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ORIGINAL PAPER

"It's Not, Can You Do This? It's… How Do You Feel About Doing This?" A Critical Discourse Analysis of Sexuality Support After Spinal Cord Injury

Chloe Bryant[1] · Tammy Aplin[1,2,5] · Diana K. Piantedosi[3,4,6] · Jenny Setchell[1,7]

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Abstract

Previous research has indicated that healthcare support for sexuality after spinal cord injury appears to be neglected or inadequately provided. The perspectives of people living with spinal cord injuries regarding what is lacking and what support they would like to be provided, and why, has yet to be explored. This paper uses critical theory to explore how societal constructs of sexuality and disability shape how sexuality is supported after a spinal cord injury. To do this, we conducted in-depth semi-structured interviews with 11 people with a spinal cord injury from Australia, the United Kingdom, and the United States. We drew from the works of various critical disability theorists to analyze what discourses underpinned the experiences people with spinal cord injuries had when receiving sexuality support. Analysis suggested that the following discourses were apparent: (1) broken bodies require repair, (2) sex is penetration, ejaculation then reproduction, and (3) sexual autonomy is required. Findings indicated healthcare professionals need to recognize people with spinal cord injuries as sexual beings with a diverse range of desires, lives, relations, and bodies. Provision of individualized comprehensive high-quality sexuality support is therefore warranted. To achieve this, healthcare professionals should aim to be aware of, and mitigate, ableist and normative assumptions.

Keywords Sexual health and wellbeing · Disability · Heteronormative assumptions · Qualitative health research · Lived experience · Australia

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✉ Chloe Bryant
chloe.bryant@uq.edu.au

[1] School of Health and Rehabilitation Sciences, The University of Queensland, Brisbane, Australia

[2] The Prince Charles Hospital, Allied Health Research Collaborative, Brisbane, Australia

[3] Department of Social Inquiry, La Trobe University, Melbourne, Australia

[4] School of Health and Social Development, Deakin University, Melbourne, Australia

[5] School of Health Sciences and Social Work, Griffith University, Brisbane, Australia

[6] Policy, Advocacy and Consumer Engagement, Women with Disabilities Victoria, Melbourne, Australia

[7] Institute for Urban Indigenous Health, Brisbane, Australia

Introduction

Throughout life a person's sexuality may be impacted by major life transitions or traumatic events [1], such as sustaining a spinal cord injury (SCI). Sexuality has been described by the World Health Organization (WHO) as a "central aspect of being human" and includes many aspects such as: intimacy, sexual activity, sexual orientation, gender identity, fantasies, desires, and beliefs [2]. Existing literature has established intimacy and sexual self-esteem are connected to quality of life and life satisfaction for most (but not all) people [3–5]. For example, research suggests that when people participate in sexual activity, there are short- and long-term benefits such as decreased pain, improved mood, improved overall-wellbeing, and decreased morbidity [6]. The benefits discussed in these studies indicate the importance of sexual expression for people with SCIs.

The ability to express one's own sexuality can be severely impacted after SCI and this altered affectation of sexual wellbeing in turn impacts overall wellbeing. Existing scholarship has explored various shifts in sexuality after SCI with focus areas such as: sexual dysfunction, fear of recommencing sexual activity, concern about losing intimacy, and a decreased sense of value as a sexual being [7–13]. Considering the many benefits of sexual expression [6], and the apparent impacts of SCI on sexuality, research has also indicated healthcare professionals (HCP)s should attend to sexuality as part of post-injury care. Suggesting HCPs play an integral role in supporting the sexual wellbeing of people with SCI [9].

Despite ubiquitous understandings that sexual expression can positively affect overall health and that HCPs can be pivotal in normalizing sex [14], literature suggests that the support received for sexuality after SCI is lacking. Over the last 30 years, research has outlined various difficulties in this area of practice, primarily the lack of available and variable quality of sexual support [15]. In a recent survey, which investigated HCP support for sexuality in Australia, results indicated sexuality support is not routinely provided for people with SCI [16, 17]. Similarly, in a qualitative phenomenological study with people with SCI, Morozowski and Roughly [18] detailed numerous limitations of sexuality support and provided suggestions to improve practice such as up-to-date educational resources, increasing HCP training, and making changes to policy and practice. These issues persist despite several studies highlighting the need for improved support [11, 13, 14, 16, 17].

Existing research identifies ongoing limitations in sexuality support however few studies have explored how societal constructs might be influencing the provision of sexuality support for people with SCI. This study aims to address that gap. Morozowski and Roughly [18] argue people may hesitate to engage in sexual relationships with people with SCI due to negative societal perspectives that perpetuate the fallacy that sex is not possible for people who use wheelchairs. Articles exploring sexuality and SCI often mention negative societal assumptions and perspectives, for example the assumption that people with SCI are asexual [10].

