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# Sex-Positive Sexuality Post-Spinal Cord Injury: A Systematic Review and Qualitative Metasynthesis

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Purpose/Objective: Many qualitative studies have focused on sex and spinal cord injury (SCI), often taking a deficit lens to interpretation and reporting. However, it is important to understand what can facilitate positive sexuality for people with SCI; therefore this study examines facilitators of sexuality for people with SCI. Research Method/Design: A systematic review and metasynthesis of 38 qualitative papers (published before February 2024) on sexuality for people with SCI was conducted following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. Thematic synthesis was conducted in three stages: line-by-line coding; the identification of common descriptive themes across papers; and the generation of novel analytical themes. Results: Thirty-eight eligible papers were analyzed. Thematic synthesis resulted in four common descriptive themes that were linked to positive sexuality: (a) being sexually active; (b) trying new and other ways of sexual expression; (c) having a positive relationship with a partner; and (d) peer support. These descriptive themes were interrelated and incorporated in two in-depth analytical themes: (a) redefining sexuality and (b) establishing a sexual identity. Conclusions/Implications: This study highlights facilitators to sexuality post-SCI. In order to maintain a sex-positive approach to sexuality rehabilitation for people with SCI, sexuality facilitators should remain at the forefront of sexual rehabilitation.

### Impact and Implications

This qualitative metasynthesis of 38 articles found that being active, trying new and other ways of sexual expression, having a positive relationship with a partner, and relying on peer support can facilitate sexuality post-spinal cord injury (SCI). Redefining sexuality and establishing a sexual identity post-SCI are important facilitators for positive sexuality post-SCI. Researchers and clinicians should pay special attention to sexuality facilitators for individuals with SCI, in order to maintain a sex-positive and inclusive approach to sexuality for people who have sustained SCI.

Keywords: sexuality, spinal cord injury, sexual function, metasynthesis, sex-positive

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Blaze Ireland served as lead for investigation and served in a supporting role for writing-original draft and writing-review and editing. Asmita

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Sexuality is an important topic for people who have sustained a spinal cord injury (SCI). Recent work has shown that sexual problems are the third highest ranked health concern for individuals with SCI across the world (Ehrmann et al., 2020). In response, researchers have focused on sexuality as an important part of SCI research. A large-scale review of papers on sexuality and SCI found over 350 papers published before 2022 that address SCI and sexuality in some way (Chantharath et al., 2022).

SCI can impact sexual function in many ways. Often, the focus on function is primarily related to loss of physical mobility and sensory changes and the associated changes to sexual encounters (Earle et al., 2020; Lombardi et al., 2010). People with SCI may experience pain (Anderson et al., 2007; Singh & Sharma, 2005) and spasticity (Anderson et al., 2007; S. W. Charlifue et al., 1992; Singh & Sharma, 2005), which can impact one's ability to experience and enjoy sex. In addition, other physical concerns such as autonomic dysreflexia (Anderson et al., 2007) and shortness of breath (Anderson et al., 2007) can impact physical sexual function. Pressure injuries (Singh & Sharma, 2005) and bladder and bowel management concerns (Anderson et al., 2007; Kreuter et al., 2011; Reitz et al., 2004) can lead to the need for changes to sexual practices which can also have a psychological impact on sexuality. Furthermore, recent work has found that depression (Burns et al., 2009; Cobo-Cuenca et al., 2015; Hajiaghababaei et al., 2014) and anxiety (Hajiaghababaei et al., 2014; Harrison et al., 1995) are related to sexual dysfunction. In turn, sexual dysfunction can have a large impact on psychological functioning and lead to distress (Barbonetti et al., 2012) and poorer quality of life (Cobo-Cuenca et al., 2015). These health issues can present difficulties that impact sexual function post-SCI.

Relationships, which are intricately connected to one's sex life, can also be impacted by SCI. Sustaining an SCI may change how partners relate to one another, in some cases necessitating taking on a caring role (S. B. Charlifue et al., 2016; Jeyathevan et al., 2019; Kreuter, 2000; Middleton et al., 2014; Sunilkumar et al., 2015) and feelings of infantilization or overassistance (Pearcey et al., 2007). However, SCI can also lead to increased connection (Engblom-Deglmann & Hamilton, 2020), improved communication (Thrussell et al., 2018), and stronger relationships in general (Kim & Mee Kim, 2020; Kreuter, 2000).

Many qualitative studies have focused on sex and SCI. These papers aim to address the physical and psychological impacts of SCI on sexuality. Influential research by Sakellariou (2006), Leibowitz (2005), and Li and Yau (2006) among others has provided a basis for the groundswell of qualitative research on sexuality and SCI. However, most of this work on sexuality and SCI is approached using a deficit lens. Often, research is focused on remediation, or identifying how sexuality was negatively impacted by a person's injury. Perhaps due to unconscious bias, much of what researchers publish on sexuality and SCI identifies barriers to sexuality—an admittedly important concern, however not the only concern.

Multiple recent reviews have been conducted on sexuality and SCI with varying foci. Earle et al. (2020) conducted a scoping review and narrative synthesis of qualitative literature that explored how women with SCI experience sexuality. Bryant et al. (2022) examined nonmedical methods to manage sexuality post-SCI, and Mair and Moses (2024) conducted a metaethnography of qualitative papers on sexuality post-SCI. However, in these studies, barriers to sexuality continue to outshine facilitators.

