



# Exploring Sexual Wellbeing from the Perspective of Persons with Chronic Pain

Claire O'Brien<sup>1</sup> · Claire Lynch<sup>1</sup> · Chloe Bryant<sup>2,3</sup>

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## Abstract

Chronic pain is a prevalent condition that can impact all aspects of daily living including sexual wellbeing. Previous research has focused on biomedical aspects of pain and the negative impacts of pain on sexual activities. More recent research shows that sexual wellbeing has been linked to psychological and physiological benefits. However, a gap in research remains which engages with individuals with chronic pain to understand their perspectives on sexual wellbeing, including their participation in sexual activities, and whether they have experienced any benefit from participation. To address this, online semi-structured interviews were conducted with seven Australians with chronic pain. Through interpretive phenomenological analysis (IPA), three themes were produced: (1) Sexual wellbeing can still be valued and enjoyable, (2) Sexual wellbeing is influenced by those around us, and (3) The challenges of navigating sexual wellbeing within society and healthcare context. Findings indicated that despite the negative impacts of chronic pain, participants emphasised the importance of engaging in sexual expression as a means and end to improving sexual wellbeing and help manage pain. Sexual wellbeing was associated with feelings of empowerment, pleasure, connection, and love. Pleasure could also act as a form of pain relief. Open and honest communication from partner(s) and healthcare professionals is important to support sexual wellbeing. However, sexual wellbeing is currently largely neglected. Healthcare professionals therefore have an important role to play in initiating this topic and ensure individuals with chronic pain receive the necessary education and resources to address this important aspect of health and wellbeing.

**Keywords** Sexuality · Sexual health and wellbeing · Sexual expression · Pain management · Relationships · Australia

## Introduction

Chronic pain is a significant global health concern, with a worldwide survey of 52 countries revealing that the average pain prevalence within a country is 27.5% [1]. Chronic pain refers to pain that exists without an acute injury or persists beyond the expected healing timeframe,

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generally exceeding three to six months, and places a significant burden on individuals and populations [2, 3]. The experience of chronic pain can be both complex and idiosyncratic. Chronic pain often has cognitive, emotional, and sensory features and may impact a person's sense of self and identity [3–6]. Chronic pain can also profoundly interfere with a person's ability to participate in daily activities [7]. As highlighted in a 2021 systematic review, the daily activities impacted by chronic pain include sexual activities, as they found that sexual dysfunction is more prevalent in chronic pain patients than in healthy populations, and that higher pain levels correlated with greater sexual dysfunction [8]. In addition, a 2021 retrospective study found that an inverse relationship was true, and that treating chronic pain through an interdisciplinary pain rehabilitation program resulted in improvements in sexual function alongside reduced pain [9].

The World Health Organization recognises sexuality as an integral part of being human [10], and a person's sexual wellbeing is a key pillar of a person's sexuality [11]. Sexual wellbeing is a term used to describe the interaction between psychological, social, biological, and behavioural dimensions of a person's sexuality [11]. Lorimer et al. [12] describes how this term encompasses a myriad of factors, including sexual activities, awareness, opportunity, function, confidence, motivation, satisfaction, intimacy, and identity. Sexual activities are only one facet of someone's sexual wellbeing, therefore in this study, the term sexual expression was used to describe the behaviours and practices that each participant considered a manifestation of their sexual wellbeing, such as grooming, masturbation, oral sex, intercourse, massaging, kissing, hugging or holding hands. In a recent public health article, the authors discuss the importance of 'operationalising' a person's sexual wellbeing i.e., to work on goals with clients/patients which seek to enhance their sexual wellbeing [11]. Furthermore, greater sexual wellbeing is associated with greater enjoyment and overall quality of life [13, 14].

Despite the existing knowledge of the benefits of sexual wellbeing for quality of life, there is limited literature exploring the benefits on chronic pain. Existing evidence suggests there may be potential for sexual wellbeing to alleviate pain [15–17]. In a study of 10 women in 1995, Komisaruk & Whipple found that pleasurable self-stimulation was linked to an increased acute pain threshold [16]. A more recent study of 742 patients attending a pain management clinic discovered that sexual expression significantly mediated the relationship between depressive symptoms and pain intensity [18]. Hambach et al. observed the impact of sexual activity on headaches in 402 participants and found that sexual activity during a migraine or cluster headache could be associated with partial or complete relief of symptoms [15]. Additionally, a 2018 study of 96 participants with chronic low-back pain revealed that participants with higher sexual wellbeing reported a lower perceived pain intensity [17]. These studies [15–18], although cross-sectional in nature and therefore limited in their ability to establish causal relationships, demonstrate a statistically significant relationship between sexual wellbeing and chronic pain. The researchers have identified that this relationship is worth exploring further, to examine if there are perceived benefits of continuing to pursue sexual wellbeing despite the presence of chronic pain, potentially including but not limited to pain relief.

