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“I just haven’t done any of that”: Applicability of the International Index of Erectile Function in Young Men with Spina Bifida

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Abstract

Purpose: To evaluate the applicability of the International Index of Erectile Function (IIEF) in young men with spina bifida and identify spina-bifida-specific sexual experiences not captured by this measure.

Materials and Methods: Semi-structured interviews were conducted between 2/2021-5/2021 with men 18 years of age with spina bifida. The IIEF was completed by participants and perspectives on its applicability were discussed. Participant experiences and perspectives around sexual health were discussed to identify aspects of the sexual experience not well captured by the IIEF. Demographic and clinical characteristics were obtained from a patient survey and chart review. Conventional content analysis framework was used for transcript coding.

Results: Of 30 eligible patients approached, 20 participated. Median age was 22.5 years (range 18-29), and 80% had myelomeningocele. Most identified as heterosexual (17/20, 85%), were not in a relationship (14/20, 70%), and were not currently sexually active (13/20, 65%). Some perceived the IIEF as applicable, while others reported it was not as they do not define themselves as sexually active. Aspects of the sexual experience not captured by the IIEF included: 1) lack of control over sexual function; 2) poor lower body sensation; 3) urinary incontinence; 4) spina-bifida-specific physical limitations; and 5) psychosocial barriers. Participant suggestions for improving the IIEF to increase its applicability were identified.

Conclusion: While many perceived the IIEF as applicable, the measure inadequately captures the diverse sexual experiences of young men with spina bifida. Disease-specific instruments to evaluate sexual health are needed in this population.

Keywords

spina bifida; sexual health; patient-reported outcome measures; erectile dysfunction

Introduction

Many men with spina bifida (SB) experience challenges with sexual health related to their underlying neurologic function.¹⁻³ Studies have assessed the prevalence of altered sexual function,¹ with many attempting to correlate sexual function with SB phenotype (e.g., level of lesion).^{4, 5} However, no consistent predictors of outcomes have been identified.¹ Instead, wide ranges of rates of sexual dysfunction, specifically erectile (7-91%), ejaculatory (26-71%), and orgasmic (26-77%) dysfunction, have been reported across studies.¹ Several factors may contribute to such variability in prevalence, including heterogeneity of SB phenotypes and retrospective and underpowered study designs, but a major contributor is lack of a SB-specific measure for sexual health.

Few studies on male sexual health in SB have used objective, validated measures of sexual health. Instead, non-SB-specific sexual health measures are often used, such as the International Index of Erectile Function (IIEF).⁶ The IIEF was designed and validated in a population of able-bodied males with previously normal function, likely limiting its applicability and validity in men with SB. The domains assessed with the IIEF may also be inadequate to capture important aspects of sexual health specific to SB beyond physical function, such as the biologic and psychosocial effects of SB on sexual health. While there has been a recognized need for SB-specific measures,² patient perspectives and experience with sex have not been sufficiently obtained to capture necessary domains to include in a measure. Additionally, patient-perceived applicability and usability of the IIEF is not known.

Furthering current understanding of how SB alters male sexual health through the perceptions of affected patients is a necessary step toward improving clinical assessment. Thus, we aimed to assess: 1) Patient attitudes toward and gaps in the IIEF; and 2) Knowledge, attitudes, beliefs, and experiences of men with SB around sexual health to determine components that are not captured by the IIEF.

Materials and Methods

This study was approved by our Institutional Review Board (IRB 2020-3993).

Research Team

A male pediatric urology fellow with formal education in qualitative research and who cares for men with SB (JR), a female researcher with a master's degree in public health with experience in qualitative research (IR), and a female researcher trained in qualitative research methods (JH) participated in data acquisition and analysis. One male (DC) and one female (CS) pediatric urologist with experience caring for patients with SB assisted in interview guide creation.

Study Sample

Convenience sampling was used to identify men with SB, 18 years old who attend a large multidisciplinary SB center. Inclusion criteria included fluency in English and lack of cognitive impairment/developmental delay limiting the ability to independently participate in interviews. Prior partnered sexual experience was not required as perceptions

of solo sexual experiences, reasons for not having partnered experiences, and sexual health knowledge and beliefs were considered meaningful. Potential participants were contacted by phone and provided with recruitment brochures outlining study details. All participants were offered a \$30 incentive for participation. Invited participants who declined participation were asked to provide reasoning for non-participation. Verbal informed consent was obtained prior to interviews.

