

Persons with Complex Regional Pain Syndrome Renegotiate Social Roles and Intimacy: A Qualitative Study

Tara L. Packham, PhD, OTReg(Ont), Kaitlyn Wainio, MSc(OT), and Ming-Kin Wong, MSc(OT)

School of Rehabilitation Sciences, Faculty of Health Sciences, McMaster University, Hamilton, Ontario Canada.

Correspondence to: Tara Packham, PhD, OTReg(Ont), School of Rehabilitation Science, Institute of Applied Health Sciences Rm. 403, 1400 Main St. West, Hamilton, Ontario L8S 1C7, Canada. Tel: 1-905-525-9140, ext. 27812; Fax: 1-905-524-0069; E-mail: packhamt@mcmaster.ca.

Disclosure and conflicts of interest: Dr. Packham was supported by a postdoctoral fellowship from the Michael G. DeGroote Institute for Pain Research and Care at McMaster University at the time of this study.

Abstract

Objective. Persons with complex regional pain syndrome often experience allodynia, where touch is painful. Allodynia is associated with poor prognosis, but the impacts on roles, activities, social relationships, and intimacy remain unclear. There is a need to examine intimacy in complex regional pain syndrome from a lived experience perspective. **Methods.** We conducted a secondary analysis of cognitive debriefing interview data from 44 persons with complex regional pain syndrome who completed a patient-reported questionnaire. Using interpretive description and thematic analysis, we analyzed items and responses addressing allodynia, relationships, and intimacy. **Results.** Two themes were developed to understand intimacy related to the pain experience: a renegotiated social identity and participation and a reinvented intimate self. These themes included elements of a) loss of control, b) loss of shared experiences, c) feeling that their condition was misunderstood, d) a need for self-preservation, e) altered self-concept, and e) the concept of intimacy is broader than sexuality. Our findings suggest that complex regional pain syndrome has pervasive impacts on relationships and intimacy that merit discussion with their health care team. **Conclusions.** Persons with persistent pain need to be supported in roles and activities that allow them to express intimacy in their everyday lives.

Key Words: Complex Regional Pain Syndrome; Allodynia; Intimacy; Interpretive Description; Qualitative; Persistent Pain

Introduction

Complex regional pain syndrome (CRPS) is a chronic pain condition characterized by persistent pain disproportionate to what would be expected from the precipitating event or injury itself [1]. This condition is more common in women than men and is more often seen in upper extremities [2,3]. However, symptoms have also been reported to spread to other parts of the body [1]. Persons with CRPS often experience allodynia, where nonpainful stimuli such as light touch are perceived as painful [4]. Allodynia is associated with central sensitization and poor prognosis [5], but the impact on physical function and social relationships has not been thoroughly investigated.

Individuals with CRPS report a lower quality of life compared with other chronic pain conditions, particularly regarding their physical health [6]. In a small study

exploring daily activities, CRPS symptoms impacted participants' activity performance across personal care tasks, functional mobility, community management, productivity-related tasks, household management, recreation, and socializing [7]. There is little qualitative research describing the lived experiences of CRPS. However, in their narrative qualitative synthesis, Johnston et al. [8] found that common themes included a) invisibility of pain and disbelief of others, b) coping with a noncompliant and painful body, c) self-management, and d) alleviating pain/treatment. These themes underpin the model of the lived experience of CRPS proposed by Johnson et al.; they posit that individuals who experience chronic pain from CRPS go through a loss of their former selves and move toward acceptance and adaptation to their new experience through gaining information and support [8].

Chronic Pain and Intimacy

Although there is no research available specifically on the impact of CRPS on intimacy, the impacts of other chronic pain conditions on sexual functioning and intimacy have been explored [9–11]. A literature review by Bazzichi et al. [10] associated fibromyalgia with sexual dysfunction, including decreases in women's sexual desire, arousal, and experience of orgasm. Chronic pain, fatigue, stress, sleep issues, depression, and anxiety were also associated with sexual dysfunction [10]. In a longitudinal cohort study of $N=3,916$ older adults, chronic pain was significantly associated with impairment in sexual health [11]. Gender and psychological factors such as body image and self-efficacy are important modifiers in the complex relationship between chronic pain and intimacy [12]. However, a spectrum of experiences has been described [10,13,14]. These include findings that physical affection such as hugging and kissing may have positive benefits for both sexual and relationship satisfaction in women with provoked vestibulodynia [15]. Conversely, women reporting female sexual problems (including painful intercourse) may avoid touch and experience stronger negative affective reactions to potential touch from romantic partners compared with healthy women after controlling for relationship status [13].

