

**An investigation of the relationship between anxiety and depression
and urge incontinence: development of a psychological model.**

Doctorate in Clinical Psychology

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Dr Sarah I Perry

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Abstract

An investigation of the relationship between anxiety and depression and urge incontinence: development of a psychological model

Dr Sarah I Perry

Aims: The study investigated the association between anxiety and depression and urge incontinence and the direction of causal pathways between these variables. The objective was to produce a psychological model that described the contribution of emotional factors in the development and maintenance of urge incontinence.

Methods: In this prospective longitudinal study, a random sample of women aged 40 years or more, registered with a general practitioner in Leicestershire or Rutland, was mailed a postal questionnaire. The questionnaire included questions on general health, urinary symptoms and the Hospital Anxiety and Depression Scale (HADS). In total, 12,568 women responded to the baseline postal survey (65.3% response rate) and 9,596 to the first annual follow-up (79.8% response rate). The prevalence and one-year incident rates of these symptoms were compared and contrasted, whilst controlling for confounding variables (e.g. long-term illness, age and other urinary symptoms).

Results: A significant proportion of women with urge incontinence reported symptoms of anxiety (56.6%) and depression (37.6%). These symptoms were positively associated with the severity of incontinence and the presence of other urinary symptoms. Anxiety and depression were associated with a number of urinary symptoms and were not exclusive to urge incontinence. Incident cases of anxiety and depression were predicted by the presence of urge incontinence at baseline. Incident cases of urge incontinence were predicted by anxiety at baseline, but not depression. Anxiety, urge incontinence and frequency appeared to interact and exacerbate each other.

Conclusion: The findings demonstrated the relevance of emotional factors in the development and maintenance of urge incontinence. Currently, assessment and treatment protocols for urge incontinence concentrate on physical symptoms and toilet behaviours. A more integrated psychological model of urge incontinence is proposed along with how this might be implemented and evaluated in clinical practice.

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Preface

I have a vivid memory of an incident that happened to me when I was 12 years old. I was in my first year at comprehensive school and felt very grown-up. A school daytrip was organised to the annual county agricultural show. With my friends, I spent the day racing around the various stalls, collecting freebies (stickers, carrier bags, pens and badges), visiting the animal tents (birds, rabbits, cavies, farm animals and exotic breeds), taking a cursory interest in the Young Farmers' and Women's Institute's displays (the future mapped out for me, perhaps?) and finally spending money at the fun fair.

I remember climbing onto the bouncy castle with my girlfriends. We started bouncing hesitantly, clinging on to each other and giggling. We became bolder and when boys arrived on the scene we inevitably, started to show off. There was mayhem, pushing and shoving, bodies flying in all directions, colliding and ricocheting off the air cushioned walls. An accident was waiting to happen. Screaming with both delight and terror, I landed in a heap and peed myself. The little squirt of urine turned into a stream before I could stop it, and before I knew it the seat of my trousers was wet. As I scrambled off the bouncy castle I left tale-tell smears behind me. I wanted to cry. I couldn't think straight I was in such a panic. Common sense or self-preservation kicked in and I pulled off my school jumper and tied it firmly around my waist, hiding my wet trousers before anyone had a chance to notice

For the rest of the afternoon and the long journey home on the bus I lived in terror of being found out. Outwardly, I must have seemed a little subdued. I think I said I had a headache. Inwardly I was miserable and desperate to get home. No one said anything to me, but I worried about leaving stains on the seat of the bus, of smelling and of being humiliated in front of my friends. I wasn't concerned that I'd peed myself – I did not think myself ill – but I was upset by what people might think of me.

I have had a couple of 'mishaps' since, as an adult, but I do not consider myself incontinent. I expect most people have similar stories of their own to tell. In my 'thirties', I was employed, as a researcher, to investigate the prevalence of urinary incontinence in order to estimate the level of need for health care to treat such symptoms. I was part of a multi-disciplinary team of 'experts' and we struggled over definitions that would enable us to distinguish between normal urinary function

and dysfunction. In other words, when does an ‘accident’ become a symptom? Deciding on a threshold to distinguish between normal and abnormal urinary leakage seemed somewhat arbitrary. We considered chronicity, frequency, volume, disability, use of aids and appliances, ability to control, contain, manage and conceal, personal and financial costs and a combination of these factors. In the end the answer was simple and obvious. A bodily function becomes a symptom or health problem when it starts to have an impact on someone’s quality of life. Individuals themselves are the best judges of their own quality of life. And so we asked people themselves to describe their toileting habits, and the impact of these habits on their life and whether they perceived their behaviour to be a problem. And in doing so, an attempt was made to integrate clinical and personal concepts of normality, different areas of expertise and the fact that adaptation to a health problem is, by necessity, an ongoing process and forever changing.

As the research progressed and my career took a change in direction away from academic research towards clinical training, I returned to my first memory of urinary incontinence (I have no recollection of potty training). Psychological factors were integral to the incident: on the one hand, my state of excitement and nervousness played an important contributory factor (along with a full bladder and physical exertion), resulting in me wetting my pants; and on the other hand, my feelings of anxiety, shame and despondency demonstrated the impact of bodily functions on psychological well-being. I became curious about the ways in which psychological factors may contribute to the development of incontinence, and also how they may maintain and exacerbate symptoms and have repercussions on an individual’s quality of life.

I wanted to share my story in order to emphasise that health and illness are relative concepts rather than discreet categories. Indeed, an incident such as wetting your pants may be regarded as trivial to one person but a tragedy to another. Additionally, a person’s reaction to incontinence can change dramatically, depending on subjective mood and social circumstances and expectations. These differences help to explain huge variations in help-seeking behaviours within and between individuals (Brittain, *et al.*, 2001).

The psychologist, George Kelly (1955), believed we all behave as scientists in trying to make sense of the world we live in. It is important to remember that research evidence is personally produced rather than objectively collated. The methods for conducting research are influenced by current scientific theories and

practices, but our own personal experiences and interests often influence the focus of our research. In this study I will move between the personal and general in order to investigate women's experience of urge incontinence and the specific contribution of anxiety and depression in the development and maintenance of this problem. This study will focus on population statistics and differences between groups of women so that clinical guidelines can be recommended. However, it is appreciated that each woman's response to urinary incontinence is unique and health care should be sensitive to these diverse personal needs.

Author's note

Throughout this thesis the terms 'urge incontinence', 'anxiety' and 'depression' are frequently used. In each instance, the terms refer to specific symptoms, which are based on self-reported data, rather than discreet diagnostic disorders based on clinical investigations.

Chapter One

What is urge incontinence?

The biological and social basis of urinary incontinence

1.0.0 Introduction

This chapter will start with the definition and classification of urinary incontinence and distinguish urge incontinence from other types of incontinence. It will then describe how common this problem is among women and theories about the aetiology of urge incontinence. This will be followed with the anatomy, physiology and development of continence and why urinary problems arise across the lifespan. The social repercussions of having this problem will be reviewed in terms of feelings of shame and embarrassment. The remainder of the chapter will summarise treatments for urge incontinence and their effectiveness.

Although this chapter concentrates mainly on the biological basis of urinary incontinence, it is impossible to do this without appreciating the influence of cultural beliefs and social conventions regarding 'toileting' behaviours. The production, storage and excretion of urine may be physiologically determined, but the disposal of urine is controlled by social conventions and customs. People who break social rules are perceived to be in possession of an attribute (a stigma), which is socially undesirable (Goffman, 1963). Some health problems are perceived to be shameful and those in possession of these attributes are fearful of rejection from others, even from experts in the field:

Some people may actually avoid medical help (e.g. for bowel cancer, venereal diseases, haemorrhoids, etc.) out of shame or because they find their first contact with treatment agencies appears insensitive to the emotional trauma of becoming ill. (Kellett & Gilbert, 2001, p.6).

Incontinence, then, also suggests that a person is incapable of following social rules concerning the concealment and disposal of urine.

1.1.0 Classification of urinary incontinence

Until very recently, the International Continence Society (ICS) defined urinary incontinence as the 'involuntary loss of urine which is objectively demonstrable and a social or hygienic problem' (Abrams *et al.*, 1988, p.423). This definition was important because it embraced the physical and social aspects of incontinence (the focus of this chapter). Thus, involuntary loss of urine was not necessarily regarded as clinically significant or pathological: it must also have an

impact on social functioning. What was intriguing about the definition, however, was the absence of the personal dimension or the psychological repercussions of such a symptom. Although incontinence was referred to as a ‘social or hygiene problem,’ the definition failed to identify to whom it was a problem: the person with incontinence, colleagues, care staff, health professionals or everyone?

In the last year the ICS (Abrams *et al.*, 2002) updated their definition of urinary incontinence: firstly, in terms of describing the physical symptom as ‘the complaint of any involuntary leakage of urine’; and secondly, in terms of the impact it has on an individual. Thus:

In each specific circumstance, urinary incontinence should be further described by specifying relevant factors such as type, frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life, the measures used to contain the leakage, and whether or not the individual seeks or desires help because of urinary incontinence.
(p.168)

This new definition places greater emphasis on personal perceptions of incontinence. However, it does not refer directly to the psychological or emotional impact of incontinence, which is central to this study.

Clinicians struggle with the ICS definitions because there are no clear thresholds to distinguish between abnormal and normal leakage. As a result, professionals may hold very different beliefs about what is normal toileting behaviour across the lifespan and sex groups. Clinic samples, after all, are very different from community populations. Although incontinence in babies is generally considered normal, there is less certainty regarding incontinence in old age. Thus, some health professionals and lay people regard incontinence as a normal part of the ageing process (Mitteness & Barker, 1995) or ‘part and parcel of being a woman’ for which there is little that can be done (Peake *et al.*, 1999). Others regard any sign of urinary incontinence in adults as abnormal but treatable. The diversity of opinions has resulted in inequities in the provision of continence services and the proliferation of arbitrary rules regarding access to services, which is not related to individual need (DOH, 2000).

Another area of confusion is the tendency to refer to urinary incontinence as if it is a single disorder. The ICS (Abrams *et al.*, 2002) emphasises that the term urinary incontinence denotes: 1) a symptom; 2) a sign; and 3) a condition. A subjective report of involuntary loss of urine made by the individual patient or carer is referred to as a ‘symptom’ of urinary incontinence. The ‘sign’ is an objective measure of urinary loss (i.e. the involuntary loss of urine is actually observed and/or

measured by a clinician). The ‘condition’ is based on the characteristic symptoms and signs alongside the observed loss of urine during urodynamic investigation (which entails the insertion of catheters into the rectum and bladder in order to measure the pressure inside the bladder and abdomen, filling the bladder and measuring the rate with which urine is emptied from the bladder in a laboratory setting), with the aim of isolating the physiological causes of urinary incontinence.

Urinary incontinence is also a generic term, which encompasses many different symptoms of urinary incontinence with different underlying pathologies (conditions) and presentations (signs) that require a range of interventions. Much more is known about the symptoms of urinary incontinence than the underlying conditions and pathology. Table 1.0 lists the symptoms of urinary incontinence, their presentation and possible underlying physiological conditions. However, it is important to remember that bladder symptoms often do not correspond precisely with specific underlying conditions. For example, the symptoms associated with urge incontinence may be associated with an overactive bladder, a urinary tract infection or cystitis.

1.1.1 Definition and presentation of urge incontinence

Terminology in this field changes frequently and can be confusing. For example the terms ‘urge incontinence’, ‘detrusor overactivity’, ‘sensory urgency’, ‘motor urgency’, ‘detrusor instability’ and ‘overactive bladder syndrome’ are often used interchangeably. This study focuses on urge incontinence, as participants were categorised according to their personal accounts of how urinary incontinence presented to them. All the other terms are based on urodynamic investigations, apart from ‘overactive bladder syndrome’, which is used to describe the presence of a number of bladder storage symptoms (i.e. urgency, urge incontinence, frequency and nocturia). Thus, a woman may report urge incontinence, with further questioning a clinician may find she has a number of urinary symptoms indicative of overactive bladder syndrome, and after urodynamic observations, she may be diagnosed with detrusor overactivity.

Table 1.0 Classification of urinary incontinence

Symptom	Presentation	Condition
Stress incontinence	Complaint of involuntary leakage on effort or exertion, or on sneezing or coughing.	Genuine Stress Incontinence (GSI): poor anatomical support of the bladder neck or loss of urethral function (sphincter deficiency).
Urge incontinence	Complaint of involuntary leakage accompanied by or immediately preceded by urgency.	Detrusor overactivity (DO), detrusor instability (DI), motor or sensory urgency, neurogenic detrusor overactivity, idiopathic detrusor overactivity.
Mixed incontinence	Complain of involuntary leakage associated with urgency and also with exertion, effort, sneezing or coughing.	GSI and DO
Unconscious incontinence	The person is only aware of incontinence after the event, by feeling wetness. No urgency.	Reflex incontinence – neuropathic bladder/urethral disorders
Continuous leakage	Complaint of continuous involuntary leakage.	Overflow incontinence: underactive detrusor (retention)
Nocturnal enuresis	Complaint of loss of urine occurring during sleep	Nocturnal polyuria, DO, small functional capacity or secondary to neurological pathology.
Post-micturition dribble	Involuntary loss of urine immediately after voiding	Urethral disorder
Functional incontinence	Involuntary loss of urine due to problems getting to or on and off a toilet.	Incontinence secondary to physical or mental limitations (e.g. neurological disorder and cognitive impairments).
Iatrogenic incontinence	Involuntary loss of urine associated with medication or complications resulting from surgery	Incontinence is a side-effect of medication or the result of damage to the lower urinary tract during surgery.

(Fantl *et al.*, 1996)

People with urge incontinence report an overwhelming sensation or compelling desire to pass urine and then suddenly do so without intention. Many things, such as opening their front door, sex, feeling nervous or the sound of running water, can trigger the symptom. Thus, they are aware of their bladder feeling full and respond to the need to urinate, but they have difficulty postponing urination until they reach a toilet. They fear that they will not be able to ‘hold on’ to their urine and

when they leak accidentally that there will be a ‘flood’ of urine rather than just a few drops. Indeed, it is not uncommon for women to report at least one occasion when urine has poured down their legs uncontrollably (Khullar & Cardozo, 2001).

The unpredictable nature of the symptom and great variability in severity and precipitating events results in many people with this symptom leading more and more restricted lives, as they dare not stray too far from a toilet and worry about leaking in public (Davila & Neimark, 2002). Table 1.1 presents women’s descriptions of urge incontinence and the significant impact it has on their lives.

Table 1.1. Women’s descriptions of urge incontinence

“It is really quite distressing sometimes to worry that you won’t be able to make it to the bathroom in time.” “I don’t visit my eldest son. I’m afraid I might have an accident.” “I was on a date, and I couldn’t get to the bathroom on time. It was terrible.” “Wherever I go, whatever I do, I always have to know right away where the bathroom is.” “I have lost control over my bodily functions, and I resent it.” “Everything seems to be progressing toward more and more isolation. You’re hardly living at all.” You’re scared to stand next to people. You’re afraid the urine smell is there.” “I retired early. This was a major factor in that.”

(Brown *et al.*, 1998, p.1267; DuBeau *et al.*, 1998, p686; Fitzgerald *et al.*, 2000, p.115).

People with urge incontinence often go to the toilet more frequently during the day (referred to as ‘frequency’) and at night (referred to as ‘nocturia’) and more urgently than before (referred to as ‘urgency’). As already mentioned, this combination of symptoms is referred to as overactive bladder syndrome. They may go to the toilet more frequently in order to empty their bladder, thus avoiding a big ‘accident’ or because they are more sensitive to bladder filling (i.e. smaller bladder capacity to store urine). It is often difficult to untangle which came first: the frequent visits to the toilet or the urge incontinence.

To summarise, the focus of this study is women who reported symptoms of urge incontinence. Urge incontinence is one of a number of symptoms of urinary incontinence. Women with this type of incontinence report that leakage occurs because they have an overwhelming desire to pass urine and find it difficult to postpone urination. Women with urge incontinence often go to the toilet frequently to empty their bladder and to avoid such accidents from happening.

1.2.0 Prevalence of urinary incontinence in the population

In the absence of agreed thresholds to distinguish between abnormal and normal leakage, estimates of the prevalence of urinary incontinence within community populations vary tremendously in the literature (Cheater & Castleden, 2000; Hampel *et al.*, 1997; McGrother *et al.*, 2001; Thom, 1998). Some published papers regard any leakage as abnormal (e.g. a few drops or isolated incidents), others only treat frequent leakage (i.e. several times a week or more often) as clinically significant and others focus on any leakage that is perceived to be a social or hygienic problem. Table 1.2 summarises the considerable variation in prevalence estimates within and between different definitions of incontinence.

Table 1.2 Review of prevalence of urinary incontinence in women by definition used.

Definition	Prevalence (%)
Any urinary incontinence	Median: 40.5 Range: 12.0 – 53.0
Regular urinary incontinence (monthly or more often)	Median: 14.0 Range: 4.5 – 37.0
Bothersome urinary incontinence	Median: 8.5 Range: 5.0 – 25.0
Socially disabling urinary incontinence	Median: 2.0 Range: 0.1 – 5.0

(Perry, 2002)

Methodological variables are also likely to have an impact on prevalence estimates. Thus, differences in the prevalence measure used (i.e. point, period or historical prevalence), the study design (e.g. postal survey or face-to-face interviews), characteristics of the sample and sampling frame (e.g. exclusion criteria and response bias) and the scarcity of well-validated measures all have an impact on the opportunity for people to participate in surveys and the likelihood that self-reports are an accurate reflection of their continence status (Perry, 2000).

Stress, urge and mixed (i.e. stress and urge) incontinence are the most common symptoms of incontinence in women, though sometimes these are the only symptoms investigated (Sandvik, 1995). The prevalence of urge incontinence has been reported in a number of epidemiological studies, with estimates ranging from 5 to 46 per cent (see Table 1.3). Unfortunately, only two of these studies actually asked

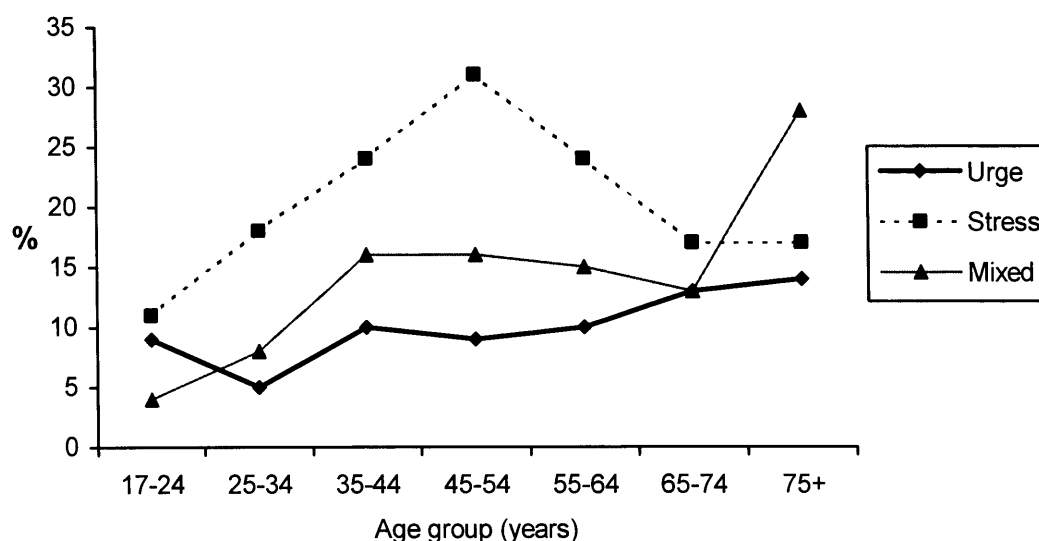
about the frequency with which urge incontinence occurred. For the remaining studies, women were simply asked whether they had ever had this type of incontinence or whether they had experienced the symptom in the last 12 months.

Table 1.3 Prevalence of urge incontinence among women as reported in community surveys

Study	Sample details	Prevalence (%)	Level of frequency
Yarnell <i>et al.</i> , 1981, UK	18+ years N = 1000	23 (18+ years) 27 (45+ years)	Not specified
Isoif & Bekassy, 1984, Sweden	61 years old N = 902	17	Not specified
Hording <i>et al.</i> , 1986, Denmark	45 years N = 522	5	Not specified
Holst & Wilson, 1988, NZ	18+ years N = 851	15 (18+ years) 21 (45+ years)	Twice a month or more frequently
Elving <i>et al.</i> , 1989, Denmark	30-59 years N = 2631	8	Not specified
Sommer <i>et al.</i> , 1990, Denmark	20-79 years N = 432	25	Not specified
Harrison & Memel, 1994, UK	20+ years N = 314	27	Not specified
Nygaard & Lemke, 1996, USA	65+ years N = 2025	36	Not specified
Kuh <i>et al.</i> , 1999, UK	48 years N = 1498	22	Not specified
Swithinbank <i>et al.</i> , 1999, UK	18+ years N = 2075	46	Not specified
Moller <i>et al.</i> , 2000, Denmark	40-60 years N = 2860	7	Weekly

There are mixed findings regarding the association between urinary incontinence and age in women, with some studies reporting a prevalence peak in old age and others around the menopause (Sandvik, 1995). There is evidence that stress incontinence predominates in younger women and urge and mixed (stress and urge incontinence) in older women (Yarnell *et al.*, 1981) (see Figure 1.0). These different patterns of presentation across the life span are probably related to different underlying aetiologies for these symptoms.

Figure 1.0 Prevalence of urge, stress and mixed incontinence in women



Source: Yarnell *et al.*, 1981

1.3.0 Natural history and aetiology of urge incontinence

There have been very few longitudinal population studies on unselected populations that have examined the development, fluctuation and progression of urinary incontinence over a lifetime and unravelled the cause and effect sequence (Cheater & Castleden, 2000). There is some evidence that adults are more likely to develop mild incontinence initially, and for about half of this group, their incontinence remains mild (Herzog *et al.*, 1990). Indeed incontinence tends to be more stable in women than in men and more likely to change from a single (e.g. stress) to mixed presentation of symptoms (e.g. stress and urge) (Herzog *et al.*, 1990).

In a study of older women (65+ years) with urge incontinence the three-year incidence and remission rates were 28.5% and 22.1% respectively (Nygaard & Lemke, 1996). Thus, new cases of urge incontinence were common, but so was the disappearance of symptoms in older age. The only significant factor associated with urge incontinence was age, which was related to increased incidence. Improvement in activities in daily living was related to increased remission of incontinence. Urge incontinence, then, may be a fluctuating and transient as well as an increasingly established, deteriorating and chronic symptom.

It is less clear what influences these fluctuations. The evidence suggests that the aetiology of urinary incontinence generally and urge incontinence in particular, is multi-factorial. In other words, urge incontinence may only present when a number

of biological, psychological and social conditions converge and some women may be more susceptible to these sorts of symptoms than others. Sometimes, urinary tract infections can irritate the bladder and increase urgency. Safety behaviours associated with urge incontinence, such as going to the toilet frequently and avoiding certain activities, may also aggravate the symptom (e.g. reduce bladder capacity or increase sensitivity). There is some evidence that urge incontinence is associated with enuresis (day or night) in childhood (Kuh *et al.*, 1999) or that it is a variant of childhood nocturnal enuresis and giggle incontinence, which tend to improve or disappear as children learn to develop voluntary control over the micturition reflex. (Dwyer & Rosamilia, 2002).

