Sexual Knowledge, Experiences, and Needs of College Students with Physical Disabilities: A Pilot Study

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SEXUAL KNOWLEDGE, EXPERIENCES, AND NEEDS OF COLLEGE STUDENTS WITH PHYSICAL DISABILITIES: A PILOT STUDY

PROFESSIONAL DISSERTATION

SUBMITTED TO THE FACULTY

OF

THE SCHOOL OF PROFESSIONAL PSYCHOLOGY

WRIGHT STATE UNIVERSITY

BY

NICOLE LYNN MATROS, M.A.

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PSYCHOLOGY

Dayton, Ohio

September, 2012

COMMITTEE CHAIR: Julie Williams, Psy.D., ABPP

Committee Member: Leon VandeCreek, Ph.D., ABPP

Committee Member: Cynthia Sieck, Ph.D.
I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY NICOLE LYNN MATROS ENTITLED SEXUAL KNOWLEDGE, EXPERIENCES, AND NEEDS OF COLLEGE STUDENTS WITH PHYSICAL DISABILITIES: A PILOT STUDY BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

Julie Williams, Psy.D., ABPP
Dissertation Director

Eve M. Wolf, Ph.D.
Associate Dean for Academic Affairs
Abstract

This study utilized a Participatory Action Research (PAR) design to modify a measure that examines the sexual knowledge, experiences, and needs of people with physical disabilities. Participants (N = 23) were college students with physical disabilities that were registered for disability services at a medium sized Midwestern university. Participants completed a secure online survey that allowed them to provide feedback on the utility of the questionnaire. Preliminary data also were gathered and reviewed. Results revealed both convergence and divergence with the existing literature. Limitations, research and clinical implications, and future directions were also explored.
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CHAPTER I

Statement of the Problem

The social construction of disability by mainstream society is largely negative with beliefs such as disability is a burden, a weakness, and a sin (Olkin, 1999; Pfeiffer, 2007). These beliefs have had damaging and pervasive affects on the quality of life of individuals with disabilities, impacting multiple domains of their lives. Specifically, quality of life studies show that individuals with disabilities experience underemployment, lower education attainments, higher rates of abuse, and lower economic status (Altman, 1996; Nosek & Hughes, 2007; Olkin, 1999; Pfeiffer, 1991). While laws help to mitigate inequities in employment, housing and educational settings, little information and few resources are available to consider, and then mitigate, the negative effects on the full expression of sexuality of individuals with disabilities (Webster & Heath, 2002).

Negative attitudes towards disability and sexuality include beliefs such as people with disabilities are asexual, they are incapable of sexual functioning, they do not have the judgment that is needed to behave in a sexually responsible manner, and they have more important things to worry about than sex (Kaufman, Silverberg, & Odette, 2003; Olkin, 1999). These erroneous beliefs play a role in denying the sexuality of people with disabilities, and may be used to justify actions that deny access to sex education for
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people with disabilities (Sobsey & Mansell, 1993). The effect can be little or no information is provided to people with disabilities, or the information provided is often limited in scope and does not pertain to disability specific needs (Sobsey & Mansell, 1993).

There are several consequences when people with disabilities are denied access to sexual knowledge. Their sexual health is affected because they may be more vulnerable to pregnancy or sexually transmitted diseases (Sobsey & Mansell, 1993). People who do not receive appropriate sex education, which includes sexual abuse prevention, may be more vulnerable to abuse or victimization (Sobsey & Mansell, 1993). People with disabilities may also acquire a negative view towards their sexual identity (Williams, 1993), and develop lower levels of sexual self-esteem (Hassouneh-Phillips & McNeff, 2005; Taleporos, Dip, & McCabe, 2002; Taleporos & McCabe, 2001).

Two groups within the disability community identified as particularly vulnerable are women with disabilities (Altman, 1996; Crawford & Ostrove, 2003; Nosek & Hughes, 2007) and college students with disabilities (Ferro & Allen, 1976; Mitchell, 1982). It is important to note that these were the most recent citations found that address the sexuality of college students with physical disabilities, which suggests that little else has been done within this area of research.

Women with disabilities are more likely to be sexually exploited, and their lives may be more affected by particular social constructions regarding sexuality and disability (Crawford & Ostrove, 2003). They are likely to lack opportunities to engage in social activities, which could increase their chances of meeting potential sexual partners (Rousso, 1996). Furthermore, women with disabilities are more likely to experience
depression, increased stress levels, lower self-esteem, social isolation, and abuse when compared to their male counterparts (Nosek & Hughes, 2007).

Students with disabilities are entering higher education institutions at increasing rates (Gilson, 1996; Hodges & Keller, 1999). Institutions have made changes that provide physical accessibility for students with disabilities, but full access to opportunities outside of the classroom are important for students in order to integrate into college/university culture (Gilson, 1996). Social involvement on college campuses has been linked to social integration, but students with disabilities may have less time for involvement in campus activities (Hodges & Keller, 1999). Hodges & Keller (1999) found that the perceptions of acceptance by students with physical disabilities influenced their social integration on college campuses. These perceptions included feeling accepted by campus peers, being affiliated with a peer group, and remaining patient as they provided education to peers without disabilities. Opportunities for participation also influenced students’ with disabilities perceptions of acceptance, but this was mitigated by the scheduling of activities and need for assistance with daily living activities (Hodges & Keller, 1999).

Students with disabilities who become involved in campus activities are likely to have greater opportunities to meet potential sexual partners. Because of the barriers that teens often face when working toward becoming healthy adults, and the myths commonly associated with disability (Kaufman, Silverberg, & Odette, 2003), college students with disabilities may want more information about sexuality issues. Research indicates that college students with and without disabilities share the same attitudes towards sexual behavior, but college students with disabilities scored significantly lower in regard to their own feelings of sexuality (Ferro & Allen, 1976). These results represent the psycho-
social aspects of disability that create negative attitudes and stereotypes towards people with disabilities (Williams, 1993), and indicate that interventions are needed in this area.

**Aim and Purpose**

There were two primary purposes of the current study. First, this study aimed to modify an existing questionnaire by utilizing the feedback provided by participants with disabilities to improve its utility, while also empowering participants to address areas relevant to their own lives. The goal of creating this questionnaire was to develop a set of questions that does not propagate the myths associated with sexuality and disability, and may be used in the future to learn about messages that people with physical disabilities have received regarding sexuality. Furthermore, it was anticipated that the information obtained would at some time be used to provide recommendations for healthcare providers.

Second, this study aimed to gather preliminary information from college students with disabilities about the types of information they have received from their educational institutions, family, and/or health care professionals regarding their sexuality, and to learn what was helpful and what is needed. The goal of collecting this information was to identify ways educational entities, families, health care professionals and members of society are and are not meeting the sexual needs of individuals with disabilities. It was expected that the participants’ responses would be similar to what the existing literature portrays. For example, it was expected that the majority of participants had not received adequate sex education, and if they did receive sex education, it would not be relevant to their disability.
CHAPTER II

Literature Review

The purpose of this literature review is to provide an overview of disability research, with a particular focus on sexuality and sexuality related issues. The review will begin by describing models of disability and how they continue to impact people with disabilities today. The review will also look at how the models of disability affect people with disabilities in multiple areas, including access to sex education, abuse, body esteem, knowledge, experiences, and feelings.

Theories of Disability

Several models of disability have been developed over time, and continue to be prevalent in society. These models continue to influence how others view people with disabilities and contribute to the myths associated with disability and sexuality.

Moral model. The oldest model of disability, the moral model, views disability as a defect caused by moral lapse or sin (Olkin, 1999). In fact, the moral model maintains that disability is self-inflicted (Mona & Gardos, 2000). This induces feelings of shame and blame for the person with a disability and the family. The moral model is closely associated with religion/spirituality. This model presents disabilities as reifications of sin, failure of faith, moral lapse, or evil; therefore, the “solutions” to disability may be found in faith, forbearance, exorcism, ostracism, and death (Olkin, 1999). This model also contains the myth of disability as mysticism. This leads to the idea that people with disabilities have special abilities to perceive, reflect, transcend, and be spiritual (Olkin,
Olkin (1999) notes that the moral model of disability continues to permeate our language, culture, and ideology today. For example, genetic conditions, or the passing of a “bad seed,” became associated with the moral model and all of its implications (Olkin, 1999).

**Medical model.** The medical model of disability primarily focuses on the diagnosis and treatment of the functional loss related to the disability (Schultz, 2009). Rather than addressing any social environmental barriers or demographic factors that may impact a person with a disability, the medical model focuses on the individual’s impairment, deficits, or disadvantages. Interventions within this then are driven by themes of cure, amelioration of the physical condition, and rehabilitation to allow the person to fit in mainstream society (Olkin, 1999). Furthermore, the medical model allows the professional to decide what action must be taken to overcome the “problem,” and the person with the disability may suffer consequences if she or he does not follow through with the professional’s advice (e.g. loss of medical assistance) (Pfeiffer, 2007). Olkin (1999) describes rehabilitation as “the adjustment of the person with the disability to the condition and to the environment” (p. 26). This model also compares persons with disabilities to non-disabled persons and may perpetuate an assumption of “normal,” further pathologizing people with disabilities (Schultz, 2009). Schultz (2009) suggests that the medical model has dominated the field of psychology, and many argue it continues to dominate the rehabilitation arena but efforts are being made to shift the focus from a medical model to the social minority model (Vash & Crewe, 2004).

**Minority model.** The minority model views disability as a social construction where the judgments made about a person are constructed by others in society (Pfeiffer,
2007). This locates the problem with in the social, political, and economic domains rather than in the realm of the person with the disability (Olkin, 1999). Specifically, Olkin (1999) posits that disability related problems occur due to the negative attitudes of people without disabilities and an environment that does not include people with disabilities. This model views people with disabilities as a minority group that has been discriminated against and received unequal treatment: yet people without disabilities continue to cite the impairment as the root of the problem for people with disabilities (Olkin, 1999). This model was initially developed in the early 1900’s but mostly disappeared until it reemerged in the early 1970’s with the passing of the Rehabilitation Act of 1973, which provided new laws, specifically, civil rights for persons with disabilities (Olkin, 1999).

**Sexuality and Disability**

Although progress in the disability movement has been made, negative attitudes and inequalities continue toward people with disabilities that permeate society. Sexuality is one specific area that has often been overlooked, which has resulted in the negative impact on the full expression of sexuality of people with disabilities (Webster & Heath, 2002).

