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Sexual Health Education and Life Satisfaction for People with Congenital Neurological Disabilities

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# Abstract

People with disabilities are sexual beings, yet there is little research on sexuality in this population. The present study explored the impact of sex education for people with congenital neurological disabilities, largely, spina bifida and cerebral palsy, on sexual self-concept and life satisfaction. This study included 104 adults with spina bifida, cerebral palsy, and other congenital neurological disabilities. Hierarchical regression analysis was used to examine the relationships between demographic variables, sexual health education variables, and outcome variables (sexual self-concept and life satisfaction). Serial mediation analysis was conducted to examine the mediating relationship of sexual self-concept variables (sexual anxiety and sexual self-esteem) between social support and life satisfaction. Results indicated that sexual self-concept was significantly predicted by relationship status, disability impact, and satisfaction with sex education. Life satisfaction was significantly predicted by relationship status, social support, disability impact, and sexual self-concept. Sexual anxiety and sexual self-esteem formed a partial serial mediating relationship between social support and life satisfaction. The findings expand upon existing literature on sex education for people with disabilities, reinforcing the notion that satisfactory sex education and strong social support positively impact the life satisfaction of individuals with spina bifida and cerebral palsy. Implications for rehabilitation research and practice are discussed.

# Keywords

Sexuality, health and well-being, life satisfaction

Sexual health education consists of information regarding the biological, sociocultural, and relational aspects of sexuality, which is often imparted by parents, schools, and medical providers (Breuner & Mattson, 2016). Policies regarding sexual health education provision in schools vary by state, with less than half of public schools requiring it. The 29 states (and the District of Columbia) that require sexual health education require it to be taught with medical accuracy and to be theory-driven, evidence-informed, and age-appropriate (Sexuality Information and Education Council of the United States, 2020). Furthermore, national sex education standards require it to be developmentally appropriate for learners with disabilities (Future of Sex Education Initiative, 2020).

Regarding the prevalence of sexual health education offered to students with disabilities today, there is little research to be found; however, throughout the last century, students with disabilities have been uneducated or undereducated regarding sexuality. Overwhelmingly, they are left out of sexual health education in schools altogether (Lam et al., 2019; Manoj & Suja, 2017). The scant research on the topic of sex education and disability focuses on those with intellectual disability, taught largely about appropriate behavior, and decision-making slanted toward abstinence but not about sexual decision-making (Gonzalvez et al., 2018). Abstinence-based education is common in the general sex education arena, but people with disabilities are found to be educated largely on abstinence and inadequately informed about sexual health topics such as contraception and safe sex (Lam et al., 2019). A compounding issue is that even when people with disabilities are allowed to participate in sexual health education, social barriers preclude them from having the opportunity to gather with peers, including romantic partners, disallowing any social learning or the opportunity for a sexual life (Brown & McCann, 2018). Although individuals with a variety of disabilities experience access barriers to sex education, this study focuses on individuals with spina bifida and cerebral palsy, conditions that affect the brain, spine, and muscles impacting physical ability and the neuromuscular system (World Health Organization [WHO], 2016). People with spina bifida and cerebral palsy, like others with disabilities, report a desire to receive sexual health education in their schools and challenges with sexual health in the areas of romance, sexuality, reproduction, and the willingness of others to talk to them about sexuality (Akre et al., 2015).

People with disabilities experience sexual growth with parallel neurophysiological development to their nondisabled peers and emotional social and cultural identities that are parallel as well (Harkins Monaco et al., 2018). They also require the same information provided in general sexual health education courses (Nguyen et al., 2016). Furthermore, these individuals experience sexual issues in the context of their disabling conditions yet are often not given information on coping with or even understanding these issues (Wienholz et al., 2016). For example, people with cerebral palsy experience a need for increased sexual communication with partners due to limited mobility and muscle spasticity (Dune, 2014) as well as a duration of puberty that starts earlier and ends later than nondisabled peers (Harkins Monaco et al., 2018). People with spina bifida experience a similar duration of puberty and have higher instance of latex allergy, leading to the need for latex-free birth control measures (Neufeld et al., 2002). Unfortunately, the incongruence between sexual development and the dearth of information received by people with disabilities is correlated with poor sexual health decision-making among youth and adults (Wienholz et al., 2016) and vulnerability to abuse (Medina-Rico et al., 2018).

Although vulnerability and concerns about the ability to handle sexual information have been cited as a reason for not providing sexual health education to individuals with disabilities in systematic reviews of the literature (Lam et al., 2019), people with disabilities express a desire to experience connection through romantic relationships, as well as interest in gaining knowledge of sexual health topics (Manoj & Suja, 2017), including navigating sexuality as impacted by their disability (Wienholz et al., 2016). Sexual health education has been found to improve the health and well-being of young people (Duberstein et al., 2016) and adults (McCarthy, 2014). Not only can sexual health education reduce the risk of unplanned pregnancy and sexually transmitted infection, including HIV (Chin et al., 2012), but it can also impact the learners’ confidence in their sexual decision-making. Access to sexual health education is shown to improve sexual self-esteem (Scales Rostosky et al., 2008), which has been correlated with life satisfaction and found to be influenced by social support and receipt of sexual health education (Potki et al., 2017).

