



Research Report

Patient and clinician perspectives of pelvic floor dysfunction after gynaecological cancer

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ABSTRACT

Purpose: To explore and compare patient and clinician experiences, knowledge and preferences in relation to screening and management of pelvic floor (PF) dysfunction in the gynaecology-oncology setting.

Methods: Semi-structured interviews were conducted with women reporting PF symptoms after gynaecological cancer treatment, and gynaecology-oncology clinicians. Interviews were transcribed and thematically analysed and were conducted until data saturation was reached.

Results: We interviewed 12 patients and 13 clinicians. We identified two main themes: (1) Experience with PF symptoms, screening, disclosure and management and (2) Future hope of what should happen to screen and manage PF symptoms. Differences between what participants had experienced and what they felt should happen highlighted a perceived need for improving PF screening and management. A sub-theme that reflected relevant barriers and enablers was also identified. Barriers included time pressure, being focussed on cancer treatment and not side-effects, and patients feeling unwell, emotional, and overwhelmed with the logistics of oncology appointments. Enablers included the patient-clinician relationship, and opportunities for improving management included integrating nursing and PF physiotherapy with oncology appointments.

Conclusions: Gynaecological cancer survivors and clinicians perceive a need to improve screening and management for PF symptoms. While barriers and differences in perception exist, there are opportunities to improve how PF symptoms can be screened and managed in this population. Further studies exploring the feasibility of providing integrated multidisciplinary PF therapy services may be warranted.

1. Introduction

1.1. Background

Gynaecological cancers account for 17% of all cancers diagnosed in women (World Cancer Research Fund, 2020). Side-effects of gynaecological cancer treatment may include changes in bladder, bowel and pelvic floor (PF) structure and function (Bernard et al., 2017; Cyr et al., 2021; Crean-Tate et al., 2020; Sekse et al., 2019) and rates of

urinary incontinence, faecal incontinence and dyspareunia may be higher after gynaecological cancer than in the general population (Ramaseshan et al., 2018; Frawley et al., 2022). Gynaecological cancer survivors have expressed a need for more information about dealing with long-term side-effects of cancer treatment (Sekse et al., 2019; Lopez et al., 2019), however gynaecology-oncology clinicians have reported limited time and a lack of referral pathways as barriers to discussing treatment side-effects during review appointments (Dahl et al., 2015). Patients may not actively seek treatment for PF symptoms, even if they

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find them bothersome (Doyle et al., 2017; Lindgren et al., 2017; Hazewinkel et al., 2010) and strategies to support patient disclosure have not been previously examined in this setting. It is important to explore current practice in screening for PF symptoms, from both the patient and clinician perspectives, to identify strategies to support patient disclosure.

Although there is available data on the prevalence of PF dysfunction (PFD) (Ramaseshan et al., 2018; Frawley et al., 2022), there is a lack of robust evidence from clinical trials in gynaecology-oncology to guide PFD treatment (Brennen et al., 2020). Many gynaecological cancer care pathways either do not include PFD screening (Colombo et al., 2013) or only include routine screening and referral for sexual dysfunction, but not for urinary or faecal incontinence (Lokich, 2019; Cancer Council Australia, 2016; Cancer Council Australia, 2016). Lindgren and colleagues (Lindgren et al., 2017) found that women with incontinence after gynaecological cancer treatment had not been told about PF muscle training during their cancer care. We therefore wanted to explore patient experiences and clinician practices for management and referral for all PFD after gynaecological cancer.

Clinician-patient interaction may play a substantial role in empowering women to seek treatment for PF symptoms after gynaecological cancer (Hazewinkel et al., 2010). Previous literature highlighted differences between patient and clinician perspectives regarding barriers and enablers to PF therapies in non-cancer populations (Frawley et al., 2015), but such research has not been conducted in the gynaecology-oncology setting. If such differences exist in gynaecology-oncology, this could result in a mismatch between patient preferences for management of PFD and what clinicians offer as part of clinical care. We therefore wanted to compare patient and clinician perspectives, to inform recommendations for potential strategies to enhance care for gynaecology-oncology patients with PF symptoms.

1.2. Aims

The purpose of this descriptive qualitative study was to explore and compare gynaecology-oncology patient and clinician experiences, knowledge and preferences in relation to screening and management for PFD.

1.3. Ethics approval

This study was approved by the Monash Health Human Research and Ethics Committee. NMA HREC Reference Number: HREC/44604/MonH-2018-151149.

2. Methods

The methods and results are reported according to the COREQ guidelines (Tong et al., 2007). Qualitative methodology was chosen as we were exploring the lived experiences, understanding and perspectives of participants. Individual semi-structured interviews were conducted with patients experiencing a range of PF symptoms after gynaecological cancer treatment, and doctors and nurses working in gynaecology-oncology medical, radiation and surgical roles at a tertiary public hospital and cancer specialist public hospital, in Melbourne, Australia. Interviews were chosen because of the intimate nature of the topic, to avoid participants being embarrassed speaking front of other participants. Inclusion criteria for patients were: experiencing PF symptoms at least six weeks after starting gynaecological cancer treatment, being 18 years or older, and speaking English. Exclusion criteria for patients were: having severe physical/psychiatric impairments or neurological disorder, or insufficient English. Inclusion criteria for clinicians were: providing gynaecology-oncology care in the participating hospitals. Exclusion criteria for clinicians were: not consenting to participate in interviews. As all clinicians worked in an English-speaking hospital and were over 18 years old, English language ability and age

were not specified as inclusion/exclusion criteria. Participants were recruited from December 2018 to January 2020. Patients were given study information by their treating clinician and asked for consent to be contacted by the primary researcher (RB) inviting participation. The primary researcher presented to team meetings at participating sites, and approached clinicians individually, by email or in-person. The heads of departments where the study was conducted were not interviewed, as they were involved in ethics and governance approval processes and had a prior relationship with the primary researcher. Interviews were conducted by the primary researcher, a physiotherapist with postgraduate qualifications in PF physiotherapy and participants were aware of her qualifications. She did not have a prior relationship with participants.