This research aimed to explore sexual wellbeing from the perspective of persons with chronic pain, highlighting their experiences and unique perspectives through qualitative research. It sought to provide insights into the complex relationship between sexual wellbeing and pain, and potential benefits or positive effects of sexual wellbeing. These insights

can potentially inform future research and clinical practice when addressing sexual wellbeing and chronic pain. Therefore, this study sought to explore how sexual wellbeing is perceived to interact with chronic pain, from the perspective of persons experiencing chronic pain.

## Method

### Research Design

Ethical approval was received by the Australian Catholic University Human Research Ethics Committee (ACU HREC). A qualitative constructivist approach using interpretive phenomenological analysis (IPA) [19] was used to explore the lived experience of Australian participants living with chronic pain. IPA is based within a constructivist paradigm [20] and was chosen as it offers a systematic approach to exploring the lived experience of idiosyncratic phenomena such as pain and sexual expression [19]. IPA is applied on small samples of less than 10 participants, allowing for more in-depth engagement with data [19, 21].

### Participants and Procedure

Participants were recruited using convenience sampling. Across three months, advertisements were posted on Facebook, Twitter, LinkedIn, Reddit, and the websites of major organisations, including Chronic Pain Australia, Arthritis Australian Capital Territory (ACT) and Pain Australia with permission from the respective administration teams. All social media advertisements were posted through the researchers' networks or to pain or sexuality-based Australian community groups. All advertisements included a link to a Participant Information Letter. Advertisements highlighted that all genders and sexual orientations were welcome, and participants were not required to be in a relationship. Potential participants then emailed the first author who conducted screening to ensure they met the inclusion criteria: over 18 years of age, located in Australia, had engaged in sexual and/or intimate activities, and had been experiencing pain for over three months. Participants who met the eligibility criteria provided informed consent prior to participating in the semi-structured recorded online interview.

The semi-structured interview guide (Appendix A) was constructed based on current literature and the research team's own knowledge and experience. The initial interview guide was then piloted with a person with lived experience of chronic pain and experience conducting similar interviews from the research team and adjustments were made to improve the questions and ensure they aligned with the research aims. Interviews were conducted online using Microsoft Teams to include participants that lived interstate or regionally, or whose pain limited their ability to travel. A transcript of each interview was generated and proofread by the first author to ensure accuracy. Each audio file and de-identified transcript were stored under a randomly generated pseudonym on Microsoft OneDrive in a password-protected file.

**Table 1** Participant Demographics

Pseudonym	Age (Years)	Gender	Sexual Orientation	Pain source	Duration of pain (Years)	Relationship status	State
Nicole	50	F	Heterosexual	Episiotomy	23	Married	QLD
Carol	NR	F	Heterosexual	Spinal Tumors	20	Married	NR
Katelyn	21	F	Undefined	Neuro-Fibromatosis type 2	21	In a relationship	VIC
Hayden	40	M	Heterosexual	Non-specific Musculoskeletal	NR	Single	VIC
Jennifer	76	F	Heterosexual	Ankylosing Spondylitis	60+	Widowed	ACT
Page	52	F	Heterosexual	Chronic Regional Pain Syndrome	30+	Single	TAS
Rebecca	57	F	Heterosexual	Osteoarthritis, Myalgic Encephalitis, Fibromyalgia, Migraines	NR	Married	ACT

<sup>a</sup>NR=Not reported by participants

## Data Analysis

Data analysis was conducted according to the IPA steps outlined by Peat et al. [19]. This began with a step-by-step immersion of each transcript separately, taking initial notes and identifying emerging themes [19 p.8]. To improve the trustworthiness of the data analysis, CO & CL independently analysed and cross-referenced two transcripts. After each transcript was analysed, the researchers examined any patterns or discrepancies across the cases. Following the initial analysis of all the transcripts, the lead author, CO, then conducted another review of the transcripts to further immerse and understand the data. Frequency codes and common categories were drafted and were reviewed by the entire research team as part of an iterative process. After a final list of agreed themes were produced, member checking was then conducted by sending a document detailing the emerging themes from the cross-case analysis to all participants for review. All participants completed member checking. The participants' feedback ranged from overall statements to specific comments on each theme to indicate if they agreed or disagreed and offering further insight. The participants' feedback was then used to corroborate and refine the themes. After incorporating the participant's feedback, the researchers incorporated existing concepts and past literature to develop the results.

