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The relationship between gender and the psychological impact of urinary incontinence on older people in Hong Kong: an exploratory analysis

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ABSTRACT
Adult incontinence violates social norms and values and undermines the personal expectation of being independent, dry and clean. Urinary incontinence is widely known to have a psychological impact on elderly people. This paper reports the findings of a study of the impact of incontinence on a convenience sample of older people in Hong Kong. Several of the results concur with those of studies in western countries. It was found that the prevalence of urinary incontinence increased with adult age, and that the condition affected women more than men. Over half of both men and women respondents had suffered for less than three years. It appeared that the period of suffering was not strongly associated with the level of incontinence. There were no significant differences between the duration and the level of incontinence, or between health status and years of suffering. About 80 per cent of the incontinent respondents had negative psychological impacts. There were significant differences between the sexes in the impact of urinary incontinence as indicated by the following items: elderly men found incontinence more stressful than their women counterparts; and elderly men more often strove to hide their incontinence from their friends. In summary, older men reported more negative psychological effects than older women. This study is not able to conclude that the psychological suffering of those who reported more negative effects is greater than that of those who reported fewer.

KEY WORDS – urinary incontinence, elderly people, psychological impact, gender.

Introduction

Many adults suffer from urinary incontinence, and the financial, physical, emotional, psychological and social impacts are demoralising and distressing for those affected. Moreover, urinary incontinence has become

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a costly public health issue (White and Getliffe 2003). Most of the considerable research on the topic has however been carried out in western countries, and electronic and library searches found no published empirical studies of the impact of urinary incontinence on older people in Hong Kong. Given that the condition is a great burden to those affected, it requires careful investigation in all nations and cultures. This study examines the significant psychological impacts of urinary incontinence in a sample of older people in Hong Kong, as a contribution to the search for a means to promote the psychological wellbeing of the city's older people. The paper reports the findings of a cross-sectional study that aimed to establish the epidemiology of urinary incontinence among older people in Hong Kong, to raise the awareness of care-givers and health professionals about the issue, to stimulate public understanding of this taboo topic and, most importantly, to promote the psychological wellbeing of older people who suffer from the illness and to encourage them to talk comfortably and confidently about the symptom.

The definition and prevalence of urinary incontinence

All forms of spontaneous, unintentional and unconscious urination are regarded as urinary incontinence. In 2003, the Committee on Standardisation of Terminology of the *International Continence Society* (ICS) defined urinary incontinence as 'the complaint of any involuntary leakage of urine' (Abrams *et al.* 2003: 38). Another definition, developed in 1996 by the United States *Agency for Health Care Policy and Research* (AHCPR) is straightforward and succinct: 'an involuntary loss of urine that is sufficient to be a problem' (AHCPR 1996: 1661). These definitions raise the question of when does urinary incontinence become a problem? Michaels and Gordon (2001) have suggested that it is when a person's urine loss is copious or frequent enough to cause distress. This study has adopted the ICS definition (as elaborated by Michaels and Gordon) to explore the issue of the psychological impact of incontinence on elderly people according to gender. For the purpose of this study, three levels of urinary incontinence are distinguished: mild, moderate and severe.

Urinary incontinence becomes more common with increasing adult age, and post-urination dribble and continuous leakage are common forms in later life. In Hong Kong as elsewhere, many incontinent elderly people will not talk about their condition or report it to physicians, in part because of their limited understanding of the illness (or symptom, as some sufferers prefer to see it), and through a fear of social rejection. Urinary incontinence is generally under-reported and under-diagnosed (DuBeau 1995;

Koch *et al.* 2000; Ueda *et al.* 2000; Ee 2001). An accurate estimate of urinary incontinence among people of all ages is unavailable. Almost all studies, however, confirm that the prevalence increases with adult age (Thakar and Stanton 2000; Dorey 2001), that the prevalence is higher for women than for men at all ages (DuBeau 2000; Fultz and Herzog 2001), and that the prevalence for elderly people in institutions is higher than that of their community-dwelling counterparts (Cooper 1997; Specht and Maas 2001).

