

Original Article

The Ethnic Cultural and Social Aspects of Incontinence – A Pilot Study

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Abstract: This cross-sectional study aimed to study the religious and cultural practices of ethnic minorities that might affect the experience and ideas that sufferers of incontinence have. Subjects were multiparous women from the local community who suffered from incontinence. Structured and unstructured interviews were conducted to assess the effect of incontinence and menstruation on home life, sexual life, personal and communal prayer, rules and customs associated with menstruation, and the ability to discuss problems with their doctor and partners. Individual women differed in how they rated their daily activities, and this was not related to religious or ethnicity. Higher restrictions on activity were perceived for fecal than for urinary incontinence. Sexual relationships were restricted for Jewish and Muslim women during menses. Incontinence led to religious restriction, which was most marked for Jewish and Muslim women, and this was related to the need for cleanliness for prayer. Less than 50% of patients sought help, and this was not related to duration and severity of symptoms. Only Muslim women had a strong preference for female doctors, and this was for cultural reasons.

Keywords: Ethnicity; Incontinence; Religion

Introduction

There are many unspoken taboos and cultural variations in micturition and defecation habits throughout the world. These variations affect not only how different women see the process of micturition and defecation, but

how they may perceive incontinence and seek advice and treatment from the medical profession. Urinary and fecal incontinence are both physically and psychologically distressing conditions, with significant effects on quality of life for many women. A woman's experience of incontinence may be affected by specific issues, such as her role inside and outside the home and the disruption of her daily life.

The exact prevalence of incontinence is underestimated, as many sufferers are reluctant to seek help owing to shame, embarrassment and ignorance regarding the availability of treatment [1]. The prevalence of urinary incontinence is estimated as 5%–7% in women aged 15–44, 8%–15% in women aged 45–64, and 10%–20% in women over 65 [2]. A MORI survey in 1991 [3] found that the emotional, social and hygienic effects of urinary incontinence were considerable. Fecal incontinence is in many cases an even more devastating symptom, and is also underreported. It is estimated to afflict up to 11% of adults [4], and 7% of those over the age of 65 have fecal incontinence at least once per week and need to wear a pad [5].

With increasing public awareness that incontinence is a common symptom, not a normal part of aging and in many cases treatable, medical, paramedical and health-care professionals need to be aware of issues that are relevant to such patients to encourage them to seek help.

Studies assessing the effects of urinary and fecal incontinence on quality of life have explored the subjective experience of these conditions, but have rarely addressed the importance of ethnicity and the social structural basis of illness, or what restraints (if any) religion or culture may impose on a sufferer. Different ethnic groups may perceive mental and physical health in different ways from traditional western medicine. This may be influenced by the woman's religion and ethnic background, her role in the home and

outside, and her ability to communicate effectively with medical personnel.

This study aims to explore religious and cultural practices within ethnic minorities that may effect the experience and ideas sufferers have of incontinence.

Methodology

This was a pilot study of multiparous women of different ethnic backgrounds from the local community, who were identified by ourselves and selected health-care workers. These workers were from within the hospital (including those who liaised specifically with ethnic minority patients) and were requested to ask any women whom they knew to be suffering from incontinence to be interviewed, even if they had not necessarily sought medical help. The religions of these women were a non-proportionate representation of religious practice within the UK. We were aware of the spectrum of practices within each religion and, when appropriate, chose to interview those who were orthodox (Muslim, Jew) to form an idea of how their generally stricter religious principles were put into practice. All subjects were required to be suffering from urinary or fecal incontinence, to have a regular sexual partner, and to be followers of a particular religion. Data regarding the effect of incontinence on various aspects of life was obtained by means of a one-to-one confidential interview with the same interviewer (CC). The interview consisted of a structured and an unstructured format. The structured interview was based on a questionnaire derived from discussion with members of our unit, as well as members of the general public with and without incontinence, who explained attitudes and perceived effects on lifestyle. An unstructured interview allowed women to discuss how they coped with incontinence and which areas of their lives they felt it affected most. This allowed us to identify areas that might not have been covered in the structured questionnaire. Sociodemographic data were also obtained to help construct a profile of these women. Issues discussed included the social taboos surrounding incontinence; the impact of incontinence on personal prayer and attendance at a house of worship, and participation in religious festivals; rules or customs associated with menstruation; the ability to discuss these problems, particularly with husbands and males; and any cultural preference for a female doctor.

