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Why Irish Women Delay Seeking Treatment for Urinary
Incontinence: A Focus Group Study

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AUTHORS DECLARATION

I, the undersigned declare that this project which I am submitting is all my own work and that the data presented is authentic.

_____ (Printed Name)

_____ (Signature)

Date / /

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1 Abstract

Why Irish Women Delay Seeking Treatment for Urinary Incontinence: A Focus Group Study.

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Background: Urinary Incontinence is defined as “any involuntary leakage of urine” (Abrams et al, 2002). Living with incontinence can effect one`s life greatly. Many women delay seeking treatment and often do not seek any help (Dolan et al, 1999), despite physiotherapy being an effective treatment (Neumann et al, 2005). Therefore, there is a need to discover why women delay seeking help, such as physiotherapy and continue to live with incontinence.

Objectives: To establish reasons why Irish women delay seeking help for incontinence, by exploring the experiences of women living with incontinence and to discover their knowledge regarding available treatment.

Methods: Qualitative focus group methodology with the group of interest – women with incontinence symptoms. Following HSE approval, under the Clinical Research Ethics Committee of the Cork Teaching Hospitals, a pilot group and two focus groups were conducted. The discussions were digitally-recorded and transcribed verbatim. Subthemes and themes were identified using thematic analysis.

Results: Different explanations were established signifying why women delay seeking treatment including a lack of awareness regarding condition prevalence and available treatments. Participants expressed a difficulty approaching treatment resources and instead developed coping strategies, to live with incontinence and avoid seeking help. Furthermore, the emotional effects of living with incontinence contributed to a delay seeking help.

Conclusions: Women are faced with various barriers when seeking treatment. This confirms the necessity to help ease the associated emotional discomfort and to develop accessible treatment routes, through the development of strategies to raise awareness of incontinence and available treatment.

{Keywords: Incontinence; Physiotherapy; seeking help}

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2 Introduction

The definition of incontinence varies in the literature and has developed from a “social or hygienic problem” to “any involuntary leakage of urine”, as defined by the International Continence Society (Abrams et al 2002). A prevalence study conducted in Northern Ireland (Dolan et al 1999), including 1 050 women, illustrated that 57% of women aged 35-74 reported incontinence symptoms. The same study reported that only 20% of this incontinent group reported symptoms to their GP. Similar studies (Hunskarr et al 2003) have been conducted on larger scales, internationally, indicating similar results. Hunskarr et al (2003) explored the prevalence rates in different European countries, consisting of 22 950 women and found that 44% of women had incontinence symptoms. However, treatment rates remained low, with only 25% of women receiving treatment. Therefore, a research gap is evident with regard to discovering why women are not seeking help for incontinence.

Literature has indicated the effect incontinence imposes on one`s life. Bogner et al (2002) explored the psychological distress of people with incontinence, using the validated General Health Questionnaire and found a higher prevalence of psychological distress in persons with incontinence compared to those without incontinence. Similarly, Fultz et al (2003) conducted a mail survey of 605 women who reported incontinence symptoms, to explore the burden which incontinence inflicts. This study (Fultz et al 2003) concluded that women reported that incontinence had a moderate to extreme impact on their lives; some perceived an impact on confidence and others on daily activities or social activities. In a different study (Fultz & Herzog 2001), it was reported that persons with incontinence reported increased loneliness or depressive symptoms, than their continent counterparts. Therefore, this reinforces the need to research this area, to help relieve such inflicting challenges women face living with incontinence.

When taking into account such effects women face living with incontinence, it is of particular interest to establish why more women do not avail of non-invasive treatment, such as physiotherapy. Neumann et al (2005) concluded that physiotherapy management is an effective treatment option for incontinence, following an observational multicentre trial. However, literature (O`Brien et al 1991) has highlighted the low patient uptake of physiotherapy treatment services. This highlights the need to

explore why more women do not seek this treatment and instead continue to live with incontinence. Currently, the majority of research investigates the reasons why this population do not seek treatment from general health practitioners, without particular regard to the physiotherapist's role. Therefore, it is important to investigate the perceptions held regarding physiotherapy as a treatment intervention, in order to establish reasons for non-treatment seeking.

Prior to this study, the majority of studies examining reasons for a lack of help-seeking behaviour in this population use research methods, such as qualitative interviews (Basu & Duckett 2008; Shaw et al 2001); questionnaires (Margalith et al 2004; Kinchen et al 2003) or surveys (Dugan et al 2001). Such studies attribute potential reasons for delayed help-seeking, as a lack of awareness regarding the condition itself, as was highlighted by Shaw et al (2001), who explored women's attitudes, receiving continence treatment, using unstructured interviews. Such a lack of awareness can also be attributed to associated treatment options, as Basu & Duckett (2008) concluded from a series of unstructured interviews, involving women with recurrent incontinence symptoms. This study (Basu & Duckett 2008) showed that women are fearful of potential invasive treatments, such as surgery, as they are unaware of other treatments, such as physiotherapy, resulting in a delay seeking any form of help.

Other studies (Dugan et al 2001) indicated that women develop their own coping strategies, thus adapting to incontinence rather than seeking help. Dugan et al (2001) conducted a telephone-survey trial, comparing the perceptions of women who had sought continence treatment to those who had not sought such treatment; both groups had incontinence symptoms. This group comparison identified that non-seekers were more likely to have the perception that incontinence was not a clinical problem and people had to live with incontinence. Another potential reason for non-help seeking includes the associated stigma, as women, attending a urology clinic for incontinence, in a questionnaire-based study (Margalith et al 2004) expressed a delay in seeking help, due to the shame of the condition. Furthermore, a two-stage cross-sectional survey (Kinchen et al 2003), including 2 310 women with incontinence, highlighted that women felt fear at the initial stages of the condition, as they feared that incontinence

was not normal and may be an indication of a severe condition, resulting in a delay seeking help due to the fear of the condition and associated treatments.

