

# Adult women's experiences of urinary incontinence: a systematic review of qualitative evidence

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## EXECUTIVE SUMMARY

### Background

Women are affected dramatically by urinary incontinence (UI). This disease is currently considered as epidemic.

### Objective

The objective of this review is to identify, through the best available evidence, how women experience UI worldwide.

### Inclusion criteria

#### Types of participants

The current review included studies of adult women who had experienced UI.

#### Phenomena of interest

Women with UI from various social and cultural settings were included in this review.

#### Types of studies

Qualitative data including, but not limited to, study designs such as phenomenology, grounded theory, ethnography, action research and feminist research were included in this review.

### Outcomes

All aspects related to the experience of UI endured by women were considered.

### Search strategy

An initial search of MEDLINE (PubMed) and CINAHL was done, followed by the exploration of all the databases and all identified studies, published in English, Spanish, French and Portuguese. The databases searched were CINAHL, PubMed, PsycINFO, Lilacs, Scielo, BVS, BVS-Psi, Scopus, Embase, Sociological Abstracts, Dissertation Abstracts International and the University of São Paulo Dissertations and Thesis bank and gray literature.

### Methodological quality

Each primary study was assessed by two independent reviewers for methodological quality. The Joanna Briggs Institute Qualitative Appraisal and Review Instrument (JBI-QARI) data extraction form for interpretive and critical research was used to appraise the methodological quality of all papers.

### Data extraction

Qualitative data were extracted using the JBI-QARI.

### Data synthesis

Qualitative research findings were synthesized using the JBI-QARI.

### Results

From the 28 studies were included, 189 findings were extracted and they were grouped into 25 categories and eight synthesized findings: (i) cultural and religious backgrounds and personal reluctance contribute to delays in seeking UI treatment; (ii) the inevitable and regrettable problem of UI endured silently and alone affects women's daily activities and their social roles; (iii) poor knowledge and the vague nature of the symptoms mask the fact that UI is a disease; (iv) the experiences provoked by UI and the sense of shame regarding the condition have contributed to impair women's lives; (v) UI has provoked negative effects on women's intimacy and sexual satisfaction and

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provoked changes in the ways they experience their sexuality and sexual function; (vi) UI is considered a consequence of pregnancy and childbirth, inherent to aging or a religious punishment; (vii) the women affected by UI adopt several strategies to improve their health status; and (viii) women have personal preferences toward care providers and treatments; they confront difficulties through UI treatment and some care needs are not met.

**Conclusion**

Personal and tailored health care should be provided, and preferences and expectations should be taken into consideration in the provision of health care to the people affected by UI.

**Keywords** Experience; qualitative systematic review; urinary incontinence; women

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**ConQual summary of findings**

Systematic review title: Adult women’s experiences of urinary incontinence Population: Women who were experiencing or have experienced the UI Phenomena of interest: Identify the meaningfulness of the best available evidence regarding the experience of urinary incontinence by women Context: Women worldwide			
Synthesized finding	Type of research	Dependability	ConQual score
Cultural and religious backgrounds and personal reluctance contribute to delays in seeking UI treatment	Qualitative	Downgrade 1 level*	Low
The inevitable and regrettable problem of UI approached in veiled and lonely ways affects women’s daily activities and social roles played	Qualitative	Downgrade 1 level*	Low
Poor knowledge and the vague nature of the symptoms mask the fact that UI is a disease	Qualitative	Downgrade 1 level*	Low
The experiences provoked by UI and the sense of shame regarding the condition have contributed to impair women’s lives	Qualitative	Downgrade 1 level*	Low
UI has provoked negative effects on women’s intimacy and sexual satisfaction and provoked changes in the ways they experience their sexuality and sexual function	Qualitative	Downgrade 1 level*	Low
UI is considered a consequence of pregnancy and childbirth, inherent to aging or a religious punishment	Qualitative	Downgrade 1 level*	Low
The women affected by UI adopt several strategies to improve their health status	Qualitative	Downgrade 1 level*	Low
Women have personal preferences toward care providers and treatments; they confront difficulties through UI treatment, and some care needs are not met	Qualitative	Downgrade 1 level*	Low

\*Downgraded 1 level due to common dependability issues across the included primary studies (the majority of studies had no statement locating the researcher and no acknowledgement of their influence on the research).

## Background

Urinary incontinence (UI) dramatically affects women's physical, psychological and social wellbeing and reduces their overall quality of life. Men and women are equally likely to experience the consequences of UI, regardless of age. However, older women are more affected than men.<sup>1</sup> The significant increase in longevity in women from an average lifespan of 73.2 years in 1997 to 76.5 years in 2007<sup>2</sup> has contributed to the aggravation of UI rates in older women. Currently, UI is considered an epidemic in the world.<sup>3</sup>

Urinary incontinence is defined by the International Continence Society as involuntary urine leakage, leading to social and/or hygienic problems.<sup>4</sup> There are three common types of UI: stress UI (SUI) refers to urine leakage provoked by exertion, urge UI (UUI) refers to a constant sense of urgency to urinate and mixed UI refers to urine leakage resulting from SUI and UUI.<sup>4</sup> Approximately 200 million people worldwide are affected by some form of UI.<sup>5</sup>

Both UI rates and the type of UI vary among countries. It is estimated that between 10% and 55% of females aged from 15 to 64 years are affected by UI, and SUI has the highest prevalence worldwide.<sup>5</sup> A multi-center study consisting of 17,080 subjects of both sexes was carried out in several European countries to estimate the UI rate.<sup>6</sup> The prevalence of UI was of 44% in France, 42% in the United Kingdom (UK), 41% in Germany and 23% in Spain. In Spain and the UK, approximately 24% of the women affected by any type of UI consulted a doctor.<sup>6</sup> The likelihood that people sought medical support for the disease was higher in France (33%) and Germany (40%).<sup>6</sup>

The prevalence of UI in a study in China, with a sample of 19,024 women aged 20–99 years, was 30.9%.<sup>7</sup> Among the women who visited a gynecological clinic in the United Arab Emirates, the prevalence of UI was 42.2%.<sup>8</sup> These women reported that physical activity, social life, family occupational work and sex were the aspects of their lives most affected by UI. Their self-esteem can also be affected, and financial problems can arise because of the effect of UI on work activities.<sup>7</sup> However, 50.5% of the women in these studies did not seek medical attention. The hope for a spontaneous resolution of UI (61.9%), embarrassment at being

examined by a clinician (35.9%), the belief that urine leakage is a normal occurrence (31.5%) and lack of awareness regarding the availability of treatment (23.9%) were their reasons for not seeking UI treatment.<sup>7</sup> Other researches have reported that on average only 25% of women affected by UI seek medical treatment.<sup>6,9</sup>

Many efforts have been made to improve the quality of life of women with UI, but these efforts need to include a better understanding of the degree to which women are affected by UI.<sup>1,10</sup> There is evidence that UI seriously affects the daily life of women. The main difficulties associated with UI are related to the lack of opportunities that those affected have to share their problems and the stigma associated with UI.<sup>1</sup> As a consequence, women face difficulties when trying to establish constructive inter-personal interactions. Women may experience fear and shame regarding UI. Often, this condition leads women to experiencing loneliness and isolation largely because of the social stigma associated with UI.<sup>1</sup> Many women experience emotional difficulties when trying to seek social support and treatment.<sup>11</sup>

The International Incontinence Society believes that the personal and social problems caused by UI can be understood by examining both subjective experiences and objective data.<sup>12</sup> International qualitative primary studies focusing on the personal experiences of UI patients have been done. These studies, which examined the condition by discussing the patient's perspectives, showed that several aspects of a woman's life are affected by this disease. Women's self esteem, daily self-care, social lives and spirituality were mentioned as being significantly affected.<sup>1,10,11</sup> The meanings attributed to UI and its consequences on a woman's daily life depends on their personal, cultural, religious and social background.<sup>10,11</sup> This systematic review of qualitative evidence will enhance our understanding of the subjective perspectives of women affected by UI.

This knowledge will permit us to identify some of the similarities and differences in the experiences of women from different cultures and social contexts. The information in the study will promote the implementation of evidence-based health care for women with UI. Knowledge on the possibilities related to women's personal, family and contextual backgrounds influencing the

experience of UI can be considered and incorporated into the planning and implementation of healthcare strategies.

An initial search for sources was done to determine whether a previous review addressing this specific question had been undertaken or was in progress. The *JBIM Database of Systematic Reviews and Implementation Reports* and the CINAHL databases were searched. The only review found was a systematic one focusing on the experience of UI that was completed in 2009 by Brazilian researchers. This report was conducted using meta-ethnography, in which the focus was primarily on cultural perspectives. In contrast, the current systematic review adopted a more comprehensive approach in the exploration of the experiences of women affected by UI. In this sense, the religious, social, family members interactions and the way healthcare providers approached them during treatments were also taken into account. This systematic review was conducted according to an *a priori* published protocol.<sup>13</sup>

### Objective

The general objective of this review was to identify the best available evidence related to how women experience UI. The question this review sought to answer was: How is UI experienced by women around the world?

### Inclusion criteria

#### *Types of participants*

The current review examined studies that included adult women (18 years or over) from a variety of cultural backgrounds where women had experienced UI. Women who had suffered brain disorders, spine injuries or were cognitively impaired were excluded from the review. Women who had suffered brain disorders and spine injuries were excluded because women with these conditions often experience UI because of the disorder or injury and should not be considered in the same category as other women experiencing UI. Cognitively impaired women were excluded because of their difficulty in verbally expressing their experiences.

#### *Phenomena of interest*

The current review considered studies that described the perspectives and opinions of women with UI.

#### *Types of studies*

The review considered studies that focused on qualitative data. This included, but was not limited to, designs such as phenomenology, grounded theory, ethnography, action research and feminist research.

#### *Context*

The current review examined how the social, financial, familial, religious and cultural circumstances of women affected their experience of UI.

### Search strategy

The search strategy aimed to find both published and unpublished studies. A three-step search strategy was applied for this review. An initial limited search of PubMed and CINAHL was undertaken. This was followed by an analysis of the words in the article titles and in the abstracts, as well as of the index terms used to describe the article. A second search using all identified keywords and index terms was then undertaken for all the databases that were included. Lastly, the reference lists of all identified reports and articles were explored to find additional studies. This strategy was developed first on July 2014 and updated on August 2016. Studies published in English, Spanish, French and Portuguese were considered for this review. No date restriction was applied to the search.

The databases searched included CINAHL, PubMed, PsycINFO, Lilacs, Scielo, BVS, BVS-Psi, Scopus, Embase and Sociological Abstracts (Appendix I). The search for unpublished studies included Dissertation Abstracts International and the University of São Paulo Dissertations and Thesis bank.

Gray literature was also accessed through the exploration of relevant worldwide web pages to find technical reports from scientific research groups and working papers from research groups or committees. Dissertation Abstracts International and University of São Paulo Dissertations and Theses Bank were explored. Both pages were explored using the following keywords: urinary incontinence, experience life, women and qualitative research. The terms “association” and “urology” were also explored in Google Scholar to find related work available on organizational websites. The reference

lists of each identified article were hand searched as well as through internet resources.

### Assessment of methodological quality

Qualitative papers selected for retrieval were assessed for methodological validity by two independent reviewers prior to inclusion in the review using standardized critical appraisal instruments from the Joanna Briggs Institute Qualitative Assessment and Review Instrument (JBI-QARI) (Appendix II). A cutoff score of 80%, a criterion established by the reviewers to guarantee the inclusion of empirical studies with good methodological quality, was used in this review. Any disagreements that arose between the reviewers were solved through discussion. A third reviewer to solve disagreements in this work was not required.

### Data extraction

Qualitative data were extracted from papers included in the review using the standardized data extraction tool from JBI-QARI (Appendix III). The data extracted included specific details about the interventions, populations, study methods, outcomes of significance to the review question and specific objectives.

### Data synthesis

Qualitative research findings were pooled using the JBI-QARI. This involved the aggregation or synthesis of findings to generate a set of statements to represent that aggregation through assembling the findings rated according to their credibility. These findings were then categorized on the basis of similarity in meaning. Primary study findings were read, and through this process, the experiences shared by the women were identified. This work was done through a repeated reading of the findings of primary studies. The description of the categories was composed through consensus among the reviewers about identification of the keywords of concepts and themes reported in primary studies. These categories were then meta-aggregated to produce a single comprehensive set of synthesized findings.

## Results

### *Description of studies*

The search, concluded first on July 2014 and updated on August 2016, produced 668 articles from

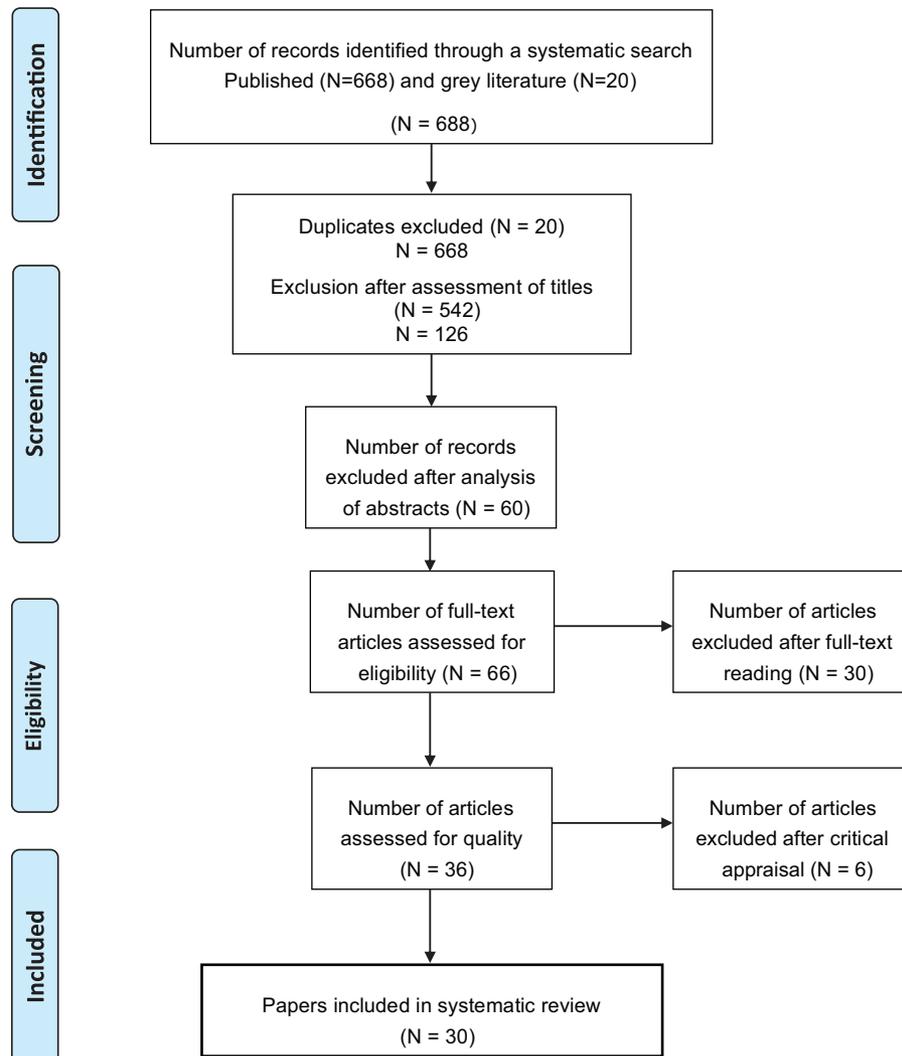
a systematic search of indicated databases, and 20 from gray literature, with a total of 688 studies. Among these, duplicates (20) and titles not related to the review (542) were excluded, leaving a remainder of 126 articles. Titles were selected if they included the aforementioned keywords that suggested relevance to the topic of the systematic review. After evaluating the abstracts of these 126 studies, 60 were excluded based on the inclusion and exclusion criteria. The remaining 66 articles were retrieved for full review. After this, 30 were also excluded based on the inclusion and exclusion criteria. This left 36 studies to be examined for methodological quality.