Although previous literature has referenced societal perspectives on sexuality and SCI more broadly, few articles have investigated this with reference to healthcare. Sakellariou [19] drew upon earlier qualitative phenomenological work with Greek men with SCI to argue that HCPs' view sexuality for people with SCI as purely a body problem and therefore essentialist in nature, often neglecting to consider other influencing factors. In later work, Sakellariou [20] undertook a detailed exploration of care and sexuality using Foucault's conceptualization of 'care of the self', where care for oneself may be perceived as an enactment of identity. Sakellariou [20] notes sexuality can be regulated by health professions and healthcare practices can often be disempowering and controlling. However, neither works by Sakellariou aimed to critically explore assumptions, perspectives, and power dynamics that influence sexual healthcare provision, beyond concepts of care. This study addresses this gap by examining what discourses are at play and how these discourses might influence the provision of sexuality support after SCI.

With this study, we intend to engage with key concepts from critical disability scholarship to explore how discourses shape healthcare and can inform practice. This type of scholarship can “challenge taken-for-granted assumptions and considerations of power,” which is important to consider within healthcare contexts [21]. This study seeks to understand the discourses (societal constructs or ‘truth claims’) that underpin the support HCPs’ provide for sexuality after SCI. The overall intention of this paper is to provide a novel perspective for key stakeholders, and to ultimately enhance sexuality support after SCI through provision of more appropriate and relevant services.

Method

Theoretical Framework

For this study, Critical Discourse Analysis (CDA) was used. The CDA methodology focusses on an in-depth consideration of which social constructs shape participant experiences. Cheek [22] states that discourse analysis is complex; there is no one definition and it can have various theoretical underpinnings. Broadly, the theoretical stance of interpretivism informed our approach. Interpretivism is concerned with exploring the social world and subjective meanings [23]. This study was thus grounded in the ontological assumption that human experience is shaped by a social world of meanings.

In recognition of this constructionist framework, this study operationalizes ‘discourse’ as “a group of ideas or patterned way of thinking which can both be identified in textual and verbal communications and located in wider social structures,” in line with the approach of Lupton [24] and Cheek [22]. Both scholars draw from Foucault’s understanding of discourse as often implicit societal ‘truth claims’ that inform how people think and act in the world [25]. Cheek [22] suggests that discourse analysis, by making such claims explicit, “offers the potential to challenge our thinking about aspects of the reality of health and healthcare practice.” By critically considering the discourses that underpin sexuality support after SCI, this methodological approach provides a deeper understanding and enables further consideration of how healthcare might be reworked to better suit people with SCI.

Theoretical Underpinnings

This CDA was underpinned by the work of critical disability theorists Tom Shakespeare, Robert McRuer, and Russell Shuttleworth. These theorists have mobilized awareness of hidden assumptions that shape understandings of disability in society. Their work is informed by interconnected theories of feminism, queer theory and crip theory. For example, Shuttleworth criticizes ableist societal discourses that people with disabilities are nonsexual [26], whilst Shakespeare addresses paradoxical discourses that people with disabilities are simultaneously viewed as asexual and hypersexual [27]. McRuer [28], a founding queer crip theory scholar, leverages the term ‘compulsory-able bodiedness’ to challenge abled/ disabled binary discourses and resist normative assumptions; chiefly the hierarchy which positions able-bodied individuals as the ideal. We have drawn from these theorists, among others, to assist with our CDA.

We acknowledge the discussions amongst critical disability theorists regarding the use of person-first or identity-first language. For the purposes of this paper, we have followed Dunn and Andrews' [29] suggested approach, which encourages authors to be informed by research participants' preferred language choice. We thus chose to use person-first language, in alignment with the people with SCI we interviewed. Equally, we acknowledge for some, identity-first language terms like 'disabled person' are purposefully used to counteract cultural shame and reject connotations of disability as 'other' [30–32].

Participants and Procedure

We conducted semi-structured interviews with people with SCI about their experiences receiving healthcare support for sexuality. Participants were recruited using convenience and snowball sampling via professional networks, social media and by emailing relevant organizations. If volunteers expressed interest in participating, CB then completed initial eligibility screening by phone. Volunteers were eligible if they: were 18 years or older, unknown to the interviewer, had a spinal cord injury, could provide informed consent, could communicate in English, were willing to discuss sexuality, and had either received or considered receiving sexuality support services in the last ten years. The 11 participants had lived with a SCI between seven months and 52 years, identified as men (n = 9) or women (n = 2), heterosexual (n = 9) or gay (n = 2), Anglo-Saxon/Caucasian (n = 10) or Eurasian (n = 1), not religious (n = 8), Christian (n = 2) or Atheist (n = 1), and the mean age was 41 years (*SD* = 8.8). Participants received between two weeks and 18 months of inpatient rehabilitation; only 2 received transitional services whilst 8 received community or outpatient services. Please refer to Table 1 for further demographic information.

