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**THE MODERATING EFFECT OF POSITIVE SEXUAL SELF-CONCEPT ON THE
RELATIONSHIP BETWEEN DISABILITY IMPACT AND SATISFACTION WITH LIFE**

ALEXANDRA M. KRIOFSKE MAINELLA, BIANCA TOCCI¹

Abstract

Research has been produced assessing both the concept of Life Satisfaction and the impact of disability. However, there has been a lack of research assessing the intersection of disability, sexuality, and life satisfaction. This study sought to understand the relationship between improved sexual self-concept, life satisfaction, and disability impact. Sexual self-concept was examined as a moderator of the relationship between disability impact and life satisfaction. It was hypothesized that improved sexual self-concept among those living with a disability will have a positive and correlating effect on life satisfaction. Additionally, it was hypothesized that the relationship between disability impact and satisfaction with life would be stronger among those who had higher sexual self-concept ratings. The study consisted of 104 adults with cerebral palsy, spina bifida, and other neurodevelopmental disabilities. Individuals completed the World Health Organization Disability Assessment Schedule (WHODAS), four subscales of the Multidimensional Sexual Self Concept Questionnaire (MSSCQ), and the Satisfaction with Life Scale (SWLS) to assess disability impact, sexual self-concept, and satisfaction with life respectively. Results indicated that higher levels of sexual self-concept were associated with higher life satisfaction rates. Furthermore, the relationship between disability impact and satisfaction with life was stronger among those who had higher sexual self-concept scores. Lastly, via moderation analysis, results indicated the relationship between disability impact and life satisfaction was moderated by sexual self-concept. Thus, there appears a need to cultivate positive sexual self-concept in individuals living with disabilities in an effort to contribute to life satisfaction.

Keywords: sexual self-concept, disability impact, life satisfaction

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Individuals with disabilities live, work, love, and exist in society alongside their nondisabled peers. Physical and attitudinal barriers can limit the access individuals with disabilities have to relationships, careers, and other aspects of society. Disability is referred to as the only minority group that anyone could join at any time, with a reported 26% of adults in the United States having a disability.² It can impact one's physical or mental state and is defined by the Americans with Disabilities Act as impairment that "limits one or more life activities" in a substantial way.³ These life activities include relationships, and the romantic and sexual relationships of people with disabilities are impacted by beneficial life experiences such as strong social support and positive relationships. Self-concept, including sexual self-concept, can also play a role in these beneficial life experiences. Because of the variety of areas of life that disability touches, individuals with disability may find support and services across interdisciplinary fields. Those working in service for people with disabilities (i.e., counselors, therapists, and doctors), those working in education (teachers and social workers), and those working on policy will all encounter individuals with disabilities in their work and may be part of interdisciplinary team. This study considers the impact of disability and sexual self-concept and the interaction of these variables on the life satisfaction of individuals with the disabilities of spina bifida and cerebral palsy. It will also touch on the implications such findings have for the myriad of people who may be providing services to these individuals.

Disability, Sexuality, and Life Satisfaction

In the United States, the Center for Disease Control (CDC) estimates that one in four people have a disability of some kind.⁴ The present study focuses on individuals with cerebral palsy and spina bifida, two different diagnoses with some commonalities. Both impact the limbs, are chronic conditions, have a range of severity, and impact health-related quality of life.⁵ Cerebral palsy is the most common motor-function disability in the US impacting an individual's balance, movement, and posture.⁶ It is diagnosed in childhood; however, it impacts an individual throughout the course of their life.⁷ Spina bifida is a

² Centers for Disease Control and Prevention. Disability and Health Data System (DHDS), last modified May 3, 2018, <http://dhds.cdc.gov>.

³ "What is the Definition of a Disability under the ADA?" Americans with Disabilities Act National Network (website), last modified May 2023, <https://adata.org/faq/what-definition-disability-under-ada>.

⁴ CDC, "Disability and Health Data System."

⁵ Sezen Tezcan and Tulay Tarsuslu Simsek, "Comparison of Health-Related Quality of Life between Children with Cerebral Palsy and Spina Bifida," *Research in Developmental Disabilities* 34, no. 9 (2013). 2726.

⁶ CDC, "Data and Statistics for Cerebral Palsy," last modified May 2, 2022, <https://www.cdc.gov/ncbddd/cp/data.html>.

⁷ CDC, "What is Cerebral Palsy?" last modified May 2, 2022, <https://www.cdc.gov/ncbddd/cp/facts.html>.

congenital disability, commonly diagnosed in childhood, that impacts the spinal cord and physical functioning.⁸ More than 75% of people diagnosed with this condition in childhood live to adulthood.⁹

Individuals with disabilities such as spina bifida and cerebral palsy experience a spectrum of impact, ranging from mild to severe. The World Health Organization has created a model to conceptualize this impact called the International Classification of Functioning Disability and Health (ICF).¹⁰ This model looks at an individual's diagnosis or condition and the way it interacts with body function and structure, the level of accessible activities of participation, and finally contextual factors—both environmental and personal.¹¹ To put the ICF model into practice, let us consider an individual with cerebral palsy. Perhaps the individual has pain, muscle tone issues, and spasticity of muscle that impacts their energy throughout the course of the day. If the individual uses a walker to ambulate, their activity may be limited to places that can be accessed physically with a mobility device. Their participation may further be impacted if their muscle tone influences speech, as others may find their speech hard to understand. In terms of personal and environmental factors, perhaps this individual has the characteristics of being positive and highly motivated, which will mitigate some of the access issues. Environmental factors such as being of a low socioeconomic status may lead to difficulty making the individual's home accessible. Another contextual factor may be that they have high levels of social support, which may buoy feelings of belonging and happiness.

Though there are high numbers of children diagnosed with such disabilities as cerebral palsy and spina bifida, there is little research on their sexual health. Further, young people in this population and their parents express a desire for information and education on sexuality and disability.¹² As noted, the impact of disability as conceptualized through the ICF model is seen in two components of life: function and context. Function is impacted by the disability itself, and the limits that an individual experiences because of their disability, and context refers to the various factors in an individual's life

⁸ CDC, "Data and Statistics on Spina Bifida," last modified September 3, 2020, <https://www.cdc.gov/ncbddd/spinabifida/data.html>.

