ORIGINAL ARTICLE

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What are the concerns and goals of women attending a urogynaecology clinic? Content analysis of free-text data from an electronic pelvic floor assessment questionnaire (ePAQ-PF)

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Abstract

Introduction and hypothesis Understanding patients' concerns and goals is essential for providing individualised care in urogynaecology. The study objectives were to undertake a content analysis of free-text concerns and goals recorded by patients using an electronic pelvic-floor questionnaire (ePAQ-PF) and measure how these related to self-reported symptom and health-related quality-of-life (HRQOL) data also recorded using ePAQ-PF.

Methods A total of 1996 consenting patients completed ePAQ-PF. Content analysis was undertaken of free-text responses to the item: '*Considering the issues that currently concern you the most, what do you hope to achieve from any help, advice or treatment?*' Key content themes were identified by the lead researcher, and three researchers read and coded all recorded responses. Student's *t* test was used to compare ePAQ-PF domain scores for patients reporting concerns in the relevant domain with those who did not.

Results In total, 63% of participants who completed the questionnaire, recorded at least one free-text item. Content analysis identified 1560 individual concerns coding into the 19 ePAQ-PF domains. Symptom scores were significantly higher for patients reporting free-text concerns in 18 domains ($p < 0.05$). Additional concerns relating specifically to body image were recorded by 11% of patients. Key areas of importance emerging for personal goals included cure/improvement, better understanding, incontinence pad use, sexual function and surgery.

Conclusions Free-text reporting in ePAQ-PF is utilised by patients and facilitates self-expression and discussion of issues impacting on HRQOL. The significant relationship between recorded free-text concerns and ePAQ-PF domain scores suggests convergent validity for the instrument. Development and psychometric testing of a domain to assess body image is proposed.

Keywords Patient-reported outcome measures · Prolapse · Incontinence · Body image

Introduction

Understanding patient's concerns about an illness and its treatment and their personal goals in terms of achieving a good health-related quality of life (HRQoL) is an important element of clinical management. This is particularly important in areas concerning sensitive conditions, as encountered in urogynaecology. Patients may not always divulge clear information about their symptomatology and what bothers them the most, particularly within the constraints of a conventional history and examination [1].

The use of technology has been shown to be of benefit in overcoming this problem. For example, computer interviewing in urogynaecology has been shown to provide patients with an opportunity to report symptoms of an intimate and sensitive nature, which may be difficult to express in a face-to-face consultation [2–4]. This means that their concerns can be more objectively assessed and appropriate investigation and treatment planned.

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The use of patient-reported outcome measures (PROMS) in urogynaecology is now well established, and their use is advocated in clinical practice [5], aiming to reliably and objectively quantify HRQoL and assess outcomes [2]. Most PROMS used in urogynaecology use multiple choice questions (MCQs) to assess symptoms and their impact. Data collected using these tools provide quantitative data about HRQOL and outcome, but may lack the sensitivity and acuity required to individualise patient's concerns and goals, particularly regarding treatment [6]. The electronic Personal Assessment Questionnaire-Pelvic Floor (ePAQ-PF) is a self-administered, interactive, web-based questionnaire that measures urinary, bowel, vaginal and sexual symptoms and their related impact [7–9]. The instrument is interactive and presents up to 132 items, depending on patients' responses to screening items, providing both summary and detailed reports, reflecting the four-dimensional assessment of urinary, bowel, vaginal and sexual conditions and their impact on HRQOL, which are used to inform and support healthcare consultations, document symptoms and monitor outcomes from the patient's perspective.

The penultimate item in ePAQ-PF is a free-text question: '*Considering the issues that currently concern you the most, what do you hope to achieve from any help, advice or treatment?*' (Fig. 1). Free-text responses to this question appear at the top of the structured report (Fig. 2) aiming to provide an additional qualitative, personalised component to patient assessment, alongside quantitative data from the closed MCQ elements of the instrument.

The objective of this study was to analyse the themes and content of free-text concerns and goals recorded in response to this item, from new patients attending a urogynaecology clinic, assess how these responses related to the quantitative data recorded in MCQ items in ePAQ-PF and identify any elements not currently addressed by the questionnaire.

