An explanation of women’s adherence to conservative therapies for stress urinary incontinence

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Abstract

Background: In 2005, NHS Greater Glasgow introduced a ‘Primary Care Management of Stress Urinary Incontinence Pathway’, aimed at providing clear clinical guidelines for Primary Care health professionals. A subsequent audit, conducted within the nurse-led continence promotion clinics in Glasgow, indicated a high percentage of women were failing to adhere to their recommended conservative therapies for the treatment of stress urinary incontinence (SUI).

Aim: To explore why some women do not adhere to therapy.

Methods: A qualitative study, which used telephone interviews.

Participants: The study used a convenience sample of twelve women. The target population was women over 16yrs old, with the symptoms of SUI, attending a primary care nurse-led clinic, who failed to adhere to therapy.

Results: Five main categories were identified as reasons for failing to adhere to SUI therapy: health issues, family issues, house issues, forgotten / mixed up appointment dates and previously failed therapy.

Conclusion: A holistic nursing assessment is essential. Improved communication, increased patient involvement in the decision-making process and the removal of specific barriers to compliance may help the women to adhere to their therapy.

Key words Stress urinary incontinence, Adherence

Introduction and Background
Stress urinary incontinence (SUI) is the uncontrolled loss of urine on exertion e.g. when coughing, laughing, sneezing, jumping (Abrams et al. 2002). It can be an extremely embarrassing and distressing condition (Mitteness, 1990), is the most common type of incontinence in women (Brocklehurst, 1993) and is associated with damage to the pudendal or pelvic nerves, or changes in the urethral position due to pelvic floor dysfunction (Allen et al. 1990). Within NHS Greater Glasgow Primary Care, there are 32 weekly nurse-led continence clinics, which specialise in providing first-line conservative therapies for urinary incontinence. Many of the women who attend have the symptoms of SUI. Current treatment options include lifestyle changes, conservative therapies, such as pelvic floor muscle therapy (PFMT) and/or drug treatment, and surgery (Cardozo et al. 2004).

Lifestyle changes include weight loss, postural changes and reducing caffeine intake (Freeman, 2006). PFMT involves the voluntary contraction and relaxation of the levator ani muscle to increase its strength and endurance thereby enhancing the force of urethral closure under certain conditions, such as a sudden increase in abdominal pressure (Allen et al. 1990). Duloxetine is a combined serotonin and noradrenaline reuptake inhibitor and is believed to reduce SUI by increasing the strength of urethral sphincter contractions. Surgery is usually seen as a final treatment option and tends to be offered to women who have failed to improve with conservative therapies (Cardozo et al. 2004).

The Scottish Intercollegiate Guidelines Network (SIGN) is a professional body that develops and disseminates national clinical guidelines containing evidence-based recommendations for effective clinical practice. In 2004, SIGN published guidelines stating that SUI should be treated with PFMT, with a consideration for supplementing PFMT with Duloxetine. If this therapy fails, then onward referral to secondary care should be considered (SIGN, 2004). In 2005, NHS Greater Glasgow introduced the ‘Primary Care Management of SUI Pathway’ (Appendix 1). The pathway follows the SIGN guidelines (SIGN, 2004) and aims to provide clear clinical guidelines for Primary Care health professionals. A subsequent audit, conducted within the nurse-led continence clinics in Glasgow, indicated a high percentage of women were failing to adhere to their recommended conservative therapies for the treatment of SUI. This finding led to the aim of this study which was to look for an explanation of women’s adherence to conservative therapies for SUI and to make suggestions to increase the completion rates of treatment.
This article describes the literature search in relation to the conservative and pharmacological management of SUI, satisfaction and compliance with therapy, and non-attendance of clinic appointments. It explains the research approach, the aim of the study and discusses the sample selected, data collection tools used, the rationale given for the chosen methodology, the analyses and ethics consent. It leads on to describe the participant characteristics and documents the results through the use of direct quotes and explanations. Next it discusses the findings from the data collected, the strengths and weaknesses of the study, and the difficulties encountered. Finally, it sums up the findings and gives recommendations for practice and future research.