People with disabilities express an aspiration to develop a positive sexual self-concept through sex education and express concern about the lack thereof (Lam et al., 2019; Wienholz et al., 2016). People with cerebral palsy indicate that, while their sexual self-concept is impacted by their disability, permission to talk about sexuality with caretakers, peers, providers, and partners increases sexual self-concept and agency (Dune, 2014). People with spina bifida also report difficulties with sexuality, are particularly impacted by lack of education, and report higher satisfaction both with sex life and life in general when given education and the opportunity to talk openly about the impact of their disability on sexuality (Kupfert Heller et al., 2016).

Although individuals with spina bifida and cerebral palsy are sexual beings and want to be included in sex education, they are still experiencing barriers to this desire. In literature reviews and meta-analyses of sex education and disability, common themes are lack of access to sex education and the regulation of sex lives by others. Barriers to sexual health for youth and adults with disabilities include lack of valid and reliable sexual health education, lack of education for teachers and parents, and fear and anxiety regarding talking about sexual health with people with disabilities (Brown & McCann, 2018; Treacy et al., 2018).

Barriers to education are cited as contributing factors to the higher rates of abuse for people with disabilities than the general population (Lund & Vaughn-Jensen, 2012) and to the report of this abuse (McGilloway et al., 2018). Children with disabilities experience sexual abuse at nearly 3 times the rate of children without disabilities (Lund & Vaughn-Jensen, 2012), while adults with disabilities are 4 times as likely to experience sexual abuse than adults without (McGilloway et al., 2018). Simply having a disability seems to impact one’s likelihood of being victim of sexual abuse, but specific disabilities contribute to higher risk. Disabilities impacting communication and dependence on others for physical care (e.g., spina bifida and cerebral palsy) as well as multiple disability diagnoses experience even higher risk levels (Higgins, 2010).

Prevention of abuse and exploitation is an important aim of education, but the promotion of positive self-concept variables such as sexual self-esteem and self-efficacy have been recommended by researchers as well (Lee & Fenge, 2016). Sexual self-esteem has been found to be positively impacted by sex education for women with developmental disabilities (McCarthy, 2014) and to be a mediator between sexual knowledge and sexual self-efficacy (Scales Rostosky et al., 2008). In general, self-esteem has been found to be a mediator between social support and satisfaction with life (Kong et al., 2013; Toplu-Demirtas et al., 2018), and positive self-esteem and self-efficacy taken together have been found to predict lower anxiety for people with disabilities (Longworth et al., 2018). Sexual health education can play a role in the promotion of positive self-concept (self-esteem) as well as prevention of the negative (anxiety).

# Purpose of the Study

The purpose of this study is to explore the impact of sexual health education variables (sexual knowledge, satisfaction with sex education) on both sexual self-concept and life satisfaction for individuals with congenital neurological disabilities (spina bifida and cerebral palsy). While the exploratory and post hoc nature of the study precludes the examination of the connection with abuse prevention, the current study aims to add to a limited but growing research base on the sexual health and well-being of individuals with disabilities. To that end, the current exploratory study focused on the research questions that follow.

Research Questions

* **Research Question 1:** How well did three sets of variables, demographics, personal (social support and disability impact), and sexual health education (receipt of sex education, sexual health knowledge, and satisfaction with sex education), predict sexual self-concept?
* **Research Question 2:** How well did three sets of variables, demographic, personal (disability impact and social support), and sexual self-concept, predict satisfaction with life?
* **Research Question 3:** Will sexual self-concept variables (sexual anxiety and sexual esteem) mediate the relationship between social support and satisfaction with life?

# Method

## Participants

The sample consisted of 104 adults with spina bifida (*n* = 67, 64.4%), cerebral palsy (*n* = 32, 30.8%), or other neuromuscular disabilities (*n* = 5, 4.8%; Vascular Ehlers-Danlos, muscular dystrophy, Vater Syndrome, and neuromuscular autoimmune disease) who completed an online survey. The mean age of participants was 35 years of age (*SD* = 10.3, range = 19–72), with 36.5% (*n* = 38) identifying as male, 61.5% (*n* = 64) identifying as female, 1% (*n* = 1) identifying as gender queer, and 1.0% (*n* = 1) identifying as transgender (FtM). In terms of the racial/ethnic background of participants, 83.7% (*n* = 87) identified as Caucasian, 3.8% (*n* = 4) identified as African American, 4.8% (*n* = 5) identified as Latinx/Hispanic, 2.9% (*n* = 3) identified as Asian American, 1.0% (*n* = 1) identified as American Indian, and 2.9% (*n* = 2) identified as “other.” The majority (67%, *n* = 52) were in some type of relationship. In terms of sexual health education variables, 89.4% (*n* = 93) reported receiving sexual health education while 10.6% (*n* = 11) reported they did not. Participants were also asked whether they were satisfied with their experience of sexual health education; 53.8% (*n* = 56) reported they were satisfied.

