgasms because she did not think bladder issues were a part of CMT because, as she noted, "There are a lot different variations [of CMT]." Nor did the doctors she saw about her bladder issues think those issues were a part of CMT. They reassured her that "that's not something that happens pretty often" with her particular disease.

By the time Zoe was 21 years old, "It became obvious to me that I didn't have all the things that I should have in terms of the sexy part."

> I [eventually] realized I did not have all the sensations and feelings when I was touched sexually. By this time, I had sex numerous times with a number of partners, both male and female. When I was done with sex, there was always lots of wetness. I always thought it was myself having a female orgasm. But I later discovered it was myself peeing on whoever I was with.

Realizing that she was urinating during sex made Zoe feel "very embarrassed and frustrated. I felt small and worthless." Despite this, Zoe claimed that her disability "has never been much of a problem in terms of relationships with other people." However, she then disclosed experiences related to the diminished sensations that accompany CMT that occurred during the time when she was trying to stand out as something more than her disability.

> There is one time when I found out there was something different in terms of appreciation. I had no idea until I was in a very strange situation. You know, nobody ever really said, "You are not sexy." But I felt I wasn't, you know. So, I felt I have to prove I can have all kinds of sexy time. There was one thing I could do: I can withstand a lot of pain and be really good at it. So, I did that for a while. I used to be [a] sadist. I wanted to be good at something. And what I was good at was pain tolerance.
>
> I moved to Chicago when I was still 20. I met something like a sadist class. The teacher called me out, like, to the front of the room and he'd inflict like this terrible pain. I was not fazed by it. So, he called me out in front of everyone

> that something was wrong with me. It was horrible. I was so humiliated. It was awful. That is the one instance I can think of right now when I know it was my disability. I went back to sit in the class for the rest of the class. It was pretty embarrassing

At no point did the instructor acknowledge that not feeling extreme pain can happen due to a disability. Nor did Zoe seek counsel from the medical community, evidence of the themes of sexual silence and much left unsaid. “I just figured I’m not normal and I would not know who to ask or what to ask.” Her latter disclosure was strong evidence of the need for a reliable source of education on sex with a disability.

Zoe reiterated that she “would have definitely appreciated finding out from a health care professional instead of just finding out on my own for a long time.” She still has many challenges. For example, MD does not interfere with the sensations of orgasm. But,

> I do get all tight and contracted. I can’t relax in my pelvic area. So, if I’m having a good time or whatever, I’ll just like cramp up. That was happening a lot. So, every time I would have really good sex, I would be [in] so much pain afterwards and then I’d throw up and feel just awful because of the pain.

Randy also experimented to find out what did and did not work sexually with his body. Like Zoe, Randy’s perspectives on the impact of MD on his relationships is unique for several reasons, foremost of which is that he was a newlywed at the time of his interview.

> You know, we just got married. Yeah, it’s great. I really love it, you know. I’m real realistic. I know that marriage is a long time and you have your ups and downs and whatnot, you know, but right now, it’s really good. I think even in difficult times we’ll do well. Hopefully, if you’re lucky, if you find someone where your strengths complement each other.

Randy’s new marriage set the stage for three examples of MD’s impact on his relationships. The first example involved the girl he befriended in high school and took to prom but with whom he was never intimate, perhaps because of his MD. “I mean we, we never ever kissed. But it was close.” He continued,

> Once again, it’s one of those things where disability does kind of play a role. I suppose [it is] an awkward time anyway and when, you know, you got this disability, it sort of it makes you more awkward. But we [would] sit around talking on the phone for hours, right. So, I mean in some respects there was a level of intimacy there. I guess we had our jokes and that sort of thing but . . .

The second example illustrated unhealthy or cynical relationships Randy had as a young adult.

> Later in life when I was older, I really didn’t have any healthy relationships in my 20s and 30s. I really wanted relationships, but it just didn’t seem like they were ever going to ease, and I certainly couldn’t convince myself that I just need to basically zero into myself and my career.

In discussing life during his 20s and 30s, Randy briefly referred to “those cynical voices in society” that say that if you were able to make a lot of money, then some girl will talk to you even if you were disabled. His comments provided evidence of the theme of being on the outside looking in.

> There is some truth to that. The girls that want to talk to you are only after the money or ones that want to have a ton of money, you know, millions of dollars kind of money. So, if I’m around a girl and it’s pretty obvious that all she’s trying to do is size me up for my bank account, that’s a pretty big turnoff. So, I didn’t have a whole lot of relationships at all. The girl I talk to still, [name removed] was her name, that was it as far as anybody I’d ever talk to, dated, or whatever. But then it kind of sort of worked out when I was 40. I kind of started up a friendship, talking with a girl that I kind of hoped would work out. But it didn’t. We ended up being friends and still are friends. That sort of, kind of, got everything going because [that was when] the frustration of the years of feeling left out and whatnot kind of bubbled to the surface.

The third example was about Cindy, Randy’s new wife.

> I finally put my mind saying, you know, when is my number going to change? In essence I started down the path that eventually [led to Cindy] because I basically said I’m not going to live the rest of my life in solitude—that if I can’t find someone to be with me, then I guess I’ll pay somebody to be with me. But I don’t have to live in solitude. Once again, ironically, it’s kind of a wobbly first step of,

> at least, finding a way to have options. Because when you have no options and you're just trapped, it leads to a very depressing cycle [that] doesn't make you a really good partner. All that negativity that you have going on personally just makes it even harder to actually find good relationships.

Randy summed it up with, "Well, Cindy was by far the intimate relationship. As far really intimate, yeah, Cindy would be the one that I truly dated." The impact of Randy's MD on his relationship with his wife means he cannot make all of her dreams come true, nor can she make his dreams come true. But he is in a relationship. This is not the case for Jim and Molly.

Jim and Molly shared more than just the experience of never discussing love and sexuality with anyone, each experiencing a form of sexual silence. As their comments about the impact of MD on intimate relationships show, they also shared two themes, being on the outside looking in and much left unsaid. Jim had had only one intimate relationship, which was years ago.

Jim is convinced that his MD interferes with having intimate healthy relationships. "Yes, it has. Finding a partner is my biggest problem. Someone open minded and understanding." That, and misgivings about "being able to satisfy my partner."

