Fear of Incontinence: An Internet Study

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Impact Statement

Incontinence, as well as a fear of incontinence, are associated with high levels of distress and functional impairment. However, affected individuals may not choose to seek or receive optimal support for these problems. This thesis addresses gaps in knowledge about help-seeking among those affected by urinary incontinence (UI), as well as providing a preliminary evaluation of a new instrument for assessing fear of incontinence.

The systematic review aims to provide a more comprehensive understanding of the barriers to help-seeking for UI. In contrast to previous reviews on this topic, the current findings highlight the importance of emotional barriers (e.g. fear, embarrassment and shame). The findings also affirm the importance of other barriers such as the normalisation of UI, the ability to self-manage symptoms, and the lack of knowledge on treatments. The insights gained from this study may help healthcare professionals and policymakers tackle the issue of the low rate of help-seeking for UI, as each of the aforementioned barriers offers a potential point of intervention.

The empirical study provides psychometric support for the 16-item Fear of Incontinence Questionnaire (FOIQ), the only existing measure for fear of incontinence. This could be an important step forward for researchers to increase their understanding of the fear of incontinence. Clinicians could use this unique questionnaire in healthcare settings for screening, assessing and monitoring the progress of interventions aimed at alleviating the fear of incontinence. Furthermore, the results of the empirical study represent a step forward in improving knowledge of this understudied anxiety in older adults, as previous literature has focused on younger adults only.

To ensure appropriate impact, the results of this thesis will be disseminated in relevant journals and presented at scientific conferences, with the hope that it will offer additional knowledge for those working with people with UI or fear of incontinence.

Overview

Part one, the systematic literature review, explores the barriers to help-seeking for urinary incontinence. Twenty studies are reviewed with consideration of the methodological quality of the studies. The findings reveal four barrier themes, including 1) Appraisal of UI as normal, 2) UI as a manageable problem, 3) Lack of knowledge of treatment, and 4) Emotional barriers.

Part two, the empirical paper, building on the existing 2011 – 2013 dataset by Langhoff (2013), describes an online study exploring fear of incontinence in adults of all ages. The study had two main objectives; the first objective was to explore the psychometric properties of fear of incontinence (FOIQ), including the factor structure, internal consistency, convergent validity, and test-retest reliability; the second objective was to examine the mediating role of avoidance agoraphobia on the relationship between fear of incontinence and depressive symptoms. The results suggest the FOIQ has a three-factor structure, and adequate or good psychometric properties. Furthermore, the mediation analyses suggested that avoidance behaviour was a partial mediator of the relationship between fear of incontinence and depressive symptoms. However, the amount of variance accounted for by avoidance was small, and the clinical importance of this mediator is therefore currently unclear.

Part three is a critical appraisal of the research project, which considers theoretical issues of fear of incontinence, as well as reflections on methodological issues such as internet recruitment, and issues that arose during the data analysis stage. It also further discusses the learning points from this project.

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Part 1: Literature Review

Barriers to Help-seeking among Individuals with Urinary Incontinence: A Systematic Review

Abstract

Aim: To review the barriers in preventing people with urinary incontinence (UI) from seeking help.

Method: A systematic search of three online databases (Medline, PsycINFO, and Web of Science), and searching reference lists of all relevant quantitative and qualitative articles. Barrier themes were extracted from the relevant articles. The quality of the quantitative and qualitative articles was appraised using the appraisal list for surveys (Crombie, 1996) and the CASP Qualitative Checklist (Critical Appraisal Skills Programme, 2018).

Results: Thirteen quantitative and seven qualitative articles were selected for inclusion. Using a thematic analysis, four barrier themes were identified: 1) Appraisal of UI as normal, 2) UI as a manageable problem, 3) Lack of knowledge of treatment, and 4) Emotional barriers.

Conclusions: Strategies for improving help-seeking should aim to improve treatment knowledge and reduce embarrassment and shame. Healthcare professionals should provide guidance on effective self-management strategies.

Introduction

Urinary incontinence (UI) has been defined as any involuntary loss of urine by the International Continence Society (Abrams et al., 2002). There are three main types of UI, namely: stress incontinence, urge incontinence and mixed incontinence. Stress incontinence is defined as the involuntary leakage on effort or exertion, while urge incontinence is defined as the involuntary leakage immediately preceded by or accompanied by urgency. Mixed incontinence is defined as involuntary leakage associated with urgency and exertion, effort, sneezing or coughing.

UI is a common problem that can occur in both men and women of all ages, although research suggests that certain demographic groups have increased risk of UI. For instance, the risk of UI increases with age and is more prevalent in women. Other potential risk factors for UI include obesity, diabetes, history of urinary tract infections, stroke and neurological disorders (Bortolotti et al., 2000; Danforth et al., 2006; Shamliyan, Wyman, Ping, Wilt, & Kane, 2009). In particular, for women, studies reported an association between UI and hysterectomy, pregnancy and menopause (Buckley, Lapitan, & Epidemiology Comm Fourth Int, 2010; Peyrat et al., 2002).

The Fourth International Consultation on Incontinence reviewed epidemiological studies that examined the prevalence of UI across different countries (Buckley et al., 2010). They reported the prevalence of UI ranged from 7 to 61% in women below 60 years of age, whereas the prevalence was approximately half in men from the same age group, ranging from 2 to 31%. Above 60 years of age, the prevalence ranged from 14 to 63% in women and 3 to 53% in men. Specifically, in the UK, one study showed that 32% of women and 13% of men living in community reported UI (Buckley & Lapitan, 2009).

The Impact of Urinary Incontinence

Although UI is not a life-threatening condition, it can have profound effects on the physical and psychological wellbeing of the affected individuals (Brown et al., 1998; Grimby, Milsom, Molander, Wiklund, & Ekelund, 1993; Kelleher, Cardozo, & Toozs-Hobson, 1995). Physically, UI has been associated with perineal yeast infections, cellulitis, and pressure ulcers due to skin exposure to urine (Gray, 2007; Yates, 2017). In terms of psychological impact, UI has been associated with emotional distress, including depression and anxiety (Bogner et al., 2002; Felde, Ebbesen, & Hunskaar, 2017; Fultz & Herzog, 2001). UI has also been linked to embarrassment and shame (Elenskaia et al., 2011; Teunissen, Van den Bosch, Van Weel, & Lagro-Janssen, 2006), which can lead to concealing behaviours to prevent others from the discovery of the condition. Some common coping strategies include restriction of fluid intake, avoidance of physical activities or places where access to a toilet is limited including public transport or theatre (Brocklehurst, 1993; Klemm & Creason, 1991; Koch, Kralik, & Kelly, 2000; Lose, 2005). Other coping behaviours include the use of pads, frequent toilet visits, and wearing specific types of clothing (Shaw, 2001). These coping strategies employed by individuals with UI often involve restriction of lifestyle, which ultimately can have an impact on the person's social life. Furthermore, it has been reported that individuals with UI can experience a greater social withdrawal and greater social isolation (Fultz & Herzog, 2001; Grimby et al., 1993; Sinclair & Ramsay, 2011). In addition, relationships with partners may also be affected in individuals with UI due to concerns with urinary leakage during intimacy (Aslan et al., 2004; Sen et al., 2006). Keeping in mind the various disruptions UI causes to individuals, it is therefore not surprising that individuals with UI commonly reported lower quality of life than those without UI (Chiaffarino, Parazzini, Lavezzari, & Giambanco, 2003; Ko, Lin, Salmon, & Bron, 2005).

Reluctance to Seek Help

As part of a larger community-based survey study conducted in four European countries (Spain, France, Germany and the United Kingdom (UK)), a randomly selected sub-sample of women with UI was followed up with a self-completion questionnaire on UI (O'Donnell, Lose, Sykes, Voss, & Hunskaar, 2005). The results showed that on average only 31% of women with UI (*N*= 1852) sought help. Specifically, in the UK, 25% of women (*N*= 307) with UI sought help . The help-seeking rate was even lower in a group of Chinese women, who was randomly selected from a larger population-based cross-sectional study (Zhu, Lang, Wang, Han, & Huang, 2008). In this study, only 12.8% (*N*= 261) of women with UI sought help. In a clinic-based cross-sectional study conducted in Saudi Arabia only 9% (*N*= 51) of woman participants with UI sought medical help (Altaweel & Alharbi, 2012; Zhu, Lang, Wang, Han, & Huang, 2008). It seems that help-seeking rates tend to be no higher than 50% in individuals with UI based on the results from studies conducted across the world (Bilgic et al., 2017; Fitzgerald, Palmer, Kirkland, & Robinson, 2002; Frawley, Sibbritt, Steel, Chang, & Adams, 2017; Grzybowska, Wydra, & Smutek, 2015; Lee, Sung, Na, & Choo, 2008). Moreover, for those who eventually seek help, this can be delayed for over three to five years (Grzybowska et al., 2015; Margalith, Gillon, & Gordon, 2004; Teunissen, van Weel, & Lagro-Janssen, 2005). The reason for not seeking help or delaying the process of help-seeking is not due to the lack of treatment for UI. In fact, there are various available interventions such as bladder training, pelvic floor muscle training, medication and surgical treatment for UI (Lucas et al., 2012).

Theoretical Framework for Help-seeking Behaviours

Several well-established models have been used to understand help-seeking behaviours, such as the Health Belief Model (Rosenstock, 1974; Rosenstock, 2005) and the Theory of Planned Behaviour (Ajzen, 1991). However, these models do not consider the role of emotion in influencing people’s decision to seek help. More recently, researchers proposed the Model of Pathways to Treatment (Scott et al., 2013), which is a framework for understanding the help-seeking process. This model suggested that there are four main intervals (appraisal, help-seeking, diagnostic, pre-treatment) which occur before the initiation of medical treatment. In particular, the appraisal interval is the time period before seeking formal help, which is relevant for understanding people’s decision to seek help. This model proposed that there are three main types of contributory factors which can influence each interval: patient factors (e.g. demographics, co-morbidities, cognitions and emotions), health care provider and system factors (e.g. policy or access to care), and disease factors (e.g. disease site and development). In addition, this model acknowledges that the contributory factors within the appraisal interval can be understood using existing psychological theory such as the Common Sense Model of Illness Self-regulation (CSM; Leventhal, Meyer, & Nerenz, 1980). This model posits that bodily changes would be normalised if it does not exceed a threshold of interference; however if the changes are unexpected or exceed a threshold of interference, this would lead to symptom appraisal, which comprises of how the symptoms are labelled, the perceived cause, the consequences of the symptoms, and the control or cure of symptoms. These representations can then have an influence on people’s ways of coping such as symptom monitoring or visiting healthcare professionals. The CSM also views that a parallel emotional response plays a role in influencing people's coping responses. For instance, if people perceive symptoms as normal and does not feel concerned about it, they are more likely to use self-management strategies. However, if people are worried or embarrassed or ashamed about their symptoms, it is possible that they would avoid or delay help-seeking as a way to manage their emotions. As can be seen, this theoretical framework can be applied to understand help-seeking behaviours for different health conditions including UI.

Proposed Barriers to Help-seeking for UI

As research suggests that treatment outcome for UI is better when symptoms are mild (Baigis-Smith, Smith, Rose, & Newman, 1989; Burgio et al., 2003; Cammu & Van Nylen, 1995), there is a growing body of research that investigates help-seeking for UI. To date, there have been three reviews that focused on this topic (Koch, 2006; Shaw, 2001; Strickland, 2014). The two earlier reviews studied factors influencing people's decision to seek help, without specifically focusing on barriers that might prevent help-seeking. The review by Shaw (2001) revealed that several factors contribute to the decision to seek help for UI: 1) the type of UI, 2) the severity of symptoms, 3) the appraisal of UI symptoms (i.e. normal part of ageing) and 4) coping resources. Similarly, Koch (2006) also found that the severity of UI and the appraisal of symptoms influence help-seeking behaviours. For example, those who agreed with the statement that 'UI is a natural part of getting older' were less likely to get help in comparison to those who disagreed with the statement. Additionally, Koch (2006) identified other factors that influenced help-seeking behaviours such as embarrassment and beliefs regarding treatment. More recently, Strickland (2014) conducted a systematic review to identify barriers to help-seeking in older women with UI. Several main barriers were identified, namely: the appraisal of symptoms (i.e. perceiving symptoms as mild and a part of normal ageing), being able to self-manage, and limited knowledge regarding treatment options. Furthermore, it was found that women's relationship with their healthcare provider influenced their help-seeking behaviours.

It should be noted that there are limitations to the review conducted by Koch (2006) as the conclusion was based on eight papers only. It was also unclear whether the search strategies were comprehensive enough to include all relevant articles as Koch used limited keywords ('urinary incontinence', 'help-seeking behaviors', 'help seeking', 'treatment-seeking behaviors' and 'treatment seeking'). The review by Strickland (2014) summarised the barriers to help-seeking for UI, but it only included studies involving older women and papers from 2007-2012, with the risk of omitting relevant articles. Eligibility criteria were not clearly described, and the study characteristics were not reported including the type of UI symptoms, the mean age of the participants, and the sample size. The lack of clarity therefore raises questions regarding the generalisability of the findings. Importantly, it is difficult to ascertain whether the search strategies used in Strickland's review were thorough enough. Keywords only included urinary incontinence and health care-seeking behaviour. However, based on the help-seeking literature, the concept of help-seeking can be represented by other keywords such as 'health care utilisation', 'service utilisation' or 'treatment seeking' (Clement et al., 2015; Hom, Stanley, Schneider, & Joiner, 2017).

The three reviews considered most of the barriers identified from the aforementioned theoretical models for help-seeking behaviours, including perceived severity, perceived benefits of treatment, and how individuals label their symptoms (Koch, 2006; Shaw, 2001; Strickland, 2014). However, all three reviews did not identify perceived expectations to seek help from important others as a barrier to help-seeking, which is a factor thought to be important according to the Theory of Planned Behaviour (Ajzen, 1991).

Aims

A more comprehensive systematic review of the literature on the barriers to help-seeking in people with UI is warranted. Specifically, the current review will focus on psychological and social barriers. Although practical barriers (e.g. insurance status) also contribute to people's help-seeking behaviours, it will not be included in this review as these factors are likely to be country-specific (Mallett, Jezari, Carrillo, Sanchez, & Mulla, 2018; Siddiqui, Ammarell, Wu, Sandoval, & Bosworth, 2016). Furthermore, previous reviews only reviewed the barriers to help-seeking for UI in women. Although research suggests UI is more prevalent in women than men, the low help-seeking rate should not be disregarded in men, and there is a need to further our understanding in this population. Specifically, this review aims to address the weaknesses of the Strickland (2014) review by using a more comprehensive search strategy, and to expand the search by including studies that involved men and women of all ages.

Specifically, this systematic review will address the questions: 1) What are the psychological and social barriers to help-seeking in both males and females with UI?

Method

Search Strategy

Three electronic databases (PsycINFO, Medline and Web of Science) were searched from 2003 to 15th December 2018. These three databases were selected as they cover areas of medicine and psychology. The search started from 2003 as the International Continence Society updated the definition for UI in 2002. The electronic searches were limited to human studies and peer-reviewed English papers. Non-English papers were excluded due to lack of language resources for translation. The two key concepts were incontinence and help-seeking behaviours. Help-seeking behaviour was operationalised as seeking treatment or advice from a healthcare professional in this study. The initial search was intentionally broad to avoid missing relevant papers, hence the search terms aimed to represent the concept of ‘help-seeking behaviours’ instead of ‘barriers’ to help-seeking. Keywords were generated for each concept by examining the terminologies used in reviews for the help-seeking literature. The keywords and subject headings were entered into the thesaurus function in PsycINFO and Medline to ensure relevant terms were searched (see Table 1 for details of search terms used). The wildcard symbol was used where there were variations in spellings.

Table 1

A summary of the literature search terms used in each database

Database	**Incontinence**	**Help-seeking behaviours**
PsycINFO	incontinen* OR explode urinary incontinence/ enuresis	explode Help seeking Behavior/ Health Care Utilization/ Health Care Seeking Behavior OR ((healthcare* or health-care* or help* or care* or treatment* or service*) adj3 seek*) mp OR ((healthcare* or health-care* or treatment* or service*) adj3 (participat* or acceptance or uptake or utili* or use*)) mp
Medline	Incontinen* OR Explode urinary incontinence enuresis	explode help-seeking behaviour/ OR ((healthcare* or health-care* or help* or care* or treatment* or service*) adj3 seek*) mp OR ((healthcare* or health-care* or treatment* or service*) adj3 (participat* or acceptance or uptake or utili* or use*)) mp
Web of Science	incontinen* OR enuresis	(healthcare* or health-care* or help* or care* or treatment* or service*) NEAR/3 seek* OR (healthcare* or health-care* or treatment* or service*) NEAR/3 (participat* or acceptance or utili* or use*)

Study Selection

The initial database search yielded 2561 published English-language abstracts. Any duplicates were then deleted. The titles were screened to eliminate studies that were clearly unrelated to help-seeking behaviours for UI. The abstracts of the remaining articles were then screened according to the inclusion and exclusion criteria.

Inclusion and Exclusion Criteria

This review included studies meeting the following criteria:

1. The study included a sample of adults aged ≥18 years.
2. The study primarily assessed UI and barriers to help-seeking.
3. The study was empirical-based and included extractable data.
4. The study used qualitative or quantitative methodologies.
5. The study was published in a peer-reviewed journal.

The following exclusion criteria were applied:

1. The study was a psychometric study, single case study, review or commentary.
2. The study focused on general help-seeking but not for UI specifically.
3. The study included a specific population such as people with cystic fibrosis, institutionalised individuals, or women with incontinence associated with childbirth or menopause.
4. The study focused on barriers to accessing mental health service or treatment uptake.

5. The study was not primarily and predominantly focused on urinary incontinence, such as: studies including participants with faecal incontinence, or studies of conditions with multiple other symptoms e.g. pelvic floor dysfunction (sexual dysfunction and prolapse),, overactive bladder (frequent urination) and lower urinary tract symptoms (problems with storage and voiding)
6. The sample included participants aged younger than 18 years to avoid the risk of including studies on children and young people with developmental issues that can lead to incontinence.

The next stage involved checking the reference lists of the articles that met the inclusion and exclusion criteria to maximise the chances of locating relevant articles.

Coding of studies

The selected studies were categorised as qualitative, quantitative, or mixed-methods depending on the method used to collect data relevant to the review. The studies were coded according to the following characteristics: author name, year of publication, country in which the study was conducted, setting of the study (community, healthcare service), sampling method, participant characteristics including age (age range, mean), participant gender (female, male, both), type of UI (stress incontinence, urgency incontinence, mixed incontinence), severity of symptoms, data collection method (survey, interview), method used to assess barriers to help-seeking (multiple choice or open-ended question), data analysis method, and reported barriers to help-seeking.

Quality Appraisal

The quality of the selected studies was appraised using the appraisal list for surveys (Crombie, 1996). The list includes 21 questions, concerning the study design, methodology, the analysis and interpretation of data, and the generalisation of the results. As this tool does not offer an objective rating for each item, no global numerical score is available. As such, key criticisms were highlighted for each item for the quantitative studies, and each study was given a subjective overall quality rating ‘Good’, ‘Medium’ or ‘Poor’.

Qualitative studies were appraised using the CASP Qualitative Checklist (Critical Appraisal Skills Programme, 2018). This checklist includes 10 items, concerned with the study design, interpretation of data, and the use of verification procedures to establish the credibility of data analysis. Each item can be rated using ‘Yes’, ‘Can’t Tell’ and ‘No’. Also, there is an additional space to provide further comments for each item. Similar to the appraisal list for surveys, this tool also does not include a global numerical score, so main criticisms were offered and a subjective overall rating ‘Good’, ‘Medium’ or ‘Poor’ was provided for each study.

Data synthesis

Thematic analysis was conducted to integrate findings from the qualitative, quantitative, and mixed-method studies. This method has been suggested to be an appropriate way to synthesise data from studies with heterogeneous design (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005; Lucas, Baird, Arai, Law, & Roberts, 2007). It involves the identification of common themes across studies (Dixon-Woods et al., 2005)

Results

Study and Participant Characteristics

The systematic search resulted in 108 potentially relevant articles. A total of 21 articles met the inclusion and exclusion criteria. Figure 1 presents the flowchart for the selection of the included studies.

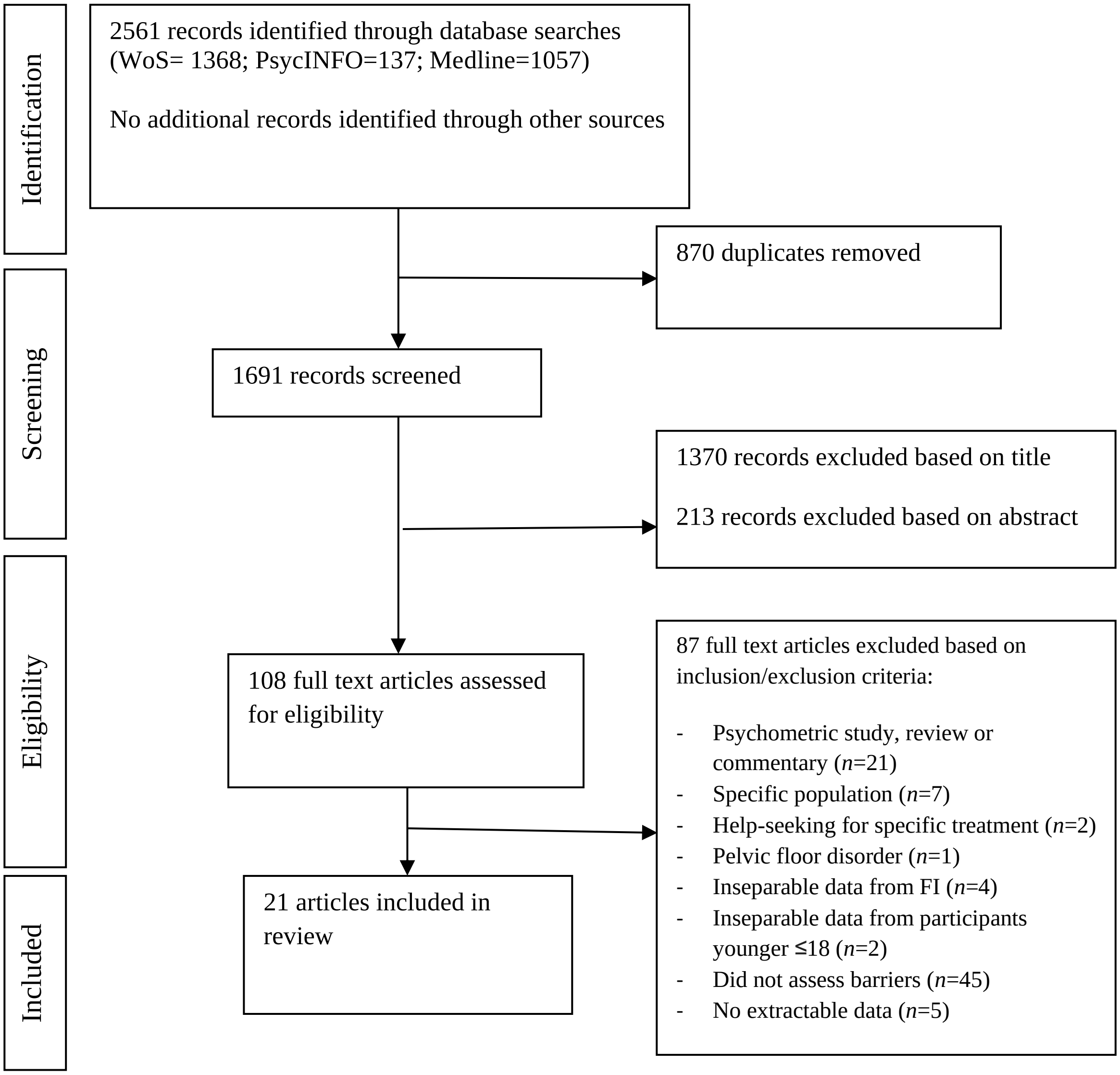


Figure 1. Flowchart of search strategy.

Note: UI=urinary incontinence; FI= faecal incontinence; OAB=overactive bladder.

After reviewing all the relevant studies, it was noted that Teunissen and colleagues published two studies using the same data from participants; the first study studied the gender difference in help-seeking behaviours (Teunissen & Lagro-Janssen, 2004) and the second study focused on help-seeking behaviours in older adults (Teunissen et al., 2005). Specifically, Teunissen et al (2005) reported less detailed but the same findings in a smaller sample of older adults. The findings on barriers to help-seeking were less detailed as the article had other objectives such as examining clinical correlates to help-seeking behaviours. Therefore, Teunissen et al (2005) was excluded from further analysis, resulting in a total of 20 studies being included in the review. Of the selected 20 studies, 13 were quantitative and seven were qualitative. The following section provides an overview of the characteristics of the selected studies. See Table 2 for details of the characteristics and key limitations of each study, and Appendix A for details of quality appraisal for each study.

Year and location of studies

The quantitative studies were published between 2004 and 2018. Of the 13 quantitative studies, two were conducted in the United States (US), and two in India. The remaining studies were undertaken in Brazil, United Arab Emirates, Singapore, Israel, Sri Lanka, Arabian Gulf, Japan, Netherlands, and Poland. The qualitative studies were published between 2003 and 2018. Of the seven qualitative studies, two were conducted in Sweden, two in the US, two in the UK, and one in the Netherlands.

Settings and sampling strategies

All studies were either conducted in a community or healthcare setting (*n*=20). Of these, four recruited participants from a gynaecological or urological setting. The majority of the quantitative studies employed convenience sampling methods (*n*=8), two used random sampling, one used purposive sampling, one used systematic sampling, and one used a combination of purposive and convenience sampling. Similarly, most of the qualitative studies employed convenience sampling *(n*=5), with the remaining two used purposive sampling.