The AHCPR (now known as the *Agency for Healthcare Research and Quality*) estimated that between 15 and 35 per cent of people aged 60 and more years living in the community have experienced some degree of urinary incontinence (AHCPR 1996). Burgio and Locher (1996) and Johnson *et al.* (2000) reported that approximately 30 per cent of elderly people living in the community suffer from urinary incontinence. It has been estimated that at least 50 per cent of nursing home residents (and older people's care-home residents in the United Kingdom and Hong Kong) are incontinent (Burgio and Locher 1996; Cooper 1997; DuBeau 2000). Yarnell and St Leger (1979) reported that between 40 and 60 per cent of nursing home residents were incontinent.

Throughout Asia, urinary incontinence remains a sensitive and indeed a taboo subject and needs to be brought into the open. The condition brings stigmatisation, social embarrassment, loss of self-esteem and loss of face, and this has produced widespread under-estimation and under-diagnosis (Ueda *et al.* 2000). There have been very few systematic studies of the prevalence and effects of urinary incontinence among elderly people in Asian countries. The *Asia-Pacific Continence Advisory Board* has however conducted a survey of 11 cities in 11 different countries and this established an overall prevalence of 12.2 per cent (with a range from 4.6 to 23.1 per cent) for people of both sexes and all ages living in the community (Lapitan 2001). A Singaporean physician reported that the prevalence of urinary incontinence among older people living in the community in Singapore range from five to 15 per cent, that more than one-in-five elderly hospital patients suffer from the condition, and that the prevalence among elderly-home residents is close to 50 per cent (Ee 2001). Tobin (1992) suggested that the higher prevalence in residential care facilities is related to the high average age and to the high prevalence of physical and mental morbidity among the residents.

Prevalence and gender

Studies in western countries have consistently found that the prevalence of urinary incontinence is higher for women than for men throughout the

lifespan (DuBeau 2000; Fultz and Herzog 2001). Thomas *et al.*'s (1980) study of 22,430 people of all ages reported that the prevalence of incontinence among women aged 15–64 years was 8.5 per cent compared with 1.6 per cent among men of the same ages. For those over the age of 65 years, the prevalence increased to 11.6 per cent for women and 6.9 per cent for men. Jirovee *et al.* (1999) and Diokno *et al.* (1986) reported that the prevalence among women was twice as high as that among men. Ueda *et al.* (2000) found that the urinary incontinence of women aged 40–75 years was five times that of men of the same age range: 53.7 per cent for women and 10.5 per cent for men. Shimanouchi *et al.* (2000) explained that older women suffer more seriously from incontinence than older men because of physical and anatomical differences. It has been found in Asia, however, that the prevalence of incontinence is not always higher among women than men, for the Asian Pacific Continence Advisory Board study reported several exceptions. In Hong Kong, the prevalence rates for men and women are respectively 13.0 and 12.0 per cent; in Korea, they are 28.6 and 22.6 per cent; and in Taiwan, they are 7.6 and 7.4 per cent (Lapitan 2001).

The psychological impact of urinary incontinence

Urinary incontinence has a devastating effect on the life of older persons, and the distress of sufferers is impossible to quantify precisely. The following quotation is a typical expression of the experience of an older person who is incontinent:

> Incontinence is soul shattering. It can completely ruin the lives of those of us who are affected by it. Humiliation, degradation and shame are familiar feelings that we experience when facing incontinence. What is important for all of us is to appreciate that this suffering is not necessary. There are a great many things that can be done to resolve incontinence. The problem is finding people who are able to offer the help and advice required (White and Getliffe 2003: 12–3).

What is the psychological impact of urinary incontinence? The question has rarely been addressed. The research of Specht and Maas (2001) suggested that the psychological impact includes the embarrassment that incontinent people endure, the shame that they feel, and the social rejection that they encounter. These experiences often lead to severe depression which, in turn, leads to self-neglect, reclusiveness, social withdrawal and low self-esteem. Some sufferers even refuse to share their experience with their spouse or sexual partner. Urinary incontinence affects one's sex life, one's feelings of sexuality, and one's confidence in a sexual relationship. As Ng (2001: 168) observed, 'leakage of urine may make a person feel embarrassed, anxious and less feminine or masculine. The appearance of a visible incontinence appliance can also affect a person's sexual appeal'.