Methods

The principle methodology for this research study was content analysis [10]. This is a social science methodology used to examine patterns in communication in a systematic and replicable manner, in this case free-text comments from a validated pelvic floor assessment questionnaire (ePAQ-PF).

Ethical approval for the study was obtained from the University of Sheffield, UK (project no. 015337). Female patients attending the urogynaecology unit at Sheffield Teaching Hospitals, UK, who completed ePAQ-PF during the study period (October 2013–September 2016) as part of their routine clinical care, prior to first assessment in the urogynaecology clinic, and gave consent for use of their data for approved research were included in the study.

ePAQ-PF is a web-based instrument that provides a comprehensive assessment of a patient's pelvic floor symptoms and their impact on HRQOL [7, 9, 11]. The instrument is completed on-line prior to clinic attendance by 80% of users [7] or, alternatively, using a touchscreen computer or tablet in a private room in the urogynaecology clinic. Patients may choose to have their partner/family member present with them when they complete the questionnaire and if they complete it in the hospital a nurse can sit with them to support them if they wish. The great majority of patients complete the questionnaire alone, unaided. Previous studies have shown that most patients find the questionnaire easy to use and a useful process that helps them to reflect and prepare for their consultation [2]. The mean completion time of ePAQ-PF, including the free-text components, is 26 min [7]. A questionnaire report may be printed or viewed electronically for use by the attending clinician, supporting consultation, diagnosis and management.

The core element of ePAQ-PF comprises of standardised multiple-choice questions, which assess both the frequency and impact of pelvic floor symptoms across four dimensions:

Fig. 1 This shows a screen grab of the free-text concerns and goals item from ePAQ-PF

ePAQ electronic Personal Assessment Questionnaire   **Ms Test Person - AA1234 - 0000000000 - 28/03/2018**

summa

ePAQ Pelvic Floor assessment for Test Person on 28/03/2018

Name	Test Person	Date of birth	12/04/1973			NHS Number	000 000 0000 (02)
Consultant	Radley	Clinic	Jessop Gynae OPD			Hospital Number	AA1234
Height	1.62 m	Weight	72 kg	BMI	27	Age	44
Treatment?	No	Condition change		Children	3	Other pregnancies	
Concerns & goals	1. Leakage of urine when I urgently need to wee 2. The prolapse dragging makes me feel rubbish. 3. I dont feel in the mood for intercourse and dont feel feminine						
Questions	1. Is there treatment for my prolpase? 2. What can i do about my bladder problem?						

Bladder & urinary symptoms		Score (0 - 100)	Impact
Pain	22		
Voiding	33		
Overactive bladder	67		
Stress incontinence	47		
Quality of life	78		

Bowel symptoms		Score (0 - 100)	Impact
Irritable bowel	13		
Constipation	44		
Evacuation	33		
Continence	19		
Quality of life	56		

Vaginal symptoms and prolapse		Score (0 - 100)	Impact
Pain & sensation	8		
Capacity		Screen negative	
Prolapse	58		
Quality of life	67		

Sex life		Score (0 - 100)	Impact
Urinary	33		
Bowel	17		
Vaginal	42		
Dyspareunia	13		
General sex life	58		

Fig. 2 A report generated from ePAQ-PF. Patient concerns and goals can be seen at the top of the report with domain scores for the 19 scored domains presented below

urinary, bowel, vaginal and sexual. Each item is presented on a separate screen, with individual Help page and navigation buttons. Response options for all these items are on a four-point scale, 'never', 'occasionally', 'most of the time' or 'all of the time', and scored 0, 1, 2 or 3 respectively. The impact attributed to each of these symptoms is also recorded, using a standard sub-question—*'How much of a problem is this for you?'*—and graded as 'not a problem', 'a bit of a problem', 'quite a problem' or 'a serious problem' and scored 0, 1, 2 or 3 respectively. The degree of frequency and bothersomeness are thereby assessed for each symptom.