Sample size and methodology

The sample sizes of the selected studies varied from 13 to 969. For quantitative studies, the majority of the sample size ranged from 23 to 290 (*n*=11). A further two quantitative studies included larger samples of 435 and 969 participants. All quantitative studies used survey methods (*n*=13), of which one study was conducted by telephone. For qualitative studies, four included between 13 and 58 participants, and three included a larger sample size between 107 to 186 participants. The qualitative studies that included a larger sample collected their data via survey (*n*=2) or focus group (*n*=1); the remaining studies used interviews (*n*=4). Notably, the quantitative study that had a small sample of 23 participants was rated as having poor overall quality.

Participant age and gender

The participants' ages varied from 18 to 89+ years old. The mean age of participants was reported in 11 out of 13 quantitative studies, which ranged from 38 to 64 years. The mean age was reported in three out of seven qualitative studies, and it ranged from 44 to 71 years. All 13 quantitative studies and four of the seven qualitative studies included only female participants. Three qualitative studies included male participants in addition to females with all three having a lower age limit of 50 or above. There were no studies that focused exclusively on males, nor any studies that included males under the age of 50 years.

Types of UI examined

Four out of the 13 quantitative studies did not specify which types of UI were experienced by participants. Of the remaining seven studies, four included participants with stressed UI only, four included participants with stress UI, urge UI, and mixed UI. In addition to the three main types of UI, one study also included ‘other types of UI’, and another study included overflow UI. For qualitative studies, the majority did not report the types of UI experienced by participants (*n*=5), with the remaining two included participants with stressed UI, urge UI, and mixed UI.

Severity of UI symptoms

Majority of the included studies did not examine the severity of symptoms (*n*=13). Of the seven studies that examined this, five were quantitative studies and two were qualitative studies. Most included participants with mild or moderate severity of symptoms.

Study quality

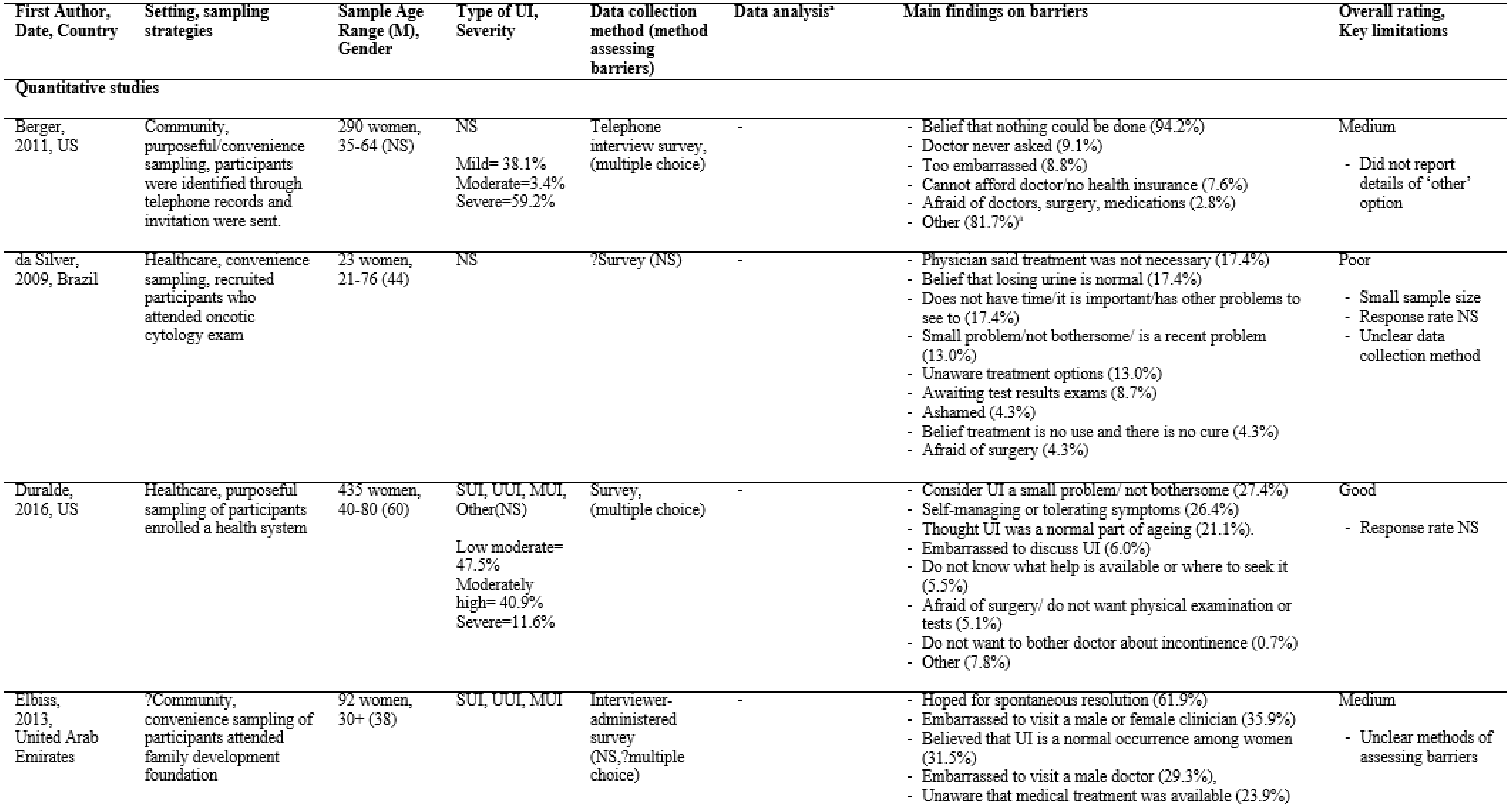
The quality appraisal highlighted several limitations. The quality of the studies in this review was generally rated as having medium quality, with four studies rated as poor quality and two rated as good quality. For quantitative studies, one general weakness concerns the recruitment strategies as over half of the studies (*n*=11) recruited participants from a healthcare setting. Specifically, generalisability of the results from participants recruited from a healthcare setting may have fewer barriers to help-seeking (e.g. no/fewer concerns around patient-doctor relationship). Additionally, most studies did not report the response rate, which could be a limitation for survey studies according to the appraisal guidance by Crombie as this limitation makes it difficult to decide the extent that findings could be influenced by those who did not respond.

Eight quantitative studies also did not provide sufficient details on how the data on barriers to help-seeking were collected. It was unclear if participants were asked to respond to an open question or closed question with multiple choice responses. Results from closed questions with limited response choices may not provide an accurate picture as to why participants did not seek help. It was noted that the exploration of barriers to help-seeking was only one of the aims among the majority of the selected studies, and therefore it seems that the assessment of barriers to help-seeking was less thorough.

As for the included qualitative studies, there was a mixture of medium and poor-quality studies in this review. One strength was that most studies involved more than one researcher in the data analysis process, allowing the extracted themes to be more reliable. However, one weakness was that researchers did not examine their own role and influences on the results, which meant the findings could be biased.

Table 2

Summary of the study charateristic



First Author, Date, Country	Setting, sampling strategies	Sample Age Range (M), Gender	Type of UI, Severity	Data collection method (method assessing barriers)	Data analysis[a]	Main findings on barriers	Overall rating, Key limitations
Quantitative studies							
Berger, 2011, US	Community, purposeful/convenience sampling, participants were identified through telephone records and invitation were sent.	290 women, 35-64 (NS)	NS Mild= 38.1% Moderate=3.4% Severe=59.2%	Telephone interview survey, (multiple choice)	-	- Belief that nothing could be done (94.2%) - Doctor never asked (9.1%) - Too embarrassed (8.8%) - Cannot afford doctor/no health insurance (7.6%) - Afraid of doctors, surgery, medications (2.8%) - Other (81.7%)[a]	Medium - Did not report details of 'other' option
da Silver, 2009, Brazil	Healthcare, convenience sampling, recruited participants who attended oncotic cytology exam	23 women, 21-76 (44)	NS	?Survey (NS)	-	- Physician said treatment was not necessary (17.4%) - Belief that losing urine is normal (17.4%) - Does not have time/it is important/has other problems to see to (17.4%) - Small problem/not bothersome/ is a recent problem (13.0%) - Unaware treatment options (13.0%) - Awaiting test results exams (8.7%) - Ashamed (4.3%) - Belief treatment is no use and there is no cure (4.3%) - Afraid of surgery (4.3%)	Poor - Small sample size - Response rate NS - Unclear data collection method
Duralde, 2016, US	Healthcare, purposeful sampling of participants enrolled a health system	435 women, 40-80 (60)	SUI, UUI, MUI, Other(NS) Low moderate= 47.5% Moderately high= 40.9% Severe=11.6%	Survey, (multiple choice)	-	- Consider UI a small problem/ not bothersome (27.4%) - Self-managing or tolerating symptoms (26.4%) - Thought UI was a normal part of ageing (21.1%). - Embarrassed to discuss UI (6.0%) - Do not know what help is available or where to seek it (5.5%) - Afraid of surgery/ do not want physical examination or tests (5.1%) - Do not want to bother doctor about incontinence (0.7%) - Other (7.8%)	Good - Response rate NS
Elbiss, 2013, United Arab Emirates	?Community, convenience sampling of participants attended family development foundation	92 women, 30+ (38)	SUI, UUI, MUI	Interviewer-administered survey (NS,?multiple choice)	-	- Hoped for spontaneous resolution (61.9%) - Embarrassed to visit a male or female clinician (35.9%) - Believed that UI is a normal occurrence among women (31.5%) - Embarrassed to visit a male doctor (29.3%), - Unaware that medical treatment was available (23.9%)	Medium - Unclear methods of assessing barriers

Kumari, 2008, India	Community, systematic sampling of participants from an area	220 women, 18+ (44)	SUI, UUI, MUI	Interviewer-administered survey, (NS)	-	- Considered symptoms as normal (54.5%) - Did not take symptoms seriously (45.5%) - Will cure naturally (22.7%) - Shyness (22.6%) - Financial problems (6.3%) - Insurable (5.7%) - Fear of hospital (5.1%) - No time (3.4%) - Tolerable (2.3%)	Medium - Unclear methods of assessing barriers
Luo, 2018, Singapore	Healthcare service, convenience sample of participants attended ear-nose-throat outpatient clinics of a hospital	81 women, 21+ (40)	NS 84.8% had mild UI	Survey (NS)	-	- Embarrassment (55.3%) - Fear of having surgery (44.8%) - Consider symptoms not severe (27.7%).	Medium - Potential selection bias - Limited diversity of severity of symptoms - Response rate (61%)
Margalith, 2004, Israel	Healthcare service, convenience sampling, participants attended a urology or gynaecology clinic	118 women, 22-65 (49)	SUI	Survey, (multiple choice)	-	- Did not have time to care for myself (n=35) - Ashamed to tell anybody (n=16) - Other women have same symptoms (n=14) - Afraid of surgery (n=14) - Belief that the problem could not be solved (n=9) - Other (n=35)	Medium - Did not report the details of ‘other’ option
Perera, 2014, Sri Lanka	Healthcare service, convenience sampling, participants attended an outpatient unit in the hospital	81 women, 20+ (42)	SUI Mild UI= 26.88% Moderate= 70.79% Severe UI= 2%	Interviewer administered survey (NS)	-	- Feel embarrassed (33.3%) - Not knowing treatment is possible or only surgery is available (28.4%) - Believe that UI is normal with ageing and parity (23.5%), - Busy with other priorities of the family (14.8%)	Medium - Limited diversity in severity - Response rate NS
Prabhu, 2013, India	Community, randomly sampled participants from a village	90 women, 20+ (NS)	SUI, UUI, MUI	Interviewer-administered survey (NS)	-	- Symptoms were not distressing (42.9%) - Accepting it as normal process of aging (25.2%) - Embarrassment (24.5%) - Lack of money/time (3.4%) - Stigma (2.7%) - Fear of hospital/surgery (1.3%)	Medium - Response rate NS
Saleh, 2005, Arabian Gulf	Healthcare service, randomly sampling among patients attended 11 primary healthcare clinics	798 women, 45-65 (48)	NS	Survey, (NS)	-	- Embarrassment at the thought of consulting a doctor, particularly a male physician	Poor - Inconsistent data for part of the results section

Tomoe, 2005, Japan	Community, convenience sampling of participants attended the lecture that aimed to provide health-related information to women.	153 women 28-89 (56)	SUI	Survey, (multiple choice, including ‘other’ option)	-	- Not serious enough to require consultation (77.3%) - Did not think it was a disease (14.3%) - Time constraint (10.1%) - A bother to go to hospital (9.2%) - Embarrassment (6.7%) - Don't want to consult a male physician (6.7%) - Unsure which department to attend (5.0%)	Medium - Did not report the details of ‘other’ option - Participants recruited from a lecture
Visser, 2012, Netherlands	Healthcare service, convenience sampling, participants recruited from a larger RCT study, where the original sample was obtained from general practices	225 women, 55+ (64)	SUI, UUI, MUI Slight= 32.3% Moderate=51.1% Severe and very severe=16.5%	Survey, (multiple choice)	-	- Symptoms not severe enough (73.4%) - Found a way to cope (57.3%) - Normal sequel of ageing (46.9%) - No cure available (23.8%) - GP didn't ask about UI (20.3%) - Thought GP would ignore (11.9%) - Other health problems take priority (10.5%) - Embarrassed to discuss (4.9%) - Treatment option too demanding (4.9%), - Perceived UI as transitory problem (3.5%)	Good - Did not report the details of ‘other’ option
Wojtowicz, 2014, Poland	Community/ healthcare service, ?convenience sampling, participants were part of a UI association or attended urodynamic clinic at a hospital or underwent urodynamic testing or the electrostimulation	141 women, 26-81 (60)	SUI, UUI, Mixed UI, Overflow UI	Survey, interviews (NS)	-	- Believe UI 'will pass on its own' (61.0%) - Perceived UI a normal part of aging (56.7%) - Shame (53.2%) - Fear (29.1%) - Lack of burdensome symptoms (5.6%) - Anxiety of surgical procedure (1.4%) - Unwillingness to see a doctor (1.4%)	Medium - Some participants recruited from urology setting
Qualitative Studies							
Hagglund, 2003, Sweden	Community, ?convenience sampling, participants recruited from an earlier study	58 women, 23-51 (NS)	NS Slight severity= 59% Moderate/severe= 41% Very severe= 0	Telephone interview survey, (open-ended questions)	Content analysis	- Manage the problems themselves (n=56) - Urine leakage is only a small problem (n=52) - Do not know what types of help are available (n=47) - Normal after giving birth (n=35) - Do not know where to seek help (n=29) - Part of normal aging (n=26) - Do not wish treatment (n=25) - Embarrassing to discuss leakage problem (n=18) - Time constraint (n=16) - Urine leakage is linked to other disease (n=9) - Did not believe treatment will be value (n=7) - Afraid of treatment (n=3)	Poor - Limited information on demographics, no descriptive statistic on age.
Hagglund, 2007, Sweden	Community, ?convenience sampling, participants recruited from an earlier study	13 women, 37-52 (NS)	SUI, UUI, MUI	Face-to-face interview	Phenomenological hermeneutic method	Reported several themes inhibiting help-seeking: - Shame and taboo associated with UI - Not bothersome enough - Not a priority	Medium - Researcher did not examine their own

						- Perceived symptoms as normal consequences of pregnancy and childbirth -	role and influences during data analysis
Horrocks, 2004, UK	Community, purposeful sampling, recruited participants from an earlier study	20 women and men, 65+ (NS)	NS	Semi-structured face-to-face interview	Grounded theory technique	Identified five barrier themes: - Independent management - Practical barriers - Reactions to incontinence (embarrassment and shame) - Attitudes (accepted as part of aging)	Medium - Researcher did not examine their own role and influences during data analysis
Mallett, 2018, US	Healthcare service, convenience sampling of participants attended an urogynecology clinic	107 women, 18+ (NS)	NS	Survey (open-ended question)	?Content analysis/thematic analysis	Identified six barrier themes: - Transportation - Cost/Insurance - Shame and embarrassment - Unsuccessful previous treatment - Lack of knowledge - Language and time	Poor - Limited information on demographics - Response rate NS
Siddiqui, 2016, US	Community, purposive sampling, participants recruited via flyers and outreach in medical and community centre	113 women, Range NS (44)	NS	Focus group	Comparative thematic analysis	Women identified various impeding factors to help-seeking: - Embarrassment and shame - Isolation (lack of support from family and spouses) - Lack of treatment understanding - Symptoms not severe enough - Symptoms perceived as normal - Patient-doctor relationship - Lack of useful information - Financial concerns	Medium - Researcher did not examine their own role and influences during data analysis
Tennissen 2004, Netherlands	Healthcare service, convenience sample recruited by sending questionnaires to individuals attended 9 different GP practice	186 women and men, 60+ (71)	SUI, UUI, MUI Mild= 7.86% Mild-moderate= 33.14% Moderate= 49.4% Severe= 9.55%	Survey and face-to-face interview, (open-ended questions)	Categorising process in grounded theory	Identified the following themes: - Severity of incontinence (not serious enough, self-management, not a priority) - Set ideas (normal consequences of aging, 'it will go away by itself', many people experience incontinence, there is no cure, other) - Patient or patient-doctor relationship factors (general help-seeking behaviour, patient-doctor relationship)	Medium - Researcher did not examine their own role and influences during data analysis
Vethanayagam, 2017, UK	Healthcare, convenience sampling, participants from three different continence services	50 women and men, 50+ (67)	NS	Semi-structured face-to-face interview	Thematic content analysis	Several sub-themes emerged: - Embarrassment and shame - Self-management - Perceived symptoms as normal aging - Unaware of available treatment	Medium - Researcher did not examine their own role and influences during data analysis

Notes. NS=not specified. [a]Data analysis method was only reported for qualitative studies as all quantitative studies used descriptive statistic.

Table 3

Themes and subthemes derived from the selected studies

Themes	Subthemes	*Berger 2003*	*da Silver 2009*	*Duralde 2016*	*Elbiss 2013*	*Hagglund 2003*	*Hagglund 2007*	*Horrocks 2004**	*Kumari 2008*	*Luo 2018*	*Mallett 2018*	*Margalith 2004*	*Perera 2014*	*Prabhu 2013*	*Saleh 2005*	*Siddiqui 2016*	*Tennissen 2004**	*Tomoe 2005*	*Vethanayagam 2017**	*Visser 2012*	*Wojtowicz 2014*
Appraisal of UI as normal	Perceived symptoms as normal		■		■				■			■					■	■			
	Normal consequences of pregnancy and childbirth					■	■				■										
	Normal consequences of ageing			■		■		■			■		■	■		■	■		■	■	■
UI as a manageable problem	Perceived UI as a minor problem		■	■		■	■			■			■	■		■	■	■		■	■
	Competing priorities						■														
	Self-management			■		■		■											■	■	
Lack of treatment knowledge	Low awareness of treatment options	■	■	■	■	■		■	■		■		■			■	■		■	■	
	Lack of perceived value of treatment		■			■											■				
	Spontaneous recovery				■				■								■				■
Emotional barriers	Embarrassment and shame	■	■	■	■	■	■	■		■	■	■	■	■	■	■		■	■	■	■
	Fear	■	■	■		■			■	■		■		■			■				■
	Fear of embarrassment and shame			■				■									■				

Notes. Filled grey squares represent that a study provided data for the corresponding subtheme. * denotes mixed gender; all other studies had only female participants.

Perceived Barriers to Help-seeking

The key findings emerged from the selected 20 articles were categorised into four themes: 1) Appraisal of UI as normal, 2) UI as a manageable problem, 3) Lack of knowledge of treatment, 4) Emotional barriers. Refer to Table 3 for a summary of themes and subthemes derived from the selected articles.

Appraisal of UI as normal

Seventeen of the 20 studies reported barriers related to this theme.

Perceived symptoms as normal. Perceiving UI symptoms as normal was identified as a barrier to help-seeking in two studies (da Silva & Lopes, 2009; Kumari, Singh, & Jain, 2008). In particular, women thought that it was not necessary to seek help as they did not consider UI to be a disease (Tomoe, Sekiguchi, Horiguchi, & Toma, 2005). Alternatively, they felt it was normal because they knew many people had the same symptoms or were told by the doctor that it was not a big problem (Elbiss, Osman, & Hammad, 2013; Margalith et al., 2004; Teunissen & Lagro-Janssen, 2004).

Normal consequences of pregnancy and childbirth. Believing it was normal to have UI after pregnancy and childbirth was found to be a barrier to seek help for women across four studies (Hagglund & Ahlstrom, 2007; Hagglund, Walker-Engstrom, Larsson, & Leppert, 2003; Mallett et al., 2018; Teunissen & Lagro-Janssen, 2004). For example, a woman in one study recalled being told that her symptoms were normal after having six pregnancies (Mallett et al., 2018).

Normal consequences of ageing. Perceiving UI as part of normal aging emerged to be a common barrier in 12 studies. This was observed in a study involving older adults (Teunissen & Lagro-Janssen, 2004), as well as studies involving younger adults (Duralde et al., 2016; Hagglund et al., 2003; Mallett et al., 2018; Perera, Kirthinanda, Wijeratne, & Wickramarachchi, 2014; Prabhu & Shanbhag, 2013; Siddiqui et al., 2016; Vethanayagam et al., 2017; Visser et al., 2012; Wojtowicz, Plaszewska-Zywko, Stangel-Wojcikiewicz, & Basta, 2014). In one qualitative study, older adults attributed UI symptoms to muscle weakness associated with ageing, therefore, instead of seeking help from professionals, they adopted an accepting attitude towards UI (Horrocks, Somerset, Stoddart, & Peters, 2004). Some doctors could have reinforced the perception that UI is part of normal ageing. In a study conducted in Poland, 11% of women reported that the idea UI is part of normal ageing was confirmed by their doctor (Wojtowicz et al., 2014). Only one study conducted in the US reported that some women acknowledged that UI might occur with age, but it does not mean it is normal (Siddiqui et al., 2016).

UI is a manageable problem

Perceived UI as a minor problem. Perceiving symptoms as not serious enough to seek help emerged as a salient barrier across 11 studies. Two studies found that a small percentage of participants (5 to 9%) reported that their UI symptoms were not bothersome enough for them to seek help (Tomoe et al., 2005; Wojtowicz et al., 2014), while other survey studies reported that 27 to 73% of participants felt a lack of symptom severity was a barrier to help-seeking (da Silva & Lopes, 2009; Duralde et al., 2016; Hagglund et al., 2003; Luo, Dai, Tay, Ng, & Koh, 2018; Prabhu & Shanbhag, 2013; Teunissen & Lagro-Janssen, 2004; Visser et al., 2012). It is possible that participants perceived their UI symptoms as minor and therefore thought their GP would ignore their complaints (Visser et al., 2012). In line with this, two qualitative studies concluded that participants were able to live with their symptoms as it was not enough of a problem to seek help for (Hagglund & Wadensten, 2007; Siddiqui et al., 2018).

Competing priorities. Prioritising other issues over UI emerged to be another barrier to help-seeking in three studies (Perera et al., 2014; Teunissen & Lagro-Janssen, 2004; Visser et al., 2012). One study conducted in India found that approximately 14% of women reported being busy with other priorities of the family as one of the reasons for not seeking help (Perera et al., 2014). In another study, 11% of women reported having other health issues, which took priority over UI (Visser et al., 2012).

Self-management. Being able to cope with UI independently was identified as a barrier for not seeking help in five studies (Duralde et al., 2016; Hagglund et al., 2003; Horrocks et al., 2004; Vethanayagam et al., 2017; Visser et al., 2012). Survey studies found 26 to 97% of the women were able to manage UI without any input from healthcare professionals (Duralde et al., 2016; Hagglund et al., 2003; Visser et al., 2012). In one study, the majority of women used pelvic floor exercises to manage UI (Hagglund et al., 2003). Other common coping strategies included wearing continence pads, avoiding social situations, avoiding activities associated with UI, and restricting fluid intake (Horrocks et al., 2004).

Lack of knowledge of treatment

Low awareness of treatment options. Low awareness of treatment options was reported to be a barrier in nine studies. Several survey studies found that women did not seek help as they did not know what treatments were available or thought surgery was the only treatment, with the percentage varying from 5 to 81% (da Silva & Lopes, 2009; Duralde et al., 2016; Elbiss et al., 2013; Hagglund et al., 2003; Perera et al., 2014). Four studies found that believing UI is incurable was a reason for participants not seeking help. One study conducted in the US found that 94% of women believed nothing could be done for their symptoms (Berger, Patel, Miller, DeLancey, & Fenner, 2011), though the percentage of women reporting this to be a barrier was lower (5.7% and 24%) in other studies (Kumari et al., 2008; Visser et al., 2012). One qualitative study suggested that knowledge of treatment options can be influenced by demographic factors (Siddiqui et al., 2016). In this study, black and white women showed knowledge of treatment options, but this was not found in Latina women.

Lack of perceived value of treatment. Three studies found that 4 to 12% of the participants did not seek help as they did not perceive treatment to be helpful (da Silva & Lopes, 2009; Hagglund et al., 2003; Teunissen & Lagro-Janssen, 2004). In one qualitative study, participants thought the doctor could not help with their symptoms, while some thought the presence of other medical conditions meant that there was no value in treating UI (Teunissen & Lagro-Janssen, 2004).

Spontaneous recovery. The perception that UI will resolve naturally was reported to be a barrier in four studies (Elbiss et al., 2013; Kumari et al., 2008; Teunissen & Lagro-Janssen, 2004; Wojtowicz et al., 2014). In two survey studies, over half of the women reported hoping UI would pass on its own (Elbiss et al., 2013; Wojtowicz et al., 2014).