For elderly sufferers, managing the ramifications of the condition is their central preoccupation. Incontinence can be very distressing. It has an impact on social activities, inter-personal relationships, personal feelings, and psychosocial wellbeing. It is reported that incontinent older people tend to be depressed, have higher levels of anxiety, feel stigmatised, have lower levels of life satisfaction, and an impaired quality of life. Empirically, urinary incontinence is found to be associated with adverse psychosocial wellbeing that will eventually lead to social isolation, withdrawal and seclusion in the home (Qualey 1995; Michaels and Gordon 2001; Shaw 2001; Wilson 2003).

Several studies have described urinary incontinence as a chronic illness. Leventhal and Nerenz (1985) point out that individuals often have both psychological and cognitive responses to the threat of illness. A person's psychological response may either increase or decrease the severity of an illness, for the response has a direct influence on the individual's appraisal of their state. Shaw (2001) noted that the impact of incontinence is associated with individual circumstances. People with other, more serious, conditions may place incontinence low on their list of concerns.

Minor leakage may be of little concern to someone who has major mobility problems, but may mean the difference between remaining independent and being forced into an institution. Some argue that one of the possible results of incontinence is premature institutionalisation (Burgio and Engel 1987; Stanley 1997; Shaw 2001). Many researchers argue that urinary incontinence is a problem that has physical, psychological and social effects: in other words, it is a quality-of-life issue. These researchers have observed that urinary incontinence leads to many secondary complications, including adverse social, psychological, and economic effects (Johnson *et al.* 2000; Merkelij 2001; Specht and Maas 2001).

It is reasonable to hypothesise that the different physiologies, lifestyles and social engagements of men and women mean that those who are older and incontinent will have different psychological and health-care needs. Two major research questions were formulated for this study: What are the psychological difficulties of elderly people suffering from urinary incontinence? Is the psychological impact the same for female and male sufferers?

Research design

Sampling

With the co-operation of a non-governmental organisation (NGO) in Hong Kong, the sample for this study was drawn from two old people's

care-homes and, for community-living respondents, from an elderly centre. The NGO participating in the study randomly chose two homes and one centre that were under its management as the research sites. All clients of the chosen homes and centre who were aged 60 and more years were potential respondents. Since the study involved retrospective thought, the respondents were required to have adequate cognitive capacity for daily social functioning. Elderly people with cognitive impairments or severe hearing problems were not considered as respondents. To keep away from possible embarrassment and subsequent labelling, the study avoided using incontinence as a selection criterion, so supervisors at the three research sites referred potential respondents to interviewers regardless of their incontinence status.

Data collection

The study was cross-sectional and used face-to-face interviews with a questionnaire mainly composed of closed-ended questions, partly because many of the respondents were likely to have been poorly educated. Informed consent was obtained from the respondents and the staff who supervised them. Supervisory staff of the care-homes and the elderly centre referred potential respondents to the study, and introduced and explained the research to their clientele. The interviewers were mature adults and trained for the project. The interviews were conducted at the elderly centre and in the care-homes during 2002.

The operational definition of urinary incontinence and the questionnaire items

For research purposes, urinary incontinence can be operationally defined according to volume, frequency and voiding criteria: *i.e.* the volume of urine excreted per occurrence of incontinence; the frequency or number of incontinent episodes; and the number of times voiding occurred over a prescribed time period (Miller *et al.* 1999). Any one or a combination of these criteria can be used in a systematic study. Fultz and Herzog (2001) used the volume of urine loss to measure severity, and this study modified their measure to 'the amount of urine lost within four hours'. The three severity levels of urinary incontinence were defined as follows:

Mild: Volume of 100 ml or less (or $\frac{1}{2}$ cup) in four hours.
Moderate: Volume of 101–200 ml (or $\frac{1}{2}-1$ cup) in four hours.
Severe: Volume exceeding 200 ml (or >1 cup) in four hours.

The interview opened with an invitation to the respondents to give a brief history of their urinary incontinence. The respondents were then asked to state whether they had mild, moderate, severe or no urinary

incontinence. The duration was established by a follow-up question: 'How long have you suffered from urinary incontinence?' The respondent's views about the psychological impact of incontinence were collected through alternative questions. Non-incontinent elderly respondents were asked, 'If an elderly person is incontinent, what kinds of psychological impact will be experienced by him/her?' Incontinent elderly respondents were asked, 'What kinds of psychological impact have you experienced?'