After informed consent was obtained, interviews were conducted via teleconferencing. The interviewer, CB, was an able-bodied, cis-gender woman, aged in their late 20s, and an allied HCP with experience working with people with disabilities and qualitative interview methods. Interview questions pertained to participants' experiences of SCI broadly, perceptions of intimacy and sexuality, personal meaning attributed to sexuality, experience of receiving sexuality support, which HCPs were involved (if any), what facilitators or barriers to accessing support existed, and suggestions for improvement. Interviews were recorded then transcribed verbatim and interviewer notes were documented after each. Pseudonyms were used to maintain anonymity and potentially identifying information was redacted from transcripts. Both the interviewer and participants attended the online interviews in a confidential setting. Although participants were reminded they could cease the interview and arrange a follow-up, all participants completed one extended interview. The average interview length was approximately 90 min (range: 60–160). Data was obtained from March 2020 until February 2021. Recruitment pace was impacted by the COVID-19 pandemic.

Data Analysis

Similar to Cheek's [22] identification of no single definition of discourse analysis (discussed above); there is no one way to conduct CDA. Variations draw from various philosophers including: Aristotle, Marx, Fairclough, Foucault and Althusser [33]. The works

Table 1 Demographic characteristics

Participant	Age	Gender	LGBT+	Ethnicity	Country	Relationship status (injury onset)	Relationship status (interview)	Type of SCI	Level of SCI
James	30s	Male	No	Caucasian	UK	Married	Married	Incomplete	Cervical
Ben	40s	Male	No	Caucasian	Aus	Relationship	De-facto	Incomplete	Thoracic
Craig	40s	Male	No	Caucasian	Aus	De-facto	Single	Incomplete	Cervical
John	60s	Male	No	Caucasian	Aus	Single	Single	Complete	Thoracic
Kristen	20s	Female	No	Caucasian	Aus	Relationship	Relationship	Complete	Thoracic
Scott	30s	Male	No	Caucasian	Aus	Single	Single	Complete	Thoracic
Richard	50s	Male	No	Caucasian	Aus	Relationship	Relationship	Complete	Thoracic
Daniel	30s	Male	Yes	Eurasian	Aus	Single	Single	Complete	Thoracic
Henry	30s	Male	No	Caucasian	Aus	Married	Married	Incomplete	Cervical
Andrew	40s	Male	No	Caucasian	US	Relationship	Single	Complete	Cervical
Remi	30s	Female	Yes	Caucasian	UK	Married	Married	Incomplete	Lumbo-sacral

This table shows the demographic characteristics for the participants with SCI included within the study. Pseudonyms are used in place of the participant's real name

Aus Australia, *LGBT+* lesbian, gay, bisexual, transgender, plus, *UK* United Kingdom, *US* United States of Fairclough are considered particularly useful to consider healthcare discourses [34]. Through in-depth language analysis, Fairclough suggests discourse is both constituted and constitutive [34]. Fairclough encourages scrutiny of linguistic data such as words, grammar, syntax, lexicons, contextualization, and the organization of text analyzed in its entirety [35]. This enables researchers carefully explore power, knowledge, and meanings to decipher dominant discourses. Van Dijk [33] states though that the common aim of all CDA approaches are to, “analyze, understand and combat inequality and injustice” with the hope of, “change through critical understanding”. The rigor of CDA is enhanced by a multidisciplinary approach and its success is measured by its capacity to enable change.

Our CDA was conducted by a multidisciplinary team comprised of two female-identifying and two non-binary people. Three are abled-bodied, HCPs (two occupational therapists and one physiotherapist with training in sociology and psychology). The fourth is a sociologist who identifies as disabled. All research team members are white, one member identifies as heterosexual and three as part of the lesbian, gay, bisexual, transgender, queer, intersex, or transgender, plus (LGBTQIA+) community. We used a modified version of Fairclough’s CDA [35] and approached it in the two stages described by Huckin [36] and applied by McGregor [37]. CB iteratively read the eleven transcripts. The first stage involved reading transcripts uncritically to note the perspectives presented by participants. The second involved ‘topicalization’ to integrate a more critical appraisal [35]. Discursive themes were produced by considering the agent-patient relations (power dynamics), omissions, presuppositions, and connotations, such as in the form of labels or metaphors, insinuations, and apparent tone [37]. JS, and DKP (who have social science training and experience with CDA) were heavily involved in the analyses. JS helped develop the analysis and the initial discourses during regular meetings. DKP was involved in the interpretation and discourse analysis and throughout writing/editing. The remaining co-investigator TA (an occupational therapist with extensive qualitative research experience) provided ongoing input into the study design and analysis.