All participants gave informed consent. All interviews were conducted in person, or by telephone when in-person interviews could not be arranged. The questions for patient interviews were developed in consultation with consumers who had experienced PF symptoms after gynaecological cancer treatment and were involved in a previous study undertaken by members of this research team (Frawley et al., 2020). Patient interviews were undertaken in a private room in the hospital or university. Clinician interviews were undertaken in clinic rooms or offices. Interviews were audio-recorded and transcribed verbatim. Individual interviews continued until all questions from the interview guides (Appendices 1 and 2) had been discussed, or the participant's available time had elapsed. Transcripts were sent to participants for verification, unless the participant requested otherwise. Demographic data, including patient health status or clinician experience, were collected by a study-specific questionnaire.

The primary researcher coded all interviews using open, focused, and theoretical coding and constant comparative techniques (Creswell and Creswell, 2018), using the NVivo 12 Plus qualitative research software program (QSR International Pty Ltd, 2018). Auto-coding was not used. The primary researcher read each transcript and coded sentences according to the words and concepts expressed by the participants, resulting in a list of codes and definitions (open coding). Codes were compared to identify relationships between codes, with some codes merged to form new codes (focussed coding). Coding on 12 interviews was then cross-checked by a second (KYL (physiotherapy lecturer with colorectal cancer research experience)) or third (HF, (physiotherapy pelvic floor researcher with qualitative research experience) researcher, with codes discussed until consensus. A concept map (Appendix 3) and themes were developed and refined in group discussion (RB, KYL, HF, LD, SES) (theoretical coding). Interviews were conducted until data saturation was identified.

3. Results

3.1. Participants

Twelve of 14 patients consented to be interviewed. Two patients declined; one did not want to discuss PF problems, and one found it too difficult to schedule the interview. Fourteen clinicians were invited to interview, and 13 clinician interviews were conducted. One clinician had scheduling conflicts, and data saturation was identified before this interview was rescheduled, therefore it did not occur. Interviews were 20–60 min long. All patients received copies of their transcript for verification, and one patient requested one minor change. One clinician received a copy of their transcript, and approved this with no changes, and twelve clinicians declined to receive a copy of the transcript.

The demographic and cancer-related clinical characteristics of patients are presented in Table 1. One patient had surgery and adjuvant therapy 31 years before the interview, four patients had surgery three-to-four years before the interview and seven patients had surgery within the previous year. This provided valuable representation from the early to long-term survivorship periods. Codes and themes arising were similar between patients in these different survivorship periods.

The demographic and professional characteristics of clinicians are

Table 1
Patient demographic and cancer-related characteristics.

Characteristic	n (%)
Age group	
40–49 years	5 (41.7)
50–59 years	1 (8.3)
60–69 years	5 (41.7)
≥70 years	1 (8.3)
Living situation	
Home by self, independent	1 (8.3)
Home with family	11 (91.7)
Education level	
Some high school	1 (8.3)
Completed high school	3 (25.0)
Completed trade school	6 (50.0)
Completed university degree	2 (16.7)
Employment status	
Sick leave	2 (16.7)
Part-time / casual	3 (25.0)
Full-time	3 (25.0)
Retired	4 (33.3)
Hormonal status	
Pre-menopausal	0 (0.0)
Peri-menopausal	3 (25.0)
Post-menopausal	8 (66.7)
Cancer type	
Ovarian	4 (33.3)
Cervical	2 (16.7)
Uterine or endometrial	6 (50.0)
Cancer stage	
I	3 (25.0)
II	0 (0.0)
III	8 (66.7)
Unknown	1 (8.3)
Type of surgery	
Hysterectomy and BSO +/- PLND	7 (58.3)
Radical hysterectomy +/- PLND	2 (16.7)
Debulking laparotomy	3 (25.0)
Adjuvant therapy	
Nil	2 (16.7)
Chemotherapy	6 (50.0)
Radiotherapy	2 (16.7)
Chemotherapy and radiotherapy	2 (16.7)
Length of stay for surgery (days), median (range)	6.5 (0–14)
Time since surgery (weeks), median (range)	39 (7–1638)
Time since treatment completed (weeks), median (range)	21 (1–1630)
Abbreviations: n = number, BSO = bilateral Salpingo-oophorectomy, PLND = pelvic lymph node dissection	

presented in Table 2, and demonstrate representation of multiple disciplines, levels of experience, clinical sub-specialities and genders.