However, despite such results, the majority of research methods utilised in the literature are limiting, as a direct insight into subject views or different opinions are absent when using passive methods such as questionnaires or surveys . Although studies including interviews do offer the subject the chance to elaborate on certain areas, such an individualized method may pressurise subjects, especially when considering the subject sensitivity. Such an aspect is highlighted by Madriz (2003), who outlined the considerations needed to take into account, when conducting research regarding women`s health. Madriz (2003) states that interviews often create an intimidating atmosphere, which affects the subject`s ease responding. In contrast, Madriz (2003) highlighted that focus-groups create a safe environment, where participants have the opportunity to discuss the topic with people of similar backgrounds, which is of particular relevance to women discussing a sensitive topic, such as incontinence. Focus-groups encourage the retrieval of new emerging themes, as participants feel comfortable and willing to divulge information, while allowing the researcher to observe participant`s interaction with one another (Kitzinger 1995). Chiarelli & Cockburn (1999) investigated the use of health promotion and women`s health, specifically incontinence and commended the use of focus groups, for this topic, as focus groups offer an appropriate forum to collect women`s perceptions and beliefs. This highlights the need for focus-group research with regards to this area.

Furthermore, research is also needed, specific to an Irish population, as the majority of studies concerning this topic are conducted internationally. It is difficult to compare an Irish population to such groups, as such studies do not account for different health structures the nations attribute, as well as different cultures, behaviours and attitudes which characterise different nations. The author could not locate any Irish research conducted in this area, to date. A consultation with a leading physiotherapist in an Irish clinical interest group for women`s health confirmed this and further highlighted the need for Irish research in this area.

The aim of this research was to explore the reasons why women do not seek help for incontinence, within an Irish population, using focus groups.

3 Objectives

- To establish reasons why Irish women delay seeking help for continence problems.
- To explore the experiences of women living with incontinence symptoms.
- To discover the knowledge that women have regarding available treatment.

4 Methodology

4.1 Study Design

A qualitative study design, using a focus-group approach was employed. Mack et al (2005) describes focus-groups as having the ability to provide information regarding people`s experiences with an issue, including intangible factors such as behaviours, beliefs and emotions, which is appropriate for the objectives of this study.

Furthermore, Krueger & Casey (2000) describe the social context provided by a focus-group, which encourages the development of ideas and is an effective method for making participants comfortable when discussing sensitive topics, such as incontinence.

Two focus-groups and one pilot study were conducted.

4.2 Ethical Approval

Ethical Approval was granted by the HSE, under the Clinical Research Ethics Committee of the Cork Teaching Hospital.

4.3 Inclusion/Exclusion Criteria

Inclusion criteria required that participants had incontinence symptoms and were beginning physiotherapy continence treatment.

Exclusion criteria required that women were not pregnant or less than 18 years of age.

4.4 Sample Selection

- The participants were selected from a list of patient names awaiting physiotherapy continence treatment, in Cork University Maternity Hospital (CUMH). Female participants are referred for physiotherapy continence classes to this unit following doctor referrals, from a general practitioner or a consulting gynaecologist. Also, some women are referred post-natal by public health nurses.
- Each participant was sent a recruitment letter (appendix 10.1) with an attached information leaflet (appendix 10.2), informing them of what the research entailed and asking them to participate in the discussion.

- Groups were held directly before the participant`s first physiotherapy class, accounting for travel expenses, as participants were attending the hospital on that day for the class, regardless of the research. Furthermore, as participants attended a physiotherapy class immediately after the focus-group, this ensured that any distress that may have been caused by the discussion was addressed by a professional immediately.

Ten recruitment letters were sent out, on each occasion, with only three and four participants attending the first and second focus-group, respectively.

For the first class, three other women attended the physiotherapy class following the focus-group and did not participate in the focus group. For the second focus-group, all class attendees participated in the focus group.

4.5 Question Development

Questions were developed, in reference to question route structures suggested in the literature (Kruger & Casey 2000) and incorporating the study objectives. The specific question route was developed in collaboration with the two main researchers (a university lecturer and final year physiotherapy student). The appropriateness of the question route was established with a pilot study, including four women attending a physiotherapy continence class. Following the pilot study, reaction to the questions was deemed appropriate and therefore an agreed question route was established (Appendix 10.4).

4.6 Data Collection

The focus-group was held in a large room where the physiotherapy continence classes are held, in CUMH. Focus groups were recorded using a digital voice recorder, which was pre-tested during the pilot-study. Participants were seated in a circle, with the moderator. Each participant signed an informed consent form (appendix 10.3).

The focus group began with an introduction, from the moderator, which outlined the research purpose and a brief description of what a focus group entails. The moderator also re-affirmed the anonymity and confidentiality associated with any discussion that may be had, during the group. The question route was followed, in both groups, with probing into vague ideas, when appropriate. The end of the focus group

concluded with the moderator questioning if participants were happy with the discussion content and inquiring if the participants had any further points to highlight. Observational notes, from the moderator, were written immediately after each focus-group interview, as recommended by Rabiee (2004).