⁹ Robin Bowman et al., "Spina Bifida Outcome: A 25-Year Prospective," *Pediatric Neurosurgery* 34, no. 3 (March 2001): 114–120.

¹⁰ "International Classification of Functioning, Disability, and Health," World Health Organization (website), accessed November 1, 2022, <https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health>.

¹¹ Bowman et al., "Spina Bifida Outcome."

¹² Elizabeth K. Schmidt, Christopher Brown, and Amy Darragh, "Scoping Review of Sexual Health Education Interventions for Adolescents and Young Adults with Intellectual or Developmental Disabilities," *Sexuality and Disability* 38, (2020): 440.

outside their disability.¹³ While people with conditions such as spina bifida and cerebral palsy tend to have a desire for social relationships—including those that are sexual in nature—that parallels their peers without disabilities,¹⁴ the limitations set by both their function and context may limit their ability to access these relationships.

The dearth of research on sexual health as it relates to individuals with disabilities is one of these contextual limiting factors. Until the late twentieth century there was very little research conducted on this topic.¹⁵ One reason for this lack of research may be found in the myths surrounding people with disabilities and sexuality. Individuals with disabilities are often seen as asexual, as unable to consent to sexual and romantic activity and advances, and as having more important concerns in their lives than sexual and romantic relationships. A qualitative exploratory study has found that, in addition to these myths around disability and sexuality, there is a pervasive fear regarding simply broaching the topic of sexual health to individuals with disabilities.¹⁶

In terms of functional factors, the diagnoses of spina bifida and cerebral palsy indicate a high instance of mobility issues, which may impact not only physical access to sexual activity but also access to social and dating environments that tend to produce sexual experiences for nondisabled individuals. Functional limitations specific to sexuality and spina bifida include earlier onset of puberty and a potential for secondary sexual issues such as prostate concerns and higher instances of urinary tract infections.¹⁷ Further, people with spina bifida are at a high risk for latex allergies, the material used most often in the production of condoms.¹⁸

People with cerebral palsy have issues with muscle spasticity and rigidity, both of which are functional limitations that may impact sexual positioning. The use of wheelchairs or other mobility aids might also present a barrier to sexual experiences.¹⁹ Puberty is also impacted by cerebral palsy: individuals tend to experience puberty at a longer duration, starting earlier and ending later than their

¹³ Bowman et al., “Spina Bifida Outcome.”

¹⁴ M. M. Cheng, and J. R. Udry. Sexual Behaviors of Physically Disabled Adolescents in the United States.” *Journal of Adolescent Health* 31 (2002): 48–58.

¹⁵ Lisa Berkman and Leonard Syme. “Social Networks, Host Resistance, and Mortality: A Nine-Year Follow-Up Study of Alameda County Residents.” *American Journal of Epidemiology* 109, no.2 (February 1979): 186–204.

¹⁶ B. Fader Wilkenfeld and Michelle Ballan, “Educators’ Attitudes and Beliefs toward the Sexuality of Individuals with Developmental Disabilities,” *Sexuality and Disability* 29 (2011), 351–61.

¹⁷ Bowman et al., “Spina Bifida Outcome.”

¹⁸ “Natural Rubber Latex Allergy: People with Spina Bifida are at High Risk for Latex Allergy,” Spina Bifida Association (website), <https://www.spinabifidaassociation.org/wp-content/uploads/NaturalRubberLatexAllergy.pdf>.

¹⁹ Tinashe Dune, “Re/Developing Models for Understanding Sexuality with Disability within Rehabilitation Counselling.” *Electronic Journal of Human Sexuality* 16 (2013).

peers.²⁰ In their 2006 literature review on adolescents with cerebral palsy, extending over thirteen years of research, Diana Wiegerink's research team found that individuals with this diagnosis cared about sexual health. These participants expressed a reduced ability for sexual expression despite a need for increased communication. This juxtaposition was often because of lower sexual self-esteem and self-efficacy due to both the limitations on function and the attitudes of others toward their sexuality.²¹ These are issues of self-concept, a variable that has buffering qualities on the impact of disability overall and can be seen as one of the contextual factors that are considered in the WHO's model of disability impact. The ICF model has been used to assess the impact of disability but also to improve outcomes for individuals with disabilities. Many programs in rehabilitation, medicine, and health services have expanded their definitions of health and function and have moved beyond the basic medical and physical treatment of disability to care for overall wellness.²² One such measure of overall wellness is life satisfaction.

Life Satisfaction and Sexual Self-Concept

Increased access to services and better understanding of disability has improved the overall quality of service for people with disabilities across the fields of medicine, psychology, education, rehabilitation, and the like; these improvements can impact the outcomes and life satisfaction of individuals with disabilities. Indeed, these various interdisciplinary services to individuals with disabilities have had the aim and the outcome of improved life satisfaction.²³

Satisfaction with life is a construct often considered within the literature on adjustment and adaptation to disability.²⁴ Life satisfaction is part of the global construct of happiness studied by Ed Diener and measured by the Satisfaction with Life Scale (SWLS);²⁵ in the SWLS, life satisfaction has three components. First, the measurement of life satisfaction is subjective—contextual factors of life such as socioeconomic status or even disability status are missing from the construct itself. Second, life

²⁰ Nancy Murphy and Ellen Roy Elias, "Sexuality in Children and Adolescents with Disabilities." *American Academy of Pediatrics* 118, no. 1 (July 2006): 398–403.

²¹ Diana Wiegerink, et al., "Social and Sexual Relationships of Adolescents and Young Adults with Cerebral Palsy: A Review." *Clinical Rehabilitation* 20 (2006): 1024.

