Unmet Treatment Needs for Women with Chronic Pelvic Pain attending a Gynaecology Outpatient Clinic in New Zealand

Karen Joseph dipsrh franzcog ffpmanzca **Gynaecologist and Specialist Pain Medicine Physician** Canterbury District Health Board

Canterbury District Health Board Te Poari Hauora ō Waitaha

INTRODUCTION

Chronic pelvic pain (CPP) has been defined as "intermittent or constant pain in the lower abdomen or pelvis for at least six months duration, not exclusively occurring with menstruation or intercourse" (RCOG 2006). This simple definition fails to convey the complexity and high burden consequent of this common condition, and the challenges encountered by those attempting to treat it.

The negative impact on many aspects of women's lives and general wellbeing is significant; they are more likely than women without CPP to have other long-standing illnesses, other conditions involving pain or fatigue, pain restricting activities, and disturbed sleep patterns.

CPP also carries a heavy economic and social burden. The 2011 Pelvic Pain Report 'the \$6 Billion Woman and the \$600 Million Girl' reviewed the high personal and societal burden of CPP in Australasia (Bush et al. 2011).

Current surgical interventions, such as the excision or ablation of endometriosis implants and lysis of adhesions, lack long-term effectiveness in pain relief and available medical interventions remain limited (Lamvu et al. 2006; Stones et al 2005). Increasingly research is demonstrating the similarities between CPP and other chronic pain syndromes and the superiority of multimodal multidisciplinary (MDT) management on outcomes.

Numerous international guidelines recommend coordinated interdisciplinary care for best outcomes. The recently released best-practice document "Diagnosis and management of endometriosis in New Zealand" (MoH 2020) also recommends that an MDT approach is incorporated into care for those with endometriosis.

Current healthcare services available in gynaecological services for women with CPP in New Zealand fall very short of providing appropriate care; with clinical focus remaining almost entirely on biomedical approaches. Women who have used New Zealand medical services for CPP report problems with diagnosis, communication and inappropriate treatment (Grace 1995). Christchurch Women's Hospital (CWH) is a tertiary level women's hospital with a catchment of approximately 400,000. Women referred to the outpatient clinic with CPP receive only a single disciplinary biomedical assessment within a short appointment time. There is limited access available to physiotherapy input, and no provision of psychology assessment or management available within CWH. Even when MDT input is provided the different specialities work in

AIMS

To inform future service delivery in a New Zealand tertiary women's hospital via an unmet needs audit and survey of doctors.

METHODS

Women referred to the CWH outpatient clinic for review of persistent pelvic pain complete a pre-appointment patient questionnaire.

Criteria for the questionnaire are: aged ≥18 referred with pelvic pain ≥6months, excluding pregnancy, malignancy or other red flags; who are triaged to a routine appointment timeframe.

A convenience sample of 100 consecutive de-identified questionnaires received between 1st August 2016 and 3rd January 2017 were analysed to determine the current level of patient needs.

A Survey Monkey electronic questionnaire was emailed to all specialists and registrars working in CWH, with questions about current assessment and management of CPP within the gynaecology outpatient department.

The Health and Disability Ethics Committee confirmed the audit status of this work and that it was out of scope for requiring review.

RESULTS from 100 women - mean age 29.6 (18-48years)

Pain intensity in the past month

Maximum pain score 8.7/10 (2–10) Minimum 3.1/10 (0-8)

Average pain score 5.7/10 (0-10)



Average duration of pain 4.3 years (0.5-32)

Number of days a month pain experienced 20.5/30days (1-30)

Impact of pain

'silos' rather than co-ordinated IDT care.

14 women reported being unemployed due to their pain



**** ****

2/3 reported their mood was detrimentally impacted by their pain

Pain Catastrophising

of the women scored in the high or severe range on the Pain Catastrophising Score (PCS), with 55% endorsing clinically significant scores for helpless catastrophising.

FIfty four of the respondents also displayed evidence of catastrophic worry in their free text responses to the questions "describe your pain" "what do you think is causing your pain?" and "what worries you most about your pain?". The most common themes were: concerns about future fertility, that the pain represented damage to the ovaries, and that the pain would never improve.

The PCS scores in this cohort were found to be higher than those in similar groups in the published international literature and also than in patients referred to the local tertiary level pain management centre.

