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# Full Length Research Paper

# Awareness and Health-Seeking Behavior in Patients with Stress Incontinence: Insights from a Prospective Study

# Eric Kinoti Mutema

SPR-Royal Preston hospital, Lancashire. E-mail: kynot76@hotmail.com.

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A prospective study was done to look at the awareness of patients to the availability of treatment for stress incontinence and whether this would have altered their health seeking pattern. Stress incontinence is when urine leaks because there is a sudden extra pressure ('stress') on the bladder. Questionnaires were distributed to all the patients admitted for continence surgery (n = 26). A second cohort included all patients attending the gynaecological outpatient clinic for any reason during a period of 2 months ( $n_1$  = 65) comprising of 2 groups A and B. After 1 month, a simple poster reminding patients with continence problems to discuss this with the doctor they were about to see. Group A was before and group B was after the implementation of the poster. In the pre-operative group, 26 patients completed the questionnaire. Of these 19 (73%) had been experiencing symptoms of involuntary urine leakage for more than 3 years. Majority of them had been referred for treatment following consultation with their doctor for an unrelated complaint. Only 42% (11) of the patients had seen the GP for the incontinence per se. More than 80% (22 patients) delayed in seeking treatment due to lack of awareness of treatment availability. With the introduction of the poster, there was an increase from 10 - 60% of patients informing the doctor of their incontinence complaints in the outpatient clinic. Lack of awareness was found to be the main reason for delayed/failure to seek treatment for incontinence.

Key words: Stress incontinence, medical taboo, lack of awareness, WHO initiative.

# INTRODUCTION

A decade after the first WHO Consultation aimed at giving advice on urinary incontinence, it still remains an embarrassing and socially isolating disease (WHO, July, 2001). Possibly, the last medical taboo. A lot of effort continues to be directed into lifting the taboo on this issue but one of the pivotal points still remains neglected. Stress incontinence is when urine leaks because there is a sudden extra pressure ('stress') on the bladder. This is because your pelvic floor muscles and urethra cannot withstand the extra pressure. Small amounts of urine may leak, but sometimes it can be quite a lot and can cause embarrassment. Urine tends to leak most when one coughs, laughs, or during exercise. In these situations there is sudden extra pressure within the abdomen and on the bladder (P.L. Dwyer, July 2004). Majority of the women affected by any form of incontinence still accept this as a natural process of ageing and a consequence of child bearing. They thus remain unaware of the availability of therapeutic measures.

Help seeking has been estimated as low as 20% and those with severe symptoms (daily leakage), only about half seek help (C. Shaw et al, 2001). A number of studies have examined reasons for not seeking help. Reasons quoted include people considering their symptoms to be

too trivial, symptoms believed to be a normal part of ageing, or the natural result of childbirth (Mitteness L.S. et al., 1987; Goldstein M. Et al., 1992).

In a survey conducted by the National Association for Continence, one quarter of women aged 18 or older reported leaking symptoms in the month preceding the

survey (NAFC, May 3, 2002). While these statistics are daunting, the most alarming fact is that most of these women suffer silently, have not reported their symptoms to their physicians and, thus, have not been diagnosed properly.

This study looked at the awareness of patients to the availability of treatment for stress incontinence and whether this would have altered their health seeking pattern.

# **METHODS AND MATERIALS**

This was a prospective survey of patients' awareness of the availability treatment options urinary incontinence. It was carried out in The Pennine acute trust (Rochdale infirmary) between December 2008 and March 2009, questionnaires were distributed to all the patients admitted for continence surgery of any form offered within the hospital. This included TVT, TOT and Botox injections mainly. They were offered questionnaires on the morning of the operation While undergoing their pre-operative assessments. 26

**Table 1.** Source of information on availability of incontinence treatment (n = 26).

Source of information	Number of patients	Percentage
Friends/Relatives	7	26.9%
Mass media	8	30.8%
Poster illustration	11	42.3%

**Table 2.** Reasons for delayed consultation (n = 26).

Reasons for delayed consultation	Number of patients	Percentage
Embarrassed and unaware of treatment availability	12	46.2%
Unaware of treatment availability	10	38.5%
Embarrassed	3	11.5%
Other	1	3.8%

Questionnaires were completed (n = 26). This was out of a total of 38 patients who had these operations during this period. The 12 that were not included were due to the questionnaire not being administered by the admitting nurse.

