THE UNIVERSITY OF SYDNEY

Sexuality and Women with Spinal Cord Injury

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A thesis submitted to fulfil the requirements of the degree of

Master of Philosophy

Faculty of Medicine and Health

The University of Sydney

2025

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Statement of Originality

This is to certify that the content of this thesis is my own work. This thesis has not been submitted for any other degree or purpose.

I certify that the intellectual content of this thesis is the product of my own work, and that all assistance received in preparing this thesis and all sources have been acknowledged.

Jolie Chantharath

Acknowledgements

I would like to thank my supervisors, Associate Professor Roxanna Pebdani and Associate Professor Jacqueline Raymond. Everybody tells me I struck gold having them as my supervisors – I sure did. Thank you for their patience, flexibility, understanding, support, guidance and teaching me so much over the last few years. I haven't found a way to thank Roxy and Jacqui for supporting me through a difficult work period. We only met on Zoom fortnightly, but they noticed the change in my energy and in me overall. Nobody else noticed this. I hope to repay them by executing everything they have taught me wherever I end up next.

I would like to express my gratitude to Elaine Tam, Academic Liaison Librarian at the University of Sydney Library, for her expertise in developing the search strategy for my scoping review.

I am grateful to the University of Sydney, which provided funding through the Postgraduate Research Support Funding Scheme, which was used for my first conference registration fee.

Thank you to the University of Sydney, Learning Hub (Academic Language and Learning) for the academic writing advice and workshops.

Thank you to the University of Sydney, Sydney Informatics Hub, for the research data management workshops.

To Tracey Pearce, for your work on the theme development. You had minimal turnaround time while juggling so many other things. Your insight and perspective were valuable and appreciated in this piece of work.

To the OG Health Sciences team for your support and friendship through the years while I pursued this thesis and other studies before this.

To the Sydney Business School, Business Co-Design team, for taking a chance on me, giving me fun opportunities and learning experiences that have helped me develop professionally and personally.

To the Sydney School of Education and Social Work – your support made the final stretch less stressful and took away any doubt of reaching the finish line.

To my friends, colleagues and family who have provided feedback on my drafts, for always listening to me talk about my research, reminded me to celebrate small wins and cheered me on from the sidelines.

This research was supported by an Australian Government Research Training Program (RTP) Scholarship.

Generative Artificial Intelligence (AI) Statement

The student used Microsoft Copilot and Grammarly for the purposes of text enhancement. The use of this generative AI tool includes spelling corrections, minor sentence restructuring, and clarity enhancement. The author confirms that where text was modified by generative AI, the content was reviewed for possible errors, inaccuracies, and bias. The author takes full responsibility for the submitted thesis, confirms the work is their own, and has used generative AI in accordance with the University's guidelines and policies.

Chapter 1: Introduction

Background and Rationale

Spinal Cord Injury (SCI)

Over 15 million people globally were living with spinal cord injury (SCI) in 2021, with the most common causes of SCI attributed to trauma, which include falls, road traffic injuries or violence (World Health Organization: WHO, 2024). Men are present in approximately 80% of the recorded cases of SCI (Raguindin et al., 2021), making women a minority in the SCI population. The percentage of women acquiring SCI has risen significantly, rising from 14.5% to 22.1% between periods 1943 to 1969 and 1990 to 2010 (Savic et al., 2017).

Health is conceptualised as a dynamic, continuous, and multidimensional state, and fundamentally shaped by an individual's ability to adapt to changing life circumstances and environmental conditions (Krahn et al., 2021). SCI impacts the physical, psychological, and social dimensions of health; however, physical implications are often the primary focus. Some common psychological conditions related to SCI include depression, anxiety and medical coping style (Liu et al., 2025). Social dimensions include impacts on social and intimate relationships, personal sense of inclusion in the community, living situation (financial, resources) and accessibility (services and equipment) (Budd et al., 2022). These physical, psychological and social dimensions of health are often interconnected and preserving health is a critical concern for individuals with SCI.

The effects of SCI are immediate, and daily activities and quality of life can be significantly diminished. The World Health Organisation (WHO) defines quality of life (QoL) as “an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (World Health Organisation, 2025). Meeting one’s QoL needs extends beyond

sheer survival; for individuals living with SCI, finding a way to adapt is critical to achieving a meaningful and satisfying life (Whalley Hammell & R, 1992).

Some common physical health conditions following SCI include spasticity, chronic pain, sexual dysfunction, UTI, autonomic dysreflexia, and bladder and bowel dysfunction (Krahn et al., 2021). Secondary health complications such as musculoskeletal pain, oedema, neuropathic pain, and urinary tract infections (Adriaansen et al., 2016) are common in SCI and can significantly diminish quality of life (Filipcic et al., 2021).

Sexuality and SCI

"Sexuality" encompasses a comprehensive concept that includes an individual's sexual identity, desires, and behaviours, as well as their sexual orientation. Sexuality can be influenced by personal, societal, and cultural factors (Neufeld et al., 2002). For cisgender men, cisgender women, and nonbinary or nongender conforming individuals, these influences continuously change sexuality throughout the lifespan.

SCI profoundly affects individuals' lives, especially their sexuality, with studies indicating that SCI impacts all dimensions of sexuality, including reduction in physical functioning and psychological health, and changes to self-identity (Alexander et al., 2017; Ehrmann et al., 2020). Physical dimensions of sexuality impacted by SCI can include reduced sexual activity and function, ejaculation, erectile dysfunction, orgasm, lubrication, bladder and bowel, and spasticity (Hess & Hough, 2012). Psychological impacts include higher levels of anxiety and depression (Craig et al., 2009). Self-identity can be impacted by body image, self-esteem, self-confidence, and redefining gender roles (Budd et al., 2022).

In addition to the impacts of SCI on physical and psychological dimensions of sexuality, social inclusion, and participation play a vital part in an individual's QoL. However, society often holds misconceived and stigmatised views towards people with disability and SCI, wrongly assuming it prevents one's ability to form relationships and lead a sexual life (Esmail et al., 2010). Sociocultural taboos about sexuality are often ingrained in laws and policies, leading to adverse effects on sexual health (Gruskin et al., 2019). For instance, the sexual desires, enjoyment, health concerns, and rights of individuals with disabilities are

often disregarded by wider society. People with SCI (and with disability in general) are often limited in accessing information and services related to sexuality and sexual health (Kismödi et al., 2015). This may influence how healthcare providers, carers, friends and family approach the sexuality of individuals with SCI. Expectation of heteronormative sex and lack of emphasis on sexual rights, information, and education are also stigmas that stem from societal perceptions (Esmail et al., 2010).

Sexuality is essential to human health and rights (Macleod & McCabe, 2020), making addressing post-SCI sexuality and sexual health imperative. Individuals with SCI often encounter inequalities in sexual healthcare (under-assessment, inadequate treatment (Nery-Hurwit et al., 2024) and face societal misconceptions of being nonsexual (Pebdani & Tashjian, 2022). Consequently, further efforts are necessary to eliminate these disparities and challenge misconceptions affecting minority groups with SCI, such as women.

Ageing, Sexuality and Sexual Health and SCI

Sexuality remains and continues to change throughout an individual's life. Understanding and acknowledging the changes in sexuality at the earlier stage of SCI is important, but also as individuals with SCI get older. With increasing life expectancy among those with SCI, sexual activity is likely to persist into older adulthood (Randazzo et al., 2024). Older adults do not become non-sexual; however, there is a misconception that they are no longer sexually active or interested in sex, and sexuality is unimportant, so it is unnecessary to ask them about their sexual health (Lee et al., 2016; Steckenrider, 2023). This societal stigma and ageism can lead to older adults not seeking and receiving sexual healthcare which in turn can impact an individual's QoL.

These issues are particularly relevant given the shifting age of people with SCI. The average age of an individual living with SCI has increased over recent decades due to population ageing (Ding et al., 2022). The percentage of newly injured people aged 60 and older nearly doubled from 8.2% (1970 to 1989) to 14.8% (1990 to 2010) (Savic et al., 2017). Another contributing factor to the change in the average age of individuals with SCI is the increasing life expectancy following SCI. A large, longitudinal study in the UK (Savic et al.,

2017) found improvements over the decades, with significant increases in life expectancy in the 1950s (30.8 years) and 1980s (43.6 years), followed by a slight increase in 2010 (47 years).

The older adult population without SCI have voiced cultural and societal views, stigma, discrimination, lack of education and training for healthcare professionals, and quality of the relationship between healthcare professionals and clients/patients as barriers to getting sexual health advice and treatment (Ezhova et al., 2020). Older adults also face other misconceptions, such as the term “sex” referring only to partnered intercourse (Steckenrider, 2023). This overlooks the need to adapt their sexual activity because of erectile dysfunction, vaginal dryness, arthritis, mobility issues, effects of medication, or serious health conditions, and disregards those who have lost or have an ill partner, or identify as LGBTQ (Steckenrider, 2023). In addition, many older adults live with disabilities that directly impact their sexual well-being (Randazzo et al., 2024), which can lead to older adults with SCI facing increased stigma and barriers generated by society.

Addressing sexuality and sexual health following SCI is vital to an individual’s QoL, regardless of age. Studies on older adults’ QoL (or life satisfaction) are limited, and there are even fewer longitudinal studies on life satisfaction for people with SCI while getting older (Zhao et al., 2024). In our systematic literature review (Chapters 2 and 3), we found a limited number of papers on ageing, sexuality and SCI (9 of 382, 2.3%). This indicates there is little emphasis on the older adult population living with SCI when it comes to their sexuality and sexual health and overall QoL. This may lead to unknown gaps or knowledge on what is experienced specific to their population.

In addition to the immediate impact SCI has on physical, psychological and social dimensions of health and well-being, which includes sexuality and sexual health, ageing-related SCI secondary health conditions also need to be factored in. Secondary health conditions – including osteoporosis chronic pain, neurogenic bowel and bladder dysfunction, urinary tract infections, pressure injuries, depression, and upper extremity musculoskeletal deterioration – may impact the sexuality and sexual health of older adults living with SCI

(Seijas et al., 2024). Women who were satisfied with their sexual life were significantly younger both at the time of follow-up from the time of injury (45 vs. 53 years) and at the time of injury (24 vs. 31 years) (Biering-Sørensen et al., 2012) – highlighting possible ageing factors impacting sexual satisfaction. Common conditions and how people from different genders experience ageing-related SCI health conditions also need to be considered.

Women and Ageing - Menopause

In addition to the common ageing-related and SCI health conditions, women will experience menopause, which is a complex condition that marks the end of a woman's menstrual cycles, resulting from the decline in cyclical estrogen and progesterone production. Menopause can occur in several ways: naturally, prematurely due to treatments like chemotherapy or radiotherapy, or surgically through the removal of the ovaries before natural menopause. Women may experience a wide range of physical, psychological, and emotional symptoms, which can vary in severity (Islam et al., 2025). Additionally, menopause is associated with increased health risks such as osteoporosis and cardiovascular disease (Schneider, 2002).

There are many perimenopausal symptoms, and a few are linked to impacts on sexuality. The Greene Climacteric Scale (GCS), a diagnostic tool includes a total of 21 items which include psychological (depression, anxiety, mood changes, irritability, unloved feelings), somatic (backache, crawling feelings under the skin, joint pain, muscle pain, headache, decreased libido, new facial hair, dry skin, dry vagina, brain fog, sleeplessness, unusual tiredness, uncomfortable intercourse, urinary frequency) and vasomotor (hot flushes, light-headedness) symptoms. Of the items listed on the GCS, four symptoms are linked to impacts on sexuality: feelings of being unloved, decreased libido, dry vagina, and uncomfortable intercourse.

Kalpakjian et al., (2010) found that women with SCI going through menopause reported being more affected by somatic symptoms, frequent bladder infections, and reduced sexual arousal than women without SCI. While these findings show the impacts SCI and menopause can have on women’s sexuality, there is limited research on menopause

generally, and this is even more limited for people with SCI experiencing menopause (Kalpakjian et al., 2010; Stuenkel et al., 2024).

One of the recommendations found in a systematic review of Clinical Practice Guidelines (CPG) for the rehabilitation and management of the ageing population with SCI was about the education for women with SCI about the effects of perimenopausal and menopausal changes on sexual function, bone health, accelerated metabolic ageing, and metabolic syndrome after SCI (Seijas et al., 2024). While this recommendation was strongly in favour of education for women with SCI about the effects of perimenopausal and menopausal changes, it lacked sufficient evidence to support such education. This demonstrates the need to direct research into this area of ageing for women with SCI, as menopause symptoms such as dry vagina, decreased libido, and uncomfortable sexual intercourse are likely to impact sexuality.

Conclusion

The impacts of SCI on an individual are life-altering in multiple ways – broadly in the physical, psychological, and social dimensions of health. SCI impacts sexuality and sexual health and has elements that fall under the physical, psychological and social elements. The journey of sexuality and sexual health continuously changes across the lifespan – being influenced by individual experiences, beliefs, cultures and societal expectations. One aspect that does not change is the human right to sexuality and sexual health throughout the lifespan (Gruskin et al., 2019). Whether it is through education, treatment, or inclusivity, access needs to be equal and equitable. SCI, sexuality, and sexual health need to be approached from the perspective of multiple lenses (men, women, older adults) to understand the impacts SCI has on people across their lifespans.

This thesis, comprised of five (5) chapters, sets out to identify the gaps and themes in sexuality over the past 70 years of SCI research, and ageing's impact on sexuality and the experiences and effects of ageing for women with SCI. The aims of this thesis are to:

1. Identify the knowledge gaps and trends in sexuality research for women with SCI
2. Identify the age-related themes in sexuality research for women with SCI
3. Identify how ageing affects the sexuality of women with SCI

Chapter 1 provides background and rationale for this thesis. Chapter 2 presents a scoping and bibliometric review, outlining the research journey of sexuality and SCI. Chapter 3 presents a report summarising the general literature on sexuality, ageing with SCI, a detailed analysis of 10 papers from the first study (Chapter 2), and the changes and impacts on sexuality and sexual health following SCI throughout the lifespan. Chapter 4 presents the findings of a qualitative study of the experiences of ageing and SCI on sexuality for women with SCI. Chapter 5 presents a comprehensive examination of the study outcomes, consolidates the overall findings, and highlights the contributions made to the current research landscape. This in-depth exploration of sexuality and SCI across the lifespan, with a focus on women's experiences, ultimately contributes to a more nuanced understanding of this often-overlooked aspect of life with SCI.

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Chapter 2

This chapter presents the paper in its original form as submitted to the journal - *Spinal Cord*. It was recommended for transfer to Spinal Cord Series and Cases two days prior to thesis submission. Instead, we intend to submit to Disability and Rehabilitation

70 Years of Sexuality and SCI Research: Where Are We Now?

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We have no conflict of interest to disclose.

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Abstract

Study Design: A **s**coping review and bibliometric analysis

Objectives: This paper examined existing studies on SCI and sexuality, aiming to identify gaps and trends, and present the current state of SCI and sexuality research.

Methods: This study used a scoping review, bibliometric analysis methodology and conducted a literature search across five academic databases. Keywords were sexuality, counselling, sex, sexual dysfunction, sexual behaviour, sex education, sexual health, sexual need, spinal cord injury, paraplegia, tetraplegia, and quadriplegia. Literature management software (Covidence) was used to manage dual review across all aspects of screening. Data were examined using descriptive statistics and Chi-square tests.

Results: This review demonstrated a consistent increase in the number of published papers on sexuality and SCI over the decades, with the majority involving men participants. The focus of papers involving men were on sexual activity and sexual function whereas for papers involving women, the focus was spread across more areas, including sexual activity, orgasm, masturbation, pain, bladder, bowel, spasticity, counselling, education, and relationships.

Conclusion: The findings show an imbalance in the research focus areas and trends in study design, areas of focus (outcomes) and interventions on sexuality for people with SCI spanning the last 70 years.

Keywords: sexuality, spinal cord injury, gender, sex, scoping.

70 Years of Sexuality and SCI Research: Where Are We Now?

Globally, over 15 million people were living with spinal cord injury (SCI) in 2021 (1). SCI significantly impacts individuals' lives, particularly their sexuality and overall well-being. Research shows that SCI affects all aspects of sexuality, including physical function, psychological well-being, and identity (2,3). Sexual function is one of the common problems frequently reported in SCI, with 77.4% reported in men and 57.5% in women (3). Men experience SCI at much higher rates than women, making women with SCI a minority within the SCI population. Consequently, women receive less support and information on sexuality compared to their male counterparts (4,5). SCI research, overall has primarily focused on men, leaving gaps in understanding comorbidities, and potential complications for women following SCI (6).