Quantitative Measures

Demographic characteristics of participants were extracted from the medical record. A web-based, REDCap survey was administered to capture bladder management strategy, assistive devices used for ambulation, living situation, relationship status, sexual orientation, and history of sexual activity. All participants were administered the IIEF, a 15-item validated measure assessing male sexual dysfunction based on their last 4-weeks of sexual activity within 5 domains: erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction.⁶ Questions are scored on a Likert scale, and response options vary by domain.

Quantitative Analysis

Descriptive statistics were performed on demographic data. Total IIEF scores and individual domain scores were determined for those who fully completed the measure.

Qualitative Interviews

Semi-structured interviews were performed by telephone by one trained interviewer (JR). Interviews were recorded and transcribed verbatim with identifiers removed. Conversations lasted between 46-91 minutes. Open ended questions probed participant experience with sexual activity and their perceptions of the IIEF, including applicability to their experiences and usability of the measure (see full interview guide, Appendix 1). Pilot testing of an interview guide was performed with a team member (JH) by the primary interviewer (JR) to enhance question clarity. The interview guide was adapted iteratively as interviews were conducted based on field notes. This study was part of a larger study assessing knowledge, attitudes, and beliefs around sexual and reproductive health in men with SB.

Qualitative analysis

Transcripts were uploaded into MAXQDA software (VERBI Software, Berlin, Germany) for coding.⁷ Conventional content analysis framework was used for coding.⁸ Review of three transcripts in tandem was performed for training, reliability, and development of the code book through inductive coding by two trained coders (JR and IR). A third coder (JH) also participated in coding the remaining transcripts which were coded either in tandem (JR, JH, and IR) with immediate consensus or independently with subsequent discussion of results for consensus among coders. First, meaningful phrases made by the participant related to the research question were identified and assigned a descriptive code, which are words or phrases that described what was said. Similar descriptive codes and phrases were categorized based on consensus. Categories were extrapolated to broader themes. Supporting representative quotations were compiled. Participant interviews continued until thematic

saturation was reached, and no new themes emerged across topic areas.⁹ Quantification of themes was not performed, and inferences cannot be made regarding the prevalence of themes outside of the study population.¹⁰ The consolidated criteria for reporting qualitative research (COREQ) checklist was followed (Appendix 2).¹¹

Results

Of 30 eligible patients approached, 20 agreed to participate in interviews, which were conducted from February 2021-May 2021. Reasons for non-participation included patient discomfort with the study and lack of patient availability to schedule an interview. Median participant age was 22.5 years (range 18-29), and 80% had a diagnosis of myelomeningocele (Table 1). Most reported being heterosexual (17/20, 85%), not being in a relationship (14/20, 70%), and not being currently sexually active (13/20, 65%). Eleven participants (55%) reported prior sexual activity. Fourteen (70%) completed the IIEF in its entirety. Of those, 9 reported that they were not sexually active over the past 4 weeks, yet still completed the IIEF.

Median overall IIEF score, and domain scores are reported in Table 2. Scores suggested severe ED, low orgasmic function and intercourse satisfaction, but high sexual desire. Participant perceptions of the IIEF with representative quotations, including applicability, understanding, and challenges were captured (Table 2). Thematic saturation was reached for the topics relevant to this study after the 17th interview.

Participant perception of the IIEF:

Several participants stated that they understood the IIEF well, though specific terms, such as erection, orgasm, and penetration, were confusing to some (Table 2). While several participants reported that the IIEF was not applicable as they had never been sexually active (“a lot of the questions didn’t really apply to me just because I’m not sexually active in my own opinion” P4, 19yo), others felt that it was applicable, regardless of sexual experience (“I think it’s pertinent, regardless, whether or not people are [sexually active].” P8, 26yo). Ways in which participants defined sexual activity, and thus approached answering the questions, varied greatly, ranging from penetrative intercourse to emotional experiences (Table 3).