The operational definition of psychological impact

Using Specht and Maas's (2001) concept of psychological impact, this study asked about the embarrassment that people suffered, the shame that they felt, the stress that they experienced, the fear of social rejection that they were prey to, and the loss of self-confidence and self-worth that they underwent. To measure the level of suffering, an operational definition of 'psychological impact' was developed using the following dichotomous (yes/no) criteria:

1. Not wanting friends to know about one's urinary incontinence.
2. Loss of self-confidence.
3. Easily angered.
4. Feelings of stress.
5. A sense of futility.
6. A lack of emotional support.
7. Feelings of isolation.

The operational indicator of the extent of psychological suffering of the older person with incontinence is the number of positive replies across these seven psychological effects. Some scholars maintain that elderly people tell investigators more in response to simple questions about their current health status and overall functioning than had previously been assumed. Johnson *et al.* (2000) observed that the adjustment for self-reported function or health status may be inappropriate. Based on these findings, the health status of elderly respondents was self-reported, in response to the following question: 'What is your health status?' (options: healthy, some minor health problems, diabetes, neurological disease of spinal cord, neurological disease of brain, urological disease, intestinal disease, and other [specify]).

Classification of options

Answers to the question about the psychological impact of incontinence were dichotomised into 'no impact and 'negative impacts'. Elderly

TABLE 1. *Characteristics of the respondents*

	Care-home residents				Elderly centre users					
	Male		Female		Male		Female		Total	
	N	%	N	%	N	%	N	%	N	%
Age groups (years)										
60–64	1	6.7	1	1.3	2	4.9	7	8.6	11	5.1
65–69	1	6.7	0	0	8	19.5	21	25.9	30	14.0
70+	13	86.7	76	98.7	31	75.6	53	65.4	173	80.8
Grand	15	100.1	77	100.0	41	100.0	81	99.9	214	99.9
Incontinence status										
Mild	0	0	27	35.0	6	14.6	17	21.0	50	23.4
Moderate+	0	0	14	18.2	8	19.5	29	35.8	51	23.8
None	15	100.0	36	46.8	27	65.9	35	43.2	113	52.8
Total	15	100.0	77	100.0	41	100.0	81	100.0	214	100.0

Note: Moderate+ indicates moderate and severe.

respondents who answered the question 'What is your health status?' with the option 'healthy' were classified as healthy, while those who chose other options were classified as unhealthy. The group of healthy respondents was used as the comparison group in the analysis presented here. Because of the high proportion of responses 'mild' and 'moderate' to the question establishing severity, and in order to increase the probability of having at least five cases per cell to conduct chi-squared tests, the three levels of incontinence were collapsed into two: 'mild' and 'moderate to severe'.

Findings

Characteristics of the respondents

A total of 214 older people were successfully interviewed, and 92 were care-home residents and 122 lived in the community (Table 1). The majority (80.8%) of the 214 respondents were aged 70 or more years, and almost three-quarters (73.8%) were women. The overall prevalence of incontinence in the study was 47.2 per cent, with differences between the care-home respondents (44.6%) and those living in the community (49.2%), which cannot be explained by this study, and between women (55.0%) and men (25%).

Of the 101 incontinent respondents, more than three-quarters (79.2%) were aged 70 or more years. A slightly higher percentage of the men who reported incontinence were of this age. Among the 101, 57.1 per cent of the men and 49.4 per cent of the women suffered from moderate to severe

TABLE 2. *Incontinent respondents' ages, health status and level of incontinence*

	Male		Female		Total	
	N	%	N	%	N	%
Age groups (years)						
60–64	0	0.0	7	13.0	7	6.9
65–69	2	14.3	12	26.1	14	13.9
70+	12	85.7	68	60.9	80	79.2
Total	14	100.0	89	100.0	101	100.0
Health status						
Healthy	3	21.4	29	34.1	32	32.3
Unhealthy	11	78.6	56	65.9	67	67.7
Total	14	100.0	85	100.0	99	100.0
Level of incontinence						
Mild	6	42.9	44	50.6	50	49.5
Moderate/severe	8	57.1	43	49.4	51	50.5
Total	14	100.0	87	100.0	101	100.0