3.2. Thematic analysis

Two main themes and one sub-theme that related to both main themes emerged. The main themes were 1) the participants' experiences with the symptoms, screening, disclosure and management of PFD, and 2) the future hope of what should happen for screening and management of PFD. The sub-theme reflected barriers and enablers for screening and management of PFD in participants' past experiences, and what they thought may prevent or support health services implementing optimal practices in the future.

Table 3a and 3b show a comparison of the perspectives of patients and clinicians on key topics arising during the interviews.

3.3. Experience with PF symptoms, screening, disclosure and management

Patients and clinicians identified a variety of PF symptoms that patients experience including difficulty voiding, urinary incontinence, vaginal pain and faecal incontinence. Clinicians believed that PF symptoms were common after gynaecological cancer treatment and most clinicians believed that patients may not disclose symptoms,

Table 2
Clinician demographic and professional characteristics.

Characteristic	n (%)
Age	
20–29 years	1 (7.7)
30–39 years	3 (23.1)
40–49 years	3 (23.1)
50–59 years	4 (30.8)
≥60 years	2 (15.4)
Gender	
Female	10 (76.9)
Male	3 (23.1)
Profession and area of work	
Medicine	8 (61.6)
Surgery	4 (30.8)
Radiation oncology	2 (15.4)
Medical oncology	2 (15.4)
Nursing	5 (38.5)
Gynaecology-oncology surgery clinic	2 (15.4)
Gynaecology-oncology nursing coordination (radiation and medical oncology)	2 (15.4)
Radiation oncology	1 (7.7)
Years of experience working in gynaecology-oncology	
0–5 years	3 (23.1)
>5 years	10 (76.9)

although one felt that “...it would be exceptionally rare for patients to be embarrassed in the context of talking to their gynaecologist that they withhold information” (Clinician 11). While clinicians identified symptom severity and bother as the main drivers for patient disclosure, patients' reasons for disclosing PF symptoms included the impact they had on activities and being concerned that things were ‘not normal’. “It sparks a ‘oh my god, is this cancer again’ kind of thing” (Patient 2).

Patients and clinicians thought that women who were older, parous or had pre-existing PF symptoms were more likely to have PF symptoms after cancer treatment. They identified that being physically active, in employment or sexually active could reveal PF symptoms that women might not otherwise experience, and that PF symptoms could cause women to stop such activities.

... is it related to that (cancer) or is it just age?. (Patient 7).

...if you were in a relationship or married whatever that would be a big problem. (Patient 7).

Patients thought that surgery, radiotherapy, and chemotherapy could provoke or exacerbate PF symptoms. Some patients reported receiving detailed information about PF symptoms that may occur post-treatment, while others reported that they had received no information about this.

...it was discussed about, because they're taking everything out, the bladder's got nothing around it so it changes how everything works. (Patient 2).

They didn't really touch base on incontinence...no one lists, you know, the sexual side of it all. (Patient 12).

Clinicians identified the type and extent of cancer treatment as influencing PF symptoms and reported using such factors to guide the information they provided patients.

If we're doing a radical hysterectomy then obviously, I am going to talk about ongoing issues and if it looks like the patient might need to have some adjuvant radiotherapy. (Clinician 9).

Most clinicians reported asking broad screening questions for symptoms related to possible cancer recurrence such as “have your bladder or bowels changed since I saw you last” (Clinician 6), and then further questions to ascertain if symptoms could be related to cancer recurrence, treatment side-effects, or pre-existing symptoms. Some clinicians, especially nurses, reported that they routinely asked detailed

Table 3

a: Similarities in patient and clinician perspectives. b: Differences in patient and clinician perspectives.

Similar perspectives expressed by both patients and clinicians		
Identified type and extent of cancer treatment as affecting pelvic floor symptoms		
Felt that there were missed opportunities for screening for pelvic floor symptoms		
Identified patient-clinician rapport as an enabler for disclosure		
Expressed a positive attitude to pelvic floor therapy, ideally should be offered to every patient		
Identified patient agency as an enabler for pelvic floor therapy		
Identified time and cost as barriers to accessing pelvic floor therapy, patients specifically mentioned parking costs and clinicians also referred to long waiting times		
Identified side-effects of cancer treatment, especially fatigue during chemotherapy, as a barrier to accessing pelvic floor therapy		
Identified being or wanting to be sexually active, as motivating adherence to dilator therapy		
Identified the need to maintain vaginal patency for speculum examinations as a motivator for adherence to dilator therapy		
Expressed that the best approach to screening and management of pelvic floor symptoms would be multidisciplinary, especially using nursing or physiotherapy staff		
Differing perspectives expressed by patients and clinicians		
Topic	Patient	Clinician
Desire for information about pelvic floor symptoms	Most wished they had received more information and thought that all patients should receive information.	Reported that they provide information to some but not all patients, guided by treatment factors.
Resignation to pelvic floor symptoms	Some expressed resignation, seeing pelvic floor symptoms as inevitable.	A minority described pelvic floor symptoms as potentially inevitable, related to specific treatments such as extensive surgery.
Perceived drivers for patients to disclose pelvic floor symptoms	Being worried that it indicates cancer recurrence, not feeling 'normal'.	Severity and bother of symptoms.
Time pressure inhibiting disclosure of pelvic floor symptoms	Staff were under time pressure but did not make patients feel rushed.	Time pressure inhibited screening and disclosure.
Discontinuity of care inhibits disclosure of pelvic floor symptoms	Identified as a barrier to disclosing pelvic floor symptoms by multiple patients.	Not identified by any clinicians.
Awareness of common pelvic floor therapies	Some patients were aware of pelvic floor exercises and dilator therapy.	All clinicians were aware of pelvic floor exercises and dilator therapy.
Awareness of bladder and bowel training	No patients mentioned bladder or bowel training.	Most clinicians described bladder and bowel training, as well as medications including oestrogen.
Understanding of pelvic floor exercises	Some patients described correct technique, some described incorrect technique, and others described exercises that were not actually pelvic floor exercises.	Most clinicians described correct pelvic floor contraction technique. One suggested that the action was pushing down rather than pulling up.
Referral for pelvic floor therapy	Some patients reported being referred on. Some had disclosed pelvic floor symptoms but not received further information or referral.	Clinicians reported providing initial education and referring patients on to specialised health professionals.