Participants viewed the IIEF as an icebreaker to talking about sex, stating “you kind of get an understanding before we talked...of what topics we should talk about.” P3, 20yo. One participant reported that completing the IIEF prior to the interview made participating in the interview more comfortable.

Sexual Experiences not Captured by the IIEF:

Unpredictable Function: Many participants expressed challenges with achieving erections, ejaculating, and orgasming when desired. Instead, several participants reported that these sexual functions occur at random times and are unpredictable, which is bothersome. (Table 2).

Urinary Incontinence: Frustration with lack of bladder control during sexual activity was expressed. One participant, who had not been sexually active with a partner, identified

incontinence as a potential barrier to partnered activity: “I have bowel and bladder control issues, so I have to wear a diaper, so I’d have to...figure out that whole thing.” P16, 29yo. Several participants reported a history of urinating with ejaculation (“My bladder muscle is pretty weak and so when I ejaculate sometimes you know pee comes out with it.” P17, 18yo). In addition to worrying about this potential embarrassment, two participants also worried this could harm a partner.

Limited Sensation: Limited lower body and penile sensation was reported as a barrier to successful and pleasurable sexual experiences (“I can’t actually feel a lot, like my lower half of my body I can’t feel a lot.” P7, 19yo). In addition to contributing to the overall experience, poor sensation was noted to be detrimental to achieving and maintaining an erection (Table 2).

Positioning Barriers: Difficulty balancing without the use of assistive devices during intercourse was reported (“There’s things I want to do and try and I can’t do it because my balance...that’s the thing that bothers me the most.” P19, 28yo). Lower extremity fatigue and pain with sex was expressed (**Fatigue:** “My legs can get a lot more tired a lot faster than somebody who doesn’t have spina bifida.” P3, 20yo. **Pain:** “I’ve learned that there’s just certain like positions that you can’t do...certain angles will hurt more.” P5, 28yo).

Psychosocial Factors: Barriers to pursuing sexual relationships including, lack of confidence, lack of hope, and fear of rejection, were reported (Table 2). Regarding confidence, one participant stated, “It definitely makes me very self-conscious...the fact that I...can’t really do what I want when I want it to happen is something that bothers me quite a bit.” P4, 19yo. Though lack of confidence was reported, some participants felt that further experience with self-exploration would increase future confidence with a partner (“The more I figure out my body, the more comfortable I’ll become with it, and with someone else seeing it.” P4, 19yo).

Suggestions for improving the IIEF:

Participants provided specific suggestions for improving and making the IIEF more applicable to men with SB. Primary themes included: 1) Adding questions about individual, non-partnered experiences; 2) Expanding the timeframe assessed beyond the last 4 weeks; and 3) Including questions regarding the unique ways in which people with SB experience sex (i.e., sensation, incontinence, pain, etc.) (Table 4).

Discussion

This study assessed the perspectives of young men with SB about their experience with sexual activity and their perception of the IIEF. Participants described a variety of prior sexual experiences, degrees of altered sexual function, and varied self-definitions of what it means to be sexually active. These findings demonstrate both the significant heterogeneity in the sexual experience of young men with SB and the critical importance of using a measure of sexual function that is both flexible and valid to accommodate that heterogeneity.

While the IIEF was viewed by many participants to be helpful for starting conversations about sex, it is evident that this measure inadequately captures the full sexual experience of participants. Some participants felt that the IIEF was applicable to their experience, although others stated the opposite, as they do not define themselves as sexually active. Understanding how patients define sexual activity is imperative as several participants included self-stimulation under the umbrella term “sexually active” and answered the IIEF fully, despite never experiencing penetrative intercourse. Several aspects of how sex is experienced by those with SB that may be detrimental to overall satisfaction were identified, many of which are poorly captured by the IIEF. These aspects include unpredictable sexual function, poor sensation, urinary incontinence, positioning limitations, and psychosocial barriers such as poor confidence. Several participants also reported no prior history of sexual intercourse, thus limiting the true applicability of the IIEF.