Literature Review

The ‘International Continence Society’ has defined stress urinary incontinence as ‘the observation of an involuntary leakage of urine from the urethra, synchronous with exertion, effort, coughing, laughing or sneezing’ (Abrams et al. 2002). This condition affects at least 14% of females who are over 30 years of age (Brocklehurst, 1993).

SUI is a condition that can diminish the quality of life (QoL) of sufferers. Sufferers tend to be more depressed, experience higher levels of anxiety (Berglund et al. 1994) and feel more stigmatised (Norton, 1988), compared to women who are not incontinent.

Urinary incontinence is widely believed to be an inevitable part of the normal ageing process. Bush et al. (2001) reported that patients’ beliefs and knowledge related to urinary incontinence, and misconceptions about the causes of incontinence and the availability of treatments, could stop them from seeking help for their problem. However, other factors that may influence adherence have yet to be identified.

Many studies have reported that conservative treatments can be helpful in managing SUI, with consensus groups recommending pelvic floor muscle training (PFMT) as the first-line treatment (Wilson et al. 2002). Unlike surgery, it has no adverse effects (AWHONN, 2000). PFMT is an effective, yet inexpensive, treatment for female SUI (Hay-Smith et al. 2001). PFMT is time consuming and requires high levels of motivation and a willingness to carry out an intense training programme, despite the fact that changes to muscle tone might not be seen for 6–8 weeks (AWHONN 2000). For best results, it is vital to maintain PFMT for 15-20
weeks (Haslam, 2004). Data on adherence to PFMT is sparse and dropout rates from therapy are high (Morkved et al. 2002). Many studies have found that non-compliance may be due to disbelief in the efficacy of treatment or a lack of support from family members (Glasgow et al. 1989; Rosner, 2006). Motivation for the treatment of SUI can be influenced by other factors such as a desire for future childbirth, rejection of surgery or the ability to cope with a certain degree of incontinence (Cammu et al. 1991). A structured PFMT programme aims at strengthening the muscles by contracting them in a timely and coordinated fashion (De Lancey, 1994). Several randomised controlled trials have demonstrated PFMT to be more effective than no treatment, with short-term cure rates varying between 44% and 70% (Bo et al. 1999; Morkved et al. 2002; Dumoulin et al. 2004). Patient satisfaction with SUI treatments was addressed in several studies. One study reported that 77% of women would recommend PFMT (n=48) (Cammu and Van Nylen, 1995). Cammu et al.’s conducted a study that looked at the efficacy of PFMT using 447 women suffering from SUI. Following treatment, 82 women (18%) felt they were cured and 139 women (31%) felt a considerable improvement. Forty-five of the women in the study (10%) dropped out. Interestingly, 33% of the drop-outs (15 out of the 45 women) received antidepressant or anxiolytic drug therapy, as compared with 16% of the women (64 out of 402 women) who completed treatment (Cammu et al. 2004).

Duloxetine is the only medication to be approved for the treatment of SUI. It is a serotonin and noradrenaline reuptake inhibitor (SNRI) that increases neural input to the urethral sphincter, thereby relieving the symptoms of SUI. The recommended dosage of Duloxetine in the European Union (EU) for the treatment of moderate to severe SUI is 40mg orally, twice daily. If adverse events are troublesome beyond the first 4 weeks, the dosage may be reduced to 20mg, twice daily (Mariappan et al. 2006). The Cochrane Database of Systematic Reviews looked at the use of SNRIs for the treatment of SUI in adults (Mariappan et al. 2006). They highlighted nine randomised trials that involved 3327 adults with predominant symptoms of SUI, randomised to receive either Duloxetine or placebo. Duloxetine was proven to be significantly better than placebo in terms of improving patients' quality of life and self-reported improvement. However, it commonly had side effects, with between 1:6 and 1:8 sufferers stopping treatment.