Although urge incontinence is associated with increasing age, it is not necessarily a normal part of the aging process. Bladder compliance (i.e. elasticity and tone of the bladder deteriorates) and capacity may deteriorate in old age, but this may be less important than musculoskeletal, neurological and cardiovascular diseases and the effects of polypharmacy and environmental factors (Cheater & Castleden, 2000; Wagg, 2001). In other words, older women have more health-related problems (e.g. dementia, stroke, mobility), that can increase their risk of incontinence, but this is not inevitable (Brown, 2002).

The cause of urge incontinence in otherwise healthy women is unknown (The Royal College of Physicians, 1995). Diuretics, which are given to remove excess water from the body, can make the symptoms of urge incontinence worse (Brown, 2002). Fluid intake is also important: too much of certain drinks (e.g. caffeine and alcohol) can stimulate the bladder and too little can irritate the bladder and cause urinary infections. Either way, the result is often a very strong desire to urinate (urgency) and sometimes urge incontinence (Wilson *et al.*, 2001).

Finally, psychological variables, such as anxiety, depression and personality types have also been associated with urge incontinence in particular. Consequently a number of commentators have stated that urge incontinence is a psychosomatic disorder (Freeman *et al.*, 1985). Chapter Two will look at the evidence in greater detail and examine the role of psychological factors in the development of urge incontinence

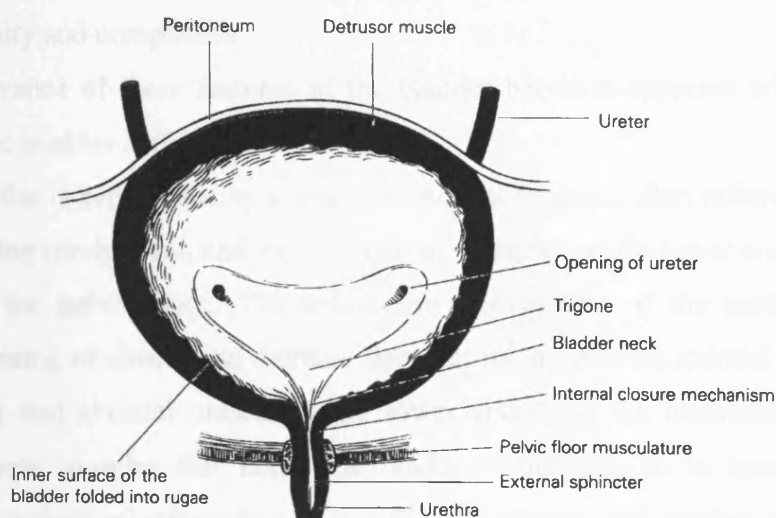
In summary, urge incontinence is a very common symptom, reported by 21 to 27 per cent of women aged 45 years or more in community surveys (Holst & Wilson, 1988; Yarnell *et al.*, 1981). It becomes more prevalent as women get older, but it is not necessarily a chronic condition: the symptom may fluctuate and remit. The

aetiology of urge incontinence is uncertain. In the absence of significant co-morbidities (e.g. cystitis, stroke, dementia, multiple sclerosis, diabetes), there is evidence that psychological factors (e.g. depression and anxiety) may be implicated in its development.

1.4.0 Anatomy of the lower urinary tract

In order to understand how continence is achieved it is important to appreciate the structure of the lower urinary tract, which can be divided into the bladder and the urethra. Where these two continuous structures meet is referred to as the vesical or bladder neck. The bladder and urethra are supported and held in position by the muscles of the pelvic floor (see Figure 1.1).

Figure 1.1. Cross –section of the female urinary bladder



(Source: Getliffe & Dolman, 1997)

The bladder is like a balloon, with a wall made of thin smooth muscle, called detrusor muscle. It acts like a reservoir for urine. The bladder wall can stretch to four times its resting length and is therefore capable of storing urine for prolonged periods of time at low pressure until it is considered appropriate to evacuate.

There are four features of the bladder wall that are important for the storage and voiding of urine:

1. Sensation The primary sensation is awareness of filling, although the bladder is also sensitive to temperature (hot and cold). Four distinct phases of sensation are associated with bladder filling: (i) the first desire to void; (ii) a sense of fullness; (iii) a strong desire to void; (iv) imminent

voiding or urgency. These sensations derive from the bladder, but awareness of them is the result of cortical activity.

2. Stability To hold urine the bladder wall needs to be stable or relaxed. The normal bladder should only contract when it needs to push urine out through the urethra when voiding is safe. The bladder is referred to as 'unstable' when contractions occur during filling.
3. Compliance This refers to the tone of the bladder wall (i.e. its elasticity). The normal bladder is very stretchy. As we become older increased amounts of collagen makes the bladder wall less compliant.
4. Capacity This refers to the volume of urine a bladder can hold comfortably before the release of urine. In adults the capacity is believed to range between 280 and 600ml (1/2 to 1 pint). However, bladder capacity varies tremendously and is a function of bladder sensitivity, stability and compliance.

The relevance of these features of the bladder becomes apparent when the physiology of the bladder is discussed.

The bladder is kept closed by a ring of muscle at its neck, often referred to as the internal closing mechanism, and by the external sphincter, at the lower end of the urethra joining the pelvic floor. The sphincteric mechanisms of the urethra are complex, comprising of elastic and detrusor tissue at the upper end, striated muscle along its length and skeletal muscle at the lower end. It is the contraction and relaxation of these muscles that keeps the bladder watertight, so to speak, and enables the evacuation of urine when it is safe. The bladder and urethra work in synchrony: the urethra is sensitive to bladder pressure and the bladder is sensitive to the flow of urine through the urethra.

1.5.0 Physiology of continence

The normal micturition cycle consists of 5 main phases: 1) bladder filling; 2) storage of urine; 3) desire to void; 4) postponement of urination; 5) micturition. Very simply, urine is produced by the kidneys and emptied through tubes, the ureter, into the bladder. As the bladder fills with urine the wall of detrusor muscles stretches. When the bladder is full and cannot distend any further, sensory nerves transmit messages via the most caudal parts of the spinal cord to the brain stem (pontine micturition centre) and areas in the frontal cortex and conscious awareness of bladder fullness is experienced.

The brain then sends a message back via the spinal cord, through the pudendal nerve to muscles external to the neck of the bladder (the external sphincter), to contract if urination needs to be postponed. The muscles of the external sphincter are under voluntary control. When it is appropriate to micturate, the muscles of the external sphincter are relaxed and the detrusor muscles of the bladder wall contract to push urine out through the neck of the bladder. The muscles at the neck of the bladder also contract so opening the way to the urethra. The detrusor and internal closing mechanism are under the control of the autonomic nervous system: the sympathetic nervous system supplies nerves to the former and the parasympathetic to the latter. Urine is then evacuated through the tube-like urethra to the outside.

1.5.1 Physiology of urge incontinence

The stability and sensitivity of the bladder appear to be disrupted in urge incontinence. Indeed urge incontinence is associated with detrusor overactivity during bladder filling and an overwhelming desire to pass urine. These two types of dysfunction are distinguished as:

1. Detrusor overactivity (often referred to as motor urgency);
2. Hypersensitivity (often referred to as sensory urgency).

In the first, the detrusor muscle contracts involuntary whilst the bladder is filling and sometimes without warning (i.e. no provocation), resulting in incontinence, and this is detected in urodynamic investigations. These involuntary contractions may be the result of neurological damage (referred to as neurogenic detrusor overactivity), but more often there appears to be no obvious underlying pathology and the cause is referred to as idiopathic. In the second, there is no evidence of involuntary contractions of detrusor muscle in urodynamic tests, but women report an overwhelming sensation to pass urine (Davila & Neimark, 2002).

Bladder overactivity and bladder urgency, then, are not always related: one can exist without the other. Additionally, sensation of bladder fullness can reduce the functional capacity of the bladder, resulting in frequent trips to the toilet to excrete urine. The idiopathic and hypersensitive nature of urge incontinence has resulted in many researchers looking for alternative explanations for the causes of urge incontinence, with an emphasis on psychological rather than physiological factors.

More recently, commentators have criticised the focus on the unstable bladder for a number of reasons: firstly, the bladder and urethra are better viewed as

a unit rather than isolated parts; secondly, it might be more important to focus on provocations or factors that trigger urge incontinence; and thirdly, urge incontinence might represent the loss of a skill rather than physiological dysfunction (Dwyer & Rosamilia, 2002). Frequently researchers and clinicians forget that other organs, developmental processes and social and environmental factors are involved in the development and maintenance of continence. Additionally, apart from cases of neurogenic detrusor overactivity, it is remarkable how little attention had been given to the role of the brain in bladder control.

1.5.2 Cortical control of micturition

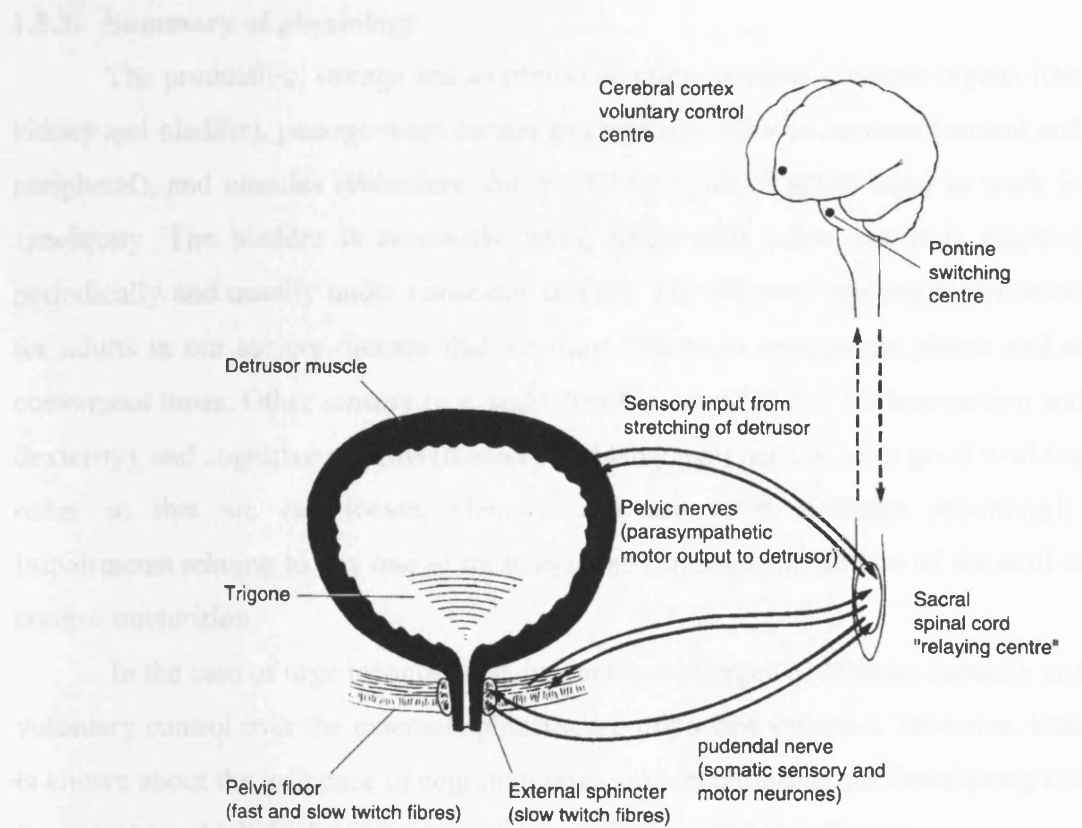
The ability to initiate micturition voluntarily, to empty the bladder completely and to maintain continence under difficult conditions (i.e. postpone micturition) is dependent on the functioning of the spinal micturition centre, in the sacral region, which acts as a relay centre for afferent sensory and efferent motor nerve impulses. Nerve fibres in this area send messages to the more primitive pontine micturition centre in the brain, which acts as a ‘neural switch’ regulating storage and voiding reflexes.

Localized areas within the frontal lobes of the cerebral cortex appear to have a role in higher centre inhibition of detrusor contractions (see Figure 1.3) and result in our conscious awareness of bladder fullness and perceptions of urgency. Lesions to any of these areas can result in dysfunction. Unfortunately, the inter-relationship between cognitive and physiological processes is little understood, nor is the effect of mood and anxiety on perceptions of urgency. The ‘gate control’ theory of pain has demonstrated the role of cognitive processes in inhibiting or activating reflexive pain responses (Melzack & Wall, 1996). It is possible that similar cognitive processes moderate perceptions of urgency and consequent somatic symptoms.

Urgency is not simply a physical sensation: it is an experience that includes perceptual processes, such as appraisals of threat and levels of emotional distress. A huge part of the brain structure and function is geared towards creating cycles of ‘desire - action – satisfaction’ that mould our behaviour (Carter, 2000). Usually these cycles work well: when we are hungry, we eat and we feel satiated. However, sometimes, it breaks down: urges do not prompt the required action or actions do not satisfy us. In the case of urge incontinence, it could be hypothesized that actions (i.e. going to the toilet) do not satisfy the insistent demands of the body for long. Women

are forced to repeat actions over and over again (e.g. going to the toilet), yet the desire to urinate continues.

Figure 1.2 Cortical control of micturition



(Source: Getliffe & Dolman, 1997)

One of the most common obsessions found in obsessive-compulsive disorder (OCD) are concerns about contamination (Wells, 1997). Maintaining continence may not be dissimilar to the hand-washing activities often described in OCD. Thus, some women with urge incontinence may be driven to carry out complicated routines, but still feel anxious and unsatisfied about their ability to control micturition. Brain scans have shown that the caudate nucleus is particularly active in people with OCD (Carter, 2000). The caudate nucleus is part of the brain associated with automatic thinking: it prompts you to wash your hands when they are dirty and to check switches are off before you leave the house.

The caudate nucleus is also in touch with the frontal lobes (orbital cortex) where thinking, assessing and planning takes place and the cingulate cortex, where conscious emotions are registered. In cases of OCD, actions do not lead to satisfaction. Instead a person continues to think of plans to deal with contamination and feels anxious and fearful about their ability to contain cleanliness. It is possible

that similar mechanisms are implicated in urge incontinence. Reporting of urge incontinence, then, may be the result of such somatic and psychogenic interactions.

1.5.3. Summary of physiology

The production, storage and excretion of urine involves multiple organs (the kidney and bladder), passage-ways (ureter and urethra), nervous systems (central and peripheral), and muscles (voluntary and involuntary), all of which need to work in synchrony. The bladder is constantly being filled with urine, but it is emptied periodically and usually under conscious control. The etiquette relating to urination for adults in our society dictates that we must urinate in appropriate places and at convenient times. Other sensory (e.g. sight, touch), muscular (i.e. for locomotion and dexterity), and cognitive systems (memory and language) need to be in good working order so that we can locate, identify, and use toilet facilities accordingly. Impairments relating to any one of these systems can result in the loss of the skill to control micturition.

In the case of urge incontinence, perceptions of urgency, bladder capacity and voluntary control over the external sphincter are important variables. However, little is known about the influence of cognitive processes on physiological functioning and the extent to which the brain moderates symptoms of urge incontinence.

1.6.0 Development of continence

Table 1.4 outlines the development of urinary continence (day and night-time) in children. Continence is dependent on the maturation of the CNS and a period of toilet training. The acquisition and maintenance of continence is a complex skill. It entails awareness of bladder fullness, the ability to connect the postponement of voiding with voluntary contractions of the external muscles and appreciation of the social conventions regarding toileting behaviour. Toilet training is also greatly influenced by cultural beliefs regarding child rearing practices as well as advances in technology. For example, the invention of washing machines and disposable nappies has taken the drudgery out of having to clean nappies and, as a result, one of the incentives for starting bladder training early has been removed (Wells, 1984).

Table 1.4 Development and management of urinary continence in children.

Age	Stage of development	Management strategies
0 – 6 months	Bladder emptying occurs frequently and automatically .	Disposal of urine dependent on caregivers. Use of nappies.
6 – 12 months	Bladder emptying less frequent due to CNS inhibition of reflex action.	As above
1 – 2 years	Child perceives bladder fullness and imminent voiding and communicates this with others.	Caregivers begin toilet training – symptom orientated. Use of nappies and underpants.
3 – 4 years	Awareness of bladder sensations increases and the ability to hold and delay urination acquired.	Toilet training alongside the teaching of cultural beliefs – i.e. only babies wet themselves and urine is dirty. Wearing underpants only.
4 – 5 years	Ability to control voiding increases: day-time continence first, followed by night-time continence. Over 80% of children continent.	Toilet training continues, with less tolerance of incontinence. Toileting becomes a private and self-conscious exercise. Awareness of differences in sexual organs between boys and girls. Indoctrination of modesty and cleanliness rules.
6 years+	Continence accomplished by the majority of children, although distressing incidents can disrupt attention enough to cause ‘accidents’.	Further socialisation of urinary behaviour outside the home. Children learn school-prescribed urinary behaviour (e.g. voiding at playtimes or asking permission to use the toilet). Voiding for girls becomes an increasingly private act, compared to boys.

(Butler, 1994, Wells, 1984)

Table 1.4 also highlights how child-rearing practices regarding the excretion and disposal of urine are very different for boys and girls. Differences in anatomy (e.g. the male urethra is significantly longer than the female’s) and the involvement and proximity of sex organs in the excretion of urine have a major influence on toileting behaviours in terms of:

- Posture (generally girls are taught to crouch and boys to stand);
- Level of exposure incurred (girls have to undress and boys unzip);
- Protection of modesty as reflected in the design of toilet facilities (girls tend to use cubicles and boys urinals);
- Verbal reinforcement and consequent toilet humour (boys tend to be praised for the strength of the flow of their urine and as men compare their ability to

direct urine, whereas girls are encouraged to hold on to urine and as women talk about weak or 'cast iron' bladders).

For boys and girls directing and delaying the flow of urine is crucial to personal hygiene and behaving in a socially acceptable way, but due to differences in anatomy and custom, girls need to be able to postpone urination for a little longer than boys.

The development sequence for loss of continence in old age, if it exists, is less easy to untangle for a number of reasons, already touched on:

- Multiple pathology – the accumulation of different diseases which interact with each other further complicating the pattern of decline or recovery (e.g. cognitive impairments and physical disability);
- Polypharmacy – many medications are capable of inducing or aggravating symptoms of incontinence (e.g. tranquillisers and sedatives);
- Age-related changes to the structure and function of organs (e.g. kidneys, bladder and brain) which require the development of different toileting behaviours
- Changes in social circumstances (e.g. move to residential home), which require socialisation into new toileting regimes.

These factors in isolation would interfere with bladder functioning, but they often interact with each other, making it difficult to separate chronic from transient incontinence and new, stable and fluctuating forms of incontinence. Ouslander and Bruskewitz (1989) provide a good overview of a multitude of age-associated factors that affect lower urinary tract functioning, though they stress that the precise role of many of these factors remains unclear.

Wells (1984) applies Erikson's (1968) life stage theory to review significant developmental aspects of the acquisition, maintenance and loss of urine control. Her paper is novel in that she explores historical conceptions of incontinence and how this may influence a generation's understanding of the problem. For example, today's elderly grew up in a less permissive society where women made their own washable pads for menstrual and urinary hygiene and information was not readily available. Set against this context, it is perhaps not surprising that many older people do not seek help for incontinence (McGrother *et al.*, 2001).

Additionally Wells (1984) examines life experiences (e.g. childbirth, employment, losses) that are likely to have an impact on urine control across the life span. Thus, older people may regard loss of continence as a sign of physical decline,

but this may be less important than other losses (e.g. death of spouse) and gains (e.g. more leisure time, grandchildren). It is important, therefore, to understand the relevance of urinary incontinence to our society and across different generations.

1.7.0 Stigma associated with urinary incontinence

Although there is a lot of controversy about the classification, physiology and epidemiology of urinary incontinence, one thing most commentators in the field agree on is that urinary incontinence is a stigmatising condition and can cause great distress to individuals (see Table 1.5).

Table 1.5 Descriptions of urinary incontinence found in publications

Incontinence can have a devastating effect on the life of sufferers and their families and can be of enormous cost to the nation. Children, men and women may be ostracised and old people institutionalised because of incontinence. The lifestyle of all may be diminished. (The Royal College of Physicians of London, 1995, p.4)
Urinary incontinence is an affliction with a wide range of severity. It is a socially humiliating disability that many sufferers are unwilling to acknowledge. (Prophet, 1998, p.20)
Incontinence causes distress, embarrassment, and inconvenience. It remains one of the last social taboos. Women should be encouraged to seek help early and to discuss their problems openly. (Thaker & Stanton, 2000, p.1330)
...men, women and children who are incontinent of bladder and bowel...are frequently: disabled by, embarrassed and often ashamed of their condition, keeping it a secret from even those closest to them; reluctant to seek help within the family and need encouragement to seek advice from health professionals; unaware of the treatments available to cure or manage their condition. (DOH , 2000, p.4)

However, the evidence to support such claims is less conclusive. The author carried out a literature search to ascertain whether women felt stigmatised by urinary incontinence (see Appendix 1 for full details of the literature review). In brief, the evidence, which is limited, indicated that about one third of people with urinary incontinence reported feelings of shame, embarrassment and were fearful of smelling in social situations. Only one study made a distinction between different symptoms of incontinence, and found that women with urge and mixed incontinence reported more distress than those with stress incontinence (Lagro-Janssen *et al.*, 1992).

Shame is not only an emotional response; it can also be measured in terms of certain behaviours (e.g. social withdrawal, avoidance, isolation and submissive behaviour). Most of the research in this area has concentrated on restrictions to daily activities (e.g. shopping, visiting friends and sporting and leisure). The evidence

suggests that 20-30% of women experience urinary incontinence, but only 1-4% actually restrict their daily activities as a result of incontinence (McGrother *et al.*, 2001). Once again the research seems to suggest that shame (in this case the avoidance of social activities which can lead to isolation), is experienced by a minority of women with incontinence. The reasons why some women find the problem so shameful and distressing, but others consider it to be a trivial problem and of little importance will be discussed in Chapter Two.

1.8.0 Treatments for urge incontinence

Good practice guidelines in continence services (DOH, 2000) stipulate the importance of a detailed assessment, which includes the patient's history, a physical examination, a few basic tests (e.g. urinalysis) and completion of a diary to monitor toileting behaviours and episodes of incontinence. If such an assessment leads to a diagnosis of urge incontinence in the absence of any neurological or physical disorder or environmental restrictions, the first line of treatment is conservative and generally carried out by specialist nurses (e.g. Continence Advisors).

Conservative treatments entail raising awareness and sharing information on factors that may have an impact on urinary function, along with physical, behavioural and biofeedback therapies and pharmacotherapy (for more details see Appendix 2). Behavioural interventions will be discussed in greater detail in Chapter Two. If there are still no improvements, advice may be given on better ways of managing (i.e. concealing) incontinence, with the use of aids such as incontinence pads, commodes and catheters and adaptations to the environment (e.g. better access to toilet facilities and handrails). Surgery is only recommended as a last resort. Thus, detrusor myectomy entails removing much of the detrusor muscle; clam cystoplasty is an operation to enlarge the bladder by inserting a piece of intestine; and a urinary diversion involves making a artificial opening in the abdominal wall to drain away the urine. (Thankar & Stanton, 2000).