## Findings

Six females and one male completed the interviews and member-checks (See Table 1).

Participants were all living in Australia and were aged between 21 and 76 at the time of the interview. They all had pain for at least three months, with an average pain duration of approximately 20 years. Their pain was associated with conditions including Ankylosing Spondylitis, Neurofibromatosis type II (NF2), Spinal Tumours, Arthritis, Myalgic Encephalomyelitis (ME)/chronic fatigue syndrome (CFS), Arthritis, Migraines, Bunions, Musculoskeletal Pain, Episiotomy, and Chronic Regional Pain Syndrome. All participants identified

as heterosexual. Four reported that they were in a relationship, whilst the remaining three were single. All seven participants expressed that their chronic pain interacted with their sexual wellbeing.

Three key themes were developed, those being: (1) Sexual wellbeing can still be enjoyable and valued (2) Sexual wellbeing is influenced by those around us, and (3) The challenges of navigating sexual wellbeing within society and healthcare context.

### **Theme 1: Sexual wellbeing can still be enjoyable and valued**

All participants except for one reported that sexual wellbeing was valued and enjoyable to them as they continued to find sexual expression "*fun*" (Rebecca) and a source of pleasure as it can make them "*feel good*" (Hayden & Nicole). Furthermore, five participants reported that they considered sexual wellbeing as a form of pain relief. Participants described either pain relief or distraction, distinguishing these terms and describing pain relief as a complete resolution of symptoms, whereas distraction as overriding or being able to ignore their pain. Hayden stated that it "*feels good and allows me to get some relief*", describing complete resolution of his pain symptoms during and up to half an hour after sexual activity. Hayden reported using sexual expression (masturbation) as a therapeutic tool to manage his chronic pain and co-morbidities as it is "*free of charge and ... you don't need anyone else to help you with relieving the pain*" (Hayden). Other participants also reported that sexual expression provided a distraction from the pain. For example, Jennifer suggested that sexual expression "*could take your mind off*", and Page reflected that their "*head blocks it out first and concentrates on... what I'm doing as opposed to [the pain]*" (Page), providing evidence that suggests sexual expression can relieve pain.

Beyond the capacity for pain relief, six participants reported that sexual wellbeing also provided other benefits including relaxation, sleep, pleasure, and empowerment. Four participants reported that they found it could help them relax and sleep, including Katelyn, who described:

*I know sex can cause dopamine and... I can feel relaxed enough to sleep. Some nights I've had too much coffee, or the melatonin just isn't working, and I can't get to sleep he'll be like let's try [having sex] and I'm able to sleep comfortably... hugging him afterwards. (Katelyn)*

Alongside sleep and relaxation, six participants highlighted the joy and sense of empowerment associated with sexual wellbeing. Participants explained that they viewed sexual expression as "*something to look forward to at the end of each day*" (Hayden), that has a "*sweet payoff*" (Nicole) and reinforcing that "*sex is great. Sex is fun*" (Rebecca). Participants also expressed that being able to be a sexual being despite their chronic pain was empowering, helping them reclaim a sense of control over their lives and their bodies. Participants noted that chronic pain had robbed them of their sense of identity and self-esteem, and "*It's hard to reclaim that and ... to feel attractive about yourself*" (Nicole). But exploring their sexual wellbeing had supported them to be "*more accepting... of my body and body image and my perception of myself instead of being disabled person... I might have disabilities, but I can still experience this and feel good*" (Hayden). In essence, participants conveyed that pursuing sexual wellbeing despite chronic pain was a meaningful and empowering experience associated with pain relief, relaxation, pleasure, and the ability to reclaim control over their lives and their bodies.

## Theme 2: Sexual wellbeing is influenced by those around us

The influence of others on a participant's sexual wellbeing was evident in all interviews. Participants suggested that their partner supported their sexual wellbeing through quality time, physical contact and communication and provided them with "*the feeling ... that somebody else cares*" (Jennifer). Participants stressed that "*touch matters*" (Rebecca), and "*it's very comforting to have somebody who will hold you, touch you, stroke your hair*" (Jennifer). Participants highlighted that this sense of intimacy and connection can occur despite adaptations to sexual activities, as "*there are days where all you want to do is have a cuddle... But because there's intimacy and there's love... and touching, that all helps. It's all positive*" (Rebecca). Partners that fostered a sense of intimacy and connection supported participants sexual wellbeing.

