National Institute for Health and Care Excellence

Draft for consultation

# Pelvic floor dysfunction: prevention and non-surgical management

## [G] Information provision related to the management of pelvic floor dysfunction (people’s views and experiences)

*NICE guideline number tbc*

*Evidence review underpinning recommendations 1.4.1 to 1.4.6 (except first bullet of 1.4.5) as well as 1.5.3 and 1.6.4 and a research recommendation in the NICE guideline*

*Evidence reviews*

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*These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists*

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# Contents

# Information provision related to the management of pelvic floor dysfunction (people's views and experiences)

## Review question

What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

## Introduction

Pelvic floor dysfunction (PFD) is a taboo topic amongst women. Women typically do not seek help for their symptoms and accept it as part of getting older. The objective of this review is to determine what information is considered valuable by women with pelvic floor dysfunction and their partners and/or their carers.

## Summary of the protocol

See Table 1 for a summary of the Population, Interest, Context, Outcome (PICO) characteristics of this review.

**Table 1: Summary of the protocol (PICO table)**

| | |
|---|---|
| **Population** | • Women and young women (aged 12 years and older) with symptoms associated with pelvic floor dysfunction<br>• Partners of women with symptoms associated with pelvic floor dysfunction<br>• Carers of women with symptoms associated with pelvic floor dysfunction<br>• Parents or carers of young women (under 18 years) with symptoms associated with pelvic floor dysfunction |
| **Phenomenon of interest** | Information which is considered valuable or helpful for women with symptoms associated with pelvic floor dysfunction, their partners and/or their carers. This information should be specific to women with symptoms associated with pelvic floor dysfunction. For example information regarding their symptoms or managing their symptoms. |
| **Context** | Included studies will be relevant for developing and improving information provided to women with symptoms associated with pelvic floor dysfunction within a health care setting. |
| **Outcome** | **Themes identified from the included literature. Themes considered potentially relevant by the committee included:**<br>• Managing symptoms over time and in the day to day<br>• Empowering self-management<br>• PFD in relation to pregnancy<br>• Accessing information<br>• Having information that is understandable/accessible/adaptable to their own situation<br>• Understanding and explaining prognosis, and the anatomy of the pelvic floor (PF)<br>• Understanding treatment options<br>• Understanding what the symptoms of PFD are<br>• Incidence of PFD, information about how "normal" their situation is and how common are their symptoms |

| | |
|---|---|
| | • Support networks (including web support, support groups, being told what support is out there/if any)<br>The identified themes may not be found in the literature, and additional themes not listed may be identified. |

*PF: pelvic floor; PFD: pelvic floor dysfunction*

For further details, see the review protocol in appendix A.

## Methods and process

This evidence review was developed using the methods and process described in Developing NICE guidelines: the manual. Methods specific to this review question are described in the review protocol in appendix A and the methods document (supplementary document 1).

Declarations of interest were recorded according to NICE's conflicts of interest policy.

## Clinical evidence

### Included studies

Fifteen qualitative studies were included for this review: Andersson 2009, Bjork 2014, Buurman 2013, Cichowski 2014, Dunivan 2014, Kiyosaki 2012, Pakbaz 2011, Pintos-Dias 2019, Rasmussen 2010, Sevilla 2013, Siddiqui 2016, Smith 2011, Smith 2019, van den Muijsenbergh 2006 & Weislander 2015.

Five studies included women with urinary incontinence (UI), including 1 study of stress urinary incontinence only (SUI; Bjork 2014), 1 study with stress, urgency or mixed urinary incontinence (SUI, UUI, MUI; Pintos-Dias 2019) and 3 studies with unspecified UI (Andersson 2009, Siddiqui 2016, van den Muijsenbergh 2006). Three studies included women with pelvic organ prolapse (POP; Dunivan 2014, Pakbaz 2011, Wieslander 2015), 2 studies included women with faecal incontinence (Cichowski 2014, Rasmussen 2010) and 1 study included women with overactive bladder (OAB; Smith 2011). Four studies included a mixed population, with 2 studies including UI or POP (Kiyosaki 2012, Sevilla 2013), 1 study including UI or UI and FI (Smith 2019) and 1 study including varying pelvic floor problems (Buurman 2013).

Seven studies were conducted in the USA (Cichowski 2014, Dunivan 2014, Kiyosaki 2012, Sevilla 2013, Siddiqui 2016, Smith 2011 and Wieslander 2015), 3 in Sweden (Andersson 2009, Bjork 2014 and Pakbaz 2011), 2 in The Netherlands (Buurman 2013 and Van den Muijenbergh 2006) and 1 each in Denmark (Rasmussen 2010), Canada (Smith 2019) and Spain (Pintos-Diaz 2019)

The included studies are summarised in Table 2.

See the literature search strategy in appendix B and study selection flow chart in appendix C.

### Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix K.

## Summary of studies included in the evidence review

Summaries of the studies that were included in this review are presented in Table 2.

1 **Table 2: Summary of included studies.**

| Study | Population | Methods | Themes applied after thematic analysis |
|---|---|---|---|
| Andersson 2009<br>Qualitative study<br>Sweden | N=14 Syrian women living in Sweden who had either experienced UI themselves, or who had helped relatives with UI.<br>Age (range): 30-80+ years | **Setting:** Not reported<br>**Data collection:** Three focus group discussions of 4-6 women | • Accessibility of information – language<br>• Accessibility of information – difficulties with access<br>• Style of communication<br>• Support networks<br>• Lack of information or knowledge |
| Bjork 2014<br>Qualitative study<br>Sweden | N=21 women aged 18 to 70 who had SUI at least once weekly<br>Age (mean, range): 47.6, 30-69 years | **Setting:** Over the telephone<br>**Data collection:** Telephone interviews | • Accessibility of information – difficulties with access |
| Buurman 2013<br>Qualitative study<br>The Netherlands | N= 26 postpartum women with varying pelvic floor problems, including pain, sexual problems, UI, haemorrhoids, other micturition problems, prolapse, defecation problems, vaginal flatulence and anal flatulence<br>Age (n), years:<br>• 20-24: 3<br>• 25-29: 6<br>• 30-35: 10<br>• 36-40: 7 | **Setting:** Not reported<br>**Data collection:** face-to-face interviews | • Style of communication<br>• Sources of information<br>• Support networks<br>• Lack of information or knowledge<br>• Prevalence<br>• Pelvic floor disorders in relation to pregnancy<br>• Information provides relief |
| Cichowski 2014<br>Qualitative study<br>USA | N=11 women diagnosed with FI, with symptoms for at least 3 months<br>Age (mean): 56 years | **Setting:** Not reported<br>**Data collection:** Two focus groups of 5-6 women | • Style of communication |
| Dunivan 2014<br>Qualitative study<br>USA | N=58 women with a diagnosis of POP who spoke either Spanish or English<br>Age (mean, range): | **Setting:** Three separate academic urology and urogynaecology centres | • Accessibility of information – language<br>• Support networks<br>• Lack of information or knowledge<br>• Prevalence |

| Study | Population | Methods | Themes applied after thematic analysis |
|---|---|---|---|
| | • English speaking women 63.8 (33-90) years<br>• Spanish speaking women 56.6 (46-77) years | **Data collection:** Eight focus group of 6-8 women (4 in English, 4 in Spanish) | • Information provides relief |
| Kiyosaki 2012<br>Qualitative study<br>USA | N=20 women with pelvic floor disorders (UI or POP)<br>Age (mean, range): 60.5 (31-87) years | **Setting:** Clinical<br>**Data collection:** Interviews before and after a physician visit | • Lack of information or knowledge<br>• Information provides relief |
| Pakbaz 2011<br>Qualitative study<br>Sweden | N=14 women with symptomatic POP<br>Age (median, range): 56.5 (42-79) years | **Setting:** Hospital (n=13) or the participants' home (n=1)<br>**Data collection:** In-depth semi-structured interviews | • Style of communication<br>• Sources of information<br>• Accessibility of information – difficulties with access<br>• Pelvic floor disorders in the media<br>• Lack of information or knowledge<br>• Prevalence |
| Pintos-Diaz 2019<br>Qualitative study<br>Spain | N=18 women attending a specialised UI centre for UI (SUI, UUI or MUI)<br>Age (mean, range): 47.32 (23-58) years | **Setting:** A private room at the UI centre<br>**Data collection:** In-depth interviews and participants' letters | • Accessibility of information – difficulties with access<br>• Prevalence |
| Rasmussen 2010<br>Qualitative study<br>Denmark | N=9 women with FI caused by anal sphincter<br>rupture due to a childbirth and lasting for at least 6 months<br>Age (median, range): 35 (28-50) years | **Setting:** Interviewer's office (n=2) or the participants' home (n=7)<br>**Data collection:** Informal, conversational individual interviews | • Style of communication<br>• Accessibility of information – difficulties with access |
| Sevilla 2013<br>Qualitative study<br>USA | N=27 Spanish speaking women with a chief complaint suggestive of POP or any type of UI | **Setting:** Not reported<br>**Data collection:** short interviews before and | • Accessibility of information – language<br>• Sources of information<br>• Lack of information or knowledge |

| Study | Population | Methods | Themes applied after thematic analysis |
|---|---|---|---|
| | Age (mean, range): 55.5 (41-71) years | after an encounter with the physician | |
| Siddiqui 2016<br>Qualitative study<br>USA | N=113 White, Black or Latina women with frequent UI (UI daily or weekly)<br>Age (mean, SD):<br>• White women 48.1 (16.9)<br>• Black women 47.12 (9.9)<br>• Latina women 38.4 (14.4) | **Setting:** Not reported<br>**Data collection:** Twelve focus groups | • Style of communication<br>• Sources of information<br>• Accessibility of information – difficulties with access<br>• Support networks<br>• Pelvic floor disorders in the media<br>• Lack of information or knowledge<br>• Prevalence |
| Smith 2011<br>Qualitative study<br>USA | N=33 women with a confirmed diagnosis of OAB<br>Age (mean, range): 67 (39-91 years) | **Setting:** Not reported<br>**Data collection:** Five focus groups | • Sources of information<br>• Support networks<br>• Lack of information or knowledge |
| Smith 2019<br>Qualitative study<br>Canada | N=9 women who used some form of absorbent product to manage UI or dual UI and FI<br>Age (mean, range): 70 (55-84) years | **Setting:** A private room in participating clinics, at the research team's university office, or by telephone<br>**Data collection:** Semi-structured interviews | • Style of communication<br>• Sources of information<br>• Accessibility of information – difficulties with access |
| Van den Muijenbergh 2006<br>Qualitative study<br>The Netherlands | N=30 Moroccan and Turkish migrant women with UI<br>Age (mean, SD): 45 (9) years | **Setting:** The patient's home or at their doctor's surgery<br>**Data collection:** Semi-structured in-depth interviews | • Style of communication |
| Wieslander 2015<br>Qualitative study<br>USA | N=58 women with symptomatic POP<br>Age (mean, range):<br>• English speaking women 63.8 (33-90) years<br>• Spanish speaking | **Setting:** Four separate medical centres<br>**Data collection:** Eight focus groups of 8 women | • Accessibility of information – language<br>• Accessibility of information – difficulties with access<br>• Sources of information<br>• Lack of information or knowledge |

| Study | Population | Methods | Themes applied after thematic analysis |
|---|---|---|---|
| | women 56.6 (46-77) years | | - Information provides relief |

*FI: faecal incontinence; MUI: mixed urinary incontinence; OAB: overactive bladder; POP: pelvic organ prolapse; SD: Standard deviation; UUI: urge urinary incontinence; UI: urinary incontinence; SUI: stress urinary incontinence*

See the full evidence tables in appendix D and thematic map in appendix M. No meta-analysis was conducted (and so there are no forest plots in appendix E).

## Quality assessment of studies included in the evidence review

See the evidence profiles in appendix F.

## Economic evidence

### Included studies

A single economic search was undertaken for all topics included in the scope of this guideline but no economic studies were identified which were applicable to this review question. See the literature search strategy in appendix B and economic study selection flow chart in appendix G.

### Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix K.

## Economic model

No economic modelling was undertaken for this qualitative review because there would be no comparative effectiveness data to assess the relative efficiency of competing courses of action.

## Brief summary of the evidence

A summary of the strength of evidence (overall confidence), assessed using GRADE-CERQual (see Appendix F), and quality of the evidence (overall methodological concerns), assessed using the critical appraisal skills programme (CASP) checklist for qualitative studies, is presented according to the main themes:

- Accessibility of information – language. Methodological concerns ranged between minor and major for the sub-themes, and the overall confidence in the sub-themes was low. The sub themes included:
  - Language barriers
  - Medical terminology
  - Use of aids (for example anatomy models)
- Accessibility of information – difficulties with access. Methodological concerns ranged between moderate and major for the sub-themes, and the overall confidence in the sub-themes was low to moderate. The sub themes included:
  - Not being able to access doctors
  - Not being able to ask questions
  - Not being taken seriously

  - Not knowing when or where to seek help
  - Perception that doctors are embarrassed to talk about pelvic floor disorders
- Style of communication. Methodological concerns ranged between moderate and major for the sub-themes, and the overall confidence in the sub-themes was low to moderate. The sub themes included:
  - Characteristics of the healthcare professional
  - Desire for direct communication
  - Preferred format of information
  - Wanting positive messages
- Sources of information. Methodological concerns ranged between moderate and major for the sub-themes, and the overall confidence in the sub-themes was low to moderate. The sub themes included:
  - Sources of information are varying
  - Women have differing levels of trust in the different sources
  - Information from the internet can be overwhelming
- Support networks. Methodological concerns ranged between moderate and major for the sub-themes, and the overall confidence in the sub-themes was low to moderate. The sub themes included:
  - Need for more support groups
  - Support networks enable women to not feel alone
  - Support networks as a source of information
- Pelvic floor disorders in the media. Methodological concerns ranged between minor and moderate for the sub-themes, and the overall confidence in the sub-themes was moderate. The sub themes included:
  - Pelvic floor disorders are not prominent in the media
  - Desire for more media visibility
- Lack of information or knowledge. Methodological concerns ranged between moderate and major for the sub-themes, and the overall confidence in the sub-themes was low to moderate. The sub themes included:
  - Information needs are not being met
  - Women demonstrated a lack of understanding of their symptoms
  - Women demonstrated a lack of understanding of their diagnosis
  - Women demonstrated a lack of understanding of the treatment options
  - Women demonstrated a lack of understanding of the causes of their PFD
  - Women demonstrated a lack of understanding of diagnostic tests
- Prevalence. Methodological concerns were moderate for the sub-themes, and the overall confidence in the sub-themes was moderate. The sub themes included:
  - Embarrassment inhibits help-seeking and information seeking
  - Women want to know if their symptoms are normal
- Pelvic floor disorders in relation to pregnancy. Methodological concerns were moderate for the sub-themes, and the overall confidence in the sub-themes was low. The sub themes included:
  - Pelvic floor disorders were viewed as normal
  - Pelvic floor disorders were not a priority
- Information provides relief. Methodological concerns were major for the sub-themes, and the overall confidence in the sub-themes was low. The sub themes included:
  - Information about the symptoms/diagnosis and treatment provides women with relief

  - Information provides women with relief that they are not alone or abnormal

## The committee's discussion of the evidence

### Interpreting the evidence

#### *The outcomes that matter most*

The committee agreed that the views of women with pelvic floor dysfunction and their partners and/or their carers should be considered to capture a broad range of perspectives.

#### *The quality of the evidence*

The quality of the evidence was assessed using GRADE CERqual and overall confidence in the review findings ranged from very low to moderate with the majority of the findings having low confidence.

- Concerns about the methodological limitations of the primary studies were assessed with the CASP checklist and ranged from "major" to "minor". The most common issues were: lack of consideration of the relationship between researcher and participants, no consideration of the role of the researcher on the research and analysis process, limited detail provided on data analysis, no discussion of ethical issues such as informed consent issues and confidentiality, no justification for the data collection methods and setting, and limited, or an absence of discussion of the contribution to the literature.
- Concerns about coherence ranged from "minor" to "no or very minor". For the majority of review findings concerns were no or very minor, as there was no data that contradicted the findings nor was there ambiguous data. A small number of review findings demonstrated minor concerns due to ambiguous or contradictory evidence without explanation for differences.
- Concerns about relevance ranged from "minor" to "no or very minor". For some of the review findings concerns were no or very minor, although the findings were not directly about the specific information valued by women with pelvic floor disorders. However, they were considered important as they had implications for the type of information that women may value.
- Concerns about adequacy ranged from "minor" to "no or very minor". There were minor concerns for review findings when some of the evidence was based on a small number of studies and participants. There were also some concerns regarding thin data, however it was noted that as most themes were not complex, so thin data may be adequate in most cases. All other review findings were based on moderately rich data and minor concerns were for review findings based on evidence from a small number of studies or participants. The number of studies used for each review finding ranged from 1 to 5.

#### *Benefits and harms*

Qualitative evidence from the style of communication and accessibility of information themes showed that women with pelvic floor dysfunction perceived some communication styles as unhelpful. Evidence from the lack of information or knowledge theme also indicated that some women are not given enough information to understand their symptoms, diagnosis, investigations or treatment. The quality of the evidence was mixed, due to concerns about methodological limitations in the design of the studies. The committee also made recommendations based on their own experience, in areas where there was no evidence (such as video and telephone consultations).

Low to moderate quality evidence from the style of communication theme and the information provides relief theme showed that women valued information provided during a face-to-face appointment. In addition, evidence from the prevalence theme indicated that due to the nature of pelvic floor dysfunction it can be perceived as embarrassing. However, the committee acknowledged the shift towards the provision of care virtually during the Covid-19 pandemic and discussed that in their experience this has been well received by some women. Particularly as it can remove the element of embarrassment and reluctance from both patients and clinicians to discuss pelvic floor dysfunction symptoms. Therefore, recommendations to establish the most effective mode of communication (including virtual consultations) were made based on both the evidence and committee consensus.

Pelvic floor dysfunction is a complex condition, with particular communication issues (such as embarrassment). Moderate quality evidence from the accessibility of information – difficulties with access theme showed also that women believed that healthcare professionals feel embarrassed about talking about symptoms and body parts related to pelvic floor dysfunction and the committee decided to raise awareness of this. Some of this embarrassment was also related around not knowing the right terminology and the theme of accessibility of information – language provided evidence that women felt that the language that healthcare professionals use could be a barrier, particularly terminology used to describe symptoms and anatomical terminology. The committee therefore recommended that healthcare professionals tailor their language to the knowledge and preference of each woman.

The committee, based on experience, noted that women with cognitive impairments may find it difficult to follow a treatment plan and therefore recommended to ask the woman if they want their family and carers or other people involved (where appropriate) so that they can help them following the instructions in their management plan.

The qualitative evidence, particularly the theme lack of information or knowledge, consistently showed that women often lacked understanding of their symptoms, diagnosis, investigations and treatment. The committee discussed how pelvic floor dysfunction is a complex condition, therefore when relaying information to patients it is important that it is in a style and manner that the patient can understand. Based on the evidence and on their experience, the committee highlighted key issues to cover when discussing pelvic floor dysfunction with women. These key issues should cover a description of the pelvic anatomy as well as topics that cover the whole pathway of care ranging from potential causes management options and possible risk factors.

The committee also noted that the type of information that is relevant would vary by age and circumstances and that the healthcare professional has to be sensitive to these different information needs and tailor the content and the communication style to each individual woman.

Evidence of moderate quality from the prevalence theme and low quality evidence from the PFD and pregnancy theme suggested that in pregnancy and in the postnatal period, symptoms of pelvic floor dysfunction may be overlooked by women or they may be embarrassed to mention symptoms. The committee discussed how new symptoms of pelvic floor dysfunction are a risk factor for the development of pelvic floor dysfunction later in life, taking into account the relevant section of this guideline (see evidence report B risk factors for pelvic floor dysfunction). Therefore, they agreed that it is important women should routinely be asked about the symptoms of pelvic floor dysfunction in the postnatal period.

There was moderate quality evidence from the style of communication theme showing that women prefer to receive encouraging information, with less focus on negative messages The committee was conscious that for long-term benefit of non-surgical interventions for pelvic floor dysfunction like pelvic floor muscle training (PFMT), patient motivation is key. Therefore, it is important that information is provided in a positive manner.

The committee were conscious that the available evidence did not address information valued by young women (aged 12 or over) or those with protected characteristics such a physical or learning disabilities. Therefore, a research recommendation was made to inform future guidance.

Several themes did not result in any recommendations, including support networks, PFD in the media and sources of information. This was because they covered areas that were already addressed by recommendations from other evidence reports (for example evidence report A: community information strategies).

### *Cost effectiveness and resource use*

This was a qualitative review and the recommendations that came out of it were largely about information content and presentation of that information. Therefore, there is a negligible resource impact from these recommendations. The committee thought the recommendations would generally further cost-effective care by promoting a better understanding of symptoms to women with pelvic floor dysfunction. Whilst there may be resource consequences from the recommendations about communication format this in practice is likely to represent greater opportunity for remote formats than has traditionally been the case and the committee thought this would normally be cost saving and would be preferred by the women who agreed to non-face-to-face communication.

### *Other factors the committee took into account*

The evidence showed that there can be barriers to certain groups of people understanding information; such as those with physical or learning disabilities or those with difficulties understanding or speaking English. Therefore, the committee acknowledged that clinicians should refer to the NICE guideline on Patient experience in adult NHS services: improving the experience of care for people using adult NHS for advice on how to tailor information to each woman.

## Recommendations supported by this evidence review

This evidence review supports recommendations 1.4.1 to 1.4.6 (except first bullet of 1.4.5) as well as 1.5.3 and 1.6.4 and a research recommendation on the experiences and information needs of children and young women (between 12 and 17 years) in the NICE guideline.

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# Appendices

## Appendix A – Review protocol

### Review protocol for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

**Table 3: Review protocol**

| ID | Field | Content |
|---|---|---|
| 0. | PROSPERO registration number | CRD42020164467 |
| 1. | Review title | Information that is valued by women |
| 2. | Review question | What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers? |
| 3. | Objective | The objective of this review is to determine what information is considered valuable by women with pelvic floor dysfunction and their partners and/or their carers.<br>This is a qualitative review, and will be considered alongside review question: "What information provision strategies are effective for women with symptoms associated with pelvic floor dysfunction?" A quantitative review; however, we will not combine the data from the reviews; therefore, no meta-synthesis will be carried out on the two reviews together. |
| 4. | Searches | The following databases will be searched:<br>• Cochrane Database of Systematic Reviews (CDSR)<br>• Cochrane Central Register of Controlled Trials (CENTRAL)<br>• MEDLINE & Medline in Process<br>• Embase<br>• CINAHL or Emcare<br>• PsycINFO<br><br>Searches will be restricted by:<br>• Date limit: 1980 onwards (see section 10 for justification)<br>• English language<br>• Human studies<br><br>Other searches: |

| ID | Field | Content |
|---|---|---|
| | | Inclusion lists of potentially relevant systematic reviews<br>The full search strategies for MEDLINE database will be published in the final review.<br>For each search, the principal database search strategy is quality assured by a second information scientist using an adaptation of the PRESS 2015 Guideline Evidence-Based Checklist. |
| 5. | Condition or domain being studied | The following symptoms will be addressed as long as they are associated with pelvic floor dysfunction: urinary incontinence, emptying disorders of the bladder, faecal incontinence, emptying disorders of the bowel, pelvic organ prolapse, sexual dysfunction and chronic pelvic pain syndromes. |
| 6. | Population | Inclusion<br>• Women and young women (aged 12 years and older) with symptoms associated with pelvic floor dysfunction<br>• Partners of women with symptoms associated with pelvic floor dysfunction<br>• Carers of women with symptoms associated with pelvic floor dysfunction<br>• Parents or carers of young women (under 18 years) with symptoms associated with pelvic floor dysfunction<br>Exclusion<br>• Studies which include women, with urinary incontinence, emptying disorders of the bladder, faecal incontinence, emptying disorders of the bowel, pelvic organ prolapse, sexual dysfunction and chronic pelvic pain syndromes which are not due to pelvic floor dysfunction will be excluded. For example, women who have urinary incontinence due to a neurological condition or pelvic cancer will be excluded. During the screening stage, the reported inclusion/exclusion criteria of studies will be examined carefully. We do not anticipate studies on urinary incontinence, emptying disorders of the bladder or pelvic organ prolapse will explicitly state "*associated with pelvic floor dysfunction*" therefore this will be a pragmatic decision based on the description of the condition provided by the study authors. Some of these symptoms (for example urinary incontinence) are most often due to a failure in the pelvic floor and therefore unless the exclusion criteria states a different cause, these studies are likely to be included. However, for studies on faecal incontinence, emptying disorders of the bowel, sexual dysfunction and pelvic pain the causes are more numerous. As such for these symptoms unless the study specifically states "*associated with pelvic floor dysfunction"* they will be excluded. If any ambiguity exists, at least two reviewers will make the final decision if to include or exclude the study.<br>• Men<br>• Babies and children |
| 7. | Intervention/Exposure/Test | Information which is considered valuable or helpful for women with symptoms associated with pelvic floor dysfunction, their partners and/or their carers. This information should be specific to women with symptoms associated with pelvic floor dysfunction. For example information regarding their symptoms or managing their symptoms. |
| 8. | Comparator/Reference standard/Confounding factors | Not applicable |
| 9. | Types of study to be included | • Systematic reviews of qualitative studies<br>• Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations<br>• Surveys conducted using open ended questions and a qualitative analysis of response |

| ID | Field | Content |
|---|---|---|
| | | Note: Mixed methods studies will be included but only qualitative data will be extracted and risk of bias assessed. |
| 10. | Other exclusion criteria | • Studies with a mixed population (for example women with symptoms such as urinary incontinence which are associated with pelvic floor dysfunction and women with symptoms that are not associated with pelvic floor dysfunction) will be excluded, unless subgroup analysis for those women with symptoms associated with pelvic floor dysfunction has been reported<br>• Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias<br>• Studies which explore the views and experiences of healthcare professionals and service managers<br>• We will exclude information which is generic to all women within healthcare, for example accessibility of care. For this type of information we would refer to the NICE guideline: Patient experience in adult NHS services: improving experience of care for people using adult NHS services [CG138]: https://www.nice.org.uk/Guidance/CG138<br>• Only articles published after 1980 will be included. This was agreed by the committee as this is the date that the condition “pelvic floor dysfunction” was recognised to include agreed terminology on symptoms. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2815805/ |
| 11. | Context | Included studies will be relevant for developing and improving information provided to women with symptoms associated with pelvic floor dysfunction within a health care setting.<br>Although relevant to the health care setting, they may be relevant on a wider context, providing information that is valued once women are in the home environment, in the community and living with pelvic floor dysfunction. |
| 12. | Primary outcomes (critical outcomes) | Themes identified from the included literature. Themes considered potentially relevant by the committee include:<br>• Managing symptoms over time and in the day to day<br>• Empowering self-management<br>• PFD in relation to pregnancy<br>• Accessing information<br>• Having information that is understandable/accessible/adaptable to their own situation<br>• Understanding and explaining prognosis, and the anatomy of the PF<br>• Understanding treatment options<br>• Understanding what the symptoms of PFD are<br>• Incidence of PFD, information about how “normal” their situation is and how common are their symptoms<br>• Support networks (including web support, support groups, being told what support is out there/if any)<br>The identified themes may not be found in the literature, and additional themes not listed may be identified. |

| ID | Field | Content |
|---|---|---|
| 13. | Secondary outcomes (important outcomes) | Not applicable |
| 14. | Data extraction (selection and coding) | All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated.<br>Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. Dual sifting will not be conducted for this review question.<br>Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion.<br>A standardised form will be used to extract data from studies. One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer. Information to be extracted from studies includes: study type, study dates, location of study, funding, inclusion and exclusion criteria, participant characteristics, and details of the themes within each study. |
| 15. | Risk of bias (quality) assessment | Risk of bias of individual studies will be performed using the following checklists:<br>• CASP (Critical Skills Appraisal Programme) Qualitative checklist.<br>• Risk of bias of systematic reviews of Qualitative studies will be assessed using the CASP Systematic Review checklist.<br>The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer. |
| 16. | Strategy for data synthesis | Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. A theme map will be developed from the extracted study themes.<br>The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesized from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance.<br>• Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate.<br>• Coherence of findings will be assessed by examining the clarity of the data.<br>• Adequacy of data will be assessed by looking at the degree of richness and quantity of findings.<br>• Relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question with respect to the characteristics of the study population, setting, place and time, healthcare system, intervention, and broader social, policy, or political issues. |
| 17. | Analysis of sub-groups | All data will initially be pooled for overall analysis; however, if data is available, separate analysis will also be conducted on:<br>• Women who are pregnant<br>• Women before and after gynaecological surgery<br>• Women aged 65 or older<br>• Young women (aged 12 to 18) |

| ID | Field | Content | | |
|---|---|---|---|---|
| | | • Women with physical disabilities<br>• Women with cognitive impairment<br>• According to those who do not identify themselves as women, but who have female pelvic organs<br>*Recommendations will apply to all those with pelvic floor dysfunction unless there is evidence of a difference in these stratified groups* | | |
| 18. | Type and method of review | ☐ | Intervention | |
| | | ☐ | Diagnostic | |
| | | ☐ | Prognostic | |
| | | ☒ | Qualitative | |
| | | ☐ | Epidemiologic | |
| | | ☐ | Service Delivery | |
| | | ☐ | Other (please specify) | |
| 19. | Language | English | | |
| 20. | Country | England | | |
| 21. | Anticipated or actual start date | September 2020 | | |
| 22. | Anticipated completion date | August 2021 | | |
| 23. | Stage of review at time of this submission | **Review stage** | **Started** | **Completed** |
| | | Preliminary searches | ☒ | ☐ |
| | | Piloting of the study selection process | ☐ | ☐ |
| | | Formal screening of search results against eligibility criteria | ☐ | ☐ |
| | | Data extraction | ☐ | ☐ |
| | | Risk of bias (quality) assessment | ☐ | ☐ |
| | | Data analysis | ☐ | ☐ |
| 24. | Named contact | **5a. Named contact**<br>National Guideline Alliance | | |

<table>
<tr><th>ID</th><th>Field</th><th colspan="2">Content</th></tr>
<tr><td></td><td></td><td colspan="2">**5b. Named contact e-mail**<br>PreventionofPOP@nice.org.uk<br>**5e. Organisational affiliation of the review**<br>National Institute for Health and Care Excellence (NICE) and National Guideline Alliance</td></tr>
<tr><td>25.</td><td>Review team members</td><td colspan="2">NGA Technical Team</td></tr>
<tr><td>26.</td><td>Funding sources/sponsor</td><td colspan="2">This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.</td></tr>
<tr><td>27.</td><td>Conflicts of interest</td><td colspan="2">All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.</td></tr>
<tr><td>28.</td><td>Collaborators</td><td colspan="2">Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual.<br>Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10123/</td></tr>
<tr><td>29.</td><td>Other registration details</td><td colspan="2"></td></tr>
<tr><td>30.</td><td>Reference/URL for published protocol</td><td colspan="2">https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=164467</td></tr>
<tr><td>31.</td><td>Dissemination plans</td><td colspan="2">NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as:<br>notifying registered stakeholders of publication<br>publicising the guideline through NICE's newsletter and alerts<br>issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.</td></tr>
<tr><td>32.</td><td>Keywords</td><td colspan="2">Information, pelvic floor dysfunction,</td></tr>
<tr><td>33.</td><td>Details of existing review of same topic by same authors</td><td colspan="2">Not applicable</td></tr>
<tr><td rowspan="3">34.</td><td rowspan="3">Current review status</td><td>☒</td><td>Ongoing</td></tr>
<tr><td>☐</td><td>Completed but not published</td></tr>
<tr><td>☐</td><td>Completed and published</td></tr>
</table>

| ID | Field | Content | |
|---|---|---|---|
| | | ☐ | Completed, published and being updated |
| | | ☐ | Discontinued |
| 35.. | Additional information | | |
| 36. | Details of final publication | [www.nice.org.uk](http://www.nice.org.uk) | |

*CASP: Critical Skills Appraisal Programme; CDSR: Cochrane Database of Systematic Reviews; CERQual: Confidence in the Evidence from Reviews of Qualitative research; CENTRAL: Cochrane Central Register of Controlled Trials; DARE: Database of Abstracts of Reviews of Effects; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; MID: minimally important difference; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence; PF: pelvic floor; PFD; pelvic floor dysfunction; RCT: randomised controlled trial; RoB: risk of bias; SD: standard deviation*

# Appendix B – Literature search strategies

## Literature search strategies for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers? (Qualitative)

### Clinical Search

**Database(s): Medline & Embase (Multifile) – OVID interface**
**Embase Classic+Embase** 1947 to 2020 June 26; **Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily** 1946 to June 26, 2020
Date of last search: 29 June 2020