Emotional barriers

Embarrassment and shame. Most studies found that participants felt too embarrassed or ashamed to discuss UI or consult a doctor (Berger et al., 2011; da Silva & Lopes, 2009; Duralde et al., 2016; Hagglund & Wadensten, 2007; Hagglund et al., 2003; Horrocks et al., 2004; Luo et al., 2018; Mallett et al., 2018; Margalith et al., 2004; Perera et al., 2014; Prabhu & Shanbhag, 2013; Saleh, Bener, Khenyab, Al-Mansori, & Al Muraikhi, 2005; Siddiqui et al., 2016; Tomoe et al., 2005; Vethanayagam et al., 2017; Wojtowicz et al., 2014). One study conducted in Japan found 7% of the women did not seek help as they had a male doctor (Tomoe et al., 2005), while the rate was higher (30%) in a study conducted in United Arab Emirates (Elbiss et al., 2013). Women viewed UI as a private problem associated with the genital area (Hagglund & Wadensten, 2007), and felt too embarrassed to be examined by doctors (Mallett et al., 2018). Moreover, two studies found that approximately 9% and 20% of the participants did not discuss their symptoms with their doctor as the doctor did not screen for UI (Berger et al., 2011; Visser et al., 2012). It could be that if healthcare professionals regularly screened for UI, participants would feel less embarrassed and ashamed about discussing their UI symptoms.

Fear. Ten studies identified that fear was another barrier to help-seeking for UI. Across eight studies, participants reported anxiety around physical examination, medication and surgery (Berger et al., 2011; da Silva & Lopes, 2009; Duralde et al., 2016; Luo et al., 2018; Margalith et al., 2004; Teunissen & Lagro-Janssen, 2004; Wojtowicz et al., 2014). Additionally, fear of the hospital appeared as a barrier for 5% and 1% of participants in two studies (Kumari et al., 2008; Prabhu & Shanbhag, 2013). One study revealed a relationship between the participants' age and their reasons for delayed help-seeking (Margalith et al., 2004). It was found that shame was the main emotional driver for younger participants in delaying help, while the fear of surgical procedures was the main reason for older participants.

Fear of embarrassment/shame. Worrying about doctor's perception regarding the complaint of UI emerged to be a barrier in three studies. Participants did not want to trouble their doctor or did not want their doctor to perceive them as a 'fussy person' (Duralde et al., 2016; Horrocks et al., 2004; Teunissen & Lagro-Janssen, 2004).

Discussion

Despite effective treatments being available for UI, many individuals with UI do not seek help. Using comprehensive search strategies, this paper offers a review of the literature on the barriers to help-seeking for UI among women and men, thus updating and extending the scope of three previous reviews that limited their search to females. Additionally, this review also seeks to explore whether perceived expectations from others to seek help would emerge as a barrier. Overall, four main barrier themes emerged from the 20 selected studies, namely: 1) Appraisal of UI as normal, 2) UI is a manageable problem, 3) Lack of knowledge about treatment, and 4) Emotional barriers. Some of the themes and subthemes corroborate with the themes identified in previous reviews, and others are novel findings. The key themes will be discussed in the context of previous reviews and related literature.

Appraisal of UI as Normal

In line with the previous reviews (Koch, 2006; Strickland, 2014), the appraisal of UI as normal due to ageing or childbirth emerged as a prominent barrier theme in most studies across different cultures. Only three out of the 20 studies did not report this barrier (Berger et al., 2011; Luo et al., 2018; Saleh et al., 2005). In the study conducted by Berger and colleagues, participants were provided with six possible reasons to explain the reasons they never discussed UI with a healthcare provider. However, none of the response options were related to appraising UI as normal. As for the other two studies, only the main barriers, but not the less prominent one, were reported (Luo et al., 2018; Saleh et al., 2005). For example, Saleh and colleagues only reported embarrassment as the main reason why participants did not seek help in their study. Hence, it is possible that the appraisal of UI as normal was a potential barrier in this study but it was not discussed. Hence, the absence of this barrier theme could be explained by the methodological limitation.

Ability to Self-manage

Consistent with the previous review (Shaw, 2001), being able to self-manage UI symptoms and not considering symptoms to be bothersome enough emerged to be further reasons for not seeking help. One study found that many women were able to manage their symptoms using methods that are recommended by healthcare professionals, such as pelvic floor exercises, wearing pads, and some by losing weight (Hagglund et al., 2003). It should be noted that there are pros and cons of managing symptoms by themselves; it can be more empowering, but there is a risk of implementing less helpful strategies. For example, severely limiting fluid intake can put people at risk for dehydration (Wilde, Bliss, Booth, Cheater, & Tennenbaum, 2014).

Lack of Treatment Knowledge

The findings indicate that a knowledge deficit of treatment options is a barrier to help-seeking for UI. Participants appeared to have limited awareness of the treatment options or misunderstood that only surgery is available, which corroborated what was reported in previous reviews (Koch, 2006; Strickland, 2014). However, even if participants were aware of the available treatments, treatment could be perceived as lacking in value. In addition, the belief in spontaneous recovery also decreased participants' help-seeking behaviours, which is a barrier that was not discussed in previous reviews. Overall, these findings therefore suggest that improving the knowledge about treatments for UI can increase help-seeking behaviours.

Emotional Barriers

Although embarrassment was acknowledged as a barrier in the review by Strickland (2014), it did not emerge as a prominent theme. The current review found that embarrassment and shame was a recurring barrier observed in different cultures. These emotional responses could be related to the stigma associated with incontinence in society (Garcia, Crocker, & Wyman, 2005). As UI is related to the function of a private body part, having a conversation about UI can be difficult. Hence, clinicians should consider ways of approaching this topic sensibly. It is important to highlight that embarrassment and shame can paradoxically also be a facilitator of help-seeking for UI. For instance, embarrassment and shame was cited to be one of the top reasons for women to seek help in a survey study (Hagglund et al., 2003). Therefore, whether embarrassment and shame are barriers or facilitators to help-seeking may depend on the level of these feelings. This interpretation is supported by a study, where women with moderate shame had stronger intentions to seek help compared to those with a low or high level of shame (Wang et al., 2014).

Fear in general was another hindering factor that was not discussed in previous reviews. In this current review, participants expressed fear around medication, surgery, and physical examination. The fear of medication and surgery are likely to interact with the aforementioned barrier – lack of knowledge about treatment – which could be managed by clarifying that there are other interventions available apart from medication and surgery. As for fear of physical examination, it is difficult to know whether participants were worried about the procedure itself or being examined by doctors around their genital area, which would instead link with the next subtheme, fear of embarrassment.

Fear of embarrassment and shame emerged to be another emotional barrier. Participants were worried about their doctors' responses if they complained about UI. This could be a reasonable worry given that evidence suggested a lack of interest from general practitioners in UI (Albers-Heitner et al., 2012). More recent studies highlighted that a lack of time and the presence of other health problems were barriers to screening incontinence and treating incontinence problems for healthcare professionals (Brown, Rogers, & Wise, 2017; Jirschele, Ross, Goldberg, & Botoros, 2015). Therefore, this is a concern that can be addressed by healthcare professionals by building a good rapport with patients, so that patients can feel safe in expressing concerns. In addition, the need to prioritise other health problems may reflect the limited resources available in the healthcare system, therefore may require consideration from policymakers at an upstream level.

Theoretical Implication

This review's findings support aspects of the Model of Pathways to Treatment (Scott et al., 2013) and also the Common Sense Model of Illness Self-regulation (Leventhal, Meyer, & Nerenz, 1980). The two models suggest that how illness is represented or labelled by people, as well as the role of emotional response such as fear, embarrassment and shame can affect their help-seeking behaviours and ways of coping with the symptoms (to seek help or avoid). These models are supported by the present findings that people commonly view UI as a normal consequence of childbirth and ageing, therefore not perceiving the cause of UI as harmful, and thus help-seeking or treatment is not considered necessary. Furthermore, emotions such as fear, embarrassment and shame are key barriers to help-seeking, hence providing further support for the two models.

Clinical Implications

The review has several clinical implications. First, anti-stigma programs should be considered for reducing embarrassment and shame among people with UI. This in turn could promote disclosure and increase access to care. Regarding other barriers such as lack of knowledge about treatments and fear, it can influence by increasing the understanding of UI among individuals with UI and the general population. Indeed, research has already been undertaken to explore the effect of providing educational brochures on incontinence knowledge and help-seeking, and the results are positive thus far (Liao, Dougherty, Liou, & Tseng, 2006; O'Connell, Wellman, Baker, & Day, 2006; Zhang et al., 2016). Nonetheless, it is possible that emotional barriers including embarrassment, shame and fear could be associated with an individual's past experiences such as medical experiences and relationship to help. Therefore, intervention at the individual level should not be neglected, and it may be helpful to explore an individual's assumptions about help-seeking for UI or help-seeking behaviours in general.

The fact that many studies have found that people with UI thought their symptoms are normal and manageable by themselves, it leads to an interesting question of whether these barriers should be viewed from a different perspective. Specifically, it raises the question whether the appraisal of UI as normal should be considered as a misconception at all, given that research indicated that the prevalence of UI could be ranged from 14 to 63% in people above the age of 60 years (Buckley et al., 2010). Therefore, experiencing UI symptoms can be argued to be the 'norm' based on the findings from some studies. It should be noted that the varied prevalence rates are likely to be the consequences of UI being operationalised differently in epidemiological research; some studies defined UI as any involuntary loss, others include a timeframe, requiring UI at least occurring monthly, weekly or even daily. Thus, a higher prevalence rate could be due to a more inclusive definition of UI being used in a study, and therefore capturing people with mild symptoms of UI. In this sense, if mild UI is indeed the 'norm' for some groups and people generally do well with self-management, one may wonder whether it would be more helpful for professionals to provide guidance to support self-management, and offer indication at what point individuals with UI should seek professional help. Given the current austerity climate within the NHS, encouraging appropriate self-care for mild UI could be a cost-effective action to help the system reduce spending.

Limitations

This review has several limitations. First, the search strategies may not have captured all relevant articles. The choice of the database has an impact on the coverage of potential articles to be selected. Although this study included Medline, which covers areas of medicine and allied health journals, there is another database (i.e. Cumulative Index of Nursing and Allied Health Literature), which also covers nursing journals and may potentially include relevant articles. Additionally, the search strategy excluded non-English journals, hence limiting the comprehensiveness of the systematic search. Future studies should consider addressing these limitations.

The second limitation concerns the critical appraisal tool used in this review. Specifically, the CASP Qualitative Checklist may not be appropriate for some of the selected qualitative studies. This was because a few studies were categorised as 'qualitative' based on the relevant data on barriers to help-seeking, but the remaining data were quantitative. Hence, this might have led to two qualitative studies being rated as having 'poor' quality overall, as they did not have the characteristics of would be expected from qualitative research e.g. analysis checked by another researcher.

A further limitation concerns the generalisation of the conclusion of this review. The generalisation of the conclusion should also be done with caution as almost half of the studies did not specify the type of UI experienced by participants, and only three studies included male participants. Finally, only studies published in peer-reviewed English journal were included in this review. Although this enhanced the scientific rigour of the findings in this current review, it may have omitted some valuable grey literature.

Future research

This review highlights several research gaps. Firstly, further research is needed to consolidate the understanding of barriers to help-seeking in men. Secondly, it was noted that there is currently one validated questionnaire available for assessing barriers to help-seeking for UI. However, the questionnaire is limited because it mostly focuses on practical barriers such as time, cost and availability of the doctor. Given this, the development of a broader measure that captures other main barriers is needed. This could contribute to a better quality of quantitative research in this area. Additionally, given this review showed the importance of embarrassment or shame on help-seeking behaviours, and that previous research suggested shame had a moderating effect on help-seeking behaviours. Further research is needed to investigate the effect of anti-stigma programs in reducing embarrassment and shame about UI. Future empirical studies should explore whether embarrassment would show a similar moderating effect. Finally, future research may investigate self-management experiences of people with UI and possibly compare it with the experiences for people who receive regular input regarding UI from healthcare professionals.

Conclusions

This review identified several barriers to help-seeking behaviours for UI across the globe. Improving knowledge about treatment for UI can possibly reduce people’s worries around surgery and mediation. The embarrassment and shame felt by people with UI should be considered not just at the societal level but also at the individual level. Researcher and clinicians should consider ways to support effective self-management given that people with mild UI may not feel the need to get formal help. More research is needed to ascertain the barriers experienced by men. Furthermore, a validated questionnaire that assesses psychosocial barriers to help-seeking for UI can improve the quality of quantitative research in this area.

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Part 2: Empirical Paper

Fear of Incontinence: An Internet Study

Abstract

Background: Fear of incontinence is an understudied anxiety associated with significant distress and impairments. The Fear of Incontinence Questionnaire (FOIQ) was previously developed, but further examination of its psychometric properties is necessary. This study aimed to 1) examine the factor structure, internal consistency, convergent validity and test-retest reliability of the FOIQ and 2) explore the mediational role of avoidance in the relationship between fear of incontinence and depressive symptoms.

Method: Cross-sectional data were collected using an online questionnaire assessing demographics, mood and fear of incontinence from 362 adults aged between 18-91 years. The FOIQ was completed again by 143 participants 2 weeks later. These data were combined with an existing dataset of people with fear of incontinence (*n* = 434) to form a larger dataset (*n* = 796).

Results: Exploratory factor analysis of a 16-item version of the FOIQ revealed a three-factor structure. The FOIQ and its three subscales were found to have good internal consistency: full scale (α = .91), Avoidance/Impact (α = .90), Safety behaviours/Catastrophising (α = .83), and Disgust/Shame (α = .81). The full scale showed satisfactory test-retest reliability (ICC = .85), with similar ICCs for the three subscales (.79 to .87). The FOIQ showed appropriate convergent validity with other related constructs. Mediation analyses indicated that avoidance partially mediated, but accounted for a small amount of variance (2%) in the relationship between fear of incontinence and depressive symptoms after controlling for age, general anxiety and subjective health.

Conclusions: This study suggests that the FOIQ is a reliable and valid measure of fear of incontinence. Avoidance was found to be a partial mediator but had limited predictive value for the relationship between fear of incontinence and depressive symptoms. .

Introduction

The fear of losing control of bowel or bladder function has been reported in the literature since the 1980s (Hatch, 1997; Jenike, Vitagliano, Rabinowitz, Gaff, & Baer, 1987). It can be observed in people with a physical condition associated with the loss of bowel or bladder control e.g. irritable bowel syndrome (Hunt, Moshier, & Milonova, 2009), but also in people without an extensive history of incontinence (Green, Antony, McCabe, & Watling, 2007). Thus far, researchers have referred the fear of losing control of bowel or bladder function using different terminology, including 'Bowel Obsession Syndrome', 'Bowel and Bladder Control Anxiety', 'Bowel and Bladder Anxiety' and 'Urinary Incontinence Phobia' (Cosci, 2013; Kamboj et al., 2015; Roy, Sarjar, Nongpiur, & Prithviraj, 2018; Tan & Lim, 2014). The fact that there is no consensus in terminology, and that it is not included as a formal diagnosis in the Diagnostic and Statistical Manual of Mental Disorders 5th ed (American Psychiatric Association, 2013), shows that the research in this area is still in its infancy. As the previous literature suggested that psychological consequences of fear of urinary incontinence and fear of faecal incontinence are very similar (Kamboj et al., 2015), they will be discussed as a single category, *fear of incontinence,* in this study.

The main symptom of fear of incontinence is the overwhelming fear of losing control of the bowel and bladder. Other characteristics include frequent checking for bowel or bladder sensations, safety behaviours such as wearing pads and using medication, limiting fluid or food intake and avoidance of places where individuals may experience the fear, in particular places with limited or unknown access to toilets (Beidel & Bulik, 1990; Cosci, 2013; Eldridge, Walker, & Holborn, 1993; Epstein & Jenike, 1990; Hatch, 1997; Jenike et al., 1987; Kamboj et al., 2015; Lyketsos, 1992; Porcelli & De Carne, 2008; Sharma, 1991). It is worth noting that the reported presentation and coping strategies to date has led researchers to conceptualise fear of incontinence in different ways (Kamboj et al., 2015; Roy et al., 2018). Some researchers view fear of incontinence as a variant of obsessive spectrum disorder (Beidel & Bulik, 1990; Jenike et al., 1987), whereas others consider it a variant of agoraphobia (Roy et al., 2018).

Cultural Background of Fear of Incontinence

The occurrence of fear of incontinence can be understood in the context of societal and cultural factors. In Western society, there is a general expectation with regards to toileting behaviours, which are considered private behaviours (Molinuevo & Batista-Miranda, 2012; Southall et al., 2017). Being incontinent can have negative consequences even if it occurs during childhood, for example, being labelled as ‘dirty’ (Shapiro, Setterlund, & Cragg, 2003). For adults, there are other threats associated with being incontinent. Individuals with continence issues can be perceived as lacking in self-control (Brittain & Shaw, 2007). Moreover, incontinence in public places can elicit disgust from others (Curtis & Biran, 2001; Reynolds, Bissett, & Consedine, 2015), leading to avoidance of the person affected by incontinence. Additionally, being incontinent can lead to feelings of shame and embarrassment in the affected individual. For example, in an interview study, participants with overactive bladder spoke about feeling embarrassed when they lost control of their bladder, and also how embarrassment prevented them from discussing the problem with doctors and family members (Nicolson, Kopp, Chapple, & Kelleher, 2008). Due to the shame and embarrassment associated with being incontinent, it is understandable that some individuals develop specific anxieties around bowel or bladder control.

Existing Research on Fear of Incontinence

To date, the research in this area is limited. There are only a few empirical studies, with the majority being case studies. The preliminary understanding of fear of incontinence is mostly based on the research conducted by Kamboj and the research team (Kamboj et al., 2015; Langhoff, 2013; Pajak & Kamboj, 2014; Pajak, Langhoff, Watson, & Kamboj, 2013). In particular, a preliminary 18-item Fear of Incontinence Questionnaire (FOIQ) was developed as part of a larger survey designed to assess checking behaviours, avoidance and safety behaviours, catastrophising thoughts, and emotional responses including shame and disgust. Using the FOIQ, Kamboj et al. (2015) offered a more detailed understanding of the characteristics of fear of incontinence, associated impacts, and the help-seeking behaviours in a sample of 140 adults under the age of 65. The findings showed that the age of onset of fear of incontinence is typically in the mid to late 20s and that only 15% of the participants had experienced incontinence five times or more in their lifetimes. This suggests that fear of incontinence can develop in people without frequent experience of incontinence. The study also confirmed that checking behaviours, avoidance and safety behaviours were common characteristics of fear of incontinence. Despite the high levels of functional impairment associated with fear of incontinence only ~50% of sufferers sought help for this difficulty. Furthermore, to verify similarities in the psychological consequences of fear of urinary incontinence and fear of faecal incontinence, Kamboj and colleagues explored the similarities and differences statistically. Only minor differences were observed in terms of the use of medication, avoidance of crowded places and wearing extra under-clothes/padding. The two former coping strategies were more common in people with fear of faecal incontinence, and these two groups of people showed similarities in other coping strategies and their emotional responses. For example, approximately 68% of the participants with fear of urinary incontinence and 78% of the participants with fear of faecal incontinence would check for access to toilets in unfamiliar places to manage their anxiety.

It is worth highlighting that although an initial study of construct validity and internal consistency of the FOIQ is described in an unpublished dissertation by Langhoff (2013), there are limitations in that study that need addressing. In particular, the convergent validity and test-retest reliability of the FOIQ have not been examined. In addition, older individuals aged 65 and above were previously excluded. Therefore, further examinations of the psychometric properties of the FOIQ, and additional data collection in people aged 65 or above are required.

Fear of Incontinence in Older Adults

Exploring fear of incontinence in older adults is important for several reasons. Firstly, the risk of incontinence increases with ageing. For urinary incontinence, the prevalence rate is ~10 to 30% in adults aged below 65, and 25 to 40% in those aged above 65 (Hannestad, Rortveit, Sandvik, Hunskaar, & Norwegian, 2000; Hunskaar et al., 2003). The prevalence rate of faecal incontinence ranged from 1 to 5% in younger adults, compared to 5 to15% in older adults (Aitola, Lehto, Fonsell, & Huhtala, 2010; Kok et al., 1992; Rommen, Schei, Rydning, Sultan, & Morkved, 2012). Older adults may develop fear of incontinence due to the presence of a physical condition that could lead to incontinence. Examples include stroke, arthritis and ‘back problems’ (Finkelstein, 2002);

these conditions can affect a person’s mobility, leading to problems in reaching the toilet in time. For some women, pregnancy and childbirth may cause injury to the pelvic floor, in turn leading to urinary and faecal incontinence (Mørkved & Bø, 2014). Another example relates to the use of diuretics, which are medications prescribed for conditions such as hypertension and heart failure (Ekundayo, 2009). Diuretics cause fluids to be excreted more rapidly, increasing urine volume and urinary urgency, possibly leading to incontinence. The aforementioned physical conditions or the side effect of mediation may cumulatively increase the risk of incontinence in older adults (especially women), leading to a fear of incontinence.

Secondly, there is research to suggest that contact with people with certain physical conditions can increase perceived susceptibility to diseases of older age, such as dementia (Kessler, Bowen, Baer, Froelich, & Wahl, 2012). Older people may therefore experience fear of incontinence due to their more frequent contact with friends or family members who have continence issues.

Finally, clinical experience suggests that fear of incontinence is not uncommon in the older population, yet this area of research has been greatly overlooked. Brock and colleagues studied the worry content and its relationship with numerous chronic health conditions in 310 community-dwelling older people aged 70 or above (Brock et al., 2011). Using the Worry Scale (Wisocki, 1988), it was found that worry around losing control of bladder or kidneys emerged to be one of the top ten worries out of a list of 35 worries, with 20% of the participants expressing such concerns. Moreover, Kogan and Edelstein (2004) developed a measure to capture fears experienced by older adults. One of the items assessed fear of incontinence, which suggests the significance of this specific fear among older adults. Furthermore, an interview study explored the reasons for older people worrying about different diseases in participants aged 66 to 83 years (Brorsson, Lindbladh, & Rastam, 1998). In this study, participants discussed the fear of urinary or faecal incontinence, with one woman expressing the fear of losing bowel control in the examination room. As little is known about fear of incontinence in older adults, further exploration is warranted. Specifically, given that fear of incontinence could be a rational worry, individuals with or without a physical condition associated with incontinence will be included.

Fear of Incontinence and Low Mood

There is evidence to suggest that fear of incontinence is associated with symptoms of depression. Using the Patient Health Questionnaire (PHQ-9), Langhoff (2013) showed that people with more severe fear of incontinence also experienced symptoms of depression. Similarly, in a naturalistic study conducted within a primary care psychological service, individuals with irritable bowel syndrome comorbid with fear of faecal incontinence had elevated depression scores (Kenwright, McDonald, Talbot, & Janjua, 2017). No previous study has explored the relationship between fear of incontinence and depressive symptoms in detail. The current study therefore aims to address this gap in the research.

Based on the wider anxiety literature, behavioural avoidance has been recognised as a mediator for the relationship between anxiety and depressive symptoms (Jacobson & Newman, 2014; Moitra, Herbert, & Forman, 2008). It has been suggested that the avoidance of feared situations may have the consequence of reducing one’s exposure to positive experiences, which may in turn lead to low mood. Similarly, it is possible that individuals with fear of incontinence may experience low mood due to the avoidance of going to public places. Thus, this study aimed to explore the mediating role of avoidance in contributing to the relationship between fear of incontinence and depressive symptoms.

Aims

In summary, the first aim of the present study is to provide further psychometric support for the FOIQ. The factor structure, internal consistency, convergent validity and test-retest reliability are explored in adults of all ages using the existing 2011-2013 dataset from the Langhoff (2013) study and combined it with the new data collected for the present study. The second aim of this study is to explore the relationship between fear of incontinence, symptoms of depression and avoidance. In particular, it is hypothesised that avoidance would mediate the relationship between fear of incontinence and depressive symptoms.

Method

Design

Both the psychometric and mediation analyses employed cross-sectional data collected from online questionnaires. The full dataset of responses to online measures was made up of data from (a) 434 participants with a fear of incontinence aged between 18 and 65 who completed measures for an earlier set of studies supervised by Sunjeev Kamboj, and (b) 362 adults with fear of incontinence over the age of 18 (*with no upper age limit*) who completed measures for the current study. The full dataset was used for factor analysis of the FOIQ. A self-selecting subset of 143 participants from the current 2018-19 online survey repeated the FOIQ two weeks after baseline to enable test-retest analysis. In addition, a secondary data analysis to establish convergent validity of the

FOIQ was carried out using 92 responses from a previous postal survey carried out between April 2011 and February 2013 using the follow psychometric tools: the FOIQ (Kamboj et al., 2015), the PHQ-9 (Kroenke, Spitzer, Williams, & Lowe, 2010), Generalised Anxiety Disorder (GAD-7) (Spitzer, Kroenke, Williams, & Lowe, 2006), Mobility Inventory for Agoraphobia (MIA) (Chambless, Caputo, Jasin, Gracely, & Williams, 1985), Work and Social Adjustment Scale (WASAS) (Mundt, Marks, Shear, & Greist, 2002), Obsessive Compulsive Inventory-Short Version (OCI-SV)(Foa et al., 2002), Social Phobia Inventory (SPIN) (Connor et al., 2000), Disgust Propensity and Sensitivity Scale-Revised (DPSS-R) (Olatunji, Cisler, Deacon, Connolly, & Lohr, 2007), Internalised Shame Scale (ISS) (Cook, 1988). See Appendix B for a description of the measures that were used for convergent validity only. Figure 1. shows the participants flow in this study.