## Procedures

The Education and Social/Behavioral Science Institutional Review Board Office at the authors’ institution approved this study’s procedures. Participants were recruited through disability service and advocacy organizations (National Council on Independent Living, Broadscope, The Spina Bifida Chapter of Wisconsin, and Disability Rights Wisconsin) and through social media-based support groups. The survey was accessible online, distributed via listservs through a survey link on social media posts or through email with a hyperlink; snowball sampling occurred through the sharing of these links among participants. Eligibility requirements for participation in the study were that the participants were (a) aged 18 or older and (b) diagnosed with spina bifida, cerebral palsy, or another congenital neuromuscular physical disability. Exclusion criteria included anyone falling into the category other than the described or co-occurring intellectual disability and not functioning in the capacity of their own guardian and therefore unable to give informed consent.

## Measures

### Demographics

A demographics questionnaire was the first portion of the survey and included general demographic variables (i.e., age and gender), type of disability, and questions about the experience of sexual health education. The sexual health education questions responses were binary with possible answers of yes or no (“Did you receive sexual health education during adolescence?,” “Are you satisfied with the sexual health education you received?”).

### Sexual knowledge

Sexual knowledge was measured using a set of questions regarding the knowledge typically taught in sexual health education courses. This scale, the Acquired Sexual Knowledge Questionnaire (ASKQ; Kriofske Mainella, 2019), is a 20-item measure developed in conjunction with the present study. An initial search of existing measures yielded few results and those found were based on only specific areas of sexual health knowledge (i.e., contraception; Davis et al., 1998), were extremely lengthy with limited or no reliability or validity data (Monge et al., 1977), or were antiquated, using out of date language (Gough, 1974). This instrument was designed to address these issues and is based on several measures of sexual health knowledge (e.g., Davis et al., 1998; Gough, 1974; Monge et al., 1977) and the National Sexuality Education Standards for schools in the United States (Future of Sex Education Initiative, 2020). The ASKQ contains questions covering the seven topic areas outlined in national standards for sex education: puberty, identity, pregnancy and reproduction, sexually transmitted infections (STI) and HIV, healthy relationships and personal safety, and condom use (e.g., “You can tell by looking at someone if they have an STI or HIV because they look sick.”). The survey allows respondents to answer with True, False, or Unsure. A global knowledge score is calculated with each correct item receiving a “1” and each incorrect item or response of unsure receiving a “0.” A mean score across items was computed, with higher scores indicating higher sexual knowledge. The reliability of the ASKQ was analyzed using a Cronbach’s alpha internal consistency reliability coefficient, found to be .66. The relatively low reliability may be due to the varied number of questions representing each topic area or the heterogeneity of the construct. Furthermore, the ASKQ has not yet been validated as a measure of sexual knowledge; therefore, the results should be considered with caution.

### Sexual self-concept

This variable as a full-scale measure used a composite score of two subscales of the Multidimensional Sexual Self-concept questionnaire (MSSCQ; Snell, 1995), a 100-item self-report instrument measuring 20 separately measured constructs related to human sexuality using a 5-point scale ranging from 1 (*not at all characteristics of me*) to 5 (*very characteristic of me*). The subscales used in the current study were sexual anxiety and sexual esteem. Sexual anxiety was reflected as a negative sexual self-concept construct and sexual self-esteem as positive. Individual subscales can have a total score from 1 to 5, with higher scores being related to higher amounts of each of the constructs. The Cronbach’s alpha coefficient for the composite score for esteem and anxiety together for the current sample was .90.

### Sexual anxiety

Sexual anxiety is described as a tendency toward feeling anxiety or tension about sexual aspects of life. Sexual anxiety can lead to reduced sexual satisfaction and feelings of guilt and shame (Janda & O’Grady, 1980). The Sexual Anxiety Subscale contains five questions about anxious feelings about sex or sexual expression (e.g., “I feel anxious when I think about the sexual aspects of my life.”). Higher scores indicate higher sexual anxiety. This subscale was used in the parallel mediation conducted in the study. The Cronbach’s alpha coefficient for this subscale has been found to be .84 (Davis et al., 1998). The Cronbach’s alpha coefficient for the current sample was .86.

### Sexual esteem

Also used in the parallel mediation equation, sexual esteem or sexual self-esteem is related, in this measure, directly to sexuality. Sexual self-esteem is the tendency to evaluate one’s own sexual capacity in a positive way. The Sexual Esteem subscale has five questions regarding the respondents’ pride and positive feelings about their ability to handle their own sexual experiences (e.g., “I am proud of the way that I deal with my own sexual desires and needs.”). Higher scores indicate higher sexual esteem. This subscale has been found to have a Cronbach’s alpha of .88 (Davis et al., 1998). The Cronbach’s alpha for the current sample was .83.

### Social support

The Multidimensional Scale of Perceived Social Support (MSPSS) was developed by Zimet and colleagues (1988) to measure the perception of social support among students in undergraduate programs in the United States. The scale measures social support among three types of groups: family (e.g., “I get the emotional help and support I need from my family”), significant others (e.g., “There is a special person around when I am in need”), and friends (e.g., “My friends really try to help me”). The MSPSS has 12 items and respondents answer questions on a 7-point scale ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*). The total score of the MSPSS, which can range from 7 to 82, represents the mean of the three subscale means; higher scores indicate higher levels of perceived social support (Zimet et al., 1988). Although the MSPSS was validated on an undergraduate population, it is considered a valid and reliable instrument with reliability coefficients ranging from .85 to .91, useful for its brevity in assessing social support in three areas in individuals’ lives and can be used across diverse populations (Zimet et al., 1990). The Cronbach’s alpha found for the full-scale score as used in the current study was .94.