Since sexuality is fundamental to an individual's health and rights (7), sexuality post-SCI is crucial to address. People with SCI often face inequalities in sexual healthcare and societal stereotypes of being non-sexual (8). Addressing the sexual needs of individuals with SCI through effective rehabilitation and educational programs is crucial for enhancing their overall quality of life (9,10,4). Further, it is essential to ensure that these programs incorporate an expanded view of sexuality, moving beyond penetrative heterosexual intercourse to encompass other expressions, such as self-exploration, masturbation, and touch, as well as the development of sexual identity and the sense of being a sexual individual (11). Additionally, inclusivity requires a deliberate effort to include individuals with LGBTQIA+ identities with SCI, especially since LGBTQIA+ individuals are frequently overlooked in sexuality and disability research (12).

Given that sexuality is an integral part of an individual's health and well-being, this paper aims to examine the current state of sexuality and SCI research by exploring and analysing available literature. By identifying and analysing gaps and trends in gender differences, physical and psychological outcomes, and types of interventions, this paper seeks to shed light on the areas requiring further investigation.

Method

This paper combines a scoping review with bibliometric analysis, based on the approach of Menzemer et al., (2023). Given the large volume of papers and broad exploration of the topic area, a scoping review protocol was used to provide an overview of the literature in SCI and sexuality and identify trends and gaps while the bibliometric analysis was conducted to identify publication numbers and locations of the literature (13). The PRISMA extension for scoping reviews (PRISMA-ScR) (14) was followed in reporting the various components of this scoping review.

Eligibility

Studies reporting on sexuality that involved participants with acquired SCI of all ages and genders were included in the review. Studies that were solely about sexual orientation, were in abstract form only, were not in English, had not been peer-reviewed or did not include human participants were excluded. Studies where data from participants with acquired SCI could not be isolated from those with congenital SCI or other types of disabilities were also excluded. When studies included data on participants other than those with SCI, only the data from participants with SCI were used. Additionally, only outcomes that were explicitly presented in the results were recorded. That is, if the study methods reported collecting relevant data, but did not report on these in the results, we did not include these outcomes in the data analysis.

Search Strategy

A librarian-assisted literature search was conducted in five databases - CINAHL Complete, Medline, Embase, PsychINFO and Scopus. Keywords were sexuality, counselling, sex, sexual dysfunction, sexual behaviour, sex education, sexual health, sexual need, spinal cord injury, paraplegia, tetraplegia, and quadriplegia. Research from the earliest record of research databases to 31 December 2023 was included.

Selection of Studies

Literature management software (15) was used for all aspects of screening. The screening was completed by three reviewers. One reviewer (JC) completed screening for all studies, with the other two authors sharing the task of duplicate review. Papers were first screened by title and abstract, then by full text. Where two authors could not come to consensus in screening, the third author was consulted. This process was then repeated for data extraction.

Data Extraction

A data extraction template was customised in Covidence. The extraction template captured paper details including location, study design, study topics and outcomes, interventions, whether partners were included in the study, gender and sexual orientation of participants, and missing areas related to sexuality and rehabilitation. The extraction template also captured reported outcomes, which were separated into physical and psychological domains. Physical outcomes included sexual activity, ejaculation, erectile dysfunction, erection, orgasm, function, frequency, vaginal lubrication, masturbation, pain, pleasure, bladder, bowel and spasticity. Psychological outcomes included counselling, desire, education, relationship, satisfaction, anxiety and depression. Similarly, papers were assessed for the inclusion of an intervention which were categorised into either physical or psychological interventions.

Analysis

Data were exported from Covidence and analysed using a statistical software package (IBM SPSS Statistics, Version 29). Descriptive statistics, including frequencies and proportions were calculated. Publication numbers and location were recorded. Location was categorised by location of study or where this information was unavailable, countries identified by lead author's affiliate institution. Chi-square tests of independence were used to compare the distribution of a categorical variable in a sample group with the distribution in another sample group by checking if the observed frequencies in one or more categories

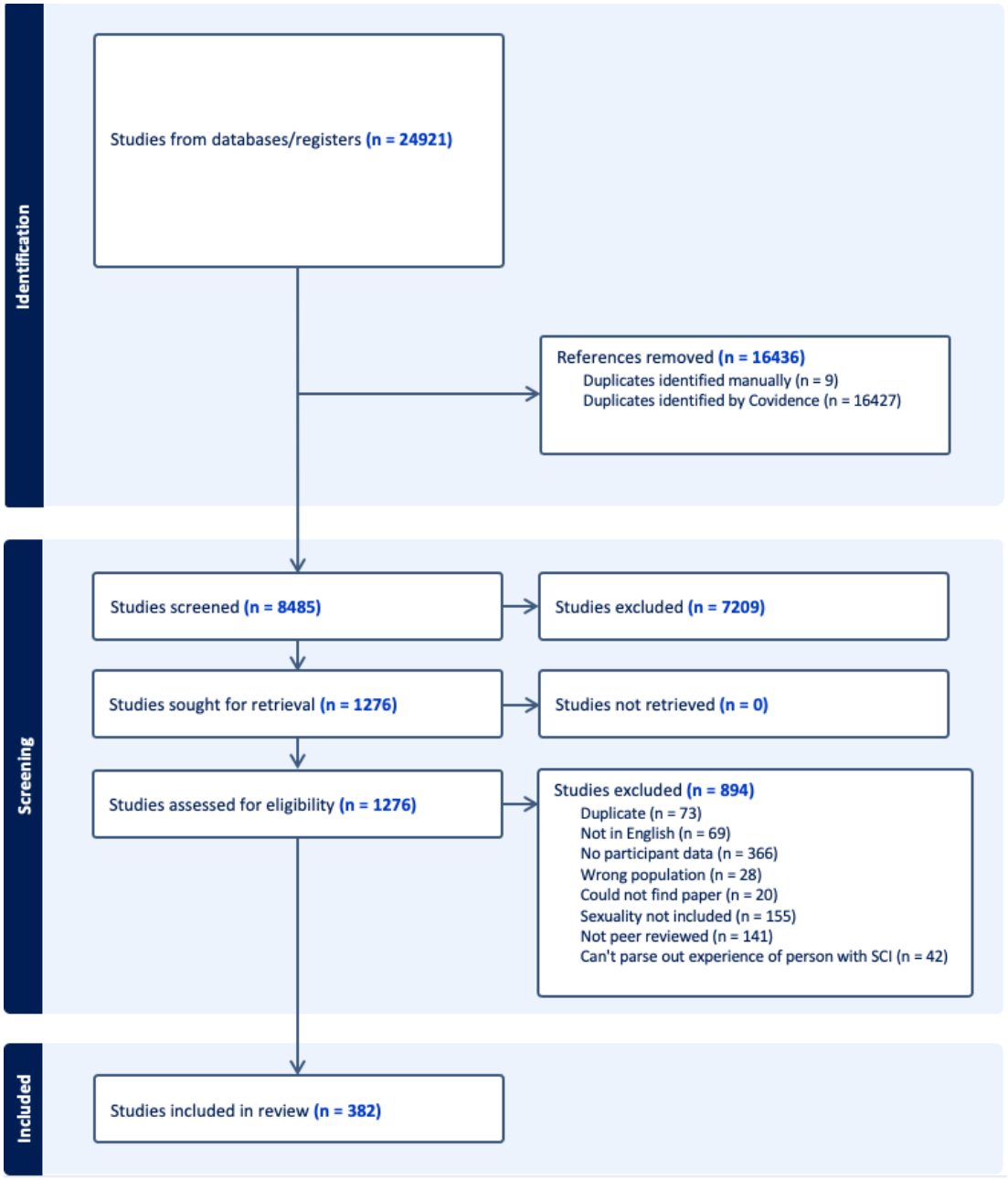
matched the expected frequencies. Where the data did not meet a minimum of five (5) cases in each cell, the Chi-square test was not completed (16). However, these data are still reported in descriptive statistics. The alpha level was set to 0.05 for all statistical tests. Microsoft Excel was used to generate graphs.

Results

In total, 24,921 papers were identified in the initial database search and 16,436 duplicates were removed. After title and abstract screening, 1,276 papers remained. Following full text review, data were extracted from 382 remaining papers. Further detail of the systematic search can be found in the PRISMA diagram (Figure 1). Of the 382 papers included in this study, 149 (39%) papers involved only men participants, 83 (21.7%) involved only women participants, and 132 involved both men and women participants. Eighteen papers did not report participant gender.

Figure 1

PRISMA diagram



Location and Publication of Studies

Published papers on sexuality and SCI increased over time, with the first study published in 1950. Twenty-eight studies were published in the 1980's, 79 published in the 1990's, 89 published in the 2000's, and 110 published in the 2010's. Through the entirety of

the study period (1950 to 2023), more papers were published with only men participants than only women participants (n=149, women n=83). Data between 1950 to 2019 showed an overall increase of publications for both men and women. Since 2020, most papers published have included both men and women (Figure 2 Appendix 2A). Studies were conducted across all inhabited continents. Between the 1950's to 2023, most studies were from North America, followed by the United Kingdom and Australia.

Gender and Study Design

The following results exclude the 18 papers where gender was not reported. Two-hundred-eighty-two papers (77.5%) used a quantitative study design and 72 (19.8%) used a qualitative study design. The remaining papers used a mixed methods design or were case reports (n=10). These were excluded from statistical analyses as Chi-square tests of independence require a minimum of five (5) cases in each cell. Of the 149 papers that included only men as participants, 123 utilised a quantitative study design (82.6%) and 25 used a qualitative design (16.8%). For the 83 papers that included only women as participants, 53 were quantitative (63.8%) and 26 were qualitative (31.3%).

Paper Outcomes

Outcomes by Gender

The following results exclude papers where gender was not reported (n=18) or papers which included both men and women participants (n=132), leaving 232 papers for analysis. A Chi-square test of independence was performed to explore the relationship between gender, physical and psychological outcomes with only men or women participants. One hundred and forty (94%) papers involving men included physical outcomes, and 81 (97.6%) of papers involving women included physical outcomes. Eighty-seven (58.4%) papers involving men included psychological outcomes. Women were more likely than men to be involved in papers that included psychological outcomes $\chi 2$ (1, n= 232) = 4.436, p= 0.035. No significant relationship was found between gender and physical outcomes $\chi 2$ (1, n= 232) = 1.556, p= 0.212.

For papers that included only men as participants (n=149), erection (n=72, 48.3%), ejaculation (n=66, 44.3%), erectile dysfunction (n=48, 32.2%), and sexual activity (n=48, 32.2%) were the most common physical outcomes. Satisfaction (n=59, 39.6%) and relationships (n=34, 22.8%) were the most common psychological outcomes.

For papers that included only women as participants (n= 83), orgasm (n=48, 57.8%), bladder (n=40, 48.2%), sexual activity (n=41, 49.4%), and vaginal lubrication (n=26, 31.3%) were the most common physical outcomes. Satisfaction (n=30, 36.1%) and relationships (n=39, 47%) were the most common psychological outcomes.

Outcomes by Study Design and Gender

Figures 2 and 3 present each outcome by study design. For quantitative papers that included only men as participants, erection (n=62, 50.4%), ejaculation (n=58, 47.1%), erectile dysfunction (n=43, 34.9%), and orgasm (n=39, 31.7%) were the most common physical outcomes. Satisfaction (n=53, 43.1%) was the most common psychological outcome. For women, orgasm (n=31, 58.5%), bladder (n=21, 39.6%), sexual activity (n=23, 43.4%), and vaginal lubrication (n=18, 34%) were the most common physical outcomes. Satisfaction (n=20, 37.7%) was the most common psychological outcome.

Figure 2

Physical and Psychological Quantitative Outcomes separated by Gender

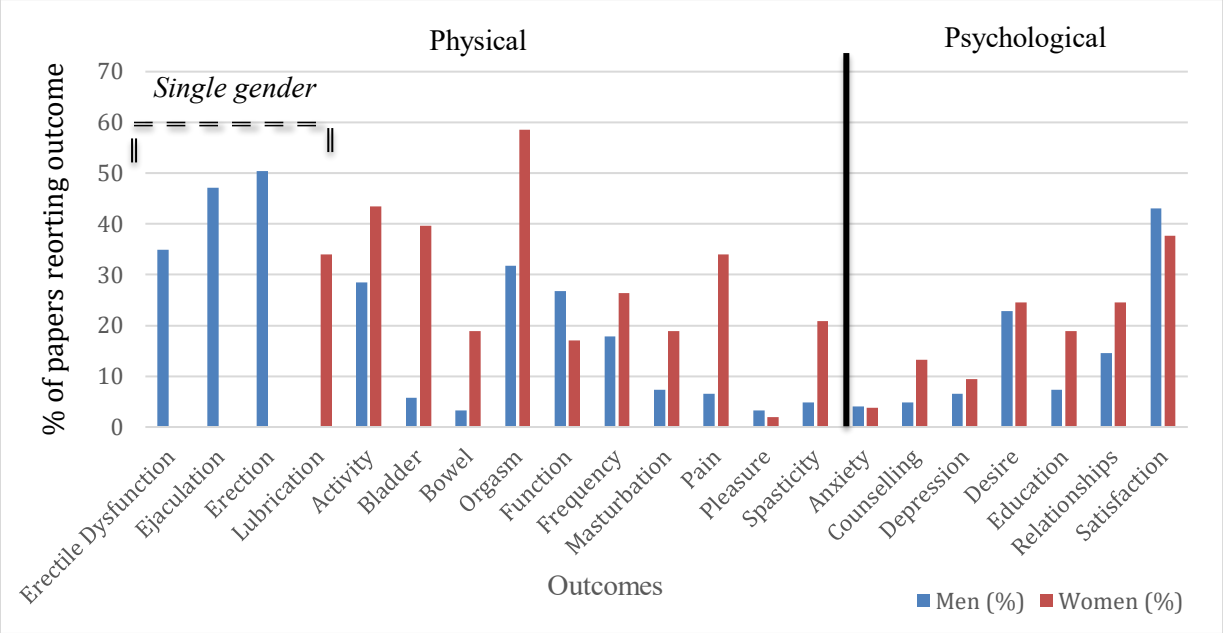
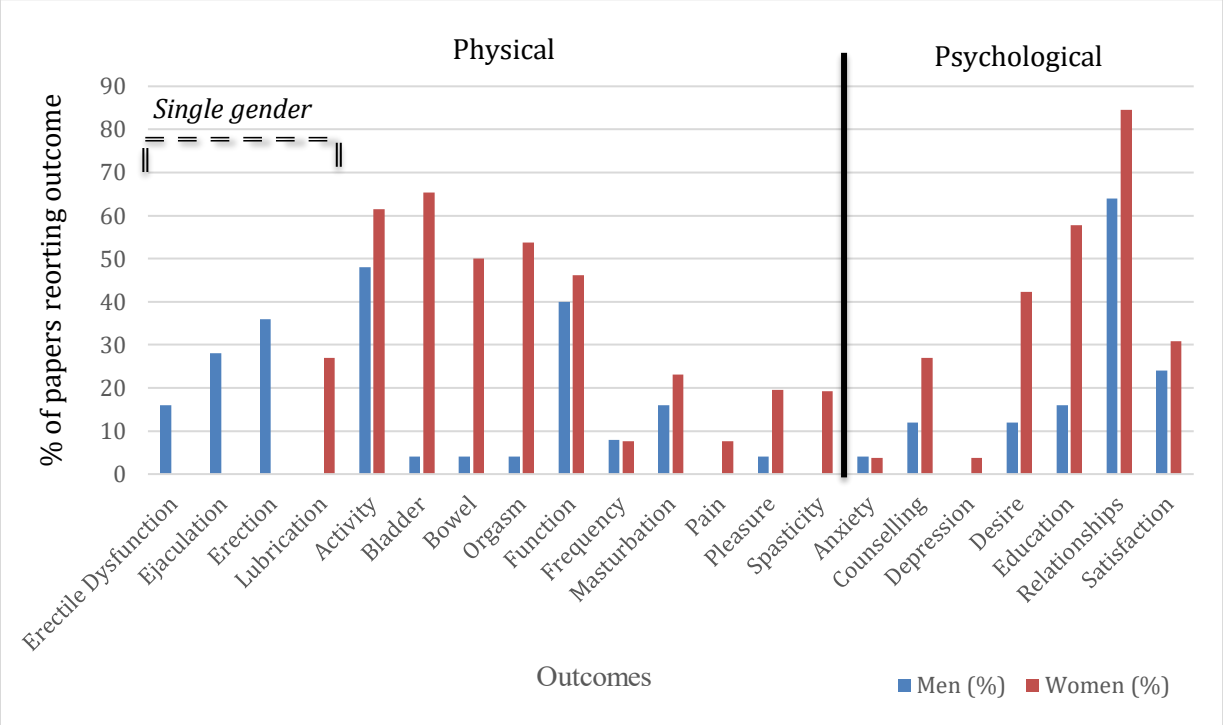


Figure 3

Physical and Psychological Qualitative Outcomes separated by Gender



For qualitative papers that included only men as participants, erection (n=9, 36%), ejaculation (n=7, 28%), erectile dysfunction (n=4, 16%), sexual function (n=10, 40%) and sexual activity (n=12, 48%) were the most common physical outcomes. Relationships (n=16, 64%) was the most common psychological outcome. For women, bladder (n=17, 65.4%), sexual activity (n=16, 61.5%), and orgasm (n=14, 53.8%) were the most common physical outcomes. Relationships (n=22, 84.6%) was the most common psychological outcome.