sexual health history questions after cancer treatment. Many clinicians indicated they were more vigilant about PF function after vaginal, vulval or cervical cancer, pelvic radiotherapy or radical hysterectomy.

Most clinicians felt they lacked sufficient knowledge or skills to fully address PF symptoms. They reported providing initial education and referring patients to clinical specialists:

If it's a bladder problem I would normally refer on to urogynecologist ... Likewise if it's a bowel problem.... And if it's a sexual problem... a referral to a pelvic floor physiotherapist... (Clinician 11).

Although some patients reported being referred to specialists, others reported that they had disclosed PF symptoms and not been referred. "They said about bladder clinic or something, but they didn't actually refer me" (Patient 5). Several patients received a referral to PF physiotherapy on the day they were identified as eligible for this study but had yet to attend these appointments. Some patients remembered seeing a physiotherapist in hospital after surgery, however most recalled the physiotherapist focusing on mobility, and few recalled receiving PF information from the physiotherapist.

Patients had developed their own coping strategies, including using pads, staying near toilets, modifying their fluid intake, eating healthily and using laxatives. Some patients expressed resignation, "I shouldn't be having to put up with this but there's nothing that can be done" (Patient 9) and some clinicians described PF symptoms as potentially inevitable, "... that might be part of the payoff for surgery and the treatment they've had" (Clinician 9).

When asked about treatment they had undertaken for PF symptoms, some patients mentioned PF muscle exercises and dilator therapy. Patients had various descriptions of PF muscle contractions:

*...tightening all my muscles of my abdomen as well. (Patient 9).
I can feel my perineum area pulling up... (Patient 12).*

...to pull in the vaginal muscles where you're not pulling your belly in and your bum in. (Patient 8).

Most patients described learning about PF exercises from midwives previously and some had seen a gynaecologist or PF physiotherapist. Several patients mentioned internet-searching and peer support groups as their primary information sources.

Clinicians described treatment options of PF muscle exercises, vaginal dilators, oestrogen treatment, and bowel and bladder training. Most clinicians described PF muscle contractions as squeezing and lifting, although one clinician described squeezing downward, rather than upward. Clinicians reported acquiring relevant clinical knowledge through self-directed learning and personal experience, and one surgeon spoke of their formal gynaecological training. "It's part of our training because we do gynaecology and urogynaecology" (Clinician 6).

3.4. Future hope of what should happen for screening and management of PF symptoms.

Some clinicians and most patients thought there were missed opportunities for screening and management of PF symptoms. Many patients and clinicians stated that pre-existing symptoms should be identified prior to cancer treatment, however some felt that the focus on cancer at this stage precluded screening for PFD.

I'm here about this cancer treatment'.... It's not their focus at that point. (Clinician 3).

Most, but not all, patients felt that being forewarned would have helped them:

*I think knowledge is power. I think if you've got it, then you have a good way of addressing it, if it does happen anyway. (Patient 2).
... but you know the more you get told the more you worry... (Patient 4).*

Patients and clinicians expressed a positive attitude towards PF therapy: *“Ideally you would offer it to everybody”* (Clinician 11). All clinicians and most patients recommended a multidisciplinary approach to screening and management of PFD. Patient and clinicians identified nursing or allied health staff as key disciplines, which seemed to relate to perceived skill set, perceived availability and gender.

If a physiotherapist can do it...rather than, you know, a surgical doctor whose time is probably considered to be a lot more valuable, or you know he can be off doing what he's really trained for. (Patient 8).

3.5. Barriers and enablers to screening and management of pelvic floor symptoms.

Participants identified barriers and enablers to discussing PF symptoms, and access to and uptake of PF therapies. These included barriers and enablers they had experienced or observed, as well as hypothesised strategies to overcome these barriers. We categorised these as: (1) general, i.e., not related to cancer or cancer treatment; (2) related to the cancer and cancer treatment experience; and (3) specific to gynaecological cancer, as shown in Table 4.

General barriers to discussing PF symptoms that patients identified included language and cultural barriers, discontinuity in care and perceived time pressure on staff. Clinicians reported *“...hoping that they don't tell me the pelvic floor things, because I can't really address that within the clinic time of 10–15 min”* (Clinician 6).