**Myths related to sexuality and disability.** All of the previously discussed disability models have contributed to the myths that are often associated with disability and sexuality. One of the most commonly held myths is that people with disabilities are asexual (Kaufman, Silverberg, & Odette, 2003; Olkin, 1999). Olkin (1999) posits that this may be because others share the belief that these behaviors are unacceptable for persons with disabilities and persons with disabilities have more important things to worry about. This leads to the false belief that people with disabilities do not need sex
education (Kaufman, Silverberg, & Odette, 2003). Another myth suggests that not only are people with disabilities undesirable, but they are unable to engage in “real” sex or function sexually (Kaufman, Silverberg, & Odette, 2003; Olkin, 1999), and if people with disabilities do engage in sexual activities, they may be falsely viewed as “perverted” (Kaufman, Silverberg, & Odette, 2003). Another myth is that able-bodied individuals will not engage in sexual relationships with people with disabilities because these individuals are undesirable (Olkin, 1999) or “pathetic” choices for partners (Kaufman, Silverberg, & Odette, 2003). Others falsely believe that people with disabilities lack the proper social skills and judgment to engage in sexual behaviors responsibly (Olkin, 1999). Finally, some myths indicate that people with disabilities are less likely to be sexually assaulted, but in fact, the opposite is true. People with disabilities are much more likely to be sexually assaulted (Kaufman, Silverberg, & Odette, 2003).

These myths can be damaging to people with disabilities in various ways. People with disabilities may internalize these myths, which may affect an individual’s self-esteem and interfere with the person’s view of self as a sexual being (Kaufman, Silverberg, & Odette). A national survey (Nosek et al, 2001) showed that women with disabilities express more negative feelings towards their body image. The researchers suggest that body image issues for women with disabilities often stem from disability related issues and meanings attributed to these issues. They identify those disability issues as the use of devices, the presence of scars, deformities, disfigurement, abnormal expressions or gestures, and the anticipatory fear of possible public bowel or bladder accidents (Nosek et al., 2001).
These myths also strengthen the misperceptions held by able-bodied people. When these individuals believe the myths, they may be more likely to perceive people with disabilities as asexual or fragile; therefore, they become less likely to be interested in people with disabilities as sexual partners (Kaufman, Silverberg, & Odette, 2003; Olkin, 1999).

**Sexual knowledge.** The research discussing sexuality and people with physical disabilities covers many different areas. Blackburn (2002) indicates that a large majority of adolescents with disabilities do not receive sex education, and those who do, do not receive any information that is relevant or informative as it relates to their disability. One study concluded that 50% of people with disabilities had not received any sex education (McCabe, 1999). Nosek and colleagues (2001) reported that women with disabilities and able-bodied women learn about sex and sexuality from similar sources but in a different order. For example, women with disabilities more frequently endorsed books and printed materials first; whereas able-bodied women more frequently endorsed having sex first and then their partner. McCabe (1999) found that people with disabilities were most likely to find out information about sexual knowledge from “other” sources such as the media or formal sex education classes. This suggests that people with disabilities may be less able to discuss sexual information with family or friends, or check the accuracy of the information they have received (McCabe, 1999). This limits the knowledge that people with disabilities may have about sexuality related issues. For example, a national study showed that 41% of women with disabilities reported not having adequate information about how their disability may impact their sexual functioning (Nosek et al, 2001).
SEXUAL KNOWLEDGE, EXPERIENCES, AND NEEDS

**Sexual experiences and needs.** Nosek and colleagues (2001) report that women with disabilities have just as much sexual desire as women in general, but they have limited opportunities for sexual activities. These women also report lower levels of sexual activity, sexual response, and satisfaction with their sex lives (Nosek et al., 2001). Other research indicates that women with physical disabilities have comparable amounts of sexual experiences in most areas, with the exception of pure coitus. Women with physical disabilities also have less knowledge about orgasm, and have more negative attitudes towards sexuality than women without disabilities (Vansteenwegen, Jans, & Revell, 2003).

Women with disabilities are as susceptible to STDs as women without disabilities, but they may be less likely to be tested because health providers may assume that they are not sexually active, and they may be less likely to complain of symptoms because of sensory or mobility impairments (Nosek et al., 2001).

**Opportunities for contact.** Mona and Gardos (2000) suggest that people with disabilities have limited social contact with others because of transportation, communication, and financial barriers. Consequently, people with disabilities may have limited experiences in the dating and sexual domains of life (Mona & Gardos, 2000). In fact, research has shown that women with disabilities have fewer opportunities to establish romantic relationships (Nosek et al, 2001). When compared to women without disabilities, women with disabilities were not as satisfied with how often they dated and indicated more difficulty attracting partners. One study found that 42% of single women with disabilities cited not being involved in a relationship because they had not been
Sexual knowledge, experiences, and needs

Sexual and body esteem. Sexual esteem can be described as “positive regard for and confidence in an individual’s capacity to experience his or her sexuality in a satisfying and enjoyable way” (Taleporos & McCabe, 2001, p. 131). Research has indicated that women with disabilities have lower body and sexual esteem than non-disabled women (Hassouneh-Phillips & McNeff, 2005). These negative evaluations are closely tied to societal devaluation of women with disabilities (Taleporos, Dip, & McCabe, 2001). For example, the standards of beauty and sexuality that society imposes represent ablelist ideals that serve as barriers to women with disabilities (Hassouneh-Phillips & McNeff, 2005). Furthermore, researchers have suggested that women with poor body and sexual esteem may have lowered expectations for intimate relationships, and may be more likely to enter and stay in abusive relationships (Hassouneh-Phillips & McNeff, 2005).

Sexual abuse. People with disabilities may experience types of abuse that are specifically disability related. For example, the withholding of needed orthotic equipment, medications, transportation, or assistance with personal tasks is considered abuse (Nosek et al., 2001). People with physical disabilities may also be more vulnerable to abuse because of their inability to escape dangerous or abusive situations, requiring the assistance of the perpetrator to carry out personal tasks, likelihood of exposure to institutional facilities, and negative stereotypes indicating that they are dependent, passive, and easy prey (Nosek et al, 2001). A national study indicated that women with disabilities experienced all types of abuse (emotional, physical, sexual), but the duration
of the abuse was significantly longer for these women than for women without disabilities (Nosek et al., 2001). Because of the different types of abuse that women with disabilities may experience, they may not be aware that they are in an abusive situation, or they may not be knowledgeable of the resources available to them to escape these situations (Nosek & Howland, 1997). Furthermore, agencies that are designed to help abuse victims may be ill prepared to respond to disability related experiences and unable to accommodate their client’s disability. For example, shelters may be located in buildings that are not accessible to people with disabilities (Nosek & Howland, 1997).

Andrews and Veronen (1993) identify several factors that are associated with vulnerability to victimization among people with disabilities. People with disabilities often rely on caregivers to assist with personal care needs, which may lead these individuals to be compliant and trusting of their caregivers, including caregivers who may be assaulting or exploiting them. Furthermore, people with disabilities may be hesitant to disclose the abuse because of fear that they will have no one to care for them (Andrews & Veronen, 1993). People with disabilities may be more vulnerable to victimization because they are still denied their basic human rights (Andrews & Veronen, 1993). The history of oppression and negative social attitudes that people with disabilities have experienced may leave them feeling powerless and more vulnerable to exploitation by perpetrators who may be perceived as powerful. People with disabilities may be targeted more frequently, because the assailant believes there is less risk of discovery because the victim has a disability (Andrews & Veronen, 1993). Many survivors of abuse also encounter difficulties being believed by others because of the myths associated with disability and sex (Andrews & Veronen, 1993). People with
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disabilities may be more vulnerable to exploitation by others through relationships that appear affectionate and accepting, especially if they are socially isolated or lonely (Andrews & Veronen, 1993).

Limitations within existing research. The notion of “deficiency” is an underlying theme in many of the writings on disability and sexuality (Kaufman, Silverberg, & Odette, 2003). This information illustrates an ableist conceptualization of sexual response by describing sexuality from the point of view of people without disabilities. Additionally, disability research appears to be biased towards heterosexual norms, which is reflected in the language and the lack of participants from different sexual orientations (Schultz, 2009).

Disability Inclusion Research Design

Some researchers (i.e. Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998; Cambell, Copeland, & Tate, 1998) have suggested processes that create more input by the participants involved in the research process. These research processes may empower participants by allowing them to study areas that are relevant to their lives.

Participatory research. Participatory Action Research (PAR) has been described as an approach to research that empowers participants in the research process by using their knowledge to increase the relevance of research topics (Whyte, Greenwood, & Lazes, 1991). It allows research participants to become more active in the research process and assist in finding solutions. Thus, PAR is considered “applied” research and significantly differs from other research models where participants are treated as passive subjects and do not actively assist in the research process (Whyte et. al., 1991).
As a response to the previously discussed limitations within existing research, researchers in the field of rehabilitation and disability advocate for the active participation of people with disabilities in the research process (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998; Cambell, Copeland, & Tate, 1998). In an effort to promote the participation of people with disabilities through Participatory Action Research (PAR), the National Institute on Disability and Rehabilitation Research (NIDRR) established a policy that promotes consumer involvement in research (Fenton, Batavia, & Roody, 1993). Participatory action research (PAR) is an approach that allows people with disabilities an opportunity to inform the research process, while also empowering them to address the areas relevant to their own lives. Specifically, this approach emphasizes direct participation of people with disabilities in the development, implementation, and dissemination of research (Balcazar et al., 1998). This approach differs significantly from traditional research approaches because it sees the inclusion of the participants in the study as critical to the research process, and creates actions that aim to generate social change (Balcazar et al., 1998). Other researchers include an emphasis on the importance of taking the point of view of people with disabilities in order to challenge the socially constructed myths surrounding disability, and ultimately combat the damaging impact on the lives of individuals with disabilities by gaining a better understanding of the perspective of people with disabilities (Campbell, Copeland, & Tate, 1998).

There are four general principles relevant to PAR conducted in collaboration with people with disabilities. First, people with disabilities must be directly involved with research by defining, analyzing, and solving the problem at hand (Balcazar et al., 1998). This helps to ensure that the research will benefit the disability community, as well as
create empowerment for individuals to take control over aspects of their lives. Second, the direct involvement from people with disabilities in the research process creates a more accurate and authentic analysis of their social reality (Balcazar et al., 1998). Again, this helps to advance the plan set by people with disabilities. Next, the PAR process itself can increase awareness among people with disabilities about their own resources and strengths (Balcazar et al., 1998). Lastly, the ultimate goal of the research process is to improve the quality of life for individuals with disabilities (Balcazar et al., 1998).