Molly had yet to experience her first kiss, much less her first intimate experience When asked if she had ever been in an intimate relationship, Molly simply said no. As to whether MD sometimes interferes, Molly was ambivalent about whether it hindered getting into a relationship or getting to the intimacy part of a relationship. First she said, "Yeah, I think so." Then she said, "I don't know. Maybe sometimes." Her disclosures were also evidence of the theme of much left unsaid when compared to her statement that "I've had tons of crushes." This illustrates that Molly often thinks about relationships but is lonely. Her unexpressed loneliness made her comment that she does not think about romance suspect, an indication of ambivalence. Molly was ambivalent about many things. The following passage shows how she equivocates about the role of her wheelchair in developing romantic relationships.

> I mainly think, guys seeing that I'm in a wheelchair, that turns them off. Maybe I'm not beautiful enough too. I don't know. I think they do see me because I've got tons of crushes. I even ask guys out. One of the guys I asked out, he actually had a girlfriend too; I didn't know. They say "No, I just want to be a friend." So I think they like me as a friend. I don't know if they can see me as an intimate partner or something, maybe because of the wheelchair.

Molly wonders if the guys wonder if she is able to have an intimate relationship, which upsets her. "It hurts. Depressed. A little bit of low self-esteem but mostly depressed I guess." Molly admitted that rejection was harder when she was younger. "I had a lot of crushes [but] I didn't always tell them I liked them either." Her disclosure was evidence of the overarching theme of sexual silence and the main theme of being on the outside looking in.

Molly’s nervousness about intimate relationships stems from her lack of experience, especially about kissing. “I’ve never kissed a guy.” Given the opportunity, she would worry about “if I was doing it right and if he liked it.” She is also nervous about moving in and out of her wheelchair in the interests of intimacy.

> I don’t know. I think some people can do it [make love] in the wheelchair but I don’t know about that. Probably the transferring, for sure, because I use a courier lift to transfer. So I’d have to show him how to use the lift.

Molly described herself as “usually, a pretty positive person, really.” For now, Molly copes with not being in a relationship and never having been in one through prayer:

> I just ask God almost every day to send me a guy that will be perfect for me. I don’t know. Eventually I just get over it. I realize, “Well, there’s got to be somebody out there. He just wasn’t the right one. He didn’t see how good of a person I am.”

Masturbation. Particularly in light of the participants’ disclosures about their difficulties of establishing intimate relationships, the topic of masturbation, or self-pleasing, was part of the interviews. However, I was cautious in posing questions about self-pleasing and took care to preface my inquiries by reassuring the participants that they did not have to discuss such personal matters if it made them uncomfortable to do so. My questions were along the lines of experiences with the positive benefits of orgasm for people with MD, with or without toys, to please themselves or their partners. Only Zoe, who is the most sexually active, did not comment.

As with other aspects of love and sexuality, Molly was on the outside looking in and has yet to experience self-pleasing. “I’ve never done it,” she admitted simply. She again equivocated about the role of her disease, saying that “maybe” her MD played a role. “I don’t know if I can reach very well because when I’m sitting up, mostly there. Then if I’m lying down in bed, it’ll be harder to reach.” This was when Molly brought up a vital point in the discussion of intimacy and disability and provided evidence of the theme of much left unsaid. Molly said she has heard of “vibrators and things” but never tried them. Nor have any of her health care providers talked with her about them, another form of sexual silence. Molly’s vital point was this: Since none of her health care providers had ever discussed intimacy with her, where could she go to get this kind of information? If she wanted to find more out, who would she ask? “I don’t know. Probably not my health care provider. I don’t know. Probably online or maybe someone like you, I guess.”

Like Molly, Jim’s physical limitations made it hard to please himself. He stated, “Yes, that’s always been a problem” and did not elaborate. For Randy, who said that he “masturbated throughout forever” as a teenager, while MD’s progressive degeneration has resulted in his becoming weaker, he is still able to self-please. “You know, I still go on. Still can. So in [other words], everybody wants to be stronger than me but my strength level is still adequate to take care of that." His relief at being able to make this disclosure was visible.

Final Thoughts to Share

The interviews ended with asking the participants if they had anything else to share. All did. They provided thoughts that in many cases reiterated the basics of life education as much as they did sex education.

Jim, who was reluctant to say much during the course of his interview, found his tongue at the end and even became impassioned. Enthused by my interest in his story, he felt free to vent: "It's been frustrating, not able to find a partner or being able to help myself." He then stated that more sexual education and experience should be an essential part of caregiving.

> Having an orgasm helps me physically and relieves anxiety. I think having someone to help you masturbate should be addressed and considered in your care. Nobody should be denied [their physical rights because] that's your right. I have someone who helps me out. There should [also] be a legal and compassionate way to help disabled people find emotional and physical intimacy without ridicule or a fee. Like there's something wrong with us because we want what other people need and have. It should be listed as one of the basic human needs for the disabled and should be addressed. But it's a taboo subject to talk about with caregivers and agencies.

Jim's final comments reflected how the other study participants have felt at one point or another.

> I try to handle any adversity thrown at me. I have been self-conscious at times and felt like an outsider at certain times in my life. That's not to say it hasn't been difficult and frustrating.

Molly's closing comments provided further evidence that the tacit assumption that people with MD are disinterested in having sex, being in love, and having fulfilling relationships is patently untrue. She spoke eloquently of her desire to have a family: "I was struggling with whether I wanted to have children or not. I thought it would be neat to have a child that was half me." Her uterine fibroid forced Molly to have a hysterectomy. "So I can't carry a child now. That kind of helped me with that decision."

Further comments from Molly reflected the theme of much left unsaid.

> But also I knew that I won't be able to carry a child just because there's so much it does to a woman's body. I already have breathing issues. That fibroid was just under a pound, and that was definitely making my breathing worse. So if I had a baby growing in there, 8 pounds or 7 pounds—I think it wasn't meant to be. I'd like to adopt some day. I can definitely see that.

Randy ultimately achieved success at work and at love, but his road was a long and bumpy one. It gave him time to give intimacy a lot of thought.

> I was so disillusioned when I figured out women don't mind talking to you but they are not interested in having a long-term intimate relationship with you—they

> just they don’t want the challenges. And that’s the thing. My life has special challenges that people who don’t have a disability don’t know how to face. So Cindy basically ends up with special challenges that she wouldn’t face if she was with a partner who didn’t have a disability.
>
> I think for everybody disabled, it’s a matter of finding a combination where your strengths fit with what that person needs and your weaknesses fit well with that other person’s strengths. In other words, for a person like me, my weakness consists of my disability; this fits very well with a person who has a higher level of empathy and compassion who doesn’t mind the extra requests and strange things like, “I’m going to need you to do this for me.” The average person would be like “Oh gosh, you’re just too much.”

