



“It’s messing with my physical health. It’s messing with my sex life”: Women’s perspectives about, and impact of, pelvic health issues whilst awaiting specialist care

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Abstract

Introduction and hypothesis Pelvic health conditions are a common health complaint among women worldwide, and conservative management is recognised as first-line treatment. There is often a time lag between referral from general practitioners to specialist consultation and conservative therapy. Therefore, the aim of this research was to explore perspectives from women with pelvic health conditions while they wait for specialist input, specifically about their understanding of their condition and its impact.

Methods This research was underpinned by a qualitative descriptive methodology. Individual semi-structured interviews were conducted with women with pelvic health conditions who were waiting for specialist gynaecology consultation.

Results A total of 11 women shared their perspectives about, and their understanding of, their condition and its impact. Thematic analysis of the interview data identified a variety of experiences and perspectives of women waiting to see the gynaecologist. These perspectives were categorised into four different themes: drivers to seek help, understanding the condition, experience/feeling being on the waiting list and expectations from the gynaecology team.

Conclusion This study identified the main drivers for seeking help were worsening and/or persistent symptoms. Participants were able to articulate their symptoms, identify possible causes and describe various treatment options, and amenable to alternate treatment options. This research sheds light on the devastating impact of pelvic health conditions on women, which may be amplified while waiting to seek specialist input. There appears to be a need for health services to better support these women during this time of waiting.

Keywords Women’s health · Pelvic floor disorders · Feedback · Waiting lists

Introduction

Pelvic health conditions are a common health complaint among women worldwide and are associated with a significant burden to the consumer and the broader health system [1–3]. The costs of illness in relation to pelvic health conditions, such as urinary or anal incontinence (UI, AI) and pelvic organ prolapse (POP), include patient costs (e.g. pads/containment, laundry, activity avoidance), health system costs [e.g. intervention (and treatment consequence) costs]

and societal costs (e.g. loss of productivity) [4]. Conservative management, such as pelvic floor muscle training and lifestyle modifications, is recognised as first-line management for pelvic health conditions such as UI or POP [5]. Many tertiary centres require specialist medical consultation before onward referral to physiotherapy for women with pelvic health conditions. This creates a time lag between referral from a general practitioner (GP) to the specialist clinic and then again before conservative therapy may be commenced.

The wait time to see the gynaecologist following GP referral has been described previously at this organisation, with women waiting on average 170 days (range 49–351 days) when referred for pelvic health conditions (e.g. POP, UI, AI) triaged to a lower priority for the service [6]. Since this study was undertaken, the booking process for lower priority gynaecology patients at this organisation has shifted

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to a patient-focussed booking model, in accordance with statewide guidelines [7]. In this booking model, women referred to the specialist service are contacted via mail when clinic spots are available, inviting them to call and book an appointment if they still require one. Anecdotally, this has seen the wait time between GP referral to gynaecology appointment reduced to approximately 3 to 4 months, on average. While a significant improvement, there remains a reasonable period of waiting before these women further progress along the care continuum.

Waitlist impact—typified by feelings of heightened anxiety, frustration and a lack of control—has been previously described for other clinical presentations such as oncology or cardiac surgery (e.g. as summarised in a systematic review by Rittenmeyer et al. 2014) but not for women experiencing pelvic health conditions, to the best of the author's knowledge [8]. This study aimed to describe perspectives from women with pelvic health conditions while they wait for specialist consultation, specifically about their understanding of their condition and its impact.

Methods

Methodology

This study was underpinned by a qualitative descriptive research methodology to explore and gain an understanding of the experiences and perspectives of women waiting to see the specialist and is reported against COREQ (CONsolidated criteria for REporting Qualitative research) guidelines [9, 10]. This research methodology evaluates descriptions of individual's characteristics, traits and behaviours that occur in everyday context using common language to provide a precise portrayal of the phenomenon of interest [9, 11]. Consequently, the findings produced are close to the collected data and within an identifiable local context.