Facilitators for sexuality are often hidden in larger bodies of work that address barriers to sexuality caused by the SCI. To our best knowledge to this date, a comprehensive view of the facilitators to sexuality for people with SCI has not been undertaken. This article addresses this gap with the intention of guiding future work on sexuality for people with SCI to adopt a sex-positive approach. Sex positivity highlights the importance of sexual pleasure while also recognizing that choice and inclusivity are paramount (Williams et al., 2013, 2015). Sex positivity is inclusive of sex that is more than that which is often defined as penetrative heterosexual intercourse. Instead, sex positivity presents a broadly positive view of inclusive sexuality which is open to many sexual acts and sexual orientations. A body of literature framed around sex positivity can help researchers and clinicians understand how best to facilitate positive sexual lives post-SCI is required. Therefore, the aim of this study was to identify sex-positive aspects and facilitators of sexuality for individuals who have sustained SCI through a systematic metasynthesis of qualitative papers on sexuality for people with SCI.

## **Materials and Method**

A systematic review and metasynthesis were conducted to develop an understanding of facilitators of sexual expression from the perspective of individuals living with spinal cord injuries. The systematic search followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (Page et al., 2021) and the synthesis of qualitative research was guided by the enhancing transparency in reporting the synthesis of qualitative research statement and associated 21 items (Tong et al., 2012). Metasynthesis involves the interpretation and explanation of qualitative findings from various studies to develop new understandings of an experience (Sandelowski et al., 2007).

Thematic synthesis was selected as the methodology for this metasynthesis adopting the methods outlined by J. Thomas and Harden (2008). Thematic synthesis has been used widely in health research to review and explore questions regarding intervention needs, effectiveness, and appropriateness. It has also been used in SCI research to provide insights into return to work, peer support, and experiences of rehabilitation (Divanoglou & Georgiou, 2017; Hilton et al., 2018; Unger et al., 2019). Unlike a linear narrative review, thematic synthesis involves the development of (a) descriptive themes which are close to the primary studies and (b) analytical themes which are interpretive constructs that go beyond the findings of the primary studies. This allows analysis that is both close to the findings of the primary studies and then synthesized to produce new concepts (J. Thomas & Harden, 2008). Theming is inductive and does not include any a priori codes and analysis is not guided by existing theory.

Researchers were dispersed geographically. The team collaborated using online methods and tools including Covidence, NVivo, Zoom, Miro, and Dropbox. The research team was compromised of five health professionals, with qualifications in nursing and midwifery, rehabilitation counselling, and occupational therapy. Their collective experience included working with people with SCI during rehabilitation, in the community, as well as experience in research in the areas of disability, rehabilitation, sexuality, and SCI. The team declared their assumptions prior to the study. Assumptions included: sexuality as valued and important for people with SCI, and that satisfactory meaningful sexual expression is possible for people with SCI.

### **Review Process**

Two authors (Blaze Ireland and Asmita Mudholkar) developed and registered a systematic review protocol on The International Prospective Register of Systematic Reviews (Registration CRD420 20221205, submitted for registration November 30, 2021). The review was conducted systematically by all five researchers using five online databases: Web of Science, Scopus, PubMed, PsychInfo, and Embase. The review process was managed using Covidence software to allow team members to review blindly. The initial search was preceded by the development of search terms and search strings with the assistance of a subject librarian. Search terms were adapted as needed to suit the five selected online databases (see Table 1 for primary search terms)

A systematic search for original qualitative research published in peer-reviewed journals was conducted in March 2022 and repeated in February 2024 to ensure an up-to-date search. Papers were included if they focused on sexuality for people with SCI—both traumatic and nontraumatic. There was no restriction of geographic location. Metasynthesis seeks a deeper understanding of an issue by synthesizing secondary data from primary papers. This requires the best quality secondary data, ideally displayed as in-depth verbatim quotation allowing reanalysis. The review only included qualitative papers and excluded mixed methods which were deemed less likely to provide sufficient data for reanalysis. See Table 2 below for inclusion and exclusion criteria.

Additional relevant articles were identified through hand searching and searching citations of selected articles. Screening was conducted in two stages using Covidence (Covidence Systematic Review Software, 2022). Initial title and abstract screening were shared by all members of the team with each record screened by two researchers. A third researcher resolved any conflicts. In some instances, conflicts were discussed with the entire team resulting in some refinement of the inclusion and exclusion criteria. Full text screening was conducted in the same way with each full text paper reviewed by two people, and a third to resolve conflicts. The team met regularly to discuss progress and to confirm suitability of included papers.

## **Quality Appraisal**

Although there is some debate about the requirement to apply appraisal in metasynthesis (Toye et al., 2014), the enhancing transparency in reporting the synthesis of qualitative research statement endorses this step. The Joanna Briggs Institute Critical Appraisal checklist for qualitative research was used to evaluate methodological strengths and limitations of the included papers (Lockwood et al., 2015). Quality appraisal of selected papers was conducted by two reviewers (Blaze Ireland and Roxanna Nasseri Pebdani) and appraisal inconsistencies were discussed and debated to reach consensus. Each paper was allocated a quality percentage between

0% and 100% (see Table 3). No papers were excluded based on quality appraisal; however, there was an expectation that higher quality papers would yield more data. Analysis of papers was conducted in order of quality appraisal scores and retrieval dates, with papers published after March 2022 analyzed in 2024.