The focus groups were transcribed verbatim. The data was analysed using thematic analysis (Krueger 1997). This analysis included:

- Reading the transcripts repeatedly, with a thorough examination of the data. This was done to immerse in the group detail (Rabiee 2004).
- The transcript was divided according to meaningful data fragments. These different fragments were assigned codes. Codes consisted of a word or phrase in the transcript margin that appears to represent the statement meaning.
- Each code was then abstracted from each transcript, where commonalities and linkages between the different categories were sought.
- Common codes were established and then quantified, with respect to the intensiveness, extensiveness, specificity and frequency given to the code, in the transcripts (Krueger 1997).
- Internal consistency was also examined, through the exploration of any participant change in opinions that may have been evident. This was done in conjunction with an analysis of the interactions between group members, in attempt to explore the group dynamics (Onwuegbuzie et al 2009). The effect of such factors on the emergent codes was then distinguished and quantified accordingly.
- The final codes were then grouped into sub-themes. After further analysis, these sub-themes were then grouped into four main themes.

The validity of the themes was pursued through member-checking (appendix 10.6), by contacting the participants, by post, to ensure that the themes sufficiently represented their feelings. However, no participants replied to these letters. This may suggest that participants were satisfied with the results, but there is no confirmation of this.

Validity was also verified in consultation with two senior women`s health physiotherapists, where a discussion was had to validate emergent themes, against their

vast experience in the area. Both physiotherapists deliver continence classes, with women of similar characteristics, to the participants of this study. The two physiotherapists stated that all themes were valid and denoted sufficient representation of the chosen population.

Trustworthiness in the analysis process chosen was pursued through the maintenance of an audit trail (Appendix 10.5).

5 Results

5.1 Group Dynamics

Initially, participants appeared nervous and uneasy with the discussion, due to the topic sensitivity, indicated by the moderator`s need to probe questions initially as participants were reluctant to offer opinions. Participants expressed that this discussion was their first time discussing incontinence in a group context or even for some the first time discussing their condition at all.

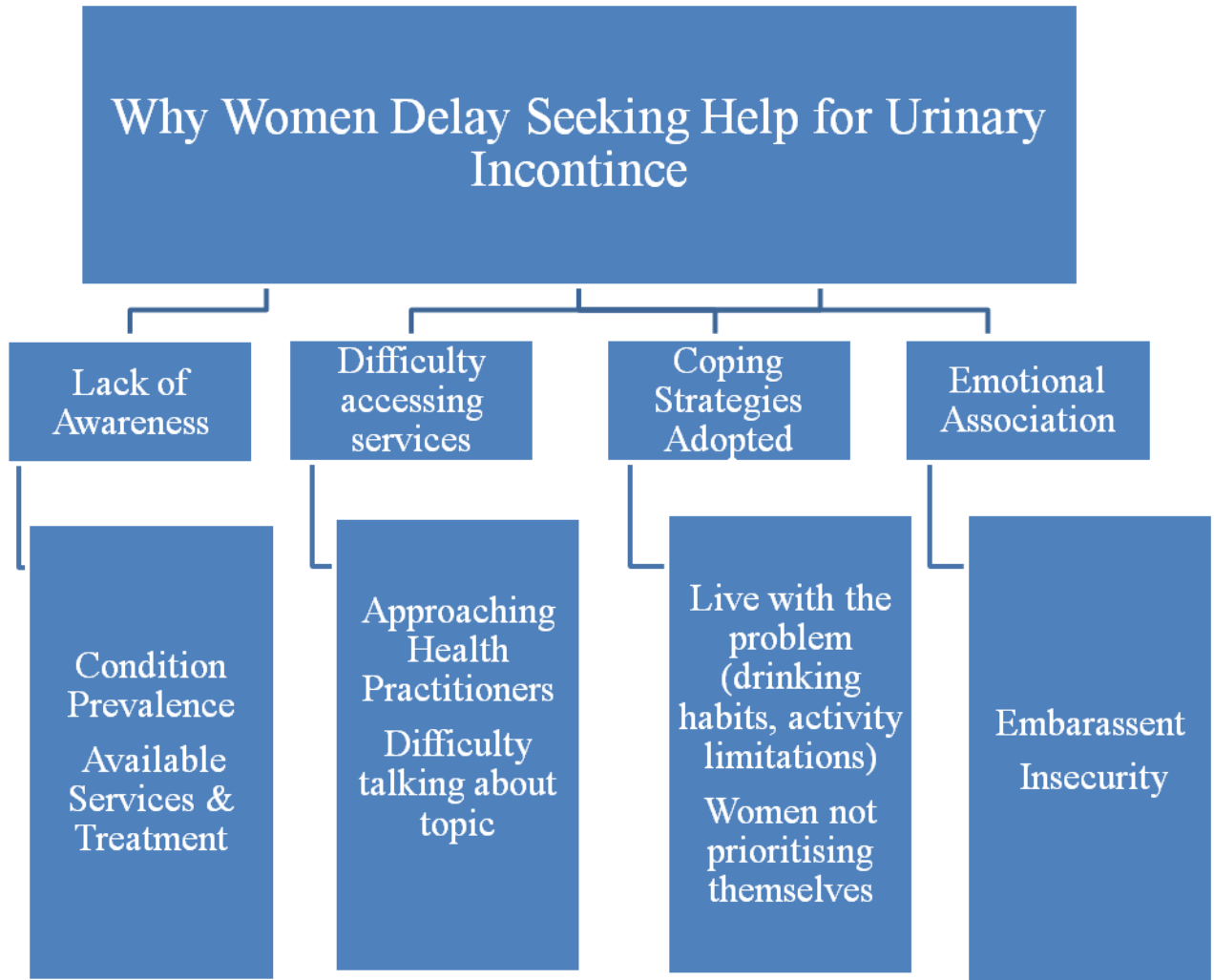
However, participants became more comfortable, as they realised that the other women had similar experiences, creating an empathetic atmosphere. Participants expressed, on completion, that they appreciated the group discussion, as it gave them reassurance and comfort discussing the condition with others, in a supportive context. A natural conversational tone was adopted by members, as they showed good interaction with one-another, as opinions were directed at all members and not just the moderator.