Systematic reviews of the literature indicate that many of the conservative therapies mentioned are more effective than no treatment, but they are likely to improve rather than eliminate symptoms of incontinence (Berghmans *et al.*, 1998; Berghmans *et al.*, 2000; Roe *et al.*, 2000)

1.9.0 Cost of incontinence

Most of the costs for incontinence services occur at primary care level where conservative treatments are administered. A total cost of £423,467,000 for the United Kingdom has been estimated, which is roughly 0.85% of the total cost of the NHS (The Continence Foundation, 2000). The greatest proportion of this money is spent on staff (i.e. general practitioners and nurses) and direct overhead costs, followed by containment products (e.g. incontinence pads), appliances (e.g. catheters) and drugs (e.g. oxybutinin). These figures are likely to be under-estimates, as they do not include the use of residential or long-term hospital care as a result of incontinence. They also do not account for financial costs to individuals, which is likely to be substantial for adults who do not seeking help for their symptoms. A recent report indicated that the private retail market for incontinence pads in the UK was worth £11.3 million (The Continence Foundation, 2000).

The cost of continence services to the NHS is substantial, but the research evidence regarding the effectiveness of different treatments is fairly weak. The costs are also likely to increase over time as the proportion of older people in the population increases and a significant proportion of the costs are devoted to the management (e.g. supply of pads) rather than alleviation of symptoms. Additionally, many of the interventions mentioned in this chapter appear to reduce rather than eliminate symptoms of incontinence and their long-term effectiveness is unclear. Improving the effectiveness of conservative treatments (e.g. bladder retraining) would reduce costs.

1.10 Summary

Continence is a skill we learn and some people may be more competent than others at maintaining this ability. Urge incontinence is a specific symptom of incontinence associated with personal accounts of an overwhelming desire to pass urine and difficulty postponing micturition. It is a relatively common symptom in women, particularly in old age. The majority of women do not seek professional help for this symptom and only a minority find it a very shameful and distressing disorder. Nevertheless, professionals in the field often assume this aspect of urinary incontinence. Interventions tend to focus on health education and promotion, and behavioural and drug therapies, which are provided primarily by nurses, under the supervision of medical doctors.

This chapter has focused on the biological and social basis of urge incontinence. These aspects of urge incontinence are important as they dominate medical and nursing culture in this field, and as they are the main providers of care, will influence women's experience of incontinence when they seek professional advice. There is an emphasis on re-training the bladder, rather than the individual, and an assumption that women will find it difficult to talk about their incontinence. Consequently, interventions are very symptom orientated and the bladder rather than the person becomes the centre of treatment. The distress associated with urge incontinence is normalised, rather than explored.

Attempts to de-stigmatise the problem have resulted in health specialists attributing blame to the 'unstable', 'irritable', 'un-educated' and 'misbehaving' bladder, thereby treating women as passive victims of their bladders. Lack of success with conservative interventions, however, may have contributed to some professionals suggesting that the personality characteristics once attributed to the bladder are in fact integral to women themselves. Thus, urge incontinence is an indicator of an unstable woman rather than an unstable bladder. Chapter Two will review the role of psychological factors in the development of urge incontinence, the way in which it is managed and the impact it has on a person's quality of life.

Chapter Two

Psychological aspects of urge incontinence: models and interventions

2.0.0 Introduction

This chapter will investigate the psychological aspects of urge incontinence in women. Probably the most influential psychological model in terms of influencing treatment interventions has been behavioural (Smith & Smith, 1987, 1993). A more controversial view, proposed by psychodynamic models, is that urge incontinence is a psychosomatic disorder (Freeman, 1987). Both of these models regard psychological factors as aetiological agents. More recently, qualitative research methods have explored illness cognitions and coping responses regarding incontinence and how these may influence help-seeking behaviour (Brown *et al.*, 1998; DuBeau *et al.*, 1998). Lastly, researchers have been concerned with the psychological consequences of urge incontinence: in other words its impact on mental health and social functioning. Within the mental health literature, much attention has been given to the prevalence of anxiety and depression among women with urinary incontinence. Each of these research areas will be summarised, along with the influence they have had on clinical practice.

Finally, the chapter will end with an overview of the strengths and weakness of the evidence base regarding the role of psychological factors in the development and maintenance of urge incontinence. The main research questions attempt to address some of the gaps in the literature.

2.1.0 Behavioural models of urge incontinence

Behavioural models regard continence as a learned behaviour or a set of learned behaviours: a skill acquired by most children as they develop and become aware of bladder fullness; are able to communicate this sensation to caregivers; and are encouraged to hold on to their urine until it is convenient to urinate (Smith & Smith, 1987). Toilet training in children is dependent on maturation and a learning approach consisting of operant conditioning (i.e. a child is rewarded for displaying appropriate behaviours), aversion conditioning (i.e. a child receives disapproval for wetting or dislikes the tactile sensations of being wet), vicarious and social learning (i.e. a child observes and imitates the behaviours of others) (Smith & Smith, 1987). Children are taught that they can control the excretion of urine: that this part of the urinary cycle is under voluntary control. A training regime of shaping, prompting,

fading and chaining results in children learning to hold on to their urine until they find an appropriate place and time to urinate (Smith & Smith, 1987).

Turner (1986) identifies three important aspects of toilet training as 1) classical conditioning in which a child acquires and then maintains inhibitory control over sphincters (i.e. awareness of bladder sensations is associated with contraction of the external sphincter); 2) the child's behaviour is modified by positive and negative reinforcements in the environment; and 3) learning is most efficient when behaviour is broken down into small steps (i.e. stimulus-response sequences that take into account not only bladder sensation and sphincter control but the ability to locate a toilet and undress independently).

It follows, then, that urinary incontinence may occur when these learned behaviours are interrupted (Butler, 1994) or new stimulus-response associations replace previous learned behaviour (e.g. bladder fullness may be associated with distress and consequent loss of sphincter control). These new associations may be the result of a single episode of incontinence (experienced first hand or observed), which had a profound effect on the person or may be the result of a more innocuous series of events, often described as the "key-in-the-lock" syndrome, whereby an environmental cue, such as arriving home after a long journey, is associated with an uncontrollable desire to urinate. Such incidents may convince a woman she has little control over her bladder or that her bladder has a mind of its own (Dowd *et al.*, 2000).

In the case of urge incontinence, awareness of the bladder filling is associated with such an overwhelming desire to pass urine that the ability to delay urination is compromised. Thus, awareness of a full bladder is associated with an urgent need to urinate, and this sense of urgency, in turn, is associated with a necessity to rush to the toilet, as micturition cannot be delayed. Continence becomes a race against time rather than a planned series of actions and the ability to postpone urination is forgotten. Urge incontinence becomes a reflex action, like the spontaneous evacuation of bladder and bowels sometimes observed in extremely dangerous or stressful situations. In urge incontinence, however, the conditioned stimulus, fear, may be an internal threat (i.e. a full bladder) rather than an external danger (e.g. traumatic or provoking events). Ultimately, bladder emptying is associated with danger or the threat of danger (i.e. having an 'accident' in public), as one woman with incontinence reported: "I was always fearful of trying something or doing

something new because I was afraid of having an accident” (Balson *et al.*, 1988, p.26).

A person with urge incontinence can become extremely attuned to bladder filling and reacts promptly to such sensations. Unfortunately, such behaviour can aggravate the problem and leakage often ensues. She learns to avoid such situations from occurring by carrying out safety behaviours, such as going to the toilet frequently to ensure her bladder is empty or staying near a toilet just in case an ‘emergency’ arises.

2.1.1 Behavioural interventions – bladder retraining programmes

Behavioural interventions, such as bladder retraining programmes, focus on these safety behaviours and the postponement of urination. Thus, patients are encouraged to void according to a schedule and to progressively increase the time intervals between voiding. In behavioural terms, bladder retraining entails retention training by shaping. Behavioural interventions are useful as they simplify what is, in fact, a complex skill into a series of tasks. Each task is also broken down into a sequence of small steps. For example, location of toilet facilities may require taking an cognitively impaired adult routinely to a toilet in the first instance; eventually, an adult may be taught to indicate a need to go to the toilet, which is identified by a carer and responded to; next an adult may ask to go to the toilet and is assisted; and lastly an adult learns to locate the toilet independently.

Behavioural models are less concerned about the causes or triggers (e.g. stressful events) and emotional aspects (i.e. anxiety and fear) of such faulty learning and concentrate instead on the present behaviour. The cognitions and emotions associated with incontinence are not dismissed, but the focus is on changing the behaviour. Diaries are used to monitor visits to the toilet to pass urine as well as incontinence episodes. The former can be used as counter-evidence, demonstrating that controlled urination does occur frequently. Sometimes, patients are taught arousal reduction methods, such as relaxation and distraction techniques, to encourage the calming effects of the parasympathetic nervous system on the bladder and brain (Hunt, 1995).

As mentioned previously the three main strands of behavioural interventions are education, voiding schedules and positive reinforcement (Fantl, 2001). Although behavioural programmes are individualised and encourage the active participation of patients, there is a danger that they do the opposite if they become too regimented

and standardised. Thus, patients may simply be: taught how the bladder functions and told that they have voluntary control over micturition; bladder charts and scheduled voiding become the focus of nurse-patient interactions; environmental factors are overlooked; and lastly, compliance to training programmes is emphasized without appreciation of the aversive aspects of programmes (i.e. keeping to a scheduled may result in more incontinence episodes).

There is little mention of the impact of failure (e.g. not complying with scheduled voiding and incontinence episodes) on motivation and self-esteem and whether women give socially desirable answers (e.g. 'the training problem really helped me') in order to avoid further feelings of blame and contact with services. It is worrying that the majority of patients who continue to have symptoms after a bladder training programme refuse further therapy (Aitchison *et al.*, 1989).

Bladder training programmes for adults can be criticised for over-simplifying behavioural models and failing to operationalise key concepts. For example, patients' toileting behaviours are routinely monitored (e.g. use of diaries), but much less attention is given to reinforcement schedules and rewards. Examples of good practice are more evident in bladder training programmes developed for adults with learning disabilities. Stanley (1997) provides an excellent description of bladder training for adults with learning disabilities, which is theoretically driven, comprehensive and appreciative of systemic factors. In mainstream adults services, in contrast, the success or failure of behavioural interventions is often placed solely with the patient:

There has to be an agreement as to what is feasible and practical, and confirmation that the patient is fully aware that it is his or her own will power and compliance with advice that will result in success. (Haslam, 2002, p.105)

Bladder retraining programmes are a good example of how a psychological model can be misapplied, albeit unintentionally. This is probably a result of an intervention becoming detached from its theoretical roots and crucial information being lost. Clinical psychologists are rarely involved with treatment programmes, either directly or on a consultation level.

An exception to the case is Espie's (1985), account of retention control training, and desensitisation for three patients with excessive urgency and frequency. As a clinical psychologist, he provides a detailed account of personalised behavioural interventions and emphasizes that despite similarities in the symptoms presented there was considerable variability in the content, sequence and pace in which behavioural techniques were used. He also discusses the importance of identifying 'safe' vs. 'unsafe' environments, as there may be circumstances where urinary

symptoms are not a problem or less severe (e.g. at home). Such variations can be used to create a desensitisation hierarchy that is meaningful to the patient and have practical implications (i.e. enable the patient to feel safe in particular situations, such as place of employment).

Behavioural assessments often focus on monitoring behaviours, but less attention is given to: antecedent events and consequences (i.e. standard ABC charts) and the functional basis of the behaviour; the importance of consistent and immediate reinforcement once a targeted behaviour has been performed; and the generalisation (i.e. effects across different situations) and maintenance (i.e. permanence) of target behaviours once change has been achieved. It is not surprising that bladder-training programmes have limited success in the long-term with high relapse and withdrawal rates (Aitchison *et al.* 1989; Diokno & Yuhico, 1995).

Two systematic reviews of randomised controlled trials of conservative treatments for women with urge incontinence concluded that there was only weak evidence to suggest that bladder training is more effective than no treatment (Berghmans *et al.*, 2000; Roe *et al.*, 2000). These findings were largely the result of methodological weaknesses, such as a small number of studies with small numbers of participants and insufficient detail of the interventions used, number of withdrawals from treatment and evaluation of outcomes. Berghmans *et al.* (2000) state that:

The term 'behavioural' treatment is particularly confusing.....[in one study it] was based on hourly checking and prompting of individuals to void.....[in another study] patients were asked to void 'by the clock' and instructed to maintain continence at all costs. This method was very controversial, because the anxiety caused by trying to force such behaviour led many patients to withdraw... [in another study] Patients were treated to a bladder training programme that included strategies to decrease urge and educate the patient, and a voiding schedule. (p. 260)

There is a danger that the apparent simplicity of behavioural models has resulted in the proliferation of interventions that lack rigour, systematic procedures and sensitivity to individual circumstances. Behavioural interventions within clinical psychology have become increasingly sophisticated as a result of theoretical developments [e.g. social learning theory (Bandura, 1986), cognitive behaviour therapy (Beck, 1976), transtheoretical model of change (Prochaska & DiClemente, 1984) and theory of planned behaviour (Ajzen, 1991)]. There is little evidence that these developments have had a significant impact on behavioural programmes for women with urge incontinence.

2.1.2 Summary of behavioural model

There is evidence that continence and incontinence are learned behaviours. Urge incontinence is associated with problems with bladder sensation, stability and capacity and consequent difficulties in postponing micturition. Behavioural interventions, such as bladder retraining, have focused primarily on the postponement of micturition, using scheduled voiding in order to encourage the retention of urine and improve bladder capacity. Less attention has been given to bladder stability and sensations, personal perceptions of symptoms and feelings of anxiety and fear. The limited success of these programmes in the long-term may be the result of oversimplifying a complex behaviour, incomplete application of behavioural therapy techniques and failing to appreciate the role of cognitions and emotions in the development of any learned behaviour.

2.2.0 Psychodynamic models of urge incontinence

Whereas behavioural models have concentrated on changing toileting behaviours, psychodynamic models have been more concerned with the origins of urge incontinence and the significance of emotional factors in the development of the symptom. Incontinence is treated as a physical manifestation of an underlying psychological problem, associated with trauma, unconscious conflicts and defence mechanisms. Urge incontinence is referred to as psychosomatic, somatoform, functional or conversion disorder. Unfortunately these terms are often used interchangeably and it is often difficult to tease out theoretical orientations and explanations.

Freeman (1987) suggests that women with urge incontinence have a long history of incontinence or enuresis in childhood, which is rooted in emotional problems. Psychodynamic models, like behavioural models, pay close attention to the period of toilet training in childhood. Particular attention is given to the degree of coercion or permissiveness shown by the primary caregiver during this important stage of development. Coercive toilet training has been linked to the 'anal character' (i.e. mean, meticulous, punctual and self-restrained): someone who associates uncontrolled and spontaneous situations with danger (see Smith & Smith, 1987, for a discussion of this literature). Such a personality might be particularly vigilant of their personal hygiene and toilet habits. However, there is no evidence linking specific toilet training experiences to different symptoms of urinary incontinence in adult-life.

In three case studies, Yazmajian (1966) describes symptoms of urgency and frequency and urination as symbolic expressions of tears relating to emotional deprivation during the phallic phase. Urinary symptoms were described as masking depressive tendencies, which were experienced whenever there was a real or fantasised threat of abandonment.

Trauma, however, does not always have to reside in early childhood experiences. Sutherland (1976) focused instead on the losses experienced in old age (e.g. loss of established roles, physical health, independence) and how such traumatic events may result in older people retreating to an earlier stage of development, which is relatively stress free. Urinary incontinence, in this context, is described as the physical manifestation of a desire to regress, to seek attention and establish dependent and secure relationships. Alternatively, it may be an expression of hostility as a result of losing control of one's life.

The conversion of emotional problems into a somatic symptom is complicated by the individual's own response to such symptoms and those of significant others. Thus, feelings of shame may result in a depressive reaction and feelings of anxiety result in apathy. Additionally, significant others may take on parental roles, becoming overly permissive and tolerant towards incontinence episodes or coercive and intolerant.

Although there is little empirical evidence to support such psychodynamic interpretations of the aetiology of incontinence, these ideas are useful for raising awareness of the emotional conflicts surrounding such symptoms. Thus, symptoms of urinary incontinence can arouse feelings of hostility, ambivalence, dependency and depression in adults with the symptom, as well as their relatives and professional caregivers. Sutherland (1976) states that such feelings need to be recognised and explored rather than suppressed or displaced so that tensions are relieved and an appropriate caring environment is created. This is particularly important for older people living in institutional settings, where the prevalence of incontinence is high and management of the symptom rests mainly with care staff (Bjurbrant *et al.*, 1993; Peet *et al.*, 1996).

Table 2.0 summarises published papers that have investigated the role of psychological or personality factors in the aetiology of urge incontinence in women. These authors have tended to look for factors that distinguish women with urge incontinence from those with other types of incontinence. These papers have either

Table 2.0 Research studies focusing on the psychosomatic origins of urge incontinence.

Author	Study details	Symptom	Measures	Main findings
Frewin 1972, UK	Female, N=100, clinic sample	Urge incontinence	Review of clinical case notes	Forcefully states that urge incontinence is a psychosomatic disorder, but belief seems to be based on success of 'psycho-medical' treatments and anecdotal evidence Suggests that onset associated with 'untoward events', although patients may not remember them. Refers to incontinence as a 'stress reactive factor'..
Hafner <i>et al.</i> , 1977, UK	Female, 18-65 years. N = 26, clinic sample	Frequency, urgency and urgency incontinence	Middlesex Hospital Questionnaire, Eysenck Personality Inventory, Fear Survey Schedule and psychiatric assessment	Paper focuses on evaluation of psychological treatment. Suggests emotional and interpersonal problems causally associated with urge incontinence, but some patients do not want to make this connection Approx. 1/3 benefited considerably from psychotherapy, 1/3 refused therapy and 1/3 improved slightly or not at all
Frewin, 1978, UK	Female, N= 40, clinic sample	Destructor instability (DI)	Clinical assessment	Focus of paper is an evaluation of 'psycho-medical' treatment, and associates failure of treatment with emotively traumatic events and stress.
Stone & Judd, 1978, USA	Women 32 -75 years, N=18, clinic sample	DI and failed to respond to treatment	Clinical interview, case reports	Severe situational factors in all 18 patients, chronic depression in 17 and hysterical personality traits in 10, with additional functional symptoms i.e headaches, backaches and gastrointestinal symptoms.
Crisp & Sutherst, 1983, UK	Female, <65 years, N=57, clinic sample	Urgency, urge, stress & mixed incontinence	Eysenck Personality Questionnaire, IPAT Anxiety Scale	Patients with urge incontinence scored higher than other groups on neuroticism and anxiety scales. Suggests this is evidence of the role of emotion in aetiology of bladder instability.
Freeman <i>et al.</i> , 1985, UK	Female, 20-81 years, N= 79, clinic sample	Genuine stress incontinence (GSI) and DI	Crown-Crisp Experiential Index, Hysteroïd-Obessoid Questionnaire Hostility and Direction of Hostility Questionnaire, Zung self-rating scale	Anxiety, neuroticism, hostility and depression, but not hysteria, increased in patients with DI compared to GSI. They conclude that the personality of DI patients is characterised by inability to express emotions and DI is a psychosomatic disorder.
Morrison <i>et al.</i> , 1986, UK	Female, N = 165, clinic sample.	DI and other types of incontinence	Eysenck Personality Inventory	Higher degree of neuroticism in incontinent group compared to normal population, but EPI scores were not statistically different for patients with DI.
Freeman, 1987, UK	Women, 17-74 years, N= 63, clinic sample	DI	Suggestibility and hypnotisability tests	Evaluation of hypnosis which was shown to be helpful in the short-term, but relapse common in long-term. Suggests women with DI have life-long history of incontinence with emotional component.

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Table 2.0 continued.

Author	Study details	Symptom	Measures	Main findings
Macaulay <i>et al.</i> , 1987, UK. Macaulay <i>et al.</i> , 1991, UK	Women, 15-79 years, N=211, clinic sample	GSI, DI, sensory urgency, mixed, frequency, nocturia and urgency	Spielberger State Trait Anxiety Inventory Wakefield depression scale Crown-Crisp Experiential Index.	Anxiety, depression and hysteria significantly higher in DI and SU groups. Evaluation of psychotherapy, bladder drill and propantheline. Psychotherapy group improved significantly on measures of urgency, incontinence and nocturia, bladder training group and drug groups improved in terms of frequency. They conclude a causal link between mental state and incontinence.
Norton <i>et al.</i> , 1990, UK	Female, N=117, clinic sample	DI, GSI, no abnormality detected (NAD)	Eysenck Personality Inventory, State-trait Anxiety Index, Present State Examination	No difference between DI and GSI on psychometric tests, but significantly higher scores in patients where no abnormality detected in urodynamics.
Walters <i>et al.</i> , 1990 USA	Female, N=90, clinic sample	DI, GSI, Mixed and continent	Minnesota Multiphasic Personality Inventory, Uplift and Hassle Scale, structured questionnaire to screen for sexual dysfunction	No difference in all psychological tests between DI and GSI, but DI scored significantly higher than continent on hypochondriasis, hysteria, depression and sexual dysfunction. Abnormal psychological results associated with incontinence in general, not specific symptoms of incontinence.
Lagro-Janssen <i>et al.</i> , 1992, Netherlands	Female, 20-65 years, N = 110, GP sample.	GSI, DI, Mixed	Health Locus of Control Internal and External, Anxiety scale, Functional Somatic Complaint Scale, Perceived physical and mental health	No difference in psychological characteristics in women with different types of incontinence. They cast doubt on the psychosomatic aetiology of urge incontinence.
Field & Hilton, 1993, UK	Female, 22-80 years, N= 100, clinic sample	GSI, DI, other, NAD	Sexual function questionnaire	Sexual dysfunction was identified in 29% of those with GSI and 71% with DI and 54% with NAD. Bladder symptoms during intercourse reported by 38% of women, in particular women with DI. Concludes it is difficult to assess the cause or effect relationship between DI and urinary symptoms during intercourse.
Hunt & Moss, 1996, UK	Female, N= 20, clinic sample	Idiopathic detrusor instability	General Health Questionnaire Golombok Rust Inventory of Sexual Satisfaction Sexual Events Questionnaire	55.5% of participants reported rape or attempted rape, 75% of participants were cases on GHQ & 57% indicated sexual dysfunction. Conclude that IDI is a psychosomatic disorder and incontinence a functional somatic symptom. Conclude that traumatic sexual experiences are a significant aetiological factor.
Chiara <i>et al.</i> , 1998 Italy	Female, 39-61 years, N = 82 clinic sample	GSI, DI, Mixed	State Trait Anger Expression Inventory CES-D Illness Behaviour Questionnaire	DI associated with higher degree of Trait anger and inner anger, irritability and hypochondria. GSI and Mixed associated with greater conviction of illness. No difference between groups on depression. Concludes that personality structures maintain symptoms of incontinence.

focused on the role of personality traits or that of trauma (in childhood or more recently) in the development and maintenance of urge incontinence.