The intimacy and connection experienced within their relationship was contingent on communication for all participants. For example, Nicole expressed "*that open communication with a partner is extremely important*". When there was not a sense of open or considered communication, participants described tolerating sexual activities for the sake of their partner's happiness rather than both partners enjoying it. Nicole recalled instances where her partner was "*come on. I just need this. It was all about him.*" so she would "*put up with it. It's like... let's just get this over and done with...*". In these instances, Nicole felt that her partner "*didn't take the time to understand*", and because of this lack of communication and empathy, she did not enjoy engaging in sexual expression.

Nicole compares her past negative experiences with a previous self-centred partner to the fulfilling intimacy she shares with her current partner, who takes the time to communicate and understand her pain:

*My now husband ... I can very happily say we were three times a day... And I think what was nice ... was that he was so patient with me and willing to do anything in terms of I'll stay down there for as long as I need to. And I'll get your rocks off, and then we can worry about me, you know. He was patient and really good about that.*  
(Nicole)

Nicole's experiences highlight the positive impact of open communication and understanding on sexual wellbeing. Other participants echoed this sentiment, describing partners who provided a safe and understanding space for communication and how they felt this supported their sexual wellbeing. Katelyn emphasised that:

*[Communication] is really important, if he doesn't want to try something he will let me know, if I'm like... what do you think of this he'll let me know his honest opinion. And I know I can trust him because he doesn't like lying or you know ... He's very honest and nothing is off limits. And it's taught me to be patient because like ok I just got to accept how it is – he doesn't want to do that, next time I can bring it up. I like to imagine we... we communicate, and we are able to enjoy each other's company.* (Katelyn)

This suggests that open communication supported Katelyn and her partner's sexual wellbeing and the overall strength of their relationship.

Communication with partners allowed for problems to be solved together, further supporting participants' sexual wellbeing. Partners decided to prioritise certain daily activities to enable more opportunities and desire for participation in sexual activities, for example:

*If I need help in the garden, we pay... someone to do that. That means I've got that much more energy, and less pain and sex is more of an option... So that we get the outcome we want. (Rebecca)*

Rebecca's reflection highlights that communication enabled them to prioritise sexual wellbeing. Participants also emphasised that communication required a "sense of safety" (Rebecca), and trust and for both partners to accept that "We're learning as we go" (Rebecca), but "we both [want] the same thing" (Jennifer). Therefore, participants viewed open communication from both partners as key to sexual wellbeing within a relationship.

### **Theme 3: The challenges of navigating sexual wellbeing within society and healthcare context**

The importance of communication extended beyond partners into wider society and healthcare settings. Participants expressed that existing societal expectations and stigma hindered their sexual wellbeing, reporting that "nobody really asks about it" (Carol). The participants' own language was further evidence of the taboo or difficulty in discussing sexual wellbeing. Participants were generally comfortable using anatomical terms, and five used specific terms such as masturbation, orgasm or ejaculation; however, two participants only used general terms such as sex or sex life. Participants commonly referred to sexual activities indirectly, such as "that stuff" (Nicole), and two participants shifted into third person or clinical terms. Rebecca describes:

*For me, being able to discuss it in more clinical terms was certainly easier. And I know that's something that I've done a lot; I will actually divorce myself from a situation or a set of feelings - instead of writing I felt this it would be this is how it can feel for someone. (Rebecca)*

Rebecca's description shows how she uses language to make it easier for her to discuss her sexual wellbeing.

The stigma experienced by participants was also affected by societal norms. For example, participants described growing up "in an environment where ... you don't talk about that" (Nicole), describing that family members did not discuss sexual wellbeing openly. Three participants also suggested that "there's almost the feeling that, if you're disabled, you shouldn't have a sex life" (Jennifer), acknowledging the lack of disabled people present in media representations of sexual wellbeing and suggesting that society no longer views them as sexual beings. Participants felt that "we should all be more open about it" (Page) and suggested that talking about sexual wellbeing more in the media and with friends, family, and healthcare professionals would help to break down the stigma and support sexual wellbeing.

The stigma surrounding sexual wellbeing is also evident in the participants' experiences with healthcare professionals. The health professions seen by the participants included General practitioners, Psychologists, Physiotherapists and other medical specialties. Sexual therapists were a notable exception to this, actively de-stigmatising the topic with their clients, but only two participants had sought out sexual therapy. Only one participant had

sought a referral to Occupational Therapy for assistance with sexual expression. Participants reported that either health professionals had never asked about their sexual wellbeing or they "*acknowledged it but [weren't] really able to offer more than that*" (Hayden). Some participants had particularly negative experiences, reporting that either they felt "*there would be no point in talking to the [doctor] as [they] just come across as very cold, efficient and I'm sure she's technically a very good doctor, but she's not somebody you talk to*" (Jennifer) or when they tried to talk about the challenges their pain had on their sexual wellbeing with a doctor "*[the doctor] was just laughing at me—he was like, oh, there's nothing wrong... And I was just thinking you've got no idea... So yeah, that conversation fizzled down the drain*" (Carol). Participants found that these negative experiences decreased their comfort in discussing sexual wellbeing with their health care providers.