The cutoff point established for the inclusion of primary studies in this review was at least eight of the 10 items of the JBI-QARI in agreement. Based on this criterion, six primary studies were excluded in this step. The types of bias that were present in the excluded studies are detailed in Appendix IV. After these exclusions, 30 studies remained for inclusion in this systematic review. The list of findings and conclusions of the included studies is shown in Appendix V. A hand search of reference lists of studies retrieved was also performed; however, no relevant studies were found in this step. Figure 1 shows the search and inclusion process.

All included studies used qualitative methodologies to accomplish the general aim of investigating the experiences of women living with UI. The studies were conducted in 13 different countries: Australia (one),<sup>14</sup> Brazil (two),<sup>1,15</sup> Canada (one),<sup>16</sup> China (two),<sup>17,18</sup> Ethiopia (one),<sup>19</sup> Germany (one),<sup>20</sup> Iran (one),<sup>21</sup> Netherlands (one),<sup>22</sup> South Asian (one),<sup>23</sup> Sweden (four),<sup>24-27</sup> Turkey/Moroccan (one),<sup>28</sup> the United Kingdom (six)<sup>29-34</sup> and the United States of America (eight).<sup>35-42</sup> A total of 557 women reported the experience of UI in the 30 primary studies included in this systematic review. The data of primary studies were collected through semi-structured interviews, audiotaped interviews, focus groups, non-directive interviews, face-to-face interviews and in-depth interviews. Data analysis methods varied in these studies, but were consistent with the qualitative methods used in each study.

### Methodological quality

Among the selected 36 studies, 30 showed good methodological quality, with scores ranging from 8 to a maximum of 10 points. Nineteen scored 8 out



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(6): e1000097.

**Figure 1: Process of study identification, selection and inclusion in the review**

of 10,<sup>16-18,22,24-26,31-42</sup> seven<sup>14,15,19,23,27,28,30</sup> scored 9 and four<sup>1,20,21,29</sup> scored full points. Refer to Table 1 for the details related to the JBI-QARI Critical Appraisal Checklist for Interpretive and Critical Research' scores attributed to the included studies. Six studies were excluded because they did not reach the cutoff point, 8 of the 10 of JBI-QARI, established in this review. Four<sup>43-46</sup>, of them were awarded a score of six items, and two<sup>47,48</sup> awarded a score of four items of the JBI-QARI. The poorer performances of the included studies were related to the sixth (46.6) and the seventh (26.6) questions of

the JBI-QARI. The reviewers considered that these questions, respectively, related to the cultural or theoretical location of the researcher and the influence of the researcher on the research, and did not interfere with the quality of this review and its transferability.

### Results of meta-synthesis of qualitative research findings

Thirty primary studies were included in this review, and from these studies, 189 findings were extracted. The findings reached by the primary researchers,

**Table 1: JBI-QARI scores attributed to the included studies**

Reference	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
Akyuz <i>et al.</i> <sup>35</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Bradway and Barg <sup>36</sup>	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Delarmelindo <i>et al.</i> <sup>15</sup>	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Gjerde <i>et al.</i> <sup>19</sup>	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Siu and Lopez <sup>17</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y
MacDonald and Butler <sup>16</sup>	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Komorowski and Chen <sup>18</sup>	Y	Y	Y	Y	Y	U	N	Y	Y	Y
Hägglund and Wadensten <sup>24</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Hayder and Schnepf <sup>20</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Higa <i>et al.</i> <sup>1</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Van den Muijsenbergh and Lagro-Jansse <sup>28</sup>	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Andersson <i>et al.</i> <sup>25</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Andersson <i>et al.</i> <sup>26</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Elstad <i>et al.</i> <sup>37</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Welch <i>et al.</i> <sup>38</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Peake <i>et al.</i> <sup>14</sup>	Y	Y	Y	Y	Y	Y	Y	Y	N	Y
Doshani <i>et al.</i> <sup>29</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Nicolson <i>et al.</i> <sup>30</sup>	Y	Y	Y	Y	Y	Y	U	Y	Y	Y
Coyne <i>et al.</i> <sup>39</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Roe and May <sup>31</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Roos <i>et al.</i> <sup>22</sup>	Y	Y	Y	Y	Y	U	U	Y	Y	Y
Sange <i>et al.</i> <sup>32</sup>	Y	Y	Y	Y	Y	Y	U	Y	U	Y
Skoner and Haylor <sup>40</sup>	Y	Y	Y	Y	Y	Y	N	Y	N	Y
Wilkinson <sup>23</sup>	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Dowd <sup>41</sup>	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Ashworth and Hagan <sup>33</sup>	Y	Y	Y	Y	Y	N	Y	Y	N	Y
Hägglund and Ahlström <sup>27</sup>	Y	Y	Y	Y	Y	U	Y	Y	Y	Y
Mason <i>et al.</i> <sup>34</sup>	Y	Y	Y	Y	Y	Y	U	Y	N	Y
Hamid <i>et al.</i> <sup>21</sup>	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Zeznock <i>et al.</i> <sup>42</sup>	N	Y	Y	Y	Y	Y	N	Y	Y	Y
%	97	100	100	100	100	47	27	100	80	100

which are often presented as themes, metaphors, findings or concepts, were extracted. Only findings of one level were extracted from each empirical study. First-level findings were extracted from 14 studies,<sup>1,19,18,22,25,30-32,36-39,41,42</sup> second-level findings were extracted from 14 studies<sup>14-17,20,21,23,24,26-29,33,34</sup> and third-level findings were extracted from two studies.<sup>35,40</sup> For each specific finding, a level of qualitative credibility was attributed. The findings were grouped into 25 categories and then into eight synthesized findings. The findings, categories and synthesized findings are presented in Table 2. The list of the included studies, their correspondent

findings and levels of credibility of the findings are presented in Appendix V.

The eight synthesized findings reveal the experiences shared by the 523 women who had participated in the 28 primary studies included in this review.

*Synthesized finding 1*

The first synthesized finding – “Cultural and religious backgrounds and personal reluctance contribute to the delay in seeking UI treatment” – is composed of two categories: “Cultural and religious backgrounds influence the decision to seek

**Table 2: Findings, categories and synthesized findings**

Findings	Categories	Synthesized findings
<b>Synthesized finding 1</b>		
Cultural influences on help-seeking and decision making behavior	Cultural and religious backgrounds influence the decision to seek treatment	Cultural and religious backgrounds and personal reluctance contribute to delays in seeking UI treatment
Religious influences on help seeking and decision making behavior		
Continence problems often delay seeking professional help	Personal reluctance to seek treatment	
Other illnesses are more important		
Reluctance to seek care		
Reluctance to seek professional support in resolving or managing their incontinence		
Seeking help		
Symptoms were not that important to prompt a consultation with the family doctor		
General influences on help-seeking and decision making behavior		
<b>Synthesized finding 2</b>		
A regrettable inevitability	An inevitable and regrettable problem	The inevitable and regrettable problem of UI endured silently and alone affects women’s daily activities and their social roles
Women viewed incontinence within a familial context		

**Table 2. (Continued)**

Findings	Categories	Synthesized findings
Avoidance	Daily life affected	
Impact of incontinence on everyday life		
Interruption of daily activities		
Sadness and regret for what was lost		
Trying to fit it into the day		
Roles in society affected	Social roles affected	
The incontinence was affecting their worship of the Islam faith		
Interruption or prevention of praying (namaz) as worst consequence of incontinence		
Severity of urinary incontinence		
Self-isolation: maintaining secrecy of UI		
Secrecy to live with UI		
Concealment to live with UI		
Social seclusion to live with UI		
Becoming apprehensive with the public perception of urine		
Worrying about leaking		
A veiled issue	Issues experienced secretly and alone	
A lonely experience		
Emotional isolation		
An isolating problem		
Silence exacerbated incontinence as a problem		
Women had not talked to a physician about their incontinence		
Incontinence is a forbidden topic		
Sharing the secret		
<b>Synthesized finding 3</b>		
Women did not remember when they experienced UI for the first time but they had experienced it with coughing and sneezing	Identification of UI via its symptoms	Poor knowledge and the vague nature of the symptoms mask the fact that UI is a disease
A vague condition difficult to identify as a disease		

**Table 2. (Continued)**

Findings	Categories	Synthesized findings
Memories of UI – remembering the first episode of UI	An ambiguous condition and thus UI is not seen as a disease	
Women did not remember when they experienced UI for the first time but they had experienced it with coughing and sneezing		
Remembering the first episode of UI		
An illegitimate problem		
Read little about the subject of continence	Poor knowledge about the disease	
Uncertainty about UI		
Among Hispanic respondents, uncertainty fueled worry		
<b>Synthesized finding 4</b>		
Anxiety about everyday living	Distressing and stigmatizing experiences	The experiences provoked by UI and the sense of shame regarding the condition have contributed to impair women’s lives
Considering IU to be an unpleasant experience		
Emotional distress		
Experiencing a less-satisfying encounter		
Living with incontinence as taboo		
Mental stress that being incontinent can cause and some appeared to be depressed incontinence as taboo		
Stigma of daytime frequency and urgency		
Responses to UI – fear		
Responses to UI – affected their lives		
Feeling morally and psychosocially vulnerable		
Emotional disruption		
Spiritual disruption		
Physical disruption		
Daily life disruption		

**Table 2. (Continued)**

Findings	Categories	Synthesized findings
Being incontinent of urine and wetting themselves in public was embarrassing	Embarrassing and humiliating experiences	
Embarrassment		
Fear and embarrassment		
Fear, shame and embarrassment, coupled with the restrictions that incontinence imposes on travel and social life caused isolation		
Feeling of shame of both being the one who leaks urine and speaking to others about the problem		
Feelings and emotions – worry, awareness of the condition and embarrassment		
Living with shame		
Sense of both the relatively trivial and embarrassing nature of the complaint		
Shame felt at being incontinent		
Responses to UI – perceptions of how UI is represented in the media		
Depression and hopelessness		
Feeling of unattractiveness		
Impact of UI on body image		
Incontinence affected how the body is seen		
Low self-image and loss of self-confidence		
Self-esteem, sexuality and embodiment		
Sufferers can come to hate their own bodies		
Threat to self-esteem		
Living with an uncontrolled body	Sense of self-blame	
Blaming themselves		
Locus of blame		
Self-blame		
Sufferers feel it is their fault		

**Table 2. (Continued)**

Findings	Categories	Synthesized findings	
<b>Synthesized finding 5</b>			
Altered sexual relationships		UI has provoked negative effects on women’s intimacy and sexual satisfaction and provoked changes in the way they experience their sexuality and sexual function	
Dyspareunia			
Orgasm			
Impact on sexuality			
Negative effects on sexual functioning			
Body image			
Sexual desire			
Sexual arousal			
Able to achieve orgasm, but may not allow self to do so			Intimacy and sexual satisfaction
Decreased sexual desire			
Fear that UI symptoms could occur during intercourse			
Feelings of blame and guilt about UI symptoms during having an intercourse			
Incontinence negatively influenced intimate relations with their husband			
Prevent leakage going to toilet before and after intercourse caused humiliation and distress for the women			
Sex arousal – increased length of time needed for arousal			
Sexual activity affected			
Sexual satisfaction not satisfied			
Variable impact on relationship			
<b>Synthesized finding 6</b>			
Accept and anticipate changes in health status as a natural feature of the aging process	A consequence of pregnancy and childbirth	UI is considered a consequence of pregnancy and childbirth, inherent to aging or a religious punishment	
Explanations for the cause of their condition			

**Table 2. (Continued)**

Findings	Categories	Synthesized findings	
Incontinence as a consequence of menopause			
Older women were “allowed” to be incontinent			
Urinary symptoms such as leakage, frequency and nocturia were a normal part of the aging process			
White respondents believed symptoms were normal aging			
Abnormality and inexplicability of own experience			
Associating UI with natural delivery			
Childbirth as one of the major causes of UI			
Incontinence as normal life event			
Making urine leakage comprehensible			
UI is abnormal consequence of pregnancy and childbirth			
Had to accept the incontinence			A religious punishment
Making sense of the leakage			
The condition was created by Allah			
<b>Synthesized finding 7</b>			
Accepting living with UI	Coping strategies		
Coping behaviors employed			
Coping strategy – minimizing it			
Doctors encourage women to accept this life trajectory			
Fear and coping strategies			
Individual coping behaviors with UI			
Living in readiness			
Sharing problems – opportunity to talk about their continence problem			
Talk about the problem viewed as a positive measure toward stress reduction			
Toning down their problem			

**Table 2. (Continued)**

Findings	Categories	Synthesized findings
Acceptance and no acceptance – contrasting attitudes with respect to how the women accepted stress incontinence	Management strategies	
Being familiar with the situation		
Being in control of the incontinence and having the lifestyle they desired		
Being prepared		
Black respondents believed symptoms were controllable		
Control of incontinence learned mostly through trial and error		
Forming a circle of trust		
Incontinence management – washing and changing routines and using absorbent products		
Incontinence management part of the normal routine		
Making adjustments in activities and behaviors		
Minimizing the UI problem		
Regain control		
Reminder as factor facilitating adherence to pelvic floor muscle exercise		
Restrict to wearing patterned materials to avoid people detecting a wet patch		
Risk reduction – avoiding certain fluids before leaving home		
Self-management of incontinence		
Special precautions become a way of life		
Strategies for living with UI – managing UI		
Strategies for living with UI – planning for episodes of UI		
Strategies for living with UI – compare themselves with others		
Strategies for living with UI – making sense		

**Table 2. (Continued)**

Findings	Categories	Synthesized findings
Supportiveness as factor facilitating adherence to pelvic floor muscle exercise		
To be distancing		
Clotting and appearance		
Intimacy and caring		
Management techniques and relationships		
Searching for a solution		
Encounters with healthcare providers		
Adhered closely to bodily cleanliness because incontinence is dirty and extremely bothersome	Self-care strategies	
Commitment as factor facilitating adherence to pelvic floor muscle exercise		
Elderly women taking care of UI		
Looking for and using possible therapies		
Perceived benefits of exercise as factor facilitating adherence to pelvic floor muscle exercise		
Perceived motivators as factor facilitating adherence to pelvic floor muscle exercise		
Seeing perspectives of improvement when finding possibilities of treatment		
<b>Synthesized finding 8</b>		
An understanding atmosphere as a expectation about care	Care needs not met	Women have personal preferences toward care providers and treatments; they confront difficulties through UI treatment and some care needs are not met
Being actively asked about UI		
Directing the UI experience: influence of staff		
Experience of support		

**Table 2. (Continued)**

Findings	Categories	Synthesized findings
Health professionals should use a more direct approach in addressing the problem		
The problem would be taken more seriously		
Women differed with respect to whether or not they sought social support and how helpful		
A problem offering no clear plan of action		
Responses to UI – medical providers and society		
Disclosure of UI		
Getting the problem solved		
Ambiguity of definition	Difficulties faced throughout treatment	
Desire for treatment		
Difficulties describing problems and understanding information about prescriptions and other treatment options		
Dissatisfaction at the way they had been taught pelvic floor exercises		
Had not received any valuable advice to manage the condition		
Incompetence as factor inhibiting adherence to pelvic floor muscle exercise		
Language as barrier that constrained participants’ understanding in interactions with health professionals and their ability to communicate problems clearly		
Not mastering language resulted in dependence on help		
Not understand the reason for the exercises		
Perceptions of discouraging as factor inhibiting adherence to pelvic floor muscle exercise		

**Table 2. (Continued)**

Findings	Categories	Synthesized findings
Failure to disclose UI to partners and relatives	Personal preferences toward care providers	
Feeling embarrassed when going to see doctor for personal reasons such as incontinence		
Having general practitioner from similar ethnic backgrounds would be preferable		
Prefer to tell to their practice nurse because the nurse would not be as busy as the general practitioner		
Preference to be seen by a female doctor		
Preference to see a female health professional particularly if a physical examination is required		
Preferred to see a doctor from the same ethnic group as themselves		
Preferred to use family members rather than the interpreting services		
Women gave preference to a female care provider		
Women would prefer to see an allied health rather than the general practitioner		
Preference for male or female health professionals		
Small group discussions, rather than large groups with healthcare professionals, would be more valuable	Personal preferences toward treatment	
Talk-based awareness campaigns were more likely to be successful than written ones		
Younger women were more likely to consider alternative therapies, older women tended to prefer to use medication as prescribed by doctor		

treatment” and “Personal reluctance to seek treatment”. Several factors contributed to the delay in seeking UI treatment, and the reluctance to ask for professional help is the primary motivation. The main motives for the delay in seeking treatment were limited opportunities for women to share their problems with care providers, a desire to solve the problem without professional help, a lack of a clear physical symptom and fears related to receiving confirmation of a severe disease.