2.2.1 Personality traits

In terms of personality types, neuroticism, depressive, hysterical and anxious traits predominate (Crisp & Sutherst, 1983; Freeman *et al.*, 1985; MacCaulay *et al.*, 1987, 1991; Stone & Judd, 1978;). It is suggested that such personality types are associated with hyper-vigilant behaviours, which in the case of urge incontinence are related to a raised awareness of bladder filling and the desire to void urine. Anger, irritability and hypochondria have also been identified as personality structures, which maintain symptoms of urge incontinence (Chiara *et al.*, 1998). There is conflicting evidence, however, and the studies with larger sample sizes have found differences in personality traits between continent and incontinent women, but no statistically significant differences between women with different types of incontinence (Lagro-Janssen *et al.*, 1992; Morrison *et al.*, 1986; Norton *et al.*, 1990; Walters *et al.*, 1990).

2.2.2 Trauma

Other commentators have been more interested in the role of trauma and how it may affect bladder functioning. Urinary retention, frequency, urgency and incontinence have all been regarded as signs of a trauma reaction (Margolis, 1965; Rowan, 1975; Straub *et al.*, 1949). However, a number of authors have suggested that stressful events are associated with urge incontinence in particular (Frewin, 1972, 1978; Hafner *et al.*, 1977; Stone & Judd, 1978;). More specifically, sexual dysfunction and unwanted sexual events have been implicated in the development of urge incontinence (Field & Hilton, 1993; Hunt & Moss, 1996). Vereecken (1989) notes that the urinary, sexual and faecal functions 'originate embryologically from the same cloaca' and are intimately related. All three functions are taboo subjects for many women and it is extremely difficult to assess the impact of one on the other. Urinary incontinence during sexual intercourse is not uncommon (Field & Hilton, 1992; Hilton, 1988), but it is rarely discussed. For some women, urge incontinence may become a functional disorder, enabling them to avoid sexual intercourse (Hunt & Moss, 1996).

2.2.3 Psychodynamic interventions

Although many authors have commented on the psychosomatic nature of urge incontinence, there have been few attempts to treat the underlying emotional problems in order to eliminate or alleviate the physical symptom. Only two studies (Hafner *et al.*, 1977; Macaulay *et al.*, 1987) have evaluated the effectiveness of psychotherapy in the treatment of urge incontinence and they are frequently cited as evidence for the psychosomatic basis of urge incontinence. However, these studies are seriously flawed methodologically (e.g. small sample size, outcome measures are not stipulated and definitions of psychotherapy are dubious).

In the Hafner *et al.* (1977) study only four women were offered 'individual psychotherapy, to enable a more detailed analysis and treatment of any relevant psychological disorders', but no details were given regarding this intervention (e.g. therapeutic model, length of intervention). Seven out of the 26 women included in the study refused 'psychological treatments' and were reluctant to accept that their symptom may be related to emotional and interpersonal problems; 9 women made no or slight improvement; and 10 showed great or moderate improvement. The authors interpreted such limited success as further evidence of how 'massive' and complex the underlying problems were and refusal was an indicator of how disturbed and inaccessible patients can be. They concluded that only about one third of their patients required 'a comparatively brief but firm and comprehensible exploration of the relationship between their life style and the emotions it generates, and their bladder activity' (Hafner *et al.*, 1977, p.214). Basically, hostile, defensive, equivocal and positive responses to treatment were all interpreted as evidence for the psychological basis of urge incontinence.

In the second study carried out by Macauley *et al.* (1987) 19 patients were randomised to 'brief eclectic psychotherapy' (described as seen by a psychiatrist for 8 to 12 weeks and offered non-symptom orientated measures of support, counselling and anxiety reducing techniques), 16 to bladder training and 15 to medication. In the psychotherapy group there were statistically significant improvements in urinary symptoms, but no differences on psychological measures. In the bladder training group there were modest improvements in urinary symptoms, but significant changes in psychological profile (i.e. reduced anxiety and depression scores). Changes in the medication group were described as similar to the psychotherapy group. The results are difficult to interpret, as the outcomes were different to what one might have expected (i.e. the psychotherapy group would have showed psychological changes).

Indeed the authors emphasize that their own explanations are speculations only. They conclude, nevertheless, that bladder training and psychotherapy produce benefits and are less expensive than gynaecological management.

The effectiveness of hypnosis in the treatment of urge incontinence has also been investigated (Freeman, 1987; Macaulay, 1989). These studies share many of the pitfalls discussed above. Methodological weaknesses and limited success have not deterred authors from making overly confident conclusions regarding the effectiveness of psychological interventions and the psychosomatic basis of urge incontinence.

It is possible that a sub-group of women reporting urge incontinence have a more complicated medical history, which might indicate the presence of a somatoform disorder. It is important that service providers are aware of such occurrences, the risk of iatrogenic harm from over-investigation and prescribing and the negative feelings such 'difficult patients' may engender among clinical staff (Bass & May, 2002). In these cases, an emphasis on coping with symptoms rather than cure is the most appropriate management strategy (Bass & May, 2002).

In fact, such an emphasis would be appropriate for all women with urge incontinence, as there is little empirical evidence that demonstrates conclusively that conservative treatments result in elimination of incontinence for the majority of patients. Unfortunately, in order to encourage more women to seek help for their urinary symptoms, professionals tend to emphasize the 'treatability' of symptoms, as the latest Department of Health good practice in continence services guidelines illustrates: '[many people are]..unaware of the treatments available to cure or manage their condition' (DOH, 2000, p.4). Although 'cure' may be achievable for some and a laudable goal to aim for, there is little discussion within medical and nursing models, of the repercussions of such messages on professional's and patient's motivation and self-worth, when expectations are frequently not achieved.

2.2.4 Summary of psychodynamic model

The evidence regarding the psychosomatic origins of urge incontinence is conflicting and limited by the fact that most studies have focused on clinic populations only. Although a number of studies have looked at personality traits, there has been little progress in terms of differentiating characteristics and identifying personality types, akin to the Type A personality associated with heart disease found in other areas of physical health (Friedman *et al.*, 1986). Studies that

have examined the role of traumatic events in the aetiology of urge incontinence have not used control groups (e.g. women with stress incontinence), so it is not possible to conclude that the two are uniquely associated. Finally, all the papers summarised in Table 2.0 were cross-sectional in design, so conclusions about causal links are speculative only. There is evidence that women with urinary incontinence have different psychological profiles from continent women, but it is less certain whether women with urge incontinence are different from women with other symptoms of incontinence.

2.3.0 Cognitive models of urge incontinence

One of the greatest areas of debate within this field of health is the major discrepancy between the large number of women reporting urinary incontinence and the relatively small numbers seeking professional help for their symptoms. Reviews of the epidemiological literature indicate that 20-30% of women report urinary incontinence, but only 4-10% seek professional help for these symptoms (McGrother *et al.*, 2001). There are many reasons why women do not seek help, but some of the most common explanations are:

- Incontinence is perceived to be a widespread, normal and trivial problem (Bush *et al.*, 2001; Jolleys, 1988; Harrison & Memel, 1994; Rekers *et al.*, 1992);
- Incontinence is perceived to be an inevitable result of childbearing or a 'normal' aspect of aging for which little can be done (Peake *et al.*, 1999; Mitteness, 1987)
- Women learn how to manage and control their incontinence themselves (Grimby *et al.*, 1993; Klemm & Creason, 1991; Skoner & Haylor, 1993)
- Women find it difficult talking about incontinence to health professionals. They feel embarrassed and have difficulty finding the right language or terminology to discuss such symptoms (Cochran, 1998; Holst & Wilson, 1988; Goldstein *et al.*, 1992)
- Lack of awareness of a range of treatments for such symptoms and/or fearful of surgery (Jolleys, 1988; Shaw *et al.*, 2001)
- Low expectations of treatment efficacy (Holst & Wilson, 1988; Harrison & Memel, 1994)

Interestingly, there is evidence that many health professionals share similar beliefs about incontinence (Mitteness & Barker, 1995; Rekers *et al.*, 1992). There is

evidence that older women with chronic symptoms and women with urge and mixed incontinence are more likely to seek professional help (Seim *et al.*, 1995). However, the specific characteristics of symptoms may be less important than individuals' representations of illness, coping strategies and illness behaviours.

Thus, a number of qualitative studies have explored such concepts and provided vivid descriptive accounts of women's experience of incontinence (Ashworth & Hagan, 1993; Bjurbrant Birgersson *et al.*, 1993; Cochran, 1998; Dowd, 1991; Eisenhandler, 1992; Herskovitis & Mitteness, 1994; Klemm & Creason, 1991; Mitteness, 1987; Mitteness & Barker, 1995; Patterson Robinson, 2000; Peake *et al.*, 1999; Skoner & Haylor, 1993; Wong, 1995). The normalisation of urinary incontinence is a theme consistently reported across these studies. Perceiving incontinence as a 'normal' physiological event serves many functions: it enables a woman to protect her own identity and self-esteem; to maintain perceptions of control and competency over her bodily functions; and to avoid feelings of guilt, shame and responsibility.

As well as normalising symptoms of incontinence (e.g. "Incontinence runs in the family", "This is how it is after having a baby"), women normalise self-management strategies to control incontinence. Indeed self-management strategies, although time consuming, become a normal part of daily routines and enable women to feel as if they were in charge of their symptoms. The variety of strategies used is illustrated in one woman's account of her incontinence:

"I buy clothes that can be washed easily...pants that are terry towel lined. [There are] washing lines in the bathroom....constantly full of pants. I change outer clothes everyday so that I don't have any smells....I don't go to people's houses because I'm frightened of having an accident. If I go in town I make sure that I keep going to toilets whether I want to go or not." (Ashworth & Hagan, 1993, p.1420)

Whereas dementia is often used as a metaphor for a failing mind, urinary incontinence is often a metaphor for a failing body:

While urinary incontinence is seen as a normal part of the aging process, it by no means an acceptable or comfortable part of aging. Incontinence is linked to incompetence and decrepitude to a degree that makes secrecy and control of information about the self (odor and wetness) an absolute imperative. The competent incontinent elder can and does control wetness and odor. The incompetent elder is visibly incontinent. (Mitteness & Barker, 1995, p.205)

Cultural conceptions of incontinence and aging have a powerful influence on help-seeking behaviour and women develop their own expertise in managing symptoms themselves. Less attention has been given to developing theoretical

models, which would help to explain how such cognitions, behaviours and emotions are maintained and could be changed to improve people's quality of life.

Levanthal's (1997) model of illness representations and consequent coping responses to illness and emotions would provide a useful guideline for professionals working with adults with incontinence. Central to the model is the view that illness is often perceived to be a threat and such threats affect mood and motivate behaviour to reduce or limit the threat. Incontinence is a threat to many people because of the beliefs they hold regarding its identity, cause, consequences, chronicity and control. The general public and health professionals would benefit greatly from educational programs that challenged some of the myths and secrecy that surround incontinence.

Only two studies have investigated illness cognitions and emotions among women with urge incontinence specifically (Brown *et al.*, 1998; DuBeau *et al.*, 1998). Both studies used focus groups to explore the impact of urge incontinence on functioning and well-being and came to similar conclusions. They found women talked most about the effects of urge incontinence on emotional well-being. Thus, women appeared to be more concerned about loss of control, feeling anxious, tired and unattractive and having a low self-esteem, than they were about carrying out normal activities and maintaining relationships with partners, family members and friends (Brown *et al.*, 1998).

DuBeau *et al.*, (1998) categorised conversations in terms of their explanatory style: locus of control (internal or external), duration (transient or ongoing) and specificity (specific or global). Statements were regarded as positive if they contained only external, transient and specific attributes and negative if they were internal, ongoing and global. Not surprisingly, there were diverse explanatory styles and combinations. However, positive explanatory styles were the most common. In other words, women tried not to blame themselves for their symptoms and to relate symptoms to specific situations and times in their life. Again the ability to cope with such symptoms was an important way of controlling negative feelings about oneself.

2.3.1. Cognitive interventions

It is only more recently that the use of cognitive interventions for adults with incontinence has been explored (Dowd *et al.*, 2000; Rovetto, 1983), with some promising results. However, as in behavioural interventions, there is a tendency to reduce complex interactions (i.e. between thoughts, feelings and behaviours) to simple and isolated tasks. Thus, Dowd *et al.* (2000) introduced cognitive strategies to

a behavioural programme using an audiotape, which consisted of instructions for relaxation, music and a series of verbal statements read by the therapist. These statements, referred to as ‘coping strategies’, focused on concepts of self and specific aspects of bladder management (e.g. “I often tighten and relax the muscles that control my urine flow”, “I am not alone; many other men and women have loss of urine and they are okay”). Patients receiving ‘cognitive strategies’ were told to listen to this tape once a day for six weeks.

Such an intervention may be helpful, but it very prescriptive and fails to appreciate the collaborative and tailored aspects of cognitive therapy. Thus, cognitive therapies are not about recognising common negative automatic thoughts (NATs) within a condition, and informing patients’ of them. Rather, a detailed assessment of a patient’s internal reality is gathered. The identification of each individual’s NATs and dysfunctional appraisals is then related to specific behaviours, feelings and bodily sensations. A process of ‘guided discovery’, using a variety of technique (e.g. education, systematic desensitisation, role plays, diaries and empirical testing) is used to challenge and modify cognitive biases. (Wells, 1997). Although standard procedures are documented within cognitive therapy, they are not administered uniformly: their strength lies in adapting them to each individual’s circumstances. There is a danger in simplifying psychological models to such an extent that the important collaborative nature of these interventions is lost, along with the fundamental theory.

2.3.2 Summary of cognitive model

Cognitive models of urge incontinence are relatively weak in terms of theory and practice, but strong in terms of description. Most studies have used qualitative research methods and have not made distinctions between different types of incontinence. However, there is evidence that illness representations, coping strategies and emotional responses to incontinence play significant roles in influencing help-seeking behaviour and compliance with treatment. Many women normalise symptoms of urinary incontinence and their own ways of managing symptoms in order to protect threats to their identity, as culturally, incontinence is associated with a failing and aging body. Cognitive therapy is rarely offered to women with incontinence. Consequently, it is not possible to evaluate its effectiveness to date.

2.4.0 Quality of life and mental health research

As already mentioned, many commentators have been interested in the impact of urge incontinence on women's quality of life (Lenderking *et al.*, 1996). Reviews of the literature indicate that only a minority of women report that incontinence is a problem to them in this respect (McGrother *et al.*, 2001). There is evidence that the severity and type (i.e. urge) of incontinence is associated with impact on quality of life (Grimby *et al.*, 1993; Hunskaar & Visnes, 1991; Lagro-Janssen *et al.*, 1990; Wyman *et al.*, 1987; Yarnell *et al.*, 1981). It is likely that the limited impact of incontinence on quality of life may be closely related to cognitive representation of illness (i.e. normalisation of symptoms) and effective self-management strategies described above.

Generic measures of quality of life [e.g. Short-Form-36 (Brazier *et al.* 1992), Sickness Impact Profile (Bergner *et al.* 1981) and Nottingham Health Profile (Hunt *et al.*, 1986)], have consistently found that urinary, and more specifically urge incontinence, have a detrimental impact on emotional well-being, social functioning and vitality (Grimby *et al.*, 1993; Hunskaar & Visnes, 1991; O'Connor *et al.*, 1998). Anxiety and depression are often used as indicators of emotional well-being or mental health. Table 2.1 lists studies that have investigated symptoms of anxiety and depression among women with urinary incontinence generally and among those with specific symptoms of incontinence. Only those studies using an experimental design with a control group and standardised measures of anxiety and depression have been included.

There is good evidence that people with urinary incontinence are more likely to experience anxiety and depression than continent controls, but there is less support for the view that these symptoms are especially associated with urge incontinence rather than any other type of incontinence. Many of the differences in findings may be related to methodological limitations or differences (see Table 2.0 for methodological details of some of the studies listed in Table 2.1). For example, some studies are based on community populations and others on clinic samples; different measures and definitions of urinary incontinence, anxiety and depression have been used; and some studies controlled for confounding variables statistically and others did not. Also, a number of studies include men in their samples. All of the studies that investigated differences between symptoms of incontinence were based on clinical populations (i.e. women who presented to a general or specialist service with

symptoms of incontinence). It is likely that this group is not representative of all women with these symptoms, as the majority do not seek help.

Table 2.1 Summary of studies that have investigated the association between anxiety and depression and urinary incontinence.

Experimental groups	Anxiety		Depression	
	+ association	No association	+ association	No association
Unspecified incontinence vs. continent	MacCauley <i>et al.</i> , 1987 Tinetti <i>et al.</i> , 1995* Vetter <i>et al.</i> , 1981*		Chiverton <i>et al.</i> , 1996; Dugan <i>et al.</i> 2000*; Herzog <i>et al.</i> , 1988*; MacCauley <i>et al.</i> , 1987; Tinetti <i>et al.</i> , 1995*; Vetter <i>et al.</i> , 1981*; Wetle <i>et al.</i> , 1995; Walters <i>et al.</i> , 1990; Zorn <i>et al.</i> , 1999*	Maggi <i>et al.</i> , 2001* Morris <i>et al.</i> , 1992*
Urge incontinence vs. stress incontinence	Freeman <i>et al.</i> , 1985 MacCauley <i>et al.</i> , 1987	Lagro-Janssen <i>et al.</i> , 1992 Norton <i>et al.</i> , 1990	Freeman <i>et al.</i> , 1985 Melville <i>et al.</i> , 2002; Zorn <i>et al.</i> , 1999*	Chiara <i>et al.</i> , 1998 MacCauley <i>et al.</i> , 1987 Walters <i>et al.</i> , 1990

* Study includes males and females, other studies are female only.

It is also difficult to gauge the prevalence of anxiety and depression across different groups, as most of the studies report differences in mean scores and odds ratios rather than percentages. Of the few studies that do report prevalence figures, Dugan *et al.* (2000) found that 43 per cent incontinent adults reported moderate to severe depressive symptoms compared to 30 per cent of continent adults; and Vetter *et al.* (1981) that 18 per cent of incontinent adults report anxiety compared to 4 per cent of the continent. Both studies include men and women in their samples. In terms of types of incontinence, Melville *et al.* (2002) found that 3 per cent of women with stress incontinence reported depression compared to 21 per cent of those with urge incontinence; and Zorn *et al.* (1999) that 14 per cent of adults with stress incontinence reported depression compared to 42 per cent with urge or mixed incontinence. On the whole, a minority of people with urinary and urge incontinence reported feelings of anxiety and depression, but the evidence is limited and extremely variable, making it difficult to come to any definite conclusions.

2.4.1 Quality of life and mental health interventions

Although many authors have reiterated the importance of measuring the impact of urinary incontinence on quality of life, there is little evidence of interventions aimed at improving quality of life and mental health directly. The exception is the Macauley *et al.* (1987) study (discussed in Section 2.2.3), which used anxiety reduction techniques as part of brief eclectic psychotherapy for women with urinary incontinence. Systematic reviews of the literature have criticised treatment trials for failing to measure quality of life (Hay-Smith *et al.*, 2003). Consequently, it is difficult to assess whether and at what level improvement in symptoms has an appreciable effect on well-being. If a reduction in symptoms does not result in improvement in quality of life generally the value of such interventions must be questioned.

Currently, conservative treatments for urge incontinence are very bladder orientated, with the assumption that elimination or reduction in urinary symptoms will result in improved quality of life and mental health. There has been little consideration of the possibility that mental health interventions may have a positive impact on urinary functioning. Urge incontinence could be viewed as a physical expression of anxiety in some women, rather than a distinct condition. It has been observed that people with anxiety disorders are high users of medical care from specialists and half of those with depression report multiple unexplained somatic symptoms, but are less inclined to report psychological symptoms (Turner, 2001). Attributions of self-blame and shame, for example, may be associated with a pervasive depressive disorder rather than a specific reaction to incontinence. Consequently, there may be real value in assessing a woman's mental health and dealing directly with symptoms of anxiety and depression when they occur rather than hope they will disappear if urinary symptoms improve.

Although the treatment goals set by professionals tend to be very symptom orientated (i.e. to be dry), less is known about patients' treatment goals. Williams *et al.* (2001) asked men and women entering a randomised control trial to assess nursing interventions, what their own personal goals were and what they hoped to achieve through treatment. The authors found that personal, social and general health goals were as common as symptom-orientated goals. Personal goals were categorised as concerns about lack of control, feelings of embarrassment and personal hygiene. For example:

“I would like to be cured of my incontinence, but I know that might be too unrealistic, but I hope I could control my bladder much more.” (p.13)

“Only that I can be confident that I won’t embarrass myself by wetting.” (p.13)

Social goals centred on being able to carry out social activities that were important to people, such as swimming, going on holidays and spending time with friends:

“To have a better social life so I won’t be embarrassed to have a good laugh knowing I won’t leak.” (p.14)

“When I go swimming I am in and out of the pool three or four times in an hour. I would like this to stop. My friends notice this, it can be embarrassing.” (p.14)

Health goals were related to improving sleep pattern, feeling more energetic and receiving a thorough assessment to check that symptoms were not related to a more serious health problem (e.g. cancer). These personal, social and health goals, which are closely related to symptom-orientated goals, could play an important role in motivating patients to comply with fairly monotonous toilet schedules.

2.4.2 Summary of quality of life and mental health research

In summary, most of the studies listed in Table 2.1 have assumed that symptoms of anxiety and depression are a consequence or reaction to urinary incontinence. It is possible, however, that urge incontinence is a consequence of an underlying anxiety or depressive disorder. It is unclear whether symptoms of anxiety and depression are more prevalent among women with urge incontinence compared to women with other symptoms of incontinence. There have been few attempts to directly improve the quality of life and mental health of women with incontinence and assess the impact this has on urinary functioning.

2.5.0 Summary of psychological models and interventions

Psychological models of urge incontinence reflect historical developments within the profession, in that over the years psychoanalytical, behavioural and cognitive models have influenced the focus and direction of research. Behavioural models of incontinence have been the most influential in clinical practice: bladder retraining, biofeedback and pelvic floor muscle training are the first line treatment for women with these symptoms. However, the effectiveness of these interventions is uncertain. Behavioural interventions focus on changing behaviour, in particular the frequency of visits to the toilet to pass urine.

Psychodynamic models, in contrast, give central stage to the emotions, hypothesizing that certain personality types (e.g. depressives) and trauma are the causes of incontinence. Although there is little evidence to substantiate such claims, this model has raised awareness of the emotional implications of any illness and, in this case, incontinence. This model also highlighted the potentially functional aspects of urinary incontinence.

Cognitive models have focused on the roles of illness representations and self-management coping strategies and how these influenced help-seeking behaviours. In the case of incontinence, women often normalise their symptoms in order to limit the threat they pose to their own self-worth. Women have become experts at 'passing' as normal (i.e. continent).

The cognitive and quality of life models have also emphasized the impact of incontinence on emotional well-being. In other words, feelings, such as anxiety and depression, may maintain or exacerbate symptoms and interfere with treatment outcomes. It is unclear whether urge incontinence differs significantly from other types of incontinence in terms of the influence of emotional factors in its development and course.