Qualitative explorations have also added insights into the impact of painful health conditions on intimacy. Women experiencing pain during sexual intercourse (vulvodynia) describe feelings of inadequacy as partners and diminished feminine identity, reflecting the impact of pain on roles and self-perception [9]. Nakayama et al.'s [14] qualitative metasynthesis on the experience of systemic scleroderma suggests that pain and physical alterations impacted both sexual function and social relationships. Taken together, the qualitative and quantitative literature indicates there is a complex relationship between chronic pain and intimacy, involving physical, psychological, social, and societal factors.

Individuals living with a disability, including chronic pain, may experience stigma related to their sexuality. The person may internalize this stigma, leading to changes in their sexual self-concept [16]. Additionally, health care professionals may not appropriately address sexuality within their practice due to societal perceptions, such as seeing individuals with a disability as asexual, and may prioritize other goals above sexuality [17,18].

Given that persistent pain conditions are associated with impairments in sexual functioning and other aspects of intimacy, it is important to consider the impact of CRPS and the associated symptom constellation on intimacy. However, no such research currently exists to inform comprehensive and compassionate management. By exploring lived experience perspectives, health care practitioners can provide better service, resulting in better

health outcomes for individuals with CRPS [8]. To address this research gap, this study aims to describe the impact of painful sensitivity and other associated symptoms on intimacy in the lived experience of individuals with CRPS.

Methods

Source Study: Participants

We recruited 45 persons with CRPS of any limb to participate in semistructured cognitive interviews as part of a measurement development study (see [19] for more details). In cognitive interviews, respondents “think aloud” while completing a written questionnaire to elicit comprehension of the questions and understand the information used to formulate scalar judgements [20]. Written informed consent was received before booking an interview and was verbally obtained again at the time of the interview. The consent explicitly stated that a secondary analysis of qualitative data was planned. One consented participant did not follow through with the interview for unknown reasons. The original study was approved by the Hamilton Integrated Research Ethics Board.

Source Study: Data Collection

Cognitive interviews in the original study were conducted by the first author, a cis female occupational therapist and PhD student with >20 years of experience working with persons with CRPS, but a relative novice to qualitative interviewing. Interviews varied in location (home, public place) and medium (videocall, telephone) for the convenience of the participant. Three interviews were conducted face-to-face. Although we did not specifically invite partners to participate, on several occasions, they were present during the interview. However, no questions were directed to them. The only minor in the study provided assent, and a parent provided consent. This same parent listened in on the first half of the phone interview, and therefore was present during the question about relationships, but not during the question about intimacy. Participants were not provided with the questionnaire (a condition-specific evaluation for CRPS: [20]) until directly before the interview to encourage spontaneous responses. Interviews were typically about an hour in length (range = 30 minutes to 2+ hours) and were audio-recorded, then transcribed and assigned a pseudonym.

Secondary Study: Data Extraction Procedures

We conducted a secondary analysis of qualitative data obtained in a previously published study [19] using an interpretive description lens [21]. The purpose of the primary study was to inform questionnaire development; however, we anticipated that the interviews would also contain rich data on the experience of CRPS. This particular question emerged early in the data collection, as

participants described the interplay of allodynia and intimacy in their CRPS experience. For this study, all original transcripts were read in their entirety by at least one author. We extracted specific interview segments addressing painful sensitivity, relationship, and intimacy items from the questionnaire (Supplementary Data), as well any other responses where issues of allodynia, relationships, and intimacy were raised. These items were then used to create a new data set for qualitative analysis.