*Multifile database codes: emczd = Embase Classic+Embase; ppez= MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily*

| # | Searches |
|---|---|
| 1 | Pelvic Floor/ or Pelvic Floor Disorders/ or exp *Urinary Incontinence/ or *Urinary Bladder, Overactive/ or exp *Pelvic Organ Prolapse/ or *Rectocele/ or *Fecal Incontinence/ or Urinary Retention/ or Fecal Impaction/ or Vaginismus/ |
| 2 | 1 use ppez |
| 3 | pelvis floor/ or pelvic floor disorder/ or exp *urine incontinence/ or *overactive bladder/ or *bladder instability/ or exp *pelvic organ prolapse/ or *rectocele/ or *feces incontinence/ or urine retention/ or defecation disorder/ or Feces Impaction/ or female sexual dysfunction/ or vaginism/ |
| 4 | 3 use emczd |
| 5 | (pelvi$ adj (floor$ or diaphragm$) adj3 (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or change$ or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 6 | (pelvi$ adj (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 7 | ((stress$ or mix$ or urg$ or urin$) adj5 incontinen$).ti. |
| 8 | (bladder$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$ or incontinen$)).ti. |
| 9 | (detrusor$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$)).ti. |
| 10 | ((urgency adj2 frequency) or (frequency adj2 urgency)).ti. |
| 11 | ((urin$ or bladder$) adj2 (urg$ or frequen$)).ti. |
| 12 | (SUI or OAB).ti. |
| 13 | (pelvic$ adj3 organ$ adj3 prolaps$).ti. |
| 14 | (urinary adj3 bladder adj3 prolaps$).ti. |
| 15 | ((vagin$ or urogenital$ or genit$ or uter$ or viscer$ or anterior$ or posterior$ or apical or pelvi$ or vault$ or urethr$ or bladder$ or cervi$ or rectal or rectum) adj3 prolaps$).ti. |
| 16 | (splanchnoptos$ or visceroptos$).ti. |
| 17 | (hernia$ adj3 (pelvi$ or vagin$ or urogenital$ or uter$ or bladder$ or urethr$ or viscer$)).ti. |
| 18 | (urethroc?ele$ or enteroc?ele$ or sigmoidoc?ele$ or proctoc?ele$ or rectoc?ele$ or cystoc?ele$ or rectoenteroc?ele$ or cystourethroc?ele$).ti. |
| 19 | ((faecal or fecal or faeces or feces or fecally or faecally or anal or anally or stool or stools or bowel or double or defecat$ or defaecat$) adj5 (incontinence or incontinent or urge$ or leak or leaking or leakage or soiling or seeping or seepage or impacted or impaction)).ti. |
| 20 | (urin$ adj3 (retention$ or retain$)).tw. |
| 21 | (voiding adj (disorder$ or dysfunction$ or problem$)).tw. |
| 22 | (empty$ adj disorder$ adj3 (bowel$ or bladder$ or vesical$ or stool$)).tw. |
| 23 | ((urogeni$ or anorec$ or ano-rec$ or ano rec$) adj3 dysfunction$).tw. |
| 24 | ((difficult$ or delay$ or irregular$ or infrequen$ or pain$) adj3 (defecat$ or defaecat$ or stool$ or faeces or feces or bowel movement$)).tw. |
| 25 | (obstruct$ adj3 (defecat$ or defaecat$)).tw. |
| 26 | ((defecat$ or defaecat$ or evacuat$) adj3 (disorder$ or dysfunction$)).tw. |
| 27 | outlet$ dysfunction$ constipa$.tw. |
| 28 | (dys?ynerg$ adj (defecat$ or defaecat$)).tw. |
| 29 | (pelvi$ adj3 dyskines$).tw. |
| 30 | pelvi$ outlet$ obstruct$.tw. |
| 31 | anismus$.tw. |
| 32 | puborectal$ contract$.tw. |
| 33 | ((rectal or rectum) adj3 urge$).tw. |
| 34 | (female adj sex$ adj (dysfunct$ or satisf$ or problem$ or symptom$ or arous$ or activit$ or disorder$)).tw. |
| 35 | (obstruct$ adj3 intercourse).tw. |
| 36 | (vagin$ adj3 laxity$).tw. |

| # | Searches |
|---|---|
| 37 | (vagin$ adj wind).tw. |
| 38 | vaginismus$.tw. |
| 39 | (vagin$ adj penetrat$ adj disorder$).tw. |
| 40 | or/2,4-39 |
| 41 | Choice Behavior/ use ppez |
| 42 | Decision Making/ use ppez |
| 43 | Decision Support Techniques/ use ppez |
| 44 | decision making/ use emczd |
| 45 | decision support system/ use emczd |
| 46 | (decision$ or choic$ or preference$).tw. |
| 47 | or/41-46 |
| 48 | Patient Compliance/ use ppez |
| 49 | Informed Consent/ use ppez |
| 50 | Treatment Refusal/ use ppez |
| 51 | exp Consumer Behavior/ use ppez |
| 52 | exp Consumer Participation/ use ppez |
| 53 | exp Health Education/ use ppez |
| 54 | patient compliance/ use emczd |
| 55 | informed consent/ use emczd |
| 56 | treatment refusal/ use emczd |
| 57 | exp consumer attitude/ use emczd |
| 58 | exp consumer/ use emczd |
| 59 | exp health education/ use emczd |
| 60 | or/48-59 |
| 61 | (decision$ adj aid$).tw. |
| 62 | ((women$ or woman$ or patient$) adj decision$).tw. |
| 63 | 61 or 62 |
| 64 | 47 and 60 |
| 65 | 63 or 64 |
| 66 | 40 and 65 |
| 67 | Patient Education as Topic/ use ppez |
| 68 | patient education/ use emczd |
| 69 | ((patient$ or consumer$) adj3 (educat$ or skill$ or teach$ or train$ or coach$)).tw. |
| 70 | or/67-69 |
| 71 | Communication/ use ppez |
| 72 | interpersonal communication/ use emczd |
| 73 | communicat$.tw. |
| 74 | Group Processes/ use ppez |
| 75 | group process/ use emczd |
| 76 | or/71-75 |
| 77 | 40 and 70 and 76 |
| 78 | 66 or 77 |
| 79 | Information Services/ or Information Dissemination/ or Access to Information/ or Mass Media/ or Consumer Health Information/ or *Health Promotion/ or *Health Education/ or *Health Knowledge, Attitudes, Practice/ or *Patient Education as Topic/ or Patient Education as Topic/st or Patient Education Handout/ or Pamphlets/ or exp Computers, Handheld/ or Internet/ or *Internet-Based Intervention/ or Web Browser/ or Social Media/ or *Social Networking/ or Mobile Applications/ or Electronic Mail/ or Text Messaging/ or Hotlines/ or *Telephone/ or Television/ or Radio/ or Bibliotherapy/ or Health Literacy/ or Therapy, Computer-Assisted/mt or Patient Advocacy/ or Social Support/ or Self-Help Groups/ or Peer Group/ or Empowerment/ or *Shame/ or *Stigma/ or *Taboo/ |
| 80 | 79 use ppez |
| 81 | information service/ or information dissemination/ or access to information/ or *help seeking behavior/ or mass communication/ or consumer health information/ or *health promotion/ or *health education/ or education program/ or *attitude to health/ or *patient education/ or patient information/ or *medical information/ or *publication/ or personal digital assistant/ or internet/ or web-based intervention/ or web browser/ or social media/ or blogging/ or *social network/ or smartphone/ or mobile application/ or e-mail/ or text messaging/ or hotline/ or *telephone/ or *teleconsultation/ or television/ or radio/ or bibliotherapy/ or *health literacy/ or *computer assisted therapy/ or patient advocacy/ or social support/ or self help/ or exp support group/ or peer group/ or empowerment/ or *shame/ or *stigma/ or *taboo/ |
| 82 | 81 use emczd |
| 83 | (information adj (seek$ or gather$)).tw. |
| 84 | (helpseek$ or help-seek$ or healthcareseek$ or healthcare-seek$ or healthseek$ or health-seek$ or health care-seek$ or health careseek$ or health care seek$).tw. |
| 85 | (care-seek$ or careseek$ or care seek$).ti. |
| 86 | ((information or informative) adj3 tool$).tw. |
| 87 | ((written or audio$ or visual) adj tool$).tw. |
| 88 | ((written or printed) adj3 (information or material$ or education$ or instruction$)).tw. |
| 89 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj5 (pamphlet$ or booklet$ or poster or posters or brochure$ or leaflet$ or sheet$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$ or smartphone$ or smart phone$ or online or on-line or on line or audiovisual or audio-visual or audio visual)).tw. |

| # | Searches |
|---|---|
| 90 | (pamphlet$ or booklet$ or brochure$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$ or bibliotherap$).ti. |
| 91 | ((patient$ or fact$ or written or printed) adj (pamphlet$ or booklet$ or poster or posters or brochure$ or leaflet$ or sheet$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$)).tw. |
| 92 | ((inform$ or reading) adj5 (magazin$ or newspaper$)).tw. |
| 93 | ((popular or women$ or woman$ or online) adj (magazin$ or newspaper$)).tw. |
| 94 | (newspaper adj cutting$).tw. |
| 95 | (information adj (card or cards)).tw. |
| 96 | flipchart$.tw. |
| 97 | ((inform$ or campaign$) adj10 (television$ or TV or radio)).tw. |
| 98 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj3 video$).tw. |
| 99 | dvd$.tw. |
| 100 | (auditory adj (inform$ or tool$)).tw. |
| 101 | (voiceover$ or voice-over$ or voice over$).tw. |
| 102 | (mobile adj (technolog$ or communicat$)).tw. |
| 103 | ((smartphone$ or smart phone$ or phone$ or iphone$ or mobile$ or tablet$ or ipad$ or digital or android$) adj5 (app or app-based or apps or application$)).tw. |
| 104 | smartphone-based.tw. |
| 105 | (helpline$ or help-line$ or hotline$ or hot-line$).tw. |
| 106 | telephone-based intervention$.tw. |
| 107 | (dedicat$ adj (mobile$ or phone$ or telephone$)).tw. |
| 108 | ((telephone$ or phone$) adj consultation$).tw. |
| 109 | (social$ adj media$).tw. |
| 110 | (social$ adj3 network$).tw. |
| 111 | (blogs or vlogs or blogger$ or vlogger$ or influencer$).tw. |
| 112 | (social$ adj influence$).tw. |
| 113 | (podcast$ or webinar$ or Facebook or Instagram or Skype or WeChat$).tw. |
| 114 | (Twitter$ or tweet$ or Youtube$).ti. |
| 115 | ((online or on-line or on line or cyber$ or internet$ or discussion$) adj3 (forum$ or group$ or intervention$)).tw. |
| 116 | ((online or on-line or on line or cyber$ or internet$) adj resource$).ti. |
| 117 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$ or device$ or guidance$ or treatment$ or therap$ or access$ or recommend$) adj3 (app or app-based or apps or web$)).tw. |
| 118 | (website$ or web-site$ or web site$).tw. |
| 119 | internet-based$.tw. |
| 120 | ((talk-based or text-based or visual) adj media$).tw. |
| 121 | (computer$ adj3 (handheld or palm top or palmtop or pda or tablet$)).tw. |
| 122 | (personal digital assistant$ or pocket pc$).tw. |
| 123 | ((emotion$ or network$ or peer$ or organi?ation$ or social) adj support$).tw. |
| 124 | (support adj (group$ or intervention$ or network$)).tw. |
| 125 | ((selfhelp or self-help or self help) adj3 group$).tw. |
| 126 | ((self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj package$).tw. |
| 127 | (group$ adj (training or education)).tw. |
| 128 | (peer$ adj3 (advice$ or advis$ or counsel$ or help$ or mentor$)).tw. |
| 129 | peer network$.tw. |
| 130 | ((public or patient or consumer) adj advoca$).tw. |
| 131 | (advoca$ adj (group$ or organization$)).tw. |
| 132 | ((lay or support) adj person).tw. |
| 133 | (patient adj empower$).tw. |
| 134 | ((psychoeducat$ or psycho-educat$ or psychosocial$ or psycho-social$) adj (support$ or group$ or intervention$)).ti. |
| 135 | (health adj literacy).tw. |
| 136 | (educat$ adj3 strateg$).tw. |
| 137 | (educat$ adj (material$ or workshop$)).tw. |
| 138 | (literature$ adj3 educat$).tw. |
| 139 | (elearn$ or e-learn$ or ehealth$ or e-health$ or mhealth$ or m-health$).tw. |
| 140 | ((educat$ or inform$) adj5 exchange$).tw. |
| 141 | ((information$ or disseminat$) adj (need$ or provi$ or strateg$)).tw. |
| 142 | source$ of information$.tw. |
| 143 | (patient$ adj (information or education)).tw. |
| 144 | ((health$ or communicat$ or educat$ or prevent$ or inform$ or disseminat$) adj3 campaign$).tw. |
| 145 | ((health or public or prevention or community) adj (information$ or education$)).tw. |
| 146 | (communit$ adj2 intervention$).tw. |
| 147 | ((rais$ or increas$ or lack$ or level$ or improv$ or greater or further$ or promot$ or enhanc$ or creat$ or disseminat$) adj3 awareness).ti. |
| 148 | ((pelvi$ floor$ or continenc$ service$ or PFM or PFD or PFMT) adj5 awareness).tw. |
| 149 | (awareness adj (program$ or campaign$ or training)).tw. |
| 150 | (community adj awareness).tw. |
| 151 | (engag$ adj3 communit$).tw. |

| # | Searches |
|---|---|
| 152 | (address$ adj3 (stigma$ or shame or taboo$)).tw. |
| 153 | unspeakable.tw. |
| 154 | (charity or charities or promocon$).mp. |
| 155 | or/80,82-154 |
| 156 | 40 and 155 |
| 157 | 78 or 156 |
| 158 | Pelvic Floor/ or Pelvic Floor Disorders/ |
| 159 | 158 use ppez |
| 160 | pelvis floor/ or pelvic floor disorder/ |
| 161 | 160 use emczd |
| 162 | 5 or 6 or 159 or 161 |
| 163 | ((rais$ or increas$ or lack$ or level$ or improv$ or greater or further$ or promot$ or enhanc$ or creat$ or disseminat$) adj3 awareness).tw. |
| 164 | 162 and 163 |
| 165 | 157 or 164 |
| 166 | limit 165 to english language |
| 167 | limit 166 to yr="1980 -Current" [General Exclusions filter applied] |

**Database(s): Cochrane Library – Wiley interface**

**Cochrane Database of Systematic Reviews**, Issue 6 of 12, June 2020; **Cochrane Central Register of Controlled Trials**, Issue 6 of 12, June 2020
Date of last search: 2 July 2020

| # | Searches |
|---|---|
| #1 | MeSH descriptor: [Pelvic Floor] this term only |
| #2 | MeSH descriptor: [Pelvic Floor Disorders] this term only |
| #3 | ((pelvi* NEXT (floor* or diaphragm*) NEAR/3 (dysfunction* or disorder* or fail* or impair* or incompeten* or insufficien* or dyssynerg* or symptom* or laxity or change* or care* or health* or wellbeing* or "well being*" or prevent* or rehabilitat* or weak* or hypertonic* or overactiv* or "over activ*"))):ti,ab,kw |
| #4 | ((pelvi* NEXT (dysfunction* or disorder* or fail* or impair* or incompeten* or insufficien* or dyssynerg* or symptom* or laxity or care* or health* or wellbeing* or "well being*" or prevent* or rehabilitat* or weak* or hypertonic* or overactiv* or "over activ*"))):ti,ab,kw |
| #5 | MeSH descriptor: [Urinary Incontinence] explode all trees |
| #6 | MeSH descriptor: [Urinary Bladder, Overactive] this term only |
| #7 | (((stress* or mix* or urg* or urin*) NEAR/5 incontinen*)):ti |
| #8 | (((bladder* NEAR/5 (overactiv* or "over activ*" or instabilit* or hyperreflex* or "hyper reflex*" or incontinen*)))):ti |
| #9 | (((detrusor* NEAR/5 (overactiv* or "over activ*" or instabilit* or hyperreflex* or "hyper reflex*")))):ti |
| #10 | ((((urgency NEAR/2 frequency) or (frequency NEAR/2 urgency)))):ti |
| #11 | ((((urin* or bladder*) NEAR/2 (urg* or frequen*)))):ti |
| #12 | (((SUI or OAB))):ti |
| #13 | MeSH descriptor: [Pelvic Organ Prolapse] explode all trees |
| #14 | MeSH descriptor: [Rectocele] this term only |
| #15 | (((pelvic* NEAR/3 organ* NEAR/3 prolaps*))):ti |
| #16 | (((urinary NEAR/3 bladder NEAR/3 prolaps*))):ti |
| #17 | ((((vagin* or urogenital* or genit* or uter* or viscer* or anterior* or posterior* or apical or pelvi* or vault* or urethr* or bladder* or cervi* or rectal or rectum) NEAR/3 prolaps*))):ti |
| #18 | (((splanchnoptos* or visceroptos*))):ti |
| #19 | (((hernia* NEAR/3 (pelvi* or vagin* or urogenital* or uter* or bladder* or urethr* or viscer*)))):ti |
| #20 | (((urethroc?ele* or enteroc?ele* or sigmoidoc?ele* or proctoc?ele* or rectoc?ele* or cystoc?ele* or rectoenteroc?ele* or cystourethroc?ele*))):ti |
| #21 | MeSH descriptor: [Fecal Incontinence] this term only |
| #22 | ((((faecal or fecal or faeces or feces or fecally or faecally or anal or anally or stool or stools or bowel or double or defecat* or defaecat*) NEAR/5 (incontinence or incontinent or urge* or leak or leaking or leakage or soiling or seeping or seepage or impacted or impaction)))):ti |
| #23 | MeSH descriptor: [Urinary Retention] this term only |
| #24 | (((urin* NEAR/3 (retention* or retain*)))):ti,ab,kw |
| #25 | (((voiding NEXT (disorder* or dysfunction* or problem*)))):ti,ab,kw |
| #26 | (((empty* NEXT disorder* NEAR/3 (bowel* or bladder* or vesical* or stool*)))):ti,ab,kw |
| #27 | ((((urogeni* or anorec* or "ano rec*") NEAR/3 dysfunction*))):ti,ab,kw |
| #28 | MeSH descriptor: [Fecal Impaction] this term only |
| #29 | ((((difficult* or delay* or irregular* or infrequen* or pain*) NEAR/3 (defecat* or defaecat* or stool* or faecal or fecal or faeces or feces or fecally or faecally or "bowel movement*")))):ti,ab,kw |
| #30 | (((obstruct* NEAR/3 (defecat* or defaecat*)))):ti,ab,kw |
| #31 | ((((defecat* or defaecat* or evacuat*) NEAR/3 (disorder* or dysfunction*)))):ti,ab,kw |
| #32 | ((outlet* dysfunction* constipa*)):ti,ab,kw |
| #33 | (((dys?ynerg* NEXT (defecat* or defaecat*)))):ti,ab,kw |
| #34 | (((pelvi* NEAR/3 dyskines*))):ti,ab,kw |
| #35 | ((pelvi* outlet* obstruct*)):ti,ab,kw |
| #36 | ((anismus*)):ti,ab,kw |
| #37 | ((puborectal* contract*)):ti,ab,kw |

| # | Searches |
|---|---|
| #38 | ((((rectal or rectum) NEAR/3 urge*))):ti,ab,kw |
| #39 | (((female NEXT sex* NEXT (dysfunct* or satisf* or problem* or symptom* or arous* or activit* or disorder*)))):ti,ab,kw |
| #40 | (((obstruct* NEAR/3 intercourse))):ti,ab,kw |
| #41 | (((vagin* NEAR/3 laxity*))):ti,ab,kw |
| #42 | (((vagin* NEXT wind))):ti,ab,kw |
| #43 | MeSH descriptor: [Vaginismus] this term only |
| #44 | ((vaginismus*)):ti,ab,kw |
| #45 | (((vagin* NEXT penetrat* NEXT disorder*))):ti,ab,kw |
| #46 | {or #1-#45} |
| #47 | MeSH descriptor: [Choice Behavior] this term only |
| #48 | MeSH descriptor: [Decision Making] this term only |
| #49 | MeSH descriptor: [Decision Support Techniques] this term only |
| #50 | ((decision* or choic* or preference*)):ti,ab,kw |
| #51 | #47 OR #48 OR #49 or #50 |
| #52 | MeSH descriptor: [Patient Compliance] this term only |
| #53 | MeSH descriptor: [Informed Consent] this term only |
| #54 | MeSH descriptor: [Treatment Refusal] this term only |
| #55 | MeSH descriptor: [Consumer Behavior] explode all trees |
| #56 | MeSH descriptor: [Community Participation] explode all trees |
| #57 | MeSH descriptor: [Health Education] explode all trees |
| #58 | #52 OR #53 OR #54 OR #55 OR #56 OR #57 |
| #59 | ((decision* NEXT aid*)):ti,ab,kw |
| #60 | (((women* or woman* or patient*) NEXT decision*)):ti,ab,kw |
| #61 | #59 OR #60 |
| #62 | #51 AND #58 |
| #63 | #61 OR #62 |
| #64 | #46 AND #63 |
| #65 | MeSH descriptor: [Patient Education as Topic] this term only |
| #66 | (((patient* or consumer*) NEAR/3 (educat* or skill* or teach* or train* or coach*))):ti,ab,kw |
| #67 | #65 OR #66 |
| #68 | MeSH descriptor: [Communication] this term only |
| #69 | MeSH descriptor: [Group Processes] this term only |
| #70 | (communicat*):ti,ab,kw |
| #71 | #68 OR #69 OR #70 |
| #72 | #46 AND #67 AND #71 |
| #73 | #64 OR #72 |
| #74 | MeSH descriptor: [Information Services] this term only |
| #75 | MeSH descriptor: [Information Dissemination] this term only |
| #76 | MeSH descriptor: [Access to Information] this term only |
| #77 | MeSH descriptor: [Mass Media] this term only |
| #78 | MeSH descriptor: [Consumer Health Information] this term only |
| #79 | MeSH descriptor: [Health Promotion] this term only |
| #80 | MeSH descriptor: [Health Education] this term only |
| #81 | MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only |
| #82 | MeSH descriptor: [Patient Education as Topic] this term only and with qualifier(s): [methods - MT] |
| #83 | MeSH descriptor: [Patient Education Handout] this term only |
| #84 | MeSH descriptor: [Pamphlets] this term only |
| #85 | MeSH descriptor: [Computers, Handheld] explode all trees |
| #86 | MeSH descriptor: [Internet] this term only |
| #87 | MeSH descriptor: [Internet-Based Intervention] this term only |
| #88 | MeSH descriptor: [Web Browser] this term only |
| #89 | MeSH descriptor: [Social Media] this term only |
| #90 | MeSH descriptor: [Social Networking] this term only |
| #91 | MeSH descriptor: [Mobile Applications] this term only |
| #92 | MeSH descriptor: [Electronic Mail] this term only |
| #93 | MeSH descriptor: [Text Messaging] this term only |
| #94 | MeSH descriptor: [Hotlines] this term only |
| #95 | MeSH descriptor: [Television] this term only |
| #96 | MeSH descriptor: [Radio] this term only |
| #97 | MeSH descriptor: [Bibliotherapy] this term only |
| #98 | MeSH descriptor: [Health Literacy] this term only |
| #99 | MeSH descriptor: [Therapy, Computer-Assisted] this term only |
| #100 | MeSH descriptor: [Patient Advocacy] this term only |
| #101 | MeSH descriptor: [Social Support] this term only |
| #102 | MeSH descriptor: [Self-Help Groups] this term only |
| #103 | MeSH descriptor: [Peer Group] this term only |
| #104 | MeSH descriptor: [Empowerment] this term only |
| #105 | ((information NEXT (seek* or gather*))):ti,ab,kw |
| #106 | (helpseek* or healthcareseek* or healthseek* or ((help or healthcare or health) NEXT seek*)):ti,ab,kw |
| #107 | (careseek* or (care NEXT seek*)):ti |

| # | Searches |
|---|---|
| #108 | (((information or informative) NEAR/3 tool*)):ti,ab,kw |
| #109 | (((written or audio* or visual) NEXT tool*)):ti,ab,kw |
| #110 | (((written or printed) NEAR/3 (information or material* or education* or instruction*))):ti,ab,kw |
| #111 | ((((inform* or educat* or illustrat* or advis* or advice* or train* or instruct* or selfhelp* or “self help*” or selfmanag* or “self manag*”) NEAR/5 (pamphlet* or booklet* or poster or posters or brochure* or leaflet* or sheet* or handout or handouts or checklist* or "check list*" or smartphone* or "smart phone*" or online or "on line" or audiovisual or "audio visual")))):ti,ab,kw |
| #112 | ((pamphlet* or booklet* or brochure* or handout or handouts or checklist* or “check list*” or bibliotherap*)):ti |
| #113 | ((((patient* or fact* or written or printed) NEXT (pamphlet* or booklet* or poster or posters or brochure* or leaflet* or sheet* or handout or handouts or checklist* or “check list*”)))):ti,ab,kw |
| #114 | (((inform* or reading) NEAR/5 (magazin* or newspaper*))):ti,ab,kw |
| #115 | (((popular or women* or woman* or online) NEXT (magazin* or newspaper*))):ti,ab,kw |
| #116 | ((newspaper NEXT cutting*)):ti,ab,kw |
| #117 | ((information NEXT (card or cards))):ti,ab,kw |
| #118 | (flipchart*):ti,ab,kw |
| #119 | (((inform* or campaign*) NEAR/10 (television* or TV or radio))):ti,ab,kw |
| #120 | ((((inform* or educat* or illustrat* or advis* or advice* or train* or instruct* or selfhelp* or “self help*” or selfmanag* or “self manag*”) NEAR/3 video*))):ti,ab,kw |
| #121 | (dvd*):ti,ab,kw |
| #122 | ((auditory NEXT (inform* or tool*))):ti,ab,kw |
| #123 | (voiceover* or (voice NEXT over*)):ti,ab,kw |
| #124 | ((mobile NEXT (technolog* or communicat*))):ti,ab,kw |
| #125 | (((smartphone* or “smart phone*” or phone* or iphone* or mobile* or tablet* or ipad* or digital or android*) NEAR/5 (app or apps or application*))):ti,ab,kw |
| #126 | (smartphone NEXT based):ti,ab,kw |
| #127 | (helpline* or hotline* or ((help or hot) NEXT line*)):ti,ab,kw |
| #128 | (telephone NEXT based NEXT intervention*):ti,ab,kw |
| #129 | ((dedicat* NEXT (mobile* or phone* or telephone*))):ti,ab,kw |
| #130 | (((telephone* or phone*) NEXT consultation*)):ti,ab,kw |
| #131 | ((social* NEAR/3 network*)):ti,ab,kw |
| #132 | (social* NEXT media*):ti,ab,kw |
| #133 | ((blogs or vlogs or blogger* or vlogger* or influencer*)):ti,ab,kw |
| #134 | ((social* NEXT influence*)):ti,ab,kw |
| #135 | ((podcast* or webinar* or Facebook or Instagram or Skype or WeChat*)):ti,ab,kw |
| #136 | ((Twitter* or tweet* or Youtube*)):ti |
| #137 | (((online or “on line” or cyber* or internet* or discussion*) NEAR/3 (forum* or group* or intervention*))):ti,ab,kw |
| #138 | (((online or “on line” or cyber* or internet*) NEXT resource*)):ti |
| #139 | ((((inform* or educat* or illustrat* or advis* or advice* or train* or instruct* or selfhelp* or “self help*” or selfmanag* or “self manag*” or device* or guidance* or treatment* or therap* or access* or recommend*) NEAR/3 (app or apps or web*)))):ti,ab,kw |
| #140 | (website* or (web NEXT site*)):ti,ab,kw |
| #141 | (internet NEXT based*):ti,ab,kw |
| #142 | (((talk or text) NEXT based NEXT media*) or (visual NEXT media*)):ti,ab,kw |
| #143 | ((computer* NEAR/3 (handheld or “palm top” or palmtop or pda or tablet*))):ti,ab,kw |
| #144 | ((“personal digital assistant*” or “pocket pc*”)):ti,ab,kw |
| #145 | (((emotion* or network* or peer* or organi?ation* or social) NEXT support*)):ti,ab,kw |
| #146 | ((support NEXT (group* or intervention* or network*))):ti,ab,kw |
| #147 | (((selfhelp or “self help”) NEAR/3 group*)):ti,ab,kw |
| #148 | (((selfhelp* or “self help*” or selfmanag* or “self manag*”) NEXT package*)):ti,ab,kw |
| #149 | ((group* NEXT (training or education))):ti,ab,kw |
| #150 | ((peer* NEAR/3 (advice* or advis* or counsel* or help* or mentor*))):ti,ab,kw |
| #151 | (peer NEXT network*):ti,ab,kw |
| #152 | (((public or patient or consumer) NEXT advoca*)):ti,ab,kw |
| #153 | ((advoca* NEXT (group* or organization*))):ti,ab,kw |
| #154 | (((lay or support) NEXT person)):ti,ab,kw |
| #155 | ((patient NEXT empower*)):ti,ab,kw |
| #156 | (((psychoeducat* or psychosocial*) NEXT (support* or group* or intervention*))):ti |
| #157 | ((health NEXT literacy)):ti,ab,kw |
| #158 | ((educat* NEAR/3 strateg*)):ti,ab,kw |
| #159 | ((educat* NEXT (material* or workshop*))):ti,ab,kw |
| #160 | ((literature* NEAR/3 educat*)):ti,ab,kw |
| #161 | ((elearn* or ehealth* or mhealth*)):ti,ab,kw |
| #162 | (((educat* or inform*) NEAR/5 exchange*)):ti,ab,kw |
| #163 | (((information* or disseminat*) NEXT (need* or provi* or strateg*))):ti,ab,kw |
| #164 | ("source* of information*"):ti,ab,kw |
| #165 | ((patient* NEXT (information or education))):ti,ab,kw |
| #166 | (((health* or communicat* or educat* or prevent* or inform* or disseminat*) NEAR/3 campaign*)):ti,ab,kw |
| #167 | (((health or public or prevention or community) NEXT (information* or education*))):ti,ab,kw |
| #168 | ((communit* NEAR/2 intervention*)):ti,ab,kw |

| # | Searches |
|---|---|
| #169 | (((rais* or increas* or lack* or level* or improv* or greater or further* or promot* or enhanc* or creat* or disseminat*) NEAR/3 awareness)):ti |
| #170 | (((“pelvi* floor*” or “continenc* service*” or PFM or PFD or PFMT) NEAR/5 awareness)):ti,ab,kw |
| #171 | ((awareness NEXT (program* or campaign* or training))):ti,ab,kw |
| #172 | ((community NEXT awareness)):ti,ab,kw |
| #173 | ((engag* NEAR/3 communit*)):ti,ab,kw |
| #174 | ((charity or charities or promocon*)):ti,ab,kw |
| #175 | {or #74-#174} |
| #176 | #46 AND #175 |
| #177 | #73 OR #176 |
| #178 | #1 OR #2 OR #3 OR #4 |
| #179 | (((rais* or increas* or lack* or level* or improv* or greater or further* or promot* or enhanc* or creat* or disseminat*) NEAR/3 awareness)):ti,ab,kw |
| #180 | #178 AND #179 |
| #181 | #177 OR #180 Publication Year from 1980 to current |

## Database(s): Database of Abstracts of Reviews of Effects (DARE); HTA Database – CRD interface

Date of last search: 29 June 2020

| # | Searches |
|---|---|
| 1 | MeSH DESCRIPTOR Pelvic Floor IN DARE,HTA |
| 2 | MeSH DESCRIPTOR Pelvic Floor Disorders IN DARE,HTA |
| 3 | ((pelvi* NEXT (floor* or diaphragm*) NEAR3 (dysfunction* or disorder* or fail* or impair* or incompeten* or insufficien* or dyssynerg* or symptom* or laxity or change* or care* or health* or wellbeing* or well-being* or prevent* or rehabilitat* or weak* or hypertonic* or overactiv* or over activ* or over-activ*))) IN DARE, HTA |
| 4 | ((pelvi* NEXT (dysfunction* or disorder* or fail* or impair* or incompeten* or insufficien* or dyssynerg* or symptom* or laxity or care* or health* or wellbeing* or well-being* or prevent* or rehabilitat* or weak* or hypertonic* or overactiv* or over activ* or over-activ*))) IN DARE, HTA |
| 5 | MeSH DESCRIPTOR Urinary Incontinence EXPLODE ALL TREES IN DARE,HTA |
| 6 | MeSH DESCRIPTOR Urinary Bladder, Overactive IN DARE,HTA |
| 7 | (((stress* or mix* or urg* or urin*) NEAR5 incontinen*)) IN DARE, HTA |
| 8 | ((bladder* NEAR5 (overactiv* or over activ* or over-activ* or instabilit* or hyper-reflex* or hyperreflex* or hyper reflex* or incontinen*))) IN DARE, HTA |
| 9 | ((detrusor* NEAR5 (overactiv* or over activ* or over-activ* or instabilit* or hyper-reflex* or hyperreflex* or hyper reflex*))) IN DARE, HTA |
| 10 | (((urgency NEAR2 frequency) or (frequency NEAR2 urgency))) IN DARE, HTA |
| 11 | (((urin* or bladder*) NEAR2 (urg* or frequen*))) IN DARE, HTA |
| 12 | ((SUI or OAB)) IN DARE, HTA |
| 13 | MeSH DESCRIPTOR Pelvic Organ Prolapse EXPLODE ALL TREES IN DARE,HTA |
| 14 | MeSH DESCRIPTOR Rectocele IN DARE,HTA |
| 15 | ((pelvic* NEAR3 organ* NEAR3 prolaps*)) IN DARE, HTA |
| 16 | ((urinary NEAR3 bladder NEAR3 prolaps*)) IN DARE, HTA |
| 17 | (((vagin* or urogenital* or genit* or uter* or viscer* or anterior* or posterior* or apical or pelvi* or vault* or urethr* or bladder* or cervi* or rectal or rectum) NEAR3 prolaps*)) IN DARE, HTA |
| 18 | ((splanchnoptos* or visceroptos*)) IN DARE, HTA |
| 19 | ((hernia* NEAR3 (pelvi* or vagin* or urogenital* or uter* or bladder* or urethr* or viscer*))) IN DARE, HTA |
| 20 | ((urethroc?ele* or enteroc?ele* or sigmoidoc?ele* or proctoc?ele* or rectoc?ele* or cystoc?ele* or rectoenteroc?ele* or cystourethroc?ele*)) IN DARE, HTA |
| 21 | MeSH DESCRIPTOR Fecal Incontinence IN DARE,HTA |
| 22 | (((faecal or fecal or faeces or feces or fecally or faecally or anal or anally or stool or stools or bowel or double or defecat* or defaecat*) NEAR5 (incontinence or incontinent or urge* or leak or leaking or leakage or soiling or seeping or seepage or impacted or impaction))) IN DARE, HTA |
| 23 | MeSH DESCRIPTOR Urinary Retention IN DARE,HTA |
| 24 | ((urin* NEAR3 (retention* or retain*))) IN DARE, HTA |
| 25 | ((voiding NEXT (disorder* or dysfunction* or problem*))) IN DARE, HTA |
| 26 | ((empty* NEXT disorder* NEAR3 (bowel* or bladder* or vesical* or stool*))) IN DARE, HTA |
| 27 | (((urogeni* or anorec* or ano-rec* or ano rec*) NEAR3 dysfunction*)) IN DARE, HTA |
| 28 | MeSH DESCRIPTOR Fecal Impaction IN DARE,HTA |
| 29 | (((difficult* or delay* or irregular* or infrequen* or pain*) NEAR3 (defecat* or defaecat* or stool* or faecal or fecal or faeces or feces or fecally or faecally or bowel movement*))) IN DARE, HTA |
| 30 | ((obstruct* NEAR3 (defecat* or defaecat*))) IN DARE, HTA |
| 31 | (((defecat* or defaecat* or evacuat*) NEAR3 (disorder* or dysfunction*))) IN DARE, HTA |
| 32 | (((outlet* NEXT dysfunction* NEXT constipa*))) IN DARE, HTA |
| 33 | ((dys?ynerg* NEXT (defecat* or defaecat*))) IN DARE, HTA |
| 34 | ((pelvi* NEAR3 dyskines*)) IN DARE, HTA |
| 35 | ((pelvi* NEXT outlet* NEXT obstruct*)) IN DARE, HTA |
| 36 | ((anismus*)) IN DARE, HTA |
| 37 | ((puborectal* NEXT contract*)) IN DARE, HTA |
| 38 | (((rectal or rectum) NEAR3 urge*)) IN DARE, HTA |