The electronic instrument automatically generates scores across 19 validated domains, providing graphic representation of both the severity and impact for each condition. Domain scores are derived by dividing the sum of all item scores in that domain by the total possible item score and multiplying this

Table 1 Domain scores for those reporting concerns are compared with those who do not report a concern for both the symptom frequency score (Student's t test) and symptom impact score (Mann-Whitney)

Domain	Number of controls (number of patients not recording a concern in this domain)	Number of cases (patients recording a concern in this domain)	Mean symptom frequency score ± 2 SD (controls)	Mean symptom frequency score ± 2 SD (cases)	Domain score p value (Student's t test)	Modal symptom impact score (controls)	Modal symptom impact score (cases)	Impact score p value (Mann-Whitney)
Urinary dimension								
Stress urinary incontinence	1143	122	23.3 ± 49.7	47.5 ± 43.3	< 0.005	0	3	< 0.005
Overactive bladder	1197	68	23.1 ± 41.7	41.7 ± 39.2	< 0.005	0	3	< 0.005
Voiding dysfunction	1212	53	16.6 ± 38.3	38.1 ± 47.4	< 0.005	0	2	< 0.005
Urinary pain and sensation	1213	52	12.3 ± 33.4	24.4 ± 45.1	< 0.005	0	2	< 0.005
QoL Urinary	1132	133	33.0 ± 66.12	66.3 ± 59.0	< 0.005	–	–	
Bowel dimension								
Constipation	1206	59	21.2 ± 40.7	53.0 ± 52.9	< 0.005	0	2	< 0.005
Irritable Bowel	1237	28	27.7 ± 41.9	46.2 ± 46.1	< 0.005	0	2	< 0.005
Bowel evacuation	1194	71	20.8 ± 38.2	47.1 ± 42.3	< 0.005	0	3	< 0.005
Bowel continence	1163	102	16.3 ± 33.0	38.4 ± 39.4	< 0.005	0	3	< 0.005
QoL bowel	1235	30	22.6 ± 60.0	53.7 ± 71.5	< 0.005	–	–	
Vaginal dimension								
Prolapse	857	408	16.5 ± 45.4	54.6 ± 52.0	< 0.005	0	2	< 0.005
Vaginal pain and sensation	1078	187	19.1 ± 39.4	33.1 ± 43.0	< 0.005	0	2	< 0.005
Vaginal capacity	1254	11	9.0 ± 41.3	34.3 ± 61.1	0.021	0	1	< 0.005
QoL vagina	1223	42	27.6 ± 60.9	63.3 ± 60.6	< 0.005	–	–	
Sexual dimension								
Sex and urinary symptoms	1242	23	25.7 ± 63.4	47.6 ± 53.16	< 0.005	0	3	< 0.005
Sex and bowel symptoms	1260	5	15.2 ± 53.09	36.6 ± 19.2	0.072	0	2	0.001
Sex and vaginal symptoms	1223	42	36.2 ± 69.0	64.4 ± 46.6	< 0.005	0	3	< 0.005
Dyspareunia	1189	76	23.3 ± 49.7	41.4 ± 44.75	< 0.005	0	3	< 0.005
General sex life QoL	1217	48	41.9 ± 57.42	66.1 ± 52.0	< 0.005	1	3	< 0.005

by 100 to produce a scale ranging from 0 (best possible health status) to 100 (worst possible health status) [7, 8].

In addition to the multiple-choice items within ePAQ-PF, the instrument also includes a free-text question (item PD6 within the final *Personal Data Dimension*) that asks: '*Considering the issues that currently concern you the most, what do you hope to achieve from any help, advice or treatment?*' Patients are invited to record up to three free-text responses, each of up to 100 characters.

Data for the present study were used anonymously from women who answered '*Yes*' to the final item of the questionnaire, which seeks consent to allow confidential use of their answers for approved research.

Data were anonymised and transferred to SPSS (version 22) for analysis. Free-text data were imported into Microsoft Excel (version 15.33). Content analysis of free-text data was conducted [10]. This approach was adopted because it is located more within a quantitative methodology and our aim was to count and record the number of concerns reported by the women and compare these against the current ePAQ-PF domain structure (e.g. looking at where there was convergence and divergence between the data sets). The lead researcher (TG) read and became thoroughly familiar with the comments recorded throughout the free-text data. These comments were then coded categorically according to the 19 domains of the ePAQ-PF instrument. Content not fitting into these categories, and therefore not assessed by ePAQ-PF, was then coded separately.