### **Data Analysis—Thematic Synthesis**

Thematic synthesis was used to conduct analysis in three stages: line-by-line coding; organizing "free codes" to create common descriptive themes across papers through grouping similar codes; and the generation of analytical themes, guided by the research question (J. Thomas & Harden, 2008). All analysis was managed using NVivo 20. According to J. Thomas and Harden (2008) the "results" or "findings" section of each article were the source for analysis. First-order constructs (direct quotations) and commentary on experiences regarding sexual expression were analyzed within each paper. Line-by-line coding was conducted independently by three reviewers (Blaze Ireland, Roxanna Nasseri Pebdani, and Michèle Verdonck). The research team met regularly to compare codes and to ensure the consistency of coding technique. Coding of the first 15 papers (ranked by quality appraisal) was initially conducted by Blaze Ireland to identify preliminary codes. These codes were then reviewed and refined by a second reviewer (Roxanna Nasseri Pebdani). The team of five then reviewed and agreed to all codes. The remainder of the papers were analyzed by two reviewers (Michèle Verdonck and Roxanna Nasseri Pebdani).

Analysis of all included papers using line-by-line coding resulted in initial codes describing the facilitators of sexual post-SCI. Descriptive themes were developed by all members of the research team by organizing and reorganizing the initial codes into common themes. This involved several meetings and interrogation of coding to ensure the descriptive themes were accurately reflected in verbatim quotations. There were several rounds of collapsing and merging of codes into groups to create dominant descriptive themes representative of the literature as a whole. This was an iterative process involving a combination of mind mapping, using an electronic white boards and virtual sticky notes. The final stage involved the development of analytical themes beyond the descriptive themes to generate new understandings of facilitators of positive sexuality for individuals who have sustained SCI. In this step, three of the research team (Asmita Mudholkar, Roxanna Nasseri Pebdani, and Michèle Verdonck) developed their own analytical overarching concepts. The team then met to discuss and contrast these concepts. Analytical themes were developed to be the overarching concepts in the source literature which were underpinned by the descriptive themes. The naming of each theme was iterative and involved several meetings and discussions to name each theme in a way that best represented the component codes and associated verbatim quotations. Data are publicly available through existing published papers.

**Table 1**Search Terms According to a Population Interest and Context Framework

Population	Interest	Context				
"spinal cord injur*" OR "spinal injur*" OR "spinal cord" OR "spinal cord trauma" OR "spinal cord lesion" OR quadriplegi* OR paraplegi* OR tetraplegi*	sex* OR sexual* OR sensual* OR intimate OR intimacy	qualitative OR "focus group" OR "grounded theory" OR interview* OR ethnography OR phenomenology OR phenomenological OR experience				

Note. Asterisk indicates truncation technique used to include a variety of word endings to broaden search.

 Table 2

 Inclusion and Exclusion Criteria

Inclusion Exclusion Studies focused on sexuality/intimacy Quantitative, surveys, and case studies Spinal cord injury (traumatic and Mixed methods studies Unable to parse out voice of nontraumatic) Qualitative studies including individuals with spinal cord injury interview and focus groups from other participant data English language Full text not available Peer reviewed publications Thesis or gray literature Qualitative findings clearly articulated

#### Results

Two thousand and one studies were identified through database searches and an additional 10 studies through hand searching. Following automated duplicate deletion in Covidence (Covidence Systematic Review Software, 2022), 1,840 studies remained. Title and abstract screening excluded a further 1,691 studies leaving 149 studies to be assessed for eligibility through full text screening. Once this was complete, 38 eligible papers addressing sexual expression in people post-SCI remained (Figure 1). All 38 studies were included, and a summary of the 38 studies is presented in the online supplemental materials available on the journal website.

The 38 studies were conducted in the United States (Christian et al., 2020; Fritz et al., 2015; Hohmann, 1966; Leibowitz, 2005; Leibowitz & Stanton, 2007; McAlonan, 1996; Money, 1960; Richards et al., 1997; Tepper et al., 2001), Australia (Beckwith & Yau, 2013; Parker & Yau, 2012; Seddon et al., 2018; Warren et al., 2018), Canada (Cramp et al., 2014; Kathnelson et al., 2020a, 2020b; Morozowski & Roughley, 2020; Osborne et al., 2023), Greece (Sakellariou, 2006, 2012; Sakellariou & Algado, 2006; Sakellariou & Sawada, 2006), South Africa (Basson et al., 2003; Robinson et al., 2011; Thurston et al., 2021), the United Kingdom (Barrett et al., 2023; Nevin & Melby, 2022; Thrussell et al., 2018), India (Sharma, 2022; Sunilkumar et al., 2015), China (Li & Yau, 2006), Finland (Angel & Kroll, 2020), Hong Kong (Pearson & Klook, 1989), Iran (Maasoumi et al., 2017), Malaysia (Rahman et al., 2019), Turkey, (Taylan et al., 2022), Spain (Touil-Satour & Levva-Moral, 2022), and Sweden (Westgren & Levi, 1999). The studies were published between 1960 and January 2023. Sample sizes ranged from four to 29 participants, with studies exploring the perspectives of men and women with various relationship status and sexual orientation post-SCI. Studies reported using semistructured and structured in-depth interviews as their data collection methods, with thematic analysis the most common method of data analysis.

Thematic synthesis of the results sections of the 38 articles identified 88 initial codes. Several rounds of analysis led to four common descriptive themes that were linked to positive sexuality with each theme encompassing several codes. The four descriptive themes represented in the literature were: (a) being sexually active; (b) trying new and other ways of sexual expression; (c) having a positive relationship with a partner; and (d) peer support.

These descriptive themes across papers were interrelated and supported two in-depth overarching analytical themes, namely (a) redefining sexuality and (b) establishing a sexual identity. Both of these analytical themes were underpointed by being sexually active,

trying new ways of sexual expression, and having positive relationships and peer support (the descriptive themes). These themes are described in more detail supported by some illustrative quotations. Figure 2 provides a visual representation of these themes.