Study participants and selection procedures

Participant recruitment was conducted by the primary author (TB), with referrals to the Women's and Children's Hospital's gynaecology service manually reviewed. Potential participants were identified using specific inclusion and exclusion criteria over a 6-month period (September 2019–February 2020). Inclusion criteria included women who (1) were triaged as a low priority (“P3”) with referral information suggestive of pelvic organ prolapse and/or incontinence, (2) responded to the patient-focussed booking process and (3) had a specialist gynaecology appointment booked. Women were excluded if they (1) were triaged as low priority (“P3”) with no suggestion of pelvic floor dysfunction (UI, AI and/or POP) on GP referral but referred with such conditions as abnormal bleeding or

fertility concerns, (2) were triaged as a higher priority (“P1” or “P2”), (3) were from culturally and linguistically diverse backgrounds who required interpreter assistance or (4) met the inclusion criteria but were currently receiving (or had recently received) physiotherapy input at the institution.

Potential participants who met the inclusion criteria were contacted by phone (maximum 3 attempts) to outline the study and seek verbal consent to receiving additional study information via mail. Those who were willing to participate returned a signed consent form (via a reply-paid envelope) and were followed up by phone to arrange a mutually agreeable time for interview.

Data collection

All data were collected via individual, semi-structured phone interviews to gain in-depth and independent understanding of participant's perspectives [12]. Interviews were conducted by the primary author (TB) who is a senior physiotherapist at the institution and did not have a previous relationship with the participants. An interview guide was developed by two members of the research team (TB and SK), which covered several broad topics, including reason(s) for GP attendance, own understanding of the pelvic health condition they were referred to gynaecology for, expectations of gynaecology care, treatment options and willingness/interest to trial physiotherapy. The interview guide comprised a wide range of open-ended questions with prompts for elaboration and clarification [13]. Each interview lasted 20–30 min, with all interviews audio-recorded (with permission) and transcribed verbatim by an independent third party.

Data analysis

Thematic analysis was selected for data analysis in this study [14]. The coding process was discussed within the research team prior to the conduct of data analysis to reach a consensus. Once this was established, coding was undertaken manually by one member of the research team (ET). Each interview transcript was read more than once by the coder and ideas generated from this process were labelled as codes. The same process was repeated across all transcripts and common codes were identified and categorised to form themes [12, 15]. These themes were subsequently labelled according to messages they presented. A second member of the research team (SK) was consulted when, if any, uncertainties were identified during the coding and theming. A final version of the categorised codes and themes was checked and confirmed by the primary author (TB) who conducted the interviews.

To enhance rigour of the data collection, analysis and interpretation processes, a range of strategies were employed to promote credibility, transferability, dependability and

