The Pursuit of Intimacy:

An Examination of Intimate Relationship Development for Women with Visible Physical Disabilities, a Consensual Qualitative Research Study

By

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CHAPTER ONE

Now there are also a lot of people that are just in the same boat of not having had the permission or invitation or whatever it takes to figure this [intimacy] out. Some people are just in the same boat... Like they missed class that day or something.

Introduction

Personal relationships and intimacy enrich and give meaning to our lives. They are both a source of, and a means of, expressing connection, love, joy, creativity, desire, identity, and individuality. Relationships and intimacy develop across a lifespan and provide many opportunities for growth and personal discovery. However, research indicates that some people with disabilities encounter obstacles in their attempts to develop relationships and explore and express their intimacy and sexuality. Adults with disabilities, who seek appropriate intimate relationships, are not operating on a level playing field. (R. J. Anderson & Antonak, 1992; Wright, 1983)

Harlan Hahn, a political scientist and a leader in the disability rights movement, in a speech said, "Like most activities in modern society, the search for conjugal partners is a competitive process in which men and women who approximate cultural ideals of physical attractiveness enjoy a decided advantage," (Harlan Hahn, *n.d.*). Physical attraction is considered an essential underpinning for intimate relationships. This may put an undue burden on people with disabilities as physical differences may be viewed as unattractive or asexual (references).

Statistics indicate that 12.6% of Americans have disabilities (Brault, 2012.), of those more than 10 million have physical disabilities. For most people, sexuality and its expressions are natural and important components to quality of life (Felce & Perry, 1997). Physical and mental impairments may alter functioning, but do not eliminate the need for intimacy (Nosek et al., 1996). However, people with disabilities may be significantly disadvantaged in the development and pursuit of satisfying intimate relationships due to a confluence of negative societal attitudes and values towards the sexuality of people with disabilities, as well as perceived and actual limitations due to disability (Chen, Brodwin, Cardos, & Chan, 2002; Milligan & Neufeldt, 2001).

Intimacy is notoriously difficult to define, and intimate relationship development even more so. Intimacy may exert profound influences on social and personal development as well as physical health (Moss & Schwebel, 1993). Moss and Schwebel (1993) state that, not only does intimacy play a critical role in passage through developmental stages, but it may also contribute to resistances to diseases and disabling conditions, as well as attributing to a lower rate of mental illness (Traupmann, Eckels, & Hatfield, 1982).

There have been many people who have tried to define intimacy. Definitions range from general, to dimensional, to operational, and still the word is vague. General definitions of intimacy have usually been based on personal interpretations of the meaning of intimacy (Billow & Mendelsohn, 1982) or were based on a larger theoretical model of human behavior (Erikson, 1993). General definitions often referred to close associations, disclosing openly and warmly, and being vulnerable (Nowinski, 1989). While general definitions tend to encapsulate the global nature of intimacy, they leave a lot to be desired when it comes to interpretation and operationalization.

Multidimensional definitions of intimacy, while also subjectively derived (Moss & Schwebel, 1993), often have empirical foundations. Researchers analyzed statements about the meaning of intimacy and developed scales related to a multidimensional theory (McAdams, 1988). These scales would formulate into component parts on which to be measured (McAdams, 1988; Waring, 2013). However, it seems as though people with disabilities are often left out of the research with regard to intimate relationships. It stands to reason that some disabilities may preclude some of the component parts of these factor definitions of intimacy.

Operational definitions of intimacy are grouped into three large categories; behavioral manifestations, self-report, and relationship status indicators (Moss & Schwebel, 1993). However, operational definitions are often not comprehensive in that they often rely on other constructs or are confined to certain bounded behaviors. Operational definitions may include amount and type of self-disclosure (Buhrmester & Furman, 1987), marital satisfaction (Chelune, Vosk, Waring, Sultan, & Ogden, 1984) or amount of physical contact (Heslin & Boss, 1980).

Moss and Schwebel (1993), attempted to combine the general, multidimensional, and operational definitions into a unified definition of intimacy by analyzing themes and components.

> *Intimacy in enduring romantic relationships is determined by the level of commitment and positive affective, cognitive, and physical closeness one experiences with a partner in a reciprocal (although not necessarily symmetrical) relationship (p. 20)*

The formal definition that specifies five components of intimacy: (a) Commitment; (b) Emotional Intimacy; (c) Cognitive Intimacy; (d) Physical Intimacy; and (e) Mutuality (Moss & Schwebel, 1993).

For the purposes of this study, this is the definition that was used to explain intimacy to participants, however the word “romantic” was removed from the definition. Specifically, the definition was focused on the qualities that attract individuals to each other and the reciprocity related to intimacy. Affective intimacy refers to feelings of caring, compassion and the exchange of emotions. Cognitive Closeness refers to the shared goals and values. Physical closeness can refer to shared physical encounters including, prolonged proximity, as well as sexuality. Finally, reciprocity implies a mutual interaction in the exchange of the affective, cognitive, and physical parts of intimacy. Also for this study, the development of intimacy, as described above, was explored in relation to dating. This can take many forms in which people explore intimacy, as described above with differing levels of tentativeness and reciprocity.

Most people seek and actively expend effort towards developing intimacy in their lives and as such, intimacy has been identified as a factor that helps individuals maintain their physical and mental health (Alpass & Neville, 2003; Kawachi & Berkman, 2001; Wallston, Alagna, DeVellis, & DeVellis, 1983). Despite this, intimacy is a relatively understudied facet of human interaction. This may be due in part to the complexity of the construct, and the difficulties such complexity adds for researchers. Additionally, intimacy research focused on people with disabilities is even more lacking because, in general, people with disabilities are not thought of as intimate beings.

Assumptions and Theoretical Frameworks

Prior to the 1970's, there was little or no research conducted on the sexuality of people with disabilities (Milligan & Neufeldt, 2001). Since then, the sexuality of people with disabilities has received some attention, but not proportionally to those without disabilities. According to Nosek et al., (1996), the lack of research efforts regarding the sexuality of persons with disabilities reflects a general failure of society, as well as, the behavioral sciences to identify sexuality as an important issue of people with disabilities. Although less pervasive today than in the past, there are myths surrounding the sexuality of people with disabilities that include; asexuality, lack of sex drive, being unable to partake in sexual activity, and lack of social judgment to behave sexually in a responsible manner (P. Anderson & Kitchin, 2000).

Stigmatizing effects of disability. Research indicates that stigmatizing effects of disability can lead to negative appraisals and reduced social acceptance, avoidance behaviors, or rejection by nondisabled people (R. J. Anderson & Antonak, 1992; Livneh, Chan, & Kaya, 2014; Wright, 1983). There exists little literature with regard to the sexual self-concept and sexual self-efficacy of persons with disabilities. People with disabilities may internalize stigma, which can lead some people with disabilities to retreat from intimacy and adopt a nonsexual lifestyle. Intimacy is shown in the literature to be highly correlated with Quality of Life; therefore, it would stand to reason that understanding issues related to intimacy for persons with disabilities be a priority for study.

Disability identity. Disability is regarded as a multidimensional identity mediated by numerous roles, expectations, goals, and perceptions that each person integrates into their concept of self (Ferreira & Fox, 2008). People with disabilities are a group particularly at risk for mental health disorders such as depression, anxiety, and stress, but additionally, social withdrawal and lack of motivation. These mental health and overall quality of life degradations may be the result of other people's reactions to people with disabilities in the form of stigma and social oppression, which can lead to an undermining of their psychosocial and psychoemotional well-being (Ferreira & Fox, 2008). People with congenital disabilities tend to report higher anxiety and lower feelings of mastery, self-esteem, and psychological well-being when compared to those with acquired disabilities.

Psychosexual development. Literature, regarding the sexuality of people with disabilities, often focuses on education and sexual health. While sexual health, education, and well-being are important aspects of psychosexual development, little attention is given to the steps that lead up to intimate contact (Barongo & Nyamwange, 2013; Boyd & Bee, 2012). It is important to consider sexuality more broadly and include positive aspects of sexual well-being, and not simply prioritize only the absence of disease or the limiting of risk behaviors. Instead, the goal of this review is to assess the available measurement instruments regarding the sexuality of people with disabilities, in an effort to broaden the current conceptualization of sexual well-being to include positive aspects of sexuality including but not limited to sexual self-concept and sexual self-efficacy.

According to developmental theorists, a major life task facing all adults is the establishment of intimate relationships with others (Erikson, 1993; Erikson & Erikson, 1998). Developmental stages, according to Erikson are eight individual processes that a healthy developing individual passes through during the course of their life. According to Erikson (1963) there exist separate stages, all present at birth, but only begin to unfold according to natural timelines and environmental upbringing. Each stage builds upon the previous stages and negotiation of each stage is largely a function of sociocultural forces. Each stage is characterized by a psychosocial crisis of two conflicting forces. According to the theory, effective achievement of each stage results in a healthy personality and the attainment of essential qualities, which are used in the resolution subsequent crises. Failure to successfully complete a stage can result in a diminished ability to complete other stages, and therefore a more unhealthy sense of self. However, these stages may be resolved successfully at a later time.

Within the realm of intimacy and sexual self-concept, at least two of Erikson's major life stages are at play. The first of these two stages, and Erikson's fifth overall stage, is Identity vs. Role Confusion (Erikson, 1994). The teen years are a time of great change. During this time, sexual organs mature, new expectations for social and academic adjustment arise, self-image typically suffers, and life tends to be very stressful (Fleming, 2004). Erikson describes this stage as "a turning point of increased vulnerability and heightened potential" (Erikson, 1963, p. 96). While many changes happen during this stage, this is the stage where young people develop a sense of self-identity and sexual self-identity. According to (Boyd & Bee, 2012), what should happen at the end of this stage is a newly integrated sense of self, of as well as one's appropriate sex role.

The sixth stage of development according to Erikson (1963) is Intimacy versus Isolation. Erikson viewed intimacy as a mutual sharing with another person as the basic strength of this stage, and isolation as its core pathology if intimacy is not achieved. Erikson believed that intimacy was only possible if each person had developed strong senses of self-identity separately (Fleming, 2004). Erikson stresses the idea of “genital utopia” (Erikson, 1993; Erikson, n.d.) to illustrate the many modalities intimacy can take to fully realize this stage. Erikson’s criteria for this are; mutuality of orgasm, a loved opposite-sex partner, a shared trust, as well as regulation of cycles of work, procreation and recreation.

Attachment. Attachment theory is a psychological construct that seeks to explain human response dynamics of long and short-term interpersonal relationships (Waters, Corcoran, Anafarta, & Waters, 2005). All infants, when provided a caregiver, become attached and develop bonds with that caregiver (Ainsworth, Blehar, Waters, & Wall, 1997). Individual differences in the quality of the bonded relationships have an effect on how the infant, and eventually adult, respond to relationships when hurt, separated, or they perceive a threat. This theory was later extrapolated by Ainsworth and Bowlby that the human drive for intimate and close relationships is an innate biological trait that has been evolutionally selected (Ainsworth & Bowlby, 1991).

Self-concept and sexual self-concept. Self-concept includes many areas including, personal, academic and sexual, and serves to answer the question “Who am I?” (Barongo & Nyamwange, 2013). Within self-concept is sexual self-concept, and that serves to answer the question, “Who am I as a sexual being?” The development of, and subsequent integration of, sexual self-concept into a greater overall identity is vital to the process of developing healthy multidimensional constructs of identity (Luyckx, Schwartz, Goossens, Beyers, & Missotten, 2011).

Social cognitive theory. Social cognitive theory (SCT) holds that an individual’s knowledge and actions are directly related to the observation of others within social interactions and experiences (Bandura, 2001). People develop a schema in which their behavior is dictated by three component parts. First, self-efficacy is the belief of a person about his or her own abilities to correctly complete the behavior. Second, outcome expectancy is the expected response after a given behavior. And finally, environmental aspects influence an individual's ability to complete the behavior successfully. SCT may be particularly useful as a framework for intimate relationship development for people with disabilities. Imperative to psychosexual development is the observation of modeling from others to develop social schema. Self-efficacy and outcome expectations are built through this modeling, as well as, environmental facilitation or hindrance.

Communication. Sexual communication is commonly highlighted as influencing sexual health behavior (Quinn-Nilas et al., 2015). Due heavily to myths surrounding the sexuality of people with disabilities such as, asexuality, lack of sex drive, inability to partake in sexual activity, and lack of social judgment (P. Anderson & Kitchin, 2000), people with disabilities have been denied the same psychosexual developable milestones as their non-disabled peers, either through lack of experience or lack of education. Because of this, lack of sexual competency and lack of decision autonomy, people with disabilities are at a considerable disadvantage when it comes to intimacy.

Statement of Research Problem

There are two main problems with dominant practice and research when it comes to intimate relationship development for people with disabilities. Either researchers and therapists believe there is no problem, and people with disabilities can find suitable partners as easily as non-disabled persons, or there is nothing to be done. Neither is true and neither is particularly comforting to people with disabilities. There is no value in denying that disability reduces chances of intimate relationship development, and there is no value in acknowledging that the situation is hopeless.

Developing and maintaining quality relationships with others may be one of the most meaningful and difficult tasks we undertake in life, and it is of particular importance due to its strong impact on our overall happiness and quality of life. We develop many different kinds of relationships throughout our lives, including family relationships, casual acquaintances, romantic relationships, schoolmates, work colleagues, and friendships. The disability rights movement and related legislation (e.g., the Americans with Disabilities Act) initiated many changes related to disability, which have improved the level of inclusion and acceptance of people with disabilities in society. However, despite these changes, stigma continues to dramatically affect the relationships that people with disabilities have. For most people, intimacy and its expressions are natural and important components to quality of life (Felce & Perry, 1997). Physical and mental impairments may alter functioning, but do not eliminate the need for intimacy (Nosek et al., 1996). Stigma creates a divide between people with and without disabilities. This divide impacts every type of relationship formed by people with disabilities, from friendships, to dating, to intimate relationships. Every type of relationship people with disabilities form is impacted. People with disabilities may be significantly disadvantaged in the pursuit of satisfying intimate relationships due to a confluence of reasons, including but not limited to, negative societal attitudes and values towards the sexuality of people with disabilities, as well as perceived and actual limitations due to disability (Milligan & Neufeldt, 2001).

Research Goals and Questions

The proposed research may have utility for both practitioners as well as lay people with disabilities. The solution to increasing the level of intimacy development for people with disabilities is clearly not achieved through engaging in a constant struggle to help promote a counter-cultural acceptance of physical appearance and attractiveness. Nor would it be helpful to adults and teenagers with disabilities to attempt to revive some long-lost notion of association between sensuality and physical difference. Additionally, constant striving to copy cultural standards of physical attractiveness impose an oppressive weight on everyone, not just people with disabilities. Moreover, not simply related to cultural standards of beauty and stigma, people often only have a vague notion of why they are not achieving certain levels of intimacy in their relationships. Taking a somewhat positive deviance strategy may be helpful in understanding the positive implications of this type of research. Positive deviance is behavioral and social change approach based on the observation that in every group there are certain individuals whose unique actions and approaches enable them to find better solutions to problems when compared to their peers, despite facing comparable or worse challenges (Marsh, Schroeder, Dearden, Sternin, & Sternin, 2004). Positive deviance is a strength-based approach that seeks to enable a community to discover successful behaviors and strategies, then promote them. A better understanding of intimacy development for people with disabilities may be useful to empower people to examine and refine strategies for developing intimacy.

Research questions. As people age, development of intimate relationships, both sexual and non-sexual are important contributors to overall quality of life for people with and without disabilities. Most of the research available on intimate relationship development seems to have been done on people without disabilities, however, since people with disabilities face unique challenges in the development of such relationships, it is important to better understand these difficulties so as to potentially address them, not only those who are currently seeking intimate relationships, but also those who will in the future pursue intimacy. The goal of this qualitative research is to add to the overall knowledge regarding the primary research question: What are the overall subjective experiences of women with visible physical disabilities in developing intimate relationships?

Within the primary research question, two additional areas of exploration were investigated. (1) What aspects of intimacy and sexuality are most important for women with visible physical disabilities? (2) What are some of the challenges of and facilitators to intimate relationship development that women with physical disabilities have experienced?

CHAPTER TWO

Literature Review

Attitudes about Sexuality

Attitudes about sexuality and disability can lead to internalization of negative attitudes and beliefs (DeLoach, 1994). These attitudes and beliefs can sometimes become self-fulfilling prophecies, leading people with disabilities to refrain from intimacy and sexuality (Milligan & Neufeldt, 2001). A review of research shows that sexual acts involving people with disabilities are viewed more negatively than when those same behaviors are considered in the context of non-disability (Milligan & Neufeldt, 2001). Persons with disabilities have been found to be more readily accepted as colleagues and casual friends than dating partners (Olkin & Howson, 1994). Wright (1983) states that having a disability impairs people from having intimate needs met and impairs the capability of expressing their sexuality. This can be especially harmful when global devaluation takes place so that people with disabilities feel less worth, less valuable, and less desirable as people. Negative attitudes towards the sexuality of people with disabilities can be expressed in many areas of life ranging from patronizing, avoidance, rejection, and to abuse that can be physical, emotional and sexual (Katz, Shemesh, & Bizman, 2013).

Common Beliefs

Sexuality and Quality of Life (QoL) are very tied together (Cummins, 1996; Cummins, McCabe, Romeo, Reid, & Waters, 1997), yet the association has received almost no attention in relation to people with disabilities. People with disabilities may have difficulties with interpersonal relationships, and few of them have received assistance regarding their confidence in initiating intimate relationships. There may be links between body image, health, sexual and social relationships, as well as levels of sexual knowledge and experience.

There exist three common core beliefs regarding the sexuality of people with disabilities (Juergens, Smedema, & Berven, 2009). The first belief is that people with disabilities have more important things to deal with and sex cannot be a priority in their lives (Kaufman, Silverberg, & Odette, 2007). The second belief is that the opportunities for people with disabilities to find intimate gratification is so limited that their sexual needs are absent or subjugated (Milligan & Neufeldt, 2001). Finally, there is a belief that non-disabled people see people with disabilities as essentially helpless, and therefore they are not acknowledged to be sexual (Kaufman et al., 2007).