TABLE 1 Comparative means of total and subscale scores on the Pain Catastrophising Scale (PCS)³⁰

PCS	Mean (SD)				
	Study sample [<i>N</i> =100]	De Graaff <i>et al</i> . ²⁸ [<i>N</i> =83]	Allaire <i>et al</i> . ¹³ [<i>N</i> =525]	van Aken <i>et al</i> . ²⁹ [<i>N</i> =48]	Burwood [<i>N</i> =221]
Total score	29.01 (12.77)	17.8 (10.9)	16.0 (IQR = 8-30)	16.88 (10.4)	25.63 (13.05)
Rumination	9.29 (4.49)				8.10 (5.03)
Magnification	6.32 (4.58)				4.88 (3.25)
Helplessness	13.28 (6.43)				12.65 (6.20)
		Cross-sectional study of women with endometriosis attending outpatients in the Netherlands	Women attending an interdisciplinary tertiary referral centre in Canada for pelvic pain and endometriosis	Cross-sectional study of women with laparoscopically and/or magnetic resonance imaging-proven endometriosis in the Netherlands	Benchmarking data of women with any chronic pain condition presenting to the local tertiary pain clinic in the study period

Severity categories for the PCS are <20 = mild, 20–30 = high, >30 = severe; clinically significant scores for each of the subscales are Rumination: 11, Magnification: 5, Helplessness: 13.

(Joseph & Mills 2019)

7100 Reported 3600 Suggestive of Bladder Pain Syndrome

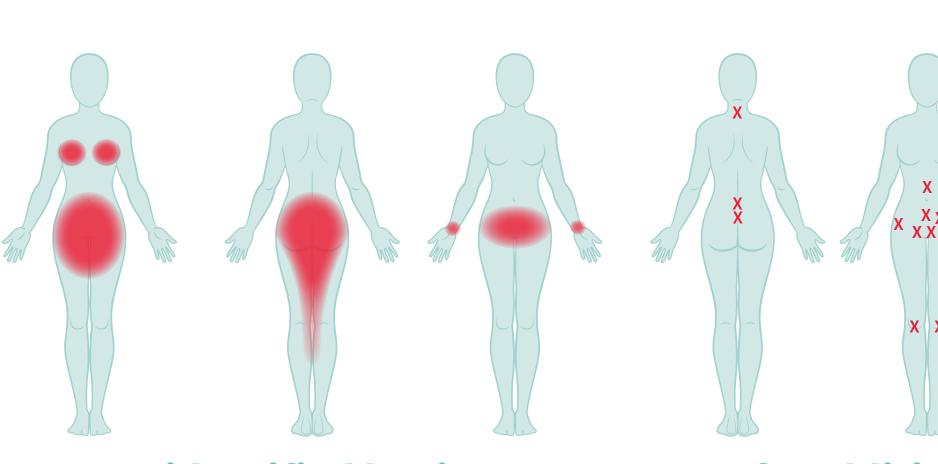
Reported symptoms

of the women reported persisting pain outside of the pelvis, 40% also reporting persisting back pain, and

38% also reporting pain in widespread areas.

This is consistent with a multicentre, observational study in the USA of adults with pelvic pain where 25% identified pain only in the pelvis on their intake pain diagram and 38% reported widespread pain.

This study also found that widespread pain was associated with greater severity of symptoms, more coexisting pain conditions, poorer psychosocial health and worse quality of life (Lai et al 2017).



Women identified having an average of 3 additional chronic pain syndromes (0-10 SD1.8)