There are also several challenges to conducting this type of research. Balcazar and colleagues (1998) cite that there may be barriers to gaining entry and developing participatory relationships. These barriers may include identity differences between the researchers and community members, perceived and actual power differences, a negative history of community members with researchers, lack of preexisting community ties, and an overly directive approach on behalf of the researchers. Another challenge is that researchers may have difficulty relinquishing control of the research endeavor (Balcazar et al., 1998). In fact, experimental control has been cited as the most significant obstacle to more extensive use of participatory research. Researchers argue that there are advantages and benefits to both qualitative and quantitative research designs (Balcazar et al., 1998). The duration of the PAR process also is a challenge for researchers (Balcazar et al., 1998). The authors indicate that participatory research typically takes several years to complete, which can be problematic for many academics. There are also unintended consequences of participatory research. For example, a positive consequence relates to all members of the PAR process developing a more critical view of the world and a better understanding of the needs and rights of people with disabilities (Balcazar et al., 1998).
SEXUAL KNOWLEDGE, EXPERIENCES, AND NEEDS

Other consequences may include attacks or reprisals from opposing agencies or forces because of their resistance to suggested changes resulting from the research. Despite these challenges, the researchers suggest that participatory research is an effective research process that will inevitably become a staple in applied disability and rehabilitation research.

This project represented the first stage of a multi-stage research project that draws upon a PAR research design. The PAR values were incorporated in this project by including people with disabilities as participants and researchers, while focusing on societal issues that continue to negatively impact the disability community. Individuals with disabilities were consulted to help with the modification and implementation of the current survey, and to help identify areas that may be of more importance to college students with physical disabilities. The feedback from participants was used to improve the existing survey before it is distributed to the disability community where more detailed information will be obtained.
CHAPTER III

Method

Participants

Participants consisted of 29 college students from Wright State University, and were registered for services through the Office of Disability Services (ODS). This project focused on people with physical disabilities, therefore five participants were dropped from further analysis because they cited cognitive and psychological disabilities (e.g., ADHD, Learning Disabilities, and Depression) rather than a physical disability. One participant did not answer any questions, and another participant only partially completed the survey. Participants’ \((N = 23)\) ages ranged from 18-56 \((M = 29.13, SD = 12.32)\). The sample consisted of seven males (30.4 %) and sixteen females (69.6 %). See Table 1 for a summary of participant characteristics.

Participants reported several physical disabilities including but not limited to: Arthrogryposis, Spina Bifida, Cerebral Palsy, Degenerative Bone Disease, Motor Sensory Hereditary Type II Neuromuscular Dystrophy, Congenital Hypomylenation Neuropathy, Fibromyalgia, Visual Impairment, and varying physical conditions due to injuries. The majority of participants reported having their disability since birth (65.2 %), whereas one individual reported 1-5 years and seven individuals reported having their disability more than five years.
Table 1

*Summary of Participant Characteristics*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>(%)</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age (range = 18 to 56)</strong></td>
<td></td>
<td>29.13</td>
<td>12.32</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>16</td>
<td>(69.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>(30.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Length of Disability</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>From birth</td>
<td>15</td>
<td>(65.2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>More than 5 years</td>
<td>7</td>
<td>(30.4)</td>
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<td>1-5 years</td>
<td>1</td>
<td>(4.3)</td>
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<tr>
<td><strong>Types of Assistance Required</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Driving Places</td>
<td>11</td>
<td>(47.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Getting Dressed</td>
<td>9</td>
<td>(39.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>9</td>
<td>(39.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking a Shower</td>
<td>8</td>
<td>(34.8)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparing Meals</td>
<td>7</td>
<td>(30.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>7</td>
<td>(30.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Hours required for ADL’s</strong></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>24</td>
<td>1</td>
<td>(4.3)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12-23</td>
<td>1</td>
<td>(4.3)</td>
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<td></td>
</tr>
<tr>
<td>1-11</td>
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<td>(56.5)</td>
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<td></td>
</tr>
<tr>
<td>0</td>
<td>8</td>
<td>(34.8)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note.* ADL= activities of daily living
Participants were also asked about the types of assistance required. Participants responded as follows: driving places (47.8 %), getting dressed (39.1 %), other (39.1 %), taking a shower (34.8 %), preparing meals (30.4 %), and none (30.4 %). Examples of “other” responses included: “personal hygiene and care,” “shopping,” “taking medications,” “any task that requires movement,” “required help depends on duty being performed,” “transferring,” “bathroom,” “household care,” and “trach care.” Finally, participants were asked how many hours per day they needed help with daily living needs. Participants responded 11-1 hour(s) (56.5 %), 0 hours (34.8 %), 12-23 hours (4.3 %), and 24 hours (4.3 %).

Setting

Participants for this study were recruited through the Office of Disability Services (ODS) on the Wright State University campus. ODS is ranked as a national leader in accommodating students with disabilities. Their philosophy states that a student's college education is an opportunity to develop academically, vocationally, and personally. Consistent with this philosophy, their program provides more than the required services, and strives to teach students skills that will assist them as they transition into the world. ODS often partners with other academic programs in researching disability related issues. The appropriate contacts through ODS were made, and a population sample was available for this project. The researchers presented the material to staff at ODS in order to inform them of the exact nature of this project and receive feedback or suggestions. Of note, several of the staff themselves had disabilities, thus were able to contribute to disability relevant questions and research design consistent with PAR. The research study
was approved by Institutional Review Board of Wright State University and the Office of Disability Services provided a letter of support for this project.

**Procedures**

The researcher utilized the ODS electronic survey system (i.e., Zoomerang), which contained an updated email list of students registered with ODS. These students received an email (Appendix A) inviting them to participate in this research study. Participants who chose to participate were directed to a secured webpage that provided them with informed consent (Appendix B), survey instructions (Appendix C), and the survey itself (Appendix D). All information remained confidential.

**Conducting Research Using the Internet**

The internet is creating many new opportunities in the area of psychological research (Kraut et al., 2004). Researchers argue that the use of the internet may help by making empirical research easier, as well as creating new social phenomenon to study (Kraut et al., 2004). Kraut and colleagues (2004) posit that the internet can decrease the cost of participant recruitment, while at the same time allowing researchers to gather a large and diverse sample. This also allows researchers, who may not have previously had the capability to undertake a large research study, to contribute to the research of psychology. The use of the internet in psychological research also allows for the unique observation of social behaviors through archival online communications that may otherwise be difficult to track, as well as access to other unrelated archival data (Kraut et al, 2004). Kraut and colleagues (2004) indicate that web surveys are more flexible and less error prone than their conventional counterparts.
The use of the internet for research also raises concerns about data quality and generalizability, as well as ethical concerns (Kraut et al., 2004). Because of these concerns, the researchers have multiple suggestions for those who choose to use the internet for research. Researchers who use the internet should only use the minimum number of participants appropriate for their research goals so they do not pollute the potential pool of participants (Kraut et al., 2004). They should also carefully analyze the data collected and check for apparent differences that may be of concern. Finally, researchers must also take the necessary steps to avoid breaches of confidentiality and assess the possible risks to participants as they typically would with any research study (Kraut et al., 2004).

Recommendations have also been made for using the internet with culturally diverse populations (Suarez-Balcazar, Balcazar, & Taylor-Ritzler, 2009). Researchers suggest that when possible, increase the access to the internet among culturally diverse populations through active outreach, and provide access to technical assistance for respondents that encounter difficulties (Suarez-Balcazar, Balcazar, & Taylor-Ritzler, 2009). It is also recommended that instruments being used be adapted to the target population, be easy to read, and visually pleasing (Suarez-Balcazar, Balcazar, & Taylor-Ritzler, 2009). Finally, because internet users are likely to be young, educated, and have access to technology resources, it may be important to supplement internet based research strategies with more traditional approaches (e.g., paper and pencil questionnaires, focus groups, or interview methods) (Suarez-Balcazar, Balcazar, & Taylor-Ritzler, 2009).
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Measures

Participants completed a modified version of the Sexuality Knowledge, Experience, and Needs Scale for People with Physical Disabilities (SexKen-PD1, McCabe, 1994). The researcher created questions that do not propagate the language that colludes with the myths associated with people with disabilities. Furthermore, the questions were written using disability affirming language and a level of language that is appropriate for individuals at the college level. Questions were added at the end of each section of the survey that asked participants for their feedback regarding the previously completed section in order to contribute to the PAR nature of this study. Other changes that were made included adding more questions about disability specific needs (e.g., “can you use a condom”) and creating multiple choice responses and additional prompts (e.g., “why or why not”) to some of the questions. More specific pictures were added in order to help identify body part knowledge and a section on sexual orientation was added. The survey was divided into specific sections (e.g., Dating and Intimacy, Sexual Interactions, Contraception) to make it easier for participants to view. The survey can be viewed in its entirety in Appendix D. Furthermore, the instructions for completing the survey (see Appendix C) were clearly detailed for participants and encouraged participants to provide feedback in the areas provided.

Design

This study used both quantitative and qualitative methods. An email (see Appendix A) that contained a link to the survey was sent to all students registered with the Office of Disability Services summarizing the nature of the study. If students decided to participate, they first reviewed the informed consent (see Appendix B). The online
survey closed after 15 participants responded, but was later re-opened to allow more participants to complete the survey. This study attempted to obtain 30 participants because of the emphasis on the qualitative nature of the design. Specifically, the project's primary aim was to gather information in order to make revisions to the survey rather than providing detailed analyses of the survey results. The qualitative portion consisted of eliciting feedback on the survey instrument by those who took the survey. Responses were used to improve the instrument for future use, and to gather information about areas that participants feel requires greater emphasis. The quantitative portion consisted of using the survey results to generate descriptive statistics and to gather preliminary information about the areas being studied.
CHAPTER IV

Results

Results of this research study will be presented in two parts. The first part of the results will describe the participants’ responses to the survey questions, and the second part of this section will focus on the qualitative feedback that was provided on the survey itself. It is important to note that responses that were left blank will not be included because the participants’ intentions were not clear (e.g., chose not to answer, did not know).

Participant Responses

Dating and Intimacy. Participants were asked to define a date. Responses generally described two people spending time together in order to become more familiar with each other and assess the possibility of a more intimate relationship. Examples of definitions included “a date is when two people who are potentially romantically attracted to each other do an activity together that may or may not help bond the attraction,” “two people going out or staying in together,” “…just hanging out with somebody you like,” “two consenting adults sharing time together,” and “a social outing with someone you’re romantically interested in.”