For all papers (quantitative and qualitative), a Chi-square test of independence was performed to examine the relationship between gender and physical outcomes with only men or only women participants. Single gender outcomes (erection, ejaculation, erectile dysfunction and vaginal lubrication) were excluded from this analysis. Studies involving women were more likely than studies involving men to report on sexual activity $\chi 2$ (1, n= 232)= 6.656, p= 0.010, orgasm $\chi 2$ (1, n= 232)= 20.717, p= 0.000, masturbation $\chi 2$ (1, n= 232)= 4.623, p= 0.032, pain $\chi 2$ (1, n= 232)= 21.153, p= 0.000, bladder $\chi 2$ (1, n= 232)= 59.575, p= 0.000, bowel $\chi 2$ (1, n= 232)= 33.916, p= 0.000, and spasticity $\chi 2$ (1, n= 232)= 17.925, p= 0.000.

For all papers (quantitative and qualitative) with single gender topics excluded (erectile dysfunction, ejaculation, erection, vaginal lubrication), a Chi-square test of independence was performed to explore the relationship between gender and psychological outcomes (counselling, education and relationships) with only men or only women participants. Women were more likely than men to be in papers that included outcomes about counselling $\chi 2$ (1, n= 232) = 8.321, p= 0.004, education $\chi 2$ (1, n= 232) = 19.47, p= 0.000, and relationships $\chi 2$ (1, n= 232) = 14.44, p= 0.000. Table 1 provides all study outcomes which are reported as a percentage of the total number of papers involving men only (n=149) or women only (n= 83).

Table 1

Chi-square test of independence: Physical and Psychological Outcomes by Study Design and Gender

		Total		Chi-square				Quantitative Study Design		Chi-square				Qualitative Study Design		Chi-square			
		Men (n, % of men only papers) (n=149)	Women (n, % of women papers only) (n=83)	n	df	Chi-square statistic	p-value	Men (n, % of men only papers)	Women (n, % of women papers only)	n	df	Chi-square statistic	p-value	Men (n, % of men only papers)	Women (n, % of women papers only)	n	df	Chi-square statistic	p-value
Physical Outcomes	Sexual Activity	48, 32.2%	41, 49.4%	232	1	6.656	0.010**	35, 28.5%	23, 43.4%	176	1	3.742	0.053	12, 48%	16, 61.5%	51	1	.943	0.331
	Ejaculation	66, 44.3%	0	-	-	-	-	58, 47.1%	0	123	-	-	-	7, 28%	0	25	-	-	-
	Erectile Dysfunction	48, 32.2%	0	-	-	-	-	43, 34.9%	0	123	-	-	-	4, 16%	0	25	-	-	-
	Erection	72, 48.3%	0	-	-	-	-	62, 50.4%	0	123	-	-	-	9, 36%	0	25	-	-	-
	Orgasm	41, 27.5%	48, 57.8%	232	1	20.717	0.000**	39, 31.7%	31, 58.5%	176	1	11.092	0.001**	1, 4%	14, 53.8%	51	1	15.253	0.000**
	Sexual Function	43, 28.9%	22, 26.5%	232	1	0.146	0.702	33, 26.8%	9, 17%	176	1	1.977	0.160	10, 40%	12, 46.2%	51	1	.197	0.657
	Frequency	24, 16.1%	17, 20.5%	232	1	0.701	0.402	22, 17.9%	14, 26.4%	176	1	1.656	0.198	2, 8%	2, 7.7%	51	-	-	-
	Vaginal Lubrication	0	26, 31.3%	-	-	-	-	0	18, 34%	53	-	-	-	0	7, 26.9%	26	-	-	-
	Masturbation	14, 9.4%	16, 19.3%	232	1	4.623	0.032**	9, 7.3%	10, 18.9%	176	1	5.132	0.023	4, 16%	6, 23.1%	51	-	-	-
	Pain	8, 5.4%	22, 26.5%	232	1	21.153	0.000**	8, 6.5%	18, 34%	176	1	22.181	0.000**	0	2, 7.7%	51	-	-	-
	Pleasure	5, 3.4%	6, 7.2%	232	1	1.771	0.183	4, 3.3%	1, 1.9%	-	-	-	-	1, 4%	5, 19.2%	-	-	-	-
	Bladder	8, 5.4%	40, 48.2%	232	1	59.575	0.000**	7, 5.7%	21, 39.6%	176	1	31.877	0.000**	1, 4%	17, 65.4%	51	1	21.029	0.000**
	Bowel	5, 3.4%	25, 30.1%	232	1	33.916	0.000**	4, 3.3%	10, 18.9%	176	-	-	-	1, 4%	13, 50%	51	1	13.542	0.000**
	Spasticity	6, 4%	18, 21.7%	232	1	17.925	0.000**	6, 4.9%	11, 20.8%	176	1	10.700	0.001**	0	5, 19.2%	51	-	-	-

Psychological Outcomes	Counselling	9, 6%	15, 18.1%	232	1	8.321	0.004**	6, 4.9%	7, 13.2%	176	-	-	-	3, 12%	7, 26.9%	51	-	-	-
	Desire	31, 20.8%	26, 31.3%	232	1	3.183	0.074	28, 22.8%	13, 24.5%	176	1	.065	0.800	3, 12%	11, 42.3%	51	1	5.878	0.015**
	Education	13, 8.7%	26, 31.3%	232	1	19.47	0.000**	9, 7.3%	10, 18.9%	176	1	5.132	0.023**	4, 16%	15, 57.7%	51	1	9.477	0.002**
	Relationship	34, 22.8%	39, 47%	232	1	14.44	0.000**	18, 14.6%	13, 24.5%	176	1	2.499	0.114	16, 64%	22, 84.6%	51	1	2.852	0.091
	Satisfaction	59, 39.6%	30, 36.1%	232	1	0.269	0.604	53, 43.1%	20, 37.7%	176	1	.437	0.508	6, 24%	8, 30.8%	51	1	.293	0.588
	Anxiety	6, 4%	3, 3.6%	232	1	0.024	0.876	5, 4.1%	2, 3.8%	176	-	-	-	1, 4%	1, 3.8%	51	-	-	-
	Depression	8, 5.4%	6, 7.2%	232	1	0.325	0.569	8, 6.5%	5, 9.4%	176	-	-	-	0	1, 3.8%	51	-	-	-

** Chi-square significant p-value <0.05, '-' less than 5 cases to perform Chi-square test.

Interventions

Overall, 121 (32%) papers included one or more physical and/or psychological interventions. Of these, 98 papers (25.6% of the full dataset) included exclusively either men participants (n=72) or women participants (n=26). Studies including an intervention were more common in papers involving men than women (73.5% versus 26.5%).

The first paper to report on an intervention was in 1976 – a physical intervention involving participants of both genders. The first publication to report on an intervention involving men only was in 1979, and for women only was in 1989 (both physical interventions).

Papers reporting on physical interventions peaked in the 1990's (n=32) and declined in the 2000's (n=24) and 2010's (n=18). Papers reporting on psychological interventions followed a similar trend, peaking in the 1990's (n=8), then declining in the 2000's (n=4) and remaining steady in the number of studies in 2010's (n=5) and 2020-2021 (n=4).

Physical interventions were more common in studies focusing on men, with 61 papers (40.9% of men-only papers) on men compared to 19 papers (22.8% of women-only papers) for women. Psychological interventions were less common, with 11 papers (7.4%) for men and 7 papers (8.4%) for women. A significant relationship was found between gender and physical interventions $\chi 2$ (1, n= 232) = 7.686, p= 0.006, with papers involving physical interventions more likely to have only men participants. However, there was no significant relationship between gender and psychological interventions $\chi 2$ (1, n= 232) = 0.082, p=0.774.

Table 2 shows the types of interventions and the number of times these were recorded. Some papers included multiple types of interventions. There were more physical intervention types than psychological, however given the small number of interventions involving women, these were not able to be statistically analysed. Physical interventions included medically facilitated interventions, for example vacuum erection devices and penile

injections (n=33, 27.2%) or pharmaceutical interventions (n=29, 23.9%). Psychological interventions included counselling and education.

Table 2

Number of Intervention types by Gender

Intervention Type		Men	Women	Both	Unknown
Physical	Medically facilitated	33	3	1	1
	Pharmaceutical	29	2	0	1
	Physiological	7	13	0	1
	Surgical	9	1	2	0
	Other	2	3	4	0
Psychological	Counselling	4	1	3	2
	Education	3	1	4	2
	Other	6	6	0	0

Note: *Interventions that were categorised as 'Other' included electroejaculation, urethral catheterisation, and audiovisual erotic material.

Partners Surveyed

Of the 382 papers, 22 (5.8%) surveyed the partners of participants with SCI. The gender of the participant's partner was not reported in any of the papers. Eleven papers that surveyed partners in addition to the individuals with SCI included only men participants (7.3% of total papers involving only men), one (1.2% of total papers on women) included only women, eight (6% of total papers that included both men and women) included participants of both genders, and two did not report on gender.

Gender Diversity and Sexual Orientation

Of the 382 papers, 47 (12.3%) reported the sexual orientation of the participants and 30 (7.8%) included participants who were lesbian, gay, or bisexual. Of the 47 papers that reported sexual orientation, 14 (29.8%) were papers that included only men, 13 (27.7%) were papers that included only women, 19 (40.4%) were papers that included men and women participants, and 1 (2.1%) was a paper that did not report gender. Five papers (1.3% of the total 382 papers) included participants who were transgender.

The first papers that reported sexual orientation of participants were in the 1970's (n=4, 8.5%). The number of papers reporting sexual orientation peaked in the 1990's (n=11,

23.4%) and remained consistent to the 2010's (n=11, 23.4%). The number of papers reporting on sexual orientation from 2020 to 2023 has already equalled the total reported in both the 1990s and the 2010s.

Missing Areas Related to Sexuality and Rehabilitation

A total of 32 papers (8%) reported that participants lacked or had missing aspects in their rehabilitation related to sexuality. Eight (25%) of these papers included only men participants and 24 (75%) included only women participants. Counselling, education and resources (n=30, 93.8%), and opportunities to discuss the topic with clinicians (n=2, 6.2%) were identified as missing areas. The first paper to report missing or lacking areas related to sexuality during rehabilitation was in 1982 and involved women. The first paper involving men was in 1999.

Discussion

This paper provides fresh perspectives and a broad overview of the relationship between SCI and sexuality. Analysing 382 papers spanning the past 70 years, we discovered that the representation of men and women in SCI research is different than previously assumed fields (4,5). While there is more research that included only men as participants, the sexuality topics in these papers are narrow and focused primarily on sexual activity and sexual function (i.e. erection, ejaculation, erectile dysfunction). In contrast, studies involving women address a wider range of physical outcomes compared to studies involving men. The area of intervention studies comparing physical and psychological approaches reveals a greater focus on physical interventions for men participants than women participants. Through comprehensive data collection and analysis across various study designs, physical and psychological outcomes, and interventions, we were able to identify significant gaps and emerging trends in the field, thereby enhancing our understanding of sexuality and SCI research.

Gender differences

The literature reflects notable differences in the outcomes reported for men and women following SCI. Research on men, has historically focused on outcomes directly related to sexual function and sexual activity – ejaculation, erectile dysfunction, erection, with comparatively less attention to secondary outcomes associated with, but not directly related to, sexual function and activity i.e. bladder, bowel, spasticity. This variation may be due to a wider focus of research on physical outcomes and physical markers of sexual performance for men, such as achieving and sustaining an erection and ejaculation (17). This is consistent with sexuality research broadly (18). In contrast, for women, research shifted away in the 1990's from exclusively examining the pathophysiological effects of SCI on sexual function, and instead moved towards a more inclusive exploration of women's sexuality as well as sexual and reproductive health (19). This likely explains the reported broader scope of outcomes such as orgasm, sexual activity, bladder, and relationships.

Sexual rehabilitation

Studies have found that improving sexual function post SCI would improve the quality of life for individuals with SCI however, sexual rehabilitation remains an underexplored area (19,20). This review found few papers (8% of the total papers) where participants reported an area lacking or missing aspects relating to sexuality during rehabilitation. Participants in our study highlighted the following areas missing from sexual rehabilitation: counselling, education, resources, and opportunities for participants to discuss sexuality with clinicians. A study by Bryant et al., (2021) noted that sexual education is essential for supporting an individual's sexuality following SCI. Despite the recognised need for education and counselling, there is a significant gap in the delivery of sexual rehabilitation (21).

While non-medical approaches (counselling and educational resources/programs) can be implemented, the support provided is often inconsistent and limited (22). Consistency and integration of sexual rehabilitation will normalise discussions about sexuality within SCI rehabilitation settings (23). As sexuality is fundamental to an individual's health and rights

(7), this highlights the necessity for broadening research across various domains to advance intervention and therapeutic strategies for sexuality and SCI (24).

Underrepresentation of populations: Women and LGBTQ+

The underrepresentation of populations in health research can lead to the generalisation of research findings for the overall population, lack of access to interventions, economic loss, and decrease in innovation (25). Despite girls and women accounting for 50% of the population, they are often excluded from research for being a “complicated” model organism compared to men (26). While women account for approximately 20% to 25% of the spinal cord injury (SCI) population (27), they represent only 12.5% to 25% of participants in various studies (6). This reflects a similar percentage of women representation in this review of 21% (83 of the 382 papers).

Similarly, very few papers reported on participants who were gender expansive (i.e. beyond a gender binary), nor did they report on the sexual orientation of participants. This underreporting suggests a prevalent assumption of gender binary and heteronormativity within participants. The lack of reporting on sexual orientation highlights a gap in addressing the diverse experiences of participants and highlights the need for more inclusive research that accounts for both gender and sexual orientation (12). In turn, collection of data will affirm LGBTQIA+ people with SCI in clinical spaces and improve research (28).

Limitations

This study, while comprehensive in its analysis of sexuality and SCI research, has several limitations. The large dataset allowed for extensive identification and analysis of research areas, but insufficient sample sizes hindered some comparisons of study design, gender, and other topics. Many papers including both men and women participants were excluded from certain analyses to focus on gender comparisons, though this data is available in the supplementary materials. The search phase excluded papers that combined SCI data with other disabilities or congenital SCI, potentially omitting relevant research. During data extraction, inconsistent reporting of study locations led to assumptions based on

lead authors' affiliations, potentially misrepresenting some study locations (Figure 3, Appendix 2B). Additionally, the exclusion of non-English papers introduced language bias, likely skewing location data and potentially adding a Westernised perspective to the analysis.

Conclusion

This paper traces the evolution of SCI and sexuality research over the past 70 years. Our study uncovered gender imbalances and stressed the need for a broader approach that includes and considers all domains of SCI and sexuality research. Through extensive data collection and analysis - covering study designs, physical and psychological outcomes, and interventions- we have identified significant gaps and emerging trends, providing a more detailed understanding of the evolving landscape of SCI and sexuality research and directions for the future.

Acknowledgements

The authors express their gratitude to Elaine Tam, Academic Liaison Librarian at the University of Sydney Library, for her expertise in developing the search strategy for this review.