Both groups consisted of one member who was hesitant offering opinions, while other more dominant members spoke more frequently. The moderator ensured good eye-contact and sufficient prompting to help alleviate this.

5.2 Main Findings

Four main themes were identified from the data collection and analysis, indicating why women delay seeking help for urinary incontinence; Lack of Awareness, Access to services, Coping Strategies Adopted, Emotional Association with the Condition. The main themes and sub-themes are illustrated in figure 1.

Figure 1. Main themes and sub-themes



5.2.1 Lack of Awareness

A lack of awareness among women and the general public regarding incontinence was indicated in both groups. Participants expressed that this lack of awareness contributed to decreased knowledge about incontinence, including prevalence rates and available treatments, thus delaying seeking help. Such a lack of awareness was referred to frequently (n=28).

Knowledge of the condition

A lack of knowledge regarding incontinence prevalence was indicated, as some women felt that they were the only ones who had incontinence symptoms

“I use be thinking that maybe I was the only one who had this problem” (p4, 2D)

In contrast, other women felt that incontinence was a common problem that happens to everyone

“I thought incontinence happened to everyone, I`d presume” (p3, 2B)

Some participants associated such a commonalty with incontinence that they saw the condition as un-problematic and not a clinical problem, which prolonged their non-help seeking behaviour

“I wouldn` t have seen it as a problem, I just saw it as part of it all” (p5, 2B)

Participants expressed perceptions that there may be many more women living with the condition, who have not sought treatment due to this lack of awareness, showing intense empathy to such women

“I don` t know how many women are out there going around in pain that they do not need to be in” (p9, 2C)

Awareness of available Services / Treatment

Participants indicated that they did not have efficient knowledge of available and potential continence treatment. Such a viewpoint was referred to frequently (n= 16), as well as good agreement between all members, showing good internal consistency

“I never knew there was anything that could be done about it” (p2, 2D)

“I don’t see a lot of women (physiotherapists) advertising for women’s services”
(p6, 1A)

Further, participants expressed that they presumed that surgical intervention was the main treatment available, which they hoped to avoid, thus delaying seeking help

“I would have thought, that (surgery) is what the options were, I would have never have known there were any other” (p12, 1C)

Access to Information

An opinion highlighted in both groups was the need for more continence information in the general public; to improve the awareness of the condition

“it wouldn’t even bother them (general public) or it wouldn’t come into their thoughts that people do suffer from this” (p7, 1A)

“important for people to be aware and know that the services are there” (p11, 2C)

There was strong agreement, with high extensiveness (n=5) of such comments, that future directives should aim to improve this awareness and information

“make it publicly aware, so that is not something that has to be swept under the carpet”
(p12, 1A)

“I just think there should be a campaign to make people aware, that people do suffer from it, it does happen and that it can be prevented and helped” (p10, 2C)

5.2.2 Access to Services

Participants indicated that they found it difficult accessing services, due to difficulty approaching the right resources or even initiating a discussion regarding their condition. Such a difficulty leads women to delay seeking help.

Approaching Health Practitioners

Participants indicated that they had to initiate the treatment process, which was extensively referred to (n=6), by approaching health practitioners, implying that if they had not initiated this, they would not receive treatment

“Yes, I asked myself, that`s how I got here, hah, \$I didn`t stand for help, I asked”
(p2, 1C)

“But if you hadn`t have come to him (Doctor), he wouldn`t have seen, you know”
(p9, 2B)

Furthermore, it was indicated that women found it difficult to establish the process needed to receive treatment or to distinguish where to seek this help, which was referred to frequently (n=20)

“I wouldn`t have a clue of where to go like, you know there are physiotherapists in ((place name)), but I don`t know do they do women`s issues” (p5, 2C)

Difficulty Talking about Topic

A difficulty talking about the topic with health practitioners was indicated; which affected the initiation of seeking help. The difficulty talking about the topic was referred to extensively in both groups (n=6)

“I know that they are busy, but, if they don`t have time to listen, I`ll just keep my mouth shut” (p4, 1A)

5.2.3 Coping Strategies Adopted

Participants indicated a tendency to develop coping strategies, to live with the condition and avoid seeking help.