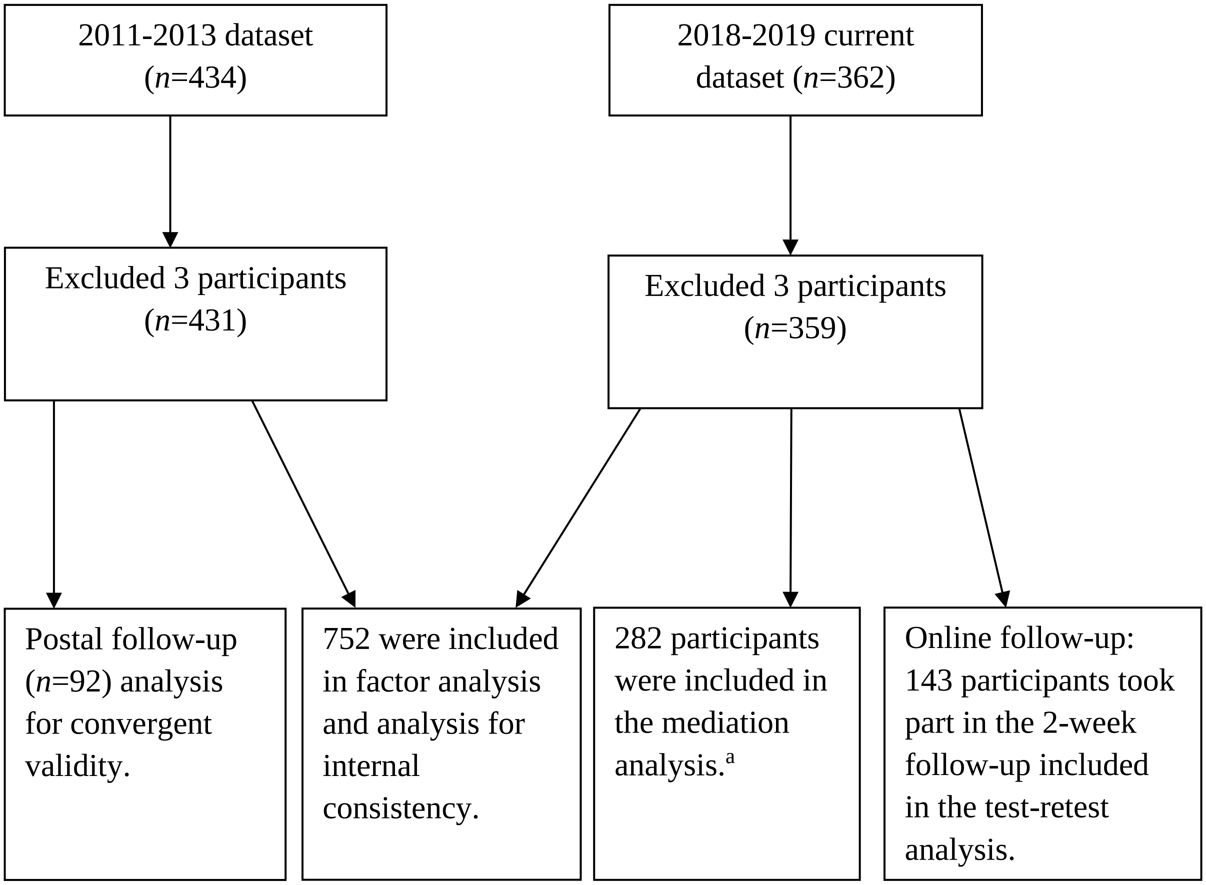


Figure 1. A flowchart illustrating the participants flow, and representing the subsamples of participants used for the analysis for convergent validity, factor analysis, internal consistency, test-retest analysis and mediation analysis.

Note. [a]The 282 participants were included as they provided complete data for the main measures required for the mediation analysis.

Ethics

Ethical approval for the study was obtained from the University College London Research Ethics Committee (Project ID number: 12619/001, see Appendix C). British Psychological Society’s Ethics Guidelines for Internet-mediated study (British Psychological Society, 2013) was used as a guideline for this study. All participants were informed of privacy and confidentiality before taking part. They were also provided with a debrief sheet after the completion of baseline and follow-up questionnaires.

Participants

Sample size and power

The sample size was estimated for the main analyses. For factor analysis, it has been suggested that over 300 cases is adequate (Field, 2013). The required sample size for multiple regression can be estimated in various ways (Field, 2013); a common rule of thumb is 10 observations for each predictor. As the final regression model included six predictors, a minimum of 60 participants was therefore required.

Recruitment

Participants were recruited online through word of mouth and advertisement posted on forums and social media platforms between November 2018 and April 2019. Online recruitment has the benefit of approaching potential participants who may otherwise feel too embarrassed to join if approached face-to-face. Facebook, Twitter and Instagram accounts were created for advertisement purpose. Using the study's Facebook account, an advertisement was posted in anxiety- and continence-related groups, which included a brief description of this project, a link to the survey, and the advert flyer (See Appendix D for the advert flyer). Using the study's Instagram and Twitter accounts, accounts affiliated with topics around continence issues, anxiety, and older adults were followed. Tweets on Twitter were made, and relevant accounts were tagged to request as a re-tweet. Moreover, Anxiety UK, and Bladder Health UK were contacted via email, and they subsequently posted about this project using their official social media accounts.

To broaden the exposure of the study to older adults, Age UK and the University of the Third Age (U3A) also invited members to join this study through their newsletters and monthly meeting. A Facebook advertisement was posted for 24 days in February 2019, which yielded 491 link clinks. Finally, the study was also advertised through the University newsletter, in libraries and cafés local to North London. See Appendix E for a summary of the recruitment strategies for the present study and Langhoff's (2013) study.

As an incentive for people to participate in this study, potential participants were informed that £200 would be donated to the charity - Bladder Health UK - once the project achieved the recruitment target.

Inclusion criteria

Inclusion criteria were that participants had to be 18 years or above, a resident in the UK at the time of participation, self-confirmed to have concerns about losing control of bowel or bladder, and self-confirmed to have the ability to provide informed consent.

Procedure

Participants were provided with an online information sheet and consent form (see Appendix F and G respectively). Participants were also asked to confirm their eligibility (see Appendix H for a comparison of the criteria used for the current study and the 2011-2013 dataset). Participants were then invited to complete a series of online surveys, taking approximately 20 to 25 minutes to complete. Two weeks after the completion of the baseline survey, participants who provided an email address were automatically invited to join the follow-up study via email. Participants were presented with a debrief sheet after the completion of the survey both at baseline and follow-up (see Appendix I). This involved completing the FOIQ again for the purpose of examining test-retest reliability.

The online survey was hosted by Qualtrics (Provo, Utah), which is a survey tool that allows online surveys to be built and distributed to the public via an internet link.

Measures

Appendix J provides a copy of the measures used in this study. Information on demographics including age, gender, marital status (single, married/cohabiting, widowed or divorced), and employment status (employed/self-employed, homemaker, unemployed, long-term sick leave, student, retired or other) were collected. Participants were also asked to quantify their recent frequency of incontinence by responding to the question ‘How many times during the past week have you been incontinent?’ (‘0’, ‘1-5’, ‘5-10’, ‘Over 10’), and whether he/she received any diagnosis associated with incontinence by asking ‘Have you received any diagnosis relating to incontinence?’ (‘IBS’, ‘Anxiety’, ‘Urge incontinence’, ‘Infection’, ‘No diagnosis’, ‘Others (please specify)’). Further, information on the type of incontinence worry was obtained by asking ‘What is your main concern?’ (‘Fear of faecal incontinence’, ‘Fear of urinary incontinence’, ‘Fear of both urinary and faecal incontinence’). A measure of subjective health assessment (‘Overall would you say your health is: 1= excellent, 2= very good, 3= good, 4= fair, 5= poor’) were also included. Finally, participants had the option to provide their email address if they wished to join the follow-up study.

Fear of Incontinence Questionnaire (FOIQ)

The FOIQ (Kamboj et al., 2015) is an 18-item self-report measure for assessing symptoms on fear of incontinence. The questionnaire was devised based on the clinical experience of the authors in consultation with experts in cognitive behaviour therapy (for details of questionnaire development see Kamboj et al (2015)). The FOIQ includes items on several domains: attentional and checking behaviours (e.g. ‘I often notice sensations in my bladder/bowel, especially when I am anxious’), safety behaviours and avoidance (e.g. ‘I limit the amount of food I eat and/or the amount of fluids I drink to reduce the chances of being incontinent’, ‘I avoid using public transport in case I am incontinent’), shame and disgust (e.g. ‘Being incontinent is the most shameful thing that could happen to a person’), catastrophising (e.g. ‘I often think about how awful it would be if I was actually incontinent in a public place’) and functional impairments due to fear of incontinence (‘My relationships have been affected by a fear of being incontinent’). Each item is rated according to the degree of agreeing, which ranged from 1 (‘Strongly disagree (very untrue about me)’) to 5 (‘Strongly agree (very true about me)’). The FOIQ provides a total score ranging from 18-90, with higher scores reflect greater severity of fear of incontinence.

Generalised Anxiety Disorder (GAD-7)

The GAD-7 (Spitzer et al., 2006) is a seven-item self-rated measure developed to assess symptoms on generalised anxiety disorder (e.g. ‘Worrying too much about different things’). Each item is scored from 0 (‘Not at all’) to 3 (‘Nearly every day’), providing a severity score of 0 to 21, with scores of ≥5, ≥10 and ≥15, representing mild, moderate and severe levels of anxiety symptoms, respectively. The GAD-7 has good internal consistency (α= .89), good convergent validity, and test-retest reliability (*ICC*= .83) (Kroenke et al., 2010; Spitzer et al., 2006).

Patient Health Questionnaire (PHQ-9)

The PHQ-9 (Kroenke et al., 2010) is a nine-item self-report instrument designed to screen for depression symptoms (e.g. ‘Feeling down, depressed, or hopeless’). Each item is scored from 0 (‘Not at all’) to 3 (‘Nearly every day’), providing a severity score from 0 to 27. PHQ-9 scores of ≥5, ≥10, ≥15 and ≥20 representing mild, moderate, moderately severe and severe levels of depression symptoms, respectively. The PHQ-9 has good internal consistency (α=.88), and test-retest reliability (*ICC*= .94) (Zuithoff et al., 2010).

The Mobility Inventory for Agoraphobia (MIA)

The MIA (Chambless et al., 1985) is a 27-item self-report measure of agoraphobic avoidance, and frequency of panic attacks. Respondents rate the degree to which they avoid 27 situations (e.g. ‘Supermarkets’) using a five-point Likert scale, with response anchors) ranging from 1 (‘Never avoid’) to 5 (‘Always avoid’), when confronted with the situation by the respondent alone (Alone Subscale; MIA – AAL) and when accompanied by another person (Accompanied Subscale; MIA – AAC). The measure provides an average score that ranges from 1 to 5 separately for the two subscales, with a higher average score indicating a more severe level of agoraphobia. Internal consistency measured by Cronbach’s α ranged from .91 to .97, and test-retest reliability measured using ICC ranged from .75 to .90 (Chambless et al., 1985).

Work and Social Adjustment Scale (WASAS)

The WASAS (Mundt et al., 2002) is a five-item measure that assesses the degree to which one’s problems interfere with ability in occupational and social functioning. Items are rated using a nine-point scale, ranging from 0 (‘No impairment at all’) to 8 (‘Very severe impairment’). The total score ranges from 0 to 40, with higher scores denoting more disability. The WASAS has been demonstrated to have good to excellent internal consistency with Cronbach's α ranging from .70 to .94, and test-retest reliability with ICC= .73 (Mundt et al., 2002).

Statistical Analysis

Data management

The baseline dataset and follow-up dataset were exported directly from the survey tool to Statistical Package for Social Sciences (SPSS) version 24 for analysis. No personally identifying information was retained in the database. The relevant data from the previous 2011-2013 dataset (including demographics, FOIQ, and measures for convergent validity) were combined with the current baseline dataset.

The next stage involved data screening. A total of 796 participants provided consent for participation. Of these, six participants (3 were from the current 2018-2019 dataset and 3 were from the 2011-2019 dataset) were excluded; one participant was excluded on the basis of answering no to the statement 'I confirmed that I have concerns about losing control of my bowels or bladder', and five responded 1 'Strongly disagree' or 2 'Mildly disagree' on all 18 items for FOIQ. Furthermore, participants that did not complete the FOIQ (*n*=38) were deleted from the dataset as they could not be considered to have consented to use of their data. This resulted in a total sample of 752 participants. See Table 1 for the sample differences between the 2011 – 2013 dataset and the current dataset.

Descriptive statistics were used to summarise the participants' characteristics. Sample differences were assessed using t-test or chi-squared test, for continuous variable and categorical variables respectively. Data distributions were examined for skewness and kurtosis by inspecting the histograms.

Factor analysis

To assess the factor structure of the FOIQ, an exploratory factor analysis was conducted using the combined sample. Preliminary analysis involved computing correlation coefficients between all items of the FOIQ. Items that did not correlate well (<.30) with other items were considered for exclusion before factor analysis was conducted. Sampling adequacy was tested using the Kaiser-Meyer-Olkin (KMO) test and Bartlett's statistic. KMO values between .5 and .7 were considered as mediocre, values between .7 and .8 were good, values between .8 and .9 were great, and values above .9 were considered as excellent (Kaiser, 1974). A significant Barlett's statistic indicated that factor analysis was appropriate for the dataset. Communalities were examined and items with inadequate communalities (<.3) were considered to be excluded (Tabachnick, 2013). To decide between orthogonal or oblique rotation, an oblique rotation (Promax) would be conducted in order to assess the correlations among factors. Based on the suggestion by Tabachnick and Fidell (2007), if the correlations among factors exceed .32 then there is enough variance to use oblique rotation. The number of factors extracted was determined using eigenvalues and inspection of the scree plot. The amount of variance accounted for by these factors was then established.

Internal consistency, test-retest reliability and concurrent validity

To assess the internal consistency of the FOIQ, Cronbach's alpha coefficient was calculated. Different acceptable values of alpha have been suggested. For example, Hair and colleagues suggested a Cronbach's alpha of .60 as acceptable (Hair, Anderson, Tatham, & Black, 2006), while Nunnally (1978) suggested a rule of thumb of .70 as an acceptable cut-off for early stage of research, .80 for basic research tools, and .90 as a minimum for clinical tools. George and Mallery (2003) proposed the following rules of thumb: Cronbach's alpha less than .50 considered as unacceptable, ≥.50 as poor, ≥ .60 as questionable, ≥ .70 as acceptable, ≥ .80 as good, and ≥ .90 as excellent. Others have proposed more stringent criteria for clinical tools, and suggested the minimum value is .90 (Bland & Altman, 1997). As a Cronbach's alpha below .70 means that over half of the variance would be attributed by measurement error, this study would use the rule of thumb proposed by George and Mallery (2003).

To assess the test-retest reliability of the FOIQ, ICC was calculated. It was recommended that ICC between .75 and .90 are indicative of good reliability, and above .90 is considered as excellent reliability (Koo and Li, 2016). To assess concurrent validity, Pearson's correlation was used to assess correlations between the FOIQ and the following measures: GAD-7, PHQ-9, WASAS, OCI-SV, SPIN, MIA, DPSS-R, and ISS. Given that a relatively high number of comparisons were investigated and aiming to limit Type II (as well as Type I) errors, the alpha value was set to 0.01.

Mediation analysis

A series of multiple regression analyses was conducted to explore the mediating role of avoidance on the relationship between fear of incontinence and depressive symptoms. Prior to the regression analyses, correlational analyses were conducted to determine the demographic and clinical variables associated with depressive symptoms.

Variables that were significantly related to depressive symptoms were considered for inclusion in the regression models as covariates. Effect sizes of the *r* values were also considered. It has been suggested that $r = .1$, .3, and .5 reflect small, medium and large effects, respectively (Cohen, 1992).

Assumptions of multiple regression were also assessed (Field, 2013). The assumption of normality was assessed using the histogram and normal probability plots of the residuals of the dependent variables. The assumption of linearity was assessed using the scatterplots. Durbin-Watson values <1 and >3 indicates residuals are not independent. To assess homogeneity of variance, the scatterplots of residuals vs predicted values were inspected. Multicollinearity was also assessed by inspecting the correlational matrix and by using the Variance Inflation Factor (VIF) statistic. VIF value above 10 would be an indication of multicollinearity (Myers, 1990).

The mediational analysis was performed in accordance with the guidance of Baron and Kenny (1986). In the current study, support for a mediating role of avoidance in the relationship between fear of incontinence and depressive symptoms would be provided if the following four conditions are met: 1) fear of incontinence (independent variable) is a significant predictor of depressive symptoms (dependent variable), 2) fear of incontinence significantly predicts avoidance (proposed mediator), 3) avoidance predicts depressive symptoms, and 4) fear of incontinence does not remain a significant predictor of depressive symptoms once avoidance is entered into the model as an independent variable. According to Baron and Kenny (1986), full mediation occurs when the effect of the independent variable on the dependent variable is reduced to zero. A partial mediation occurs when the impact of the independent variable on the dependent variable is significantly reduced when the proposed mediator is included in the model. Finally, the significance of the mediation effect was tested using the Sobel test (Baron & Kenny, 1986; Sobel, 1982). The Sobel test was computed using an online interactive platform (Preacher & Hayes, 2004). A significant result from the Sobel test indicates that the mediation effect is statistically significant.

Results

Characteristics of the Total Sample

Table 1 provides descriptive statistics of the sample from the previous 2011 – 2013 dataset (*n*= 431) and the 2018 – 2019 current dataset (*n*= 321). Participants in the 2011 – 2013 dataset had a mean age of 32.04 (*SD*= 11.63), 68% were female and 55.7% were single. Most were either employed/self-employed (44.8%) or student (33.6%). Reported types of fear of incontinence was 50.8% fear of faecal incontinence, 28.1% fear of urinary incontinence and 21.1% fear of urinary and faecal incontinence. Participants in the 2018 – 2019 dataset had a mean age of 57.46 (*SD*= 18.67) and 73.5% were female. Over half (56.3%) were married and 51.6% were retired. Reported types of fear of incontinence was 51.7% fear of faecal incontinence, 29% fear of urinary and

faecal incontinence, and 19.3% fear of urinary incontinence. Significant differences emerged for all variables except for gender.

Table 1

Characteristics of study participants for the 2011 – 2013 dataset and 2018 – 2019 database

	2011 – 2013 dataset (*n*= 431)	2018 – 2019 dataset (*n*= 321)	Statistical comparison
Age (years (SD))	32.04 (11.63)	57.46 (18.67)	*p* <.001
Gender			
Male	138 (32.0)	85 (26.5)	
Female	293 (68.0)	236 (73.5)	*p* = .100
Marital Status [a]			
Single	240 (55.7)	50 (19.8)	
Married/co-habiting	163 (37.8)	142 (56.3)	
Widowed	4 (0.9)	28 (11.1)	
Divorced	24 (5.6)	32 (12.7)	*p* <.001
Employment Status [a]			
Employed/self-employed	193 (44.8)	79 (31.3)	
Homemaker	17 (3.9)	5 (2.0)	
Unemployed	38 (8.8)	9 (3.6)	
Long-term sick leave	20 (4.6)	8 (3.2)	
Student	145 (33.6)	11 (4.4)	
Retired	11 (2.6)	130 (51. 6)	
Other	7 (1.6)	10 (4.0)	*p* <.001
Types of Fear of Incontinence			
Fear of urinary incontinence	121 (28.1)	62 (19.3)	
Fear of faecal incontinence	219 (50.8)	166 (51.7)	
Fear of urinary and faecal incontinence	91 (21.1)	93 (29.0)	*p* =.001

Note: FOIQ = Fear of Incontinence Questionnaire; [a] missing data from 69 participants; all values are numbers (% in parentheses) except for age, which are means ± SDs; sample differences are assessed using chi-square test, except for age

The combined sample included 752 participants, which was used for the factor analysis and internal consistency, Participants' mean age was 42.89 years old (*SD* = 19.60), and females were the majority (~70%). Approximately 45% of the participants were married, and most were employed (~40%). Fifty-one percent of the participants reported that fear of urinary incontinence was their main fear. Table 2 summarises the characteristics of participants included in the analyses for psychometric properties.

Table 2

Characteristics of participants included in the analyses for psychometric properties including factor analysis and internal consistency, convergent validity and follow-up test-retest reliability and internal consistency.

	Factor Analysis and Internal Consistency (*n*=752)	Convergent Validity (*n*=92)	Follow-up analysis (*n*=143)
Age (years (*SD*))	42.89 (19.60)	34.21(12.64)	59.90 (16.54)
Gender			
Male	223 (29.7)	16 (17.4)	37 (25.9)
Female	529 (70.3)	76 (82.6)	106 (74.1)
Marital Status[a]			
Single	290 (42.5)	43 (46.7)	31 (21.7)
Married/co-habiting	305(44.7)	38 (41.3)	79 (55.2)
Widowed	32 (4.7)	2 (2.2)	12 (8.4)
Divorced	56 (14.5)	9 (9.8)	21(14.7)
Employment Status[a]			
Employed/self-employed	272 (39.8)	41 (44.6)	42 (29.4)
Homemaker	22 (3.2)	6 (6.5)	3 (2.1)
Unemployed	47 (6.9)	8 (8.7)	4 (2.8)
Long-term sick leave	28 (4.1)	5 (5.4)	3 (2.1)
Student	156 (22.8)	28 (30.4)	5 (3.5)
Retired	141 (20.6)	4 (4.3)	83 (58.0)
Other	17 (2.5)	0	3 (2.1)
Types of Fear of Incontinence			
Fear of urinary incontinence	385 (51.2)	29 (31.5)	31 (21.7)
Fear of faecal incontinence	183 (24.3)	52 (56.5)	67 (46.9)
Fear of urinary and faecal incontinence	184 (24.5)	11 (12.0)	45 (31.5)

Note. [a] Missing data for 69 participants; all values are numbers (% in parentheses) except for age, which are means ± SDs

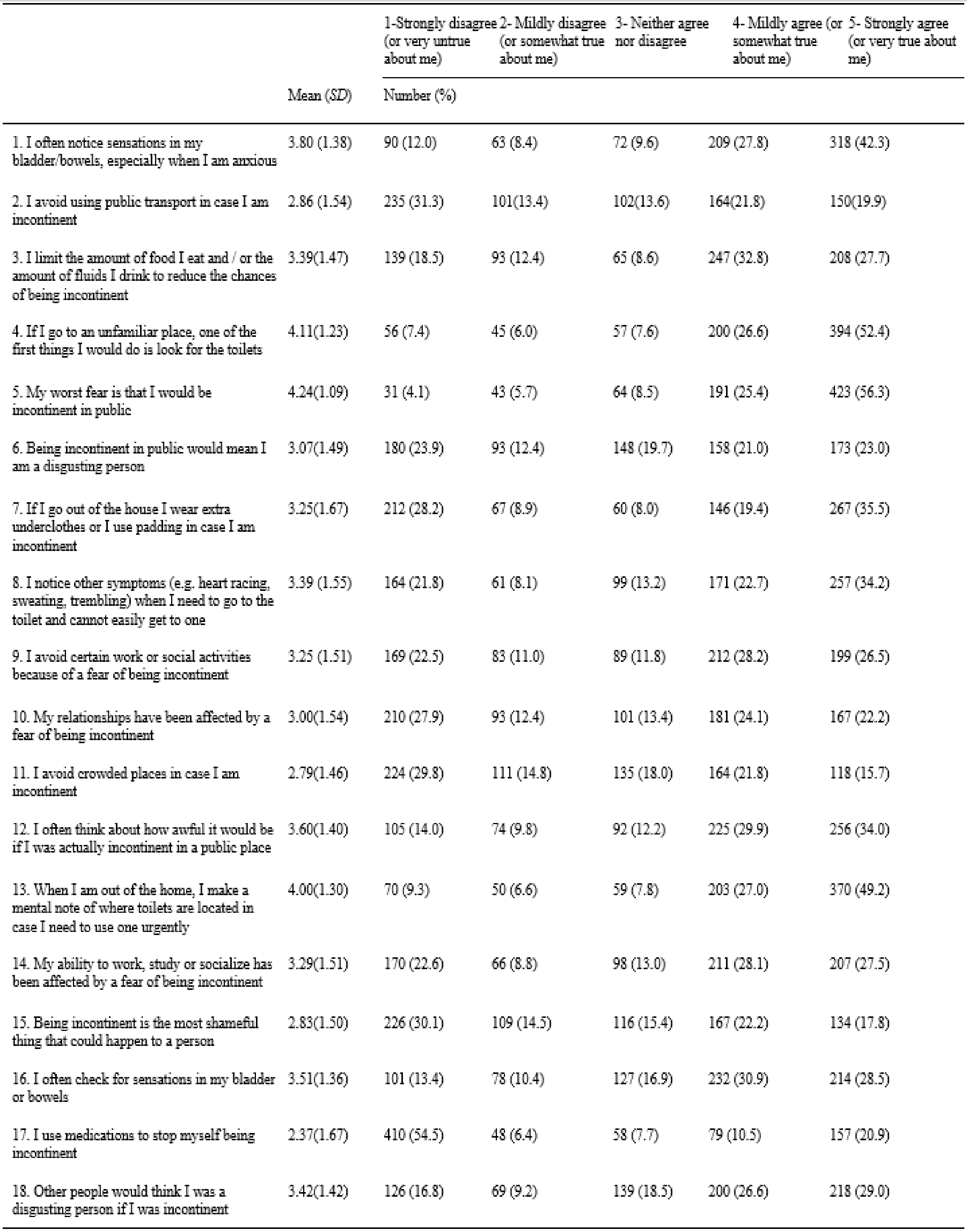
Psychometric Properties of the FOIQ

Descriptive Data and Response Distribution

The mean score for the FOIQ is 60.17 (*SD* = 16.12), and the score ranged from 18 to 90. Distribution of responses for each FOIQ item is presented in Table 3.

A full range of responses was observed for each item, for four items, there was a greater tendency for responding at the extremes (1 or 5). Over half of the participants (56%) responded 'Strongly agree' to item 5 ('My worst fear is that I would be incontinent in public'). Fifty-two percent of the participants reported 'Strongly agree' to item 4 ('If I got to an unfamiliar place, one of the first things I would do is look for the toilets') and 49% reported 'Strongly agree' to item 13 ('When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently'). Over half (55%) of the participants reported 'Strongly disagree' to item 17 ('I use medications to stop myself being incontinent').