During the structured interview subjects were asked to grade the severity of domestic, sexual and religious restriction due to urinary incontinence on a visual analog score graded from 1 to 10 (1 = no inconvenience, 10 = severe restriction). The same questions were asked in relation to fecal incontinence (all subjects were asked to estimate their response to a similar degree of fecal incontinence) and menstruation.

The interviews lasted between 30 and 90 minutes, and the notes were transcribed immediately to see how participants viewed their urinary incontinence and

menses, and how they would view a similar degree of fecal incontinence.

Results

Characteristics of Participants

Thirty-four women participated in the study: 7 Muslims, 9 Hindus, 6 Jewish, 3 Buddhists and 9 Christians. All spoke fluent English and there were no obvious communication difficulties.

The average age was 48.2 years (range 32–74). Nine women were from social class I, 22 from social class II, and 3 from social class III; 29 women had full-or part-time jobs. All had completed college education, though none were professional.

All women had their closest social contacts with women of their own ethnic group. Access to medical help was similar for all women, as judged by the efficiency all women had for routine health checks such as cervical screening and mammography.

Symptoms

Twenty-two women complained of weekly or daily urinary incontinence episodes that required them to wear sanitary protection, and which for the majority placed some restriction on their lives. The others complained of occasional urinary incontinence (once or twice monthly) that did not necessitate the wearing of sanitary protection and was not a restriction on their lives, although they all complained that even this occasional incontinence did trouble them. The frequency and severity of urinary incontinence was not related to ethnic group.

None of the subjects complained of fecal incontinence, and those who were premenopausal did not complain of menstrual problems.

Medical Help

Only 8 women sought medical help for their urinary incontinence: 6 Jewish women, 1 Hindu and 1 Christian. All complained of weekly or daily incontinent episodes. Seeking medical help did not seem to be related to the duration of symptoms, which ranged from weeks to years before help was sought. All Jewish women suffering from incontinence sought help, which may be a factor of cultural and social influences. Those women who did not seek help gave reasons such as embarrassment, the feeling that this was a 'normal part of aging', and ignorance regarding the available treatment.

Gender of Doctor

All subjects were asked about their preference for a male or female doctor for discussion of their incontinence, and for any intimate vaginal examination. All the Muslim

women preferred female doctors. The Jewish, Christian and Buddhist women expressed no preference. Four out of 9 Hindu women preferred female doctors, which seemed to be related to individual preference, not religious rules.

Ability to Discuss Incontinence

All women felt they could discuss their incontinence with their partners, but this was seen most among the Jewish women, where it seemed that health education and disease prevention were highly important issues. Among the Muslim and Hindu women the first family members to be informed were close females, not male relatives. All women felt that they would not feel free to discuss incontinence with anyone outside the immediate family generally, as others might perceive them as ‘unclean’ or ‘dirty’. The majority felt that there was some degree of taboo in the discussion of incontinence in society.

Restriction of Activities

Individual women differed in how they rated the restriction of their day-to-day activities, and this did not seem to be related to religious and cultural influences, but rather the severity of symptoms and the degree of adaption they had made. Generally, higher restrictions on domestic and sexual activity were perceived for fecal incontinence than for urinary incontinence (Figs 1, 2). Embarrassment regarding odour and ‘feeling unclean’ were highlighted by many women as the reasons for restriction of activities. Sexual relationships were prohibited for Jewish and Muslim women during menses, and this was reflected by the high restriction scores on sexual activity during menses (Fig. 3). The degree of sexual restriction due to incontinence differed among individuals, and seemed to be related to decreased libido associated with ‘feeling unclean’, rather than religious restrictions.

Jewish women were able to pray during menses but Muslim women were not. Religious restriction due to incontinence was most marked in Jewish and Muslim

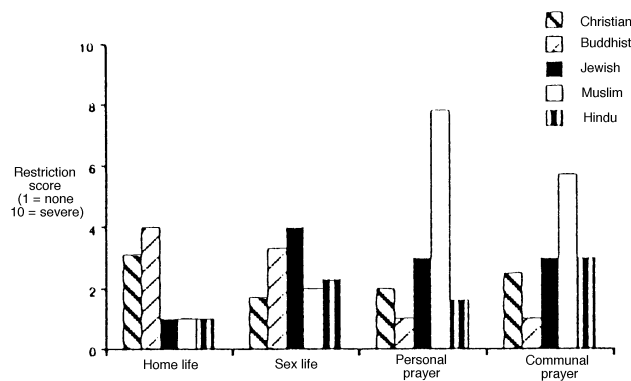


Fig. 1. Effect of urinary incontinence on quality of life.