Healthcare use



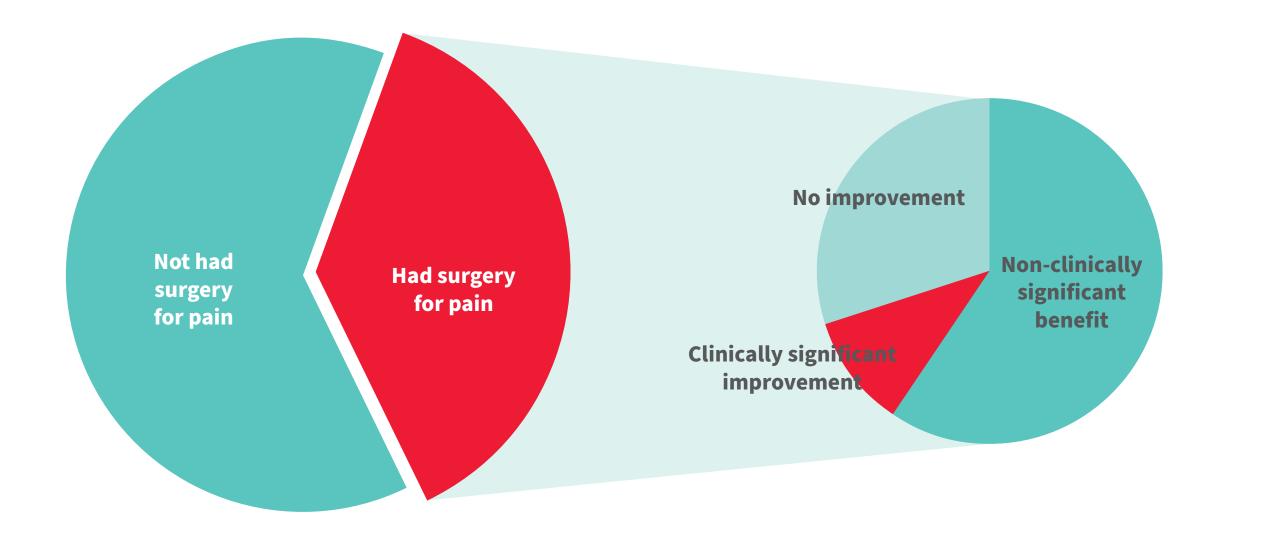
In addition to the burden to the women her family and society chronic pelvic pain also brings costs to the heath service – women reported an average presentations (0-28) to healthcare services in the preceding three months.

Surgery

37 of the women had previously had surgery at least once for their pain.

26 reported benefit from their surgery – 11 (30%) reporting no improvement, or worsening of their pain with surgery. Of those who did find benefit this was only for mean 8 months (0.5-42, SD 9.4 months)

Minimal clinically significant improvement is usually considered to be >2 years, which was reported by only 4 (11%) of those who had previous surgery.



Doctors survey

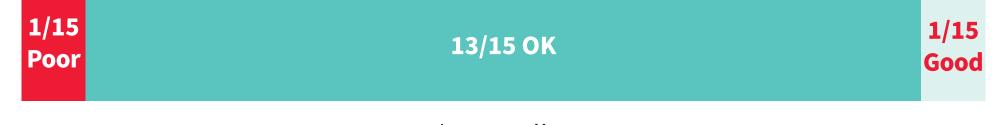
A survey of doctors in CWH asked:

How comprehensive is your assessment of women referred to gynaecology clinic with CPP?

10/15 OK 5/15 poor

0/15 good, 0/15 excellent

How would you rate the quality of your assessment?



0/15 excellent

How would you rate the support available for assessment or management of CPP?



0 good 0 excellent

CONCLUSIONS

The majority of respondents had complex and multifactorial pain syndromes. Most of the patients reported multisite pain, with a number of Chronic Overlapping Pain Conditions. Despite a third reporting surgical management for pain at least once in the past, this was not successful in resolving symptoms. Clinically women often under-report pain believing that non-pelvic pain is not of interest to their gynaecologist. There is also a tendency to overestimate the length of time that surgery is helpful for, so the complexity is likely to be even higher. Results show an unexpectedly high level of catastrophic worry within the sample. Most endorsed negative psychosocial impacts on their life including low mood and impaired ability to work.

A growing body of research clearly shows complex pain presentations cannot be successfully managed by a single clinician or purely biomedical approach. The benefits of interdisciplinary team management for people living with CPP has been recognised for over four decades, with the supporting evidence base continuing to grow as knowledge about pain neurobiology increases. Research literature and numerous guidelines, from as early as 1990, have discussed the importance of multifactorial interventions to manage the complexities often associated with pelvic pain. Despite this, such interventions are not available to most women in New Zealand.

The lack of alternative services when medical management fails to bring about a satisfactory resolution of symptoms can lead to unnecessary repeat investigations, surgical procedures, avoidable admissions to acute hospital services, and ongoing patient distress.

This unmet needs audit further underlines the urgent need to develop MDT pain management services within gynaecology services.

References