In regards to dating information, the majority of participants (73.9%) reported that they did not want more information about dating, yet 60.9% of participants reported that they would like to be dating someone or they would like to go on more dates. Participants who reported that they would like more information about dating reported
that they would like information about when to disclose their disability, how to help
others adapt to disability needs without them feeling uncomfortable, activities, dating for
“queer disabled people,” “how to find people like me,” “how to find dates,” and how to
find people to date who are not “squeamish” about dating someone with a disability.
Also, several participants (N= 8) noted their disability or disability related reasons (e.g.,
lack of transportation and “non-physical stimulating dating activities”) have prevented
them from dating more.

The number of dates that participants (N = 15) reported ranged from 0-50+, with a
mode of two. One participant noted that she or he had fewer dates since becoming
disabled. Participants responded that dates often consisted of staying in together, going
to the movies, talking, going out to eat, or attending various outings together.
Furthermore, participants were asked the last time they were involved in a romantic
relationship. Responses included: never (17.4%), during the past month (34.8%), 1-6
months ago (17.4 %), 6-12 months ago (8.7 %), and over a year ago (21.7%).

Participants were also asked to define intimacy. Responses included a theme of
emotional and physical intimacy descriptions. Participants described emotional intimacy
as deepening the connection with another through trust and compassion for each other.
Examples included “…share valuable moments with the person…,” “…having trust and
faith in each other,” “bonding with one another on a deeper level…,” and “openness with
each other, emotional connection.” Physical intimacy was generally described as
physical affection towards another. Participant examples included “sex, cuddling,
making out;” “snuggles, oral sex…;” “touching;” “a sensual moment;” and “…doing
anything sexual.”
**Body part identification.** Participants were asked about their knowledge of both female and male sexual anatomy, and results were broken down by gender. When asked how knowledgeable they were of the female sexual anatomy, female participants reported a lot (56.3%), moderately (31.3%), and a little (12.5%), whereas male participants reported moderately (57.1%), a little (28.6 %), and a lot (14.3%). All of the participants correctly identified an ovary. The majority of female participants, 93.8%, correctly identified a fallopian tube, while 71.4% of male participants correctly identified this feature. Both female and male participant’s correctly identified the vaginal opening at similar rates, 81.3% and 85.7% respectively. Interestingly, all male participants correctly identified the clitoris, while 87.5% of female participants correctly identified this area.

Participants were also asked to describe the functions of the previously discussed anatomical parts. Almost all participants described the ovaries as the area where eggs are produced and stored. One female and two male participants added that they release hormones and one female participant said that she did not know the function. The most common response that participants provided when describing the fallopian tubes was that they were the area that the eggs traveled through or they provided transport for the eggs. One female participant responded that she did not know the function and another stated “makes babies.”

Participants reported multiple functions for the vaginal opening. Most participants described the vaginal opening as an area of sexual activity (e.g. intercourse, masturbation, “where the penis goes”). Some participants also stated that the vaginal opening was part of the birth canal, as well as the area where menstrual fluids exit. One female participant described the vaginal opening as a “protection barrier for germs,” and another added that
“drugs” may be inserted in this area. Another female participant cited this as the area where “ovaries dissipate,” while a male participant noted that it is the area that allows the “passage of urine.” Finally, one female participant reported that it is the “entrance to the uterus” and another stated “I don’t know.”

Almost all participants described the clitoris as an area of “pleasure” or “sexual arousal” for woman. Two female participants stated that they did not know the function of the clitoris and one male participant said that it “has no function.” This individual added that the term “functional” may lead others to think that women are denied pleasure.

When participants were asked how knowledgeable of the male sexual anatomy they were, female participants reported a little (43.8%), moderately (25%), a lot (18.8%), and not at all (6.3%). On the other hand, male participants reported a lot (71.4%) and moderately (28.6%). Moreover, 56.3% of female participants correctly identified both the scrotum and the testicles, 31.3% of female participants correctly identified the prostate gland, and 37.5% of female participants correctly identified the vas deferens. Male participants fared better with 85.7% correctly identifying the scrotum, 100% correctly identifying the testicles, 57.1% correctly identifying the prostate gland, and 85.7% correctly identifying the vas deferens.

Participants were also asked to describe the function(s) of these previously described anatomical parts. Many participants described the scrotum as the body part that houses and protects the testicles. Two female and two male participants added that the scrotum is important in managing the temperature of the testicles, and three female participants reported that the scrotum stores semen. Four female participants stated that they did not know the function of the scrotum.
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The majority of participants described the testicles as the area that produces sperm. Two male participants and one female participant added that the testicles also assist in hormone regulation and two female participants described the testicles function as protecting the scrotum. Finally, two female participants stated that they did not know the function of the testicles.

Participants reported varying functions of the prostate gland. Six female participants and one male participant stated that they did not know the function of the prostate, and four female participants described it as the area that produces “hormones” that help to produce sperm. Two male and one female participant reported that the prostate gland secretes other “fluids” into the sperm to improve its viability, and another female participant added that it “produces the lubricant and makes sure that it is at just the right pH to neutralize the ‘hostile’ acidic environment of the vaginal cavity to prolong sperm life.” One female participant described the prostate gland as serving “urinary purposes,” and another stated that it “connects the penile tube to the vas deferens from the bladder and back again.”

Finally, several participants described the vas deferens as the unit that transports semen and/or other fluids. Specific participant responses varied as to where the semen and/or other fluids were transported to (e.g. penis, urethra, prostate). One female participant reported that the vas deferens “joins the seminal vesicle and forms the ejaculatory dust.” Four female participants stated that they did not know what the function of the vas deferens was.

**Sex and sex education.** Participants were asked where they have received information about sex and responded as follows: books (82.6%), school (78.3%), friends
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(69.6%), media (69.6%), internet (60.9%), parents (52.2%), doctor (47.8%), siblings (30.4%), and other (13.0%). Other responses included: girlfriends, boyfriend, college course, and sex education theater group. Most participants identified the information being received “somewhat” to “very” useful. One participant commented that information obtained from the doctor was “not so useful.” Furthermore, many participants remarked that this sex education was not relevant to their disability, whereas some (N=6) noted some relevant disability information was provided. For example, one person commented that a “redo” in sex education through a disability lens would be helpful because she or he were not disabled when they originally received their sex education. Another participant commented on having an “invisible” disability. Some participants commented that their disability does not impact their sex lives, and another described the importance of “communication.”

Despite these results, only 21.7% of participants reported that they would like more sex education. For those who wanted more information, they cited the following topics: “anything to do with disability and sex,” “navigating sex under different disabilities and interdisability,” “how someone who has tremors and a muscle disease can have a positive sexual experience with a female,” “the male and female anatomy,” and “masturbation, intercourse, toys.”

Participants were also asked to describe their beliefs towards sex. Responses fell into the following general themes. Some participants (N=5) indicated that they believed that sex was a “natural need” and “human right” for all individuals. Four participants stated that they believed individuals should engage in sex if they are in “love,” and three participants added that the individuals should be in a “relationship.” Three participants
also commented that they believed that sex should not occur before marriage. Other responses to this question included: “It’s good,” “relieves stress,” “reproductive and recreational activity,” “when a man loves a woman,” “it is to be respected,” and “each person has a right to say what happens to their own body… sex should always be consensual… protection against STDs and pregnancy should be taken and communication should be practiced… sex is nothing to be ashamed of, but it should be treated with respect, knowledge, and educated caution.”

Participants reported the following results about how often they talked to family members about sex: never (26.1%), once (4.3%), a few times (34.8%), often (8.7%), and very often (17.4%). 8.7% did not respond to this question.

Participants reported the following results about how often they talked to friends about sex: never (17.4%), a few times (39.1%), often (30.4%), and very often (8.7%). 4.3% did not respond to this question.

The frequency with which participants reported engaging in sex ranged from “never” to “a few times per week” to every 1-3 months. Participants who reported engaging in sex weekly also commented that they were either married or lived with their partner. Seven participants reported that they have never engaged in sex. Four participants commented “not often enough” or “not much.” One participant indicated that she had sex after acquiring a disability while she was married, but since then she reported that she is “too wrapped up with survival” to even consider what sex with another person would be like with her disability. Another participant reported engaging in “phone sex.”
Participants were also asked if they were able to negotiate their sexual needs with their attendant, if they had one. Of the eight participants who indicated that they had an attendant, 50% responded yes and 50% responded no. Two participants stated that they had an attendant, but did not negotiate their sexual needs with this person because they required their sexual partner to help them. Another participant commented “they aren’t prostitutes. That’s a horrible misunderstanding of the whole situation.” Another participant stated “what does this even mean…I would never involve my attendant in this aspect of my life…I don’t have that good of a relationship with my attendant…” One participant also commented that “it’s embarrassing and she’s very conservative about sex.”

**Sexual interaction.** The number of sexual partners that participants reported ranged from 0 to 50+. One participant reported that she or he did not want to share this information. Some participants added information to clarify the sexual interaction (e.g., “vaginal intercourse,” “making out,” “digital insertion,” “oral sex”). The majority of participants (69.6%) reported that they were able to communicate their disability related needs to their partner. The individuals who indicated that they were not able to communicate their disability specific needs (17.4%) reported the following reasons: “I have never done it;” “One of the top reasons I don’t have sex is this exact issue…I don’t feel comfortable enough to even go into it for fear that the other person would not have the patience. Disability has just made it extra complicated…I communicated my needs a little, but he walked out in the middle…,” “disability developed as a result of an incident, wasn’t always present,” and “he wasn’t easy to talk to.” For participants who have been sexually active, the reported comfort level in communicating their disability specific
needs was as follows: not at all (4.3%), a little (21.7%), moderately (13.0%), and a lot (26.1%).

The majority of participants (56.5%) saw themselves as sexually attractive. Some reasons participants did not view themselves as sexually attractive were as follows: “insecure with my body,” “I am too fat,” “I feel that definitely my disability makes me feel less sexually attractive to others than before,” “I am short,” “I have always had some issues seeing myself as attractive,” “I’m overweight and I’m in a wheelchair.”

A large percentage of participants (60.9%) reported that they were not aware of resources that provide disability specific information about sexual needs. Participants who reported being aware of such resources (30.4%) commented that they can look online or in books, and ask professionals who specialize in disability and sexuality.

Several participants (34.8%) admitted to being involved in unwanted sexual contact. One participant added that this occurred prior to her or his disability. Some participants (N=6) reported that they were not aware of resources for people with disabilities who may be experiencing unwanted sexual contact. One added that “most places are inaccessible for people with physical disabilities and/or hearing impairments.” Other participants suggested resources (e.g., police, “victim assistance,” “pepper spray,” trusted “professional,” “RAINN”) and another commented “the same ones available to able bodied people in that situation.” One participant stated that “if the unwanted contact is an attendant or someone else that, because of your disability you feel dependent on, then you have the right to not continue working with that person.”