Acceptance of Condition

A tendency to accept the condition with an effort to conceal the symptoms and avoid seeking help was portrayed

“Women just learn to live with it” (p11, 1A)

“stay at home and put up with it like” (p8, 1B)

It was indicated extensively (n=5) that this behaviour may be due to the fact that women do not prioritise their health

“women do not place enough importance on themselves” (p6, 2C)

Strategies adopted

Participants indicated, with specificity to personal experiences, that they adopted different strategies to help live with incontinence, including restricting drinking habits, developing abnormal toileting regimes or restricting activities. This was referred to extensively (n=6)

“I’d have to know there was a toilet everywhere I go, I wouldn’t drink. I wouldn’t drink water” (p3, 2C)

“I always liked walking and exercising, but I just couldn’t, if I went down and there wasn’t a toilet...I’d be in trouble” (p3, 2D)

As women develop these strategies they felt that they had sufficient management strategies and could avoid seeking help

“You pretend it’s not happening. Once it doesn’t get worse, you can manage the stage you are at, it’s not °great°, but you can live with it” (p5, 1A)

5.2.4 Emotional Association

Participants in both groups indicated the strong emotions they associate with incontinence, as they often feel embarrassed or insecure towards incontinence, thus delaying seeking help

Embarrassment

Participants referred to the embarrassment attributed towards incontinence frequently (n=12)

“You would be saying that this is embarrassing and I didn`t really have anyone to talk to” (p4, 2D)

Participants attributed such embarrassment particularly as incontinence was associated with old-age, in both groups

“You know it`s something associated with getting old....<God all mighty, you can`t be incontinent at this age or you know what I mean, it`s crazy>” (p2, 1A)

Participants indicated that they felt that there was a certain stereotypical association with incontinence that they felt uncomfortable talking about the topic with others

“I would never have talked about it.... not a nice topic of conversation” (p7, 1C)

Insecurity

It was also indicated that women feel insecurity or feelings of vulnerability living with incontinence

“a fear with it, the fear of losing complete control, a fear that is always there” (p8, 1C)

Participants felt such negative emotions with the condition, that this often affected them and they prolonged the time to seek help. Such emotions were portrayed with great intensity

“it took me a long time to accept it and come to treatment” (p8, 2D)

6 Discussion

6.1 Reasons for a delay seeking continence help

A lack of awareness regarding incontinence and the associated prevalence was a prominent theme emerging from groups. Participants portrayed that they did not have sufficient knowledge regarding the condition, including general information about prognosis and available services or continence treatment. This led to an uncertainty or lack of understanding regarding incontinence, entailing that women delayed seeking help, as they did not have sufficient information to adopt an approach to seek help.

Such a lack of awareness has been highlighted in the literature previously. A questionnaire-based study (Hannestad et al 2002), including 6 625 women with incontinence, indicated one of the main reasons why women do not seek help for incontinence is based on a lack of information. Shaw et al (2001) reported that the majority of participants, in unstructured interviews, were completely unaware of available interventions, as they presumed that continence treatment was unavailable. Such results are comparable to the results of this present study, as participants felt unsure of information regarding condition prevalence and demonstrated a lack of awareness regarding available treatment, contributing to a delay seeking help.

Shaw et al (2001) also indicated that participants presumed that incontinence was a trivial problem and not a medical condition. Similarly, Kinchen et al (2003) conducted a two-stage cross sectional survey of 2 310 women with incontinence symptoms and found that the perception of incontinence as a problem was one of the strongest predictors of treatment seeking. Therefore, if women did not perceive incontinence as a problem, they were less likely to seek help. Comparable viewpoints were exposed during the focus groups, as women admitted the belief initially that incontinence was a condition that all women were subject to and was not a serious medical problem. Such a barrier to treatment seeking is noted in a three-phase women`s health seeking model, as proposed by Currie & Wiesenburg (2003), which outlines that the first step in seeking medical treatment is the recognition of a health problem. Therefore, in application to this population, if women do not realize that incontinence is a health problem, that can be treated clinically, they will not seek help.

The focus groups indicated that participants had difficulties accessing services. The majority of participants initiated the treatment process themselves, by approaching a health practitioner. Participants contemplated whether there are more women in the public, with incontinence, who have not initiated such a discussion and therefore are not receiving treatment. Participants found it difficult initiating such a discussion mainly due to discomfort talking about incontinence, due to the emotional association attributed with incontinence. Currie & Wiesenburg (2003) identified that women are particularly reluctant to seek gynaecological treatment, which includes continence treatment, as there is often a stigmatizing or shameful association with such conditions. Kinchen et al (2003) showed that non-treatment seekers were embarrassed to discuss urinary problems with physicians. Similarly, Margalith et al (2004) investigated the reasons for delayed help-seeking, in a questionnaire-based study, involving 131 women, with incontinence and concluded that shame or embarrassment was one of the main reasons for a delay seeking help. Furthermore, Mason et al (2001) highlighted that those experiencing incontinence avoided talking about incontinence not just with friends and family but also with health professionals, due to discomfort initiating such discussions, thus indicating a barrier to seeking help. Such discomfort was also noted in the focus groups, as participants described the embarrassment associated with the condition and attributed a certain stigma with incontinence, therefore avoiding discussions regarding incontinence. Participants felt that it was their own responsibility to seek treatment and that there was a lack of health practitioners approaching them inquiring about their continence health.

In further relation to access to services, it was expressed in the groups that participants often felt unsure as to which health practitioners to approach when seeking help. Although, some women conveyed that even though they were aware that physiotherapy was an efficient treatment, they still did not know which physiotherapist would be appropriate to approach, questioning if every physiotherapist specialized in such an area and expressed that more physiotherapists should advertise such services. Literature signifying such a reason for delayed help-seeking is not evident in the literature, to the author's knowledge.

However, literature does indicate that women delay seeking help, because they are unsure what treatment entails. Shaw et al (2001) indicated that women who were aware of available treatment interventions were often fearful of potential treatment content and invasive examinations. This can be compared with the insecurity or uncertainty that women associated emotionally with incontinence, as evident in the results section. Participants indicated that it often took time to accept the condition and seek help with many of them fearful of invasive treatment.