### Disability impact

This outcome variable was measured using the WHO’s (2001) Disability Assessment Schedule (WHODAS) 12-question instrument. The WHODAS is a brief and effective measure of disability impact asking questions about disability impact (e.g., “In the past 30 days, how much difficulty did you have with standing for long periods?”) with answers on a 5-point scale from 0 (*none*) to 4 (*extreme or cannot do*). The WHODAS has been found to be a reliable instrument with a Cronbach’s alpha of .98 (WHO, 2010) and with a Cronbach’s alpha coefficient of .78 for the current sample.

### Life satisfaction

This outcome variable was measured using the Satisfaction with Life Scale (SWLS) created by Diener and colleagues (1985). The SWLS is a brief 5-item measure designed to measure the global construct of satisfaction with life. The five questions are answered on a 7-point scale from 1 (*strongly disagree*) to 7 (*strongly agree*; e.g., “I am satisfied with my life.”). The SWLS is scored by adding up the total score ranging from 5 to 35, indicating the degree of life satisfaction, and has been found to be a reliable instrument with a Cronbach’s alpha of .88 (Diener et al., 1985). The Cronbach’s alpha coefficient found for the current sample was .91.

## Preliminary Analysis

SPSS was used for the screening and cleaning of data (e.g., ensuring data entry accuracy, transforming categorical variables, and reverse coding items as necessary). Descriptive statistics of the scales were calculated, and normality, skewness, and kurtosis of the data were assessed; all data were within the guidelines for normality (Kline, 2011). Mahalanobis distance was used to screen outliers. The Mahalanobis distance in the current study included six variables; the critical chi-square value was 22.46 with no distances greater than this. Missing data were addressed through simple conditional mean imputation. The correlation matrix (see Table 1) identified relationships between variables and potential multicollinearity. Descriptive statistics (range, mean, *SD*, and Cronbach’s alpha) of the eight variables used in the regressions, as well as their intercorrelations, are provided in Table 1.

**Table 1.** Correlation Matrix With Range, Mean, Standard Deviation, and Cronbach’s Alpha of Measured Outcome Variables (*N* = 104).

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Measure [construct] | Range | M | SD |  | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |
| 1. Perceived Social Support | 1–7 | 5.14 | 1.8 | .94 | — |  |  |  |  |  |  |  |
| 2. Disability Impact | 0–4 | 3.84 | 1.2 | .78 | −.282\*\* | — |  |  |  |  |  |  |
| 3. Sexual Health Knowledge | 0–19 | 16.31 | 2.38 | .66 | .139 | −.123 | — |  |  |  |  |  |
| 4. Satisfaction Sex Ed | 0–1 | 0.55 | 0.500 | n/a | n/a | n/a | n/a | — |  |  |  |  |
| 5. Sexual Self- Concept Total | 1–5 | 3.71 | 1.61 | 0.90 | .292\*\* | −.252\* | .184 | .203\* | — |  |  |  |
| 6. Sexual Anxiety | 1–5 | 3.36 | 1.19 | 0.86 | −.085 | .137 | −.244\* | −.125 | −.779\*\* | — |  |  |
| 7. Sexual Self-Esteem | 1–5 | 3.75 | 1.80 | 0.83 | .369\*\* | −.297\*\* | .129 | .231\* | .822\*\* | −.412\*\* | — |  |
| 8. Life Satisfaction | 1–7 | 4.40 | 1.89 | 0.91 | .550\*\* | −.429\*\* | .169 | .122 | .460\*\* | −.345\*\* | .413\*\* | — |

\**p* < .05. \*\**p* < .01.

## Main Analysis

SPSS software was used to perform the two Hierarchical Regression Analyses (HRA) related to Research Questions 1 and 2 with sexual self-concept and satisfaction with life as criterion variables. HRAs were conducted to determine the degree to which sexual self-concept and life satisfaction were predicted by the demographic and personal report variables (Hoyt et al., 2008). HRA can be used to predict an effect of one variable on another in a proposed future outcome, useful in examining rehabilitation interventions and outcomes (Hoyt et al., 2008). Research Question 3 asked about mediating variables; serial mediation is a relational analysis that can be used to study the causal relationships between two or more variables (Hayes, 2017). This study made use of Andrew Hayes’ (2017) method for serial mediation analysis (see Figure 1 for the mediator model for this study).

[
                        figure
                    ](https://journals.sagepub.com/doi/10.1177/00343552211031870)

**Figure 1.** Path coefficients for serial mediation analysis on satisfaction with life (*N* = 98).

*Note.* Mediation model assessed using Hayes’ PROCESS model six (2018). Indirect effect of social support on subjective well-being through sexual anxiety and sexual self-esteem. Standardized effects are presented. The effects on the direct path from social support to satisfaction with life depict the direct effect and the (total effect).

\**p* < .05. \*\**p* < .01. \*\*\**p* < .001.