Despite the IIEF’s apparent inability to capture all sexual health domains, the 2018 SB Association Guidelines on Men’s Health suggest that the IIEF should be provided to patients to “characterize and document erectile function.”¹² While the IIEF is validated for this task in able-bodied males, the same cannot be achieved in all patients with SB. The IIEF is designed to diagnose sexual dysfunction in sexually active men with new or acquired sexual dysfunction.⁶ In contrast, men with lifelong atypical sexual function may have a different perspective of what they consider “dysfunction.” Additionally, the IIEF scores of participants in this study suggested sexual “dysfunction,” but only 5 of the 14 participants reported any sexual activity in the past month. Thus, inactivity may be misinterpreted as dysfunction. The same misinterpretation may be true in previously published studies that assessed erectile dysfunction prevalence in men with SB using the IIEF.^{5, 13, 14} While many participants in our study reported understanding the IIEF, domain scores and patient statements during interviews lacked congruency. Some participants reported high domain scores and overall satisfaction, but, during discussions, reported inability to achieve and maintain an erection and having never experienced an orgasm. The cause of such discrepancies is not clear but is likely related to terminology. Participants reported specifically not understanding the terms “orgasm” or “penetration”, highlighting the need to clearly define terms used within any future measures.

Disease-specific sexual health measures have been designed in other neuropathic disease processes, most notably in multiple sclerosis (MS).¹⁵ The MS Intimacy and Sexuality questionnaire is a 15-item measure created to recognize the complex ways that MS affects sexual function and sexuality. Key drivers of sexual dysfunction were categorized as primary (“MS-related neurologic changes”), secondary (“MS-related physical changes that affect the sexual response indirectly”) and tertiary (“psychological, emotional, social, and cultural aspects of MS that affect sexuality”) sexual dysfunction. This measure includes an expanded timeframe of activity of 6-months. Such a measure may serve as a model for measure development in patients with SB. Expanding the timeframe of questioning, and including questions regarding non-partnered experience and specifically how individuals with SB experience sex were suggested by our study participants as ways of making a future measure more relevant to men with SB.

This study has several strengths. The use of individual interviews allowed for in-depth and detailed descriptions of sensitive and personal experiences. Such detail would unlikely have been obtained through other methodologic approaches, including surveys or focus groups. Our study also has limitations, including lack of transferability to other populations. Differences in our study participants and the broader population of males with SB may also exist regarding cognitive ability, prior sexual experience, relationship history, sexual orientation, and gender identify. We excluded individuals with SB whose primary language was not English, so may have missed potential cultural influences on sex and sexual health. Given that we interviewed men 18 years of age, the experiences provided may not be representative of the experiences of younger patients. Regardless, we reached thematic saturation with our study population.

Conclusion:

Participants identified several areas of sexual function that are unique to men with SB. While many study participants perceived the IIEF to be applicable and generally helpful, the measure lacks the ability to objectively capture the diverse sexual experiences of young men with SB. Suggestions for improving the measure were offered and may assist with future disease-specific measure development. Future steps include development of a conceptual model from our data and the current literature to capture and characterize drivers of sexual function that are unique to men with SB. This will inform item bank creation and refinement to work toward the development and later validation of a new sexual health measure.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Participant demographics

Participant Characteristic	No. (%)
Median Age in Years (IQR)	22.5 (19-28)
Self-Reported Race	
Asian	1 (5)
Black/African American	2 (10)
Other	5 (25)
White	12 (60)
Self-Reported Ethnicity	
Hispanic or Latino	5 (25)
Not Hispanic or Latino	15 (75)
Type of Spina Bifida	
Myelomeningocele	16 (80)
Lipomyelomeningocele	4 (20)
Romantically Interested in	
Women	17 (85)
Men	0 (0)
Both	2 (10)
Unsure	1 (5)
Currently in a relationship?	
Yes	6 (30)
No	14 (70)
Previously in a relationship?	
Yes	10 (50)
No	10 (50)
Currently Sexually Active?	
Yes	7 (35)
No	13 (65)
Previously Sexually Active?	
Yes	11 (55)
No	9 (45)
Shunted Hydrocephalus?	
Yes	15 (75)
No	5 (25)
Primary Bladder Management	
CIC per urethra	15 (75)
CIC per catheterizable channel	5 (25)
Assistive Devices for Ambulation ^a	

Participant Characteristic	No. (%)
AFOs	7 (35)
Crutches or Braces	8 (40)
Wheelchair for distance	5 (25)
Wheelchair	5 (25)
Living Situation	
Living Alone	0 (0)
Living with Parents	13 (65)
Living with other family members	2 (10)
Living with partner	3 (15)
Living with room mates	1 (5)
Other ^b	1 (5)
Do you have children?	
Yes	0 (0)
No	20 (100)

^a Several reported use of multiple devices

^b College dorm

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Table 2.