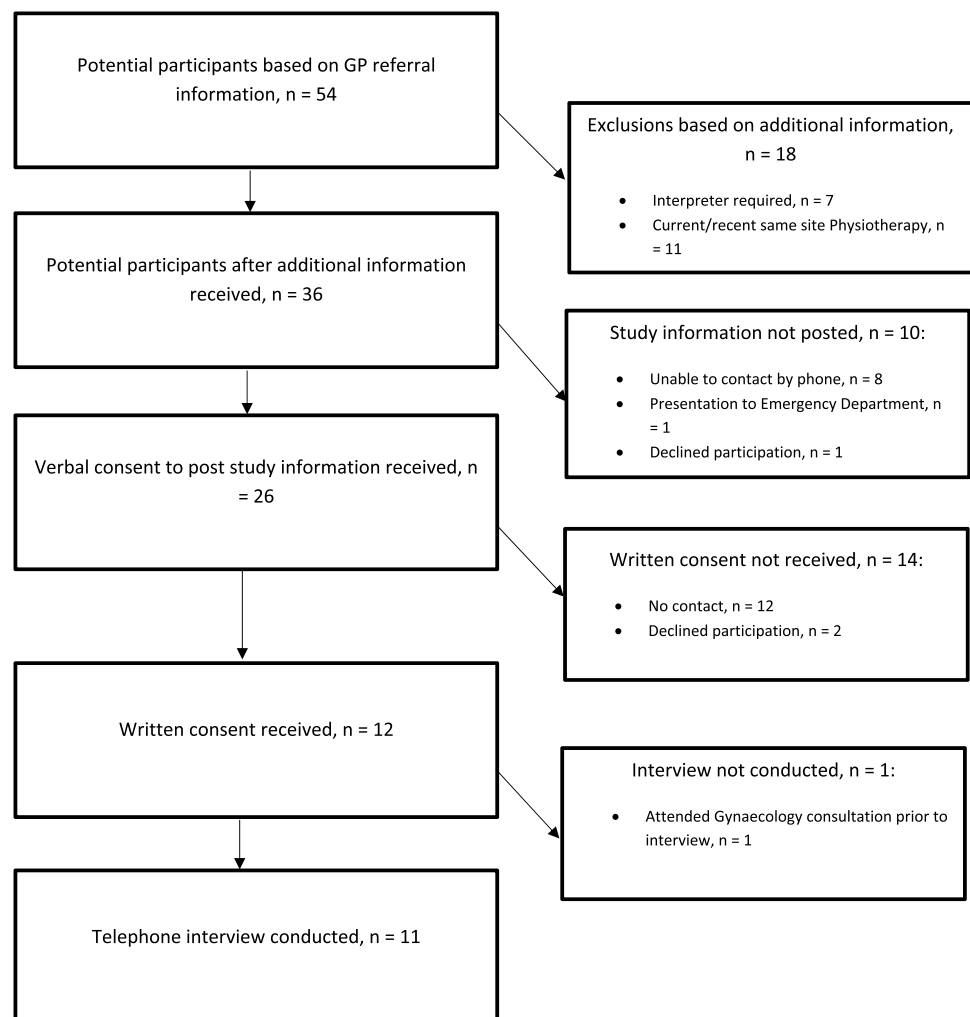
confirmability. These included adherence to the semi-structured interview guide, audiotaping interviews, transcribing verbatim by an independent and external typist and cross checking within the research team [16, 17]. These strategies had been used previously and thus were familiar to the research team [11, 18]. Prior to the commencement of the study, an independent review of the research processes was undertaken by the Human Research Ethics Committee with study approval granted in June 2019 from the Women's and Children's Health Network Human Research Ethics Committee (HREC/WCHN/19/016).

Results

Overview of study participants

A total of 11 women participated in the semi-structured interviews which occurred between November 2019 and May 2020. Participant recruitment is illustrated in Fig. 1.

Fig. 1. Study participant recruitment



The interviewed cohort were aged 56 (range 35–73) years on average—comparatively, the women were of similar age in the cohort who did not proceed to interview ($n = 25$) with overlapping range (average 49 years; range 22–79 years). On average, the interviewed women waited 119 (range 93–145) days between GP referral to specialist appointment. A subset of the potential participants ($n = 10/36$) were affected by the global pandemic Covid-19 response and had their scheduled gynaecology appointment indefinitely postponed, with five of these women in the interview cohort. All women who participated in the semi-structured interviews described symptoms of POP, UI and/or AI, or a combination of both.

Outcomes

Thematic analysis of the interview data identified a variety of experiences and perspectives of women waiting to see the specialist. As a means of presentation, these perspectives were categorised into four themes (most with sub-themes): drivers to seek help, understanding the condition,

experience/feeling being on the waiting list and expectations from the gynaecology team.

Theme 1: Drivers to seek help

This theme answered the question about why the women chose to attend their GP to discuss their symptoms and/or seek help. Persistent/worsening symptoms and impact of condition were two main reasons described and discussed by the women.

Persistent/worsening symptoms

All women reported persistent or worsening symptoms as a key driver for GP presentation.

“The stress incontinence, I would say, quite a few years ago...five or six years ago I noticed it, but it wasn't a problem because it didn't happen often...It got really bad about six weeks before the shutdown of COVID. I could actually feel my bladder when I walked.” P3

“...I just had what at the time felt like really bad, like a stitch. You know that awful, dreadful cramping feeling that you get?...And it didn't go away. First of all I thought, ‘I've probably done it gardening or something.’ But then it didn't go away, so I made an appointment with him [the GP].” P7

Some women further reported a fear of worsening symptoms and expressed concerns in relation to their age, with a desire to seek help now before they advanced in age.