Results

Our analyses produced three prominent discourses: (1) broken bodies require repair, (2) sex is penetration, ejaculation then reproduction, and (3) sexual autonomy is required. Although each discourse is discussed individually below, all three are interrelated.

Broken Bodies Require Repair

Throughout the transcripts, participants spoke of support from HCPs which aimed at attempting to ‘fix’ an issue, usually pertaining to bodily functions. Numerous experiences were described where HCPs focused on prescribing medications for erections or offering fertility options for reproduction. At times this was all that was offered. Craig noted how medication appeared to be used as a quick fix, “Take Viagra… there you go, off you go home”. In this example, there is an assumption that the physical aspects of (heteronormative) sex, the erection, were in need of repair, underpinned by the discourse of a ‘broken body’.

A way in which the ‘broken bodies’ discourse was also apparent, was the absence of discussions around emotional and embodied elements of sexuality. As Richard indicated, “There was never anybody who pinpointed, okay, what do you feel about sexuality? What are your concerns?" Despite participants emphasizing the importance of HCPs addressing emotions and embodied experiences, this lack of support persisted. James reflects, "It's not, can you do this? It's like, *how do you feel* about doing this?" Aligned with this discourse, James further suggested that HCPs need to broaden the support provided beyond repair of 'broken bodies', as described below:

> The mechanical act of sex is, kind of one small aspect, I think… there should be, probably more specific questioning about the experience of having sex, not the mechanics of whether you can get an erection or ejaculate.

Daniel also alluded how support should focus less on addressing perceived dysfunction, and instead encourage engagement in sexual activity. For example, drawing on various aspects of the person such as the brain and skin, "the biggest sexual organs." Relatedly, Richard felt that using imagination, relaxation and trust with his partner were effective ways to enable him to express his sexuality, "Learning to relax, learning to let that person love you or pleasure you…feel that touch. Close your eyes and imagine what's beautiful." Such reflections suggest ways to disrupt the discourse of 'broken bodies' by broadening what is considered important when supporting sexuality with people with SCIs. Often though, these learnings and adjustments were realized long after the participants' injuries and through personal experimentation, not with the help of HCPs.

Another way in which the 'broken bodies' discourse underpinned participants' experiences was the tendency for HCPs to judge patients based on the severity of their disability. Rather than attending to individual needs, participants were stacked up on a scale of functioning. Seemingly the more disabled the individual, the more in need of interventions (fixing) they were. For example, James expressed frustration that his needs were not attended to because his incomplete SCI was considered "mild" compared to others, "it's almost like a lack of curiosity about the impact, that the mild illness has had… there's almost an assumption of—of function and recovery". This quote shows how there appears to be an approach in healthcare that favors providing outcome-focused treatment to people with more 'broken' bodies. Comparatively, Andrew who had a complete cervical SCI, discussed that because his injury was perceived as severe, his HCPs' expectations were low and their priorities for him did not necessarily align with his. As Andrew lamented:

> I don't know that they expected enough for me when I was in rehab. I mean I think they were looking at me as a C3, C4, … lucky to be off a ventilator, you know, [thinking] as long as we get this guy so that he can sit up in his chair, we've succeeded.

Together, Andrew and James's experiences highlight how disability is approached with this view of 'fixing,' and further to this, there appears to prioritization for 'fixing' people and their 'problems' which are deemed (as viewed within healthcare) as 'fixable.' A duality appears to exist where those who sit at polarities and who are perceived to have more "mild" or "severe" disabilities may be at increased risk of having their sexuality needs neglected.

Lastly, another apparent assumption was that women appeared to be seen as less 'broken'. Craig, reflected that having a SCI is "different" for women and may not impact on their sexuality as much. This may relate to discourse that because cis women are still able to be penetrated, they are able to fulfil normative sexual intercourse expectations and therefore do not need to be 'fixed.' One female participant, Remi, spoke of wanting more medical support for her sexuality but felt unsure if it was okay to ask as a woman. As Remi recalled:

> So, obviously, for me to then go, "Can I have Viagra?" would be a bit of a – probably a bit of you know, an odd one for them… Because, you know, would that be something that could potentially help with sensation in some way? Is there some science to back that as a reasonable request?

This quote again reflects notions in healthcare where people with SCI are viewed as having (heteronormative—as discussed below in discourse 2) physical dysfunctions (broken bodies) that require interventions to fix functional issues (repair). The body's intelligibility is reduced to mechanical functionality, which neglects consideration of other factors that may impact a person's sexuality and sexual expression.