Now happily married, Randy has few sexual anxieties related to his MD with his wife but still has some concerns.

> In general, no, I don’t get all that worried about it. I, and Cindy, would say that I want it all the time. But I guess I do worry a little bit, not a lot, but obviously, muscular dystrophy like mine is fairly severe. But, you know, we can definitely have sex. It is not like we can do a wide variety of positions. There is some possible variation but not a lot. You know, she’s the one that has more of the strength. It is going to have to be her muscles. I guess there have been times I worry that maybe it will get kind of boring, same old thing kind of thing. Once again, sex is just like one aspect of the larger relationship. My feeling is when the

> sex is good, oftentimes it’s because the relationship is good, or it was a really great day or something. It’s not about the physical. It’s about the emotional. Are we happy? Are we at a good place?

Randy went on to relate a discussion he would have with his younger self and concluded with advice for others with disabilities.

> If I go back to my younger self and give myself a piece of advice, [it would be about] some education and good input. I would probably have a pointed discussion with my other self and say, Look, sorry, but yeah, having a disability definitely impacts, you know, some of your abilities with sex and relationships. Yes, and that sucks. But you got a choice to make. You can get discouraged and basically give up. There was a time in my life where that’s more or less essentially what happened. Or you can look at the choices in front of you. You can look at your options and try to experience as much as you can with the proviso that you’re not out there trying to hurt anyone. You’re just trying to have experiences that everyone else did. I think there are a lot of people need to throw this conventional wisdom out the door and take a good long look at what it is they really want.
>
> For me, my life is better and more fulfilling [after] I could finally break out of that depressing cycle. When you’re depressed, it’s sad. All you do is think about yourself. You don’t even know it because you don’t feel you’re being selfish. You’re thinking about yourself and what you’re missing and where you’re

> being left out and whatnot. You miss all these opportunities to get relationships with other people who are also, by the way, lonely and looking for somebody. They don't need someone who's hung up on what they've been missing out on. They need someone who can be supportive and help out with their problems, because they've got problems too. And in essence, you can't help them with their problems if you're hung up on your own problems. You've got to find a way to break out of that cycle. So that's the education. You give to everybody, not just people with disability. But it becomes more for people with disabilities because people without disabilities sort of stumble through it but in the end, it all kind of works out. For a person with disability, you got to sort of kind of make it happen.

Zoe also voiced some recommendations. First she addressed parents; she called for breaking the sexual silence:

> I think that if parents have a child who has muscular dystrophy or some other kind of physical disability, especially one that's visible to other people, then they can really do their kids a world of good by socializing them with people who have disabilities so they can share common experiences. I think that had I had that, I wouldn't have made the sad decisions that I did. Not that all of them were bad, like I'm really proud of a lot of what I did, in terms of things that I'm very incredible with.

Like Jim and Randy, Zoe touched on the need for optimistic education:

> People need to know that all parts can be sexy parts. You know, it's not like you have to have your penis functioning this way [or] your vagina functioning this way. You're going to have a good sexy time [whether] its things that are body parts or things that aren't body parts [sex toys]. It's all okay. I'm going to say it: Make it more than penis goes into vagina—you know that's really what happens. [But] talk about it as a more holistic experience. Also talking about consent is really important.
>
> I would just restate that other people who have muscular dystrophy or some kind of disability that affects their ability to have sensation, I just hope that they know that they're still sexy people. And, you know, there's someone out there for everyone.

In closing, Molly brought up yet another vital point that encompassed the full theme of sexual silence: "I never really thought of having sex ed for people with disabilities until I got involved with talking to you. It wasn't really a part of my growing up, the whole human sexuality thing. But it is important."

Summary

Four individuals with MD, two men and two women, were interviewed about their experiences with sex education. All had well-defined definitions of intimacy and had been diagnosed with MD as children. All four had attended basic sex education classes and indicated that these classes provided inadequate sexual education.

The overarching theme of sexual silence emerged as an absence of discussion between study participants and parents, doctors, and health care providers about anything associated with sexual education or the role of sex in their lives as people with disabilities. The overarching theme was reinforced by five specific main themes (a) general sexual education provided basic exposure to the essentials of reproductive biology but little else (reflecting RQ1); (b) sexual education was inadequate (reflecting RQ2); (c) participants were on the outside looking in when it came to intimate relationships; (d) most of the realities of sexuality remained unstated and unexplored; and (e) parents, doctors, and other health care providers behaved as if people with MD were disinterested in having sex, being in love, and having fulfilling relationships.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

In this study, I explored the experiences of individuals with MD regarding their sexual behavior and human sexuality education. By conducting a multiple case study, I investigated each individual's unique challenges stemming from their MD in terms of sexual intimacy and pleasure, what type of sexual education they have received, and what they perceived to be their sexual education needs. I used semistructured interviews in which I asked four study participants two primary research questions and a series of follow-up questions. The primary research questions were as follows: What sexual education, if any, have individuals with MD received, and if sexual education was provided, did it meet the individual's needs? Based on these research questions, I used guided inquiry to ask participants to describe what kind of sexual education they have received, if any. I also asked them to describe how the education they have received influenced their experiences of physical and emotional sexual desires and discuss how sexual education or the lack of it may have influenced or affected their experiences with sexual anxieties and dysfunctions. Participants were encouraged to share their experiences of sexual anxieties and dysfunctions and how their MD has affected or influenced their sexual experiences.

The key findings related to the primary research questions included the following themes: general sex education provided basic exposure to the essentials but little else, sexual education was inadequate, tacit assumptions about the needs and desires of individuals with MD about sex and sex education, much was left unsaid, needing permission to be sexual, and being on the outside and looking in. Combining all of these themes further reflects the overarching theme of sexual silence. These themes parallel findings in other studies regarding disability and sex education (Kedde et al., 2010; Kim, 2011; O’Dea et al, 2012). There was further parallelism with the research findings of Areskoug-Joseffson (2013) concerning the lack of literature on sexual health among adult individuals with MD specifically related to sexual pleasure. In addition, the findings revealed a depth of skepticism and fear of intimacy among the participants, similar to findings in Esmail et al. (2010). Hence, the participants had feelings of self-doubt and questions about intimacy and affection and doubted that their self-worth or sexual needs were worthy of being discussed because of their disability. Specifically, in his interview Jim made the stout disclaimer that “My sexual needs don’t matter because I’m disabled.” The other emerging themes provide a fuller understanding of the reasons why the sex education received was inadequate and illustrate the impact of lack of education on participants’ lives.