Free-text comments were then analysed, coded independently by three members of the research team (TG, SS, SP), and any ambiguities were resolved by discussion. A similar approach was also undertaken by the lead researcher to analyse the text that patients had reported for patient goals (TG). Again, these were then coded independently by two members of the research team (TG, SP) and any further ambiguities were resolved by discussion.

Student's *t* test was used to compare ePAQ-PF domain symptom frequency scores for patients reporting concerns in the relevant domains compared with those who did not. The Mann-Whitney test was used to compare the domain impact scores in the same manner.

Results

During the 3-year study period, 2498 women completed ePAQ-PF as part of their routine clinical care prior to their first consultation in the urogynaecology clinic. One hundred ninety-nine women (8%) declined consent for using their data for research, and a further 303 did not complete the consent question. Therefore, data from 1996 women were included in the study. Of these, 1266 (63%) recorded one or more responses to the question: 'Considering the issues that currently concern you the most, what do you hope to achieve from any help, advice or treatment?' During the study period, > 90% of patients attending the urogynaecology outpatient department at Sheffield Teaching Hospitals, UK, completed ePAQ-PF. Reasons for non-completion were not formally recorded or studied, but often related to advanced age, computer literacy or lack of time to complete it during the clinic visit.

Patient concerns

Five hundred thirty-one patients (42%) recorded one concern, 472 (37%) recorded two concerns, 100 (8%) patients recorded three concerns and 102 (8%) recorded more than three. Sixty-one patients (5%) completing this item recorded free-text content that did not relate to a concern or goal, for example, writing a question or making a statement about their care.

Content analysis identified 1560 components from recorded concerns that all coded into the 19 domains of ePAQ-PF.

Domain scores were significantly higher in 18 of the 19 ePAQ-PF domains for women reporting concerns in the salient domain compared with those who did not ($p < 0.05$) (Table 1). Domain impact scores were also significantly higher in all 19 ePAQ-PF domains for those reporting concerns in the salient domain compared with those who did not ($p < 0.05$) (Table 1).

Additional themes not coding into the existing ePAQ-PF domain structure were identified: 160 specific body image concerns were recorded by 136 patients. These body concerns were grouped into themes of smell (16.3%), scarring (6.9%), appearance (37.5%) and emotions (39.3%). The frequency of the most commonly used words or phrases used in relation to body image concerns is shown in Table 2.

Table 3 provides examples of some of the intimate concerns and goals recorded by patients in the study; 102 patients reported faecal incontinence, 23 reported coital urinary incontinence and 5 reported coital faecal incontinence. A word cloud, graphically illustrating the words most frequently used by women recording concerns about their condition, was created (Fig. 3).

Personal goals

Overall 85% of patients completing the free-text item recorded at least one goal. A total of 596 patients (47%) recorded one goal, 332 (26%) recorded two goals, 116 (9%) recorded three goals and 102 (3%) recorded more than three; 189 (15%) did not record a goal. Content analysis identified seven key themes related to personal goals: (1) aiming for cure or improvement, (2) better understanding their condition, (3) improving physical activity, (4) reducing use of incontinence pads, (5) improving their sex life, (6) reducing pain and (7) undergoing surgery.

Discussion

The primary objective of this study was to undertake a content analysis to assess themes emerging from free-text concerns and goals recorded in ePAQ-PF. The secondary objective was to assess how concerns recorded related to symptoms and HRQOL recorded in the quantitative components of ePAQ-PF and thereby support a patient-focussed approach to updating and potentially introducing new elements to the questionnaire.

The main findings are that the free-text component of ePAQ-PF was used by over 60% of patients completing the instrument. The majority (90%) of themes identified from the content analysis fitted into the existing domain structure of the instrument. Specific body-image concerns were recorded by 10% (n = 136) of patients responding to the free-text question, which are not currently addressed by the MCQ items of ePAQ-PF. The most commonly reported goals related to seeking improvement or cure of conditions, improving physical and sexual function and undergoing surgical treatment.