Physical and mental impairments may alter functioning, however they do not eliminate the need for love, affection, and intimacy. Negative societal values and attitudes towards the sexuality of people with disabilities, combined with real and/or perceived limitations, may lead people with disabilities to being significantly disadvantaged in the pursuit of satisfying intimate relationships. Societal and cultural beliefs surrounding disabilities has put people with disabilities at a serious disadvantage during critical stages of sexual identity development. People with disabilities are often prevented from exploring and learning about their own sexuality, as they may not be exposed to the same psychosexual developmental opportunities as people without disabilities (Weissinger, 1980). This can be extremely detrimental to the self-esteem of people with disabilities to be considered unattractive and have essentially a nonsexual status in society (Milligan & Neufeldt, 2001). It is often perceived that people with disabilities are unable to function sexually and believed to be incapable of or lack interest in sexual fulfillment (Webb, 1994). In some, or many cases, perceived, or actual rejections may lead some people with disabilities to retreat from intimacy and adopt a nonsexual lifestyle.

Attachment

Attachment theory is a psychological model that centers around the human response dynamics of long and short-term interpersonal relationships when hurt, separated from loved ones, or perceiving a threat (Waters et al., 2005). The theory postulates that personality development and enduring patterns of social interaction result from caregiver response during infancy (Ainsworth et al., 1997). This theory was later extrapolated by Ainsworth and Bowlby that the human drive for intimate and close relationships is an innate biological trait that has been evolutionally selected for (Ainsworth & Bowlby, 1991).

Because infants are unable to escape unpredictable and insensitive caregiving relationships, they are forced to form attachments with whomever provides most of their care (Holmes, 2010; Umemura, Jacobvitz, Messina, & Hazen, 2013). Infants must manage themselves as best they can whoever is providing them primary care, despite the type of care they are receiving (Ainsworth & Bell, 1970). Based on her Strange Situation Protocol, Ainsworth and colleagues observed infant responses to the procedures of the experiment. They determined that children have differing patterns of attachment depending on how they experienced their primary caregiving. Early attachment seemed to shape, but not determine, expectations in later relationships (Bretherton & Munholland, 1999). Initially three, then eventually four different attachment styles were identified in children: secure, anxious-ambivalent, anxious-avoidant, and disorganized attachment (Main & Cassidy, 1988). Secure attachment is the result of proper care. Avoidant attachment is associated infant care that does not provide appropriate support for emotional regulation. Ambivalent attachment is the result of inconsistent infant care. Finally, disorganized attachment usually results from of explicit abuse and neglect (Main, 1986).

In the 1980s, the theory was extended to adults by Hazen and Shaver (Hazan & Shaver, 1987, 1994). They noticed that interactions between adults, specifically romantic partners and adult parents, shared similarities to interactions between children and caregivers. Hazen and Shaver explained the working models that underlie attachment styles contain information about the self and information about others. These working models are organized into 3 tiers of relational schema, models of all relationships, models of relational relationships (e.g. friends, parents, intimate partners) and models of specific relationships (Hazan & Shaver, 1990).

Attachment style is relatively stable (Baldwin & Fehr, 1995; Kirkpatrick & Hazan, 1994; Waters, Merrick, Treboux, Crowell, & Albersheim, 2000); however, some people do experience changes in attachment style. These changes can occur over relatively short periods of time such as weeks and months (Baldwin & Fehr, 1995). There is evidence that negative life experiences tend to affect attachment style (Hamilton, 2000; Waters et al., 2000). Davila, Karney and Bradbury have identified several factors that cause changes in attachment style: situational events and circumstances, changes in relational schemas, personality variables, and a combination of personality variable and situational events (Davila, Karney, & Bradbury, 1999).

With regards to intimacy, Bowlby (2005) wrote:

> Attachment theory regards the propensity to make intimate emotional bonds to particular individuals as a basic component of human nature, already present in

> germinal form in the neonate and continuing through adult life into old age. (pp. 120-121)

Relevant Behaviors

Because of functional limitations and societal barriers, people with disabilities might have difficulty participating in social activities. This may consequently lead to social marginalization and isolation. Isolation limits opportunities for social interaction, including dating and sexual activity. A survey of people with disabilities reported that the lack of available partners was the most frequent reason for sexual dissatisfaction (Di Giulio, 2003).

There also exists a difference between congenital and acquired disabilities. People with congenital disabilities may have stunted psychosexual development due to neglect of that particular area by parents as well as inadequate peer interactions. This may contribute to social inhibition (Hwang, 1997) and lack of sexual experimentation . People with congenital disabilities have been found to have lower levels of sexual knowledge and experience compared to their able-bodied peers. They are given little privacy and fewer opportunities to talk to peers and friends about sexuality. They are given fewer opportunities for the development of relationships as well (Thomas, Bax, & Smyth, 1989). Functional limitations may limit social networks outside of school settings, a circumstance which limits opportunities for normative social interactions. Additionally, adolescents with disabilities may encounter negative reactions to peers in regards to attractiveness, personal characteristics, and their suitability for friendship or dating (Gordon, Tschopp, & Feldman, 2004). This may lead to increased isolation at a time when social development is critical to learning about sexuality from their peers. Because of all of these factors, adolescents with congenital disabilities may not grow up having a clear sense of their sexual identity, and may believe they are asexual (Mona, Gardos, & Brown, 1994).

Research has been done that indicates that young people with disabilities do not socially develop in terms of their sexuality at the same rate as their non-disabled peers. Research indicates that dating occurs with a significantly lower frequency among adolescents with a physical disability (Börjeson & Lagergren, 1990).

People who acquire disabilities later in life face similar but different issues related to their sexuality. People who acquire disabilities may experience problems modifying physical, psychological, emotional and sexual components of their identity as the result of their acquired disability. If disability occurs after their psychosexual development, they may experience a profound sense of loss and might have to adjust to a new way of experiencing sexuality (Charmaz, 1994). Typical discussions of sexuality are performance oriented and focus on sexual acts, sexual function, beauty, and size. Social and empirical evidence demonstrates discriminatory attitudes toward people with disabilities who try to obtain and maintain sexual relationships (Milligan & Neufeldt, 2001). These societal norms of beauty, power, and productivity may present challenges to developing positive approaches to sexuality (Di Giulio, 2003). Acquired disability may affect many aspects of a person’s life, and they may be forced to come to grips with sexual limitations associated with disability. These effects may include actual and perceived physical limitations, actual and perceived changes in attractiveness, and misconceptions about sexual functioning following a disability.

With all of these factors in mind, it seemed clear that intimate relationships are an essential part of the quality of life and life satisfaction for people with disabilities. While sexual health, education, and well-being are important aspects of psychosexual development, little attention is given to the steps that lead up to intimate contact. It is important to consider sexuality more broadly and include positive aspects of sexual well-being, and not simply prioritize only the absence of disease or the limiting of risk behaviors. Instead, the goal of this review is to examine constructs important for people with disabilities, in an effort to broaden the current conceptualization of sexual well-being to include positive aspects of sexuality in an effort to normalize intimacy for people with disabilities.

Identification of Behaviors and Beliefs

Because of functional limitations and societal barriers, people with disabilities might have difficulty participating in social activities. This may consequently lead to social marginalization and isolation. Isolation limits opportunities for social interaction, including dating and sexual activity. As stated previously, people with disabilities reported that the lack of available partners was the most frequent reason for sexual dissatisfaction (Griffith, 2000). Particularly, young people with disabilities do not develop psychosexually and psychosocially at the same rate as their peers without disabilities, and dating occurs at a significantly lower rate, and later among adolescents with disabilities (Börjeson & Lagergren, 1990).

With all of these factors in mind, it seemed clear that intimate relationships are an essential part of quality of life related to people with disabilities. The self-efficacy scales available for people with disabilities are primarily focused on sexual health behaviors. While I could not find specific behaviors related to the initiation of an intimate relationship, three independent researchers have developed three underlying parameters, related to sexual self-efficacy based on (Knapp, Vangelisti, & Caughlin, 2014) stages of intimate relationships, for people with disabilities. These behaviors are initiation, communication, and outcome expectancy.

Self-Concept

Self-concept is the collection of self-schemas and the interaction between those schemas with self-esteem, self-knowledge, and the social self to form a concept of the self as a whole. Self-concept encompasses past, present and possible future selves which may have an impact on certain behaviors (Markus & Nurius, 1986). Self-concept encompasses many domains including, personal, academic and sexual. Self-concept usually serves to answer the question of “Who am I?” (Barongo & Nyamwange, 2013).

Sexual Self-Concept. Within the realm of sexuality, self-concept is an important subject because it may be the starting place for which researchers can bridge the gap between sexuality and life satisfaction. People with disabilities, for various reasons stated in the literature review, are conditioned to think of themselves without sexuality. Flanagan (1978) identified 13 life domains as being important for quality of life. Bishop (2005) in his Disability Centrality Model stated that quality of life was moderated by domain importance, and therefore only those life domains deemed as important contributed greatly to the quality of life of an individual. For the purposes of measurement, sexuality of people with disabilities has not usually had a great impact on their quality of life, however, this effect may be due to societal removal of that importance. People with disabilities are conditioned to devalue their own intimacy and therefore it may not play as large of a role in their overall quality of life. This has led to gaps in the literature involving the intimacy of people with disabilities and must be corrected.

Sexual identity, or the concept of one’s self as a sexual being, has been traditionally equated with sexual orientation or perceived gender identification (Berkey, Perelman-Hall, & Kurdek, 1990). However, sexual identity and sexual self-concept go deeper than this. True and accurate conceptualization of sexual identity incorporates, understanding of people’s sexuality, how they derive these understandings, and how those understandings influence sexual interaction and behavior Breakwell & Fife-Schaw, 1992)

Breakwell & Millward (1997), utilize the theory of social representations (Moscovici, 1988) to interpret the relationship between the societal definition of socially imposed societal categories and a personal definition of self. Breakwell and Millward (1997) state that self-definitions shape the readiness of an individual to accept and use particular social representations to organize their behavior. They then utilize the example of women who view themselves as “feminine” as more likely to accept and identify with traditional societal representations prescribed to traditional feminine traits (e.g., passivity and chaste). Certain societal representations restrict identity possibilities as well as actions, and as such, women may take steps to fulfill societally imposed roles so as not to invalidate their own perceptions of themselves. Therefore, identity is a function of the tension between societal representations of an identity and available challenges to that identity.

Breakwell and Millard (1997) describe that sexual self-concept emerges around various identities. Specifically, they focus on male and female identities and the self-concepts for males dimensioning around socioemotional and relational aspects while female self-concept dimensions around assertiveness. It would stand to reason that disability identity might have a particular dimension of sexuality self-concept that is of itself unique. Sexual self-concept likely relates to the sexual experience and activity of an individual, as well as the importance that individual places on their sexuality. For people with disabilities societal concepts of sexuality do not readily include them, and as stated in the literature review previously, this may lead to a devaluation of sexual identity personally and societally. It is important that self-concept is taken into account as well when looking at the sexuality for people with disabilities. It is also important to remember that people are the products of multiple identities and that these identities may play a large role in their sexual self-concept.

Self-Efficacy and Outcome Expectations

Renowned psychologist, Albert (Bandura, 1977, 1986) defined self-efficacy as one's belief in their ability to succeed in specific situations. Therefore, one’s sense of self-efficacy can play a major role in how one approaches and motivates to achieve goals, accomplish tasks and tackle challenges. The level of self-efficacy one can determine certain factors such as resilience. For all the reasons stated above, people with disabilities are often excluded from the realm of sexuality. Self-efficacy related to intimate relationships might be a specific route of intervention for people with disabilities.

Self-Efficacy. According to Bandura (1977), perceived self-efficacy is related to an individual’s beliefs they can do a particular task or set of tasks. Self-efficacy is built on the principle that cognitive processes mediate behavior and that our cognitions are shaped by the experience of mastery resulting from successful task performance (Bandura, 1977; Strauser, 1995). Self-efficacy is both domain and task-specific, meaning that individuals can have high self-efficacy in one domain or task while having low self-efficacy in another.

Gist (1987) states that self-efficacy often works cyclically in both positive and negative directions to alter performance. For instance, people with high self-efficacy tend to engage more in tasks related to activities and persist longer in coping efforts. This persistence leads to higher occurrences of mastery experiences, which in turn leads to increased self-efficacy. Conversely, individuals with low self-efficacy tend to give up more easily in challenging situations, which serves to reinforce low self-efficacy (Gist, 1987).

Multi-domain measures reveal the patterning and degree of generality of people's sense of personal efficacy. There is no all-purpose measure of perceived self-efficacy. The "one measure fits all" approach usually has limited explanatory and predictive value because most of the items in an all-purpose test may have little or no relevance to the domain of functioning. Moreover, in an effort to serve all purposes, items in such a measure are usually cast in general terms divorced from the situational demands and circumstances. This can leave vagueness about what is truly being measured, and therefore scales of perceived self-efficacy must be tailored to the specific domain of functioning that is the object of importance.

Outcome Expectations. Complimentary to the construct of self-efficacy is that of outcome expectations (Bandura, 1977). Outcome expectancies are people's estimate that a given behavior will lead to certain outcomes (Bandura, 1977). Self-efficacy and outcome expectancy both effect behavior but are distinctly different, and it is possible for individuals to have high levels of one without high levels of the other (Bandura, 1997). Bandura (1997) described characteristics of behavior types that arise at a given level of self-efficacy and environmental responsiveness. He described people as developing successful and motivated attitudes if they have positive attitudes towards their own abilities and they are able to affect change in their environment. Bandura (1997) said that people would become depressed if people have a highly reactive and changing environment, but little to no faith in their own abilities. This leads people to stop trying. People become helpless when they have low confidence in their own abilities and are unable to affect change in the environment. This leads to an attitude that, trying is useless and continued effort is pointless. However, when a person has high confidence in their own abilities, despite an unresponsive environment, they will most likely increase efforts towards goal attainment or allow for flexibility toward shifting goals.

It is important to note that self-efficacy and outcome expectancy are two very distinct constructs with several areas of overlap. However, it is important to recognize that most of the interventions to address outcome-expectancy focus on the environment which a person lives in.

Sexual Health and Sexual Communication

It stands to reason that because of the factors mentioned in this literature review, lack of sexual competence, lack of decision autonomy and lack of timing, people with disabilities are at a considerable disadvantage when it comes to intimacy and may be at greater risk for sexually transmitted diseases. Poor verbal communication between partners may be a significant factor contributing to risk-taking. People who communicate more frequently with their partners about intimacy issues, such as HIV, pregnancy, condom use, and other contraceptive use issues are more likely to use contraception consistently.

Sexual communication is commonly highlighted as influencing sexual health behavior (Quinn-Nilas et al., 2015). Research by (Troth & Peterson, 2000) found that people who have optimistic attitudes about safer sex communication use condoms more frequently and employ other safer sex practices. (Grossman et al., 2008) found that more frequent discussion of condom use predicted consistent use and similarly less frequent discussion was predictive of unpredictable condom use.

It is important to consider sexuality more broadly to include positive aspects of sexual well-being and not simply prioritize the absence of disease or limiting risky behaviors. A broader conceptualization of sexuality allows for a view of sexuality as a normative part of overall well-being for people with disabilities. Encouraging positivity regarding sexuality has been shown to have important implications for the sexual health of adolescents (Philpott, Knerr, & Maher, 2006). Positive attitudes about sexuality have been shown increase effectiveness of HIV/STI and pregnancy prevention interventions and help encourage people to take the onus of having enjoyable and fulfilling sex lives (Ivankovich, Leichliter, & Douglas, 2013). It stands to reason that similar interventions may be useful for a person with disabilities considering the psychosexual impediments they face. A study showed that undergraduate students were more likely to use protection and report a positive first sexual experience if they rated the person they had that experience with as caring (Smiler, Ward, Caruthers, & Merriwether, 2005). Quality communication with sexual partners is associated with the positive outcomes of relationship quality and sexual satisfaction (Byers, 2005). General sexual communication, specific to disability (e.g., functional limitations, fantasies, desires, pain, positioning, etc.) may have untold benefits for people with disabilities.

Many people, especially those with disabilities often have difficulty discussing issues about sex with their partners. Self-efficacy may be a key factor in sexual communication for people with disabilities. While self-efficacy is commonly addressed in sexual health research, it is often associated with health or contraceptive behaviors. Specifically, condom self-efficacy is associated with more positive attitudes regarding condoms as well as increased use (Halpern-Felsher, Kropp, Boyer, Tschann, & Ellen, 2004).

There exist a number of scales that measure aspects of communication within relationships. Scales have been developed to measure communication frequency and well sexual communication self-efficacy. Halpern-Felsher and colleagues (2004) utilized single-item measures, while (Rostosky, Dekhtyar, Cupp, & Anderman, 2008), focused particularly on management of risky sexual behaviors. Quinn-Nilas and colleagues (2015) sought to address issues with other sexual-communication self-efficacy scales by expanding on existing scales and developing their own scale.

CHAPTER THREE

METHODOLOGY

A research paradigm is guided by assumptions about the world and how it should be studied (Denzin & Lincoln, 2005; Ponterotto, 2005). These assumptions address a wide range of subjects from ontology (the nature of reality), epistemology (the relationship between the researcher and the researched), axiology (the role of a researcher's values), rhetorical structure (language used to present research to an audience), to methodology. This research utilized Consensual Qualitative Research (CQR) as its primary research paradigm.

Consensual Qualitative Research Paradigms

There are three different qualitative research paradigms, positivism, post-positivism, and constructivism that are important in understanding the philosophical basis for CQR.

Positivism. Positivism is most exemplified with true scientific methodology and quantitative approaches. The focus of positivistic research is discovering objective truths through a priori hypotheses, controlled experimental methods, and inferential statistics (Stahl, Taylor, & Hill, 2012). Positivism espouses the idea that there is one true reality and that reality can be identified and measured (ontology). Positivists believe that the researcher and the researched exist independently and do not influence each other in a way that would introduce bias (epistemology). Positivists also believe that researcher values have no place in the research process (axiology) (Heppner, Wampold, & Kivlighan, 2007).

Post-Positivism. Post-positivism shares many similarities with positivism however it is subtly different. Similar to positivism, post-positivism utilizes experimental methods to control variables and test hypotheses (Heppner et al., 2007; Ponterotto, 2005). Post-positivists are different from positivists in their ontologies. Similar to positivism, post-positivism believes in an objective truth, however, post-positivism believes that only an approximation of the objective truth can be achieved (Ponterotto, 2005). Whereas a positivist might assume a generalizable truth through single experimentation, post-positivists assume an understanding of a version of the truth through multiple methodical experiments (Heppner et al., 2007).