# Results

## Impact of Personal and Sexual Health Education Variables on Sexual Self-Concept

An HRA was conducted to examine the impact of independent variables on sexual self-concept. The results are summarized in Table 2. As demographic variables are considered useful to enter in the first step of an HRA (Cohen & Cohen, 1983), the demographic covariates for the study were entered first. As can be seen in this table, the set of demographic covariates accounted for 12% of the variance in sexual self-concept scores, *R* = .350,  = .122, *F*(99) = 13.22, *p* < .001. Relationship status was found to significantly contribute to sexual self-concept scores in the final model,  = .226, *t*(99) = 2.19, *p* = < .05. Thus, being in a relationship was associated with a more positive sexual self-concept in the model.

**Table 2.** Summary of Hierarchical Regression Analysis for Predictors of Sexual Self-Concept (*N* = 99).

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | At entry into the model |  |  | Final model |  |  |
| Variable |  |  | *B* | *SE B* |  | *B* | *SE B* |  |
| Step 1 | . | .122\*\*\* |  |  |  |  |  |  |
| Age |  |  | 0.040 | 0.149 | −.030 | 0.055 | 0.150 | .041 |
| Gendera |  |  | 4.79 | 3.05 | .169 | 2.09 | 3.15 | .074 |
| Racea |  |  | −3.79 | 4.12 | −.10 | −2.51 | 4.07 | −.066 |
| Relationship statusa |  |  | 14.11 | 3.88 | .350\*\*\* | 9.15 | 4.17 | .226\* |
| Step 2 | .184 | .062\* |  |  |  |  |  |  |
| Social support |  |  | 0.180 | 0.123 | .150 | 0.168 | 0.121 | .140 |
| Disability impact |  |  | −0.521 | 0.304 | −169 | −0.634 | 0.305 | −.205\* |
| Step 3 | .238 | .054\* |  |  |  |  |  |  |
| Sexual health educationb |  |  | 7.65 | 6.22 | .116 | 7.65 | 6.22 | .116 |
| Satisfaction with sexb |  |  | 7.94 | 3.96 | .197\* | 7.94 | 3.96 | .197\* |
| Sexual health knowledge |  |  | 0.661 | 0.812 | .080 | 0.661 | 0.812 | .080 |

aGender ( 1 = *male*), Race (1 = *Caucasian*), Relationship Status (1 = *in a relationship*).

bSexual health education (1= *yes*), satisfied with sex (1 = *yes*). All other measures centered at their means.

\**p* < .05. \*\**p*< .01. \*\*\**p* < .001.

Personal self-report variables were entered in the second step of the analysis; these variables included both disability impact and perceived social support. Life satisfaction has been shown to be correlated with both social support (Potki et al., 2017) and disability impact (Bishop et al., 2009). Although social support did not significantly contribute to the model, it was found that disability impact accounted for a significant amount of variance beyond what was explained by relationship status, *R* = .429,  = .184, *F*(99) = 3.54, *p* > 05. Examination of the standardized partial regression coefficients indicated that disability impact had a significant negative impact on sexual self-concept in the final model, β = −.634, *t*(99) = −2.08, *p* = < .05. The more limited the participant felt by their disability, the less likely they were to have positive sexual self-concept scores, even after controlling for demographic variables, including the significant impact of relationship status.

In the third and final step of the regression equation, sexual health education variables were entered (the receipt of sexual health education, sexual knowledge scores, and satisfaction with sexual health education). The study sought to explore the impact of sexual health education on sexual self-concept; thus, this was the final set of variables entered. This model was also significant, *R* = .450,  = .238, *F*(99) = 4.02, *p* < .05. Although the receipt of sexual health education and sexual knowledge scores did not significantly contribute to the model, satisfaction with sexual health education did have a significant impact on sexual self-concept, β = .197, *t*(99) = 2.01, *p* = < .05. Thus, having reported satisfaction with sexual health education experience was significantly correlated with positive sexual self-concept.

## Impact of Sexual Self-Concept on Life Satisfaction

A second HRA was conducted to answer the second research question. Three sets of predictors were entered into the equation sequentially in a similar order to Research Question 1. In the first step of the HRA, the demographic covariates were entered. This set of predictors accounted for 16% of variance in life satisfaction, *R* = .40,  = .16, *F*(99) = 3.98, *p* < .01. After examining the standardized partial regression coefficients, relationship status was found to significantly contribute to life satisfaction scores after controlling for the other predictor variables in the model,  = .399, *t*(99) = 3.72, *p* = <.001. Gender, race, and age were not found to contribute significantly to the model. Thus, being in a relationship was associated with more satisfaction with life in the model.

Personal self-report variables were entered in the second step of the regression analysis, including both disability impact and perceived social support. This set of predictors accounted for a significant amount of variance beyond what was explained by relationship status, *R* = .661,  = .437, *F*(99) = 20.17, *p* > .001. Examination of the standardized partial regression coefficients indicated social support,  = .440, *t*(99) = 4.81, *p* = <.001, and disability impact,  = −.274, *t*(99) = −3.01, *p* < .01, significantly contributed to additional variance in satisfaction with life. Thus, higher perceived social support significantly contributed to life satisfaction, while the higher reported impact of disability negatively and significantly impacted life satisfaction.