Poor compliance by patients with prescribed medication or other therapies, such as lifestyle changes, is a widely acknowledged problem (McGraw, 2004). A large number of
patients, as many as 25%–40%, are non-compliant and this has been found to have significant
effects on treatment outcomes (Di Matteo et al. 2002). Depression is a well-documented risk
factor for non-compliance with medical therapies (Goodenow et al. 1990). One study looked
at the baseline characteristics of women in whom therapy was a success, compared to the
characteristics of the other women (Cammu et al. 1991). They found that the chronic use of
psychotropic drugs was significantly more common in women who had failed therapy than in
those who were treated successfully.

Methodology

A qualitative study was conducted to allow the researcher to look at the women’s individual
experiences and take into account their cultural, social and other external factors that
influenced their behaviour. As qualitative research allows for an interactive process, it helped
the researcher to seek new ways of improving care through patient participation. However, as
it is grounded in real life experience, she recognised that there was no way of abolishing bias
related to data collection and analyses (Greenhaugh 2004). The data were generated by
individual interviews.

The sampling method used in this study was ‘convenience sampling’, i.e. where the
researcher deliberately chooses whom to include in the study on the basis that the selected
participants can provide them with the necessary data (Parahoo 1997). The sample was
selected on a first-come first-served basis. The target population was all of the women who
had attended the nurse-led continence promotion clinic and had commenced on the SUI
pathway but then dropped out of therapy. From this sample, the researcher hoped to be able
to obtain data that are representative of the population.

The inclusion criteria were women over 16yrs old, with the symptoms of SUI and
attending a nurse-led clinic in Primary Care. SUI was diagnosed by assessment and
symptoms. Women were excluded if they had predominant symptoms of another type of
incontinence, or had a learning disability or cognitive impairment. Informed consent for
inclusion in the study was obtained from all the women.

A ‘topic guide’ with core, open-ended questions was used (Appendix 2) and each
interview was taped, with consent. The interviews were carried out by the same researcher
over a 6-month period. All of the interviews were tape recorded and transcribed verbatim.
Each transcript noted who was speaking, exactly what was said and any additional comments
such as the tone of voice used. The transcripts were examined for emerging themes. To maintain confidentiality, all tapes and paperwork were stored in a locked filing cabinet. Additionally, each participant was allocated a personal identification number which was used on their paperwork and their tape and all evidence of each participant’s name and personal identifiable details were omitted. Key features of qualitative interviews are flexibility and versatility, and the aim was to explore the research question (Parahoo 1997). In this study new perspectives were uncovered and insights gained, and each interview differed in content. Interviewing usually stops when data saturation occurs i.e. no new data emerges (Parahoo 1997).

The Research Ethics Committee and the Research and Development team within NHS Greater Glasgow granted permission for the study.

Results

This section describes the key findings that were identified from the twelve interviews. The achieved sample included the following characteristics:

<table>
<thead>
<tr>
<th>Pt</th>
<th>Age</th>
<th>Current Depression</th>
<th>Point last seen in pathway</th>
<th>Ethnic group</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>65</td>
<td>Yes</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>2</td>
<td>53</td>
<td>Yes</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>3</td>
<td>55</td>
<td>Yes</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>4</td>
<td>45</td>
<td>No</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>5</td>
<td>37</td>
<td>No</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>6</td>
<td>43</td>
<td>No</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>7</td>
<td>51</td>
<td>No</td>
<td>PFMT</td>
<td>British Asian</td>
</tr>
<tr>
<td>8</td>
<td>62</td>
<td>No</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>9</td>
<td>28</td>
<td>No</td>
<td>PFMT</td>
<td>British</td>
</tr>
</tbody>
</table>
Table 1 - Patient characteristics