Table 3. *Descriptive data and response distribution for each FOIQ item*



		1-Strongly disagree (or very untrue about me)	2- Mildly disagree (or somewhat true about me)	3- Neither agree nor disagree	4- Mildly agree (or somewhat true about me)	5- Strongly agree (or very true about me)
	Mean (*SD*)	Number (%)				
1. I often notice sensations in my bladder/bowels, especially when I am anxious	3.80 (1.38)	90 (12.0)	63 (8.4)	72 (9.6)	209 (27.8)	318 (42.3)
2. I avoid using public transport in case I am incontinent	2.86 (1.54)	235 (31.3)	101(13.4)	102(13.6)	164(21.8)	150(19.9)
3. I limit the amount of food I eat and / or the amount of fluids I drink to reduce the chances of being incontinent	3.39(1.47)	139 (18.5)	93 (12.4)	65 (8.6)	247 (32.8)	208 (27.7)
4. If I go to an unfamiliar place, one of the first things I would do is look for the toilets	4.11(1.23)	56 (7.4)	45 (6.0)	57 (7.6)	200 (26.6)	394 (52.4)
5. My worst fear is that I would be incontinent in public	4.24(1.09)	31 (4.1)	43 (5.7)	64 (8.5)	191 (25.4)	423 (56.3)
6. Being incontinent in public would mean I am a disgusting person	3.07(1.49)	180 (23.9)	93 (12.4)	148 (19.7)	158 (21.0)	173 (23.0)
7. If I go out of the house I wear extra underclothes or I use padding in case I am incontinent	3.25(1.67)	212 (28.2)	67 (8.9)	60 (8.0)	146 (19.4)	267 (35.5)
8. I notice other symptoms (e.g. heart racing, sweating, trembling) when I need to go to the toilet and cannot easily get to one	3.39 (1.55)	164 (21.8)	61 (8.1)	99 (13.2)	171 (22.7)	257 (34.2)
9. I avoid certain work or social activities because of a fear of being incontinent	3.25 (1.51)	169 (22.5)	83 (11.0)	89 (11.8)	212 (28.2)	199 (26.5)
10. My relationships have been affected by a fear of being incontinent	3.00(1.54)	210 (27.9)	93 (12.4)	101 (13.4)	181 (24.1)	167 (22.2)
11. I avoid crowded places in case I am incontinent	2.79(1.46)	224 (29.8)	111 (14.8)	135 (18.0)	164 (21.8)	118 (15.7)
12. I often think about how awful it would be if I was actually incontinent in a public place	3.60(1.40)	105 (14.0)	74 (9.8)	92 (12.2)	225 (29.9)	256 (34.0)
13. When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently	4.00(1.30)	70 (9.3)	50 (6.6)	59 (7.8)	203 (27.0)	370 (49.2)
14. My ability to work, study or socialize has been affected by a fear of being incontinent	3.29(1.51)	170 (22.6)	66 (8.8)	98 (13.0)	211 (28.1)	207 (27.5)
15. Being incontinent is the most shameful thing that could happen to a person	2.83(1.50)	226 (30.1)	109 (14.5)	116 (15.4)	167 (22.2)	134 (17.8)
16. I often check for sensations in my bladder or bowels	3.51(1.36)	101 (13.4)	78 (10.4)	127 (16.9)	232 (30.9)	214 (28.5)
17. I use medications to stop myself being incontinent	2.37(1.67)	410 (54.5)	48 (6.4)	58 (7.7)	79 (10.5)	157 (20.9)
18. Other people would think I was a disgusting person if I was incontinent	3.42(1.42)	126 (16.8)	69 (9.2)	139 (18.5)	200 (26.6)	218 (29.0)

Exploratory Factor Analysis

An exploratory factor analysis was performed on the FOIQ to determine the factor structure. Preliminary analysis showed that item 7 and item 17 had a low correlation with other items and inadequate communalities (<.3). As such, these items were dropped from the analysis. Excellent sampling adequacy was found with Kaiser-Meyer-Olkin test (KMO = .92). Bartlett's statistic (χ^2 (6009), *df*=120, *p*<.01) also indicated that the sample was adequate for factor analysis. Analysis suggested that the correlation among factors were above .32, therefore Promax rotation was used. The first three eigenvalues were 7.01, 1.56 and 1.15, indicating a three-factor solution, whereas the scree plot suggested the possibility of two- or three-factor solutions (see Figure 2). Based on factor interpretability, a three-factor solution was selected as the final structure. This solution accounted for 60.8% of the variance (see Table 4 for factor loadings and communalities), with most variance explained by the first factor (43.9%), which included five items and was named *Avoidance/Impact*. The second factor represented eight items and named *Safety behaviours/Catastrophising*, accounting for 9.8% of the variance. The third factor named *Disgust/Shame*, which consisted of three items and accounted for 7.2% of the variance.

As can be seen in Table 4, item 12 ('I often think about how often it would be if I was actually incontinent in a public place') has loadings on more than one factor with similar but slightly higher loading on factor 2 (labelled *Safety behaviours/Catastrophising*, loading .357*)* and factor 3 *(Disgust/Shame*, loading .345*)*, suggesting that item 12 is not unique to either of the factors. As item 12 loaded slightly higher on factor 2 it was included in the Safety behaviours/Catastrophising factor.

Internal Consistency

The internal consistency for the FOIQ and its three subscales was evaluated using Cronbach's alpha coefficient at baseline (*n* = 752) and at follow-up (*n* = 143). At baseline, Cronbach's alpha coefficient for the FOIQ total score was excellent (α=.91). Cronbach's alphas for the three subscales were .90 for Avoidance/Impact, .83 for Safety behaviours/Catastrophising, and .81 for Disgust/Shame. At follow-up, Cronbach's coefficient for the FOIQ total score was also .91, therefore identical to baseline. Cronbach's alphas for the three subscales at follow up were .91 for Avoidance/Impact, .80 for Safety behaviours/Catastrophising, and .82 for Disgust/Shame.

Table 4

Item factor loadings and communalities based on an exploratory factor analysis with promax rotation for the 16-item version of the Fear of Incontinence Questionnaire (FOIQ) (N=752)

		Factor			
	Subscale/Item	1	2	3	Communalities
Avoidance/Impacts					
10	My relationships have been affected by a fear of being incontinent	**.937**	-.162	.012	.716
11	I avoid crowded places in case I am incontinent	**.872**	-.092	.060	.712
9	I avoid certain work or social activities because of a fear of being incontinent	**.865**	.032	.001	.787
14	My ability to work, study or socialise has been affected by a fear of being incontinent	**.762**	.098	.034	.715
2	I avoid using public transport in case I am incontinent	**.691**	.186	-.067	.630
Safety behaviours/Catastrophising					
1	I often notice sensations in my bladder/bowels, especially when I am anxious	-.305	**.846**	.057	.501
4	If I go to an unfamiliar place, one of the first things I would do is look for the toilets	.138	**.776**	0.200	.641
13	When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently	.157	**.731**	-.123	.629
16	I often check sensations in my bladder or bowels	-.046	**.677**	.120	.499
8	I notice other symptoms (e.g. heart racing, sweating, trembling) when I need to go to the toilet and cannot easily get to one	.166	**.530**	.091	.487
5	My worst fear is that I would be incontinent in public	.001	**.530**	.187	.401
3	I limit the amount of food I eat and / or the amount of fluids I drink to reduce the chances of being incontinent	.180	**.493**	-.091	.346
12	I often think about how awful it would be if I was actually incontinent in a public place	.184	**.357**	.345	.531
Disgust/Shame					
6	Being incontinent in public would mean I am a disgusting person	-.066	-.021	**.884**	.718
18	Other people would think I was a disgusting person if I was incontinent	-.004	-.003	**.848**	.714
15	Being incontinent is the most shameful thing that could happen to a person	.127	-.022	**.785**	.707

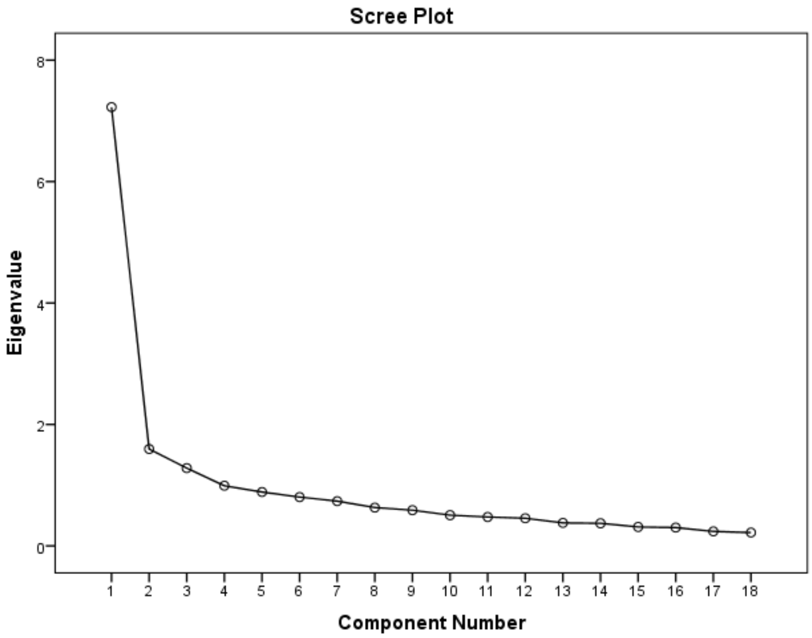


Figure 2. The scree plot based on exploratory factor analysis for the 16-item version of the Fear of Incontinence Questionnaire (FOIQ) (*N*=752)

Test-retest Reliability

The test-retest reliability of the FOIQ was evaluated using 143 participants over 2-week intervals. Analysis suggested that the FOIQ has good reliability with an ICC of 0.86 for the total score. For the three subscales, the ICCs were 0.87 for Avoidance/Impact, 0.79 for Safety behaviours/Catastrophising, and 0.79 for Disgust/Shame. All were significant at p<.01 level.

Convergent validity

The convergent validity of the FOIQ was assessed based on the 92 participants from the 2011-2013 dataset using Pearson's correlation. The FOIQ total score had a positive correlation with all measures, except for the OCI-SV. The FOIQ total score correlated moderately with the GAD-7 (*r*= .45, *p*<.001) and the PHQ-9 (*r*= .46, *p*<.001), indicating that higher scores on the FOIQ are associated with greater symptoms of generalised anxiety and depression. The FOIQ total score correlated highly with the WASAS (*r*= .64, *p*<.001). There was also a moderate correlation with the SPIN (*r*= .43, *p*<.001), and high correlations with the ISS (*r*= .51, *p*<.001), the MIA-Alone subscale (*r*= .51, *p*<.001) and the MIA-Accompanied subscale (*r*= .52, *p*<.001). The FOIQ had a significant but low correlation with the DPSS-R (*r*=0.28, *p=.022*). The subscales of the FOIQ demonstrated a similar pattern of results (see Table 5 for a summary of the correlations), except for the MIA-AAL and the DPSS-R. The MIA-AAL did not show a significant correlation with FOIQ-factor 3, and the DPSS-R did not show a significant correlation with FOIQ-factor 2 and factor 3.

Table 5

Correlation matrix of the FOIQ and its three subscales with the other measures (n=92)

	FOIQ full scale	FOIQ-factor 1	FOIQ-factor 2	FOIQ-factor 3	Mean (*SD*)
GAD-7	.452*	.358*	.364*	.466*	10.02 (6.16)
PHQ-9	.458*	.400*	.328*	.416*	9.91 (6.57)
WASAS	.635*	.645*	.401*	.433*	13.08 (9.67)
MIA-AAL	.509*	.526*	.394*	.270*	2.28 (1.07)
MIA-AAC	.517*	.533*	.409*	.211	1.96 (.97)
OCI-SV	.181	.187	.144	.117	15.70 (13.78)
SPIN	.433*	.411*	.289*	.432*	24.86 (16.74)
DPSS-R	.277*	.288*	.177	.225	22.16 (14.11)
ISS	.505*	.449*	.390*	.473*	60.02 (17.76)

Note. FOIQ= Fear of Incontinence Questionnaire; GAD-7=Generalised Anxiety Disorder; PHQ-9=Patient Health Questionnaire; WASAS=Work and Social Adjustment; MIA – AAL = Mobility Inventory for Agoraphobia – Avoidance Alone subscale; MIA – AAC = Mobility Inventory for Agoraphobia – Avoidance Accompanied subscale; OCI-SV= Obsessive Compulsive Inventory – Short Version; SPIN= Social Phobia Inventory; DPSS-R= Disgust Propensity and Sensitivity Scale-Revised; ISS= Internalised Shame Scale. * Correlation is significant at 0.01 level.

Mediational Analysis

The following mediation analysis was conducted on the 282 participants from the 2018-2019 dataset.Approximately half of the participants (*n* = 139; 49%) were aged 65 years or above. Of the 282 participants, majority (*n* = 177; 63%) scored above 4 on the PHQ-9, which is the cut-off for mild level of depressive symptoms. The distribution of PHQ-9 score are as followed: 0 – 4 (*n* = 105; 37%), 4 – 9 (mild depression; *n* = 87; 31%), 10 – 14 (moderate depression; *n* = 40; 14%), 15 – 19 (moderately severe depression; *n* = 31; 11%), and 20 – 27 (severe depression; *n* = 19; 7%). See Table 6 for other characteristics of participants).

Table 6

Characteristics of study participants for mediation analysis (n = 282) and group difference for PHQ-9 scores based on One-way ANOVA.

Characteristics	Number (%)	PHQ-9 Mean (*SD*)	*p*
Age (years (SD))	57.50 (18.34)	-	-
Range	18 - 91		
Gender			
Male	78 (27.7)	7.44 (6.65)	
Female	204 (72.3)	8.10 (6.48)	.447
Ethnicity[a]			
Asian	4 (1.6)	7.75(8.02)	
Black	3 (1.2)	15.67(2.08)	
White	231 (94.7)	7.85(6.59)	
Mixed	5 (2.1)	15.80(3.70)	
Other	1 (0.4)	11(n/a)	n/a[c]
Marital Status[b]			
Single	50 (20.4)	9.82 (6.88)	
Married/co-habiting	138 (56.3)	8.00(6.65)	
Widowed	26 (10.6)	5.04(4.65)	
Divorced	31 (12.7)	8.16(6.98)	.030
Employment status[b]			
Employed/self-employed	79 (32.2)	9.25(7.30)	
Homemaker	5 (2.0)	10.20(8.67)	
Unemployed	9 (3.7)	15.00(5.92)	
Long-term sick leave	8 (3.3)	14.13(4.79)	
Student	11 (4.5)	7.55(5.24)	
Retired	124 (50.6)	5.82(6.84)	
Other	9 (3.7)	15.67 (6.84)	.000
Organic disorder associated with incontinence			
Yes	110 (39.0)	8.05(6.00)	
No	171 (61.0)	7.83(6.85)	.831
Types of fear of incontinence			
Fear of urinary incontinence	144 (51.1)	6.89(5.69)	
Fear of faecal incontinence	56 (19.9)	8.38 (6.85)	
Fear of urinary and faecal incontinence	82 (29.1)	9.40 (7.37)	.017
Number of incontinence episodes (past week)			
0	70 (24.8)	7.46 (7.03)	
1-5	128 (45.4)	6.91 (5.86)	
5-10	35 (12.4)	8.57 (5.84)	
Over 10	49 (17.4)	10.79 (7.18)	.006
Subjective health status			
Excellent	22 (7.8)	5.27(4.91)	
Very good	74 (26.2)	4.16 (3.81)	
Good	98 (34.8)	8.03 (6.57)	
Fair	70 (24.8)	11.04 (6.68)	
Poor	18 (6.4)	13.39 (6.32)	.000

Note. [a] Missing data from 38 participants. [b]Missing data from 37 participants. [c]One-way ANOVA was not performed due to low number of participants for some categories for the employment variable.

Prior to the mediation analysis, the inter-relationships among different variables were assessed, including demographics and incontinence-related variables. As expected, PHQ-9 had a significant positive relationship with the FOIQ, GAD-7, MIA – Alone subscale. These correlations were all relatively strong (>.5). The PHQ-9 was negatively correlated with age (*r*= -.31), suggesting that the PHQ-9 score reduces as age increases. Interestingly, age demonstrated a negative relationship with all other measures, however, these correlations ranged from .2 to .3, suggesting a low to medium effect size. Table 7 presents correlations among continuous variables respectively.

Table 7

Correlation matrix of the PHQ-9, age, FOIQ, GAD-7 and the MI-Alone subscale (n=282).

	1	2	3	4	M (*SD*)
1.PHQ-9					7.91 (6.52)
2.Age	-.308**				57.58 (18.84)
3.FOIQ	.513**	-261**			57.58 (15.31)
4.GAD-7	.729**	-.358**	.458**		6.66 (5.69)
5.MIA-AAL	.503**	-.246**	.653**	.506**	2.75 (.72)

Note. FOIQ= Fear of Incontinence Questionnaire; GAD-7=Generalised Anxiety Disorder; PHQ-9=Patient Health Questionnaire; MIA – AAL = Mobility Inventory for Agoraphobia – Avoidance Alone subscale. **Correlation is significant at .01 level.

As for the other categorical variables, one-way ANOVA revealed significant differences for the PHQ-9 scores in participants with different marital status (*F*(3, 241)= 3.04, *p*=.03), employment status (*F*(6,238)= 9.08, *p*<.01), varied frequency of incontinence in the past week (*F*(3, 278)= 4.27, *p*=.01) , and subjective health status (*F*(4, 277)= 17.88, *p*<.01). See Table 5 for PHQ-9 scores according to participants' characteristics. Table 6 presents the PHQ-9 scores according to different groups and the significant values for one-way ANOVA.

Variables that were significantly associated with the PHQ-9 were considered to be included as covariates in all mediational analysis. Although there were group differences in depression scores for marital status and employment status, it was decided that they were not included as covariates due to a high proportion of missing data. Further, the number of incontinence episodes in the past week was also not included as a covariate. This was because the inclusion of this variable would involve creating a two-level dummy variable, representing people who had no incontinence episode vs at least one episode of incontinence. As the majority of the participants experienced at least one recent episode of incontinence, it would not be appropriate to include it as a covariate.

To test the hypothesis that avoidance will mediate the relationship between fear of incontinence and depressive symptoms, the approach by Baron and Kenny (1986) was used. Tables 8, 9, 10 and 11 summarise the regression results. Data were screened for violations of assumptions of multiple regression prior to analysis. Diagnostic tests suggested that influential cases were not a concern, and the assumptions of linearity, normality and homoscedasticity were met. Correlational analysis showed that although all independent variables were correlated, the correlations were not strong enough to suggest multicollinearity, with all VIF statistics below 10.

The first regression analysis examined whether fear of incontinence predicted depressive symptoms after controlling for age, subjective health and generalised anxiety. In step 1, the covariates accounted for 57% of the variance, with subjective health and generalised anxiety emerging as significant predictors. In step 2, after controlling for the confounding variables, fear of incontinence contributed only a small, albeit significant, 3% increment in variance, to the prediction of depressive symptoms (see Table 8).

The second regression model was conducted to examine whether fear of incontinence significantly predicts avoidance after controlling for age, subjective health and generalised anxiety. In step 1, the covariates accounted for 33% of the variance; subjective health and generalised anxiety were the significant predictors. In step 2, fear of incontinence and covariates were entered as independent variables, with avoidance entered as a dependent variable. When controlling for covariates, fear of incontinence contributed an additional 18% of the unique variance (see Table 9).

The third regression analysis was conducted to determine whether the proposed mediator, avoidance, significantly predicted depressive symptoms after controlling for covariates. In step 1, the covariates accounted for 57% of the variance, with subjective health and generalised anxiety being the significant predictors. In step 2, avoidance accounted for additional2% of the variance in depressive symptoms when controlling for covariates, emerging as a significant predictor (see Table 10).

The final model involved examining the relationship between fear of incontinence and depressive symptoms while controlling for the covariates and avoidance. Results showed that the confounding variables accounted for 57% of the variance, with subjective health and generalised anxiety being significant predictors in step 1. In step 2, avoidance contributed a small but significant increment in variance, 2%. Fear of incontinence remained as a significant predictor in the final step, but only accounted for a small amount of variance, 1% (see Table 11). As the effect of fear of incontinence on depressive symptoms had reduced when avoidance was included, it suggests that avoidance partially mediated the fear of incontinence-depressive symptoms relationship. This was further supported by the result from Sobel's test of mediation (test statistics= 3.47, *SE*= 0.01, p<.001). The mediation model can be found in Figure 3.

Table 8

Summary of regression analysis (enter method) for FOIQ predicting PHQ controlling for age, GAD, and subjective health (n=282)

Variable	*B*	*SE B*	*t*	*sig*	R^2	ΔR^2
Step 1						
Age	-.01	.02	-.79	.429		
Subjective Health	1.37	.26	5.29	<.001		
GAD	.74	.05	14.79	<.001	.57	
Step 2						
Age	-.01	.01	-.35	.726		
Subjective Health	1.17	.26	4.59	<.001		
GAD	.65	.05	12.48	<.001		
FOIQ	.09	.02	4.55	<.001	.60	.03

Note. B=unstandardized regression coefficient, *SE B*= standard error B, ΔR^2=R^2 change.

Table 9

Summary of regression analysis (enter method) for FOIQ predicting MIA-AAL controlling for age, GAD, and subjective health (n=282)

Variable	*B*	*SE B*	*t*	*sig*	R^2	ΔR^2
Step 1						
Age	.00	.00	-1.03	.304		
Subjective Health	.15	.04	4.26	<.001		
GAD	.06	.01	8.08	<.001	.33	
Step 2						
Age	.00	.00	-.18	.861		
Subjective Health	.10	.03	3.13	.002		
GAD	.03	.01	4.98	<.001		
FOIQ	.02	.00	9.96	<.001	.51	.18

Note. B=unstandardized regression coefficient, *SE B*= standard error B, ΔR^2=R^2 change.

Table 10

Summary of regression analysis (enter method) for MIA-AAL predicting PHQ controlling for age, GAD, and subjective health (n=282)

Variable	*B*	*SE B*	*t*	*sig*	R^2	ΔR^2
Step 1						
Age	-.01	.02	-.79	.429		
Subjective Health	1.4	.26	5.29	<.001		
GAD	.74	.05	14.79	<.001	.57	
Step 2						
Age	-.01	.02	-.58	.561		
Subjective Health	1.14	.26	4.31	<.001		
GAD	.65	.05	12.01	<.001		
MIA - AAL	1.55	.43	3.64	<.001	.59	.02

Note. B=unstandardized regression coefficient, *SE B*= standard error B, ΔR^2=R^2 change.

Table 11

Summary of regression analysis (enter method) for FOIQ predicting PHQ controlling for age, GAD, subjective health, and MIA-AAL (n=282)

Variable	*B*	*SE B*	*t*	*sig*	R^2	ΔR^2
Step 1						
Age	-.01	.02	-.79	.429		
Subjective Health	1.37	.26	5.29	<.001		
GAD	.74	.05	14.79	<.001	.57	
Step 2						
Age	-.01	.02	-.58	.561		
Subjective Health	1.14	.26	4.33	<.001		
GAD	.65	.05	12.01	<.001		
MIA-AAL	1.55	.43	3.64	<.001	.59	.02
Step 3						
Age	-.01	.01	-.34	.738		
Subjective Health	1.09	.26	4.23	<.001		
GAD	.63	.05	11.54	<.001		
MIA-AAL	.77	.49	1.58	.115		
FOIQ	.07	.02	3.10	.002	.60	.01

Note. B=unstandardized regression coefficient, *SE B*= standard error B, ΔR^2=R^2 change.

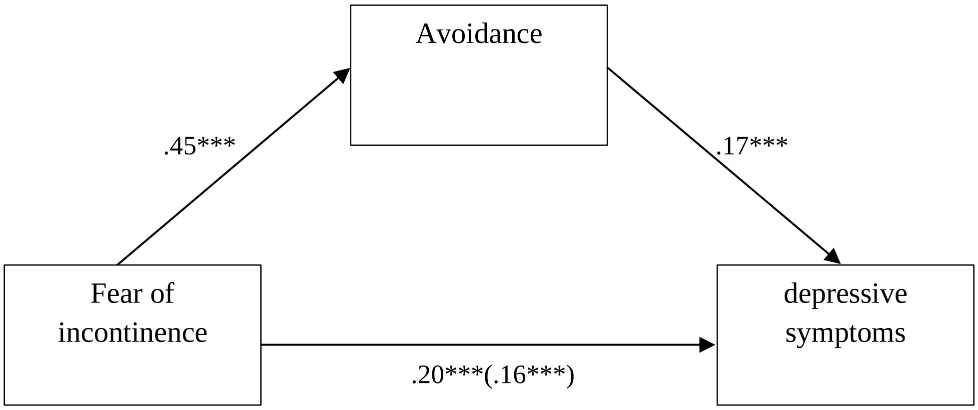


Figure 3. Hypothesised mediation model relating fear of incontinence (independent variable), avoidance (mediator), depressive symptoms (dependent variable). The value inside the brackets denotes the effect of fear of incontinence on depressive symptoms, with avoidance as mediator.

Note. ***p<.001

Discussion

The goals of this study were to examine the psychometric properties of the FOIQ and to explore the relationship between fear of incontinence, avoidance and depressive symptoms. The current study provided support for adequate or good psychometric properties of the FOIQ. Further, results from the mediational analysis suggested that avoidance partially mediates the relationship between fear of incontinence and depressive symptoms. The main findings are discussed below.

Response Distribution and Psychometric Properties of the FOIQ

Prior to evaluating the psychometric properties of the FOIQ, analyses were conducted at item level to explore response distribution. Results showed over 50% response rate for ‘Strongly agree’ to item 4, 5, and 13, suggesting high levels of fear for public incontinence and the importance of being able to locate toilets in public places.

Moreover, 54% of the participants responded with ‘Strongly disagree’ to item 17 (‘I use medications to stop myself being incontinent’). This was an interesting finding as clinical experience suggests that the use of medication is one of the main strategies for managing fear of incontinence (see Kamboj et al., 2015). However, it should be noted that as the current sample was recruited online, and the sample’s characteristics may be different compared to those presented in a clinical setting. It is possible that participants recruited from a clinical setting have a more severe fear of incontinence symptoms, and therefore may employ different strategies. For example, knowing the locations of the toilets may not be a sufficient safety behaviour in isolation for help-seeking participants, who may employ multiple safety behaviours.