Regarding epistemology, post-positivists take the stance that researchers and participants should remain independent, but they inevitably influence one another within the research process. Epistemologically, this is a slight difference from positivism, which allows for researcher objectivity and no influence of bias. Acknowledging the influence researchers can have on those being researched leads to some methodological means of addressing this. Researchers acknowledge bias and values and attempt to contain them through methodological means. For instance, research may utilize research assistants who are blind to the hypotheses of the study and/or conditions of the participants (Heppner et al., 2007; Ponterotto, 2005).

Constructivism. Constructivism differs from positivism and post-positivism in its ontological view that one true reality does not exist. Instead, there exist multiple realities which are all socially constructed. Constructivists believe that interaction between the researcher and participant is essential to understanding the lived experiences of those being researched (Sthal, Taylor, & Hill, 2012). Due to the nature of the paradigm, and the interest in lived experiences, methodologies tend to be more naturalistic and interactive. With regards to axiology, constructivist researchers acknowledge that the values of the researcher cannot be removed from the research process because values inherently affect interpretation (Heppner et al., 2007; Ponterotto, 2005). Constructivist researchers attempt to control the impact of their values and biases, by explicitly acknowledging them, a process referred to as "bracketing" (Heppner et al., 2007), as opposed to ridding or controlling for them, which they believe is impossible. Constructivist research often includes reports of researcher biases, values, and thought processes throughout the research process (Heppner et al., 2007; Ponterotto, 2005).

Constructivist research differs from positivist and post-positivist research in that, while the latter two focuses on determining, through experimentation if one condition is better than another, constructivist research utilizes the provision of vivid descriptions of experiences to.

Philosophical Underpinnings of Consensual Qualitative Research

Consensual Qualitative Research (CQR) is an inductive form of research that allows results to emerge from the stories and contexts given by participants. CQR consists of a team of researchers to collaborate and consensually analyze the data, as well as auditors to examine the work of the research team and provide feedback at each step of the process (Stahl et al., 2012).

Hill and colleagues in 2005 described Consensual Qualitative Research (CQR) as "predominantly constructivist with some post-positivist elements" (p. 197). CQR qualitative methods which are both naturalistic and interactive in that meaning is surmised from words and texts, the context of participants' responses, and the interaction of interviewers with participants through interview, probes, and clarifications (Hill et al., 2005; Ponterotto, 2005).

Ontology. With respect to the view of nature and realty, CQR holds to the constructivist view that reality is a socially constructed concept in which there are multiple and equally valid truths (Stahl et al., 2012). Researchers accept the unique qualities of experiences from individual participants while searching for commonalities in said experiences. CQR is not wholly constructivist in its ontology. CQR has an emphasis on researchers, auditors, and team members working to construct a version of the truth with the representation of data through the integration of multiple perspectives (Ponterotto, 2005). This leads CQR to being partially post-positivist in addition to constructivist. During the consensus process in CQR, a best representation of the data is sought after the researchers independently examine the data and formulate their own ideas of it (Hill, Thompson, & Williams, 1997). Individual perspectives are encouraged, respected, and combined, in addition to returning to the raw data to help capture the complexity of the data. Different team member's perspectives help to capture different nuances that no one member could achieve. The CQR process is designed to bypass the biases of any one researcher, as well as control for groupthink by allowing a variety of viewpoints to emerge and help the researchers best approximate the truth (Hill et al., 1997). CQR differs from other constructivist approaches because its consensus process circumvents the singular reliance of a researcher's understanding of the data, such as in grounded theory (Ponterotto, 2005; Strauss, Corbin, & others, 1990).

With regards to epistemology, CQR is again primarily constructivist with some post-positivist workings. CQR recognizes the mutual influence of the researcher and participants. Specifically, the interviewer not only learns about the phenomenon and experiences to be studied, but also helps the participant explore the experience through the interview process and utilizing follow-up probes (Burkard, Knox, & Hill, 2011). The post-positivist component of CQR's epistemology is the use of a standardized semi-structured interview protocol. The interview is flexible to query further information where needed in order to obtain the same types of information from each participant. This type of interview is more in line with post-positivist interviews as opposed to purely constructivist protocols which are more subject to change.

Axiology. Again, with regards to axiology, CQR sits firmly between post-positivism and constructivism. CQR acknowledges aligns with constructs in that it acknowledges that researcher biases as inevitable and states that they should be discussed explicitly. CQR holds that biases can be bracketed in such a way their influences on the data are minimized and the data reflects participants' views of their experience, not the researchers. Bracketing biases is an ideal held in both a constructivist and post-positivist alignment approach. CQR uses the post-positivist approach of interviewing by using the same semi-structured interview protocol for all the participants to minimize the impact of individual interviewers, however CQR also acknowledges that the interviewer biases impact the way they conduct the interview, which may shape the interview accordingly (Sim, Huang, & Hill, 2011).

While CQR exists mostly in a space between constructivist and post-positivistic, with leanings toward constructivism, the rhetorical structure of CQR is primarily post-positivistic (Stahl et al., 2012). Research is presented as objectively as possible with an avoidance of broad interpretations and use of third person to report the data. The goal of CQR is to summarize participants' experiences and find themes across participants with the hope of transferring results to a larger population (Hill et al., 2005; Ponterotto, 2005). The rhetorical structure, while primarily post-positivistic, has some constructivism present in that it contains quotations to better illustrate the lived experience of participants.

Study Appropriateness for Qualitative Research

The purpose of a CQR study is to explore or understand a phenomenon experienced by certain individuals. Our goal was to hear from people with disabilities themselves about the meaning of intimacy and the ideas related to the development of it. Current literature makes broad speculation based on quantitative data of self-efficacy (Knapp et al., 2014), self-concept (G. M. Breakwell & Millward, 1997), and quality of life (Bishop, 2005). A qualitative approach was especially suited for studying intimate relationship development to a depth that quantitative methods had failed to achieve. The goal of the research was to obtain rich contextual data about the factors that facilitated or impeded the development of intimate relationships for people with disabilities.

Research Team

According to Thompson, Vivino, and Hill (2012), both richness and validity of data in consensual qualitative research depend largely on the research team. A research team is traditionally composed of some combination of graduate students, professors and practicing professors (Hill et al., 2005). There are several criteria that are important for the development of a quality research team. Important criteria to consider when developing a successful consensual qualitative research team are commitment, experience, skill factors, personality factors, and teamwork.

The research team consisted of the author of the research two master's level students and one additional Ph.D. student. For the primary researcher and the two of the master's level students, CQR constituted a major time commitment. It was important that the team members actively participated and voiced their opinions. Their motivation contributed to the process overall. The process was explained thoroughly to the contributing team members.

While according to Vivino and colleagues (2012), experience is another important criterion when selecting team members, it was clear the masters level clinicians had limited to no experience with qualitative research. While researchers were assessed for the experience with research, they were also, and more importantly assessed for their other personality and other skills. Specifically, all of those from the research pool were clinicians in training, which, according to Hill, Thompson, and Williams (1997), make for good group members because of their openness to feedback, motivation, and good interpersonal skills. Group members were also addressed for extraversion, emotional constancy, openness to new experience, lack of dominance, and thoroughness (Driskell, Goodwin, Salas, & O'Shea, 2006). Personality traits and training seem to address and compensate for lack of experience.

The final considerations of the make-up of the research team were done with respect to as much diversity as possible. A diverse research team helped bring multiple perspectives to the research topic. Because of the complexity of the research topic, a diverse team lent itself to a more rich interpretation of the data. Additionally a more diverse team addressed special concerns that arose when conducting the research. While the primary researcher did all the interviews, other researchers were trained to administer the interviews in the event any of the participants preferred a female interviewer.

Compensation. It is unusual for team members to receive financial compensation for their participation in consensual qualitative research, however students have often received course credit because of the rigors of consensual qualitative research (Sim et al., 2010; Williams et al., 1998). However, since this researcher was not in a place to compensate researchers with additional course credit, the research team was provided with food at every research team meeting. The research team participated because they enjoy both the topic and the collaborative process, as well as the experience gained from research. Through additional research and additional experience with collaboration, researchers gained a developed understanding that can benefit them in the future both clinically and professionally.

Team structure. The research team was assembled by and headed by the principal investigator for whom this dissertation is being submitted for the requirements of obtaining his PhD in rehabilitation psychology. The team structure consisted of the principal investigator, a Ph.D. candidate, and two master's level students as investigators and additionally another Ph.D. student who served as auditor.

There may be some concerns with power differentials within the team that may affect the team process (Hill et al., 2005, 1997). Thompson et al.(2012) discuss that the presence of formal or social power by the principal investigator may cause students to be, at least initially, more reluctant to participate in the process of voicing their opinions due to concerns about alienation or deference to authority. Because there was a good chance that the principal investigator had served in a teaching and grading capacity previously for the master's level researchers and a chance the principal investigator would later serve again in a grading capacity towards the other master's level researchers, researchers were given a guarantee that their participation in the project had no positive or negative effect on their academic grades. If needed, or if they feel uncomfortable with the principal investigator grading them in the future, they were given the option to request an outside party to grade their work without consequence.

In consensual qualitative research, research teams can take several forms including set teams, rotating teams and multiple topic/dissertation teams (Vivinio, Thompson, & Hill 2012). Rotating teams consist of 4 to 12 team members who rotate doing all of the tasks associated with CQR. Rotating teams can analyze large sets of data (Vivino, Thompson, & Hill, 2012). Teams may also work on multiple dissertation teams that utilize the same interview protocol, but to study different topics. Teams rotate on responsibilities. The chosen form that the team takes in this project is a set team. The principal investigator was in charge of the development of the interview protocol as well as all of the interviews. As stated previously, at least one female researcher was trained in the interview protocol to aid in the comfort of female participants, if desired.

Training. Training is a key aspect for researchers new to CQR (Hill et al., 2005). Since the principal investigator has experience with CQR, he took the lead with regards to training. Training consisted of several informal steps that took place over the course of several weeks. First, each team member was asked to review the book *Consensual Qualitative Research: A Practical Resource for Investigating Social Science Phenomena* (Hill, 2012) and several exemplar articles (e.g., Knox, Burkard, Johnson, Suzuki, & Ponterotto, 2003; Vivino, Thompson, Hill, & Ladany, 2009; Williams et al., 1998). There were at least three meetings to discuss the process of CQR. The first meeting was an introductory meeting to describe the process of CQR in detail and review examples from previous studies. The second meeting consisted of practical exercises, during which team members practiced going through the steps of consensual qualitative research (developing domains, constructing core ideas, cross-analysis) and reaching consensual agreements using a small sample from a completed study. The final meeting was a review as well as a means of addressing bias.

Biases

Researcher bias is an evitable part of the qualitative research process and unquestionably affects the coding process and results. The addressing of such biases is an important part of the qualitative research process because the findings rely heavily on researcher interpretation of the data.

According to Fisher (2009), qualitative research that includes examples of how biases and assumptions have been identified and managed is regarded as more rigorous than research in which researchers do not examine their own assumptions. Bracketing addresses biases and expectations and allows CQR researchers to safeguard the data in a way that other researchers would likely come to the same understandings of the data (Fischer, 2009). Researchers participating in the study were asked to record their biases and expectations prior to interviews, then, compare those with the results at the end of the data analysis. If after that comparison, it was noted that, the results may have been improperly influenced by researcher preexisting assumptions, then researchers were to take appropriate steps to address those concerns. Seeing as no biases were identified as unduly influencing the data, no further steps were needed.

Additionally, the reporting of biases and expectations can help the intended audience understand research findings by putting within the researcher’s context (Hill et al., 1997) and understand researcher's perspective (Fisher, 2009), as well as take a different perspective if they wish.

Defining bias and expectations. The term bias typically has a negative connotation and as such, biases may be difficult to report. It is important to note that biases can be both positive and negative, but because of the connotation of the word, many first thoughts are negative. Hill and colleagues (1997) defined biases as personal issues that make objectivity toward data difficult. Therefore, reactions to the data, be they positive or negative, may have a basis in the cultural backgrounds, beliefs, experiences and values of the researchers (Hill et al., 2005). Qualitative research acknowledges that no person can be free of biases and thus cannot be completely objective. There are steps that must be present to properly acknowledge and address the effects of biases (Sim et al., 2010).

Distinctly different from biases are expectations. Hill and colleagues (1997) defined expectations as the beliefs that are the result of a review of the literature and thinking about the development of research questions. Unlike bias, expectations, has a more neutral connotation and therefore expectations may be more readily reported.

Upon reviewing a sum of the total published CQR studies, Hill and colleagues (2005), noticed that there was confusion regarding the reporting of biases and expectations because many people use the terms interchangeably. As such, Hill and colleagues (2005) recommended recording and reporting only biases, with the rational that expectations were implied in the introductory sections of the research.

Sim, Huang, and Hill (2012) however explicitly state the need to address biases as well as expectations. They state that by addressing only biases, some influential expectations may not be discussed, and those expectations may be reflected in the coding process.

Addressing biases. While the team selection was derived from a limited pool, it is important to the CQR process to choose team members who have a variety of biases and expectations (Hill et al., 1997). Diverse team members were better able to detect biases than team members who have similar cultural backgrounds.

The principal investigator for this project took one full meeting to train team members about biases and expectations. This meeting consisted of rationales, definitions, and examples to ensure that team members understood the importance of the distinctions in biases and expectations. The meeting was also used to set a precedent for setting boundaries and rules about addressing biases and expectations. The end of this meeting was utilized to allow team members to begin to write a list of their biases and expectations. Team members were encouraged not to discuss their biases and expectations until they had all completed their initial lists. This document was recorded and the researchers were encouraged to add to their list as they think of more biases and expectations. Additionally, the information in the lists was coded so as to distinguish when the biases and expectations were expressed, be it before data collection, after, or during analysis.

Sim, Huang, and Hill (2012) place particular emphasis on the importance of revisiting biases and expectations during the data analysis and reflect on its difficulty. The particular difficulty they address is the ease of neglect because of the intense focus on the data itself. Sim, Huang, and Hill (2012) recommend addressing biases and expectations at certain points in the data analysis process. First, they recommend readdressing biases and expectations when certain team members too often agree with other team members without their own opinion. This may indicate that there is groupthink occurring or a problem with the power dynamics of the team. Particularly, this might occur if there is a difference in the personality types of people on the team and more dominant members are advertently or inadvertently pressuring less dominant members.

Additionally, there are many other times that biases and expectations were regularly revisited. There is always the potential for conflicting bias or expectation among team members when there is prolonged disagreement when a consensus cannot be reached, when the team seems to always acquiesce to one individual, or when some researchers are not offering their own opinions. Biases were revisited twice when the team seemed to acquiesce too easily for the researcher's comfort.

From the initial meeting, the principal investigator strived to create an environment that was welcoming of opinions and one that encouraged any member of the research team to call attention to a concern. This was not only encouraged from the initial training sessions, but also modeled through the research process. This environment was also encouraged by rotating which team member is designated as the first one to express an opinion, which hopefully allowed all researchers to share their opinions with minimal influence by other team members.

Finally, the team had a debriefing at the end stage of analyses to discuss the influence of biases and expectations on the results. Each team member was encouraged to discuss the power dynamics of the group, how the dynamics were managed, and how they could have been managed better.

The researcher as instrument. Qualitative studies utilize researchers as the primary instruments for data collection and analysis (Denzin & Lincoln, 2005). A researcher's personal biases, values, and experiences can influence the rigor of research. Hill et al. (2005) discuss the need for researchers to openly discuss biases, expectations, and assumptions that may be relevant to the study beforehand and include how those biases, expectations, and assumptions influenced the data after the data is collected and analyzed.

The principal investigator, Derek Ruiz, received his bachelor's degree in psychology from Washington University in St. Louis. After which he worked for the State of Texas at Austin State Supported Living Center as a psychology assistant and psychiatry assistant. Of particular focus during this time was the psychosocial development of the clients under his care. He then pursued a Master's in Rehabilitation Counseling from Illinois Institute of Technology. During which he interned at Thresholds Chicago and Asian Human Services. These internships focused on multiple minority populations in psychiatric recovery, substance abuse recovery, recovery from HIV, or a combination of the three. The researcher is currently pursuing his Ph.D. in Rehabilitation Psychology at the University of Wisconsin-Madison and has doctoral level experience counseling at Mendota Mental Health Hospital and Journey Mental Health and Wellness Center. The master's level students

Research interests include, the psychosocial adjustment to disability, and specifically, self-efficacy, sexuality, and stigma related to disability. Research interests intersect with personal interests specifically regarding intimacy and sexuality for people with multiple minority statuses. He has had the privilege of working with several researchers who have studied sexuality and intimate relationships. Additionally, he has worked as a youth outreach counselor at OutReach! Austin, an LGBT youth outreach program in Austin, Texas. Finally, he has also been awarded a scholarship for a suicide education and prevention program developed and targeted at subgroups in the LGBT population.

The master's level researchers, one first year and the other second year, are both Caucasian women in their mid to late twenties. Both women have experience working with varying types of disability, but never any direct work with intimacy or sexuality. Both students have had exposure to an undergraduate psychosocial aspects of disability course and thus have been exposed to at least one lecture on the dimensions of sexuality for people with disabilities.

The auditor is a Ph.D. student in her second year of study. She has a master's degree in public service and an extensive history working with people with disabilities, particularly in the field of sexual health education for young people with disabilities. She is also a Caucasian female in her forties, married with two children.

Researcher bias is an inevitable part of qualitative research and has the potential to affect all elements of this research (Sim et al., 2010). This researcher is fully aware that the aforementioned experiences could have a significant biasing effect, therefore as previously mentioned, specific attention has been paid to the bias bracketing methods presented. Other researchers and coders were asked to complete a similar process of contextualizing themselves and experiences in an attempt to further explore biases. These histories were be reviewed prior to, and after the research was completed in an attempt to address any biases that may have had particular influence on the research.