Participants alluded to different coping strategies adopted while living with incontinence. Such strategies included limiting fluid intake, restricting activities and abnormal toileting regimes. Basu & Duckett (2009) report comparable perspectives that women feel that they can cope with incontinence, by employing such strategies. Dugan et al (2001) noted that women accepted the condition as a normal part of life and adopted limiting coping strategies to live with incontinence. This accepting attitude is also highlighted in a study (Kinchen et al 2003) exploring the views of people who had sought treatment. Respondents in this study (Kinchen et al 2003) did not rank reasons such as a concern that they had to start wearing panty liners as an important reason for seeking treatment, which indicates that women were happy to adapt to the condition and adopt coping strategies, rather than seek help. Such a behaviour can be compared to a passive acceptance described in the literature (Mason et al 2001), as women place less concern on incontinence as a problem and instead accept the condition.

Such coping behaviour is also contributed by the perspective that women do not prioritize their health substantially. Participants indicated that they tended to avoid seeking help for incontinence or delayed the process as they felt that there were other more prominent needs, such as their children`s health. Currie & Wiesenburg (2003) also highlight such a factor, as they refer to the relationship between gender and health seeking, by indicating that women are less likely to consult modern health services and are reluctant to spend resources on their own needs. Such a female behaviour has been highlighted and targeted internationally, such as in objectives derived by the Healthy People leadership (Maise 2010) under the U.S. Department of Health and Human Services, which highlights that women need to prioritize their health needs more and seek help.

6.2 Recommendations

Participants in both groups emphasized that there is need to address the lack of continence awareness publicly, through the use of promotional campaigns, to increase the general population`s knowledge regarding incontinence and available treatment. Such motives are also recommended in the literature, as one study (Mason et al 2001), including post-natal women, with incontinence symptoms, participating in semi-structured interviews, indicated that an increased knowledge of the condition would enable women to realize that incontinence did happen to other people and diminish the reluctance to seek help. On the other hand, information regarding the condition would indicate to those who believe that incontinence is a trivial problem that it is a medical condition, which can be treated clinically.

Another focus-group study (Chiarelli & Cockburn 1999) investigated the perceptions of women, not specifically with incontinence; regarding continence health and concluded that participants attained a poor knowledge and awareness regarding incontinence. Chiarelli & Cockburn (1999) recommended the development of a health promotion program to help alleviate this lack of awareness. Furthermore, Buckley et al (2010) developed clinical uncertainties and research needs relating to continence treatment, in consultation with clinician and patient organizations and concluded the necessity to explore the effectiveness of guidance on appropriate pathways of care, with the aim to develop the continence treatment. This further highlights the need to develop awareness and continence education, with regard to treatment, in order to alleviate such barriers to seeking treatment.

As was indicated previously, participants felt that there was a lack of health practitioners approaching them inquiring about their continence health and instead it was the participant`s responsibility to initiate discussions about their continence problems and seek help. The focus groups suggested that structures should be in place to make this more accessible for women, with health practitioners inquiring specifically about continence symptoms. This would alleviate the discomfort described initiating such a discussion. Mason et al (2001) recommended that health professionals need to initiate the conversation and should enquire as a matter of routine whether individuals had a problem with incontinence.

7 Methodological Considerations

A notable limitation of the study was the novice moderator, with no experience in conducting focus groups previously, which may have affected data collection. Furthermore, the researcher had no experience performing thematic analysis, which may have led to the retrieval of inaccurate findings. However, attempts were made to ensure a successful focus group, by conducting a pilot group prior to the group, to ensure the question route was appropriate. Validity of themes was also sought through member checking and in consultation with two senior physiotherapists, specializing in women's health. However, the employment of an assistant moderator, to attend focus groups, would have aided in increasing the theme validity and verification.

Another notable missing component in the research is specific participant information, including demographic characteristics, which was omitted. Another methodological consideration includes the small number of groups conducted (two focus groups), as it is recommended to conduct minimally three to four focus groups (Krueger 1998), in order to reach "theoretical saturation". Further, a methodological consideration may be the small participant numbers present in the groups (three in the first group and four in the second group), as literature (Stewart & Shamdasani, 1990) recommends 6-12 members to be present in focus groups. However, due to the topic sensitivity, smaller group numbers may have been more appropriate to allow the participants to feel comfortable and less reluctant offering opinions.

Finally, it is important to note the methodological considerations associated with employing a focus group design. Focus group findings are specific to group members and may be susceptible to change (Kitzinger 1995). Thus, results are not universally representative and cannot be extended to all populations.

8 Conclusion

The findings of this study indicate that women are still challenged to overcome barriers, in order to seek continence treatment in Ireland, including physiotherapy. Such barriers include a lack of awareness regarding incontinence and a lack of accessible treatment routes. Also, contributing to these challenges is the emotional association women place with incontinence and the tendency of developing coping strategies to live with the condition, instead of seeking help.

Such results indicate the need to alleviate such a reluctance to seek help, by easing the emotional discomfort felt discussing the topic and developing accessible treatment routes. Recommendations from this work include the development of strategies to raise public awareness regarding the condition and the available treatment.

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10 Appendices

10.1 Recruitment Letter



UNIVERSITY of LIMERICK
UNIBESCOIL LUIMNIGH

xx/ xx / 2010

Dear xxxx

I am writing to you regarding your upcoming physiotherapy class, at CUMH. I am a physiotherapy student, from the University of Limerick, currently conducting research regarding incontinence treatment, for a female Irish population. As part of my research, I wish to gain an insight and opinions from females suffering from incontinence.

I am asking you to attend a group discussion next week, on the same day as your first physiotherapy class, with Senior Physiotherapist, Jean Dennehy. The content of the research and information regarding the discussion are attached, in a subject information leaflet.