International Index of Erectile Function Total Score and Domain Scores for those who completed the measure in full (N=14). A higher score represents better function or greater satisfaction. Representative quotations depict ways in which the measure may adequately and poorly capture an individual's experience.

IIEF Domain and Median Score of Study Participants (IQR)	Example Items from IIEF Domain	Adequately Captures	Poorly Captures
<u>Erectile Function</u> (range 1-30) ^a 8 (3.0-23.8)	How often were you able to get an erection during sexual activity? During sexual intercourse, how difficult was it to maintain your erection to completion of intercourse? How do you rate your confidence that you could get and keep an erection?	Ability to maintain an erection: "They go up and they stay up until I'm done and then they go down." P17, 18yo "I personally can't maintain an erection. For more than a minute, a minute maybe." P11, 28yo Confidence achieving an erection: "I can achieve like some sort of degree of an erection but it's not something that...is very satisfying...like I wish I was able to achieve more of it." P4, 19yo	Poor understanding of terminology: "Q: How happy are you with your erections? A: Uh well, I don't think I've really had one." Q: Do you know what that means? A: I think so, although maybe yeah explain it again." P1, 22yo Unpredictable nature of erections: "They happen when I don't want them to and they don't happen when I want them to." P4, 19yo "Although they happen, I don't know when they happen...only way I know if they happened, is if I looked down and it's there." P10, 20yo Poor penile sensation impairs erections: "I don't have that sensation...nobody's just going to grab ahold of it and it's just gonna...stand at attention." P15, 28yo
<u>Orgasmic Function</u> (range 1-10) 2.5 (0-7.8)	When you had sexual stimulation or intercourse, how often did you ejaculate? When you had sexual stimulation or intercourse, how often did you have the feeling of orgasm or climax?	Unable to ejaculate: "I haven't reached the point of ejaculation but I have reached that point of the - of that climax... it's a rare instance." P13, 21yo Unable to orgasm: "If it were to happen, it'd be a miracle...I've never experienced it." P10, 20yo "I don't necessarily feel an orgasm when I masturbate or when I'm having sex." P5, 28yo Able to orgasm/ejaculate: "Yeah, I'm able to experience that. I'm pretty happy about it...when I masturbate." P6, 19yo	Poor understanding of terminology: "I can't really tell what that experience truly is...I just don't fully understand the topic." P7, 19yo Unpredictable nature of ejaculation/orgasm: "I'll be like walking down the street and all of a sudden I'll feel it, um but it's never when I masturbate or have sex, you know, it's always at random times." P5, 28yo Pain with orgasm: "There have been a few times where it's just unbearable pain...I think it has something to do with my bladder" p17, 18yo Incontinence with ejaculation: "Every time I masturbate, there will be at least...a stream of pee that will...come out." P6, 19yo
<u>Sexual Desire</u> (range 2-10) 7.5 (4.5-8.8)	How often have you felt sexual desire? How would you rate your level of sexual desire?	Lack of desire: "I actually never had sex before... it's never been something that I've desired." P20, 26yo Some desire: "It's like the thrill of it...I just want to...experience it from time to time." P6, 19yo Strong desire: "Yeah physical intimacy is probably very important to me." P16, 29yo	Lack of hope affecting desire: "Um, sex-wise...pretty interested. But again, I think I'm a lost 'cause so it doesn't matter that much." P7, 19yo Focus on non-partnered experiences: "In like intercourse, I'm not really interested in that yet... just exploring someone else's body would uh, I'm interested in like, but nothing more than that." P4, 19yo
<u>Intercourse Satisfaction</u> (range 0-7.5) 0 (0-7.5)	How many times have you attempted sexual intercourse? When you attempted sexual intercourse, how	Intercourse experience: "Q: What opportunities have you had to be sexually active? A: Um, not really any." P22, 25yo Overall satisfied:	Sensation altering satisfaction: "One reason I don't like to have sex is 'cause I...don't have great sensation down there...so I won't feel myself ejaculate." P5, 28yo Nerves affecting satisfaction:

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IIEF Domain and Median Score of Study Participants (IQR)	Example Items from IIEF Domain	Adequately Captures	Poorly Captures
	often was it satisfactory for you? How much have you enjoyed sexual intercourse?	“I don’t think I have anything particularly negative to say about it if I’m being honest.” P8, 26yo	“It felt good for a bit, but then...I was just like...I don’t think I can do this, um, I’m pretty nervous.” P3, 20yo Experience outside of 4-week timeframe: “I’ll say like two months ago, I experienced oral sex for the first time.” P10, 20yo
<u>Overall Satisfaction</u> (range 2-10) 5 (2.5-6.0)	How satisfied have you been with your overall sex life? How satisfied have you been with your sexual relationship with your partner?	Poor satisfaction: “Pretty unsatisfied. I mean like, I just don’t get that pleasure.” P2, 18yo “I’m a people pleaser, so it like bothers me that I can’t always satisfy a woman.” P11, 28yo Overall content with sexual function: “When I, I’m doing this solo, um I’m finishing, I’m starting and finishing so.” P17, 18yo	Not satisfied due to unpredictable function: “The fact that I...can’t really do what I want when I want it to happen is something that bothers me quite a lot.” P4, 19yo No partnered experiences: “Even though I haven’t had sex before...I don’t think it would be a big issue for me.” P20, 26yo Difficulty finding a partner: “I’ve never been in a stable enough relationship...the opportunity just really hasn’t presented itself.” P10, 20yo “You know they don’t want somebody that has spina bifida...they’ll have a few experiences and be like, well this isn’t quite for me.” P15, 28yo
<u>Total Score</u> (range 6-75) 26.5 (11.3-49.3)			

^aSeverity of erectile dysfunction (ED) classified as: no ED (EF score 26 to 30), mild (EF score 22 to 25), mild to moderate (EF score 17 to 21), moderate (EF score 11 to 16), and severe (EF score 6 to 10)¹⁵

Table 3.

Example participant definitions of what it means to be sexually active. Bolded statements by study authors to highlight key ideas.

Question	Participant Responses
What does being "sexually active" mean to you? How would you define it?	"I'm not really sure how I guess I would define that... I don't know. " P1, 22yo
	" Oral sex and intercourse is what I would consider sexually active" P3, 20yo
	"I would define it as sexually active like with a partner " P17, 18yo
	"Definitely like masturbation and... serious displays of affection between two people" P20, 26yo
	"It's kind of more the emotional and mental part for me at least than the physical" P13, 21yo
	"as long as there's no clothes involved , that's sexual activity, but like touching...uh in areas is sexual activity as well, even through clothes " P11, 28yo
"for me, I think um, it's like a form of... excitement in a way. " P12, 19yo	

Table 4.

Participant suggestions for improving the IIEF. Bolded statements by study authors to highlight key ideas.

Suggestions for Improving IIEF	Representative Quotations
Expand timeframe of sexual experience assessed	"I would've changed, instead of four weeks, either been like your entire life or the last year. .. four weeks is not enough time to do anything." P5, 28yo
Include questions on non-partnered experiences	"Not everyone is gonna be sexually active with another person, necessarily...I don't think that there was a section on self exploration... I think maybe that there could've been another section about what have you done with yourself. " P4, 19yo "Be more specific on how the single body works instead of kind of more on uh- on relationships and everything." P13, 21yo
Include items specific to the way SB affects sexual function	"I don't know if it really mentioned medical issues... specifically, like...not feeling things. " P7, 19yo "like as a question maybe just bring up like...what's your ejaculation like, if that makes sense? Like, is urine in it, or can't, or...painful." P17, 18yo

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