Experiences of chronic pelvic pain in Aotearoa New Zealand

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**Project Summary**

Chronic pelvic pain (CPP) research in Aotearoa New Zealand, as with the rest of the world, is a small but growing field, and the impacts of CPP on life are starting to be acknowledge and understood, within and beyond the healthcare professions. Despite some shifts, CPP remains relatively poorly understood, both in terms of life impacts and in relation to experiences related to acknowledgement and treatment of the condition. Seeking diagnosis and healthcare is often complex and challenging. This research aims to build in-depth understanding of the realities of CPP and its impacts on everyday life, as well as healthcare experiences, to better inform healthcare practices in Aotearoa New Zealand.

**Background and context for the project**

There is a long history of analysis and evidence of the gendered inequality in health and healthcare, across a spectrum from access to healthcare, to diagnosis, and treatment. The failure to take seriously, diagnose and treat those conditions differentially impacting women both reflects and reinforces a) a historical pathologisation of both female reproductive biology and associated 'conditions' and b) a comparative disinterest in and consequent lack of investment in researching and understanding 'women's health issues'. Chronic pelvic pain (CPP) – although not solely a (cisgendered) women's experience (Jones, 2021) – falls within the many conditions that have failed to fully be investigated, as 'women's health' concerns and pain have not been taken seriously. This has, recently, started to change. CPP can be understood as one of a number of *gendered disabilities*

that affect “at least ten percent of cisgender women as well as unmeasured numbers of cisgender men and transgender and gender nonconforming people, occurring more commonly than migraines or Crohn’s disease” (Jones, 2021: 195) – and that’s just considering endometriosis. Indeed, CPP is now understood to be an “epidemic” – a claim based both on a high incidence rate and the significant burden on the patient, economy and healthcare system (Grover & Joseph, 2021) that such gendered disabilities can and do produce (Jones 2021).

Despite this pervasive impact, research into CPP – and the predominant cause of CPP, endometriosis – has been under-researched (Latthe et al, 2006), and there is a need for research into both the lived experience and the healthcare of those experiencing CPP. It has been noted that the overwhelming majority of the clinical practice guidelines for treatment and management of CPP/endometriosis do not derive from high-quality scientific evidence.(Grover & Joseph, 2021). This places specialists in a position where they must deliver recommendations to mitigate the substantial burden of suffering from a very limited and low-quality evidence base (Grover & Joseph, 2021).

CPP is a challenging condition for both patients and medical professionals alike. We know that people with CPP suffer greatly and often experience a low quality of life (Bhide et al., 2021; Bourdel et al., 2019). Here in Aotearoa New Zealand, we know that CPP patients are not receiving the help they need, and struggle to access treatment (Joseph & Mills, 2019). Recently, at the 38-year update of The Dunedin Multidisciplinary Health and Development study, almost half of the female participants reported pelvic pain in the last 12 months – showcasing robust prevalence rates and simultaneously highlighting the desperate need for further research in this field (Righarts et al., 2018). There is a burgeoning of social health research interest in the lived realities and healthcare complexities of this space (e.g. Cole et al., 2021; Young et al., 2020), including in Aotearoa New Zealand (e.g. Grace, 2000, 2003; Grace & MacBride-Stewart, 2007, 2008; Grace & Zondervan, 2004).

A multidisciplinary approach to researching CPP has been identified as an essential avenue for understanding, and informing the management of, what for most is a lifelong and multifaceted condition. This is yet to standard practice (Falcone & Flyckt-Rebecca, 2018; Leyland et al., 2018; Metzger, 2008; Milburn et al., 1993), and most of the current research used to inform practice is quantitative, and more medical. *Qualitative* research into the experiences of people with CPP – which gives access to nuanced and contextualised understanding of their life-worlds (Clarke & Braun, 2019 ) – is critical to balance this, and to gain an in-depth understanding of the realities and challenges of living with this burdensome condition (Mellando et al, 2019). Such research allows us to understand how the pain of CPP is experienced and the impact this has on the social (and other) domains of a person’s life (Mitchell & MacDonald, 2009). Detailed insight into subjective experiences of CPP that qualitative research can deliver has the potential to contribute to improving healthcare practices and influencing treatment outcomes (Mellado et al., 2019; Mitchell & MacDonald, 2009).

**Aims and objectives**

- To gain insight into contemporary experiences of living with CPP in Aotearoa New Zealand.
- To contextualise the experience of living with CPP in Aotearoa New Zealand.
- To enhance and developed the Aotearoa New Zealand-specific knowledge through the lived experience of persons with CPP.
- To develop a rich understanding of the challenge’s persons with CPP encounter in their social, familial, and spiritual lives.