The way in which a woman’s religious background can contribute to the reluctance to seek UI treatment is exemplified in the experiences expressed by Muslim women. Some of these women expressed that they delayed seeking treatment for UI because they believed they would be cured by God and therefore should not seek medical cures. One woman stated: “Life, death and health are from Allah. When Allah gives you an illness, you will receive cure from him too. I know Allah will not let me suffer.”<sup>32(p.52)</sup>

Many women attributed little importance to their UI symptoms and expressed that there were other health problems that were more important. One woman claimed: “I never thought it was a problem to go see the family doctor. I thought it was a small problem and it would go away, maybe I drank too much water, never thought it was such a big problem with so many people affected. You don’t go to see your family doctor for small problems.”<sup>29(p.588)</sup> Another stated: “I’ve never considered queuing up for an operation for UI as long as things are going as well as they are. I had a hip joint operation last autumn. It was more important to have that done.”<sup>25(p.118)</sup>

### *Synthesized finding 2*

The second synthesized finding, “The inevitable and regrettable problem of UI endured silently and alone affects women’s daily activities and their social roles” is composed of three categories: “An inevitable and regrettable problem”, “Daily life affected” and “Social roles affected”. The women in this study expressed regret about having UI. This sense of regret was due largely to the fact that the people around them were also affected by the condition. The women’s daily life was also affected by the consequences of UI. For example, a woman might avoid some of the daily activities that they used to do before the beginning of UI symptoms. A social consequence of UI was that some women would reduce

their participation in religious and social gatherings. Women might fear receiving public judgment about their condition.

The components of this synthesized finding indicate some of the inevitable and regrettable problems of UI. Many women with the condition silently endured a feeling of loneliness. Much of their absence from social activities was due to the need to visit the bathroom many times per day. One woman stated: “Sometimes my sister asks me to go shopping. I just think we will have to walk a long way to get to the toilets if I need them, so I don’t go.”<sup>23(p.2)</sup> Their ability to participate in social life was affected by their concerns about the public perception of urine. They felt that they should maintain UI as a secret condition: “If you tell other colleagues that you have urinary incontinence, they will laugh at you, saying that ‘oh! You are already old. You are not suitable to work’.”<sup>17(p.129)</sup> As a consequence, many women chose to experience their UI secretly. One woman claimed: “We hear people commenting about stench of urine. So we think [. . .]. They’re talking about our scent too! When I pee on clothing, I try to distance myself more for other people, do not get too close.”<sup>1(p.631)</sup>

### *Synthesized finding 3*

The third synthesized finding, “Poor knowledge and the vague nature of the symptoms mask the fact that UI is a disease”, is composed of three categories: “Identification of UI via its symptoms”, “An ambiguous condition and thus UI is not seen as a disease” and “Poor knowledge about the disease”. This synthesis discusses the incomplete knowledge about UI. This lack of knowledge about UI is due to researchers having not read sufficiently about the issue and the vague nature of the description of UI symptoms. These problems have contributed to the difficulties in creating a clear description of UI as a disease. In summary, these synthesized findings and their categories indicate that UI was understood when its symptoms persisted over a longer period of time and the nature of the disease became more evident. Urinary incontinence was initially seen by researchers as an ambiguous condition and was thus not identified as a disease.

Women’s knowledge of UI was poor because this condition was not often discussed: “We say that we are educated but you don’t realize and I didn’t realize how big a problem this is and that something

can be done about it . . . I've lived in this country all my life, I was educated here and I didn't think that this was a problem, so I never saw a doctor about it."<sup>29(p.588)</sup> Often UI was not identified as a disease in an individual until its symptoms had persisted for a long time and became more obvious. Another woman stated: "Since I was 40, I cannot hold my urine while coughing and sneezing. I did not mind this situation at first; I thought it as a temporary thing. Then I thought that everything would return to normal but it did not."<sup>35(p.27)</sup>

#### *Synthesized finding 4*

The fourth synthesized finding is "The experiences provoked by UI and the sense of shame regarding the condition have impaired women's lives". It is composed of four categories: "Distressing and stigmatizing experiences", "Embarrassing and humiliating experiences", "Sense of impairment" and "Sense of self blame". These findings discuss the anxiety, distress and stigma associated with urination frequency and urgency. The most embarrassing and humiliating experiences were when involuntary urine leakage occurred in public. The disruption to activities was due to feelings of depression, hopelessness and low self-esteem provoked by the UI. The sense of shame was provoked by the lack of adequate self-care practices.

These findings indicate that UI often leads to an emotional experience and is a condition that involves significant distress, stigma and embarrassment: "My mood is very bad for being always wet. I am so unhappy that I feel very annoyed. I am angry with myself, I always scold other people, and sometimes I find myself scolding people without reason."<sup>17(p.130)</sup> "If I go to someone's house and I have to go to the bathroom a lot, maybe it might not be the right time to go to the bathroom to pee, but since I have this weakness in my bladder, I have to go right away . . . I worry because I think other people are going to think 'what's wrong with her? Why is she going to the bathroom so much' It's truly not normal for someone to need to go to the bathroom so much!"<sup>37(p.2464)</sup> The disruption to everyday functioning and the experience of shame are apparent in the following quote: "To talk about diabetes and diet for example is of general interest, what you are supposed to eat and what you're not. But a bladder control problem is a bit private; it doesn't feel as natural to talk about. It's connected to a feeling of

shame. Urinary incontinence has to do with the genital area."<sup>24(p.308)</sup> "It affects your whole life. It definitely does. Very uncomfortable. As I say at the beginning it was really bad but now I just take every day as it comes. It actually got me so depressed that it made me ill."<sup>30(p.350)</sup>

#### *Synthesized finding 5*

The fifth synthesized finding is "UI has provoked negative effects on women's intimacy and sexual satisfaction and provoked changes in the way they experience their sexuality and sexual function". It is composed of two categories: "Changes in sexuality and sexual function" and "Intimacy and sexual satisfaction". These findings show that feelings of fear, shame, blame and guilt about the UI symptoms have negatively affected women's intimacy and sexual satisfaction.

The main negative effect was related to the occurrence of UI symptoms during sexual intercourse: "In fact, menopause, and my situation caused a decrease in our intercourse. Although your husband helps you, you feel bad yourself while in bed, you don't want to do it. It is a very difficult situation."<sup>35(p.27)</sup> Sexual functioning can be affected by UI: "We are in the mood, we are ready to go, and we are just about to do it, but I get this little voice in my head, I got to go pee, I got to go pee. So, I have to stop, fall out of the mood, go pee, and I might only go just a little bit, but it feels like I got to go a lot."<sup>39(p.661)</sup>

#### *Synthesized finding 6*

The sixth synthesized finding, "UI is considered a consequence of pregnancy and childbirth, inherent to aging or a religious punishment" is composed of two categories: "A consequence of pregnancy and childbirth" and "A religious punishment". These categories indicate that UI is often considered to be a natural consequence of pregnancy and childbirth. This belief contributed to the belief that involuntary urine leakage is a natural event of aging.

Urinary incontinence was also seen as a punishment or a condition determined by the religious leaders. As a consequence of these beliefs toward UI, it was often considered to be a condition to be accepted by the women affected by this disease. Some examples illustrate UI as a condition provoked by pregnancy and childbirth or inherent to aging: "Have heard old age causes UI but for me giving

birth has caused me to leak”<sup>32(p.50)</sup> and “I don’t think that was a problem, just like see me was saying, that I thought it was part of getting old and not really a problem.”<sup>29(p.587)</sup>

#### *Synthesized finding 7*

The seventh synthesized finding is “The women affected by UI adopt several strategies to improve their health status”. It is composed of three categories: “Coping strategies”, “Management strategies” and “Self-care strategies”. Such strategies are characterized by helping patients to accept the disease, undertake self-care practices, avoid having bad thoughts about the disease, share the problem with partners and join a social group of trusting people.

Some of the strategies women used to manage the condition included learning more about UI to minimize the problem and control the consequences of the disease. The women affected by UI also asked for therapies and palliative strategies to improve their health status.

The following quotations provide examples of the strategies used by women to manage UI. One woman downplayed the impact of UI on her life and described how she felt that UI was something that she should keep secret: “It is not really a problem.”<sup>33(p.1421)</sup> “... I wouldn’t ever tell anybody other than somebody who admired to me as well.”<sup>33(p.1421)</sup> Another woman described how she managed her condition while in public spaces: “I make sure I park in the same area of the mall so I don’t have to think about whether I am on one side or the other ... the side where the bathrooms are.”<sup>40(p.554)</sup> “Against the background of leading a life as normal as possible, some of those with incontinence use a variety of creative strategies to relieve symptoms and manage the consequences of their problems. Their goal is to regain control.”<sup>20(p.486)</sup> One woman expressed how the condition impacted her ability to wear clothing “I’m getting really fed up with having to wash myself and change my clothes all the time, these are the biggest problems. I am having trouble keeping it up, although I want to have everything really clean.”<sup>28(p.947)</sup> Another woman stated how the condition had affected her social life. “It didn’t improve with physiotherapy. I have been prevented from doing activities that take a long time, such as going out, traveling, going to receptions, church services and celebrations.”<sup>15(p.1985)</sup>

#### *Synthesized finding 8*

The eighth synthesized finding is “Women have personal preferences towards care providers and treatments; they confront difficulties through UI treatment and some care needs are not met.” It is composed of four categories: “Care needs not met”, “Difficulties confronted throughout treatment”, “Personal preferences towards care providers” and “Personal preferences towards treatment”. These findings indicate that the care needs of women were not being adequately attended to by healthcare providers. Their concerns were related to the lack of interest from doctors in the patient’s problems, as well as feeling that they had not being taken seriously by the medical system. The women faced several other difficulties in their treatment. Their main difficulties were related to miscommunication due to different languages, the lack of a precise medical diagnosis and plan of action for their condition, and challenges in understanding and adhering to the treatments proposed by healthcare providers. In terms of preferences for medical treatment, women generally preferred female and allied healthcare providers, family members rather than professional interpreters and people from the same ethnic background. Regarding the nature of the treatment, women expressed preferences for discussions and small groups as a way to receive healthcare information. A preference for alternative therapies was expressed by younger women, while older women expressed a preference for medications prescribed by doctors.

One woman spoke about preferences for medical doctors of a certain ethnicity: “The other thing I’ve noticed is that Asian people tend to go to Asian doctors. They think that there will be no language or cultural issues. Like when we were young my parents changed to a Muslim general practitioner, because somebody said that when you die they do this and they do that and if you have a Muslim doctor then he understands the procedures and my mum and dad thought excellent, let’s change to a Muslim doctor.”<sup>29(p.589)</sup> Another expressed a preference for a female caregiver: “The nurse is a lady so I felt ok about it. If the nurse is a man, I wouldn’t like that.”<sup>23(p.4)</sup> A third woman described her preference for small group meetings for treatment for UI: “Small community centers that these elder women go to and give them talks, in a small group they are more likely to be receptive, but if they know a little

bit about it they will talk, better than you giving a talk in a large group.”<sup>29(p.590)</sup> Lastly, a woman described her preference for alternative medications for certain symptoms: “I would take the hospital’s medicine; my son is a doctor you see. I would take the doctor’s medicine or herbal medicine, I wouldn’t mix and match. I don’t think it would help, sometimes I would take herbal medicines if the problem was small.”<sup>29(p.589)</sup>

## DISCUSSION

The results of this review suggest that UI is a complex health condition. Women often had difficulties recognizing that they were experiencing the symptoms of UI and therefore did not easily identify themselves as being a person affected with the condition. Women often attributed the occurrence of UI to pregnancy and childbirth, to aging or to a religious punishment. The difficult psychological experiences associated with UI were often endured alone. Women who had the condition often experienced a sense of guilt as well as low self-esteem. These feelings were often related to inadequate or poor self-care practices. The social stigma surrounding UI had severe consequences on women’s daily lives and social roles. Many women limited their participation in social activities because of UI symptoms. Women’s sexual lives were also affected as the disease could lead to changes in sexual intimacy and other sexual experiences.

The cultural and religious backgrounds of women, among other factors, contributed to the attitude of reluctance to seek treatment for UI. Care providers played an important role in challenging myths and breaking down the barriers that prevented women from seeking help for UI conditions. The role of care providers should include enabling women to explore issues surrounding UI.

The relationship between UI and religion was reported in previous empirical studies. Muslim women with UI often restricted their daily activities, including religious practices. Such restrictions were motivated by the need to be in a condition of cleanliness to pray.<sup>49</sup> Urinary frequency and the sense of urgency regarding urination affected women’s personal lives and their social roles.<sup>37</sup> Younger women were more likely to be under stress. This increased degree of stress was largely due to problems related to employment and single parenthood.

The relationship between UI and religion was reported in a number of empirical studies. Many Muslim women with UI restricted their daily activities, including their religious practices. Such restrictions were motivated by the need to be in a condition of cleanliness to pray.<sup>49</sup> Urinary frequency and the sense of urgency about urination affected women’s personal, inter-personal and social relations.

Younger women were more likely to be under stress. This increased degree of stress was due to problems related to unemployment and being a single parent. Younger women were also more likely to be ashamed of their UI. Often, this was because of their lifestyle.<sup>50</sup> Many previous researchers<sup>51,52</sup> reported that embarrassment was of central concern for women affected by UI.

The problems associated with UI were endured in isolation by many women. Women’s lives and social roles were intimately affected by this experience. One report found that only a few women had disclosed the fact that they had UI to public health workers.<sup>19</sup> Such findings indicate the need to pay special attention to the stigma that women with UI experience. This stigma was associated with worse health outcomes. Stigma was also associated with stress, which made it a general risk factor for disease. Stigma compromised the ability of women to cope with the various experiences involved in their disease.<sup>53</sup> The stigma associated with UI symptoms involved confusion as to the nature of a non-specified health problem and hesitation in revealing health conditions such as UI in public settings.<sup>37</sup>

Urinary incontinence was seen by some women as a difficult condition that involved significant suffering and which was often experienced silently. The emotions most often associated with UI were embarrassment, shame and distress. Stigma was a prevalent experience for many women. Many women experienced depression, hopelessness and decreased self-esteem as a result of the disease. Many women felt guilty about having UI and felt that their lives had been impaired.