### **Descriptive Theme 1: Being Sexually Active**

The first descriptive theme highlighted that positive sexual experience with SCI was facilitated by sexual activity itself. Participants across studies referred to opportunities to gain sexual experience (Beckwith & Yau, 2013; Christian et al., 2020; McAlonan, 1996; Thrussell et al., 2018), the process of reestablishing their sex life (Angel & Kroll, 2020; Leibowitz & Stanton, 2007; Richards et al., 1997; Sakellariou, 2006; Seddon et al., 2018; Tepper et al., 2001; Thrussell et al., 2018; Thurston et al., 2021; Touil-Satour & Leyva-Moral, 2022), and the art of problem solving (Beckwith & Yau, 2013; Thrussell et al., 2018) to determine alternative ways of sexual expression (described in more detail in the next theme).

Some participants described their first sexual encounters postinjury as empowering and "a great experience" (Beckwith & Yau, 2013, p. 321). These experiences led to increased motivation in seeking further sexual expression opportunities. Some described these opportunities as turning points in their sexual lives (Angel & Kroll, 2020; Christian et al., 2020; Tepper et al., 2001). Participants also addressed pleasure, describing that sexual satisfaction and expression was "fantastic ..., the icing on the cake" (Warren et al., 2018, p. 25).

Being sexually active provided opportunities for participants to communicate their sexual needs with their partners (Seddon et al., 2018; Touil-Satour & Leyva-Moral, 2022) as this new life situation after the injury frequently required additional time to plan sexual encounters (Sakellariou & Sawada, 2006; Touil-Satour & Leyva-Moral, 2022; Warren et al., 2018). Communication was especially important when participants had issues such as neuropathic pain, continence difficulties, and sexual positional challenges. To manage these challenges, participants described strategies to improvise and accommodate (Beckwith & Yau, 2013; Leibowitz & Stanton, 2007; Sharma, 2022; Taylan et al., 2022) such as having their "chair reclined as far back as possible" (Leibowitz & Stanton, 2007, p. 50) and "increasing the temperature of the air conditioner [...] emptying my bladder [...] avoiding long foreplays [...] send [ing] tempting messages on WhatsApp" (Sharma, 2022, p. 293). This gave the participants autonomy to "have more control over things that [were] happening to [them]" (Richards et al., 1997, p. 278) and therefore to have more control and autonomy to express their sexual needs to their partners (Richards et al., 1997). Furthermore physical and financial autonomy enabled sexual activities (Richards et al., 1997; Sakellariou & Algado, 2006; Sakellariou & Sawada, 2006), which increased the possibility of attracting partners (Beckwith & Yau, 2013).

# Descriptive Theme 2: New and Other Ways of Sexual Expression

The second descriptive theme addressed positive aspects of sexuality and facilitators to sexuality, called "new and other ways of sexual expression." This included willingness to experiment, exploring erogenous zones and sensuality, improvisation, and discovering alternative methods of sexual expression. Participants discussed the importance of an attitudinal change that increased willingness to experiment sexually (Beckwith & Yau, 2013;

 Table 3

 Results of Quality Appraisal of 33 Papers Rated Using the JBI Checklist

Study	Quality appraisal checklist question										
	1	2	3	4	5	6	7	8	9	10	Quality (%)
Angel and Kroll (2020)	Y	Y	Y	Y	Y	N	N	N	Y	Y	70
Barrett et al. (2023)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80
Basson et al. (2003)	N	Y	Y	Y	Y	N	N	Y	CT	Y	60
Beckwith and Yau (2013)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100
Christian et al. (2020)	Y	Y	N	Y	Y	Y	Y	Y	N	Y	80
Cramp et al. (2014)	Y	Y	Y	Y	Y	N	N	Y	CT	Y	70
Fritz et al. (2015)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	90
Hohmann (1966)	N	N	Y	N	N	Y	Y	Y	N	Y	50
Kathnelson et al. (2020a)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80
Kathnelson et al. (2020b)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100
Leibowitz (2005)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80
Leibowitz and Stanton (2007)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100
Li and Yau (2006)	Y	Y	Y	Y	Y	N	Y	Y	N	Y	80
Maasoumi et al. (2017)	N	Y	Y	Y	Y	N	N	Y	Y	Y	70
McAlonan (1996)	N	Y	Y	Y	Y	N	N	N	Y	Y	60
Money (1960)	N	Y	Y	N	CT	N	N	N	Y	Y	40
Morozowski and Roughley (2020)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90
Nevin and Melby (2022)	Y	Y	Y	Y	N	Y	Y	Y	Y	N	80
Osborne et al. (2023)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90
Parker and Yau (2012)	N	Y	Y	Y	Y	N	N	Y	Y	Y	70
Pearson and Klook (1989)	N	Y	Y	N	Y	Y	N	Y	N	Y	60
Rahman et al. (2019)	Y	Y	Y	N	Y	N	N	Y	Y	Y	70
Richards et al. (1997)	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	100
Robinson et al. (2011)	N	Y	Y	CT	CT	N	N	N	Y	CT	30
Sakellariou (2006)	N	N	Y	Y	N	N	N	Y	Y	Y	50
Sakellariou and Algado (2006)	Y	Y	Y	N	Y	N	Y	N	Y	Y	70
Sakellariou and Sawada (2006)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	90
Sakellariou (2012)	Y	Y	Y	Y	N	N	N	N	Y	CT	50
Seddon et al. (2018)	N	Y	Y	Y	Y	N	N	Y	Y	Y	70
Sharma (2022)	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	90
Sunilkumar et al. (2015)	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	90
Taylan et al. (2022)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80
Tepper et al. (2001)	Ŷ	Ŷ	Ŷ	Ŷ	Ŷ	N	N	Ň	Ŷ	Ŷ	70
Thrussell et al. (2018)	Ŷ	Ŷ	Ŷ	Ŷ	Y	Y	N	Y	Ŷ	Ŷ	90
Thurston et al. (2021)	N	Ý	Y	Y	Y	Y	Y	N	Y	Y	80
Touil-Satour and Leyva-Moral (2022)	Y	Y	Y	Y	Y	N	N	Y	Y	Y	80
Warren et al. (2018)	N	Ý	Y	Y	Y	N	N	Ý	Y	Y	70
Westgren and Levi (1999)	Y	Ý	Ý	N	Y	N	N	Ý	Y	Y	70