²² Janette McDougall, et al., "Employing the International Classification of Functioning, Disability, and Health to Enhance Services for Children and Youth with Chronic Physical Health Conditions and Disabilities," *Paediatrics and Child Health* 13, no. 3 (2008): 177.

²³ Gillian King, et al., "Bringing the Life Needs Model to Life: Implementing a Service Delivery Model for Pediatric Rehabilitation." *Physical and Occupational Therapy in Pediatrics* 26, no. 1 (2006): 52.

²⁴ Fong Chan, Elizabeth Da Silva Cardoso, and Julie Chronister, *Understanding Psychosocial Adjustment to Chronic Illness and Disability: A Handbook for Evidence-Based Practitioners* (New York: Springer, 2009), 228–230.

²⁵ Ed Diener, et al., "Satisfaction with Life Scale," *Journal of Personality Assessment* 49 (1985): 71–75.

satisfaction is considered a positive measure, which is very much in line with Beatrice Wright's work on individuals with disability and their ability to forge a positive and satisfactory life.²⁶ Wright was a pioneer in working with individuals with disabilities on fostering positive self-esteem through a positive, strength-based approach. Third, the measurement of life satisfaction is assessed globally as an overall measure; in the current study, as it is most often, expressed with a numeric score.

Much work with individuals with disabilities is done with the aim of increasing positive psychosocial factors such as self-efficacy and self-esteem, factors which, when improved, also increase their life satisfaction.²⁷ Disability can, however, impact life satisfaction. In a study measuring disability impact and access to services for children with disabilities, higher disability impact and lower access was correlated with lower scores in life satisfaction.²⁸ It is important to note that while life satisfaction may be impacted by disability, access to services and other positive life experiences can have a buffering effect.

In terms of life satisfaction and sexuality for people with disabilities, one study found that those who had been given access to both sexual experiences and information reported higher life satisfaction which correlated with better sexual self-concept and the aforementioned access opportunities.²⁹ Social support, including access to romantic and sexual relationships, is desired by individuals with disabilities and correlates with a higher SWLS score.³⁰ Positive self-concept and life satisfaction are linked, and have been considered as a valid measure in people with and without disabilities, independent of any disability impact.³¹

Self-concept, when positive, is part of life satisfaction. Sexual self-concept is a component of self-concept developed by all individuals (regardless of ability) during adolescence and is defined as one's understanding of themselves as a sexual person.³² Self-concept in general is part of identity formation and is developed through interactions with others, the narratives we hear, and exposure to

²⁶ Beatrice Wright, *Physical Disability: A Psychosocial Approach* (New York: Harper and Row, 1983).

²⁷ Malachy Bishop and Sonja Feist-Price, "Quality of Life in Rehabilitation Counseling: Making the Philosophical Practical," *Rehabilitation Education* 15, no. 3 (2001): 202.

²⁸ Janette McDougall, et al., "Applying the ICF Framework to Study Changes in Quality-of-Life for Youth with Chronic Conditions," *Developmental Neurorehabilitation* 14, no. 1 (2011): 41.

²⁹ Bishop and Feist-Price, "Quality of Life in Rehabilitation Counseling."

³⁰ Hannah Tough, Johannes Siegrist, and Christine Fekete, "Social Relationships, Mental Health, and Wellbeing in Physical Disability: A Systematic Review." *BMC Public Health* 17, no. 1 (May 2017): 420.

³¹ Ed Diener, "Subjective Well-Being," *Psychological Bulletin* 95, no. 3 (1984): 547.

³² Bishop and Feist-Price, "Quality of Life in Rehabilitation Counseling."

ideals such as those found in the media and the world around us.³³ People with disabilities may find that ideas presented in the world around them, the media they consume, and the interactions they have with others do not take into account the experience of disability. This exclusionary construction of self without representation of disability can have a negative impact on both self-concept in general as well as sexual self-concept.³⁴ Sexual self-concept has been conceptualized and measured in multiple ways; for the purposes of this study, it is being used as the moderating variable and is composed of four parts: sexual self-esteem, sexual self-efficacy, sexual optimism, and sexual anxiety.

Self-esteem is generally defined as a positive view of oneself and one's worth.³⁵ Positive self-esteem is linked, in research, with psychosocial adaptation to disability and adaptive coping with disability's impact.³⁶ As Beatrice Wright was one of the first to take a positive, strength-based approach to working with individuals with disabilities, she understood that focusing on the assets of individuals with disabilities, rather than the deficiencies caused by the impact of disability, could actually reduce the impact of the disability itself. In her work, Wright found no differences in the global personalities of people with and without disabilities;³⁷ however, studies have connected the impact of disability stigma, health concerns, and learning challenges with self-esteem.³⁸ Self-esteem, in terms of sexuality, is a variable of sexual self-concept, characterized by one's positive view of self within the context of healthy sexuality.³⁹

Self-efficacy is the belief about one's ability to perform and succeed in life. Self-efficacy motivates an individual's behavior as well as their self-assessment of their own behaviors. Those with a strong sense of self-efficacy are able to recover from their failures and set reasonable goals for themselves.⁴⁰ Because those with disabilities are often required to adjust and adapt to the inaccessibility of their environments while also dealing with the functional limitations imposed upon them by the

³³ Laura Vandenbosch and Steven Eggermont, "The Interrelated Roles of Mass Media and Social Media in Adolescents' Development of an Objectified Self-Concept: A Longitudinal Study," *Communication Research* 43, no. 8 (December 2016): 1119.

³⁴ "Natural Rubber Latex Allergy: People with Spina Bifida are at High Risk for Latex Allergy," Spina Bifida Association (website), <https://www.spinabifidaassociation.org/wp-content/uploads/NaturalRubberLatexAllergy.pdf>.

³⁵ Albert Bandura, *Social Foundations of Thought and Action: A Social Cognitive Theory* (Englewood Cliffs, NJ: Prentice Hall, 1986).

³⁶ Chan, Cardoso, and Chronister, *Understanding Psychosocial Adjustment*, 111–112.

³⁷ Wright, *Physical Disability*.