Some researchers reported that several women perceived UI as being a personal issue rather than a health issue. As a result, UI was often seen as something that did not require intervention.<sup>54</sup> Long term female UI particularly was primarily conceptualized as a condition integrated into a larger life story.<sup>55</sup> Urinary incontinence on its own was not seen as worthy of any attention. This behavior could

be a result of a conflicting set of beliefs in which the external UI was deviant, yet internally it was seen as normal.<sup>50</sup>

Healthcare providers should provide opportunities to women with UI to share their experiences with the condition. Adequate treatments according to women's physical condition associated with their personal preferences should be provided. The benefit of pelvic floor muscle training (PFMT) when added to other treatments is clear when compared to effectiveness of that treatment without PFMT. The interpersonal support and PFMT performed correctly have increased the effectiveness of PFMT in urine leakage reduction, even in patients who have very few symptoms of SUI.<sup>56</sup> Multi-dimensional exercises, such as the stretching exercises associated with fitness exercises, are effective to reduce all types of UI when added to the PFMT.<sup>57</sup> The home-based PFMT practice program, when followed and supported by nurse's monitoring, significantly improves the efficacy of UI treatment.<sup>58</sup> Integrated and standardized nursing interventions, which include the PFMT, reduce urine leakage and the use of protective materials.<sup>59</sup>

Some women affected by UI require special attention from medical staff. Particularly, Hispanic women have a tendency to keep urinary symptoms a secret from other people and therefore require a certain approach from caregivers.<sup>37</sup> Practitioners should also take into account a woman's social setting. The treatment of women who live in low-income settings may be enhanced by briefly drawing upon two major strands of theory within medical anthropology.<sup>19</sup> Within particular historical and cultural settings, the perceptions, experiences and actions related to any symptoms of suffering are dependent upon shared understandings and meanings given to the condition.<sup>60</sup> Some women never seek help for their condition anywhere. This attitude is derived from their belief that UI is a condition without a cure.<sup>19</sup>

Among care providers, nurses are in a privileged position to initiate discussions about UI. In general, women with UI are more likely to discuss their problem when a health professional brings it up first. This is strong evidence suggesting that health professionals should use this approach to communicate with their patients.<sup>61</sup>

The finding that many sufferers of UI have poor and vague knowledge about the disease and its

symptoms needs to be brought to the attention of healthcare providers. The feelings experienced by patients, such as shame, fear and anxiety, create impediments to seeking support.<sup>1</sup> Women with UI want to be understood as people who face a difficult issue. They especially want to be understood by their husbands, because they would like them to empathize with them and accompany them in their search for treatments.<sup>62</sup>

One of the main concerns regarding UI is its consequences on marital relationships and social life. Shame, embarrassment and fear of being discriminated against often lead patients to hide their involuntary urine leaks. The findings of this review indicate that women who were not able to hide their urine leak often experienced humiliating comments and discrimination from others. Sometimes, this condition led to divorce and self-isolation. The adoption of strategies to manage, cope and improve one's health status was undertaken by participants of primary studies. Older women were able to adopt coping strategies to avoid problems that affected their quality of life. The coping strategies they used included the acceptance of the disease, practices to avoid negative thoughts related to the disease and sharing feelings with their husbands to overcome impediments to sexual activity caused by urinary leakage during intercourse.

Several studies have focused on the relationship between sexuality and UI. The leakage of urine during sexual intercourse was a significant factor in lowering quality of life scores.<sup>63</sup> Urinary incontinence interfered with sexual functioning and had an adverse impact on quality of life scores. It was particularly impactful on the psychological aspects of sexual health.<sup>50</sup> Women felt inhibited in their sexual relations with their partner as a consequence of UI.<sup>24</sup> Healthcare providers should take into account the research findings demonstrating the influence of women's psychosexual history on their adoption of strategies to manage urinary leakage during sex. If a woman has had a healthy psychosexual development throughout all of her development stages, this will minimize the amount that urinary leakage has on her sexual life. The use of the "Psychosexual Biography Questionnaire", considered as a useful tool for evaluating the psychosexual functioning of women afflicted with SUI, was suggested. This questionnaire is useful in obtaining insights about the causes of the disorder and the

strategies that women can use to deal with UI in a variety of sexual practices.<sup>64</sup>

Sexuality is an integral aspect of women's health. The way in which women view their sexuality is closely linked to their self-esteem. Fear and shame toward the possibility of involuntary urine leakage during sexual intercourse decrease sexual satisfaction.<sup>65</sup> The sexual function of women with UI is impaired when they can no longer concentrate on and enjoy sex due to their fear of involuntary urine leakage.<sup>15,35</sup>

Some women see UI as a natural consequence of pregnancy and childbirth, as being closely associated with the changes of menopause and as a condition inherent in aging. Although an association has been found between UI and childbirth, the number of pregnancies and vaginal deliveries is also higher among women affected by UI when compared with continent women.<sup>66</sup> A study with a focus on UI related to pregnancy also found that among women without UI before pregnancy, almost a third of them were affected by the condition six months after childbirth.<sup>67</sup>

Although several studies have reported an increased prevalence of UI with age, this issue is still controversial.<sup>68</sup> Half of American women develop UI in their lifetime. A large population-based survey on the prevalence of UI among women aged 30 to 90 years found that a third of women aged 80 years were affected by severe UI.<sup>69</sup> A high prevalence of UI was also found among women in the United Kingdom.<sup>70</sup> Among Brazilian women aged over 20, vaginal birth was identified as a risk factor for UI. Aging and a number of pregnancies have also been identified as correlated factors.<sup>66</sup> Other researchers did not find associations between menopause and UI. Women involved in moderate-to-heavy manual labor showed a trend toward being more affected by UI. Associations between chronic smokers and the occurrence of UI were not found.<sup>71</sup>

Healthcare providers should take into account that if UI is considered to be inherent in aging, it may follow that the condition would not normally occur among younger women.<sup>72</sup> However, in general, women with UI create their own set of practices to cope with the condition<sup>51</sup> and have also adopted several strategies to manage, handle, treat and improve their health status. It is a dynamic and active process that entails much learning and trial and error.<sup>20</sup> Management strategies allow women to

acquire familiarity with their situation and regain control over the disease. Strategies using liners/diapers, although often seen as a psychological barrier to social interaction, are often used to minimize the problem. This method is also used by women to try to hide incontinence from people who are not in their social circle.<sup>1</sup>

Women with UI expressed their personal preferences for privacy. Many women believed that it was important for care providers to listen carefully, be concerned with their complaints and maintain open communication. They expressed a preference for caregivers of the female gender. This would improve their comfort level for discussing urinary symptoms.

Among an ethnically diverse sample of perimenopausal women affected by UI, only 12% reported discussing it with their healthcare provider.<sup>73</sup> The main barriers for these women to seeking help for UI included embarrassment, lack of knowledge about treatment options, fear of surgical intervention and the belief that UI was a normal aspect of aging.<sup>74</sup> Other barriers to seeking help for UI were the desire to independently manage incontinence through the use of self-management strategies such as the use of pads.<sup>55</sup> Early intervention for UI is important as treatment is often more successful when implemented at a stage when the symptoms are mild.<sup>54</sup>

Healthcare providers should consider that women who disclose their symptoms usually have a close friend or family member who supports them.<sup>19</sup> Clinicians can encourage discussions about their symptoms and experiences by directly approach the subject of UI with patients. One study reported that women may need to hear a question from a caregiver multiple times before being able to discuss it comfortably.<sup>75</sup>

Educational programs to inform women about UI have some potential value. Such programs can increase women's ability to practice self-care management in many different ways. The inclusion of specific details about UI and its treatments, as well as the use of easy to understand language, are essential to create meaningful discussions with women affected by this disease. Women can acquire information from educational programs that allow them to get the information they need without having to directly ask for it. These are important opportunities for women with UI to share the problems they are

experiencing with friends and family members. These meetings can also provide a venue where women can be introduced to local healthcare providers that specialize in UI treatment.<sup>75</sup>

As part of the healthcare team, nurses and midwives have the important responsibility of assessing women who attend healthcare facilities for risk factors of UI. Advice about preventive practices and invitations to participate in seminars to improve health status can be given by nurses and midwives when they meet with patients. These interactions are also opportunities for nurses and midwives to discuss the likelihood of a patient having UI. This is especially important for older women. These women should be advised that UI is a treatable health problem that does not have to burden an individual for their lifetime.<sup>76</sup>

The provision of care directed to patients who are living in low-income settings requires special attention from healthcare providers. In these settings, there is the possibility of limited access to hygiene resources. For example, some Ethiopian women have limited access to resources such as water, soap, pads and spare clothes, and are sometimes unable to manage the UI symptoms that are related to cleanliness. Low-income women also face difficulties in disclosing the problem of UI to others and in accessing health information and healthcare facilities. Considering a woman's sociocultural dimensions is essential to understanding how women in such low-income environments handle, perceive and experience living with this health problem.<sup>19</sup>

Based on an integrative review of the non-pharmacological and non-surgical treatments for UI, some recommendations related to the health care of UI patients were suggested. As identified in the findings of this systematic review of qualitative evidence, the need to take into account the patient's background factors, such as religious, educational, cultural and personal issues, is crucial for quality care for women affected by UI.<sup>77</sup>

Specialists on the topic of UI have recommended and disseminated the following resources derived from the available evidence about UI treatments. In summary, their recommendation consists of a systematized assessment of the UI condition and the choice of the best treatment after consideration of all available scientific evidence. They suggest following a consensus of expert opinion when this evidence is not available.<sup>78</sup> Regardless of the nature

of UI symptoms and the patient's care preferences, treatment should be offered to each of them. Across the entire treatment process, the care should be centered on their own care needs.

It is also essential that healthcare providers know and consider that the individual or group PFM training, monitoring and provision of educative support are essential factors for improving the effects of UI treatments. The evidence derived from an integrative review of UI treatments has demonstrated that when these are included in the treatment process, there is an improvement in the condition or cure of UI.<sup>77</sup>

## Conclusion

Urinary incontinence is a condition that has a large impact on the life of a woman. The first synthesized finding showed that reluctance to discuss one's own experiences, influenced by cultural, social and religious backgrounds, contribute to delays in seeking treatment. The lack of knowledge and the vague nature of UI symptoms made it difficult for women and their care needers to identify UI as a disease. Urinary incontinence was usually diagnosed only when its signs and symptoms persisted and became stronger. The disease took a long time to reach the point where the symptoms and signs were prominent, which contributed to patients' delay in looking for professional support and commencing UI treatments.

Women felt impaired by the symptoms of UI. Some of this resulted from feelings of distress, stigma, embarrassment and humiliation that were a consequence of involuntary urine leakage in both public and private settings. The impairment to their private lives was mainly related to the consequences of urine leakage during sexual intercourses. Such experiences were permeated by feelings of fear, shame, blame and guilt. This had strong negative consequences on women's intimacy and sexual satisfaction.

Urinary incontinence was often seen by women as a difficult problem that came as an inevitable consequence of pregnancy and birth. Women also closely associated UI with menopause and aging. The belief that UI is an inevitable part of living has contributed to women hiding their UI condition. Some women endured UI in isolation. These women were more likely to feel that their daily activities,

social roles, intimacy and sexual satisfaction were negatively affected by UI.

Women with UI adopted several strategies to improve their health status. The main coping strategies they used were avoiding negative thoughts about the disease, sharing their problems with other women dealing with the same condition and discussing their experiences with their husbands. Women tried to cope with UI by surrounding themselves with people they trusted. The adoption of self-care practices was also a way for women to improve their own health status. The main practices they used were the incorporation of available therapies into their daily lives and the efforts they made to find new possibilities of treatment.

The women had preferences regarding their care providers, as well as complaints about the lack of some treatments. Their personal choices included preferences related to the ethnic and religious background of a care provider or of the gender of the care provider (specifically, female doctors or nurses were preferred). Regarding women's preferences related to the nature of their treatment, some indicated that they preferred small group discussions rather than large-group environments. The women also stated a preference for personal and talk-based communication about UI instead of written communication.

### *Implications for practice*

The following implications for practice have been developed and given grades (Grade A or Grade B) in accordance with the JBI approach to assigning grades of recommendation.<sup>79</sup>

Cultural and religious backgrounds caused some women to delay seeking treatment for UI. Considering this reluctance to seek UI treatment due to religious backgrounds, we recommend a personalized healthcare plan that accounts for women's own religious and cultural beliefs. Each woman's personal needs, preferences and expectations should be identified and supported accordingly (Grade A).

*The UI condition is often lived in isolation* – We recommend offering adequate opportunities for women to discuss their experience with other women living with the disease. We also recommend that women be given opportunities to share their problems with care providers. These opportunities are useful as they provide women with the chance

to listen to one another and share coping strategies. Women should also be encouraged to understand their symptoms and learn to feel comfortable speaking openly about doubts and uncertainties about UI. Lastly, women should be encouraged to verbalize their problems so that their perceptions of the disease can be understood by caregivers, family and friends. This supportive approach also helps to identify what women are afraid of regarding their UI (Grade A).

*The poor state of knowledge of UI and the vague nature of UI symptoms make it hard for women and caregivers to identify UI as a disease* – We suggest that there be multi-disciplinary involvement in the health care of women with UI. Each professional could contribute from their own professional background. Health status can be improved, and the avoidance of further complications and damage to health can be enhanced. A complete history of UI symptoms is also essential to classifying the disease and adopting adequate treatments. We also suggest improving the availability of educational activities that address the religious, social, cultural and psychological factors of the disease. These educational activities can be important opportunities for women to obtain the information they need to understand their own UI manifestation (Grade B).

*The distressing and embarrassing experiences associated with UI provoke a sense of impairment and self-blame* – Women should be advised about the resources available regarding the reduction of public exposition of urine leakage. We suggest advising patients on strategies such as the use of hygienic absorbent protective aids during social events. These strategies can be useful especially for some Muslim women, who sometimes avoid religious meetings due to fears they have about exposing urine leakage (Grade B).

*The negative effects of UI on women's intimacy* – Women require counseling regarding the sexual and emotional changes caused by UI. We recommend that a personally designed treatment approach is created for dealing with the sexual aspect of UI. Detailed advice on the possible sexual and emotional changes caused by UI should be offered throughout the various stages of diagnosis and treatment. We recommend paying attention to emotional and sexual changes throughout the treatment because it contributes to effective care. The early awareness

of these changes can mitigate the emotional and sexual impact of UI. The support of psychologists and occupational therapists may be necessary if women are to manage and cope more successfully with the emotional and sexual changes caused by UI (Grade A).

*The perception that UI is a consequence of pregnancy and childbirth by some women* – These women should be taught about the effects of pregnancy hormones on their bodies and the way in which the effects fade after the puerperium period. We recommend the specific approach of urine leakage in the post-partum consultation. The identification of this problem is essential for the provision of adequate support in terms of pelvic floor exercises. It is essential that this problem be properly identified before administering therapies such as pelvic floor exercises. These exercises promote the avoidance of involuntary urine leakage. Healthcare providers should provide lessons to patients about the way to do these exercises. Women also should be advised that the increased frequency of urination or the incontinence urge usually occurs during pregnancy. After the birth, however, involuntary urine leakage is not a normal occurrence (Grade A).

*Women affected by UI adopt several strategies to improve health status* – We recommend that professional support for the improvement of self-care strategies be given to the women as there is often a shortage of self-care resources available to them. The use of beneficial self-care practices can be promoted by increasing their awareness of the condition. Healthcare providers should create opportunities for women to discuss their condition and their self-care with health professionals whose knowledge and skills relating to UI will empower women and improve their health status. It is important that women become aware of the support available to them. The members of nursing staff play a central role in listening to women and helping them to deal with the various aspects of their condition (Grade A).

*The effect of UI on daily life and social roles* – The possibilities related to the adoption of coping strategies can be negotiated in creative and dynamic ways. We recommend advising women about strategies to manage involuntary urine loss, notifying them of the social supportive resources available nearby their homes, and discussing with them the

need to create a treatment plan that accounts for the specific needs of each woman (Grade A).

*Women experience difficulties with UI treatment and some care needs are not provided* – Measures to improve women's choices related to UI treatments are required. Women consider this to be a central goal of their treatment, rather than as an additional outcome. Measures also should be taken to make women more aware about UI and about the treatments available to manage the symptoms (Grade A).

### Implications for research

Educational approaches and support models on quality of life, coping strategies, prevention of disease progression, self-management, resilience and social support require further assessment. Further empirical studies are required to better understand the impact of UI on the quality of life of younger women.

A comprehensive analysis of the conditions leading to UI is required to guide healthcare providers in the adoption of protective health measures, improvement of health status and early diagnosis of UI. Such measures assume influential roles in the prevention and treatment of UI.<sup>76</sup>

More studies are required to deepen our knowledge about the influence of racial, ethnic and cultural background on the ways that people experience UI.<sup>68</sup> Considering that some Muslim women attribute the occurrence of UI to a punishment given by Allah, the experiences lived by women from other religions should also be explored.