<table>
<thead>
<tr>
<th>No.</th>
<th>Age</th>
<th>Dropout</th>
<th>Therapy</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>65</td>
<td>No</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>11</td>
<td>57</td>
<td>Yes</td>
<td>PFMT</td>
<td>British</td>
</tr>
<tr>
<td>12</td>
<td>60</td>
<td>Yes</td>
<td>Yentreve and PFMT</td>
<td>British</td>
</tr>
</tbody>
</table>

The average age of the women was 52yrs, one woman came from an ethnic minority background and five suffered from clinical depression. Eleven of the women had dropped out of therapy during the first 12-weeks of the pathway i.e. PFMT, with only one woman dropping out whilst on drug therapy and PFMT combined.

The findings of this study are presented using description and direct quotes. To help with the analyses, a coding framework was designed and analytic categories established. An example from the framework is below:

**Why did the women drop out of therapy?**

<table>
<thead>
<tr>
<th>Coding framework</th>
<th>Analytic categories</th>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Depression</td>
<td>• Nurse’s awareness of holistic health problems of women</td>
<td>Health issues</td>
</tr>
<tr>
<td>• Believes it is part of her other health problems</td>
<td>• Requirement for discussion of possible side-effects of therapy</td>
<td></td>
</tr>
<tr>
<td>• In alcohol rehabilitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Stress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Unwell due to side-effects of Duloxetine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Caring for disabled partner</td>
<td>• Nurse’s awareness of holistic needs of the women and their families.</td>
<td>Family issues</td>
</tr>
<tr>
<td>• Family unwell</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Going on holiday</td>
<td>• Importance of women being</td>
<td>Household issues</td>
</tr>
<tr>
<td>Issues</td>
<td>Social Issues</td>
<td>Treatment Issues</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Ceiling fell in</td>
<td>awareness of need to inform clinic of social issues that may affect treatment</td>
<td>Flexibility with appointments</td>
</tr>
<tr>
<td>Loft had a leak</td>
<td></td>
<td></td>
</tr>
<tr>
<td>House being renovated</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgot appointment</td>
<td>Lack of information given to women regarding how to rearrange / check appointment</td>
<td>Forgotten / mixed up / unsuitable appointment dates</td>
</tr>
<tr>
<td>Got dates mixed up</td>
<td>Flexibility of appointment times around working women</td>
<td></td>
</tr>
<tr>
<td>No evening clinics</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tried PFMT before and didn’t work / didn’t like doing them</td>
<td>Discussion on women’s expectations / desires of therapy</td>
<td>Previously failed therapy / dislike of doing PFMT</td>
</tr>
<tr>
<td>PFMT makes her feel sick</td>
<td>Discussion on previous therapies tried</td>
<td></td>
</tr>
<tr>
<td>Can’t do PFMT</td>
<td>Additional support for women who are struggling with advice</td>
<td></td>
</tr>
</tbody>
</table>

Table 2: Example of coding framework

During the interviews, the participants were asked why they had come forward for help with their SUI. Only one woman stated she was not seeking any intervention and that she really just wanted containment products: ‘I had tried all that exercise before and it never worked and I just thought maybe, just get the pads’. Two of the women were seeking drug therapies – one had heard about the stress incontinence medication, Duloxetine, on daytime television and stated that the lady on the television said ‘it changed her life’, whilst the other just wanted medication as it was ‘easy’, whilst one woman was hoping for surgery.