Qualitative Data Analysis

We analyzed the selected data segments using a thematic analysis approach [22] within an interpretive description methodology [21]. Interpretive description is a qualitative methodology used most often in health research from the applied health sciences disciplines [23], as the primary purpose of an interpretive description is to inform clinical practice. This was concordant with our goal of creating understanding of the experience to inform care for persons with CRPS. A priori codes were developed through discussion and consensus based on initial readings of the transcripts, and a codebook was developed. Sets of selected excerpts from two participants were used as trainers, with one being coded by the three researchers together and the other being coded by the three researchers separately: coding agreement used as feedback to support learning rather than an appraisal of reliability.

Coding of the selected excerpts continued independently with consensus discussions in weekly team meetings of the coded data segments. New codes were added to the codebook during this process, prompting returns to the data for review and recoding. Memos were attached to the text to capture any questions or insights generated by the coding process. During this period, journaling about broader learning and analytical ponderings was used to promote critical reflexivity in researchers. After coding was completed, each code was discussed, the definition refined, and examples provided by each team member to ensure a common understanding of the construct. The resultant codes were grouped into summative categories and then reconfigured into themes through discussion and comparison to the literature. We adopted a conceptualization of themes as “an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature or basis of the experience into a meaningful whole” [24]. Challenged by Sandelowski and Barrosa’s classifications of qualitative findings [25], we strove for abstracted and interpretive descriptive analysis, not data reporting. Finally, we asked other researchers with either lived experience with CRPS or experience conducting qualitative research on pain and/or intimacy to review an executive summary of our findings, inviting them to

Table 1. Participant demographics (N = 44)

Variable	Mean (SD)	Range
Age, y	47.8 (14.7)	15–81
Duration of CRPS symptoms, mo	67.3 (78.6)	4 mo–20 y
Variable	Frequency	Percentage
Gender		
Female	40	91
Male	4	9
CRPS affects		
Upper limb	21	47
Lower limb	12	28
Multiple limbs	11	26
Social (living) status		
Lives alone	11	25
Lives with partner	24	55
Lives with others (children, parents, housemate)	10	20

CRPS = complex regional pain syndrome.

identify areas of discordance or concordance with their experience and the broader literature. This triangulation helped to confirm our analysis and enrich the discussion.

Participant demographics were compiled using descriptive statistics such as means, frequencies, and percentages.

Results

The majority of the 44 participants in this study were women (91%), ranging in age from 15 to 81 years (see Table 1 for a complete summary of demographic characteristics); over half of participants reported that they currently resided with a partner or spouse. However, it is important to note that a) some participants who reported lived alone also described being actively engaged in intimate relationships without cohabitation and b) not all relationships were heteronormative.

We constructed two overarching themes from 30 individual codes and six content categories from our qualitative data set. The codes, categories, and resultant themes are catalogued in Table 2. The first theme, “Renegotiated Social Identity and Participation,” depicts the changes in social roles and activities as a result of living with pain and painful sensitivity that often limited opportunities for intimate interactions. The second theme, “Reinvented Intimate Self,” represents how participants described an evolution in how they viewed themselves and governed their own behaviors related to intimacy as a consequence of alterations in pain sensations and function. Both themes incorporated a spectrum of experiences, as persons with CRPS identified both losses and gains in the numbers and qualities of intimate relationships.

Renegotiated Social Identity and Participation

This theme reflects both positive and negative changes experienced in social, relational, and intimate

Table 2. Codes, categories, and themes from qualitative analysis

Theme	Renegotiated Social Identity and Participation		
Category	Loss of control	Shared experiences	They don't understand
Codes	Loss of control Pain hurts intimate interactions	Loss of shared experiences Perception of isolation Change in roles and dynamics Social isolation – imposed by others Guilt Sharing physical space	Social isolation – infrastructure Validation of symptoms Trust issues Partner is supportive (negative case) “True friends” Need for more info (all codes)
Theme	Reinvented Intimate Self		
Categories	Self-concept	Self-preservation	Intimacy as a spectrum
Codes	Body image Symptom shame Emotions toward limb Change in self perception	Sensitivity to the environment Sensitivity to touch Pain alters intimate contact Social exclusion – self-imposed Impact of fatigue Relationships are fragile Participant made no disclosures re: intimacy	Sexual function Partner Intimacy as sex Intimacy is not a priority Nonsexual intimate interactions (personal care, emotional connection)

participation. Many participants expressed difficulties with social interactions because of the lack of control they had over their symptoms. A sense of lost control extended to responses to intimate behaviors, and this was sometimes difficult for others to understand.