Note. JBI checklist questions were as follows: (1) Is there congruity between the stated philosophical perspective and the research methodology? (2) Is there congruity between the research methodology and the research question or objectives? (3) Is there congruity between the research methodology and the methods used to collect data? (4) Is there congruity between the research methodology and the interpretation of results? (6) Is there a statement locating the researcher culturally or theoretically? (7) Is the influence of the researcher on the research, and vice-versa addressed? (8) Are participants, and their voices, adequately represented? (9) Is the research ethical according to current criteria or, for recent studies, is there evidence of ethical approval by an appropriate body? (10) Do the conclusions drawn from the research report flow from the analysis, or interpretation, of the data? JBI = Joanna Briggs Institute; Y = yes; N = no; CT = cannot tell.

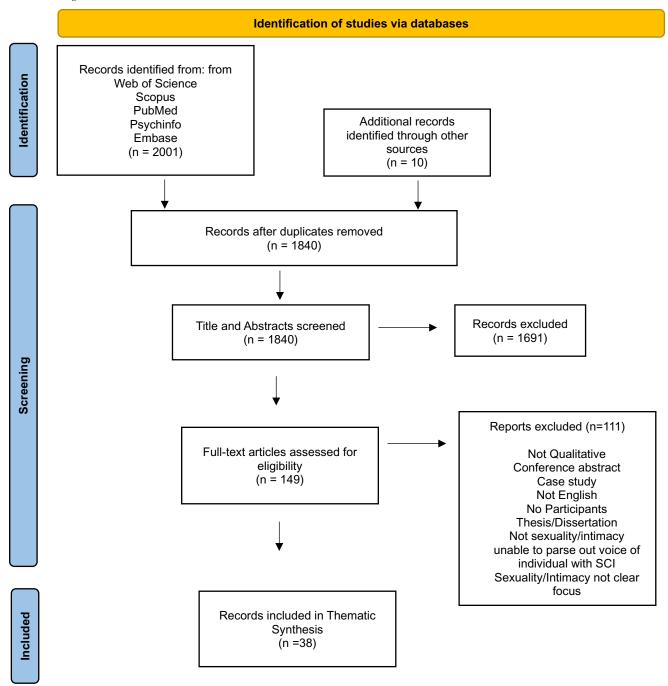
Leibowitz, 2005; Morozowski & Roughley, 2020; Osborne et al., 2023; Sakellariou, 2012; Seddon et al., 2018; Sharma, 2022; Taylan et al., 2022; Touil-Satour & Leyva-Moral, 2022) and not to "refrain from trying anything" (Westgren & Levi, 1999, p. 314). For some this meant having the courage to engage in casual sex with strangers "to gain the experience [...] without having to have the pressure of being expected to build a relationship" (Beckwith & Yau, 2013, p. 321).

Participants further described having "an open mind and not be[ing] as scared to try different things" (Leibowitz & Stanton, 2007, p. 51). The sexual exploration of nongenital areas and other parts of the body was described as being more "inventive ... and more experimental" (Richards et al., 1997, p. 278), and involved exploring a range of altered sexual expressions through "trial and

error" (Osborne et al., 2023, p. 666). Participants also expressed that the stimulation of erogenous zones, which now included hypersensitive areas, could be used to achieve orgasm in a new way (Beckwith & Yau, 2013; Leibowitz, 2005; Li & Yau, 2006; Sakellariou & Algado, 2006; Sakellariou & Sawada, 2006; Taylan et al., 2022; Thrussell et al., 2018). These areas included the nipples, the center of the back, the inner aspect of the thigh, head, lips, earlobes, and "other parts of [the] body [that were] still sensitive" (Li & Yau, 2006, p. 14), all areas that remained sexually arousing after sustaining the injury (Li & Yau, 2006).

Using these new and different methods enhanced participants' pleasure during individual and partnered sexual expression supported people with lived experience to feel that "it didn't really matter that [they] were paralyzed" (Parker & Yau, 2012, p. 20). In addition,

Figure 1
PRISMA Diagram



Note. PRISMA = Preferred Reporting Items for Systematic Reviews and Meta-Analyses; SCI = spinal cord injury. See the online article for the color version of this figure.

participants identified that masturbation (Parker & Yau, 2012; Richards et al., 1997; Seddon et al., 2018; Sharma, 2022; Taylan et al., 2022; Thrussell et al., 2018; Touil-Satour & Leyva-Moral, 2022) and genital exploration remained an important process in understanding their body postinjury (Li & Yau, 2006; Touil-Satour & Leyva-Moral, 2022) and emphasized the importance of not being "afraid to touch yourself" (Thrussell et al., 2018, p. 1090).