Following the results of this, a second cohort was included into the study. This included all patients attending the gynaecological outpatient clinic for any reason during the period of March to April 2009 (2 months). They were requested to complete the questionnaires at the reception desk after completing their consultation if they had not done so in a previous visit. They were divided into 2 groups, A and B ( $n_1 = 65$ ). Group A was in the  $1^{\rm st}$  month. 35 patients accepted to fill out the questionnaire. After one month, a simple poster reminding patients with continence problems to discuss this with the doctor they were about to see so as to get treatment was put up in the waiting room. In Group B, 30 patients accepted to fill out the questionnaire. This was if they had not done so in a previous visit. This was carried out over 1 month as well, April 2009.

#### **RESULTS**

In the pre-operative group, 26 patients completed the questionnaire. Of these 19 (73%) had been experiencing symptoms of involuntary urine leakage for more than 3 years. The rest (27%) were between 1 - 3 years with none suffering for less than 1 year.

Majority of them had been referred for treatment following consultation with their doctor for an unrelated complaint. Only 42% (11) of the patients had seen the GP for the incontinence per se.

Of the patients having continence surgery, a significant number were made aware of treatment availability via an illustration in the GP surgery's waiting room. As illustrated in Table 1.

When asked of the reasons for the delay in consultation (for more than 3 years in most cases), the answers were as shown in Table 2.

Thus, 22 patients (84.7%) in total were unaware of the availability of treatment options. Other than a single patient, these all (95.4%) responded that they would have

sort treatment earlier if they had had the information.

Sixty five patients filled the questionnaires following clinic attendance, 35 in the first month (group A) and 30 in the second month (group B). 22 (33.8%) had complaints of involuntary urinary leakage.

Twenty (30.8%) of these patients had been experienceing involuntary leakage of urine for more than a year, with 2 (3%) suffering for a period of 6-12 months. These included 10 in group A and 10 in group B. On further analysis of the patients with symptoms for more than 1 year, 75 % had been experiencing the symptoms for more than 3 years and 25% for 1 - 3 years.

When those suffering for more than 1 year were asked as to whether they had mentioned the problem to a doctor, the results are shown in Table 3.

Of the patients who had previously mentioned their incontinence with the GP (in both groups) only one had been offered any form of treatment.

## **DISCUSSION**

For patients to seek treatment, they should at least be aware that there is help available. The "incontinence pads" industry is constantly advertising their product and it is easy to see why women may fall to the false belief that this is something they have to find ways to live with. This is without considering the cost of purchasing these products as they are not provided by the NHS.

In this study, more than 70% of patients admitted for continence surgery had been experiencing this symptoms for more than 3 years with some indicating it was more than 10 years even though not part of the options in the questionnaire. Despite this, majority of them were offered this treatment while consulting their doctor for unrelated issues.

Most interesting was the fact that the main reason for not seeking treatment was lack of awareness of the availability of treatment. This included about 85% of them

Table 3. Patients informing their doctors of existing urinary incontinence and have had symptoms for 1 year or more.

	Group A -Before implementing the poster		Group B -After implementing the poster	
	Number of patients	percentage	Number of patients	percentage
Did not inform any doctor	7	70%	1	10%
Informed GP	2	20%	3	30%
Informed the doctor they had just seen	1	10%	6	60%

as compare to 57% who stated embarrassment as one of the main reasons for not seeking treatment.

In the groups that were surveyed in the gynaecology outpatient clinics, it was interesting to note that the simple addition of a poster illustration changed the figures from having only 10% to 60% discussing their incontinence issue with the doctor they had just seen.

These findings are not peculiar to the region of the hospital as in a recent national study involving over 1000 face-to-face interviews showed up to 26% of women interviewed especially in the south west of Britain were not even aware of the availability of urinary incontinence.

As more effort is being put into lifting the taboo off discussing and seeking treatment for urinary incontinence, similar if not more effort should be directed toward making women aware that there is help available for the incontinence.

We recommend simple awareness campaigns to enable access to patient-friendly information e.g. leaflets and posters in GP surgeries and other public areas.

An important facet of this is also to increase awareness of the GPs so as to ensure history taken on incontinence is not just put down as routine history taking for completeness sake. This will encourage institution of the appropriate basic treatment measures and/or referral.

With about a third of all British women over the age of 30 experiencing this condition, we cannot afford to take our foot off the pedal in tackling the barriers to seeking treatment for incontinence.

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#### Conclusion

Up to 70% of women especially with light adult incontinence can be helped and most without resulting to surgery. Yet we still fail to get patients presenting with their incontinence problems. Lack of awareness was the main reason for delayed/failure to seek treatment for incontinence. A significant increase in patients discussing their incontinence problems was shown with the introduction of an informative poster. With over £24 million spent on disposable continence products in 2001 only, it

is imperative that effort is correctly targeted and more is done to increase awareness that is obviously lacking.

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