| # | Searches |
|---|---|
| 39 | ((female NEXT sex* NEXT (dysfunct* or satisf* or problem* or symptom* or arous* or activit* or disorder*))) IN DARE, HTA |
| 40 | ((obstruct* NEAR3 intercourse)) IN DARE, HTA |
| 41 | ((vagin* NEAR3 laxity*)) IN DARE, HTA |
| 42 | ((vagin* NEXT wind)) IN DARE, HTA |
| 43 | MeSH DESCRIPTOR Vaginismus IN DARE,HTA |
| 44 | ((vaginismus*)) IN DARE, HTA |
| 45 | ((vagin* NEXT penetrat* NEXT disorder*)) IN DARE, HTA |
| 46 | #1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 |
| 47 | MeSH DESCRIPTOR choice behavior IN DARE,HTA |
| 48 | MeSH DESCRIPTOR decision making IN DARE,HTA |
| 49 | MeSH DESCRIPTOR decision support techniques IN DARE,HTA |
| 50 | ((decision* or choic* or preference*)) IN DARE, HTA |
| 51 | #47 OR #48 OR #49 OR #50 |
| 52 | MeSH DESCRIPTOR patient compliance IN DARE,HTA |
| 53 | MeSH DESCRIPTOR informed consent IN DARE,HTA |
| 54 | MeSH DESCRIPTOR treatment refusal IN DARE,HTA |
| 55 | MeSH DESCRIPTOR consumer behavior IN DARE,HTA |
| 56 | MeSH DESCRIPTOR community participation IN DARE,HTA |
| 57 | MeSH DESCRIPTOR health education IN DARE,HTA |
| 58 | #52 OR #53 OR #54 OR #55 OR #56 OR #57 |
| 59 | ((decision* NEXT aid*)) IN DARE, HTA |
| 60 | (((women* or woman* or patient*) NEXT decision*)) IN DARE, HTA |
| 61 | #59 OR #60 |
| 62 | #51 AND #58 |
| 63 | #61 OR #62 |
| 64 | #46 AND #63 |
| 65 | MeSH DESCRIPTOR Patient Education as Topic IN DARE,HTA |
| 66 | (((patient* or consumer*) NEAR3 (educat* or skill* or teach* or train* or coach*))) IN DARE, HTA |
| 67 | #65 OR #66 |
| 68 | MeSH DESCRIPTOR Communication IN DARE,HTA |
| 69 | MeSH DESCRIPTOR Group Processes IN DARE,HTA |
| 70 | ((communicat*)) IN DARE, HTA |
| 71 | #68 OR #69 OR #70 |
| 72 | #46 AND #67 AND #71 |
| 73 | #64 OR #72 |
| 74 | MeSH DESCRIPTOR Information Services IN DARE,HTA |
| 75 | MeSH DESCRIPTOR Information Dissemination IN DARE,HTA |
| 76 | MeSH DESCRIPTOR Access to Information IN DARE,HTA |
| 77 | MeSH DESCRIPTOR Mass Media IN DARE,HTA |
| 78 | MeSH DESCRIPTOR Consumer Health Information IN DARE,HTA |
| 79 | MeSH DESCRIPTOR Health Promotion IN DARE,HTA |
| 80 | MeSH DESCRIPTOR Health Education EXPLODE ALL TREES IN DARE,HTA |
| 81 | MeSH DESCRIPTOR Health Knowledge, Attitudes, Practice IN DARE,HTA |
| 82 | MeSH DESCRIPTOR patient education as topic WITH QUALIFIER mt IN DARE,HTA |
| 83 | MeSH DESCRIPTOR Patient Education Handout IN DARE,HTA |
| 84 | MeSH DESCRIPTOR Pamphlets IN DARE,HTA |
| 85 | MeSH DESCRIPTOR Computers, Handheld IN DARE,HTA |
| 86 | MeSH DESCRIPTOR Internet IN DARE,HTA |
| 87 | MeSH DESCRIPTOR web browser IN DARE,HTA |
| 88 | MeSH DESCRIPTOR social media IN DARE,HTA |
| 89 | MeSH DESCRIPTOR social networking IN DARE,HTA |
| 90 | MeSH DESCRIPTOR mobile applications IN DARE,HTA |
| 91 | MeSH DESCRIPTOR electronic mail IN DARE,HTA |
| 92 | MeSH DESCRIPTOR Text Messaging IN DARE,HTA |
| 93 | MeSH DESCRIPTOR Hotlines IN DARE,HTA |
| 94 | MeSH DESCRIPTOR television IN DARE,HTA |
| 95 | MeSH DESCRIPTOR radio IN DARE,HTA |
| 96 | MeSH DESCRIPTOR Bibliotherapy IN DARE,HTA |
| 97 | MeSH DESCRIPTOR Health Literacy IN DARE,HTA |
| 98 | MeSH DESCRIPTOR Therapy, Computer-Assisted IN DARE,HTA |
| 99 | MeSH DESCRIPTOR Patient Advocacy IN DARE,HTA |
| 100 | MeSH DESCRIPTOR Social Support IN DARE,HTA |
| 101 | MeSH DESCRIPTOR Self-Help Groups IN DARE,HTA |
| 102 | MeSH DESCRIPTOR Peer Group IN DARE,HTA |
| 103 | ((information NEXT (seek* or gather*))) IN DARE, HTA |
| 104 | ((helpseek* or help-seek* or healthcareseek* or healthcare-seek* or healthseek* or health-seek*)) IN DARE, HTA |

| # | Searches |
|---|---|
| 105 | ((care-seek* or careseek*)):TI IN DARE, HTA |
| 106 | (((information or informative) NEAR3 tool*)) IN DARE, HTA |
| 107 | (((written or audio* or visual) NEXT tool*)) IN DARE, HTA |
| 108 | (((written or printed) NEAR3 (information or material* or education* or instruction*))) IN DARE, HTA |
| 109 | (((inform* or educat* or illustrat* or advis* or advice* or train* or instruct* or self-help* or selfhelp* or self help* or self-manag* or selfmanag* or self manag*) NEAR5 (pamphlet* or booklet* or poster or posters or brochure* or leaflet* or sheet* or handout or handouts or hand-out or hand-outs or checklist* or check-list* or check list* or smartphone* or smart phone* or online or on-line or on line or audiovisual or audio-visual or audio visual))) IN DARE, HTA |
| 110 | ((pamphlet* or booklet* or brochure* or handout or handouts or hand-out or hand-outs or checklist* or check-list* or check list* or bibliotherap*)):TI IN DARE, HTA |
| 111 | #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91 OR #92 OR #93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 |
| 112 | (((inform* or reading) NEAR5 (magazin* or newspaper*))) IN DARE, HTA |
| 113 | (((popular or women* or woman* or online) NEXT (magazin* or newspaper*))) IN DARE, HTA |
| 114 | ((newspaper NEXT cutting*)) IN DARE, HTA |
| 115 | ((information NEXT (card or cards))) IN DARE, HTA |
| 116 | (flipchart*) IN DARE, HTA |
| 117 | (((inform* or campaign*) NEAR10 (television* or TV or radio))) IN DARE, HTA |
| 118 | (((inform* or educat* or illustrat* or advis* or advice* or train* or instruct* or self-help* or selfhelp* or self help* or self-manag* or selfmanag* or self manag*) NEAR3 video*)) IN DARE, HTA |
| 119 | (dvd*) IN DARE, HTA |
| 120 | ((auditory NEXT (inform* or tool*))) IN DARE, HTA |
| 121 | ((voiceover* or voice-over* or voice over*)) IN DARE, HTA |
| 122 | ((mobile NEXT (technolog* or communicat*))) IN DARE, HTA |
| 123 | (((smartphone* or smart phone* or phone* or iphone* or mobile* or tablet* or ipad* or digital or android*) NEAR5 (app or app-based or apps or application*))) IN DARE, HTA |
| 124 | ((smartphone-based)) IN DARE, HTA |
| 125 | ((helpline* or help-line* or hotline* or hot-line*)) IN DARE, HTA |
| 126 | ((telephone-based NEXT intervention*)) IN DARE, HTA |
| 127 | ((dedicat* NEXT (mobile* or phone* or telephone*))) IN DARE, HTA |
| 128 | (((telephone* or phone*) NEXT consultation*)) IN DARE, HTA |
| 129 | ((social* NEAR3 network*)) IN DARE, HTA |
| 130 | ((social* NEXT media*)) IN DARE, HTA |
| 131 | ((blogs or vlogs or blogger* or vlogger* or influencer*)) IN DARE, HTA |
| 132 | ((social* NEXT influence*)) IN DARE, HTA |
| 133 | ((podcast* or webinar* or Facebook or Instagram or Skype or WeChat*)) IN DARE, HTA |
| 134 | ((Twitter* or tweet* or Youtube*)):TI IN DARE, HTA |
| 135 | (((online or on-line or on line or cyber* or internet* or discussion*) NEAR3 (forum* or group* or intervention*))) IN DARE, HTA |
| 136 | (((online or on-line or on line or cyber* or internet*) NEXT resource*)):TI IN DARE, HTA |
| 137 | (((inform* or educat* or illustrat* or advis* or advice* or train* or instruct* or self-help* or selfhelp* or self help* or self-manag* or selfmanag* or self manag* or device* or guidance* or treatment* or therap* or access* or recommend*) NEAR3 (app or app-based or apps or web*))) IN DARE, HTA |
| 138 | ((website* or web-site* or web site*)) IN DARE, HTA |
| 139 | ((internet-based*)) IN DARE, HTA |
| 140 | (((talk-based or text-based or visual) NEXT media*)) IN DARE, HTA |
| 141 | (personal digital assistant* or pocket pc*) IN DARE, HTA |
| 142 | (((emotion* or network* or peer* or organi?ation* or social) NEXT support*)) IN DARE, HTA |
| 143 | ((support NEXT (group* or intervention* or network*))) IN DARE, HTA |
| 144 | (((selfhelp or self-help or self help) NEAR3 group*)) IN DARE, HTA |
| 145 | (((self-help* or selfhelp* or self help* or self-manag* or selfmanag* or self manag*) NEXT package*)) IN DARE, HTA |
| 146 | ((group* NEXT (training or education))) IN DARE, HTA |
| 147 | ((peer* NEAR3 (advice* or advis* or counsel* or help* or mentor*))) IN DARE, HTA |
| 148 | ((peer NEXT network*)) IN DARE, HTA |
| 149 | (((public or patient or consumer) NEXT advoca*)) IN DARE, HTA |
| 150 | ((advoca* NEXT (group* or organization*))) IN DARE, HTA |
| 151 | (((lay or support) NEXT person)) IN DARE, HTA |
| 152 | ((patient NEXT empower*)) IN DARE, HTA |
| 153 | (((psychoeducat* or psycho-educat* or psychosocial* or psycho-social*) NEXT (support* or group* or intervention*))):TI IN DARE, HTA |
| 154 | ((health NEXT literacy)) IN DARE, HTA |
| 155 | ((educat* NEAR3 strateg*)) IN DARE, HTA |
| 156 | ((educat* NEXT (material* or workshop*))) IN DARE, HTA |
| 157 | ((literature* NEAR3 educat*)) IN DARE, HTA |
| 158 | ((elearn* or e-learn* or ehealth* or e-health* or mhealth* or m-health*)) IN DARE, HTA |
| 159 | (((educat* or inform*) NEAR5 exchange*)) IN DARE, HTA |
| 160 | (((information* or disseminat*) NEXT (need* or provi* or strateg*))) IN DARE, HTA |
| 161 | ((source* of information*)) IN DARE, HTA |

| # | Searches |
|---|---|
| 162 | ((patient* NEXT (information or education))) IN DARE, HTA |
| 163 | (((health* or communicat* or educat* or prevent* or inform* or disseminat*) NEAR3 campaign*)) IN DARE, HTA |
| 164 | (((health or public or prevention or community) NEXT (information* or education*))) IN DARE, HTA |
| 165 | ((communit* NEAR2 intervention*)) IN DARE, HTA |
| 166 | (((rais* or increas* or lack* or level* or improv* or greater or further* or promot* or enhanc* or creat* or disseminat*) NEAR3 awareness)):TI IN DARE, HTA |
| 167 | (((pelvi* floor* or continenc* service* or PFM or PFD or PFMT) NEAR5 awareness)) IN DARE, HTA |
| 168 | ((awareness NEXT (program* or campaign* or training))) IN DARE, HTA |
| 169 | ((community NEXT awareness)) IN DARE, HTA |
| 170 | ((engag* NEAR3 communit*)) IN DARE, HTA |
| 171 | ((charity or charities or promocon*)) IN DARE, HTA |
| 172 | #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91 OR #92 OR #93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113 OR #114 OR #115 OR #116 OR #117 OR #118 OR #119 OR #120 OR #121 OR #122 OR #123 OR #124 OR #125 OR #126 OR #127 OR #128 OR #129 OR #130 OR #131 OR #132 OR #133 OR #134 OR #135 OR #136 OR #137 OR #138 OR #139 OR #140 OR #141 OR #142 OR #143 OR #144 OR #145 OR #146 OR #147 OR #148 OR #149 OR #150 OR #151 OR #152 OR #153 OR #154 OR #155 OR #156 OR #157 OR #158 OR #159 OR #160 OR #161 OR #162 OR #163 OR #164 OR #165 OR #166 OR #167 OR #168 OR #169 OR #170 OR #171 |
| 173 | #46 AND #172 |
| 174 | #73 OR #173 |
| 175 | (((rais* or increas* or lack* or level* or improv* or greater or further* or promot* or enhanc* or creat* or disseminat*) NEAR3 awareness)) IN DARE, HTA |
| 176 | #46 AND #175 |
| 177 | #174 OR #176 Publication Year from 1980 to current |

## Database(s): EMCare – OVID interface

Date of last search: 29 June 2020

| # | Searches |
|---|---|
| 1 | pelvis floor/ or pelvic floor disorder/ or exp *urine incontinence/ or *overactive bladder/ or *bladder instability/ or exp *pelvic organ prolapse/ or *rectocele/ or *feces incontinence/ or urine retention/ or defecation disorder/ or Feces Impaction/ or female sexual dysfunction/ or vaginism/ |
| 2 | (pelvi$ adj (floor$ or diaphragm$) adj3 (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or change$ or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 3 | (pelvi$ adj (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 4 | ((stress$ or mix$ or urg$ or urin$) adj5 incontinen$).ti. |
| 5 | (bladder$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$ or incontinen$)).ti. |
| 6 | (detrusor$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$)).ti. |
| 7 | ((urgency adj2 frequency) or (frequency adj2 urgency)).ti. |
| 8 | ((urin$ or bladder$) adj2 (urg$ or frequen$)).ti. |
| 9 | (SUI or OAB).ti. |
| 10 | (pelvic$ adj3 organ$ adj3 prolaps$).ti. |
| 11 | (urinary adj3 bladder adj3 prolaps$).ti. |
| 12 | ((vagin$ or urogenital$ or genit$ or uter$ or viscer$ or anterior$ or posterior$ or apical or pelvi$ or vault$ or urethr$ or bladder$ or cervi$ or rectal or rectum) adj3 prolaps$).ti. |
| 13 | (splanchnoptos$ or visceroptos$).ti. |
| 14 | (hernia$ adj3 (pelvi$ or vagin$ or urogenital$ or uter$ or bladder$ or urethr$ or viscer$)).ti. |
| 15 | (urethroc?ele$ or enteroc?ele$ or sigmoidoc?ele$ or proctoc?ele$ or rectoc?ele$ or cystoc?ele$ or rectoenteroc?ele$ or cystourethroc?ele$).ti. |
| 16 | ((faecal or fecal or faeces or feces or fecally or faecally or anal or anally or stool or stools or bowel or double or defecat$ or defaecat$) adj5 (incontinence or incontinent or urge$ or leak or leaking or leakage or soiling or seeping or seepage or impacted or impaction)).ti. |
| 17 | (urin$ adj3 (retention$ or retain$)).tw. |
| 18 | (voiding adj (disorder$ or dysfunction$ or problem$)).tw. |
| 19 | (empty$ adj disorder$ adj3 (bowel$ or bladder$ or vesical$ or stool$)).tw. |
| 20 | ((urogeni$ or anorec$ or ano-rec$ or ano rec$) adj3 dysfunction$).tw. |
| 21 | ((difficult$ or delay$ or irregular$ or infrequen$ or pain$) adj3 (defecat$ or defaecat$ or stool$ or faeces or feces or bowel movement$)).tw. |
| 22 | (obstruct$ adj3 (defecat$ or defaecat$)).tw. |
| 23 | ((defecat$ or defaecat$ or evacuat$) adj3 (disorder$ or dysfunction$)).tw. |
| 24 | outlet$ dysfunction$ constipa$.tw. |
| 25 | (dys?ynerg$ adj (defecat$ or defaecat$)).tw. |
| 26 | (pelvi$ adj3 dyskines$).tw. |
| 27 | pelvi$ outlet$ obstruct$.tw. |
| 28 | anismus$.tw. |

| # | Searches |
|---|---|
| 29 | puborectal$ contract$.tw. |
| 30 | ((rectal or rectum) adj3 urge$).tw. |
| 31 | (female adj sex$ adj (dysfunct$ or satisf$ or problem$ or symptom$ or arous$ or activit$ or disorder$)).tw. |
| 32 | (obstruct$ adj3 intercourse).tw. |
| 33 | (vagin$ adj3 laxity$).tw. |
| 34 | (vagin$ adj wind).tw. |
| 35 | vaginismus$.tw. |
| 36 | (vagin$ adj penetrat$ adj disorder$).tw. |
| 37 | or/1-36 |
| 38 | decision making/ |
| 39 | decision support system/ |
| 40 | (decision$ or choic$ or preference$).tw. |
| 41 | or/38-40 |
| 42 | patient compliance/ |
| 43 | informed consent/ |
| 44 | treatment refusal/ |
| 45 | exp consumer attitude/ |
| 46 | exp consumer/ |
| 47 | exp health education/ |
| 48 | or/42-47 |
| 49 | (decision$ adj aid$).tw. |
| 50 | ((women$ or woman$ or patient$) adj decision$).tw. |
| 51 | 49 or 50 |
| 52 | 41 and 48 |
| 53 | 51 or 52 |
| 54 | 37 and 53 |
| 55 | patient education/ |
| 56 | ((patient$ or consumer$) adj3 (educat$ or skill$ or teach$ or train$ or coach$)).tw. |
| 57 | 55 or 56 |
| 58 | interpersonal communication/ |
| 59 | communicat$.tw. |
| 60 | group process/ |
| 61 | or/58-60 |
| 62 | 37 and 57 and 61 |
| 63 | 54 or 62 |
| 64 | information service/ or information dissemination/ or access to information/ or *help seeking behavior/ or mass communication/ or consumer health information/ or *health promotion/ or *health education/ or education program/ or *attitude to health/ or *patient education/ or patient information/ or *medical information/ or *publication/ or personal digital assistant/ or internet/ or web-based intervention/ or web browser/ or social media/ or blogging/ or *social network/ or smartphone/ or mobile application/ or e-mail/ or text messaging/ or hotline/ or *telephone/ or *teleconsultation/ or television/ or radio/ or bibliotherapy/ or *health literacy/ or *computer assisted therapy/ or patient advocacy/ or social support/ or self help/ or exp support group/ or peer group/ or empowerment/ or *shame/ or *stigma/ or *taboo/ |
| 65 | (information adj (seek$ or gather$)).tw. |
| 66 | (helpseek$ or help-seek$ or healthcareseek$ or healthcare-seek$ or healthseek$ or health-seek$ or health care-seek$ or health careseek$ or health care seek$).tw. |
| 67 | (care-seek$ or careseek$ or care seek$).ti. |
| 68 | ((information or informative) adj3 tool$).tw. |
| 69 | ((written or audio$ or visual) adj tool$).tw. |
| 70 | ((written or printed) adj3 (information or material$ or education$ or instruction$)).tw. |
| 71 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj5 (pamphlet$ or booklet$ or poster or posters or brochure$ or leaflet$ or sheet$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$ or smartphone$ or smart phone$ or online or on-line or on line or audiovisual or audio-visual or audio visual)).tw. |
| 72 | (pamphlet$ or booklet$ or brochure$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$ or bibliotherap$).ti. |
| 73 | ((patient$ or fact$ or written or printed) adj (pamphlet$ or booklet$ or poster or posters or brochure$ or leaflet$ or sheet$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$)).tw. |
| 74 | ((inform$ or reading) adj5 (magazin$ or newspaper$)).tw. |
| 75 | ((popular or women$ or woman$ or online) adj (magazin$ or newspaper$)).tw. |
| 76 | (newspaper adj cutting$).tw. |
| 77 | (information adj (card or cards)).tw. |
| 78 | flipchart$.tw. |
| 79 | ((inform$ or campaign$) adj10 (television$ or TV or radio)).tw. |
| 80 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj3 video$).tw. |
| 81 | dvd$.tw. |
| 82 | (auditory adj (inform$ or tool$)).tw. |
| 83 | (voiceover$ or voice-over$ or voice over$).tw. |
| 84 | (mobile adj (technolog$ or communicat$)).tw. |

| # | Searches |
|---|---|
| 85 | ((smartphone$ or smart phone$ or phone$ or iphone$ or mobile$ or tablet$ or ipad$ or digital or android$) adj5 (app or app-based or apps or application$)).tw. |
| 86 | smartphone-based.tw. |
| 87 | (helpline$ or help-line$ or hotline$ or hot-line$).tw. |
| 88 | telephone-based intervention$.tw. |
| 89 | (dedicat$ adj (mobile$ or phone$ or telephone$)).tw. |
| 90 | ((telephone$ or phone$) adj consultation$).tw. |
| 91 | (social$ adj media$).tw. |
| 92 | (social$ adj3 network$).tw. |
| 93 | (blogs or vlogs or blogger$ or vlogger$ or influencer$).tw. |
| 94 | (social$ adj influence$).tw. |
| 95 | (podcast$ or webinar$ or Facebook or Instagram or Skype or WeChat$).tw. |
| 96 | (Twitter$ or tweet$ or Youtube$).ti. |
| 97 | ((online or on-line or on line or cyber$ or internet$ or discussion$) adj3 (forum$ or group$ or intervention$)).tw. |
| 98 | ((online or on-line or on line or cyber$ or internet$) adj resource$).ti. |
| 99 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$ or device$ or guidance$ or treatment$ or therap$ or access$ or recommend$) adj3 (app or app-based or apps or web$)).tw. |
| 100 | (website$ or web-site$ or web site$).tw. |
| 101 | internet-based$.tw. |
| 102 | ((talk-based or text-based or visual) adj media$).tw. |
| 103 | (computer$ adj3 (handheld or palm top or palmtop or pda or tablet$)).tw. |
| 104 | (personal digital assistant$ or pocket pc$).tw. |
| 105 | ((emotion$ or network$ or peer$ or organi?ation$ or social) adj support$).tw. |
| 106 | (support adj (group$ or intervention$ or network$)).tw. |
| 107 | ((selfhelp or self-help or self help) adj3 group$).tw. |
| 108 | ((self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj package$).tw. |
| 109 | (group$ adj (training or education)).tw. |
| 110 | (peer$ adj3 (advice$ or advis$ or counsel$ or help$ or mentor$)).tw. |
| 111 | peer network$.tw. |
| 112 | ((public or patient or consumer) adj advoca$).tw. |
| 113 | (advoca$ adj (group$ or organization$)).tw. |
| 114 | ((lay or support) adj person).tw. |
| 115 | (patient adj empower$).tw. |
| 116 | ((psychoeducat$ or psycho-educat$ or psychosocial$ or psycho-social$) adj (support$ or group$ or intervention$)).ti. |
| 117 | (health adj literacy).tw. |
| 118 | (educat$ adj3 strateg$).tw. |
| 119 | (educat$ adj (material$ or workshop$)).tw. |
| 120 | (literature$ adj3 educat$).tw. |
| 121 | (elearn$ or e-learn$ or ehealth$ or e-health$ or mhealth$ or m-health$).tw. |
| 122 | ((educat$ or inform$) adj5 exchange$).tw. |
| 123 | ((information$ or disseminat$) adj (need$ or provi$ or strateg$)).tw. |
| 124 | source$ of information$.tw. |
| 125 | (patient$ adj (information or education)).tw. |
| 126 | ((health$ or communicat$ or educat$ or prevent$ or inform$ or disseminat$) adj3 campaign$).tw. |
| 127 | ((health or public or prevention or community) adj (information$ or education$)).tw. |
| 128 | (communit$ adj2 intervention$).tw. |
| 129 | ((rais$ or increas$ or lack$ or level$ or improv$ or greater or further$ or promot$ or enhanc$ or creat$ or disseminat$) adj3 awareness).ti. |
| 130 | ((pelvi$ floor$ or continenc$ service$ or PFM or PFD or PFMT) adj5 awareness).tw. |
| 131 | (awareness adj (program$ or campaign$ or training)).tw. |
| 132 | (community adj awareness).tw. |
| 133 | (engag$ adj3 communit$).tw. |
| 134 | (address$ adj3 (stigma$ or shame or taboo$)).tw. |
| 135 | unspeakable.tw. |
| 136 | (charity or charities or promocon$).mp. |
| 137 | or/64-136 |
| 138 | 37 and 137 |
| 139 | 63 or 138 |
| 140 | pelvis floor/ or pelvic floor disorder/ |
| 141 | 2 or 3 or 140 |
| 142 | ((rais$ or increas$ or lack$ or level$ or improv$ or greater or further$ or promot$ or enhanc$ or creat$ or disseminat$) adj3 awareness).tw. |
| 143 | 141 and 142 |
| 144 | 139 or 143 |
| 145 | limit 144 to english language |
| 146 | limit 145 to yr="1980 -Current" [General Exclusions filter applied] |

**Database(s): PsycINFO** 1806 to June Week 4 2020 **– OVID interface**

Date of last search: 29 June 2020

| # | Searches |
|---|---|
| 1 | pelvis floor/ |
| 2 | pelvic floor disorder/ |
| 3 | (pelvi$ adj (floor$ or diaphragm$) adj3 (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or change$ or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 4 | (pelvi$ adj (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 5 | or/1-4 |
| 6 | exp *Urinary Incontinence/ |
| 7 | *overactive bladder/ |
| 8 | *bladder instability/ |
| 9 | ((stress$ or mix$ or urg$ or urin$) adj5 incontinen$).ti. |
| 10 | (bladder$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$ or incontinen$)).ti. |
| 11 | (detrusor$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$)).ti. |
| 12 | ((urgency adj2 frequency) or (frequency adj2 urgency)).ti. |
| 13 | ((urin$ or bladder$) adj2 (urg$ or frequen$)).ti. |
| 14 | (SUI or OAB).ti. |
| 15 | or/6-14 |
| 16 | exp *pelvic organ prolapse/ |
| 17 | *rectocele/ |
| 18 | (pelvic$ adj3 organ$ adj3 prolaps$).ti. |
| 19 | (urinary adj3 bladder adj3 prolaps$).ti. |
| 20 | ((vagin$ or urogenital$ or genit$ or uter$ or viscer$ or anterior$ or posterior$ or apical or pelvi$ or vault$ or urethr$ or bladder$ or cervi$ or rectal or rectum) adj3 prolaps$).ti. |
| 21 | (splanchnoptos$ or visceroptos$).ti. |
| 22 | (hernia$ adj3 (pelvi$ or vagin$ or urogenital$ or uter$ or bladder$ or urethr$ or viscer$)).ti. |
| 23 | (urethroc?ele$ or enteroc?ele$ or sigmoidoc?ele$ or proctoc?ele$ or rectoc?ele$ or cystoc?ele$ or rectoenteroc?ele$ or cystourethroc?ele$).ti. |
| 24 | or/16-23 |
| 25 | exp *Fecal Incontinence/ |
| 26 | ((faecal or fecal or faeces or feces or fecally or faecally or anal or anally or stool or stools or bowel or double or defecat$ or defaecat$) adj5 (incontinence or incontinent or urge$ or leak or leaking or leakage or soiling or seeping or seepage or impacted or impaction)).ti. |
| 27 | 25 or 26 |
| 28 | urine retention/ |
| 29 | (urin$ adj3 (retention$ or retain$)).tw. |
| 30 | (voiding adj (disorder$ or dysfunction$ or problem$)).tw. |
| 31 | (empty$ adj disorder$ adj3 (bowel$ or bladder$ or vesical$ or stool$)).tw. |
| 32 | ((urogeni$ or anorec$ or ano-rec$ or ano rec$) adj3 dysfunction$).tw. |
| 33 | defecation disorder/ |
| 34 | feces impaction/ |
| 35 | ((difficult$ or delay$ or irregular$ or infrequen$ or pain$) adj3 (defecat$ or defaecat$ or stool$ or faeces or feces or bowel movement$)).tw. |
| 36 | (obstruct$ adj3 (defecat$ or defaecat$)).tw. |
| 37 | ((defecat$ or defaecat$ or evacuat$) adj3 (disorder$ or dysfunction$)).tw. |
| 38 | outlet$ dysfunction$ constipa$.tw. |
| 39 | (dys?ynerg$ adj (defecat$ or defaecat$)).tw. |
| 40 | (pelvi$ adj3 dyskines$).tw. |
| 41 | pelvi$ outlet$ obstruct$.tw. |
| 42 | anismus$.tw. |
| 43 | puborectal$ contract$.tw. |
| 44 | ((rectal or rectum) adj3 urge$).tw. |
| 45 | or/28-44 |
| 46 | female sexual dysfunction/ |
| 47 | (female adj sex$ adj (dysfunct$ or satisf$ or problem$ or symptom$ or arous$ or activit$ or disorder$)).tw. |
| 48 | (obstruct$ adj3 intercourse).tw. |
| 49 | (vagin$ adj3 laxity$).tw. |
| 50 | (vagin$ adj wind).tw. |
| 51 | Vaginismus/ |
| 52 | vaginismus$.tw. |
| 53 | (vagin$ adj penetrat$ adj disorder$).tw. |
| 54 | or/46-53 |
| 55 | 5 or 15 or 24 or 27 or 45 or 54 |
| 56 | Choice Behavior/ |
| 57 | Decision Making/ |

| # | Searches |
|---|---|
| 58 | Decision Support Systems/ |
| 59 | (decision$ or choic$ or preference$).tw. |
| 60 | or/56-59 |
| 61 | compliance/ |
| 62 | Informed Consent/ |
| 63 | Treatment Refusal/ |
| 64 | exp Consumer Behavior/ |
| 65 | exp Consumer Attitudes/ |
| 66 | exp Health Education/ |
| 67 | or/61-66 |
| 68 | (decision$ adj aid$).tw. |
| 69 | ((women$ or woman$ or patient$) adj decision$).tw. |
| 70 | 68 or 69 |
| 71 | 60 and 67 |
| 72 | 70 or 71 |
| 73 | 55 and 72 |
| 74 | Client Education/ |
| 75 | ((patient$ or consumer$) adj3 (educat$ or skill$ or teach$ or train$ or coach$)).tw. |
| 76 | 74 or 75 |
| 77 | Interpersonal Communication/ |
| 78 | communicat$.tw. |
| 79 | 77 or 78 |
| 80 | 55 and 76 and 79 |
| 81 | 73 or 80 |
| 82 | Information/ or Information Services/ or Information Dissemination/ or Information Seeking/ or exp Help Seeking Behavior/ or Health Education/ or Health Information/ or Health Promotion/ or exp Educational Programs/ or Health Knowledge/ or Health Attitudes/ or Client Education/ or Educational Audiovisual Aids/ or Reading Materials/ or Tablet Computers/ or Computers/ or Multimedia/ or exp Internet/ or *Digital Interventions/ or Websites/ or Social Media/ or *Online Social Networks/ or Blog/ or Mobile Applications/ or Smartphones/ or Computer Mediated Communication/ or Text Messaging/ or Hot Line Services/ or Telephone Systems/ or Television/ or Radio/ or Bibliotherapy/ or Health Literacy/ or exp Computer Assisted Therapy/ or Advocacy/ or Social Support/ or *Self-Care Skills/ or exp Support Groups/ or Empowerment/ or Shame/ or Stigma/ or Taboo/ |
| 83 | (information adj (seek$ or gather$)).tw. |
| 84 | (helpseek$ or help-seek$ or healthcareseek$ or healthcare-seek$ or healthseek$ or health-seek$ or health care-seek$ or health careseek$ or health care seek$).tw. |
| 85 | (care-seek$ or careseek$ or care seek$).ti. |
| 86 | ((information or informative) adj3 tool$).tw. |
| 87 | ((written or audio$ or visual) adj tool$).tw. |
| 88 | ((written or printed) adj3 (information or material$ or education$ or instruction$)).tw. |
| 89 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj5 (pamphlet$ or booklet$ or poster or posters or brochure$ or leaflet$ or sheet$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$ or smartphone$ or smart phone$ or online or on-line or on line or audiovisual or audio-visual or audio visual)).tw. |
| 90 | (pamphlet$ or booklet$ or brochure$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$ or bibliotherap$).ti. |
| 91 | ((patient$ or fact$ or written or printed) adj (pamphlet$ or booklet$ or poster or posters or brochure$ or leaflet$ or sheet$ or handout or handouts or hand-out or hand-outs or checklist$ or check-list$ or check list$)).tw. |
| 92 | ((inform$ or reading) adj5 (magazin$ or newspaper$)).tw. |
| 93 | ((popular or women$ or woman$ or online) adj (magazin$ or newspaper$)).tw. |
| 94 | (newspaper adj cutting$).tw. |
| 95 | (information adj (card or cards)).tw. |
| 96 | flipchart$.tw. |
| 97 | ((inform$ or campaign$) adj10 (television$ or TV or radio)).tw. |
| 98 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj3 video$).tw. |
| 99 | dvd$.tw. |
| 100 | (auditory adj (inform$ or tool$)).tw. |
| 101 | (voiceover$ or voice-over$ or voice over$).tw. |
| 102 | (mobile adj (technolog$ or communicat$)).tw. |
| 103 | ((smartphone$ or smart phone$ or phone$ or iphone$ or mobile$ or tablet$ or ipad$ or digital or android$) adj5 (app or app-based or apps or application$)).tw. |
| 104 | smartphone-based.tw. |
| 105 | (helpline$ or help-line$ or hotline$ or hot-line$).tw. |
| 106 | telephone-based intervention$.tw. |
| 107 | (dedicat$ adj (mobile$ or phone$ or telephone$)).tw. |
| 108 | ((telephone$ or phone$) adj consultation$).tw. |
| 109 | (social$ adj media$).tw. |
| 110 | (social$ adj3 network$).tw. |
| 111 | (blogs or vlogs or blogger$ or vlogger$ or influencer$).tw. |
| 112 | (social$ adj influence$).tw. |
| 113 | (podcast$ or webinar$ or Facebook or Instagram or Skype or WeChat$).tw. |

| # | Searches |
|---|---|
| 114 | (Twitter$ or tweet$ or Youtube$).ti. |
| 115 | ((online or on-line or on line or cyber$ or internet$ or discussion$) adj3 (forum$ or group$ or intervention$)).tw. |
| 116 | ((online or on-line or on line or cyber$ or internet$) adj resource$).ti. |
| 117 | ((inform$ or educat$ or illustrat$ or advis$ or advice$ or train$ or instruct$ or self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$ or device$ or guidance$ or treatment$ or therap$ or access$ or recommend$) adj3 (app or app-based or apps or web$)).tw. |
| 118 | (website$ or web-site$ or web site$).tw. |
| 119 | internet-based$.tw. |
| 120 | ((talk-based or text-based or visual) adj media$).tw. |
| 121 | (computer$ adj3 (handheld or palm top or palmtop or pda or tablet$)).tw. |
| 122 | (personal digital assistant$ or pocket pc$).tw. |
| 123 | ((emotion$ or network$ or peer$ or organi?ation$ or social) adj support$).tw. |
| 124 | (support adj (group$ or intervention$ or network$)).tw. |
| 125 | ((selfhelp or self-help or self help) adj3 group$).tw. |
| 126 | ((self-help$ or selfhelp$ or self help$ or self-manag$ or selfmanag$ or self manag$) adj package$).tw. |
| 127 | (group$ adj (training or education)).tw. |
| 128 | (peer$ adj3 (advice$ or advis$ or counsel$ or help$ or mentor$)).tw. |
| 129 | peer network$.tw. |
| 130 | ((public or patient or consumer) adj advoca$).tw. |
| 131 | (advoca$ adj (group$ or organization$)).tw. |
| 132 | ((lay or support) adj person).tw. |
| 133 | (patient adj empower$).tw. |
| 134 | ((psychoeducat$ or psycho-educat$ or psychosocial$ or psycho-social$) adj (support$ or group$ or intervention$)).ti. |
| 135 | (health adj literacy).tw. |
| 136 | (educat$ adj3 strateg$).tw. |
| 137 | (educat$ adj (material$ or workshop$)).tw. |
| 138 | (literature$ adj3 educat$).tw. |
| 139 | (elearn$ or e-learn$ or ehealth$ or e-health$ or mhealth$ or m-health$).tw. |
| 140 | ((educat$ or inform$) adj5 exchange$).tw. |
| 141 | ((information$ or disseminat$) adj (need$ or provi$ or strateg$)).tw. |
| 142 | source$ of information$.tw. |
| 143 | (patient$ adj (information or education)).tw. |
| 144 | ((health$ or communicat$ or educat$ or prevent$ or inform$ or disseminat$) adj3 campaign$).tw. |
| 145 | ((health or public or prevention or community) adj (information$ or education$)).tw. |
| 146 | (communit$ adj2 intervention$).tw. |
| 147 | ((rais$ or increas$ or lack$ or level$ or improv$ or greater or further$ or promot$ or enhanc$ or creat$ or disseminat$) adj3 awareness).ti. |
| 148 | ((pelvi$ floor$ or continenc$ service$ or PFM or PFD or PFMT) adj5 awareness).tw. |
| 149 | (awareness adj (program$ or campaign$ or training)).tw. |
| 150 | (community adj awareness).tw. |
| 151 | (engag$ adj3 communit$).tw. |
| 152 | (address$ adj3 (stigma$ or shame or taboo$)).tw. |
| 153 | unspeakable.tw. |
| 154 | (charity or charities or promocon$).mp. |
| 155 | or/82-154 |
| 156 | 55 and 155 |
| 157 | 81 or 156 |
| 158 | ((rais$ or increas$ or lack$ or level$ or improv$ or greater or further$ or promot$ or enhanc$ or creat$ or disseminat$) adj3 awareness).tw. |
| 159 | 5 and 158 |
| 160 | 157 or 159 |
| 161 | limit 160 to (english language and yr="1980 -Current") [General Exclusions filter applied] |

## Economic Search

One global search was conducted for economic evidence across the guideline.