Sex is Penetration, Ejaculation then Reproduction

Entwined with the previous discourse, the assumption of broken bodies, the second discourse evident relates to the apparent assumption that all sexual activity involves penetration of a penis in vagina, primarily for procreation. The resulting inference is that sexuality support need only consider sexual intercourse that is normatively understood to be typical for able-bodied heterosexual couples of reproductive ages. As Ben described, "There was the questions with regard to—particularly when I was first married and so on, you know, about, you know, fertility." People and practices that sit outside of these parameters therefore appear to be perceived as not requiring sexuality support.

Just as societal views of sex appear to be construed in fixed ways i.e., heterosexual intercourse, the interventions provided appeared to be based on these same normative views. HCPs tended to provide therapy that had a teleological focus, where therapy was directed toward an outcome derived from dominant societal norms. For example, therapists focused on providing interventions to achieve and maintain an erection or ejaculate, particularly with cis men. Similarly, participants also had goals that were focused on normative outcomes. Richard spoke of receiving a penile implant, however, noted that the intervention wasn't as effective as he hoped, "It looked sort of wrong." Interestingly, another quote by Richard again spoke to wider societal perceptions, "Normal people perceive sex as having intercourse."

This quote indicates there are strong socially constructed views about what is considered "normal" in society, and these can impact on both HCP and people with SCIs' expectations and assumptions. Participants however reported their views and approaches to sexual activity had to change after their injury. One participant however positively recalled how his views on sexual activity began to change after speaking with his sexual health nurse, "We talked more about, um, elements of intimacy and sexuality and ways that a person can still enjoy having a healthy, um, sex life". Daniel's quote suggests that HCPs can rework ableist norms to help people with SCI to express their sexuality in ways that are pleasurable and meaningful to them.

Interventions also appeared to be heteronormative as they were not directed towards people in same-sex relationships. Remi noted online educational resources were often designed for heterosexual couples, and this meant she was reluctant to receive support:

> I always get a little bit nervous around health professionals, from the point of view that generally, it is kind of like a heteronormative kind of approach to things… I'm always very cautious about what language I use because I don't want to be instantly judged by them by essentially coming out when I don't need to.

Daniel similarly described preferring to receive support at a dedicated LGBTQIA+ health service as he was “able to build that rapport” which was more helpful.

Taken together, the transcripts indicate that sexuality support narrowly focuses on three heteronormative elements of sexual activity: penetration with an erect penis, achieving orgasm or ejaculation, and conceiving.

Sexual Autonomy is Required

Numerous participants spoke of the difficulty they had accessing support for sexuality, which meant they were often having to search for answers on their own. Some of the reasons why people couldn’t access adequate sexuality support included: HCPs choosing patients’ goals, personal care goals prioritized over sexuality-related goals, or lack of suitable environments for private discussions with HCPs. This left many participants uncomfortable as they did not want to have to self-advocate for this type of support:

> I had to, like, ask multiple nurses multiple times, like, oh, when is the sexual health nurse going to be in, like, when can I see someone, before I actually, yeah, got – got an appointment… Because every time – the more you bring it up the more people – you just feel like people, like, don’t want to talk to you about it, and it – it makes you feel weird. (Kristen)

As this quote by Kristen indicates, people with SCIs are reluctant to initiate this conversation out of fear of judgement.

A primary barrier to receiving support though was because HCPs, often physicians, acted as ‘gatekeepers’ of referrals. This process removed control and autonomy from the individual. John recalled how his healthcare team were dismissive of his request for a referral and his physician appeared to “reserve” consultations for people in relationships. In this way, HCPs are effectively reproducing broader societal expectations, namely, to be deserving of sexuality support requires sex to occur in monogamous, heterosexual relationships with a procreative purpose (as discussed above in discourse 2).

Considering these compounding barriers, the denial or limited provision of sexuality support may, at least in part, be due to an underlying assumption that people with SCI should be responsible for their own sexual health. Participants were responsible for seeking out information independently and ultimately were responsible for navigating sexual expression and sexual pleasure on their own. This stood out in contrast to other dimensions of rehabilitation which were reported as readily supported (e.g., toileting and walking) and was in opposition to the reported wants and needs of participants. As Remi articulated,

> [It should be] compulsory that they are acknowledged as a sexual being… it certainly needs to be embedded within the staff that surrounds these people as something that is standard and not out there… And not something that’s progressive, it should just be.