General barriers to accessing PF therapy included waiting times, travel time and cost, particularly for patients from regional and remote areas. Patients and clinicians identified the difficulty of doing PF muscle contractions correctly as a barrier to PF muscle exercises, and some patients reported that inconsistent follow-up affected dilator therapy adherence: *“I knew I had to use it, but I thought, you know, if nobody's going to mention it, I don't want to use it.”* (Patient 6).

Patients and clinicians described patient-clinician rapport as a general enabler for discussing PF symptoms and uptake of PF therapies. Regarding adherence to PF therapy, participants spoke about individual agency of the patient being an important enabler. *“You've got to have that desire to solve the problem... no one can do it for you”* (Patient 1). Clinicians and some patients described being sexually active as the most important enabler for dilator adherence.

I want to be able to have a decent sex life again with my husband so I figure...if you don't do that then you can't complain if you're not having a decent sex life. (Patient 11).

Individual PF physiotherapy was suggested by patients and most clinicians as their main strategy to assist in performing PF muscle exercises correctly. Clinicians working with patients after radiotherapy also described the use of the vaginal dilator as *“a sensory focus ...the anatomical site where they can put pressure”* (Clinician 1). Bundling of dilator therapy and PF muscle exercises was used to facilitate adherence to both of these therapies.

The effects of cancer and cancer treatments were identified by patients and clinicians as barriers to uptake of and adherence to PF therapy.

...if you are actually feeling very, very, poorly and lethargic from the chemo... (Patient 12).

For the patient who is kind of overwhelmed with the diagnosis, prognosis, this may be the last thing they are thinking about. (Clinician 4).

Many participants identified the number of cancer treatment appointments as a barrier to additional PF physiotherapy appointments but suggested providing PF physiotherapy in conjunction with other appointments to overcome this. *“I think it would be probably a bit too much for them (other patients), unless you can somehow incorporate it with one of the appointments...”* (Patient 6).

Gynaecology-oncology specific barriers to uptake of PF therapy were

Table 4
Barriers and enablers groups by category.

Category	Barriers	Enablers
General	Disclosure and discussion of pelvic floor symptoms: discontinuity in care time pressure on staff Discussion of symptoms and access to and uptake of pelvic floor therapies: language and cultural barriers waiting times demand on services access to and uptake of pelvic floor therapies: travel time cost Uptake of and adherence to dilator therapy: inconsistent information and follow-up for dilator therapy Uptake of pelvic floor muscle exercises: lack of knowledge of how to do pelvic floor muscle exercises	Discussion of symptoms and access to and uptake of pelvic floor therapies: patient-clinician rapport patient agency Uptake of and adherence to dilator therapy: being sexually active bundling of dilator therapy and pelvic floor muscle exercises Uptake of and adherence to pelvic floor muscle exercises: individual pelvic floor physiotherapy use of the vaginal dilator as a sensory focus bundling of dilator therapy and pelvic floor muscle exercises
Related to cancer and cancer treatments	Uptake of and adherence to pelvic floor therapy including pelvic floor muscle training: side-effects of cancer treatment (feeling unwell, fatigue, pain, memory loss) feeling emotionally overwhelmed the high number of cancer treatment appointments	Suggested (hypothetical) enabler to uptake of pelvic floor therapy: provide pelvic floor physiotherapy in conjunction with oncology appointments
Gynaecological-cancer-specific	Discussion of symptoms and access to and uptake of pelvic floor therapies: the private nature of symptoms psychological and physical trauma from gynaecological cancer diagnosis and treatment	Uptake of pelvic floor therapy: self-esteem and control long-term nature of the relationship between clinicians and patients during gynaecology-oncology follow-up Uptake of pelvic floor muscle training: not being able to have surgical pelvic floor treatment due to side-effects of gynaecological cancer treatments Adherence to dilator therapy: need to monitor for gynaecological cancer recurrence using speculum examinations

raised by both patients and clinicians.

I'm loath to go and see about it because I've had enough people poking around in my private areas. (Patient 8).

Things like dilators... bring back a lot of the trauma of the diagnosis. (Clinician 1).

Gynaecology-oncology specific enablers for uptake of PF therapies identified by participants included the long-term relationship between clinicians and patients during gynaecology-oncology follow-up and the need to monitor for cancer recurrence.

Many women...do form quite a close relationship with their gynaecological-oncologist...may well be taken a little bit more seriously than if it's said to them by other doctors. (Clinician 11).

It becomes very much a medical model of: '...This is where recurrences happen. We need to be able to look at it' (Clinician 2).

4. Discussion

This study explored the perspectives of gynaecology-oncology patients and clinicians regarding screening and management of PF symptoms. Our findings indicate gynaecological cancer survivors and clinicians perceive a need to improve screening and management for PF symptoms throughout the cancer journey. Patients and clinicians identified barriers and enablers in relation to discussing PF symptoms, and undertaking PF therapies, that were general, i.e., not related to their cancer or cancer treatment; related to their cancer and cancer treatment experience; and specific to gynaecological cancer.

There were many topics on which the perspectives of patients and clinicians aligned quite closely, while there were others in which these diverged. One of the most notable topics was in the information about PF symptoms provided prior to cancer treatment. Patients expressed a desire for more information on PF symptoms and felt this information should be provided to all women prior to gynaecology-oncology treatment, contrasting with clinicians' report of discussing PF symptoms with specific patients who were at risk of developing symptoms due to the extent or nature of their cancer treatment. Previous studies have similarly found that patients want more information than they have been provided (Sekse et al., 2019; Lindgren et al., 2017; Williams et al., 2020).