**Database(s): NHS Economic Evaluation Database (NHS EED); HTA Database – CRD interface**

Date of last search: 3 February 2021

| # | Searches |
|---|---|
| 1 | MeSH DESCRIPTOR Pelvic Floor IN NHSEED,HTA |
| 2 | MeSH DESCRIPTOR Pelvic Floor Disorders IN NHSEED,HTA |
| 3 | MeSH DESCRIPTOR Urinary Bladder, Overactive IN NHSEED,HTA |
| 4 | (((pelvi* NEXT (floor* or diaphragm*) NEAR3 (dysfunction* or disorder* or fail* or impair* or incompeten* or insufficien* or dyssynerg* or symptom* or laxity or change* or care* or health* or wellbeing* or well-being* or prevent* or rehabilitat* or weak* or hypertonic* or overactiv* or over activ* or over-activ*)))) IN NHSEED, HTA |
| 5 | MeSH DESCRIPTOR Urinary Incontinence EXPLODE ALL TREES IN NHSEED,HTA |
| 6 | MeSH DESCRIPTOR Urinary Bladder, Overactive IN NHSEED,HTA |
| 7 | ((((stress* or mix* or urg* or urin*) NEAR5 incontinen*))) IN NHSEED, HTA |
| 8 | (((bladder* NEAR5 (overactiv* or over activ* or over-activ* or instabilit* or hyper-reflex* or hyperreflex* or hyper reflex* or incontinen*)))) IN NHSEED, HTA |
| 9 | (((detrusor* NEAR5 (overactiv* or over activ* or over-activ* or instabilit* or hyper-reflex* or hyperreflex* or hyper reflex*)))) IN NHSEED, HTA |
| 10 | ((((urgency NEAR2 frequency) or (frequency NEAR2 urgency)))) IN NHSEED, HTA |
| 11 | ((((urin* or bladder*) NEAR2 (urg* or frequen*)))) IN NHSEED, HTA |
| 12 | (((SUI or OAB))) IN NHSEED, HTA |
| 13 | MeSH DESCRIPTOR Pelvic Organ Prolapse EXPLODE ALL TREES IN NHSEED,HTA |
| 14 | MeSH DESCRIPTOR Rectocele IN NHSEED,HTA |
| 15 | (((pelvic* NEAR3 organ* NEAR3 prolaps*))) IN NHSEED, HTA |
| 16 | (((urinary NEAR3 bladder NEAR3 prolaps*))) IN NHSEED, HTA |
| 17 | ((((vagin* or urogenital* or genit* or uter* or viscer* or anterior* or posterior* or apical or pelvi* or vault* or urethr* or bladder* or cervi* or rectal or rectum) NEAR3 prolaps*))) IN NHSEED, HTA |
| 18 | (((splanchnoptos* or visceroptos*))) IN NHSEED, HTA |
| 19 | (((hernia* NEAR3 (pelvi* or vagin* or urogenital* or uter* or bladder* or urethr* or viscer*)))) IN NHSEED, HTA |
| 20 | (((urethroc?ele* or enteroc?ele* or sigmoidoc?ele* or proctoc?ele* or rectoc?ele* or cystoc?ele* or rectoenteroc?ele* or cystourethroc?ele*))) IN NHSEED, HTA |
| 21 | MeSH DESCRIPTOR Fecal Incontinence IN NHSEED,HTA |
| 22 | ((((faecal or fecal or faeces or feces or fecally or faecally or anal or anally or stool or stools or bowel or double or defecat* or defaecat*) NEAR5 (incontinence or incontinent or urge* or leak or leaking or leakage or soiling or seeping or seepage or impacted or impaction)))) IN NHSEED, HTA |
| 23 | MeSH DESCRIPTOR Urinary Retention IN NHSEED,HTA |
| 24 | (((urin* NEAR3 (retention* or retain*)))) IN NHSEED, HTA |
| 25 | (((voiding NEXT (disorder* or dysfunction* or problem*)))) IN NHSEED, HTA |
| 26 | (((empty* NEXT disorder* NEAR3 (bowel* or bladder* or vesical* or stool*)))) IN NHSEED, HTA |
| 27 | ((((urogeni* or anorec* or ano-rec* or ano rec*) NEAR3 dysfunction*))) IN NHSEED, HTA |
| 28 | MeSH DESCRIPTOR Fecal Impaction IN NHSEED,HTA |
| 29 | ((((difficult* or delay* or irregular* or infrequen* or pain*) NEAR3 (defecat* or defaecat* or stool* or faecal or fecal or faeces or feces or fecally or faecally or bowel movement*)))) IN NHSEED, HTA |
| 30 | (((obstruct* NEAR3 (defecat* or defaecat*)))) IN NHSEED, HTA |
| 31 | ((((defecat* or defaecat* or evacuat*) NEAR3 (disorder* or dysfunction*)))) IN NHSEED, HTA |
| 32 | ((((outlet* NEXT dysfunction* NEXT constipa*)))) IN NHSEED, HTA |
| 33 | (((dys?ynerg* NEXT (defecat* or defaecat*)))) IN NHSEED, HTA |
| 34 | (((pelvi* NEAR3 dyskines*))) IN NHSEED, HTA |
| 35 | (((pelvi* NEXT outlet* NEXT obstruct*))) IN NHSEED, HTA |
| 36 | (((anismus*))) IN NHSEED, HTA |
| 37 | (((puborectal* NEXT contract*))) IN NHSEED, HTA |
| 38 | ((((rectal or rectum) NEAR3 urge*))) IN NHSEED, HTA |
| 39 | (((female NEXT sex* NEXT (dysfunct* or satisf* or problem* or symptom* or arous* or activit* or disorder*)))) IN NHSEED, HTA |
| 40 | (((obstruct* NEAR3 intercourse))) IN NHSEED, HTA |
| 41 | (((vagin* NEAR3 laxity*))) IN NHSEED, HTA |
| 42 | (((vagin* NEXT wind))) IN NHSEED, HTA |
| 43 | MeSH DESCRIPTOR Vaginismus IN NHSEED,HTA |
| 44 | (((vaginismus*))) IN NHSEED, HTA |
| 45 | (((vagin* NEXT penetrat* NEXT disorder*))) IN NHSEED, HTA |
| 46 | (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45) IN NHSEED, HTA |

**Database(s): Medline & Embase (Multifile) – OVID interface**

**Embase Classic+Embase** 1947 to 2021 February 01; **Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily** 1946 to February 01, 2021
Date of last search: 3 February 2021

*Multifile database codes: emczd = Embase Classic+Embase; ppez= MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily*

| # | Searches |
|---|---|
| 1 | Pelvic Floor/ use ppez |
| 2 | Pelvic Floor Disorders/ use ppez |
| 3 | pelvis floor/ use emczd |
| 4 | pelvic floor disorder/ use emczd |
| 5 | (pelvi$ adj (floor$ or diaphragm$) adj3 (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or change$ or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 6 | (pelvi$ adj (dysfunction$ or disorder$ or fail$ or impair$ or incompeten$ or insufficien$ or dyssynerg$ or symptom$ or laxity or care$ or health$ or wellbeing$ or well-being$ or prevent$ or rehabilitat$ or weak$ or hypertonic$ or overactiv$ or over activ$ or over-activ$)).tw. |
| 7 | or/1-6 |
| 8 | exp *Urinary Incontinence/ use ppez |
| 9 | *Urinary Bladder, Overactive/ use ppez |
| 10 | exp *urine incontinence/ use emczd |
| 11 | *overactive bladder/ use emczd |
| 12 | *bladder instability/ use emczd |
| 13 | ((stress$ or mix$ or urg$ or urin$) adj5 incontinen$).ti. |
| 14 | (bladder$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$ or incontinen$)).ti. |
| 15 | (detrusor$ adj5 (overactiv$ or over activ$ or over-activ$ or instabilit$ or hyper-reflex$ or hyperreflex$ or hyper reflex$)).ti. |
| 16 | ((urgency adj2 frequency) or (frequency adj2 urgency)).ti. |
| 17 | ((urin$ or bladder$) adj2 (urg$ or frequen$)).ti. |
| 18 | (SUI or OAB).ti. |
| 19 | or/8-18 |
| 20 | exp *Pelvic Organ Prolapse/ use ppez |
| 21 | exp *pelvic organ prolapse/ use emczd |
| 22 | *Rectocele/ use ppez |
| 23 | *rectocele/ use emczd |
| 24 | (pelvic$ adj3 organ$ adj3 prolaps$).ti. |
| 25 | (urinary adj3 bladder adj3 prolaps$).ti. |
| 26 | ((vagin$ or urogenital$ or genit$ or uter$ or viscer$ or anterior$ or posterior$ or apical or pelvi$ or vault$ or urethr$ or bladder$ or cervi$ or rectal or rectum) adj3 prolaps$).ti. |
| 27 | (splanchnoptos$ or visceroptos$).ti. |
| 28 | (hernia$ adj3 (pelvi$ or vagin$ or urogenital$ or uter$ or bladder$ or urethr$ or viscer$)).ti. |
| 29 | (urethroc?ele$ or enteroc?ele$ or sigmoidoc?ele$ or proctoc?ele$ or rectoc?ele$ or cystoc?ele$ or rectoenteroc?ele$ or cystourethroc?ele$).ti. |
| 30 | or/20-29 |
| 31 | *Fecal Incontinence/ use ppez |
| 32 | *feces incontinence/ use emczd |
| 33 | ((faecal or fecal or faeces or feces or fecally or faecally or anal or anally or stool or stools or bowel or double or defecat$ or defaecat$) adj5 (incontinence or incontinent or urge$ or leak or leaking or leakage or soiling or seeping or seepage or impacted or impaction)).ti. |
| 34 | or/31-33 |
| 35 | Urinary Retention/ use ppez |
| 36 | urine retention/ use emczd |
| 37 | (urin$ adj3 (retention$ or retain$)).tw. |
| 38 | (voiding adj (disorder$ or dysfunction$ or problem$)).tw. |
| 39 | (empty$ adj disorder$ adj3 (bowel$ or bladder$ or vesical$ or stool$)).tw. |
| 40 | ((urogeni$ or anorec$ or ano-rec$ or ano rec$) adj3 dysfunction$).tw. |
| 41 | defecation disorder/ use emczd |
| 42 | Fecal Impaction/ use ppez |
| 43 | Feces Impaction/ use emczd |
| 44 | ((difficult$ or delay$ or irregular$ or infrequen$ or pain$) adj3 (defecat$ or defaecat$ or stool$ or faeces or feces or bowel movement$)).tw. |
| 45 | (obstruct$ adj3 (defecat$ or defaecat$)).tw. |
| 46 | ((defecat$ or defaecat$ or evacuat$) adj3 (disorder$ or dysfunction$)).tw. |
| 47 | outlet$ dysfunction$ constipa$.tw. |
| 48 | (dys?ynerg$ adj (defecat$ or defaecat$)).tw. |
| 49 | (pelvi$ adj3 dyskines$).tw. |
| 50 | pelvi$ outlet$ obstruct$.tw. |
| 51 | anismus$.tw. |
| 52 | puborectal$ contract$.tw. |

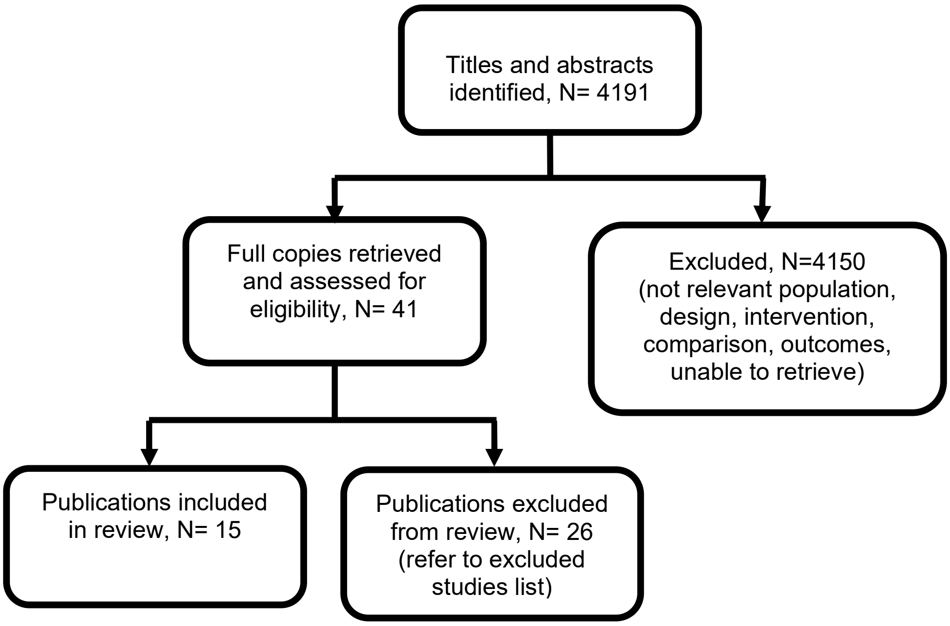
| # | Searches |
|---|---|
| 53 | ((rectal or rectum) adj3 urge$).tw. |
| 54 | or/35-53 |
| 55 | female sexual dysfunction/ use emczd |
| 56 | (female adj sex$ adj (dysfunct$ or satisf$ or problem$ or symptom$ or arous$ or activit$ or disorder$)).tw. |
| 57 | (obstruct$ adj3 intercourse).tw. |
| 58 | (vagin$ adj3 laxity$).tw. |
| 59 | (vagin$ adj wind).tw. |
| 60 | Vaginismus/ use ppez |
| 61 | vaginism/ use emczd |
| 62 | vaginismus$.tw. |
| 63 | (vagin$ adj penetrat$ adj disorder$).tw. |
| 64 | or/55-63 |
| 65 | 7 or 19 or 30 or 34 or 54 or 64 |
| 66 | Economics/ use ppez |
| 67 | Value of life/ use ppez |
| 68 | exp "Costs and Cost Analysis"/ use ppez |
| 69 | exp Economics, Hospital/ use ppez |
| 70 | exp Economics, Medical/ use ppez |
| 71 | Economics, Nursing/ use ppez |
| 72 | Economics, Pharmaceutical/ use ppez |
| 73 | exp "Fees and Charges"/ use ppez |
| 74 | exp Budgets/ use ppez |
| 75 | health economics/ use emczd |
| 76 | exp economic evaluation/ use emczd |
| 77 | exp health care cost/ use emczd |
| 78 | exp fee/ use emczd |
| 79 | budget/ use emczd |
| 80 | funding/ use emczd |
| 81 | budget*.ti,ab. |
| 82 | cost*.ti. |
| 83 | (economic* or pharmaco?economic*).ti. |
| 84 | (price* or pricing*).ti,ab. |
| 85 | (cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab. |
| 86 | (financ* or fee or fees).ti,ab. |
| 87 | (value adj2 (money or monetary)).ti,ab. |
| 88 | or/66-87 |
| 89 | 65 and 88 |
| 90 | limit 89 to english language |

# Appendix C – Clinical evidence study selection

## Study selection for: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

The search for this review question also covered the evidence for review's A and and H.

**Figure 1: Study selection flow chart**



# Appendix D –Evidence tables

## Evidence tables for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

Table 4: Evidence tables

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| **Full citation**<br>Andersson, G, Johansson, J. E, Nilsson, K, Sahlberg-Blom, E., Perceptions of urinary incontinence among Syrian Christian women living in Sweden, Journal of Transcultural Nursing, 20, 296-303, 2009<br>**Ref Id**<br>1284209<br>**Country/ies where the study was carried out**<br>Sweden<br>**Study type**<br>Qualitative<br>**Study dates**<br>Between April and October 2006 | **Recruitment strategy**<br>Syrian women aged 30 to >80 years. A nurse known both to the researcher and in the Syrian community recruited the first group. In the following groups, the women were selected by network or snowball sampling, which means that they were nominated by some of the other participants. As the aim was to study a common perception of UI, it was not an inclusion criterion that the women should have experienced UI themselves. This was decided to facilitate participation for the women. However, it turned out that all the participating women had own experience of UI, either having experienced UI themselves or having helped relatives with UI.<br>**Setting**<br>All focus group discussions (FGDs) were performed on the premises of the Syrian Society or Church and lasted 35 to 60 minutes.<br>**Participant characteristics**<br>**Group 1**<br>N=4 | **Findings (including author's interpretation)**<br>**Managing urinary incontinence**<br>The women described how important other women in the Syrian group are for each other, such as family members, neighbours, or friends. Older women are mainly supported by their daughters and daughters-in-law, who are important discussion partners with regard to problems such as UI, and assist with dealings with the health care system. The younger women told about how the older women needed their help. However,1 woman described how this could lead to a feeling of inadequacy, she could wonder whether she had done the best possible for the older woman. The women knew that incontinence protection for UI is available and can be prescribed by the public health nurse. Difficulties getting help with this at the medical center were mentioned, however. Some of the women chose instead to buy incontinence protection in the store. Another way of handling leakage of urine was to stay close to a toilet because the women needed to empty their bladders often. Nevertheless, the women indicated they would seek care for UI if they felt they needed it. | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of the study aims.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to understand women's' perception of UI.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes, the use of focus groups is justified as being useful when the aim is to explore people's experiences and thoughts, and that discussion helps participants to clarify their views.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the recruitment method is briefly described, however the inclusion |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| | Age (range): 30-60<br>Years in Sweden: 10-35<br>Number of children: 3-6<br>**Group 2**<br>N=6<br>Age (range): 50-70<br>Years in Sweden: 26-31<br>Number of children: 0-9<br>**Group 3**<br>N=4<br>Age (range): 70-80+<br>Years in Sweden: 22-30<br>Number of children: 7-10<br>**Data collection and analysis**<br>Each focus group discussion opened with the question, “What comes to mind when I mention urinary incontinence?” Follow-up questions about their perception of UI were continuously asked. In the focus group with the Swedish-speaking women, detailed field notes were taken due to difficulties with the tape recorder. The other 2 focus groups were audio recorded and later transcribed verbatim. When the FGDs were transcribed to text, doubts emerged as to whether all parts of the focus group discussion had been correctly translated, and therefore an independent professional interpreter was engaged to increase the trustworthiness of the data. She translated the spoken Syrian part of the narratives, and statements were found that had been neglected by the first interpreter.<br>The focus group discussions were analysed using content analysis, | They held the doctor just below God, and most women accepted both male and female doctors. The women also differed with regard to their ideas about treatment for UI. Some of them had been operated for leakage and thought this was the optimal treatment for UI. Others had instead been prescribed medication and denied surgery, which made them wonder why they had not been offered the best treatment.<br>**Communication with the healthcare system**<br>Not being able to speak or read Swedish was seen as a big problem, especially for the older women. Communication problems meant that the women had difficulties describing their problems and understanding information about prescriptions and other treatment options, which could lead to a situation in which the expected help did not materialize. Not mastering the Swedish language also resulted in dependence on help from daughters and daughters-in-law. In these cases, opening hours of the health care facilities became an obstacle because the younger women usually worked during consultation hours. To overcome the language problem, an interpreter was often used during visits to the doctor. This was perceived as positive, but could also entail problems. Most women wanted a female interpreter and thought it inconceivable to talk about UI, or get undressed, in front of a male interpreter. The women described how they refused going to the doctor when a male interpreter was to be present during the consultation. Instead, they often brought | and exclusion criteria is not described. It is unclear how many women were approached and whether any declined to participate.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)**<br>Can't tell, the setting is not described, however it is clear that the focus groups were either audio recorded or recorded with detailed field notes. Data saturation is not discussed.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)**<br>No, the relationship between the researcher and participants is not discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)**<br>Can't tell, no mention of confidentiality issues, and states that written consent was not possible due to some participants not being able to read. The study was approved by an ethics committee<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No)**<br>Can't tell, the analysis method is briefly described and it is clear how themes |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| | describing the obvious, visible components of the focus group discussions. The whole text was read through several times to gain an overall impression of the content. Thereafter, the analysis consisted of the following 5 steps:<br>1. The text was divided into meaning units, where each unit is a constellation of words and statements that are connected to each other through their content.<br>2. Each meaning unit was condensed, which means the text was shortened without changing the core.<br>3. Each condensed meaning unit was labelled with a code.<br>4. The codes from all FGDs were grouped by content.<br>5. Finally, the codes–groups were abstracted to subcategories and, thereafter, to categories.<br>The field notes were handled in the same way; with meaning units, condensation, codes, and abstraction to subcategories and finally to categories. These steps were performed with a constant moving back and forth between each of the steps. A co-author (read all the focus group discussions, and subcategories and categories were discussed. | a female friend or relative. Another problem that was described was that they had previously met the interpreter at the Syrian Society or in church, which could be perceived as embarrassing. The importance of communicating was clarified by the women who understood Swedish and perceived themselves as integrated into Swedish society. According to them, being able to speak, read, and understand Swedish also gives the opportunity to seek and understand information about a medical problem such as UI.<br>**Example quotes**<br>“Yes, the main thing is that you know the language. If you don’t know the language you have to have relatives who know the language and who also have time”<br>“Even if we scream and make a fuss they don’t help us”<br>“If it’s a male doctor then we ask for another. We’re ashamed”, “It doesn’t matter to me [whether it’s a female or a male doctor]. If I have a problem, then I have a problem | were derived. However, there is no mention of the influence of the researcher on the analysis process, or how the presented data were selected. The themes do seem well supported by the data.<br>**9. Is there a clear statement of findings? (Yes/Can’t tell/No)**<br>Yes, there is a clear statement of findings, and these are discussed in relation to the original aims of the study.<br>**10. How valuable is the research?**<br>The researcher discusses some considerations that are the result of the study, and how these impact the healthcare system<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate limitations<br>**Source of funding**<br>The Örebro County Council’s Research Fund provided financial support for this study. |
| **Full citation** | **Recruitment strategy**<br>The interviewed women had all participated in the previously mentioned | **Findings (including author’s interpretation)**<br>**Hidden but Present** | **1. Was there a clear statement of the aims of the research? (Yes/Can’t tell/No)** |

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| Bjork, Anna-Bell, Sjostrom, Malin, Johansson, Eva E, Samuelsson, Eva, Umefjord, Goran, Women's experiences of internet-based or postal treatment for stress urinary incontinence, Qualitative health research, 24, 484-93, 2014<br>**Ref Id**<br>1284215<br>**Country/ies where the study was carried out**<br>Sweden<br>**Study type**<br>Qualitative<br>**Study dates**<br>2011, no further details. | RCT, comparing the effect of an Internet based treatment program for SUI with the effect of a treatment program sent by post. 250 participants were recruited for the randomised controlled trial via the project's Web site. All participants in the study were women aged 18 to 70 years and had SUI at least once weekly, diagnosed using self-assessed validated questionnaires, 2-day bladder diaries, and a telephone interview with a urotherapist. Shortly after follow-up, the researchers approached a selected sample of the women by email and asked if they were willing to elaborate on their experiences in a telephone interview. A strategic selection was used, aiming for diversity of age, location, and group allocation.<br>**Setting**<br>Interviews took place on the phone.<br>**Participant characteristics**<br>N=21<br>Age (mean, range), years: 47.6 (30-69)<br>**Data collection and analysis**<br>Semi-structured individual telephone interviews were used. As preparation for constructing the interview questions, the researchers coded the open-ended questions used in the 4-month RCT follow-up and used the emerging preliminary categories from this process to compose a semi-structured interview guide. The questions in the guide were | Having sought care on previous occasions, some women felt they had not been taken seriously or had even been ignored. On mentioning their incontinence, they had experienced a dismissive and sometimes embarrassed attitude from health care providers: "Well, I haven't explicitly looked for it, but since I was there I asked them and told them about my problems, but they didn't think there was much to be concerned about". Overall, many of the women described the barrier for seeking help as relatively high. The more impact the leakage had on everyday life, the greater the motivation for seeking help. One woman said that a reason for seeking help was the limitation of not being able to play with her children any more. | Yes, the aims of the research are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, the research aims to understand women's experiences of an RCT, as well as understanding aspects of the patient provider relationship.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes, the use of interviews is justified and appropriate.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the selection of participants is described, but unclear how many participants were approached, and if any participants declined to take part.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the use of telephone interviews is not justified, and the use of interviews is not explained. The methods of the interview are explicit and it is clear what form the data are in. |

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| | open ended, and intended to give a deeper understanding of several factors: what led to participation in the study ("Why did you join the study?"), aspects of living with incontinence ("Could you describe your symptoms before joining the study?"), feelings experienced during the treatment ("How did you experience the treatment?"), treatment effect ("In what way has the treatment altered your incontinence symptoms?") and, when applicable, the relationship with the urotherapist ("How was your contact with the urotherapist?"). The first author (a woman) conducted all of the telephone interviews. During each interview, she encouraged the participant to talk freely about her experiences, and at the end of the interview asked her to raise any subject not yet covered. For better preunderstanding, the first author read the encrypted email contact between the participants and the urotherapist before interviewing women in the Internet group. The mean interview time was 23 minutes (range = 11 to 45 minutes).<br>The first author recorded and transcribed verbatim 19 of the 21 interviews. One woman did not want the interview to be recorded, and 1 interview could not be recorded because of technical problems. Instead, the first author took notes during and after these 2 interviews.<br>Data collection, transcription, and preliminary analysis proceeded simultaneously. All authors contributed to the analytical process. We compared and discussed the codes, and identified new topics for further elaboration in forthcoming interviews. As with the | | **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, the relationship between the researcher and participants has not been discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>Can't tell, states that informed consent was obtained, but no further information was given. The study was approved by an ethical review board.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, there is a brief description of the analysis process, however no description of how the presented data were selected, or the role of the researcher in the analysis process, although the role of the researcher on the interviews themselves if briefly considered. Categories are sufficiently supported by the data.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of findings, which are discussed in relation to the original research question. Methods to ensure credibility are also briefly discussed. |

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| | codes, the emerging categories were continuously discussed within the research group, and constant comparisons were made between the new findings and the raw material in the transcribed interviews. The interviews continued until no new categories emerged (that is, until saturation was reached).<br>To check the trustworthiness of the analysis, a group of researchers participating in a qualitative research course coded and discussed 1 part of an interview. These researchers, who were not involved in the present study, recognized and thereby confirmed the findings. | | **10. How valuable is the research?**<br>The study is valuable in shedding light on the research question, but the authors do not discuss implications in great deal, or identify new areas for research.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate<br>**Source of funding**<br>The study was supported by grants from the Swedish Council for Working Life and Social Research, Västernorrland County Council, Jämtland County Council, Västerbotten County Council (ALF), and Visare Norr, Northern County Councils, Sweden.<br>**Other information**<br>Other themes were reported that were relevant to the protocol however not extracted because theoretical saturation was reached (see Supplement 1: methods). |
| **Full citation**<br>Buurman, M. B. R, Lagro-Janssen, A. L. M., Women's perception of postpartum pelvic floor dysfunction and their help-seeking behaviour: A qualitative interview study, Scandinavian Journal of Caring Sciences, 27, 406-413, 2013 | **Recruitment strategy**<br>Women were selected from 2 practitioner populations in different parts of the Netherlands. The 2 practitioners offered a full range of general practice healthcare. Obstetric care was provided by midwife or gynaecologist. The inclusion criteria included: vaginal delivery, at home or in hospital, of a | **Findings (including author's interpretation)**<br>**Feelings of shame**<br>Women reported feelings of shame about their pelvic floor problems. These feelings inhibited many women from seeking help as women felt embarrassed and feel pelvic floor problems are associated with being dirty and old. They | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, aim is clearly stated as "improve our understanding of women's cognitions relating to pelvic floor dysfunction and of impediments to help-seeking behaviour so as to improve the match between patients' needs and medical help." |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| **Ref Id**<br>1284220<br>**Country/ies where the study was carried out**<br>The Netherlands<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | viviparous baby without serious abnormalities, in the period between 1 November 2008 up until 1 November 2009, prepared to participate in the study, Dutch-speaking, with no history of serious psychiatric issues. The women were personally invited to participate in the study during consultation hours or by telephone.<br>**Setting**<br>Not reported<br>**Participant characteristics**<br>N=26<br>**Age (n)**<br>20-24: 3; 25-29: 6; 30-35: 10; 36-40: 7<br>**Ethnicity**<br>Dutch: 24; Indonesian: 1; Bulgarian: 1<br>**Education level**<br>Secondary school: 5; Intermediate vocational education: 6; Higher vocational education: 6; University: 9<br>**Parity**<br>1: 14; 2: 10; 3:1; 4:1<br>**Pelvic floor problems**<br>Pain: 26; Sexual problems: 19; Urinary incontinence: 17; Haemorrhoids: 16; Other micturition problems: 13; Prolapse: 12; Defecation problem: 11; Vaginal flatulence: 6; Anal flatulence: 5 | thought that healthcare professionals could help by asking direct questions about pelvic floor problems. Doing this has led to women being convinced that they are a normal problem to talk about with your doctor.<br>**The role played by initiates and help-seeking behaviour**<br>Women looked for support in their immediate environment, including female relatives or close female friends who had had deliveries. These initiates provide comfort to the women that they are not abnormal.<br>**Lack of information about pelvic floor dysfunction**<br>Women demonstrated a lack of knowledge regarding the pelvic floor and what it does, as well as the various pelvic floor problems that can arise after pregnancy and delivery. Many women, were unaware of the relation between vaginal flatulence, constipation, sexual dysfunction, and reduced pelvic floor support function. Women stated they had not been sufficiently informed about pelvic floor dysfunction and treatment options by their midwife or gynaecologist. Those who had taken yoga or done post-partum exercise had been been given a brief explanation about pelvic floor problems and pelvic floor exercises. Most women badly needed information, both before and after delivery. They wanted to be prepared for what might happen to them. In addition, they wanted to know when they had to call in medical help. Women believed that pelvic floor exercises could | **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, constant comparative methods were used to ensure that recruitment continued until data-saturation was reached and no new themes were found.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes, qualitative semi-structured interviews were appropriate<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Yes, the recruitment strategy includes only postpartum women, which is not explicitly mentioned in the aims of the study, but is made clear elsewhere in the paper.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Mostly yes, the researcher does not specify the setting of the interviews, however does state how the data were collected (semi-structured interviews), although this is not given an in depth justification. The researcher is clear that a topic guide was used, and states they were recorded, although unclear if this |