Nearly all the women stated that they found the pathway easy to understand and were happy with it. This would indicate that a lack of understanding of the pathway itself was not
the reason for dropping out. The woman who was not happy stated: ‘I was given these pelvic floor exercises, and I had tried them before ... and I didn’t really find them very good and I don’t like doing them’. Three women reported negative feelings towards carrying out PFMT. These included: ‘they’ve always made me feel a bit queasy and I just kind of stop’, ‘I don’t really like doing them, I’ve tried them before and ... they make me feel a wee bit sick’ and ‘just trying to keep it up, you know, it’s no very good’. No study in the literature review reported on the feelings of queasiness or nausea related to PFMT. From the author’s experience as a Clinical Nurse Specialist, this is an occasionally reported complaint from women which is felt whilst doing PFMT. These findings indicate that one of the reasons for failing to adhere to therapy may be that some women have an aversion to doing the exercises. This is similar to findings in a previous study, which found that only 73.5 - 77% of women would recommend PFMT to friends and relatives (Cammu and Van Nylen, 1995). Further research into this area may be beneficial to practice.

Each interview tried to establish whether the women thought that the treatment pathway being recommended for them would be successful. Interestingly, it highlighted that only four women thought this treatment pathway was the right plan for them, five were unsure and three thought it wouldn’t work. Comments included:

‘it’s going to improve things ... even if it doesn’t totally solve the problem’, ‘I didn’t think it would work at all’, ‘no cos I tried it before ... and it didn’t’, ‘not really sure... I was thinking it’s my age ... and I wonder if it’s really going to help somebody my age’ – this lady was 65yrs old. These findings indicate that despite understanding the pathway, some of the women were unsure or had negative feelings about its effectiveness. It is important that sufferers have confidence in the treatment they are being recommended, especially if they are being advised to carry out an intensive PFMT programme. It is therefore not surprising that women stop following the programme if they are not confident in its effectiveness. All of the women felt that doing 12 weeks PFMT was an acceptable time-scale.

Two women commented that they had not received any written information at the clinic and would have found this helpful. As the literature review found a link between non-
compliance with therapies and a lack of knowledge about the treatment plan (Rosner, 2006), this emphasises the importance of checking a woman’s understanding of the therapy and providing written information.

Three of the women reported SUI as being a taboo subject and/or the stigma attached: ‘I didn’t want to find myself in an incontinence clinic. I just couldn’t, I just couldn’t bring myself to face up to coming’. Two of the women in particular seemed greatly affected by the stigma attached to having an incontinence problem. This is similar to findings in several other studies (Zinner et al. 2004; Cochran, 1998). Additionally, two women mentioned the stigma attached to attending a clinic and the possibility of a signpost above the consulting room door, having to seek directions inside the health centre or having to hand their name in to a receptionist. This was an interesting finding and one that appears not to have been reported before.

Four of the women described their own health problems, as well as those of their family, as being a reason for failing to continue therapy: ‘I seemed to go into a depression... so I thought, oh to be honest with you, I just couldnae be bothered with anything’, ‘I wasn’t feeling too good’ and ‘I’ve got a problem with drink and ... it’s just no been the right time really. I was in detox’. Three women described family issues as being a reason: ‘my partner... he’s blind and he’s disabled and I look after him’, ‘we’re just all getting over the flu’ and ‘my mum wasnae keeping too well’. Three women discussed household issues: ‘It’s because my ceiling fell in’ ‘What’s happened is, we went to get all the [Christmas] decorations out the loft and my whole loft is damp ... and we are waiting on ***** [the roofer]’ and ‘it’s because they’re eh renovating up these houses ... I’ve had workmen in and out like yo-yos. I’m really under stress with it’. Three women reported forgotten/mixed-up appointment dates, whilst three women discussed their previously failed therapy: ‘I was given these pelvic floor exercises, and I had tried them before, I used to go to the physio ... and they never worked then, so I don’t think they would work now’. Two women reported a reduction to their symptoms, whilst two women got dry: ‘It made a huge difference’ and ‘It’s such a difference ... I’m happy now’. One woman dropped out due to the side-effects of her treatment: ‘It’s because of the medication I’m on at the moment... it’s making me nauseous and sleepy’ – this lady was referring to her prescription of Duloxetine 20mg BD, which she had been taking for just over 2 weeks. One woman had problems continuing with therapy due to work
commitments: ‘I went from part-time to full-time work and couldn’t get days or time off to go because all the appointments were during the day’.