This was particularly important for participants who perceived sexuality more as an overall sensual experience. They described sensual experiences such as

wonderful feeling [...] You don't have to be having sex... to have that. It's like, sitting in a hot sudsy tub [...] and you can get smooth, silky bath gel, and you use your hands... And it's just oooh! [...] You are sexy, and

Facilitators of Sexuality for Individuals who have sustained a Spinal Cord Injury

Descriptive Themes

Analytical Theme

Redefining
Sexual
Peer
Support

Positive
Relationship
with a
Partner

Figure 2
Visual Representation of Themes

*Note.* See the online article for the color version of this figure.

you are a sexual being, and you're a human being, all that at the same time. (Leibowitz & Stanton, 2007, p. 51)

# **Descriptive Theme 3: Peer Support**

The third descriptive theme supported across multiple studies was the importance of peer support as a facilitator of positive sexual expression. Participants described that peer support was imperative for them to feel heard when exploring questions related to their sexuality after the injury (Leibowitz & Stanton, 2007; Nevin & Melby, 2022; Thurston et al., 2021). This support was valued both on an individual level as well as in group format (Robinson et al., 2011) promoting camaraderie (McAlonan, 1996; Morozowski & Roughley, 2020). Participants felt that they were, "not the only person in this position, that other people have had to deal with it and there are ways to work with it" (Leibowitz & Stanton, 2007, p. 49). Peer support was further valued because it allowed learning from others' lived experiences (Nevin & Melby, 2022) as, "it is better to have someone who has been through it, rather than an able bodied person ... [because] they have been through similar experiences ... [to] talk about things that might have been embarrassing" (Parker & Yau, 2012, p. 19). Participants reported that through peer support, they were able to be more open about their sexual needs (Cramp et al., 2014; McAlonan, 1996), which facilitated sexual adjustment post injury (Leibowitz & Stanton, 2007; Morozowski & Roughley, 2020; Nevin & Melby, 2022; Tepper et al., 2001; Thurston et al., 2021).

# Descriptive Theme 4: Positive Relationship With a Partner

The fourth descriptive theme focused on the importance of having a positive relationship with a partner as a facilitator of sexuality. This included the importance of open communication (Barrett et al., 2023; Beckwith & Yau, 2013; Cramp et al., 2014; Fritz et al., 2015; Kathnelson et al., 2020b; Leibowitz, 2005; Leibowitz & Stanton, 2007; Morozowski & Roughley, 2020; Osborne et al.,

2023; Parker & Yau, 2012; Richards et al., 1997; Tepper et al., 2001; Thrussell et al., 2018; Thurston et al., 2021; Westgren & Levi, 1999). Open communication was seen as beneficial "to explain ... [sexual] needs and wants [because] there is more to sex than intercourse, even just having good communication and being about to talk to each other about your fantasies, your dreams or whatever is really, really healthy" (Parker & Yau, 2012, p. 20). One participant said "It [was] like anything [with] relationships, whether it is sex or not sex. If the communication part is no good, then you are just setting yourself up to fail" (Morozowski & Roughley, 2020, p. 359).

Participants further described the importance of trust (Angel & Kroll, 2020; Hohmann, 1966; Seddon et al., 2018; Warren et al., 2018) and having an understanding and supportive partner (Cramp et al., 2014; Parker & Yau, 2012; Sharma, 2022; Taylan et al., 2022). This facilitated meaningful and deep experiences (Seddon et al., 2018). Partners who supported participants to overcome challenges to rediscover sexual expression enabled them "[to feel] loved ... [and] liked" (Parker & Yau, 2012, p. 19). Supportive partners further reassured their partners and held the space for them to be open about all aspects of sexual expression when living with an SCI (McAlonan, 1996).

Furthermore, sexuality was anchored in reciprocity (Seddon et al., 2018). This included satisfying one's partner through both the giving and receiving of pleasure (Angel & Kroll, 2020; Barrett et al., 2023; Hohmann, 1966; Sakellariou & Sawada, 2006; Seddon et al., 2018; Tepper et al., 2001; Touil-Satour & Leyva-Moral, 2022; Warren et al., 2018; Westgren & Levi, 1999).

# **Analytical Theme 1: Redefining Sexuality**

The first analytical theme underpinned by the descriptive themes described above was redefining sexuality through an evolving understanding of sexuality. This in turn facilitated sexual expression post injury. Being sexually active allowed participants to explore how they defined sexuality. Similarly, finding new ways of sexual expression inherently changes definitions of sex. To redefine was not a solo process and linked to positive relationships as well as support from

peers who understand changes and redefinition. Participants portrayed changes in how they defined sexuality after sustaining their injury by "exploring the changing definition of sex" (Osborne et al., 2023, p. 666). This was associated with participants' ability to revise their expectations of getting, "past what would be considered as a traditional method [of sex]" (Kathnelson et al., 2020a, p. 5). This new outlook of sexual expression changed participants' characterization of sexual expression and they were able, "to define it in a different way" (Kathnelson et al., 2020a, p. 5) as compared to preinjury (Fritz et al., 2015; Kathnelson et al., 2020a; Touil-Satour & Leyva-Moral, 2022). For some participants, this gave them the opportunity to have a satisfactory sex life that was not as rigid as perceived by society (Sakellariou & Sawada, 2006; Seddon et al., 2018). Participants acknowledged that reestablishing a sexuality is a

long road getting to that point where you get past what you would be considered a method [of sex], however you want to define it. It becomes about things that you may not have realized were quite as important before ..., you have to define it in a different way, you don't really have a choice. You can't try to define [sexuality] by the same way it was pre-injury. (Kathnelson et al., 2020a, p. 5)