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Appendices

Table 1 (Appendix 1A)

Number of Papers Published on SCI and Sexuality by Country and Gender

Country	Number of papers	Number of papers for only men participants	Number of papers for only women participants
United States	139	52	43
Canada	39	20	4
United Kingdom	21	6	3
Australia	20	5	3
Italy	18	9	2
Sweden	18	3	4
Iran	14	5	6
France	12	9	1
Brazil	11	7	1
Turkey	11	3	1
Republic of Korea	9	2	0
Spain	8	2	2
Denmark	7	2	2
Germany	7	5	0
Greece	6	4	2
India	6	2	2
Finland	5	2	2
Norway	5	2	2
The Netherlands	5	2	0

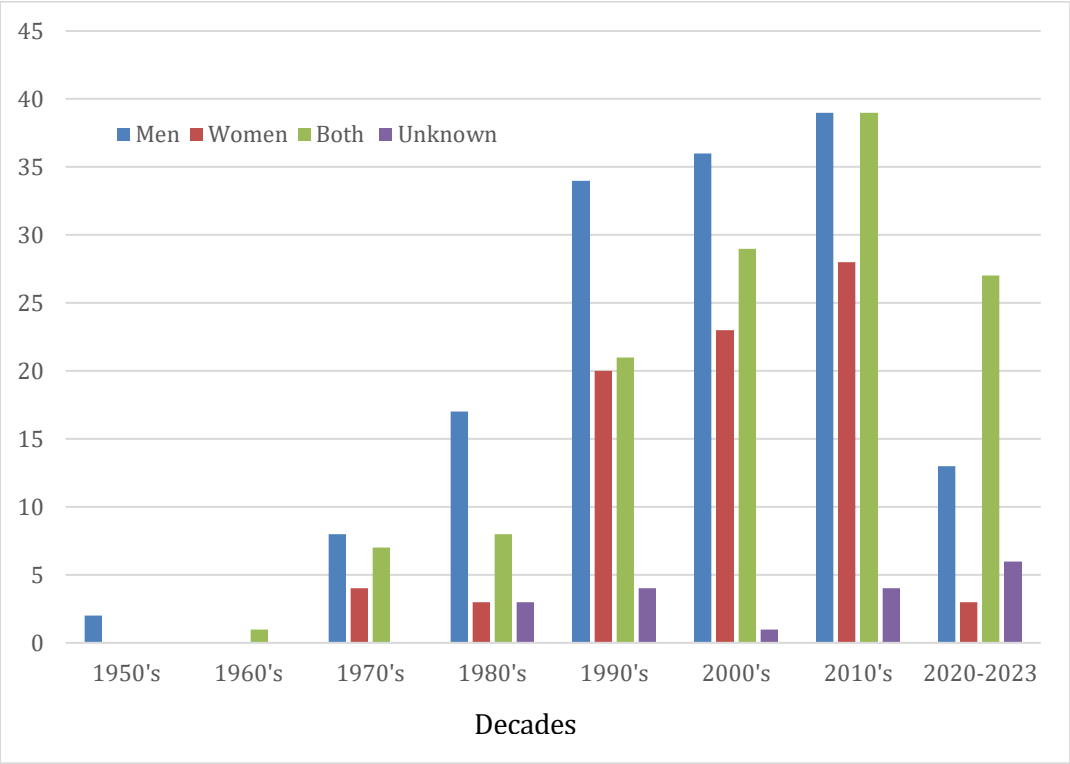
Note: Papers not in English were excluded as per study inclusion criteria. Four studies were conducted in China, three papers in Israel, Japan, Malaysia, Poland,

Taiwan, two papers in Belgium, Colombia, Iceland, New Zealand, South Africa and Switzerland, and one each in Austria, Bangladesh, Botswana, Chile, Czech Republic, Ghana, Indonesia, Mexico, Northern Ireland, Pakistan, Portugal and Sri Lanka.

The table (Appendix 1A) provides a list of countries that recorded five or more papers between 1950's to 2023 and includes a breakdown of location of papers for each gender category.

Figure 2 (Appendix 2A)

Number of Papers Published on SCI and Sexuality by Decade and Gender

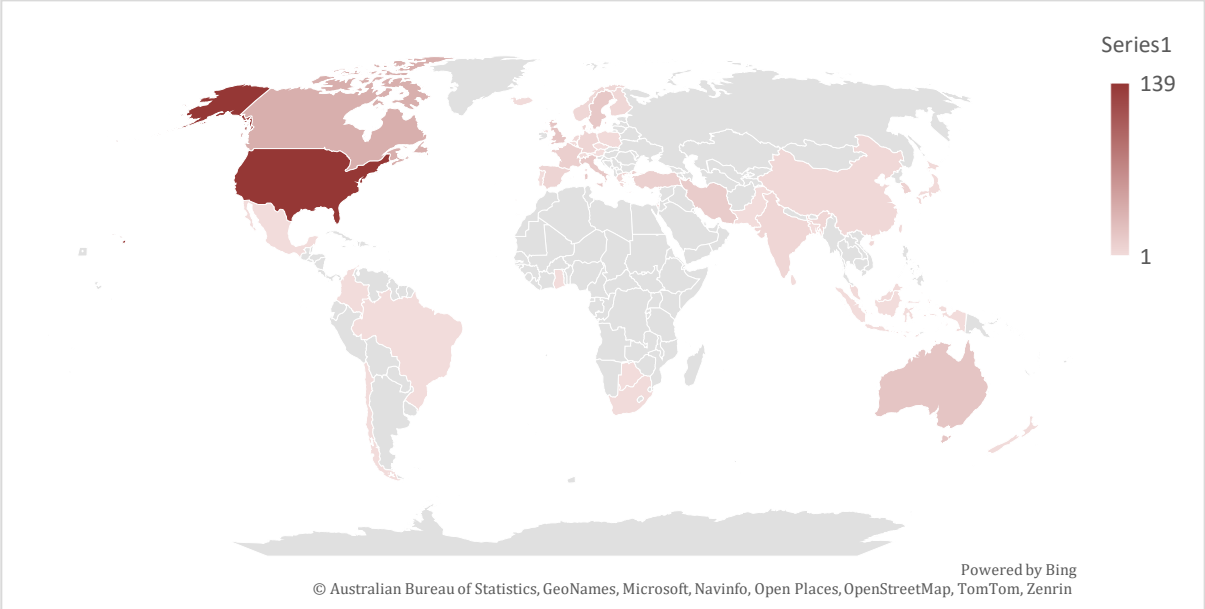


Note: 2020-2023 Incomplete decade

Figure 3 (Appendix 2B)

Heat Map of Publications on SCI and Sexuality by Country

The heat map indicates the location where studies were conducted or the lead author's affiliate institution if the study location was not clearly identified.



Chapter 3:
Ageing, Sexuality and SCI

Abstract

Background

Individuals with spinal cord injury (SCI) can face age-related social, physical, and psychological health issues that are closely linked to sexuality and sexual health (Smith et al., 2015). Sexuality and sexual health are human rights and remain relevant throughout a person's life, but individuals with SCI often face inequalities in sexual healthcare and are subjected to societal misconceptions as being nonsexual (Esmail et al., 2010; Pebdani & Tashjian, 2022). As the general population continue to live longer (Béjot & Yaffe, 2019) and the life expectancy of people with SCI has similarly improved (Randazzo et al., 2024), it is increasingly important to understand the physical, psychological, and social dimensions of sexuality and sexual health in ageing individuals with SCI.

Aim

This chapter aims to explore the physical, psychological, and social dimensions of sexuality and sexual health in individuals ageing with SCI, recognising the growing importance of understanding these interrelated factors in the context of long-term wellbeing.

Method

This chapter draws from the larger scoping review of 382 papers on sexuality and people with SCI in Chapter 2. Ageing-related articles within this larger study were isolated using the following keywords: age, ageing, older, menopause, and longitudinal. This resulted in a subset of 10 papers, which were then analysed and synthesised.

Results

Men and women ageing with SCI experienced physical outcomes related to sexuality and sexual health, such as decreased sexual activity, sex drive and sexual

dysfunction, as well as psychological outcomes that included decreased or low satisfaction with sex life and wanting access to counselling or educational resources.

Conclusion

The limited studies available point to consistently low sexual satisfaction in this population and highlight the need for greater attention to gender-specific experiences, especially those of women. These findings underscore the importance of developing inclusive, tailored approaches to sexual health education and support. Future research should prioritise filling these gaps to enhance sexual well-being and overall quality of life for ageing individuals with SCI.

Introduction

Chapter 3 builds upon the findings of the scoping review presented in Chapter 2. The scoping review provided the landscape of SCI research, which showed an imbalance in the research focus areas and trends in study design, areas of focus (outcomes) and interventions on sexuality between men and women with SCI spanning the last 70 years.

As longevity and health outcomes improve among the ageing population, including individuals with SCI, sexual activity is increasingly likely to continue into later life (Randazzo et al., 2024). However, misconceptions about sexuality in older adults persist, leading to societal stigma and barriers to sexual healthcare (Steckenrider, 2023). This issue is further heightened for older adults with SCI, who face additional sexuality-related challenges associated with their SCI (Gillen & Reynolds, 2021). Some of these challenges include bowel and bladder incontinence, difficulties with vaginal lubrication, and erectile dysfunction (Jörgensen et al., 2021). Despite the universal nature of sexuality and its importance throughout the human lifespan, there is limited research on the interconnection of ageing, sexuality, and SCI.

The impact of SCI on sexuality and sexual health is complex, involving physical, psychological, and social well-being (relationships, community, belonging). Additionally, ageing-related secondary health conditions associated with SCI, such as osteoporosis,

chronic pain, and neurogenic bowel and bladder dysfunction, further affect sexual health and overall quality of life (Schneider, 2002; Seijas et al., 2024). Gender-specific concerns, such as menopause in women with SCI, add another layer of complexity to the issue, with less common menopause symptoms such as fatigue, general aches and pains, low mood, and atrophic vaginitis often being misdiagnosed or overlooked (Barber & Charles, 2023).

Through a sub-analysis of research papers from the larger study in Chapter 2, this chapter aims to explore the physical, psychological, and social dimensions of sexuality and sexual health in individuals ageing with SCI, recognising the growing importance of understanding these interrelated factors in the context of long-term wellbeing.

Methods

This chapter draws from the larger scoping review on sexuality for people with SCI in Chapter 2. The review employed a scoping review and bibliometric analysis, conducting a literature search across five academic databases using keywords related to sexuality and spinal cord injury. In this chapter, ageing-related articles within this larger study were isolated using the following keywords: age, ageing, older, menopause, and longitudinal. The ageing-related articles' participant gender numbers, physical and psychological outcomes were included for analysis.

Results

A total of 382 papers were included in the larger scoping review on sexuality and SCI. Following the isolation of ageing-related papers from that study, ten (2.6%) papers were identified that were published between 2002 and 2021. Three papers (Pentland et al. 2002; Dannels and Charlifue 2004; and Kalpakijan et al. 2010) included only women participants (n= 175), five papers (Jorgensen et al., 2021; Smith et al., 2015; Fisher et al., 2002; Krause et al. 2005, 2006 & 2011) included both men and women participants (men n= 287, women n= 68), one paper (Lombardi et al., 2010) included only men participants (n= 99), and one paper (Smith et al., 2015), did not report the gender breakdown for the participants with SCI.

Two papers (Dannels and Charlifue 2004; and Kalpakijan et al. 2010) were about menopause, and four (Fisher et al., 2002; Jörgensen et al., 2021; Lombardi et al., 2010; Smith et al., 2015) were general ageing studies with a variable related to sexuality. Nine papers (Dannels and Charlifue 2004; Kalpakijan et al. 2010; Lombardi et al., 2010; Jorgensen et al., 2021; Smith et al., 2015; Fisher et al., 2002; Krause et al. 2005, 2006 & 2011), used quantitative research methods, and one paper (Pentland et al., 2002) used qualitative research methods.

Table 1 presents the study design and key outcomes of the 10 papers. Two papers included physical outcomes only (Dannels & Charlifue, 2004; Kalpakjian et al., 2010), four included psychological outcomes only (Krause & Bozard, 2012; Krause & Broderick, 2005; Krause & Coker, 2006; Pentland et al., 2002), and four included both physical and psychological outcomes (Fisher et al., 2002; Jörgensen et al., 2021; Lombardi et al., 2010; Smith et al., 2015). Physical outcomes included sexual activity (Dannels & Charlifue, 2004; Fisher et al., 2002; Lombardi et al., 2010; Smith et al., 2015), ejaculation (Lombardi et al., 2010; Smith et al., 2015), erection/erectile dysfunction (Fisher et al., 2002; Lombardi et al., 2010; Smith et al., 2015), sexual frequency (Fisher et al., 2002), vaginal lubrication (Fisher et al., 2002; Kalpakjian et al., 2010; Smith et al., 2015), masturbation (Fisher et al., 2002), orgasm (Fisher et al., 2002; Lombardi et al., 2010; Smith et al., 2015), pain (Jörgensen et al., 2021; Smith et al., 2015), bladder and bowel (Jörgensen et al., 2021; Kalpakjian et al., 2010), arousal (Fisher et al., 2002; Kalpakjian et al., 2010), and spasticity (Jörgensen et al., 2021). Psychological outcomes included anxiety (Smith et al., 2015), counselling (Fisher et al., 2002), depression (Smith et al., 2015), desire (Fisher et al., 2002), education (Fisher et al., 2002; Pentland et al., 2002), relationships (Lombardi et al., 2010) and satisfaction (Fisher et al., 2002; Jörgensen et al., 2021; Krause & Bozard, 2012; Krause & Broderick, 2005; Krause & Coker, 2006; Smith et al., 2015).

Papers including both men and women

Papers by Krause et al. (2005, 2006 & 2011), and Jorgensen et al. (2021) presented outcomes from life satisfaction surveys that included sexual life, in which participants

reported low levels of sexual satisfaction. Fisher et al.'s (2002) quantitative study found that participants were primarily concerned with their partner's sexual satisfaction, followed by their own.

Smith et al. (2015) was the only study that presented outcomes separated by gender as well as pooled gender outcomes. For example, men may experience erectile dysfunction, while women may have issues with vaginal lubrication. Smith et al.'s study showed that sexual function was the strongest predictor of sexual satisfaction for men and women, with depression also negatively impacting women's sexual experiences. Men with SCI reported lowest levels sexual satisfaction when compared to men with muscular dystrophy or post-polio syndrome (two other populations with disabilities in this study).

Papers including only men

Lombardi et al. (2008) surveyed two age groups – one aged under 60 years (n=44) and one over 60 years (n=55). There were significant differences in sexual activity without sexual intercourse and preferences for sexual activity. While 77.3% of the younger group reported engaging in sexual intercourse in the past year, only 23.6% of the older group did so. Erectile dysfunction was more common in the older group (78.1% vs. 65.9%), yet fewer of these individuals sought pharmacological treatment (1.8% vs. 29.5%). Notably, 52.7% of older participants preferred non-penetrative physical intimacy over intercourse, compared to 6.8% in the younger group. Across both cohorts, a longer relationship duration was statistically linked to greater overall sexual satisfaction.

Papers including only women

Papers by Pentland et al. (2002), Dannels and Charlifue (2004) and Kalpakijan et al. (2010) spoke to the physical and psychological outcomes women with SCI experienced with age, which included sexuality and sexual health or age-related conditions (e.g. menopause), which potentially impacted their sexuality and sexual health. Pentland et. al., (2002) studied women's overall experiences with ageing with SCI. Changes and symptoms reported included bowel/bladder, gynaecological/sexuality, and socio-emotional well-being. Physical changes in gynaecological health/sexuality ranked highest of concern for the women

participants. Women also reported feeling isolated and believed that many of their concerns were dismissed or disregarded by healthcare and service providers.

In two of the three papers that included only women, menopause was discussed exclusively with women participants - Dannels and Charlifue's (2004) and Kalpakjian et al's., (2010) studies highlighted the experiences of menopause and sexuality for women with SCI. Dannels and Charlifue (2004) reported that 38% of women with SCI experienced decreased sex drive. Kalpakjian et al., (2010) found that women with SCI going through menopause reported being more affected by somatic symptoms, frequent bladder infections, and reduced sexual arousal than women without SCI. The lack of education and information for women and healthcare providers on menopause was a common point in these papers.