I hope to see you next Monday,

Kind Regards,

Mairead Ni Aileasa

(UL Physiotherapy Student)

10.2 Subject Information Leaflet



SUBJECT INFORMATION LEAFLET

Title of the Study:

An investigation into the reasons why an Irish Population delay seeking treatment for Urinary Incontinence Symptoms.

Investigators : Karen McCreash (University of Limerick Lecturer – Dept. Of Physiotherapy)

Mairead Ni Aileasa (University of Limerick Physiotherapy Student)

Aim of the Study:

To investigate the reasons why an Irish population, who have not received treatment previously, delay seeking help for urinary incontinence symptoms, within a physiotherapy unit.

What will you have to do?

If you are willing to participate, on the first day of your physiotherapy class, you will be asked to attend one hour earlier, to attend a group discussion regarding urinary incontinence symptoms. The content of this discussion will consist of topics such as your experience of living with continence problems, your awareness regarding available treatments and the opinions you possess regarding these treatments. You are not obliged to discuss any topics which you may feel uncomfortable discussing, with the group.

Who is taking part?

The discussion will be led by a researcher, a fourth year physiotherapy student, from the University of Limerick. There will be five other females in the group, all of whom will be attending the physiotherapy class, with you, following the discussion.

What are the benefits for you?

There are no direct benefits for you; however you will be helping the investigators complete an important piece of research, which is likely to help future research into urinary incontinence problems.

What are the risks to you?

The researchers do not anticipate any risks to the participants. However if you;

- Are under 18
- Are pregnant

Then you will not be eligible to participate in this study

What Happens to the Data?

The study information will be safely stored in the Health Science Building, University of Limerick. The data collected at the end of the study will be used in writing a research paper for this investigation. Anonymous literary quotes may be published in conjunction with this research paper. However, no personal data, that may identify you, will be published or discussed with others.

Participants can withdraw at anytime, without any obligation or consequences.

If you would like to take part please contact the CUMH Physiotherapy Department at (021) 4290500.

'If you have concerns about this study and wish to contact someone independent, you may contact Dr. Michael Hyland, Committee Chairman of Clinical Research Ethics Committee Of The Cork Teaching Hospitals,

Ferndale, Traberg Lawn, Douglas, Cork.

10.3 Consent Form

CONSENT BY SUBJECT FOR PARTICIPATION

Section A

Name: _____

Title of Protocol: An investigation into the reasons why an Irish Population delay seeking treatment for Urinary Incontinence Symptoms
Directing Research: Karen McCreesh

You are being asked to participate in a research study. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This process is known as informed consent. This consent form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate.

Section B

I. NATURE AND DURATION OF PROCEDURE(S):

You are being asked to attend a group discussion regarding urinary incontinence symptoms. The content of this discussion will consist of topics such as your experience of living with continence problems, your awareness regarding available treatments and the opinions you possess regarding these treatments. You are not obliged to discuss any topics which you may feel uncomfortable discussing, with the group.

II. POTENTIAL RISKS AND BENEFITS:

There are no direct benefits for you; however you will be helping the investigators complete an important piece of research, which is likely to help future research into urinary incontinence problems.

The researcher does not anticipate any risks, however if the discussion causes any distress, this will be addressed by a professional immediately.

III. POSSIBLE ALTERNATIVES:

You are not obliged in any way to participate in this study. Participation does not affect your subsequent physiotherapy treatment in any way.

Section C

AGREEMENT TO CONSENT

The research project and the treatment procedures associated with it have been fully explained to me. All experimental procedures have been identified and no guarantee has been given about the possible results. I have had the opportunity to ask questions concerning any and all aspects of the project and any procedures involved. I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. When required by law, the records of this research may be reviewed by government agencies and sponsors of the research.

I understand that the sponsors and investigators have such insurance as is required by law in the event of injury resulting from this research.

I, the undersigned, hereby consent to participate as a subject in the above described project conducted at the Cork Teaching Hospitals. I have received a copy of this consent form for my records. I understand that if I have any questions concerning this research, I can contact the doctor(s) listed above. If I have further queries concerning my rights in connection with the research, I can contact the Clinical

Research Ethics Committee of the Cork Teaching Hospitals, Lancaster Hall, 6 Little Hanover Street, Cork.

After reading the entire consent form, if you have no further questions about giving consent, please sign where indicated.

Investigator: _____

Guardian
of minor, if applicable)

Witness: _____
_____AM

(Circle)

PM

Signature of Subject, Parent or
(include a separate line for assent

Date: _____ Time:

10.4 Question Route (Krueger 1998)

Question Type	Question
Opening	“I would like to begin by asking everyone to tell us their first-name and tell us why you have come to be referred to physiotherapy”
Introductory Question	“What comes into your mind when you hear the words urinary incontinence?”
Transition	“Tell me about the first time you approached a health practitioner about your condition”
Key	“Tell me about how you coped with the condition before seeking treatment.” “What did you know about available treatment?” “Were there any reasons for a delay in seeking help?” “How do you feel talking to friends / family about the condition?”
End Question	“What are your hopes / expectations for treatment?”