Regarding enablers and barriers to disclosure of PF symptoms and access to PF therapy, there were similarities and differences between the perspectives of patients and clinicians. Some clinicians in our study felt that patients would usually disclose PF symptoms if they were sufficiently bothersome, however previous studies have shown that even patients severely bothered by symptoms may not disclose them (Doyle et al., 2017; Williams et al., 2020), especially if they are unaware of treatment options (Lindgren et al., 2017; Hazewinkel et al., 2010). Both patients and clinicians in our study felt that patient-clinician rapport supported patients to disclose PF symptoms, but only patients identified that discontinuity of care deterred them from doing so. Rapport and continuity of care are also identified as potential enablers to disclosure of PF symptoms in previous literature (Williams et al., 2020). Although discontinuity of care may be difficult to overcome within current hospital staffing structures, routine screening for PF symptoms by every clinician would provide multiple opportunities for patients to disclose symptoms. This would facilitate timely referral to specialist clinicians, a need which has also been previously identified (Lopez et al., 2019; Hazewinkel et al., 2010). Patients' lack of knowledge of treatment options has been identified as a barrier to accessing care for PF symptoms after gynaecological cancer (Lindgren et al., 2017; Hazewinkel et al., 2010). If clinicians fail to share information about treatment options for PFD, they act as gatekeepers who decide for the patients, rather than empowering patients to decide for themselves about treatments they may wish to access.

Many of the barriers (e.g., lack of time or knowledge) and enablers (e.g., patient motivation) that were not specifically related to cancer were similar to barriers and enablers identified in non-cancer populations (Frawley et al., 2015). Strategies that have been implemented to overcome these barriers and utilise these enablers in the general population should be considered in gynaecology-oncology. These could include behaviour change strategies such as establishing credibility, enhancing self-efficacy and cognitive planning and attention (Hay-Smith et al., 2016).

Barriers (e.g., cancer-related fatigue and distress) and enablers (e.g., multidisciplinary care, patient's ownership of their healthcare) that

patients and clinicians discussed in relation to cancer and cancer treatments were similar to barriers and enabler to general exercise for other cancer patients (Clifford et al., 2018). Clinicians could look to existing literature in patients with other cancers for strategies to overcome such barriers and utilise such enablers. Behavioural support interventions such as personalised exercise programs, tracking devices, exercise reminder messages and phone calls, and group interaction (DeScenza et al., 2021; Haynam et al., 2021; Chan et al., 2020), could be investigated for PF therapy in gynaecology-oncology.

Pelvic floor therapists may need to be aware of unique gynaecological cancer-related barriers raised by participants in this study. Trauma-informed care principles have been developed to guide clinicians working with patients with a history of trauma, and trauma-sensitive gynaecological care principles have been developed to guide women's health clinicians working with survivors of sexual abuse (Brooks et al., 2018). It may be beneficial for clinicians to consider applying these principles when working with women who may have experienced trauma (physical or psychological) from gynaecological cancer diagnosis and treatment (Adellund Holt et al., 2016; Sukegawa et al., 2006). Clinicians may wish to consider screening for potential psychological trauma associated with vaginal examinations (Kezelman and Stavropoulos, 2020) and consider alternative PF assessment options, such as visual observation or transabdominal ultrasound, if trauma is identified.

The suggestion of a multidisciplinary approach, endorsed by both patients and clinicians in our study, indicates a need to investigate the feasibility of integrating specialised physiotherapy or nursing management for bladder and bowel symptoms into gynaecology cancer care-pathways. For services without capacity to integrate specialised clinicians, referral pathways may need to be easily accessible for timely referral and management of PFD during or after gynaecological cancer treatment. This is especially important considering the difference we found between clinicians who reported that they provided information and referred women on to PF specialists if they had PF symptoms, and some patients who had disclosed PF symptoms but were not referred.

Strategies to address the logistical and financial barriers raised in this study should be explored, e.g., coordination of appointments with oncology follow-up or consideration of distance-care options including telehealth. One recent study recommended using telephone-based nursing follow-up after gynaecological cancer to provide services in rural and remote areas (Schlittenhardt et al., 2016) and one small (n = 8) case-study series (Bernard et al., 2021) explored telephone-based physiotherapy treatment for urinary incontinence after endometrial cancer. Further studies investigating the feasibility and effectiveness of telehealth services for PF symptoms after gynaecological cancer are warranted.

4.1. Limitations

Patients were interviewed at least six weeks after starting gynaecological cancer treatment and their retrospective views on pre-treatment screening and management for PFD may not have reflected the intensity of emotion that many patients experience at diagnosis. Because most patients were not referred or had yet to attend PF physiotherapy appointments, we were unable to explore their experience of structured PF physiotherapy. Interviews were explicitly about PFD, so patients who were unwilling to discuss intimate health subjects may not have participated, and their views would therefore not be represented. Participants knowing that the interviewer was a physiotherapist may have influenced responses (Krumpal, 2013). Strategies to mitigate these limitations and ensure rigour included asking indirect questions (e.g. what would you tell other women who were about to undergo gynaecological cancer treatment about potential bladder, bowel or pelvic floor problems), prompting for specific examples from participants' experience (e.g. can you tell me about an occasion that a patient disclosed symptoms of pelvic floor dysfunction and how you reacted), transcript

verification and reaching data saturation (Bergen and Labonté, 2020). Thus, the findings of this study are credible and provide insights into the experiences, knowledge and preferences of gynaecology-oncology patients and clinicians.