I tell my husband I am like Goldilocks; it can't be too hard, it can't be too soft, it can't be too hot or too cold, it's got to be just right. I'm too fussy, he says. (Judy)

Disproportionate or discordant (i.e., painful) responses to stimuli such as light touch and temperature are characteristic of allodynia [4]. However, although participants understood this to be a feature of their condition, they still expressed personal and partner frustrations with these evoked responses. Participants discussed changes in shared experiences with partners, friends, and family members after CRPS onset. “For the first almost year, we slept in separate bedrooms, because I had to sleep with my arm elevated” (Rhonda). Shared experiences were diminished not only in frequency, but also in the quality and variety of interaction. Sunny reported:

A year ago, I wouldn't even go to friends' houses for dinner or anything. It wasn't just always the pain, it was the embarrassment that I can't even cut my food half the time.

Some participants felt that changes in intimate social relationships were influenced by the understanding others had about CRPS. “So they think it's in my head” (Lucina). These changes resulted in participants having to renegotiate their social identity and participation.

Participants overwhelmingly talked about how CRPS had affected many of their close relationships; however, there was a spectrum of responses. “My husband kicked me out when the pain came back. Said it wasn't his

responsibility to look after me” (Carmen). Conversely, Hailey found her pain experience verified her support network. “It just made me realize how great people are, and it affirmed my relationships.” This experience of relationships deepened by adversity was described by a number of participants, who often identified these newly strengthened relationships as being “true friends.” However, the bi-directional nature of the relationship transaction was also acknowledged. Participants recognized the efforts required to renegotiate relationships and roles.

It is a constant work for me to do, as well as managing my symptoms, is manage my relationship so it stays alive. I didn't have to do that before. (Michelle)

Many participants experienced role changes, such as moving from caregiver to care recipient, including receiving help from young children.

If you can imagine, my [younger] daughter was two when I got hurt. I went from a super mom to a mom who can't even change a diaper now. She's had to grow up really quick. I also have a 19-year old daughter who always knew me a certain way and for her to deal with me, almost being helpless for a lot of things, it was horrible on her.... She couldn't figure it out. (Sunny)

Such role changes were usually perceived as losses and were often related to functional losses. Persons with CRPS talked about picking and choosing friends, what activities to participate in, and how the unpredictability of pain and sensitivity directed how, when, and even whether they engaged in the activity. “It can become a very, very depressive situation because you become reliant on others to pick you up, and the phone doesn't ring”

(Jack). Judy lamented, “Or anything that your friends want to get together to do, you miss out on that too, because you know you just can’t.” The combination of having to redefine themselves and how they engaged in roles and activities greatly affected engagement in shared experiences and, by extension, appeared to diminish quality of life. However, these losses were mitigated by social support and validation of the pain experience associated with CRPS.

I think I have the most amazing family, the most amazing friends. . . . They have lifted me up, and they have been so strong for me when I don’t have, when I feel like I don’t have the strength. (Serena)

Conversely, even with validation from social group members, others described feelings of isolation and difficulties adjusting to a “new normal.”

With this disease, it’s the support that I’m missing. And talking to others [with CRPS], we feel so alone. Even if we have a strong support group, we still feel alone. (Melanie)

Reinvented Intimate Self

This theme incorporates self-perception and self-preservation related to changes in intimate relationships and interactions. Participants appeared to make adjustments to new levels of function and sensation in order to preserve or re-invent intimacy and sustain close relationships. “If your husband can’t hug you, it is pretty hard to have intimacy. We have had to find other ways to do it” (Apple). This positive adaptation fostered healthy relationships and positive self-perception. However, sometimes symptom management was in conflict with the desire to engage in social and intimacy-producing interactions, resulting in actions of self-preservation that were at odds with self-perception about social identity. Self-preservation was described in the context of social situations, where physical or emotional distancing were self-imposed to minimize potentially painful interactions.