Further to this, more diverse understandings of ways to engage in sexual activities, many of which require assistance from other people or objects, should be considered as part of sexuality support. Assistance could include: experimenting sexually with other people (such as with an intimate partner, multiple partners, and/or sex workers), discussing sexuality concerns with social supports (e.g., voicing fears/concerns with trusted family members), using alternative therapies and substances in line with medical advice (such as creams/supplements), incorporating sexual assistive devices (sex toys), using assistive technology during sexual activity (e.g., having sex on a wheelchair), exploring kink, writing and reading sexual fantasies or stories, and/or watching pornographic material to increase arousal. This is only a snapshot of many forms of ‘assistance’ that were used by participants to enhance their sexual wellbeing. However, these tools had to be discovered independently and were not actively encouraged within healthcare settings. Potentially because use of these assistive tools sits in opposition of apparent discourse that people should be sexually autonomous. Participants noted though that many of the listed options, such as sex toys and sex work, are also stigmatized in society more broadly. For example, Daniel mentioned, “I’m afraid of what kind of judgments I might get” if he was to ask for support to receive sex work services. This quote indicates that although there are other ways people with SCIs would like to receive support from HCPs, some of these options are influenced by underlying societal norms.

Participants, both male and female, considered sex work as an important way for people with SCI to adjust to their body post-injury. Many also advocated that funding should support access to these services. Several participants had paid for sex work services for sexual pleasure, sexual “release” or self-improvement, finding this to be a positive experience overall. Though often those who did seek out sex work services, only did so for a short period of time as a way of regaining confidence. For example, Craig reflected:

> After accessing sex workers and having sexual relations…. I do – I feel confident now. I feel like I’ve got – I feel like I’ve got a lot to offer someone now… it would only be a couple of times…. [to] make me feel better, um, about myself.

Participants often used similar language to describe the support they received from sex workers, as they did when describing the support received in healthcare environments. For example, participants stated people should be “referred” or “recommended” to sex workers by HCPs. Indicating sex work could be considered a form of care work or sexual support for people with SCI. However, as Daniel’s earlier quote indicated, fear of judgement means many people are unlikely to seek out this support and many HCPs are unlikely to refer or recommend this either. This further demonstrates how healthcare systems, HCPs themselves and people with SCIs are situated within and influenced by (and reproduce) wider societal discourses.

Not all care work supports a person’s sexual wellbeing. Current or potential partners having to provide care was a concern for most participants. Dual roles of partner and carer appeared to be in competition with each other. Ben rejected his partner’s offer of moving in with her after his injury as, “I didn’t want her to become my carer,” also noting that his partner was, “Awesome. Yeah. Um, very caring and pushes me.” Together Ben’s quotes demonstrate that in relationships, caring qualities are valued but providing acts of care may not be considered ‘sexy’. One participant articulated the complex entwining of personal care and intimacy when receiving care from his wife:

> The first couple of days in the hospital, felt like our link was extremely intimate… you know, feeding me, like, water with a straw… So I think I felt extremely close and intimate with her in that way. Um, but in the lead-up, in the first couple of days that I got home, …. I didn’t feel like a man anymore. I felt like a patient... And that felt horrible. Like, it felt really, um, like my body was — was not for intimacy in the way that it had been before. (James)

This quote conveys how care can be both deeply intimate but also a barrier to intimacy.

It seems because there is a discourse that people should be sexually autonomous (which exists for both people with and without disability), sexuality support is neglected in healthcare. This in turn can negatively impact on sexual wellbeing after SCI. Participants widely agreed that easy access to sexuality support which considers more diverse ways of expressing sexuality should be available to all people with SCI.

Discussion

The three discourses identified provide insight into various societal assumptions and power structures that appear when sexuality is supported (or not) in healthcare with people with SCI. These discourses are interrelated and have the potential to negatively impact a person with SCI's sexual wellbeing. Perspectives and assumptions that underly these three discourses have been discussed in previous sexuality and disability literature. Pamela Block and colleagues [38] argue rehabilitation which focuses on individual function after SCI is, "absolutely necessary", however by focusing on normative function, many important aspects of sexuality, such as desire, are neglected. Block et al. [38] addresses the problematic nature of HCPs approaching sexuality with binary views of 'function and 'dysfunction.' This contextualizes the first discourse, where people with SCI are considered as requiring repair within healthcare.

The first discourse is rooted in societal beliefs that view people with disabilities as 'broken.' This is based on ableist notions that able-bodied individuals are considered the ideal or 'complete' [28] and are stacked up on a scale of functioning [38]. In healthcare, disability and impairment are treated synonymously, yet the definitions and understanding of both are different [39]. Approaching people as impaired, which is derived from able-bodied norms, perpetuates negative associations of physicality after SCI. This can have consequences for a person's self-image [39]. Relatedly, as healthcare often focuses on impairments, it can neglect external factors impacting sexuality. The individual is expected to adapt to suit society rather than attempting to change socio-cultural or environmental factors. Social models of disability suggest it is society, not impairment that is disabling [27].