- To develop a nuanced understanding of the challenges people with CPP encounter when navigating the Healthcare System.
- To explore the ways people with CPP situate themselves in relation to disability and experiencing an invisible illness.

**Methodology**

*Overall study design*

This study uses a qualitative interview design, with one-on-one virtual interviews (of approximately 20 participants). Specifically, it deploys a semi-structured interview method (interview guide included) for data collection, with data transcription into textual format, and subsequent analysis mode yet to be determined. Analysis will most likely thematic analysis (possibly also discourse analysis) – the open nature of this is appropriate to both the inductively-oriented qualitative design, and the relative newness of the topic, where what might be analytically important cannot be determined in advance. One of the joys and advantages of qualitative research is that it often 'reveals' new and unexpected things, which can mean unanticipated modes of analysis become the most appropriate (Braun & Clarke, 2013; 2021).

*Participants*

The number of participants (range from 15-25, with an estimate of 20) has been determined based on research experience, in line with general guidelines for qualitative research and a project of this scope (Braun & Clarke 2013). The final number will be determined during data collection, considering the concept of information power (Malterud et al., 2016).

Participants will be recruited using a range of well-established qualitative recruitment methods (Patton, 2002) including word of mouth/snowballing, social media advertising, fliers, and (if approved) advertising on Endometriosis New Zealand Facebook group. The participant sample will – broadly – constitute a convenience sample, selected *from*, or constituted by *all* of those who meet eligibility criteria and are interested and commit to participating.

*Eligibility criteria*

1. Identify as experiencing CPP
2. Meet the Royal Australian and New Zealand College of Obstetricians and Gynaecologists' (RANZCOG, 2021) criteria for CPP for at least 1 year: "Pain anywhere below the stomach and into the pelvic area that has been present and continuous for more than 3 months"
3. Actively seeking some sort of treatment (medical or alternative) for CPP
4. 18 years or older
5. Live in, and have received all diagnosis/treatment for CPP, in Aotearoa New Zealand
6. Speak English comfortably/fluently

*Procedure – data collection*

Data will be collected via zoom interviews – using a one-on-one video format. Potential participants will be invited to contact the researcher – for participants who meet the inclusion criteria and wish

to participate, a zoom interview will be organised at a time that suits. The interviews will be semi-structured in nature, and will last approximately 1.5 hours (estimated range 1-2 hours). Participants will have the opportunity to stop the interview and restart at a later time, should pain interfere with their ability to participate.

Interviews will cover a range of topics including life impacts of CPP (including personally, socially, spiritually, relationally, professionally…), experiences of seeking healthcare and receiving healthcare, and understandings and impacts of CPP Within the framework of disability.

Participants will also complete a brief demographics and illness survey at the end of the information, to fulfil the ethical obligation to understand who has participated in the project.

*Procedure – analysis*

The zoom video recordings will be transcribed into textual form of the audio – and the transcribed data will form the primary basis of the qualitative analysis, which will examine and report patterning across the dataset. The method of analysis is most likely to be reflexive thematic analysis, given the scope and flexibility of that method, and the nature of the research questions (Braun & Clarke, 2021; 2022). However, analytic method and scope is unable to be fixed in advance, and indeed, this is in fact undesirable from a design perspective, given the open nature of qualitative methodologies (Braun & Clarke 2013; 2021).

**Ethics**

*Confidentiality and anonymity*: the information disclosed by the participant during the interview will remain confidential to the research team; small, anonymised segments of data may be shared in research settings and outputs (conferences, research groups, publications, thesis) but will not be linked to participant identity. Identity of participants will not be disclosed. Names of participants will be changed, and any specific identifying details will be changed or removed to preserve anonymity. Interviews will be conducted in a private setting; headphones will be used by the interviewer to eliminate the risk of any of the conversation being overheard. Data will be held on a password protected computer and University secured server. The zoom interview channels will be private. Anonymised data will be stored securely (e.g. hard copy in locked office, home; digital version on password protected computer/secured server) when not being analysed. Consent forms will be stored securely and separately from the data.

*Informed Consent and withdrawal*: Participants will receive a participant information sheet prior to consenting to involvement in the study. The information sheet will clearly outline the aim of the study, address confidentiality and anonymity and inform participants of their right of withdrawal from participation and right to withdraw their data (up to one month after the interview has been complete). Participants will be made aware of potential risks and benefits of participating. They will be notified that they have the right to ask any questions prior to signing a consent form. The consent form will be sent to participants ahead of the interview and will be gone through and verbally agreed at the start of each interview – giving the participant the opportunity to ask any questions before beginning. They will also complete and email the signed form before the interview commences.

*Compensation for participants*: participants will be made aware in the participant information sheet that participation in the study is voluntary and there is no compensation or koha for participation.