In terms of the factor structure, item 7 and 17 were dropped following preliminary analysis. The resulting 16-item version of the FOIQ was demonstrated to have a three-factor structure representing Avoidance/Impact, Safety behaviours/Catastrophising, and Disgust/Shame, which was partially different to the two-factor solution reported in the study by Langhoff (2013). The factor *Disgust/Shame* was also found in the Langhoff’s study, therefore appeared to be a more robust factor compared to the other two factors. The different factor structure could be due to the use of different inclusion and exclusion criteria. In this study, participants with physical conditions associated were included. Additionally, item 5 (‘My worst fear is that I would be incontinent in public’) was included in the factor analysis in the current study. These differences could result in a different factor structure for the FOIQ.

It is also worth highlighting that item 12 (‘I often think about how awful it would be if I was actually incontinent in a public place’) did not load exclusively on factor 2

Safety behaviours/Catastrophising; it showed similar loading on factor 3 Disgust/Shame. This suggests that item 12 does not discriminate factor 2 and 3 well, therefore future studies should consider dropping the item in the future.

The findings supported the FOIQ to be a psychometrically sound measure. The FOIQ and its three subscales were demonstrated to have good internal consistency at baseline and follow-up. The FOIQ was found to have satisfactory test-retest reliability and appropriate convergent validity. The FOIQ was associated with other constructs related to fear of incontinence. The FOIQ correlated with depressive symptoms, general anxiety, avoidance, and functional impairment. Notably, fear of incontinence was found to be correlated significantly with the measure of social phobia. This association may reflect the fear of embarrassment in social situations that is common to both conditions. Moreover, fear of incontinence was associated with disgust sensitivity and internalised shame. Disgust has been suggested to be involved in the development and maintenance of some anxiety disorders, such as emetophobia (van Overveld, de Jong, Peters, van Hout, & Bouman, 2008). Hence, it is possible that disgust is also involved in the development and maintenance of fear of incontinence. In terms of the association with internalised shame, it could be that participants experienced an understandable increased level of shame as a consequence of fear of incontinence, or participants who are more vulnerable to experiencing shame are more likely to develop fear of incontinence, or both. Moreover, no significant correlation was found between the FOIQ and the measure of obsessive-compulsive disorder. This was a surprising finding given the debate around whether fear of incontinence should be conceptualised as part of obsessive-compulsive spectrum disorder because of the overlapping intrusive thoughts and imageries characteristics (Roy et al., 2018).

The mediating role of avoidance in the relationship between fear of incontinence and depressive symptoms

The current study suggests that fear of incontinence is related to low levels of depressive symptoms. However, the shared variance between fear of incontinence and depressive symptoms was small in the present study, exhibiting only 3% of common variance after taking into account confounding variables. Furthermore, avoidance emerged as only a partial mediator for the relationship between fear of incontinence and depressive symptoms in a sample of 282 adults. Of note, although the mediation effect was statistically significant, its unique contribution was small, explaining only 2% of variability in depressive symptoms. The majority of the variance was accounted for by subjective health status and general anxiety. The current findings therefore provide some evidence, albeit limited, for the conceptualisation that individuals with a fear of incontinence would use avoidance as a coping strategy, thus contributing to low mood.

Moreover, although the main aim of this study was not to explore the association between age and fear of incontinence, correlational analyses that were carried out prior to the mediation analysis demonstrate some interesting findings. Age was found to be correlated negatively with all the main measures, including the FOIQ, measures for depressive symptoms, general anxiety and avoidance. This therefore suggests that the symptoms of fear of incontinence and other psychological distress reduce as someone ages. As further analysis suggested that older participants are more likely to use pads as a coping strategy, it is possible that older adults employ different strategies that successfully reduce fear of incontinence, and therefore has a positive impact on their overall mood. It is also worth highlighting that although the negative correlation between age and the several main measures were statistically significant, the effect size ranged from low to medium, therefore suggesting that the correlations were not clinically significant.

Strengths and Limitations

The present study needs to be considered in light of the various limitations that indicate the need for further work in this area.

One limitation of this study is the cross-sectional design. Thus, the findings should be interpreted with caution as it does not allow one to infer causation. Specifically, depressive symptoms were interpreted to be the consequence of fear of incontinence in this study. However, it is possible that depressive symptoms occur before fear of incontinence for some individuals. In fact, there is evidence to suggest that depressive symptoms increase the risk of incontinence (Felde et al., 2017). Further research is necessary to disentangle the temporal relationship between fear of incontinence and depressive symptoms.

Moreover, there are advantages and disadvantages of collecting data anonymously. It enables the exploration of a topic that could be considered as embarrassing to discuss face-to-face. However, it is impossible to ascertain whether participants have provided data twice, for example, once for the Langhoff's study and once for the more recent recruitment. However, given there is a six-year gap between the two studies, it is likely that the users of the online platforms have changed over time and this therefore reduces the risk of people participating twice.

Furthermore, despite the suggestion in the literature that it would be feasible to recruit older adult through the internet (Li, Gajos, & Reinecke, 2018; Office for National Statistics, 2017), this study encountered difficulty when recruiting older adults. As such, charities including Age UK and U3A were contacted to support the recruitment process. Although no information was collected on how participants heard about this project, it was possible that the majority of the older participants were recruited through the U3A via their general monthly meetings. This meant these older participants may not struggle with going out as a result of fear of incontinence as they were able to attend the meetings. Hence, it is possible that participants were less likely to be representative of people in clinical settings.

In addition, the study sample comprises mostly white participants, therefore generalisation of the results to other ethnic populations needs to be done with caution. Also of note is that there were fewer male participants than female. Incontinence is an issue that affects more females than males, so the higher number of older female participants could be a reflection of the higher prevalence of incontinence in this population. However, it might also be that issues around incontinence are more stigmatised for males than females, therefore leading to fewer male participants.

Clinical Implications

The study gives rise to clinical implications for the assessment and management of fear of incontinence. Analyses show that the majority of the participants reported at least one episode of incontinence in the past week, which suggests that fear of incontinence was likely to be a normal concern for these people. Thorough assessment and formulation is therefore essential when deciding whether psychological support is appropriate and what should be offered. A value-based approach may be useful for those experiencing rational worry, however, this would require further empirical support. Of note, it is important for clinicians to consider the consequences of pathologising anxiety in regard to incontinence, which may be harmful rather than helpful if a person does experience continence issues.

The findings from this study have implications for the Improving Access to Psychological Therapies (IAPT) programme in the UK. In particular, the Department of Health has expanded the IAPT service to offer therapy for individuals with co-morbid anxiety/depressive symptoms and chronic physical illness (Department of Health, 2012, 2014). In this sense, this would include people with fear of incontinence and comorbid physical conditions associated with incontinence. However, there is currently no formal guidance or treatment manual available for managing fear of incontinence. Hence, more research is required to provide a greater understanding of fear of incontinence and to ensure the support provided is based on scientific evidence.

Implications for Future Research

The current findings point to several future research directions. First, although this study provided support for the psychometric properties of the FOIQ, it would be beneficial for future research to replicate or confirm the three-factor structure found in this study. Further research should also examine divergent validity, and the sensitivity and specificity of FOIQ.

Given that the earlier research only explored the phenomenology of fear of incontinence in adults below the age of 65, further investigation should elaborate on the understanding of fear of incontinence in older adults. For example, exploring clinical features such as the onset and history of the problem, help-seeking behaviours and medical history. It would also be interesting to explore this anxiety in both people with and without physical conditions associated with incontinence, and potentially explore whether the construct is different in these two groups. In addition, recruiting participants from clinical settings (including primary mental health services, GP services or even specialised health departments), and collecting data via clinical interviews may provide a more comprehensive picture of fear of incontinence.

Moreover, fear of incontinence has been conceptualised differently by researchers, and some have argued that it may overlap with other types of anxiety, including agoraphobia, social phobia, obsessive-compulsive disorders and panic disorders (Beidel & Bulik, 1990; Jenike et al., 1987; Roy et al., 2018). However, these studies have only explored fear of incontinence in young adults in their 20s and 30s, and it is possible that fear of incontinence in older adults may overlap with other constructs such as ageing anxiety, which includes concerns about age-related declines in several domains, including health and physical functioning, financial well-being, changes in physical appearance and also cognitive abilities (Lynch, 2000). It is possible that fear of incontinence maybe different depending on age; in younger adults the catastrophic thoughts may be associated with social embarrassment or judgment from others (Pajak et al., 2013), whereas in older adults there may be other concerns related to ageing or loss of identity or control. The current study was unable to provide detailed insight into these issues, and future research should explore what fear of incontinence may imply particularly in older adults using a qualitative method as it enables people to provide a more detailed account of their concerns.

Finally, as avoidance only partially mediated the relationship between fear of incontinence and depressive symptoms (explaining 2% of the variance), it suggests that there may be other potential mediators. One possible mediator could be internalised shame, given that shame was found to be correlated with both fear of incontinence and depressive symptoms in this study. Internalised shame reflects the experience of feeling ashamed, which is an emotion that could lead an individual to avoid social contacts, and possibly lead to depressive symptoms. Further research is required to explore other possible mediators, which would be helpful in contributing to the formulation and treatment for fear of incontinence.

Conclusion

In summary, the current study provides support for the psychometric properties of FOIQ, demonstrating adequate or good internal consistency, convergent validity, and test-retest reliability. The FOIQ was revealed to have a three-factor structure: *Avoidance/Impact*, *Safety behaviours/Catastrophising*, and *Disgust/Shame*. In addition, avoidance was found to be a partial mediator but had limited predictive value for the relationship between fear of incontinence and depressive symptoms. The clinical importance of this mediator is therefore currently unclear.

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Part 3: Critical Appraisal

Introduction

This critical appraisal provides a reflection detailing the process of planning and conducting an empirical study. First, I will discuss my personal background, which influenced my decision to choose this topic as my research project. Next, I will discuss the theoretical construct of fear of incontinence. I will then reflect on the methodological issues I encountered, including difficulties associated with the recruitment process and the use of an online survey, as well as the data analysis method. Finally, I will reflect on the overall journey of undertaking this research project and discuss what I have learned.

Personal Experience

My interest in studying fear of incontinence comes from my personal experience of living with my grandmother. She has been affected by diabetes for over a decade, and she has a limited desire to leave her house due to her worry of being unable to find a toilet, which is associated with increased urinary frequency. I witnessed the impact fear of incontinence can have, for example, refusing to attend a family gathering that involves a long drive, which ultimately reduces quality of life. I feel this is an area that can easily be overlooked by researchers as older adults are often confronted with different physical health problems that might take priority.

Theoretical Construct of Fear of Incontinence

Upon reviewing the literature on fear of incontinence, I noted that this fear has been conceptualised differently by researchers. It seems that the presentation of fear of incontinence overlaps with different anxiety disorders, including agoraphobia, social phobia, obsessive-compulsive disorders and panic disorders. Some researchers conceptualise it as an obsessive spectrum disorder because the person with fear of incontinence is preoccupied with intrusive thoughts and images of bladder and bowel sensations or motions (Beidel & Bulik, 1990; Jenike et al., 1987). Some, however, view it as a subtype of agoraphobia because the person has a fear of going to places where escape (to a toilet) is difficult (Kamboj et al., 2015). Thus far, most case studies have reported using the cognitive behavioural technique as a psychological treatment for fear of incontinence (Beidel & Bulik, 1990; Eldridge et al., 1993; Hatch, 1997; Tan & Lim, 2014). Nonetheless, these case reports focus only on adults, with irrational worry around being incontinent.

The purpose of the empirical paper is to expand our understanding of fear of incontinence in older adults. Therefore, I have spent time pondering whether the presentation of fear of incontinence would be different in older adults compared to younger adults. One main difference is that because older adults are more likely to have health problems, and fear of incontinence therefore may more likely be a realistic concern in older adults. This would mean the techniques that have been applied to younger adults, such as exposure or challenging the likelihood of being incontinent, may not be appropriate for older adults. More importantly, given that ageing is a risk factor for incontinence, I also wondered whether fear of incontinence may overlap with the construct of ageing anxiety, in which older adults have a generalised concern regarding the ageing process (Lynch, 2000). Specifically, I wondered whether being incontinent would have additional meanings for older adults, i.e. being incontinent may trigger the worry that other people would show a disgust response, but it may also lead to general worries about the ageing process or the loss of bodily function, with an associated sense of embarrassment or shame for the person with incontinence. Future research should continue to explore fear of incontinence in older adults. In particular, as a first step, it would be helpful to develop a more in-depth understanding of fear of incontinence using a qualitative approach. This can produce additional research and raise clinical implications as it would help researchers decide whether the Fear of Incontinence Questionnaire (FOIQ) needs further development for use on older adults.

Methodological Issues

Recruitment Process

When designing this project, it was decided the data would be collected via the Internet. This method of data collection was chosen for its multiple advantages. First, online studies allow researchers to have access to people who might otherwise be difficult to reach. As fear of incontinence is a concern that is associated with private body parts, individuals can understandably feel embarrassed and ashamed about it. As such, people may not be keen to take part in the study if they are approached in person. An additional advantage of recruiting participants via the Internet is that it allows people to participate anonymously, which, again, may increase people's willingness to take part in the study. On a more practical note, collecting data through an online survey is more efficient than collecting data face-to-face. This is particularly helpful for clinical psychology trainees, who usually need to strike a balance between the demand for clinical work and research projects.

Although there are advantages to recruiting participants with fear of incontinence via the Internet, the reviewer of this project expressed concerns regarding the feasibility of recruiting older adults using this method. Nonetheless, based on the clinical and research experiences of my supervisors, I thought that recruiting participants online (including older adults) would be a sensible strategy. After a search through the literature on the suitability of recruiting older adults using the Internet, researchers also suggested that Internet recruitment would be a viable method for reaching older adults (Li, Gajos, & Reinecke, 2018). Similarly, statistics suggest that many older adults in the UK are Internet users—78% of older adults between age 65–74 and 41% of older adults aged 75 or above were considered to be recent Internet users (Office for National Statistics, 2017).

Despite what the statistics show, one of the main difficulties in conducting this project was the online recruitment of older adults. The original plan was to recruit both younger and older participants using a variety of online platforms, including Facebook, Twitter and online forums. Unfortunately, I quickly learned that it is difficult to recruit older adults through online forums. This was because online forums for older adults typically have an age restriction for members. More importantly, any forms of advertisement, including research adverts, are usually prohibited. I began the recruitment process around mid-November 2018, and when I reviewed the progress in January of this year, I realised that I only had approximately 20 older participants but over 100 younger participants. This suggested that the advertisements I posted on Facebook and Twitter only recruited very few older participants.

Given the time pressure to recruit a large sample of older adults in January, I thus decided to contact Age UK and the University of Third Age (U3A) (charities for older people) to see whether they could help with the advertisement of the project. The national office of Age UK informed me that they did not have the capacity to support my project, but they suggested I contact the local Age UK. The lack of response from the national office of these charities was not a surprise given that other researchers would likely want to recruit participants via charities, and therefore it would be difficult to fulfil every request. As such, I decided to email the local Age UK and the local U3A in London and in other parts of the UK directly. A total of 190 local U3As were contacted. Of these, 26 agreed to support the recruitment of this project by including information in their newsletter or by informing its members during general monthly meetings.

A few local U3As provided an explanation for not being able to support the advertisement of this project. Some explained that they receive many several requests for participant recruitment, and therefore they are only able to support projects that have been approved by the national office. Some local U3As were concerned about issues related to advertising research projects; one local U3A explained that the introduction of the General Data Protection Regulation (GDPR) meant that they were unable to include the details of the study in their newsletter, while another local U3A expressed concerns about the processing of participants' email address. Furthermore, one particular local U3A felt that its members would not respond well to a project that focused on an embarrassing topic. This, once again, reflect the taboo nature of continence-related issues. Interestingly, I noted that among the U3A committees that agreed to help, many disclosed personal experiences of living with continence issues. Therefore, it seems that personal experiences with continence worries influenced people's decision to help with this project.

Further Issues with Internet Study

One additional issue concerning conducting Internet research is the difficulty of not knowing participants' reaction after they completed the survey. I received a few follow-up emails from participants who completed the survey. They provided similar comments and said they felt the survey did not capture their fears of incontinence due to the closed nature of the questions in the online survey. More specifically, one participant provided more detailed feedback about the survey. The participant felt that the items about feelings of disgust and embarrassment did not fit her experience of living with continence issues. In fact, the participant thought the research would not help people with continence worries at all because the FOIQ made the assumption that people should feel disgusted and embarrassed. Although I felt upset that the participant was dissatisfied with the study, it provided an opportunity for me to reflect on the limitations of this project and determine what could be improved for future research. In hindsight, I felt it would be helpful to provide a space that would allow participants to share qualitative information relevant to the research project or any comments at the end of the survey. Moreover, it would have been helpful if I had run a small pilot study with older adults and/or, specifically, people with fear of incontinence. This would provide an opportunity to seek participants' opinions about the survey and address any potential limitations. Furthermore, as the participant highlighted that people around her are understanding and supportive, and she did not feel embarrassed about her continence issues, it would be interesting for future research to explore the effect of social support on fear of incontinence.

Another issue with conducting Internet research is the ethical consideration. The importance of this is reflected by the BPS Ethical Guideline for Internet Study (British Psychological Society, 2013). One issue that is particularly relevant to this project is the use of incomplete data. The lack of face-to-face contact meant that it was difficult to determine participants who exited the survey halfway through it after having provided consent for using the data that have already been stored on the survey platform. For this study, it was assumed that participants provided consent for using incomplete data unless they contacted us to withdraw their consent. According to the BPS Guideline, a more ideal setup would be to display a visible ‘exit’ or ‘withdraw’ button on each page of the survey, which would allow participants to indicate if they wish to withdraw their data. On reflection, the ‘withdraw’ option is currently not available on the Qualtrics, and it is a limitation of the package that should be addressed by Qualtrics developers. Hence, future online survey studies should incorporate this feature when building an online survey.

Design of the Internet Survey

As the empirical study aimed to expand prior fear of incontinence research conducted by Kamboj and the research team (Kamboj et al., 2015; Langhoff, 2013; Pajak et al., 2013), I decided the current study would include the same questionnaires that were previously used. One advantage of this is the option to combine the current dataset with the previous dataset in the study by Langhoff (2013). However, this puts a limitation on the questionnaires I was able to include. Furthermore, as the current study aimed to recruit older people (which was not the case for the previous study), I was unable to use another questionnaire that may be suitable for older adults. For example, the Activities of Daily Living Checklist could be a better measurement for functioning impairment in older people. An additional problem regarding the choice of questionnaire was the use of the Mobility Inventory for Agoraphobia (MIA). It was difficult to build a computer-friendly version of the MIA using Qualtrics. I attempted to build the questionnaire in various ways; however, I was unable to develop a layout that I was fully satisfied with. I considered replicating the paper version of the MIA by presenting it in a matrix table. However, this would not be a good idea for people using their mobile phones because the matrix table would be too large to fit on the screen of a mobile phone. As such, I ultimately decided to use a multiple-choice option for each item from the Mobility Inventory. Each item from the Mobility Inventory represented one situation (e.g. supermarket, buses), and participants had to rate how often they avoid that situation when they are alone and also when they are accompanied by another person. As the Mobility Inventory included 27 situations, this meant participants had to essentially answer 54 items for the MIA alone. From my own experience of completing the MIA, it felt more effortful to complete the online version of the MIA compared to the paper version. Therefore, it is possible that the layout of the Mobility Inventory led to more participants ending the survey early.

Data Analysis

One of the main aims of this study was to explore the mediating effect of avoidance on the relationship between fear of incontinence and depressive symptoms. This was tested using the causal steps approach by Baron and Kenny (1986). This approached has been widely used, but it has been criticised on several grounds. As described in the empirical paper, Baron and Kenny’s approach requires four conditions to be met in order to demonstrate the presence of a mediator variable; the first condition requires a significant relationship between the independent variable and the dependent variable (Baron & Kenny, 1986). However, researchers highlight that under certain circumstances, it is possible that a mediator can be present, despite the absence of a relationship between the independent variable and the dependent variable (Zhao, Lynch Jr, & Chen, 2010). This can be the case if there is a suppressing variable that has opposing effects and cancels out the effect of the mediator. Furthermore, simulation studies have demonstrated that the causal steps approach has the lowest power in testing the mediating effects in comparison to other methods for testing such as structural equation modelling (Fritz & MacKinnon, 2007; Hayes, 2009). In other words, if the effect of the independent variable on the dependent variable is due to the indirect effect of the mediator, the causal steps approach is the least likely to be able to detect this effect. Although the current study observed a significant relationship between fear of incontinence and depression, future research that aims to study mediation should consider the use of other statistical approaches in light of these limitations. One example is the bootstrap test, which is considered as rigorous and powerful by researchers (Zhao et al., 2010).

Final Reflection

My personal experience of conducting research goes back to my undergraduate studies and my first job as a research assistant for a psychosis project. However, this current project was the first time I had the opportunity to follow the entire process of conducting research, beginning with writing the proposal, applying for the ethics application and then completing the data collection and write-up. This was a challenging but fruitful experience. What was also different in the current project was that I did not have a partner, and therefore there were fewer opportunities for me to discuss any problems with others.

Although I had the experience of working with people with anxiety, I had no clinical experience working with people with fear of incontinence. From doing the research project, I developed a good understanding of fear of incontinence, how it can impact someone’s life and common strategies. In this study, it was found that many participants cope with fear of incontinence by noting the location of toilets when they are in public places. Given that this sample was based on online recruitment, I would be curious to explore whether people recruited from a clinical setting (presumably with more severe symptoms) would use similar coping strategies.

Furthermore, from doing this project, I grew more empathetic for people who have continence concerns given the impairment that is associated with it and how it is stigmatised, exemplified by the fact that some people expressed that this project would likely not be perceived well by the U3A members. The taboo nature of this topic is also reflected by the response I received when I spoke to others about my project; one healthcare professional even asked whether I arrived late for the research fair (and therefore ended up with this project!). Linking what I have learned from Part 1 of this thesis (the systematic review), I came across literature that suggested doctors had to prioritise other health conditions that are perceived as more urgent and important than continence issues (Jirschele, Ross, Goldberg, & Botros, 2015; Jirschele, Ross, Goldberg, & Botoros, 2015). I thus wondered whether in academia, researchers also choose to study other mental health issues that receive greater attention and are possibly less embarrassing. As such, fear of incontinence is a topic that has received very little attention thus far.

Conclusion

This critical appraisal highlighted that fear of incontinence is an interesting topic that warrants additional research in both younger and older adults. The embarrassing nature of this topic makes it potentially more difficult to recruit participants. Internet recruitment can overcome some of the barriers related to the stigma associated with continence issues or worries. However, there are other issues, such as reaching older adults through the Internet, ethical issues, the design of online surveys and managing the potential distress felt by participants completing the study.