³⁸ Mark Ferro and Michael Boyle, "Self-Concept among Youth with a Chronic Illness: A Meta-Analytic Review," *Health Psychology* 32, no. 8 (2013): 846.

³⁹ Sharon Rostosky, et al., "Sexual Self-Concept and Sexual Self-Efficacy in Adolescents: A Possible Clue to Promoting Sexual Health?," *Journal of Sexual Research and Policy* 45, no. 3 (July–September 2008): 284.

⁴⁰ Albert Bandura, *Self-Efficacy* (New York: Academic Press, 1984).

disability itself, self-efficacy becomes especially important. For people with disabilities, including those with spina bifida and cerebral palsy, self-efficacy has been correlated with both life satisfaction and adjustment to disability.⁴¹ Simply defined as the belief in one's ability to meet their own sexual needs, sexual self-efficacy is also correlated with lower risk in sexual behavior and reports of higher sexual satisfaction.⁴²

Optimism as a construct is a subset of a larger higher order positivity construct (along with hope and resilience) called psychological capital. Psychological capital is associated with good physical health and higher self-reported life satisfaction.⁴³ For people with disabilities, an optimistic approach to life is linked with more life satisfaction, strong relationships, and more success in the completion of personal goals.⁴⁴ Sexual optimism can be seen as one's belief in the eventual reward in their sexual future.

While the other three subconstructs of self-concept are positive, sexual anxiety is negative. Anxiety, in general, is considered a typical reaction to life's stressful feelings and events. Anxiety alone can be beneficial in coping with dangerous situations and associated with increased satisfaction with one's performance.⁴⁵ People with disabilities commonly experience anxiety as a natural part of psychosocial adaptation to their disability and its impact.⁴⁶ Meta-analysis has shown that anxiety outside the scope of typically occurring and performance-beneficial anxiety, though, is linked to lower subjective well-being measures, negatively impacting emotional health and social function in people with a variety of disabilities.⁴⁷ Sexual anxiety is defined as fear or worry regarding sexuality, impacting sexual function and desire. Like general anxiety, sexual anxiety can be experienced seldomly or persistently, on a scale from normal anxiety to dysfunction.⁴⁸

⁴¹ Chan, Cardoso, and Chronister, *Understanding Psychosocial Adjustment*, 268.

⁴² Rostovsky, et al., "Sexual Self-Concept and Sexual Self-Efficacy in Adolescents," 282.

⁴³ Michael Scheier and Charles Carver, "Optimism, Coping, and Health: Assessment and Implications of Generalized Outcome Expectancies," *Health Psychology* 4, no. 3 (1985): 245–247.

⁴⁴ Chan, Cardoso, & Chronister, *Understanding Psychosocial Adjustment*, 256.

⁴⁵ Elliot Cohen, *The Dutiful Worrier: How to Stop Compulsive Worry without Feeling Guilty* (Oakland, CA: New Harbinger Publications, 2011), 50–53.

⁴⁶ Hanoch Livneh and Lisa Wilson, "Coping Strategies as Predictors and Mediators of Disability-Related Variables and Psychosocial Adaptation: An Exploratory Investigation," *Rehabilitation Counseling Bulletin* 46, no. 4 (July 2003): 194–208.

⁴⁷ Christophe Maiano, et al., "Prevalence of Anxiety and Depressive Disorders among Youth with Intellectual Disabilities: A Systematic Review and Meta-Analysis," *Journal of Affective Disorders* 236 (August 2018): 230–242.

⁴⁸ Oluwatosin Adekeye, Taiwo Lateef Scheikh, and Olufunke Tmitope Adekeye. "The Assessment and Management of Sexual Anxiety among Selected University Undergraduates," *Gender and Behavior* 10, no. 1 (June 2012): 4523–32.

Current Study

People with disabilities, their families, caregivers, social networks, and service providers often search for ways to increase life satisfaction, mitigate the disability impact, and provide opportunities for social connections. Research suggests that social connections can improve life satisfaction; romantic and sexual relationships can improve one's self-concept, sexual self-concept, and satisfaction with life. A moderator variable, in social psychology research, is an interaction variable that changes the relationship between two other variables.⁴⁹ In the current study, the research team hypothesized that improved sexual self-concept would have a positive and correlating effect on life satisfaction, and that the relationship between disability impact and satisfaction with life would be stronger among those who had higher sexual self-concept scores. Examining sexual self-concept as a moderator of the relationship between disability impact and life satisfaction allows for further exploration of this area and has implications for an interdisciplinary array of service providers as well as people with disabilities themselves and their support networks.

Method

Participants

In total, 104 adults with cerebral palsy, spina bifida, and other neurodevelopmental disabilities participated in the study. The participants described themselves as White (83.7%), Latinx or Hispanic (3.8%), African American (2.9%), Asian American (2.9%), and Other (3.9%). The majority of the participants identified as female (64%), with 36.5% identifying as male and 2% identifying as nonbinary. About half of the participants were in a relationship (49%) and 51% were single. Participants' ages ranged from 19–72, with a mean age of 35.

Procedures

Following approval from the Institutional Review Board (IRB), participants were recruited across the US from national advocacy organizations, through online support groups for people with cerebral palsy and spina bifida, and through snowball sampling. Participants were recruited over a six-month period and were eligible if they were (a) 18 years of age and older, (b) spoke English as a first language, and (c) diagnosed with cerebral palsy, spina bifida, or other neurodevelopmental disabilities impacting physical function. Exclusion criteria included those who indicated they did not have a disability falling into the prior two categories, non-English speakers, and those who had an appointed guardianship and

⁴⁹ Petar Milin and Olga Hadzic, "Moderating and Mediating Variables in Psychological Research," in *International Encyclopedia of Statistical Science*, ed. Miodrag Lovric (Berlin: Springer, 2011), 849.

were unable to give informed consent. The eligibility criteria questions were provided online; if participants were eligible, they were directed to a series of questions including informed consent, a demographics questionnaire, and the study's measures.