Free-text data are commonly included in patient-reported outcome measures alongside quantitative components, though such data are rarely used in research as components of free-

Table 2 The frequency of the most commonly used words to describe body image concerns in relation to urogynaecology conditions

Emotional words/phrases used in relation to body self-image	Number of times repeated
Embarrassment	18
Worry	6
Fear	5
Lack of confidence/self-conscious	4
Depression	4
Gets me down	2
Shame	1
Mortifying	1
Anxiety	1
Scared	1
Distress	1
Mental effects	1
Feeling low	1
Mentally disturbing	1
Dirty	1
Ashamed	1
Paranoid	1
Miserable	1
Psychological effect	1
Overall unhappy	1
Annoying	1
Upsetting	1

text responses may vary in relevance to the research question posed [12] and analysis of qualitative data presents methodological challenges. As such, free-text data are often neglected as a potentially rich source of data, which can supplement, augment and compliment more traditional quantitative data [13].

The free-text concerns and goals questions of ePAQ-PF are presented towards the end of the questionnaire. This aims to ensure that patients have first completed the core MCQ component of the PROM, giving them the opportunity to reflect on their condition and then provide considered responses to these items. A previous qualitative study, using semi-structured interviews with 20 women completing ePAQ-PF, observed that patients found the use of ePAQ-PF helped them better understand and have further insight into their condition and its impact on their HRQOL in addition to giving them the confidence to disclose embarrassing personal issues [2]. Previous studies have also found that patients using electronic questionnaires feel more comfortable when reporting embarrassing or taboo problems with this approach than during a consultation with a healthcare professional [2, 9, 14]. The content analysis of the concerns in this study recorded included a large volume of personal detail including faecal incontinence, coital urinary incontinence and coital faecal incontinence. All these symptoms are also incorporated in the MCQ component of ePAQ-PF. The fact that these patients felt sufficiently enabled to record these intimate symptoms using their own words suggests that these symptoms are likely to be having a significant impact on their HRQOL and hence we are seeking to ensure these concerns are addressed during the consultation and subsequent treatment.

In this study, we undertook a deductive approach, hypothesising that there would be significantly higher domain scores in ePAQ-PF for patients reporting a free-text concern in the salient domain compared with those who did not, which was observed from the analysis. In questionnaire psychometrics, convergent validity refers to the degree to which two different measures of constructs that theoretically should be related are in fact related. This translates to the degree to which an instrument measures what it purports to measure [15] and is one component in establishing the overall construct validity of an instrument. The significant differences in domain scores between women recording free-text concerns in the salient domain compared with those who did not provide evidence of convergent validity for ePAQ-PF and fulfils the objective of the study. We found that women reporting free-text concerns for a specific domain had significantly higher domain scores than those who did not in 18 of the 19 ePAQ-PF domains. The only domain that was not statistically significant was *sex and bowel symptoms*. Only five women recorded a concern in this domain, and therefore the lack of statistical significance in this instance may have been due to the small sample size (type 2 error) with effect not being detected

Table 3 Examples of real concerns recorded by patients included in this study

REAL CONCERNS AND GOALS FROM PATIENTS INCLUDED IN THE STUDY

"*I would like to sleep without getting up 2–3 times each night*"

"*Being able to go out without having to know where the toilets are*"

"*The lump protruding out of my vagina and lack of sex and closeness with my husband. It is ruining my life*"

"*Urge incontinence*"

"*I have bowel leakage and splattering. I never know when I have finished opening my bowels. I never feel clean or empty properly. This is mentally disturbing and I feel dirty and ashamed, in fear*"

"*I have urine leakage when walking on uneven ground, urine leakage when lifting and carrying grandchildren, urine leakage when running and jumping and urine leakage when coughing and sneezing*"

"*I am not able to urinate later in the day. I feel that I am not emptying my bladder, then going two minutes later. My bladder prolapse interferes with wiping bottom. I feel ugly*"

"*My bladder is hanging down, I can't go far without needing the toilet. I am avoiding sex, due to anxiety about my problem. I get depressed about my problem, I don't want it to spoil our relationship*"

"*I am unable to stop leaking when laughing. I feel the need to be close to a toilet. I need to wear pads. I hate having to get up during the night*"

"*The prolapse dragging makes me feel just rubbish. I don't feel in the mood for intercourse and don't feel feminine. I have concerns about ulceration on my prolapse*"

"*I leak urine when walking, running and walking on concrete. I do not have sex with my husband, he denies me sex because of his mistress*"

because of the very small numbers of concerns recorded for these less common but intimate and taboo symptoms.