5. Conclusion

We explored the experiences, knowledge and preferences of gynaecology-oncology patients and clinicians in relation to screening and management of PF symptoms. We identified two themes focused on what they had experienced and their future hope of what should happen, and a sub-theme about barriers and enablers to screening and management of PF symptoms. Our findings support identifying opportunities for screening and management for PF symptoms throughout the cancer journey and demonstrate a need for accessible referral pathways to appropriate specialised clinicians. Further studies should explore the feasibility of integrated multidisciplinary services that include continence or PF nursing or physiotherapy.

Author contributions

All authors made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data. Robyn Brennen, Helena Frawley and Kuan-Yin Lin conceived the work and designed the analysis. Robyn Brennen collected the data and performed the initial data analysis. All authors contributed to the analysis and interpretation of the data. All authors drafted the work or revised it critically for important intellectual content, approved the version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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Ethics approval

This study was approved by the Monash Health Human Research and Ethics Committee. NMA HREC Reference Number: HREC/44604/MonH-2018-151149. The procedures used in this study adhere to the tenets of the Declaration of Helsinki.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent for publication

Informed consent was obtained from all individual participants to use quotes and aggregated demographic and health/professional characteristics data in journal article publication.

Availability of data and material

The datasets generated during and/or analysed during the current study are not publicly available as these datasets could be used to identify research participants.

Author's contributions

All authors made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data. All authors drafted the work or revised it critically for important intellectual content, approved the version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Interview plan – Patient participants

Statement: Pelvic floor dysfunction can cause bladder problems, including incontinence, urinary urgency or incomplete emptying, bowel problems, including incontinence, urgency or constipation, sexual problems, including pain or poor sensation during sex or inability to have sex, and vaginal problems, including vaginal pain or bulging/discomfort in the vagina.

Question 1: Can you please tell me about your experience of any of these problems since your cancer treatment?

Prompts: tell me more about that, what were your reactions to that, how did you feel about that.

If some aspects discussed, ask whether they had any other symptoms (list whichever had not been discussed of bladder/bowel/sexual/vaginal). If women had symptoms before – Can you tell me how these have changed since before the cancer treatment? (better/worse/no change/the same).

Question 2: Can you tell me how you have responded to or managed these problems?

Prompts: What has made it easier to cope with these problems? What has made it harder to cope with these problems? Have you involved other people in managing these problems? How did you approach these other people? How did they respond? How have these problems affected your activities?

Question 3: Before or after you had your cancer treatment, were you aware of the possibility that bladder, bowel or sexual problems may occur? (Can you tell me about how you found out about this?).

Question 4: Can you tell me about any (other (if has already discussed in questions 1 and 2) interactions you have had with your doctors or nurses about pelvic floor dysfunction or symptoms (re-list if desired)?

Prompt: Were you aware of any treatment options for pelvic floor problems?

Question 5: How would you like healthcare providers to approach these issues with women having treatment for gynaecological cancer?

Prompt: Who would you prefer to talk to you about the possibility of bladder, bowel or sexual problems? When would you like them to talk about these issues?

Statement: Pelvic floor physiotherapy is used to treat pelvic floor dysfunction in women without cancer. Pelvic floor muscle training, exercises to help strengthen or relax the muscle in the pelvic floor, is a large component of pelvic floor physiotherapy.

Question 6: Can you tell me about your experiences with pelvic floor exercises?

Prompts: What have you heard about pelvic floor exercises?

(If yes) How did you hear about this? Have you done pelvic floor exercises? Can you tell me more about the pelvic floor muscle training you have done?

(If no) Statement: The pelvic floor muscles are muscles inside the pelvis that support the bladder, uterus and bowel. They help prevent us leaking urine or stool and need to relax when we want to let these out on the toilet. Pelvic floor exercises are about learning to contract these muscles for increased support when we need it and relax them properly to go to the toilet. They also help with sexual comfort and function. (Show anatomical location on diagram/model).

Question: Based on this, what do you think about pelvic floor exercises? Can you tell me about your reactions to this information?

(All) Who would you like to hear about the pelvic floor exercises from?

Question 7: What would help women who are having gynaecological cancer treatment to do pelvic floor exercises?

Of all the things you can think of that would help women to do pelvic floor exercises, which do you think is the most important/helpful?

Question 8: What things would make it harder for women who are having gynaecological cancer treatment to do pelvic floor exercises?

Of these, which do you think are the most important/problematic?

Appendix B. Interview plan – Clinician participants

Statement: Pelvic floor dysfunction can occur after treatment for gynaecological cancer. Symptoms include bladder problems, including incontinence, urinary urgency or incomplete emptying, bowel problems, including incontinence, urgency or constipation, sexual problems, including pain or poor sensation during sex or inability to have sex, and vaginal problems, including vaginal pain or prolapse.

Question 1: From your experience, how common are pelvic floor symptoms after treatment for gynaecological cancer?

If any, what are the most common types of pelvic floor dysfunction that your patients have reported?