Participants said they felt more comfortable raising the topic if they felt supported by their treating clinician and if the clinician reacted with empathy and understanding. Participants also appreciated clinicians who could tailor their communication style and were honest about their level of expertise:

*Being able to turn around and say I'm not the best person for you to talk to about this, but I can point you to somebody who could be a lot better... having somebody turn round and say I can't do that, but I know someone who can. That is a level of honesty that I certainly appreciate. (Rebecca)*

Nicole, who is an occupational therapist herself, reflected on how she is working on approaching sexual wellbeing with her clients:

*There's gonna be some questions and I'm gonna ask you that might feel a little bit confrontational or a little bit personal. And by all means, if you feel uncomfortable, you don't have to answer them... Like it's ok. I've given you permission to say no. If you choose to. But I've also given you permission to talk about it. If you want to... (Nicole)*

Nicole's description highlights the importance of permission, the sense that the healthcare provider has given the impression to the consumer that it is okay to discuss sexual wellbeing and that they will be taken seriously. Jennifer echoed this sentiment, expressing that "*my new GP is excellent, as she would talk about it if I raised it*", and so did Rebecca who stated "*I'm incredibly fortunate with my doctor, my general practitioner. She has always been supportive. She knows that I'm somebody who will go and research and come up with okay—Do we try this? And she's open to [trying it]*" highlighting that participants felt more confident to discuss their sexual wellbeing if they felt that their health provider would be open and supportive.

## Discussion

The association between chronic pain and a reduction in the frequency of or desire to engage in sexual expression compared to a healthy population is well documented [9, 22–27]. The participants reinforced these findings, recognising that chronic pain can negatively affect their physical ability and mental capacity to engage in sexual expression. However, this

study examined sexual wellbeing beyond sexual activities, and the results suggest that there are benefits to continuing to pursue sexual wellbeing despite chronic pain. Since sexual wellbeing is linked to participants confidence, sense of identity, autonomy, and intimacy, participants revealed that there are a wide range of benefits for psychological and physiological health by taking steps to foster sexual wellbeing.

When looking at the experiences of the participants that continued to engage in sexual expression despite their chronic pain, the most interesting result was the level of pain relief experienced by each participant. The participants that did report pain relief suggested that it was experienced through either distraction, where the pain was less noticeable, or symptom resolution, where the pain disappeared, after engaging in sexual activities. The pain relief experienced by participants could be attributed to the phenomenon known as task-induced analgesia, where engaging in a cognitively demanding and rewarding task distracts from and potentially inhibits the experience of pain [28]. Sexual activities may also contribute to the release of neuropeptides that inhibit pain and result in excess dopamine production [29, 30]. The potential for sexual wellbeing to relieve pain appears to vary between individuals but is worth additional research.

Previous studies have suggested that there may be a difference in the experience of pain between genders [31–35]. Only one participant within this study reported complete resolution of pain symptoms following sexual activity, the male participant. Within the context of sexual expression, it has been found that males with migraine or headaches were more likely to experience pain relief after sexual expression than female patients [15], reflecting the experience of this male participant. Understanding the relationship between gender and pain is important for pain management and, as such, it has recently been the focus of the International Association for the Study of Pain, with 2024 designated the “Global year about sex and gender disparities in pain” [36]. At least in the case of the male participant, it is important to understand that there is potential for sexual expression to be used as a therapeutic tool to alleviate pain.

Aside from pain relief, all but one participant reported other positive effects from pursuing sexual wellbeing. Participants stated that engaging in sexual expression in the form of self-care, holding hands, touching, cuddling, oral or penetrative sex provided a sense of empowerment, relaxation, improved sleep, excitement, self-confidence, body confidence, fun, enjoyment, and a sense of intimacy and connection. These benefits are also evident in the literature, with a study by Gianotten et al. reporting a range benefits of sexual expression, including pleasure, pain relief, reduced stress, improved sleep, improved mood, improved self-esteem, improved cardiovascular health and immune system function [37].