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Appendices

Appendix A

Table A1

Table showing the appraisal for quantitative studies using the appraisal list for surveys (Crombie, 1996)

	Berger	**da Silver**	**Duralde**	**Elbiss**
Who was studied?	290 women, 25-64 years old	23 women, 21-76 years old	435 women, 40-80 years old	92 women, 30+ years old
How was the sample obtained?	Community, purposeful/convenience sampling, participants were identified through telephone records and invitation were sent.	Healthcare, convenience sampling, recruited participants who attended oncotic cytology exam	Healthcare, purposeful sampling of participants enrolled a health system	?Community, convenience sampling of participants attended family development foundation
What was the response rate?	69%	NS	NS	NS
Are the aims clearly stated?	Yes	Yes	Yes	Yes
Design appropriate to the stated objectives?	Yes	Yes	Yes	Yes
Was the sample size justified?	Yes	No	Yes	Yes
Measurements likely to be valid and reliable?	No	No	No	No
Are the statistical methods described?	Yes	Yes	Yes	Yes
Is there a suggestion of haste?	No	No	No	No
Did untoward events occur during the study?	No	No	No	No
Were the basic data adequately described?	Yes	Yes	Yes	Yes
Do the numbers add up?	Yes	Yes	Yes	Yes
Was the statistical significance assessed?	-	-	-	-
Were the findings serendipitous?	-	-	-	-
What do the main findings mean?	-	-	-	-
How could selection bias arise?	Convenience sampling	Possible selection biased, approached women attended oncotic cytology exam.	Possible selection biased, participants recruited from healthcare setting	Convenience sampling, recruited from family development foundation
How are null findings interpreted?	-	-	-	-
Are important effects overlooked?	Possible, did not report what other reasons for not seeking help	No	No	No
Can the results be generalised?	Yes	Difficult to conclude due to small sample size and unclear response rate	Yes, but should be done with caution	Yes, but should be done with caution
How do the results compare with previous reports?	-	-	-	-
Implications for your practice?	-	-	-	-

	Kumari	**Luo**	**Margalith**	**Perera**
Who was studied?	220 women, 18+ years old	81 women, 21+ years old	118 women, 22-65 years old	81 women, 20+ years old
How was the sample obtained?	Community, systematic sampling of participants from an area	Healthcare service, convenience sample of participants attended ear-nose-throat outpatient clinics of a hospital	Healthcare service, convenience sampling, participants attended a urology or gynecourology clinic	Healthcare service, convenience sampling, participants attended an outpatient unit in the hospital
What was the response rate?	95.6%	61%	99%	NS
Are the aims clearly stated?	Partial	Yes	Yes	Partial
Design appropriate to the stated objectives?	Yes	Yes	Yes	Yes
Was the sample size justified?	Yes	Partial	Yes	Yes
Measurements likely to be valid and reliable?	No	No	No	No
Are the statistical methods described?	Yes	Yes	Yes	Yes
Is there a suggestion of haste?	No	No	No	No
Did untoward events occur during the study?	No	No	No	No
Were the basic data adequately described?	No	Yes	Yes	Yes
Do the numbers add up?	Yes	Yes	Yes	Yes
Was the statistical significance assessed?	-	-	-	-
Were the findings serendipitous?	-	-	-	-
What do the main findings mean?	-	-	-	-
How could selection bias arise?	No	Convenience sample recruited from a outpatient clinic at a hospital	Convenience sample recruited from a healthcare service	Convenience sample recruited from healthcare services
How are null findings interpreted?	No	No	No	No
Are important effects overlooked?	Yes	Yes, but should be done with caution	Yes	Yes, but should be done with caution
Can the results be generalised?	-	-	-	-
How do the results compare with previous reports?	-	-	-	-

	Prabhu	**Saleh**	**Tomoe**	**Visser**
Who was studied?	90 women, 20+ years old	798 women, 45-65 years old	153 women 28-89 years old	225 women, 55+ years old
How was the sample obtained?	Community, randomly sampled participants from a village	Healthcare service, randomly sampling among patients attended 11 primary healthcare clinics	?Community, convenience sampling of participants attended the lectures	Healthcare service, convenience sampling, participants recruited from a larger RCT study, where the original sample were obtained from general practices
What was the response rate?	NS	79.8%	NS	NS
Are the aims clearly stated?	Partial	Yes	Yes	Yes
Design appropriate to the stated objectives?	Yes	Yes	Yes	Yes
Was the sample size justified?	Yes	Yes	Yes	Yes
Measurements likely to be valid and reliable?	No	No	No	No
Are the statistical methods described?	Yes	Yes	Yes	Yes
Is there a suggestion of haste?	No	No	No	No
Did untoward events occur during the study?	No	No	No	No
Were the basic data adequately described?	Yes	No	No	Yes
Do the numbers add up?	Yes	No	Yes	Yes
Was the statistical significance assessed?	-	-	-	-
Were the findings serendipitous?	-	-	-	-
What do the main findings mean?	-	-	-	-
How could selection bias arise?	Difficult to conclude- unclear response rate	Participants recruited from healthcare services	Participants recruited from lectures	Convenience sample recruited from hospital
How are null findings interpreted?	No	No	No	No
Are important effects overlooked?	Yes	Yes, but should be done with caution	Yes, but should be done with caution	Yes, but should be done with caution
Can the results be generalised?	-	-	-	-
How do the results compare with previous reports?	-	-	-	-

	Wojtowicz
Who was studied?	141 women, 26-81 years old
How was the sample obtained?	Community/ healthcare service, ?convenience sampling, participants were part of a UI association or attended urodynamic clinic at a hospital or underwent urodynamic testing or the electro stimulation
What was the response rate?	NS
Are the aims clearly stated?	Yes
Is the design appropriate to the stated objectives?	Yes
Was the sample size justified?	Yes
Are the measurements likely to be valid and reliable?	No
Are the statistical methods described?	Yes
Is there a suggestion of haste?	No
Did untoward events occur during the study?	No
Were the basic data adequately described?	Yes
Do the numbers add up?	Yes
Was the statistical significance assessed?	-
Were the findings serendipitous?	-
What do the main findings mean?	-
How could selection bias arise?	Convenience sampling method
Are important effects overlooked?	No
Can the results be generalised?	Yes, but should be done with caution
How do the results compare with previous reports?	-
What implications does the study have for your practice?	-

Table A2

Table showing the appraisal for qualitative studies using the CASP(Critical Appraisal Skills Programme, 2018)

	Hagglund 2003	Hagglund 2007	Horrocks
1.Was there a clear statement of the aims of the research?	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes, although the research did not justify the research design, it appears to be appropriate.	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes, participants were recruited from an earlier study.	Yes, participants were recruited from an earlier study.
5. Was the data collected in a way that addressed the research issue?	Yes	Yes	Yes, the data were collected through semi-structured interviews.
6. Has the relationship between researcher and participants been adequately considered?	No, the research did not examine their own role, potential bias and influence during the process of conducting the research.	No, the research did not examine their own role, potential bias and influence during the process of conducting the research.	No, the research did not examine their own role, potential bias and influence during the process of conducting the research.
7. Have ethical issues been taken into consideration?	Can't tell, the study sought ethics approval, though did not provide details on how the research was explained to participants.	Can't tell, the study sought ethics approval, though did not provide details on how the research was explained to participants.	Can't tell, the study sought ethics approval, though did not provide details on how the research was explained to participants.
8. Was the data analysis sufficiently rigorous?	Yes, the author employed content analysis.	Yes, the author provided sufficient information on the data analysis process and sufficient data to support finding. However, it was noted that the researcher did not critically examine their own role and potential bias.	Yes, the author provided sufficient information on the data analysis process and sufficient data to support finding. However, it was noted that the researcher did not critically examine their own role and potential bias.
9. Is there a clear statement of findings?	Yes, the findings are explicit, but the research did not provide information on the credibility of the findings.	Yes, there was more than one analyst.	Yes, analysis was checked by another researcher, and was validated by writing to participants detailing the main points arising from their interviews, and asking for corrections.
10. How valuable is the research?	Research did not discuss the findings on barriers in relation to the existing knowledge and relevant future research.	Research discussed findings in relation of current research, future research, and clinical implication for nurses.	Researchers discussed the implication of the research (i.e. address issues around lack of information about incontinence)

	Mallet	Siddiqui	Tennissen
1.Was there a clear statement of the aims of the research?	Yes	Yes	Yes
2. Is a qualitative methodology appropriate?	Yes. However, the research does not explore the subjective experiences of participants	Yes	Yes
3. Was the research design appropriate to address the aims of the research?	Yes	Yes	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes	Yes, participants recruited via flyers and outreach in medical centres and local community centres.	Can't tell, participants were recruited via several GP practices, and they were not purposefully selected.
5. Was the data collected in a way that addressed the research issue?	Yes, the data was collected through open response from a survey.	Yes, data was collected using focus groups.	Yes, data was collected using interviews.
6. Has the relationship between researcher and participants been adequately considered?	No, the research did not examine their own role, potential bias and influence during the process of conducting the research.	No, the research did not examine their own role, potential bias and influence during the process of conducting the research.	No, the research did not examine their own role, potential bias and influence during the process of conducting the research.
7. Have ethical issues been taken into consideration?	Can't tell, the study sought ethics approval, though did not provide details on how the research was explained to participants.	Can't tell, the study sought ethics approval, though did not provide details on how the research was explained to participants.	Can't tell, the study sought ethics approval, though did not provide details on how the research was explained to participants.
8. Was the data analysis sufficiently rigorous?	Yes, themes were derived from the data, though the author did not provide detail on the analysis process.	Yes, the author provided sufficient information on the data analysis process and sufficient data to support finding. However, it was noted that the researcher did not critically examine their own role and potential bias.	Can't tell, the research did not explain how the data present were selected from the original sample to demonstrate the analysis process.
9. Is there a clear statement of findings?	Yes, the findings are explicit, however, the research did not discuss the credibility of their findings.	Yes, there was more than one analyst.	Yes, more than one researcher conducted the coding.
10. How valuable is the research?	The findings were discussed in relation to relevant research and made suggestions on what to change for current practice, however, did not identify new research areas.	The findings were discussed in relation to relevant research and made suggestions on what to change for current practice (educational strategies to increase knowledge about UI), however, did not identify new research areas.	The implication of the research was discussed for male were particularly discussed.

	Vethanayagam
1.Was there a clear statement of the aims of the research?	Yes
2. Is a qualitative methodology appropriate?	Yes
3. Was the research design appropriate to address the aims of the research?	Yes
4. Was the recruitment strategy appropriate to the aims of the research?	Yes
5. Was the data collected in a way that addressed the research issue?	Yes, data was collected using semi-structured interview.
6. Has the relationship between researcher and participants been adequately considered?	No, the research did not examine their own role, potential bias and influence during the process of conducting the research.
7. Have ethical issues been taken into consideration?	Can’t tell, the study sought ethics approval, though did not provide details on how the research was explained to participants.
8. Was the data analysis sufficiently rigorous?	Yes, the data analysis process was sufficiently described but the research did not examine their own role or bias when selecting data for presentation.
9. Is there a clear statement of findings?	Yes, two researchers were involved in data analysis, and data coding was reviewed by another researcher.
10. How valuable is the research?	The research discussed implication for GP practice in improving the care for incontinence problems in older adults.

Appendix B- Additional Questionnaires

The following questionnaires were completed by participants who took part the second phase of the Langhoff (2013) study.

Obsessive Compulsive Inventory-Short Version (OCI-SV)

The OCI-SV (Foa et al., 2002) is an 18-item self-report measure of symptoms on obsessive compulsive disorder (e.g. ‘I check things more often than necessary’). Each item is scored on a scale from 0 (‘Not at all’) to 4 (‘Extremely’), providing a severity score ranges from 0 to 72. The OCI-SV has good internal consistency with Cronbach’s alpha coefficients ranging from .81 to .93, and test-retest reliability with ICC ranging from .74 to .91 (Foa et al., 2002).

Social Phobia Inventory (SPIN)

The SPIN (Connor et al., 2000) is a 17-item self-report measure designed to measure symptoms associated with social phobia (e.g. ‘I am afraid of people in authority’, ‘Parties and social events scare me’.) Each item is scored from 0 (‘Not at all’) to 4 (‘Extremely’) with a total score ranges from 0 to 68. The SPIN has good internal consistency with Cronbach’s alpha coefficients of .87 to .94 and .82 to .90, and test-retest reliability ICC= .78 and .89 (Connor et al., 2000).

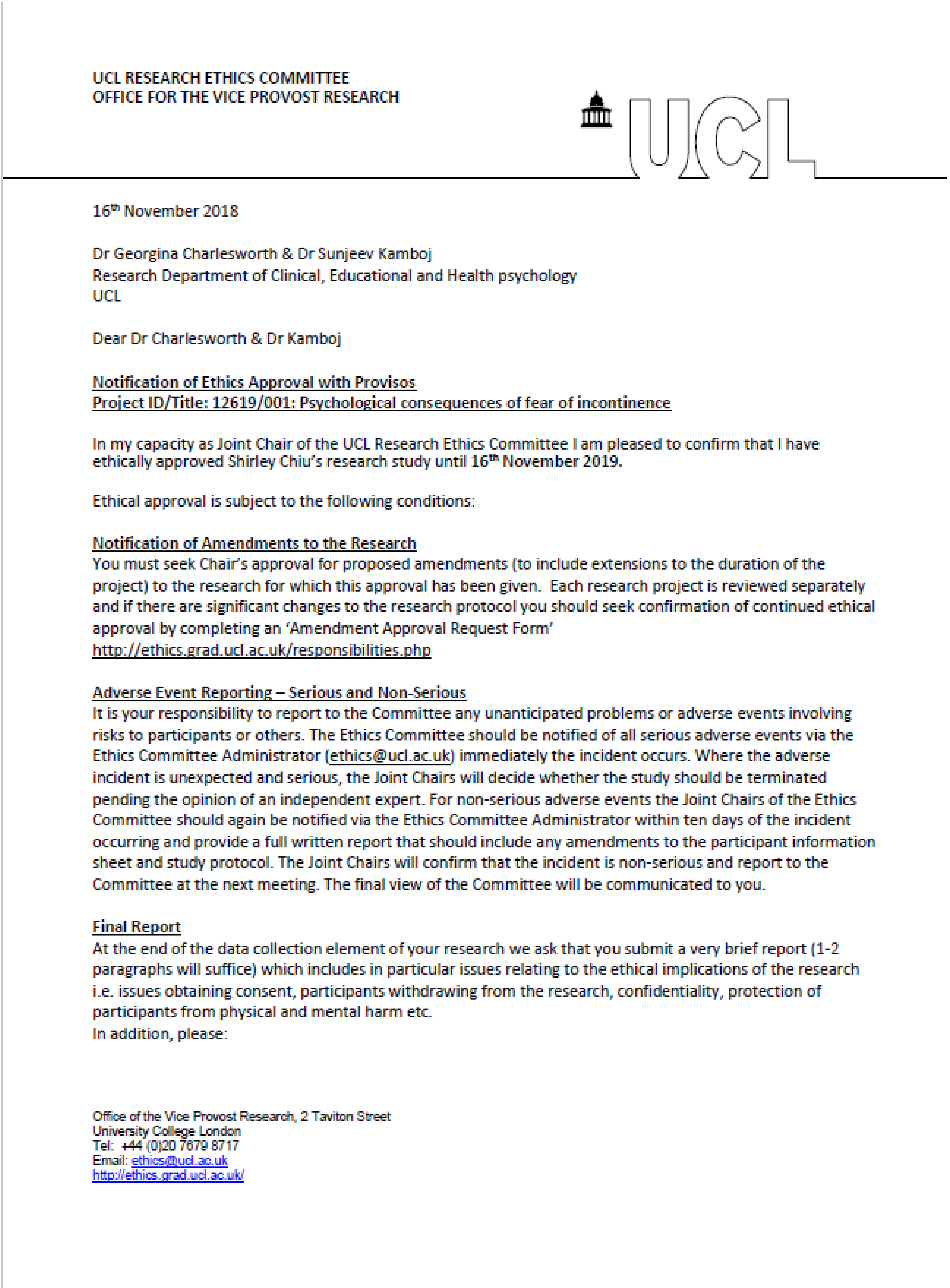
Disgust Propensity and Sensitivity Scale-Revised (DPSS-R)

The DPSS-R (Olatunji, Cisler, Deacon, Connolly, & Lohr, 2007) is a 16-item self-report measure, assessing the tendency to experience disgust in a variety of situations (disgust propensity e.g. ‘I experience disgust’) and the emotional impact of disgust experiences (disgust sensitivity e.g. ‘I think feeling disgust is bad for me’). Items are rated using a 5-point scale ranging from 1 (‘Never’) to 5 (‘Always’), with a total score ranging from 16 to 80. The DPSS-R has been demonstrated to have excellent internal consistency with Cronbach’s alpha of .90. The ICC for test-retest reliability for the disgust propensity subscale and the disgust sensitivity subscale were.69 and .77, respectively (Olatunji et al., 2007).

Internalised Shame Scale (ISS)

The ISS (Cook, 2001) is a 30-item self-report measure of internalised shame (e.g. ‘When I compare myself to others I am just not as important.’) Items are rated using a 5-point scale ranging from 0 (‘Never’) to 4 (‘Almost always’). It provides two scores for the subscale of self-esteem and shame, and a total severity score that ranges from 0 to 120. The ISS has good internal consistency, with Cronbach’s alpha ranging from .88 to .96. The test-retest reliability measured using ICC were .75 and .81 (Del Rosario & White, 2006).

Appendix C- Ethics Approval Letter



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

16th November 2018

Dr Georgina Charlesworth & Dr Sunjeev Kamboj
Research Department of Clinical, Educational and Health psychology
UCL

Dear Dr Charlesworth & Dr Kamboj

Notification of Ethics Approval with Provisos
Project ID/Title: 12619/001: Psychological consequences of fear of incontinence

In my capacity as Joint Chair of the UCL Research Ethics Committee I am pleased to confirm that I have ethically approved Shirley Chiu's research study until **16th November 2019.**

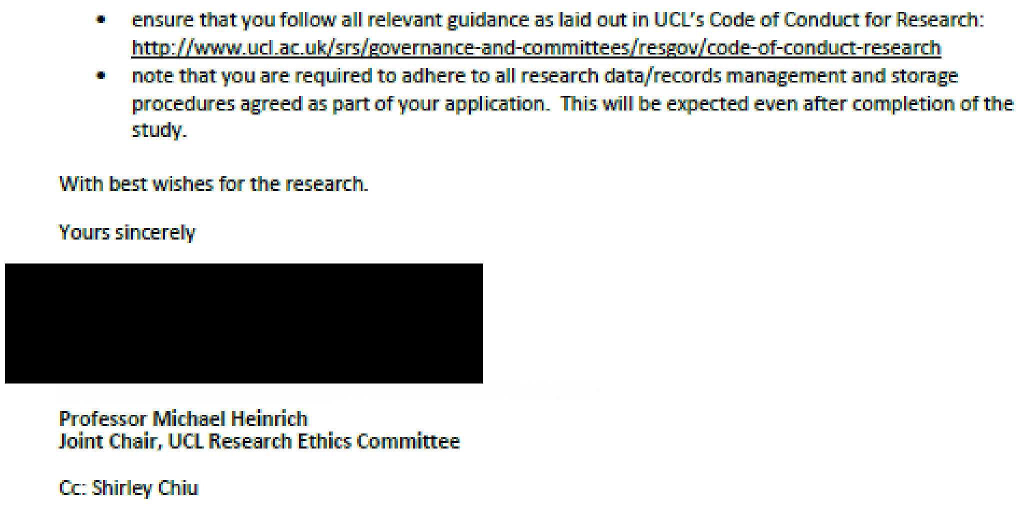
Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.
In addition, please:

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/



- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Cc: Shirley Chiu

Appendix D- Advert Flyer

DEPARTMENT OF CLINICAL, EDUCATIONAL
AND HEALTH PSYCHOLOGY

UCL

Do you worry about losing control of your bowels or bladder?

We are recruiting participants to study the impact of worrying about continence issues on mood and daily activities. This study involves completing an **online** anonymous survey, which should take about **20-25 minutes.**

Your participation will help contribute to a donation of £200 to Bladder Health UK!

Are you:

- Aged 18 years or above
- Worrying about losing control of your bowels or bladder
- Living in the UK

If you want to access the survey link, follow https://goo.gl/ue8azE

Or follow our Facebook page: Fear of Incontinence_UCL https://www.facebook.com/fearofincontinence/

If you have further questions, please email shirley.chiu.16@ucl.ac.uk

UCL Ethics Committee Approval (ID: 12619/001)

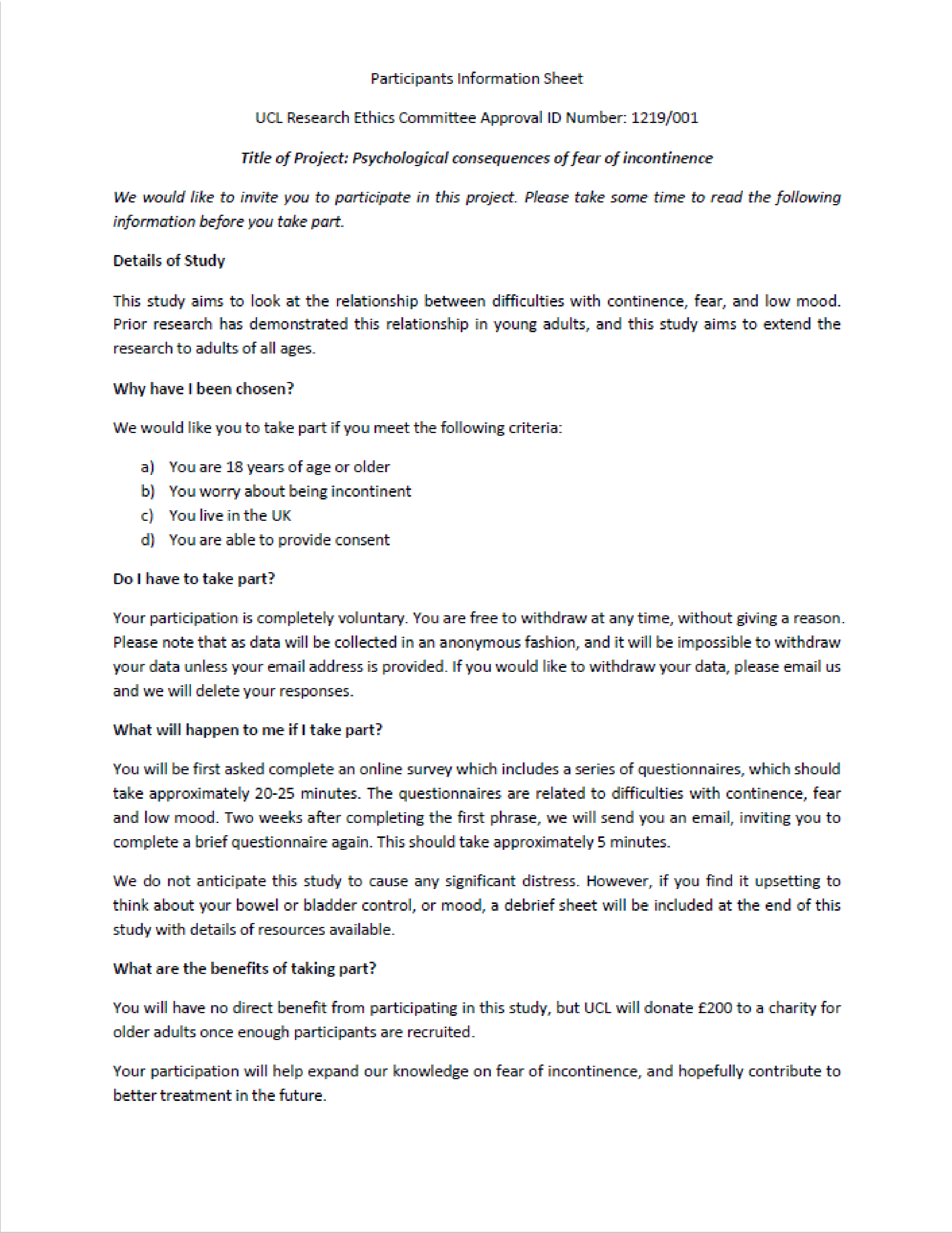
Appendix E- Recruitment Strategies

A summary of recruitment strategies targeting adults of all ages:

	Current study	Langhoff’s study (2013)
Facebook Groups/Page	Anxiety Disorders Anxiety & Panic Attack Support (UK only) Medical Incontinence Support LIBBI UK - Leaks, incontinence, bladder and bowel issues Ibs support group uk Irritable Bowel Syndrome IBS support group IBS (Irritable Bowel Syndrome) and Anxiety Support Group Incontinence Support OAB support group Bladder and Bowel Community Support Group UK Congestive Heart Failure Support Group Advantages of Age Older is wiser Contact the elderly Born in the 60s Grew up in the 70s Gransnet Silver user Over 60s Friendship Group UK	Understanding Fear of Incontinence – Research Project (Created Own Page) Incontinent Friends Incontinence Support Group Incontinence Support and Discussions Adult Incontinence Community Irritable Bowel Syndrome Self Help and Support Group Discussions Agoraphobia Anxiety UK BEAT anxiety Support for mental illness Toilet Phobia Coprophobia… Social Anxiety and Social Phobia and Agoraphobia Support Group Shy Bladder Syndrome Support Group Being completely unable to pee when someone else is near (a.k.a Pee -shy)
Online Forums	Anxiety UK* United Kingdom Paruresis* No More panic* Talkhealth – Continence Fourm Healthunlocked (IBS, diabetes, anxiety and invisible illness page) Incontinence Forum The Student Room Reddit Pensioners Forum Over50s Forum Gransnet	Anxiety UK United Kingdom Paruresis Trust No More Panic OCD Action oFear – Anxiety and Phobia Forum Shy Bowel Anxiety Care UK No Panic Anxiety Forum Anxiety Zone Mental Health Forum
Others	Bladder Health UK Anxiety UK U3A Age UK Twitter Facebook advertisement UCL newsletter Local libraries and local cafe	Gumtree Twitter UCL Announce – UCL based advertisement system

Note: *Langhoff (2013) used the same platform for data collection

Appendix F- Information Sheet



Participants Information Sheet

UCL Research Ethics Committee Approval ID Number: 1219/001

Title of Project: Psychological consequences of fear of incontinence

We would like to invite you to participate in this project. Please take some time to read the following information before you take part.

Details of Study

This study aims to look at the relationship between difficulties with continence, fear, and low mood. Prior research has demonstrated this relationship in young adults, and this study aims to extend the research to adults of all ages.

Why have I been chosen?

We would like you to take part if you meet the following criteria:

a) You are 18 years of age or older
b) You worry about being incontinent
c) You live in the UK
d) You are able to provide consent

Do I have to take part?

Your participation is completely voluntary. You are free to withdraw at any time, without giving a reason. Please note that as data will be collected in an anonymous fashion, and it will be impossible to withdraw your data unless your email address is provided. If you would like to withdraw your data, please email us and we will delete your responses.

What will happen to me if I take part?

You will be first asked complete an online survey which includes a series of questionnaires, which should take approximately 20-25 minutes. The questionnaires are related to difficulties with continence, fear and low mood. Two weeks after completing the first phrase, we will send you an email, inviting you to complete a brief questionnaire again. This should take approximately 5 minutes.

We do not anticipate this study to cause any significant distress. However, if you find it upsetting to think about your bowel or bladder control, or mood, a debrief sheet will be included at the end of this study with details of resources available.

What are the benefits of taking part?

You will have no direct benefit from participating in this study, but UCL will donate £200 to a charity for older adults once enough participants are recruited.

Your participation will help expand our knowledge on fear of incontinence, and hopefully contribute to better treatment in the future.

Will my taking part in this project be kept confidential?

All data will be handled in accordance with the General Data Protection Regulation (see below), meaning that all information will be handled in confidence. You will be given a participant number for identification, and all contact information provided will be kept separate from study data. All responses will be anonymous.

Confidentiality will be maintained, but may be limited and conditional as the researcher has a duty of care to contact relevant authorities in the case of possible harm and danger to any person.

What will happen to the results of the research study?

The research will be part of my Doctorate in Clinical Psychology thesis, and may be published in psychology journals or used in scientific reports. If you would like a copy of the results, please email us after participating. You will not be identified in any publication.

Data Protection Privacy Notice
Notice:
The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data.

The legal basis that would be used to process your *personal data* will be performance of a task in the public interest. The legal basis used to process *special category personal data* will be for scientific research.

Your personal data will be processed so long as it is required for the research project. We are anticipating that this will be September 2019. The personal data (i.e. your email) will be deleted once the project is completed. All your data will be kept anonymous. The anonymised data will be kept for 10 years after the project ends.