Studies are also needed to assess treatment modalities or educational programs that promote the development of skills to counteract the effects of shame and anxiety and promote body experiences that develop competence and confidence. The findings of such studies can contribute to expanding our understanding of the ways in which women discuss or do not discuss UI with healthcare providers and could provide directions for interventions to increase the level of women seeking help.<sup>75</sup>

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**Appendix I: Databases explored and correspondent details****CINAHL**

First searched on May 7, 2014, updated August 1, 2016

Search	Query
No. 1	(MH “Urinary Incontinence+”) AND “experience” <i>n</i> = 145
Limit to: sex: female; language: English, Spanish, French and Portuguese	

**PubMed/MEDLINE**

First searched on May 8, 2014, updated August 1, 2016

Search	Query
No. 1	:(urinary incontinence AND woman AND experience) AND (instance: “regional”) AND (db:(“MEDLINE”) AND limit:(“female”)) <i>n</i> = 26
No. 2	“Urinary Incontinence”[Mesh] AND “Life Change Events”[Mesh] NOT (“men”[MeSH Terms] OR “men”[All Fields]) <i>n</i> = 6
Limit to: sex: female; language: English, Spanish, French and Portuguese	

**PsycINFO**

First searched on July 18, 2014, updated August 1, 2016

Search	Query
No. 1	(MH “Urinary Incontinence+”) AND “experience”
Limit to: sex: female; language: English, Spanish, French and Portuguese	

**DECS**

First searched on July 5, 2014, updated August 1, 2016

Search	Query
No. 1	((Index Terms Filter: (“Urinary incontinence”): AND Any Field: (“Experience”) AND Population Group Filter: (“Female”)). (PsycINFO) <i>n</i> = 57
No. 2	tw: (urinary incontinence AND experience) AND (instance: “regional”) AND (db:(“LILACS”) AND limit:(“female”)) (LILACS) <i>n</i> = 47
Limit to: sex: female; language: English, Spanish, French and Portuguese	

**Sociological abstracts**

First searched on July 21, 2014, updated August 1, 2016

Search	Query
No. 1	(female urinary incontinence) AND (experience OR life experiences) <i>n</i> = 4
No. 2	(urinary incontinence) AND woman AND (experience OR life experiences) <i>n</i> = 5
Limit to: sex: female; language: English, Spanish, French and Portuguese	

**SCOPUS**

First searched on July 18, 2014, updated August 2, 2016

Search	Query
No. 1	TITLE-ABS-KEY (urinary incontinence) AND TITLE-ABS-KEY (woman) AND TITLE-ABS-KEY (experience OR experience life) <i>n</i> = 347
Limit to: sex: female; language: English, Spanish, French and Portuguese	

**Embase**

First searched on July 21, 2014, updated August 2, 2016

Search	Query
No. 1	(female urinary incontinence) AND (experience OR life experiences) <i>n</i> = 31
No. 2	(urinary incontinence) AND woman AND (experience OR life experiences) <i>n</i> = 0
Limit to: sex: female; language: English, Spanish, French and Portuguese	

Appendix II: QARI appraisal instrument

**JBI QARI Critical Appraisal Checklist for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year ..... Record Number .....

	Yes	No	Unclear	Not Applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is there congruity between the research methodology and the research question or objectives?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Is there congruity between the research methodology and the methods used to collect data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is there congruity between the research methodology and the representation and analysis of data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there congruity between the research methodology and the interpretation of results?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Is there a statement locating the researcher culturally or theoretically?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Is the influence of the researcher on the research, and vice-versa, addressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Are participants, and their voices, adequately represented?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal:  Include  Exclude  Seek further info.

Comments (Including reason for exclusion)

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Appendix III: QARI data extraction instrument

**JBI QARI Data Extraction Form for Interpretive & Critical Research**

Reviewer ..... Date .....

Author ..... Year .....

Journal\_ ..... Record Number .....

**Study Description**

Methodology  
\_\_\_\_\_  
\_\_\_\_\_

Method  
\_\_\_\_\_  
\_\_\_\_\_

Phenomena of interest  
\_\_\_\_\_  
\_\_\_\_\_

Setting  
\_\_\_\_\_  
\_\_\_\_\_

Geographical  
\_\_\_\_\_  
\_\_\_\_\_

Cultural  
\_\_\_\_\_  
\_\_\_\_\_

Participants  
\_\_\_\_\_  
\_\_\_\_\_

Data analysis  
\_\_\_\_\_  
\_\_\_\_\_

Authors Conclusions  
\_\_\_\_\_  
\_\_\_\_\_

Comments  
\_\_\_\_\_  
\_\_\_\_\_

Complete                      Yes                       No



**Appendix IV: Excluded studies**

Borba A MC, Lelis MAS, Brêtas ACP. The meaning of urinary incontinence and be incontinent-women opinion. *Texto Context Enferm.*2003; 17 (3): 527–535.

**Reason for exclusion:** Lack of congruity between stated philosophical perspective and research methods, and poor congruity between research methodology and representation of data.

Bradway C. Women’s narratives of long-term urinary incontinence. *Urol Nurs.*2005; 25 (5): 337–344.

**Reason for exclusion:** Lack of congruity between stated philosophical perspective, lack of correlation between research question and study methodology.

Bradway C, Strumpf N. Seeking care: women’s narratives concerning long-term urinary incontinence. *Urol Nurs.*2008; 28 (2): 123–129.

**Reason for exclusion:** Lack of congruity between research methodology and representation of data, and lack of illustrations supporting study findings.

Li FLW, Low LPL, Lee DTF. Chinese women’s experiences in coping with urinary incontinence. *J Clin Nurs.*2007; 16 (3): 610–612.

**Reason for exclusion:** Lack of participants’ voices illustrating study findings, lack of congruity between methodology and interpretation of results, and conclusions not substantiated by study findings.

Pakgohar M, Hamid TA, Ibrahim R, Dastjerdi MV. Elderly community dwelling women’s experiences of managing strategies for urinary incontinence. *Elder Health J.*2015; 1 (1):2–4.

**Reason for exclusion:** Lack of detail related to study methods and participants’ voices.

Paranhos RFB, Paiva MS, Carvalho ESS. Sexual and emotional experiences of women with urinary incontinence secondary to HTLV. *Acta Paul Enferm.*2016; 29 (1): 27–52.

**Reason for exclusion:** Lack of congruity between methodology and interpretation of results, and lack of participants’ voices illustrating and supporting the study findings.

## Appendix V: List of included studies and their findings

### In her own words: living with urinary incontinence in sexual life<sup>35</sup>

Finding: 1	Individual coping behaviors (U)
Illustration	“I go to the bathroom twice before the intercourse in order not to have UI. I try not to think about this too much as well. I try to relax. However, this situation is causing us not to live a comfortable sexual relationship” <sup>35(p.29)</sup>
Finding: 2	Sharing with the husbands (U)
Illustration	“My husband is very sensitive and helpful. He too wanted me to see a physician. Perhaps my UI recently increased and it sometimes even happened during sexual intercourse. We were both afraid. What would I do without him” <sup>35(p.29)</sup>
Finding: 3	Negative effects on sexual functioning (U)
Illustration	“I wish I did not have a UI because it is causing me to feel bad at home. Thank god I have a good marriage, but now I’m so ashamed towards my husband during intercourse . . . It just takes all my desire away . . .” <sup>35(p.28)</sup>
Finding: 4	Experiences of Women When the Symptoms First Occurred (U)
Illustration	“Since I was 40, I cannot hold my urine while coughing and sneezing. I did not mind this situation at first; I thought it as a temporary thing. Then I thought that everything would return to normal but it did not . . . it did not improve Sometimes, I felt powerless” <sup>35(p.27)</sup>
Finding: 5	Shame (U)
Illustration	“I am sorry to say but it happens also during intercourse with my spouse. Our intercourse is not very often but it still continues. This is so hard . . . My God, maybe it does not kill but makes me very ashamed. God helps me that I am not embarrassed from now on . . .” <sup>35(p.27)</sup>
Finding: 6	Fear that UI symptoms could occur during intercourse (U)
Illustration	“It does not affect the sexual relationship with my husband at this moment; however, I am afraid I would if I am forced. Of course, this situation has begun to affect my psychology. Sometimes I am worried if it might happen. I guess it would be shameful” <sup>35(p.28)</sup>
Finding: 7	Blame and Guilt (U)
Illustration	“We had regular intercourse, but it decreased with age, I think . . . Also, once I got the bed wet, everything got dirty and I felt very bad” <sup>35(p.27)</sup>

### Perceptions of urinary incontinence among Syrian Christian women living in Sweden<sup>26</sup>

Finding: 1	feelings of shame and embarrassment about having UI (U)
Illustration	“No, not the son, you go to some neighbor for help; and we don’t want to talk with our husbands about it” <sup>26(p.4)</sup>
Finding: 2	Not mastering the Swedish language also resulted in dependence on help (U)

Illustration	“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. The children or daughters-in-law work and don’t come home until 5 or 6, then it’s closed everywhere. That’s also a problem. Otherwise, it becomes an emergency and you have to go to the emergency room” <sup>26(p.5)</sup>
Finding: 3	Difficulties describing their problems and understanding information about prescriptions and other treatment options (U)
Illustration	“They gave me something that I have to weigh, to see how much it leaks. It’s difficult for me. Sometimes there’s so much urine that the diaper is completely heavy. I don’t know what I should do . . . I don’t know why, but they have not given me anything [any pads]” <sup>26(p.4)</sup>

Accepting and adjusting: older women’s experiences of living with urinary incontinence<sup>25</sup>

Finding: 1	Other illnesses are more important (C)
Illustration	“I’ve never considered queuing up for an operation for that [UI] as long as things are going as well as they are. I had a hip joint operation last autumn. It was more important to have that done” <sup>25(p.118)</sup>
Finding: 2	Reluctance to seek care (C)
Illustration	“If someone had asked me [about UI], it would have been different. But then you think, what would the response be if I nine . . . would they play it down and say it wasn’t important?; I was in [the] hospital for two and a half months, and in that time, they could have told me that I can get help for the UI” <sup>25(p.1198)</sup>

The meaning of incontinence: a qualitative study of non-geriatric urinary incontinence sufferers<sup>33</sup>

Finding: 1	Incontinence is a forbidden topic (U)
Illustration	“I wear those panty shield things, can I mention that to you” <sup>33(p.1419)</sup>
Finding: 2	An isolating problem (U)
Illustration	“I suppose it’s just like a trickle really, it’s not like a big gush or anything like that, but I don’t know if that’s serious or not really I mean, it seems quit bad to me – but I don’t know what’s classed as in other woman” <sup>33(p.1419)</sup>
Finding: 3	An illegitimate problem (U)
Illustration	“She’s like me but we didn’t go into great detail like, in case hers was worse than mine or vice versa you know, you didn’t want to find out” <sup>33(p.1419)</sup>
Finding: 4	A problem offering no clear plan of action (U)
Illustration	“I once took down the number of [a source of help], but never got round to contacting them There might be an operation or some other sort of [major intervention] available, I wasn’t sure – I am still womed” <sup>33(p.1419)</sup>
Finding: 5	A regrettable inevitability (U)

Illustration	“When the problem had got a bit worse, I just tended to think, well, it’s a fact of life After all, my mother always crossed her legs when she sneezed” <sup>33(p.1420)</sup>
Finding: 6	Sufferers feel it is their fault (U)
Illustration	“I would be embarrassed in a supermarket queue, imagining that [others were] thinking, ‘What a stupid woman this is in front of me, with these problems’” <sup>33(p.1420)</sup>
Finding: 7	Sufferers can come to hate their own bodies (U)
Illustration	“Yuk! I don’t really think about it, my body, I don’t hate myself for be this way but I can’t be any different I’m obsessed with it [the smell of her body] I’m constantly thinking about it” <sup>33(p.1420)</sup>
Finding: 8	Special precautions became a way of life (U)
Illustration	“I buy clothes that can be washed easily pants that are terry towel hned [There are] washing lmes m the bathroom constantly full of pants I change my outer clothes everyday so that I don’t have any smells, whether they look dirty or not, they’re changed everyday I don’t go to people’s houses because I’m frightened of having an accident If I go town I make sure that I keep going to toilets whether I want to go or not.” <sup>33(p.1420)</sup>
Finding: 9	Sadness and regret for what was lost (C)
Illustration	“I mean I can’t do anything I’ve had to give up Well I mean that’s it – I’m restricted to what I can do As I say, I don’t do any outside activities” <sup>33(p.1421)</sup>
Finding: 10	Coping strategy – minimizing it (U)
Illustration	“It is not really a problem” <sup>33(p.1421)</sup>
Finding: 11	Coping strategy – renaming it (C)
Illustration	“I just leak, you know, I’m not incontinent” <sup>33(p.1421)</sup>
Finding: 12	Coping strategy – maintenance of secrecy (U)
Illustration	“I wouldn’t ever tell anybody other than somebody who admired to me as well” <sup>33(p.1421)</sup>

**Developing a cultural model for long-term female urinary incontinence<sup>36</sup>**

Finding: 1	Memories of UI – remembering the first episode of UI
Illustration	“I was in the tub, just got in the tub, didn’t have to go before I got in that tub. I was going to take a nice bath, just relax. Well here it come. So I had to go in the tub. Then I had to end up taking a shower instead of a bath so I could let the nasty water out, is what I called it, and take a shower. So that was strange ... I ... I felt bad. I wanted to take a ... I just wanted to sit in there. But after that happened, I couldn’t, I didn’t want t sit in there after that happened ... I couldn’t even get out and get on the toilet. It just came. It just came like that” <sup>36(p.3154–3155)</sup>
Finding: 2	Strategies for living with UI – managing UI (U)

Illustration	“I never had any accidents. That would have been awful. How would ... [I] explain it to people (Laughs)? You’d say, ‘Oh, what happened here?’ (Laughs), ‘I must of sat in a puddle’. (Laughs)” <sup>36(p.3155)</sup>
Finding: 3	Strategies for living with UI – planning for episodes of UI (U)
	“I mean this had such an impact on my life now that my husband and I are even reluctant to go certain places, it’s not just a comfortable evening ... I make sure that I bathe before bed. I bathe before I go some place in the evening. I make sure that I get home in time to bathe again. I’m just very conscious about all these different things ... Everything I do, I have to think about you know” <sup>36(p.3155)</sup>
Finding: 4	Strategies for living with UI – compare themselves with others (C)
Illustration	“Well you know you can have a lot worse chronic diseases. All the immune diseases like rheumatoid arthritis. People are crippled (Laughs). Hey listen. I’m very active, you know like I walk the dog. If I ever get stuck out in the woods, I mean you can go (Laughs) pee in the woods (Laughs) so it’s not the worst thing could happen. I never felt like I was being punished or ‘Oh my God. This is horrible.’ It’s like well, something you gotta deal with ... It could be ... I could be dealing with some kind of mental illness” <sup>36(p.3155)</sup>
Finding: 5	Strategies for living with UI – making sense (C)
Illustration	“And also I think the weight [affects the UI]. Because I noticed—I’m beginning to notice that I’m having a bit of control now that I just lost this little bit of weight. And that’s—that’s why I’m going to keep pushing on this weight situation” <sup>36(p.3156)</sup>
Finding: 6	Responses to UI – fear (U)
Illustration	“... in the future what I worry about is, we had to put my mother in a nursing home and my mother was a beautiful – she was a very fancy dresser and when we put her in a nursing home everybody had to wear diapers in the nursing home and it was a very beautiful nursing home but the reason that everybody had to wear them was because they didn’t have enough staff to wake them up at a certain time and take them to the bathroom. And when they put the diaper on my mother, it was just like the worst thing they could have done. And um, I remember that ...” <sup>36(p.3156)</sup>
Finding: 7	Responses to UI – affected their lives (U)
Illustration	“(Crying) You know you got to know, incontinence is a very privately and proudful type thing. You know, from uh, from potty training on. Something of yours. It’s a personal accomplishment; you know? And uh, I mean that very first time that you lose it is a very painful – you lose a piece of your pride. You’re losing one of our [first] accomplishments” <sup>36(p.3156)</sup>
Finding 8	Responses to UI – medical providers and society (U)