Many prominent scholars have challenged dualistic and harmful assumptions of the body [28, 40–42]. McRuer argues crip theory (whilst drawing from disability and queer movements), can challenge compulsory able-bodied perspectives and normative assumptions by pointing out the inadequacies of binary logic [28, 40]. Another normative assumption, heteronormativity, was also identified throughout the transcripts. Healthcare practice appears to assume sexual activity only involves penetrative sex with a penis and vagina (heterosexual sexual intercourse) for the purpose of procreating. This is despite heterosexual intercourse only being one of many ways that humans may wish to express their sexuality. For example, people may wish to have relationships only with themselves or with people of the opposite sex, among many other possibilities. Disability scholar Dan Goodley [43] argues HCPs assume heterosexual encounters within healthcare whilst also prioritizing men's needs. This is reflected within the current study as there was an apparent focus on sexual dysfunction, particularly for men.

Our analysis included some discussion of gender, where women felt less able to voice their sexuality concerns. Although only two participants identified as women, previous literature has noted similar concerns [16]. For example, women have voiced how sexuality support is often targeted towards men [13, 44–46], and nursing staff assume women's sexuality is a lower priority [47]. Building on previous literature, this study indicates power imbalances based on gender.

Power imbalances have been extensively discussed in feminist literature where it intersects with disability theory. Feminist theory has a symbiotic relationship with critical disability literature as both unsettle the certainties of mainstream ‘norms’ by exposing differential relationships to power. Feminist ideology views the personal as political and examines public versus private matters in the context of sexuality and disability [40]; in relation to this study, HCPs viewed sexuality after SCI as a private matter, resulting in these topics being avoided. In contrast, Shildrick [48] argues the avoidance and denial of disabled sex is more about separating needs from desires rather than a ‘personal is political’ issue [26]. In this view, oppression of disabled sexual expression is not an issue limited to top-down control (or healthcare policy in the context of this study). It reveals anxieties around the sexualization of disability which threatens dominant normative views. Normative discourses implicitly govern which bodies are desirable and equally, which bodies are capable of desiring, and under what conditions desire should be exercised. These compounding factors lead to the deprioritization of sexuality which remained a source of frustration for participants.

Deprioritization of sexuality support, means people with SCI are often required to assume responsibility for their own sexual readjustment, with repercussions for a person’s sexual wellbeing. For example, in one qualitative study involving women with SCI, many participants reported embarrassment when returning to sexual activity, noting that a lack of support contributed to challenges faced [49]. Lack of sexuality support in healthcare may also contribute to harmful assumptions that people with disabilities are nonsexual or asexual. Conversely, when people are viewed as asexual due to their disability, they may have trouble accessing sexual healthcare [42]. Understanding sexuality within the domain of human rights however necessitates recognition that people are sexual citizens who should be able to exercise their sexual rights [50].

Enacting sexual rights and expressing sexuality requires facilitation for people with different access needs. Shuttleworth conceptualizes this through the notion of ‘sexual access’, where restrictive practice is interrogated [38, 40]. Shuttleworth defines sexual access as “both the impediments and avenues to sexual wellbeing for disabled people” [51]. He argues issues of inclusion–exclusion and competing cultural meanings of disability and desirability are amongst the most impinging factors on a person’s sexual expression. This discussion of sexual access aligns with our study as people with SCI were assumed to have responsibility for their own sexual wellbeing. There appears to be a lack of support for disabled sexuality broadly, be that familial, institutional, and/or societal support. However, Shuttleworth argues provision of support for sexuality and disability might result in, “more positive sexual self-identification and heightened sexual self-esteem, which might also result in many nondisabled people perceiving them in a more sexual light” [51]. Therefore, the empirical data supporting this theoretical work strongly indicates a need for greater provision of support for sexuality after SCI.

Although more sexuality support is needed, the expectation for people with SCI to be sexually autonomous was prominent. Interestingly, Shuttleworth [42] has discussed that the men he interviewed in his research who were able to self-manage and learn to navigate the complexities of disability and desirability were ‘highly successful lovers’, however what this constitutes is vague. Importantly, not all people may be able to self-manage and increased support for sexuality is clearly warranted. We argue relying on self-management whilst neglecting to provide sexuality support in healthcare is indicative of a neoliberal mindset [52]. In society, people are celebrated for moments of ‘self-care,’ i.e., independence. Economic structures may encourage people to be independent as self-responsibility is assumed to require fewer financial resources. Research has challenged this neoliberal mindset, urging healthcare policy to, “place the rights of people before the rights of capital,” [52]. Healthcare broadly should challenge neo-liberalist expectations of self-responsibility which appear to be reproduced in healthcare settings. Ultimately this is an important factor for HCPs when making recommendations, for example advocating for more paid care work could help reduce perceived burden on intimate partners. However, some people feel having a paid carer can add stress to a relationship [27]. Therefore, understanding how to approach caring roles to enhance sexual expression for people with SCI requires nuanced consideration.

