

EndoCost Aotearoa: The impact of chronic pelvic pain (CPP) on women following a nationwide online survey

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Background

CPP affects a significant proportion of reproductive-aged females, with worldwide estimates of up to 24-26% ^{1,2}. Endometriosis is the most common cause ³, accounting for 24-40% of CPP diagnoses ^{4,5}. International prevalence estimates of endometriosis are between 5% ⁶ and 11% ⁷ for reproductive-aged females. Worldwide data demonstrates that endometriosis and CPP has negative impacts on all aspects of an individual's life ⁸⁻¹³ and is compounded by significant diagnostic delay, with reported averages ranging from 6.4 to 13 years ^{9,11,12,14,15}. There is a paucity of prevalence data for CPP and endometriosis in Aotearoa New Zealand; however, older prevalence studies have reported a quarter of females in Aotearoa New Zealand experience some pelvic pain ¹³. Given this high prevalence, understanding the factors contributing to diagnostic delay and symptom presentation in Aotearoa New Zealand is crucial to ameliorate negative impacts of CPP on individuals' quality of life. Diagnostic delay and CPP impact are likely to vary between countries based on cultural factors, health literacy and access to medical care ⁹. Whilst Australian and worldwide data are useful, current local data is necessary to understand areas of unmet patient need.

Aim

The aim of this cross-sectional national survey was to assess the impact of CPP on social, sexual, occupational, financial, and educational aspects of overall quality of life, within an Aotearoa New Zealand cohort with self-reported CPP, with or without a formal endometriosis diagnosis. Additionally, for individuals with a diagnosis of endometriosis, diagnostic delay and contributing factors were explored.

Methods

The NZ Health and Disability Ethics Committee deemed that this survey was out-of-scope for full ethical review. Informed consent was explicitly obtained prior to survey commencement. Participation was fully anonymous. All methods described were in accordance with relevant best practice guidelines and oversight from MRINZ (and the research team). This study utilised the World Endometriosis Research Foundation (WERF) EndoCost tool ¹⁶. This consisted of a modified 99-item retrospective patient questionnaire delivered via REDCap. Demographic data were collated along with data regarding diagnosis, education, work, social wellbeing, and recent prevalence (< 3 months) of pelvic pain symptoms. Recruitment used social media platforms (Facebook, Instagram and Twitter), driven by authors and their organisational affiliations, with targeted dissemination to Māori through the first author's (JTS) academic and social networks. Recruitment efforts through flyers disseminated at various private and public hospital gynaecology clinics in Auckland and Christchurch also took place. The survey remained open for 10 weeks (March 2021 to May 2021) and was estimated to take around 60 minutes to complete. Eligibility was as follows: aged >18, living in Aotearoa New Zealand and affected by CPP (pain in the lower abdomen for 6 months, severe enough to limit function or require medical intervention), with one of the following symptoms: dysmenorrhea, dyspareunia or dyschezia.

Data descriptions were reported by mean and standard deviation, or medians and interquartile ranges. Categorical values were described by counts and proportions expressed as percentages. For data needing comparison between groups, t-tests, chi-square tests or Fisher's exact were used. The impact from major endometriosis diagnostic guidelines on diagnostic delay was explored *a priori*, in keeping with the previous Australian study ⁹. The Society of Human Reproduction and Embryology (ESHRE) diagnostic guidelines were published in 2005¹⁷; both the World Endometriosis Society (WES) diagnostic guidelines⁸ and updated ESHRE¹⁸ guidelines were published in 2013. Therefore, analyses for diagnostic delay used three groups: presentation before 2005, presentation between 2005 and 2012, and presentation after 2012. Pearson's and Spearman's rank correlations were used to estimate the correlation between first presentation to a doctor, number of years to diagnosis, number of doctors consulted until diagnosis, the year when symptoms started and delay in accessing medical care.

Results

Variable	Endometriosis (N=620)	CPP (N=180)
	N	N
	Mean (SD)	Mean (SD)
Age when symptoms first started ^a	613 19.93 (6.05)	178 18.66 (6.82)
Time between symptom onset and 1st doctors visit (years) ^b	604 2.88 (4.04)	176 2.44 (3.63)
Time between 1st doctors visit and diagnosis of endometriosis (years) ^b	615 5.79 (5.7)	NA
Number of doctors seen before diagnosis of endometriosis ^b	613 4.83 (3.77)	NA
Pelvic pain symptoms at onset of symptoms ^a	N (%)	N (%)
Severe dysmenorrhoea	550 (88.7)	157 (87.2)
Non-cyclical pelvic pain	399 (64.4)	128 (71.1)
Ovulation pain	286 (46.1)	87 (48.3)
Chronic fatigue	287 (46.3)	82 (45.6)
Cyclical/peri-menstrual symptoms	248 (40)	74 (41.1)
Deep dyspareunia	173 (27.9)	52 (28.9)
Subfertility	45 (7.3)	10 (5.6) CPP (N=180)
	Endometriosis (N=617)	CPP (N=180)
	N (%)	N (%)
Pelvic pain with periods in the last 3 months ^b		
No	102 (16.5)	14 (7.8)
Yes	515 (83.5)	166 (92.2)
	Endometriosis (N=513)	CPP (N=165)
	N (%)	N (%)
Pelvic pain frequency ^b		
Occasionally (with 1 of my last 3 periods)	30 (5.8)	5 (3)
Often (with 2 in 3 of my last 3 periods)	54 (10.5)	13 (7.9)
Always (with all of my last 3 periods)	429 (83.6)	147 (89.1) CPP (N=166)
	Endometriosis (N=515)	CPP (N=166)
	N (%)	N (%)
Taken prescribed painkillers ^b		
No	122 (23.7)	38 (22.9)
Yes	393 (76.3)	128 (77.1)
	Endometriosis (N=513)	CPP (N=166)
	N (%)	N (%)
Taken over the counter painkillers		
No	87 (17)	38 (22.9)
Yes	426 (83)	128 (77.1)