In Chapter 5, I present an interpretation and analysis of the study findings. This interpretation and analysis covers the study results that were presented in Chapter 4. The emerging themes that reflect the overarching theme of sexual silence are the key focus of this interpretation and analysis. I also discuss the study limitations, recommendations for further study, and implications for positive social change.

Interpretation of the Findings

Four study participants were interviewed in depth regarding their sexual behavior and experiences with human sexuality education. Each case provided a rich description of the participant’s lived experiences. In the following sections, I provide detailed depictions of the participants’ experiences by presenting interpretations of the findings organized by each emerging theme.

Sexual Silence

Sexual silence was the overarching theme that emerged from the study results. This theme was common in all study participant comments as they reflected the lack of adequate information regarding sexual education provided by health care professionals and parents. Human rights theory holds that these rights include the freedom for individuals to express their wants, desires, and needs. These human rights can encompass areas such as rehabilitation, curiosity, and a supportive framework as well as practical and social intelligence. They also include the expression of sexual needs and desires for intimacy. Individuals have the right to be equal in terms of freedom, dignity, personal integrity, and self-determination (Blau & Moncada, 2015; Human Rights Watch, 2012).

One aspect of these rights is the fundamental human right to sexual pleasure for all people, including people with physical disabilities (Nucci, 2010). Furthermore, these sexual rights are universal positive fulfillment of the fundamental law of humanity (Appel, 2010). However, basic human rights are often denied to many individuals with physical disabilities as they are seen as asexual and, as such, are left out of discussions and educational processes regarding relationships, sex, and intimacy (East & Orchard, 2014a). The present study findings also reflect those of Tepper (2015), who stated that basic human rights are indeed being denied to individuals with physical disabilities. Based on the present study findings, this denial is largely in the form of sexual silence.

The evidence of sexual silence underscored the majority of the participants' comments. This theme was revealed in several forms throughout the interviews as participants told their stories regarding the absence of communication from health care professionals, parents, and educators on the aspects of sex and intimacy in the lives of people with a physical disability. This overwhelming theme of sexual silence illuminated five subthemes that directly correspond with the predominant theme of sexual silence. I discuss each theme in detail next.

Minimal Exposure to Sexual Education and Inadequate Sex Education

Most of the study participants had never discussed sexuality, intimacy, or relationships simply because these subjects were never broached by educators or health care providers. The lack of sexual education can impact one's ability to understand the unknown; in this case, the role of sex in the lives of people with disabilities. Esmail et al. (2010) noted a general lack of information and education regarding disability and sexuality and stated that this lack could negatively impact confidence, desire, and ability to find a partner as well as distort overall sexual self-concept in individuals with disabilities. The remarks from participants in the present study are consistent with the findings from the literature review as they reflected a lack of sex education among individuals with MD and that this lack persisted throughout various stages of their lives. There was further consistency with findings in the literature review that health care professionals and educators find it difficult to address sexual behavior among individuals with disabilities and that this group is viewed as asexual due to preconceived notions of what is considered natural (Esmail et al., 2010).

Outside of sex education classes, the study participants received no further formal education about sexuality, intimacy, or relationships. For example, Molly only received basic sex education during her health class in her earlier years. She was never approached to learn more through family, friends, school, or health care professionals. She was denied basic educational and human rights in the area of sexual education. Molly took it upon herself to seek out further education by taking a class at the university. Zoe also sought out different ways of educating herself on sex and intimacy. Both women agreed they would have benefited from further sexual education in their earlier years, further illustrating that individuals with MD will benefit from sexual education and that it can have positive effects on several areas related to sexual anxieties.

This finding aligns with others showing that individuals with physical disabilities receive less sex education and face various barriers to receiving education specifically focused on what their sexual abilities might be as determined by their physical limitations (Rowen et al., 2015; WHO, 2013). Sexual rights and desires are a universal positive fulfillment of the fundamental laws of humanity (Appel, 2010; Nucci, 2010). Participants in the present study had to overcome barriers to fulfill these fundamental laws for themselves. Their actions followed those detailed by Rowen et al. (2015), who stated that humans accumulate knowledge through beliefs, morals, and family and societal rules.

Health care professionals and educators are at the forefront of being able to discuss and provide education on intimacy and relationships with individuals with physical disabilities (Esmail et al., 2010). The fact that they do not provide this discussion and education results in significant barriers for individuals with physical disabilities, including people with MD. Individuals with physical disabilities continue to face isolation and social stigmas due to lack of education regarding sexual health (UNICEF, 2013). Once again, this avoidance from health care professionals illuminates that individuals with a physical disability are seen as asexual (Rowen et al., 2015).

Comments from study participants reflected various barriers to approaching the subject of sexuality with health care providers. Jim, for example, faced barriers related to embarrassment, lack of resources, and emotional distress. Because of these barriers, Jim would not approach the subject of sexuality with his health care providers. Instead, Jim depended on others to inform him and for assuring his sexual feelings and needs. This affirms that people have normal desires for relationships and intimacy regardless of physical limitations (WHO, 2012). MD does not eliminate this basic drive or desire for love, affection, and intimacy. Instead, societal barriers had a far greater effect on the participants’ emotional well-being.

Tacit Assumptions About Sex and People With Disabilities

Despite the fact that all study participants have health care providers who could discuss sexual issues with them, these health care providers mostly avoided such discussions. This avoidance strongly suggests that medical professionals and related personnel have the tacit assumption that people with disabilities do not have or want a sex life or are unable to have one (Rainey, 2011; Rowen, 2015). Higgins et al. (2012) noted that this avoidance is also possibly due to health care providers' embarrassment, lack of skills, lack of knowledge/education, and fear of offending the person with the physical disability. As the WHO (2013) stated, "The challenges in sexual health are not just part of having a disability but instead often reflect stigma and discrimination, lack of social attention, legal protection, accessibility of services, understanding and support" (p. 1).