Sexual self-concept was entered into the final step of the regression analysis. The addition of sexual self-concept (sexual self-efficacy, sexual esteem, and sexual anxiety) accounted for a significant amount of additional variance in life satisfaction, *R* = .697,  = .486, *F*(99) = 7.69, *p* < .01. Examination of the standardized partial regression coefficients indicated sexual self-concept did significantly contribute to the variance in life satisfaction,  = .247, *t*(99) = 2.77, *p* = < .01., above and beyond the control demographic and personal variables. Positive sexual self-concept overall significantly contributed to positive scores in life satisfaction.

In the final regression model (see Table 3), relationship status, perceived social support, disability impact, and sexual self-concept were significantly related to life satisfaction among this study’s sample. Disability impact was negatively related to life satisfaction, while the remaining variables were positively related. Thus, being in a relationship with someone, high scores in perceived social support, lower impact of disability, and higher reported sexual self-concept were all found to make unique contributions to the prediction of satisfaction with life.

**Table 3.** Summary of Hierarchical Regression Analysis for Predictors of Life Satisfaction (*N* = 99).

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  |  | At entry into the model |  |  | Final model |  |  |
| Variable |  |  | *B* | *SE B* |  | *B* | *SE B* |  |
| Age |  |  | −0.068 | 0.083 | −.085 | −0.038 | 0.079 | −.048 |
| Gendera |  |  | 3.13 | 1.70 | .186 | 2.77 | 1.66 | .165 |
| Racea |  |  | −0.807 | 2.30 | −.036 | −0.388 | 2.20 | −.017 |
| Relationship statusa |  |  | 6.52 | 1.73 | .399\*\*\* | 6.14 | 1.73 | .162\* |
| Step 2 | .437 | .277\*\*\* |  |  |  |  |  |  |
| Perceived social support |  |  | 0.215 | 0.045 | .440\*\*\* | 0.194 | 0.044 | .398\*\*\* |
| Disability impact |  |  | −0.347 | 0.115 | −.274\*\* | −0.297 | 0.112 | −.234\* |
| Step 3 | .486 | .049\*\* |  |  |  |  |  |  |
| Sexual self-concept |  |  | 0.100 | 0.036 | .247\*\* | 0.100 | 0.036 | .247\*\* |

aGender (1 = *male*), Race (1 = *Caucasian*), Relationship Status (1 = *in a relationship*); all other measures centered at their means.

\**p* < .05. \*\**p*< .01. \*\*\**p* < .001.

## Serial Mediating Relationship of Sexual Self-Concept on Life Satisfaction

Serial mediation explores the possibility of a causal chain between constructs (Hayes, 2017). Given the current study’s findings of statistically significant relationships among social support, sexual self-concept, and life satisfaction, it was hypothesized that the sexual self-concept variables used in the study (sexual anxiety and sexual esteem) have a mediating relationship between social support and life satisfaction. The relationship among these variables was found in Research Question 2; prior studies have found a causal relationship between anxiety and self-esteem in the general population (Hong et al., 2018) and among individuals with disabilities (Longworth et al., 2018). Therefore, a serial mediation analysis was conducted to answer the final research question. The analysis was performed using Model 6 of Andrew Hayes’ (2018) PROCESS. The model (as seen in Figure 1) shows social support as the independent variable, satisfaction with life as the dependent variable with sexual anxiety as the first mediator, and sexual esteem as the second mediator. Serial mediation in this model calculates the indirect effects through both mediators along with the indirect effects through each mediator on its own (Hayes, 2018). The indirect effects of the mediation model were tested using a macro for SPSS for conducting bootstrap tests of mediator models by Andrew Hayes (2018) (http://afhayes.com/spss-sas-and-mplus-macros-and-code.html) and reported as standardized beta coefficients.

Figure 1 illustrates the standardized regression coefficients for the mediation model. As the figure shows, the total effect (C = .47, *SE* = .02, *t* = 15.76, *p* < .001) of social support on satisfaction with life was at a significant level. In addition, the direct effects of social support on sexual anxiety (β = −.08, *SE* = .02, *t* = −1.99, *p* < .05) and sexual self-esteem (β = .34, *SE* = .01, *t* = 9.79, *p* < .001) were statistically significant. The direct effect of sexual anxiety as the first mediating variable on the second—sexual self-esteem (β = −.38, *SE* = .03, *t* = −10.98, *p* < .001)—is also significant. The direct effect of the mediating variables on satisfaction with life showed that the effects of sexual anxiety (β = −.26, *SE* = .04, *t* = −7.49, *p* < .001) and sexual self-esteem (β = .13, *SE* = .05, *t* = 3.38, *p* < .01) were significant. When social support and the mediating variables were simultaneously entered into the equation, the direct effect between social support and satisfaction with life remained significant (β = .47, *SE* = .02, *t* = 13.81, *p* < .001). The standardized indirect effect was (.54) (.47) = .25. The bootstrapped standardized indirect effect was .017, and the 95% confidence interval ranged from .042 to .106. Therefore, the indirect effect was statistically significant, supporting the sexual self-concept variables of sexual anxiety and sexual esteem as partial serial mediators for the relationship between social support and life satisfaction. The overall model was found to be significant (*F* = 3.96, *p* < .05) and explained 29% of the total variance in life satisfaction.

