

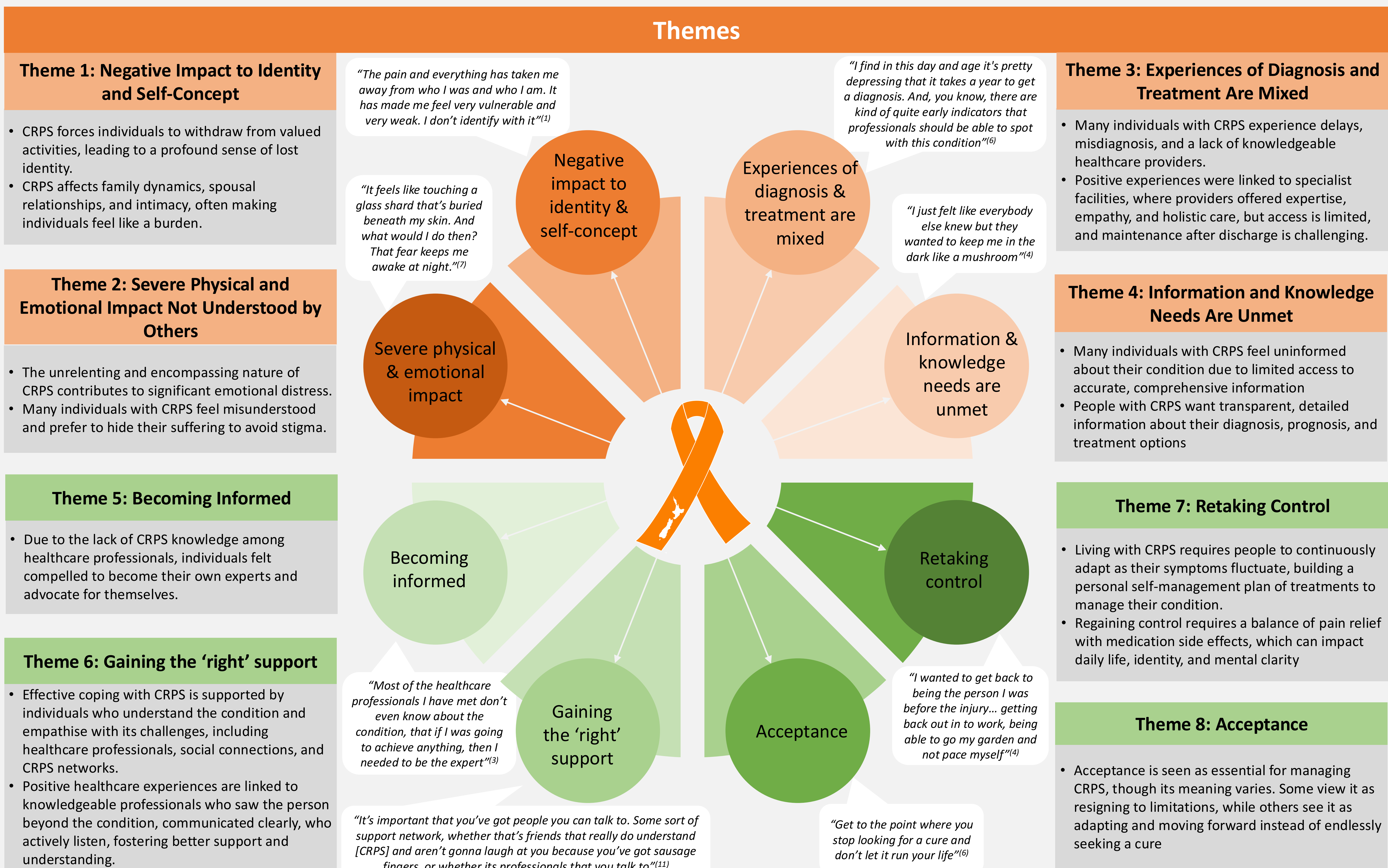
What is the lived experience of CRPS?: A narrative synthesis