Illustration	“So I told him [her doctor] . . . He just said, ‘Oh lots of people get that. Don’t worry about it’. And I don’t know if that’s cause he doesn’t know, or if he’s a guy or whatever but it’s probably not cause he’s a guy cause I’m sure he’s seen lot of people doing exercises . . . And I guess, ‘Don’t worry about it’ meaning don’t feel like an idiot but . . . which is great but I’ve sort of also wanted to know how to fix it.” <sup>36(p.3156–3157)</sup>
Finding 9	Responses to UI – perceptions of how UI is represented in the media (U)
Illustration	“No. It’s [UI] not public. It’s funny; I got books on everything else. I think I’ll get one on that seems to be a deep dark secret. (Laughs) . . . Because you hear of everything else that uh, you really don’t see an ad specifying it. You know? You might see an ad for the pads but you don’t know why. They say, ‘If this happens try this’. But they don’t uh, don’t mention it. It’s an unmentionable. (Laughs)” <sup>36(p.3157)</sup>

### Overactive bladder and women’s sexual health: what is the impact?<sup>39</sup>

Finding: 1	Sexual desire – incontinent women (U)
Illustration	“As far as my relationship with my husband, I am always subconscious about the odor, and so I don’t ever want to initiate anything unless I am fresh from the shower. I don’t want to be spontaneous . . . because I am not comfortable with the odor” <sup>39(p.660)</sup>
Finding: 2	Sex arousal – incontinent women (U)
Illustration	“We are in the mood, we are ready to go, and we are just about to do it, but I get this little voice in my head, I got to go pee, I got to go pee. So, I have to stop, fall out of the mood, go pee, and I might only go just a little bit, but it feels like I got to go a lot” <sup>39(p.661)</sup>
Finding: 3	Able to achieve orgasm, however, they may not have allowed themselves to climax to avoid leaking urine (U)
Illustration	“Mine tends to be more of a mental thing because I am worried about . . . getting through this, and so [I think] ‘look, hurry up aged it over with’ because . . . I know I am not going to get any satisfaction just based on that, and so it’s not very pleasurable to me, and that’s another deterrent to wanting to even try” <sup>39(p.661)</sup>
Finding: 4	Lack of sexual satisfaction (U)
Illustration	“Well, it’s an awful lot of bother to go through not to have an orgasm at the end. If I am going to go through the process of taking a shower and getting fresh, and having all of these things set up, then, I had better get what I want out of it. It doesn’t have to be every time, but it has to be a good percentage” <sup>39(p.662)</sup>
Finding: 5	Loss of self-confidence and self-image (U)
Illustration	“So, all of those things that made me feel like a desirable woman, that I would do to make myself feel good, I don’t do anymore, because it seems pointless. It would be like spraying a carnation with rose scent . . . it just doesn’t work” <sup>39(p.662)</sup>
Finding: 6	Relationship with sexual partner – incontinent women (U)

Illustration	“It’s more internal – I mean my husband doesn’t care. He doesn’t want to have to stop when he’s driving, he doesn’t want to have me get up and go, things like that, that I think what’s it matter to him? He sees a big issue for that, but as far as sex ... the only thing that bothers him is that I am not spontaneous, he feels like he has to work a little harder to get me in the mood, because I really have to be stroked ... I am not as comfortable as I used to be, and I don’t initiate anymore” <sup>39(p.663)</sup>
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### Between suffering and hope: rehabilitation from urinary incontinence as an intervening component<sup>15</sup>

Finding: 1	Becoming apprehensive with the public perception of urine (U)
Illustration	“UI makes me nervous ... , because it’s more difficult to control urination, so I feel limited to going to certain places” <sup>15(p.1985)</sup>
Finding: 2	Associating UI with natural delivery (U)
Illustration	“When I was pregnant with my first child, I had to have a C-section; he was very big; I had to have a C-section. During pregnancy, I was sometimes walking with my husband or taking a short walk, and I would leak urine. [...] I have three children, and the first was rather larger than the other two. I can remember it more clearly because it was a remarkable experience” <sup>15(p.1983–1984)</sup>
Finding: 3	Considering IU to be an unpleasant experience (U)
Illustration	“It’s very unpleasant; it has prevented me from doing what I did before ... , I can’t control urine output. It’s not very severe incontinence, but it hinders my well-being” <sup>31(p.1983)</sup>
Finding: 4	Feeling morally and physiopsychosocially vulnerable
Illustration	“Even though I’m older, the fear of feeling embarrassed and humiliated out of home still exists in face of the possibility of urinating near other people.” <sup>15(p.1985)</sup>
Finding: 5	Resorting to palliative strategies when perspectives of improvement are not seen (U)
Illustration	“I have been prevented from doing activities that take a long time, such as going out, traveling, going to receptions, church services and celebrations” <sup>15(p.1985)</sup>
Finding: 6	Seeing perspectives of improvement when finding possibilities of treatment (U)
Illustration	“I found out that UI is reversible by reading a magazine. After the physiotherapy, the problem ended, but I still do exercises, and now I can laugh without leaking urine” <sup>15(p.1986)</sup>

### Culturally sensitive continence care: a qualitative study among South Asian Indian women in Leicester<sup>29</sup>

Finding: 1	Urinary symptoms such as leakage, frequency and nocturia were a normal part of the ageing process (U)
Illustration	“I don’t think that was a problem, just like Seema was saying, that I thought it was part of getting old and not really a problem” <sup>29(p.587)</sup>
Finding: 2	Explanations for the cause of their condition (U)

Illustration	“Part of the reason is that muscles have gone weak, and we feel there is no cure for weakness, it has to happen so it will, we are old, nothing can be done” <sup>29(p.588)</sup>
Finding: 3	Read little about the subject of continence (U)
Illustration	“We say that we are educated but you don’t realize and I didn’t realize how big a problem this is and that something can be done about it . . . I’ve lived in this country all my life, I was educated here and I didn’t think that this was a problem, so I never saw a doctor about it” <sup>29(p.588)</sup>
Finding: 4	Symptoms were not that important to prompt a consultation with the GP (or family doctor) (U)
Illustration	“I never thought it was a problem to go see the GP. I thought it was a small problem and it would go away, maybe I drank too much water, never thought it was such a big problem with so many people affected. You don’t go to see your GP for small problems” <sup>29(p.588)</sup>
Finding: 5	Had not received any valuable advice to manage the condition (U)
Illustration	“The doctor said that because you have so many children your womb has dropped and said you are getting old, it will get better, didn’t give me any medication” <sup>29(p.588)</sup>
Finding: 6	Feeling embarrassed when going to see their GP for personal reasons such as incontinence (U)
Illustration	“I’m embarrassed to see the doctor, I have a male GP, but if I tell him he will refer me to the female GP, but I don’t want that because they will examine me and I don’t want that?” <sup>29(p.588)</sup>
Finding: 7	Preference to be seen by a female doctor (U)
Illustration	“I think having a female makes it easier to talk about your personal problems especially those down below, because it’s embarrassing” <sup>29(p.589)</sup>
Finding: 8	Women would prefer to see an allied health professional (i.e. continence nurses, practice nurses, physiotherapists and healthcare visitors) rather than the GP (U)
Illustration	“I have a practice nurse and when we make an appointment they say ‘whom do you want to see?’ and I say ‘the nurse, I don’t want to talk to the doctor’” <sup>29(p.589)</sup>
Finding: 9	Having GPs from similar ethnic backgrounds would be preferable (U)
Illustration	“The other thing I’ve noticed is that Asian people tend to go to Asian doctors. They think that there will be no language or cultural issues. Like when we were young my parents changed to a Muslim GP, because somebody said that when you die they do this and they do that and if you have a Muslim doctor then he understands the procedures and my mum and dad thought ‘excellent, let’s change to a Muslim doctor’” <sup>29(p.589)</sup>
Finding: 10	Dissatisfaction at the way they had been taught pelvic floor exercises (U)

Illustration	“They told me to do pelvic floor exercises when you have a baby, they don’t exactly say it’s for your bladder, they just said ‘you have had a baby and it will help with your muscles’, it was not said ‘if you don’t do this you will have bladder problems later” <sup>29(p.589)</sup>
Finding: 11	Younger age group women were more likely to consider alternative therapies, including herbal medication. The older women tended to prefer to use medication as prescribed by their doctor (U)
Illustration	“I would take the hospital’s medicine; my son is a doctor you see; I would take the doctor’s medicine or herbal medicine, I wouldn’t mix and match. I don’t think it would help, sometimes I would take herbal medicines if the problem was small” <sup>29(p.589)</sup>
Finding: 12	Preferred to use family members rather than the interpreting services (U)
Illustration	“I wouldn’t feel comfortable, again it would be a complete stranger and you end up talking to two people who you don’t know. The interpreter may go home and talk about it and they come from the same community” <sup>29(p.589)</sup>
Finding: 13	Health professionals should use a more direct approach in addressing the problem (U)
Illustration	“If the nurse asks you then it’s like it’s recognized, it’s not just something you have, it’s an issue, that’s why she has brought it up and because it affects so many women” <sup>29(p.590)</sup>
Finding: 14	Talk-based awareness campaigns were more likely to be successful than written ones (U)
Illustration	“My mother in law can’t read. I have to translate it for her. Talks are the way forward” <sup>29(p.590)</sup>
Finding: 15	Small group discussions, rather than large groups with healthcare professionals, would be more valuable (U)
Illustration	“Small community centres that these elder women go to and give them talks, in a small group they are more likely to be receptive, not 100%, but if they know a little bit about it they will talk, better than you giving a talk in a large group” <sup>29(p.590)</sup>

### Discovering older women’s experience of urinary incontinence<sup>41</sup>

Finding: 1	Threat to self-esteem (C)
Illustration	“(…) I was never so embarrassed in my life. It was great big all over, big spot. Others could see that it was wet, that I had wet. It’s something I’m telling you. It’s embarrassing. (…)” <sup>41(p.181)</sup>

### Beyond incontinence: the stigma of other urinary symptoms<sup>37</sup>

Finding: 1	Stigma of daytime frequency and urgency (U)
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Illustration	“If I go to someone’s house and I have to go to the bathroom a lot, maybe it might not be the right time to go to the bathroom to pee, but since I have this weakness in my bladder, I have to go right away . . . I worry because I think other people are going to think ‘what’s wrong with her? Why is she going to the bathroom so much’ . . . It’s truly not normal for someone to need to go to the bathroom so much!” <sup>37(p.2464)</sup>
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### Silently waiting to heal experiences among women living with urinary incontinence in Northwest Ethiopia<sup>19</sup>

Finding: 1	Seeking help (C)
Illustration	“It never came to my mind that I could get cured, so I never attempted to seek advice” <sup>19(p.957)</sup>
Finding: 2	Fear and embarrassment (U)
Illustration	“I prefer to keep it as a secret and I haven’t told anybody about it” <sup>19(p.955)</sup>
Finding: 3	Making sense of the leakage (U)
Illustration	“We worship Kole, but it turned against us because I failed to slaughter a sheep when I first faced disease” <sup>19(p.957)</sup>
Finding: 4	Experience of support (U)
Illustration	“My husband has slept in a separate bed during the last 3 or 4 years as he says it has a bad smell . . . I repeatedly ask him to send me to the health institution, but he refuses” <sup>19(p.956)</sup>
Finding: 5	Keeping clean (U)
Illustration	“I would prefer cleaning with soap to avoid the smell, but the market is far away and we face shortage of money” <sup>19(p.954)</sup>

### Experiencing and managing urinary incontinence: a qualitative study<sup>20</sup>

Finding: 1	Being prepared (U)
Illustration	“If I go from here into town-when I go by tram-I’m in town in five to seven minutes, so I’ve reached the first point in a quarter of an hour. Yes and then I go there, I go for a coffee. Because the other toilets aren’t open yet, but the cafés are open, so I go there and it’s nearest to the tram stop” <sup>20(p.486-487)</sup>
Finding: 2	Looking for and using possible therapies (U)
Illustration	“If I felt worse or really bad, then I had certainly do it, but up to now it’s bearable, and I must say that in the meantime I’ve learnt how to deal with the problem” <sup>20(p.489)</sup>
Finding: 3	Forming a circle of trust (U)
Illustration	“I must also say that I didn’t talk about it at first, and then began to talk to friends about it, with good female friends” <sup>20(p.490)</sup>

Life experiences of Brazilian women with urinary incontinence<sup>1</sup>

Finding: 1	A veiled issue (U)
Illustration	“You can see that people are not commenting on what [...]. So I am in mine, stay still, not talk. [...] [Laughter] [...]. No one ever said, I do not know if are embarrassed also. One always gets embarrassed to talk” <sup>1(p.630)</sup>
Finding: 2	A lonely experience (U)
Illustration	“We see people talking, that woman is stinking urine. So we think [...]. They’re talking about us too! When this happens, I try to distance myself more, do not get too close.” <sup>1(p.631)</sup>

The meaning of women’s experience of living with long-term urinary incontinence is powerlessness<sup>27</sup>

Finding 1	Living with an uncontrolled body (U)
Illustration	“When urine runs down your legs, it’s a feeling you can’t compare to anything else. No, there’s nothing you can compare it to, there really isn’t. It’s very, very hard to take, not being in control of your body. You feel upset, and pretty often you get angry. Getting angry’s best, it’s easiest that way” <sup>27(p.1950)</sup>
Finding: 2	Living with incontinence as taboo (U)
Illustration	“I don’t have sauna with my husband and children any more. I can’t explain urine leakage, it’s sort of too intimate for them-it doesn’t exist for them, simply” <sup>27(p.1951)</sup>
Finding: 3	Experiencing a less satisfying encounter (U)
Illustration	“I was badly treated and upset. The nurse should be able to help and give you advice. No, incontinence pads were only for the older people, the ones who were 60–70. But when you are only 50 you are considered far too young for it” <sup>27(p.1951)</sup>
Finding: 4	Living in readiness (U)
Illustration	“I’ve got into a sort of routine, go to the toilet at least once an hour. It’s automatic, you don’t think about it” <sup>27(p.1951)</sup>
Finding: 5	Making urine leakage comprehensible (U)
Illustration	“I’m not ashamed of it I think it’s perfectly normal to have it when you’ve given birth to so many children. It must be because I weigh a lot too” <sup>27(p.1951)</sup>
Finding: 6	Accepting living with UI (U)
Illustration	“I thought it was my own fault I was incontinent, hadn’t done the pelvic floor exercises as I should. Then I encountered a gynecologist who said that it wasn’t my fault things were the way they were. It was very liberating. Nowadays I’m in control” <sup>27(p.1951)</sup>
Finding: 7	Being familiar with the situation (U)
Illustration	“No, I don’t see it as a problem. I do weight-lifting so that there won’t be a leak, and I wear incontinence pads and I pee before go in” <sup>27(p.1951)</sup>

Fear of humiliation inhibits women's care-seeking behavior for long-term urinary incontinence<sup>24</sup>

Finding: 1	Minimizing the UI problem (U)
Illustration	"I have a problem with bladder control. I would get help if it affected my way of life and if my panties were wet every day. Yes, quite simply, if I were to feel dirty and have yucky feeling about myself" <sup>24(p.309)</sup>
Finding: 2	Altered sexual relationships (U)
Illustration	"I'm beginning to feel the need to do something about the bladder control problem. It's becoming more and more of a hindrance. Intimate relations with my husband don't feel fresh unless they are planned and that's not fun, it's not spontaneous" <sup>24(p.308)</sup>
Finding: 3	Living with shame (U)
Illustration	"To talk about diabetes and diet for example is of general interest, what you are supposed to eat and what you're not. But a bladder control problem is a bit private; it doesn't feel as natural to talk about. It's connected to a feeling of shame. Urinary incontinence has to do with the genital area and is linked to a person's muscles being weak" <sup>24(p.308)</sup>
Finding: 4	Need for distancing (U)
Illustration	"I think to myself, when I get to the hill with the birch trees I'm not going to have to urinate, and when I get to the boulder, I can't hold myself any longer. But just quitting thinking about it, having someone along with me on the walk, then the thought doesn't enter my mind and I manage the walk, it is psychological" <sup>24(p.309)</sup>
Finding: 5	UI is a normal consequence of pregnancy and childbirth (U)
Illustration	"I didn't bring this injury on myself, I've ended up with a bladder control problem, I associate it with giving birth and having children since it didn't happen before that, it's a natural thing, it's nothing I could of done something about" <sup>24(p.309)</sup>
Finding: 6	Being actively asked about UI (U)
Illustration	"The last time I was in for a PAP test, the gynecology nurse didn't ask me anything except if I was using any type of birth control. That was all that seemed to matter. But I had expected more questions that covered a little of everything like how a person is doing. I'm soon 40 and I've had three kids so of course I expected some questions on bladder control and if I had any problems with things like that. I think it is important that the gynecology nurse has questions about urine leakage as standard questions" <sup>24(p.309)</sup>
Finding: 7	An understanding atmosphere (U)
Illustration	"No, I don't know, it's nothing a person just brings up so there. That's how I feel. If a person were to compare it with menstruation, well everyone knows that all women have it, than a person sort of knows that the other person understands. But a person knows that not everyone has a bladder control problem. You don't discuss it then either" <sup>24(p.310)</sup>
Finding: 8	Toning down their problem (U)