When my signs and symptoms occur in a social situation. . . and I have to withdraw, I am uncomfortable with that because I don’t want people to think of me as being antisocial. But I physically can’t handle it any longer. (Tiana)

Participants shared experiences about their intimate lives—sometimes sexual in nature, other times emotional. “I mean, he wants back the woman he married, and I can’t blame him because I want her back too” (Sunny). This included changes in sexual function related to medications, as described by one participant (Sue). “Since I started taking medication, I’ve been having a lot of trouble orgasming. And um. . . it’s really weird because I don’t really feel it almost.” Several participants attributed changes in their relationships to health problems experienced by their partner, including erectile dysfunction.

Others noted that sex was not a priority because they did not currently have an intimate partner. “I am so busy and so single! [laughs] So there is no sex in my life in any way, shape, or form, hands or no hands!” (Hailey).

Participants also talked about how their self-concept had changed as a result of CRPS, affecting how they perceived themselves and their bodies.

Others that are normal see you as a disability, and a disability is like having an ugly thing on your body. They don’t want to be with somebody like that. (Michelle)

Social and sexual desirability appeared to be entwined with the self-perception of being healthy and was seen as diminished by pain and other symptoms. Several persons expressed shame about their symptoms. “What did embarrass me was at work, when I would go to shake peoples’ hands. . . . It would profusely sweat. And you’re at work!” (Hailey). Shame and embarrassment were also experienced in intimate relationships, particularly in relation to physical symptoms. “After a flare-up, I’m really sick and I vomit a lot, I just look really bad and I’m embarrassed for him to see me so sick” (Mac).

Persons with CRPS and allodynia engaged in self-preservation by controlling their environment to minimize the pain experience. This included changing if and how they engaged in sex to prevent or minimize the pain experience. “I couldn’t have even a sheet touch my foot, so forget about “getting comfortable <chuckles>” (Lucina). Self-preservation behaviors also extended to altering clothing choices to reduce tactile allodynia. However, some of the participants described how these wardrobe changes threatened their self-expression, fashion identity, and self-image.

You have to watch what you wear, and I won’t wear certain clothes ever again that I used to wear all the time, that used to be my favorites, because now I am sensitive to it.” (Michelle)

These self-preservation behaviors led to reinvention of the intimate self and changed how participants engaged in intimate behaviors ranging from emotional connection to sexual activity. “Well. . . yeah. I’m going to say sexual intimacy, because the symptoms prevent it and my pain and the act itself causes me pain, will trigger pain” (Tiana). Pain also interfered with the motivation to engage in sexual activities. Tom put it frankly, “It takes the starch out of the moment. <laughs> I have to say that the way it is. Yeah, it is, you just don’t feel like it [engaging in sex].” Self-care occupations were sometimes challenging, and altered routines for personal hygiene influenced self-image and perceived desirability to intimate partners.

Showers are just, uh, I can only get up my motivation to put myself through that kind of pain about once every six

to eight days. I get pretty disgusting. <pause> I feel terrible for my husband. (Sue)

However, not all participants referred to intimacy exclusively in the context of sexual activities. Many participants referred to intimacy in a nonsexual fashion, including emotional intimacy with friends, children, and family members. Intimacy was also referred to related to contact with their intimate partner in the context of needing assistance to perform personal care. “I stayed over at my boyfriend’s... I couldn’t stand up long enough in his shower, so I sat down in the bathtub, and then couldn’t get up. And he had to come rescue me” (Lana).

Discussion

Our findings suggest that CRPS has widespread impacts on relationships, and consequently the ability to engage in activities and roles where intimacy can be expressed. The impact of allodynia, persistent pain, and other symptoms on intimacy became even clearer when participants described their experiences of intimacy in a variety of contexts. Although some participants referred to intimacy as sexual activity, many participants depicted more nuanced and multidirectional experiences of intimacy, related to a) the need to renegotiate their social roles and identities in the context of their relationships and b) modifying their self-perception as intimate beings. Overall, these findings provide insights into the pervasiveness influence of painful sensitivity on the intimacy and relationships of the everyday lives of persons with CRPS.