Table 1: Aspects included in studies on ageing, sexuality and SCI

Title	Author	Type of study	Men (n)	Women (n)	Physical Outcome	Psychological Outcome
Cross-Sectional						
The perimenopause experience for women with spinal cord injuries	Dannels & Charlifue, 2004	Quantitative	0	230	Decreased sex drive, changes to sexual relations; symptoms associated with perimenopause	
Global and domain-specific life satisfaction among older adults with long-term spinal cord injury	Jörgensen et al., 2021	Quantitative	53	25	Bladder; bowel; pain; spasticity	Satisfaction with sexual life
Menopause Characteristics and Subjective Symptoms in Women With and Without Spinal Cord Injury	Kalpakjian et al., 2010	Quantitative	0	62	Menopause related symptoms in women with SCI (bladder, sexual arousal, vaginal dryness)	
Sexual life of males over 50 years of age with spinal-cord lesions of at least 20 years	Lombardi et al., 2010	Quantitative	99	0	Sexual activity; ejaculation; erectile dysfunction; sexual function; orgasm	Relationships; satisfaction
Women with spinal cord injury and the impact of aging	Pentland et al., 2002	Qualitative	0	29		Education
Sexual function, satisfaction, and use of AIDS for sexual activity in middle-aged adults with long-term physical disability	Smith et al., 2015	Quantitative	Not reported for participants with SCI	Not reported for participants with SCI	(M) Ejaculation; erection; sexual activity; Other: Sexual aides (injection, pills, pump (W) Vaginal lubrication; pain; orgasm; Other: Sexual aides (vaginal moisturiser, hormones) (M/W) Spasticity.	(M/W) Satisfaction; anxiety; depression
Longitudinal						
Sexual health after spinal cord injury: a longitudinal study	Fisher et al., 2002	Quantitative	32	8	Sexual activity; erection; frequency; vaginal lubrication; masturbation; orgasm; arousal	Counselling; desire; education; satisfaction
A 25-year longitudinal study of the natural course of aging after spinal cord injury	Krause & Broderick, 2005	Quantitative	79	16		Satisfaction with sex life

Aging after spinal cord injury: A 30-year longitudinal study	Krause & Coker, 2006	Quantitative	67	11		Satisfaction with sex life
Natural course of life changes after spinal cord injury: a 35-year longitudinal study	(Krause & Bozard, 2012)	Quantitative	56	8		Satisfaction with sex life

Discussion

Of the 382 papers on sexuality and SCI identified in the scoping review in Chapter 2, 10 included papers with older populations. Synthesis of this subset of papers reveals key themes regarding life satisfaction and ageing with SCI, particularly concerning sexual satisfaction. The sub-analysis of the papers on ageing, sexuality, and SCI revealed gaps and emerging priorities for research and practice, particularly regarding sexual satisfaction, gender-specific experiences, and the need for lifelong rehabilitation and healthcare support.

Multiple studies examined sexual satisfaction among individuals with SCI, reporting low levels of sexual satisfaction among participants with SCI (Fisher et al. 2022; Krause et al. 2005,2006 & 2011, and Jorgensen et al. 2021). The literature suggests that sexual satisfaction is multifaceted and goes beyond genital function and physical impairment for men and women with SCI (Lopes et al., 2022; Piatt et al., 2022). Research highlights the importance of personal and contextual factors—especially those that support social participation— that appear to play a greater role in shaping sexual activity and satisfaction than the physical effects of the injury (Lopes et al., 2022). Studies have shown that satisfaction with one's sex life is significantly associated with factors such as partner relationships, mobility, mental well-being, sexual desire, and body image (Reitz et al., 2004). This finding underscores the need for further research to understand why sexual satisfaction is low among older adults with SCI, especially when compared to other areas such as social life, employment, finances, and health, aligning with the observations of Krause and Broderick (2005).

The analysis and synthesis reveal a gap in gender-specific research. Only one paper that included men and women presented the outcomes by gender. While women were included in the other five papers, the outcomes reported were pooled, not disaggregated by gender. It is important to report results by gender as sex and gender interact in numerous ways to affect health and well-being and ultimately form treatment outcomes (Heidari et al., 2016). For example, in Fisher et al. (2022), Krause et al. (2005,2006 & 2011), and

Jorgensen et al. (2021), it is unknown if the similarly aged women participants in these studies experienced menopausal symptoms that impacted their sexuality and sexual health like the participants in Dannels & Charlifue (2004) and Kalpakijan et al. (2010) studies. Failing to consider sex and gender analysis in these contexts may lead to inaccurate findings, reduced research efficiency, and limited applicability of results (Tannenbaum et al., 2019).

Changes in sexual satisfaction via self-reported ratings in older individuals and individuals living with SCI over time were reported in papers by Fisher et al. (2022), Krause et al. (2005,2006 & 2011), and Jorgensen et al. (2021). Krause & Broderick (2005) recommend further research to identify explanatory factors that account for the decline in sexual satisfaction levels, as sexuality in older adults is influenced by a complex mix of physical, psychological, social, and cultural factors (Penhollow, 2024).

Krause & Broderick (2005) also suggest that rehabilitation throughout the life span may assist with adaptation to ageing changes with SCI. Krause & Broderick (2005) report that individuals who may have aged significantly since their initial rehabilitation may not have access to informed knowledge and resources regarding sexuality and sexual health. This reflects the concerns of older adults who generally face stigma surrounding sexuality and sex, and need tailored support; however, evidence on effective strategies to support sexual health in later life is limited (Stowell et al., 2023). This leads to the ongoing need for further research in this area, including the reasons behind the changes in sexual satisfaction levels.

Lombardi et al. (2008) identify erectile dysfunction (ED) as a predominant factor contributing to the decline in sexual activity and satisfaction among older men with SCI. ED often leads to a shift toward non-penetrative forms of physical intimacy, particularly in comparison to younger men with SCI. ED emerges to be the most commonly reported problem impacting sexual function and satisfaction in men with SCI (Gomes et al., 2017; Lee et al., 2016), which supports Lombardi et al.'s (2008) finding of the shift toward non-penetrative forms of physical intimacy.

This sub-analysis reveals potential gender differences in the experience of ageing with SCI. While many age-related changes appear similar across genders, Pentland et al., (2002) reported that women experienced a more pronounced sense of isolation and unique perceptions of healthcare interactions regarding their sexuality. Generally, women face a healthcare system that is based on the male patient and are often treated as smaller men (Figueroa & Hiemstra, 2024). This can lead to failures in diagnosis when women present differently from the typical man and creates barriers to access care when symptoms that women experience are evaluated differently from men (Figueroa & Hiemstra, 2024). Women with SCI report that sex education and counselling are geared primarily towards men, and expressed the need for women-only education and support groups, information on sex and SCI, and reported being ignored or dismissed by healthcare professionals (Pentland et al., 2002; Thrussell et al., 2018).

Limitations

Although this chapter analysed a subset of studies from a larger and comprehensive dataset on sexuality and SCI in Chapter 2, the initial inclusion criteria did not explicitly target ageing or age-related changes in the context of sexuality and SCI. As a result, relevant studies may have been inadvertently excluded. Consequently, the conclusions are primarily based on studies that either addressed aspects of ageing incidentally or employed longitudinal designs, which may limit the depth and comprehensiveness of findings related to older adults with SCI.

Conclusion

This chapter highlights a gap in the literature at the intersection of ageing, sexuality, and SCI. Out of 382 studies examined in Chapter 2, only a small fraction focused on ageing populations, highlighting that relatively few have specifically addressed this population in research. The synthesis of these limited studies reveals persistent issues of low sexual satisfaction among older adults with SCI, emphasising the importance of sexuality as a

component of overall life satisfaction. This chapter also points out significant gaps in gender-specific research, underscoring the need for more comprehensive studies that disaggregate data by gender. Additionally, there are potential gender differences in the experience of ageing with SCI, with women reporting unique challenges in healthcare interactions concerning their sexuality. These findings highlight the importance of tailored approaches to sexual health education and support for both men and women with SCI.

Moving forward, further research is needed to address these identified gaps and to develop more comprehensive, gender-specific strategies for improving sexual satisfaction and overall quality of life for ageing individuals with SCI. Building on the findings of this chapter, the next chapter will investigate the impacts of ageing on sexuality and sexual health for women with SCI.

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Chapter 4:
Impact of Ageing on Sexuality and Sexual Health for Women with Spinal Cord Injury

Abstract

Background

Over the past 70 years, studies on sexuality and SCI have gradually increased, but women's experiences, especially those related to ageing, remain underexplored. As life expectancy increases, a growing number of women with SCI are now navigating older age while living with SCI. This study seeks to address current knowledge gaps by examining how ageing impacts the sexuality and sexual health of women living with SCI. The results will enhance our understanding of sexuality in the context of SCI throughout the lifespan, providing valuable insights and information for both healthcare professionals and women with SCI.

Method

Individuals aged 45 and older, living with SCI for at least one year, identifying as women or non-binary with lived female hormone experience, who were English-fluent, were invited to participate in this qualitative study. The phenomenological approach explored experiences of ageing, sexuality, and sexual health. Braun and Clarke's thematic analysis framework was used. Themes were developed inductively and refined collaboratively by the student researcher, research assistant and supervisors.

Results

Thirteen women with SCI aged 45 and over were interviewed. Five key themes reflected on the impacts of ageing on sexuality and SCI: (1) *Self-perceptions, desire, identity and societal attitudes;* (2) *Decreased sexual desire;* (3) *Bodily constraints, changes, and image;* (4) *Perceptions of Lifespan;* (5) *Shifting priorities regarding sexuality and sex.* Illustrative quotations from participants supported each theme.

Conclusion

This study showed the multidimensional impact ageing has on sexuality for women with SCI, revealing the intersection of physiological, psychological and social factors. Neither ageing nor SCI were a standalone factor in shaping sexuality. Further research is essential to help understand and reduce the stigma faced by women with SCI.

Introduction

Findings from Chapter 3 revealed a gap in existing literature at the intersection of ageing, sexuality, and SCI. Older adults often encounter stigma surrounding sexuality and require tailored support to address their sexual health needs; however, there remains limited empirical evidence on effective interventions in this area (Stowell et al., 2023). These challenges are further compounded for older adults living with spinal cord injury (SCI), who experience additional sexuality-related challenges linked with their SCI (Gillen & Reynolds, 2021). The synthesis of these limited studies revealed persistent issues of low sexual satisfaction among older adults with SCI, emphasising the importance of sexuality as a component of overall life satisfaction. It also highlighted the need for gender-specific strategies for improving sexual satisfaction and overall quality of life for ageing individuals with SCI.

In addition to the effects of SCI, menopause is a pivotal, gender-specific transition in a woman's life that can significantly affect sexual health. Perimenopause and menopause bring changes that impact sexual health both physically through symptoms like vaginal dryness and discomfort during sexual intercourse, and psychologically with effects such as decreased libido, mood changes, anxiety, depression and feelings of being unloved (Greene, 1998). Women with SCI who went through menopause reported being more affected by somatic symptoms, frequent bladder infections, and reduced sexual arousal than women without SCI (Kalpakjian et al., 2010), shedding further light on the common effects of ageing on this demographic.

Having outlined the broader challenges older adults with SCI face regarding sexuality, our attention turned to the unique outcomes and experiences of women in this demographic. Chapter 4 expands on Chapter 3 by examining the impacts of ageing on sexuality and sexual health for women with SCI.

Methods

To understand how ageing impacts the sexuality of women with SCI, a phenomenological approach was used. This research method explores the significant experiences that people personally lived through (Neubauer et al., 2019). Interview questions were influenced by a phenomenological perspective, which empowered participants to express their experiences. Phenomenologists believe that our conscious experience is the primary means by which we gain knowledge (Gallagher, 2022). This was crucial for the study, as each woman's experience with SCI and ageing is shaped by factors such as the age at which the injury occurred, the type of injury, rehabilitation experiences, and cultural and societal influences.

Participants and Recruitment

Individuals aged 45 years and older, who had lived with SCI for a minimum of one year, identified as a woman or non-binary person (with lived experience with female hormones), and were fluent in reading and speaking English, were invited to participate. Global disabled people's organisations (DPOs), SCI rehabilitation clinics/hospitals, and research centres were contacted for assistance in recruiting participants. Social media platforms also played a role in participant recruitment. This study was approved by the University of Sydney Human Ethics Committee (2024). The target number of participants for this study was 20-30; however, due to time constraints and difficulties with recruitment, only 13 consenting women with SCI were interviewed via Zoom.

Data Collection

Participants completed a pre-interview survey, which asked for the year their SCI was acquired, age, whether participants were sexually active before their SCI, whether they were currently sexually active, whether they were partnered, their lesion level, and their geographical location. During the interview, participants were asked to identify any

menopausal symptoms from the Greene Climacteric Scale (Greene, 1998), a diagnostic tool comprised of 21 items which include psychological (depression, anxiety, mood changes, irritability, unloved feelings), somatic (backache, crawling feelings under the skin, joint pain, muscle pain, headache, decreased libido, new facial hair, dry skin, dry vagina, brain fog, sleeplessness, unusual tiredness, uncomfortable intercourse, urinary frequency) and vasomotor (hot flushes, light-headedness) symptoms.

Semi-structured interview questions (Appendix 5) were used with consenting participants to facilitate two-way communication during the session. This allowed for the collection of unique, in-depth insights and perceptions of participant experiences with sexuality, ageing and SCI (McGrath et al., 2019). Transcripts were automatically generated from the Zoom recordings and subsequently reviewed and quality checked for accuracy and completeness by the thesis author.

Analysis

De-identified transcripts were imported into NVivo (NVivo 14) for coding, theme development and analysis. A thematic analysis approach was employed to examine the data. Following Braun and Clarke's (2021) six-phase framework, familiarisation with the data was achieved through reading the transcripts, followed by the exclusion of conversational fillers and extraction of relevant excerpts into a Microsoft Word document. This task assisted with the familiarisation and retention of the data (Hanzawa & Suzuki, 2023).

Without reference to pre-existing ideas or hypotheses, the student researcher implemented the semantic coding method. This was followed by inductive analysis of the data, which led to sub-themes and themes of ageing experiences and impacts on women with SCI's sexuality. Subsequently, the research assistant read all transcripts and student-researcher developed codes in order to familiarise themselves with the data. The student researcher and research assistant then independently categorised codes into subthemes which were then compared - not to reach consensus but to capture diverse

interpretations and perspectives of the data. Sub-themes that aligned with the research questions were refined through multiple reviews by the student researcher and a research assistant - a process overseen by both supervisors.

Reflexivity Statement

The research team for this study consisted of PhD researchers from various fields (rehabilitation counselling, exercise physiology), a master's degree in research student (rehabilitation counselling), and an associate lecturer (physiotherapy). All team members identify as women, and although none have lived experience with SCI, they bring a broad range of expertise in areas related to women, disability and SCI. The team's combined knowledge includes academic research, clinical practice and disability advocacy, with experience levels ranging from an emerging scholar to established experts. This formed a multifaceted interpretation of the lived experiences of women with SCI.

Results

Demographics

The thirteen participants in this study were aged between 47 and 69 years, with the age of SCI onset ranging between 14 to 54 years. Time since injury ranged from 7 to 46 years. Participants were located in Australia, Canada, Chile, the United Kingdom, the United States, and South Africa. Interview durations ranged from 34 minutes to 77 minutes (mean, 60 minutes). Table 1 summarises participant demographics and interview duration.

Themes

This study identified five key themes reflecting on the impacts of ageing on sexuality and SCI: (1) *Self-perceptions, desire, identity and societal attitudes;* (2) *Decreased sexual desire;* (3) *Bodily constraints, changes, and image;* (4) *Perceptions of Lifespan;* (5) *Shifting priorities regarding sexuality and sex.* Illustrative quotations from participants support each theme discussed. To preserve anonymity, participants are referred to by their participant number, age, and country (e.g., P1, 60, US).