Illustration	“My generation has always worked double and haven’t thought about their own problems that much. A person puts off getting help. But there is a limit and then a person wants help right away. I started thinking about it when the last child moved out” <sup>24(p.309)</sup>
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### Female urinary incontinence in China: experiences and perspectives<sup>18</sup>

Finding: 1	Uncertainty about UI (U)
Illustration	“I may have caught UI from the person I sit next to at work. She is always going to the bathroom” <sup>18(p.175)</sup>
Finding: 2	Self-blame (U)
Illustration	“I think it [UI] is because I had a bad habit of always going to the bathroom when I was little” <sup>18(p.175)</sup>
Finding: 3	Avoidance (U)
Illustration	“I cannot go out freely” <sup>18(p.175)</sup>
Finding: 4	Emotional isolation (U)
Illustration	“Others do not understand this disease. They do not consider me to be sick because I look fine” <sup>18(p.175)</sup>
Finding: 5	Desire for treatment (U)
Illustration	“When I went to see the doctor he told me that no treatment existed” <sup>18(p.175)</sup>

### Silent no more elderly women’s stories of living with urinary incontinence in long-term care<sup>16</sup>

Finding: 1	Self-isolation: maintaining secrecy of UI (U)
Illustration	“It is very, very embarrassing being incontinent and it affects your self-esteem” <sup>16(p.17)</sup>
Finding: 2	Elderly women taking care of UI (U)
Illustration	“I do something that is very wrong. I try not to drink too much but that’s so wrong. So how can you drink a lot, you would be soaked all the time. I can’t make clothes” <sup>16(p.18)</sup>
Finding: 3	Directing the UI experience: influence of staff (U)
Illustration	“The girls are all overworked here and they are too short staffed. Sometimes I have to wet my bed before they get here, you know, and they are all busy and I have to wait for somebody, then I can’t control it” <sup>16(p.18)</sup>

### The experience of stress incontinence after childbirth<sup>34</sup>

Finding: 1	Acceptance and non-acceptance (U)
Illustration	“I think I’ve learnt to live with it and know that I can’t run. Will always have to wear a pantyliner.” <sup>34(p.167)</sup>

Finding: 2	Women differed with respect to whether or not they sought social support and how helpful they found it (U)
Illustration	“People laugh as if it’s some sort of joke – even my boyfriend. I used to say don’t laugh at me” <sup>34(p.167–168)</sup>
Finding: 3	Blaming themselves (U)
Illustration	“Sometimes I think it’s my own fault; that’s why I’ve never pushed it, because I’ve never done these exercises. So the Dr. would say if you’ve done pelvic floor exercises, then you wouldn’t be here.” <sup>34(p.168)</sup>
Finding: 4	Feelings and emotions (U)
Illustration	“On social occasions – at Christmas I was very concerned during my husband’s work party. You’re aware of it all the time, worried of having a wet patch on my skirt” <sup>34(p.168)</sup>

### It’s just the worry about not being able to control it! A qualitative study of living with overactive bladder<sup>30</sup>

Finding: 1	The experience of urgency (U)
Illustration	“Directly I get anywhere . . . If I go anywhere, I will go [to the toilet] ‘N’ times before I leave the house because I can’t take a chance. Directly I get to where I’ve got to or vice versa, I will immediately want to go there [toilet], then an hour after, then I might be all right for a bit” <sup>30(p.348)</sup>
Finding: 2	Fear and coping strategies (U)
Illustration	“My thing is carrying pads . . . I only have like the small ones, do you know what I mean, the pant liners but it is still something to have around in my handbag, you know, carrying them with me just in case. Sometimes it is even a matter of taking a pair of pants with me if it is winter time, because I might need to change” <sup>30(p.349)</sup>
Finding: 3	Anxiety about everyday living (U)
Illustration	“Well I am going out tonight and I am sick [with worry]. I don’t go out normally ‘I don’t. Not even like say going to the doctor because if I have an accident’ I will die” <sup>30(p.350)</sup>
Finding: 4	Depression and hopelessness (U)
Illustration	“It affects your whole life. It definitely does. Very uncomfortable. As I say at the beginning it was really bad but now I just take everyday as it comes” <sup>30(p.350)</sup>
Finding: 5	Embarrassment (U)
Illustration	“Just the embarrassment actually of . . . you know . . . of admitting that it was happening. Once you go and see about it then there isn’t a problem . . .” <sup>30(p.351)</sup>
Finding: 6	Self-esteem, sexuality and embodiment (U)

Illustration	<p>“PN: Have you put on weight?          Yes, I have put on weight. I am quite a few stone over weight.          PN: Really. How did that happen? Was it some of the treatments that made you put on weight?          No, No . . . I think it was just myself being depressed and eating”<sup>30(p.351)</sup></p>
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#### Part and parcel of being a woman: female urinary incontinence and constructions of control<sup>14</sup>

Finding: 1	Reluctance to seek professional assistance in resolving or managing their incontinence (U)
Illustration	<p>“You go to the doctor with a medical problem that has to do with your body – the doctors deal with medical problems but they do not know what to do with my medical problem so I revert to a fall-back position and say, ‘Well, it must be just me’. It’s a way of solving the dissonance between two opposite points of view – doctors know about ailing bodies, but [in this instance] the doctor knows nothing about my ailing body”<sup>14(p.270)</sup></p>
Finding: 2	Ambiguity of definition (U)
Illustration	<p>“When I first mentioned it to the GPs, they never really sort of explained fully what was happening, and they just sort of said, ‘It will probably get worse over the years, do exercises, if it doesn’t get any better, we will, you know, you can go and get it fixed up’. I was just sort of fobbed off as to what was happening . . . I am inclined to accept that they just fob you off and just sort of basically treat you like you should know what is going on and, you know, accept it”<sup>14(p.272)</sup></p>
Finding: 3	The problem would be taken more seriously (U)
Illustration	<p>“I mentioned it [FUI] to them, but the strange thing is that they fob you off. Not one of them ever checked it out or asked me questions about it. They were doing a survey once, not too sure about what, one of the questions they asked about was FUI. I said that I had it and that it was a problem for me and that I was trying to fix it up. They wrote it down in the notes, but they have never followed it up or asked me if I wanted to do anything about it”<sup>14(p.272)</sup></p>
Finding: 4	Sense of both the relatively trivial and embarrassing nature of the complaint (U)
Illustration	<p>“Well, it’s very personal, it isn’t life-threatening. If it was something that you couldn’t control at all, then you would have to do something about it – but when it is just something that is ‘Oh well, you have got to be careful’ – you think that is enough, that you can do that – just be wary about what you’re doing and think about how you are doing it – and you weigh this up against how embarrassed you are going to be about doing anything about it, so there is that sort of little see – saw there, working out embarrassment against working it out yourself”<sup>14(p.273)</sup></p>
Finding: 5	Incontinence as a consequence of menopause (U)

Illustration	“I can remember as a teenager, around 15 or 17, at a ball one night, and laughing about something and wetting myself, and being terribly embarrassed by it all and going to the toilet . . . And then it’s gone on and been exacerbated over the years with childbirth and so on. When I had finished, when I decided that I wasn’t going to have any more [children] after my last baby, the doctor said to me ‘When your stress incontinence gets really bad, you will know and will want to do something about it’” <sup>14(p.273)</sup>
Finding: 6	Incontinence had affected how she viewed her body (U)
Illustration	“I don’t really know because I have had it so long . . . I would say it has not changed anything at all because it had always been there and through my young years and my young married, young mother years. I always had it through my later years as a premenopausal lady and then after menopause. It’s always been there, through all the different stages of womanhood . . . It’s just one of those facts in my life that I deal with” <sup>14(p.273)</sup>
Finding: 7	Abnormality and inexplicability (C)
Illustration	“Very few of my friends know that I have got this problem, even my closest friends. I don’t want them to know. I had a friend with a baby with projectile vomiting. No one invited her out. I don’t think my friends would do that, but just the thought of them knowing . . . They know that I have had a crook [bad] back, and they know that I have had problems with my bladder and that I’ve had a lot of infections, but they don’t know that I am incontinent of urine, and I don’t want them to know . . . (. . .)” <sup>14(p.274)</sup>
Finding: 8	Doctors encourage women to accept this life trajectory (U)
Illustration	“I used to be very up in arms about this issue, but now I have mellowed. I used to think, ‘Why do women put up with this when treatment is so easy?’ [A gynecologist] sat me down and explained to me that women don’t expect their bodies to be the same after childbirth. I have now developed the awareness that all people have problems, both men and women . . . a lot depends on your philosophy. Incontinence is one of a series of little things one puts up with – not a bad thing really” <sup>14(p.274)</sup>
Finding: 9	Older women were “allowed” to be incontinent (U)
Illustration	“It is more acceptable in older people. A young woman told me she had to be careful. She was really young, and I was surprised that she had incontinence (. . .)” <sup>14(p.275)</sup>
Finding: 10	Accept and anticipate changes in health status as a natural feature of the aging process (U)
Illustration	“I just feel women shouldn’t be so afraid to go and seek help for the problem. It is probably rather a silent type of complaint that people want to keep quiet about, I’m sure they do. Because nobody wants to . . . and when people are about 80, that might be different, but when you’re 40 and 50 I think it’s not something you want to go broadcasting really to people” <sup>14(p.276)</sup>

**Incontinence and sexuality: findings from a qualitative perspective<sup>31</sup>**

Finding: 1	Clothing and appearance (U)
Illustration	“I won’t wear plain colored clothes because if I should wet and you know it shows on those, but if it is patterned it doesn’t show so much” <sup>31(p.575)</sup>
Finding: 2	Intimacy and caring (U)
Illustration	“... coming to terms with our realization how, there has been no spinal cure around the corner, there has been no bladder cure around the corner and its coming to terms with this kind of long term issue” <sup>31(p.575)</sup>
Finding: 3	Management techniques and relationships (C)
Illustration	“I have to do it [SIC] when I am completely on my own ... as it is so embarrassing ... If I was married to anyone I couldn’t do it. I have to have complete privacy” <sup>31(p.576)</sup>

**Pelvic floor dysfunction: women’s sexual concerns unraveled<sup>22</sup>**

Finding: 1	Body image (U)
Illustration	“Because there is a sense of, you know, real embarrassment that this isn’t something that should be happening, that you should be able to control yourself, and you just can’t” <sup>22(p.748)</sup>
Finding: 2	Sexual desire (U)
Illustration	“Compared to a lot of other people we hardly ever do it. And it is (...) the main thing is the lump; it’s uncomfortable and I just, I’m very conscious of it, and I know [partner] can feel it so, you know” <sup>22(p.749)</sup>
Finding: 3	Sexual arousal (U)
Illustration	“Whereas now it’s very mechanical and I’m more worried what’s down there. (...) I convinced myself that I enjoy it, but it takes a long time and usually it’s sort of done before I get to really enjoy it?” <sup>22(p.749)</sup>
Finding: 4	Orgasm (U)
Illustration	“I think It takes you longer now, for me anyway, because that is when I’m scared, that I’m just going to let go and that [incontinence] could happen. So you find you’re trying to fight [reaching an orgasm].” <sup>22(p.749)</sup>
Finding: 5	Dyspareunia (U)
Illustration	“It’s where the lump is. I get like an ache, like, like a dragging ... (...) It just feels like a dragging, horrible pain. (...) It’s different positions. Uhm laying down I can still feel it, but not as bad, to be honest. Uhm but when we are sort of like in another position it is just there. (...) Also when you orgasm Everything seems to move down there and I know I’m going to get a tummy pain” <sup>22(p.749)</sup>

Urinary incontinence in Muslim women<sup>32</sup>

Finding: 1	General influences on help-seeking and decision making behavior (U)
Illustration	“I have heard old age causes UI but for me giving birth has caused me to leak. I was fine before them” <sup>32(p.50)</sup>
Finding: 2	Cultural influences on help-seeking and decision making behaviour (U)
Illustration	“I don’t know if this is written in the book [Quran or Hadith] but I [am] sure it is” <sup>32(p.51)</sup>
Finding: 3	Preference for male or female health professionals (U)
Illustration	“I would prefer to tell the nurse, they have more time, doctors are always busy but if I can’t speak English how would I say it?” <sup>32(p.51)</sup>
Finding: 4	Disclosure of UI (U)
Illustration	“He would probably find it awkward. He is quite a strict Muslim and I don’t think he would want to talk about it” <sup>32(p.52)</sup>
Finding: 5	Religious influences on help seeking and decision making behaviour (U)
Illustration	“Life, death and health are from Allah. When Allah gives you an illness, you will receive cure from him too. I know Allah will not let me suffer” <sup>32(p.52)</sup>

Chinese women’s experiences of stress incontinence: a descriptive qualitative study<sup>17</sup>

Finding: 1	Severity of urinary incontinence (U)
Illustration	“I am a key member of a Women’s Committee and I have to join the activities there. If I have to dance, I have to put on maternity pads. There is no use even using these thick pads. I only allow myself to dance for a little while. If I do not use pads, I dare not walk in the street. You know, suddenly while I am walking, all at once, it (urine) is running down between my thighs” <sup>17(p.128)</sup>
Finding: 2	Influence of incontinence on everyday life (U)
Illustration	“I also have colleagues with the same problems (urinary incontinence). Sometimes I heard saying that urine comes out during coughing. Then gradually, I feel that it is ... quite normal (laughs)” <sup>17(p.128)</sup>
Finding: 3	Secrecy (U)
Illustration	“My husband will feel that ‘you are getting old, (your muscles) become lax, of course you should have this problem (urinary incontinence)? And, if you tell other colleagues that you have urinary incontinence, they will laugh at you, saying that’ oh! You are already old. You are not suitable to work” <sup>17(p.129)</sup>
Finding: 4	Concealment (U)