Demographics:

800 surveys were completed (620 self-reported diagnosis of endometriosis whilst 180 reported CPP, either from another diagnosis (e.g. painful bladder syndrome, vulvodynia) or without a formal diagnosis of endometriosis). Most respondents were European, followed thereafter by Māori, Asian, Pacific, and Middle Eastern, Latin American and African (MELAA), respectively. Most respondents were nulliparous and reported university level education, closely followed by postgraduate studies, post-secondary studies (not in university) and then upper secondary school. Most respondents had income of \$501 to \$1500 NZD per week.

Diagnostic Delay:

With respect to the impact of diagnostic endometriosis guidelines, before 2005 the mean delay from presentation to diagnosis was 8.38 ± 7.01 years, from 2005 to 2012 was 5.26 ± 3.96 years and after 2012 was 2.01 ± 1.89 years. There was also a weak negative correlation between the year of the first doctor's visit and the number of doctors consulted until diagnosis of endometriosis (r=0.18 and p<0.0001). There was a moderate negative correlation between the year of the first presentation to a doctor for those with a diagnosis of endometriosis (r=-0.60, p=<0.0001), and a weak to moderate negative correlation for those with CPP (r=-0.32, p<0.0001), suggesting less delay for both groups in seeking medical attention over time.

Pelvic Pain Symptoms:

Most respondents within the endometriosis group reported their endometriosis was stage III or stage IV (30.2% and 27.3%, respectively) at their most recent laparoscopy. Severe dysmenorrhoea (period pain) was the most common pelvic pain symptom and was similar between groups (88.7% of endometriosis respondents and 87.2% of CPP respondents).

Variable	Endometriosis N/620 (%)	CPP N/180 (%)
Period pain prevented attending work or carrying out daily activities in the last 3 months ^a	N=511	N=166
Never	58 (11.4)	9 (5.4)
Occasionally (in 1 of my last 3 periods)	150 (29.4)	41 (24.7)
Often (in 2 of my last 3 periods)	136 (26.6)	51 (30.7)
Always (in all of my last 3 periods)	167 (32.7)	65 (39.2)
Pelvic pain during sex, or within 24 hours, within the last 3 months ^b	N=617	N=178
Not applicable: I have not had sex in the last 3 months	119 (19.3)	35 (19.7)
No	63 (10.2)	13 (7.3)
Yes	418 (67.7)	122 (68.5)
I don't wish to answer these questions	17 (2.8)	8 (4.5)
Frequency of pelvic pain during sex, or within 24 hours ^b	N=416	N=121
Never	3 (0.7)	1 (0.8)
Occasionally (with less than a quarter of my periods)	75 (18)	26 (21.5)
Often (a quarter to half of the times)	69 (16.6)	17 (14)
Usually (more than half of the times)	120 (28.8)	34 (28.1)
Always (every time)	148 (35.6)	42 (34.7)
Can't remember	1 (0.2)	1 (0.8)
Ever interrupted sex because of pelvic pain ^b	N=420	N=122
No	81 (19.3)	22 (18)
Yes	339 (80.7)	100 (82)
Ever avoided sex because of pelvic pain ^b	N=418	N=122
No	80 (19.1)	23 (18.9)
Yes	338 (80.9)	99 (81.1)
CPP ever affecting personal relationship negatively ^b	N=476	N=127
No	108 (22.7)	32 (25.2)
Yes	368 (77.3)	95 (74.8)
How did it affect relationships? ^{a, b}	N=368	N=95
Caused significant problems with partner	245 (66.6)	64 (67.4)
Created problems with family	107 (29.1)	30 (31.6)
Caused a relationship to split	80 (21.7)	12 (12.6)
Made it difficult to look after children	76 (20.7)	29 (30.5)
Affected friendships	218 (59.2)	53 (55.8)
Lost time to education due to chronic pelvic pain ^b		
No	159 (33.3)	42 (33.1)
Yes	318 (66.7)	85 (66.9)
Effect on education ^{a, b}	N=318	N=85
Gave up studies	76 (23.9)	19 (22.4)
Changed studies	35 (11)	6 (7.1)
Delayed exams or postponed assignments	169 (53.1)	45 (52.9)
Other	87 (27.4)	30 (35.3)
Chronic pelvic pain affecting job ^b	N=474	N=124
Yes	363 (76.6)	90 (72.6)
No	74 (15.6)	15 (12.1)
N/A - not employed in the last 12 months	37 (7.8)	19 (15.3)
How did it affect work? ^b	N=363	N=90
Lost job	47 (12.9)	7 (7.8)
Changed job	41 (11.3)	8 (8.9)
Reduced work hours	191 (52.6)	49 (54.4)
Other	161 (44.4)	39 (43.3)
Occasions where a woman was scared to tell their employer about CPP because of fear that it might affect your prospects? ^b	N=473	N=121
No	128 (27.1)	34 (28.1)
Yes	345 (72.9)	87 (71.9)