What is striking about all of this literature is the increasing emphasis on psychological factors in the development and treatment of urge incontinence, but the scarcity of psychologists (academic, clinical and health) within the field of adult urinary incontinence. The detrimental implications this can have, in terms of applying psychological theory to clinical practice in continence services, have already been discussed. A handful of psychologists (Hunt, 1995, 1996; Hunt & Moss, 1996; Smith & Smith, 1987, 1993; Turner, 1986), have made significant contributions to this area of health in the United Kingdom, but their work is overshadowed by the enormous quantity of literature published by medical and nursing professions every year. This study is unusual in that it focuses on a very common but little talked about health problem within clinical psychology.

2.6.0 Main research questions

The lack of longitudinal research in this field means that very little is known about the natural course of urge incontinence and how this is related to changes in emotional well-being over time. There are, then three main research questions:

1. What is the prevalence of anxiety and depression among women with urge incontinence?

2. Are emotional problems more prevalent among women with urge incontinence compared to other symptoms of incontinence?
3. How do emotional factors and urge incontinence interact with and influence the development and progression of these symptoms?

The last research question is the most complex. Table 2.2. lists a number of propositions regarding causal pathways between emotional variables and urge incontinence. Proposition 1, would be favoured by the psychodynamic model of incontinence in that it stipulates that emotional factors are a cause of incontinence (not necessarily *the* only cause). Although there was some evidence for Proposition 1, in that emotional factors precipitated or triggered problems with continence in the first instance, within this literature little explanation was given to how such events maintained symptoms in the long-term.

Table 2.2 Propositions regarding the causal relationship between urge incontinence and emotional factors

Proposition	Nature of causal association
Proposition 1.	Emotional factors cause urge incontinence
Proposition 2.	Urge incontinence causes emotional factors
Proposition 3.	Urge incontinence and emotional factors co-exist, interact and maintain each other.
Proposition 4	Urge incontinence and emotional factors are associated with another factor but do not influence each other.
Proposition 5.	Urge incontinence and emotional factors are not related to each other

There appears to be more research evidence in support of Propositions 2 and 3. Proposition 2 is more in line with the quality of life and mental health research, in that it stipulates that emotional factors are a reaction to somatic symptoms. This chapter has demonstrated that there is reasonable evidence that depression and anxiety are associated with incontinence, but not necessarily urge incontinence specifically.

Proposition 3 is supported by evidence from behavioural and cognitive models. Although behavioural models tackle safety behaviours and cognitive models dysfunctional schemas or misinterpretations, both models recognise the role of

anxiety (i.e. fear or the threat of public humiliation) in maintaining these behaviours and beliefs.

Proposition 4 stipulates that the relationship between emotional factors and urge incontinence is not causal and there exists a secondary association only. In other words, emotional factors and urge incontinence do not influence each other, but they are both directly associated with another factor (e.g. neurological lesion). Proposition 4 is another credible possibility and much effort will be made in this study to control for confounding variables (e.g. co-morbidities).

Proposition 5 is equivalent to the null hypothesis in that it stipulates that there is no association between emotional and incontinence symptoms. It is important to remember that emotional factors and incontinence may not be related. Before this proposition is accepted, however, it will be important to rule out the existence of discreet sub-groups where the association between these variables may be statistically and causally significant.

This study will investigate these individual propositions. Specific hypotheses will be detailed in the next chapter. Results from this study and findings from the studies reviewed in this chapter will be integrated to produce a psychological model of urge incontinence.

Chapter Three

Methodology

3.0.0 Background to the study

The present study entails new analyses of data collected by the Leicestershire MRC Incontinence Study (see Appendix 3 for information on the MRC study). Previous to starting the doctorate in clinical psychology the author was employed on the Incontinence Study as a researcher, with a particular interest in the prevalence of a variety of urinary symptoms in the adult population and how these symptoms impacted on people's quality of life. During the author's employment on the programme she was primarily responsible for the design, development, piloting and validation of research instruments to measure the prevalence and severity of urinary symptoms and estimate need for health care (e.g. postal questionnaire, home interview, urinary diary and pad test), the training of a team of interviewers and the analyses of prevalence data from the postal survey. The present study will analyse data sets from the postal surveys of the community population.

The doctorate in clinical psychology provided an opportunity to ask epidemiological questions with a psychological emphasis regarding the development of urge incontinence and the effectiveness of psychological interventions carried out generally by health professionals outside the field of clinical psychology.

3.1.0 Ethical monitoring

The Leicestershire MRC Incontinence Study was registered with Leicestershire and Rutland Healthcare NHS Trust and received ethical approval from Leicestershire Research Ethics Committee (LREC) in 1995 (reference number 3650). Before commencing the present study the LREC was informed of the proposed further analyses of the data. Approval was given to the amended application (reference number RFB 0064) in December 2002 (see Appendix 4).

3.2.0 Aims and objectives

As the previous chapter demonstrated, there is very little evidence regarding the natural course of urge incontinence and how this is related to emotional well-being over time. The aim of this study was to investigate the associations between anxiety and depression and urge incontinence in women and to assess whether these factors are causally related or exacerbate each other. Although there is some

indication that urge incontinence, compared to other symptoms of incontinence, is specifically associated with emotional distress, there are conflicting results in the literature and the evidence remains inconclusive.

This study will attempt to address some of the gaps in the literature; the methodological limitations associated with previous research; and look closer at causal relationships. The objective is to produce a psychological model of urge incontinence, which addresses the emotional aspects of the symptom and how these may influence the development of incontinence and responses to clinical interventions.

3.3.0 Research questions and hypotheses

This study investigated associations between anxiety, depression and urge incontinence and possible causal pathways. Three main research questions were identified in the previous chapter. These questions are listed below, together with more specific research hypotheses. These hypotheses were based on either proposition 2 or 3 (see Table 2.2, Chapter 2). To recap, Proposition 2 stipulates that emotional factors are a response to urge incontinence and Proposition 3 that urge incontinence and emotional factors interact and maintain each other.

3.3.1. What is the prevalence of anxiety and depression among women with urge incontinence?

There is only limited quality of life literature specific to urge incontinence. The evidence reviewed previously (see Chapter Two, Section 2.4) suggested that only a minority (approximately one third) of women with urinary incontinence perceived their symptoms to be distressing to them, albeit a significant minority. If anxiety and depression are responses to incontinence, it is not necessarily the case that all women will experience these emotions, but when these emotions are present they will exacerbate symptoms of urge incontinence. Consequently, the following hypotheses were made:

Hypothesis 1: A minority of women with urge incontinence will report symptoms of anxiety and depression.

Hypothesis 2: Symptoms of anxiety and depression will be positively associated with the severity of urge incontinence and the presence of multiple urinary symptoms associated with urge incontinence.

3.3.2 Are emotional problems more prevalent among women with urge incontinence compared to other symptoms of incontinence (i.e. stress incontinence)?

The evidence is inconclusive regarding the association between anxiety and depression and urge incontinence specifically (see Chapter Two, Section 2.4). It is hypothesised that depression and anxiety have different associations with urge incontinence, which relate to Propositions 2 and 3 respectively. Thus, it is hypothesised that depression is a non-specific response to incontinence, and it is likely that it will be as prevalent among women with urge incontinence as in women with other types of incontinence and urinary symptoms. In line with Proposition 3 and evidence from cognitive and behavioural models, it is hypothesised that that anxiety and associated feelings of urgency, interacts, exacerbates and maintains symptoms of urge incontinence. Anxiety, then, is likely to be more prevalent among women with urge incontinence compared with those with other symptoms of incontinence. These hypotheses can be summarised as follows:

Hypothesis 3: Symptoms of depression will be associated with many urinary symptoms and this association will be no stronger in urge incontinence than in other symptoms.

Hypothesis 4: Symptoms of anxiety will be associated with many urinary symptoms, but the association will be strongest in urge incontinence.

3.3.3. How do emotional factors and urge incontinence interact and influence the development and progression of these symptoms?

There is minimal evidence regarding the natural history of urge incontinence and no studies have related this to the natural history of emotions over the same time period. The longitudinal data will enable an investigation of association and more importantly, the temporal relationship between anxiety, depression and urge incontinence. This will enable a better understanding of the direction and nature of causality.

Hypothesis 5 stipulates that depression is more likely to be a response to urge incontinence rather than a cause (in line with Proposition 2). It was proposed that incident (new) cases of depression would be predicted by the presence or not of urge incontinence at baseline, whilst controlling for other significant variables.

Anxiety, on the other hand, was likely to have a more complicated relationship with urge incontinence, and be both a consequence and cause of this

symptom (in line with Proposition 3). It was hypothesized that incident cases of anxiety would be predicted by the presence or not of urge incontinence at baseline and vice versa, In other words, these two symptoms reinforced each other. Thus, hypotheses 6 and 7 were proposed.

Hypothesis 5: Incident cases of depression will be predicted by symptoms of urge incontinence at baseline.

Hypothesis 6: Incident cases of anxiety will be predicted by symptoms of urge incontinence at baseline

Hypothesis 7: Incident cases of urge incontinence will be predicted by symptoms of anxiety, but not depression, at baseline.

3.4.0 Study design

Epidemiology is the study of the distribution and determinants of diseases in populations; with especial interest in the frequency with which diseases occur, their causation and natural history. Epidemiology attends also to the burden of disease over time and the long-term effectiveness of health interventions in different groups of people (Beaglehole *et al.*, 1993). Epidemiologists are primarily interested in groups of people rather than individuals and clues as to the causes of disease are based on comparing rates of disease in groups with different levels of exposure. In this way high risk and priority groups are identified (Coggon *et al.*, 1993).

The two main measures of disease frequency are prevalence and incidence. Prevalence of a disease is the proportion of a population that are cases at a point in time. Incidence is the rate at which new cases occur in a population during a specified period. This study will report on prevalence of symptoms and incident cases of symptoms over a one-year period.

A distinction is often made between cross-sectional and longitudinal research studies: in the former cause (exposure) and effect (i.e. disease) measurements are collected at the same point in time; in the latter, cause and effect are measured at two or more points in time. Longitudinal studies are often referred to as cohort studies as a population is followed-up over time with repeated monitoring of risk factors and health outcomes. Although cross-sectional studies are important means of identifying associations between variables, they are less useful at assessing whether the exposure precedes or follows the effect. This is where longitudinal studies are invaluable as they can observe the development of disease over time and with age and be more confident about whether an association is causal.

The strength of this study, then, was its longitudinal design. A postal survey was used to select a cohort of subjects who were followed up prospectively, on an annual basis, in order to investigate the natural history of urinary symptoms and the risks associated with developing these symptoms. The study was also observational, rather than experimental, in that variables were measured, but no attempt was made to intervene (i.e. change exposure or the course of symptoms). Rather, groups of people were categorised as cases or non-cases, according to whether they reported clinically significant symptoms or not, and then compared in terms of exposure to risk factors suspected of causing these symptoms.

Although epidemiological studies have proved to be vital in improving public health and preventing illness (e.g. uncovering the relationship between smoking and lung cancer), they are dependent on measuring diseases accurately. Unfortunately there are many opportunities for errors to occur and they can never be completely eliminated. Three of the most important errors are:

Selection bias – this refers to whether a cohort or sample is representative of the population about which the conclusions are made. Bias occurs when: a) sampling procedures systematically exclude certain members of the population (e.g. hospitalised, homeless, migrant populations); b) subjects choose to participate in a survey (because they are particularly worried about their health) or not (because the survey is not relevant to them) resulting in response bias; or c) missing data for the reasons mentioned above or because the questionnaire is badly designed, difficult to read, comprehend or complete.

Measurement error – the ability to classify cases and risk factors accurately is dependent on the quality of measurements used. The validity (i.e. sensitivity and specificity) and reliability (i.e. repeatability) of measures is, therefore, important, as is their proven applicability to the population being studied.

Information bias – otherwise referred to as recall bias. This occurs when a group of people (i.e. cases) are highly motivated to recall specific information compared to another (i.e. non-cases), because they are also looking for causes for their problem or they are aware of widely held theories. Consequently, the association between risk factors and diseases can be exaggerated, if the respondent is in support of a theory, or underestimated, if they are more likely to deny an association. The latter is particularly relevant in the case of incontinence, where normalising a symptom may be a particularly important coping strategy.

Longitudinal studies have an additional problem with selection bias in that as the years pass the cohort decreases in size (i.e. deaths, migration, loss of interest in the study) and becomes increasingly selected. Nevertheless, it is usually possible to compare cohort members with those lost to follow-up on some demographic and health characteristics collected previously and to account for such biases. The following sections will address these types of errors and how they were minimised within the study

3.5.0 Sample details and procedures

The target population for the Leicestershire MRC Incontinence study was the population of Leicestershire and Rutland aged 40 or more years registered with general practitioners (GPs) on the Leicestershire Health Authority general practice list. The age threshold was chosen to capture the increase in prevalence of incontinence in middle and old age. Permission to approach patients on the Health Authority register was sought at practice level (i.e. all GPs in a practice had to consent to participate in the study). The sampling frame, then, was this population of men and women whose GPs agreed to participate in the study. In total, 108 general practices (71% of the practices in Leicestershire and Rutland) participated in the study. The age and sex distribution of patients registered with participating and non-participating GPs was not significantly different and both are representative of patients recorded on the Leicestershire Health Authority patient register. The age, sex and ethnic group structure of the sample was similar to the population of Leicestershire as a whole (see Table 3.0).

Table 3.0 Demographic characteristics of sample and Leicestershire population.

Variable	Respondents (%)	Population+ (%)
Age (years)		
40-49	6,445 (27.8)	119,003 (31.2)
50-59	6,131 (26.4)	90,004 (23.6)
60-69	5,132 (22.1)	83,784 (22.0)
70-79	3,955 (17.1)	58,273 (15.3)
80+	1,519 (6.6)	30,276 (7.9)
Total	23,182 (100.0)	381,380 (100.0)
Sex		
Female	12568 (54.2)	201,394 (52.8)
Male	10614 (45.8)	179,986 (47.2)
Ethnicity (> 39 years)		
White	21210 (92.9)	356,850 (93.6)
South Asian	1312 (5.7)	20,247 (5.3)
Other	314 (1.4)	4,283 (1.1)

+ Population estimates for Leicester taken from the 1991 Census (OPCS, 1992).

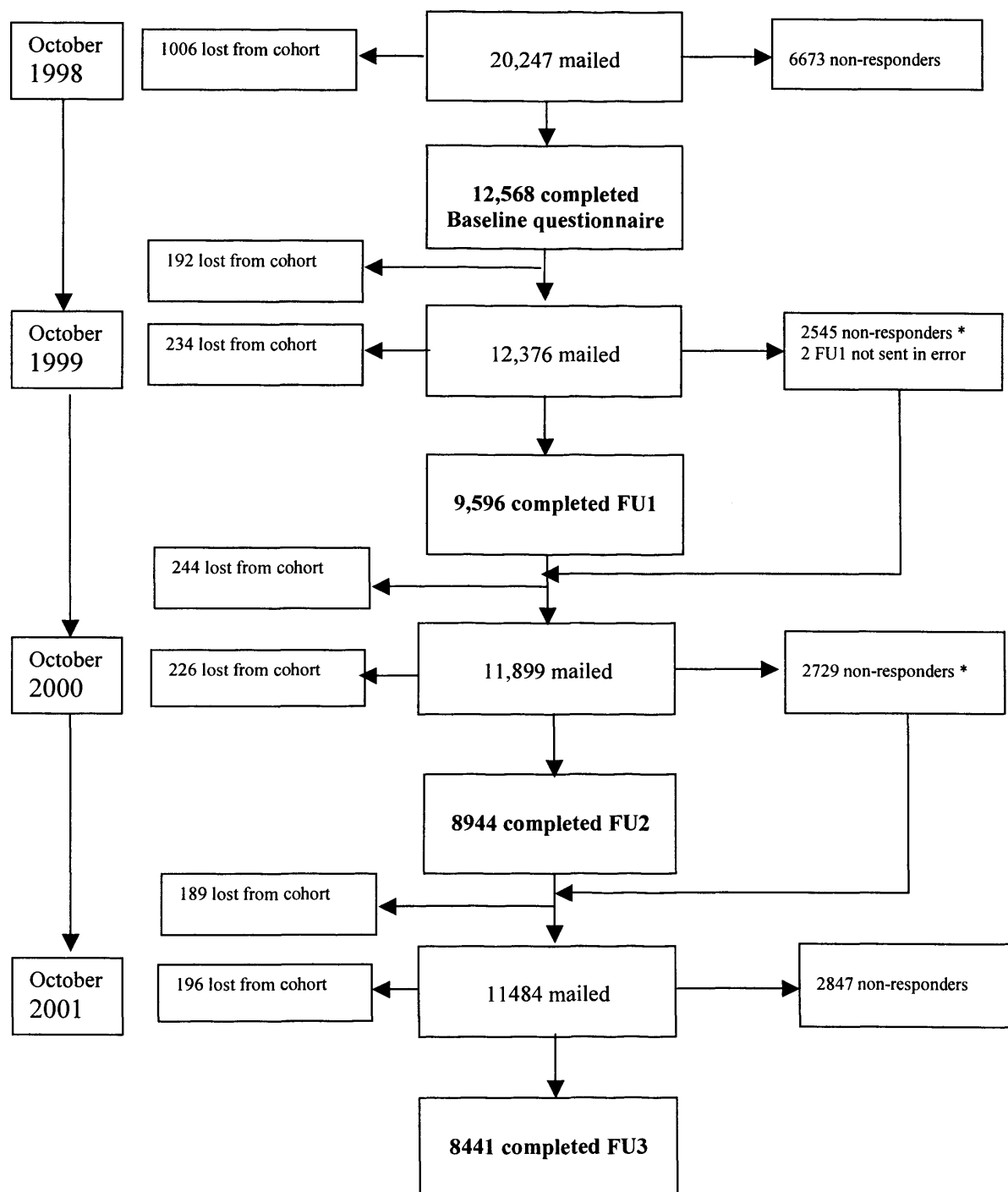
The Leicestershire MRC Incontinence study sample was selected randomly by household from the sampling frame. People living in nursing and residential homes were excluded from the sampling frame, as it was appreciated that a postal survey was not appropriate for this group. It was decided that a separate study would be required to investigate symptoms in this particularly vulnerable group. Information on the prevalence, incidence and remission rates, the natural history of incontinence, the length of follow-up, likely response, attrition and refusal rates and annual loss of subjects from the sample was used to calculate the size of the sample required. Predictions were based on conservative estimates of incidence of only 1%, a 70% response rates to postal questionnaires and 10% annual loss of subjects from the sampling frame.

Thus, 39,603 adults were mailed a postal questionnaire in October 1998. Two additional mailings of the questionnaire were sent to non-responders at four-week intervals. Responders to this mailing were referred to as the 'baseline sample'. The baseline sample was followed up annually for the next three years (1999, 2000, 2001) using the same methods. The first annual follow-up was referred to as 'FU1', the second as 'FU2' and the third as 'FU3'.

The sample for the present study was different from the Leicestershire MRC Incontinence Study in one respect only, and that was the exclusion of males. The presentation and epidemiology of urinary incontinence differs in men and women, and most of the research to date has focused on women only (see Chapters One and Two). In order to make comparisons with other studies it was necessary to focus on women only. It will be important to carry out similar analyses for men, but that work will require a separate protocol.

Details of the size of the sample, numbers of responders and losses to the sample are summarised in Figure 3.0. The flow chart demonstrates that the study sample was not static: as the years progressed subjects moved, became ill, died, refused to complete the questionnaire or lost interest in the study. Thus, the size of the sample decreased at each mailing. Participation in the study was also not consistent either. For example, a person might have completed baseline and FU1 questionnaires, not responded to FU2, but participated at FU3 again. Thus, the number of responders at FU3 does not represent those for whom there is data at every point in time. Problems with response bias and attrition of the sample, along with the complexity of analyses over time led the author to focus on Baseline and FU1 data only for this study.

Figure 3.0 Details of the female sample throughout the study



Definitions

Non-responder: did not respond, completed by the wrong person, late return, returned to sender or refused

Lost from cohort: deceased, moved to nursing home, moved out of study area with no forwarding address, requested no further mailings or physically/mentally unable to participate.

*: non-responders (except refused) were mailed the following year.

3.6.0 Response rates and bias

A detailed analysis of response rates was carried out to assess the potential response bias in the study. Differences in response rates by age group at baseline and FU1 are shown in Table 3.1. Response rates were lowest in the youngest and oldest age groups at both time points. To assess whether responders were different to non-responders at baseline a random sample of 1050 non-responders stratified by sex and age group was follow-up by trained interviewers by telephone or home visit (Dallosso *et al.*, 2003). It was concluded that there was little evidence of response bias in the group overall, but the greater reporting of urinary symptoms by older non-responders suggest that prevalence rates in this age group may be underestimated (see Appendix 5 for further information on the non-responder study).

Table 3.1. Response rates at each mailing by age group

Baseline 1998			
Age group (years)	Eligible sample*	Respondents	Response rates (%)
40 – 49	5583	3443	61.7
50 – 59	5014	3274	65.3
60 – 69	3816	2729	71.5
70 – 79	3206	2156	67.2
80+	1622	966	59.6
Total sample	19241	12568	65.3
FU1 1999			
40 – 49	3358	2555	76.1
50 – 59	3184	2595	81.5
60 – 69	2631	2185	83.0
70 – 79	2025	1646	81.3
80+	836	615	73.6
Total sample	12034	9596	79.7

*Eligible sample = Mailed – lost from cohort

As already mentioned, the cohort decreased in size over the years, which led to concerns about selection bias. It was possible to compare those who participated in FU1 to those who did not on characteristics collected at baseline. Thus, 69% of respondents who indicated they were depressed at baseline participated at FU1 compared to 78% of those who were not depressed ($\chi^2=97.6$, $p<0.001$). The difference was not so marked for those who reported anxiety or not at baseline (75% and 73% respectively, ($\chi^2=7.0$, $p=0.008$). There was no statistically significant difference in subsequent participation regarding those reporting urge incontinence or not at baseline (76% and 77% respectively, $\chi^2=0.7$, $p=0.401$). There was then, some

evidence of selection bias in that depressed and anxious respondents were less likely to participate in follow-up surveys.

3.7.0 Measures

The postal survey was described as a ‘Confidential Survey on Health and Lifestyle’ (see Appendix 6 for a summary and copy of the questionnaire, covering letters and information sheets). It was emphasized that taking part was voluntary and any information given was strictly confidential and would not be seen by the individual’s doctor. Recipients of the questionnaire were informed that the Medical Research Council and National Health Service funded the survey and contact details were provided if further information was required or help needed to complete the questionnaire.

The 20-page questionnaire was designed by the Leicestershire MRC Incontinence team. During the pilot phase of the study, the author paid attention to the layout and content of the questionnaire. The wording of the questions were improved so that it was easy to read and comprehend and the instructions were made precise so that the form was easily and properly completed. This resulted in little missing data (generally less than 5% for most questions) and good response rates to a questionnaire, which included many sensitive health questions. Some of these questions were developed by the team for the study (e.g. urinary symptom questions), some are taken from previously published surveys (e.g. demographic questions derived from the census) and some represented standardised instruments with known population characteristics regarding validity and reliability [e.g. Hospital Anxiety and Depression Scale (HADS), (Zigmond & Snaith, 1983)]. The content of the questionnaire reflected the aims of the MRC Incontinence study, the interests of the researchers involved and risk factors associated with incontinence. Of particular interest to the present study were the urinary symptom questions and the HADS.