Table 1 – Participant Demographics

Participant	Age	Time since injury	Sexually active prior to SCI	Currently sexually active	Sexual orientation	Partnered	Area impacted	Country	Interview duration
1	54	7	Yes	No	Aromantic	No	Upper, lower body and torso	South Africa	34 mins
2	59	36	Yes	No	Heterosexual	No	Upper, lower body	United States	68 mins
3	52	29	Yes	No	Heterosexual	Yes	Upper, lower body and torso	Canada	77 mins
4	53	7	Yes	No	Heterosexual	No	Upper, lower body and torso	Chile	50 mins
5	51	29	Yes	Yes	Heterosexual	Yes	Upper, lower body, torso	United States	47 mins
6	69	25	Yes	Yes	Heterosexual	Yes	Lower body	United Kingdom	57 mins
7	60	18	Yes	Yes	Heterosexual	Yes	Lower body	United States	52 mins
8	48	10	Yes	Yes	Heterosexual	Yes	Upper, lower body and torso	Canada	76 mins
9	53	29	Yes	No	Bisexual	No	Upper, lower body and torso	Australia	66 mins
10	60	6	Yes	No	Heterosexual	Yes	Lower body, torso	Australia	67 mins
11	56	40	Yes	Yes	Heterosexual	Yes	Lower body, torso	Australia	60 mins
12	60	46	No	No	Heterosexual	Yes	Lower body, torso	United States	67 mins
13	47	25	Yes	Yes	Heterosexual	Yes	Lower body	United Kingdom	59 mins

Self-perceptions, desire, identity and societal attitudes

Participants discussed a range of interconnected factors that shaped their willingness and capacity to engage in romantic relationships. These included self-perceptions related to body image, age, and the impacts of SCI, as well as anticipation regarding future dating and relationship dynamics. These concerns were shaped not only by self-perception but also by societal attitudes towards SCI and sexuality.

Self-perceptions of desirability and sexual identity had shifted over time, with a participant who had lived with SCI for 36 years reflecting that SCI had no impact on their ability to date or engage in sexual activity: *"At the beginning of my disability, I never had a problem with guys wanting to go out with me, have sex with me*." [P2, 59, US]. However, with age, the participant observed a loss of desirability despite still wanting to be sexually desired: "*The older I've gotten, it's that I'm viewed so differently. I don't have that sexual appeal anymore. And I still want that."* [P2, 59, US].

A participant described feeling apprehensive while navigating the dating scene: *"I was self-conscious about my weight, self-conscious about the chair, self-conscious about my age."* [P7, 60, US]. Describing themselves as at a disadvantage in the dating game, the participant reflected on the impact, stating: "*I felt like I had 3 strikes against me […], dating was getting harder as I aged"* [P7, 60, US].

Challenges related to sexuality and intimacy, which had extended beyond the initial stages of dating, were reported, surrounding broader concerns about how these needs would be acknowledged and supported in future care settings. This participant reflected via anticipatory thinking, where they contended with the difficulty of prioritising sexuality as an ongoing need: "*I think what I'd find challenging to do is to prioritise it (sexuality). And to go, 'This is important to me.'"* [P9, 53, Australia]. This participant provided context for their reflection, which showed their concern for self-advocating for their sexuality in a traditional facility for older adults: "*When my sister and I went to look at nursing homes for my dad, I would ask the question, 'What if he wants to have a relationship with one of the other?*

What's your policy around them, sharing a bed?' And they were very kind of coy about answering that question." [P9, 53, Australia].

These reflections revealed how self-perception concerning sexuality and desirability evolves with SCI and age. It highlighted that sexuality remains a meaningful and valuable aspect of life in older adulthood.

Decreased sexual desire

Participants shared evolving experiences of sexuality shaped by ageing, shifting personal priorities, and changing attitudes toward intimacy. Many described their decline in sexual desire to be attributed to broader life transitions, evolving self-concept, and competing responsibilities.

A participant expressed fear of their partner seeking sexual relations elsewhere: *"I'm scared that one day he (husband) will go somewhere to get it,* [P8, 48, US]. This participant attributed this fear to being older and having less need for sex: "*I will be older; I have less need to have sex."* [P8, 48, US]. A different participant highlighted the challenges of navigating changes in sexual desire: *"I will say getting older, like when I noticed that my sexual drive was dwindling."* [P12, 60, US].

Menopause, an age and gender related transitional condition, was described to have had a direct impact on sexual desire: "*I've gone through menopause and menopause just kills the desire."* [P11, 56, Australia]. In addition to menopause, this participant also experienced shoulder pain (a result of using a manual wheelchair) and felt that sex was an obligation as well as being a part of relationship maintenance: "*To me, it's like a chore. Now it's like, 'Oh, just get over and done with'. I'm more doing it for him because I'm not enjoying, I don't enjoy it (sex). Because the (shoulder) pain is there."* [P11, 56, Australia].

A reflection on the evolving nature of sexual desire across the lifespan and opinion on sexual frequency showed a sense of fulfilment: *"It's not something I want to do on a daily basis. Anyway. I've been there, done that."* [P6, 69, UK]. They also expressed a sense of prioritising and experiencing other meaningful areas of life: "*We had lots of fun and enjoyed*

sex a lot but then I think you do until you have kids, and then it kind of slides down a bit. And then, as you get older and menopausal, you know, there's better things in life." [P6, 69, UK]. The reflection from this participant further shed light on the shift in priorities following parenthood and menopause.

Despite experiencing decreased sexual desire, some participants were optimistic about remaining sexual with age: *"I hope it continues. You know I hate to say this because I come from a very passionate family. And so my dad was in his 80's when he passed away, and he was still going strong, and God bless them! I hope that I continue that way as well."* [P7, 60, US].

This participant had hoped and expressed their vision of ageing sexually: *"I foresee myself still being physically active, sexually active, still enjoying, you know, going out doing things*," [P5, 51, US]. Further reflection had highlighted the importance of remaining sexually active, which might have helped with exploring and learning new ways of receiving pleasure: "*I think that foreplay or just being romanced. I think that's like a really important thing in a person with a spinal cord injury because you're trying to receive pleasure through different areas that maybe you wouldn't have thought about prior to your accident."* [P5, 51, US].

The willingness to improve their sexual desire and arousal, if an accessible intervention and information had been available, was shared by participants: *"I was willing to try if they had a female Viagra or something. I would be willing to try something like that."* [P12, 60, US]. But an effort to seek information specifically for women on sexual desire had proved difficult as well: "*Trying to find information for women regarding sexual drive, and it was difficult."* [P12, 60, US].

Participants described how their experiences of sexuality had evolved with age, which many had linked to decreased sexual desire due to ageing, menopause, and other life obligations and responsibilities. Despite the challenges, some individuals had remained hopeful about maintaining sexual activity and had been willing to seek intervention and information to support their sexual health.

Bodily constraints, changes, and image

Participants described a range of age-related physical changes that had influenced their experiences with sexuality and approaches to self-management. Some of these physical changes had been gender specific, as well as shaped by the intersection of age and SCI-related bodily changes.

A reflection on ageing and further decline in physical shape had not been anticipated, but the prolonged use of a manual wheelchair had contributed to the secondary physical limitation of the upper body for this participant: *"As I continue to age, because not that I'm anticipating getting more out of shape, but I think there's more limitations. As you've used your body in ways that you're not supposed to be using them, you know, relying on your shoulders and your arms."* [P5, 51, US].

Several participants had described women-specific changes in sexual health: *"I would say definitely I think typical women issues with vaginal dryness."* [P12, 60, US]. Seconding this via pre-emptive thinking, this participant had predicted the likelihood of vaginal dryness/lubrication issue with time: *"For now it's not a problem [..]. Yeah, it will become (a problem), because most women, lack of lubrication (comes) with the time."* [P8, 48, Canada]. One participant had shared their self-management approach to vaginal dryness or lack of vaginal lubrication: "…*you try everything that everyone else would, lubricant and that kind of thing."* [P12, 60, US].

Changes in body hair associated with ageing had also been reflected by an individual: *"Then there's hair as you get older the hair gets coarser and grayer, hey?"* [P11, 56, Australia]. The need to groom the pubic hair had not been for aesthetic reasons but to reduce skin irritation: "*I've always liked it to be tidy around the supra pubic. But yeah, I have gotten like red. I've never had a pressure sore. I've had grazers, but I have got a bit of a red mark or a graze or something when there's too much hair there."* [P11, 56, Australia].

Participant reflections and experience have shown how the intersection of SCI and ageing shaped their perception of limited upper body from prolonged wheelchair use and

grooming practices. Vaginal dryness had not been SCI-related but was specific to women's ageing.

Perceptions of Lifespan

In response to being asked to reflect on their perception of sexuality in later life, some individuals did not express a desire to be able-bodied or younger again, but expressed uncertain reflections upon their longevity while living with SCI. The collective impact of trauma, management of ongoing health conditions, and chronic pain had contributed to a sense of diminished desire to live into older age. These narratives showed that the perceptions of lifespan were shaped not only by physical health but also by responsibilities and evolving identity.

Participants shared their challenges, which shaped their perspectives on longevity with SCI: *"I don't want to live very long with SCI, you know. It's so terrible with all this health care all the time."* [P8, 48, Canada]. The burden of needing health care had led this participant to share a potential age they may want to live to: "*Not sure. I wanna after like 65, I'm not sure that's worth (living). But with the menopause, with the osteoporosis, with all the consequences. I don't know what's gonna happen."* [P8, 48, Canada]. This participant had predicted how much longer they could operate physically: *"I don't think I've got another 5 years out of this body."* [P11, 56, Australia]. Despite the predicted functional time with their body, this participant wanted to improve their sex life: *"It needs to be improved (sex). […], and we're looking at nerve blocking and changing of the going on to a stronger medication. So yeah, it's something that needs to be improved, even if it's not for my benefit, it's for my husband."* [P11, 56, Australia].

An individual reported an evolution in their outlook over time: *"I know this is going to sound a bit ridiculous, but I never really saw myself living that long after I got injured, because I was kind of like '40 years of being in a chair.' I mean, like what a nightmare, you know."* [P13, 47, UK]. But the initial pessimism regarding long-term survival had shifted to renewed motivation, influenced by interpersonal relationships or caregiving responsibilities:

"*But now I'm kind of like I want to stay healthy for my boy, so that I can see him (my son) grow up and I can be in his life."* [P13, 47, UK].

Participants had also expressed an accelerated experience of SCI attributed to their ageing: *"The old people do less with the time, it gets faster with the SCI."* [P8, 48, Canada]. Another participant indicated ageing prematurely with SCI and revealed the need to direct attention to sexuality due to age: *"I'm ageing prematurely with spinal cord injury. I think this is the sort of thing that anyone experiences as your age, your sexuality and things like that, it's something you gotta work on."* [P11, 56, Australia].

The reflection on the physicality in a relationship in the later stages of life shared by this participant showed it was easier at a younger age: *"It's a very challenging time for a physical relationship when you hit the sixties, fifties, I would say, at least, that's what I found. Have fun while you're young."* [P12, 60, US].

Participants' reflections on their perceptions of longevity while living with SCI had shown a collective interaction between physical health, resilience, evolving identity and responsibilities. These narratives had highlighted how the experiences with ageing can shape perceptions of lifespan.

Shifting priorities regarding sexuality and sex

Participants articulated evolving perspectives on sexuality and sexual activity following SCI, highlighting a complex interplay among physical, emotional, and relational factors. While some individuals continued to regard sexual intimacy as integral to health and well-being, others observed a change in prioritisation of sexual activity in the context of broader life changes, such as caregiving responsibilities, physical changes, and the demands of daily SCI management.

Firstly, participants expressed their priorities towards sexuality and its importance in their lives: *"I think sex is really important and that kind of intimacy. I think it's really important for health and for well-being."* [P9, 53, Australia]. This participant stated that regardless of SCI, sexuality is a need: *"We still have our needs, although you're paralysed."* [P1, 54, South

Africa]. However, the shift in prioritisation had shifted for an individual after childbearing: *"I think my concerns were more around, how am I gonna actually physically get about with a tiny baby and stuff, you know? But yeah, again, less about the sex."* [P13, 47, UK].

The spontaneity of sexual encounters was replaced by routine and planning, often influenced by concerns regarding bowel and bladder function, hygiene, and physical limitations. While not directly attributed to ageing, these factors represented persistent challenges that had impact on daily routine and sexual activity: *"So the routines around sex have become ... much less spontaneous. We're focused on making sure that, like my partner's clean, I'm clean, you know, before and after. And it's a bit less sexy, right?"* [P13, 47, UK].

An individual shared their biggest fear during sexual activity: *"Years before my husband and I got together, that was one of the biggest things was 'Oh, jeez! Am I gonna shit myself?' It's no different to if you accidentally fart during sex and like, 'Oh, where'd that come from?' A bit different if you have an accident. No, it's not a squeaky couch (where the sound came from)."* [P11, 56, Australia].

Gendered expectations and emotional intimacy also shaped participants' shifting desires, with some expressing satisfaction with other forms of physical intimacy. One participant shared her views on men's sexuality: *"I don't think men ever get tired of sex, or they want less (sex). I don't think they ever change."* [P1, 54, South Africa]. The opposite was said for women: "*I think it's mainly on the ladies' side when they think it's not necessary anymore."* [P1, 54, South Africa]. Expanding on this, this participant hypothesised a scenario: *"Women would rather a cuddle in bed if it leads to something […]. You give a bloke a cuddle, and they think it's going to lead to something. Well, they're hopeful that it does."* [P11, 56, Australia].

The view of the necessity of sex and frequency was shared: *"I just don't need to do it that often. We don't need to do it as often, you know."* [P13, 47, UK]. The type of intimacy preferred was also shared, which indicated emotional intimacy provided more satisfaction and enjoyment: "*I think because for me it's so much about the emotional connection, like, if*

I'm not feeling it I don't get that much out of it really." [P13, 47, UK]. One participant reflected a sense of sexual fulfilment, which indicated sexual activity was no longer a priority: *"It's not something I want to do on a daily basis. Anyway. I've been there, done that."* [P6, 69, UK]

These narratives illustrated a reconfiguration of sexual identity and priorities shaped by SCI. Gendered perceptions, life stage transitions, and adaptive strategies in response to SCI all played a role in how participants valued and prioritised sexuality over time.

Discussion

This study shares the lived experiences of thirteen women with SCI, highlighting how ageing intersects with sexuality through participant quotes. Drawing on their narratives, our research provides rich insights into how women navigate ageing and its impact on sexuality in the context of SCI. The individuals in this study, all aged 45 and over and identifying as women, bring a diverse and multidimensional understanding of their realities. Our data and analysis frame our understanding of human experiences through an in-depth examination of prominent themes, which showed that different perspectives and experiences ageing had on sexuality for women with SCI were captured through five key themes*: Self-perceptions, desire, identity and societal attitudes; Decreased sexual desire; Physical constraints and changes; Perceptions of Lifespan; Shifting priorities regarding sexuality and sex.*

The narratives presented suggest that ageing is not the sole factor that impacts sexuality for women with SCI. Women with SCI experience gender-specific physiological and social differences that affect their sexuality outcomes, and ageing can highlight these differences (Estores & Sipski, 2004). It is essential to consider factors that intersect with ageing, sexuality, and SCI, as these systems influence how individuals experience later life (Miller et al., 2021). Ageing can be perceived as either a positive or negative stage of life, with an individual's perception towards ageing reflecting their personal beliefs and attitudes towards the ageing process (Joshanloo, 2024). Individuals ageing with SCI can experience

added complexity, with an increase in secondary health and activity limitations (Guízar-Sahagún et al., 2023).

Some of the shared lived experiences did not specifically refer to ageing, but rather described their experiences and perspectives over time, which we interpret as the passage of time or the accumulation of years. While this study is on women with SCI, we did not exclude or ignore factors related to gender, roles and responsibilities that non-disabled women experience with ageing as well. Some of these roles and responsibilities include relationships, employment, and parenting.

We found ageing for women with SCI to have an impact on their interpersonal relationships. SCI was not perceived as a barrier to their dating life; rather, they attributed this to their status as an older adult. It raises the question of whether society's bias towards ageism and ableism differs, or whether this self-perception is internalised. In both cases, ageism or negative attitudes towards ageing is a multidimensional phenomenon that includes discrimination towards others or internalised fear or disassociation with one's own ageing process (Gendron et al., 2024). Women in general are often held to youthful standards when it comes to appearance and beauty, which may explain why older women experience more difficulty in their dating lives (Miller et al., 2021). This, in turn, could impact women's confidence and ageing being perceived as a negative or an unacceptable stage in life, which resonates with our attribution of ageing and not SCI as the challenge with interpersonal relationships. Women in our study perceived themselves as less sexually appealing despite still wanting to be sexually desired. This is consistent with previous research -body image following the onset of SCI has been reported to have an impact on women's self-perception and sexual identity (Parker & Yau, 2012).

From a gender perspective, women with SCI may also face societal biases regarding the acceptance of men and women with disability. A survey by Timmons et al., (2024) reported that men who use wheelchairs were more likely to be accepted than women who use wheelchairs when it comes to starting a family. The higher acceptance of men wheelchair users compared to women wheelchair users prompts the reflection on societal

and self-perceptions related to image/appearance, ageing and ableism, and prompts an analysis of which factors contribute most significantly to bias or stigma.