An important finding of this study was that 10% of concerns recorded related to body image issues, which are not currently assessed by ePAQ-PF. This supports previous research suggesting that many women who attend urogynaecology clinics have body image concerns [16, 17]. The analysis demonstrated that women were most concerned about smell, the

presence of scars and the appearance of their pelvic area, often using emotive language to describe and express these concerns.

'Body image' refers to the mental picture that an individual has of themselves, which depicts not only details available to objective investigation by others (e.g. height, weight, hair colour, etc.), but also details that have been learned about themselves, either from personal experiences or by internalising the judgments of others [18]. The term *genital self-image* has also been used to describe the mental picture that an individual has of his or her external genitalia [18]. This may include components such as appearance, smell, function and the perceptions of others (including partners and healthcare professionals).

Pelvic floor disorders including urinary incontinence and pelvic organ prolapse have been shown to have a negative impact on body image [16, 17]. A previous qualitative study of patients completing a quantitative urogynaecology PROM (King's Health Questionnaire) also found that women reported body image concerns during the qualitative analysis, which were not covered by the quantitative components of the questionnaire [6]. Currently, there is no specific instrument available that assesses body image exclusively in women with pelvic floor conditions. The definition of the female genitalia does not necessarily include the perineum, vagina and perianal region, which are often involved in pelvic floor conditions, including incontinence and pelvic organ prolapse. Therefore, a broader definition than *genital self-image* is required for the assessment of body image concerns experienced by women with pelvic floor disorders and we suggest that the term *pelvic body image* may be more appropriate. Whilst ePAQ-PF provides a comprehensive and robust assessment of a women's pelvic floor symptomatology, it does not specifically address related body image concerns. The authors propose further

Fig. 3 A word cloud showing the most frequently repeated words from the patient's concerns in this study; the larger the word, the more frequently it was repeated

work to develop items in a new domain within ePAQ-PF, evaluating related body image issues.

The content analysis of goals in this study demonstrated that fewer patients mentioned cure compared with improvement in symptoms as a personal goal (29 vs. 40%). This may suggest that patients do have realistic expectations about their treatment outcomes and the higher likelihood of *improvement* compared with outright *cure* of their condition. Previous studies have observed that the majority of women with urinary incontinence and overactive bladder do have realistic expectations regarding outcome and are willing to accept improvement and tolerate ongoing minor lower urinary tract symptoms [19]. Previous studies have also identified similar themes when assessing personal goals in semi-structured interviews. Srikrishna et al. (2009) identified goals around role limitation, physical activity, sexual function and less frequent use of incontinence pads [4]. Almost 10% of patient's goals recorded referred to sexual function, again confirming the impact that pelvic floor conditions have on sexual function and patient's desires for interventions to improve this.

The use of patient-orientated goals has been described as a more sensitive approach to counselling women, assessing outcome and identifying these goals via a PROM prior to initial consultation or discussions about investigation and intervention is a useful way to aid counselling and enhance shared decision making [20]. Structured questionnaires functioning as PROMS may lack the sensitivity to understand and individualise a patient's expectations regarding treatment if they do not include free-text components that aim to enhance self-expression. Providing an individualised summary report (Fig. 2) that headlines personal goals allows the consultation to focus on issues of the greatest concern to the patient and therefore is the most useful clinically. Electronic data capture via instruments such as ePAQ-PF might enable the development of personalised decision aids, using individual patient data, such as a symptom profile, along with personal circumstances, concerns and goals to model information relevant and meaningful to the individual. This is important as women affected by pelvic floor disorders, including urinary incontinence and pelvic organ prolapse, face challenging and complex decisions about their treatment.