3.7.1 Measures of urinary symptoms

The questionnaire included 36 questions relating to urinary symptoms: 19 questions focus on the presence of symptoms; 3 on the use of aids and appliances (e.g. pads and catheter, plastic sheets); 3 on help-seeking and contact with services; 10 questions on perceptions of urinary symptoms and the impact they have on quality of life; and finally one question on family history of urinary problems. These questions were developed by the Leicestershire MRC Incontinence Study. More

recently, a number of validated questionnaires have been developed to measure incontinence and lower urinary tract symptoms and their impact of quality of life (Berstein *et al.*, 1996; Black *et al.*, 1996; Brown *et al.*, 1999; Donovan, 1996; Gunthorpe *et al.*, 2000; Ishiko *et al.*, 2000; Jackson *et al.*, 1996; Kelleher *et al.*, 1997; Patrick *et al.*, 1999; Shumaker *et al.*, 1994). However, when the Incontinence Study in Leicestershire started in 1995, few existed and those that did focused on specific symptoms, such as incontinence and prostate problems and tended to concentrate on clinic rather than community populations (Barry *et al.*, 1992, Bo 1994, Lee *et al.*, 1995; Rai *et al.*, 1994; Sanvik *et al.*, 1993; Yu, 1987).

In developing the questionnaire, reference was made to the ICS definitions and standardisation of urinary incontinence (Abrams *et al.*, 1988), reviews of the literature, which have already been discussed, and a pilot study was conducted (information and results from the pilot study can be found in Perry *et al.* (2000) and Perry *et al.* (2001)). In the pilot study semi-structured interviews were carried out with respondents to a mailing of the postal questionnaire to gather their opinions about the questionnaire, the acceptability of individual questions included in the survey and the language they used to talk about incontinence. It soon became clear the word 'incontinence' was rarely used to describe symptoms. People referred to 'accidents', 'water-work problems' and 'leaking'. Similar findings were reported by Ashworth and Hagan (1993):

Sufferers did not even have a word they could confidently use to refer to their problem.

In the absence of any opportunity to talk about a thing, it cannot have any shape or form. So sufferers offered vague and hesitant accounts of the problem and described correspondingly vague and hesitant ways of coping with it. (p.1418)

The challenge, then, was to find terminology that was explicit, but not offensive or alien to a particular age group or section of the community and to design questions that were applicable to a community population with a wide range of severity of symptoms. In the final version, the term 'incontinence' was not used anywhere in the questionnaire. Instead, descriptions of circumstances in which people may 'leak' urine were used and respondents were asked to report on the urinary symptoms they had experienced in the last 12 months. Table 3.2 details the urinary symptom questions that were particularly relevant to this study.

The validity and reliability of some of the symptom questions (i.e. incontinence, urgency, frequency and nocturia) included in the postal survey were investigated in a validation study (Shaw *et al.*, 2002). The results from the validation study were encouraging and the questions used in the survey appear to be acceptable,

sensitive and to discriminate between different levels of symptom severity (see Appendix 5 for further details).

Table 3.2. Urinary symptom questions used in the postal survey relevant to this study.

Measure	Question	Response categories	Definition of a case
Urge incontinence	Do you have such a strong desire to pass urine that you leak before reaching the toilet?	Several times a day Several times a week Several times a month Several times a year Never/rarely	Several times a month or more often
Stress incontinence	Does any urine leak when you laugh, cough or exercise?	Several times a day Several times a week Several times a month Several times a year Never/rarely	Several times a month or more often
Frequency	During the daytime, how often do you <u>usually</u> go to the toilet to pass urine? About every:	Half hour Hour 2 hours 3 hours 4 hours	Hourly or more often
Urgency	When you need to pass urine, how strong is the urge <u>usually</u> ?	Overwhelming Very strong Strong Normal Weak Never have this sensation	Very strong or overwhelming

3.7.2 Case definition for urge incontinence

Table 3.2. also details how the severity of symptoms was measured in the study and definitions of cases. For example, the severity of urge incontinence was assessed by asking participants to rate the frequency of these events in the past 12 months. Although there is no consensus regarding thresholds for distinguishing between cases and non-cases for incontinence, reviews of the literature (Hampel *et al.*, 1997; Thom, 1998) found that studies tend to distinguish between: 1) any incontinence (i.e. ‘ever’ incontinent); 2) more severe incontinence (i.e. clinically significant), which is usually based on the frequency of incontinent episodes; and socially disabling incontinence, which is based on loss of urine which is perceived to be a social or hygienic problem and objectively demonstrable. The threshold for

severe or regular incontinence tends to be weekly episodes (i.e. more than once a month).

In this study then, urge incontinence was regarded as a clinically significant case if it occurred several times a month or more often. Non-cases were classified as women who leaked several times a year or less often. ICS guidelines (Abrams *et al.*, 1988) and reviews of the literature also guided case definitions for the other urinary symptoms shown in Table 3.2 (Barry *et al.*, 1992; Hampel *et al.*, 1997; Thom, 1998).

3.7.3 Measures of anxiety and depression

Symptoms of anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The HADS consists of two separate subscales, which were designed to measure anxiety (HADS-A) and depression (HADS-D) in a non-psychiatric population. It is a 14-item self-administered scale (7 items relate to anxiety and 7 to depression), and respondents rate how they have felt in the past week (see Table 3.3 for examples of items in the scale). The HADS is a measure of present or current mood. Many of the items composing the anxiety scale derive from the Present State Examination and are indicative of anxiety neurosis and those from the depression scale were based largely on the anhedonic state. It was originally designed for a hospital outpatient population and as a result does not include any somatic items (e.g. dizziness, fatigue and headaches), which can inflate false positives among people with a high rate of physical illness and co-morbidity.

Table 3.3 Examples of items on the HADS.

Subscale	Item
Anxiety	Do you feel tense or wound up? • Most of the time • A lot of the time • From time to time, occasionally • Not at all •
Depression	Do you still enjoy the things you used to enjoy? • Definitely as much • Not quite so much • Only a little • Hardly at all

Zigmond and Snaith (1983) reported good correlations between the two subscales and psychiatric ratings and good performance on case identification in terms of sensitivity (low proportion of false negatives) and specificity (low proportion of false positives). Many measures of anxiety and depression for non-psychiatric adult populations exist (e.g. Hopkins Symptom Checklist (SCL), Centre for Epidemiological Studies of Depression Scale (CES-D), General Health Questionnaire (GHQ), Beck Depression Inventory (BDI), State-Trait Anxiety Inventory (STAI)). The HADS had become very popular in health research because of its brevity, simplicity and lack of effect from physical conditions (Bowling, 1995). These features were considered important for the postal survey described here. The HADS is also useful for detecting psychological distress and disorder at the more pathological end of the spectrum.

3.7.4 Case definition for anxiety and depression

Zigmond and Snaith (1983) made a distinction between non-cases, doubtful cases and cases for each of the two subscales (HADS-A and HAD-D): non-cases scored 7 or less; doubtful cases 8 – 10; and definite cases 11 or more. They concluded that the cut off point for a case might be either the upper (10/11) or lower end (8/9) of the borderline range. If a research project only wants to include those subjects with a high probability of having a mood disorder, the upper end should be used, but if it were more important to include all possible cases the lower end would be more appropriate. Deciding on a suitable cut off point to identify cases is about trying to obtain a balance between the sensitivity and specificity of the measure.

The HADS has been used extensively on different clinical populations since it was first published. The HADS has not been used as widely on general populations so it is difficult to find normative data for non-clinical samples. Crawford *et al.*, (2001) administered the HADS to a non-clinical sample aged 18 years or more in the UK and found that apart from gender (more women reported anxiety and depression than men) demographic variables had little influence on scores. In total, 33.2 per cent of women reported anxiety and 11.4 per cent depression. Anxiety and depression scores were moderately correlated and the authors concluded that they were not independent variables, but measures of general psychological distress. They concluded that the HADS was a useful screening tool for distress rather than a case finder for psychiatric disorder. Similar conclusions were made by Spinhoven *et al.*

(1997) in a study of a population registered with a general practitioner. However, they found that older people had slightly elevated scores of depression.

Mykleton *et al.* (2001), in a much larger study, also administered the HADS to a general population. They concluded that the HADS had good psychometric properties in terms of factor structure, sub-scale inter-correlation, homogeneity and internal consistency, although the two-factor structure was more prominent in groups with identified mental health problems, compared to somatic problems and health respondents.

A recent review of the literature to assess the validity and reliability of the HADS concluded that: firstly, most factor analyses supported the two-dimensional subscales for anxiety and depression and there was good internal consistency within these scales; secondly, an optimal balance between sensitivity and specificity was achieved when caseness was defined as a score of 8 or more; and lastly, there were good to excellent correlations between HADS and other commonly used measures. (Bjelland *et al.*, 2002).

On the basis of this evidence, this study used a score of 8 or above on the HADS-A and HADS-D to identify cases of anxiety and depression respectively. Cases in this study refer to symptoms of anxiety and depression, rather than psychiatric disorders. Non-cases were identified as those scoring 7 or less. Bjelland *et al.* (2002) also found that the HADS scores were good indicators of the severity of anxiety and depression. This was an important factor, as this study was interested in how changes in severity of emotional distress may be associated with changes in severity of urge incontinence. Finally, the HADS was found to be a valid measure in somatic, psychiatric, primary care patients and the general population. This author was confident that it would perform well in terms of identifying cases in the community sample surveyed in this study.

3.8.0 Summary

The aim of this study was to investigate the association between anxiety and depression and urge incontinence and the direction of causal pathways between these variables. The objective was to produce a psychological model that described the contribution of emotional factors in the development and maintenance of urge incontinence. The seven research hypotheses were:

Hypothesis 1: A minority of women with urge incontinence will report symptoms of anxiety and depression.

Hypothesis 2: Symptoms of anxiety and depression will be positively associated with the severity of urge incontinence and the presence of multiple urinary symptoms associated with urge incontinence.

Hypothesis 3: Symptoms of depression will be associated with many urinary symptoms and this association will be no stronger in urge incontinence than in other symptoms.

Hypothesis 4: Symptoms of anxiety will be associated with many urinary symptoms, but the association will be strongest in urge incontinence.

Hypothesis 5: Incident cases of depression will be predicted by symptoms of urge incontinence at baseline.

Hypothesis 6: Incident cases of anxiety will be predicted by symptoms of urge incontinence at baseline

Hypothesis 7: Incident cases of urge incontinence will be predicted by symptoms of anxiety, but not depression, at baseline.

Table 3.4 summarises the main methodological features of this study, in terms of its design, selection criteria, sampling procedure and size, the measures used and definitions of cases.

Table 3.4 Summary of the methods used in this study

Detail	Description
Design	Longitudinal prospective postal survey.
Selection criteria	• Registered with a GP practice in Leicestershire or Rutland; • GP practice consented to the study; • Female; • Age 40 years or more; • Not living in a residential or nursing home;
Sampling procedure	Random sample. Those who responded to the first mailing were referred to as the baseline sample. This sample was followed up annually for three years (FU1, FU2, FU3), excluding those not eligible (i.e. deceased, moved to residential home or out of study area or questionnaire returned to sender).
Sample size	Baseline: n = 12,568 FU1: n = 9,596
Measures	20-page “Confidential Survey on Health and Lifestyle” postal questionnaire, which included items on urinary symptoms, developed by the Leicestershire MRC Incontinence study, and the HADS. These items will be used to estimate the prevalence and incidence of symptoms of urge incontinence, anxiety and depression..
Definition of cases	Urge incontinence = reported such a strong desire to pass urine that they leaked before reaching the toilet and this occurred several times a month or more often. Anxiety = score of 8 or above on the HADS-A Depression = score of 8 or above on the HADS-D

The next chapter will outline data analysis and report on the main research findings. It is hoped that this study will provide a thorough analysis of the contribution of anxiety and depression in women's experience of urge incontinence. This will point to the role of clinical psychology in helping women with this condition. Such factors may only be important to a minority of women with incontinence, but this group may represent women who need more complex psychological interventions or at least interventions that directly deal with symptoms of anxiety and depression. In these cases consultation with or referral to clinical psychologists may be the most appropriate course of action.

Chapter Four

Results

4.0.0 Introduction

This chapter will begin with an outline of statistical analysis and information on the characteristics of the sample. The results of data analyses are divided into three sections in line with the main research questions. The first section is largely descriptive and will examine the prevalence of anxiety and depression among women with urge incontinence. The second part will attempt to discriminate between different symptoms of incontinence to assess whether anxiety and depression are specifically associated with urge incontinence or not. The third part will investigate causality to assess whether emotional factors are a cause or consequence of urge incontinence.

4.1.0 Statistical analysis

The data was analysed using SPSS (version 9) for Windows software. Data analyses started with descriptive statistics in order to present the distribution (e.g. prevalence and incidence) of symptoms in the population surveyed. This was followed by univariate analyses, which compared the prevalence of symptoms across different groups (e.g. women with stress or urge incontinence). Mann-Whitney U tests were used for continuous variables (e.g. age), chi-square (χ^2) for nominal and ordinal variables (e.g. disease status and age group). All variables that were significantly associated with the dependent variables in the univariate analyses ($p < 0.05$) were entered into the multivariate logistic regression models. Multivariate logistic regression models were the most appropriate, as the dependent variables were dichotomous (i.e. case or non-case). These multivariate models were used to investigate the contribution of variables in predicting the prevalence and incident cases of urge incontinence, anxiety and depression. Backward stepwise techniques were used to build a final model, using likelihood ratio tests (odds ratios) with 95% confidence intervals to determine the significance of variables.

4.1.1 Adjusting for confounding variables

Increasing age and physical diseases have been identified as risk factors for urinary incontinence (see Chapter One). These factors were, therefore, controlled for in multivariate analyses by entering age and the reported presence of a long term

illness, health problem or handicap which limited daily activities or the work people do (Question 17 in the postal questionnaire) in the model. Additionally, frequency and urgency were also adjusted for, as they were known to be associated with urge incontinence in particular (i.e. overactive bladder syndrome). Similarly, both anxiety and depression were entered in all regression models, as they were known to correlate with each other.

4.1.2 Missing data

In the descriptive and univariate analyses missing data was excluded on individual variables. The denominator, therefore, differs slightly in each analysis. To ensure that exclusion of missing data did not inflate differences between groups in multivariate analyses, further analyses was performed to include respondents with missing data. Individual items on the questionnaire generally had a small amount of missing data (less than 5 per cent), but when items were summed to form anxiety and depression scores, this resulted in a higher percentage of missing data. When there were less than 3 missing items on the anxiety or depression scores imputed values were used. When there were 3 or more missing items, respondents were excluded from the analyses. Repeating the analyses without imputation produced comparable results.

4.2.0 Characteristics of the baseline sample: the distribution of symptoms

In Chapter Three the demographic characteristics of the sample were found to be comparable to the population of Leicester (see Table 3.0), though response rates to the survey were slightly lower in the youngest and oldest age-groups (see Table 3.1). Table 4.0 summarises additional characteristics of the baseline sample. The medium age of the sample was 58 years. A significant proportion was retired (42 per cent) and the majority (73 per cent) rated their health as good to excellent. Nevertheless, about one third reported a long-term illness. More specifically, 15 per cent reported urge incontinence, 20 per cent depression and 39 per cent anxiety.

There were many statistically significant differences between women with urge incontinence and those without the symptom. Thus, women with urge incontinence were older, in poorer physical health and were more likely to report other long-term illness and urinary symptoms than the control group. More than half of the sample with urge incontinence reported anxiety (57 per cent) and 38 per cent reported depression, which was double that of those without urge incontinence.

Table 4.0 Characteristics of the baseline sample and comparison between women with or without urge incontinence.

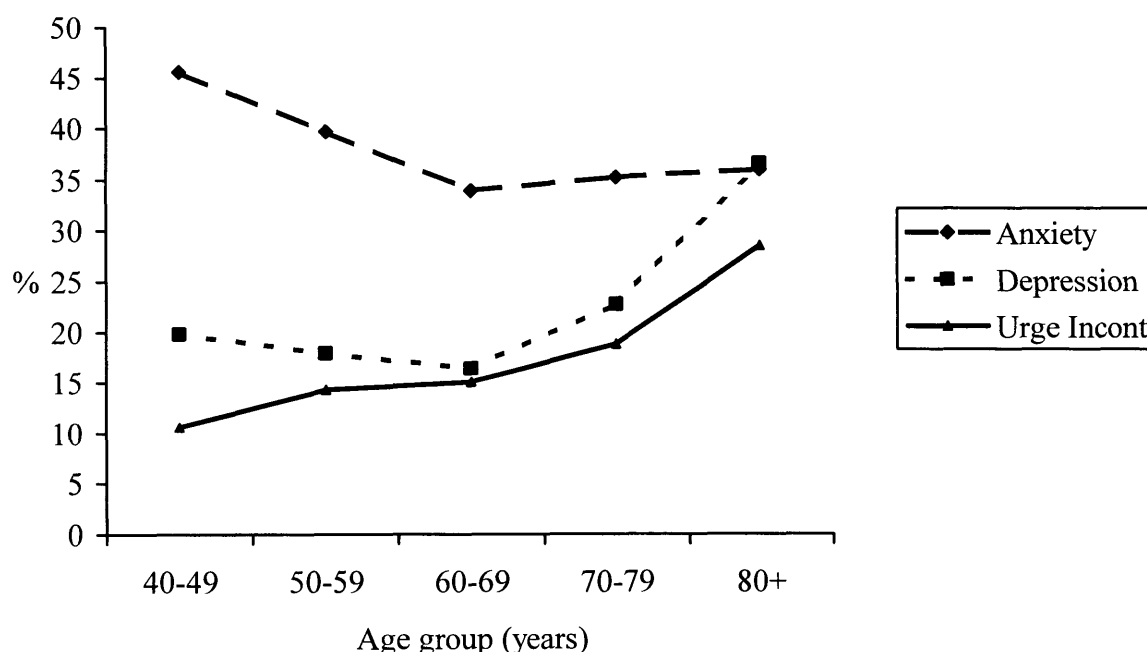
Characteristic	Baseline sample N (%)	Women with urge incontinence N= 1851	Women without urge incontinence N = 10272	p-value
Median age – years (IQR)	58 (49-69)	62 (52–74)	57 (48-68)	< 0.001 ^a
Age group				
40 – 49 years	3443 (27.4)	357 (19.3)	3006 (29.3)	< 0.001 ^b
50-59 years	3274 (26.1)	454 (24.5)	2721 (26.5)	
60-69 years	3729 (21.7)	401 (21.7)	2253 (21.9)	
70-79 years	2156 (17.2)	387 (20.9)	1664 (16.2)	
80+ years	966 (7.7)	252 (13.6)	628 (6.1)	
Ethnic group				
White	11565 (93.4)	1689 (93.1)	9504 (93.6)	0.152 ^b
Asian	665 (5.4)	110 (6.1)	524 (5.2)	
Other		16 (0.9)	122 (1.2)	
Living alone	2690 (22.3)	479 (27.2)	2063 (20.9)	< 0.001 ^b
Employment				
Working FT/PT	5163 (41.9)	539 (29.8)	4507 (44.5)	< 0.001 ^b
Unemployed	675 (5.5)	170 (9.4)	478 (4.7)	
At home	1062 (8.6)	138 (7.6)	892 (8.8)	
Retired	5172 (41.9)	920 (50.9)	4029 (39.8)	
Other	264 (2.1)	39 (2.2)	216 (2.1)	
General health	8881 (72.6)	885 (50.3)	7732 (76.9)	< 0.001 ^b
Good to excellent,				
Long term illness limits activities	3862 (33.6)	927 (55.6)	2795 (29.5)	< 0.001 ^b
Stroke	436 (3.6)	125 (7.0)	285 (2.9)	< 0.001 ^b
Treated for urinary symptoms	816 (6.7)	301 (16.7)	488 (4.9)	< 0.001 ^b
Urge incontinence	1851 (15.3)	-	-	
Stress incontinence	2161 (17.8)	1236 (68.3)	892 (8.9)	< 0.001 ^b
Urgency	791 (6.4)	488 (26.9)	282 (2.8)	< 0.001 ^b
Frequency	1058 (8.7)	465 (25.6)	561 (5.6)	< 0.001 ^b
Anxiety	4803 (39.0)	1028 (56.6)	3629 (35.9)	< 0.001 ^b
Anxiety score (IQR)	7.0 (4.0-9.0)	8.0 (6.0-11.0)	6.0 (4.0-9.0)	< 0.001 ^a
Depression	2505 (20.3)	683 (37.6)	1725 (17.0)	< 0.001 ^b
Depression score (IQR)	4.0 (2.0-7.0)	6.0 (4.0-9.0)	4.0 (2.0-6.0)	< 0.001 ^a
Anxiety and depression	1924 (15.8)	554 (30.7)	1310 (13.0)	< 0.001 ^b

a = Mann-Whitney *U* test; b = Pearson Chi-square test; IQR = Inter-quartile range.

4.2.1 Influence of age on the prevalence of symptoms

The prevalence of symptoms of urge incontinence, anxiety and depression by age group are shown in Figure 4.0. The pattern of prevalence with age was different for each of the symptoms: urge incontinence increased with age; depression increased with age from 60 years onwards; and anxiety decreased with age until 60 years onwards when it becomes stable. Whereas, the percentage of women reporting urge incontinence almost trebled from 40 to 80+ years (10.6 to 28.6 per cent), and depression nearly doubled (19.8 to 36.6 per cent), changes in prevalence of anxiety were less dramatic, though it started high (45.6 per cent), it declined with age until 60 years onwards, where it stabilises between 34.0 and 36.1 per cent.