10.5 Audit Trail

- On completion of both groups, the moderator reflected upon the group in a reflective diary. This reflective diary consisted of the main ideas generated in each group and particular issues highlighted. Also included were notes regarding group dynamics and the different interactions present for each group.
- Transcribing was done with care, noting any fluctuations in tone, any abnormal pauses or hesitations at response and intensity of expression using the Jefferson Transcription Technique (Atkinson and Heritage 1999).
- The transcripts were then read, while simultaneously listening to the audio files, to ensure that data corresponded.
- This data was analysed using thematic content analysis (Krueger, 1997). This analysis included:
 - **Data Familiarisation** – Transcripts were read numerous times (approximately 8-10 times), to familiarise the moderator with the data. This was done to immerse in the detail of the group, before attempting to break the transcript into parts (Rabiee, 2004).
 - **Data Fragments** - The transcript was divided according to meaningful data fragments. These different fragments were assigned codes. These codes consisted of using a word or phrase in the transcript margin that appears to represent the statement meaning.
 - **Code Analysis**- Each code was then abstracted from each participant's transcript, where commonalities and linkages between the different categories were sought. Common codes were established and then quantified, with respect to the intensiveness, extensiveness, specificity and frequency given to the code, in the transcript (Krueger, 1997).
 - **Internal consistency** - was also examined, through the exploration of any participant change in opinions or views that may have been evident. This was done in conjunction with an analysis of the interactions between group members, in attempt to explore the group dynamics created (Onwuegbuzie et al, 2009). The effect of such factors on the emergent codes was then distinguished and quantified accordingly.
 - **Sub-theme and Theme Generation**- The final codes were then grouped into sub-themes. After further analysis, these sub-themes were then grouped into main themes.
 - **Defining Themes** – The main themes were reflected upon in relation to the transcripts, to ensure definition and accuracy.
 - **Theme Clarification** – Themes were verified by sending letters summarising the main themes to all participants and asking for them to verify that the themes are an accurate representation (member checking). Clarification was also verified in a consultation with two senior women's health physiotherapists, where a discussion was had to validate the

emergent themes, against their vast experience in the area. This was of relevance as both physiotherapists had experience in holding continence classes, with women of similar characteristics, to the subject participants of this study.

Following the theme clarification, four main final themes were defined.

10.6 Member Checking Letter



UNIVERSITY of LIMERICK
UNIBESCOIL LUIMNIGH

05/04/2011

Dear xxxxx

I am writing to you regarding your participation in a group discussion prior to a physiotherapy class, in CUMH, last year. I am a physiotherapy student, from the University of Limerick, currently conducting research regarding physiotherapy continence treatment, for a female Irish population. As part of my research, I sought insights and opinions from females attending such classes.

I am currently in the write-up stage of the project and am writing to you to clarify the main themes or viewpoints, which I feel were portrayed by the group. I have divided such themes into four main areas, which are all explained and illustrated in the page overleaf.

I would really appreciate if you could take the time to read these results and provide feedback as to whether you feel that these areas reliably represent the thoughts of the group or if I have omitted any important view-points. My contact details are also present overleaf.

Finally, I would like to take this opportunity to thank you for your participation in the groups. Your opinions were greatly valued and will contribute to future research in the area that, may improve the treatment available to women in the future.

Kind Regards,

Mairead Ni Aileasa

(UL Physiotherapy Student).

Main Themes from Group Discussions:

Difficulty accessing services

Group members expressed the difficulty approaching the right services, to receive treatment. This was expressed by some women as they were unsure of which physiotherapists are specialised in women's health, as this is often not advertised as much as other physiotherapy services (e.g. sport). Other women stated that they felt that health practitioners (e.g. doctors, public health nurses) should be inquiring how a woman's health is, with specific questions regarding issues, such as incontinence. This would help women to receive treatment, as the majority of women expressed that they had to initiate treatment-seeking, which is a difficult task.

In conjunction with the difficulty approaching the right direction, to initiate treatment, many women felt that this was made more difficult as incontinence is a particularly sensitive topic to discuss, which again delays the time women take for seeking help.

Lack of Awareness

Women felt that there was a lack of awareness of incontinence between women themselves and the general public. This was illustrated by women expressing a lack of certainty regarding the prevalence of the condition (i.e. if most women post-natally have incontinence or if they were the only ones). This lack of awareness was also evident regarding available treatments, as many women expressed that they were not aware of the possible interventions, such as physiotherapy, previously.

This lack of awareness led to a stigmatising association with the condition, as it was not discussed in social contexts or in the general public, which leads further to a delay in help-seeking behaviour. One approach to help alleviate this is the development of a national awareness campaign, which was recommended by all groups.

Coping Strategies Adopted

It was expressed in the groups, that women often feel that they can cope and manage with incontinence well enough and do not need to seek treatment. Such coping strategies adopted include restricting drinking habits, the avoidance of certain activities, the use of pads, in an effort to avoid the condition.

Such coping strategies were applied in conjunction with the thoughts that women do not prioritise themselves enough, as they think of others primarily (e.g. the post-natal population worry about their baby's health first). Further, it was expressed that women do not have time to worry about their own health, due to other commitments, thus delaying help-seeking for incontinence.

Emotional Association

It was highlighted throughout the groups, the emotional association with incontinence, as many women felt embarrassed or insecure when they discovered the condition initially. This may be due to the fact that women often associate the condition with

an older population, thus leading them to question why women of a younger age develop the condition. This association leads to women feeling insecure and unsure of the prognosis of the condition, this again leads to discomfort talking about the condition, thus delaying seeking help.

If you feel that I have left out any important points or that these main areas do not sufficiently represent your thoughts, you can contact me by phone or writing:

Mairead Ni Aileasa

E-mail: 0735345@studentmail.ul.ie

Address: Cahircarney, Ballymakeera, Macroom, Co.Cork.

Phone: 086-1628925