Beyond dating, self-perception towards ageing and sexuality seems to be influenced by societal attitudes. There is a stigma attached to older adults as having reduced physical performance, being sick or always tired (Coelho-Junior et al., 2024). Whether or not this stigma also leads society to believe older adults no longer desire sex or are capable of sexual activity, misconceptions about sexuality in older adults persist (Steckenrider, 2023).

The taboo surrounding sex for older adults parallels that of people with disabilities - both groups often being categorised as non-sexual, with this issue further intensified for older adults with SCI who face additional sexuality-related challenges associated with their condition (Gillen & Reynolds, 2021). However, we saw the stigma, but the participants did not demonstrate those feelings of non-sexuality in this study. Instead, we saw competing responsibilities, shifting priorities, physical changes and challenges, and gendered perceptions on ageing and sexuality. Ageing or SCI were not standalone contributors to the decrease in sexual desire or activity.

We found mixed perceptions women with SCI had towards ageing and sexual desire and activity. The decline in sexual desire was commonly reported, as has been reported in previous work (Kreuter et al., 2008), and the individuals in our study expressed that with age, they do not see sex as a necessity or desire it as frequently. This was not shaped by societal attitude or stigma but was their perception based on their life experiences, such as feeling fulfilled by their sex life in the earlier stages of their life or as a result of menopause or other priorities. Our participants also perceived men as having higher sexual desire and needs than women, which does correlate, as men typically have higher levels of sexual desire than women due to testosterone levels (van Anders, 2012).

Nevertheless, the fruition of women's sexual desire over time is shaped by multiple factors. A longitudinal study (13 years) reported women's sexual desire was slightly more variable than men due to life transitions, ageing and relationship factors; however, over the short term (7 days), both men and women showed similar levels of sexual desire (Harris et

al., 2023). Our participants reported similar experiences, stating that menopause, parenting, and secondary SCI conditions (pain, bowel and bladder) either contributed to the decrease or challenged their sexual desire and activity. In addition to the various factors influencing women's sexual desire, these elements also appear to affect participants' perceptions of their lifespan, presenting a more sombre theme than previously mentioned.

When asked to reflect on their perception of sexuality in later life, some individuals did not express a desire to be able-bodied or younger again. Instead, they shared their desired life expectancy. Their reasons for not wishing to live past a certain age or only for a handful of quality years in their current physical state suggest that sexuality is not at the forefront of their mind. These insights into the perceived burdens of ageing and living with SCI highlight the relationship between ageing and SCI. It is known that women ageing with SCI define their ageing experience as “accelerated” and report health problems such as fatigue and pain that impact their activities of daily living (ADLs) (McColl et al., 2004).

This study had its limitations. The diversity of lived experiences presented in our study was worthy, but extending the participant locations of origin to include individuals from regions such as Asia and Europe would have broadened the cultural breadth of our data. Whilst we have obtained rich data, the recruitment of further participants would have been favourable in reaching data saturation and providing greater insight into the narratives.

Regardless, this study is an important piece that provides insights into the impacts of ageing on sexuality for women with SCI. The results show the multidimensional impact ageing has on sexuality for women with SCI, revealing the intersection of physiological, psychological and social factors. For women in this study, ageing or SCI was not a standalone factor in shaping sexuality. The scarcity of literature addressing the intersection of women with SCI, sexuality and ageing resulted in limited opportunities for comparative analysis and highlighting gaps in the current body of research. This scarcity also generates important questions about societal bias and stigma on SCI, sexuality, women and ageing. With further research, these issues can be deeply understood, paving the way to address and reduce the bias and stigma that women with SCI face.

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Chapter 5:
Discussion and Conclusion

This chapter concludes this thesis by presenting a comprehensive examination of the studies' outcomes, consolidating the overall findings, and highlighting the contributions made to the current SCI research landscape. It addresses this thesis's aims of:

1. Identifying the knowledge gaps and trends in sexuality research for women with SCI
2. Identifying the age-related themes in sexuality research for women with SCI
3. Identifying how ageing affects the sexuality of women with SCI

Key Findings and Discussion

Sexuality – gender differences

This work revealed that the research outcomes related to sexuality differed between men and women with SCI (Chapter 2). The key difference was that most outcomes investigated for men were narrowly focused on sexual function (erection, erectile dysfunction, and ejaculation), whereas for women, there was a broader range of outcomes (orgasm, sexual activity, bladder and relationships, in addition to sexual function). The review in Chapter 2 also revealed that physical interventions were more of a focus for men than women with SCI. Research outcomes for ageing, sexuality and SCI, although limited to our scoping and bibliometric review dataset, showed similar trends for men and women; however, menopause was a gender specific ageing transitional condition for women (Chapter 3).

In Chapter 4, whilst there were no data comparing women with men, women reported outcomes that were similar to those in Chapters 2 and 3 (e.g. sexual function, sexual activity, bladder and bowel, menopausal impacts on sexuality, satisfaction, relationships, and desire) and beyond. For example, the competing responsibilities, the accumulation of time lived,

and personal experiences of women with SCI shaped their perception of sexuality. Women did not view sexuality as a priority, but some still saw its importance for health and for their relationships. Women seemed to perceive men's sexuality as always wanting or desiring sex more than women, which is aligned with results of Chapter 2 and 3 indicating a larger focus on sexual function research in men with SCI. Sex education and counselling in rehabilitation settings were also highlighted by participants as being designed towards men with SCI.

Gender differences in research outcomes identified in Chapter 2 were identified when papers presented their results segregated by gender. It was observed in some studies that pooled the outcomes of all participants (men and women combined), which limited gender specific analysis. This also occurred in our analysis in Chapter 3, where menopause in ageing women was highlighted. This may be due to smaller sample sizes of women, which were identified during our analysis in Chapter 2. Women-only specific studies and analyses on women with SCI are rare, and being unable to complete gender-specific analysis can lead to limited clinical improvements, especially since women experience variations in the gender-specific hormones that uniquely impact women (Raguindin et al., 2021; Regensteiner et al., 2025).

Women in Chapter 4 reported a wide range of factors that impacted their sexuality, often beyond ageing or SCI. Although it may seem self-evident that physical changes influence sexuality, these findings revealed that women consider a broad spectrum of life experiences when discussing their sexuality. Although men with SCI were not included in the study, it is important to note that men and women often approach these topics from different perspectives. Women overall tend to have a more holistic perspective in general, which involves analysing and understanding information through logic and intelligence (Mehta et al., 2024). Women also tend to show more emotional empathy, while men are more inclined towards cognitive empathy (Christov-Moore et al., 2014).

The holistic perspective often associated with women may explain why women in this study, when speaking about their sexuality, attributed the impacts to changes beyond the physical dimension, encompassing different areas of their lives. Consequently, the women's

analysis of their age, physical and psychological state, competing responsibilities (e.g. parenting), and their personal priorities led to the identification of impacts on their sexuality that were not solely related to sexual function. Although there were no complaints about their partners, the absence of acknowledgement of sharing the load of responsibilities with them often gave the impression that they were not in a partnership, and they felt responsible for managing all aspects of the relationship.

Participant perspectives on men's sexuality, which reflected on men's (their partner) higher desire for sexual activity, additionally highlight gender differences in biology and psychology. In some cases, women in this study allowed a 'friends with benefits' arrangement for their partners (outside of their relationship) as part of their relationship maintenance, which further demonstrates that sexual activity and desire may sit as a lower priority for women than men.

Sexuality and SCI research for women has been predominantly conducted on physical function (sexual activity) (Nery-Hurwit et al., 2024), which aligns with the Chapter 2 findings. This thesis demonstrates that women with SCI experience a range of factors that impact their sexuality beyond sexual function and activity. Recognising this will improve intervention and educational resources for women with SCI that take a holistic perspective and remind researchers that men and women with SCI have individualised needs.

Limited studies on sexuality, ageing and SCI

Based on the papers included in this thesis's scoping and bibliometric review from Chapter 2, it was found that only 2.6% of the papers on sexuality and SCI also addressed an ageing element (presented in Chapter 3). Globally, the number of individuals with disabilities and those growing older with disabilities is on the rise (Pili et al., 2018) and with sexual satisfaction low amongst the older SCI population (Randazzo et al., 2024), it is increasingly important to understand the physical, psychological, and social dimensions of sexuality and sexual health in ageing individuals with SCI.

The lack of papers that reported on sexuality, ageing and SCI within this large body of literature shows this intersection is underexplored. Research literature on sexuality and older adults with disability is also limited (Syme et al., 2020); however, sexuality and ageing in non-disabled literature has been explored, highlighting that older people have a better quality of life when there is less sexual dysfunction (Boyacıoğlu et al., 2023).

People of different genders, experiencing sexuality and ageing, have also been explored within non-disabled literature. Older men report erectile dysfunction and delayed ejaculation as the most common sexual dysfunction issues (Dominguez & Barbagallo, 2016), but also typically have higher levels of sexual desire than women due to testosterone levels (van Anders, 2012). In contrast, women report decreased sexual interest, decreased arousal, genito pelvic pain, and difficulties with penetration in older women (Dominguez & Barbagallo, 2016).

Comparisons of the depth and quantity of research into the impact of ageing on people with SCI, disability overall, and non-disabled people show that there are gaps. There is a broader stigma around older individuals and being non-sexual, but people with SCI or other disability may face further stigma. This could be the driver behind the limited research for the SCI population in the field of sexuality and ageing, despite sexuality being a vital part of an individual's lifespan. The stigma attached to older adults as having reduced physical performance, being sick or always tired (Coelho-Junior et al., 2024) may lead to the belief that sexuality is no longer a consideration, especially for individuals with SCI or other disability.

The impacts of ageing and sexuality

In exploring the impacts of ageing on sexuality for women with SCI in Chapter 4, it became clear that ageing nor SCI are standalone factors in shaping sexuality for women with SCI. A number of respondents identified competing priorities (such as parenting and work), menopause symptoms, and secondary SCI conditions (such as bladder management, autonomic dysreflexia, overuse injury and pain) which impacted their experiences of the

intersection of ageing, SCI and sexuality. For example, various findings were reported regarding the confluence of SCI, menopause symptoms and secondary SCI conditions. Women who began perimenopause before acquiring their SCI were confident in identifying that their symptoms were related to menopause. Some women said they did not know whether they were experiencing menopause symptoms or a SCI-related condition/symptoms.

For some participants, sexuality was not a priority. In response to being asked to reflect on their perception of sexuality in later life, a number of respondents did not respond with answers about sexuality but instead commented on their longevity or lifespan – for example, not wanting to live decades with SCI, nor wanting to live beyond a certain age due to the burden of healthcare and injuries associated with SCI (relying on the upper body). While these responses did not relate to sexuality, they demonstrate what is at the forefront of participants' minds. It was surprising to hear an unexpected response to this interview question, and it was just as surprising to have multiple individuals share similar responses. However, upon reflection, if sexuality is not a priority, it is reasonable to expect individuals to offer an alternative answer.

An additional unexpected finding was that women with SCI perceived ageing as a bigger source of bias and stigma in the context of dating than SCI itself. This was unexpected, as the intersection of ageing and SCI/disability had not been previously considered in the context of dating, and disability and ageing are underrepresented populations in the context of intersectionality (Langmann & Weßel, 2023).

Chapter 3 builds on the existing research landscape of sexuality and SCI, with the physical and psychological outcomes relating to sexuality in the older SCI population being similar to those in Chapter 2. Factoring in the age at which SCI was acquired assists with how an individual adapts to life with SCI, whether in the immediate or over the long term, and across different life stages, with particular attention to sexuality (Keusen et al., 2023; Piatt et al., 2022). One outcome that was not evident in Chapter 2 but became evident in Chapter 3 was menopause and how it impacts sexuality. The Chapter 2 results did not

clearly reveal the menopause findings due to the limited number of papers exclusively focusing on women with SCI, sexuality and ageing.

Menopause can present different psychological, somatic, and vasomotor symptoms for women, and a few menopause symptoms can directly impact a woman's sexuality. These symptoms include dry vagina, decreased libido, feelings of being unloved, and uncomfortable/painful sex. Menopause can be difficult for a non-disabled woman, and it can exacerbate existing medical conditions (McCarthy & Raval, 2020), including physical disabilities.

Further exploration of the relationship between SCI and menopause is needed. For example, women with SCI often report vaginal dryness as a sexual problem (Taylan et al., 2022). Vaginal dryness may be exacerbated during perimenopause or may be mistakenly attributed to SCI when it is related to perimenopause. Upon initial consideration, the significance of identifying the underlying cause of the symptom may be questioned. However, determining the underlying cause can change and influence the treatment options. When the cause of vaginal dryness is due to perimenopause or menopause, sometimes, over-the-counter lubricants are not sufficient in alleviating the dryness; estrogen therapy remains the primary treatment option (Stabile et al., 2021). Accurate attribution to the cause of the symptom is vital, as it can expand treatment options, resulting in less pain and discomfort.

Vaginal dryness is also an example of one of the symptoms that women with SCI may experience difficulty seeking a diagnosis and treatment for. An individual interviewed in Chapter 4 study shared that their doctor attributed her menopause symptoms to her SCI. It is common for women overall to have their doctors not proactively ask them about sexuality and sexual health during menopause (Patterson & Jehan, 2024). Women generally are ignored by medical professionals when seeking help with managing or diagnosing their symptoms, with fertility and other health services prioritised instead (Shams et al., 2025). Considering the stigma attached to menopause (Dahlgren et al., 2023), the additional stigma

attached to people with disabilities around sexuality, and the bias women generally face with ageing, combined, menopause would be challenging to manage for women with SCI.

Limitations

As with all research, this thesis had a number of limitations. Individual limitations for each chapter are presented in their respective discussion sections. This section addresses overarching limitations for the entire thesis. All three chapters were impacted by us taking a monolingual approach to the research. In chapters 2 and 3, this potentially limited the representativeness of papers, excluding papers from other countries. In chapter 4, only women who spoke English were interviewed, which similarly limited the study's participant pool and contributed to the difficulties in recruitment.

The exclusive recruitment of women in Chapter 4 restricted the potential for comparative data. Consequently, gender comparisons were incorporated in Chapters 2 and 3, but not in Chapter 4, due to the single-gender recruitment. Whilst the author wanted to represent different genders and focus on underrepresented areas in each chapter, this was not achieved due to time limitations.

Another limitation of this thesis was the absence of perspectives of other stakeholders/parties in the area of SCI. Consultation with an individual who possesses lived experience with SCI would have provided more valuable insights into the study's design and data interpretation. The absence of healthcare professionals in the area of SCI also limited the rehabilitation, primary care and educational perspectives in this thesis.

Future research

The findings of this thesis provide significant insights into experiences of sexuality for women with SCI and highlight multiple areas that warrant further investigation and research. Firstly, it is important to increase studies on ageing, sexuality and SCI for both men and women, ensuring outcomes are reported by gender, to accurately represent minority populations.

Secondly, it is important to replicate the study in Chapter 4 with men participants for comparative analysis. In addition, the recruitment of more women participants is also important to provide more data and diversity. Conducting similar research on ageing and sexuality for men with SCI is important - men and women remain as sexual beings regardless of age.

Lastly, further research is needed to explore how menopause affects other aspects of health that may indirectly shape sexuality and sexual health, such as osteoarthritis and mobility. An investigation is required into what the most bothersome symptoms are for women with SCI, how to better manage them and which symptoms increase the risk of secondary SCI conditions (e.g. bladder, osteoarthritis, anxiety). Additionally, it is important to investigate the needs of individuals with SCI relating to resources and education (what women with SCI know and do not/want to know). Several participants highlighted their encounters with healthcare professionals who demonstrated a lack of knowledge regarding the intersection of SCI and menopause. Investigating the gaps in knowledge and training in this area would establish a valuable foundation for future research. It is equally important to understand how ageing, SCI itself and the secondary SCI conditions impact women with SCI's sexuality, but also other aspects of life that are continually changing as these individuals live.

Conclusion

The landscape of SCI research has changed over the decades. This thesis, focusing on women's sexuality and ageing, explored, highlighted and addressed existing and new areas of study in SCI. The essential takeaways are that women with SCI still view sexuality as an important area of their health or relationships, even if sexuality is not a priority for them, and a holistic approach needs to be considered when reviewing the impacts of ageing on women with SCI.