The physical aspect of penetrative sex decreased in importance post injury, because "[sex] it's also an emotional thing" (Fritz et al., 2015, p. 5). There was a redefinition with increased emphasis and prioritization on intimacy and romance for participants (Christian et al., 2020; Fritz et al., 2015; Kathnelson et al., 2020a; Li & Yau, 2006; Richards et al., 1997; Sunilkumar et al., 2015; Taylan et al., 2022; Thrussell et al., 2018). Women, in particular described sex to be more "affectionate [and have] more 'romance'" (Fritz et al., 2015, p. 5). When participants spoke about the meaning of sexuality, changes were observed in how feelings of intimacy, romance and connection with their partners became increasingly important on an emotional level, "and instead of just having sex, it's more loving, touching, squeezing" (Leibowitz & Stanton, 2007, p. 49). Participants further described a deeper level of whole-body intimacy, for example, adding "soft music, candles, then gentle foreplay before and after ... caressing" (Leibowitz & Stanton, 2007, p. 49). While this approach supported sexual reengagement, it also lead to sexual expression that was more fulfilling (Leibowitz & Stanton, 2007).

There was a commonality in many studies about the value of a holistic understanding of sexuality beyond penetration (Barrett et al., 2023; Basson et al., 2003; Hohmann, 1966; Kathnelson et al., 2020a; Leibowitz, 2005; Sakellariou & Sawada, 2006; Seddon et al., 2018; Touil-Satour & Leyva-Moral, 2022; Warren et al., 2018). Increased satisfaction in the sexual lives of both individuals and partners was linked to the incorporation or prioritization of intimacy and emotional connection over the physical and physiological aspects. This involved "leaning towards the nonpenetration side of a variety of sexual activities" (Kathnelson et al., 2020a, p. 5). People felt more satisfied because "sexuality is [a] package which includes your attitudes and includes a process of intimacy" (Warren et al., 2018, p. 26). The sexual connection was valued "more than the actual act of penetration" (Warren et al., 2018, p. 26).

Sexual expression further involved relearning what sexuality should look like post injury (Angel & Kroll, 2020; Christian et al., 2020; Fritz et al., 2015; Morozowski & Roughley, 2020; Nevin & Melby, 2022; Sakellariou & Sawada, 2006). Participants especially outlined that it was extremely important for them to reframe the way they think about and how they practice sex (Angel & Kroll, 2020; Leibowitz,

2005; Leibowitz & Stanton, 2007; McAlonan, 1996; Seddon et al., 2018), which facilitated a positive growth mindset underpinned by redefining sexuality. This included improved communication and sharing feelings with partners, emphasizing the cognitive or mental component of sex, and modifying their previous methods (Basson et al., 2003; Cramp et al., 2014; Hohmann, 1966; Leibowitz & Stanton, 2007; Osborne et al., 2023; Sakellariou, 2012; Seddon et al., 2018). This growth mindset described "the actual pleasuring [as] physical; the touching [as] emotional" (Seddon et al., 2018, p. 296). This was linked to emotional healing (Seddon et al., 2018) and was described as liberating to be free from inhibitions and preconceptions of what sexual expression should look like for someone who sustained an SCI (Basson et al., 2003; Cramp et al., 2014; Hohmann, 1966; Leibowitz & Stanton, 2007; Sakellariou & Sawada, 2006).

This was a powerful realization in the concept of sexuality compared to before and after injury and participants reported that "after [the] accident and with the subsequent loss of sensation and motion in [their] lower limbs, sexuality is all about a need to get intimate with another human body rather than having anything to do with [their] own body" (Sakellariou & Sawada, 2006, p. 315).

# Analytical Theme 2: Establishing a Sexual Identity

The second analytical theme related to establishing one's personal sexual identity after the injury to facilitate sexuality. This analytical theme is underpinned by the descripted themes of being sexually active as a requirement to establish a sexual identity, as well as experiencing new and other ways of sexual expression which is supported by peers and positive relationships with a partner. Establishing a sexual identity included embracing sex to be important and normal. Furthermore, it involved being proactive, feeling attractive as well as positive attitudes and attributes.

Sex was identified as important and normal to people with SCI and establishing a sexual identity was a priority for some (Angel & Kroll, 2020; Beckwith & Yau, 2013; Christian et al., 2020; Cramp et al., 2014; Fritz et al., 2015; Hohmann, 1966; Leibowitz & Stanton, 2007; Morozowski & Roughley, 2020; Nevin & Melby, 2022; Sakellariou, 2012; Sharma, 2022; Taylan et al., 2022; Warren et al., 2018). Women participants described that "being paralysed does not mean that sexual intimacy is taken away ... and that women with SCI are able to enjoy their womanhood" (Fritz et al., 2015, p. 3).

Establishing a sexual identity, involved being proactive in exploring new avenues of sexual expression as described in the associated themes above including being sexually active and new ways of expression. This proactive approach included seeking specialist sexuality support and guidance to facilitate the reestablishing of a sexual identity (Beckwith & Yau, 2013; Thurston et al., 2021). One participant described how a health professional "book[ed] a taxi and [took them] to a sex shop ... to determine which sex products would suit their functional needs" (Beckwith & Yau, 2013, p. 319).