The influence of partners on sexual wellbeing has also been explored in existing literature. It has been found that partners can trigger, maintain, or exacerbate pain by amplifying their partner's fear of pain or reinforcing pain-avoidance tendencies [38], whereas perceived partner consideration, in the form of validation, empathy and accommodations has been positively correlated with sexual satisfaction despite pain [9, 38, 39]. The influence of partners was reflected in participants responses, as they expressed that the impact of pain on their sexual wellbeing was worse if their partner was not understanding. In contrast, if their partner was understanding and empathetic, they were better able to pursue their sexual wellbeing. Perceived support and greater communication between partners have been significantly associated with lower pain and greater sexual functioning and satisfaction [40]. Interestingly, participants ascribed significant value to physical touch in supporting their

sexual wellbeing. Calming touch has been shown to decrease acute pain intensity [41, 42], and a higher touch frequency is associated with lower feelings of loneliness [43]. Therefore, having a supportive partner that validates the experience of chronic pain and is willing to provide physical and emotional comfort may enhance the associated benefits of sexual wellbeing.

Participants' relationship with their sexual wellbeing was also influenced by the wider society. There remains a stigma surrounding discussions of sexual wellbeing, especially for individuals with disabilities or chronic illnesses [44]. Media portrayals of sexual activity largely do not represent disabled populations and even impose assumptions of asexuality [44]. The minimisation or fetishisation of disabled sexual expression in media reflects the social exclusion and stereotyping that people with chronic illnesses or disabilities experience in daily life [45]. The participant's use of clinical language is evidence that societal stigma has manifested in their personal discomfort broaching the topic of sexual wellbeing. In an article examining the language of pain it has been suggested that the use of 3rd person language may be an attempt to disconnect one-self from the taboo topic and regain a sense of control [5]. A higher perception of control has been strongly associated with reduced pain intensity and greater sexual wellbeing [46–48]. The stigma associated with sexual wellbeing also impacts the ability to discuss it in healthcare settings [49, 50].

Sexual wellbeing is still an under-addressed area in healthcare contexts despite the growing recognition of its value and importance [51]. This may be due to prioritising more acute needs such as nutrition, sleep or mobility [52], a lack of time, privacy, or training [53], and the ongoing taboo or discomfort associated with discussing sexual wellbeing in healthcare settings [49, 50]. It is important that all healthcare providers be aware of and open to addressing sexual wellbeing in their practice [54].

All the participants expressed how important it was to feel comfortable talking to their healthcare practitioner and that their healthcare provider need to be comfortable discussing sexual wellbeing. The first step is being willing to listen and explicitly permit patients to talk about it if they want to. Giving patients permission is also reinforced in existing literature as central to normalising and improving sexual wellbeing [55, 56]. Indeed, interdisciplinary pain management programs have demonstrated promising results in reducing pain severity and increasing sexual wellbeing [9, 57], highlighting the potentially enhanced treatment outcomes that can arise from addressing sexual wellbeing. To do this, clinicians need to recognise that everyone has a sexual identity and that it is their role to be prepared to discuss it regardless of the scope of their role.

## Limitations

The results of our study are strengthened by the diverse ages and conditions of our participants. However, one limitation of our study was imposed by the sampling method and size. Convenience sampling methods risk non-participation and motivation errors [58], and whilst we did not provide a monetary incentive to attempt to minimise these risks, the sample population being only Australians and mostly heterosexual females still limits the generalisability of our findings. In addition, our research findings are subject to volunteer bias, and therefore there may be an increased prevalence of participant accounts that value their sexual wellbeing and an exclusion of viewpoints that do not value sexual wellbeing as

they are less likely to have responded to our advertisements. Furthermore, despite targeted advertising efforts, we were unable to recruit participants from LGBTQIA+, gender non-conforming, polyamorous and non-western populations. This limitation highlights the need for future research to ensure greater representation and inclusivity.

## Conclusion

The key finding of this research is that individuals may still prioritise their sexual wellbeing for pain relief, relaxation, intimacy, connection, fun, enjoyment and pleasure despite chronic pain. Partners and healthcare professionals can support a person's sexual wellbeing especially if they foster open communication and trust. In the words of one of our participants, Sexual wellbeing *"Is definitely worth doing and pursuing and... I think knowledge is power, so the more you can find out about it, the more you can talk about it. The more awareness I think that we put out there. The better it is"* (Nicole).

## Appendix A: Interview Guide

The text that follows was used as a guide for the semi-structured interviews to support consistency across data collection. It was piloted and refined in a trial run with the 3rd researcher who has lived experience with chronic pain and experience with trauma-informed interview techniques.

## Introduction

Hello [Name of Participant], thank you for coming today and for agreeing to be a part of this study. Do you mind if I hit record?