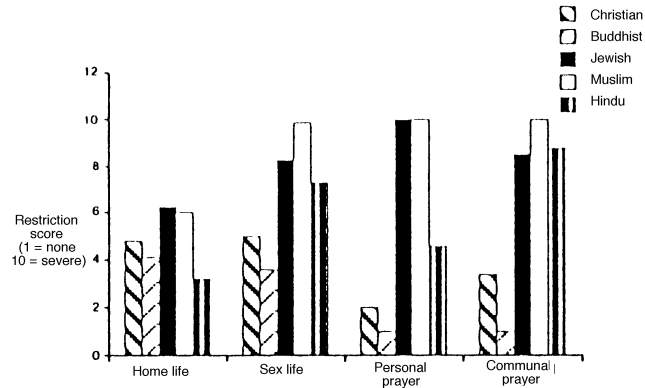


Fig. 2. Effect of fecal incontinence on quality of life.

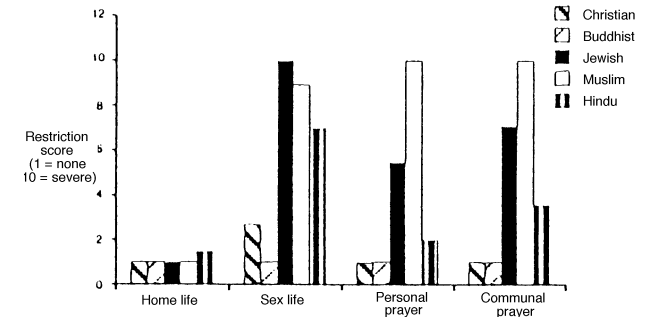


Fig. 3. Effect of menstruation on quality of life.

women, and this was related to the need for cleanliness at prayer and attendance at a house of worship. Those with long-term incontinence had modified prayer routines in order to allow for their incontinence, and were able to pray as long as they could ‘keep clean’. This involved voiding before prayer, restriction of fluid intake, and for some of the Muslim women altering the position of prayer to the sitting rather than the prostrate position.

Discussion

Epidemiological and clinical studies have documented that incontinence may have significant consequences on quality of life, affecting social activities, domestic, physical, recreational, occupational and sexual activities [6–9]. Data from studies of women suffering from other chronic conditions show that ethnicity may play a part in the experiences of disease, and that this may be influenced by personal, social and political factors [10–12].

Structured and unstructured interviews were used to assess responses to incontinence to provide qualitative data from a small number of sufferers to paint a picture of how incontinence affects their lives. Qualitative research complements quantitative data and allows us to understand how diverse influences can affect a woman’s life and shape her experience of incontinence. This study did not intend to obtain statistical data about sufferers, which would have required a much larger-

scale survey than this one of 34 women, and would extend the analysis of these issues and reveal significant patterns of behavior. However, we hoped to illustrate potential differences in lifestyle that may be affected, especially in women who had not formally received specialist help. This study also illustrates the difficulty in recruitment of patients with symptoms such as these, which are often embarrassing and not freely discussed. A further extension of this study would be to analyze each religious group in greater depth, including their education standards, and widening the group studied to all members of the religion, not only those who are orthodox. We acknowledge that the choice of religion was restricted in that orthodox may not be wholly representative of religious practice, but it is none the less a valuable group that gives the extremes of religious views.

All women felt they could discuss their incontinence freely with their partners, but it was obvious that taboos still exist in society regarding this common problem. The ease of discussion with partners may be related not only to general health awareness within a family, but also to relationships within the marriage, which were not assessed. Muslim women in this study preferred female doctors, and although this is not dictated by the Quran it is a cultural practice adopted by some societies. Subjects were asked to grade how their lifestyles would be restricted by the same degree of fecal incontinence, and this was generally higher than for urinary incontinence. As embarrassment regarding odour and 'feeling unclean' were significant factors, this may have been the reason for the perception of greater restriction.