Participants appeared to consider support for sexuality similar to care work in our study and literature supports this view, with Shuttleworth [26] arguing facilitation of sex as a form of providing care. Facilitation referring to assistance which enables a person to access and express their sexual self. Care for sexuality can take many forms, for example setting reminders about taking birth control pills or assisting with sexual stimulation. Support for sexuality is therefore not limited to that provided by intimate partners or HCPs such as physicians, allied health professionals, etc. The different types of care to support sexuality may also be provided by various other people such as personal carers, sex workers or sexual surrogates [26].

The current study suggests funding care work to facilitate sex, such as sex workers, would assist sexual adjustment post-SCI injury. The role of sex workers and personal carers in facilitating sex with people with disabilities is underexplored in the research [38]. There is need for further investigation of this nuanced issue. Our research adds to previous research which suggests that sex work appears helpful for some but remains highly stigmatized in society—it also raises questions about what type of sex is valued by society/healthcare, with sex with a partner potentially valorized over other forms.

The three discourses found in this study indicate HCPs can play an important role in a person’s adjustment and acceptance after their injury. This study indicates that limited access to sexuality support and narrow considerations of sexuality devalue people with SCI as sexual citizens with sexual rights. Just as HCPs have the power to negatively impact a person’s sexual adjustment, conversely, HCPs can positively influence sexual expression. Good healthcare though is not simply about providing choice, it is about also doing away with assumptions of control and perfectionism. As Annemarie Mol states “Let us refrain from distinguishing endlessly between people who are able and people who are not… So let us care instead” [53]. Our analysis, in conjunction with existing critical disability theory, indicates many ways to improve care for people with SCI, including:

- Offering comprehensive sexuality support which goes beyond assumptions of ‘fixing’ body function and structures.
- Challenging ableist and heteronormative assumptions within healthcare at every institutional level.
- HCPs reflecting on their practice and considering if they provide sexuality support more for certain populations over others.
- Clear attempts to shift how sexuality is viewed within multidisciplinary rehabilitation settings by involving medical and allied health professionals in more discussions and training related sexuality.
- When providing sexuality support, HCPs need to consider and understand that care is complex and impacts on a person’s sexuality.
- Healthcare and other institutional systems should consider policy/practice changes that aim to increase funding and enable more paid and varied care work to support sexuality of people with SCI.

Although these implications for practice are important to consider, there are several limitations to the existing research. The participants were mainly located in Australia, so the findings are likely to be most relevant to countries with similar cultural assumptions and healthcare systems. Participants were also predominantly Caucasian and further research with more ethnic and/or racial variation would be beneficial. While the research team included researchers with different training and life experiences, and an academic with a physical disability, none of the team has had lived experience of SCI. As is always the case with qualitative research, the perspectives and experiences of the research team influence the findings. This research has two notable strengths. Firstly, participants all have lived experience of SCI, and secondly, the authors have used theory to help broaden understandings of practice concerns. Block et al. [38] pointed out the need for research that has both of these qualities. Further research though is needed to explore discourses apparent in sexuality support with other population groups. Importantly, there is opportunity for similar research to be conducted in non-Western countries and research is also needed which explores the role of paid support for facilitating sexual expression.

This CDA has provided a novel way of understanding some of the complexities and issues that exist when sexuality is supported in practice with people with SCI. In healthcare, there is a focus on goals related to sexual dysfunction (*broken bodies require repair*), particularly so for people with SCI of a certain demographic such as heterosexual couples of reproductive ages (*sex is penetration, ejaculation then reproduction*). Further, healthcare appears to neglect to provide opportunities for support for other aspects of sexuality (if at all), such as engaging in discussions about how care impacts their relationship. Therefore, people with SCI are left to decipher their sexual health needs on their own (*sexual autonomy is required*). The three discourses are all interrelated and require consideration together to understand how this area of practice is approached and could be improved upon. This research provides a novel perspective on sexuality support after SCI which could help to inform practice and/or policy changes at all levels.

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Data Availability Due to the nature of this research, participants of this study did not agree for their data to be shared publicly, so supporting data is not available.

Declarations

Conflict of interest To the best of our knowledge, there are no potential conflicts of interest.

Ethical Approval Ethics approval (2019002292) was received by the University of Queensland Human Research and Ethics Committee prior to data collection. The study complied with the National Statement on Ethical Conduct in Human Research.

Consent to Participate Informed consent was obtained from all individual participants included in the study.

Consent to Publish The authors affirm that the research participants provided informed consent for the results of the research to be published.

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