My name is [de-identified] and this research project is part of my Honours program within the Bachelor of Occupational Therapy at [de-identified]. *[If the supervisor is attending during this interview introduce her: Also in attendance today is my supervisor [de-identified]. If supervisor is not attending this session, declare that a supervisor is available on-call if either of us require some assistance].*

We are very thankful to have the opportunity to listen to your experience of sexual wellbeing and chronic pain today.

How are you?

[If they have brought an additional person, get them to introduce themselves, and clarify that that individual may provide moral or emotional support by assisting to answer questions, clarify facts, or help articulate the participants story].

## Interview Proceedings

Before we begin today, I do have a couple of formalities I would like to complete. I would like to go over the participant information letter, consent forms and then I would like to briefly explain what will be involved in today's interview. After this we can have a chat about your perspective on chronic pain and sexual wellbeing. How does this sound? [Allow time for verbal consent] [Confirm that all consent forms, including the support persons has been signed or recorded prior to continuing with the interview].

Thank you. To begin, I would like to read through the participant information letter that you have seen previously, to answer any questions you may have. Please let me know at any point if you would like further information.

I will also quickly explain to you what today's interview involves. This interview is expected to take approximately 60 min; we are able to take breaks or end this interview early if either of us need to. Before we begin it is important that I mention I will be asking you about your chronic pain and sexual wellbeing [as defined in the Participant Information Letter]. If either of these topics may make you feel uncomfortable, feel free to ask for a break or we can stop this interview at any time. If this interview has raised any concerns or caused you any discomfort, we encourage you to seek support from your friends, family or the supports listed at the start of your participant information letter including BeyondBlue (call 1300 22 4636) or lifeline (a 24-h crisis support and suicide prevention service available on 13 11 14). These services are listed in the participant information letter that you received, can I check that you still have access to that list or would you like to write down these numbers?

**Can I just confirm that you have given and are still happy to give informed consent to participate in this interview and for us to record it in video and audio format?** We will ensure that your information is kept confidential – we will use a different name when your interview is transcribed and when we write up the results. Only an audio copy of the recording will be kept and it will be stored in a secure OneDrive folder that only the research team have access to. The audio file and digital transcript will be stored for 15 years and then it will be deleted.

You also have a right to pause or withdraw from this interview at any time by asking us to stop. If you do withdraw prior to the completion of today's interview, I can delete your interview, and your data will not be included in the final study. If you chose to withdraw after the completion of the interview, please note we will not be able to delete your data as it will have been de-identified and not linked to your original interview. If you would prefer to skip or not answer a question that is fine, just let me know and I will move on to a different question. There are no wrong or right answers, today I am just interested in hearing about your experiences and your perspective.

After hearing all of this, are you happy to proceed? Do you have any Questions? [Pause].

## Interview Questions

To start with, I would like to get to know you a little better. **Can you tell me about yourself?**

- **I am interested in finding out what were some of the reasons that made you decide**

**to become a participant in this study?**What helped you make this decision?

- **Can you tell me about the pain that you experience?**How does this pain impact you day to day? (does this have any relation to sexual wellbeing?)
- How do you address your pain currently?

[Transition].

Thank you for talking to me about your pain, now for the next set of questions, I would like to learn about your thoughts and previous experiences regarding your sexual wellbeing. These questions will include what kind of sexual experiences you have had in the past and exploring the impacts you have noticed on your chronic pain. If any of these questions make you feel uncomfortable, please interrupt me or let me know that you would like to pause or skip that question, or we can stop the interview entirely.

**Can you tell me what sexual wellbeing means to you?**

Thank you for your answer. [acknowledge their perspective, incorporate it into sexual wellbeing] explore the definition.

Sexual wellbeing is a broad term, used in this study to encompass the psychological, social, behavioural and biological dimensions of sex. It can be expressed through thoughts, fantasies, desires, beliefs, attitudes, behaviours and relationships.

**Does this fit/change/alter your view of sexual wellbeing? Why or why not?**

If I continue to use the word sexual wellbeing, will it be clear that I am talking about all of these things including intimacy and sexual activity? Or would it be clearer if I use the individual terms e.g. sexual activity, masturbation, kissing or holding hands?

Thanks again for talking to me about your view of sexual wellbeing. As these questions get more personal, I would just like to reiterate that you do not have to answer any of these questions, if you let me know we are able to pause or move on if you are uncomfortable with a certain question. If a question is unclear, you are also welcome to ask me to rephrase it. Is that okay?

Are you in a relationship currently?

Do you feel comfortable discussing your current or past relationships?

**Can you tell me about the sexual experiences you have had?**

This may include relationships, but also includes your own sexual expression, through your behaviours, attitudes or beliefs, thoughts, desires, fantasies, and can be with yourself or others.