There was a consensus among the study participants that health care professionals, educators, and family members assumed they did not need any type of sex education. With the exception of Randy, all participants expressed that they saw health care professionals on a regular basis because of their MD, but that these professionals either did not offer any advice on sexual health or avoided the topic when raised, echoing Rowen et al.'s (2015) findings that health care professionals oftentimes do not view individuals with physical disabilities as sexual beings or assume that they are asexual and simply do not need to know about sex and intimacy. Not only do these beliefs held by health care professionals and others deny individuals with physical disabilities the basic human rights previously discussed, they prevent this group from gaining access to knowledge and information on sexual health.

Participants' family members also tended to avoid discussing sexual education or any type of intimacy issues, again speaking to a tacit assumption that the participants did not need this information or that they were disinterested in it. For example, Molly stated that she "talked to my mom a little bit about my period and stuff, but we never talked about sex . . . With my family, we didn't really talk about human sexuality." While Molly ascribed some of the avoidance of the topic to her family's Catholic faith, her experiences, as limited as they were, could also reflect her mother's assumption that such conversations simply were not necessary. Zoe remembered her feelings of bewilderment as an 11 year old when her mother told her told her to get used to no one wanting her sexually but then gave her a bag of condoms, stating that even 11 year olds need to know about sex and wanted her to "be safe." Zoe reiterated being bewildered and confused and stated that she had been objectified. The result of such avoidance is that people with physical disabilities often feel invisible or that they are on the outside looking in when it comes to sexuality, intimacy, or relationships. For Zoe, this encounter with her mother was the start of her finding other ways to feel sexy.

On the Outside Looking In

Throughout the interviews it became apparent that participants went through periods of their life with feelings of lower self-esteem and depression due to having MD and the physical limitations that it causes. These feelings often reflected their concerns about not being able to have fulfilling intimate relationships because of the physical limitations MD causes. All participants stated that they have learned different accommodations and adaptions to cope with their feelings of inadequacy but still feel emotional and somewhat excluded, or on the outside looking in, in terms of a fulfilling intimate relationship. These comments from the study participants confirmed that individuals with physical disabilities experience a number of emotional issues surrounding the ability to experience love in an intimate and sexual way (Rainey, 2011).

All study participants spoke to skepticism of intimacy they have consistently encountered from others and that they themselves have held throughout their adolescent and adult lives. Further, the study participants stated that this skepticism has become an accepted factor in their lives. Participants all have wondered or continue to wonder if they would ever find individuals who would look past their wheelchairs and look at them for who they are regarding their character, personality, intelligence, and humor as opposed to being just the person in the wheelchair.

These findings parallel Marini et al.'s (2011) finding that individuals without a physical disability are likely to be friends with an individual with a physical disability but not engage in a romantic or intimate relationship. Further, participants in Marini et al. stated that they would not be interested in dating or marrying a person with a physical disability because they perceived that this person would be too much work or would require too much caregiving. This finding was echoed in Jim's comments about feeling anxious and frustrated because he wants to find someone to share his life with as a friend and a companion but as he became close with different individuals, these individuals only wanted friendship. He believes they viewed him as “too much work” due to his disability. Sadly, this has resulted in Jim never having been on a date. “Finding a partner is my biggest problem, someone open minded and understanding.”

Comments from all participants in the present study confirmed feelings of exclusion and being on the outside looking in in terms of sex, intimacy, and relationships. During the interview, Randy said, “As far as sex, you know, sex lives weren’t really open to me. You just know in general for a person with a disability there are limited opportunities for sex that’s a fact. And definitely that comes with frustration.” Feelings such as these lead people with disabilities to feel excluded, to feel that they are on the outside looking in, and to fear intimacy as they do not reflect and cannot meet what society considers normal standards of physical attractiveness (Cordes et al., 2013).

Needing Permission To Be Sexual

Further interpretation of the research results corresponds with the present study’s theoretical framework of humanistic psychology and human rights. All participants felt that they had some sort of disconnection or exclusion from sexual education and their desire for sexual fulfillment. This disconnection or exclusion again reflects the overarching theme of sexual silence in that the participants felt they needed permission to have intimate relationships, and if they did not express their desire for intimacy, such desire would remain unheard.

This aspect of needing permission stood in the way of participants meeting the basic human needs that are consistent with the fundamental human drive for intimacy (Kim, 2011). Furthermore, the participants were also being denied the potential for growth and self-actualization as well as the fulfillment of personal worth and social recognition, all of which are part of humanistic psychology. If individuals with MD are unable to experience the human rights of life and dignity and a life worth living through those they are taught to trust and who educate them, how can individuals with MD have equality when it comes to freedom, dignity, personal integrity, and self-determination?

All participants experienced psychological and emotional factors due to experiences of living with MD. Because this is a progressive disease, participants' emotions and frustrations developed and changed over time. All participants discussed their decline of physical mobility and needing more and more help from caregivers and family members to do the daily tasks of bathing, dressing, and more. One of the frustrations expressed by all participants was that constant need to ask for help even with things such as rolling over in bed or getting a drink of water. Over time, the participants became used to asking for help even though they may not have liked to ask. This included not liking to ask for sex or about topics related to sex. Because they have had to ask for help with so many things, there was the feeling of needing permission to have their sexual needs met, and even needing permission to express that they are sexual beings with the same basic needs as individuals without physical disabilities.

When I broached the topic of sexual needs with study participants, there was a consensus that they all have sexual desires and want to sexually pleasure themselves but were unsure how to go about asking for help or resources. This concept and lack of communication results in people with physical disabilities lacking resources and awareness revolving around sex education and intimate relationships. Hence, the final theme brought forth in this study— much left unsaid.

Much Left Unsaid

As previously mentioned, the study participants agreed there was lack of communication and resources regarding their sexual education, specifically regarding their MD. The study participants were forthcoming with their thoughts and feelings toward health care professionals and educators and how they did not broach the subject of sex with them. In other words, much left unsaid, both by study participants and the individuals who could have been resources in their search for information on sexual health and intimacy. Since much was left unsaid, the study participants did not know who or where to go to for sexual health resources. They had to forge their own paths in the silence.