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| | **Data collection and analysis**<br>Two female interviewers conducted the interviews. Female interviewers were chosen because female patients disclose intimate medical information more easily to female doctors. The interviewers had had no delivery themselves, but they had the impression that being female and being an almost graduated medical student was enough for the participants to disclose. The 2 interviewers took an interviewing class. To elicit women's cognitions and help-seeking behaviour for these sensitive problems, semi-structured face-to-face interviews were used. The interviews were digitally recorded and conducted by means of an interview guide, which had been compiled on the basis of the literature and expert opinion. The interviews started with an introduction on pelvic floor dysfunction. Exploration of women's cognitions and help-seeking behaviour was guided by a list of topics, including women's ideas on the cause and disappearance of their problems, the influence they had on their problems, feelings of shame, impact on everyday life, help-seeking behaviour and received professional information. Prior to the interview, the interviewees completed a brief questionnaire with personal data and delivery data.<br>Content analysis was performed using the technique of constant comparative analysis. The interviewers transcribed the recorded interviews in full. The interviews were analysed by the authors and the interviewers independently. They were divided into meaningful fragments | help, but did not know what exercise to do or how to do them.<br>**Example quotes**<br>"No, I didn't call in medical help because my relatives, especially my mum and my gran, said that it would just pass off. So I was like if my mum and my gran say so, it'll be all right"<br>"So I think that's very odd, that this midwife told me nothing about the pelvic floor during my pregnancy. She only said something about it at a check-up visit when I mentioned that I had such a heavy feeling. So it turns out that's your pelvic floor"<br>"Well, I thought to myself sometimes: am I doing this right? For you might be training as much as you like and then find out afterwards that you're not doing the right exercises. So this would have no effect at all: you'd be training the muscles in your buttocks instead of the proper ones in your pelvic floor."<br>"'Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal"<br>"It's like there's a train that's driven right through you. I understand that your body needs time to recover. If I just look after myself properly and don't neglect my body, I expect this prolapse won't be so painful after a while" | was by tape recordings, or video recordings.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, some discussion of the use of female interviewers to improve the relationship between the researcher and the participants, but no reflective statement about any of their own biases at any stage.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>Can't tell, women were given a written invitation and information of the study, but unclear how long they had to decide whether or not to participate. No mention of whether there was a discussion regarding informed consent, confidentiality etc. States that upon consultation, ethical approval was not required.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, gives some detail on the method of data analysis although this is not in depth. Themes are well supported by the presented data. No evidence of researcher examining their own role during the analysis or selection of data for presentation, although does state that this was done by committee. |

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| | belonging to the themes in the interview guide. As analysis occurred concurrently with data collection, emerging topics, which did not match the previously identified themes of the interview guide, could be explored in later interviews. In the case of encoding differences, frequent discussions between the researchers ensured thorough and consistent coding. Subsequently, the researchers read the interviews a number of times in their entirety so as to define the core themes that had been raised in the interviews; these core themes were discussed by the supervisory committee (the supervisors of the PhD student, a senior researcher and another PhD student). Significant quotations were selected and added to the report to underpin the themes. All researchers read and analysed the interviews. | "When you've just had a delivery, you've got a thousand things on your mind and you're a bit of a scatterbrain. So to be honest, I wasn't really thinking about my problem holding my stools in, as I had more important things on my mind. I just thought: it'll be all right."<br>"I was very happy when I read that vaginal flatulence existed because I thought it was impossible, but it was possible indeed!"<br>"Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal." | **9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, main conclusions are presented clearly and in relation to the original aims.<br>**10. How valuable is the research?**<br>Discusses both the implications for women in practice and also implications for research.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate limitations<br>**Source of funding**<br>No funding |
| **Full citation**<br>Cichowski, Sara B, Dunivan, Gena C, Rogers, Rebecca G, Komesu, Yuko M., Patients' experience compared with physicians' recommendations for treating fecal incontinence: a qualitative approach, International Urogynecology Journal, 25, 935-40, 2014<br>**Ref Id**<br>1284228<br>**Country/ies where the study was carried out** | **Recruitment strategy**<br>Physicians from a wide geographical area of North America were asked to participate in a cognitive interview and were intentionally recruited because of significant publications or notoriety in the field of FI. Participants were screened by asking whether they "routinely cared for women with FI." Those who did consented and continued the interview process.<br>Women with bothersome FI for >3 months were recruited from an academic urogynecology clinic to participate in focus groups. Inclusion criteria were age | **Findings (including author's interpretation)**<br>Initial line-by-line coding revealed 12 themes discussed by the focus groups: embarrassment, worry, ability to do things that you enjoy, effect on lifestyle, smell, no treatment recommendations from physicians, wanting to be/feel healthy, will to get better, desire to get better, personal effort, hope, and living life.<br>When the context of these themes was reviewed, there was an overarching consensus in the groups that they wanted a motivational message | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, the aims of the research are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to explore physician and patient perspectives regarding the treatment for FI. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| USA<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | >18 years of age, diagnosed with FI by 1 of the attending physicians, bothersome FI symptoms for at least 3 months, ability to give informed consent, and ability to speak, read, and comprehend English. Bothersome was defined as having sought care for FI combined with subjective assessment that FI interfered with daily activities Exclusion criteria were diagnosis of colorectal or anal malignancy, inflammatory bowel disease, rectovaginal fistula, rectal prolapse, and/or history of pelvic floor or abdominal radiation therapy.<br>**Setting**<br>Not reported<br>**Participant characteristics**<br>Eight physicians with specialties in colorectal surgery, gastroenterology, or urogynecology were recruited and agreed to participate in the cognitive interviews. No recruited physicians refused participation.<br>Eleven women recruited from an academic urogynecolgic clinic took part in focus groups.<br>Age (mean), years: 56<br>Duration of FI symptoms (mean), years: 10<br>**Data collection and analysis**<br>Cognitive interviews with physicians: Physicians were asked to | from the physician. As 1 patient summarized: "That every word be an action word… how many of you let us lapse into negative energy because of this condition? You can get really depressed about your life…" Therefore, we synthesized the negative themes into a positive theme generated by the focus group. For example, the themes of smell, embarrassment, and worry were grouped into the theme of living life. Results of this analysis produced 3 emerging concepts regarding treatment options that physicians did not identify but that patients felt important.<br>First, patients wanted doctors to communicate hope for improvement in their condition. Many women had experienced a feeling of futility after seeing a provider; "[I]t's not like our lives are like this or like this (makes a straight or ascending line with her hand). They are like this (makes an up and down motion with her hand). So we need to keep that emotion piece… Hope. Hope is really important."<br>Second, women wanted physicians to give guidelines about treatments but overall wanted to hear physicians tell them to continue living their life. As 1 participant said: "There are many people who get really down and depressed about this condition…and you have to continue to be optimistic and live your life."<br>Finally, women wanted to be counselled that it would take personal effort to achieve improvement in their condition. As 1 woman summarized: "It's like whatever works for you, because everybody's situation is so different. And | **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, not clear why cognitive interviews were used for physicians and focus groups for participants.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the inclusion and exclusion criteria are reported, but not justified. There is no discussion of whether any people who were approached but declined take part.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, it's clear how the data were collected, and the form of the data is described, but the setting is not clear or justified. Data saturation is discussed, and data was collected until it was reached, after 2 focus groups.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, this is not discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)** |

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| | describe the barriers they perceived to affect care-seeking behaviour of patients with FI and to describe their typical nonsurgical treatment recommendations and counselling using an initial set of questions. The initial set was designed as probe questions that then allowed the interviewer to ask additional questions as the physician began leading the conversation in a think-aloud process that fully allows interviewees to express their opinions. Two investigators then reviewed the de-identified transcripts of the cognitive interviews and coded them for themes. Questions were modified, and further specific probe questions were added based on transcript coding, although minimal modification was needed. However, all physicians were asked the initial screening questions and asked to pretend they were counselling a patient with FI regarding nonsurgical options. We planned to interview physicians until thematic saturation was reached. These themes were also used to generate a patient focus-group interview guide that addressed the treatments physicians typically recommended for FI.<br><br>Focus groups with women with FI: Topics discussed in the focus groups included: knowledge and personal experience with FI symptoms, barriers to seeking care, and knowledge of treatments. The groups were scheduled for 90 min and conducted by trained moderators (not a care provider or any investigator in the study. The standardized interview guide allowed for probing and discussion around the topic of FI treatment but also allowed the | I'm the only one who knows on a daily basis how I feel, how regular I am, how much signal I have of whether I'm going to poop or not, how often I have to change my pads, or how much of a regular or normal life I can have."<br><br>**Example quotes**<br><br>"But I think not talking about these things like hope is a mistake. I think we need to have hope and happiness to know that there is a positive outcome possible for us." | Can't tell, approval was obtained from the institutional review board, and stated that consent was obtained, but no details are provided to detail how this was done, and no mention of other issues such as confidentiality.<br><br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, the method of analysis is briefly outlined, but not in detail. There is no explanation of how the presented data were selected or discussion of the potential impact of the researcher on the process. Methods used to increase trustworthiness are described.<br><br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, the findings are clearly stated and discussed in relation to the research question.<br><br>**10. How valuable is the research?**<br>The study identified the needs of women with FI which is valuable, and has implications for physicians caring for women with FI. Other avenues for future research are also briefly explored.<br><br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate |

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| | group to collectively discuss their experience with nonsurgical treatment in order to fully express their opinions and feelings. This structure, typical for focus groups, was used in order to begin the conversation and provide a basis for discussion while not squelching discussion; participants were encouraged to discuss issues important to them. At the end of each group meeting, themes were summarized, and members verified that the moderator's interpretation of discussion was in agreement with their understanding. Based on investigator experience, planned recruitment was for 6-8 participants per group; we anticipated that we would reach thematic saturation with 3-4 groups. Focus group discussions were recorded; audiotapes were transcribed, de-identified, and transcripts independently reviewed and coded.<br>For physician interviews and patient focus group discussions, qualitative data analysis was performed using a constructivist, grounded-theory methodology. Briefly, grounded theory assesses the research situation and theory available for study. Initially, the researcher codes line-by-line transcripts, identifying key phrases in the patient's own words. Then, phrases are grouped together to create clusters and preliminary themes. These themes are then summarized into emergent concepts so that the researcher has taken an active role in the process of developing the emerging theory. Dominant trends were identified within | | **Source of funding**<br>This study was supported by a pilot grant from the Clinical and Translational Science Center at the University of New Mexico. Supported by the National Center for Research Resources and the National Center for Advancing Translational Sciences.<br>**Other information**<br>Other themes were reported that were relevant to the protocol however not extracted because theoretical saturation was reached (see Supplement 1: methods). |

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| | each focus group, and groups were compared in order to generate themes or patterns in the way participants described their experiences. Each transcript was reviewed by 2 independent researchers trained in grounded theory methodology and were then reviewed collectively to identify consensus. One external reviewer researched the process and audited findings for accuracy. If consensus was not reached, a third reviewer assessed the transcript. Content reviews were conducted after each focus group in order to modify the script and further explore concepts with subsequent focus groups. This was an iterative technique that ensured a thorough and systematic review of all thematic content in each transcription. Results generated a list of conceptual gaps in existing treatment recommendations. The combination of physician cognitive interviews and patient focus groups provided different data sources and allowed for triangulation to better understand how physician and patient perspectives overlapped and differed. | | |
| **Full citation**<br>Dunivan, Gena C, Anger, Jennifer T, Alas, Alexandriah, Wieslander, Cecilia, Sevilla, Claudia, Chu, Stephanie, Maliski, Sally, Barrera, Biatris, Eiber, Karyn, Rogers, Rebecca G., Pelvic organ prolapse: a disease of silence and shame, Female Pelvic Medicine & Reconstructive Surgery, 20, 322-7, 2014<br>**Ref Id** | **Recruitment strategy**<br>Patients seen in any of these Urology or Urogynecology clinics were recruited at the time of their initial visit and invited to participate in a 1.5-hour focus group. Inclusion criteria included a diagnosis of pelvic organ prolapse (POP) based on physician diagnosis, preferred language of either English or Spanish, age 21 or older, no significant pelvic issues such as pelvic pain or painful bladder syndrome, and no significant psychiatric history. | **Findings (including author's interpretation)**<br>Themes are reported for English and Spanish groups separately, however these are not described in detail (title of theme and a quote only). Two concepts that were shared between the 2 groups, and 1 unique to the Spanish group were described in more detail:<br>**Patients lack of knowledge:**<br>This lack of knowledge included basic knowledge about anatomy and the | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, aims are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to address the aims, to understand women's experiences with POP. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| 1284233<br>**Country/ies where the study was carried out**<br>USA<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | **Setting**<br>Three separate academic Urology and Urogynecology centers, including Cedars-Sinai Medical Center (a non-profit private hospital in Los Angeles), Olive View Medical Center (a public hospital in northern Los Angeles County) and the University of New Mexico (a large academic health complex in Albuquerque, New Mexico).<br>**Participant characteristics**<br>N=58<br>Primary language: 25 English, 33 Spanish<br>Age (mean): English group - 63.8 years (range 33-90 years); Spanish group 56.6 years (range 46-77 years)<br>**Data collection and analysis**<br>A total of 8 focus groups of 6-8 women each were planned, with 4 groups in English and 4 in Spanish. Patients were placed in either an English or Spanish focus group based on their preferred language. A single, trained bilingual moderator conducted all of the focus groups and each focus group was for approximately 1.5 hours. A standardized open-ended topical guide in English and | prevalence of pelvic organ prolapse. This resulted in patients' reported embarrassment regarding their condition, feelings of humiliation, and feeling somehow unnatural or less like a woman. This subsequently lead to the concept of shame and silence regarding their condition, including the feeling of self-blame for the development of the prolapse.<br>**More information and education about pelvic organ prolapse is needed:** Participants felt that more information and education about their condition would allow for more dialog with their families, healthcare providers and community. This information and dialog would help address their fears and difficulty coping with pelvic organ prolapse. Increased knowledge and dialog could also lead the way to relieve the humiliation and shame that women felt. Women felt relief in knowing they were not alone.<br>**Spanish-only speaking women face additional communication challenges:** Many women in the Spanish-only group expressed concerns about their communication with providers that didn't speak Spanish. They expressed concerns that they felt a lack of confidence in a provider that did not speak Spanish, and also frequently offered praise for the providers they had that did speak Spanish. Some women expressed that they not only felt uncomfortable in the presence of interpreters, but that they felt that the interpreters were not accurately translating what they said. | **3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the use of focus groups is not justified by the researchers.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, inclusion criteria are suitable to address the study aims, but exclusions are not justified. No discussion regarding any women who were invited but decided not to take part.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, not much information given regarding the setting or justification of methods used. Does give information regarding the form of data (recordings) and how the data were collected (focus group), and the methods (open ended topic guide). Saturation of data is not discussed.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, no mention of the role of the researcher, and their potential biases/influences. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | Spanish was used to elicit patients' perceptions, their knowledge and experience with pelvic organ prolapse symptoms, diagnostic evaluation, physician interactions, and treatments. All focus groups were recorded and transcribed. Focus groups in Spanish were transcribed and translated verbatim by a qualified translator.<br>Qualitative analysis was performed using grounded theory. Grounded theory is hypothesis generating. Briefly, this involved line-by-line coding of the transcripts to identify key phrases from the focus group participants' words. These key phrases were naturally grouped together to form preliminary themes, from which emergent concepts arose. Patient quotes were pulled to illustrate and support the preliminary themes and concepts. Three separate researchers independently completed the line-by-line coding to reduce subjectivity. Discrepancies between codes were resolved through discussion and consensus. | **Example quotes**<br>“I'm part of a big group of women here. It's not just me” … “You're not alone! And it doesn't have to be so private”<br>“I went to the bathroom and I felt myself and I didn't know what it was and I was scared”<br>“My mother would always caution me to not lift heavy things because later when you grow up, your insides will fall out”<br>“You’re not alone!” | **7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)**<br>No mention of any ethical issues being discussed with participants. The study did obtain IRB/HRRC approval.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No)**<br>Can't tell, analysis is described very briefly, although it is clear how themes arose from the data. States that quotes were pulled out to illustrate the themes, but does not state how those quotes were selected. Themes are not well described, but concepts have more details, although generally only supported by 1 or 2 direct quotes.<br>**9. Is there a clear statement of findings? (Yes/Can’t tell/No)**<br>Yes, findings are explicit. Three researchers completed coding to reduce subjectivity. Findings are discussed in relation to aims.<br>**10. How valuable is the research?**<br>The researcher describes future research to build on what was found in this study, but has not mentioned how findings may translate to other populations. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | | | **Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations<br>**Source of funding**<br>Funded by a National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Patient-Oriented Research Career Development Act Award and an American Recovery and Reinvestment Act, supported by a pilot grant from the Clinical and Translational Science Center at the University of New Mexico, National Center for Research Resources and the National Center for Advancing Translational Sciences |
| **Full citation**<br>Kiyosaki, K, Ackerman, A. L, Histed, S, Sevilla, C, Eilber, K, Maliski, S, Rogers, R. G, Anger, J., Patients' understanding of pelvic floor disorders: what women want to know, Female Pelvic Medicine & Reconstructive Surgery, 18, 137-142, 2012<br>**Ref Id**<br>1284268<br>**Country/ies where the study was carried out**<br>USA<br>**Study type**<br>Qualitative | **Recruitment strategy**<br>Patients were recruited from a single female urology specialty clinic within the UCLA health care system. Women eligible included new patients with referrals or chief complaints suggestive of any types of UI or POP. Potential subjects were excluded if they did not speak English, were younger than 21 years, or had dementia prohibiting effective interviewing. Files of all new female patients were screened on patients' arrival to the office for referrals or chief complaints of SUI, OAB symptoms, MUI, and POP of any compartment at any stage. Patients with chief complaints consistent with POP or UI were recruited at their first office visit, and informed consent was obtained. Diagnoses were confirmed by the physician based on history and physical examination. Patients were excluded if, | **Findings (including author's interpretation)**<br>**Good understanding of treatment despite incomplete understanding of their diagnosis**<br>Even patients who could not recall their diagnosis could explain their treatment options. One patient was confused about her diagnosis of MUI but understood her treatment and said, ''I have stress incontinence and laugh, cough, sneeze incontinence. I should restrict fluid intake, do Kegel exercises, and try the medication.'' This lack of understanding of diagnosis is further demonstrated by hearing the diagnoses in the patients' own words before and after the physician's visit. When tangible terms such as ''overactive bladder'' are given, patients had a better recall of their diagnosis. | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, the purpose of the study and the rationale is clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to assess women's understanding of PFDs.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, there is no justification or explanation for the use of interviews. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| **Study dates**<br>Not reported | once examined, they were determined to not have a diagnosis of UI or POP. The patients participated in a health literacy assessment and interview session with a trained female research assistant before and after their physician encounter.<br>**Setting**<br>Clinical<br>**Participant characteristics**<br>N=20<br>UI symptoms: n=16<br>POP symptoms: n=4<br>Mean age (range), years: 60.5 (31-87)<br>Race: Caucasian 15; Hispanic 3; African American 1; Asian 1<br>Education level: College + 8; Some college 6; High school 4; Declined to state 2<br>**Data collection and analysis**<br>Before the initial physician's visit, a trained female assistant used pre-scripted questions to interview patients. The interviewer was a research coordinator with medical knowledge and training in qualitative theory methodology. The questions included the following: ‘‘Please explain to me why you are here to see the doctor today and what you think your diagnosis might be.’’ After the physician's visit, the female assistant interviewed patients again using pre-scripted questions: ‘‘Can you please tell me what the doctor told you your diagnosis was today?’’ and ‘‘What | **Relief because their disorder is not as bad as they feared**<br>The patients felt relief when they learned that their diagnosis was not as severe as they initially feared. Several patients were thankful to discover they did not have cancer, whereas others were relieved to learn that their condition did not warrant surgery.<br>**Relief because something can be done to gain control or problem**<br>There was a sense of relief the patients felt because they could do something to gain control of their condition. Patients with prolapse expressed a sense of relief that their symptoms would resolve.<br>**Example quotes**<br>“I didn't even hear my diagnosis. She gave me Vesicare and Kegel exercises”<br>“The doctor doesn't think it's as severe as the original person I saw. I'm relieved because I don't need surgery” … “The doctor found problems and can fix them” | **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the inclusion and exclusion criteria is stated but not justified. There is no discussion of how many women were approached and if any declined participation.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the setting is not stated or justified, and there is not a lot of detail regarding the explicit methods of carrying out interviews. It is also unclear what form the data is in. Data saturation is also not discussed.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, no discussion of the relationship between the researcher and the participants.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>Can't tell, states that informed consent was taken but does not say how. Study was approved by the institutional review board. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | treatment options did your doctor offer you today?'' All interviews were audio recorded and transcribed.<br>During the physicians visit: Physician's treatment plans were based on patients' diagnosis and were consistent with current standards of care. All patients were counselled on their diagnosis and treatment plan with the use of pelvic models. During physical examination, all patients were also tested on pelvic muscle strength and given a demonstration on how to perform pelvic floor exercises.<br>The interview transcripts were analysed using qualitative grounded theory methodology as outlined by Charmaz. Unlike quantitative research methodology, qualitative methodology does not test a hypothesis. Instead, it allows the researcher to search for a theory implicit in the data. The researcher identifies key issues by coding and finding categories, which include initial line-by-line coding of transcripts using key phrases in the patients' own words. Next, similarly coded phrases are grouped together into preliminary themes. Then, preliminary themes are aggregated to develop categories. Finally, core categories or emergent concepts are derived from these themes. To reduce subjectivity, 3 individual investigators performed line-by-line coding and derived preliminary themes that were later compared and merged. The investigators included a combination of clinical MDs and PhDs | | **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, there is a very brief description of the analysis process that describes how themes were developed from the data. However, there is no explanation of how the data presented were selected from the original sample, and no discussion of their own role in the analysis and selection process. The themes are not described in detail, but are supported by sufficient data.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of findings.<br>**10. How valuable is the research?**<br>The researcher discusses their findings and potential future research, but does not consider the findings in relation to current practice.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations<br>**Source of funding**<br>Funded by a Patient-Oriented Research Career Development Award, American Recovery and Reinvestment Act |

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| | with expertise in female urology and qualitative methodology. | | Supplement from the National Institute of Diabetes and Digestive and Kidney Diseases<br>**Other information**<br>Other themes were reported that were relevant to the protocol however not extracted because theoretical saturation was reached (see Supplement 1: methods). |
| **Full citation**<br>Pakbaz, Mojgan, Rolfsman, Ewa, Mogren, Ingrid, Lofgren, Mats, Vaginal prolapse--perceptions and healthcare-seeking behavior among women prior to gynecological surgery, Acta Obstetricia et Gynecologica Scandinavica, 90, 1115-20, 2011<br>**Ref Id**<br>1273701<br>**Country/ies where the study was carried out**<br>Sweden<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | **Recruitment strategy**<br>Women with symptomatic POP were recruited from the waiting list for prolapse reconstructive surgery of a hospital in northern Sweden. Symptomatic POP was defined as present of a vaginal bulge and/or other symptoms from the bowel or the bladder. Prolapse was assessed using the POP-Q classification system, and prolapse of stage II or more was identified at gynaecological examination. The inclusion criterion for the study was symptomatic vaginal prolapse for which corrective surgery was planned in the near future. Exclusion criterion was recurrent vaginal prolapse with previous surgical intervention. Recruitment of the informants with planned surgery was according to 'purposive sampling', for instance, the greatest variation of characteristics such as age, occupation, parity, BMI, and marital status in order to capture wide narratives from the informants.<br>**Setting** | **Findings (including author's interpretation)**<br>**Obstacles to healthcare**<br>*Absence of information*<br>Informants expressed that information on vaginal prolapse was not easily accessed. They had not observed any information about prolapse in brochures or weekly magazines by accident. They had to actively search for information on prolapse. Insufficient knowledge about the condition at an individual level, as well as within the societal arena, made the informants uninformed and uncertain. They couldn't address which condition they were actually suffering from.<br>*Feeling ignored by the doctor*<br>The informants reported having had symptoms of prolapse several years before they decided to seek health care for the problem. Some informants expressed that their symptoms had not been confirmed at previous consultations with doctors, which made them doubt their own perceptions of the condition. They expressed that the inconvenience they felt was not | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, the study aims are clearly described.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to elucidate the experiences of living with vaginal prolapse and its impact on daily life.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, no justification of the use of interviews specifically.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)** |

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| | All but 1 interview took place in a separate room within the hospital. One interview was performed in the home of the informant.<br>**Participant characteristics**<br>N=14<br>Age (median, range), years: 56.5 (42-79)<br>Duration of symptoms (range): 2-10 years<br>**Data collection and analysis**<br>An interview guide was developed by the investigators, including open-ended questions addressing different topic areas based on the scientific literature of determinants for vaginal prolapse and the clinical experiences from this medical field available within the research group. The interview guide was thereafter processed in the research group in order to integrate as many appropriate aspects of the research question as possible. The interview guide was later revised during the data collection, according to an emergent study design.<br>In-depth interviews lasting 40-50 minutes were conducted. The interviewer specifically stated to the informants at the beginning of each interview that the interview was a research event, not a medical consultation. The interviewer strived to create an atmosphere of interest and respect for the experiences conveyed by the informant. All | acknowledged and confirmed, leading to a further delay until they generated enough motivation and courage to visit the doctor again. Several of the informants experienced that they had not received information from their doctor on the procedure for the planned operation.<br>**Example quotes**<br>“When he [the doctor] had seen it [in earlier consultation], he thought, 'This isn't a problem'. I was disappointed, so, 'It wasn't so bad'? I was a bit surprised, and I feel that I have problems. But I believed [what the doctor said], 'There is no problem' so I carried on. That's why I went so long [before seeing the doctor again]”<br>“I think there is very little written about this problem [prolapse] if you read just about anything, like weekly magazines. You know, you can read a lot about genital problems in magazines, but this particular problem I haven't run across often”<br>“There isn't any information really [on prolapse], not in the way that you just stumble across it somehow. If I haven't searched [for the information] myself, I don't think I just happen to read about it by accident” | Can't tell, the inclusion and exclusion criteria is described but not justified. Two women declined participation and the reasons for this are not reported.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)**<br>Can't tell, the setting of the interviews was described but not justified. The use of an interview guide is described in detail, and there is an explanation of changes to the interview guide and data saturation.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)**<br>The relationship between the researcher and participants was briefly described for 1 participant who had a patient-surgeon relationship with 1 of the researchers, however the impact of this was not discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)**<br>Yes, there is a description of how participants gave informed consent, and that a discussion of confidentiality was had. The study was approved by an ethics committee. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | communication skills were used to ensure an open discussion and to encourage the informants to fully describe their experiences. By using follow-up questions like 'Could you tell me more about it?' and 'What do you mean?' or 'Would you please give an example?' the experiences of the informants were further elaborated. At the end of each interview, the investigator made a verbal summary of the informant's statements to ensure that the history given by the informant had not been misunderstood.<br>The first author transcribed verbatim the first 3 tape-recorded interviews. Pauses and interruptions were also noted. The remaining interviews were transcribed by a secretary who used the same approach and procedure in the transcription process as the first author. After 8 interviews with concurrent analyses, a revision of the interview guide was made and an additional 4 informants were recruited to the study, thus constituting an emergent design. At this stage when 12 interviews were performed, saturation of data related to the research question was obtained however, 2 final informants were recruited to ensure that no new substantial experiences were expressed.<br>The interviews were analysed using qualitative content analysis. Both the manifest content, that is, what the text said, and the latent content, what the text described and expressed were analysed. Qualitative content analysis focuses on the subject and the context illustrating the differences between, and | | **8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, the data analysis methodology is described in detail, and it is clear how themes were derived. It is not stated how the presented data were selected or the researchers influence on the process, however it is stated that consensus was reached between researchers which may have reduced subjectivity.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of findings, which are discussed in relation to the original aims of the study. The trustworthiness of the research is also discussed.<br>**10. How valuable is the research?**<br>The researchers discuss areas for further research, as well as how the study helps inform current practice.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Minor limitations<br>**Source of funding**<br>Not reported |

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| | similarities within, codes and categories. Content analysis is a stepwise process. First, the interviews were thoroughly read several times to obtain a sense of the whole and identify the content area. Second, the text was divided into meaning units and condensed to make the text shorter, while retaining its core message. At the third step, the condensed meaning units were abstracted and labelled with codes. Fourth, the various codes were compared on the basis of similarities and differences and sorted into schemes labelled categories and subcategories. The final step of the analysis was to identify a theme. In order to seek consensus between the researchers, the categories and subcategories were further discussed, which led to refinement of the scheme of categories, and the identification of a single theme, which was interpreted as the underlying or latent message of the abstracted categories. | | |
| **Full citation**<br>Pintos-Diaz, Maria Zahara, Alonso-Blanco, Cristina, Paras-Bravo, Paula, Fernandez-de-Las-Penas, Cesar, Paz-Zulueta, Maria, Fradejas-Sastre, Victor, Palacios-Cena, Domingo, Living with Urinary Incontinence: Potential Risks of Women's Health? A Qualitative Study on the Perspectives of Female Patients Seeking Care for the First Time in a Specialized Center, International Journal | **Recruitment strategy**<br>Patients with UI who attended the specialized UI center (Madrid, Spain) for the first time were enrolled in the study between June 2015 and June 2017. Purposeful sampling methods were employed based on the relevance to the research question (not based on clinical representativeness). All patients were recruited during their first visit to the clinic to ensure that none had experienced a significant improvement at the time of the study. The recruitment | **Findings (including author's interpretation)**<br>**Information based on Beliefs and Myths Regarding UI**<br>*Lack of information*<br>All the women who participated in the study complained about the overall lack of information and about how the little information was available to them was unclear. Many had not heard of UI before suffering the initial symptoms and were | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, the aims of the research are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate for identify the experiences of Spanish women diagnosed with UI |

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| of Environmental Research and Public Health, 16, 2019<br>**Ref Id**<br>1273769<br>**Country/ies where the study was carried out**<br>Spain<br>**Study type**<br>Qualitative<br>**Study dates**<br>Participants were enrolled between June 2015 and June 2017 | took place when the women initially visited the clinic. If they met the inclusion criteria and agreed to participate, then they were included in the research project. During this first visit, they were given information on the study and participation in the study was confirmed 2 weeks later by telephone. The women who agreed to participate were consecutively enrolled in the study. The interviews were scheduled during the following 2 weeks. The sampling process continued until the researcher achieved information redundancy, at which point no new information emerged from the data analysis. No participants withdrew from the study.<br>The subjects included in the study were: (a) females aged >18 years old; (b) who attended the center due to an involuntary loss of urine; (c) with UI symptoms and signs according to the American Urological Association and Society of Urodynamics, Female Pelvic Medicine guidelines, for example stress, urgency, coital urinary incontinence, nocturnal enuresis, extraurethral incontinence, etc. The exclusion criteria included: (a) a pregnancy and/or post-natal situation (up to 3 months after delivery); (b) pelvic organ prolapse; (c) persistent urinary tract infections; (d) serious systemic and/or psychiatric disorders; (e) recipients of physical therapy interventions for the pelvic area over the previous year; and (f) inability to communicate in Spanish or to sign the informed written consent form. | unaware of where to go to receive treatment<br>**Example quotes**<br>“For chest pain it seems quite clear to me, bleeding also, but for this…where should I go (for help)?” | and to describe the reasons that trigger the search for help for the first time.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can’t tell/No)**<br>Yes, the researcher discusses why the research design was used, and this is appropriate<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can’t tell/No)**<br>Can't tell, the researcher has explained how participants were selected but has not explained by they were thought to be the most appropriate. They state that no participants withdrew, but it is unclear if any declined to participate.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can’t tell/No)**<br>Yes, it is clear how the data were collected and the methods are justified and explicit. The form of the data is clear; however, data saturation was not discussed.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)**<br>Can't tell, the researcher discusses the use of bracketing, to 'allow critical |

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| | **Setting**<br>A private room at the UI centre<br>**Participant characteristics**<br>N=18<br>Diagnosis: SUI 61.11%; UUI 22.22%; MUI 16.66%<br>Mean age (range), years: 47.32 (23-58)<br>Duration of symptoms, range: 1-46 months<br>**Data collection and analysis**<br>First-person data collection tools (in-depth interviews and participants' letters) were used. Open-ended interviews were used as the main tool for data collection. These were minimally structured and without time limitations. After establishing rapport, the initial questions asked participants to describe their experience in as much detail as possible. The interviews started with an open question: 'What is your experience with UI?' What are the reasons that made you seek help for the first time? Thereafter, the researchers listened carefully, noted the key words and topics identified in the females' responses, and used their answers to clarify the content. The following questions focused on points of elaboration and clarification. Reflective statements are used to encourage participants to describe the event or experience things in more detail. Verification can occur by restating earlier parts of the conversation. The interviews were conducted by a female researcher. | | examination of a phenomena without influencing the researchers own beliefs', but does not explicitly examine their role and potential biases in the research design or collection.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>Can't tell, states that informed consent was obtained but unclear how and no mention of whether confidentiality was discussed. Ethical approval was obtained.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, the analysis process is described, including how themes were derived from the data, however there is no explanation of how the presented data were selected, or if the researcher examined their own role in the process. The themes are supported by the data.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of findings.<br>**10. How valuable is the research?**<br>The research has valuable implications regarding information needs of women and support needs. Future research is explored. |

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| | All women were interviewed alone. The interviews were conducted in Spanish.<br>The women participating in the study were asked to write personal letters, which were used as part of the analysed data, bringing the task of data collection into the respondents' everyday world. These letters were meant to obtain information in a non-obstructive manner by capturing ordinary events and observations that might be neglected by single-recording methods because often participants perceive these as being insignificant, or fail to remember them. Participants were given a 2 -week period to respond to the same questions used in the interviews. This procedure sought to avoid affecting how the participant conceptualized their responses, and perceived events. The participants were requested to describe the most relevant aspects of their experience according to their perspective, with no limits to the length of the accounts nor the contents of the same. Participants were recommended to write at least once a day, whenever they chose to do so. The written accounts were subsequently handed in either in paper or electronically, according to their personal preference. The field notes were collected during the interviews with the aim of noting participants' gestures and non-verbal language (for example: nervousness or discomfort). The researcher also collected descriptions of the place where the interviews were held, comments on methodological aspects and descriptions of any event (for example: interruptions during the interview) taking place during data | | **Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate<br>**Source of funding**<br>This research received no external funding.<br>**Other information**<br>Other themes were reported that were relevant to the protocol however not extracted because theoretical saturation was reached (see Supplement 1: methods). |