Both Jewish and Muslim women reported greater restriction scores on prayer for urinary and fecal incontinence than did women from other religious groups. This can be explained by their strict religious rules regarding cleanliness for prayer. In Jewish Law, according to the Torah commandment (Deuteronomy 23.15), a person may not engage in a sacred task, such as prayer or the study of the Torah, in the presence of excrement, and the Rabbis have extended this prohibition to apply similarly to urine. Islamic rules state that a person must be in a state of cleanliness ('tahaarah') to perform certain acts of worship and for prayer to be valid. This involves either washing of the arms, face and feet, a complete bath or dry cleansing (with earth, sand or clean dust) in the absence of water. Defecation and urination nullify the state of tahaarah. Women should cleanse themselves prior to the time for new prayer and, if intermittent urinary, fecal or uterine discharge is occurring, the prayer should be delayed until the flow ceases, as long as there remains time in which to make prayer. Body parts and clothes that are soiled should be washed prior to purification for prayer.

Prayer routines were more affected for Muslim than for Jewish women, owing to the fact that cleansing rituals and the frequency of praying were greater. Communal prayer was affected for both Jewish and Muslim women.

Menstruation was used to assess how a normal physiological process (compared to a pathological one

such as incontinence) compared on restriction of lifestyle. Apart from religious and sexual restrictions for Muslim and Jewish women, menses did not affect day-to-day activities. This may be because adaptation to menstruation has been made from adolescence, and also that social taboos surrounding menstruation are much less than those surrounding incontinence.

One of the limitations of this study was the exclusion of women who were not in touch with health-care workers, and these may be the group whose experience of incontinence may be most relevant, as they may not be in contact with or feel unable to approach a western system of health care and community agencies. Assessing the reasons for delay in seeking treatment in this group of women would have given us more insight to how medical personnel should target sufferers in the community. Unfortunately, our recruitment strategy was not able to avoid this problem, and we were aware that information derived from women in contact with health-care workers might not be representative of the entire population. However, the rules for religious cleanliness would still apply.

There is a need for the public to be made aware that incontinence is a common problem which in many cases is treatable. In order for this to be possible, health-care workers need to recognize the experience of women in their community who are from different ethnic backgrounds, and what their differing needs and fears may be. Sensitivity to the emotional, social and cultural impact of symptoms is essential in the evaluation and management of sufferers, as well as understanding potential factors in the development and exacerbation of symptoms. In order to target the treatment of incontinence, the full impact of incontinence on daily life must be understood to allow us to deliver culturally sensitive care and to encourage women to seek help. This study has highlighted areas of daily life not previously explored, and a larger epidemiological study is planned to address these issues further.

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EDITORIAL COMMENT: This pilot study takes an initial look at the clinical and social experience of ethnic minorities in regard to urinary and fecal incontinence. Clear distinctions are seen between the small groups of Muslim, Jewish, Hindu, Buddhist and Christian women who participated in this interview- and questionnaire-based study. These differences seem to be culturally linked. The authors are to be congratulated on attempting to tackle this very complex topic, and should be encouraged to further their evaluation using standard epidemiological techniques to test a formulated hypothesis.

Review of Current Literature

Effect of Preoperative Voiding Mechanism on Success Rate of Autologous Rectus Fascia Suburethral Sling Procedure

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Obstet Gynecol 1998;91:577–581

Fifty patients had a suburethral sling procedure with autologous rectus fascia for genuine stress incontinence and low urethral closure pressure, or those with normal urethral closure pressure and no urethral hypermobility. Closure pressure less than 20 cmH₂O was indicative of intrinsic sphincter deficiency (ISD). Patients whose abdominal pressures increased more than 10 cmH₂O during voiding were defined as Valsalva voiders (13 patients). Postoperative urodynamic testing was carried out at 3 months in 48 of 50 patients. Stress incontinence was subjectively cured in 47 (94%) and objectively in 73%. Preoperative urethrovesical

junction (UVJ) mobility was not related to cure rate. The incidence of de novo detrusor instability was 30%. Pre-existing detrusor instability resolved in 43% of patients. In 13 patients identified preoperatively as Valsalva voiders, 54% remained incontinent based on objective testing, compared to 17% of the 35 patients in the non-Valsalva group.

Comment:

Patients identified preoperatively as Valsalva voiders may experience higher objective failure rates following rectus fascia suburethral sling procedures for urinary stress incontinence. The higher incidence of failure in these patients may be related to excessive forces impairing sling integrity in the immediate postoperative period. Not only did these patients have a higher failure rate, they also took longer to void. One strong feature of this paper is that patients with urethral hypomobility did not have a higher failure rate than those with hypermobility, and the former group comprised 40% of those with ISD.