Sample

With regards to sample composition, Hill and colleagues (1997, 2005) recommend that the sample be randomly selected from a similar population who are familiar, knowledgeable and have recent experience with the phenomenon to be investigated. Since the phenomenon that is being studied is about the experience of developing intimate relationships, experience and lack of experience is just as equally valid, and may lead to a richer data set. The only confound that had potential to be foreseen with the population is if any of the population studied identifies as asexual. Asexuality, while a valid form of human sexuality may not lend itself to the overall goal of this study, which is to develop a better understanding of the subjective experiences of intimate relationship development for people with disabilities.

Women specifically were chosen for this particular sample because of their general underrepresentation in research, and specifically rehabilitation research (Vidaver, Lafleur, Tong, Bradshaw, & Marts, 2000). Vidaver et al. (2000) showed that, for 5 year periods of analysis of National Institutes of Health funded research, approximately 1/5 of all of the research analyzed included no women at all, and between ¼ and 1/3 of the research that included women analyzed data by sex of subjects. Additionally, traditionally, women tend to be considered to be asexual (Nosek et al., 1996; Ray & West, 1984). At one point in time it was not uncommon for women with disabilities to view themselves as “damaged goods” (Phillips, 1990). However, as times have changed, and with the advent of dating services, as well as increased representation of women with disabilities in media, I sought to better understand the changes in public attitudes and self-perceptions of women with physical disabilities.

Sample Size. With regard to sample size, Hill and colleagues (1997, 2005) recommend using 8-15 total participants for the final data with at least one or two participants utilized to help refine the interview protocol. Hill et al. (2005) recommend utilizing 12 or more participants if there is a possibility of heterogeneity. However, due to the limitations of the study, as well as the financial limitations, one participant utilized to help refine the interview protocol and the sample was limited to 6 participants.

Recruitment. Participants were drawn from two particular pools of people. Access to Independence in Madison, Wisconsin as well as the Association of Youth Leadership Forums. From the initial posting, a snowball convenience sampling method of those initial participants was used to recruit other participants. The participants were provided with a participant number and identifying information was anonymized for data analysis.

Interview Protocol

While some qualitative research (Glaser, 1967) holds that the best way to avoid bias is to avoid review of the literature prior to the development of an interview protocol, Hill, Thompson, and Williams (1997) take the opposite approach with CQR researchers being encouraged to review existing literature to better develop an understanding of the empirical findings on a given topic, ensure that the study builds on prior research, and to help in the avoidances of mistakes made by previous researchers. While Hill and colleagues (1997) acknowledge that a previous foundational understanding of the research is important for the development of a study that is connected to and advances prior research, that understanding may also cause assumptions about the topic that may restrict the development of a research protocol, as well as contribute to the development of biases and expectations (Burkard et al., 2011).

Development of the interview protocol. In addition to the literature, CQR emphasizes the use of personal experience with regard to the interview protocol. Given the subject matter of topic, the researchers have some insights about attitudes and beliefs related to the study.

The interview protocol was developed very intentionally with regard to structure. Burkard, Knox, and Hill (2011) structure the interview protocol with respect to two primary goals. The first goal was to develop rapport with the participants, and the second was to gather consistent yet idiosyncratic information about the phenomenon to be studied.

Due to the nature of the topic being studied in this research, particular emphasis has been placed on the first section of rapport building, as well as gauging comfort levels. Additionally, the first section engages participants with questions that are less emotionally evocative, yet still broadly related to the topic being studied.

The second section of the interview protocol focused on the main topic of interest and focused on the definition of terms according to the research, but also asked participants to provide their own definitions. Scripted questions were used to ensure consistent information and probed specifically for attitudes, beliefs, and feelings about certain experiences. Additional probes consisted of antecedents to specific intimate relationship events, factors that affect the event, reactions to the event and how they even affected the relationship

The final section of the interview protocol asked participants to reflect more broadly on issues related to intimate relationship development. Specifically, of interest were examples and ideas for positive deviance.

An important consideration when designing the interview protocol was its length. Hill et al. (2005) found that most CQR researchers were using between 3 and 30 questions in an hour-long interview, with 12 being the median and 15 being the mode. Burkard, Knox, and Hill (2011) have several cautionary notes with regard to the length of the interview protocol. A lengthy interview protocol can lead to thin data that does not capture the richness of experience, while a short interview protocol can miss topic areas. Hill et al. (2005) recommend the use of 8 to 10 scripted, open-ended questions per interview hour.

Content experts. The initial interview protocol was developed after an extensive review of the literature. The principal investigator also sought the expertise of two outside researchers (Dr. Kelly Kazuauskas & Dr. Amanda Easton) who are knowledgeable about the topic area to ensure that the interview was capturing relevant data. Additionally, the principal investigator has sought feedback from one person with lived experience, of disability, who is able to offer feedback that may not have been readily apparent to researchers.

Pilot. As an additional assessment of the interview protocol, as per Hill and colleagues (2005), the protocol was piloted with one person who fulfilled the participation criteria but was not part of the final sample. This provided valuable information to the principal investigator about the understanding of questions, whether the questions yielded the data about specific topics relevant to the study, and whether questions flowed logically. The interviewer actively sought feedback from the participant about any troublesome parts of the protocol, and this feedback was used to revise the protocol.

Interview. Interviews were collected by phone as that allowed the researcher to draw from a broader geographical sample (Knox & Burkard, 2009). Additionally, this served to limit logistics around coming to interviews so as not to inconvenience participants beyond a limited, predefined, block of time. Audio-only interviews not only serve to preserve privacy because people can choose to provide a pseudonym or block their number for the purposes of the interview but also encourage participants to be more comfortable, and share more due to the physical and psychological distance from the interviewer (Sturges & Hanrahan, 2004). Furthermore, participant access to the nonverbal cues from researchers may increase the likelihood of response bias, as they may read interviewer reactions to their disclosures then alter what they choose to share (Marcus & Crane, 1986; Musselwhite, Cuff, McGregor, & King, 2007). Limitations of phone interviews were balanced with what would be lost and gained from an in-person interview. In-person interviews provide access to non-verbal data and may facilitate rapport building (Carr & Worth 2001; Shuy, 2003), which may have proved helpful for dealing with the sensitive nature of this subject. Ultimately, it was decided that disability considerations were the most important for this particular group of respondents.

Interviews were to be conducted by either the principal researcher or a trained alternate interviewer. The alternate interviewer was trained to ensure interviews are consistent with the interviews of the principal investigator. The alternate interviewer was also female due to the nature of the sensitivity of the subject and the comfort of participants (Adler & Adler, 2003). Respondents were asked open-ended questions about intimate details of their lives while knowing practically nothing about the interviewer. Given this context, it was important for the interviewer to develop a research alliance, which incorporates trust, rapport, and a sense of safety. A strong research alliance is essential because the stronger the alliance the more rich (Knox & Burkard, 2009), and the more valid, the data (Adler & Adler, 2003; Kvale, 1996). Participants were asked, during the initial demographic collection if they had a preference on their interviewer's gender and none of the respondents reported discomfort with the primary researcher. Thus, the alternate interviewer was not utilized.

Interviewer notes were also taken during and after the interview. Burkard, Knox, and Hill (2011) emphasize that these types of notes can provide vital information in reviewing transcriptions for accuracy, as well as provide context to interview content.

Interview protocol dissemination. Burkard Knox and Hill (2012) recommend providing the interview protocol to participants before the interview. Providing participants with the interview protocol allowed participants to have an idea of the type of research they have agreed to and allowed them to gauge if they have had relevant experience, and decide if they were still willing to participate, so as to not waste their own or the researcher's time with a lengthy interview process. This allowed interviewees to give fully informed consent and not be surprised by interview questions that may be sensitive. This also allowed for participants to reflect on their experiences before the interview itself and gather their thoughts on potential responses. This provided for a richer data set.

Recording. Interviews were recorded to ensure complete and accurate transcriptions. Recordings have been kept digitally, copied, and encrypted. The original is being kept by the principal researcher, while the copy was provided to the transcriber. Once the transcription was completed, the transcriber deleted the recording as per agreement made between the transcriber and researcher. When the transcript was verified, and the data analyzed, the original recording was deleted as per the agreement of the informed consent.

Ethical considerations and participant safety. Participant privacy, physical and mental health were critically considered throughout the study. Due to the nature of this particular study, the researchers were posing probing questions examining, in detail, the participant's personal thoughts, feelings, and intimate experiences (Stacey, 1988). The present study did not present readily identifiable risks, however given the context of the study and its relation to intimacy some considerations were kept in mind.

Given the potential intrusiveness of CQR, it was especially important to attend to issues of informed consent through this study. Participants were provided with the interview protocol in advance to let them review the types of questions asked, as well as initial informed consent materials prior to the study. The materials and interviewer explained the autonomy to participate and withdraw at any point without any consequences should they be so inclined. Participants were told in the initial written informed consent and orally before the interview process that all information shared would be held in confidentiality. An oral informed consent was also obtained prior to the interview where the information was reviewed prior to interviewing. Participants were also offered the opportunity to ask questions prior to the interview process. In moments of intense emotions during interviews, the interviewers are trained to respond to participant distress, offer support and referrals, and then reassess the participants' desire to continue with the interview. The interviews concluded with asking specifically about the participants' reactions to the interview questions. Additionally, questions were also carefully formulated with special attention to psychological well-being. No participant demonstrated distress while, or as a result of, participating in this study.

Additionally, participants were treated in accordance with the ethical guidelines of the University of Wisconsin, Madison Institutional Review Board.

Simple steps were taken to protect the identity of participants and any individuals they refer to relevant to their experiences. Additionally, steps were taken to de-identify settings, locations, or other attributes to further protect the identities of all involved and referred to. Each case was assigned a code number. For the duration of the study, participant names and code numbers are kept in a password protected computer file to which only the principal investigator had access. At the completion of the study the code list was deleted. Prior to any data analysis, all transcriptions were de-identified by removing names, geographical references, and any other potentially identifying information.

Data Analysis Procedures

Coding domains. The transcribed interviews were used to create a list of meaningful and unique topic areas, called domains. There are two main approaches for developing the domain list (Hill et al., 2004; Hill, Thompson, & Williams, 1997). The first and most common approach is that the researchers develop a starting list of proposed domains based on a review of the literature (Miles & Huberman, 1994) and the primary research questions. This list was then applied and revised based on the transcripts to ensure that it accurately reflects the data given. The second method for developing a domain list involves reviewing the transcripts first bracketing the extant literature and interview protocol, and seeing which domains emerge from the raw data (Thompson, Vivino, & Hill, 2012). Researchers independently reviewed the data and identified proposed domains, then the team met to compare notes and consensually created a domain list that best fits the data and the focus of the study.

This research study utilized the latter approach to the development of domains. Due to the broad nature of this research topic, there was little to no straightforward topics from which to draw initial domains.

The domain list was then given to the auditor to review. The auditor provided feedback about the clarity of the domain titles and gave opinions regarding the appropriateness of the level of specificity of the domains.

Data was then blocked and assigned to domains. This was done by each researcher individually blocking data and then placing that data into domains.. The group came together and formed a consensus on the appropriateness of the block and its domain.

Core Ideas. The next step was the construction of core ideas from the existing data. This provide a clear language of what the participant was saying in clear, understandable language that enabled researchers to compare data across cases. This allowed use of consistent language across cases. This process was done similarly to the development of domains. Researchers began and developed core ideas together for several cases, then work on their own to develop core ideas for the remaining cases. The team met again to form consensus on the core ideas for the remaining cases. From consensus, a consensus version of the data was produced in which each case was presented in a format that includes case number, location of the data (line numbers), the raw data, core ideas and the domains. The auditors again reviewed the consensus version and recommended changes. The team met again to discuss the proposed changes.

Validity and Trustworthiness

Qualitative researchers employ numerous validation approaches to ensure their research works are credible and rigorous. The importance of establishing validity is in any empirical study (Choudhuri, Glauser, & Peregoy, 2004) cannot be understated. However qualitative research presents unique challenges to establishing traditional validity. Qualitative researchers have no *p* value, interrater reliability, or error variance on which to rely (Williams & Morrow, 2009).

Qualitative researchers have been using the term *trustworthiness* instead of *validity* (Elliott, Fischer, & Rennie, 1999) which refers to the researchers' assertion to have utilized appropriate, adequate, and reliable methods to correctly report the findings. These criteria are used to address questions to the procedural rigor of qualitative research (Hoyt & Bhati, 2007). For the purposes of this dissertation, these criteria have been further refined by Williams and Morrow (2009) to include; 1) Establishing integrity of the data, 2) Balance of the tension between subjectivity and reflexivity, 3) Clearly communicating findings and their applicability to research and practice.

Integrity of the data. Integrity of the data refers to the clear description to the methods and results (Patton, 2002). A first step of establishing integrity of the data is the provision of enough methodological detail as to allow for replication of the study's procedures. This can be found in the above Methodology section. The results section follows this one.

The use of theoretical saturation was also used as a method of establishing trustworthiness (Williams & Morrow, 2009). *Theoretical saturation* is a point where no new data emerges during a study and the point where the researcher becomes empirically sure of the findings (Glaser, 1967; Glaser & Strauss, 2009). Hill, Thompson, and Williams, (1997) refer to this in consensual qualitative research as *stability of findings*.

Hill and colleagues (2005) do not recommend the use of a stability check, as there are no clear standards for what constitutes stability. Rather than a stability check, the research team attempted to use a relatively large sample (#) that is relatively homogenous as an attempt to obtain consistent findings. Additionally, the research team worked hard to connect individual results to the overarching categories determined by the cross analysis.

Reflexivity and subjectivity. Due to the subjective nature of qualitative research, the research team was especially careful to explore and manage their biases and expectations. Reflexivity, according to (Rennie, 2004), is the process of exploring and managing biases and expectations through self-awareness. To manage our own biases and expectations, the research team utilized the strategy of bracketing our expectations and biases per Hill and colleagues (2005).

Our study addressed the need to balance reflexivity and subjectivity by having multiple layers of consensus. CQR is built on the concept that multiple perspectives increase our approximation of the truth and help to free researchers from bias, while external auditors help to alleviate groupthink. The research team was continually challenged by one another through interactive and formative feedback that facilitated collaborative learning.

Communication of findings. The proposed research may prove to be useful to practitioners as well as lay people with disabilities. A better understanding of intimate relationships, specifically related to people with disabilities, may be useful to enable people to examine and improve strategies for developing intimacy.

CHAPTER FOUR

Results

> *I think we should constantly be looking for that new friendship, new intimacy, new relationship, new person to hang out with. We all need newness. A lot of us do. A lot of people are really happy with their rote, safe lives, but that's not me. We want newness. We want people to inspire our lives, and we want to inspire other people in their lives too.*

Overview of Study

The current study investigated subjective experiences with intimate relationship development. As stated in Chapter 3, the study consisted of responses from six females, with visible physical disabilities, to a designed and structured interview protocol consisting of 8 broad questions with 10 sub-questions (see Appendix 1 for the Interview Protocol). Specifically, the research aims were to explore the following questions:

a) What are the overall subjective experiences of women with visible physical disabilities in developing intimate relationships?
b) What aspects of intimacy and sexuality are most important for women with physical disabilities?
c) What are some of the challenges to and facilitators of developing intimate relationships for women with visible physical disabilities?

This section presents data from one-on-one interviews on how women with visible physical disabilities have experienced and continue to experience intimate relationships. This chapter also provides an overview of participants involved in the study. Findings are presented for understanding of perceptions and experiences that contributed to those perceptions

Description of participants. Six women completed the interview process by means of a phone interview. All were offered in-person interviews or face-to-face electronic interviews, but all refused and instead said it was more convenient for them to complete phone interviews. Because of the snowball sampling method, interviewees were located in Wisconsin, Florida, and Washington D.C. Participants in this study ranged in age from 23 to 60 years old and most, five out of six, identified as Caucasian with the other identifying as Black. All of the women who participated self-identified as having visible physical disabilities. When asked about their specific disabilities, three endorsed having muscular dystrophy, two with cerebral palsy, and the final person identified as having amniotic band syndrome. The relationship statuses, sexual orientations and education levels of all of the participants were mixed and represented a broad range of experience. More detailed information can be found in Table 1.

Table 1. Demographics

Case	Age	Race	Disability Reported	Relationship Status	Sexual Orientation	Level of Education
584	23	Caucasian	Muscular Dystrophy	Single	Bisexual	College
589	58	Caucasian	Muscular Dystrophy	Partnered	Homosexual	High School
3027	28	Black	Cerebral Palsy	Partnered	Homosexual	Some College
3145	31	Caucasian	Cerebral Palsy	Single	Heterosexual	Graduate School
6202	27	Caucasian	Amniotic Band Syndrome	Single	Heterosexual	College
6555	60	Caucasian	Muscular Dystrophy	Single	Bisexual	College

Organization of the results. This analysis, using the Consensual Qualitative Research method (Hill et al., 2005) produced eight distinct domains and 25 distinct categories). As defined in Chapter 3, domains are broad subject areas used to group information or data about similar topics, while categories represent thematically associated text clustered within a particular domain. Similarly, sub-categories are a way to more clearly break down the information presented within each category.

Each domain is defined. It should be noted that in every domain, all participants are represented in at least one category, with the exception of the domain entitled “Stigmatizing Effects of Disability.” In this domain, 4 out of 6 participants are represented, but it should be noted that because of overlap in some of the theoretical foundations of the topics being studied, that similar information may be captured within other domains. Ideally, domains should be unique, and all of the information should be uniquely captured within them, but for the purposes of this study, similar concepts across domains existed that warrant closer examination. More details about this phenomenon are discussed within the limitations and future research sections of this dissertation. After each domain, categories pertaining to that domain are listed, then listed with a representativeness identifier (e.g. general, typical, variant or rare)(Hill et al., 1997). The representativeness identifiers are labeled as follows: “general” denotes 5 or 6 total participants, “typical” denotes 3 or 4 participants, “variant” denotes 2 participants, and “rare” denotes a single participant. The number of participants whose responses were coded into that particular category is also cited in parentheses. Selected quotations follow each defined category in an attempt to expand and enrich the reader’s understanding. Quotations may have been edited for clarity and to maintain confidentiality.