**Contraception.** Participants were asked how knowledgeable they are of contraceptive methods and responded as follows: a lot (52.2%), moderately (34.8%), and
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a little (8.7%). Furthermore, they reported receiving information about contraception from the following sources: doctor (65.2%), school (56.5%), friends (52.2%), books (47.8%), media (43.5%), internet (43.5%), parents (34.8%), siblings (17.4%), and other (8.7%). Other responses included “girlfriends,” “television,” and the same places where sex education was received.

For participants who have been sexually active, several types of contraception were reportedly used. These included: condoms, spermicide, birth control pills, pull out, tracking fertilization, rhythm method, IUD, diaphragm, female condoms, dental dams, gloves, and vasectomy. Three participants reported not using any type of contraception, and one of these participants reported that she or he had never engaged in sex. The majority of participants (73.9%) reported that they could use a condom. One participant stated that she used “feminine suppositories and other female based methods” because they are unable to use a condom. Finally, participants were also asked about other types of contraceptives/birth control methods. Responses varied and included: IUD, cervical cap, hormones, birth control pills, condoms, douches, diaphragms, abstinence, hysterectomy, sterilization, the sponge, creams, foams for females, vasectomy, plan B, pulling out before ejaculation, female condom, dental dams, patches, and shots.

**Pregnancy, abortion, childbirth.** Results showed that the majority of participants (69.6%) have not received disability specific information on pregnancy, abortion, or childbirth. For participants who have received information, they reported the following information: “I received information about gynecologists who are familiar to working with disability…impact pregnancy has on my body pertaining to my specific disability…methods used in child birth for my disability…list of specialists;” “tons of it, I
have two kids;” “I had both children prior to becoming disabled;” “medication used if pregnancy occurs simultaneously…this may cause birth defects;” and “risks of getting pregnant with my disability.” Additionally, the majority of participants (60.9%) indicated that they would not like more information about these topics. Participants who reported that they would like more information in this area reported that they would like the following information: “I have no intention of ever getting pregnant again…and have doubts that anyone is going to be able to provide me with the necessary information...” and “how safe is pregnancy/childbirth with my disability.”

Most of the female participants (68.8%) reported that they have never been pregnant. The remaining respondents (31.3%) indicated that their pregnancy ended in childbirth. The majority of participants (60.9%) do not have any children. The number of children that participants with children reported ranged from one to five.

**Sexually transmitted diseases (STDs).** Eight participants responded that they knew about many STDs and some individuals attempted to list them while others did not. One participant reported that she or he had only heard of one STD. Participants named the following STDs in their responses: HPV, chlamydia, HIV/AIDS, pubic lice, gonorrhea, herpes (simplex 1, 2, 3), syphilis, genital warts, bacterial vaginosis, trichomoniasis, hepatitis (A, B, C), UTI’s, and mono. When asked how STDs are transmitted, almost all participants \(N=20\) noted sexual interaction in their responses. Seven participants specified unprotected sex and one participant noted multiple partners. Other participants added the transmission of fluids including blood and saliva, as well as any “physical contact.” Three participants reported that STDs can be transmitted by
sharing needles and two reported blood transfusions. One participant reported that you can get an STD by using “non-clean sex toys.”

A large percentage of participants (78.3%) indicated that they did not want more information about STDs. Respondents who did want more information about STDs stated that they would like the following information: “…how to get others to cooperate with protection when dealing with sexual situations other than female male vaginal/penile or anal/penile penetration.;” “everything;” and “…specific types…symptoms…how do you treat them, are they curable, and how do you prevent them.”

Participants were also asked how they would feel if they got an STD. Many participants (N=9) indicated that they would be angry or upset. Other respondents reported they would feel terrible, scared, depressed, horrified, concerned, ashamed, embarrassed, stupid, and dirty. One respondent stated that they would be “okay” with it if it was “temporary,” and another respondent stated that it “depends” which STD she or he had. Another participant added feeling “overwhelmed” and “annoyed” because of the required interactions with medical professionals and stated that this is “related to the barriers imposed by my disability.”

Participants were also asked how they could tell if they had an STD. Several participants (N=11) indicated that they would be aware of changes in their body that may include burning, unusual discharge, itching, inflammation, redness, smells, and sores. Seven participants indicated that individuals should participate in regular STD screenings or get tested if they suspect an STD. Two individuals commented that some STDs are asymptomatic and three individuals responded that they did not know how to tell if they had an STD.
Many participants (47.8%) have been tested for STDs, and 13% of participants admitted that they have had an STD. Seven participants stated that they requested to be tested, one commented that it was part of a routine exam, and another stated that it was encouraged by others. Most participants (65.2%) reported that they were not concerned about getting an STD. Some of these participants explained by stating they were married or not currently engaging in sexual activities. Participants who did report concern about getting an STD explained that it is a “risk” when sexually active. One participant stated “…the fear of getting an STD, especially since I have less control over my life, my health, and post coital barriers access to testing and treatment, that fear of getting an STD and not being about to use adequate protection, test, or treat for STDs in a timely manner is one more prohibition to having sex.”

Participants were also asked to discuss what they know about HIV and AIDS. Several participants (N=8) described HIV and AIDS as fatal and incurable. Six participants discussed the impact that these diseases can have on the immune system and the body’s ability to fight infections. Four individuals commented that HIV eventually turns into the AIDS virus. Three individuals described how the virus can be transmitted and one added that safe sex can help to prevent transmission. Two participants commented on antiviral medications that have been developed and extend the life of someone with HIV or AIDS. One person stated that “everyone needs to be tested,” and six participants reported that they knew a lot of information but did not elaborate. Many participants (47.8%) have not been tested for HIV or AIDS.

Participants were also asked to describe ways to prevent contracting HIV and AIDS. Eighteen participants indicated that practicing safe sex can reduce your risk and
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cited condoms, abstinence, monogamy, and limiting the number of sexual partners as specific examples. Five participants indicated that asking or requiring their partner to be tested is another way to prevent contraction. Three participants stated that individuals should not share needles and two respondents noted being cautious around blood.

**Masturbation.** Participants were asked to describe how they feel about masturbation. All participants, except one, described masturbation positively. For example, some said “great,” “I enjoy it,” “feels good,” and “it’s natural.” Two participants added that masturbation should be done in private. Participants were also asked how often they masturbate. Responses varied from never to daily, to weekly, too often. Most participants (65.2%) reported that they have not been able to obtain assistance with masturbation. Four participants explained that assistance was not necessary and two participants cited “shyness” or “embarrassment” as reasons why they have not asked for assistance. One participant stated that if she or he had assistance, they would consider it a “sex act” rather than masturbation.

Some participants (17.4%) indicated that they would like disability specific information about masturbation. One participant was not sure what kind of information was available and would like “any” type of information, and another person requested information about “where do you do it and what toys are there to use.”

**Sexual orientation.** Participants described their sexual identity or preference as follows: heterosexual (65.2%), lesbian (8.7%), bisexual (8.7%), other (8.7%), and questioning (4.3%). The participant who endorsed “other” specified that her or his “holistic orientation of the persona is more important than the gender.” They went on to say that the “pheremonal identity is in this order: gender queers, women, men.” Some
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participants (21.7%) indicated that they would like more information about GLBTQ identities. These respondents reported that they would like more information on “gay, bisexual, and questioning,” “…how these identities cope with and interact with the world and find each other for support when they are disabled,” and “sex, relationships, and coming out.”

Participants were asked to discuss where they have received information about GLBTQ identities. Individuals reported several areas including classes, friends, mentors, siblings, various literature, internet, media, movies, organizations (i.e. Rainbow Alliance), and “everywhere.” One participant reported “nowhere.”

Additional Questions. Participants were asked to describe any questions that were not asked about sexuality, why they should be included, and why they are important. One participant described “parents of gay, lesbian, bisexual, and questioning. How does this affect your lifestyle? Does having a GLBQ son/daughter affect your sexual lifestyle?” Another participant stated “I believe that what is needed are accessible swingers clubs with attendants who may be able to assist those consenting persons living with disabilities during the sexual act.”

Participants were also asked if they preferred someone with a disability to speak with them about sexuality related information. Some participants (21.7%) reported that they preferred someone with a disability to discuss sexuality related information. Two participants reported that they would prefer this individual to have the same disability as them and one stated that she or he had no preference. One participant stated that she or he would like to talk to more than one person with a disability and preferred someone with a “similar” disability. Another person reported that it would be “impossible” for
someone with the same disability to speak with her or him and added that they preferred someone in a wheelchair.

Finally, participants were asked to share any additional comments about the clarity of this questionnaire. One participant made several comments that included: “dating and relationships overlap but are not necessarily the same…I want access to sex, access to intimacy, and access to dating, which may or may not be rolled up into one ball…need to be educated on how to navigate the world in this way, finding other disabled people as well as integrating in the abled society, which can be well meaning but don’t have a clue…would love for the public to be educated that we are full humans, not asexual pity dolls…would love to be connected to resources…about sex and disability.”

**PAR Questions**

Participants were asked to provide feedback on the clarity of each section of the survey. In regards to dating and intimacy, one participant commented on addressing additional routes (not just dating) as a means to physical and emotional intimacy. Another participant questioned what defines a “romantic relationship,” whereas another indicated that this portion of the survey does not apply to those already in a relationship.

Feedback on the body part identification portion of the questionnaire yielded one response. One participant discussed the picture that was used when identifying the male anatomy. She or he stated that the picture “threw” them a bit because of the perceived location of the prostate gland. This participant added that they were unsure of the location because of one detail in the picture.

When asked to provide feedback on anything that was unclear in the sex and sex education section of the questionnaire, one participant commented “the anatomy of a
male,” and another commented “what is a sexual attendant and how does one obtain one?”

Only one participant provided feedback on the sexual interaction portion of the questionnaire. This person stated she or he was unclear about the question that asked participants “what resources are available for people with disabilities who may be experiencing unwanted sexual contact?”

One participant commented in the feedback area regarding contraception. They indicated wanting more information about “birth control for males besides condoms.”

**Questionnaire Evaluation**

Participants were offered the opportunity to provide feedback regarding the clarity of the questionnaire and this feedback has been incorporated into a revised version. The revised questionnaire can be viewed in Appendix E. Some participants made suggestions regarding the dating and intimacy section of the questionnaire. One participant pointed out that parts of this section do not apply to individuals who are currently in relationships. It is still important to gather information about individual’s dating histories, even if they are currently in a relationship; therefore, response choices were modified to include an option for *not applicable* or *currently in a relationship* for dating questions (i.e., questions 8, 11, 12, and 13) that previously did not appear applicable to those in relationships. Another participant pointed out that there may be additional routes besides dating as a means to intimacy; therefore another question was added (i.e., question 15) that asked participants to share other ways to achieve intimacy with another person. Another participant questioned the definition of a “romantic relationship,” but no change
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was made to the survey because all other participants appeared to understand this definition.