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| | collection. All the interviews were digitally audio recorded and transcribed verbatim. The average time of each interview was 80.55 minutes. The full literal transcription of each of the interviews, the women's letters and the researchers' field notes were all collated in order to perform a qualitative analysis.<br>A thematic analysis was performed, which began by analysing the most descriptive content in order to reach meaningful units. This then went into further depth to produce thematic code groups (grouping meaningful units referring to the same issue or with the same content until the main topics emerged). To identify the relevant content, researchers read and reread the data at 3 different levels: literally, interpretively, and reflexively. In this manner, an increasing level of abstraction and complexity was established for the analysis from meaningful units to thematic code groups and, finally, themes. Immediately after each interview, data analysis procedures began. Each interview was analysed by 2 different members of the research team. The analysis of the women´s letters were integrated into a matrix, together with the analysis of the interviews. Subsequently, meetings were held to identify and compare the results obtained. The final outcome was the identification of themes that represented the women's experiences with UI who sought care for first time. No qualitative software was used to analyse the data. Data was classified, categorized, and organized using Microsoft Excel. | | |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| **Full citation**<br>Rasmussen, J. L, Ringsberg, K. C., Being involved in an everlasting fight - a life with postnatal faecal incontinence. A qualitative study, Scandinavian Journal of Caring Sciences, 24, 108-115, 2010<br>**Ref Id**<br>1284290<br>**Country/ies where the study was carried out**<br>Denmark<br>**Study type**<br>Qualitative.<br>**Study dates**<br>Not reported | **Recruitment strategy**<br>Women were strategically selected, for instance the faecal incontinence had to be caused by anal sphincter rupture due to a childbirth, the incontinence should have lasted for at least 6 months, and they should be fluently Danish speaking in order to avoid misunderstandings during the interview. They had all prior to the study, visited the surgery outpatient department at a hospital of middle size in Denmark, for investigation and/or treatment for faecal incontinence. The women formed a heterogeneous group with regard to the duration and intensity of the disorder (the amount of operations and need for necessities), symptoms, work-related factors (sick-leave, disability pension, working), age, number of children and living with a partner. The selection of participants was made by nurses at the clinic.<br>**Setting**<br>The women chose the place for the interview. Seven were interviewed in their homes and 2 at the interviewer's office.<br>**Participant characteristics**<br>N=9<br>Age (median, range), years: 35 (28-50)<br>Number of children (mean, range): 2 (1-3) | **Findings (including author's interpretation)**<br>**Fighting against attitudes**<br>*Fighting against professionals' attitudes*<br>The women stated that it was important for them that the professionals listened to them in order to understand their problem. They meant that by not being taken seriously was humiliating and undermined their self-esteem. One woman told that the doctor at the maternity ward had neglected her problems. The same woman further explained '…faeces would keep oozing after my visiting a toilet, and I remember that I mentioned it to a nurse…and it was received in an extremely bad way. // She said, ''Well, haven't you got a leaflet?'' and I told her, ''Yes, I've got a leaflet, but maybe I need to talk about it'' but they didn't understand me'. Some of the women had experienced that their problem was neglected by their GP. One woman was told by her GP that it was quite normal after childbirth to have problems with faecal incontinence and flatulence. She also felt that the health care staff had difficulties understanding faecal incontinence as being a problem at all. The women felt neglected and not confirmed by them as they were expected to be able to wait for a very long time for an operation. One woman had to wait 18 months after the childbirth for an operation.<br>**Example quotes**<br>"…faeces would keep oozing after my visiting a toilet, and I remember that I | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, the aims of the research are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to understand the experience of women with FI and how they cope with their condition.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes, the use of qualitative interviews was justified and is appropriate to address the research aims.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the inclusion and exclusion criteria are described but not justified. There are no details regarding how many women were approached and whether any decided not to take part.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the setting of the interviews is not justified, and it is unclear if a topic |

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| | **Data collection and analysis**<br>The interviews were informal and conversational in style, which lasted approximately up to 1 hour. The interviews covered the following 2 main themes 1) What is it like to live with faecal incontinence due to a childbirth complication? and 2) How do you cope with being in that situation? The themes were discussed in all interviews and followed up by probing and follow-up questions in relation to psychological and social aspects, on family life, sexuality, self-perception as a woman and wishes for the future. They were also free to introduce other issues. The first author carried out all the interviews. She had no earlier relation to the women. The nurses at the outpatient department were prepared to take care of them if the interview had raised questions of such a sensitive character that they had a need of discussing it further. However, this did not occur. Saturation was reached after 8 interviews, confirmed in the ninth interview.<br><br>The interviews were tape recorded and transcribed verbatim. Data collection and data analysis occurred simultaneously in line with the guidelines of grounded theory. The hierarchical analysis was made by open, axial and selective coding as described by Strauss and Corbin. The open coding began by line-by-line coding, in close proximity to data, analysing every word and sentence in order to derive as many substantive codes as possible from data. These codes were written in the margin of the | mentioned it to a nurse…and it was received in an extremely bad way. // She said, ‘‘Well, haven’t you got a leaflet?’’ and I told her, ‘‘Yes, I’ve got a leaflet, but maybe I need to talk about it” | guide was used. The form of the data is clear, and data saturation is discussed.<br><br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)**<br>Can't tell, there is a brief statement that the researcher had no earlier relation to the women, but no critical examination of their own role or any potential biases.<br><br>**7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)**<br>Yes, the researchers describe the process of obtaining informed consent and confidentiality. The study had ethical approval.<br><br>**8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No)**<br>Can't tell, the methods for analysis are described sufficiently, and there is a brief description regarding the selection of data. There is sufficient data to support the themes. The role of the researcher in this process is not examined.<br><br>**9. Is there a clear statement of findings? (Yes/Can’t tell/No)**<br>Yes, there is a clear statement of findings that is discussed in relation to the original study aims. |

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| | transcribed protocols. During the axial coding the main focus was on grouping the codes into sub categories and main categories by constant comparison by asking questions about the material and by writing memos. During the selective coding a theoretical structure was formed with a core category around which all the categories were integrated. At last a substantive theory was formulated. Table 2 presents the interplay between the categories, sub categories and examples of codes. When building up the categories, constant comparisons were made between different parts of the data, such as different incidents and experiences. The questions continuously asked to the data were such as: 'What is going on? What does this mean?' Thus theoretical sampling was conducted in order to refine and saturate each category with information. To further increase, the theoretical sensitivity memos were written during the whole process of data collection and analysis.<br>The substantive codes and the categories have been discussed continuously between the authors. To ensure the adaptation of the constant comparison there has been a constant memo writing during the whole process of data collection and analysis. When formulating the substantive theory the guidelines by Strauss and Corbin as described by Hallberg have been followed. Quotations from the interviews are presented in order to facilitate the reader's evaluation of the validity of the results. To ensure confidentiality no | | **10. How valuable is the research?**<br>The research has implications for health care professionals in terms of their communication and needs of women with FI. The researchers also discuss the contribution of the paper in terms of knowledge and understanding.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Minor<br>**Source of funding**<br>Not reported |

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| | identification has been added after the quotations. There are quotations from all participants. | | |
| **Full citation**<br>Sevilla, C, Wieslander, C. K, Alas, A. N, Dunivan, G. C, Khan, A. A, Maliski, S. L, Rogers, R. G, Anger, J. T., Communication between physicians and Spanish-speaking Latin American women with pelvic floor disorders: a cycle of misunderstanding?, Female Pelvic Medicine & Reconstructive Surgery, 19, 90-7, 2013<br>**Ref Id**<br>1284296<br>**Country/ies where the study was carried out**<br>USA<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | **Recruitment strategy**<br>Women were eligible to participate in this study if they were primarily Spanish-speaking and if they had received a referral or had a chief complaint suggestive of POP or any type of UI. Potential subjects were excluded if their primary language was not Spanish, they were younger than 21 years, or if they had cognitive deficits or psychiatric conditions prohibiting effective interviewing. After medical charts were screened by chief complaint, patients who had symptoms suggestive of SUI, UUI, MUI, and/or POP of any anatomic compartment at any stage were recruited at the first office visit.<br>**Setting**<br>Setting not reported<br>**Participant characteristics**<br>N=27<br>Age (mean, range), years: 55.5 (41-71)<br>Pelvic floor problem<br>• POP 6<br>• UI 11<br>• POP/UI 10 | **Findings (including author's interpretation)**<br>**Preliminary themes:**<br>**Before physician encounter**<br>*Poor understanding of anatomy*<br>Patients' oftentimes used the word ''bola'' (''ball'') to describe POP. Similarly, patients used the word uterus and bladder interchangeably without knowing what compartment was actually prolapsed. For several patients, this was the first time they had seen pelvic anatomy models and/or pictures<br>*Desperation with symptoms*<br>Patients felt desperation and helplessness with their symptoms. As 1 patient explained, ''One gets to a point where you stop feeling like a woman because you feel so uncomfortable.''<br>*Reliance of physician*<br>Women reported a complete reliance on the physician to solve the patients' problem, a reliance that was present before the physician encounter. It was common for patients to also rely on the physician for their decision making. Before meeting the physician, 1 patient stated, ''It's up to the doctor to decide what to do with me. I will do whatever she says.''<br>**During physician encounter**<br>*Patients - Seeking physicians' recommendation* | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, aims of the study are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to assess understanding of pelvic floor disorders<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the use of interviews is not explained or justified.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the recruitment method is not described, and the selection of participants is not justified. There is no description of if/why any participants declined to take part.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the setting if not justified, but there is a description of how the data |

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| | Mean PFDI symptom severity:<br>• Urinary Distress Inventory 108 (2-215)<br>• POP Distress Inventory 104 (0-258)<br>• Colorectal-Anal Distress Inventory 80 (0-240)<br>Country of origin<br>• Mexico 70 (19)<br>• El Salvador 14 (4)<br>• Guatemala 4 (1)<br>• Honduras 4 (1)<br>• Nicaragua 4 (1)<br>• Peru 4 (1)<br>Education level<br>• No schooling 7 (2)<br>• Less than high school 56 (15)<br>• Some high school 11 (3)<br>• High school diploma 18 (5)<br>• Some college 4 (1)<br>• Associate degree 4 (1)<br>Religion<br>• Catholic 70 (19)<br>• Christian 26 (7)<br>• None 4 (1) | Patients would commonly ask the physician what they recommended or would often say, ‘‘tell me what to do.’’<br>*Patients - Fearing surgery*<br>Patients feared both surgery and pessaries as treatment options. Patients commonly inquired about risks associated with them, and how each treatment would affect their daily lives. Nevertheless, even with the fear of surgery and pessaries, only 15 of the 27 women asked detailed questions about their condition or treatment options.<br>*Physicians - Avoiding medical terminology*<br>Physicians commonly avoided medical terminology and used simple words to describe the diagnosis. For example, 1 physician described a patient’s MUI as having a ‘‘urine problem’’ and explained to the patient that it was a problem with ‘‘leaking urine without control and leaking urine with coughing, laughing, and sneezing.’’ However, the physician never used SUI or UUI<br>*Physicians - Lack of Spanish proficiency*<br>It was common for physicians to use broken Spanish and English or ‘‘Spanglish’ ’during counselling of patients. In addition, several physicians spoke for several minutes at a time without pausing. This had the effect of bombarding the patients with information and not giving them the opportunity to ask questions.<br>**After physician encounter**<br>*Good understanding of treatment despite poor understanding of diagnosis* | were collected and the form of the data. Data saturation is briefly mentioned.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)**<br>No, the relationship between the researcher and the participants is not examined.<br>**7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)**<br>Can't tell, states that participants gave written informed consent, but does not say how this was obtained. No mention of confidentiality. Approval was obtained from the institutions review board.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No)**<br>Can't tell, there is a description of the analysis process, and it is clear how themes emerged from the data, however it is less clear how the presented data were selected, and some of the themes are not well supported or elaborated on/.<br>**9. Is there a clear statement of findings? (Yes/Can’t tell/No)**<br>Yes, there is a clear statement of findings, including discussion in relation to the aims or the study and discussion of attempts to reduce subjectivity. |

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| | **Data collection and analysis**<br>Patients were asked to participate in a short interview with a trained Spanish-speaking female research assistant before and after the encounter with the physician. Before the physician interview, patients were asked 2 pre-scripted questions about their symptoms and presumptive diagnosis. After the physician encounter, patients were then asked 2 pre-scripted questions about their final diagnosis and treatment plan given by the physician. All interviews were audio recorded and transcribed verbatim.<br>The physician visit involved patients being counselled about their diagnosis and treatment plan after being examined by the physician. To capture real-world variation between providers, the counselling encounters were not standardized. Therefore, counselling included a range of explanations from physicians of different training levels including residents and attending physicians. Other factors that varied between encounters included Spanish proficiency of the physician and the use of pelvic models to explain the diagnosis to the patient. In cases where physicians were not Spanish proficient, interpreters were used and interpreter comments were included in the analysis of transcripts. All counselling interactions were audio recorded and transcribed.<br>All interview and counselling interactions were transcribed and analysed qualitatively using constructivist | Patients had a good understanding of treatment, despite a poor knowledge of diagnosis. When asked their diagnosis and treatment, 1 patient responded, ‘‘The names are just too difficult, but I have 3 problems. One with the bladder, and something about urine, and with my uterus, but who knows what it is. My treatment includes exercises (Kegels), a vaginal cream that I’ll put on, and she told me about a surgery I could have in the future.’’<br>*Not knowing all diagnoses given*<br>There was an even greater difficulty in naming all diagnoses given in cases where more than 1 diagnosis was present. Patients could usually name or describe their POP, but often times struggled in remembering or differentiating between the 2 types of incontinence in the setting of mixed incontinence.<br>*Describing diagnosis without medical terminology*<br>Patients often described their ‘‘bladder/uterus falling,’’ but were unable to give the specific prolapse diagnosis.<br>*Allowing physician to make decisions*<br>Patients were frequently unsure about what treatment option to choose and would frequently ask the physician, ‘‘What should I choose?’’ or ‘‘Just tell me what to do.’<br>**Concepts**<br>From the several preliminary themes relating to patient and provider communication, 3 main concepts emerged. | **10. How valuable is the research?**<br>There is discussion of how this study contributes to the knowledge/ evidence base.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate<br>**Source of funding**<br>Supported by an NIDDK Career Development Award |

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| | Grounded Theory methods. In Classic Grounded Theory works, Glazer and Strauss describe the discovery of theory as emerging from data separate from the scientific observer. Constructivist Grounded Theory takes the position that the observer is a part of the world studied and the data collected.<br>Grounded theory provides guidelines for analysing data at several points in the research process. Quantitative research methodology is used to test a hypothesis. Grounded theory, however, allows the researcher to search for a theory implicit in the data and is considered to be hypothesis-generating. The initial analysis involves line-by-line coding of the patient’s own words with the purpose of finding key phrases that can be grouped together to form preliminary themes. Next, these preliminary themes are compared and aggregated to form core categories or emergent concepts. Three different researchers analyse the data independently to reduce subjectivity and perform line-by-line coding in search of preliminary themes. These preliminary themes are then compared and combined to form emerging concepts. Throughout the data process, memos or written explorations of ideas about the data and themes were written to assist in integrating the analyses. The researchers sought to interview approximately 25 women to achieve thematic saturation, in which new themes no longer occur with each additional interview. | First, women lacked knowledge about their condition both before and after the physician encounter. There was only minor improvement in knowledge about these conditions despite extensive explanations using pelvic models and/or interpreters.<br><br>The second concept identified was that patients seemed to be overwhelmed with the amount of new information being given to them, despite being assured that their condition was not life threatening. One patient said, ‘‘The words she (the physician) used were too hard to understand. All I know is that I have 3 problems.’’ Several women were unable to recall their diagnoses. However, some women were able to recall their treatments even if they did not know their exact diagnosis. Patients not only received too much information at 1 time but also felt overwhelmed because of desperation, concern, and fear about their condition. Several patients described being worried about their pelvic floor condition because they thought it could be cancerous.<br><br>The final emergent concept that arose was that patients placed complete trust in the physician and ultimately relied on the physician to make decisions for them. Even before meeting the physician, patients were already anticipating and expecting the physician to take full control and responsibility in managing their care.<br><br>**Example quotes** | |

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| | | "She said it like… it was how she said it… the names are very difficult. Oh, that I have three problems. The problem with my bladder and the one with… I don't know if it is the urine or... and my uterus… my womb, I don't know what it is… yes I have all three problems. Well, the treatment was the exercises, anointment that I am going to put on, and what he told me about the operation." | |
| **Full citation**<br>Siddiqui, Nazema Y, Ammarell, Natalie, Wu, Jennifer M, Sandoval, Juan S, Bosworth, Hayden B., Urinary Incontinence and Health-Seeking Behavior Among White, Black, and Latina Women, Female Pelvic Medicine & Reconstructive Surgery, 22, 340-5, 2016<br>**Ref Id**<br>1284298<br>**Country/ies where the study was carried out**<br>USA<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | **Recruitment strategy**<br>Purposive sampling was used to recruit adult community-dwelling women to participate in a 2-hour focus group with a trained moderator. The researchers were interested in distinguishing sociocultural perspectives, therefore focus groups were stratified by race/ethnicity (white, black, and Latina).<br>Women were recruited via flyers and outreach in Duke University Medical Center and local community centers. The potential study candidates were screened by a trained research coordinator in the woman's native language. Women were excluded if they were pregnant, up to 3 months postpartum, mentally incapable of completing self-administered questionnaires, or if they did not fall into predefined categories for the focus groups. The candidates were asked to self-identify their racial and ethnic categories, and to self-quantify the presence and frequency of UI (daily, weekly, monthly, rarely, or never). Based on these responses, they were invited to participate in a focus group corresponding with their race/ethnicity and frequency of UI. Women were | **Findings (including author's interpretation)**<br>**Understanding**<br>Within the category of understanding, the awareness or knowledge of the condition of UI differed among racial/ethnic groups. White women expressed an early awareness of this condition, perhaps starting in childhood, as something overheard in discussion with female family and friends. In contrast, black women remarked that there was a lack of awareness in younger age groups. Latina women also expressed a lack of awareness, but this seemed to persist into older adults. Both white and black women expressed the belief that treatment options exist for UI, although this was not expressed in Latina focus groups. Women mentioned that if they had some knowledge that treatment options exist, they may be more likely to seek care. The awareness of UI also was affected by women's ready access to information and choice of media, which varied by racial/ ethnic group. For white women in our focus groups, the Internet, blogs, and Web-based resources were the dominant means of gathering information about UI. Compared with other groups, white | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, the aims of the study are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to address the aims, which were to understand treatment seeking behaviours.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, there is no justification of the research design (focus groups).<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Yes, the researcher has explained how participants were selected and why, and explained the processes of selection, however there was no discussion of if |

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| | considered eligible for the groups with frequent UI if they reported UI occurring daily or weekly. Women were considered eligible for the infrequent UI groups if they reported UI monthly, rarely, or never. Women did not require a physician's visit before enrolment, and thus, we did not further stratify groups based on type of UI.<br>**Setting**<br>Not reported<br>**Participant characteristics**<br>N=113<br>Ethnicity:<br>- White 39<br>- Black 41<br>- Latina 22<br>Age (mean, SD), years:<br>- White 48.1 (16.9)<br>- Black 47.12 (9.9)<br>- Latina 38.4 (14.4)<br>Any UI (n, %)<br>- White 30 (77)<br>- Black 33 (81) | women more commonly discussed researching treatment options for UI. This is in contrast to black women, who more often expressed a desire for mass media and social outlets to gather information. In Latina women, there was very little discussion about seeking information and more emphasis on the need for resources with the belief that medical providers should provide information. Latina women also believed that television advertisements would be a good medium to convey information as long as the messages were in Spanish.<br>**Behaviours**<br>Women from all groups expressed a desire to have health professionals screen for UI symptoms. This desire for screening from health care professionals was especially dominant in the black and Latina focus groups. The relationship with the doctor and the lack of useful information that women received from doctors was identified as a barrier. Women expressed frustration that when they finally decided to talk to their doctors about UI, they did not receive adequate information or might not have been taken seriously. Women discussed that when they did not receive a serious response, it was especially frustrating because it usually took some time and level of courage to bring up the issue in the first place. Many women felt that concerns regarding UI are better dealt with by a specialist than a general primary care or ob/gyn provider because they do not receive adequate information from non-specialty providers<br>**Example quotes** | there were any women who declined to participate.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the methods (focus group) were described but not in detail, for instance, unclear if a topic guide were used or what questions were asked. Data saturation not discussed.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, the relationship between the researcher and the participants is not discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>Can't tell, does say that individual informed consent was obtained, but does not specify how this was obtained, or mention other issues such as confidentiality. The study was approved by the Institutes review board.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, there is very limited detail about the analysis process and so it is unclear how the themes were developed. Does not state how the presented data |

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| | - Latina 30 (91)<br>Weekly or daily UI (n, %)<br>- White 17 (44)<br>- Black 20 (49)<br>- Latina 10 (30)<br>**Data collection and analysis**<br>Two-hour focus groups with a trained moderator were conducted. Focus group sessions with white and black women were conducted in English. Groups with Latina women were conducted in Spanish. All groups were conducted by moderators with expertise in facilitating focus groups. The moderators then led the groups in discussions about UI and care-seeking behaviours according to a semi-structured focus group guide.<br>The sessions were recorded using digital audio recorders, transcribed verbatim, and Spanish-language transcripts were translated by the session moderator or a bilingual physician into English. All transcripts were uploaded into Atlas.ti (Scientific Software Development GmbH, Chicago, Ill) to facilitate analysis. All session transcripts were reviewed, and a codebook was created that included a number of a priori codes related to the aims of the study and codes created during our initial transcript review. Each session transcript was then coded separately or theme content by 2 investigators: 1 a qualitative researcher | "In the Hispanic culture…people feel shy to talk about certain things. And from what I have seen, not only our culture but in different cultures too, they are concerned about what people may think or say. This stops them from asking anything, and if they don't say anything or ask they will not receive the necessary help"<br>"I was sent to a urologist first…so not saying that a man really shouldn't know how you feel, but he really didn't understand"<br>"I think that if your doctor asks you during a physical, 'Do you have any issues with this?' you're more likely to say actually yes, than you having to bring it up on your own"<br>"You go to the doctor, first of all you've got to talk to the people that you know so you can get information, then you have to get on the internet and do research, because they don't present information to you"<br>"I think the conversations are helpful. And I think there need to be more services and conversations…support groups"<br>"Have commercials like [what they do] for breast cancer" | were chosen, and it does not appear that the researcher considered their role in the analysis or selection of data.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of findings which are discussed in relation to the original aims of the study.<br>**10. How valuable is the research?**<br>This study contributes to the existing knowledge by showing that there are differences in help-seeking behaviours between women of different backgrounds. There are implications for ways in which to reduce disparities in treatment of PFDs.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate limitations<br>**Source of funding**<br>Dr. Siddiqui has received research grant funding from Medtronic, Inc and was supported by the National Institute of Diabetes and Digestive and Kidney Diseases. This study was supported by the American Urogynecologic Society Foundation and the Charles B. Hammond Research Fund at Duke University |

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| | and 1 a content-area expert. Code definitions were created to ensure consistency in coding. The codebook was refined during the coding process with further transcript review and discussion by the 2 primary. A third investigator reviewed 2 coded transcripts to check reliability in coding and to ensure that all themes were identified. Using code frequencies, a comparative thematic analysis was performed to assess for similarities and differences in our participants. | | |
| **Full citation**<br>Smith, Ariana L, Nissim, Helen A, Le, Thuy X, Khan, Aqsa, Maliski, Sally L, Litwin, Mark S, Sarkisian, Catherine A, Raz, Shlomo, Rodriguez, Larissa V, Anger, Jennifer T., Misconceptions and miscommunication among aging women with overactive bladder symptoms, Urology, 77, 55-9, 2011<br>**Ref Id**<br>1284302<br>**Country/ies where the study was carried out**<br>USA<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | **Recruitment strategy**<br>Participants were recruited from the female urology specialty clinics in the Department of Urology. Potential subjects seen over a 2 -year period were first selected based on International Classifications of Diseases codes for OAB-related symptoms over a 2 -year period Records were then reviewed to confirm a diagnosis of OAB and for exclusion criteria, which included pelvic organ prolapse (greater than or equal to stage 2), painful bladder syndrome/interstitial cystitis, pelvic pain, mixed urinary incontinence, as well as anti-incontinence or other pelvic surgery within the last year. Potential subjects were also excluded if they did not speak English, were younger than age 21, were unable to ambulate (and therefore unlikely to achieve significant symptom improvement), or had dementia prohibiting effective focus group participation. Women were recruited with both OAB-wet symptoms (frequency and urgency accompanied by urge urinary incontinence) and OAB-dry symptoms (frequency and urgency without urge | **Findings (including author's interpretation)**<br>**Themes**<br>**1. Misconceptions**<br>*Lack of understanding*<br>There was a lack of understanding over the aetiology of OAB. Patients believed OAB was a natural part of aging and therefore something they must just accept.<br>*Confusion of OAB with other disorders*<br>When asked to describe their experience with OAB, patients described a multitude of pelvic floor disorders, including prolapse, urinary tract infections, stress urinary incontinence, and painful bladder syndrome. When asked about the onset of their OAB symptoms, 1 woman reported the following: "I blamed my hysterectomy, I say [my gynaecologist] did something to my bladder".<br>*Lack of understanding of diagnostic tests*<br>There was a lack of understanding of diagnostic tests, specifically urodynamics and cystocopy. Participants lacked | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, the aims of the research are clearly stated.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to understand women's experiences with the care they receive regarding OAB.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes, the researcher states that focus groups were chosen because they allow discussion and extrapolation when interesting points and introduced. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | urinary incontinence). After files were screened, participants were recruited by telephone and asked them to participate in a 90-minute focus group session. Participants were provided with a small honorarium for their time.<br>**Setting**<br>Not reported<br>**Participant characteristics**<br>N=33<br>Women with OAB symptoms.<br>Age (mean, range), years: 67 (39-91)<br>**Data collection and analysis**<br>Focus groups were conducted with trained female non-clinician moderators using a standardized open-ended script for 1.5-hour sessions. Focus groups were audiotaped and transcribed verbatim. The topics covered in the focus groups encompassed women's perceptions of OAB symptoms, their aetiology and pathophysiology, as well as their experiences with diagnosis, evaluation, treatment, and outcomes of care. Topics for the focus group were developed through reviews of the literature and validated questionnaires. | understanding about what was happening to their bodies during these studies. They also lacked information about what useful information these studies would provide. Participants often expected a potential therapeutic outcome from undergoing these diagnostic studies<br>*Definitions of incontinence*<br>Some Participants believed that if they wore an incontinence pad, then they did not have an incontinent episode if their leakage was contained in the pad. In fact, all women initially denied bedwetting, but on further questioning, the majority leaked into a diaper at night.<br>**2. Miscommunication**<br>Miscommunication between participants and providers regarding Kegel exercises, specifically the instruction and feedback, was also identified. When asked who taught them Kegel exercises, 1 patient reported: "I learned from friends." Prior to seeing a specialist, very few participants had been examined while performing the exercises to determine whether they were doing the exercises correctly. Another miscommunication between participants and providers occurred over medications, specifically with respect to unrealistic expectations of cure and side effects. Patients interpreted the prescription from their physician as a cure for their problem, something they took for a short time then discontinued after things were "fixed." Furthermore, side effects, rarely understood by participants, often led to discontinuation. | **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, describes how participants were selected but no mention of if there were women who refused to participate<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the setting of the focus groups is not stated, but it is clear how the data were collected and what form they were in. The methods are justified. Data saturation is not discussed.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, the relationship between the researcher and participants is not discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No, there is no mention of any ethical issues being discussed with the participants, although it does state that approval was obtained from the institution.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | The same topical guide was used for each focus group.<br>Grounded theory methodology, as illustrated by Charmaz, was used to analyse the data. Grounded theory methodology is a qualitative research methodology that allows the researcher to identify key issues by coding and identifying categories. Briefly, this includes initial line-by-line coding of transcripts utilizing key phrases in the participant's own words. This is followed by a grouping together of similarly coded phrases into preliminary themes. Preliminary themes are then grouped together to develop categories, from which core categories, or emergent concepts, are derived. Four investigators separately performed line by line coding. Preliminary themes were then compared and merged. | "You get to the point where all of a sudden you can't say the next word; your mouth is so dry it won't move. I was scared."<br>**Concepts**<br>The women were, dissatisfied with their treatment outcomes. "First you go to the doctor for advice and if that doesn't work you start playing doctor yourself doing what you think should be done. I mean what can you do?".<br>Second, it is clear that women have expectations that exceed what current state of the art medical care can provide, (for instance the unrealistic expectation that a course of drug therapy can cure OAB). They need to learn from their providers what to realistically expect from behavioural modification, medications and Kegel exercises.<br>Third, more effective communication is needed to optimize patients' understanding, expectations, satisfaction and, ultimately, outcomes.<br>**Example quotes**<br>I don't think my regular doctor would be prepared to talk about it" … ""It's like not all doctors are the same and some people we are more comfortable with [discussing incontinence] than others."<br>"I learned [Kegel exercises] from friends." | Can't tell, methods of data analysis are briefly mentioned, but unclear how the presented data were selected. Some themes were less well supported than others, with only1 quote to support them. The role of the researcher in the analysis and selection of data is not reported.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of findings, which are related to the original research aims.<br>**10. How valuable is the research?**<br>The value of this research in terms of its contribution and identification of new areas of research is not discussed.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate limitations<br>**Source of funding**<br>Supported by the NIDDK |
| **Full citation** | **Recruitment strategy**<br>Local participants who had taken part in the quantitative part of the study were | **Findings (including author's interpretation)**<br>**Using existing knowledge** | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)** |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| Smith, N, Hunter, K. F, Rajabali, S, Milsom, I, Wagg, A., Where Do Women With Urinary Incontinence Find Information About Absorbent Products and How Useful Do They Find It?, Journal of Wound, Ostomy, & Continence NursingJ Wound Ostomy Continence Nurs, 46, 44-50, 2019<br>**Ref Id**<br>1284303<br>**Country/ies where the study was carried out**<br>Canada<br>**Study type**<br>Mixed methods<br>**Study dates**<br>Not reported | invited to take part in interviews by calling a telephone number provided at the end of the online survey or at clinic survey completion. The inclusion criteria for the quantitative part was: Canadian, community-dwelling adult women 18 years or older who used some form of absorbent product to manage urinary incontinence or dual urinary and faecal incontinence. Participants required sufficient English proficiency to complete the survey; those who participated in the interviews were from the researchers' local area. Participants were excluded if they had no urine leakage.<br>**Setting**<br>Interviews took place in a private room at participating clinics, at the research team's university office, or by telephone<br>**Participant characteristics**<br>N=9<br>Age (mean, range), years: 70 (55-84)<br>**Data collection and analysis**<br>Interview questions focused on improving our understanding of participants' use, knowledge of, and information sources related to containment products. Interviews were no longer than 30 minutes, digitally recorded, and transcribed verbatim. All identifying data were removed at the | This theme reflects participant knowledge about containment products, including product qualities/construction, accessibility, and availability of financial assistance. Knowledge of absorbent products was generally limited, and participants tended to draw on previous experience with menstrual products to inform their choice. Only 2 participants understood the difference between menstrual pads and pads designed for absorption of urinary incontinence. Most participants had used disposable pads, with little knowledge of reusable options or where to purchase these. Similarly, few knew how to access financial assistance for products<br>**Seeking knowledge**<br>Participants sought knowledge of options, effectiveness, and costs from various sources. The most desirable source was a trustworthy person with whom they were comfortable. Sources such as television, magazines, and pamphlets were acceptable, although participants were wary of advertisements and preferred a one-on-1 discussion with someone perceived as knowledgeable and without bias. Three women thought HCPs would be an excellent source, with1 identifying the family physician as potentially most knowledgeable. In contrast, another participant thought her family physician would not be prepared to discuss incontinence. Comfort in discussing incontinence and absorbent products varied, leading some participants to select less personal information sources such as the television or the Internet. Other participants thought that trying | Yes, the aims of the study are reported clearly.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to understand what sources of information women use regarding urinary and/or fecal incontinence<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the use of interviews is not justified in the text.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the researcher describes how participants were selected, but does not explain why these were the most appropriate, or discuss reasons for not taking part.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, not much detail provided on how the interviews took place, if they were semi-structured or open etc.). No discussion of research saturation. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | transcription stage. A $15 gift card was offered for participation, in addition to parking expense reimbursement.<br>Qualitative analysis was completed using a conventional content analysis approach without preconceived categories. Transcripts were analysed using a constant comparative approach; probes to the semi-structured interview guide were adjusted as new insights emerged. The 2 interviewers independently coded the first transcript and then together developed a coding framework; additional codes were added to this framework as they were identified in subsequent transcripts. Codes were collapsed into categories and finally into themes reflecting interpretation of both manifest and latent content. Trustworthiness was addressed by having 2 researchers involved in the analysis of data collected in a consistent manner, and an audit trail of methodological and reflective notes was kept during the analysis process to ensure dependability of findings. | product samples would be useful, suggesting a preference to learn through experience.<br>**Finding the right pad**<br>Family members who wore absorbent products or worked in healthcare influenced participants, either by product recommendations or experience in previously purchasing products for others.<br>**Perceptions of HCPs' roles**<br>Respondents indicated that HCPs should be a good source of information regarding incontinence and products, as they were seen as reliable and knowledgeable, although expectations were often higher than actual experience. Some found physicians ill-informed, embarrassed, or reluctant to discuss incontinence. Conversations about incontinence did not occur due to limited interaction time or a perception that incontinence was of little importance. The women identified a lack of HCP knowledge of containment products. Although HCPs were identified as potentially reliable sources of product information, there was a mismatch between HCP responses and quality of information received compared to what was desired.<br>**Example quotes**<br>“I’d think I’d rather be told personally”<br>“First you go to the doctor for advice and if that doesn’t work you start playing doctor yourself doing what you think | **6. Has the relationship between researcher and participants been adequately considered? (Yes/Can’t tell/No)**<br>No, the relationship between the researcher and participant was not discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can’t tell/No)**<br>Can't tell, ethical approval was obtained, and states that written informed consent was obtained, but no discussion how this was obtained or any other ethical issues such as confidentiality being discussed.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can’t tell/No)**<br>Can't tell, the description of the analysis process was brief, and it is unclear how the data presented was selected. However, the themes are well supported by the data. The role of the researcher in the analysis process is not discussed.<br>**9. Is there a clear statement of findings? (Yes/Can’t tell/No)**<br>Yes, there is a clear statement of findings.<br>**10. How valuable is the research?**<br>The research contributes to knowledge regarding information needs of women with PFDs and demonstrates that better |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| | | should be done. I mean what can you do?"<br>"I think it is easy to be suspicious of things that come online, somethings you know are ads and you don't particularly trust them. Yeah I'd prefer to be told by a reliable source but sometimes the reliable source is your friends rather than the healthcare professionals." | access to product information is needed. Further avenues for future research is also briefly discussed.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Moderate limitations<br>**Source of funding**<br>Studentship provided by First Quality. |
| **Full citation**<br>van den Muijsenbergh, M. E. T. C, Lagro-Janssen, T. A. L. M., Urinary incontinence in Moroccan and Turkish women: A qualitative study on impact and preferences for treatment, British Journal of General Practice, 56, 945-949, 2006<br>**Ref Id**<br>1284308<br>**Country/ies where the study was carried out**<br>The Netherlands<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | **Recruitment strategy**<br>To comply with the criterion of achieving the widest possible variation in study population that is a requirement of such a qualitative approach, women were recruited in different ways. At 6 general practices with large numbers of immigrant families on the practice lists in 4 different cities in the Netherlands, the general practitioner (GP) approached Moroccan and Turkish women who were either known to have incontinence or had asked for a prescription for incontinence materials. In addition, patients were recruited by 1 female physiotherapist who specialised in pelvic floor muscle exercise therapy and by 2 female Moroccan care consultants. All the eligible women were sent a letter in Dutch and/or Arabic with information about the study.<br>**Setting**<br>Interviews were held at the patient's home or at their doctor's surgery. | **Findings (including author's interpretation)**<br>**Expectations about treatment**<br>Slightly more than half of the women in this study (n = 17) had consulted their GP because of urinary incontinence. Five women visited a doctor in their country of origin for this problem. The women who had not sought help were not aware that their GP could do anything for them. Some felt ashamed towards a male GP or did not dare to bring up the subject, or considered the incontinence to be a normal situation at their age. Most of the women (n = 23) gave preference to a female doctor:<br>In Islam, a woman must always choose a female physician.' (Moroccan, 36 years.)<br>In this study population, the 9 women who had been referred to a physiotherapist had stopped going: they did not understand the reason for the exercises, they were unable to do the exercises regularly, or they soon gave up because they did not notice any effect: | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of the aims of the research.<br>**2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, qualitative methodology is appropriate to understand women's perceptions of UI, the consequences it has on their lives, and their wishes regarding treatment.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Yes, there is a very brief description to justify the use of qualitative methods, although the use of interviews specifically is not justified. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| | **Participant characteristics**<br>N=30<br>Nationality: Moroccan 13; Turkish 17<br>Age (mean, SD), years: 45 (9.0)<br>Duration of living in the Netherlands (mean, SD), years: 24 (7.0)<br>PRAFAB severity score: moderate 10; severe 16<br>**Data collection and analysis**<br>The interviews took between 45 and 60 minutes. patient's home or at their doctor's surgery. A trained Muslim female researcher conducted all the interviews, audiotaped the conversations and transcribed them verbatim. If necessary, a female family member or translator was present. The interviewer followed an interview guide that contained the following themes: perception of the incontinence, psychosocial consequences and influence on intimate relations, experience with and expectations about treatment. This interview guide was formulated on the basis of the literature and the outcomes of a discussion with a panel of experts in the field of urinary incontinence and cultural diversity. Interview data were all analysed independently by 2 researchers to isolate the most important themes (investigator triangulation). Citations were selected that supported the major themes derived from the interviews. | 'I thought, do I have to do sport here? Ridiculous! Will it help? How am I supposed to contract and relax my pelvic floor muscles?' (Turkish, 33 years.)<br>One-third of the women felt their GP had not taken them seriously; they wanted not only to talk about the problem, but also to be examined and referred for further tests when treatment was unsuccessful. They believed Allah had sent them this condition and they owed it to Him to seek the best possible treatment. Only if it became evident that there was no solution available, then they had to accept the incontinence:<br>'For all things you receive from Allah, just say "Al-hamdu li-Llah." You must try everything: going to the GP, taking your medication. When at last you can't get better then you have to accept it; that is qadr, predestinated.' (Moroccan, 48 years.)<br>Although most of the women said that they had understood the explanation given by their GP (16 women had needed a translator for this), a number of women indicated clearly that they had been troubled by language problems. All the women lacked basic knowledge and understanding of the function of the bladder and genital organs. It also appeared that they were unaware of the favourable effects and the aim of exercise therapy. | **4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the participants are described but the justification for their selection is not reported. There are no discussions regarding recruitment such as if any women who were invited declined to take part.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the setting is described but not justified. Semi structured in depth interviews were used using an interview guide until data saturation was reached.<br>**6. Has the relationship between researcher and participants been adequately considered? (Yes/Can't tell/No)**<br>No, the relationship between the researcher and participants is not discussed.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>No, no mention of procedures such as informed consent, and an ethics committee was 'not applicable'.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)** |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
|---|---|---|---|
| | | | Can't tell, the methods for data analysis are not described.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear summary of the main findings which are discussed in relation to the research aims and existing literature.<br>**10. How valuable is the research?**<br>The study discusses implications in terms of future research and clinical practice. For instance, it identifies a need for information provision, and identifies preferences in terms of who women want this information from.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious<br>**Source of funding**<br>'Not applicable' |
| **Full citation**<br>Wieslander, C. K, Alas, A, Dunivan, G. C, Sevilla, C, Cichowski, S, Maliski, S, Eilber, K, Rogers, R. G, Anger, J. T., Misconceptions and miscommunication among Spanish-speaking and English-speaking women with pelvic organ | **Recruitment strategy**<br>Women with symptomatic POP were recruited from a female urology specialty practice at Cedars-Sinai Medical Center (Los Angeles) and from urogynaecology clinics at Olive View-UCLA Medical Center (Northern Los Angeles) and the University of New Mexico Medical Center. To ensure that a broad | **Findings (including author's interpretation)**<br>**Patient misconceptions**<br>Generally, patients had a poor understanding of POP, its causes, what specific pelvic anatomy was involved and treatments available. Many women were unaware of what POP is and that it exists as a condition. Both groups also | **1. Was there a clear statement of the aims of the research? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of the aims of the research. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| prolapse, International Urogynecology Journal, 26, 597-604, 2015<br>**Ref Id**<br>1284311<br>**Country/ies where the study was carried out**<br>USA<br>**Study type**<br>Qualitative<br>**Study dates**<br>Not reported | experience of POP was represented, we included women with untreated POP, women using a pessary for prolapse, and women who had recently undergone prolapse surgery. Since the researchers were interested in each patient's understanding of her condition and her experience of prolapse symptoms, they did not collect data on what specific treatments the patient had undergone. Exclusion criteria were women younger than 18 years, women with asymptomatic prolapse, women with dementia, and women who did not speak either English or Spanish. Women with other coexisting PFDs, such as stress urinary incontinence (UI) and overactive bladder (OAB), were included. Participants were identified by treating physicians<br>**Setting**<br>Not reported<br>**Participant characteristics**<br>English speaking participants<br>N=25<br>Age (mean, range), years: 63.8 (33-90)<br>Spanish speaking participants<br>N=33<br>Age (mean, range), years: 56.6 (46-77)<br>**Data collection and analysis**<br>Focus groups were 90 minutes long. A trained bilingual moderator used a standardized open-ended script as a | confused vaginal prolapse with actual herniation of their bowel or bladder. Due to lack of knowledge of anatomy, women often confused uterine or vaginal prolapse with the descent of the bladder or rectum. Both English-speaking and Spanish-speaking women also tended to view POP and UI as 1 condition. Further, patients' lack of awareness that POP existed and misconceptions about the symptoms also caused fear in many women, for example that it may be a sign of cancer. Due to "smell" or "itching" it was also a common misconception that the POP was either currently an infection or would lead to an infection. This theme existed in both English-speaking and Spanish-speaking women, but appeared more commonly among women in the Spanish-speaking focus groups. Some women did correctly attribute the risk factor of childbirth to the development of POP, but none attributed POP to aging or obesity.<br>**Miscommunication: physician side**<br>Many women stated that the physicians did not use the actual name of the diagnosis, such as "pelvic organ prolapse" or "vaginal prolapse," but rather used descriptions of the condition, such as your "bladder has fallen down," or "uterus has fallen." On the other hand, it was also common for patients to say that their physician used complicated language that they did not understand. Many women stated that they preferred simple language. It was also common for women to state that they were given too much information about treatment options, while too little time was spent | **2. Is a qualitative methodology appropriate? (Yes/Can't tell/No)**<br>Yes, the qualitative methodology is appropriate to understand the factors that prevent understanding of POP in Spanish and English speaking women.<br>**3. Was the research design appropriate to address the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the use of qualitative methodology and the specific method of analysis is justified, but the use of focus group specifically is not discussed.<br>**4. Was the recruitment strategy appropriate to the aims of the research? (Yes/Can't tell/No)**<br>Can't tell, the inclusion and exclusion criteria are described but not explained. Unclear if any women that were invited decided not to participate.<br>**5. Was the data collected in a way that addressed the research issue? (Yes/Can't tell/No)**<br>Can't tell, the focus groups used an open ended script, and were audio recorded, however the setting is not stated or justified, and there is no discussion of data saturation.<br>**6. Has the relationship between researcher and participants been** |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | guide. Focus groups were audiotaped and the discussions were transcribed verbatim. Transcriptions in Spanish were translated into English by a bilingual translator. The topics addressed patients' emotional responses when noticing their prolapse, how they sought support, what verbal and written information was given to them, what treatment options were offered and their overall feelings about the process. Additionally, patients were asked about their experience with their treating physician. Topics for the focus group scripts were created through reviews of the literature and previous experience with patient focus groups.<br>Grounded theory methodology was used to analyse the data. Initial line-by-line coding of transcripts was performed, and key phrases were then grouped into preliminary themes. Four investigators separately performed line-by-line coding to minimize subjectivity. Preliminary themes were then combined to develop categories. Emergent concepts became evident after combining the preliminary themes into categories. Preliminary themes were then compared and merged between English-speaking and Spanish-speaking groups. | explaining the diagnosis. Thus they were confused about what treatment to choose when they did not fully understand what actually needed to be treated. It is possible that the lack of knowledge of the exact diagnosis in combination with complicated language and language barriers led to confusion and decreased disease understanding in this group. Both English-speaking and Spanish-speaking women had a poor understanding about their pelvic anatomy. Many wished that their physician had used a visual aid (pelvic model or picture) to explain the anatomy and the exact appearance of their prolapse. If a pelvic model or picture was used during the consultation, women stated that it had been extremely helpful. Women also felt overwhelmed with the amount of new information given to them during the consultation with the physician. All groups felt that a written handout or brochure with pictures would have been very helpful to take home after the visit as a reminder of what had been said, although this was more commonly mentioned in the English-speaking focus groups.<br>**Miscommunication: patient side**<br>It was common for patients to be afraid to ask their providers questions, even though they had a poor understanding of their disease. Some women felt so overwhelmed with all the information given by the physician that they did not even know what to ask or where to start. Some women were concerned that they were annoying the physician when they asked questions, and thus did not ask for clarification. In addition to being afraid to | **adequately considered? (Yes/Can't tell/No)**<br>No, no discussion of the relationship between the participants and the researchers.<br>**7. Have ethical issues been taken into consideration? (Yes/Can't tell/No)**<br>Can't tell, the study was approved by the institutional review board, however no discussion of informed consent/confidentiality.<br>**8. Was the data analysis sufficiently rigorous? (Yes/Can't tell/No)**<br>Can't tell, the methods of analysis are briefly described, but no discussion of the researchers' influence on the process, or how the presented data were selected. The themes are well described and well supported by the presented data.<br>**9. Is there a clear statement of findings? (Yes/Can't tell/No)**<br>Yes, there is a clear statement of findings. This is discussed in relation to the study aims.<br>**10. How valuable is the research?**<br>There is very brief discussion of how this study should affect physician practice, by spending more time to explain the diagnosis of POP rather than just treatment options and using visual aids. |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | | ask the physician questions, patients were also reluctant to confide in family or friends about their disease and ask questions due to a perceived lack of understanding or embarrassment. Being afraid to ask questions of the provider and being afraid to seek outside information from outside sources, such as friends or family were common themes in both English-speaking and Spanish speaking focus groups. Finally, many patients expressed difficulty using the internet to seek information about prolapse. Some women did not have a computer or did not know how to access the internet, while other women with internet access stated that they felt overwhelmed with the number of websites and with the amount of information. English-speaking women were more likely to mention the internet during the focus group interviews than Spanish-speaking women.<br>**Example quotes**<br>"They used complicated words I wouldn't understand.", "…she explained for half an hour all the things…but the problem is that I can't memorize the words she used…"<br>"Any nation that can send a man to the moon can make a model of this so that women can understand. I don't want to look at a normal body. I want to see a prolapse.", ""Having a brochure… A cheat sheet that you can go back and look at later."<br>"I didn't know what kind of questions to ask."<br>"The amount of information that I was able to get was overwhelming to me." | However, there is no discussion of further research or if findings could be transferable.<br>**Overall methodological limitations (No or minor/Minor/Moderate/Serious)**<br>Serious limitations<br>**Source of funding**<br>Funded by a National Institute of Diabetes and Digestive and Kidney Diseases Patient-Oriented Research Career<br>Development Act Award and an American Recovery and Reinvestment Act Supplement, Supported by the National Center for Research Resources and the National Center for Advancing Translational Sciences |