TABLE 3. *Years of suffering of the incontinent respondents*

	Years of suffering									
	Less than 1		1–2.9		3–4.9		5 or more		All	
	N	%	N	%	N	%	N	%	N	%
Gender										
Male	2	14.3	6	42.9	2	14.3	4	28.6	14	100.0
Female	23	26.4	33	37.9	10	11.5	21	24.1	87	100.0
Level of urinary incontinence										
Mild	9	17.6	20	39.2	7	13.7	15	29.4	51	100.0
Moderate+	25	24.8	39	38.6	12	11.9	25	24.8	101	100.0
Health status										
Healthy	17	25.4	24	35.8	7	10.4	19	28.4	67	100.0
Unhealthy	125	25.3	38	38.4	11	11.1	25	25.3	99	100.0

incontinence but, in contrast, women's health status was on average better than men's (although a chi-squared test found both differences to be insignificant) (Table 2). Turning to the reported duration of incontinence, 64 of the 101 (63.4%) incontinent respondents reported that they had suffered from the problem for less than three years, and only 25 (24.8%) had suffered for more than five years (Table 3). Somewhat unexpectedly, no significant difference was found in the distribution of durations by gender, severity or health status. To summarise, the majority of incontinent respondents for both sexes were aged in the seventies and had suffered for less than three years. It appeared that the period of suffering was not a crucial factor in determining the level of incontinence.

TABLE 4. *Psychological effects on the incontinent respondents*

Item	Men N	Women N	Both sexes N	Both sexes %	Gender difference χ^2	Gender difference *p*
Not wanting friends to know about one's urinary incontinence	8	26	34	33.7	4.01	0.05
Easily angered	7	24	31	30.7	2.85	0.09
Feelings of stress	8	23	31	30.7	5.35	0.02
Loss of self-confidence	4	19	23	22.8	0.31	0.58
A sense of futility	3	15	18	17.8	0.14	0.70
A lack of emotional support	3	10	13	12.9	1.06	0.30
Feelings of isolation	0	8	8	7.9	1.40	0.24
Sample size	14	87	101			

Note: Multiple not principal reported reactions are tabulated.

Psychological impacts of incontinence

Among the incontinent respondents, the most frequently mentioned impact of the condition was 'not wanting friends to know about one's urinary incontinence', for 33.7 per cent gave this answer (Table 4). One interpretation of this finding is that it demonstrated the importance to older Hong Kong people of 'saving face', which many had been trained since youth to do everything possible to keep. Many would rather make heavy financial, emotional, and physical sacrifices than lose face among their friends and relatives. The next most common statements of the psychological impact of incontinence were that they were 'easily angered' (30.7%) and had 'feelings of stress' (30.7%). These responses were closely associated with the sufferers' physical comfort, mental health and inability to perform daily activities. Those affected worried that the illness would have an effect on their normal social interactions and activities: the condition adversely affected their human relationships and mental health.

Slightly more than one-fifth (22.8 per cent) of the respondents with incontinence claimed that their self-confidence was negatively affected. Reference group theory could elucidate this low percentage. The respondents with incontinence might compare their situation with that of their friends who admitted to incontinence and assume that their situation was no worse, which might explain why close to 80 per cent indicated that they had maintained their self-confidence.

Suffering from 'a sense of futility' (17.8 per cent) was much less frequently cited. Almost all of the respondents were retired and accustomed to being regarded as 'unproductive' by the general public. In Chinese societies it had been common for children to look after their elderly parents and to live with them for as long as possible. Many older people who co-resided with children or other relatives considered themselves

productive, if unpaid, helpers. They contributed their time and energy to household tasks, looking after grandchildren, and serving as reliable doorkeepers. They were useful to their children because their work relieved family members from assuming these responsibilities. Elderly people who lived alone or in care-homes felt that they contributed to society by taking care of themselves and leading an independent life, rather than relying on social resources. To be independent in later life was considered a great achievement. Many incontinent respondents considered that, despite their condition, they had a sense of their own worth and a healthy degree of self-esteem. It was therefore heartening that more than 80 per cent of the respondents maintained a sense of usefulness.