The main limitations of this study are that not all patients completing ePAQ-PF provided a response to the free-text question. The length and quality of the free-text comments provided were also variable. Both issues are likely to be related to questionnaire fatigue, the time taken to complete the up to 132-item questionnaire. This may be exacerbated as the free-text item is positioned at the end of the instrument and this may have had an impact on data quality. Variation in literacy, patient engagement or a lack of significant ongoing concerns or goals may have also contributed to non-responses. It is also possible that presenting free-text items after the MCQ component of the questionnaire may have introduced recall

bias by prompting free-text responses related to the most recent MCQ items. For example, the reporting of sexual dysfunction may have been favoured as this dimension immediately precedes the personal data dimension containing free-text items.

In-depth semi-structured qualitative interviews would provide an alternative approach to eliciting information regarding concerns and goals, though face-to-face interview data may also prove unreliable, because of non-disclosure of sensitive issues; previous studies assessing both urinary incontinence and coital urinary incontinence have shown patients are significantly less likely to disclose sensitive symptoms to an interviewer compared with a questionnaire [1, 9].

Detailed demographic data for the 1996 women are also lacking, including parity and ethnicity, menopausal status, prolapse grade, urodynamic findings and other physical and mental health issues. The comparison of domain scores for those reporting free-text concerns for the stress urinary incontinence (SUI) and overactive bladder (OAB) domains of ePAQ-PF with salient domain scores for patients not reporting concerns potentially did not include a number of patients with SUI and OAB symptoms. This is because patients ($n = 451$) who reported urinary incontinence did not report specific symptoms of overactive bladder or stress urinary incontinence. The authors were therefore unable to categorise these as such, so the numbers of patients reporting a concern for the stress urinary incontinence and overactive bladder domains of ePAQ-PF may have been underestimated. Nonetheless the scores in these two domains were still significantly different for both symptom frequency and impact for those reporting SUI or OAB concerns.

Despite the limitations of this observational study, its strengths include a large sample size, subject to a systematic analysis. This is the first paper to publish an in-depth analysis of free-text data from an electronic questionnaire used in routine clinical practice.

Currently, including free-text data within ePAQ-PF is a helpful way to provide an individualised qualitative element that will help to improve the acuity of the PROM when it is used in clinical practice to facilitate discussion and aid shared decision making about treatment [9]. The patient's response to the open free-text question regarding concerns and goals in ePAQ-PF is automatically populated in the summary report and appears as headline information, showing the clinician clear individual qualitative information about what most concerns the patient and what their goals are regarding their condition. This helps to ensure that these concerns and goals can then be appropriately addressed during the consultation, as the report draws stark attention to them.

The main clinical implication of this study is that validated questionnaires used in clinical practice, including ePAQ-PF, can help to identify concerns and goals that relate to symptoms. Another clinical implication is that a significant

proportion of patients attending a urogynaecology clinic will have body image concerns that may need to be addressed and development and use of questionnaires to identify these issues and their impact in urogynaecology patients need to be considered.

Conclusions

The present study has found the free-text component of ePAQ-PF to be well utilised by patients and the concerns and goals recorded may be of value in guiding and focussing the subsequent consultation. Many of the concerns recorded related to intimate issues and helped to highlight the issues affecting patients HRQOL the most. The significant relationship between domain symptom frequency scores and domain impact scores with reporting of free-text concerns supports the convergent construct validity of the instrument. A significant proportion of concerns recorded by patients related to body image, which is not currently assessed by ePAQ-PF and is an area of further development and psychometric testing. An individualised electronic patient decision aid to address patient goals could also be of value and is worthy of further research.

Compliance with ethical standards

Conflicts of interest Mr. Stephen Radley is a director and shareholder of ePAQ Systems Limited, an NHS spin-out technology company (www.epaq.co.uk). The other authors declare they have no conflicts of interest. Mr. Radley did not collect or analyse the data for this study. The other authors have no financial or commercial interests in ePAQ Systems, Ltd.