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Background	Complex regional pain syndrome (CRPS) is a limiting and distressing pain condition. Like much of 20 th -century chronic pain research, CRPS research has drawn on biomedical frameworks, testing quantitative objective measures that focus on diagnosis, mechanisms, and pharmacological treatment efficacy. Whilst this information is certainly valuable, the experience expressed by those living with CRPS remains poorly understood.	Methods	<p>This review aimed to:</p> <ol style="list-style-type: none"> 1 Synthesise all literature describing the experiences of living with CRPS. 2 Use a thematic analysis to identify themes to inform service delivery and clinical practice. <p>We conducted literature searches between May 2022 and January 2024 using the databases: CINAHL, MEDLINE, SPORTDiscus, PsycINFO, Scopus and Google Scholar.</p> <p>Inclusion criteria All qualitative or mixed methods literature exploring the lived experience of CRPS.</p> <p>Exclusion criteria Non-English, paediatric populations, lack of clear diagnostic criteria (e.g. Budapest criteria), mixed populations (e.g. chronic pain and CRPS), and experiences post-intervention (e.g. spinal cord stimulator).</p> <p>The results sections of included studies were coded line-by-line and synthesised using thematic analysis.</p>
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Findings	Eleven qualitative or mixed-method studies met the inclusion criteria. Studies included the experiences of living with CRPS, ^(1,2,6,7,11) receiving information about CRPS, ⁽³⁾ diagnosis and healthcare for CRPS, ^(4,9) attending and transitioning home after a CRPS pain management programme, ^(5,10) and intimacy in relationships for people with CRPS. ⁽⁸⁾	Included studies	<ol style="list-style-type: none"> 1. Antunovich, D., Tuck, N., Reynolds, L. M., & Bean, D. J. (2021). "I don't identify with it": A qualitative analysis of people's experiences of living with complex regional pain syndrome. <i>Pain Medicine</i>, 22(12), 3008-3020. 2. Beales, D., Carolan, D., Chuah-Choong, J., Hammond, S., O'Brien, E., Boyle, E., Ranelli, S., Holthouse, D., Mitchell, T., & Slater, H. (2021). Exploring peoples' lived experience of complex regional pain syndrome in Australia: A qualitative study. <i>Scandinavian Journal of Pain</i>, 21(2), 393-405. 3. Grieve, S., Adams, J., & McCabe, C. (2016). 'What I really needed was the truth': Exploring the information needs of people with complex regional pain syndrome. <i>Musculoskeletal Care</i>, 14(1), 15-25. 4. Griffiths, G. S., Thompson, B. L., Snell, D. L., & Dunn, J. A. (2023a). Experiences of diagnosis and treatment for upper limb complex regional pain syndrome: A qualitative analysis. <i>Pain Medicine</i>, 24(12), 1355-1363. 5. Johansson, C., Nehlin, C., Gordh, T., Hysing, E.-B., & Bothelius, K. (2023). Patients' experiences of treatment-relevant processes in multimodal pain rehabilitation for severe complex regional pain syndrome - a qualitative study. <i>Disability and Rehabilitation</i>. 6. Johnston-Devin, C., Oprescu, F., Gray, M., & Wallis, M. (2021). Patients describe their lived experiences of battling to live with complex regional pain syndrome. <i>The Journal of Pain</i>, 22(9), 1111-1128. 7. Kwon, S. J., & Kim, Y. (2021). Analysis of the experiences of adults with complex regional pain syndrome. <i>Healthcare</i>, 9(7), 878. 8. Packham, T. L., Wainio, K., & Wong, M. K. (2020). Persons with complex regional pain syndrome renegotiate social roles and intimacy: A qualitative study. <i>Pain Medicine</i>, 21(2), 239-246-246. 9. Raja, S. N., Buvanendran, A., & Marcondes, L. (2021). Complex regional pain syndrome: A comprehensive qualitative research study on unmet needs in the "patient journey". <i>Journal of Pain Research</i>, 14, 2391-2401. 10. Rodham, K., Boxell, E., McCabe, C., Cockburn, M., & Waller, E. (2012). Transitioning from a hospital rehabilitation programme to home: Exploring the experiences of people with complex regional pain syndrome. <i>Psychology & Health</i>, 27(10), 1150-1165. 11. Rodham, K., McCabe, C., Pilkington, M., & Regan, L. (2013). Coping with chronic complex regional pain syndrome: advice from patients for patients. <i>Chronic Illness</i>, 9(1), 29-42.
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Conclusion

Living with CRPS presents both physical, emotional, and social challenges that negatively impact one's identity. People living with CRPS want to be better informed, but information is difficult to find, with much of the information inaccurate and misleading. People's experiences of diagnosis and treatment are disappointing unless seen through specialty services, although this only applies to a small percentage of people. Healthcare services could benefit from further lived experience inclusion into service development and delivery.

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