Can you tell me about any experiences you have had with patients reporting these symptoms?

Prompts: Have you found that patients bring these issues up themselves? Have you also had experiences with patients with (list any PF symptoms not discussed already)? Can you tell me more about those?

Question 2: Can you tell me how you have responded to or managed these experiences?

Prompts: Can you tell me about your usual advice or management you might give in response to this? Are you aware of any resources available for patients on these topics?

Question 3: How do you think healthcare providers should approach discussing pelvic floor symptoms with women having treatment for gynaecological cancer?

Prompt: At what stage/when do you feel healthcare providers could do this?

Health professionals often report that routine and checklists help them to talk to their patients about specific issues. Do you think this is applicable regarding pelvic floor issues?

Are you aware of any screening that is done for pelvic floor symptoms before, during or after gynaecological cancer treatment? Who do you think is the most appropriate person to discuss these issues with women (e.g., oncologist, nurse, GP, gynaecologist, physiotherapist).

Question 4: Can you tell me about your understanding of pelvic floor therapies?

Prompts: What have you heard about it? What advice or management have you given to patients about pelvic floor therapies? Where did you learn about this information yourself?

Statement: Pelvic floor physiotherapy is often used to treat pelvic floor dysfunction in non-cancer populations. Pelvic floor therapies to manage UI, FI, OAB, defecatory disorders, sexual pain, can include pelvic floor muscle training, which may include exercises for awareness, coordination, strengthening, relaxation, or functional use.

Question 5: How do you think pelvic floor therapies should be approached by health professionals who are working with women who are having treatment for gynaecological cancer?

Question 6: What access do you have to physiotherapists who do pelvic floor therapies or other pelvic floor therapy resources in your healthcare services or networks?

Question 7: If pelvic floor therapy was indicated, what do you think would help women who are having gynaecological cancer treatment to take this up?

Are there unique factors that could help women who have had gynaecological cancer to do pelvic floor therapy?

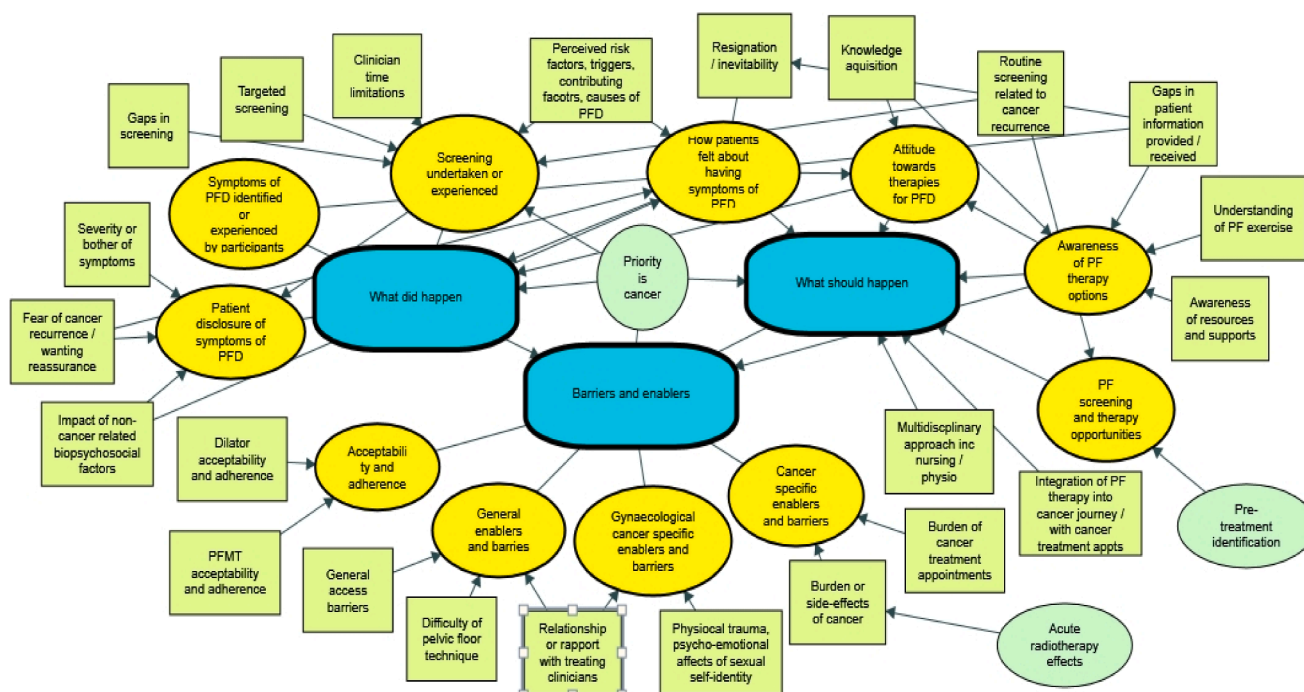
Of these, which do you think is the most important facilitator that helps women who have had gynaecological cancer to do pelvic floor therapy?

Question 8: If pelvic floor therapy was indicated, what do you think are the barriers for women who are having gynaecological cancer treatment to do this?

What are unique barriers to pelvic floor therapy for women who have had gynaecological cancer treatment?

Of these, which do you think is the most important barrier to overcome?

Appendix C **Concept map**



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