Figure 4.0 Prevalence of symptoms of urge incontinence, anxiety and depression by age group

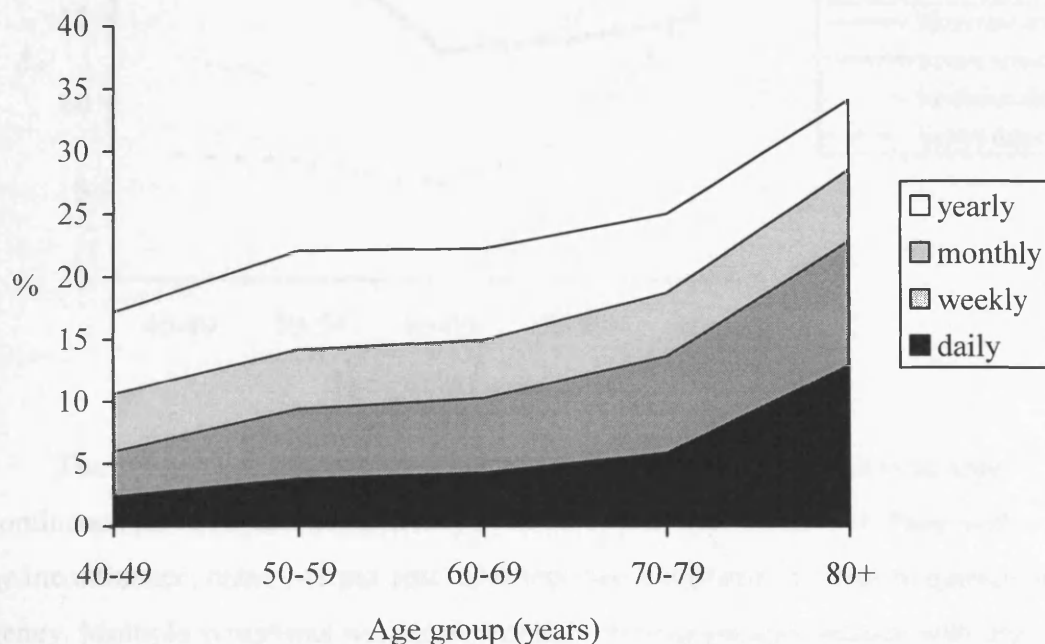


	40-49y	50-59y	60-69y	70-79y	80+y	Total
Anxiety	45.6	39.7	34.0	35.3	36.1	39.0
Depression	19.8	17.9	16.4	22.8	36.6	20.3
Urge incontinence	10.6	14.3	15.1	18.9	28.6	15.3

Figure 4.1 provides more detailed information on the prevalence of different severities of urge incontinence by age group. The prevalence of severe urge incontinence (i.e. daily or weekly) increased with age. For example, only 2 per cent of 40-49 year old women reported urge incontinence occurring several times a day,

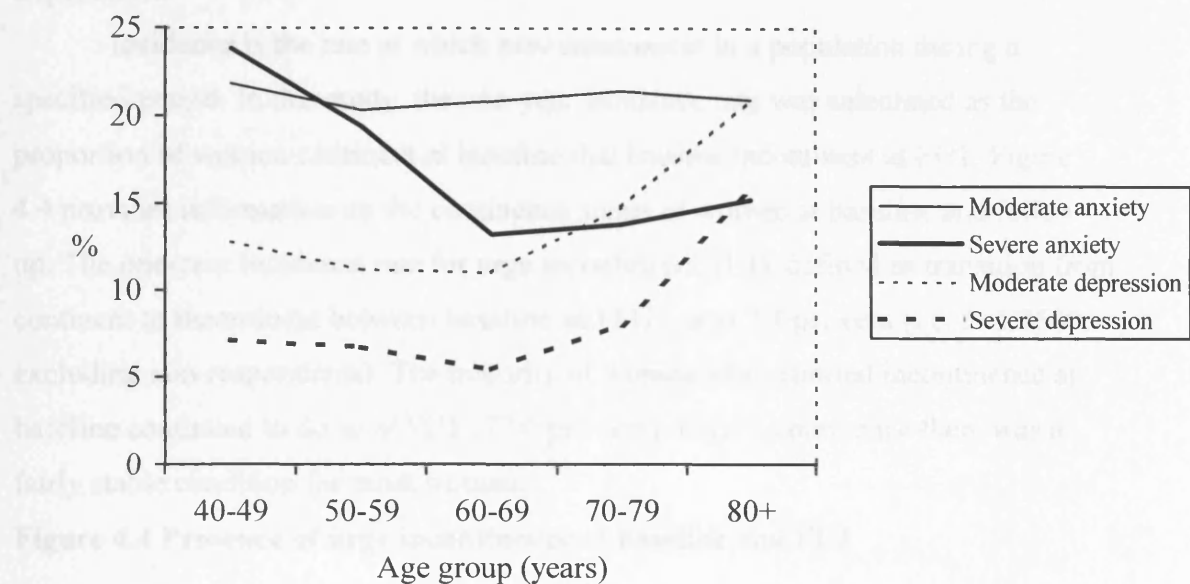
compared with 13 per cent of women aged 80 years or more. The prevalence of milder forms of incontinence (i.e. several times a month/year) did not differ greatly with age.

Figure 4.1 Prevalence of different severities of urge incontinence by age group.



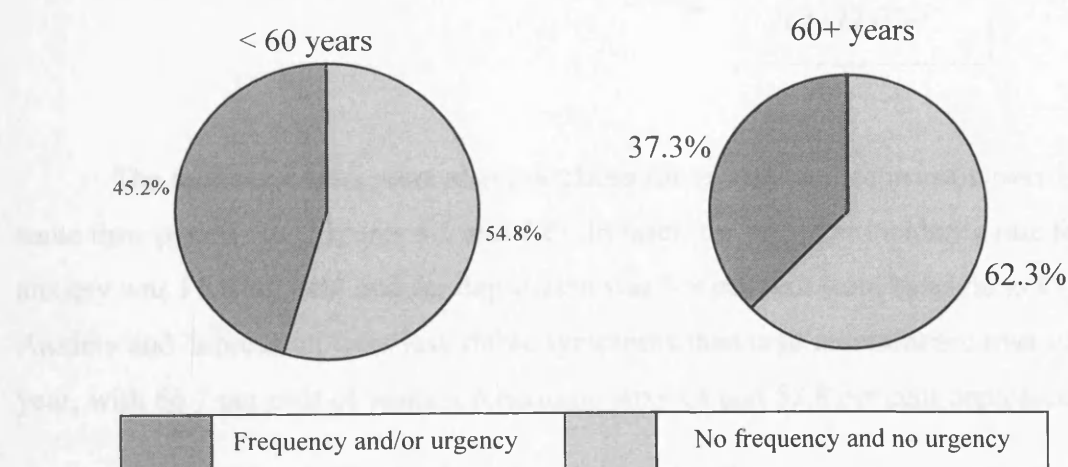
The prevalence of moderate and severe forms of anxiety and depression with age were also investigated (see Figure 4.2). Women scoring more than 7 but less than 11 were categorised as having moderate anxiety/depression and those scoring 11 or more as having severe anxiety/depression. Both moderate and severe depression tended to increase with age, from the age of 60 years onwards. The pattern is very different for anxiety, with severe anxiety decreasing dramatically with age from 40 to 70 years, but the prevalence of moderate anxiety remained fairly constant across the age groups. Urge incontinence and depression, then, followed similar patterns of prevalence and severity with age, with the oldest age groups reported the highest and severest prevalence figures. Anxiety in contrast, is most common and severe in younger women, although the prevalence of moderate anxiety does not differ greatly with age.

Figure 4.2. Prevalence of anxiety and depression by severity and age.



The presence of other urinary symptoms, commonly associated with urge incontinence (i.e. overactive bladder syndrome) was also examined. Of those with urge incontinence, many (41 per cent) also reported symptoms of either frequency or urgency. Multiple symptoms were more common among younger women with urge incontinence (<60 years) than older women (60+ years) ($\chi^2=10.0$, $p<0.002$) (see Figure 4.3).

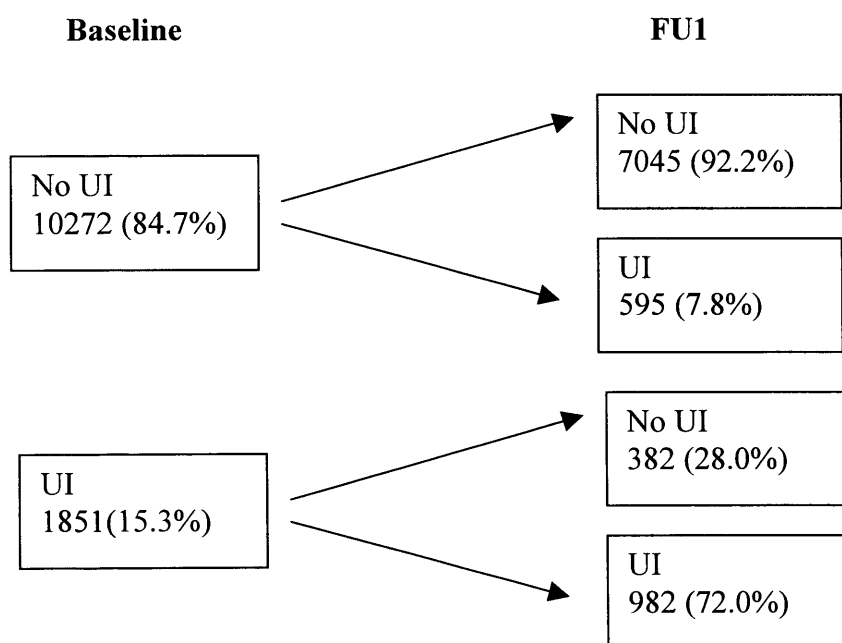
Figure 4.3 Proportions of women with urge incontinence reporting frequency or urgency



4.2.2 One-year incidence rates of symptoms of urge incontinence, anxiety and depression.

Incidence is the rate at which new cases occur in a population during a specified period. In this study, the one-year incidence rate was calculated as the proportion of women continent at baseline that became incontinent at FU1. Figure 4.4 provides information on the continence status of women at baseline and follow-up. The one-year incidence rate for urge incontinence (UI), defined as transition from continent to incontinent between baseline and FU1, was 7.8 per cent (i.e. 595/7640, excluding non-respondents). The majority of women who reported incontinence at baseline continued to do so at FU1 (72.0 per cent). Urge incontinence then, was a fairly stable condition for most women.

Figure 4.4 Presence of urge incontinence at baseline and FU1



The incidence rates were also calculated for anxiety and depression over the same time period (see Figures 4.5 and 4.6). In brief, the one-year incidence rate for anxiety was 11.9 per cent and for depression was 5.9 per cent from baseline to FU1. Anxiety and depression were less stable symptoms than urge incontinence over one year, with 66.7 per cent of women remaining anxious and 55.8 per cent depressed.

Figure 4.5 Presence of anxiety at baseline and FU1

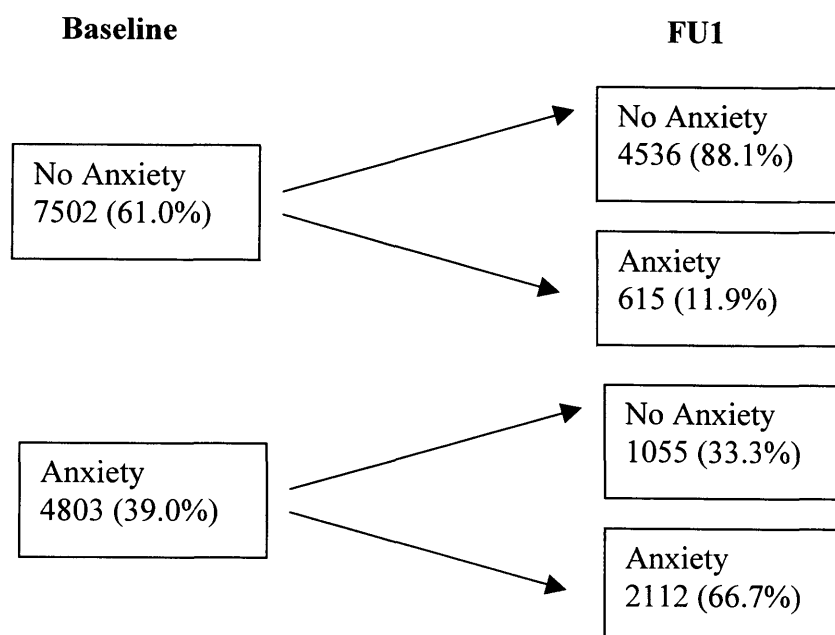
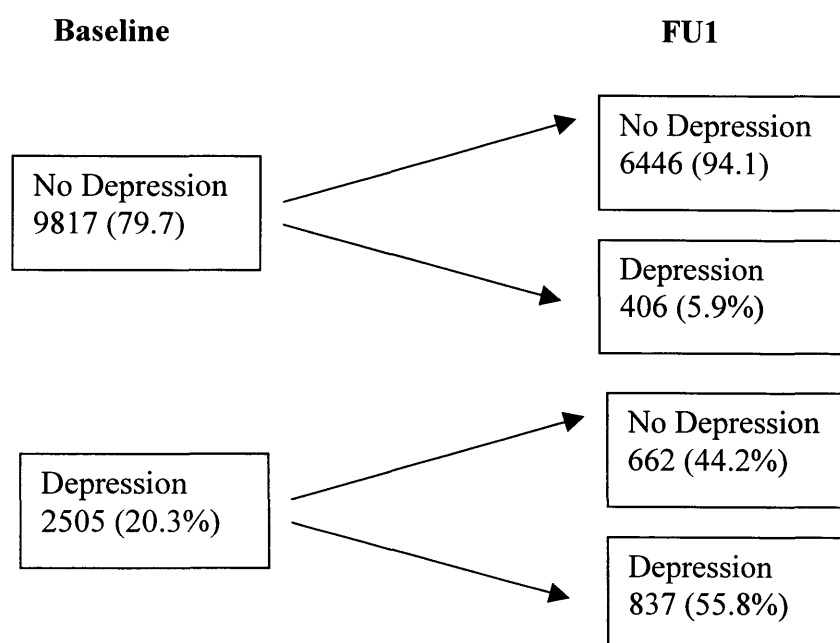


Figure 4.6 Presence of depression at baseline and FU1



4.2.3 Summary of characteristics of the baseline sample

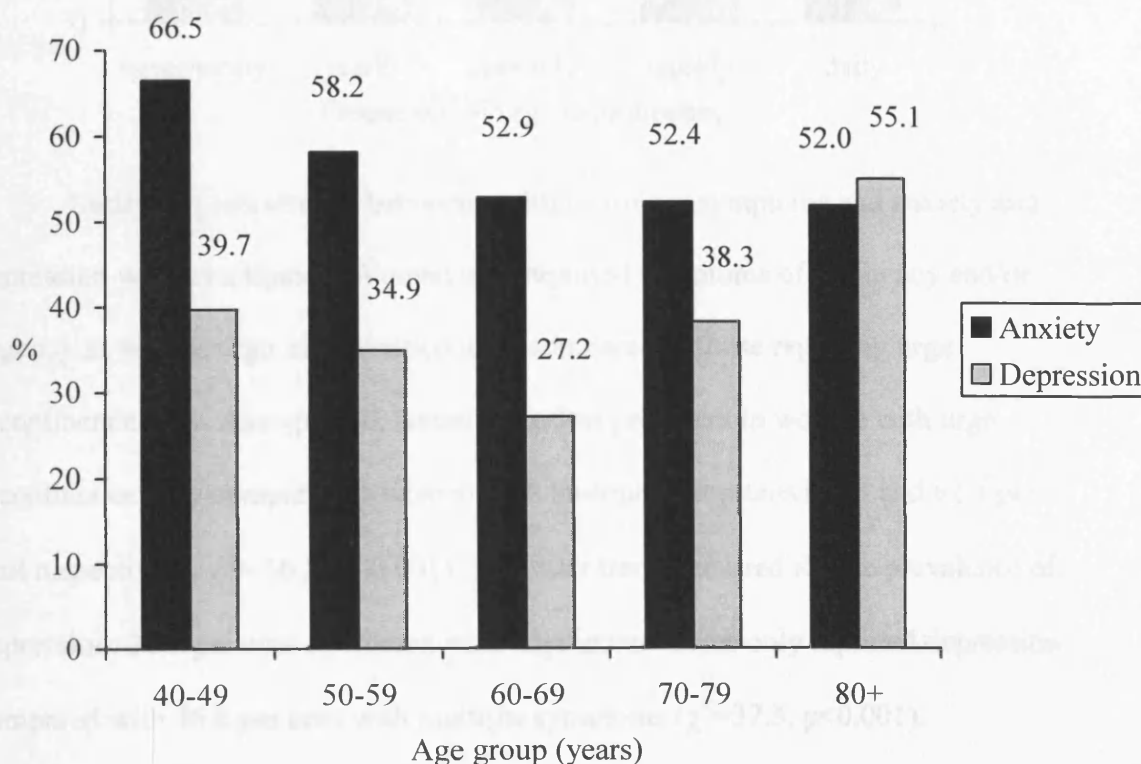
Urge incontinence, anxiety and depression were fairly common symptoms in women aged 40 years or more, reported by 15.3, 39.0 and 20.3 per cent of the sample respectively. Whereas, urge incontinence and depression tended to become more prevalent with age, anxiety was most prevalent in the youngest age groups (40s and 50s). Indeed the distribution of urge incontinence with age was more complicated than anticipated. Urge incontinence tended to be less severe in younger women, but it

was more likely to be accompanied by other symptoms, such as frequency and urgency. Analysis of the longitudinal data demonstrated that the one-year incidence rates of urge incontinence, anxiety and depression were 7.8, 11.9 and 5.9 per cent respectively.

4.3.0 What is the prevalence of anxiety and depression among women with urge incontinence?

The first stage of the analyses focused on patterns of distribution of anxiety and depression among women with urge incontinence. Figure 4.7 details the prevalence of anxiety and depression across different age groups. The majority of women with urge incontinence reported anxiety (57 per cent): two thirds of those in the youngest age group and just over a half in the oldest group. Fewer women reported depression (38 per cent): just over a third in the youngest age groups and over one half in the oldest age group.

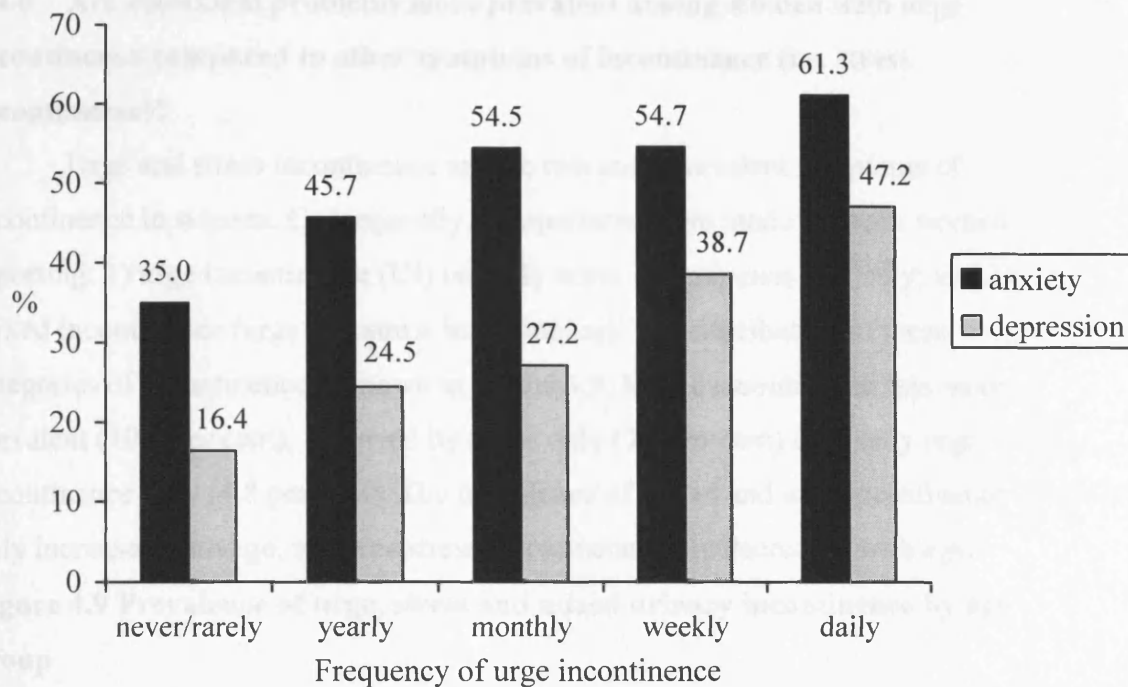
Figure 4.7 Prevalence of anxiety and depression among women with urge incontinence.



The prevalence of anxiety and depression also increased with severity of urge incontinence ($\chi^2 = 321.1$, $p < 0.001$) (see Figure 4.8). When urge incontinence occurred several times a month or more often, the majority reported anxiety.

Increases in the severity of incontinence, from several times a month, week to day, corresponded with increases in depression of about 10 per cent.

Figure 4.8 Prevalence of anxiety and depression by the severity of urge incontinence.



Lastly, the association between multiple urinary symptoms and anxiety and depression was investigated. Women who reported symptoms of frequency and/or urgency as well as urge incontinence were compared to those reporting urge incontinence only. As expected, anxiety was less prevalent in women with urge incontinence only compared to women with multiple symptoms (52.4 and 62.2 per cent respectively, $\chi^2=16.5$, $p<0.001$). A similar trend occurred for the prevalence of depression: 31.7 per cent of women with urge incontinence only reported depression compared with 46.0 per cent with multiple symptoms ($\chi^2=37.3$, $p<0.001$).

4.3.1. Summary of the distribution of symptoms of anxiety and depression among women with urge incontinence

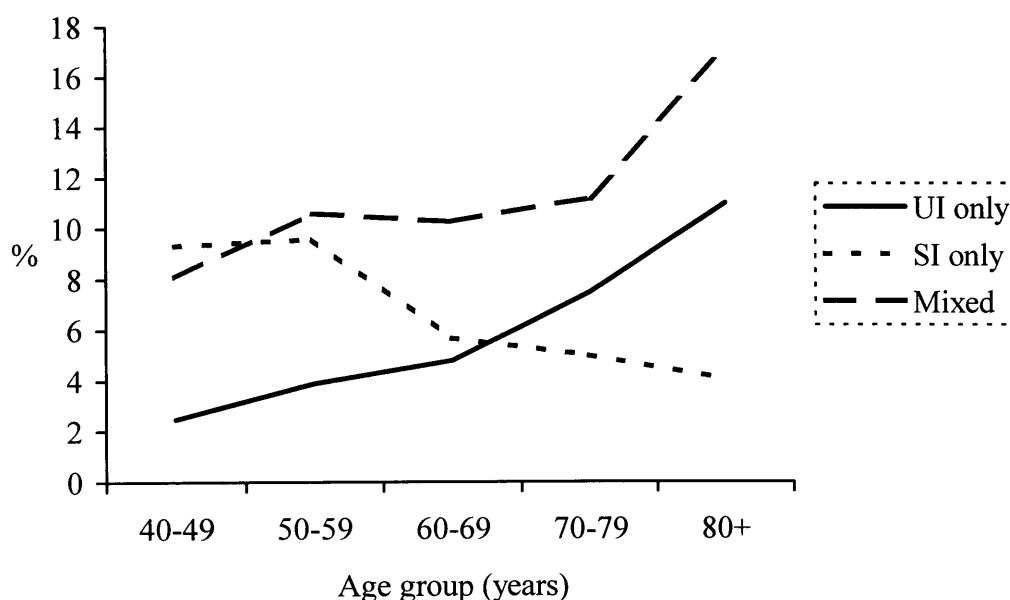
Anxiety was reported by more than one half of women, 56.6 per cent, with urge incontinence: in particular, younger women, those with more severe

incontinence and those with multiple urinary symptoms. Depression was reported by the minority or women, 37.6 per cent, with urge incontinence, and was more common in the oldest age group. Depression was also positively associated with the severity of incontinence and multiple symptoms.

4.4.0 Are emotional problems more prevalent among women with urge incontinence compared to other symptoms of incontinence (i.e. stress incontinence)?

Urge and stress incontinence are the two most prevalent symptoms of incontinence in women. Consequently, comparisons were made between women reporting: 1) urge incontinence (UI) only; 2) stress incontinence (SI) only; and 3) mixed incontinence (urge and stress incontinence). The distribution of these categories of incontinence is shown in Figure 4.9. Mixed incontinence was more prevalent (10.4 per cent), followed by stress only (7.5 per cent) and lastly urge incontinence only (4.8 per cent). The prevalence of mixed and urge incontinence only increased with age, whereas stress incontinence only decreased with age.