Our findings are concordant with other qualitative studies addressing the impact of health conditions on intimacy. A qualitative study of sexuality in women after spinal cord injury reported that participants constructed sexual intimacy as a form of well-being, entwined with stable romantic partnerships; however, others contextualized it in terms of physical behaviors and sexual activities [26]. While sexual intimacy is only one aspect of the intimacy construct, sexual dysfunction appears to be a common experience described in chronic pain samples [11, 12, 15, 27]. In an online survey, Finn and colleagues [12] found that 43% of the males and 48% of the females in their chronic pain sample experienced sexual dysfunction. Reported elements of sexual dysfunction after chronic pain have included reductions in all aspects of the sexual response (desire, arousal, and orgasms), [10, 12, 28], reduced frequency of sexual intercourse [12, 27], and reduced affectionate and nonaffectionate touch [13, 15]. Our study illustrates similar findings in the CRPS population, as participants often discussed changing the methods and frequency of engagement in sexual acts and activity outcomes (e.g., orgasm) because of persistent pain and fatigue.

Although the emotional and relational aspects of intimacy seemed to be important contributors to the overall

intimacy experiences of persons with CRPS, this is less represented in the literature. A narrative ethnography by Smith [29] reported that chronic pain in one or both partners often resulted in diminished physical closeness, leading to feelings of frustration and distancing from one another. These experiences became internalized and affected self-image; she noted that women described themselves as “old and unattractive” (p. 140), whereas others described changes in roles and activities affecting their perceptions of intimacy with their partner. Eaves and colleagues [30] explored the embodied risk of physical pain and social rejection in persons living with temporomandibular disorders. They described the forging of new stoic identities supporting participants’ desire to soldier on despite pain. This stoicism was seen to conflict with intimacy and intimate exchanges [30]. Changes in self-perception when living with chronic pain are supported by Finn, Morrison, and McGuire [12], who found a statistically significant moderate negative correlation between sexual function and body image dissatisfaction and pain severity. Taken together, these findings are concordant with the interpersonal process model of intimacy, which posits that when an individual’s sharing of personal thoughts and emotions is met with validation, emotional intimacy is developed and sustained [31]. When persons with pain fail to feel validated or feel they must hide their pain from others (as our participants described), emotional intimacy is threatened or diminished [31]. This further supports our thematic findings that persons living with CRPS undergo a process of renegotiating their social identities and participation and must reinvent their self-conceptualization as intimate beings.

Implications for Practice

Health care professionals should consider the pervasive impacts of allodynia for persons with CRPS in their everyday occupations as they relate to intimacy. However, awareness of the concerns is not sufficient: welcoming persons seeking health care to ask questions or discuss concerns regarding intimacy and sexual function is also required to improve holistic care [18]. These discussions should reflect the spectrum of relationships where intimacy can occur and recognize the potential changes in the quantity and quality of relationships that persons with CRPS experience following the development of persistent pain, as well as the contributions of medications and normal aging. Professionals within rehabilitation and psychology are well positioned to discuss issues of intimacy, given their understanding of how individuals see themselves in their everyday contexts and how those reflections influence whether they are able or choose to engage or not engage in specific roles and activities [17, 18]. Open communication between the person with pain and persons within their social sphere can facilitate the strengthening of relationships that may have been weakened during adaptation to persistent pain in CRPS.

Referral to relationship therapists, sex therapists, social workers, or family counselors, among others, may be required to assist these clients in rebuilding relationships. By ensuring that persons with CRPS are supported in opportunities to express their intimate selves, health professionals can help these individuals in one of the most vulnerable and personal aspects of their identity.

Strengths and Limitations

There are several strengths to this study. The original sample was relatively large for qualitative traditions, yielding data rich in breadth and depth. There are few studies on the experiences of persons living with CRPS [8], and to our knowledge, this is the only study exploring how intimacy is experienced in this population. Finally, the shared occupational therapy perspective of the research team privileged consideration of intimacy as an occupation and supported examination of the transactions between individuals' pain and sensitivity, their contexts, and their intimate roles and activities.