Questions:

- **Can you tell me about any past relationships?**
- **How does intimacy and sexual wellbeing factor into those relationships? Or your want to engage in relationships?**
- **Can you tell me about any times you have engaged in behaviours that are sexually pleasurable?**
- **Do you feel comfortable discussing if you have engaged in masturbation?**
- **Can you tell me about the kinds of sexual behaviours/activities you have engaged in?**

**In your opinion, could you tell me about some ways, if any, that living with a chronic pain has affected your sexual wellbeing or ability to be intimate or in a relationship?**

Prompts:

- Can you provide any examples?
- Why do you think this?

**And in reverse, in your opinion, could you tell me about some ways, if any, that your sexual wellbeing has affected your chronic pain?**

Prompts:

- What does this look like for you?
- Why do you think this?
- **Do you think there are any positive effects of sexual wellbeing on your chronic pain? Or have you noticed any positive experiences in other people you know?** Can you please expand on this? Can you provide any examples?
- Why do you think this?
- **Do you find that sexual experiences ever relieves your chronic pain?** What are your thoughts on the potential for chronic pain to be relieved by sexual expression?
- Why do you think this?

**Do you still find enjoyment in engaging in intimate or sexual behaviours despite the pain? What do you still find enjoyable?**

**Could you tell me about your experiences when talking about your sexual wellbeing with a health professional or a person from the community (e.g. family member or friend)?**

Prompts:

- Have you had many opportunities to discuss your sexual wellbeing?
- Is this important to you?
- Can you expand on this?
- what would a good experience with a health professional look like?
- Are there any suggestions you would have for health professionals in exploring this topic, or improving your sexual wellbeing?

**Q: do you have any other suggestions to enhance how other people can improve their sexual wellbeing?**

- **Are you, or have you in the past, found any resources or supports helpful for your sexual wellbeing with chronic pain?** E.g. medical professionals,
- Assistive devices, (anything that assists you to engage in sexual behaviour, not limited to vibrators or commercially available toys)
- Medications?

Thanks again for answering all those questions, just before we go I have some final questions, again if these feel too personal you can ask me to move on you do not have to answer these.

- **Demographic questions:**How old are you?
- What gender do you most identify as? (if you feel comfortable disclosing this)
- What sexual orientation do you most identify with? (if you feel comfortable disclosing this)

## Conclusion

We are approaching the end of our interview for today; I have no further questions. I would like to ask you if there is anything that you would like to add to the interview or if you have any questions.

You're welcome to take a few moments to yourself to think about everything that we have spoken about today.

The next step is for us to begin analysing all of the data we have collected, and we will send out an email with a summary of the themes we have collected for you to review. The results of the study will also be provided to you if you like. Would you like to receive a copy? [If yes, their email (only their email, no other identifying info) will be added to a mailing list in a password-protected document].

Thank you again for the interview today. Your time has been greatly appreciated and you have provided us with lots of great information. I would like to remind you of the supports that are freely available for you to access if this interview has raised any concerns or caused you any discomfort:

- Beyond Blue. Free service for anyone feeling anxious or depressed. Call 1300 22 4636, 24 h/7 days a week, chat online at [beyondblue.org.au](http://beyondblue.org.au)
- Lifeline. For any mental health crisis call 13 11 14 or go to [lifeline.org.au](http://lifeline.org.au)
- 1800RESPECT. Call 1800 737 732 to contact the national domestic, family and sexual violence counselling, information and support service.
- Suicide call-back service. Free service available to anyone thinking about suicide. Call 1300 659 467 or email [suicidecallbackservice.org.au](mailto:suicidecallbackservice.org.au)
- SANE Australia provides support to anyone in Australia affected by complex mental health issues, as well as their friends, family members and health professionals. Call 1800 18 7263, 10am–10 pm AEST (Mon–Fri), or chat online.

If you know of anyone else that would be interested in our project, please share our information with them.

Take care and all the very best.

[Conclude interview].

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## Authors and Affiliations

Claire O'Brien<sup>1</sup>  · Claire Lynch<sup>1</sup>  · Chloe Bryant<sup>2,3</sup> 

✉ Claire O'Brien  
clairecobrien@yahoo.com.au

✉ Claire Lynch  
claire.lynch@acu.edu.au

Chloe Bryant  
drchloebryant@outlook.com

<sup>1</sup> Australian Catholic University, Melbourne, Australia

<sup>2</sup> University of Queensland, Brisbane, Australia

<sup>3</sup> Present address: Torrens University Australia, Adelaide, Australia