Measures

Demographics. A demographics questionnaire was given to each participant to gain information on age, racial/ethnic identity, gender, relationship status, education level, disability, and living situation (including living independently or with support).

Disability Impact. Disability impact was measured using the World Health Organization Disability Assessment Schedule (WHODAS),⁵⁰ a twelve-item measure of disability impact. The participants rated their ability regarding the specified activities over a period of 30 days with a five-point scale ranging from 1 (no difficulty) to 5 (extreme difficulty). Overall, the WHODAS is found to have good psychometric properties with a high reliability. The Cronbach's alpha is (0.98) and the scale has face validity; research on the WHODAS and its ability to measure disability impact found that it was an accurate measurement as defined by the ICF model. The Cronbach's alpha found for total scores for the sample in the present study was (0.78).

Sexual Self-Concept. Four subscales of the Multidimensional Sexual Self-Concept Questionnaire (MSSCQ)⁵¹ were used to assess sexual self-concept. The full MSSCQ is a 100-item measure in which respondents answer on a five-point scale ranging from 1 (not at all characteristic of me) to 5 (very characteristic of me). To reduce the time spent on the survey, the full measure was not used; further, the data of interest was limited to the four subscales used. Overall Cronbach's alpha coefficients could not be found, but the subscales are more than adequate, ranging from (0.72–.94).⁵² The four subscales used together to measure sexual self-concept in the current study are sexual anxiety, optimism, self-efficacy, and self-esteem. Sexual anxiety questions are about discomfort or tension with sexual aspects of life. Sexual self-efficacy questions are about belief in one's ability to deal with sexual needs, desires, and problems. The questions regarding sexual optimism explore future positive expectations in one's sexual life, and those questions regarding sexual self-esteem are about the participants' pride and

⁵⁰ T. B. Üstün. et al., "Measuring Health and Disability: Manual for WHO Disability Assessment Schedule, WHODAS 2.0," (Geneva, Switzerland: World Health Organization Press, 2010).

⁵¹ William Snell, "Measuring Multiple Aspects of the Sexual Self-Concept: The Multidimensional Sexual Self-Concept Questionnaire," in *Handbook of Sexuality-Related Measures*, 3rd ed., eds. Terri Fischer, Clive Davis, and William Yarber (New York: Routledge, 2011), 545.

⁵² Robin Milhausen, et al., eds., *The Handbook of Sexuality Related Measures*, 4th ed. (New York: Routledge, 2020), 550.

positive feelings about their ability to handle their own sexual desires and experiences. The four subscales used together in the present study totaled a twenty-item measure of sexual self-concept and, as a full-scale, score had a Cronbach's alpha of (0.71).

Satisfaction with Life. Satisfaction with life was measured using the Satisfaction with Life Scale (SWLS).⁵³ The SWLS is a five-item measure designed to gauge the construct of life satisfaction through participant self-report. The five questions are answered on a seven-point scale from 1 (strongly disagree) to 7 (strongly agree). The SWLS has been evaluated for reliability and validity and is found to have good internal consistency with a Cronbach's alpha of (0.88) Construct validity for the SWLS was found through the correlations with other global measurements of happiness and life satisfaction. The measured construct of satisfaction with life and overall happiness had a good convergent and discriminant validity for this scale.⁵⁴ The SWLS was used in the current study to measure participants' satisfaction with life as the outcome measure, and the Cronbach's alpha coefficient for the sample in the present study was (0.91).

Data Analysis

Analyses were conducted using SPSS v.24. Pearson correlations were first calculated to examine the relationship between disability impact and satisfaction with life. Then PROCESS was used to test the moderated effect of sexual self-concept on the relationship between disability impact and satisfaction with life. PROCESS is an SPSS program package that uses regression analysis to estimate moderation.⁵⁵ Prior to moderation calculations, the correlation between the outcome variable (Life Satisfaction) and covariates (i.e., gender, racial identity, relationship status) was examined. This included accounting for the differences between participants with cerebral palsy and those with spina bifida. No significant differences between covariates were found.

Results

The first hypothesis, that higher levels of sexual self-concept would be associated with higher life satisfaction, was supported. In this analysis, sexual self-concept was the independent variable and life satisfaction the dependent. The analysis showed both the overall model $F(1, 104) = 106.9, p < .001$,

⁵³ Diener, et al., "Satisfaction with Life Scale."

⁵⁴ Üstün. et al., "Measuring Health and Disability."

⁵⁵ Andrew Hayes, *Introduction to Mediation, Moderation, and Conditional Process Analysis: A Regression-Based Approach*, 3rd ed. (New York: Guilford Press, 2022).

$R^2 = (.35)$, and the interaction between sexual self-concept and satisfaction with life $B = .47$, $p < .001$, 95% confidence interval = [.3083, .6399], $t = 5.61$, $p < .001$ were significant.

The second hypothesis, that the relationship between disability impact and satisfaction with life would be stronger among those who had higher sexual self-concept scores, was also supported. In this analysis, disability impact was the independent variable, satisfaction with life was the dependent variable, and sexual self-concept the moderating variable. The analysis showed the interaction between disability impact and sexual self-concept was significant. The conditional effect of disability impact on satisfaction with life showed a significant relationship among people who had higher levels of sexual self-concept at the 25th, 50th, and 75th percentiles (see figure 1).