“It was just more that I sort of...started to notice that things weren't all sitting right. And I thought, ‘Well, no, I'm going to go and get that looked sooner rather than later.’...I thought if I don't get on top of it now I might be in big trouble.” P1

Impact of condition

The impact of symptoms on their physical, mental and/or sexual health was also revealed as a significant driver for GP presentation. Many described feelings of embarrassment, frustration, burdened, anxiety/worry and always being aware of their condition/symptoms.

“It's messing with my physical health. It's messing with my sex life. It's just utterly inconvenient...I get frustrated because I'm used to being busy and active, and I hate sitting down and feeling like a geriatric.” P8
“...And now, definitely, my pelvic floor is really bad. I can't lift anything without being incontinent. I can't laugh unexpectedly. I can't walk down a step without being [incontinent]...it's just horrible.” P10

For those wishing to be active and engage in activities outside of the house (e.g. employment), the women voiced concerns about their presentation, with fears of leaking, wet or soiled clothes and odours.

“...I've been in situations where I have to walk really fast to something...my office is upstairs...And sometimes you rush down in a hurry and that last step and then you wet yourself...It's just, every day, I've got to wear pads...it does weigh on me, and I think it's a resentment that you hold a little bit too. Like it shouldn't be like this. Yeah. Because I'm relatively young, so.” P10

Theme 2: Understanding the condition

This theme related to the participant's own understanding of the pelvic health condition they were referred for, including causes, symptoms and sources of information and support.

Causes

All women displayed sound health literacy, articulating their condition, their symptoms and logically describing possible causes/contributing factors. Most women attributed their condition to a self-identified cause—either pregnancy/child-birth (“I've got a bladder prolapse as a result of my first pregnancy...” P10), a history of manual labour/heavy lifting (“...I think it got worse because I do a lot of physical work, and didn't recognize what was actually happening...” P8) or an event causing prolonged periods of increased intra-abdominal pressure, such as acute respiratory infection (“I picked up a really, really bad viral respiratory infection...and I just couldn't stop [coughing]. Every time I started coughing, all of a sudden this incontinence came. It got really bad.” P3).

Self-reported symptoms

All women interviewed could clearly articulate symptoms consistent with the pelvic health condition they were referred for. A handful of women reported additional pelvic health symptoms on further questioning, which were not described on the original referral information but, in each case, these were downplayed and not seen as a significant concern.

“I have slight incontinence...I wouldn't have a clue but I'd say I'd sit on the average scale. It's not as if I have to wear incontinent pads all the time, or if it's a bit of urge incontinence...and very occasionally I have an accident...” P11

Many commented on the variability in their symptoms from day to day, describing key activities/strategies that either aggravate or ease their symptoms.

“...but most of the time I wouldn't know anything was wrong, but certain movements give me this funny pulling feel on one side, and particularly mopping. When I mop the floor, because I use an old fashioned bucket and mop, that I pull through, and that motion seems to be the motion that really triggers it...” P4

Information sources about their condition

In addition to speaking with their GP, several women had spoken with family and friends for additional information, particularly around treatment/management options.

“...since I have seen the doctor and that, my daughter has done research, because she goes into panic mode, and worries about me. She has done research and said, ‘there's these different options and you can have this, that and the other.’” P4

Further to this, a number of women reported similar symptoms as they were experiencing occurring in immediate family members (such as mothers or daughters) and described adopting management strategies prescribed for their family members to self-manage their own complaints.

“...I've been managing it with exercises that the physio gave my daughter.” P8

Some reported sourcing additional information from the intranet via reputable pelvic health sites as well as general internet searching, while two women had high levels of pre-existing clinical knowledge from their own health-related qualifications/employment.