However, interpretation of our findings should take into consideration the limitations of the research data and methods used. First, because it was a secondary data analysis, the data used in this study were not purposefully collected to answer our specific research question, and we were unable to continue sampling to confirm data saturation. Some answers on intimacy may have been limited in the depth of description due to the sensitive nature and social unacceptability of discussing sexuality and intimacy. In addition, partners or a parent were present for portions or the entirety of several interviews, which may have influenced what was said on the subject of intimacy. Despite this, we are confident that the data shared by participants have produced insights useful to inform clinical care of persons presenting with this syndrome. The data set used in the study may have been influenced by the first author's occupational therapy background, as well as the transactions of information seeking and sharing between the interviewer and participants. The design of the source study [19] called for the questions to be presented in a randomized order to minimize order bias on ratings. However, for this investigation, randomization may have had the effect of limiting the flow of conversation and truncating deep discussions and sharing.

Second, rather than using the original transcripts in their entirety, we specifically sought out any responses in the data set addressing the constructs of relationships, intimacy, and allodynia, including the questionnaire items pertaining to these constructs. Although this could have narrowed our understanding of the spectrum of intimacy experienced by the participants, intimacy was addressed by participants relative to a number of the questionnaire items. The original study did not endorse or enforce a specific definition of intimacy during data collection: participants were encouraged to provide responses based on their own definition of intimacy. Some participants thus

defined their understanding of intimacy explicitly, but most participants alluded to their definitions. This resulted in a broad construct including both physical and emotional elements and identified intimate interactions including parents, children, partners, spouses, work colleagues, and friends.

Third, our research team included only the discipline of occupational therapy, which may have influenced our understanding of the findings. Although occupational therapy considers the personal, environmental, and occupational domains of a person's being, the perspective of other disciplines such as sex therapy, nursing, medicine, social work, and/or physical therapy could have resulted in identification of more, or different, themes. Although we did seek other perspectives as part of our triangulation efforts, this work could be strengthened by triangulating our findings with clients with CRPS and engaging other disciplines within the research team.

Conclusions and Future Directions

Research must engage multiple perspectives to assist in unraveling the complexity of the CRPS experience, including the impacts of painful sensitivity on intimacy and social roles. Although this study provides a first look into the topic, much more work is needed using both quantitative and qualitative methods to explore intimacy in complex regional pain syndrome, and in the broader field of persistent pain. Such work can inform a framework to assist clinicians on how best to address intimacy in all its forms as part of comprehensive and compassionate care.

Acknowledgments

The authors would like to thank the research participants for sharing their experiences. We would also like to thank Promoting Awareness of RSD and CRPS in Canada (PARC) for assisting in the recruitment of the participants. Finally, we wish to thank Drs. Natalie Rosen and Peter Moscovitz for their insightful comments on the thematic summary.

Supplementary Data

Supplementary data are available at *Pain Medicine* online.

References

1. Bruehl S. Complex regional pain syndrome. *BMJ* 2015;350:h2730.
2. de Mos M, Huygen F, Dieleman JP, Koopman J, Stricker B, Sturkenboom C. Medical history and the onset of complex regional pain syndrome (CRPS). *Pain* 2008;139(2):458–66.