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List of Appendices

THE UNIVERSITY OF SYDNEY

RESEARCH INTEGRITY & ETHICS ADMINISTRATION

HUMAN RESEARCH ETHICS APPROVAL

The University of Sydney confirms that this project meets the requirements of the National Statement on Ethical Conduct in Human Research.

Project identifier:	2024/HE001566
Project title:	Impact of ageing on sexuality and sexual health for women with spinal cord injury
Application version:	0.02
Chief Investigator:	Associate Professor Roxanna Pebdani
Project team:	Associate Professor Jacqueline Raymond Ms Jolie Chantharath
Project start date:	10 Mar 2025
Project end date:	09 Mar 2029
Date of issue:	Monday, 10 March, 2025

Project summary

The objective of this research is to explore and understand how ageing affects the sexuality and sexual health of women with spinal cord injury (SCI). To accomplish this goal, researchers will conduct interviews with women who have SCI, focusing on their age-related experiences that may influence their sexuality, interactions with healthcare providers, and other relevant factors, including the potential impact on their partners.

Documents approved

Document type	File name	Document version	Application version
Participant Consent Form (PCF)	participant-consent-form_20250221_clean.docx	1	0.02
Participant Information Statement (PIS)	Participant Information Statement_20250221_clean.docx	1	0.02
Project description / Protocol	Project description_SCI_sexuality and ageing_20250221_clean.docx	1	0.02
Recruitment or advertising material	Research advertisement flyer.pdf	1	0.01
Other	Interview Questions_final.docx	1	0.01
Other	Organisation email.docx	1	0.01
Survey	Qualtrics Survey .pdf	1	0.01

Conditions of Approval

- Research must be conducted according to the approved proposal.

- An annual progress report must be submitted on or before the anniversary of approval and a final report on completion of the project.
- You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
  - Serious or unexpected adverse events (which should be reported within 72 hours).
  - Unforeseen events that might affect continued ethical acceptability of the project.
- Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- Researchers working on this project must be sufficiently qualified by education, training, and experience for their role, or adequately supervised. Changes to the project team must be reported and approved.
- Researchers must disclose any actual, potential of perceived conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- Research data and primary materials must be retained and stored in accordance with relevant legislation and University guidelines.
- Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures, and governance requirements.
- If your research project is a clinical trial and is being sponsored by the University or is to be conducted on a University of Sydney site, you must comply with additional University governance requirements prior to commencing your Clinical Trial.
- The University may conduct audits on approved projects.
- The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

Ethics Committee Representative

Chair
On behalf of the University of Sydney

The University of Sydney HRECs are constituted and operate in accordance with the National Statement on Ethical Conduct in Human Research and the Australian Code for the Responsible Conduct of Research (NHMRC). All personnel named on the project should be acquainted with these documents.

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ABN 15 211 513 464
CRICOS 00026A

Participant Consent Form

Women living with spinal cord injury, aged 45 years and over.

Research study: Impact of ageing on sexuality and sexual health for women with spinal cord injury

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Participant Name _____

I agree to take part in this research study. In giving my consent, I confirm that that:

- The details of my involvement have been explained to me, and I have been provided with a written Participant Information Statement to keep.
- I understand the purpose of the study is to explore and gain insights into the sexual experiences of women living with spinal cord injury as they age.
- I acknowledge that the risks and benefits of participating in this study have been explained to me to my satisfaction.
- I understand that in this study I will be required to participate in an interview.
- I understand that participation involves audio and transcript recordings.
- I understand the research team may have follow-up questions after the interview
- I understand that if I provide consent my information may be used in future research by this research team in relation to this research topic of women living with spinal cord injury, sexuality and aging.
- I understand that being in this study is completely voluntary.
- I am assured that my decision to participate will not have any impact on my relationship with the research team or the University of Sydney.
- I understand that I am free to withdraw from this study at any time and that I can choose to withdraw any information I have already provided (unless the data has already been de-identified or published).

- I have been informed that the confidentiality of the information I provide will be protected and will only be used for purposes that I have agreed to. I understand that information identifying me will only be told to others with my permission, except as required by law.

- I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

- I confirm the following:

I consent to recordings (audio)	Yes ☐ No ☐
I consent to being contacted for follow-up questions	Yes ☐ No ☐
I would like to review a summary of the data analysis	Yes ☐ No ☐
I consent to being contacted for future studies	Yes ☐ No ☐
I consent to my data being used in future research	Yes ☐ No ☐
I would like feedback on the overall results of this study	Yes ☐ No ☐

If you answered **yes** to receiving feedback or being contacted in the future, please provide your preferred contact details (email/telephone/postal address):

_____

_____

_____

_____

- By clicking "I agree" I am consenting to be a participant of the research study, as outlined above.

Participant Name _____

Signature _____

Date _____

Participant Information Statement

Women living with spinal cord injury, aged 45 years and over.

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1. What is this study about?

We are conducting a research study about women living with spinal cord injury and their experiences with sexuality and aging. Gaining insights into women's experiences can lead to better understanding and improvements in healthcare and managing related symptoms and conditions.

Taking part in this study is voluntary.

Please read this sheet carefully and ask questions about anything you don't understand or want to know more about.

2. Who is running this study?

The study is being carried out by the following researchers:

- Associate Professor Roxanna Pebdani (Responsible Researcher), Rehabilitation Counselling, Sydney School of Health Sciences, Faculty of Medicine and Health.
- Associate Professor Jacqueline Raymond, Exercise and Sport Science, Sydney School of Health Sciences, Faculty of Medicine and Health.
- Jolie Chantharath, Research Student, Sydney School of Health Sciences, Faculty of Medicine and Health.

Jolie Chantharath is conducting this study as a basis for a Master in Philosophy at the University of Sydney.

No conflict of interest has been declared.

3. Who can take part in the study?

We are seeking participants who:

- Have a spinal cord injury;
- Have lived with their injury for a minimum of one year;
- Fluent in reading and speaking English
- Are a woman*
- and are 45 years and over.

*identify as a woman or non-binary person (with lived experience with female hormones)

4. What will the study involve for me?

If you decide to take part in this study, you will be asked to:

- Complete a short pre-study online survey to confirm study eligibility, collect demographic information, and collect contact information so that we may schedule to interview you at a time that is convenient for you
- Participate in an online interview in which you answer questions that describe your experiences with sexuality and aging since living with a spinal cord injury.

After you have completed the pre-study online survey, we will contact you to organise a date and time convenient to you to conduct the interview on Zoom (online or phone).

The total time commitment is 70 minutes which includes:

- A short pre-study online survey: 10 minutes
- Participant interview: 60 minutes

The interview will be facilitated by student researcher Jolie Chantharath.

The interview will be recorded via Zoom on a laptop so that we can automatically transcribe the audio.

The research team may have follow-up questions after the interview. This may be to confirm the transcription and/or seek further insight into the response you have provided. The time commitment will be no more than 15 minutes if required.

Preliminary results will be shared with you if you have ticked the relevant box on the consent form. This will be in the form of a one-page lay summary, which will be emailed to you prior to formal publication of results. You will have a week's review time and to return any amendments

and comments via email. You will be unable to amend your transcript once the thematic analysis has begun.

5. Can I withdraw once I have started?

Being in this study is completely voluntary and you do not have to take part.

Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you decide to take part in the study and then change your mind, you can withdraw by emailing Jolie Chantharath **jcha3920@uni.sydney.edu.au**

If you take part in an interview you may refuse to answer any questions that you do not wish to answer.

If you decide to withdraw, we will stop collecting information from you. You can choose to withdraw any information you have already provided (unless the data has already been de-identified or published). Any information that we have already collected will be kept in our study records and may be included in the study results as the information will have been pooled with other participants, and non-identifiable.

6. Are there any risks or costs?

There are very few risks involved with your participation in this study because the research has been carefully designed and approved by the university's ethics committee. However, it is possible that the interviews will involve questions about sexuality and aging experiences, which could make you uncomfortable or cause distress. The interview may take 60 minutes, and that time commitment may be inconvenient for you. In such situations, you may choose to withdraw your participation.

If any emotional discomfort is caused during your participation in the study, you can access free counselling from Lifeline (13 11 14), Beyond Blue (1300 224636 or chat online) or Spinal Cord Injuries Australia's Peer and Family Support Telehealth (non-urgent 1800 819 775).

7. Are there any benefits?

Indirect Benefits

By participating in this study, you will be contributing to research on women living with spinal cord injury and their experiences relating to sexuality and growing older. This can lead to improving healthcare and managing related conditions and symptoms.

Direct Benefits

You will not receive any direct benefits from being in the study.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information from or about you for the purposes of this study.

Any identifiable information you provide us, recordings, and transcripts will be stored securely under the University of Sydney data security framework and will only be disclosed with your permission unless we are required by law to release information.

We plan to publish the study findings in a peer-reviewed journal ensuring transparency and contribution to the broader community.

You will not be individually identifiable in these publications.

We will use Zoom to transcribe interviews. This will involve sharing your information with Zoom. We will not share this information with anyone else without your consent unless we are required to do so by law. Zoom is owned by Zoom Video Communications Inc. and is headquartered in San Jose, CA, USA.

We will store this information and dispose of it securely following the University's Recordkeeping Policy. For more details about how your information will be handled please see the University's privacy webpage.

There is potential use of this de-identified data for future research.

9. Will I be told the results of the study?

You have the right to receive feedback about the overall results of this study. If you wish to receive feedback, tick the relevant box on the consent form. This feedback will be in the form of a one-page lay summary. You will receive this feedback after the study is completed.

10. What if I would like more information?

When you have read this information, the following researcher(s) will be available to discuss it with you further and answer any questions you may have:

- Jolie Chantharath, Student Researcher, **jcha3920@uni.sydney.edu.au**

11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [ethics reference: 2024/HE001566] according to the National Statement on Ethical Conduct in Human Research.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176

This information sheet is for you to keep

THE UNIVERSITY OF SYDNEY

CALL FOR WOMEN WITH SPINAL CORD INJURY OVER THE AGE OF 45

Researchers are looking for women with spinal cord injury and want to hear about their experiences with sexuality, sexual health and ageing.

Are you eligible?

- Have a spinal cord injury
- Have lived with your injury for a minimum of one year
- Aged 45 years and over
- A woman*
- Fluent in reading and speaking English

*identify as a woman or non-binary (with lived experience with female hormones)

What is required:

- A pre-study online survey (10 mins)
- An interview online via Zoom (approximately one (1) hour)

Want to participate?

Click here or scan the QR code below

QR Code

For more information:

Please contact **Jolie Chantharath**, Master in Philosophy student
Sydney School of Health Sciences - Faculty of Medicine and Health
jcha3920@uni.sydney.edu.au

This study has been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [2024/HE001566]

Appendix 5: Interview Questions

Interview Questions

Eligibility questions – Collected via Qualtrics Survey

1. Do you have a spinal cord injury?
2. When did you obtain your spinal cord injury? (year) (text)
3. How old are you? (text)
4. Identify as a woman or non-binary person (with lived experience with female hormones)
5. Are you fluent in reading and speaking English? (yes/no)

Pre-study questions (after consent, also on Qualtrics form)

1. Impacted areas of physical function (drop list and other – upper (e.g. shoulder, neck) lower body (e.g. legs), torso (e.g. abdominal, chest)? Other:
2. How did your spinal cord injury occur? (text)
3. What is your sexual orientation? Choose all that apply. (purpose to interview a broad representation of the population) (drop list)
   - Aromantic
   - Asexual
   - Bisexual
   - Gay
   - Heterosexual
   - Lesbian
   - Pansexual
   - Queer
   - Other:
   - Rather not say
   (https://aifs.gov.au/resources/resource-sheets/lgbtiqa-glossary-common-terms#orientation)
4. Are you currently partnered? (yes/no/rather not say)
5. Were you sexually active before your injury? (yes/no/rather not say)
6. Have you been sexually active since your injury? (yes/no/rather not say)
7. Are you currently sexually active? (yes/no/rather not say)

Main Questions (Zoom)

Participants will be orally re-consented and asked if they agree to the interview being recorded (which they will be aware of from the original consent process). The Zoom recording will then commence. Remind participants:

- only the audio transcript will be stored/kept
- they have the right to pause or cease the interview at any point
- refuse to answer any of the questions

- ask for something they said to be omitted, which will not be transcribed
- all data will be de-identified

Ask participants if they have any questions before starting.

Preamble

Possible script:

"Our research is looking at the impacts of ageing on sexuality and sexual health for women with SCI. I'll be asking for your perspectives, experiences and understanding of this.

I'll briefly explain what aspects we're looking at for sexuality and sexual health. Sexuality is about your thoughts, desires, beliefs, values, and attitudes and sexual health is about your physical, emotional, mental and social well-being in relation to sexuality. I'll repeat this when I ask the question (no need for participant to memorise)"

Confirm/talk about the time spent living with injury and how the injury occurred (from pre-study and eligibility screening) to lead into the first question (build rapport during this time)

1. a) What do you value or prioritise with your sexuality?
   This is about your thoughts, desires, beliefs, values, and attitudes towards sexuality.

   If the participant is unsure, provide an example: relationships, gender.

   b) Can you tell me about your experiences with sexuality?
   e.g. how you express your sexuality, how it's changed.

Potential follow-up questions:

- Why does XYZ matter to you?
- Has this/How has this changed, say from your 20's-30's to the present?
- How do you think this might change as you get older?
- What do you think has contributed to the changes?
- (if sexually active before SCI) Can you share any differences or similarities you've experienced before and after the SCI?
- If partnered, has this been influenced by being partnered? Have you experienced barriers to this? What kind of barriers?

2. a) What do you value or prioritise towards your sexual health?
   This is related to what you have just mentioned but in the context of your physical, emotional, mental and social well-being (participant may answer parts of this in Q1).

   If the participant is unsure, provide an example: sexual activity, function, frequency, safe sex.

b) Can you tell me about how your experiences with sexual health? For example positive or less positive experiences with a value or priority you've mentioned.

Potential follow-up questions:

- Why does XYZ matter to you?
- Has this/How has this changed, say from your 20's-30's to the present?
- How do you think this might change as you get older?
- Ask about activity, frequency, and satisfaction.
- What do you think has contributed to the changes?
- (if sexually active before SCI) Can you share any differences or similarities you've experienced before and after the SCI?
- If partnered, has this been influenced by being partnered? Have you experienced barriers to this? What kind of barriers?

3. Can you tell me the first thing that comes to mind for you when you hear this statement "I want to continue being a sexual person for as long as I live."

Potential follow-up questions:

- (if participant doesn't want to be a sexual person), why?
- If yes, what does this look like?
- Possible participant may not have considered this, why not? Maybe they never thought it was possible to continue to be a sexual person.

4. Have there been any health conditions you've experienced where you have been unsure if it is SCI or age-related? Have any of these condition/s impacted your sexual health?
   E.g. menstrual cycle changes, dry vagina, bladder/urinary issues, change in desire/arousal.

Follow-up questions:

a. Impact/QoL (physical/psychosocial)
b. Frequency
c. Management (self and medical)
d. Have you discussed this with a medical professional or been given advice?

5. Have you accessed sexual health services since your injury? If yes, can you tell me about the service/s. For example with an OBGYN.

Potential follow-up questions:

- Were the services helpful/useful?
- What made them helpful/useful or not (helpful/useful)?

- (if participant has chosen not to access services) why not?

6. Are you experiencing or have you experienced any symptoms (show on screen) that you believe are associated with peri/menopause?

Symptoms List:

Hot flushes	Unusual tiredness
Lightheaded feelings	Backache
Headaches	Joint pains
Irritability	Muscle pains
Depression	New facial hair
Unloved feelings	Dry skin
Anxiety	Crawling feelings under the skin
Mood changes	Less sexual feelings
Sleeplessness	Dry vagina
Uncomfortable intercourse	Urinary frequency
Sweating at night	Memory problems

   a. Which of these symptoms on the screen reflect your experiences with peri/menopause? E.g. sweating (confirm this is related to peri/meno).
   b. Are any of these symptoms related to your SCI?

7. Do any of these symptoms impact your sexual health? If yes, please describe how.

<u>Potential follow-up questions:</u>

- Have these symptoms impacted any other parts of your life? (e.g. relationships)
- Have you sought medical advice for these symptoms? Helpful/not helpful?

8. Based on your experiences so far (with SCI, sexuality and aging), what do you want to see or be done differently about healthcare and information resources (if you've had access or used them)?

   a. How would you like to receive/access these resources?