| Study details | Methods and participants | Results | Risk of bias assessment using the CASP qualitative checklist |
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| | | | |

*BMI: body mass index; CASP: Critical Appraisal Skills Programme; FI: faecal incontinence; GP: general practitioner; HCP: healthcare professional; MUI: mixed urinary incontinence; OAB: overactive bladder; PFD: Pelvic floor dysfunction; PFDI: Pelvic Floor Distress Inventory; POP: Pelvic organ prolapse; POP-Q: Pelvic Organ Prolapse Quantification; PRAFAB: Protection Amount Frequency Adjustment Body Image Score; RCT: randomised controlled trial; SD: standard deviation; SUI: stress urinary incontinence; UI: urinary incontinence; UUI: urge urinary incontinence*

# Appendix E – Forest plots

## Forest plots for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

No meta-analysis was conducted for this review question and so there are no forest plots.

# Appendix F – GRADE CERQual tables

## GRADE tables for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

**Table 5: Evidence profile: Theme 1. Accessibility of information – language**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 1.1: Language barriers** | | | | | |
| 3 (Andersson 2009, Dunivan 2014, Sevilla 2013) | 2 qualitative studies using focus groups, 1 qualitative study using interviews | Women who do not speak the language of the country they are living in have issues accessing information. This seems to be largely due to not being able to understand the doctor during consultations. Some women reported relying on family members who could speak the language, whereas some women used interpreters. However, there were issues with this, including the gender of the interpreter, and some women felt that the interpreter was not always accurate or do not explain things well.<br>"Yes, the main thing is that you know the language. If you don't know the language you have to have relatives who know the language and who also have time" (Andersson 2009) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 1.2: Medical terminology** | | | | | |
| 2 (Sevilla 2013, Wieslander 2015) | 1 qualitative study using focus groups, 1 qualitative study using interviews | Women sometimes struggled to understand or remember medical terminology, indicating that it is important for healthcare professionals to explain pelvic floor disorders using lay terms.<br>"They used complicated words I wouldn't understand.", "…she explained for half an hour all the things…but the problem is that I can't memorize the words she used…" (Weislander 2015) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 1.3: Use of aids** | | | | | |
| 1 (Weislander 2015) | 1 qualitative study using focus groups | Women discussed the desire for various types of aids, to help with the understanding of their condition and to aid with their memory of what the doctor told them. In particular, models to explain the anatomy of POP were suggested, as were brochures and literature that could be referred to at a later time.<br>"Any nation that can send a man to the moon can make a model of this so that women can understand. I don't want to look at a normal body. I want to see a prolapse.", ""Having a brochure… A cheat sheet that you can go back and look at later." (Wieslander 2015) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |

1 *CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research; POP: pelvic organ prolapse*

2 **Table 6: Evidence profile: Theme 2. Accessibility of information – difficulties with access**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 2.1: Not being able to access doctors** | | | | | |
| 2 (Andersson 2009, Siddiqui 2016) | 2 qualitative studies using focus groups | Women reported difficulties in accessing a doctor which resulted in difficulties accessing information. For instance, some women had difficulties with waiting times at their medical centres, and others felt that they were not helped when they asked for it. Additionally, some women felt that doctors did not always provide them will all the information, or tell them where they could find helpful information. | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | | “Even if we scream and make a fuss they don’t help us” (Andersson 2009) | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 2.2: Not being able to ask questions** | | | | | |
| 2 (Weislander 2015, Siddiqui 2016) | 2 qualitative studies using focus groups | Women expressed that they sometimes had difficulty accessing information as they felt unable to ask questions to obtain the information they wanted. This was due to a number of factors, including being unsure what to ask, feeling too embarrassed, or the perception that the doctor was unwilling to answer questions.<br>“I didn’t know what kind of questions to ask.” (Wieslander 2015)<br>“In the Hispanic culture…people feel shy to talk about certain things. And from what I have seen, not only our culture but in different cultures too, they are concerned about what people may think or say. This stops them from asking anything, and if they don't say anything or ask they will not receive the necessary help” (Siddiqui 2016) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 2.3: Not being taken seriously** | | | | | |
| 3 (Bjork 2014, Pakbaz 2011, Rasmussen 2010) | 3 qualitative studies using interviews | Women sometimes reported that their symptoms or queries were not taken seriously, resulting in a delay of accessing information and treatment. For instance, some women reported instances of their queries or concerns being disregarded or brushed off as not serious.<br>“When he [the doctor] had seen it [in earlier consultation], he thought, 'This isn't a problem'. I was disappointed, so, 'It wasn't so bad'? I was a bit surprised, and I feel that I have problems. But I believed [what the doctor said], 'There is no | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns | |

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| | | problem' so I carried on. That's why I went so long [before seeing the doctor again]" (Pakbaz 2011) | | Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 2.4: Not knowing when or where to seek help** | | | | | |
| 1 study (Pintos-Diaz 2019) | 1 qualitative study using interviews | Some women where unclear as to whether they could receive help with their pelvic floor disorder, and who to go to for help. This suggests that more information and awareness is needed so that women know who they can seek help from if symptoms occur.<br>“For chest pain it seems quite clear to me, bleeding also, but for this…where should I go (for help)?” | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |
| **Sub-theme 2.5: Perception that doctors are embarrassed to talk about pelvic floor disorders** | | | | | |
| 1 study (Smith 2019) | 1 qualitative study using interviews | Some women found that healthcare professionals were sometimes embarrassed or reluctant to talk about incontinence, which made it difficult to access information.<br>“I don’t think my regular doctor would be prepared to talk about it”… ““It’s like | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP | Low |

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| | | not all doctors are the same and some people we are more comfortable with [discussing incontinence] than others." (Smith 2019) | | qualitative checklist | |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |

1 *CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

2 **Table 7: Evidence profile: Theme 3. Style of communication**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| **Sub-theme 3.1: Characteristics of the HCP** | | | | | |
| 3 (Andersson 2009, Siddiqui 2016, van den Muijenbergh 2006) | 2 qualitative studies using focus groups, 1 qualitative study using interviews | Some women felt that the gender of the doctor was important, as they would not feel comfortable talking about pelvic floor disorders with male doctors, whereas for other women, the gender of the doctor was not important as the priority was addressing the disorder. Cultural differences may be important to consider, as some women mentioned that in Islam, they must choose a female doctor.<br>"If it's a male doctor then we ask for another. We're ashamed", "It doesn't matter to me [whether it's a female or a male doctor]. If I have a problem, then I have a problem" (Andersson 2009) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Very low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |

| **Study information** | | **Description of theme or finding** | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | | **Criteria** | **Level of concern** | **Overall quality** |
| | | “I was sent to a urologist first…so not saying that a man really shouldn't know how you feel, but he really didn't understand” (Siddiqui 2016) | Coherence | Minor concerns<br>Some evidence is ambiguous or contradictory without a credible explanation for differences | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 3.2: Desire for direct communication** | | | | | |
| 3 (Buurman 2013, Pakbaz 2011, Siddiqui 2016) | 2 qualitative studies using interviews, 1 qualitative study using focus groups | Women felt that they would be better able to discuss pelvic floor disorders if they were asked directly by healthcare professionals, rather than having to bring it up themselves. This may be due to embarrassment about the condition preventing them from initiating the discussion.<br>“I think that if your doctor asks you during a physical, ‘Do you have any issues with this?’ you're more likely to say actually yes, than you having to bring it up on your own” (Siddiqui 2016) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 3.3: Preferred format of information** | | | | | |
| 2 (Rasmussen 2010, Smith 2019) | 2 qualitative studies using interviews | Women value being given information in a face-to-face way and having chance to have conversations with their healthcare professional about their pelvic floor disorders.<br>“I’d think I’d rather be told personally” (Smith 2019) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | | "…faeces would keep oozing after my visiting a toilet, and I remember that I mentioned it to a nurse…and it was received in an extremely bad way. // She said, ''Well, haven't you got a leaflet?'' and I told her, ''Yes, I've got a leaflet, but maybe I need to talk about it" (Rasmussen 2010) | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants, and there were concerns regarding data richness | |
| **Sub-theme 3.4: Wanting positive messages** | | | | | |
| 1 (Cichowski 2014) | 1 qualitative study using focus groups | Women wanted a positive, or motivational message from their healthcare professionals. It was important to women to receive communication of hope for improvement in their condition, rather than focusing on negative aspects.<br>"But I think not talking about these things like hope is a mistake. I think we need to have hope and happiness to know that there is a positive outcome possible for us." (Cichowski 2014) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |

*CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research; HCP: healthcare professional*

1 **Table 8: Evidence profile: Theme 4. Sources of information**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 4.1: Sources of information are varying** | | | | | |
| 5 (Buurman 2013, Pakbaz 2011, Siddiqui 2016, Smith 2011, Smith 2019) | 3 qualitative studies using interviews, 2 qualitative studies using focus groups | Women gathered information about their pelvic floor disorders from a wide variety of sources, including healthcare professionals, friends and family, the internet, and other women with pelvic floor disorders. There also seemed to be variation in the success of these information sources, with some women trying to get information from healthcare professionals and then doing their own research when that was not successful. Some women expect to do their own research before seeing a healthcare professional, whereas others were disappointed that they felt the healthcare professionals were not able to provide sufficient information.<br>“You go to the doctor, first of all you've got to talk to the people that you know so you can get information, then you have to get on the internet and do research, because they don't present information to you” (Siddiqui 2016)<br>“First you go to the doctor for advice and if that doesn’t work you start playing doctor yourself doing what you think should be done. I mean what can you do?” (Smith 2011) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 4.2: Women have differing levels of trust in the different sources** | | | | | |
| 2 (Sevilla 2013, Smith 2011) | 1 qualitative study using focus groups, 1 qualitative study using interviews | Some women demonstrated a high level of trust in their healthcare professional, saying that they will do whatever the doctor recommends. Information from a healthcare professional was generally seen as trustworthy. On the other hand, information on the internet was seen as less trustworthy. Additionally, some women identified friends as being a reliable source of information.<br>“I think it is easy to be suspicious of things that come online, somethings you know are ads and you don’t particularly trust them. Yeah I’d prefer to be told by a reliable source but sometimes the reliable source is your friends rather than the healthcare professionals.” (Smith 2011) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | Minor concerns<br>Evidence comes from a small number of | |

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| | | | | studies or participants | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |
| **Sub-theme 4.3: Information from the internet can be overwhelming** | | | | | |
| 1 (Wieslander 2015) | 1 qualitative study using focus groups | Whilst many women seem to do their own research to gather information using the internet, some reported that this was sometimes overwhelming due to the vast amount of information available online. This suggests that women need to be given specific information by their healthcare professional, or directed to specific sources of information online.<br>“The amount of information that I was able to get was overwhelming to me.” (Weislander 2015) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Very low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |

*CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

1 **Table 9: Evidence profile: Theme 5. Support networks**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 5.1: Need for more support groups** | | | | | |
| 1 (Siddiqui 2016) | 1 qualitative study using focus groups | Women who reported access to support groups were very positive about their impact and found them helpful. However, they also voiced a need for more support groups, and some women reportedly did not have access to such groups resulting in feeling unsupported and alone.<br>"I think the conversations are helpful. And I think there need to be more services and conversations…support groups" (Siddiqui 2016) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |
| **Sub-theme 5.2: Support networks enable women to not feel alone** | | | | | |
| 2 (Dunivan 2014, Buurman 2013) | 1 qualitative study using focus groups, 1 qualitative study using interviews | There were several benefits of support networks. One that was commonly mentioned by women was that they allowed women to find others with similar problems. Pelvic floor disorders are not often talked about which can result in a great deal of isolation and feeling like they are not normal, therefore finding others who were similar to them gave them a great sense of relief.<br>"I'm part of a big group of women here. It's not just me" … "You're not alone! And it doesn't have to be so private" (Dunivan 2014) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Very low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns | |

| **Study information** | | **Description of theme or finding** | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | | **Criteria** | **Level of concern** | **Overall quality** |
| | | | | Evidence comes from a small number of studies or participants | |
| **Sub-theme 5.3: Support networks as a source of information** | | | | | |
| 4 (Andersson 2009, Buurman 2013, Siddiqui 2016, Smith 2011) | 3 qualitative studies using focus groups, 1 qualitative study using interviews | The other main function of support networks was to provide women with information about their condition. This information could be practical, for instance, some women reported learning Kegel exercises from their friends, and family helping with language barriers. Alternatively, sometimes this information acted as reassurance that things would get better or that they were not alone. Whilst women expected their support networks to provide information, some women reported not receiving information from their family.<br>“I learned [Kegel exercises] from friends.” (Smith 2011)<br>“No, I didn’t call in medical help because my relatives, especially my mum and my gran, said that it would just pass off. So I was like if my mum and my gran say so, it’ll be all right” (Buurman 2013) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | Minor concerns<br>Some evidence is ambiguous or contradictory without a credible explanation for differences | |
| | | | Adequacy | None or very minor concerns | |

*CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

1 **Table 10: Evidence profile: Theme 6. Pelvic floor disorders in the media**

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 6.1: Pelvic floor disorders are not prominent in the media** | | | | | |
| 1 (Pakbaz 2011) | 1 qualitative study using interviews | Women noted that unlike other health problems, pelvic floor disorders are rarely written about in media such as magazines.<br>"I think there is very little written about this problem [prolapse] if you read just about anything, like weekly magazines. You know, you can read a lot about genital problems in magazines, but this particular problem I haven't run across often" (Pakbaz 2011) | Methodological limitations | Minor concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |
| **Sub-theme 6.2: Desire for more media visibility** | | | | | |
| 1 (Siddiqui 2016) | 1 qualitative study using focus groups | Women expressed a desire for pelvic floor disorders to feature more frequently in the media to increase awareness.<br>"Have commercials like [what they do] for breast cancer" (Siddiqui 2016) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns | |

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| | | | | Evidence comes from a small number of studies or participants | |

*CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

## Table 11: Evidence profile: Theme 7. Lack of information or knowledge

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| Number of studies | Design | Description of theme or finding | Criteria | Level of concern | Overall quality |
| **Sub-theme 7.1: Information needs are not being met** | | | | | |
| 5 (Buurman 2013, Kiyosaki, Pakbaz 2011, Siddiqui 2016, Weislander 2015) | 2 qualitative studies using focus groups, 2 qualitative studies using interviews | Many women noted that they had been surprised at the lack of information provided by healthcare professionals. Women also reported a general lack of information from other people they might try to talk to, such as family and colleagues. As a result, women often carried out their own research, but some women still reported difficulty finding information this way, particularly in relation to prolapse. Additionally, some women reported receiving incorrect information, such as an incorrect diagnosis.<br>“So I think that’s very odd, that this midwife told me nothing about the pelvic floor during my pregnancy. She only said something about it at a check-up visit when I mentioned that I had such a heavy feeling. So it turns out that’s your pelvic floor” (Buurman 2013)<br>“There isn't any information really [on prolapse], not in the way that you just stumble across it somehow. If I haven't searched [for the information] myself, I don't think I just happen to read about it by accident” (Pakbaz 2011) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 7.2: Women demonstrated a lack of understanding of their symptoms** | | | | | |
| 3 (Buurman 2013, Dunivan 2014, Sevilla 2013) | 1 qualitative study using focus groups, 2 qualitative | There were several instances of women not understanding their pelvic floor disorder symptoms, which results in feeling scared and confused. Women also report feeling happy when they had later found out an explanation for their symptoms. | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP | Moderate |

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | studies using interviews | “I went to the bathroom and I felt myself and I didn't know what it was and I was scared” (Dunivan 2014) | | qualitative checklist | |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 7.3: Women demonstrated a lack of understanding of their diagnosis** | | | | | |
| 3 (Kiyosaki 2012, Sevilla 2013, Smith 2011) | 1 qualitative study using focus groups, 2 qualitative studies using interviews | Having received a diagnosis, many women struggled to recall or describe their condition, demonstrating a lack of understanding of the diagnosis they had received. Women seemed to often focus on the treatment aspect of a consultation with a healthcare professional, rather than the diagnosis, which may contribute to this lack of recall and understanding.<br>“She said it like… it was how she said it… the names are very difficult. Oh, that I have three problems. The problem with my bladder and the one with… I don’t know if it is the urine or... and my uterus… my womb, I don’t know what it is… yes I have all three problems. Well, the treatment was the exercises, anointment that I am going to put on, and what he told me about the operation.” (Sevilla 2016)<br>“I didn’t even hear my diagnosis. She gave me Vesicare and Kegel exercises” (Kiyosaki 2012) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 7.4: Women demonstrated a lack of understanding of the treatment options** | | | | | |
| 4 (Andersson 2009, Buurman 2013, Sevilla 2013, Smith 2011) | 2 qualitative studies using focus groups, 2 qualitative studies using interviews | The main treatments that were discussed by women included pelvic floor muscle exercises, surgery and medication. When discussing pelvic floor muscle exercises, some women noted how they were unsure if they were performing them correctly. Women taking medication reported early discontinuation due to the perception that they were not working, or because of side effects. There was confusion among women when it transpired that some women had been offered surgery, whereas others had not, or because women who were initially offered surgery were later told it was not an option. | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | None or very minor concerns | |

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | | "Well, I thought to myself sometimes: am I doing this right? For you might be training as much as you like and then find out afterwards that you're not doing the right exercises. So this would have no effect at all: you'd be training the muscles in your buttocks instead of the proper ones in your pelvic floor." (Buurman 2013) | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 7.5: Women demonstrated a lack of understanding of the causes of their disorder** | | | | | |
| 3 (Dunivan 2014, Smith 2011, Wieslander 2015) | 3 qualitative studies using focus groups | There were varying beliefs among the women in terms of the causes of their pelvic floor disorders. Several women cited heavy lifting as a cause, whereas others believed it was a normal part of aging. Others believed that their problem was because they had not worn a girdle in earlier life. For several women, this information came from their mothers.<br>"My mother would always caution me to not lift heavy things because later when you grow up, your insides will fall out" (Dunivan 2014) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 7.6: Women demonstrated a lack of understanding of diagnostic tests** | | | | | |
| 1 (Smith 2011) | 1 qualitative study using focus groups | Women lacked understanding about what was involved in diagnostics tests, as well as the useful information that these tests could provide. This suggests that more information is needed in relation to diagnostic testing, what they involve, and what the outcomes of such tests could be.<br>"They put me on a table and turned me upside down" … "The doctor stuck a wand in my bladder." (Smith 2011) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small | |

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | | | | number of studies or participants | |

*CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

### Table 12: Evidence profile: Theme 8. Prevalence

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 8.1: Embarrassment inhibits help-seeking and information seeking** | | | | | |
| 4 (Buurman 2013, Dunivan 2014, Pakbaz 2011, Siddiqui 2016) | 2 qualitative studies using interviews, 2 qualitative studies using focus groups | Women reported feeling shame and embarrassment about their symptoms. This meant that women were often too embarrassed to talk about their symptoms, which contributed to the feeling of being alone and not knowing if what they were experiencing was normal.<br>"It [prolapse] is a rather covert condition, because you don't talk [about it]. You don't discuss it during a dinner party, 'Well, my uterus is prolapsing'; you just don't say that" (Pakbaz 2011) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Moderate |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 8.2: Women want to know if their symptoms are normal** | | | | | |
| 3 (Buurman 2013, Dunivan 2014, Pintos-Diaz 2019) | 2 qualitative studies using interviews, 1 qualitative | Some women described how they were unsure if their symptoms were normal, due to the difficulty in talking to others about them. This can be quite isolating and disorientating, with women unsure of whether to worry about their symptoms or not. | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP | Moderate |

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | study using focus groups | "'Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal" (Buurman 2013)<br>"You're not alone!" (Dunivan 2014) | | qualitative checklist | |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence is not sufficiently rich | |

1 *CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

2

3 **Table 13: Evidence profile: Theme 9. Pelvic floor disorders in relation to pregnancy**

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 9.1: Pelvic floor disorders were viewed as normal** | | | | | |
| 1 (Buurman 2013) | 1 qualitative study using interviews | There appeared to be differences in how postpartum women viewed pelvic floor disorders compared to non-postpartum women. For instance, post-partum women often viewed prolapse or incontinence as a normal part of the recovery process and so were not as concerned or fearful. They also believed that their symptoms would resolve spontaneously and therefore were unlikely to seek help.<br>"It's like there's a train that's driven right through you. I understand that your body needs time to recover. If I just look after myself properly and don't neglect my body, I expect this prolapse won't be so painful after a while" (Buurman 2013) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small | |

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| | | | | number of studies or participants | |
| **Sub-theme 9.2: Pelvic floor disorders were not a priority** | | | | | |
| 1 (Buurman 2013) | 1 qualitative study using interviews | Postpartum women did not view their pelvic floor disorder issues as a priority, and their own physical health was not important as they had a new baby to look after and prioritise. This also contributed to a reduced likelihood to seek medical help.<br>"When you've just had a delivery, you've got a thousand things on your mind and you're a bit of a scatterbrain. So to be honest, I wasn't really thinking about my problem holding my stools in, as I had more important things on my mind. I just thought: it'll be all right." (Buurman 2013) | Methodological limitations | Moderate concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | Minor concerns<br>Evidence is not directly relating to valued information | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |

*CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

## Table 14: Evidence profile: Theme 10. Information provides relief

| **Study information** | | | **CERQual assessment of the evidence** | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| **Sub-theme 10.1: Information about the symptoms/diagnosis and treatment provides women with relief** | | | | | |
| 3 (Buurman 2013, Kiyosak | 2 qualitative studies using | Receiving information regarding the diagnosis and potential treatment of their pelvic floor disorders provide women with relief. This was sometimes because | Methodological limitations | Major concerns about | Low |

| Study information | | | CERQual assessment of the evidence | | |
|---|---|---|---|---|---|
| **Number of studies** | **Design** | **Description of theme or finding** | **Criteria** | **Level of concern** | **Overall quality** |
| 2012, Weislander 2015) | interviews, 1 qualitative study using focus groups | they had thought their symptoms might be due to something more serious, such as cancer, or because they just did not know what it was which lead to fear. Therefore, it was a relief to find out it was not as serious as feared. Women were also sometimes relieved that the recommended treatment was not as severe as they had thought. This demonstrates the importance of receiving information regarding diagnosis and treatment.<br>"The doctor doesn't think it's as severe as the original person I saw. I'm relieved because I don't need surgery" … "The doctor found problems and can fix them" (Kiyosaki 2012)<br>"I was very happy when I read that vaginal flatulence existed because I thought it was impossible, but it was possible indeed!" (Buurman 2013) | | methodological limitations of the evidence as per CASP qualitative checklist | |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | None or very minor concerns | |
| **Sub-theme 10.2: Information provides women with relief that they are not alone or abnormal** | | | | | |
| 2 (Buurman 2013, Dunivan 2014) | 1 qualitative study using interviews, 1 qualitative study using focus groups | Being informed about their condition allowed women to understand their condition better and make them feel that they are not alone or abnormal. Women feel relieved that others are going through something similar to them, and that they do not have to go through it alone, especially given the covert nature of the disorders and the fact that they are not commonly discussed with anyone other than the doctor.<br>"Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal." (Buurman 2013) | Methodological limitations | Major concerns about methodological limitations of the evidence as per CASP qualitative checklist | Low |
| | | | Relevance | None or very minor concerns | |
| | | | Coherence | None or very minor concerns | |
| | | | Adequacy | Minor concerns<br>Evidence comes from a small number of studies or participants | |

1 *CASP: Critical Appraisal Skills Programme; CERQual: Confidence in Evidence from Reviews of Qualitative research*

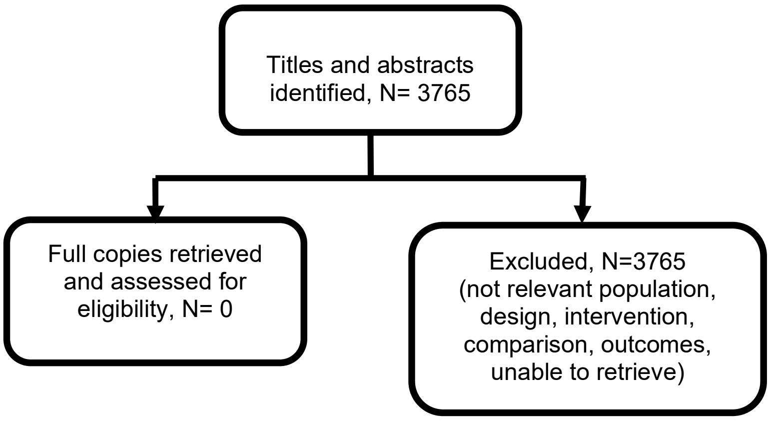
2

# Appendix G – Economic evidence study selection

## Economic evidence study selection for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

No economic evidence was identified which was applicable to this review question.