Table 2. Domain and Category List with Category Frequencies

Domain	Category	Representation	n	Percent
Attitudes about Intimacy				
	Barriers to Intimacy	General	6	100%
	Non-Romantic Intimacy	Typical	4	67%
	Core Values	General	6	100%
Disability Identity				
	Change Over Time	Variant	2	33%
	Formative Experiences	Typical	3	50%
	Validating Relationships	Typical	3	50%
Limitations of Disability				
	Partners	Variant	2	33%
	Perceived Barriers	General	5	83%
	Physical Barriers to Intimacy	Typical	4	67%
	Societal Barriers	Typical	3	50%
Online Dating/ Social Media				
	Barriers	Variant	3	50%
	Non-Romantic Use	Variant	2	33%
	Self-Disclosure	Typical	5	83%
Outcome Expectancy				
	Formative Experiences	Typical	3	50%
	Hope for Future Relationships	General	6	100%
Self-Concept				
	Confidence	General	4	67%
	Effects of Disability	Typical	6	100%
	Formative Experiences	Variant	2	33%
	Media Effects	Rare	1	17%
Self-Efficacy				
	Confidence	Typical	4	67%
	Formative Experiences	Typical	3	50%
	Personal Strengths		6	100%
Stigmatizing Effects of Disability				
	Societal Barriers	Typical	4	67%

The representativeness identifiers are labeled as follows: "general" denotes 5 or 6 total participants, "typical" denotes 3 or 4 participants, "variant" denotes 2 participants, and "rare" denotes a single participant.

Attitudes about Intimacy

This domain represents a synthesis of information from the initial prompt of asking about important relationships and why they were important, as well as other information that developed naturally over the course of the interviews. Attitudes about intimacy varied across participants. Categories that emerged were core values related to intimacy, barriers to intimacy, core values related to intimacy, non-romantic intimacy, and one additional category that is labeled as other.

Table 3. Attitudes about Intimacy - Categories and Sub-Categories

Category	n	Percent	Sub Category	n	Percent
Barriers to intimacy	6	100%			
			Conflicting Roles of Intimacy	2	33%
			Communication	2	33%
			Perceived Barriers	2	33%
			Priorities	1	17%
			Stigmatizing Effects of Disability	3	50%
Core Values	6	100%			
			Attraction	2	33%
			Casual Intimacy	1	17%
			Communication	3	50%
			Evolution over Time	2	33%
			Openness to Intimacy	2	33%
			Shared Values	4	67%
			Shared Experiences	4	67%
Non-romantic Intimacy	4	67%			
			Caregivers	1	17%
			Familial Intimacy	1	17%
			Friendship	3	50%
			Formative Experiences	1	17%

Attitudes about intimacy: core values (6, general). Every participant endorsed what this researcher has labeled as core values of intimacy. Every participant gave insight as to what was most important for them with regards to intimate relationship development. These core values were broken down even further into 7 sub-categories.

The most endorsed sub-category was *Shared Experiences (4)*. Attitudes ranged from the joys of dating and sharing experiences, “Just being able to connect with someone… even if it was just for an evening.” to an emphasis on the shared experiences of longer term relationships. One participant described the experiences that she has shared with her partner and their importance on intimacy.

> *We've been through such horrendous, horrendous things, but yet we stick with each other because we know that there is a real, true love and connection that we have. She is a pain in the ass, but I love her anyway, and I'm a pain in her ass sometimes, but she loves me. Again, it's that we've seen each other through some really hard times, some really great times.*

Along a similar vein, participants endorsed what was coded as the sub-category of *Shared Values (4)*. Everyone endorsed they considered some of the most important core values about intimacy. These values often related to their partners sharing those values. Of particular note were two comments from different participants. One participant emphasized disability as a “…lens to see the world through. How you define beauty, how is beauty important, and do you have people that see past the surface?” Relatedly one participant reflected on how the lack of shared values ended a previous relationship.

The sub-categories next most endorsed were *Honesty and Trust, Openness to Intimacy, Evolution over Time, and Attraction*, each with 2 endorsements. *Honesty and Trust* were just that, participants stated that what they valued within relationships was honesty and trust, and with that honesty and trust came a comfortability to be one’s self. Two participants encapsulated the sub-category *Evolution over Time* in which they talked about how both their understanding of intimacy has evolved over time as well as how their relationships have evolved over time. Attraction as a sub-category provided some insight because it highlighted both the need for emotional, as well as physical attraction in intimate relationships. One person denounced physical attraction and went so far as to call it “shallow,” while the other person emphasized that relationships that were purely emotional were lost because, “You kind of have to be attracted to someone in other ways that are not in the emotional.”

Two participants talked at great length about their openness to intimacy and how that was important to them and what they believed to be the most contributing factor to their development of intimate relationships. Both participants who endorsed this sub-category commented how their openness has contributed to their success, one said, “It has to do with my openness and willingness to do intimate things,” while the other said, “I think also having that level of confidence in my sexuality and my sexual preferences, also I would say would be a success.”

Finally, *Casual Intimacy (1)* bears mentioning. This was a special case coding in that the crux of the idea was that the participant endorsed casual dating for dating sake. She said, “I don't think [intimacy] necessarily has anything to do with dating itself, because I like dating. I don't necessarily see intimacy as a part of dating,” but then went on to explain that she had a bad experience with intimacy early on and does not equate dating and intimacy.

Attitudes about intimacy: barriers to intimacy (5, general). Most of the participants identified major barriers to intimacy; specifically, the barriers mentioned condensed down to 5 distinct sub-categories, *stigmatizing effects of disability (3), communication (2), conflicting roles of intimacy (2), perceived barriers (2) and priorities (1)*. While there may appear to be some overlap with other sub-categories, specifically within the later discussed category of core-values, the coding within this category focused specifically on barriers to intimacy.

Three people mentioned that *Stigmatizing Effects of Disability (3)* was a major barrier to intimacy, one participant said,

> *…The idea of having a physical disability creates celibacy or creates a lack of aptitude when it comes to sexual activities or a lack of enjoyment when it comes to sexual activities. I don't think any of those are true, obviously. At the same time, like I said, it's also been a filter for people who may be close-minded.*

Two participants mentioned *Communication (2)* as a barrier to intimacy. One participant focused on her culture affecting her style of communication and therefore her attitudes about intimacy, while the other focused on disability impacting her ability to communicate with her partner.

There was some overlap with the sub-category *Communication* and sub-category *Perceived Limitations (2)*, specifically having to do with how disability affects perceptions of others. One participant acknowledged her inability to communicate her needs effectively and attributes that to assumptions about her partner's perception of her disability.

> *I think that's something that would come up again and again would be, and this was a breaking point I think for a lot of my relationships looking back on it, is that when I am afraid that there's something about what I'm going through in terms of chronic pain or*

> *disability issue… I'll just assume that the other person won't get it, and I won't talk about it, and I'll just shut down.*

Similarly, the same participant focused on the overcoming these *Perceived Limitations* as a process "…That has actually been more of a barrier to me than the people themselves, or the way that they treat me."

Two participants talked about how *Conflicting Roles of Intimacy (2)* can be a barrier. Participants recounted difficulty for partners switching intimate roles to and from emotional and physical intimacy to and from caretaker intimacy. One participant focused her difficulty of a careworker switching to a romantically intimate role, while the other lamented the necessity of her romantic partner being forced into a careworker role.

> *It bothers me when my partner of 20 years has got to help me to the bathroom. I don't always want her to have to be in that position. That's not sexy. It's super intimate, but there is nothing sexy about going to the can with me. Nothing sexy about wiping my butt after I poop, but boy is that ever intimate.*

Of interesting note was one particular participant whose priorities about intimate relationships have shifted because of her disability. She reported that while dating was a priority for her, and it was going well, that pain and disability management became more of a focus for her.

> *…Trying to get a handle on everyday functioning I think have really changed as I have gotten older, getting a sense of mastery over that, or at least getting a sense of managing that has really taken precedent for me right now especially in relation to my other priorities.*

For this particular participant, disability management became more of an intrusive issue, and they reported that it caused them to shuffle around their other priorities, specifically mentioned were friends, family, and accomplishing everyday tasks such as going to work.

Attitudes about intimacy: non-romantic intimacy (3, typical). While the initial intent of the project was to develop a better understanding of romantic intimacy, the definition of intimacy was left broad so as to better capture the experiences of the women participating. Three women elicited three separate sub-categories within the category of non-romantic intimacy, *Friendship (3), Familial Intimacy (1) and Caregiver Intimacy (1)*.

All three women recognized friendships as having a significant impact on their attitudes about intimacy, both romantic and non-romantic. Each of the women focused on the comfort, value, and deep emotional connection that comes with friendship.

> *Our relationship is also very intimate without having ever had sex… With my friend of 42 years I can share things that I won't share with my partner of 20 years…It's really important that you are able to share your heart…I think that's when you have your most intimate, wonderful relationships.*

Another individual focused on friendship where they don't feel judged and are given permission to be “flawed at something.”

One participant focused heavily on *Familial Intimacy (1)*, and how it affected her relationships romantically and non-romantically. She concentrated specifically on the foundational familial relationships of her mother and brother, both of whom were very supportive of her. Her mother provided her with a “grounded and consistent and respectful, mutual relationship.” The relationship with her brother, she recounted with similar consistency and understanding, “I could always count on him to be there, and to understand and to have fun. So that consistency was really important.” Her mother died of cancer after a long stint with the participant as her care taker and that reportedly, “Definitely colored, I think, the way that I approach relationships,” because death the death of someone in that formative of a role, “Shakes your sense of what you can rely on and what you can trust.”

There was one participant who focused on *Caregiver Intimacy (1)*. She specifically recounted how he forced intimacy of having to rely on a caregiver has shaped her attitudes about intimacy. She said it didn’t matter how long she knew the person having to help her go to the bathroom that sort of forced intimacy is different and that she has learned to, “Put my modesty aside. Put my shame aside. Put my, oh, we all have these body parts, what's the difference? Put that forward, and try not to let it bother me.”

Disability Identity

The next domain that emerged from that data was how navigation of intimate relationships affected participant’s identity as a person with a disability, as well as the inverse, how participants’ disability identity affected how they develop intimate relationships. Within this domain, three main categories emerged*, Formative Experiences (4), Validating Relationships (4,)* and *Change over Time (2).*

Table 4. Disability Identity - Categories and Sub-Categories

Category	n	Percent	Sub Category	n	Percent
Change over time	2	33%			
Formative Experiences	6	67%			
			Cultural Implications	1	17%
			Disclosure	1	17%
			Family Values	1	17%
			Shared Experience	1	17%
Validating Relationships	3	50%			
			Shared Experience	3	50%

Disability identity: Formative Experiences (4, Typical). The participants' *Formative Experiences (4)* represented a diversity of experiences that ranged from *Cultural Implications of Disability*, both positive and negative, *Family Values, Shared Experiences,* and *Media Effects of Disability.*

With regard to *Cultural Implications of Disability (1) and Family Values (1)* one particular participant recounted that disability is seen as a weakness in her culture and family, and growing up she internalized those messages. She felt, “How dare I cause you more shame?” But, after escaping cultural isolation through adulthood and college experiences, the paradigm shifted, and her disability was reported as somewhat of a novelty. “People kind of want to date me just because they want to see what it's like to date someone with a disability.” While the other participant recounted that her confidence, in her identity as a person with a disability, stems from the values instilled in her growing up. She reported, “A lot of confidence in the fact that I am very secure about my disability,” and,

> *I don't know if it was just my family trying to raise me because they didn't know what it was like to raise a kid with a disability, so they just said screw it.*

One participant poignantly talked about the importance of *Shared Experiences (1)* with a friend growing up as important to her in the development of her disability identity.

> *From a disability perspective, an interesting, at least emotionally intimate relationship that I've had throughout my life has been with my friend who was… the only other person in my grade who had a significant physical disability. [Adults] didn't always allow us to express ourselves, and I think that we knew that adults were going to try to define us and our experience in certain ways or dissuade us from being negative sometimes or complaining or just being snarky. So, we had the opportunity to be that way with each other. I don't think that otherwise I really would have had that opportunity.*

Finally, within the category, one participant recounted that her identity as a person with a disability was shaped heavily by the media before she eventually connected with role models within the community. She expressed her concerns about how the media shaped her identity and how it is shaping the identity of other young people with disabilities.

> *I worry about younger generations where beauty is becoming more photoshopped, especially in the disability community and how we can shape that so that more girls, or young people in general, just feel like they can accept their body.*

Disability identity: Validating relationships (4, Typical). "The things that validate were, other people with disabilities had the same fears, and the same wants that I did, and we all talked about those." Validating Relationships was an important category that was endorsed by 2/3 of the respondents. Validating relationships were operationally defined differently than formative experiences in that Formative Experiences related to early experiences that shaped identity and Validating Relationships were defined as experiences, most often as adults, that validated disability identity. There were two responses that summed up the category very well, first,

> *It was actually really the first time that I had opened up with someone about the process of going through an injury and dealing with chronic pain and showing them what that was like on a day to day basis, and to realize that I could do that, and that the person wouldn't be completely freaked out and overwhelmed was important for me.*

The second respondent said,

> *It's nice when I find someone who doesn't have to ignore it but then at the same time it isn't a factor. If that makes sense. Something we don't have to talk about constantly… Taking disability into effect. Just as I do, but then not making it the defining characteristic for everything.*

Disability identity: Change over time (2, Variant). Both of the respondents in this category underscored that changes in their disability identity, over time, affected how they relate to others on an intimate level. This category was separated because it didn’t have a particular formative experience or validating relationship tied to it, rather comfort with disability identity happened over time. One participant talked about being people with disabilities being, “late bloomers,” which she “think[s] is pretty typical for people with physical disability.” She reported that it wasn't until college that she started to develop her identity and ability to trust and share with partners. One participant, in particular, recounted her feeling out of place in high school because of her visible disability, but as she progressed through college she was eventually able to say,

> *I don't really care what people think, you're either going to like, and you're going to get over my physical appearance, or you're not and then we're not going to be friends, and then I'm not going to care.*

Limitations of Disability

Every participant also reflected on the Limitations of their Disability within the context of intimate relationship development. Categories that emerged were: *Perceived Barriers to Intimacy (5), Physical Barriers to Intimacy (4), Societal Barriers to Intimacy (3),* and *Partner Compatibility (2)*.

Table 5. Limitations of Disability - Categories and Sub-Categories

Category	n	Percent	Sub Category	n	Percent
Partners	2	33%			
			Roles	2	33%
Perceived Barriers	5	83%			
			Lack of Spontaneity	1	17%
			Not Insurmountable	1	17%
Physical barriers to Intimacy	4	67%			
			Logistics	1	17%
			Physical Limitations	4	67%
Societal Barriers	3	50%			
			Perceived Fragility	1	17%
			Stigma	2	33%

Limitations of disability: Perceived barriers to intimacy (5, General). *Perceived barriers* provided potentially valuable insight into how these particular women viewed disability as limiting. This category had three sub-categories, which emerged from the data. The three sub-categories were; *No Perceived Limitations (4)* and *Lack of Spontaneity (2)*.

More than one of the participants stated that they felt that they had *No Perceived Limitations* of disability with regard to the development of intimate relationships or at least with the development of specific intimate relationships. One commented on how disability does not affect her ability to pursue causal intimacy, "I really enjoy that I can go out there and not even second guess the fact that I don't have an arm and leg and go hook up with random people." One recounted past relationships where she felt that there were no barriers in regard to disability, she felt her partners' attitudes were, "'Oh, I recognize this person as a human being, regardless of the mobility to a device they use, or any of the other medical complications they have." The others generically mentioned that they did not believe there were barriers, at least if there were, they were oblivious to them. One respondent did emphasize that there were strains that disability put on intimate relationship development, but that it was not a limiting factor. She reported, "Disability has never really broken up a relationship, but it has put a shit ton of strain on it, like this relationship…". She then recounted medical and physical effects of disability.

Limitations of disability: Physical barriers to intimacy (4, Typical). Four participants shared struggles related to physical barriers to intimacy. Within the context of these limitations, two subcategories emerged, *Physical Limitations (4)* and Logistics *(1).*

Physical Limitations (4) is a sub-category that captured the various biological, and functional limitations disability poses on intimate relationship development. Some of the items mentioned are reflected or echoed in other categories. For instance, disability causes physical distance, and lack of spontaneity in relationships.

> *I've always wanted to hold someone's hand and walk, but because I have a walker, or I use crutches, that never happens… We can't necessarily make out in a car because the fact of my disability makes it awkward and difficult to do that. So, a lot of the times it*

> *has to be very planned intimacy. Any time that it's been reckless intimacy we'd probably get caught because it's complicated.*

Similarly, another participant commented,

> *We can't sit next to each other on the couch together, and that is definitely a barrier to being intimate. Definitely, there is a lot of barriers as far as being able to just get close to a human being even if you're having a conversation and reach out to their hand and grab it. Because man, my foot pedals stick out way over there, and I can only reach this far, and your hand's way over there.*

Not only does disability cause physical separation, but the physical implications can cause impediments to intimate relationship development as well. Two people surveyed recounted how disability, and the many complications that secondary conditions and progressive disabilities have caused their love lives. “Well, yeah, broken legs, hysterectomy, the things that have physically made my disability worse, have put a wedge in between sexuality and intimacy, that's for sure.” Similarly, another participant recounted that she, “Disability changed to the point where I'm not able to move my arms anymore. I need a lot of physical support and a lot of personal care.”

With regard to *Logistics*, one client focused mostly on accessibility and acceptance in dating-spaces. She recounted putting personal ads in newspapers and meeting people in traditional dating-spaces such as bars, and the difficulties associated with that.

> *I never understood how other people made it work because again music's so loud you have to scream at each other. You're not looking at each other. Well, I'm not because I'm sitting down. That's a big deal… I can't look you in the eye, and especially if you're*

> *talking to something over there, I'm not going to get into the three-person conversation. … You're really feeling like you're being left out of certain conversations or situations because of it.*

Limitations of disability: Societal barriers to intimacy (3, Typical). Three of the conversations focused on what was coded as societal barriers to intimacy. Societal barriers were defined as limitations of disability that are imposed by others. Within the category, the sub-categories of *Stigma (2)* and *Perceived Fragility (1)* emerged.

Within the context of *Stigma*, respondents recounted how the perceptions of others shape their dating lives. One respondent believes that people often do not consider her as a romantic partner because of her disability. “I think they "friend zone" me relatively quickly because a lot of people that I date…have limited experience with the disability community.” Another respondent reported feeling an overall pressure and vulnerability related to her disability and how the able-bodied world interacts with women with disabilities.