Every participant had their own story to tell about how, when they had questions about sex and intimacy, they had to seek out the information on their own, and they all described different techniques and approaches for obtaining this information. Molly felt she gained insight from watching soap operas and television shows where people were in intimate relationships and later realized she wanted to learn more, so she took a class on sexuality and relationships at the university she attended. Zoe experimented with sexual pleasuring of herself and others to learn more of what her body was capable of doing sexually.

Clearly, much is left unsaid about sexuality and intimacy for people with physical disabilities. But, they are not alone. Their experiences also reflect findings from the Centers for Disease Control (CDC) about the lack of sex education in general in U.S. schools, leaving youth at risk (Brener et al., 2017). Middle and high schools are not teaching all of the essential sex education topics that the CDC recommends—thus, much left unsaid. As such, the theme of much left unsaid, although important for individuals with physical disabilities, is also a greater societal concern. Sex education not only needs to be more inclusive of individuals with physical disabilities (Kim, 2011), it also needs to be more available for more youth in the United States.

Limitations of the Study

This study had several limitations. First was the small sample of four participants—two women and two men. Although this small sample size provided a rich understanding of the participant experiences, such a small sample cannot be considered a representation of all individuals with MD. A second limitation was participant recruitment. Because of this study's sensitive nature, some individuals inquired about the research but opted out of the interview for undisclosed reasons. Logistics were a third limitation. Because I was unable to travel to the different locations and the different states, and because of some of the participants' health conditions, only one interview was conducted face to face. This caused a limitation because I was unable to see the facial expressions and body language of all the participants. Not being able to see the participants' body language made it somewhat difficult to decipher some of the emotions that they expressed during the interviews. For example, due to Jim's health limitations he was unable to interview by phone or in person, so I conducted this interview via text messages. Because of this, I was unable to determine whether there was any type of emotional or physical distress or fatigue that may have impacted some of his responses. As such, when I interviewed Jim I stopped more frequently and asked him how he was doing than I did with other study participants.

Recommendations

Sexuality is an important aspect of quality of life for all individuals, with and without physical disabilities. Further research is suggested by taking these results and digging deeper into how and when to best broach the topic of sexual education. Future research could focus on larger sample sizes and potentially involve participants with different types of MD. Also, with a larger sample size it may be possible to further investigate sexual encounters between individuals with disabilities and their caregivers, which surfaced in this study. Are the caregivers becoming the sex education providers to individuals with MD or are they merely helping to satisfy the need for intimate relations? Findings from the present study showed that participants were severely limited in who they could talk to about their sexual needs and desires. Some participants felt a certain need for permission to broach the subject and how it relates to their disability.

Future research is also suggested on how individuals with MD can resolve their sexual needs, which again brings up the theme of sexual silence regarding resources for discussing intensely intimate and perhaps embarrassing topics such as pleasuring oneself. As an example, researchers have found that reaching orgasm can reduce spasms and create positive emotional status (Tepper, 2015), a finding that was affirmed by one of the present study's participants who said that her muscle spasms decrease at night after orgasm. However, individuals with MD may have limited motor skills, making it difficult to resolve their sexual needs. In Randy's case, he turned to pornography and eventually a prostitute to fulfill his sexual frustrations and desires, which helped end his frustration and helped him figure out what works. "My life it was more better and fulfilling I could finally break out of that depressing cycle." Comments like these suggest research that could identify healthy, nonstigmatizing sources of information on this intimate topic that individuals with disabilities could turn to. Investigations such as these could also lead to exploring sexual hesitancy among people with physical disabilities; specifically, why do some people with physical disabilities go on to have satisfying intimate relationships while others do not?

A final recommendation for future research would be to further investigate the psychological aspects of MD as they relate to intimacy. Questions that could be asked include what is it like to be aware of the slow deterioration of one's physical abilities from MD and does this awareness play a role in intimate relationships? Inquiries such as these could lead to further research regarding health care professionals and what education they receive on sexual education and physical disabilities. If health care professionals are at the forefront of providing up-to-date information, then it is also recommended that they receive adequate information, resources, and education so they are better able to adequately inform all of their patients.

Implications

That there is a large population of individuals with physical disabilities is undeniable. Upon analysis of this study's findings, it is clear that regardless of the challenges people with disabilities face, they still have feelings of sexual desire and the need for intimacy and closeness. These desires and needs should be acknowledged and supported. The tacit assumption that people with physical disabilities are disinterested in having sex, being in love, and having fulfilling relationships needs to be addressed and dispatched. A collaboration needs to occur among health care professionals and educators that results in communicating the importance of sexual education and opens the lines of communication so that sexuality information can be accessed. Health care professionals and educators are in a primary position to educate individuals with physical disabilities as well as support their needs and desires to gain access and support to sexual education. Needless to say, health care providers and education professionals are not broaching the subject.

The consensus of the study participants was that health care providers never approach the subject of sex with them, despite countless opportunities to do so. This avoidance speaks to health care professionals having the attitude and mindset of believing people with a physical disability do not need the same sexual health care education as people without a physical disability. However, study findings show that not only do people with physical disabilities need the same health care education as people without disabilities, they also want it. For example, Zoe reiterated throughout her interview that she “would have definitely appreciated finding out from a health care professional instead of just finding out on my own for a long time.” Zoe went through a horrible and humiliating sexual experience, after which she sat in silence as she had no idea who to ask for guidance and help. This stands out as a vital example of the need for and importance of comprehensive sex education for people with disabilities.

Health care professionals are overlooking people with physical disabilities in terms of educating them on their sexual health and well-being; an education that should be comprehensive and all-encompassing, not just on reproduction. Because health care professionals are at the forefront for teaching, they themselves need to be further educated. Health care professionals need to know that regardless of physical limitations, individuals with physical disabilities can feel the same discomfort or reluctance as individuals without disabilities and may be reluctant to reach out for help. As part of professional practice and responsibilities, health care professionals need to create safe and open lines of communication that individuals with physical disabilities can be encouraged to access and need to support their desire to obtain sexual information and sexual health-related services.

Results from this study and others have shown that people with physical disabilities are interested in sexual activity and reproduction. Health care professionals must no longer make the assumption that they are not. Therefore, it is vital for health care professionals to further expand their own education so they can properly communicate human sexuality education as an ongoing process, starting with patients at an early age and continuing throughout adulthood. Such education should encompass basic body awareness, health information, communication skills, decision-making, and social skills. Health care professionals should also acknowledge and be guided by the understanding that there are differences between sexual intercourse and intimacy. Individuals with a physical disability do not stop having the need and desire for intimate relationships because of their disability. As human beings, craving human touch is innate. Therefore, it is imperative that the skepticism regarding sexuality in individuals with MD comes to a halt so society will discontinue perceiving sexual behavior among individuals with disabilities as a taboo topic.