Another area of the survey that participants did not seem to understand related to the questions under the sex and sex education section regarding attendants. One participant commented, “what is a sexual attendant and how does one obtain one?” Since some individuals appeared confused by this question (i.e., question 42), it was modified to increase clarity and provide a definition.

It was assumed that other portions of the questionnaire were clear because participants did not provide feedback suggesting otherwise.
CHAPTER V

Discussion

The following discussion will focus on the two primary purposes of this study. First, the preliminary data will be compared to the existing literature and briefly reviewed. Next, study limitations, clinical implications, and research implications will be described. Lastly, future research directions will be discussed.

Convergence and Divergence in the Literature

Several themes noted in the analysis of the survey responses were both consistent and inconsistent with the literature. For example, results of this study revealed that college students with disabilities have fewer opportunities to date. This is consistent with the literature that suggests that people with disabilities, particularly women, have fewer opportunities to establish romantic relationships (Nosek et al., 2001), and due to limited social contact because of various barriers (e.g., transportation, communication, financial), people with disabilities have fewer dating experiences (Mona & Gardos, 2000). Participants also cited disability related factors that hindered more dating opportunities. Furthermore, the number of dates reported by participants was very low. For example, 17.4% identified that they have never dated.

Contrary to expectations, many of the participants in this study indicated that they had received some form of sex education, but consistent with the literature (Blackburn, 2002), the participants reported that the sex education received was rarely relevant to their disability. The vast majority of participants correctly identified female sexual
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anatomy, but there was much more error and variation in responses related to male sexual anatomy. Specifically, male participants were more likely to correctly identify male anatomical parts when compared to the female participants. This indicates that even though sex education may have been provided, sexual anatomy may not be fully understood by individuals. Furthermore, the quality of the sex education received may be questioned based on these results. Finally, the results showed that people with disabilities are not receiving disability specific information regarding sex.

The literature identifying where people with disabilities obtain the majority of their sexual knowledge is mixed. Some researchers report that the majority of information is obtained from books and printed materials (Nosek et. al., 2001); while others indicate that the majority of information comes from sources such as the media or formal sex education classes (McCabe, 1999). The results of this study showed that participants received the most sexual knowledge from books, and it was indicated that few participants talked to family members or friends about sex regularly.

Consistent with the literature (Andrews & Veronen, 1993; Nosek et. al., 2001) several participants in this study admitted to being involved in unwanted sexual contact. Furthermore, some participants were not aware of resources for people with disabilities who have experienced unwanted sexual contact, which is also consistent with the literature (Nosek & Howland, 1997).

The literature showed that women with disabilities have lower body and sexual esteem (Hassouneh-Phillips & McNeff, 2005), but many of the participants viewed themselves as sexually attractive, which disagrees with the literature. On the other hand,
several participants did not view themselves as sexually attractive and cited disability related reasons (e.g. “I’m in a wheelchair”) for this.

In regards to contraception, sexually transmitted diseases, and pregnancy, the literature revealed that women with disabilities are less likely than women without disabilities to be tested for STDs (Nosek et. al., 2001) or receive disability specific information about contraception or pregnancy. The results of this study revealed that participants were familiar with a wide variety of contraceptive methods and most of this information was received from doctors. Many participants had been tested for STDs, but the majority had not.

**Study Limitations**

There were several limitations to this study. This type of design provided subjective responses from a specific group of individuals and therefore, the results represent the opinions of those respondents limiting generalizability.

The primary scope of this study was to focus on college students with physical disabilities because there is no current literature that focuses on sexuality and this population. Because this study focused on college students with physical disabilities, the results cannot be generalized to all people with disabilities. College students with physical disabilities may have had more opportunities to increase their sexual knowledge and experiences compared to people with physical disabilities who have not attended college. Attending college allows for various educational opportunities that may not otherwise be offered. Also, residing on a college campus, or being involved in the campus community as a student, may allow for more opportunities to engage with others and participate in social activities, which may not be available in the general community.
Furthermore, this study also failed to ask participants about other important aspects of their identity. Although gender, disability, and sexual orientation were all addressed in the survey, other identity variables such as religion, race, ethnicity, and socio-economic status were absent from the questionnaire. Religion and cultural beliefs can play a significant role in how people view sex and sexuality, especially within a society that often views sex as a taboo topic. Also, even though participants described the medical description of their disability, it would be beneficial to find out more specific information about their disability. For example, individuals could also report if their disability is congenital or acquired, and if they acquired a disability, that their survey responses reflect their experiences from the time that they acquired the disability. These variables are important to consider because they may impact the attitudes and beliefs that people with disabilities have towards sex. The context that could inform the responses obtained in this survey may be limited because these previously addressed identity variables were not asked.

This study utilized a qualitative design and the appropriate number of participants was obtained rather quickly. The survey was closed after receiving the required number of participants, which left any other potential participants unable to take part in the survey. It is possible that there are factors that impacted the participants’ willingness to complete the survey and the openness of some responses. Some participants who provided in-depth responses may have had a greater interest in the topic or may have been more comfortable speaking about sexuality related issues. On the other hand, some participants did not provide responses to the open ended questions or failed to respond to some questions in specific sections. It may be advantageous to add a question to the
survey asking participants to comment on the reasons why they did not respond to all parts of the survey.

**Clinical Implications**

There were several clinical implications that will be discussed as a result of this study. First, results of this study, as well as current literature indicate that the sexual health of people with disabilities is being compromised. People with disabilities are not receiving the appropriate information or services, which leaves them more vulnerable sexually. Furthermore, these results indicate that healthcare providers and educators are not providing disability specific information about sex and sexuality. For example, individuals with disabilities in this study cited that they have received little disability specific information in regards to contraception, pregnancy, and STDs. This contributes to the discrepancies in sexual knowledge and may increase the sexual risks for people with disabilities. Additionally, less than half of participants in this study have been tested for STDs and most were not concerned with becoming infected. This is especially problematic in the college student population because of the higher rates of STDs within this group and the number of individuals who were sexually active at the time of this survey.

The reproductive healthcare of people with disabilities is also compromised leading to additional sexual health concerns. Women with disabilities have described several barriers to effective reproductive healthcare including structural issues (e.g. accessibility and appropriate physical accommodations) and the relationship with their healthcare provider (Becker, Stuifbergen, & Tinkle, 1997). These barriers lead to fewer gynecological examinations for women with physical disabilities and fewer discussions
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about important sexual health issues (e.g. STDs, contraception). Furthermore, discussions by healthcare providers with individuals with physical disabilities regarding contraceptives are not addressing disability specific concerns. For example, people with physical disabilities may not have the dexterity to use certain contraceptive methods and oral methods may interact with current medications, have side effects, or create other health concerns (Becker et. al., 1997). Women with disabilities who become pregnant or are considering pregnancy feel “discouraged” when attempting to talk to their healthcare providers (Becker et.al., 1997). Finally, individuals with disabilities, particularly women, are more likely to experience sexual abuse and remain in abusing relationships (Becker et. al., 1997; Hassouneh-Phillips & McNeff, 2005; Nosek et. al., 2001). Increased vulnerability for abuse in women with physical disabilities may result from low sexual and body esteem created by societal devaluation (Hassouneh-Phillips & McNeff, 2005) or the overall cultural devaluation of people with disabilities (Nosek et. al., 2001). In fact, several participants (34.8%) from this study admitted that they had been involved in unwanted sexual contact.

Because of these previously discussed issues, clinicians need to educate themselves about sexuality in general as well as sexual concerns for people with disabilities. Training and resources for clinicians is needed in order to provide adequate information to promote sexual health. Furthermore, clinicians may need to make more effort to introduce the topic of sex to their clients with disabilities. In fact, Olkin (1999) indicates that it is the clinician’s responsibility to initiate discussions on sex with clients with disabilities because individuals with disabilities have internalized negative messages that impede these types of discussions. Clinicians may use the modified questionnaire
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created in this study to help develop an outline of topics for individual or group therapy discussions.

Additionally, clinicians need to be careful not to generalize information obtained to all people with disabilities or even people with similar disabilities. Each individual holds their own views and beliefs that may be impacted by a number of multicultural variables. Clinicians need to approach clients with disabilities with the same sensitivity and open mindedness that they would with other clients. Finally, clinicians need to seek out appropriate resources and/or consultation or ask questions of their clients, rather than remaining silent, if they are not familiar with specific sexual issues or concerns.

Another implication that the literature and this study recognized is the potential relationship between sexuality and mood disorders. Research has shown that college students who are in romantic relationships experience fewer mental health problems (Braithwaite, Delevi, & Fincham, 2010) and individuals in relationships may have more opportunities for sexual experiences. A large number of participants in this study (60.9%) reported that they would like to be dating someone or go on more dates, and some participants commented that they would like to have more sexual interactions.

Other research has shown that sexual satisfaction is correlated with life satisfaction (Moin, Duvdevany, & Mazor, 2009; Taleporos, Dip, & McCabe, 2002) and that younger adult women with disabilities had more negative body image and sexual identity issues than more mature women with disabilities (Moin, Duvdevany, & Mazor, 2009). Other researchers have shown that people with more severe physical disabilities experience lower levels of sexual esteem and sexual satisfaction and higher levels of sexual depression (McCabe, Taleporos, & Dip, 2003).
Individuals with disabilities may also experience more anxiety and nervousness during dating and sexual experiences. This was inferred from the qualitative feedback that participants provided. For example, some participants reported that they were not comfortable or able to communicate their disability specific needs in sexual relationships, and other participants reported that they would like more disability specific dating information (e.g. when to disclose a disability, how to find dates with people who are not “squeamish” about dating someone with disability).

This information indicates the relationship between sexuality and potential mood issues including anxiety and depression. Clinicians need to be informed about all aspects of mood disorders including how sexual health impacts mood and use this information appropriately.

Even though there has been a shift towards the social minority model of disability, there continues to be many myths and assumptions that surround sex and disability. The previously discussed implications, as well as other variables continue to illustrate ways that society continues to oppress people with disabilities. Because of this, people with disabilities experience internalized oppression and begin to believe the negative messages that society consistently portrays. Olkin (1999) describes this concept of disability prejudice as “internalized ableism” and adds that not only may people with disabilities begin to believe these prejudices towards themselves, but they may also begin to hold prejudices against other people with disabilities. This illustrates the damage that societal oppression has on people with disabilities and has contributed to the myths attached to disability and sexuality. Clinicians need to work to change the directionality of how we provide our interventions to individuals with disabilities by focusing on society rather
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than people with disabilities as sources of injury. Clinician’s working with people with disabilities need to focus on client empowerment in order to build resiliency to prevent and combat internalized oppression. Resources and training programs for clinicians focusing on disability need to be more readily incorporated into settings in order for clinicians to be culturally competent in this area.