Elderly people suffering from incontinence often assumed that the act of seeking help, or even emotional support, involved surrendering their hard-won independence and inviting humiliation. Consequently, only 12.9 per cent of the respondents claimed to 'a lack of emotional support'. Only 7.9 per cent of the respondents with incontinence reported 'feelings of isolation'. Social workers regularly arranged social activities for the care-home residents, and it was unlikely that they could be physically and socially isolated. Community-dwellers' centre membership also effectively reduced these respondents' feelings of isolation.

There were significant differences between the two sexes in the frequency of reports of the two negative effects: 'not wanting friends to know about one's urinary incontinence' ($\chi^2 = 4.01$, df = 1, $p = 0.045$) and 'feelings of stress' ($\chi^2 = 5.35$, df = 1, $p = 0.021$). Relatively more male than female respondents reported these two anxieties. It is believed that in Hong Kong older men, by comparison with older women, were more active socially, more anxious to preserve face, more self-conscious about maintaining self-esteem, and more determined to retain their self-image. Like men in western countries (Koch *et al.* 2000), Chinese men seldom discussed their incontinence with doctors and friends. Among the respondents with incontinence, many men experienced a great deal of stress during social interactions with friends and relatives, while the women were more likely to discuss their physical condition with physicians, and to a lesser degree with friends and relatives. The relief that came from sharing the anxieties reduced the feelings of stress among women. In Hong Kong, it was found that there was a significant difference between the sexes with regard to fear of detection of urinary leakage and feelings of stress.

It has been noted that there is no readily available measure for the extent of psychological suffering of older people with incontinence. Counting the impacts reported by the respondents with incontinence was adopted as a simple indicator (Table 5). More than one-fifth (21.8 %) reported that they had not experienced any of the itemised negative psychological effects.

TABLE 5. *Incontinent respondents' reported number of negative psychological effects*

	Male		Female		Total	
Number of effects	N	%	N	%	N	%
No effects	2	14.3	20	23.0	22	21.8
1	2	14.3	31	35.6	33	32.7
2	4	28.6	21	24.1	25	24.8
3	3	21.4	11	12.6	14	13.9
4–6	3	21.4	4	4.6	7	6.9
Total	14	100.0	87	99.9	101	100.1
Average number	2.36		1.44		1.56	

These people were presumably leading a normal life, regardless of their level of incontinence. On the other hand, 32.7 per cent were affected by one of the effects listed, 24.8 per cent by two, 13.9 per cent by three, and 6.9 per cent by four or more. The overall mean number of reported negative effects was 1.56, and there was a substantial and significant gender difference (2.36 for men, and 1.44 for women: $t=2.51$, df$=99$, $p=0.014$).

Summary and conclusions

One of the prerequisites of living an active, independent life in society is to maintain continence (Hanson 1996). Urinary incontinence usually has a negative impact, and studies conducted in western countries have shown that it leads to a deterioration of the sufferers' quality of life. The impacts include restrictions on the capacity to pursue healthy exercise or enjoy social outings. It leads to many secondary complications for those affected. Although the respondents to this study were not a random sample of older people in Hong Kong, some of the results concur with those from other countries. For example, the prevalence of urinary incontinence increases with adult age, and the condition affects women more than men. Close to 80 per cent of the respondents suffered from at least one negative psychological effect, and the majority cited one to three effects. This study is not able to conclude that the psychological suffering of those who reported more negative effects is greater than that of those who reported fewer. The high prevalence should encourage the development of appropriate interventions and services to reduce the negative psychological impact of incontinence. With full understanding, proper medical advice, effective prevention, and efficient treatment, incontinence and its psychological consequences can be greatly alleviated.

Men are more likely than women to fear detection on the part of their friends and to experience stress due to their condition. With regard to

the number of negative psychological effects, elderly men reported more effects than women. It is likely that the self-image and expectations of men in a Chinese society play a significant role in producing these differences. One of the aims of the study has been to encourage professional workers to become aware of this condition and its impact, so as to demystify some of the stereotypes and myths with which it is associated. Such objective findings will enhance professional workers' current knowledge about urinary incontinence.

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