Many individuals with physical disabilities bodies experience continuous changes in their bodies and in their strength and fatigue levels. Therefore, another recommendation is to begin healthy sexual education at an earlier age so that individuals with and without physical disabilities can better understand and accept that relationships are possible despite physical limitations. As the study findings showed, individuals with disabilities crave some sort of emotional and physical contact. Like individuals without physical disabilities, they want to feel loved, and they want to experience intimacy.

Personal Reflection

I am a 44-year-old woman who has had a form of MD my entire life. I have gone through a multitude of trials and tribulations but have also had some huge successes in my life. However, for as long as I can remember I have always wondered why I was excluded from various programs in school and even as an adult. I became increasingly aware of being treated differently when I spoke with health care professionals when I started dating and later on about wanting to have my own children. I had very negative responses from my health care providers. More than one stated that it would not be a good idea for me to have a child. Not because my own health would be in jeopardy but because there would be a chance the child could also have MD. I was even told that if I got pregnant it would be in the child's best interest for me to abort the pregnancy. I never felt comfortable with these health care professionals, and I found new health care professionals who supported my dreams of being a mother while still considering my safety.

For a number of years, I have questioned what health care professionals and educators were teaching their students and patients in terms of disability. I did not understand why they would not educate individuals with physical disabilities to the full extent as they would for individuals without physical disabilities. This was by far my first steppingstone on the path to conducting this study. The final clincher was when I was a keynote speaker at a rehabilitation facility. I spoke in front of doctors, occupational therapists, physical therapists, nurses, families of patients, and others on the necessity of not only focusing on the patient’s ability to improve in rehab but also recognizing the emotional aspects of what the patient is going through. I was speaking to them not only from a professional standpoint but from a personal standpoint as I spent 3 months in a rehab facility to regain my motor skills, relearn to eat, and much more. I had two children under the age of 2 years at home, and I was a single mom. I was not only concerned for my own well-being; I was concerned about going home and caring for my children, and I wondered if I would ever find love or somebody who would want me. Somebody who would find me attractive as I sit in a wheelchair with limited motor function.

During my presentation, two physicians walked out. I did not think anything of it as we were in the hospital rehab center, so they would have patients that they must tend to. However, after the presentation and questions, I made my way around the room and saw that the two physicians had returned. I asked them if they had any questions on anything they had missed due to them having to leave. Their response was, “No, I don’t think this is appropriate to be discussing as our patients need to focus on getting better, not on what they need in their sex lives.” This was the tipping point for me as I could not believe that health care professionals did not think their patients would not have concerns about intimacy in relationships or that their patients’ spouses or significant others would not have questions about what was going to happen in terms of intimacy in their relationship. It was then I decided that I was going to find out how a physical disability plays a role in intimacy in relationships and if any of the people I would speak to had received any sex education regarding their disability and what to expect. Hence, the research began.

I was nervous before interviewing the participants in this study for a couple of reasons. First, as I have been through some of the situations I was asking the participants about, I really wanted to ensure that I did not bring my own bias into the interviews. Therefore, before each interview I journaled what my own thoughts were, and after the interview I journaled more of what my own thoughts were and if they brought up any emotions. Second, I did not know what I was going to hear, and I was a bit fearful of how I was going to react. I did not want to be emotional as I did not want to show my own bias. The journaling helped a great deal during the interviews as I was able to control my own bias.

After the interviews and as Chapters 4 and 5 were coming together was when I began to struggle with myself. I become very angry, frustrated, and emotional because I knew how these participants were feeling and the struggles they were going through. For each of the stories that were told, I had a story that was very similar, that showed the feelings of depression, withdrawal, and “why me?” I found myself angry and frustrated because I still could not figure out or fathom why after all these years health care professionals and educators are still not broaching the subjects of sex, intimacy, and relationships with people with physical disabilities unless it had to do with reproduction.

I always think to myself that, obviously, sex happens because we are all here, so why is it that it is such a taboo topic to discuss, especially among those to whom we are supposed to entrust our feelings and desires regarding our health. As I went back over the interviews, my heart was torn for the study participants who stated that if they would have received better sexual education, they may not have been in some of the circumstances they were in. They were in some of these circumstances because they were trying to find out on their own how their bodies would react to sexual stimulation. They felt they had no health care professional or other educational resources they could turn to. It saddened me to think that there are so many individuals with and without disabilities who fear asking their health care professionals about their intimate relations because it is a topic that society deems is not acceptable to discuss.

Overall, conducting this study was a positive experience. I became more passionate about this topic and recognized just how vital the need is for further and more inclusive sexual education from health care professionals and in the schools. Teaching more inclusive sex education to health care professionals in medical school and to students in elementary schools could make a huge difference in our society. Inclusive sexual education includes the concepts of communication, a healthy relationship, disability, reproduction, and more. Society needs to get past the concept that sex and intimacy is something shameful to talk about. Sex and intimacy is not an ugly thing. It is a powerful and empowering concept that makes individuals feel good both physically and emotionally. Social change can happen with this research.

Conclusion

Human sexuality education is much more than the teaching and understanding of the reproductive system and sexual activity. Human sexuality education encompasses an ongoing process that allows individuals to learn and understand basic body awareness, receive health information regarding physical disabilities for individuals who have them, and learn how to communicate when approaching an intimate relationship as well as the decision-making process and social skills that go along with intimate relationships. Knowledge is available, and this knowledge can be empowering to individuals with physical disabilities. Acknowledging all of the basic human needs of individuals with physical disabilities can help to put aside the sexual silence they experience and allow them to embark on fulfilling their intimate desires and needs. My findings show that all participants in this study either have or crave intimacy, both emotionally and physically. It is time society puts the taboo of sex aside and stops the sexual silence for people with physical disabilities.

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Appendix A: Interview Questions

Hi, my name is Leanne Beers. Thank you for taking the time to talk with me. Your participation is greatly appreciated and valued for this study. I will be interviewing three other individuals and yourself for this project. First of all, your participation is totally voluntary, therefore, at any time I ask you a question and you don't want to answer or if you need to stop the interview at any time, just let me know. All of the information you provide today will be kept confidential, as well as, any written reports will not use your name instead I will use pseudonyms. The information you provide will be used to improve research education for future users. Do you have any questions? This interview will take no more than 30 minutes, is that time period okay for you?