However, they will be offered a copy of their interview for their personal 'records' should they wish to have it, and they will be offered the opportunity to receive a 'summary output' from the research.

*Risk of harm*: The in-depth nature of the interviewing and the topic of discussion place participants in a vulnerable position, with potential to experience emotional and psychological distress. Disclosing private details around sensitive issues such as fertility, sexual/gynaecological health and personal relationships could prove distressing for participants. Recounting experiences of pain and subsequent experiences due to this pain could also prompt distress in participants. However, given the pervasive impact of CPP on people's lives, the level of distress is not expected to be substantially different to that experienced in everyday life. To minimize unexpected emotional distress, the PIS makes clear what the scope of the that the interview will be, and that the researcher herself experiences CPP, and so will interview from an 'insider' perspective. Participants are told in the PIS, the consent form, and in the introduction to the interview that they are under no obligation to answer any particular questions should they wish not to, that they can pause the interview at any time, and that there is no pressure to continue until they wish (or ever, should they wish to stop the interview at that point).Given the nature of pain experienced with CPP, we will also give participants the opportunity to stop an interview and resume at a later point, should they need to.

Building trust and rapport with participants will be important, especially given the sensitive nature of the topic. Trust and rapport will be built by engaging in open conversation prior to interviewing, including discussion of the researcher's insider position as someone with CPP (which is included in recruitment materials). Self-disclosure from the researcher will encourage trust through empathy and understanding and may help the participant to be more forthcoming in their own experiences. However, a reflexively cautious position will be taken that centres the voices and experiences of participants, not of the researcher. We will aim to be sensitive to the cultural inflections of CPP for participants and make space for tikanga as appropriate to the participant in interviews, by situating the researcher and inviting the participants if there are tikanga, cultural and/or spiritual elements/processes they would wish to bring into the interview space, such as an invitation to personally open and close the interview in a way that is resonant for them.

The interviews will end with an opportunity for the participant to comment and reflect on anything they wish to add to the process. A digital list of support organisations will be available to give to participants, should they wish to take it.

There is also risk of harm to the researcher that needs to be considered. Being close to the topic being studied may be emotionally triggering at times for the researcher. This will be managed via use of a reflexive journal and debriefing when required with the supervisor (applicant). This will also be considered in scheduling interviews.

*Cultural aspects*: we expect that most, if not all the participants will identify as female and women, as CPP disproportionately occurs in females. We are not recruiting for participants from any specific or targeted ethnic or cultural group, nor excluding anyone from participating (as long as they meet the inclusion criteria). Ways of understanding and indeed comfort discussing pelvic pain and associated gynaecological issues can vary by culture. The full scope of focus of discussion will be clearly advertised for the project and will be raised in discussion with any potential participants before they agree to participate. We will attempt to navigate this terrain by being sensitive to the situated nature of the interviewer, and sensitively asking questions about the influence of culture of all participants. The broad scope of the question and understanding sought here is broadly resonant

with models like Te Whare Tapa Wha and aims to provide an understanding CPP in a holistic (and culturally responsive) way.

*Deception:* No deception is involved.

*Data management*: The recorded data will be transcribed for textual analysis and all participants anonymised in the transcripts. Data will be stored on a secure device (not on any shared devices) and password protected. Only (anonymised) excerpts of data will be shared in academic fora and outputs as noted above.

**Project Management**

*Participating site(s) and persons*
Research is conducted in Aotearoa New Zealand with interviews via zoom by the student researcher (Michaela Callaway). Meaning the physical site will be – for participants – in locations of their choosing. Dependant on covid alert levels, the researcher will conduct interviews from home or from the city campus at the University of Auckland; participants will we asked to select a quiet and private location of their choosing.

*Data ownership*

The researchers will own the intellectual property rights to the data and results.

*Risk management of project*

*Physical or psychological risk of the participant*: If a participant becomes upset during an interview, they will have the opportunity to pause until they wish to resume or stop the interview altogether. A pre-prepared list of support organisations and information will be supplied to all participants via email at the end of the interview as part of the thank you email. Given the nature of CPP, participants may also experience pain during an interview, and wish or need to stop for this reason. They will be able to stop the interview should they need to and resume it at a later time.

*Physical or psychological risk of the researcher*: There is a chance that hearing participants' stories will be distressing, given that the interviewing researcher has personal experience of CPP, and of seeking and receiving treatment, and brings that history into the interview space. However, this potential for distress is well understood, and is being discussed in supervision. Furthermore, such distress is unlikely to constitute harm.

**Timetable**

- Data recruitment, collection and transcription: November-December 2021
- Data analysis: January – May 2022
- Project completion: July 2022

## Resources

This study is self-funded by the student researcher.

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