> *I feel vulnerable as a person as a person with a disability in the world in general… I feel vulnerable to the judgment of other people, and to microaggressions, and to being framed in a specific way according to the language and the stereotypes that our culture uses around people with disabilities. I guess that plays out for me on a day to day basis in everything that I do, and it gets magnified when I am trying to connect with another person because all of those things… cross over into the way that I interact with other people, and the things that I say to them, and what I expect from them.*

One of those surveyed reflected at length about how *Perceived Fragility* is a limiting factor in her development of intimate relationships, both romantic and non-romantic.

> *People are afraid that again they're going to hurt me, or hit the wrong part of my wheelchair, or send my flying, or knock me over. They don't do a lot of reaching and touching*.

Limitations of disability: Partner compatibility (2, Variant). Two participants described partner compatibility as a limitation due to disability. Two participants focused on the roles that their partners were taking with relation to disability and the difficulties switching roles, or the incompatibility of what they believed their roles to be. One participant believes that her disability was the primary reason that her caretaker couldn't switch roles to being a romantic partner. Another focused primarily on the role of partners as caretakers and the difficulties navigating those roles.

> *There was a time where we were explaining our relationship to someone, and he said that he was my caretaker. That shocked me, because I'm really independent, and there's not a lot that he does for me. So, we definitely had a big rift with that, because I don't want to be ... I'm not his patient… The various routes definitely have been figuring out that role, as far as say, the person that you love probably shouldn't be the person that helps you in the bathroom all the time. That definitely has been a barrier.*

Finally, within *Partner Compatibility,* one participant dated someone with the same disability as her but had compatibility issues related to how disability affected them differently.

> *Technically speaking, we have the exact same disability, it affected us in exactly the same way, so I didn't understand his perspective, saying he couldn't get into the shower because I could get into the shower. From my perspective, so could he.*

Self-Concept

Each of the participants endorsed what was eventually coded to be Self-Concept. Each of the categories that emerged, *Effects of Disability (6)*, *Confidence (3)*, *Formative Experiences (2)*, and *Media Effects (1)*, all reflect participants' concepts of selves, and how they were shaped, through the broad lens of relationship development. Self-concept and Self-efficacy, the next domains to be described, are both closely related topics. Self-efficacy is a cognitive conclusion of one's ability within a specific area, whereas self-concept makes a clear allusion to normative superiority (or inferiority) of one's ability or one's self, more broadly (Bandura, 1977; Bong & Clark, 1999; Rostosky et al., 2008).

Table 6. Self-Concept - Categories and Sub-Categories

Category	n	Percent	Sub Category	n	Percent
Confidence	4	67%			
			Comfort with Intimacy	2	33%
			Projecting Confidence	3	50%
Effects of Disability	6	100%			
			Insecurity	5	83%
			Positive	3	50%
Formative Experiences	2	33%			
			Acceptance	1	17%
			Insecurity	1	17%
			Positive	1	17%
			Challenges	1	17%
Media Effects	1	17%			
			Physical Beauty Standards	1	17%

Self-concept: Effects of Disability (6, General). Each person that participated in the interviews spoke of the *Effects of Disability* their sense of self-concept. Five participants reflected on the insecurities that their disabilities caused. One participant said, "I think that somewhere deep down inside of me I have some sort of insecurity about my physical disability." Another participant recounted relationship difficulties that stemmed from her insecurities about her disability.

> *When it comes to disability or chronic pain I'm not always sure that a person will understand, and rather than taking the risk of being misunderstood, sometimes I just won't share or be honest when I should be. I'm less confident in those areas … I was less confident in sharing about those parts of myself, and also that means that I'm less confident in terms of sharing how I am feeling … Also, if things are bad, letting the other person help me, I'm not good at that either.*

While another reported that she was so insecure because of her disability and that she "…Was just so urgently needy for someone to find me attractive, or find me valuable as a female, or potential sexual partner," that she allowed herself to be put in a situation where she accepted a date with someone who kidnapped her and tried to have her exorcised.

Two of the participants were able to identify positive *Effects of Disability* on self-concept. One person reflected on the strengths their personal journey through disability has given them, while the other reinforced that she was forced into developing a thick skin because of stigma and stereotypes. The idea of stereotypes and stigma for a filter for romantic partners came up throughout the interview process, but this particular client reported a shift in her thinking because of it,

> *While I, initially, viewed my disability as a hindrance, I now see it as kind of the first date, if you can't put up with my disability as a friend or as a human being, then you probably don't deserve to date me as a romantic partner.*

Self-concept: Confidence (3, Typical). The category of Confidence emerged from the domain with three respondents. This category was closely related to the category Effects of Disability but separated because of its positive valence. Additionally, the constructs mentioned were separated from disability. Two sub-categories within this category emerged, *Projecting Confidence (2)*, and *Comfort with Intimacy (2).*

The first sub-category *Projecting Confidence* was closely related to the effects of disability for at least one of the respondents. Not counted within this particular sub-category because the core idea of her statement revolved around insecurity, but one respondent used the projection of confidence to mask her insecurity. The two respondents who were included within this sub-category didn't list any particular insecurity that they were trying to mask, they were only focused on the projection of confidence. Two examples, in particular, stand out as indicative of this confidence.

> *You have to be strong. If you can be a confident human being, the world's going to look at you like a confident human being. If you're going to whimper and cry in a corner, well ... My motto in life, … I always have the right and ability to sit in the corner and pity myself. Taking myself out of that corner and facing the world, even if it's just a little corner of the world, you know what? It feels a lot better than sitting in the corner crying.*

> *If you ask any one of my friends, they will say XXXXX's very unabashedly, unashamed in making new friendships…. I'm very direct in my creation of new relationships because I think that I'm worth knowing and that power and that confidence, I think, comes across and kind of rubs off and other people are like, "Oh, okay, I think she's*

> *worth knowing, too." I think my disability actually helps me …because I very easily stand out in a crowd.*

The second sub-category was *Comfort with Intimacy*. One participant talked about general openness with non-romantic intimacy. She explained that she has grown into a person who is confident enough to ask for the intimacy that she wants, even though it may be uncomfortable. For instance, she makes it a point to ask to be met where she is at with regard to reaching out. “If you're talking to somebody, even if you can't stick your hand out real far, you put your hand out a little, and say, ‘Grab my hand, and give me a squeeze.’” The other respondent in this category reported a particular comfort and confidence in her sexuality and sexual preferences. She said,

> *I am also very open about sex in general, so I think that with the right person that seems too fast track us into a more intimate relationship because sex is obviously a very intimate act… I have no problem talking about it socially or talking about it on a first date or really at any level.*

Self-concept: Formative experiences (2, Variant). This category centers on certain formative experiences shaping self-concept. These two women had a range of formative experiences that shaped their self-concept. One woman recounted family values about intimacy and disability particularly formative and lasted most of her life. There was, “not a lot of embracing of disability,” and she, “… just didn't embrace my own self, and I didn't get kicked in the ass enough to reject all that other stuff.” It wasn't until she took an interpersonal development class for people with disabilities, then became the instructor and she finally was able to develop accepting relationships with other people like her.

> *I had the most intimate love relationships with all those people. They were genuine, and they were real, and I could be myself no matter how angry, no matter how sad, no matter how excited, no matter how joyous or how glad. All the emotions were perfectly acceptable. While I was involved with that organization, I was at my best with relationships.*

The other person captured within the category focused on two things. First, it focused on the challenge of navigating the world of care workers. Specifically, she felt that she was being treated as less than human by care workers that are supposed to care for her. "Those people that are in charge of sending people out to my house, they have really beat me down." From that, she gained a strength where she would say to them, "Fuck you. I am a human being just like you, and I have every right to be on this planet and live my life just like you do." She seemed to carry that strength through her stories of intimate relationships and dating. Her negative dates she wrote off as shallow. She did have an affirming relationship

> *"That's not at all anything. I can care less about you're in a wheelchair or not; I like who you are." That's what she said to me right off the bat. I think that that's what really grew my confidence."*

Self-concept: Media effects on self-concept (1, Rare). The final category within the domain was Media Effects on Self-Concept. One participant recounted that her identity not only as a person with a disability but also as an agent of intimacy, was shaped heavily by the media. She expressed her concerns about how the media shaped her identity and how it is shaping the identity of other young people with disabilities. She said, "The media is trying to infiltrate the way I think about beauty. That was really hard for me for a really long time." She talked about how the media influenced her before she eventually connected with role models within the community and also expressed concern for how young people without mentors were viewing themselves.

Self-Efficacy

As described earlier there is some overlap between the concepts of self-concept and self-efficacy. Within the scope of this project, self-efficacy was specifically defined as beliefs of one’s ability to form intimate relationships. This is a much more specific definition than used with the above domain about general self-concept. This domain yielded three distinct categories *Personal Strengths (5)*, and *Confidence (4)*, and *Formative Experiences (3)*. The overlap between this domain and the above can be explicitly seen within some of the categories, but it should be noted that the categories here are specific to intimate relationship development. Self-efficacy is a cognitive conclusion of one's ability in a particular area. That cognitive process assigns different weights to diverse sources of information when arriving at such a conclusion. Self-efficacy puts a heavy emphasis on one's prior performance and mastery criteria (Bong & Clark, 1999; Rostosky et al., 2008).

Table 7. Self-Efficacy - Categories and Sub-Categories

Category	n	Percent	Sub Category	n	Percent
Confidence	4	67%			
			Low Self-Efficacy	2	33%
			Positive Self-Efficacy	2	33%
Formative Experiences	3	50%			
			Caution Due to Past Experiences	1	17%
			Positive	2	33%
Personal Strengths	6	100%			
			Dating Skills	2	33%
			Interpersonal Skills	5	83%
			Openness and Risk Taking	1	17%
			Sustained Relationships	1	17%
			Evolution Over Time	1	17%

Self-efficacy: Personal strengths (5, General). With the domain of self-efficacy, the category *Personal Strengths* emerged as one of the most endorsed. Traits and abilities that participants saw as aiding them with intimate relationship development were coded as personal strengths. Within the category, several sub-categories emerged. Sub-categories were *Interpersonal Skills (5)*, *Dating Skills (2)*, and *Openness to Risk Taking (1).* Also coded as sub-categories of Personal Strengths, but discussed separately were *Evolution of Strengths over Time (3)* and *Skills that Sustained Relationships (2).*

With regard to *Interpersonal Skills,* one particular participant reflected that her interpersonal skills adept at relationship building are mitigating factors for her disability. She said, “My disability makes me physically weak, but my personality, I think my guess has always been kind of strong.” She then recounted some of her interpersonal skills.

> I *guess I'm the kind of person who's going to talk deeply, and I'm going to find out as much about this new person that I've just met by asking them questions. If they want to know more about me, well isn't that how any two people develop an intimate relationship.*

Similarly, within this sub-category, two of the participants focused emotional skills such as boundary setting and the challenges that come with that, and another reflected on the fact that she is looked at as someone who can be trusted, but is slow to trust herself. Two of the participants also focused on how interpersonal skills evolve over time. One participant reflected that getting older requires people to have more fully developed interpersonal skills if they wish to maintain and develop relationships and friendships. Another participant focused on the skills she is still in the process of developing, such as not being closed off because those behaviors "end up being really destructive."

Similar to Interpersonal Skills was the category of *Dating Skills*. This warranted a separate sub-category because, within this sub-category, participants specifically referred to skills and abilities relative to dating, as opposed to more generic interpersonal skills that could refer to any type of intimate relationships, such as friendship. Both of the respondents within this sub-category focused on their confidence in knowing what they want and how they achieve it. "I often think I'm quite confident in developing intimate relationships. I really value them highly, and I think I display that in my intentions going forward." She continued about her lack of subtlety and confidence in letting people know her intentions. Similarly, the other respondent focused on dating skills, their acquisition, and their applications as a means to meet her needs.

> *I really enjoy reading dating books and learning a lot about how people approach it almost strategically, and I find that fascinating. So, I like to try to hone those skills because people put so much thought into what people think about you. And if I don't care about what people think about me, then I can put so much thought into how I'm going to act in a relationship or how I'm gonna, for a lack of a more positive word, manipulate it, …it's all about getting what you want.*

Risk Taking is another sub-category in the same vein as the two listed previously, but due to its unique nature warranted separate categorization as it may be meaningful and applicable to other persons with disabilities.

> *Yeah, well, I think the one thing is I'm very daring. That is one thing. I'm willing to really push the odds a little bit, they say, or bend rules that are out there in the general population. Rules that say you can't do this.*

Sub-categorized separately but still within the category of Personal Strengths was the sub-category *Skills that Sustained Relationships*. When asked specifically what sustained relationships for the people in relationships, respondents commented on certain strengths they possess that have helped to sustain their relationships. Both of the respondents within this sub-category endorsed some sort of listening and communication as the major sustaining factor within their relationships. “I think what's been successful for me emotionally being intimate is wanting to listen. A lot of people don't know how to, and that's something that you learn.” The other end of communication as a sustaining factor has to do with communication within the relationship about wants and needs. “The fact that I'm able to express myself so well when it comes to intimate things make it easier to be intimate because they don't have to guess.”

Self-efficacy: Confidence (4, Typical). The category of Confidence with intimate relationship development also emerged in which three respondents explicitly spoke specifically to their confidence in their ability to develop intimate relationships. Two of the respondents endorsed high self-efficacy, and two endorsed low self-efficacies. With regards to low self-efficacy, one participant endorsed an overall inability to deal with emotional intimacy. She reported that, “I don’t think I know how to decipher those feelings or those thoughts properly.” While the other participant who endorsed low self-efficacy related it to continued rejection,

> *It's just been too long that it didn't work, and I have risked it many times. I have risked asking people out that were available, people that were not partnered, and I'm like, "Let's go out for dinner, drinks," or on a date, or whatever. There was one ... I don't think that any one person has ever said yes that I've asked, and so I don't have much confidence in my ability to develop an intimate relationship.*

The women who endorsed high self-efficacy mainly focused on their confidence, and over-confidence, in developing relationships in general, and they have applied that to intimate relationships. “I honestly have no doubt in my mind that I could probably start a relationship with any human, male human more than likely.”

Self-efficacy: Formative experiences (3, Typical). Three people acknowledged different experiences that directly affected their self-efficacy with respect to relationship development. Within this category, two distinct sub-categories emerged. All three subjects captured within this category talked about *Positive Formative Experiences (3)*, and two of those talked about *Caution Due to Past Experience (2)*.

Concerning *Positive Formative Experiences*, one participant recounted having a lot of trouble with relationships, and that she believed, “This whole thing that I don't deserve intimacy in relationships.” She took a class about personal development for people with disabilities, and it changed her life. She proceeded to get involved with the program for the next 15 years. She recounted several relationships, but one particular relationship she notes as formative because she took a positive experience from a very negative and abusive relationship. She reported that she reached the point where she, “Had gotten myself back. Wasn't willing to settle, and I wasn't willing to abuse myself by letting that person stay in my life.” A different participant recounted a deep fear of rejection during dating, but she had several positive experiences before ultimately reaching someone who rejected her. She reports that she was grateful for those experiences because it helped her realize that if she was with someone who didn’t accept her totally and completely, that she wouldn’t want to be with that person anyway.

> *Honestly, who wants to be with someone who is just looking at your body frame, or body type, or what you're sitting in… That's not going to be a real intimate, personal, loving, long-lasting relationship.*

One particular woman described *Caution Due to Past Experiences* as affecting their self-efficacy in relationship development. One focused heavily on her guard being up for romantic relationships because of lack of understanding in previous relationships and the risk sometimes being too great. The other focused on the constant rejection that she experienced throughout her life.

Stigmatizing Effects of Disability

Stigmatizing effects of disability: Societal barriers (4, General). This domain and the subsequent category are the only one in which not all of the participants are captured. This is most likely due to overlapping concepts that are difficult to tease apart. It is difficult to have a discussion about formative experiences of people's self-concept, self-efficacy, and attitudes about disability without some involvement about the stigmatizing effects of disability. This limitation will be discussed in the next chapter. This category focused on the various experiences of people with disabilities, societal perception of disability, physical beauty standards, family views about disability and specific negative experiences, and how those played a role in their development of intimate relationships.

Table 8. Stigmatizing Effects of Disability - Categories and Sub-Categories

Category	**n**	**Percent**	**Sub Category**	**n**	**Percent**
Societal Barriers	4	67%			
			Negative Experiences	2	33%
			Perception	4	67%
			Physical Beauty Standards	1	17%
			Family View on Disability	1	17%

With regard to societal perception, one client recounted her experiences with someone she dated in college. She eventually came to find out that the reason they did so many activities at home was that her partner felt they were trying to protect her because when they were in public, "It made him uncomfortable how everyone else would stare or gawk or approach me." Several others referred to people not viewing them as dateable or intimate beings. One even recounted being viewed as a means of satisfying curiosity about how people with disabilities have sex.

> *Society has created this idea that having a physical disability means you are immediately celibate. Once people get past the logistical stage of my body, they find a really cool character.*

Another of the respondents reflected on how society is uncomfortable with physical contact with her, and they assume that she doesn't like or want it.

> *Touching, because of my wheelchair, I feel that most everybody, and I mean a lot of people, even my own family members, are sometimes very uncomfortable hugging, touching, they're afraid. They're afraid it might hurt me. They're afraid they might hit my joystick, which moves my chair. They're afraid they might do something wrong.*

One participant spoke about physical beauty standards and how she believed that, even though she would be considered attractive, her disability limited her to only dating other people with disabilities.

Another participant recounted how her family's views on disability played a particular role in internalized stigma.

> *I was told directly, very directly, that that would never happen for me. My family thought it would be impossible, and they never thought of me as a sexual being. It would just never be a possibility or any kind of reality for me to have a partner… my view of myself was tainted by my family rejecting the reality that I could have a physical or sexual relationship or even intimate relationship.*

These feelings for here were re-validated every time she had difficulties in relationships. She even reported that she was asked to prom in high school, and was so excited because she finally deigned to considerer herself datable when "They took me to a priest for some kind of a ritual that would cure me of my disability. That was a horrible four hours of my life."

Online Dating/Social Media

Participants in the study were asked specifically how they navigate online dating and social media with regard to intimate relationship building. Categories addressed by participants within the domain were *Self-Disclosure of Disability (5)*, *Barriers (3)*, and *Non-Romantic Use (2)*.