Illustration	“While I am happy, I still have to suppress myself. That is my whole person cannot be free. That is, the emotions cannot be so free. Sometimes, while I am talking to my good friends, I am laughing loudly, I will forget my condition (urinary incontinence), he bottom part will have urine leaking out. I know I have to suppress my emotions, do not let my emotion to be so high. It is because if I have a little bit of urine coming out, I can control it. But if I still let me to be so high, it will leak like urination” <sup>17(p.129)</sup>
Finding: 5	Social seclusion (U)
Illustration	“Sometimes when my friends ask me to go out, I always try to make an excuse to refuse them. I feel it is very troublesome because there may not have a toilet available in that place. You know I have to find a toilet, if I always have to ask people about the toilet, it is not so good. Sometimes even if I have an opportunity to go for a trip; my heart does not want to go, because I have to bring extra things. Now I seldom go anywhere, even my family ask me to go for a short trip just for a few days; I also do not want to go” <sup>17(p.129)</sup>
Finding: 6	Sexual relationship (U)
Illustration	“Actually I dare not tell my husband, it is very nasty . . . I recognized that men ahh . . . know that you have so many problems and especially if you have lax bottom muscles . . . actually many of these private things I will not tell him. I have incontinence, lax bottom parts and sexual activities are very important. At first, I told him that my bottom part was lax. I saw from his appearance that he was not happy” <sup>17(p.129–130)</sup>
Finding: 7	Roles in society (U)
Illustration	“I hope I do not have urinary incontinence while I am playing with my children. I want to play with them. It is not possible for me to run or jump, like that . . . that is . . . if they ask me to run . . . I have to make excuses to refuse them by saying: ‘I am tired’, ‘I do not have energy’, ‘I do not have any gas’. In this way, I feel that I have missed a lot of chances to get along with my children” <sup>17(p.130)</sup>
Finding: 8	Emotional distress (U)
Illustration	“My mood is very bad for being always wet. I am so unhappy that I feel very annoyed. I am angry with myself, I always scold other people, and sometimes I find myself scolding people without reason” <sup>17(p.130)</sup>
Finding: 9	Feeling of unattractiveness (U)
Illustration	“Every day I wet my trousers a bit. Sometimes the sanitary pads cannot absorb all of the urine. Then it sticks on the inner sides of my thighs, and my skin became red. I always have to clean my bottom part. Even at home, I dare not sit anywhere . . . I am afraid that I will suddenly sneeze and then I will wet the sofa and have some smell” <sup>17(p.130)</sup>
Finding: 10	Locus of blame (U)
Illustration	“My mother says: ‘many women will be like this (having incontinence) after they have given birth to children’. Sometimes I tell my children that ‘women are very poor, especially as being a mother they have to sacrifice a lot’. Emm. hoping that they will care for me more and not be so naughty” <sup>17(p.131)</sup>

Finding: 11	Supportiveness (U)
Illustration	“My family encourages me to do pelvic floor muscle exercise. Sometimes while I am sitting and watching television, my daughter will remind me to do it. She says, ‘You should work harder, otherwise it will not be so good’ They are very supportive” <sup>17(p.131)</sup>
Finding: 12	Reminder (U)
Illustration	“I have a habit of touching my ear lobe each morning to remind myself of the things that I have to do . . . each day when I touch my earlobe, I will remember to do the exercise. I absolutely will keep on with it” <sup>17(p.131)</sup>
Finding: 13	Perceived motivators (U)
Illustration	“I have done what was recommended because I do not want to wet my trousers always, no need to put on thick pads. Before, the urine always soaked through my pads, my skin became red and sometimes breakdown. While walking, it will be painful (because of the soreness). It takes about one week to heal. I remember to do the pelvic floor exercise, because I know my situation” <sup>17(p.131)</sup>
Finding: 14	Commitment (U)
Illustration	“I already tried my very best to do pelvic floor muscles exercise. I do it while waiting for the bus. Actually, I try to go there earlier (laughs). That is my usual practice. I regard it as my habit. Because there are not many people waiting at the bus stop, I can count the numbers of exercises verbally . . . I do it in the morning, afternoon and at night” <sup>17(p.132)</sup>
Finding: 15	Perceived benefits of exercise (U)
Illustration	“Now I have become better. If I do the pelvic floor muscles exercise, I will be better. I have not had urinary incontinence for a few months. Coughing mildly, I do not have urinary incontinence. I really have improved a lot. Now I have more confidence. I can really feel the tightening up of my (pelvic floor) muscles” <sup>17(p.132)</sup>
Finding: 16	Incompetence (U)
Illustration	“I only did the pelvic floor muscles exercise a few times. Ahh . . . it may be a problem with my confidence. I do not have confidence, it seems that (I am) not practicing that . . . that particular area. It is because I need . . . need to feel whether I am exercising that particular area. It is different from hands or feet that we can touch and see. I cannot do it according to what was taught. I can only maintain the skills for a few days. After a few days, I was unable to do the skills, then I become lazy and do less and less exercise” <sup>17(p.132–133)</sup>
Finding: 17	Uncertainty (U)
Illustration	“Sometimes I do not know whether it works. There is no way this simple exercise can work, can be helpful. My confidence is not so great. After doing it for some time, I still do not have confidence in its effectiveness” <sup>17(p.133)</sup>
Finding: 18	Perceptions of discouraging as factor (U)
Illustration	“Being nervous, having a bad mood and bad weather affect whether I do the exercise. Back pain will cause me to have bad mood for doing exercise . . . having no interest to do it. If I have bad mood I feel disorderly, and incapable” <sup>17(p.133)</sup>

Managing incontinence: women's normalizing strategies<sup>40</sup>

Finding: 1	Acknowledging a problem (U)
Illustration	"I made the mistake of not going to the bathroom as quickly as I should have and had some accidents. Now I go to the bathroom as soon as I have the urge" <sup>40(p.553)</sup>
Finding: 2	Making adjustments (U)
Illustration	"I switched from a high to low impact aerobic class. I don't do heavy lifting now" <sup>40(p.553)</sup>
Finding: 3	Being vigilant (U)
Illustration	"If I am not paying attention and really relax, like when I warm my hands under warm running water, I might be incontinent if I am not careful" <sup>40(p.554)</sup>
Finding: 4	Incontinence management part of the normal routine (U)
Illustration	"It is not incapacitating me. It doesn't keep me from doing my exercise. I just take that extra precaution. It doesn't keep me from going out or from going to work" <sup>40(p.554)</sup>
Finding: 5	Self-management of incontinence (U)
Illustration	"When I come down with an illness, I have more difficulty making that control with a cough or sneeze. I have to wear a pad continually at those times" <sup>40(p.555)</sup>
Finding: 6	Women viewed incontinence within a familial context (U)
Illustration	"My sister has it; my mother has it; all my mother's sisters have it; my grandmother has it" <sup>40(p.556)</sup>
Finding: 7	Incontinence to normal life events (U)
Illustration	"I think it is a situation from labor and delivery – you know, pregnancy and that sort of thing" <sup>40(p.556)</sup>
Finding: 8	Incontinence management compromised when it was perceived as intruding in a woman's social life (U)
Illustration	"I went dancing the other night and found I couldn't dance more than one dance without having to go to the bathroom" <sup>40(p.555)</sup>
Finding: 9	Delaying medical counsel (U)
Illustration	"Emotionally I am just blocking it right out" <sup>40(p.557)</sup>

Urinary incontinence in Moroccan and Turkish women: a qualitative study on impact and preferences for treatment<sup>28</sup>

Finding: 1	The incontinence was affecting their worship of the Islam faith (U)
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Illustration	“I can’t go to the mosque and pray straight away any more. I can’t guarantee that after ablution I will retain the state of purity. Having to wash myself 5 to 7 times a day is really starting to get me down. Sometimes I can’t pray because there is nowhere I can wash” <sup>28(p.946)</sup>
Finding: 2	Adhered closely to bodily cleanliness. They therefore found incontinence dirty and extremely bothersome (U)
Illustration	“I’m getting really fed up with having to wash myself and change my clothes all the time, these are the biggest problems. I am having trouble keeping it up, although I want to have everything really clean” <sup>28(p.947)</sup>
Finding: 3	Shame was the most important reason to hide it from their husband (U)
Illustration	“A man wants a healthy wife who also wants sex” <sup>28(p.947)</sup>
Finding: 4	Their condition was created by Allah (U)
Illustration	“It has nothing to do with shame. Some things we receive from Allah, and I am not going to feel ashamed about them” <sup>28(p.947)</sup>
Finding: 5	Women gave preference to a female doctor (U)
Illustration	“In Islam, a woman must always choose a female physician” <sup>28(p.947)</sup>
Finding: 6	Not understand the reason for the exercises (U)
Illustration	“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?” <sup>28(p.947)</sup>
Finding: 7	Had to accept the incontinence (U)
Illustration	“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 predestinated” <sup>28(p.947–948)</sup>

### Race and ethnic differences in health beliefs about lower urinary tract symptoms<sup>38</sup>

Finding: 1	White respondents believed symptoms were normal aging (U)
Illustration	“There have been times when, and this I definitely attribute to age, where I actually lose control. Now that really bothers me . . . You start to say, ‘Oh my God Am I losing control of my functions?’ And, it’s not a nice feeling” <sup>38(p.5)</sup>
Finding: 2	Black respondents believed symptoms were controllable (C)
Illustration	“The time factor in which I’m taking the fluids. I think that’s why I have to get up during the night and go to the bathroom” <sup>38(p.6)</sup>
Finding: 3	Among Hispanic respondents, uncertainty fueled worry (C)
Illustration	“So, sometimes I worry because I don’t know if it has something to do with any disease I might be getting but still haven’t gotten. I haven’t had a check up so that I can be sure about what is happening” <sup>38(p.7–8)</sup>

Ovid: Pakistani women's perceptions and experiences of incontinence<sup>23</sup>

Finding: 1	Shame that they felt at being incontinent (U)
Illustration	"I feel very ashamed but what can I do?" <sup>23(p.5)</sup>
Finding: 2	Fear, shame and embarrassment, coupled with the restrictions that incontinence imposes on travel and social life caused isolation (U)
Illustration	"When I go out I have to think about how I am going to cope ... I have to know whether there is a toilet where I am going" <sup>23(p.5)</sup>
Finding: 3	Mental stress that being incontinent can cause, and some appeared to be depressed (U)
Illustration	"... I have a lot of problems in my head. Sometimes I am very worried about myself and I cry a lot" <sup>23(p.5)</sup>
Finding: 4	Talk about the problem was viewed as a positive measure towards stress reduction (U)
Illustration	"... I talk to people and I feel better after talking to people ... so I feel better" <sup>23(p.5)</sup>
Finding: 5	Interruption of daily activities (U)
Illustration	"... sometimes my sister asks me to go shopping. I just think we will have to walk a long way to get to the toilets if I need them, so I don't go" <sup>23(p.6)</sup>
Finding: 6	Restricting and avoiding certain fluids before leaving home (U)
Illustration	"When I set off in the morning I only had a cup of tea ..." <sup>23(p.6)</sup>
Finding: 7	Incontinence management – washing and changing routines and using absorbent products (U)
Illustration	"I used to change through the day quite a lot because my clothes got wet and a lot of dirty washing for me to do, but thank God now I have these pads and they are very useful" <sup>23(p.6)</sup>
Finding: 8	Sharing problems – opportunity to talk about their continence problem (U)
Illustration	"I worry about it a lot. I think about it and it affects my brain. When I talk to someone I feel better about it ..." <sup>23(p.6)</sup>
Finding: 9	Prevent leakage going to toilet before and after intercourse (...). This caused humiliation and distress for the women (U)
Illustration	"When he starts intercourse I have to stop him and say that I have to go to the toilet first and he says 'you should have done that before' but even if I do go before intercourse I still have to go in-between ..." <sup>23(p.6)</sup>
Finding: 10	Interruption or prevention of praying ( <i>namaz</i> ) as the worst consequence of incontinence (U)
Illustration	"I feel clean and pure and I think God likes people that keep clean and the person feels good in themselves" <sup>23(p.7)</sup>
Finding: 11	Continence problems often delay seeking professional help (U)

Illustration	“I was very embarrassed. That’s why it took me so long to tell the doctor about this problem and that’s why the problem got worse” <sup>23(p.8)</sup>
Finding: 12	Preference to see a female health professional, particularly if a physical examination is required (U)
Illustration	“The nurse is a lady so I felt OK about it. If the nurse is a man, I wouldn’t like that” <sup>23(p.9)</sup>
Finding: 13	Language was perceived as barrier that constrained participants’ understanding in interactions with health professionals and their ability to communicate problems clearly (U)
Illustration	“There was no one to interpret for me, so one of my neighbour’s daughters went with me” <sup>23(p.8)</sup>
Finding: 14	Preferred to see a doctor from the same ethnic group as themselves (C)
Illustration	“Yes. If I can speak to them then I can . . . I can explain everything” <sup>23(p.9)</sup>

**“Stain in life”: the meaning of urinary incontinence in the context of Muslim postmenopausal women through hermeneutic phenomenology<sup>21</sup>**

Finding: 1	Emotional disruption (U)
Illustration	“Feel embarrassed. I am ashamed, and I think everybody knows that I cannot control my urine because it leaks in front of people. If I go to a gathering, I have to secretly take my cloth and shorts and go to toilet to change them. If I go to a gathering, I am afraid wet their sofa or carpet will be unclean due to my urine leakage” <sup>21(p.516)</sup>
Finding: 2	Spiritual disruption (U)
Illustration	“Couldn’t control myself, my urine was leaking all the time and I had to repeatedly wash myself, so I couldn’t pray well. It made me heartsick, since I cannot go to Mecca that is my great dream. I can’t make pilgrimages, because my urine is leaking all the time and I have to repeatedly wash myself. I am sure that you know everybody who wants to go to religious journey should be ceremonial clean, but I cannot, and for that reason I am always so sad” <sup>21(p.516)</sup>
Finding: 3	Physical disruption (U)
Illustration	“I can’t sleep at nights. I have to go to the toilet 5–6 times at nights, and then I would be fine!” <sup>21(p.516)</sup>
Finding 4	Daily life disruption (U)
Illustration	“Most of my times spend in the toilet. It has much bad effects on my life because all my time is spent in the toilet” <sup>21(p.516)</sup>

**Living with urinary incontinence: experiences of women from “The Last Frontier”<sup>42</sup>**

Finding: 1	Sharing the Secret (U)
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Illustration	“I would think there’s a lot of people out there that have this problem, and they just don’t want to talk about it. Because it’s personal! It’s like . . . who wants to be peeing on themselves . . . . It’s not a really comfortable subject to talk about to too many people. Yet if I were to see this flyer hanging up someplace, I would have laughed. Are you kidding, you think I’m going to tell anybody?” <sup>42(p.160)</sup>
Finding: 2	Trying to Fit It into the Day (C)
Illustration	“Let’s see what else I had to do to alter my life. Well, one major thing, where I work is under construction, and eventually, we’ll have a lovely restroom to accommodate all of the people that work there, but right now the females have one toilet. So I’ve given up trying to selfcath at work. It’s just . . . it just doesn’t work, and every female . . . ends up . . . and I can’t hold it, and it’s hurry up, hurry up, hurry up. So, that’s been difficult to deal with. In the future, one thing I ask is, please, with all these females that I work with, have enough toilets” <sup>42(p.160)</sup>
Finding: 3	Worrying about Leaking (U)
Illustration	“I was working, and I changed my pad in the morning, and I think maybe that was overflow because all of a sudden, I knew I was really soaking the pad. And I was in school with my kids, and all of a sudden, one of them said, ‘There’s a wet spot on the back of your slacks’. And I said, ‘Oh my God’, and for a kid to recognize it. ‘You wet your pants!’ Just out loud in front of everybody in the class, and that was my most embarrassing moment. I ran out of the classroom” <sup>42(p.160–161)</sup>
Finding 4	Searching for a solution (U)
Illustration	“If there’s a Web site where I could look and read something, I would. I mean I have to try to figure this out all by myself like some professional or something . . . . I mean I’ve tried . . . you know when you see a news flash on the TV ‘Bladder Control’ or whatever, you know, if you have trouble holding it or whatever. I’ve seen a couple” <sup>42(p.161)</sup>
Finding 5	Encounters with healthcare providers (U)
Illustration	“At that point, I sought a urologist, and I was very much hoping for a quick fix, and I was upset to find out that I wasn’t a candidate for a quick fix and would need a graft and a lot more work . . . than I had anticipated. I respected the doctor because I think to go through all of that and then have problems, it would have been devastating. My alternative, and this works well. It was a little harder in the beginning; it’s self-catheterization, and it’s really improved my life a lot” <sup>42(p.161)</sup>
Finding 6	Getting the Problem Solved (C)
Illustration	“Many of my female friends also have incontinence, so the more I talk about it, the more it’s an outside thing, and I encourage them to seek care. There are so many women that suffer in silence, and being a nurse, I see it all the time . . . . I think it’s important for nursing schools and medical schools to instruct their students about this silent problem. I think it’s getting a little bit better, but I think we have a long way to go. You’d hope that when they come in for a yearly check-up . . . that’s a great time to encourage women to relate their problems. It’s the right environment if they feel safe” <sup>42(p.161)</sup>