3. de Mos M, de Bruijn GJ, Huygen F, et al. The incidence of complex regional pain syndrome: A population-based study. *Pain* 2007;129(1-2):12-20.
4. Gierthmühlen J, Maier C, Baron R, et al. Sensory signs in complex regional pain syndrome and peripheral nerve injury. *Pain* 2012;153(4):765-74.
5. Brunner F, Nauer M, Bachmann LM. Poor prognostic factors in complex regional pain syndrome 1: A Delphi survey. *J Rehabil Med* 2011;1(8):783-6.
6. Van Velzen GAJ, Perez R, Van Gestel MA, et al. Health-related quality of life in 975 patients with complex regional pain syndrome type 1. *Pain* 2014;155(3):629-34.
7. Brincat R. The impact of complex regional pain syndrome type I on an individual's occupational performance. *Br J Hand Ther* 2004;9(3):96-104.
8. Johnston CM, Oprescu FI, Gray M. Building the evidence for CRPS research from a lived experience perspective. *Scand J Pain* 2015;9(1):30-7.
9. Ayling K, Ussher JM. "If sex hurts, am I still a woman?" The subjective experience of vulvodynia in hetero-sexual women. *Arch Sex Behav* 2008;37(2):294-304.
10. Bazzichi L, Giacomelli C, Rossi A, et al. Fibromyalgia and sexual problems. *Reumatismo* 2012;64(4):261-7.
11. Wade K, Wu FCW, O'Neill TW, Lee DM. Association between pain and sexual health in older people. *Pain* 2017;7079-1.
12. Finn E, Morrison TG, McGuire BE. Correlates of sexual functioning and relationship satisfaction among men and women experiencing chronic pain. *Pain Med* 2018;19(5):942-54.
13. Rancourt KM, MacKinnon S, Snowball N, Rosen NO. Beyond the bedroom: Cognitive, affective, and behavioral responses to partner touch in women with and without sexual problems. *J Sex Res* 2017;54(7):862-76.
14. Nakayama A, Tunnicliffe DJ, Thakkar V, et al. Patients' perspectives and experiences living with systemic sclerosis: A systematic review and thematic synthesis of qualitative studies. *J Rheumatol* 2016;43(7):1363-75.
15. Vannier SA, Rosen NO, Mackinnon SP, Bergeron S. Maintaining affection despite pain: daily associations between physical affection and sexual and relationship well-being in women with genito-pelvic pain. *Arch Sex Behav* 2017;46(7):2021-31.
16. Esmail S, Darry K, Walter A, Knupp H. Attitudes and perceptions towards disability and sexuality. *Disabil Rehabil* 2010;32(14):1148-55.
17. Mc Grath M, Sakellariou D. Why has so little progress been made in the practice of occupational therapy in relation to sexuality? *Am J Occup Ther* 2016;70(1):7001360010p1-5.
18. Couldrick L, Sadlo G, Cross V. Proposing a new sexual health model of practice for disability teams: The Recognition Model. *Int J Ther Rehabil* 2010;17(6):290-9.
19. Packham TL, MacDermid JC, Michlovitz SL, Buckley N. Content validation of the patient-reported Hamilton Inventory for complex regional pain syndrome [in French]. *Can J Occup Ther* 2018;85(2):99-105.
20. Nápoles-Springer AM, Santoyo-Olsson J, O'Brien H, Stewart AL. Using cognitive interviews to develop surveys in diverse populations. *Med Care* 2006;44(11 Suppl 3):S21-30.
21. Thorne S. *Interpretive Description*. Walnut Creek, CA: Left Coast Press, Inc; 2008.
22. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. *Nurs Heal Sci* 2013;15(3):398-405.
23. Oliver C. The relationship between symbolic interactionism and interpretive description. *Qual Health Res* 2012;22(3):409-15.
24. DeSantis L, Ugarriza DN. The concept of theme as used in qualitative nursing research. *West J Nurs Res* 2000;22(3):351-72.
25. Sandelowski M, Barroso J. Classifying the findings in qualitative studies. *Qual Health Res* 2003;13(7):905-23.
26. Fritz HA, Dillaway H, Lysack CL. Don't think paralysis takes away your womanhood: Sexual intimacy after spinal cord injury. *Am J Occup Ther* 2015;69(2):6902260030p1.
27. Ambler N, Williams A, Hill P, Gunary R, Cratchley G. Sexual difficulties of chronic pain patients. *Clin J Pain* 2001;17(2):138-45.
28. Dargie E, Gilron I, Pukall CF. Provoked vestibulodynia a comparative examination of mental health, sleep, sexual functioning, and relationship adjustment. *Clin J Pain* 2017;33(10):870-6.
29. Smith A. Intimacy and family relationships of women with chronic pain. *Pain Manag Nurs* 2003;4(3):134-42.
30. Eaves ER, Nichter M, Ritenbaugh C, Sutherland E, Dworkin SF. Works of illness and the challenges of social risk and the specter of pain in the lived experience of TMD. *Med Anthr Q* 2015;29(2):157-77.
31. Reis H, Shaver P. Intimacy as an interpersonal process. In: Duck S, ed. *Handbook of Personal Relationships: Theory, Research and Interventions*. Chichester, UK: John Wiley & Sons, Inc.; 1988:367-89.