# Discussion and Implications

People with disabilities, including those with spina bifida and cerebral palsy, experience sexual growth and development equivalent to their peers without disabilities. As such, they desire and can benefit from information about sexual health; yet, they experience a dearth of opportunities for sexual health education and even access to relationship development (Nguyen et al., 2016). The results of this study indicate a need for more studies on sexual health knowledge, sexual self-concept, and sex education for people with disabilities. The study results also have implications for rehabilitation professionals working to serve this population and their families.

## Sexual Self-Concept

The importance of positive sexual self-concept has been cited as having an impact on sexual decision-making and development of a healthy sexual self through systematic review (Potki et al., 2017). People with disabilities express that refusal to discuss sexuality and the regulation of their sexual lives contributes to negative sexual self-concept (Medina-Rico et al., 2018; Wienholz et al., 2016). For people with cerebral palsy, the importance of being seen as sexual beings through the provision of sexual education is crucial to sexual self-concept (Dune & Mpofu, 2015); and those with spina bifida experience both healthier sexuality and self-esteem through sex education (Akre et al., 2015).

In the current study, relationship status (being in a relationship), the impact of one’s disability, and satisfaction with sexual health education experience together had a correlating relationship with the variance in sexual self-concept. There are three major implications of these findings. The first is the importance of access to social support for individuals with congenital neurological disabilities. Intimate relationships are central to the lives of people across culture and age (Donaghue, 2009). Regardless, people with disabilities are often denied access to these relationships or are discouraged due to parental and teacher anxiety and lack of training (Treacy et al., 2018), even while they express a strong preference for developing them (Manoj & Suja, 2017). Rehabilitation counselors can encourage their clients to seek out and develop relationships with others, particularly those that might become intimate, thus developing a more positive sexual self-concept.

The second implication is the impact of disability on sexual self-concept. Some studies have suggested that severe disability is correlated with lower sexual self-esteem (Salehi et al., 2015). Other studies have shown evidence for the impact of social support on sexual self-esteem (Potki et al., 2017) and as a protective factor against anxiety (Savage et al., 2014). The results of this study indicated the significant impact disability severity has on sexual self-concept. Recommendations have been made for parents and clinical providers not only to discuss sexual topics with young people with disabilities but to also help them understand how their disability impacts their sexuality (Treacy et al., 2018). Rehabilitation counselors can be among the providers that assist with this understanding.

People with disabilities access rehabilitation professionals to assist them to foster independence, increase employment, and for assistance with many aspects of their lives, sexuality being one. Rehabilitation professionals express some discomfort regarding the discussion of sexual topics with their clients with disabilities. However, this discomfort decreases with the increase in training and knowledge in sexuality-based topics for both rehabilitation graduate students (Juergens et al., 2009) and certified rehabilitation counselors (Kazukauskas & Lam, 2010). People with disabilities express a desire to have sexual health education both from their parents and their caregivers as well as in their schools (Nguyen et al., 2016); this could extend to rehabilitation counselors.

Finally, satisfaction with sexual health education was significantly correlated with positive sexual self-concept. There is little to be found in the research regarding what makes sexual health education satisfactory to the recipient, but qualitative research reviews have found that sex education is desired by individuals with disabilities, both intellectual (Medina-Rico et al., 2018) and physical (Wienholz et al., 2016), and this education should include support to express healthy sexuality (Brown & McCann, 2018). Future qualitative research could delve into the experience of sexual health education for individuals with disabilities as well as what constitutes satisfactory sex education. Furthermore, rehabilitation professionals would benefit from training to discuss sexual health with clients and understanding the benefit thereof.

## Life Satisfaction

In a 2014 systematic review, disparities in life satisfaction between individuals with and without disabilities were largely accounted for in social and educational access barriers not because of disability itself (Savage et al., 2014). In the current study, taken together, relationship status, disability impact, social support, and sexual self-concept had a significant impact on life satisfaction. Implications for rehabilitation professionals include assisting individuals with disabilities to address barriers to social support through social skills development and advocacy for integration into social activities. This can also include addressing disability-related barriers as well as those that preclude their clients from accessing sexual health information.

While the formalized task of sexual health education may not fall to the rehabilitation professional, counselors can advocate for sexual health education in schools and other institutions frequented by their clients. Research supports the need for sex education for adults with intellectual disabilities (Brown & McCann) as well as youth with disabilities in schools (Future of Sex Education Initiative, 2020). Literature review finds that resources exist to teach sexual health, but access to these resources is limited (Treacy et al., 2018). Rehabilitation professionals can increase their knowledge and comfort with the topic, answer client questions about sexuality, and direct them to resources so clients can increase their own knowledge. They can additionally, encourage caregivers to openly discuss sexual health and acknowledge the sexuality of the people with disabilities for whom they care.

The findings of this study also had some research implications such as a need for more comprehensively developed and analyzed measures of sexual health knowledge and sexual self-concept. Sexual self-esteem and satisfaction are little researched for people with disabilities and therefore lacking in an evidence base for interventions for practitioners (Lee & Fenge, 2016). Full-scale qualitative research would be useful in defining sexual self-concept, what predicts it, and exploring what variables would increase its impact on life satisfaction. To investigate the causal relationships between sexual health education variables and well-being outcomes, longitudinal research is recommended.