“...I've spoken with my friend who has had prolapse... She had surgery. I've done research on Dr. Google. I've got as much information as I can...” P8

“...I've got a [degree]...I know a lot about all the specialties and gynae was a specialty I spent six months in [role]...just sort of learning about all what the options were like the mesh and the slings and what they can all do...So I sort of had an understanding of what the damage was that happened from bearing children. And depending on what labour you had as well.” P10

Theme 3: Experience/feeling being on the waiting list

This theme addressed the question of how this cohort of women feel while waiting for specialist consultation.

A small proportion of the women described some anxiety over being on a waitlist; however, the remainder denied any concern over waiting for specialist consultation, citing

an understanding of the public health system. Many women noted that they had managed with symptoms for some time, and additional waiting would not pose a problem.

“But in the meantime, I've been able to improve it by the exercises...So I do what I can, and then we just have to stay the course of them.” P8

Among the women whose appointments were affected by the global Covid-19 pandemic, few of them specifically felt that their pelvic health condition was of lower priority (in the context of the pandemic) than when they first presented at the GP.

“...Other things come to the top of the list and I understand that...it's gone down on the bottom of my list, not up the top any more...As long as it's not getting worse, and it's not. It's still inside; it's not outside yet.” P7

A small number of these women also reported some level of indifference if they had to wait longer for their specialist appointment as a result of the pandemic.

“Oh, well I mean I've dealt with this problem for quite a few years, so I would just have to be patient, wouldn't I?” P5

Theme 4: Expectations from the gynaecology team

Under this theme, the women described their expectations from specialist consultation, and specifically what key topics they were hoping to have addressed by specialist review.

Understanding the condition and options for treatment/management

Several women were keen to seek clarity and confirmation from the gynaecologist and gain a deeper understanding of the condition, the treatment/management options as well as a sense of likely prognosis.

“Well I guess I just want to touch base and see...If I've got any worse, I guess. And then...just if it is any worse what are my options? ... So I just want to get a bit more feel for, okay, where am I heading with this? ... that's just life for me or what are my options?” P1

Of these, some were specifically interested in specialist physical examination to confirm the provisional diagnosis and assessment by the GP.

“Well I need to talk to them [the gynaecologist] now. Like I said, I would like them to have a look at me again. I don't know whether an operation is going to happen now. Because I've done all these exercises and I'm hoping that they're going to say, ‘Look, you've

strengthened your pelvic floor muscles now.’ And I want their opinion.” P2

Attitudes to treatment options

Almost all women articulated their willingness to commit to whatever treatment plan is proposed by the specialist, with mixed views about jumping straight to surgical options ahead of conservative therapy.

“Look...I’ve had that many surgeries, I’m kind of of the mindset of I do what needs to be done. If I’m told to do exercises for a year I’ll just do it. If I’m told to do a procedure, I’ll do it if it fixes the problem. I’d much rather just get it resolved because otherwise, the discomfort every day it’s something I have to be wary of all the time and I shouldn’t have to always be so conscious of that.” P9

“I’m open to surgery but I don’t really want to have surgery.” P10

When provided with additional brief context about the value of conservative therapy, either as a precursor or as alternative to surgery, all of the women expressed interest in trialling physiotherapy.

“...if I can go to physio rather than surgery that would be my number one decision. If you offered me physio or a small op, I would say can I try physio first. That’s how I feel.” P6

Resolving the problem/a solution

A desire to seek resolution of their symptoms and a solution for their condition at specialist consultation was indicated by a handful of women during the interview.

“My hope is to resume and get back to normal and be able to do whatever I want to do without being concerned about lifting or anything like that. I don’t want to be confined in my actions and my movements....” P4

Discussion

Through semi-structured interviews, this study has described the perspectives and impact of pelvic health conditions on women who are waiting for specialist input. While the women interviewed demonstrated that they were largely in tune with their condition, able to identify possible relevant contributing factors and familiar with a range of potential management options, there appears to be an opportunity to better use the waiting time and provide additional support while waiting for specialist consultation.

Through the action of seeking help from their general practitioner (GP) and self-sourcing additional information from relatives, friends and other sources (e.g. the internet) as identified in the interviews, one could assume these women were keen to affect change. Applying Norcross et al.’s transtheoretical model of behaviour change (“stages of change”), these women appeared to be in the preparation and/or action stage of change—beginning to take the necessary individual steps to address their problem [19]. Given this to be so, it may be an ideal opportunity to commence timely conservative therapy approaches, many of which rely on active, patient-driven behaviour-based change such as lifestyle modifications and adherence to an exercise regime.