**Figure 2: Study selection flow chart**



# Appendix H – Economic evidence tables

## Economic evidence tables for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

No evidence was identified which was applicable to this review question.

# Appendix I – Economic evidence profiles

## Economic evidence profiles for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

No economic evidence was identified which was applicable to this review question.

# Appendix J – Economic analysis

## Economic evidence analysis for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

No economic analysis was conducted for this review question.

# Appendix K – Excluded studies

## Excluded studies for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

### Clinical studies

It should look like this

**Table 15: Excluded studies and reasons for their exclusion**

| Study | Reason for exclusion |
|---|---|
| Anger, J. T, Khan, A, Smith, A. L, Nissim, H. A, Le, T. X, Sarkisian, C. A, Maliski, S. L, Litwin, M. S, Raz, S, Rodriguez, L. V., Misconceptions and miscommunication among aging women with OAB, Journal of Urology, 181, 565, 2009 | No qualitative data on phenomena of interest. |
| Basu, M, Wise, B, Duckett, J., A qualitative study of women's preferences for treatment of pelvic floor disorders, BJOG: An International Journal of Obstetrics and Gynaecology, 118, 338-344, 2011 | No qualitative data on phenomena of interest. |
| Chiarelli, P, Cockburn, J., The development of a physiotherapy continence promotion program using a customer focus, Australian Journal of Physiotherapy, 45, 111-119, 1999 | Incorrect population |
| Doshani, A, Pitchforth, E, Mayne, C. J, Tincello, D. G., Culturally sensitive continence care: A qualitative study among South Asian Indian women in Leicester, Family Practice, 24, 585-593, 2007 | Incorrect population |
| Filipetto, Frank A, Fulda, Kimberly G, Holthusen, Amy E, McKeithen, Thomas M, McFadden, Pam, The patient perspective on overactive bladder: a mixed-methods needs assessment, BMC family practice, 15, 96, 2014 | Incorrect population |
| Gonzalez, G, Vaculik, K, Khalil, C, Zektser, Y, Arnold, C, Almario, C. V, Spiegel, B. M. R, Anger, J. T., Women's Experience with Stress Urinary Incontinence: Insights from Social Media Analytics, The Journal of urology, 2019 | Not a qualitative study |
| Gonzalez, G, Zekster, Y, Khalil, C, Vaculik, K, Arnold, C, Almario, C. V, Spiegel, B. M. R, Anger, J. T., A large-scale social media analysis of overactive bladder posts: what do patients know and want to know?, Journal of Urology, 201, e122ââ‚¬Â  e123, 2019 | Abstract |
| Gonzalez, G, Zekster, Y, Khalil, C, Vaculik, K, Arnold, C, Almario, C. V, Spiegel, B. M. R, Anger, J. T., Using digital ethnography to understand the biopsychosocial illness experience of women suffering from pelvic organ prolapse, Journal of Urology, 201, e12, 2019 | Abstract |
| Gonzalez, G, Zektser, Y, Khalil, C, Vaculik, K, Arnold, C, Almario, C. V, Spiegel, B. M. R, Anger, J. T., Using digital ethnography to understand the biopsychosocial illness experience of women suffering from pelvic organ prolapse, Neurourology and Urodynamics, 38, S231, 2019 | Abstract |
| Gonzalez, G, Zektser, Y, Khalil, C, Vaculik, K, Arnold, C, Almario, C. V, Spiegel, B. M. R, Anger, J. T., Women's experience with stress urinary incontinence: insights from a qualitative social media analysis, Neurourology and Urodynamics, 38, S91ââ‚¬Â  S92, 2019 | Abstract |
| Gonzalez, G, Zektser, Y, Vaculik, K, Khalil, C, Arnold, C, Almario, C. V, Spiegel, B. M. R, Anger, J. T., A large-scale social media analysis of overactive bladder posts: What do patients know and want to know?, Neurourology and Urodynamics, 38, S135-S136, 2019 | Abstract |
| Hatchett, Lena, Hebert-Beirne, Jennifer, Tenfelde, Sandi, Lavender, Missy D, Brubaker, Linda, Knowledge and perceptions of pelvic floor | Incorrect population |

| Study | Reason for exclusion |
|---|---|
| disorders among african american and latina women, Female Pelvic Medicine & Reconstructive Surgery, 17, 190-4, 2011 | |
| Hazewinkel, M. H, Sprangers, M. A. G, Taminiau-Bloem, E. F, Van Der Velden, J, Burger, M. P. M, Roovers, J. P. W. R., Reasons for not seeking medical help for severe pelvic floor symptoms: A qualitative study in survivors of gynaecological cancer, BJOG: An International Journal of Obstetrics and Gynaecology, 117, 39-46, 2010 | Incorrect population |
| Heit, M, Blackwell, L, Kelly, S., Adapting the theory of care seeking behavior to the clinical problem of urinary incontinence, Journal of Pelvic Medicine and Surgery, 14, 29-35, 2008 | Not a qualitative study |
| Khan, A, Sevilla, C, Rashid, R, Wieslander, C, Maliski, S, Rogers, R, Anger, J., Identifying barriers to communication and disease understanding among spanish-speaking latinas with pelvic floor disorders, Neurourology and Urodynamics, 30, 248-249, 2011 | Abstract |
| Liapis, A, Bakas, P, Liapi, S, Sioutis, D, Creatsas, G., Epidemiology of female urinary incontinence in the Greek population: EURIG study, International Urogynecology Journal, 21, 217-222, 2010 | Not a qualitative study |
| Lyatoshinskaya, P, Gumina, D, Popov, A, Koch, M, Hagmann, M, Umek, W., Knowledge of pelvic organ prolapse in patients and their information-seeking preferences: comparing Vienna and Moscow, International Urogynecology Journal, 27, 1673-1680, 2016 | Not a qualitative study |
| Makara-Studzinska, M, Madej, A, Trypka, E, Leszek, J, Tarasov, V. V, Ashraf, G. M, Yarla, N. S, Samsonova, A. N, Aliev, G., Quality of life and social support in women with urinary incontinence, Current Women's Health Reviews, 15, 123-129, 2019 | Not a qualitative study |
| Pakbaz, M, Persson, M, Lofgren, M, Mogren, I., 'A hidden disorder until the pieces fall into place' - a qualitative study of vaginal prolapse, BMC Women's Health, 10 (no pagination), 2010 | Not a qualitative study |
| Paterson, J, Dunn, S, Kowanko, I, van Loon, A, Stein, I, Pretty, L., Selection of continence products: perspectives of people who have incontinence and their carers, Disability & Rehabilitation, 25, 955-63, 2003 | Incorrect population |
| Santini, S, Andersson, G, Lamura, G., Impact of incontinence on the quality of life of caregivers of older persons with incontinence: A qualitative study in four European countries, Archives of Gerontology & Geriatrics, 63, 92-101, 2016 | Population includes men and results not presented separately for women |
| Sevilla, C, Horton, C, Volpe, K, Baezconde-Garbanati, L, Unger, J, Stern, M, Rodriguez, L., Factors contributing to health disparities in spanish-speaking latina women with pelvic floor disorders, Neurourology and Urodynamics, 38, S233-S234, 2019 | Abstract |
| Sevilla, C, Horton, C, Volpe, K, Unger, J, Stern, M, Rodriguez, L., Factors contributing to health disparities in Spanish-speaking latina women with pelvic floor disorders, Journal of Urology, 201, e11, 2019 | Abstract |
| Shaw, C, Williams, K. S, Assassa, R. P., Patients' views of a new nurse-led continence service, Journal of Clinical Nursing, 9, 574-582, 2000 | Incorrect population |
| Vardeman, J, Antosh, D, Muir, T, Spiers, A., Perceptions of pelvic floor disorders in community dwelling women in the United States, International Urogynecology Journal, 29, S120, 2018 | Abstract |
| Vardeman, J, Antosh, D. D, Muir, T. W, Spiers, A., Perceptions of pelvic floor disorders in community dwelling women in the united states, Female Pelvic Medicine and Reconstructive Surgery, 24, S151-S152, 2018 | Abstract |

## Economic studies

No economic evidence was identified for this review.

# Appendix L – Research recommendations

## Research recommendations for review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

### Research question

What are the experiences and information needs of children and young women (between 12 and 17 years) with pelvic floor dysfunction?

### Why this is important

Pelvic floor dysfunction is a condition that can have a significant impact on the lives of individuals regardless of age. Although there have been several studies into experiences of women older than 20 years, currently there is very little research addressing the experiences and information needs for children and young women (age <20). Therefore, it is important that further research is done in this area to ensure that care for children and young women (age< 20) with PFD is tailored to meet their specific needs. Having a greater understanding of the experiences and information needs of this group could work toward addressing any inequalities and barriers to care.

**Table 16: Research recommendation rationale**

| Research question | What are the experiences and information needs of children and young women with pelvic floor dysfunction? |
|---|---|
| **Why is this needed** | |
| **Importance to 'patients' or the population** | Gathering information about the experiences and information needs of children and young women will ensure that the needs of this particular group are recognised and addressed. It is important that children / young women with PFD are engaged with services which could improve outcomes in the long term. |
| **Relevance to NICE guidance** | The relative absence of evidence regarding this topic currently restricts NICE guidance from making recommendations for tailored resources and services for children/ young women (<20 years) with PFD. The outcome of this research would allow such recommendations to be developed and become part of NICE guidance. |
| **Relevance to the NHS** | Understanding the experiences and adjusting information giving to meet the needs of children/ young women (<20 years) could support them to make changes that may prevent need for treatments that are costlier to the NHS. It may be that the recommendations could be combined with existing advice. |
| **National priorities** | Providing patients with more control over their health and personalised care when they need it – NHS Long Term Plan 2019. |
| **Current evidence base** | No evidence currently available. |
| **Equality** | The management of PFD is currently based on evidence from older women, it could be that some aspects are not optimal for this younger age group. |
| **Feasibility** | Consideration will need to be given to the ethical aspects of research involving children and the researchers will need expertise in eliciting the views of children and young adults. |
| **Other comments** | None |

*PFD: pelvic floor dysfunction*

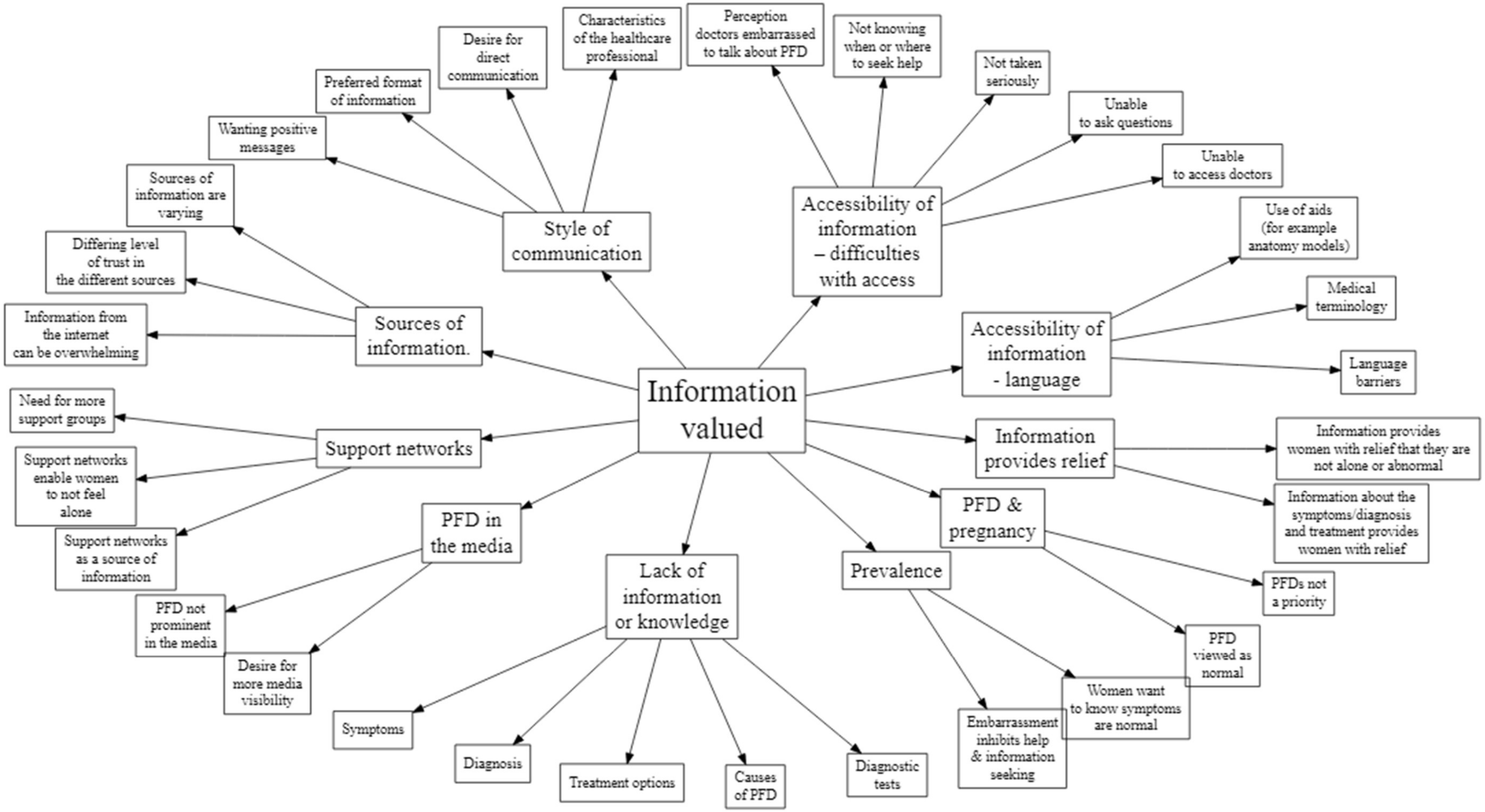
**Table 17: Research recommendation modified PICO table**

| Criterion | Explanation |
|---|---|
| **Population** | Children / Young women aged 12 to 20 years with symptoms of PFD |
| **Intervention** | Not applicable |
| **Comparator** | Not applicable |
| **Outcomes** | Experiences of care, satisfaction with care, information needs, assessment of knowledge and understanding of condition |
| **Study design** | Qualitative – open-ended questionnaire or interview |
| **Timeframe** | 1 year |
| **Additional information** | None |

*PFD: pelvic floor dysfunction*

# Appendix M – Thematic maps

**Figure 3: Thematic map for the information valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers**



# Appendix N – Quotes supporting themes

## Quotes supporting themes for the review question: What information is valued by women with symptoms associated with pelvic floor dysfunction and their partners or carers?

| Study (author and year) | Theme | Subtheme | Quotes |
|---|---|---|---|
| Andersson 2009 | Accessibility of information – language | Language barriers | “When we want to go to the doctor or somewhere, we can’t read and write Swedish, so it is difficult for us.”<br>“An interpreter has to come; if it is a woman, we can say everything, if it’s a man, nothing.”<br>“Yes, the main thing is that you know the language. If you don’t know the language you have to have relatives who know the language and who also have time” |
| | Accessibility of information – difficulties with access | Not being able to access doctors | “The way it is at the medical center is not good . . . we have to wait and wait.”<br>“Even if we scream and make a fuss they don’t help us” |
| | Style of communication | Characteristics of the HCP | “If it’s a male doctor then we ask for another. We’re ashamed”<br>“It doesn’t matter to me [whether it’s a female or a male doctor]. If I have a problem, then I have a problem”<br>“An interpreter has to come; if it is a woman, we can say everything, if it’s a man, nothing.”<br>“When I came to the medical center I saw that there was a male interpreter and then I said no and brought in my daughter instead.”<br>“Once I was at the medical center and a Somalian man came who was going to interpret. I said to the doctor immediately, “I don’t want that. I can talk if he leaves, then I can say everything.” |
| | Support networks | Support networks as a source of information | “If you don’t know the language you have to have relatives who know the language and who also have time” |
| | Lack of information or knowledge | Women demonstrated a lack of understanding | “I have a cousin… it’s the same with her. She had surgery and she became well, or better. I think that she [V] needs an operation. |

| Study (author and year) | Theme | Subtheme | Quotes |
|---|---|---|---|
| | | of the treatment options | V: I was first offered surgery, but then was told that it couldn't be operated.<br>A: Oh, so if you wait too long it can't be operated?" |
| Bjork 2014 | Accessibility of information – difficulties with access | Not being taken seriously | "Well, I haven't explicitly looked for it, but since I was there I asked them and told them about my problems, but they didn't think there was much to be concerned about" |
| Buurman 2013 | Style of communication | Desire for direct communication | "I think asking direct questions about it [pelvic floor problems] is a good idea. For when they ask you an open question, perhaps it's difficult to mention the subject, especially when you're embarrassed or you're not sure whether this is normal or not" |
| | Sources of information | Sources of information are varying | "No, I didn't call in medical help because my relatives, especially my mum and my gran, said that it would just pass off. So I was like if my mum and my gran say so, it'll be all right"<br>"Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal" |
| | Support networks | Support networks enable women to not feel alone | "Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal" |
| | | Support networks as a source of information | "No, I didn't call in medical help because my relatives, especially my mum and my gran, said that it would just pass off. So I was like if my mum and my gran say so, it'll be all right" |
| | Lack of information or knowledge | Information needs are not being met | "So I think that's very odd, that this midwife told me nothing about the pelvic floor during my pregnancy. She only said something about it at a checkup visit when I mentioned that I had such a heavy feeling. So it turns out that's your pelvic floor" |
| | | Women demonstrated a lack of understanding of their symptoms | "I was very happy when I read that vaginal flatulence existed because I thought it was impossible, but it was possible indeed! Well, I don't know what's causing them, but I do think they're a pretty nuisance"<br>"I don't really understand the constipation. You see, that I'm not feeling the flatulence, that has got something to do with pelvic floor weakness, but why I have constipation? I don't know" |
| | | Women demonstrated a lack of understanding | "Well, I thought to myself sometimes: am I doing this right? For you might be training as much as you like and then find out afterwards that you're not doing the right exercises. So |

| Study (author and year) | Theme | Subtheme | Quotes |
|---|---|---|---|
| | | of the treatment options | this would have no effect at all: you'd be training the muscles in your buttocks instead of the proper ones in your pelvic floor." |
| | Prevalence | Embarrassment inhibits help-seeking and information seeking | "I think asking direct questions about it [pelvic floor problems] is a good idea. For when they ask you an open question, perhaps it's difficult to mention the subject, especially when you're embarrassed or you're not sure whether this is normal or not" |
| | | Women want to know if their symptoms are normal | "Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal" |
| | Pelvic floor disorders in relation to pregnancy | Pelvic floor disorders were viewed as normal | "It's like there's a train that's driven right through you. I understand that your body needs time to recover. If I just look after myself properly and don't neglect my body, I expect this prolapse won't be so painful after a while" |
| | | Pelvic floor disorders were not a priority | "When you've just had a delivery, you've got a thousand things on your mind and you're a bit of a scatterbrain. So to be honest, I wasn't really thinking about my problem holding my stools in, as I had more important things on my mind. I just thought: it'll be all right." |
| | Information provides relief | Information about the symptoms/diagnosis and treatment provides women with relief | "I was very happy when I read that vaginal flatulence existed because I thought it was impossible, but it was possible indeed!" |
| | | Information provides women with relief that they are not alone or abnormal | "Well, because several women told me they lose a little urine sometimes. So I feel I'm not the only one and that this is quite normal" |
| Cichowski 2014 | Style of communication | Wanting positive messages | "But I think not talking about these things like hope is a mistake. I think we need to have hope and happiness to know that there is a positive outcome possible for us."<br>"Emotions are important to include…because we have something going on in our bodies that we feel like we have no control over." |
| Dunivan 2014 | Accessibility of information – language | Language barriers | "For me, I feel more trust if the doctor understands me directly without interpreter, I like it that way"<br>"They (the interpreters) don't explain things well many times" |
| | Support networks | Support networks enable | "I'm part of a big group of women here. It's not just me" |

| Study (author and year) | Theme | Subtheme | Quotes |
|---|---|---|---|
| | | women to not feel alone | “You're not alone! And it doesn't have to be so private” |
| | Lack of information or knowledge | Women demonstrated a lack of understanding of their symptoms | “I didn't know that it happened to women”<br>“I went to the bathroom and I felt myself and I didn't know what it was and I was scared” |
| | | Women demonstrated a lack of understanding of the causes of their disorder | “My mother would always caution me to not lift heavy things because later when you grow up, your insides will fall out” |
| | Prevalence | Embarrassment inhibits help-seeking and information seeking | “When you sit down there is a sound like air that happens and it's embarrassing. You feel horrible.” |
| | | Women want to know if their symptoms are normal | “You're not alone! And it doesn't have to be so private” |
| | Information provides relief | Information provides women with relief that they are not alone or abnormal | “You're not alone! And it doesn't have to be so private” |
| Kiyosaki 2012 | Lack of information or knowledge | Information needs are not being met | “I don’t know what kind of incontinence I have but I’m a good candidate for sling surgery” |
| | | Women demonstrated a lack of understanding of their diagnosis | “I didn’t even hear my diagnosis. She gave me Vesicare and Kegel exercises”<br>‘‘I have stress incontinence and laugh, cough, sneeze incontinence. I should restrict fluid intake, do Kegel exercises, and try the medication.’’ |
| | Information provides relief | Information about the symptoms/diagnosis and treatment provides women with relief | “The doctor doesn’t think it’s as severe as the original person I saw. I’m relieved because I don’t need surgery”<br>“The doctor found problems and can fix them” |
| Pakbaz 2011 | Accessibility of information – difficulties with access | Not being taken seriously | “When he [the doctor] had seen it [in earlier consultation], he thought, 'This isn't a problem'. I was disappointed, so, 'It wasn't so bad'? I was a bit surprised, and I feel that I have problems. But I believed [what the doctor said], 'There is no problem' so I carried on. That's why I went so long [before seeing the doctor again]” |

| Study (author and year) | Theme | Subtheme | Quotes |
|---|---|---|---|
| | | | “I contacted you [the gynaecological outpatient ward] five years ago. It felt pressing... I felt heaviness, and it felt unnatural. The condition [prolapse] was not treated at all, so I took no contact until four years later, when the prolapse started to emerge out of the vagina” |
| | Style of communication | Desire for direct communication | “You don't go arond far and wide and talk about it [prolapse], but you can do it in the right context” |
| | Sources of information | Sources of information are varying | “There isn't any information really [on prolapse], not in the way that you just stumble across it somehow. If I haven't searched [for the information] myself, I don't think I just happen to read about it by accident”<br>“You have to search for information [about prolapse], because there isn't anything, really. There is more [information] about urinary incontinence and incontinence sanitary pads; otherwise, there is no information about prolapse”<br>“I have two cousins who are midwives, and when I explained my problems [with prolapse] to my cousin, and she had listened, she said 'Well, I think you have prolapse'” |
| | Pelvic floor disorders in the media | Pelvic floor disorders are not prominent in the media | “I think there is very little written about this problem [prolapse] if you read just about anything, like weekly magazines. You know, you can read a lot about genital problems in magazines, but this particular problem I haven't run across often” |
| | Lack of information or knowledge | Information needs are not being met | “There isn't any information really [on prolapse], not in the way that you just stumble across it somehow. If I haven't searched [for the information] myself, I don't think I just happen to read about it by accident”<br>“You have to search for information [about prolapse], because there isn't anything, really. There is more [information] about urinary incontinence and incontinence sanitary pads; otherwise, there is no information about prolapse”<br>“I think there is very little written about this problem [prolapse] if you read just about anything, like weekly magazines. You know, you can read a lot about genital problems in magazines, but this particular problem I haven't run across often. I didn't even know there was another condition called prolapse, |

| Study (author and year) | Theme | Subtheme | Quotes |
|---|---|---|---|
| | | | besides when the uterus falls out. It was the only kind of prolapse I knew existed” |
| | Prevalence | Embarrassment inhibits help-seeking and information seeking | “It [prolapse] is a rather covert condition, because you don't talk [about it]. You don't discuss it during a dinner party, 'Well, my uterus is prolapsing'; you just don't say that”<br>“It is sort of unpleasant to talk about it [prolapse]. Not nefarious, but close to. Somehow, it is more sensitive to talk about one's intimate parts” |
| Pintos-Diaz 2019 | Accessibility of information – difficulties with access | Not knowing when or where to seek help | “For chest pain it seems quite clear to me, bleeding also, but for this… where should I go (for help)?” |
| | Prevalence | Women want to know if their symptoms are normal | “You feel disoriented, you don’t know if it is normal or not, whether you should worry or not” |
| Rasmussen 2010 | Style of communication | Not being taken seriously | “…faeces would keep oozing after my visiting a toilet, and I remember that I mentioned it to a nurse…and it was received in an extremely bad way” |
| | Accessibility of information – difficulties with access | Preferred format of information | “She said, ‘‘Well, haven’t you got a leaflet?’’ and I told her, ‘‘Yes, I’ve got a leaflet, but maybe I need to talk about it” |
| Sevilla 2013 | Accessibility of information – language | Language barriers | “We can also give a, it’s a disc…how do you say it…I don’t know…it’s a plastic, a disc….pessary that we put inside your vagina because it can support your uterus and prevent falling.” |
| | | Medical terminology | “She said it like… it was how she said it… the names are very difficult” |
| | Sources of information | Women have differing levels of trust in the different sources | “Today I have come to see the specialist because he is the one that is going to decide what he will do with me.”<br>“I want to see the specialist to see what it is that he recommends or what he tells me to do. He is going to give me a treatment or surgery. Whatever he says I’ll do.” |
| | Lack of information or knowledge | Women demonstrated a lack of understanding of their symptoms | “Oh my God...I feel a giant ball. A giant ball that is popping out. I bend over and I can see it.” |
| | | Women demonstrated a lack of understanding | “She said it like… it was how she said it… the names are very difficult. Oh, that I have three problems. The problem with my bladder and the one with… I don’t know if it is the urine or... and my uterus… my womb, I don’t know what |

| Study (author and year) | Theme | Subtheme | Quotes |
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| | | of their diagnosis | it is… yes I have all three problems. Well, the treatment was the exercises, anointment that I am going to put on, and what he told me about the operation."<br>"How do you say it,…interec... the urine thing... irretention… and that my vagina is… don't know… something to do with my vagina… do know… what I don't know is how to explain it. He gave me options regarding exercise or medicine and later…. I am going to see if they can do the surgery for the other cough problem"<br>"The urgency to go to the bathroom. With the urine. And the other one that I also have...it's just that I can't remember it… something about stress… that I also have to try to do exercises" |
| | | Women demonstrated a lack of understanding of the treatment options | "She told me that since my uterus is only hanging a little bit and they can put a mesh there. But she says that she doesn't recommend it because she says that what I have hanging is very little"<br>"He gave me options regarding exercise or medicine and later…. I am going to see if they can do the surgery for the other cough problem" |
| Siddiqui 2016 | Accessibility of information – difficulties with access | Not being able to access doctors | "In the Hispanic culture…people feel shy to talk about certain things. And from what I have seen, not only our culture but in different cultures too, they are concerned about what people may think or say. This stops them from asking anything, and if they don't say anything or ask they will not receive the necessary help"<br>"You go to the doctor, first of all you've got to talk to the people that you know so you can get information, then you have to get on the internet and do research, because they don't present information to you. And there can be stuff out there that can help you, and they don't even tell you about it" |
| | | Not being able to ask questions | "In the Hispanic culture…people feel shy to talk about certain things. And from what I have seen, not only our culture but in different cultures too, they are concerned about what people may think or say. This stops them from asking anything, and if they don't say anything or ask they will not receive the necessary help" |
| | Style of communication | Characteristics of the HCP | "I was sent to a urologist first…so not saying that a man really shouldn't know how you feel, but he really didn't understand" |
| | | Desire for direct communication | "I think that if your doctor asks you during a physical, 'Do you have any issues with this?' |

| Study (author and year) | Theme | Subtheme | Quotes |
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| | | | you're more likely to say actually yes, than you having to bring it up on your own” |
| | Sources of information | Sources of information are varying | “You go to the doctor, first of all you've got to talk to the people that you know so you can get information, then you have to get on the internet and do research, because they don't present information to you. And there can be stuff out there that can help you, and they don't even tell you about it”<br>“Well I think a lot of health issues today are really left for us to become self-educated. And that we are expected to challenge some of the things our doctors tell us because we research it ourselves and get some information” |
| | Support networks | Need for more support groups | “I think the conversations are helpful. And I think there need to be more services and conversations…support groups”<br>“They will not receive the support…from their partner. I imagine if you think you don't have your partner's support... they may think that no one else will support them” |
| | | Support networks as a source of information | “I mean I guess in a way I don't have anybody to really have a serious conversation with except for my doctor. And…my mom doesn't give me any advice” |
| | Pelvic floor disorders in the media | Desire for more media visibility | “Have commercials like [what they do] for breast cancer” |
| | Lack of information or knowledge | Information needs are not being met | "Well I think a lot of health issues today are really left for us to become self-educated. And that we are expected to challenge some of the things our doctors tell us because we research it ourselves and get some information”<br>“You go to the doctor, first of all you've got to talk to the people that you know so you can get information, then you have to get on the internet and do research, because they don't present information to you. And there can be stuff out there that can help you, and they don't even tell you about it” |
| | Prevalence | Embarrassment inhibits help-seeking and information seeking | “In the Hispanic culture…people feel shy to talk about certain things. And from what I have seen, not only our culture but in different cultures too, they are concerned about what people may think or say. This stops them from asking anything, and if they don't say anything or ask they will not receive the necessary help” |
| Smith 2011 | Sources of information | Sources of information are varying | “I learned [kegel exercises] from friends.”<br>“First you go to the doctor for advice and if that doesn’t work you start playing doctor yourself |

| Study (author and year) | Theme | Subtheme | Quotes |
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| | | | doing what you think should be done. I mean what can you do?" |
| | | Women have differing levels of trust in the different sources | "I think it is easy to be suspicious of things that come online, somethings you know are ads and you don't particularly trust them. Yeah I'd prefer to be told by a reliable source but sometimes the reliable source is your friends rather than the healthcare professionals." |
| | Support networks | Support networks as a source of information | "I learned [kegel exercises] from friends." |
| | Lack of information or knowledge | Women demonstrated a lack of understanding of their diagnosis | "My bladder fell and they had to tie it up."<br>Nocturnal enuresis: If the sheets of the bed are not wet, they didn't "wet the bed." |
| | | Women demonstrated a lack of understanding of the treatment options | "Well you just squeeze as hard as you can all the way up to the mid area. Just squeeze down there to make the muscles firm."<br>"I was taking the pills, but then I stopped it because it didn't make the leakage go away." |
| | | Women demonstrated a lack of understanding of the causes of their disorder | "I just thought it was a process of getting older and you can't do anything for it, I have been a frequent urinator and I kind of just accepted it, like this is my plight in life."<br>"I blamed my hysterectomy, I say [my gynecologist] did something to my bladder". |
| | | Women demonstrated a lack of understanding of diagnostic tests | "The doctor stuck a wand in my bladder." |
| Smith 2019 | Accessibility of information – difficulties with access | Perception that doctors are embarrassed to talk about pelvic floor disorders | "I don't think my regular doctor would be prepared to talk about it"<br>"It's like not all doctors are the same and some people we are more comfortable with [discussing incontinence] than others." |

| Study (author and year) | Theme | Subtheme | Quotes |
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| | Style of communication | Preferred format of information | "I'd think I'd rather be told personally. I think it is easy to be suspicious of things that come online, somethings you know are ads and you don't particularly trust them. Yeah I'd prefer to be told by a reliable source but sometimes the reliable source is your friends rather than the healthcare professionals." |
| | Sources of information | Sources of information are varying | "I would have thought the nurses would know"<br>"Yeah I'd prefer to be told by a reliable source but sometimes the reliable source is your friends rather than the healthcare professionals." |
| Van den Muijenbergh 2006 | Style of communication | Characteristics of the HCP | 'In Islam, a woman must always choose a female physician. |
| Wieslander 2015 | Accessibility of information – language | Medical terminology | "They used complicated words I wouldn't understand.", "…she explained for half an hour all the things…but the problem is that I can't memorize the words she used…"<br>"…she explained for half an hour all the things…but the problem is that I can't memorize the words she used…"<br>"…well I have already forgotten. It's cause they tell you so many things that you end up forgetting" |
| | | Use of aids | "Yes, models with the anatomy would have helped."<br>"…because in the beginning you don't know where the uterus is…"<br>"Any nation that can send a man to the moon can make a model of this so that women can understand. I don't want to look at a normal body. I want to see a prolapse."<br>"That way we could have something to actually take with us."<br>"Having a brochure… A cheat sheet that you can go back and look at later." |
| | Accessibility of information – | Not being able to ask questions | "I didn't know what kind of questions to ask." |

| Study (author and year) | Theme | Subtheme | Quotes |
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| | difficulties with access | | "I almost felt like I was annoying them with my questions I was asking." |
| | Sources of information | Information from the internet can be overwhelming | "It's impossible to look at all the websites."<br>"The amount of information that I was able to get was overwhelming to me." |
| | Lack of information or knowledge | Information needs are not being met | "You don't really get any information from other people because they don't know what you're talking about."<br>"I did not know that happened to women." |
| | | Women demonstrated a lack of understanding of the causes of their disorder | "I thought it was from lifting the heavy things and from bending over…"<br>"My mom…would tell me not to lift heavy things because…it would get worse"<br>"You need to put a girdle. I wouldn't do that…and it caught up with me." |
| | Information provides relief | Information about the symptoms/diagnosis and treatment provides women with relief | "I was scared because I didn't know what it was." |