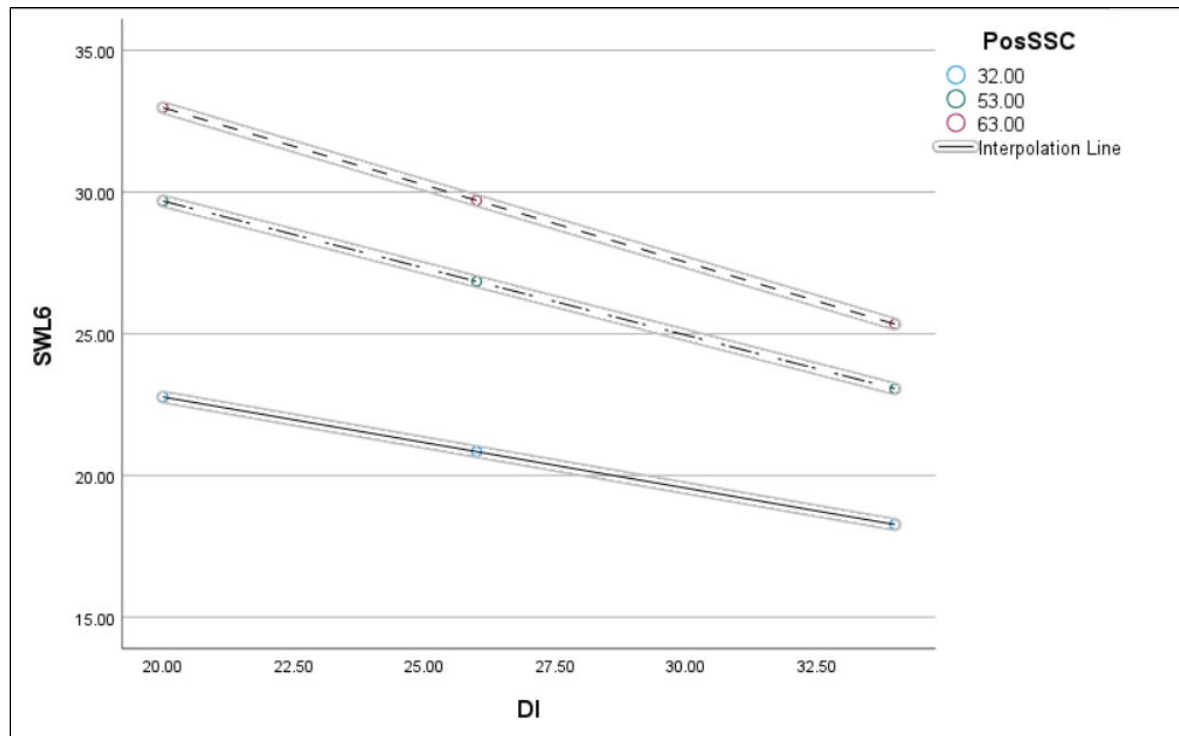


Fig. 1: Graph illustrating the interaction between disability impact (DI) and life satisfaction (SWL6) at the 25th, 50th, and 75th percentile of scores on the Positive Sexual Self Concept (PosSSC) survey.

Finally, a moderation analysis was explored for each level of sexual self-concept on the relationship between disability impact and life satisfaction. Disability impact was the independent variable, life satisfaction was the dependent variable, and sexual self-concept was the moderating variable in the model. In the sexual self-concept model, the relationship between disability impact and life satisfaction was moderated by sexual self-concept. Both the overall model and the interaction term were significant

(see figure 2). The conditional effect of disability impact on life satisfaction showed a significant relationship between the two variables.

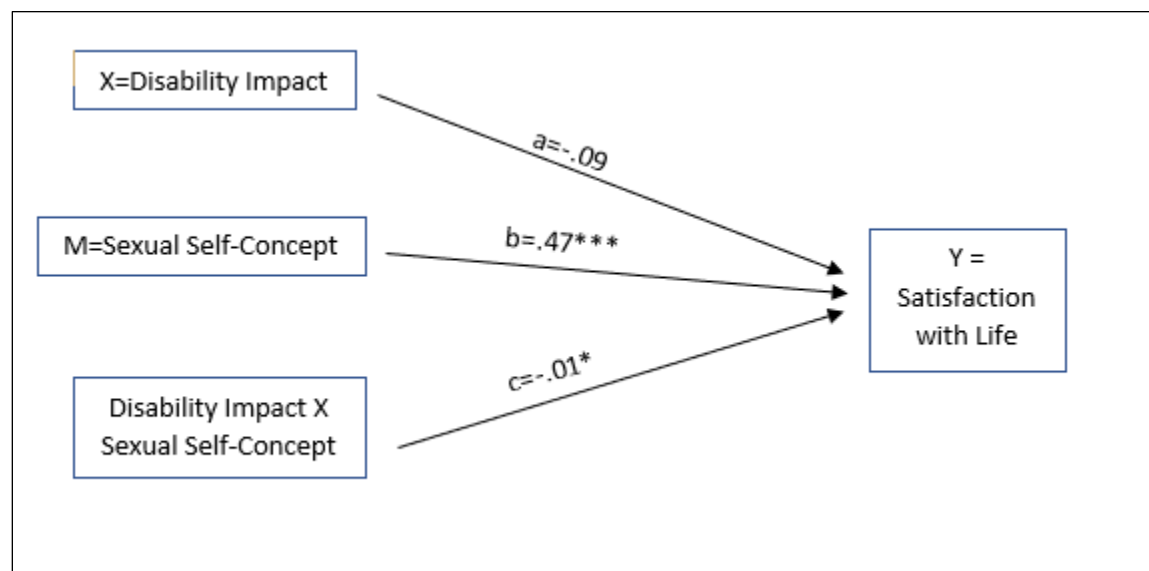


Fig. 2: Moderation path analysis including the impact of the predictor variable (disability impact), the moderator variable (sexual self-concept), and the interaction variable on the outcome variable (satisfaction with life). Lines a and b are the correlation coefficients, and line c is the interaction term.

Discussion

The current study examined the relationships among the impact of disability, sexual self-concept, and life satisfaction in individuals with cerebral palsy and spina bifida. Sexual self-concept as a moderating variable was explored. Research has shown that the impact of disability negatively correlates with life satisfaction and sexual self-concept.⁵⁶ An important caveat is that people with disabilities are not necessarily less satisfied with their lives (adaptation to disability is more predictive of life satisfaction than disability itself),⁵⁷ and increased social support including the presence of a partner is significantly correlated with life satisfaction.⁵⁸

Since positive sexual self-concept has been correlated with more life satisfaction,⁵⁹ the question of how to improve sexual self-concept becomes an important one. Studies show that positive sexual

⁵⁶ Victor Moin, Ilana Duvdevany, and Daniela Mazor, "Sexual Identity, Body Image and Life Satisfaction among Women with and without Physical Disability," *Sexuality and Disability* 27, no. 2 (2009): 83–95.