In this study cohort, it was interesting that many of the women displayed some level of apathy when discussing the wait time for specialist consultation, happy to accept that accessing the public health system meant waiting—and they would wait as long as they had to (seemingly indefinitely for some of those women affected by Covid-19). While this study did not particularly focus on the topic, the wait time acceptance may reflect prohibitive barriers to accessing primary health care in the private setting, where conservative therapy can be accessed without specialist consultation but often comes with significant financial costs and a lack of service options (particularly in rural/remote settings). Another possible explanation for this might be some women may be in the contemplation stage and not yet ready for effective change [19]. This may have potential negative implications for clinical improvement via conservative therapy, i.e. the women may have booked their GP consultation with no genuine readiness to affect change or preparedness to take the necessary personal steps to influence change.

The women in this study were able to articulate their pelvic health condition, its symptoms and possible causes/contributing factors but were seeking clarity about their diagnosis (including the severity of their condition) and prognosis from the specialist gynaecologist. When asked, many of the women described additional pelvic health symptoms not described on the original referral from the GP but then downplayed the significance of these. This is somewhat different to the findings of Kiyosaki et al. (2012) and Anger et al. (2012), whose studies demonstrated patients with pelvic health conditions had poor recall of their diagnosis and poor understanding of their condition, particularly in terms of severity, after being referred to a specialist (and before completing the first specialist consultation) [20, 21]. Mazloomdoost et al. (2016) showed that women with pelvic health conditions are high internet users but only 4.9% used the internet to learn about their condition, with many (39.4%) preferring to wait to speak with the specialist for education and resources [22]. In our study, just over a third of women had accessed the internet to research their condition and nearly half had drawn upon the experiences of their

immediate family with similar symptoms, adopting some of the self-management strategies that family members had been instructed to commence for themselves. It could be suggested that this enhanced access to information and support may also explain the wait time acceptance for this cohort, as many had already sourced some additional information and resources independent of specialist consultation.

The interviewed women were keen to consider and explore a range of therapy options, and some had already begun to independently implement conservative therapy strategies such as pelvic floor muscle exercises to help manage their symptoms prior to specialist consultation. Advanced scope models of care in this clinical context, whereby the woman is first assessed by an experienced Women's Health Physiotherapist before implementing conservative management ahead of specialist consultation, are becoming increasingly popular to facilitate access to timely, effective, efficient patient centred care [23]. An advanced scope physiotherapy pilot programme for women with pelvic health conditions demonstrated overwhelmingly positive patient satisfaction with the model of care for women who had engaged with the service [24]. The perspectives described in this study suggest an openness and willingness to explore all treatment options available and a desire to seek additional information from a range of sources, starting prior to specialist consultation, which further supports the advanced scope model of care concept. The demonstrated benefit for advanced scope models is the timeliness of contact and filling the waiting time period with intervention/action, thereby capitalising on the woman's desire to affect change.

As with all research, there are limitations to this study as well. This study included women sourced from one tertiary institution located in a large metropolitan centre. Furthermore, women from Culturally and Linguistically Diverse (CALD) backgrounds, who required interpreting assistance for medical appointments, were not included in the sample. However, the detailed descriptions of participants, use of detailed quotes and comparing and contrasting similar findings from other settings, through published research, may improve transferability.

This study has described the perspectives of women waiting for specialist consultation for pelvic health conditions and the often-devastating impact of their condition across a range of health domains driving them to seek specialist input. There appears a clear opportunity for health services to better support women during the waiting time, and this adds further evidence in support of advanced scope models of care in this clinical context.

Author contributions Tara Beaumont: Study conceptualisation, data collection, data analysis and manuscript writing

Esther Tian: Data analysis and manuscript editing
Saravana Kumar: Study conceptualisation, data analysis and manuscript editing

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Declarations

Conflicts of interest None.

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