Table 9. Online Dating / Social Media - Categories and Sub-Categories

Category	n	Percent	Sub Category	n	Percent
Barriers	3	50%			
			Physical Beauty Standards	1	17%
			Perceived Financial Barriers	1	17%
			Personal Experience	2	33%
Non-Romantic use	2	33%			
			Keeping in Touch	2	33%
Self-Disclosure	5	83%			
			Disability Disclosure	2	33%
			Disclosure Either	2	33%
			Presentation	1	17%

Online Dating/Social Media: Self-disclosure (5, General). Five participants were categorized as commenting on *Self-Disclosure* as it relates to their online identity. Two women saw strictly benefits in self-disclosure of disability, and two were ambivalent about it. The final person in the category didn't address disability. The two that endorsed disability disclosure made statements such as, "I'm not shy about my disability on social media, so they're very aware when they swipe left," and "I always try to make a point before I'm ever going to meet someone in person…to let them know I still don't have an arm and a leg." One of those women even reflected that she likes to make her disability a defining characteristic, and for others that may not be the case.

> *I like to make confident jokes about how having a few limbs short of a full deck, stuff like that so that people can view my humor around it. I have a lot of friends that haven't been able to figure that out, and they haven't had any success doing it because they don't want to make that such a defining characteristic because they don't view it that way.*

Two women were ambivalent about disclosure, iterated the benefits of each, and ultimately settled on ambivalence. “I don't know. I think they both take a lot of attitude to do. Great. I don't think either one's wrong or right.” “I don't really know what the best way to do that is, or if there is a best way.” One woman really liked to experiment with both disclosures of her disability and not disclosing it and then see what the reactions she got. The woman who didn’t address disability at all when referencing self-disclosure online instead focused on the presentation of an idealized version of herself.

Online Dating/Social Media: Barriers (3, Typical). Three respondents endorsed what came to be categorized as Barriers. Within this category, barriers to utilizing social media varied between, personal experiences and sometimes caution due to past experiences, perceived financial barriers, and physical beauty standards.

One particular person surveyed encapsulated many of these experiences. She reported a lot of apprehensions using social dating websites because of her past experience dating in the real world. She also has an experience where one of the dating websites asked her annual income. She didn't want to answer because she believed it to be a criterion for acceptance onto the site.

> *I applied to some of the dating websites out there …but you have to have X number of income, a certain dollar amount of income to even apply before they'll even take you in.*

She then reported that she had never followed through with signing up for an online dating site. Another respondent commented on the perceived shallowness of online dating and how it has pushed intimacy from emotional to physical.

> *You don't really have to work too hard, in my opinion, with social media. I think it has kind of evolved to more of a physical than an emotional intimacy type of network. Whereas before, for me, it was a lot of emotional more than physical.*

Online Dating/Social Media: Non-romantic use (2, Variant). This particular category captured how some of these women used social media for non-romantic purposes. Both utilized social media to keep in contact with close and intimate friends that they developed through various activities. Interestingly, both of the women captured within this category stated why they didn't utilize social media as an online dating resource. One recounted using various social networking apps, but not liking them. "I don't really like all of them. Using social media on top of disability as a filter and as a lens to weed people out, visual disability… scares a lot of people." The other respondent was sparked by this interview and reflected,

> *I just don't know how to write a good ad for a website. I actually think that I would really need to figure out a little bit more about what are my barriers. What is it that's blocking me. I am curious, and this whole interview has made me even more curious as to what is*

> *it, and why is it that I'm not taking that risk… I'm just really curious to explore that whole conversation with myself.*

Outcome Expectancy

The final domain explored within this research is the domain of Outcome Expectancy. Outcome Expectancy is the belief of the likelihood certain behaviors will lead to certain outcomes (Bandura, 1986). The two categories that emerged from this domain are *Hope for Future Relationships (6)* and *Formative Experiences (4)*. The two categories are discussed below in reverse order as the final question of the survey was about hope for future.

Table 10. Outcome Expectancy - Categories and Sub-Categories

Category	n	Percent	Sub Category	n	Percent
Formative Experiences	3	50%			
			Disability Identity	2	33%
			Negative	3	50%
Hope for future Relationships	6	100%			
			Future Relationships	6	100%
			Romantic and Non-Romantic	2	33%

Outcome Expectancy: Formative Experiences (4, Typical). The category formative experiences encapsulated specific experiences that people reported that affected their outcome expectancy, most often negatively. Experiences varied but centered around negative outcome expectancy because of past experience sometimes centered around disability identity. One participant had a negative outcome expectancy for dating other people with disabilities because of her previous experience. Another reflected that she had her heart broken too many times to have hope for an intimate relationship "it is no longer something I have been able to do is be intimate because I've gotten my heart broken way too many times." Another focused on messages that she had gotten from her family early in life that she is still combatting, “Those kinds of rejections were again validating maybe mom was right. Maybe I'm not supposed to have friends or partners.” Finally, another talked about bad experiences dating,

> *I think that in my head, I'm just like, "Well, they probably really don't want to talk to me, they probably just want to get in my pants. So, I'm just not going to give it to them," so that probably has affected the way that I act intimately in one sense.*

Outcome Expectancy: Hope for the Future (6, General). The interview concluded with a question about hope for the future. Each of the women was able to articulate either what they wanted from themselves, what they wanted from their partners, or what they wanted in intimate friendships. This particular category was hard to parse out, but two major sub-categories emerged, *Mixed- Romantic and Non-Romantic Relationships* and *Future Romantic Relationships* and all six participants endorsed some hope for *Future Romantic Relationships*. The responses were wide and varied, within the category. One participant hoped for the relationship she had now but in the future. While others talked about matching partner values and relationships,

> *Where I can feel comfortable being vulnerable with the other person and sharing the parts of myself that are most complex, and a lot of times that means my disability and the way that it affects my identity and the way that I think about myself.*

Still, yet, another participant hoped for a romantic relationship that is healthy, both emotionally and sexually, despite the work that comes with longer-term relationships.

> *I like the butterflies that you get when you're dating someone, especially when it's new. It is much different than when you've been in a long-term relationship. You kind of have to work at getting those butterflies.*

With regard to *Mixed- Romantic and Non-Romantic Relationships*, one participant specifically mentioned intimate friendships. She is confident that she will develop more intimate friendships and while had mentioned that she was too old for romantic relationships earlier in the interview,

> *There is a glimmer that's always ... I never put out the flame. I've never been willing to turn off the idea that I will find someone that might find me sexually attractive or intimacy attractive.*

Chapter 5

Conclusions

This study investigated the human phenomenon of intimate relationship development as it pertains to women with visible physical disabilities. Six women, who self-identified- as having visible physical disabilities, participated in structured interviews that were designed to help answer three research questions: 1) What is the overall subjective experiences of women with visible physical disabilities in developing intimate relationships? 2) What aspects of intimacy and sexuality are most important for women with visible physical disabilities? 3) What are some of the challenges of and facilitators to intimate relationship development that women with physical disabilities have experienced? In this chapter, the findings are summarized, interpreted, and discussed within the context of the related research reviewed in Chapter 2. Additionally, strengths and limitations of this study are described followed by a discussion regarding the implications of the present findings for clinical practitioners. Finally, recommendations for future research are offered. The first section of this chapter is organized according to the major research questions.

Overall subjective experiences

This study, though very broad, yielded interesting results relative to the development of intimate relationships. It should be noted that though relevant to the participants "overall subjective experiences," this section does not contain specific and current limitations and barriers to the development of intimate relationships. Limitations and barriers are discussed within the review of the third research question specific to challenges of and facilitators to intimate relationship development.

Delayed intimate relationships. As previously noted in the literature review, there are several common societal beliefs that prevent people with disabilities from exploring and learning about their own sexuality. Because of such, they may not be exposed to the same psychosexual developmental opportunities as people without disabilities (Weissinger, 1980). Several clients stated that they didn't have opportunities to date or develop romantically intimate relationships before leaving high school, which is supported by the literature (Börjeson & Lagergren, 1990). From the literature review, it is clear that attitudes about sexuality and disability can lead to internalization of negative attitudes and beliefs (DeLoach, 1994). These attitudes, as shown through these interviews, derive from a multitude of places. Some participants reported negative societal attitudes as specific barriers to intimacy; one even reported that she was kidnapped and exorcized, while some reported familial values that hindered their development of intimate relationships, both romantic and platonic. This can be extremely detrimental to the self-esteem of people with disabilities to be considered unattractive and have essentially a nonsexual status in society (Milligan & Neufeldt, 2001). Isolation from peers, and not being perceived as suitable for dating (Gordon et al., 2004) seemed to have attributed to an unclear sense of sexual identity (Mona et al., 1994) for several of the women surveyed.

Sexual self-concept. Breakwell and Millard (1997) described sexual self-concept as emerging around various identities. For people with disabilities, societal concepts of sexuality do not readily include them, and thus lead to a devaluation of sexual identity personally and societally. It is also important to remember that people are the products of multiple identities and that these identities may play a large role in their sexual self-concept. Several participants identified family values as playing a role in how they conceptualize themselves. One in particular participant focused on her intersecting identities as a person with a disability and her cultural identity as of Caribbean descent. Disability was seen as a weakness in her culture and a negative reflection on her family. Another participant discussed how her other identities (e.g., student, worker, friend) took priority over her identity with respect to relationships. This holds with Bishop's (2005) Disability Centrality model that discusses quality of life as moderated by domain importance. For that particular participant, intimate relationships shifted to a lower importance when compared to her other identities and her disability management.

Availability of partners. Pertinent to the literature review of relevant behaviors, research indicates that lack of availability of partners was the most frequent reason for sexual dissatisfaction (Griffith. 2000). Even though on-line questions did not surface until the end of the interview, online dating and social media were present throughout the conversations. All of the women utilized social media for maintaining intimate friendships, but five specifically talked about it with regard to the development of intimate romantic relationships. Interestingly enough, while the other woman hadn't used online dating/ social media for intimate relationship development, another reported utilizing personal ads in the local newspaper. Each of the women talked about the trials and tribulations navigating social media, and even print media, specifically focused on the area of self-disclosure. Availability of partners seemed to directly affect the women in the study. The older women had more traditional dating experiences, such as starting to date at a later age, limit of available partners, etc., while the younger women all utilized social networking in some aspect which increased their overall availability of partners. Those women who endorsed disclosure of their disability also were able to filter their experiences through the social networking. There is less opportunity for a negative interaction that is disability related because desire for contact is mutually agreed upon. There is also a lower risk involved for women utilizing social networking for dating as they might not have to face rejection personally, as there is some level of disconnect from it. This should not be interpreted as devaluing real rejection experiences from people online, just to say that there may be some level of protective factor compared to in-person rejection.

It should be noted that in general, the women who were more successful with online dating seemed to have higher reported self-concept and self-efficacy. Research suggests that higher self-esteem moderates effects of interpersonal rejection (Ford & Collins, 2010). The research in Social Cognitive Theory suggests self-efficacy is cyclical, potentially manifesting in both the positive and negative directions (Gist, 1987). Women who reported positive self-efficacy seemingly engaged more in tasks related to intimate relationship development and also seemed better able to cope with rejection. Conversely, individuals who appeared to have low self-efficacy, with respect to intimate relationship development, had fewer opportunities and seemed to give up more easily which served to lower self-efficacy. Thus, participant's self-efficacy, whether positive and negative, seemed to dictate the participant's sense of identity and behavior with respect to intimate relationships (Mona et al., 1994).

Aspects of Intimacy and Sexuality Most Important

Some of the most interesting results related to participant's perceptions of the most important aspects related to intimacy and sexuality. Of particular interest, for this and possibly future research, were the areas of Core Values, and Outcome Expectancy. Each participant gave their insight as to what was most important for them with regards to intimate relationship development. The general themes of responses, with relation to this research question, were centered around openness to experience, shared values, and validating relationships.

Openness to experience. It is important to consider intimacy more broadly to include positive aspects of romantic and non-romantic intimacy, and to be asset focused as opposed to deficit-focused. A broader conceptualization of intimacy and sexuality allows for a view of intimacy as a normative part of overall well-being for people with disabilities. Encouraging positivity regarding intimacy has been shown to have important implications for the overall health and quality of life (Philpott et al., 2006). Participants were careful to distinguish intimacy as connectedness and broadly relational and not as just sexually related. The following quotation exemplified the participants' desire to impart wisdom to other people with disabilities and the importance of openness to experience and intimacy in general.

> *If you're willing to experiment, if you're willing to change your mindset from the missionary position to something else…there's more than one way to be intimate with a person sexually. Sometimes that can be just rubbing their feet…. It doesn't always have to be a grand orgasm.*

Shared values. There were many values listed that were of particular importance to people with disabilities. Of particular note were the qualities that were identified as being shared with their partners. Of all the values listed, of which there were many, the most salient throughout the entirety of the interviews was communication. Communication was detailed as, a strength, a limitation, and an important quality in a future intimate relationship. Communication, with respect to intimate relationships may be directly linked to relationship self-efficacy. This will be further discussed in the next section about barriers and facilitators to intimate relationship development. Other aspects of core values that were identified were honesty, trust, comfort, and attraction.

Validating relationships. Another major theme that was present, though not surprising, had to do with validating relationships and shared experiences. The presence of validating relationships, whether by family, peers, or romantic partners seemed to be integral to the success of intimate relationship development. Several participants shared experiences of validating or invalidating relationships with peers, family, and friends. Those validating and invalidating relationships influenced many aspects of their lives including; their disability identity, their self-efficacy and self-concept with regard to relationships, as well as their outcome expectations. One participant shared how she sought to combat an intimate partner's invalidation by another romantic partner.

> *I remember this person that I lived with for five years. We had a really, really wonderful beginning, and it was great. I introduced him to just stepping up a little bit. He had a really grungy life, and I told him. I said, "You know, you don't have to settle for crap."*

She reported that eventually that friendship grew to be romantic in nature and they maintained that for several years. It stands to reason that similar to self-efficacy, relational validation or invalidation serves to either alter or reinforce identity and attachment. Two women commented that they had poor self-concepts until they were able to be around people who validated their experiences and provided mentorship and hope.

Challenges and Facilitators to Intimate Relationship Development

The larger scope of this project was to gain a better understanding of barriers and facilitators to intimate relationship development. Psychosocial research often focuses primarily on barriers. The intent and hope of this research was to focus more on the facilitators to intimate relationship development.

Barriers. When asked specifically about barriers, four out of six participants said that disability, itself, did not present any barriers to developing relationships, or that the barriers were not insurmountable. Most of the barriers that were mentioned were societal and completely out of the control of these women. With respect to barriers, this research supported past investigation that enumerated the multiple barriers that people with disabilities face within any psychosocial interactions. There were a few barriers that bear mentioning in that they help form a richer picture of intimate relationship development for women with physical disabilities, and the hardships they endure.

Women in the study talked about specific barriers to intimacy that shaped how they perceive and navigate intimate relationships. As stated previously, women were careful to distinguish between different types of intimate roles which ranged from a caregiver, to a friend, to a romantic partner. Several women noted conflicting roles within intimate relationships, specifically conflict between caregiving roles and romantic roles can cause problems. This posed difficulties for not only the partners switching roles from romantic to caregiver, but also for those surveyed switching from romantic partner to care recipient. Other specific barriers mentioned were physical limitations of disability that included age, and functionality, and the physical logistics of spontaneity. Some women reported that society perceived them as frail and lacking desire based on their disability. These perceptions are often perpetuated by myths about disability (Nosek et al., 1996).

Of course, stigma plays a significant role in shaping how these women navigate intimate relationship development. Several of the women focused on negative societal barriers and the stigmatizing effects of disability. Of particular note was how these women were perceived by their peers, their families, and their potential dating partners. These findings are supported by the literature that these women are perceived as less worthy, less valuable, and less desirable as intimate partners (Katz et al., 2013; Olkin & Howson, 1994; Wright, 1983). They reported avoidance, rejection, and patronization. Several mentioned specific formative negative experiences as a result of stigma that influenced their identity, their self-concept, their self-efficacy, and their outcome expectations.

Similarly, these feelings of societal stigma shaped how many approach intimate relationship development. Specific to online dating, the women noted several barriers that prevented them from engaging to a greater degree. Among the barriers to online dating that were noted, one of the most salient barriers was physical beauty standards. Five of the women talked about self-disclosure of disability while engaging in social dating. I use the term social dating here because, one person in particular hasn't used online social networking in that context, but instead previously engaged in newspaper personal ad placement. From the interviews, it is clear that physical beauty standards and how they relate to stigma play a major role in how these women have navigated intimate relationship development. Two of the women reported that they always disclose their disability, two reported that they sometimes did, and the final one reported on presenting an idealized version of herself. This need for impression management seems to be an artifact of societal stigma related to disability and is a barrier that all people with disabilities who engage in online dating must contend with.

Facilitators. Some of the women surveyed were definitely more successful and seemed happier overall with their navigation of intimate relationship development. Success, in this case, was not formally measured, nor was it indicated simply by relationship status. Of the two people in relationships, one expressed that she is content in her relationship, while the other expressed uncertainty. Of the single women, one deprioritized intimate relationships to focus on other things.

There were three standout themes with regard to facilitators of intimate relationships; openness, communication capacity, and self-concept. The women were asked about some of their personal strengths and what sustained their relationships. One of the most salient themes was openness. Several women who had successful intimate relationships talked about their openness, not only to intimacy but also openness on a much boarder scale as it relates to risk taking. Several talked about openness to intimacy and the various forms that it takes that are beyond the traditional views of sex. On a broader scale, openness as it relates to interpersonal risk-taking. The women that were more open to new experiences and risk-taking had well developed interpersonal skills and communication skills.

In the same vein, communication skills were a repeated theme throughout the research process. For instance, one participant noted a communication skill deficit hindered her relationships, while another participant, who was reportedly more successful with relationships, noted it as one of her personal strengths. The reportedly more successful women were not only confident enough to initiate relationships but also confident in expressing and advocating for their wants and needs.