References

1. Gray T, Li W, Campbell P, Jha S, Radley S. Evaluation of coital incontinence by electronic questionnaire: prevalence, associations and outcomes in women attending a urogynaecology clinic. Int Urogynecol J. 2017. https://doi.org/10.1007/s00192-017-3380-x.
2. Dua A, Jones G, Wood H, Sidhu H. Understanding women's experiences of electronic interviewing during the clinical episode in urogynaecology: a qualitative study. Int Urogynecol J. 2013;24(11):1969–75.
3. Radley SC, Jones GL. Measuring quality of life in urogynaecology. Br J Obstet Gynaecol. 2004;111(1):33–6.
4. Marshall S, Haywood K. Fitzpatrick R (2006) impact of patient reported outcome measures on routine practice: a structured review. J Eval Clin Pract. 2006;12:559–68.
5. NICE. Clinical guideline 171. Urinary incontinence in women: management. 2015.
6. Srikrishna S, Robinson D, Cardozo L. Qualifying a quantitative approach to women's expectations of continence surgery. Int Urogynecol J. 2009;20(7):859–65.
7. Radley SC, Jones GL, Tanguy EA, Stevens VG, Nelson C, Mathers NJ. Computer interviewing in urogynaecology: concept, development and psychometric testing of an electronic pelvic floor assessment questionnaire in primary and secondary care. BJOG. 2006;113:231–8.
8. Jones GL, Radley SC, Lumb J, Jha S. Electronic pelvic floor symptoms assessment: test of data quality of ePAQ-PF. Int Urogynecol J Pelvic Floor Dysfunct. 2008;19:1337–47.
9. Schüssler-Fiorenza Rose SM, Gangnon RE, Chewning B, Wald A. Increasing discussion rates of incontinence in primary care: a randomized controlled trial. J Women's Health. 2015;24(11):940–9.
10. Bryman A. Social research methodology. 3rd ed. Oxford: Oxford University Press; 2008.
11. Bulchandani S, Toozs-Hobson P, Parsons M, McCooty S, Perkins K, Latthe P. Effect of anticholinergics on the overactive bladder and bowel domain of the electronic personal assessment questionnaire (ePAQ). Int Urogynecol J. 2015;26(4):533–7.
12. Hilgart J, Phelps C, Bennett P, Hood K, Brain K, Murray A. "I have always believed I was at high risk…" the role of expectation in emotional responses to the receipt of an average, moderate or high cancer genetic risk assessment result: a thematic analysis of free-text questionnaire comments. Familial Cancer. 2010;9(3):469–77.
13. Pill R, Wood FC, Renold E, Robling M, Edwards A, Wilkinson C. Welsh women's comments about breast problems and the care given: a qualitative study in the community. Eur J Cancer Care. 2003;12(3):240–8.
14. Bachman JW. The patient-computer interview: a neglected tool that can aid the clinician. Mayo Clin Proceed. 2003;78:67–78.
15. Fayers PM, Machin D. Quality of life: the assessment, analysis and interpretation of patient-reported outcomes. 2nd ed. New York: Wiley; 2013.
16. Handelzalts JE, Yaakobi T, Levy S, Peled Y, Wiznitzer A, Krissi H. 2017. The impact of genital self-image on sexual function in women with pelvic floor disorders. Eur J Obstetri Gynecol Reprod Biol. 2017;211:164–8.
17. Iles D, Khan R, Naidoo K, Kearney R, Myers J, Reid F. The impact of anal sphincter injury on perceived body image. Eur J Obstetr Gynecol Reprod Biol. 2017;212:140–3.
18. Waltner R. Genital identity: a core component of sexual- and self-identity. J Sex Res. 1986;22:399–408.
19. Robinson D, Anders K, Cardozo L, Bidmead J, Dixon A, Balmforth J, et al. What do women want?: interpretation of the concept of cure. Female Pelvic Med Reconstruc Surg. 2003;9(6):273–7.
20. Elkadry EA, Kenton KS, FitzGerald MP, Shott S, Brubaker L. Patient-selected goals: a new perspective on surgical outcome. Am J Obstet Gynecol. 2003;189(6):1551–7.