⁵⁷ Dylan Smith, et al., "Happily Hopeless: Adaptation to a Permanent, but Not to a Temporary Disability," *Health Psychology* 28, no. 6 (2009): 787.

⁵⁸ Rohabeth Potki, et al., "Bio-Psycho-Social Factors Affecting Sexual Self-Concept: A Systematic Review," *Electronic Physician* 9, no. 9 (September 2017): 5175–76.

⁵⁹ Ngaire Donaghue, "Body Satisfaction, Sexual Self-Schemas and Subjective Well-Being in Women," *Body Image* 6, no. 1 (January 2009): 37–42.

self-concept is correlated with the biological factors of age and disability, but that psychosocial factors that correlate, such as relationship status and body image, may potentially be influenced through interventions such as social and peer support.⁶⁰

Findings from this study along with the strengths-based perspective taken by those who provide service to, those who care about, and those who are themselves, individuals with disabilities,⁶¹ suggest the need for acknowledging sexual selves in individuals with disabilities, providing education, and improving psychosocial variables that may contribute to life satisfaction.

Clinical Implications

In the present study, satisfaction with life was found to increase among individuals with disabilities when there was also an increase in sexual self-concept. While a direct link to sexual self-concept from a correlating variable may not be found in the data, counselors and other professionals working with individuals with disabilities could still broach topics of sexual health in hopes of positively impacting sexual self-concept. These findings also emphasize the importance of working with individuals with disabilities on their social, romantic, and sexual lives to help improve sexual self-esteem, optimism, and efficacy and to reduce anxiety in this area. The development of sexual self-concept is a typical task of the adolescent period of life,⁶² yet one often denied to individuals with disabilities. Research has found that positive sexual self-concept can be fostered through talking about sex positively,⁶³ and having opportunities for sexual, romantic, and other relationships.⁶⁴

In working with individuals with disabilities, doctors, nurses, physical therapists, and others in the medical field can recognize that sexuality is an important part of the lives of people with disabilities that intersects with their needs for services regarding their physical and bodily health. Despite sexual health being a naturally occurring topic in the fields of medicine and physical health, providers express a lack of confidence on how to tailor these topics for disability, and a lack of comfort in broaching sexual topics and answering sexual questions.⁶⁵ People with disabilities, like their peers without

⁶⁰ Dylan Smith, et al., "Happily Hopeless."

⁶¹ Wright, *Physical Disability*.

⁶² Rostosky, et al., "Sexual Self-Concept and Sexual Self-Efficacy in Adolescents," 278.

⁶³ Snell, "Measuring Multiple Aspects of the Sexual Self-Concept."

⁶⁴ Emily Impett and Deborah Tolman, "Late Adolescent Girls' Sexual Experiences and Sexual Satisfaction." *Journal of Adolescent Research* 21, no. 6 (2006): 628–646.

⁶⁵ Margaret McGrath, et al., "Addressing Sexuality among People Living with Chronic Disease and Disability: A Systematic Mixed Methods Review of Knowledge, Attitudes, and Practices of Health Care Professionals," *Archives of Physical Medicine and Rehabilitation* 102, no. 5 (2021): 999.

disabilities, go to the doctor and often want to discuss sexual health, suggesting that their physical health providers do not broach these topics with them.⁶⁶ Health care professionals agree that they routinely omit sexual health from their assessment of patients with disabilities.⁶⁷

Given that the results of this study showed significant increases in life satisfaction for those impacted by disability when sexual self-concept was increased, medical health professionals can better assist people with disabilities to improve their sexual self-concept by acknowledging the sexuality of their patients through the inclusion of these topics in practice. As one reason for hesitancy to broach sexuality among providers was lack of comfort, providers can strive to increase their comfort in learning about the impact of sexual health on disability and vice versa. The expertise that providers already possess in the medical realm can only be improved by the additional knowledge of clinical skills and information regarding sexual health and disability. It has been recommended that service providers can improve competence by paying attention to how disability factors among other psychosocial factors can affect sexual health and the conversation therein.⁶⁸

In their work with individuals with disabilities, teachers, counselors, therapists, and others in the mental, intellectual, and emotional health field can broach the topic of sexual health as well as empower clients to seek out social opportunities and see themselves as sexual beings. Sexual health is an infrequently broached topic in counseling and education, even more so for people with disabilities. The findings of this study suggest that being willing to do so as a service provider can impact sexual self-concept, and sexual health, despite disability impact.

There is a long history of educators, counselors, and other service providers working under the myth that individuals with disabilities are not sexual and cannot handle sexual information.⁶⁹ Even as educators, counselors, and other service providers begin to recognize the value of sex education in general, they express hesitancy to discuss sexual topics with people with disabilities due to a lack of skills to address sexual topics and sexuality as specific to people with disabilities.⁷⁰ Those serving the education and mental health of people with disabilities will do well to recognize the important balance

⁶⁶ Linda Mona, Rebecca Cameron, and Colleen Clemency Cordes, "Disability Culturally Competent Sexual Health Care," *American Psychologist* 72, no. 9 (2017): 1000.

⁶⁷ Rostosky, et al., "Sexual Self-Concept and Sexual Self-Efficacy in Adolescents."

⁶⁸ Snell, "Measuring Multiple Aspects of the Sexual Self-Concept."

⁶⁹ Matthew Manoj and M. K. Suja, "Sexuality and reproductive health in Young People with Disability: A Systematic Review of Issues and Challenges," *Sexuality and Disability* 35 (2017): 516.