## Sexual Self-Esteem and Sexual Anxiety as Mediators

Social support was found to be related to life satisfaction through the mediating effects of sexual anxiety and self-esteem. The serial mediating effect of sexual anxiety and self-esteem between social support and life satisfaction can also be addressed in practice. A systematic review has found that in addition to social support’s impact on self-esteem and life satisfaction, sexual self-esteem can also be impacted by a reduction in sexual anxiety through the way parents and peers talk about sexuality to clients, their exposure to sexual messages in the media, access to positive mental health activities, positive body image, and a lack of sexual abuse in childhood (Potki et al., 2017). The serial mediation of sexual anxiety and self-esteem between social support and life satisfaction found in the current study indicates the need for rehabilitation counselors to address the way their clients view their own sexuality and messages from the media and increasing positive mental health and encouragement of social supports to broach sexual topics with them. Although the correlation between social support and sexual anxiety as well as between sexual esteem and life satisfaction were found to be relatively small in this study (see Figure 1), rehabilitation counselors can still work toward the goal of lowering sexual anxiety and increasing sexual self-esteem of their clients. As discrepancies in assessment of life satisfaction are found largely in denial of access to opportunities, not the disability itself, addressing sexual self-concept is an important measure that rehabilitation professionals can take with their clients to improve their outcomes.

Finally, although this study focused primarily on positive outcomes, such as higher sexual self-concept and life satisfaction, another implication of the study is the reduction of sexual assault perpetrated against people with disabilities. As people with disabilities experience sexual abuse at a reported rate of 2 to 4 times the general population (Lund & Vaughn-Jensen, 2012; McGilloway et al., 2018), and lack of education has been highlighted as one of the factors contributing to this problem (Smith & Harrell, 2013), as well as a predictor of sexual self-concept (Potki et al., 2017), rehabilitation professionals can encourage sexual health information imparted to individuals with disabilities to reduce sexual abuse.

# Limitations

Any conclusions drawn from the findings of this study should be considered along with its limitations. The limitations of the current study include the study design, population, instruments used, and the nature of the research topic. First, the study relied on an online survey design and therefore was limited to individuals who were able to access the internet. There are also generalizability concerns with the participants being predominantly white (83.7%), female (64%), and having received some form of higher education (72.2%). The participants predominantly accessed the survey through an existing support system (e.g., Spina Bifida Association), which may also impact generalizability. Second, the ex-post facto study design can be used to understand some associations between variables but cannot be used to show the impact or the effect of predictor variables on the outcome. Third, hierarchical regression and mediation analyze associations among many variables, thereby presenting replication difficulties and may not include the most meaningful variables in the equation (Derksen & Keselman, 1992).

The study participants ranged in age from 19 to 72, with a mean age of 35. This points again to the ex-post facto nature of the study and the likelihood of participants, who traditionally receive sexual health education in youth, remembering with clarity the content, nature of this education, and whether it was satisfactory. The relatively small number of participants is another limitation; a general a priori power analysis for a power of .80 with an alpha coefficient of .05 and a medium effect size (*f*2 = .15; Cohen, 1988) using eight predictor variables calls for a sample size of 108 (Erdfelder et al., 1996). Due to missing data, the current study sample size in the current study was 99.

The scales used in the study were self-report, contributing to the lack of scientific measurement of the constructs. Sexual self-concept and its covariates are not empirically proven to have universal defining characteristics. Furthermore, the MSSCQ is not well-validated (Scales Rostosky et al., 2008). Finally, the ASKQ was a newly created scale developed for this study to address shortcomings in existing measures and has not been validated, as a full-scale investigation was outside the scope of this study. Furthermore, the scale was found to have low reliability. Consequently, the results regarding sexual knowledge should be considered with caution, and further development, including factor and reliability analyses, should be conducted on the ASKQ should it be used in future studies.

In addition, due to the sensitive nature of sexuality as a topic, participants may have given answers based on a sense of social acceptability, leading to validity issues with the scales in question. Bias in sexuality research has been found as a flaw in design; specifically, those who voluntarily participate in sexuality research tend to have a more positive attitude toward sexual health (Strassburg & Lowe, 1995). Stigma in participating in research that involves sexual topics may have precluded diverse numbers from contributing to the study (Irvine, 2014).

# Conclusion

This study provided support for increased social support, mitigating the impact of disability and satisfactory sex education on positive sexual self-concept. The study also provided support for increased social support, mitigating disability impact, and positive sexual self-concept on life satisfaction for adults with cerebral palsy and spina bifida. This study is unique in its examination of the sexuality of specific populations of individuals with disabilities and can be duplicated with different groups, larger sample sizes, proximal research to the experience of sexual health education, and additional research questions.

Sexual health education is a needed piece of the overall education of individuals with disabilities, and the impact of this education has profound results on healthy sexual decision-making, understanding, and reporting sexual abuse and positive sexual self-concept. The current study and its results can be used by rehabilitation professionals in consideration of providing sexual health information or advocating that their clients receive it from other sources to impact both positive sexual self-concept and overall satisfaction with life. Future research requires the continuation of positive sexual health outcome studies to further understand the impact of sexual health education on sexual self-concept and life satisfaction of people with disabilities and understanding what makes a positive and satisfactory sexual health education experience for those who receive it.

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