Research Implications

This study utilized a research design where people with disabilities were both participants and researchers. Specifically, individuals with disabilities were consulted to assist with the creation of research questions, dissemination of the survey, and were asked to provide feedback on the survey itself. Furthermore, although this study only represented the first step in a multi-step project, the end goal of this multi-step research project is to go beyond the reported results by providing information to the appropriate sources (e.g. educational institutions, healthcare resources) that would benefit from improved understanding of how disability and sexuality interact. This is consistent with Olkin and Pledger’s (2003) emphasis that disability research should be expanded to the political and societal realms. The implications are that this research reflects the social model of disability and expands awareness and knowledge in an area (i.e., disability and sexuality) where there is little research.

Moreover, the literature shows that there has been much more research on the social construction of other diversity variables (e.g. race, ethnicity, gender, sexual orientation), while disability research remains marginalized. Furthermore, disability research that has been conducted may not always reflect the new paradigm of disability. Specifically, the new paradigm of disability studies reflects the tenets of the independent
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living movement, is grounded in the social model of disability, embraces and validates disability history and culture, and aims to not duplicate the marginalization and oppression that people with disabilities have experienced (Olkin & Pledger, 2003).

Disability specific sexual issues such as dating, sex, contraception, STDs, reproductive issues, and abuse need to be further identified and understood. For example, this research study illustrated that the concept of facilitated sex is not known or understood well and more research on this topic would be beneficial to both the disability community as well as individuals who provide assistance to people with disabilities. The pervasive impact of the lack of available research on sex and disability is that information is not available to others. The lack of available information represents a barrier because it leads to continued silence about a very important topic. More research and support is needed in order to improve the information that is available regarding sex and disability.

Future Research

The results of this research created various questions that may be addressed in future research. For example, it may be beneficial to look at various facets of disability, as well as other identity variables. For example, analyses could be done that compare individuals with visible versus invisible disabilities, as well as acquired versus congenital disabilities. Also, gender comparisons, the amount of time a person has had a disability, as well as other cultural variables would be of greater interest because they would help to inform the context of various responses.

Based on the minimal open ended responses regarding feedback of the survey itself, the modified questionnaire could be submitted for further review by experts in the area of disability. This would continue the PAR nature of this project and provide more
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information about this instrument’s utility. It may also provide further information about specific areas of sex and disability and help propel additional research projects.

After obtaining additional feedback and making further modifications to the survey, it is anticipated that the survey will once again be introduced to college students with physical disabilities to gather more quantitative data in order to accurately assess the sexual knowledge, needs, and experiences of this specific group of individuals. This data will then be used to help inform educators and healthcare providers about the intersection of sex and disability.

Conclusions

The sexual expression of people with physical disabilities is often overlooked because people continue to hold negative attitudes towards people with disabilities (Kaufman, Silverberg, & Odette, 2003; Olkin, 1999). The feedback obtained in this study has been utilized to refine a measure that addresses the sexual knowledge, experiences, and needs of people with physical disabilities. More research needs to be completed utilizing this measure to gather more information so recommendations can be made to healthcare providers or educational entities. Clinical services also need to be further developed to improve the sexual practices and healthcare for clients with physical disabilities.
Appendix A

E-mail

TO: Wright State University Students

Nicole Matros, a doctoral student in the School of Professional Psychology at Wright State University, is conducting a research study to develop a survey that will gather information about the sexual knowledge, experiences, and needs of college students with physical disabilities. This research is being conducted under the supervision and advisement of Dr. Julie Williams.

You have been asked to evaluate the survey because of your affiliation with the Office of Disability Services (ODS). If you decide to participate, you will be asked to fill out a secure, online survey about your impressions of the survey that should take approximately forty-five minutes to complete.

If you are interested in participating, please click on the following link which will take you to the study:

http://www.zoomerang.com/Survey/?p=WEB229ZN7BTDH6

For further information about this research study, you may contact Nicole Matros or Dr. Julie Williams, at matros.2@wright.edu or julie.williams@wright.edu.
Appendix B

Consent Form

Sexual Knowledge, Experiences, Needs of College Students with Physical Disabilities

This consent page is to certify my willingness to participate in this research study.

Nicole Matros, a doctoral student in the School of Professional Psychology at Wright State University in Dayton, OH, is conducting a research study to gather information about the sexual knowledge, experiences, and needs of college students with physical disabilities. I am being asked to participate in this study because I am a college student with a physical disability registered with the Office of Disability Services (ODS).

My participation in this study will involve completing an online survey which should take approximately forty-five minutes to complete. I will be asked to answer several questions about sexuality related issues, including my own personal experiences and knowledge. I will also be asked some questions about my demographics, such as my age and race. This information will not be used in any way to identify me personally. Information that I provide will be kept strictly confidential and any responses I provide will not be associated with my identity in any way.

It is possible that my participation in this study may elicit mild psychological distress related to the disclosure of information of a personal and potentially difficult nature. If I experience psychological distress that is intolerable or beyond what I expect, I may choose to contact Counseling and Wellness Services at 937-775-3407.

There will be no direct benefit to me from participating in this study. However, the information that I provide may help to identify what types of sexuality related information may be added to programs that focus on these issues. My participation or non-participation in this study will in no way impact my standing with the Office of Disability Services or Wright State University.

Any information about me obtained from this study will be kept strictly confidential and I will not be identified in any report or publication. PARTICIPATION IN THIS RESEARCH IS VOLUNTARY. I am free to decline to be in this study, or to withdraw from it at any point. If I choose to withdraw from the study, I may exit the study at any time by closing my internet browser on any page of the survey. Completion of the survey implies my consent to participate.

If I have questions about this research study, I can contact the researcher, Nicole Matros, at 937-371-3173 or matros.2@wright.edu or Dr. Julie Williams, faculty advisor, at 937-775-3407 or julie.williams@wright.edu. If I have general questions about giving consent or my rights as a research participant in this research study, I
can call the Wright State University Institutional Review Board at 937-775-4462. If I would like a copy of the group (not individual) results of this study, I can contact Nicole Matros at the phone number or e-mail address provided above. These results will be available by July 2010.

I have read and understand the above statements, and by clicking on the "Submit" button below, I indicate my consent to participate in this study.
Appendix C

Survey Instructions

Thank you for your participation in this survey. Your responses are appreciated and valued. The purpose of this research study is to evaluate a survey that was developed to investigate the sexual knowledge, experiences, and needs of college students with physical disabilities.

First, you will be asked to complete a series of questions about your sexual knowledge, needs, and experiences. Some of these questions will require you to choose from the response options given, and some of these questions will require you to create your own responses. The length of the responses is not important, as long as the response is clear.

The previously discussed questions are grouped together in categories with a heading in BOLD type. At the end of each category is a text box with the question “If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below.” If any of the questions in that category are unclear to you in any way, please comment on what was unclear about it in this text box.

After you have completed the questions about sexuality related issues, and you have commented about any questions that were unclear, you will be asked to answer some additional questions about the clarity and ease-of-use of the survey.

The total time estimated to complete the survey is 45 minutes. Remember, you may exit the study at any time by closing your internet browser. Thank you for your participation.
Appendix D

Modified* Sexuality Knowledge, Experience, and Needs Scale for People with Physical Disabilities (McCabe, 1994) with author permission.

Before beginning the survey, could you please answer the following questions about yourself.

1. What is your age?
2. What is your gender?
   ___ Male
   ___ Female
3. What is the medical description of your disability?
4. How long have you had this disability?
   ___ Less than 1 year
   ___ 1-5 years
   ___ More than 5 years
   ___ From birth
5. What types of tasks do you require assistance for?
   ___ None
   ___ Preparing meals
   ___ Getting dressed
   ___ Driving places
   ___ Taking a shower
   ___ Other (please describe):
6. How many hours per day do you need help with daily living needs?
   ___ 24 hour

*Italicized items have been modified or newly created for the purposes of this study with author’s permission
DATING AND INTIMACY

7. K How would you define a date?

8. N Would you like more information about dating?

   If so, what types of information would be most helpful?

9. E How many dates have you been on?

10. E What did you do on your dates?

11. F If you are not currently dating anyone, would you like to be?

12. N Would you like to go on more dates?

   If so, what types of things have prevented you from dating more?

13. E When was the last time you were involved in a romantic relationship?

   __Never
   __During the past month
   __1-6 months ago
   __6-12 months ago
   __Over a year ago

14. K What does intimacy mean to you?
15. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:

[Blank text box]

**BODY PART IDENTIFICATION**

16. K  How knowledgeable are you of the female sexual anatomy?

___ Not at all
___ A little
___ Moderately
___ A lot

![Diagram of female sexual anatomy](image.png)
17. K Using the above image, identify an ovary?

18. K What is the function of the ovaries?

19. K Using the above image, identify a fallopian tube?

20. K What is the function of the fallopian tubes?

21. K Using the above image, identify the vaginal opening?

22. K What is the function of the vaginal opening?

23. K Using the above image, identify the clitoris?

24. K What is the function of the clitoris?

25. K How knowledgeable are you of the male sexual anatomy?
26. **K** Using the above image, identify the scrotum?
27. **K** What is the function of the scrotum?
28. **K** Using the above image, identify the testicles?
29. **K** What is the function of the testicles?
30. **K** Using the above image, identify the prostate gland?
31. **K** What is the function of the prostate gland?
32. **K** Using the above image, identify the vas deferens?
33. **K** What is the function of the vas deferens?
34. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:

SEX AND SEX EDUCATION

35. E Where have you received your information about sex? (mark all that apply)

___ School
___ Doctor
___ Parents
___ Siblings
___ Friends
___ Media
___ Books
___ Internet
___ Other (please specify)

36. F For each source checked, how useful was this sex education?

37. F How relevant to your disability was this sex education?

38. N Would you like more sex education?

If yes, what topics or areas would you like to know more about?

39. F Describe your beliefs towards sex?

40. E How often do you talk to family members about sex?

___ Never
41. E How often do you talk to your friends about sex?

___ Never
___ Once
___ A few times
___ Often
___ Very often

42. E How often do you have sex?

43. E If you have an attendant, are you able to negotiate your sexual needs with this person?

If no, what has prevented this?

44. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:
SEXUAL INTERACTION

45. E How many sexual partners have you had?

46. E Were you able to communicate your disability related needs with your partner?

If yes, please describe this experience?

If no, what prevented you from doing so?

47. E If you have been sexually active, how comfortable were you communicating specific needs to your partner?

48. F Do you see yourself as being sexually attractive?

Why or why not?

49. N Are you aware of resources that can provide you with disability specific information about your sexual needs?

50. E Have you ever been involved in unwanted sexual contact?

51. K What resources are available for people with disabilities who may be experiencing unwanted sexual contact?

52. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:

______________________________________________________________

CONTRACEPTION

53. K How knowledgeable are you of contraceptive methods?

__Not at all

__A little
Where did you obtain this information about contraceptives? (mark all that apply)

___ School
___ Doctor
___ Parents
___ Siblings
___ Friends
___ Media
___ Books
___ Internet
___ Other (please specify)

If you have been sexually active, what type of contraception did you use, if any?

Can you use a condom?

If no, what other forms of contraception do you use, if any?

What other types of contraceptives/birth control methods are you aware of?

If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:
PREGNANCY, ABORTION, CHILDBIRTH

59. E Have you ever received disability specific information on pregnancy, abortion, or childbirth?

If yes, what kinds of information did you receive?

60. N Would you like more information about pregnancy, abortion, and childbirth?

If yes, what types of information would you like?

61. E Have you ever been pregnant?

If yes, how did the pregnancy end?

___ Childbirth
___ Abortion
___ Miscarriage
___ Other (please specify)

62. E How many children do you have?

63. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:

SEXUALLY TRANSMITTED DISEASES

64. K How many types of Sexually Transmitted Diseases (STDs) have you heard of? Please name them.

65. K How do you catch STDs?
66. N  Would you like to know more about STDs?
      If so, what kinds of information would you like?

67. F  How would you feel about catching an STD?

68. K  How can you tell if you have an STD?

69. E  Have you ever been tested for STDs?
      If yes, was it per your request or suggested by someone else?

70. E  Have you ever had an STD?

71. F  Are you concerned about getting an STD?

72. K  What do you know about HIV and AIDS?

73. E  Have you ever been tested for HIV or AIDS?

74. K  What are the best ways to prevent contracting HIV and AIDS?

75. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:

MASTURBATION

76. F  How do you feel about masturbation?

77. E  How often do you masturbate?

78. N  Have you been able to obtain assistance with masturbation if needed?
      If no, what has prevented this?

79. N  Would you like disability specific information about masturbation?
      If yes, what types of information would be most helpful?
80. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:


SEXUAL ORIENTATION

81. E How would you describe your sexual identity or preference?
___ Heterosexual
___ Gay
___ Lesbian
___ Bisexual
___ Transgender
___ Questioning
___ Other (please specify)

82. N Would you like to know more about gay, lesbian, bisexual, transgender, and questioning (GLBTQ) identities?
If yes, what types of information would be most helpful?

83. E Where have you received information from about GLBTQ identities?

84. If there is anything that was unclear about the above questions, please describe what was unclear in the text box provided below:
ADDITIONAL QUESTIONS

85. If there were questions that were not asked in the survey about sexuality that you think should be included, please describe them and why you think they are important.

86. Would you prefer someone with a disability to talk with you about sexuality related information?
If so, do you prefer that this person have the same disability as you?

87. Please share any additional comments on the clarity of the survey.

McCabe, M.P. (1994). Sexuality knowledge, experience, and needs scale for people with physical disabilities (SexKen-PD1). School of Psychology, Deakin University-Burwood Campus. Deakin University 221 Burwood Highway Burwood, VIC 3125.
Appendix E

Revised* Sexuality Knowledge, Experience, and Needs Scale for People with Physical Disabilities (McCabe, 1994) with author permission.

Before beginning the survey, could you please answer the following questions about yourself.

1. What is your age?
2. What is your gender?
   - Male
   - Female
3. What is the medical description of your disability?
4. How long have you had this disability?
   - Less than 1 year
   - 1-5 years
   - More than 5 years
   - From birth
5. What types of tasks do you require assistance for?
   - None
   - Preparing meals
   - Getting dressed
   - Driving places
   - Taking a shower
   - Other (please describe):
6. How many hours per day do you need help with daily living needs?
   - 24 hours
   - 23-12 hours
   - 11-1 hour(s)
   - 0 hours

**DATING AND INTIMACY**

7. K How would you define a date?
8. N Would you like more information about dating?
   - Yes

*Italicized items have been modified or newly created for the purposes of this study with author’s permission*
___ No
___ Not currently dating
If so, what types of information would be most helpful?

9. E How many dates have you been on?

10. E What did you do on your dates?

11. F If you are not currently dating anyone, would you like to be?
   ___ Yes
   ___ No
   ___ N/A

12. N Would you like to go on more dates?
   ___ Yes
   ___ No
   ___ N/A
If so, what types of things have prevented you from dating more?

13. E When was the last time you were involved in a romantic relationship?
   ___ Never
   ___ Currently in a romantic relationship
   ___ During the past month
   ___ 1-6 months ago
   ___ 6-12 months ago
   ___ Over a year ago

14. K What does intimacy mean to you?

15. K Are there other ways, besides dating, that you have used to achieve intimacy with another person? If so, please describe.
BODY PART IDENTIFICATION

16. K  How knowledgeable are you of the female sexual anatomy?
      ___ Not at all
      ___ A little
      ___ Moderately
      ___ A lot

17. K  Using the above image, identify an ovary?

18. K  What is the function of the ovaries?

19. K  Using the above image, identify a fallopian tube?

20. K  What is the function of the fallopian tubes?
21. K  Using the above image, identify the vaginal opening?
22. K  What is the function of the vaginal opening?
23. K  Using the above image, identify the clitoris?
24. K  What is the function of the clitoris?
25. K  How knowledgeable are you of the male sexual anatomy?
   ___ Not at all
   ___ A little
   ___ Moderately
   ___ A lot
26. K Using the above image, identify the scrotum?
27. K What is the function of the scrotum?
28. K Using the above image, identify the testicles?
29. K What is the function of the testicles?
30. K Using the above image, identify the prostate gland?
31. K What is the function of the prostate gland?
32. K Using the above image, identify the vas deferens?
33. K What is the function of the vas deferens?

SEX AND SEX EDUCATION

34. E Where have you received your information about sex? (mark all that apply)
   ___ School
   ___ Doctor
   ___ Parents
   ___ Siblings
   ___ Friends
35. F For each source checked, how useful was this sex education?

36. F How relevant to your disability was this sex education?

37. N Would you like more sex education?
If yes, what topics or areas would you like to know more about?

38. F Describe your beliefs towards sex?

39. E How often do you talk to family members about sex?

   __ Never
   __ Once
   __ A few times
   __ Often
   __ Very often

40. E How often do you talk to your friends about sex?

   __ Never
   __ Once
   __ A few times
   __ Often
   __ Very often

41. E How often do you have sex?

42. E If you have an attendant, are you able to negotiate your sexual needs with this person? This may include requesting help to set-up, assisting with positioning, and/or removal of clothing. The attendant is not involved in the sexual activity.
If no, what has prevented this?

SEXUAL INTERACTION

43. E How many sexual partners have you had?
44. E Were you able to communicate your disability related needs with your partner?
If yes, please describe this experience?
If no, what prevented you from doing so?

45. E If you have been sexually active, how comfortable were you communicating specific needs to your partner?

46. F Do you see yourself as being sexually attractive?
Why or why not?

47. N Are you aware of resources that can provide you with disability specific information about your sexual needs?

48. E Have you ever been involved in unwanted sexual contact?

49. K What resources are available for people with disabilities who may be experiencing unwanted sexual contact?

CONTRACEPTION

50. K How knowledgeable are you of contraceptive methods?

___ Not at all
___ A little
___ Moderately
___ A lot

51. K Where did you obtain this information about contraceptives? (mark all that apply)
___ School
___ Doctor
___ Parents
___ Siblings
___ Friends
___ Media
___ Books
___ Internet
___ Other (please specify)
52. E If you have been sexually active, what type of contraception did you use, if any?

53. E Can you use a condom?
If no, what other forms of contraception do you use, if any?

54. K What other types of contraceptives/birth control methods are you aware of?

PREGNANCY, ABORTION, CHILDBIRTH

55. E Have you ever received disability specific information on pregnancy, abortion, or childbirth?
If yes, what kinds of information did you receive?

56. N Would you like more information about pregnancy, abortion, and childbirth?
If yes, what types of information would you like?

57. E Have you ever been pregnant?
If yes, how did the pregnancy end?
___ Childbirth
___ Abortion
___ Miscarriage
___ Other (please specify)

58. E How many children do you have?

SEXUALLY TRANSMITTED DISEASES

59. K How many types of Sexually Transmitted Diseases (STDs) have you heard of? Please name them.

60. K How do you catch STDs?

61. N Would you like to know more about STDs?
If so, what kinds of information would you like?

62. F How would you feel about catching an STD?

63. K How can you tell if you have an STD?

64. E Have you ever been tested for STDs?
If yes, was it per your request or suggested by someone else?

65. E Have you ever had an STD?
66. F Are you concerned about getting an STD?
67. K What do you know about HIV and AIDS?
68. E Have you ever been tested for HIV or AIDS?
69. K What are the best ways to prevent contracting HIV and AIDS?

MASTURBATION

70. F How do you feel about masturbation?
71. E How often do you masturbate?
72. N Have you been able to obtain assistance with masturbation if needed?
   If no, what has prevented this?
73. N Would you like disability specific information about masturbation?
   If yes, what types of information would be most helpful?

SEXUAL ORIENTATION

74. E How would you describe your sexual identity or preference?
   ___ Heterosexual
   ___ Gay
   ___ Lesbian
   ___ Bisexual
   ___ Transgender
   ___ Questioning
   ___ Other (please specify)

75. N Would you like to know more about gay, lesbian, bisexual, transgender, and questioning (GLBTQ) identities?
   If yes, what types of information would be most helpful?

76. E Where have you received information from about GLBTQ identities?

ADDITIONAL QUESTIONS

77. If there were questions that were not asked in the survey about sexuality that you think should be included, please describe them and why you think they are important.

78. Would you prefer someone with a disability to talk with you about sexuality related information?
   If so, do you prefer that this person have the same disability as you?
McCabe, M.P. (1994). *Sexuality knowledge, experience, and needs scale for people with physical disabilities (SexKen-PD1).* School of Psychology, Deakin University-Burwood Campus. Deakin University 221 Burwood Highway Burwood, VIC 3125.
References


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