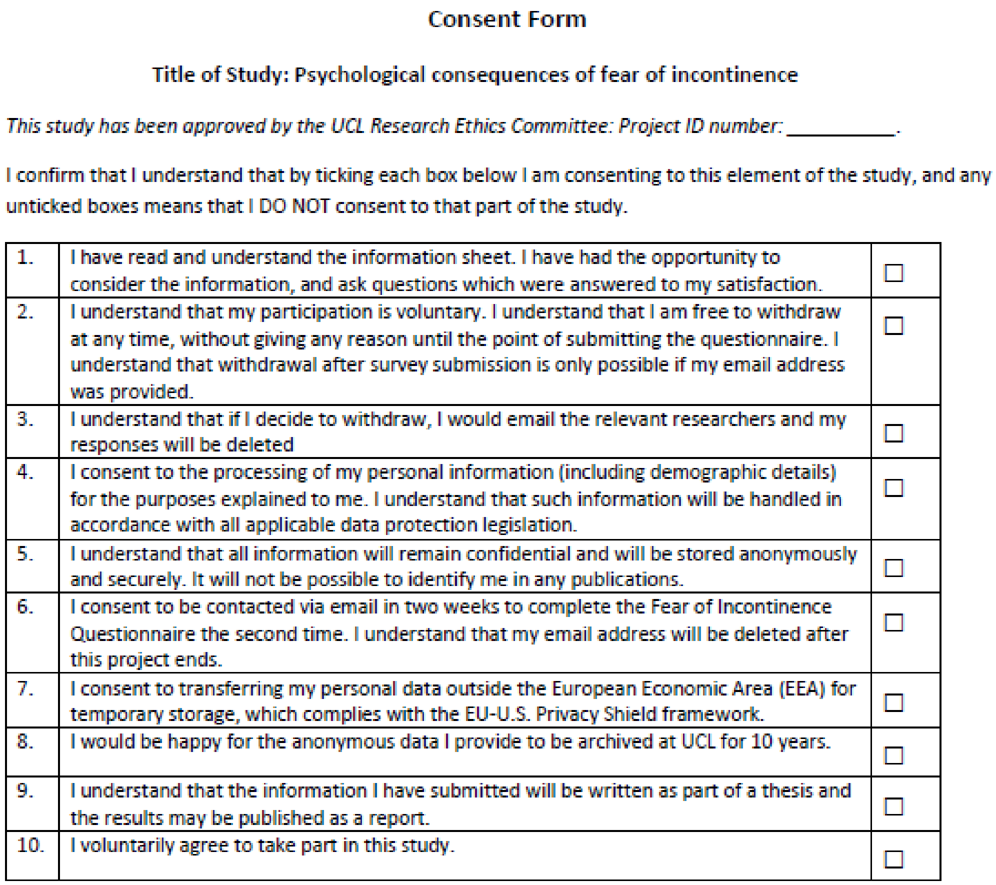
If you have any concerns or queries, you may contact the Data Protection Office and Officer at data-protection@ucl.ac.uk**.** If you remain unsatisfied, you may contact the ICO. Contact details, and further details of data subject rights, please see: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Contact Details
If you would like more information or have any concerns, you may contact: Shirley Chiu, Trainee Clinical Psychologist, UCL: shirley.chiu.16@ucl.ac.uk

Or you may contact others involved in the research: Dr Georgina Charlesworth, Senior Lecturer, UCL: g.charlesworth@ucl.ac.uk or Dr Sunjeev Kamboj, Reader, UCL: sunjeev.kamboj@ucl.ac.uk

Thank you for reading this information sheet and consideration of participating in this research study.

Appendix G- Consent Form



Consent Form

Title of Study: Psychological consequences of fear of incontinence

This study has been approved by the UCL Research Ethics Committee: Project ID number: __________.

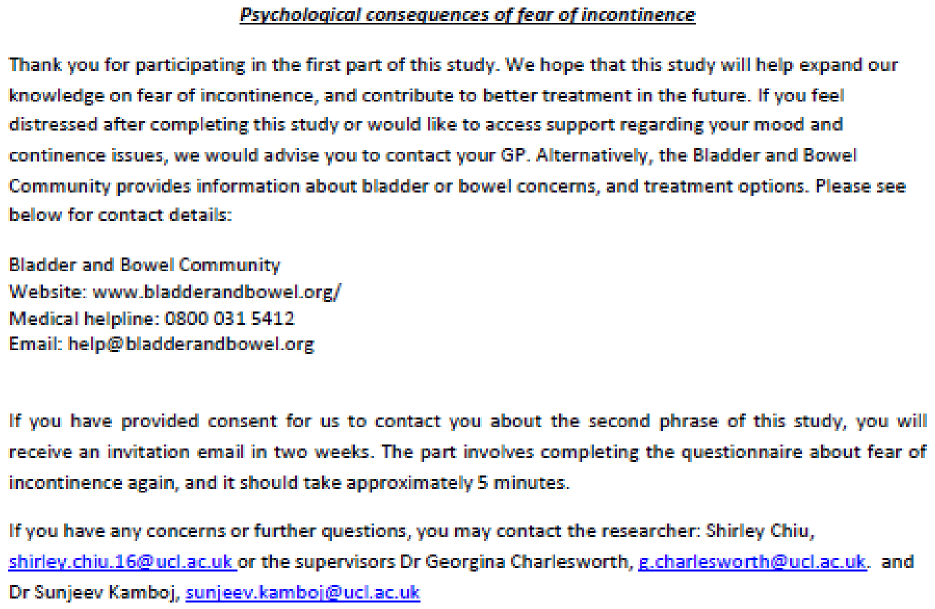
I confirm that I understand that by ticking each box below I am consenting to this element of the study, and any unticked boxes means that I DO NOT consent to that part of the study.

1.	I have read and understand the information sheet. I have had the opportunity to consider the information, and ask questions which were answered to my satisfaction.	☐
2.	I understand that my participation is voluntary. I understand that I am free to withdraw at any time, without giving any reason until the point of submitting the questionnaire. I understand that withdrawal after survey submission is only possible if my email address was provided.	☐
3.	I understand that if I decide to withdraw, I would email the relevant researchers and my responses will be deleted	☐
4.	I consent to the processing of my personal information (including demographic details) for the purposes explained to me. I understand that such information will be handled in accordance with all applicable data protection legislation.	☐
5.	I understand that all information will remain confidential and will be stored anonymously and securely. It will not be possible to identify me in any publications.	☐
6.	I consent to be contacted via email in two weeks to complete the Fear of Incontinence Questionnaire the second time. I understand that my email address will be deleted after this project ends.	☐
7.	I consent to transferring my personal data outside the European Economic Area (EEA) for temporary storage, which complies with the EU-U.S. Privacy Shield framework.	☐
8.	I would be happy for the anonymous data I provide to be archived at UCL for 10 years.	☐
9.	I understand that the information I have submitted will be written as part of a thesis and the results may be published as a report.	☐
10.	I voluntarily agree to take part in this study.	☐

Appendix H- Eligibility Criteria

Eligibility criteria	
Current study: 2018-2019 dataset	Langhoff (2013) study: 2011-2013 dataset
• Aged 18 years of above	• Aged between 18 and 65 years
• Have concerns around losing control of bladder and bowels	• Can proficiently read and write English
• Live in the UK	
• Able to provide consent	

Appendix I- Debrief Sheet for Baseline



Psychological consequences of fear of incontinence

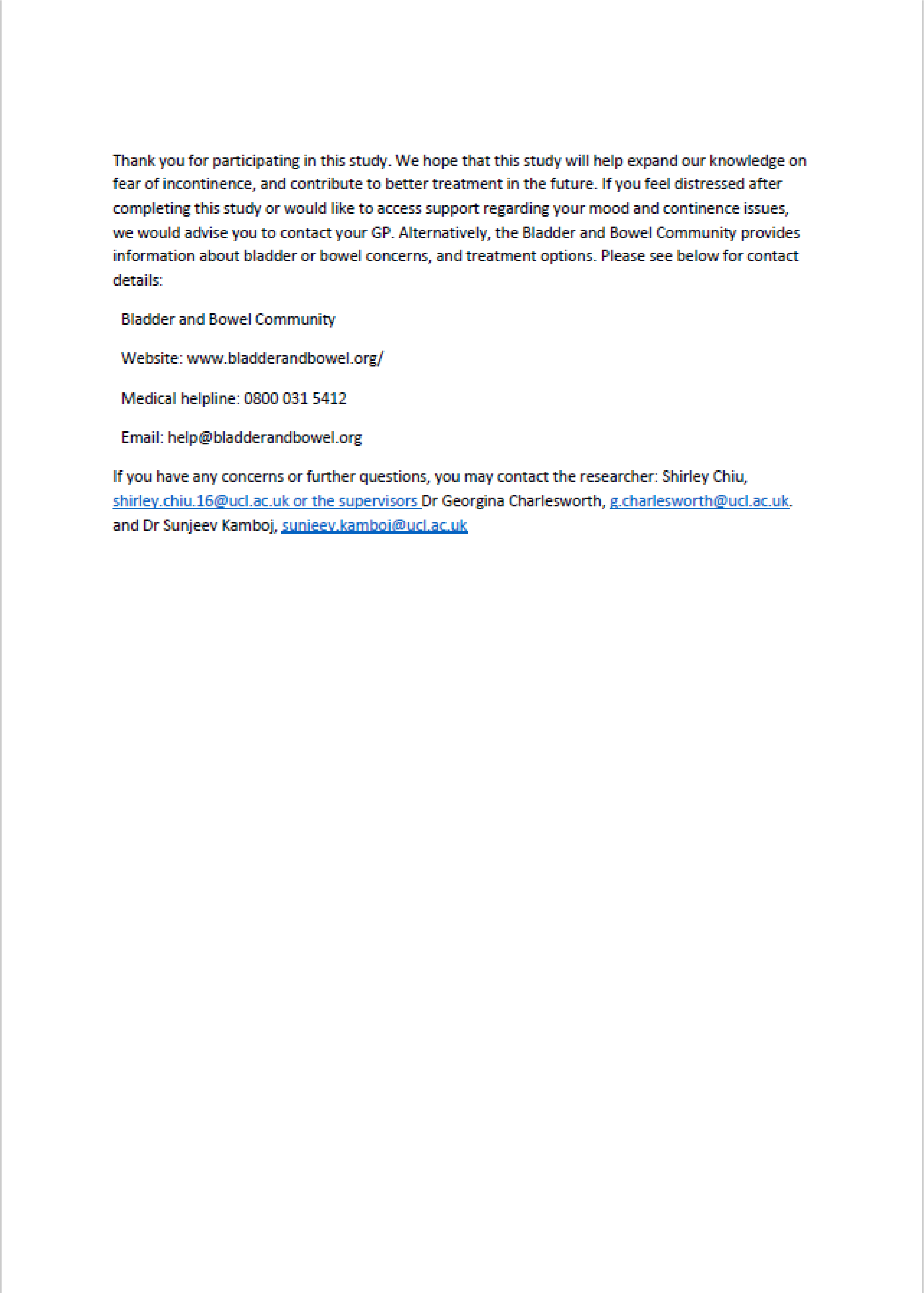
Thank you for participating in the first part of this study. We hope that this study will help expand our knowledge on fear of incontinence, and contribute to better treatment in the future. If you feel distressed after completing this study or would like to access support regarding your mood and continence issues, we would advise you to contact your GP. Alternatively, the Bladder and Bowel Community provides information about bladder or bowel concerns, and treatment options. Please see below for contact details:

Bladder and Bowel Community
Website: www.bladderandbowel.org/
Medical helpline: 0800 031 5412
Email: help@bladderandbowel.org

If you have provided consent for us to contact you about the second phrase of this study, you will receive an invitation email in two weeks. The part involves completing the questionnaire about fear of incontinence again, and it should take approximately 5 minutes.

If you have any concerns or further questions, you may contact the researcher: Shirley Chiu, shirley.chiu.16@ucl.ac.uk or the supervisors Dr Georgina Charlesworth, g.charlesworth@ucl.ac.uk. and Dr Sunjeev Kamboj, sunjeev.kamboj@ucl.ac.uk

Debrief sheet for follow-up:



Thank you for participating in this study. We hope that this study will help expand our knowledge on fear of incontinence, and contribute to better treatment in the future. If you feel distressed after completing this study or would like to access support regarding your mood and continence issues, we would advise you to contact your GP. Alternatively, the Bladder and Bowel Community provides information about bladder or bowel concerns, and treatment options. Please see below for contact details:

Bladder and Bowel Community

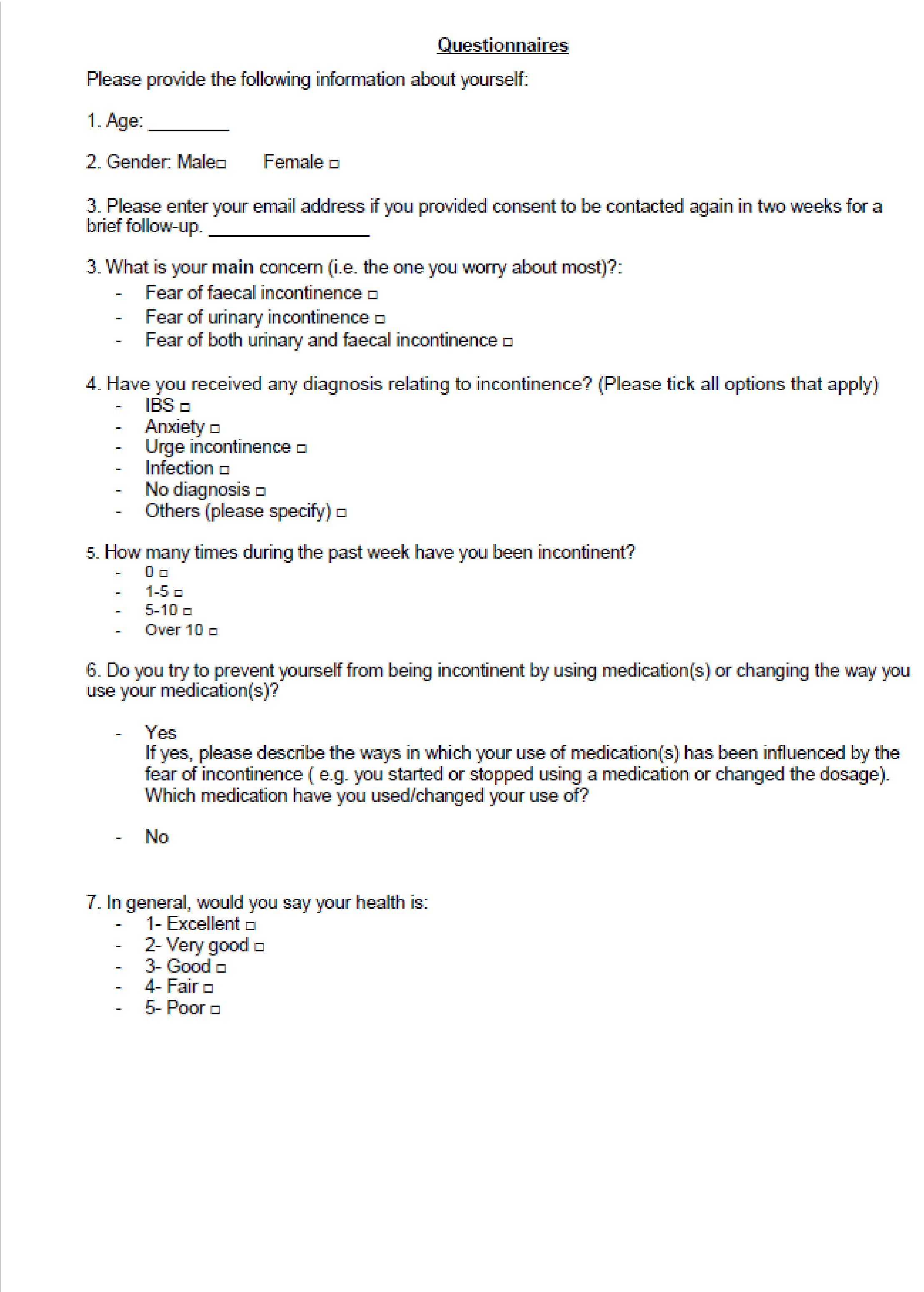
Website: www.bladderandbowel.org/

Medical helpline: 0800 031 5412

Email: help@bladderandbowel.org

If you have any concerns or further questions, you may contact the researcher: Shirley Chiu, shirley.chiu.16@ucl.ac.uk or the supervisors Dr Georgina Charlesworth, g.charlesworth@ucl.ac.uk. and Dr Sunjeev Kamboj, sunjeev.kamboj@ucl.ac.uk

Appendix J- A Copy of the Included Questionnaires



Questionnaires

Please provide the following information about yourself:

1. Age: ________

2. Gender: Male☐ Female ☐

3. Please enter your email address if you provided consent to be contacted again in two weeks for a brief follow-up. ________________

3. What is your **main** concern (i.e. the one you worry about most)?:
- Fear of faecal incontinence ☐
- Fear of urinary incontinence ☐
- Fear of both urinary and faecal incontinence ☐

4. Have you received any diagnosis relating to incontinence? (Please tick all options that apply)
- IBS ☐
- Anxiety ☐
- Urge incontinence ☐
- Infection ☐
- No diagnosis ☐
- Others (please specify) ☐

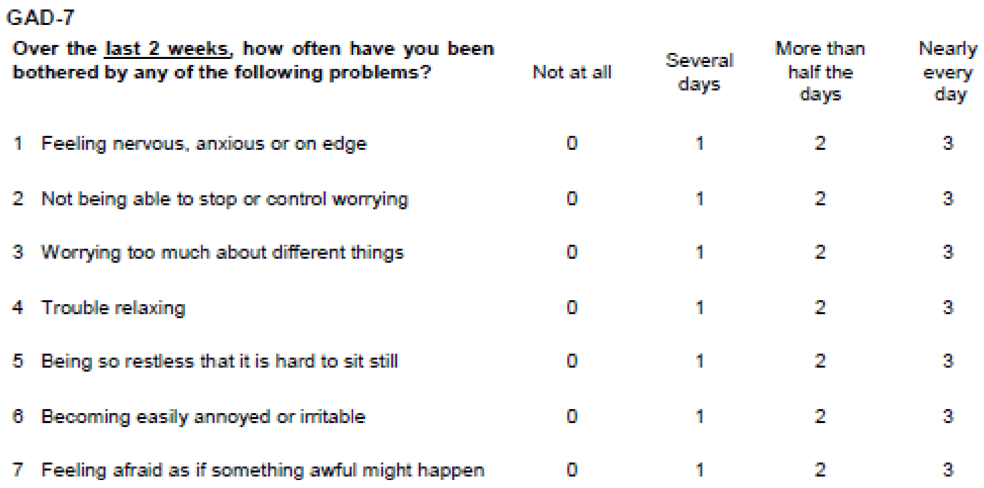
5. How many times during the past week have you been incontinent?
- 0 ☐
- 1-5 ☐
- 5-10 ☐
- Over 10 ☐

6. Do you try to prevent yourself from being incontinent by using medication(s) or changing the way you use your medication(s)?

- Yes
  If yes, please describe the ways in which your use of medication(s) has been influenced by the fear of incontinence (e.g. you started or stopped using a medication or changed the dosage). Which medication have you used/changed your use of?

- No

7. In general, would you say your health is:
- 1- Excellent ☐
- 2- Very good ☐
- 3- Good ☐
- 4- Fair ☐
- 5- Poor ☐



GAD-7

Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1 Feeling nervous, anxious or on edge	0	1	2	3
2 Not being able to stop or control worrying	0	1	2	3
3 Worrying too much about different things	0	1	2	3
4 Trouble relaxing	0	1	2	3
5 Being so restless that it is hard to sit still	0	1	2	3
6 Becoming easily annoyed or irritable	0	1	2	3
7 Feeling afraid as if something awful might happen	0	1	2	3

PHQ- 9

	Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1	Little interest or pleasure in doing things	0	1	2	3
2	Feeling down, depressed, or hopeless	0	1	2	3
3	Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4	Feeling tired or having little energy	0	1	2	3
5	Poor appetite or overeating	0	1	2	3
6	Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7	Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8	Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9	Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

MOBILITY INVENTORY

1. Please indicate the degree to which you avoid the following places or situations because of discomfort or anxiety. Rate your amount of avoidance when you are with a trusted companion and when you are alone. Do this by using the following scale:

1	2	3	4	5
never avoid	rarely avoid	avoid about half of the time	avoid most of the time	always avoid

Circle the number for each situation or place under both conditions: when accompanied and when alone. Leave blank situations that do not apply to you.

PLACES	WHEN ACCOMPANIED					WHEN ALONE				
Theaters	1	2	3	4	5	1	2	3	4	5
Supermarkets	1	2	3	4	5	1	2	3	4	5
Shopping malls	1	2	3	4	5	1	2	3	4	5
Classrooms	1	2	3	4	5	1	2	3	4	5
Department stores	1	2	3	4	5	1	2	3	4	5
Restaurants	1	2	3	4	5	1	2	3	4	5
Museums	1	2	3	4	5	1	2	3	4	5
Elevators	1	2	3	4	5	1	2	3	4	5
Auditoriums/stadiums	1	2	3	4	5	1	2	3	4	5
Garages	1	2	3	4	5	1	2	3	4	5
High Places	1	2	3	4	5	1	2	3	4	5
Please tell how high										
Enclosed spaces	1	2	3	4	5	1	2	3	4	5
OPEN SPACES	**WHEN ACCOMPANIED**					**WHEN ALONE**				
Outside (for example: fields, wide streets, courtyards)	1	2	3	4	5	1	2	3	4	5
Inside (for example, large rooms, lobbies)	1	2	3	4	5	1	2	3	4	5
RIDING IN	**WHEN ACCOMPANIED**					**WHEN ALONE**				
Buses	1	2	3	4	5	1	2	3	4	5
Trains	1	2	3	4	5	1	2	3	4	5
Subways	1	2	3	4	5	1	2	3	4	5
Airplanes	1	2	3	4	5	1	2	3	4	5
Boats	1	2	3	4	5	1	2	3	4	5
DRIVING OR RIDING IN A CAR	**WHEN ACCOMPANIED**					**WHEN ALONE**				
At anytime	1	2	3	4	5	1	2	3	4	5
On expressways	1	2	3	4	5	1	2	3	4	5
SITUATIONS	**WHEN ACCOMPANIED**					**WHEN ALONE**				
Standing in lines	1	2	3	4	5	1	2	3	4	5
Crossing bridges	1	2	3	4	5	1	2	3	4	5
Parties or social gatherings	1	2	3	4	5	1	2	3	4	5
Walking on the street	1	2	3	4	5	1	2	3	4	5
Staying home alone	1	2	3	4	5	1	2	3	4	5
Being far away from home	1	2	3	4	5	1	2	3	4	5
Other (specify):	1	2	3	4	5	1	2	3	4	5

PANIC ATTACKS

3. We define a panic attack as:
    1. A high level of anxiety accompanied by………
    2. strong body reactions (heart palpitations, sweating, muscle tremors, dizziness, nausea) with…….
    3. the temporary loss of the ability to plan, think, or reason and……….
    4. the intense desire to escape or flee the situation (Note: this is different from high anxiety or fear alone).

Please indicate the number of panic attacks you have had in the past 7 days:____________

How severe or intense have the panic attacks been? (Place an X on the line below):

1	2	3	4	5
very mild	mild	moderately	very	extremely

4. Many people are able to travel alone freely in the area (usually around their home) called their safety zone. Do you have such a zone? If yes, please describe:

a. Its location:

b. Its size (e.g. radius from home):

FOIQ

The following is a questionnaire specifically designed to ask questions related to a person's fear of incontinence. Although you may have answered related questions in the sections above, please still answer the questions below.
Please indicate how much you agree with each of the following statements, or how true it is about you. Please select a number (0-4) to indicate your answer e.g. 0 - Strongly Disagree (very untrue about me) and 4 - Strongly Agree (very true about me):

		Strongly disagree (very untrue about me)	Mildly disagree (some what true about me)	Neither agree nor disagree	Mildly agree (somewhat true about me)	Strongly agree (very true about me)
1.	I often notice sensations in my bladder/bowels, especially when I am anxious	1	2	3	4	5
2.	I avoid using public transport in case I am incontinent	1	2	3	4	5
3.	I limit the amount of food I eat and / or the amount of fluids I drink to reduce the chances of being incontinent	1	2	3	4	5
4.	If I go to an unfamiliar place, one of the first things I would do is look for the toilets	1	2	3	4	5
5.	My worst fear is that I would be incontinent in public	1	2	3	4	5
6.	Being incontinent in public would mean I am a disgusting person	1	2	3	4	5
7.	If I go out of the house I wear extra underclothes or I use padding in case I am incontinent	1	2	3	4	5
8.	I notice other symptoms (e.g. heart racing, sweating, trembling) when I need to go to the toilet and cannot easily get to one	1	2	3	4	5
9.	I avoid certain work or social activities because of a fear of being incontinent	1	2	3	4	5
10.	My relationships have been affected by a fear of being incontinent	1	2	3	4	5
11.	I avoid crowded places in case I am incontinent	1	2	3	4	5

12.	I often think about how awful it would be if I was actually incontinent in a public place	1	2	3	4	5
13.	When I am out of the home, I make a mental note of where toilets are located in case I need to use one urgently	1	2	3	4	5
14.	My ability to work, study or socialize has been affected by a fear of being incontinent	1	2	3	4	5
15.	Being incontinent is the most shameful thing that could happen to a person	1	2	3	4	5
16.	I often check for sensations in my bladder or bowels	1	2	3	4	5
17.	I use medications to stop myself being incontinent	1	2	3	4	5
18.	Other people would think I was a disgusting person if I was incontinent	1	2	3	4	5

1. Marital Status: Single☐ Married/co-habiting☐ Widowed☐ Divorced☐

2. Employment Status:
   a) Employed or self-employed ☐
   b) Homemaker ☐
   c) Unemployed ☐
   d) Long-term sick leave ☐
   e) Student ☐
   f) Retired ☐
   g) Other ……………………………………………

3. Ethnicity:

- White British ☐
- White Irish ☐
- White Other ☐
- Black Caribbean ☐
- Black African ☐
- Indian ☐
- Pakistani ☐
- Bangladeshi ☐
- Other Asian ☐
- Mixed – White & Caribbean ☐
- Mixed – White & Afican ☐
- Mixed – White & Asian ☐
- Mixed – Other ☐
- Chinese ☐
- Another other ethnicity ☐
- Prefer not to say ☐