Also within the same vein, the third salient theme that was a facilitator of intimate relationships was self-concept and self-efficacy. Women who were more confident in their identities as people with disabilities, as measured by willingness to disclose disability, were more apt to have higher intimate relationship self-efficacy. For these particular women, higher or lower self-concept and disability identity seem to be related to specific formative experiences. Specific formative experiences such as the imposition of family values related to disability or specific experiences related to disability may serve to alter attachment patterns of individuals. Research into attachment theory states that adverse experiences may strongly affect attachment style, which can, in turn, affect how people develop and maintain intimate relationships. Higher self-concept seemed to be related to positive familial and community values about disability and intimacy, as well validating experiences with peers and mentors with disabilities. Lower self-concept seemed to be specifically related to stigma and isolation either from peers or family. These values, be they positive or negative, become internalized and reinforced. Opposite valence stimuli have less of an effect on changing internalization than similarly valenced stimuli. Negative internalizations are reinforced when dealing with rejection and stigma and are less prone to changing when faced with positive stimuli such as acceptance. Positive internalizations are less affected by stigma and help to reinforce self-concept and self-efficacy. This may have a multitude of clinical implications which will be discussed later.

The results provide some insight into the question “What makes some people more successful than others at developing intimate relationships?” In any community, there are people with uncommon but successful strategies that help them find better solutions to problems than their peers. This research has sought to label a few of the facilitators of intimate relationships for people with physical disabilities and it is the hope that future research will focus more specifically on this severely neglected area that is of the utmost importance to people with disabilities.

Strengths and Limitations of Research Method

Strengths and limitations of the present study are discussed in reference to Hill and colleagues (1997, 2005) six criteria for evaluating Consensual Qualitative Research: 1) trustworthiness of the method; 2) coherence of the results; 3) representativeness of the results to the sample; 4) testimonial validity; 5) applicability of the results; 6) replication across studies.

With regard to the trustworthiness of the methodology, Hill and colleagues (1997, 2005) recommend the researchers scrutinize suitability of the questions and sample makeup, the consensual process, the auditing process, and the consistency of analysis across cases. The interview was developed by the primary researcher with input from several experts in various fields. The principal investigator also sought the expertise of two outside researchers within the rehabilitation field. Dr. Kelly Kazuauskas and Dr. Amanda Easton are both experts in the topic area, as defined by multiple articles written about disability and sexuality, and were consulted to ensure that the interview would capture the relevant data. The principal investigator also sought feedback from two rehabilitation methodologists to within the Department of Rehabilitation Psychology and Special Education at the University of Wisconsin Madison to ensure that interviews would capture adequate information that could be applied. The principal investigator has sought comments from one person with lived experience who is able to offer feedback that may not have been obvious to researchers. The resulting interview protocol was semi-structured to hold with the methodology and allow open-ended responses from participants while ensuring similarity of experience across those interviewed.

With regards to the composition of the sample, the primary investigator sought to ensure, as best as possible, the sample was appropriate for the study. Each participant in this study met the predetermined criteria previously discussed for inclusion, and it is felt that each was able to express her experiences clearly.

At each phase of the analysis, the research team worked individually with the data before assembling to discuss their individual viewpoints. Each team member was encouraged to share their perspectives. Analysis continued when all team members reach consensus. The auditor of this study evaluated the work of the research team and gave helpful feedback. This feedback was discussed and incorporated by the research team. The primary investigator also took measures to ensure the analysis was reliable across cases and as the analysis progressed, new domains and categories emerged, then rules for classifying data to those changed.

Hill and colleagues' (1997, 2005) next criterion, coherence of the results, refers to the degree to which the conclusions are clear and logical. Additionally, coherence requires that the results be plausible and represent the views of all the participants in the study. The researcher chose the CQR method in an attempt to provide data that would be both meaningful and understandable. The data is believed to be a good representation of the women who shared their experiences with the researchers. The results section made an attempt to accurately represent every participant's experience as equally as possible. The overlap of this study's conclusions with previous research suggests the plausibility of the present findings. Hill and colleagues (1997) also recommend triangulation of the data by utilizing additional analytical methods or collecting alternate data, unfortunately, triangulation was not within the scope of this research project and thus is a limitation.

With regard to the third criterion, representativeness of the sample, the results are reported such that readers can assess the degree to which the domains and categories represent the sample. A characteristic limitation of all qualitative studies is generalizability, due to their small and often homogenous samples. Hill and colleagues (2005) suggest that qualitative studies be assessed by their representativeness of the results to the sample. To assist readers in evaluating representativeness, the researcher classified the representation using the words “general,” “typical,” “variant,” and “rare.”

The fourth criterion, testimonial validity, represents another limitation present in this research. Testimonial validity is achieved through participant review of study findings to ensure researcher interpretations accurately reflect their lived experiences. Due to the time-intensive nature of the analysis as well as the time constraints of the research project, participant review was not included.

Applicability of the results requires that the results are evaluated by their usefulness to others in the field. Given the scarcity of research regarding intimate relationships for people with disabilities, it is the assertion of the researchers that the results presented are applicable and useful.

Finally, the last criterion, per Hill and colleagues (1997, 2005) is the replication across studies. Because this study material is rare, replications do not exist. Instead Hill and colleagues (1997) suggest alternative ways to replicate findings such as having a second team analyze the same data set. This represents another limitation of the present study but is recommended for alternative research.

Additional limitations deserve mention. The implications of this study must be considered within the context of a few limitations. First, the generalizability of the findings is limited due to many factors. The interview was limited due to the resources the writer was able to put into transcription. Due to the high cost of transcription, the interview was limited to 8 questions with a targeted time at 30/45 min. The number was chosen to be roughly half of the recommended questions for an hour-long interview (Hill et al., 2005). Similarly, the number of participants was roughly half of the recommended participants by Hill and colleagues (2005). Future research, less bound by time and financial concerns should more truly adhere to the CQR model.

Second, the researcher does not expect the views and behaviors of this small sampling are all inclusive of the wide range of viewpoints of all women, or all people with visible physical disabilities. The non-random convenience and snowball sample accessed through Access to Independence, an Independent Living Center, and through social network, may hinder the generalizability of data. It is possible to have a sampling bias within my sample due to part of the sample having knowledge of and using of community resources, specifically for those through Access to Independence. Additionally, three of those sampled were specifically knowledgeable about and active within the disability community.

Another limitation was the subject material itself. The subject material, while consented to, may have yielded responses that may have been subject to bias from the discomfort of participants in discussing other intimacy issues. It is possible that the participants, who had no prior professional relationship with the interviewer, may have been inhibited in their responses or may have tried to represent themselves, their coping techniques, and their relationships in a socially desirable light.

A final limitation involves the interview protocol itself and questions that were not specifically included in the interview protocol's initial development. At the behest of the research team, an additional question was included to examine information pertinent to online dating and use of social media. The finalized question was added to the end of the interview. This information proved to be useful and pertinent in that every participant brought up the use of social media or online dating before the question was asked.

Despite these limitations, the present study provides a rich description of the experiences of these women with regard to intimate relationship development. The results suggest several implications for practice and have generated additional questions for future research.

Suggestions for Future Research

The present study's limitations are best addressed by future research. Triangulation of the data, which improves the validity using different sources or methodologies, is especially important when the sample size is small. Future research that investigates intimate relationship development would likely benefit from the inclusion of a quantitative questionnaire or separate, concurrent analysis. Additionally, future studies would be strengthened by the inclusion of participant feedback regarding the accuracy of the analysis.

Given the absence of current research focused on intimate relationship development, the literature would benefit from a replication of the current study. Such research would help to solidify or disconfirm, the current findings. Ideally, replication of the study would include more women so a more accurate picture can be gained of the effects of age, specific disability, and other interpersonal characteristics. The inclusion of more people, and eventually men, would highlight the inter and intrapersonal factors that facilitate intimate relationship development.

Obtaining additional information about a person's family of origin may be imperative in helping tease out the role of early attachment. Research indicates that attachment style may be highly correlated with self-efficacy beliefs with regard to intimacy (Amiri, Shukuhadat, Hossein, & Yousef, 2013). Amiri and colleagues (2013) research indicates that attachment style may have a direct correlation with the level of fear of failure, decision-making, coping style, and critical thinking and problem-solving ability, which are all connected directly to self-efficacy beliefs about intimate relationships. Additionally, it may be helpful to gain a better understanding of attachment if researchers examine how life experiences may change attachment patterns. Research into attachment theory states that adverse experiences may strongly adversely affect attachment style, even with secure familial attachment (Waters et al., 2000). This research may be able to be taken to its logical conclusions with regard to disability. Even with secure attachment and supportive familial values, adverse experiences related to the disability experience may alter attachment style whereby interfering with intimate relationship development. This investigation lends itself to future mixed methodology study as well as potentially to specific instrument development. Measures would also benefit from a dimension of self-esteem and situation specific self-efficacy. Research shows that self-esteem moderates psychological responses to interpersonal rejection (Ford & Collins, 2010). The addition of quantitative measures would allow for randomization and possible control groups within studies. Additional studies would benefit from larger sample sizes which would not only increase generalizability, but also help to identify potential casual links between the identified constructs and the outcomes desired.

Future research should include measures of domain importance and life satisfaction. Sexual self-concept may be an area of intervention towards increasing domain importance, and therefore overall quality of life with respect to intimacy. Of particular importance, as indicated by the participant's stated values about intimate relationships, as well as hope for future relationships, including scales that measure aspects of communication. There exist many scales that measure communication both in intimate relationships (Halpern-Felsher et al., 2004), focused on sexual behavior (Rostosky et al., 2008), as well as sexual-communication self-efficacy (Quinn-Nilas et al., 2015) that could be useful in future explorations.

Expanding research in this area may serve as an initial point for new interventions that seek to increase the relational capacities and sexual well-being, reduce the sexual risk-taking, and enhance the intimate relationships of people with disabilities.

Implications for Practice

It would seem obvious that people with disabilities, due to many reasons (e.g., lack of knowledge, lack of availability, stigma, etc.), may show deficits in areas of sexual well-being. It is the responsibility of rehabilitation professionals to assist with reduction of sexual risk-taking as well as to enhance the intimate relationships of people with disabilities. Rehabilitation professionals, educators, and parents seeking to increase initiation of intimate relationships and sexual communication self-efficacies should be made cognizant of deficits present in the disability community and aim to increase self-efficacy in the areas identified through research. A research study Kazukauskas and Lam (2010) indicated that roughly 40% of rehabilitation counselors did not receive any sexuality-related training at all in graduate school. The more knowledge that rehabilitation counselors have with regard to intimacy and sexuality issues with their clients, the more comfortable they will be when addressing educational and counseling related sexuality and intimacy issues. Integration of more intimacy, sexuality, and relationship training within the rehabilitation curriculum will be a boon to both counselors as well as clients and fill a gap in training that has long been an issue. Intimacy related goal planning, as part of integrated care plans, may help all people struggling disability-related intimacy issues, but may be especially helpful to people who acquire disabilities, as well as older individuals within in the community who have been experienced greater stigma related to disability and intimacy.

It becomes the responsibility of researchers and practitioners to help people with disabilities conquer stigma related to intimate relationship development. Several of the participants endorsed the importance of mentorship relationships and the development of interpersonal skills through either mentorship or through specific classes. These types of programs could be utilized not only to teach specific interpersonal skills to people with disabilities, but also serve as a place where people with disabilities can find validating relationships from people with similar experiences. These type of programs, especially if initiated early in school, or as an adjunct to typical schooling may facilitate intimate relationship empowerment. Empowerment has been argued as being the opposite of self-stigma Corrigan, Kerr, & Knudsen, 2005) and is defined as having control over one's treatment and life. A strong sense of personal empowerment is highly correlated with high self-efficacy and self-esteem

(Corrigan et al., 2005). Self-esteem has been identified as a moderator for psychological responses to interpersonal rejection (Ford & Collins, 2010). Other programming may include online impression management, which could help young people manage the tension between impression management and the presentation of an authentic self. Communities may be able to foster personal empowerment, and pride, through programming that provides access to education, normalization of experiences, and community mentors.

This type of programming, if introduced early on, may also help reduce family stigma related to disability. Literature suggests that one of the main strategies for combating stigma is interpersonal contact with people within the stigmatized group (Pettigrew & Tropp, 2008). Research shows that improvements in attitudes toward, and reduction in stereotypes, are most marked when there is contact with a person who moderately disconfirms stereotypes (Reinke, Corrigan, Leonhard, Lundin, & Kubiak, 2004). It would stand to reason that exposure to other adults with disabilities early on would reduce self-stigma, as well as imposed familial stigma. The following is a quote illustrating the importance of contact:

> *It wasn't, I think, until I got involved with the disability community and I started having mentors that I thought were not only effective leaders, but effective role models and living independently, or semi-independently and just were confident in who they were.*

Finally, and likely most importantly, rehabilitation professionals need to instill hope.

Levels of hope are associated with many outcomes that are affected by attachment style. Hope is strongly correlated with high optimism, self-esteem, perceived control, and problem-solving abilities. Literature indicates that hope levels are responsive to targeted interventions that provide goal-directed thinking, adaptive coping, and focus on attachment-related outcomes (Connell, Coates, Doherty-Poirier, & Wood, 2013; Davidson, Feldman, & Margalit, 2012; Snyder, Lehman, Kluck, & Monsson, 2006). Rehabilitation and community settings may provide settings in which to implement hope theory-based interventions (Snyder et al., 2006) and apply them directly to intimacy related constructs such as sexual communication self-efficacy, coping with rejection, and intimacy related goal planning.

This researcher was asked by participants throughout the process, “What can be done?” and the answer is, a lot. Rehabilitation professionals are responsible for normalizing intimacy. That can be accomplished simply by asking people about it. Rehabilitation professionals can be strong advocates for ways that people with disabilities can gain the social skills and self-confidence necessary to combat the stigma that is present within our society.

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Appendix 1

Interview Protocol:

1) Will you begin by telling me a little bit about yourself and about your disability if you are comfortable?
2) This study is about people with disabilities establishing meaningful and intimate relationships and some of the facilitators, barriers, and significant challenges in establishing, maintaining and developing those relationships. I will be asking you questions about intimacy related to dating and love. Are you comfortable if I ask you these questions?
3) Could you describe what you would consider some of the important intimate relationships you've had in your life?
    a. Can you tell me what aspects of intimate relationships are most important to you and why they are important?
    b. *[If previous relationship]* Can you tell me a little bit about what sustained that/those relationships? Can you tell me about what limited the relationship?
    c. *[If current relationships]* What are your hopes for this intimate relationship in the future?
4) How would you describe your confidence in developing intimate relationships? Why?
    a. Please describe your ability to develop meaningful intimate relationships.
5) Can you tell me a little bit about the experiences you have you had with dating, both positive and negative?
    a. How have your experiences affected your intimate relationships?

   b. How have your experiences views about yourself affected your intimate relationships?
   c. What barriers, if any, has your disability caused in dating and developing intimate relationships?

6) Could you describe what has been most successful for you with regards to forming intimate relationships?
   a. Are there personal strengths that have contributed to your success in developing intimate relationships?
   b. Are there any personal challenges that have gotten in the way of your success with intimate relationships?
7) What are your hopes for intimate relationships in the future?
   a. Describe what an ideal intimate relationship would look like for you?
8) Can you tell me a little bit about how you use social media and social networking?
   a. How do social media and social networking play into development of intimate relationships?

Appendix 2

UNIVERSITY OF WISCONSIN-MADISON

Research Participant Information and Consent Form

Title of the Study: A Qualitative Analysis of Intimate Relationship Development
Principal Investigator: David Rosenthal PhD, CRC (phone: (608) 262-4776) (email: drosenthal@education.wisc.edu)
Student Researcher: Derek Ruiz MS, CRC (email: druiz2@wisc.edu)

DESCRIPTION OF THE RESEARCH

You are invited to participate in a research study about positive factors and potential barriers to people with disabilities developing and maintaining intimate relationships.

You have been asked to participate because you have self-identified as an adult woman with a visible physical disability.

The purpose of the research is to gain a better understanding of how people with disabilities develop and maintain intimate relationships.

This study will take place at either Journey Health and Wellness (49 Kessel Ct.) or the School of Education Building (1000 Bascom Mall) at the University of Wisconsin - Madison. The locations will be chosen by the participant based on convenience and accessibility.

Audio tapes will be made of your participation. The research team and transcription service will hear the audiotapes, as will a professional transcription service. Audio recordings will be kept until transcription upon which time they will be destroyed.

WHAT WILL MY PARTICIPATION INVOLVE?

If you decide to participate in this research you will be asked to complete an in-person interview lasting between 45 minutes to 1 hour.

ARE THERE ANY RISKS TO ME?

The main risk of taking part in this study is that your study information could become known to someone who is not involved in performing or monitoring this study. Due to the sensitive nature of the discussions, there may be some questions that make you feel uncomfortable or bring up bad memories, but we feel that there is very limited risk associated with participation. It is important that you know you do not have to respond to any of the questions and may quit at any time, without penalty. You will be provided a list of resources should you need any additional mental health support.

ARE THERE ANY BENEFITS TO ME?

You are not expected to benefit directly from participating in this study. Your participation in this research study may benefit other people in the future by helping us learn more about things that help and hinder intimate relationships for people with disabilities.

WILL I BE COMPENSATED FOR MY PARTICIPATION?

You will receive 20 dollars for participating in this study.If you do withdraw prior to the end of the study, you will receive 5 dollars for your time.

HOW WILL MY CONFIDENTIALITY BE PROTECTED?

While there will probably be publications as a result of this study, your name will not be used only de-identified information will be used. The study results will include quotations but quotations will be coded to maintain confidentiality.

If you participate in this study, we would like to be able to quote you directly without using your name. If you agree to allow us to quote you in publications, please initial the statement at the bottom of this form.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

You may ask any questions about the research at any time. If you have questions about the research after you leave today you should contact the Principal Investigator David Rosenthal PhD, CRC at (608) 262-4776. You may also call the student researcher, Derek Ruiz MS, CRC at (608) 262-4776.

If you are not satisfied with response of research team, have more questions, or want to talk with someone about your rights as a research participant, you should contact the Education and Social/Behavioral Science IRB Office at 608-263-2320.

Your participation is completely voluntary. If you decide not to participate or to withdraw from the study it will have no effect on any services or treatment you are currently receiving.

Your signature indicates that you have read this consent form, had an opportunity to ask any questions about your participation in this research and voluntarily consent to participate. You will receive a copy of this form for your records.

Name of Participant (please print):_ ______________________________

_ ________________________________ _______________
Signature Date

_ ______ I give my permission to be quoted directly in publications without using my name.