Following analyses of the results, five main categories of reasons for dropping out of therapy were identified:

1. Health issues, e.g. having the flu
2. Family issues, e.g. caring for a sick relative
3. House issues, e.g. work being carried out in the house
4. Forgotten / mixed up / unsuitable appointment dates, e.g. no available evening clinics
5. Previously failed therapy

The aim of this study was to explore the reasons why the women had failed to adhere to therapy. Several reasons were given during the interviews and a few common themes emerged. Some of the reasons given were superficial, e.g. damp Christmas decorations. However, it is clear that people prioritise circumstances in their lives in different ways and their giving up on SUI therapy due to minor catastrophes indicates a lack of motivation towards their therapy and perhaps an element of apathy. As the literature search carried out prior to commencing this study indicated that depression is a risk factor for non-compliance of therapies (Goodenowe et al. 1990), it was included in the participants’ characteristics to check for similar findings. Five of the women interviewed reported a diagnosis of clinical depression, which may support the possible link between clinical depression and therapy non-compliance.

Conclusion and Recommendations

The study highlights the need for a holistic perspective to appreciate the reality of the women’s experiences. Assessments should include adequate discussion on previous treatments and whether the woman wants to try conservative therapies again. Women should not only have their progress monitored regularly but also a discussion at each appointment regarding what their desires and needs are. Due to the possible link between depression and therapy non-compliance, increased support may also be beneficial for sufferers of clinical depression. A nation-wide campaign to increase the public’s knowledge on urinary
incontinence problems may help reduce the stigma attached to the problem. The removal of specific barriers to compliance may reduce the numbers of women dropping out of therapy, e.g. the option of house calls being offered to those women who are caring for sick relatives and the provision of evening clinics.

A larger version of this study would provide the basis for development of the identified themes and new, additional categories may emerge.

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Appendix 1

PRIMARY CARE
MANAGEMENT OF STRESS INCONTINENCE

SUI PATHWAY

PATIENT PRESENTS WITH SUI IN P C

CONTINENCE NURSE / PHYSIO PRIMARY CARE

CONSERVATIVE MANAGEMENT WITH PFMT FOR 12 WEEKS

G.P. FOR DULOXETINE IF SYMPTOMS PERSIST

CONTINUE PFMT MANAGEMENT AND PHARMACOLOGY FOR 12 WEEKS

FAILURE TO RESPOND – REFERRAL TO SECONDARY CARE

DRY – GP REVIEW IN 3 MONTHS AND CONSIDER TRIAL WITHOUT DULOXETINE

REVIEW AFTER 12 WEEKS AND AGAIN AFTER 24 WEEKS AND ? AUDIT FOR EFFICACY
Appendix 2

Topic guide

1. Why have you stopped attending your clinic appointments?
   - Find out if there are any specific reasons for stopping and discuss
   - Find out what the participant was actually seeking from the service
   - Were they satisfied with the service they received?

2. What did you think of the care pathway that the nurse discussed with you?
   - Discuss what they felt about the pathway – good and bad, and why
   - Discuss the timescales involved in the pathway
   - Establish if the pathway was understandable
   - Did the participant think the pathway would work for them? If not – why?
   - Establish if this is what the women actually wanted from the service
   - Were they happy with the pathway?

3. Attitudes towards SUI
   - Did they think that their SUI could be treated – if not, why?
   - How does the SUI impact on their life / relationships?
   - Does the SUI cause concern?

4. Was there anything else the nurse could have done to help them follow the pathway and attend their clinic appointments
   - Encourage an open discussion
   - Inform them the option to return is always open
Acknowledgements to Dr Joanne Booth, NMCH, Glasgow Caledonian University

Career status

The author works as a Clinical Nurse Specialist in Continence Care within the community of Glasgow. She has just started a part-time, two-year secondment in Glasgow Caledonian University as a Senior Clinical Fellow.