In addition, I will be copying your responses into my own document; do I have your permission?

Yes *No*

If it is okay with you, I would like to record our conversation today. The recording will only be used by me to ensure the accuracy of my notes. In other words, I will be taking notes while we talk, and only use the recording to refer back to items I may have missed or feel that I misunderstood during our conversation. Once I complete my notes, I will immediately delete the recording. Is it okay with you if I record our conversation?

[If interviewee answers "yes," say: "okay, I will begin recording now."]

[If interviewee answers "no," say: "no problem, I will just take notes by hand."]

Let’s get started.

II. Questions

- What type of muscular dystrophy do you have?
- At what age was the onset of the muscular dystrophy?
- In your own words please describe your disability.
- Did you receive any human sexuality education (covering intimacy and relationships) during your school years?
  - *If no did school offer this education?*
  - *If school did offer human sexuality education please explain in your own words why you were not part of the education course?*
  - *If yes, did you participate in the human sexuality course and if so please explain what was covered.*
- Did you receive any human sexuality education (covering intimacy and relationships) after your school years from any healthcare professionals?
  - *If no did you feel comfortable asking?*
  - *If yes explain what was covered and by what kind of health care professional?*
- In your own words please explain what intimacy means to you.
- Please describe what a healthy relationship is.
- Describe what your first date was like?
- Have you ever been in an intimate relationship?

  - *If yes at what age was your first intimate relationship?*
  - *Did disability affect any of these relationships? Please explain... Role of partner?*
  - *If no do you feel your disability plays a part in not being in an intimate relationship? Please explain....*
- Please describe your sexual anxieties in terms of your muscular dystrophy that you encounter regarding an intimate relationship with a partner or in regards to sexual satisfaction with yourself.
- Is there anything else you would like to share regarding intimacy and/or relationship that I have not asked you about or that you would like to have the opportunity to say?

III. End Interview Questions

As we come to the end of the interview I would like to once again thank you for your time and your willingness to help with this project.

Appendix B: Confidentiality Agreement

CONFIDENTIALITY AGREEMENT

Name of Signer:

During the course of my activity in interviewing participants for this research: “Living With Muscular Dystrophy: Sexual Education” I will have access to information that is confidential and should not be disclosed. I acknowledge that the information must remain confidential, and that improper disclosure of confidential information can be damaging to the participant.

By signing this confidentiality agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including friends or family.
2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any confidential information except as properly authorized.
3. I will not discuss confidential information where others can overhear the conversation. I understand that it is not acceptable to discuss confidential information even if the participant’s name is not used.
4. I will not make any unauthorized transmissions, inquiries, modification or purging of confidential information.
5. I agree that my obligations under this agreement will continue after termination of the job that I will perform.
6. I understand that violation of this agreement will have legal implications.
7. I will only access or use systems or devices I’m officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

By signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

Appendix C: Resources

The following is a list of free or low-cost referrals and resources.

Universal Declaration of Human Rights
http://www.un.org/en/documents/udhr/index.shtml

National Organization for Human Services
http://www.nationalhumanservices.org/ethical-standards-for-hs-professionals
Strengthen the community of human services by:

- Expanding professional development opportunities.
- Promoting professional and organizational identity through certification.
- Enhancing internal and external communications.
- Advocating and implementing a social policy and agenda.
- Nurturing the financial sustainability and growth of the organization.

We believe in:

- The capacity of human growth and change.
- Advocating for social justice.
- Recognizing and utilizing peoples' strengths and abilities.
- Supporting physical, mental, emotional and spiritual health.
- Promoting collaboration and accountability.
- Including all members of the human services community.

About Human Services:

The field of Human Services is broadly defined, uniquely approaching the objective of meeting human needs through an interdisciplinary knowledge base, focusing on prevention as well as remediation of problems, and maintaining a commitment to improving the overall quality of life of service populations. The Human Services profession is one which promotes improved service delivery systems by addressing not only the quality of direct services, but also by seeking to improve accessibility, accountability, and coordination among professionals and agencies in service delivery.

American Association of Sexuality Educators, Counselors and Therapists
https://www.aasect.org/

- The American Association of Sexuality Educators, Counselors and Therapists (AASECT) is a not-for-profit, interdisciplinary professional organization. In addition to sexuality educators, sexuality counselors and sex therapists, AASECT members include physicians, nurses, social workers, psychologists, allied health professionals, clergy members, lawyers, sociologists, marriage and family counselors and therapists, family planning specialists and researchers, as well as students in various relevant

professional disciplines. These individuals share an interest in promoting understanding of human sexuality and healthy sexual behavior.
- AASECT affirms the fundamental value of sexuality as an inherent, essential, and beneficial dimension of being human.
- AASECT accepts as its mission the advancement of the highest standards of professional practice for educators, counselors and therapists.
- In general, AASECT opposes all psychological, social, cultural, legislative, and governmental forces that would restrict, curtail or interfere with the fundamental values of sexual health and sexual freedom that we espouse. AASECT also opposes all abuses of sexuality including, but not limited to, harassment, intimidation, coercion, prejudice, and the infringement of any individual's sexual and civil rights.

Sexuality Information and Education Council of the United States
http://www.siecus.org/

- SIECUS affirms that sexuality is a fundamental part of being human, one that is worthy of dignity and respect. We advocate for the right of all people to accurate information, comprehensive education about sexuality, and sexual health services. SIECUS works to create a world that ensures social justice and sexual rights.
- SIECUS educates, advocates, and informs.

- Educate: We help schools and communities develop comprehensive sexuality education curricula, train teachers to provide high quality sexuality education in the classroom, and help parents talk to their kids about sex.

- Advocate: We educate policymakers and their staff about issues related to sexuality and train advocates on the local, state, and national levels to build support for comprehensive sexuality education and access to reproductive health information and services.

- Inform: We produce countless resources for a wide variety of audiences—from policymakers to parents, healthcare providers to teens—to ensure that everyone has access to accurate, complete, and up-to-date information about sexuality.

The Electronic Journal of Human Sexuality
http://www.ejhs.org/tocv16.html