⁷⁰ Becky Nelson, Karen Odberg Pettersson, and Maria Emmelin, "Experiences of Teaching Sexual and Reproductive Health to Students with Intellectual Disabilities," *Sex Education* 20, no. 4 (2020): 398.

between adaptation and self-concept regarding disability and acknowledgment of their client as a social and sexual self.⁷¹

Implications for People with Disabilities and their Loved Ones

There are also implications here for people with disabilities themselves. In disability studies, it is often noted that people with disabilities are often talked *about* and spoken *for* and not seen as central to their own lives, their own relationships, and their own decision-making.⁷² In terms of sexuality, it is important to note that while people with disabilities report similar levels of sexual activity and satisfaction to the general population, there are also studies that show people with disabilities, particularly those with co-occurring disabilities or more profound impact of disability, have reported significantly lower levels of sexual satisfaction and sexual activity.⁷³ The findings of these studies are supported by the current one: people with more significant impact of disability are likely to report lower levels of life satisfaction. However, with increased social support and opportunity and—as the current study also suggests—with improvement in self-concept including sexual self-concept, life satisfaction increases despite one’s disability. People with disabilities have endorsed this and called for an approach by all those in their circle of care to be acknowledging of their sexual selves as well as approaching these topics with dignity and care.⁷⁴

People with disabilities themselves have expressed an interest and investment in their own sexual lives and studies have shown that life satisfaction does not have to be correlated with disability.⁷⁵ While the support and care of service providers and social support networks is important to the self-concept of all individuals, including those with disabilities, people with disabilities can play a role in their own sexual lives as self-advocates and informed consumers through conversations with providers as well as partners. Research has pointed to the need for increased communication with partners on the part of people with disabilities, the ability of which can be buffered by providing individuals with a disabilities access to sexual health information themselves.⁷⁶ Getting access to that information can

⁷¹ Mona, Cameron, and Clemency Cordes, “Disability Culturally Competent Sexual Health Care,” 1003.

⁷² Tom Shakespeare, “Disabled Sexuality: Toward Rights and Recognition,” *Sexuality and Disability* 18, no. 3 (2000): 159.

⁷³ Freideriki Carmen Mamali, et al., “A National Survey on Intimate Relationships, Sexual Activity, and Sexual Satisfaction among Adults with Physical and Mental Disabilities,” *Sexuality and Disability* 38 (2020): 470.

⁷⁴ Manoj and Suja, “Sexuality and Reproductive Health in Young People with Disability,” 514.

⁷⁵ Diener, “Subjective Well-Being,” 547.

⁷⁶ Mona, Cameron, and Clemency Cordes, “Disability Culturally Competent Sexual Health Care.”

help in improving the conversations with others as well as increased sexual self-concept variables. The current study results point to the importance of sexual self-concept's role in life satisfaction.

Limitations

This study looked at the impact of sexual self-concept on life satisfaction and as a moderator of disability impact. Given the nature of the study, there are a number of limitations that must be considered. First, the online survey design limited access only to those who received the link to the study and had access to a computer and the internet. This limits the generalizability of the findings. In addition, the study's focus was on individuals with spina bifida and cerebral palsy, which could limit generalizability to other populations of people with disabilities. The nature of the topic of sexuality is also a study limitation; it is not uncommon to find bias in sexuality research and those who are willing to participate in such a study may already have a positive attitude toward sexuality as well as their own sexual selves,⁷⁷ also limiting generalizability. Finally, all scales in the study were self-report measures; this can impact the scientific measurement of the constructs. The results of this study should be interpreted with caution; causality should not be assumed from the data, though many of the correlations support past research findings.

Future Directions

Future research should examine the construct of sexual self-concept; the measure used in the current study was not used in its entirety and more qualitative research is needed to truly define the construct. Given that sexual self-concept did correlate with life satisfaction despite impact of disability, future studies on how sexual self-concept can be cultivated, particularly among adolescents with disabilities, are needed. Future research could also explore the moderating impact of sexual self-concept among other populations of individuals with disabilities.

Additionally, any future interdisciplinary work should include the acknowledgement that providing culturally competent services includes addressing sexuality and disability. Providers in the medical and social fields should acknowledge that given the population of people with disabilities that they will very likely have patients or clients with disabilities and that they should seek training and education on disability as well as the way disability and sexuality are interconnected. An approach that

⁷⁷ Donald Strassberg and Kristie Lowe, "Volunteer Bias in Sexuality Research," *Archives of Sexual Behavior* 24, no. 4 (August 1995): 369.

is both disability positive and sexuality positive takes into account the need for advocacy, education, and a strengths-based and positive approach to serving these clients/patients.⁷⁸

Finally, given the barrier of lack of knowledge and fears about competency, it is important to encourage more discussion about sexual topics to people with disabilities across interdisciplinary fields.⁷⁹ Training programs for medical care staff, psychologists and counselors, and rehabilitation professionals would be a good first step in broaching these topics during service, thus improving sexual self-concept and life satisfaction.

Conclusion

This study contributes to the current research on sexual health and disability, and the impact of sexual self-concept on life satisfaction. It explored the variances in the relationships among disability impact, sexual self-concept, and life satisfaction, finding that sexual self-concept significantly correlated with life satisfaction at low, medium, and high levels of impact of disability. This suggests that practitioners and service providers can help cultivate more positive sexual self-concept in individuals with disabilities to promote positive measure of this construct and improve life satisfaction, and it also suggests that training programs could facilitate these discussions by offering practitioners more opportunities to learn about sexual health and disability and allow them to practice broaching these topics with patients and clients. Finally, as numerous studies have shown, individuals with disabilities would not only like to have access to sexual health information and sexual and romantic relationships, but they would also like to have agency over these conversations and aspects of their lives. Having this agency can lead to more discussion on sexuality and disability and improve the sexual self-concept and life satisfaction of people with disabilities overall.

⁷⁸ Mona, Cameron, and Clemency Cordes, "Disability Culturally Competent Sexual Health Care," 1003.

⁷⁹ See Diener, "Subjective Well-Being"; Nelson, Odberg Petterson, and Emmelin, "Experiences of Teaching Sexual and Reproductive Health to Students with Intellectual Disabilities," 407.

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