A positive sexual identity was also attributed to physical appearance such as wearing nice clothes, being clean, and wearing makeup (Angel & Kroll, 2020; Beckwith & Yau, 2013; Li & Yau, 2006; Parker & Yau, 2012; Westgren & Levi, 1999). This made it easier to attract a sexual companion post injury (Angel & Kroll, 2020). Engaging in sex gave participants "a very powerful feeling, [to feel] normal" (Westgren & Levi, 1999, p. 312). Feeling normal was important and helped participants to "start to have that little bit of self-love then you can start to grow from there" (Beckwith

& Yau, 2013, p. 320). Participants reported that positive sexual identity was also linked to positive attitudes and attributes. This included a variety of examples including incorporating creativity and curiosity (Beckwith & Yau, 2013; Richards et al., 1997; Sharma, 2022), openness (Angel & Kroll, 2020; Beckwith & Yau, 2013; Leibowitz & Stanton, 2007; McAlonan, 1996; Seddon et al., 2018), courage (Angel & Kroll, 2020), humor (Parker & Yau, 2012), self-acceptance (Fritz et al., 2015), and resilience (Morozowski & Roughley, 2020; Sunilkumar et al., 2015).

### Discussion

This article explores facilitators to sexuality for individuals with SCI. It synthesizes the existing qualitative literature on sexuality for people with SCI with a focus on positive aspects of sexuality post-SCI as opposed to the commonly identified barriers to sexuality. This review focused exclusively on people with lived experience rather than service provision, with an intentional lived experience focus rather than one on health service provision.

Overall, the results highlight the value of a strength-based approach. The findings show many facilitators to support a journey towards positive sexual experiences for people with SCI. These facilitators include being sexually active, new and other ways of sexual expression, peer support, and having a positive relationship with one's partner. Of course, these themes are intricately intertwined—for example, the impact of peer support impacts sexual activity, expression, and relationships; sexual activity and sexual expression are closely interrelated; and relationships relate to all themes.

Broadly, when these descriptive themes were combined, two deeper analytical themes emerged. Building positive sexuality post-SCI requires redefining sexuality and establishing a sexual identity. Postinjury sexuality can look different, but this is not a bad thing—it can include finding other areas of sexual pleasure, connecting with oneself or with partners in a different way, and viewing sexuality more holistically. Establishing a sexual identity incorporates embracing sex as a normal part of life, exploring new ways to express one's sexuality, and feeling and being perceived as sexual.

These, of course, are consistent with broader bodies of literature that recognize one's sexuality as an important, normal, and acceptable part of a person's experience—one's sexual citizenship (Weeks, 1998). In order to promote sexuality for people with SCI, we must, first and foremost, recognize their sexual citizenship—their right to be and be seen as a sexual being. When SCI research takes a barrier-focused approach to sexuality research, people's rights to sexual citizenship can be stymied.

Instead, we must take a sex-positive (Williams et al., 2013, 2015) approach to sexual rehabilitation for people with SCI. To promote sexuality, sexual activity can be facilitated by approaching sexual rehabilitation with knowledge of SCI levels, consideration of support levels available, and an open mind. Clinicians can support the exploration of new erogenous zones by providing access to adaptive sex toys and can refer clients to expert sexual-health workers who can facilitate body exploration to guide this process (Crane et al., 2023). Other facilitators include developing appropriate peersupport programs with well-trained peers which has been a source of support to couples post-SCI (Bryant et al., 2022; Osborne et al., 2023) and supporting access to adaptive clothing that can enhance body image and help people feel sexy (E. V. Thomas et al.,

2019). Sex-positive sexual rehabilitation should occur often and unobtrusively—gently opening the door to discussions of sexuality during inpatient rehabilitation and continuing those discussions in the years after injury. Clinicians of all types should be prepared to discuss sexuality at any time.

There is extensive literature highlighting the common struggles and possible changes to identity which inform practice. Sexuality research for people with SCI often identifies sexuality as a problem to be solved, leading to a focus on barriers. Of course, this is true for much of the research on sexuality and disability—unconscious biases are common (Antonopoulos et al., 2023) and can present in research questions leading to negatively framed research. This metasynthesis has demonstrated that despite barrier-focused research on sexuality and SCI, there are a plethora of facilitators to sexuality post-SCI, and the same is likely true for all sexuality and disability research.

This study does have limitations—the first of which is that all included papers were published in English. It is likely that important work has been published in languages other than English, and yet we miss the incorporation of those papers. Very few of the papers we included were from non-English-speaking cultures, presenting another related limitation. The choice to exclude mixed methods papers means that some relevant qualitive data may have been omitted from review; however, the high representation of barriers to sexuality and a health service provider focus in the existing literature is an indication that mixed method studies were unlikely to offer significant source data related to positive sexuality in a community setting. In addition, there was almost no research incorporating the views of individuals who were lesbian, gay, bisexual, transgender, queer/questioning, intersex, and asexual+ (LGBTQIA+), and for even more of the studies, sexual orientation was undisclosed, generally stemming from or leading to assumptions of heterosexuality.

Future sexuality research should be framed within a sex-positive lens, with an intentional eye to providing holistic and inclusive studies of sexuality post-SCI. Inclusivity is not limited to redefining sexuality beyond penetrative heterosexual intercourse and into other forms of sexuality including self-exploration and masturbation and touching but also establishing sexual identity and feeling like a sexual being. Inclusivity also includes intentionality relating to including people with LGBTQIA+ identities who have sustained SCI, particularly since people who are LGBTQIA+ are often excluded from sexuality and disability research either intentionally or by omission (Kokay et al., 2023).

Regardless, this is the first study to specifically and intentionally explore facilitators that promote positive sexual experiences post-SCI. Sex positivity should be a framework for sexuality work to educate and overcome societal disability related myths and to increase sexual opportunities—not just for individuals living with SCI but for sexuality research for people with any type of disability. There is a clear need for further exploration of sexuality facilitators within SCI and within disability at large. This study provides a strong basis for this exploration, noting that there are important facilitators to sexuality for people with SCI that should be discussed—clinicians and researchers should take heed.

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