Impact of Pelvic Pain:

Negative impact on education, work, as well as sexual and other personal relationships was observed. Mean days of studying lost per month by endometriosis and CPP respondents was 8.03 ± 18.26 and 10.24 ± 40.65 respectively, with almost half of respondents reporting delayed exams/assignments. A proportion of respondents gave up studying completely. Mean days taken off work per month for endometriosis and CPP respondents were 3.15 ± 3.38 and 2.86 ± 2.89 respectively, with more than half of respondents needing to work reduced hours. 88.7% of endometriosis respondents and 94.6% of CPP respondents reported being unable to attend work, or carry our daily activities, due to period pain for at least 1 of their last 3 periods. Both groups reported a proportion that were unable to work over the last year because of pelvic pain symptoms (7.8% of endometriosis respondents and 15.3% CPP respondents) and further to this, 12.9% of endometriosis respondents and 7.8% of CPP respondents lost their jobs due to symptoms. Both groups reported effect on their employment with over 70% having either lost jobs, changed jobs or reduced working hours due to symptoms. Around two thirds of respondents reported that pelvic pain had caused significant problems with their partner and experienced dyspareunia over the last 3 months with most indicating that pelvic pain caused them to interrupt or avoid sex. More than half reported that social activities with families were affected 'moderately' (27.9% endometriosis respondents and 28% CPP respondents), 'quite a bit' (25.6% endometriosis respondents and 28% CPP respondents), and 'extremely' (10.5% endometriosis respondents and 16.6% CPP respondents).

Discussion & Conclusion

Individuals with CPP, irrespective of diagnosis/aetiology, reported a high prevalence of pelvic pain symptoms (predominantly dysmenorrhoea), with a profoundly negative impact on quality of life and an early onset of symptoms (under 20 years of age). Chronic fatigue was one of the most prevalent non-gynaecological symptoms, reported by more than 45% of respondents. The impact of pelvic pain symptoms on education, work, and relationships highlights the significant burden for individuals, their family and society. Symptom burden rather than underlying cause, is a crucial factor in the negative impact observed, consistent with international evidence ^{9,19}. It is important that healthcare and support are provided for all causes of CPP in Aotearoa New Zealand, rather than focussing on endometriosis alone.

Diagnostic delay was around eight years, with components of diagnostic delay for endometriosis, time to presentation to a health professional and time from presentation to diagnosis, decreasing over time. It is likely that the publication of diagnostic guidelines (ESHRE and WES^{9,17,20}) have contributed to the reduction of diagnostic delay, and number of doctors seen before diagnosis, however in part, may be due to increasing public awareness and menstrual health literacy of endometriosis and other forms of CPP ²¹. Despite this, mean time to diagnosis is still lengthy, during which time there is demonstrable negative impact across all domains of respondents' lives. For CPP sufferers, the current healthcare model is inadequate, highlighting a specific area of unmet patient need ²². Furthermore, an extensive body of international literature shows that the culture of normalising CPP may contribute to diagnostic delay^{23,24}. Lack of clinician expertise in gynaecology and missed diagnosis of symptoms may also contribute to diagnostic delay ^{15,25}.

It is recognised amongst professionals working within this area of health that there is need for a women's health strategy on the basis of human rights, gender equality and health equity ²⁶. Furthermore, this call to action has been signalled globally to improve awareness, fill knowledge gaps, and create effective policy and interventions for the betterment of society ²⁷. In Aotearoa New Zealand, there are currently systematic changes being made to promote equity and efficiency within the public health sector, which are hoped will address CPP and endometriosis outcomes.

Strengths and Weaknesses:

This study provides new data on symptom impact and diagnostic delay for those with CPP and endometriosis in Aotearoa New Zealand. This study utilised the WERF EndoCost tool to allow direct comparison with other data sets globally ¹⁶, including Australia. The sample size of 800 respondents was greater than both previous Australian studies ²⁰. Additional recruitment may have been possible if the survey was less extensive. Sampling bias may exist given the recruitment process focused upon online social media platforms which were promoted heavily by author affiliated organisations. Furthermore, it is recognised that respondents who follow these organisations on social media may have a propensity to have more severe symptomatology compounding this sampling bias ²⁸.

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