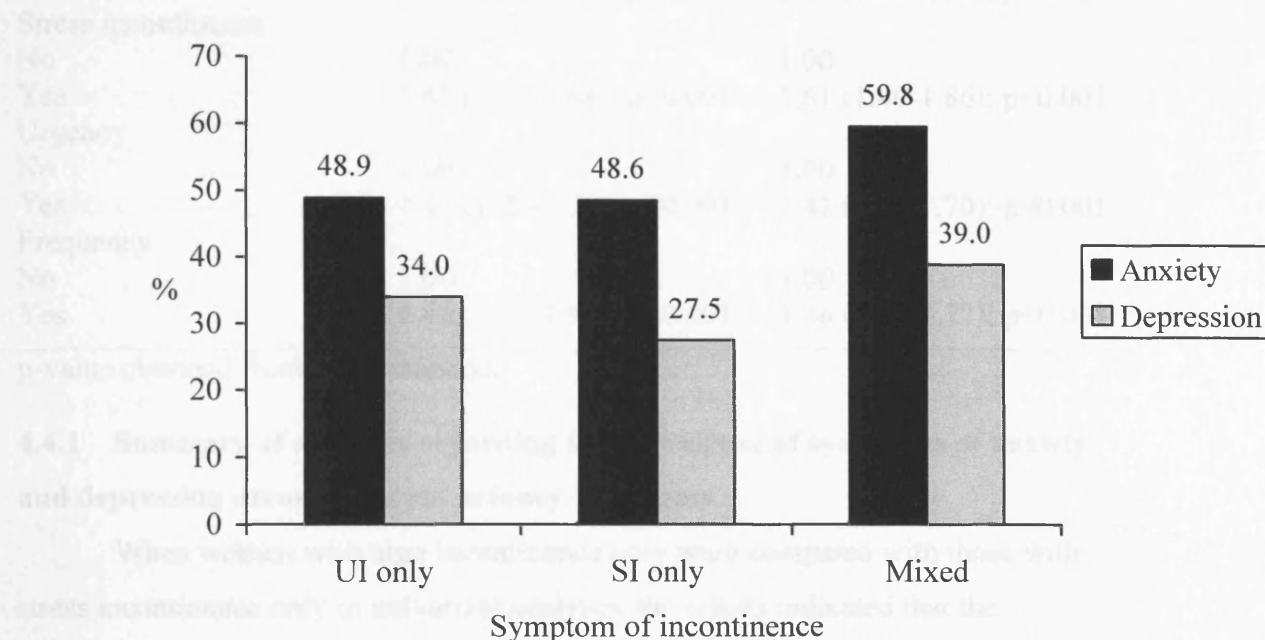
Figure 4.9 Prevalence of urge, stress and mixed urinary incontinence by age group



	40-49y	50-59y	60-69y	70-79y	80+y	Total
UI only	2.5	3.9	4.8	7.5	11.0	4.8
SI only	9.3	9.6	5.7	5.0	4.1	7.5
Mixed	8.1	10.6	10.3	11.2	17.1	10.4
Total	19.8	24.1	20.9	23.7	32.3	22.7

The baseline data was used to assess the prevalence of anxiety and depression across these symptoms of incontinence (see Figure 4.10). The prevalence of anxiety was similar for women with either urge or stress incontinence only, but higher for those with mixed ($\chi^2=32.1$, $p<0.001$). The prevalence of depression was lowest for women with stress incontinence, and highest for those with mixed ($\chi^2=29.9$, $p<0.001$). Women with urge incontinence only were significantly more likely to be depressed than women with stress incontinence only ($\chi^2=6.8$, $p=0.009$).

Figure 4.10 Prevalence of anxiety and depression by symptom of incontinence



Multiple logistic regression analyses were carried out to ascertain the contribution of different urinary symptoms, age and limiting long-term illness in predicting symptoms of anxiety and depression (see Table 4.1). The analyses demonstrated that each of these variables was significantly associated with anxiety and depression, when the remainder variables were adjusted for. For example, women with a long-term illness were three times as likely to report depression than those with no long-term illness (OR 3.42; 95 per cent confidence interval 3.06 – 3.81). Anxiety and depression were not specifically associated with urge incontinence. Indeed they were not specific to incontinence, as the inclusion of frequency and urgency in the model demonstrated.

Table 4.1 Multivariate logistic regression exploring the association between urinary symptoms and anxiety and depression in baseline data

	Odds ratio (95% confidence interval)	
	Anxiety (N=10546)	Depression (N=10556)
Age (increase in 1 year)	0.98 (0.97-0.98); p<0.001	1.00 (0.99-1.00); p=0.762
Long-term illness		
No	1.00	1.00
Yes	2.04 (1.86-2.24); p<0.001	3.42 (3.06-3.81); p<0.001
Urge incontinence		
No	1.00	1.00
Yes	1.42 (1.23-1.63); p<0.001	1.44 (1.23-1.69); p<0.001
Stress incontinence		
No	1.00	1.00
Yes	1.45 (1.28-1.64); p<0.001	1.61 (1.40-1.86); p<0.001
Urgency		
No	1.00	1.00
Yes	1.45 (1.21-1.73); p<0.001	1.41 (1.16-1.70); p<0.001
Frequency		
No	1.00	1.00
Yes	1.43 (1.23-1.66); p<0.001	1.46 (1.23-1.72); p<0.001

p-value obtained from Wald statistic.

4.4.1 Summary of analyses regarding the prevalence of symptoms of anxiety and depression across different urinary symptoms.

When women with urge incontinence only were compared with those with stress incontinence only in univariate analyses, the results indicated that the prevalence of anxiety was similar across these two groups (approximately 49 per cent). The prevalence of depression was significantly higher among women with UI only (34.0 per cent) compared with those with stress incontinence (27.5 per cent). When multivariate analyses were carried out to adjust for possible confounding variables, such as age and long-term illness, it was found that all the urinary symptoms entered into the model were significantly associated with anxiety and depression. These emotional factors, then, were not specific to women with urge incontinence.

4.5.0 How do emotional factors and urge incontinence interact and influence the development and progression of these symptoms?

In order to address this question, one-year incident cases of urge incontinence, anxiety and depression were related to baseline characteristics. Thus the dependent variables in the separate analyses were incident (new) cases of anxiety, depression or urge incontinence at FU1 and the independent variables were baseline

characteristics (i.e. age, long-term illness, frequency, urgency and stress incontinence).

Previous analyses indicated that age, long-term illness, stress incontinence, frequency, urgency, and urge incontinence were associated with anxiety and depression. These factors, as reported at baseline, were entered into a multivariate logistic regression model to assess whether they predicted incident cases of anxiety and depression at FU1. Table 4.2 shows only those variables that were significantly able to predict the incidence of anxiety and depression. Incident cases of anxiety were significantly predicted by decrease in age, long-term illness, urge incontinence, frequency and depression, but not stress incontinence or urgency. Incident cases of depression were significantly predicted by long-term illness, urge incontinence, frequency and anxiety, but not age, urgency or stress incontinence.

Table 4.2 Multivariate logistic regression model exploring factors that predict incident cases of anxiety and depression

	Odds ratio (95% confidence interval)	
	Anxiety (N=4607)	Depression (N=6126)
Age (increase in 1 year)	0.98 (0.97 – 0.99); p<0.001	
Long-term illness		
No	1.00	1.00
Yes	1.42 (1.15 – 1.75); p<0.001	2.71 (2.18 – 3.40); p<0.001
Urge incontinence		
No	1.00	1.00
Yes	1.52 (1.17 – 1.98); p=0.002	1.56 (1.18 – 2.06); p=0.002
Frequency		
No	1.00	1.00
Yes	1.58 (1.13 – 2.20); p=0.007	1.58 (1.12 – 2.24); p=0.01
Anxiety		
No	-	1.00
Yes		3.13 (2.50 – 3.91); p<0.001
Depression		
No	1.00	-
Yes	2.22 (1.63 – 3.04); p<0.001	
p-value obtained from Wald statistic		

Similar analyses were carried out to assess which variables at baseline predicted incident cases of urge incontinence at FU1. Thus, increasing age, long-term illness, stress incontinence, urgency, frequency and anxiety predicted incident cases of urge incontinence. There was no significant association with depression.

Table 4.3 Multivariate logistic regression model exploring factors that predict incident cases of urge incontinence

	Odds ration (95% confidence interval)
	Incidence of UI (N = 6788)
Age (increase in 1 year)	1.02 (1.01 - 1.03); p<0.001
Long-term illness	
No	1.00
Yes	1.47 (1.20 – 1.79); p<0.001
Stress incontinence	
No	1.00
Yes	3.91 (3.11 – 4.93); p<0.001
Urgency	
No	1.00
Yes	2.91 (1.97 – 4.29); p<0.001
Frequency	
No	1.00
Yes	1.95 (1.42 – 2.68); p<0.001
Anxiety	
No	1.00
Yes	1.36 (1.12 – 1.64); p=0.002

p-value obtained from Wald statistic

4.5.1 Summary of causal pathways between anxiety, depression and urge incontinence

These results indicated that anxiety was both a risk factor and a consequence of urge incontinence. Depression appeared to be a consequence of urge incontinence only. Interestingly, urge incontinence and frequency were significant predictors of anxiety and depression, but stress incontinence was not.

4.6.0 Further exploration of the association between anxiety, urge incontinence and frequency

Further analyses were carried out to examine more closely the relationship between symptoms of anxiety, urge incontinence and frequency, as these three variables appeared to be particularly interrelated. More detailed analyses were carried out to assess whether the severities of anxiety, urge incontinence and frequency were positively associated with each other (see Figures 4.11 and 4.12). In other words, were women with severe anxiety also likely to report severe urinary symptoms?

Figure 4.11 Association between anxiety score and severity of urge incontinence

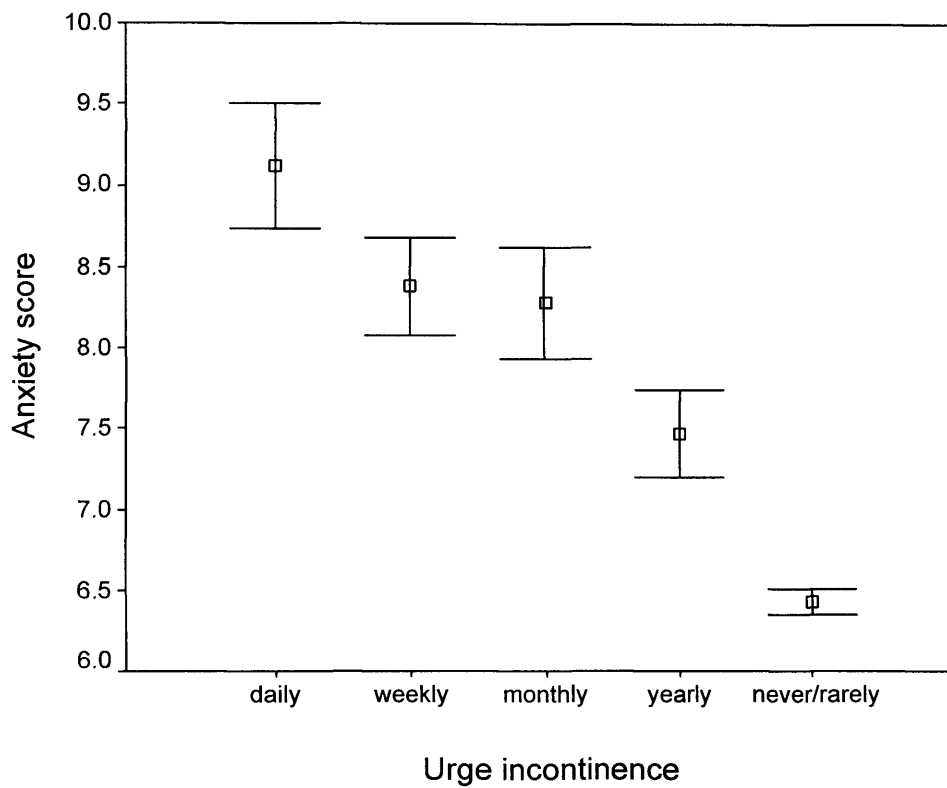
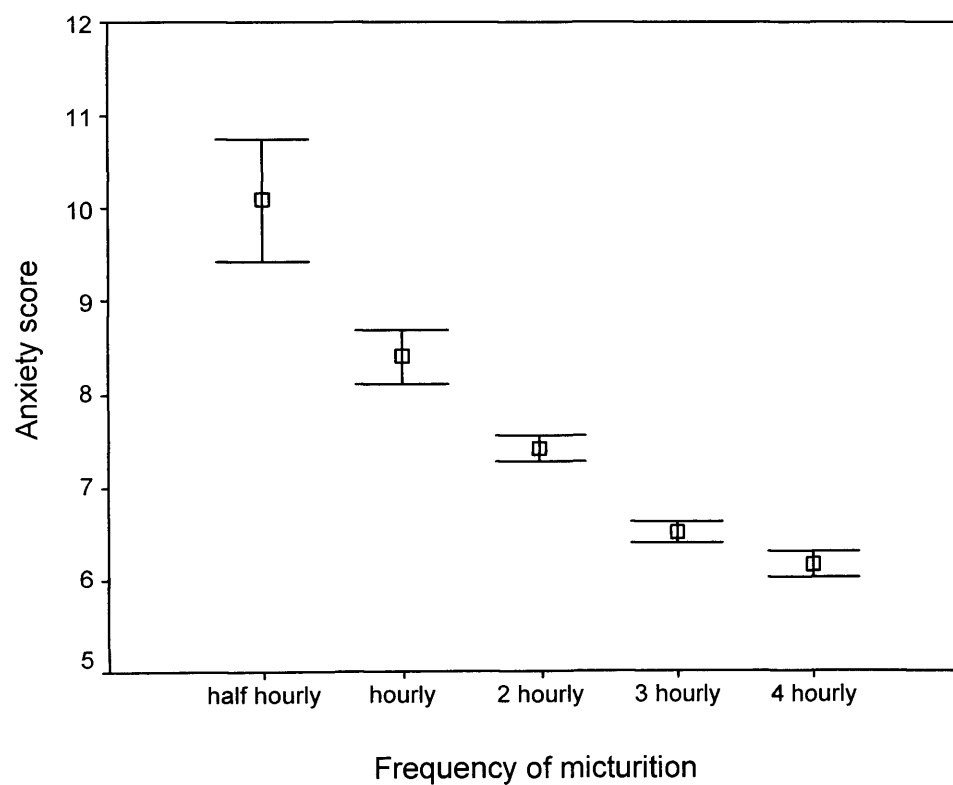


Figure 4.12 Association between anxiety score and severity of frequency

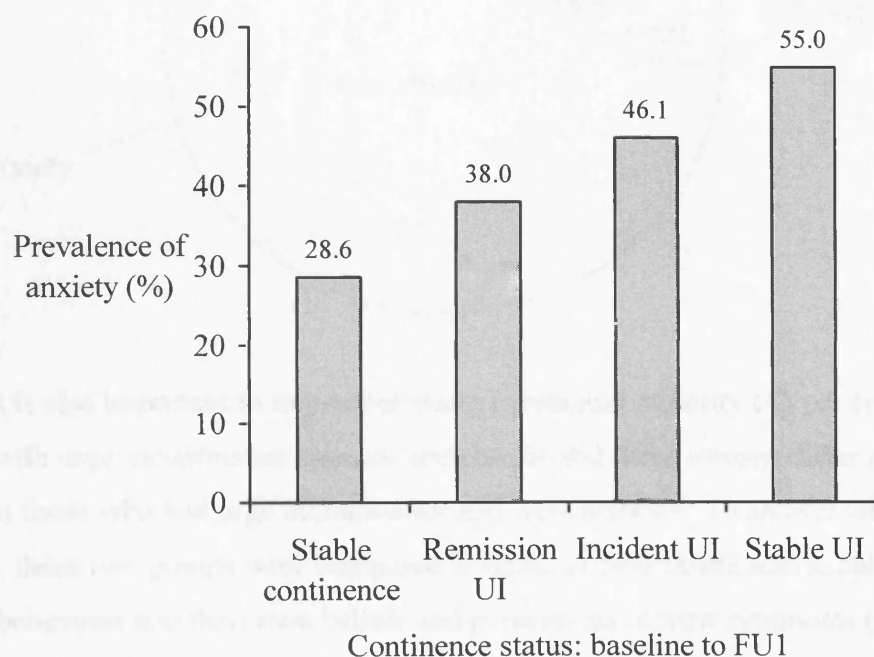


In Figures 4.11 and 4.12 the mean anxiety score, with 95 per cent confidence intervals, is plotted against the severity of urge incontinence and frequency. It is

interesting to note that case definition for urge incontinence (i.e. leakage several times a month or more often) and frequency (i.e. going to the toilet every hour or more often) coincides with case definition for anxiety (score > 7).

It was also predicted that the stability of urge incontinence would be related to the prevalence of anxiety. In this case baseline and FU1 data were compared in order to categorise women as having either: 1) stable incontinence; 2) incident incontinence; 3) remission of incontinence (i.e. transition from incontinent to continent); or 4) stable continence. The level of anxiety reported at FU1 was examined across these groups (see Figure 4.13). The prevalence of anxiety was highest in those with stable urge incontinence, followed by incident cases of urge incontinence, then incontinence in remission and lowest in those with stable continence ($\chi^2=286.7$, $p<0.001$). A similar pattern was found regarding the stability of frequency and the prevalence of anxiety ($\chi^2=188.8$, $p<0.001$).

Figure 4.13 Prevalence of anxiety by the stability of urge incontinence

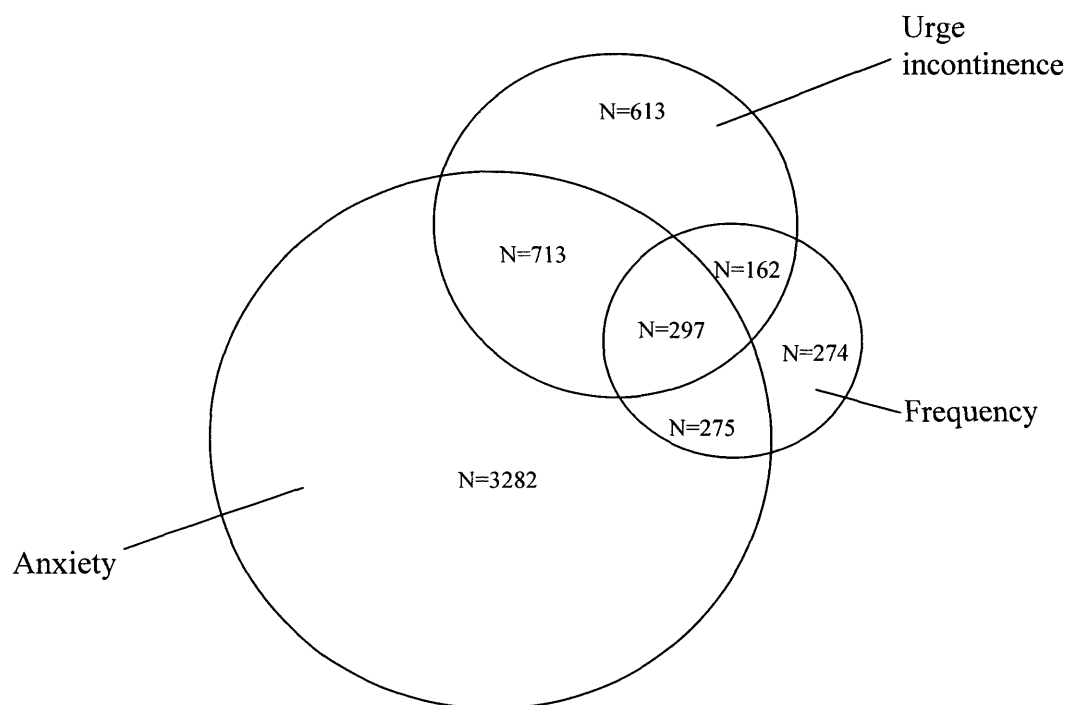


The prevalence of anxiety was similar among women with frequency only or urge incontinence only (50.1 and 53.8 per cent respectively) and much higher in those with both symptoms (64.7 per cent).

The reporting of urge incontinence, frequency and anxiety in the sample surveyed is shown in Figure 4.14. Anxiety was approximately 2.5 times more prevalent than urge incontinence and 4.5 times more prevalent than frequency. Consequently, the majority of women with anxiety (72 per cent) did not report

urinary symptoms. Symptoms of anxiety, however, were typical for women with urge incontinence or frequency (reported by 57 per cent). Although women reporting both urge incontinence and frequency were particularly vulnerable to anxiety, the number of women represented in this group was much smaller (N = 297; 4 per cent of the sample) than the numbers reporting either symptom with anxiety (N= 988; 13 per cent of the sample).

Figure 4.14 Presentation of anxiety, urge incontinence and frequency in the sample surveyed



It is also important to remember that a substantial minority (43 per cent) of women with urge incontinence was not anxious. So did these women differ in any way from those who had urge incontinence and were anxious? To answer this question, these two groups were compared in terms of their health status, help-seeking behaviour and their own beliefs and perceptions of their symptoms (see Table 4.4).

Table 4.4 Comparisons between women with urge incontinence and anxiety and those with urge incontinence but no anxiety.

Characteristic	Urge incontinence with anxiety N=1028 (%)	Urge incontinence and no anxiety N=788 (%)	p-value
Age – years (IQR)	60 (50-73)	65 (54-75)	< 0.001
Long-term illness	551 (60.6)	364 (49.6)	< 0.001
Stroke	75 (7.6)	47 (6.2)	0.26
Diabetes	73 (8.9)	57 (8.4)	0.72
Dementia	15 (1.9)	5 (0.8)	0.07
Multiple sclerosis	11 (1.4)	16 (2.4)	0.15
Cystitis	320 (32.4)	175 (22.8)	< 0.001
Taking diuretics	237 (24.1)	186 (24.4)	0.88
Urinary symptoms rated a severe problem	85 (8.6)	29 (3.8)	< 0.001
Urinary symptoms affect quality of life a lot	120 (13.4)	38 (5.4)	< 0.001
Relatives have urinary symptoms	226 (22.5)	148 (19.1)	0.05
Feel need help for urinary symptoms	163 (16.6)	94 (12.2)	< 0.001
Spoken to GP about urinary symptoms	249 (24.2)	174 (22.1)	0.28
Spoken to nurse about urinary symptoms	100 (9.7)	79 (10.0)	0.83
Received treatment	164 (16.4)	133 (17.2)	0.01

There were some significant differences between these two groups. Thus, women with urge incontinence who were anxious were younger and more likely to report a long-term illness that limits their activities, but there were no significant difference between the two groups in terms of illnesses and drugs that are recognised risk factors for urge incontinence (e.g. stroke, diabetes, dementia, multiple sclerosis and diuretics). However, cystitis was more prevalent among women with urge incontinence and anxiety compared with those with no anxiety.

For women in both groups only a small number perceived their symptoms to be a problem to them. Nevertheless, there were some interesting differences: women with urge incontinence who were anxious were more likely to perceive their urinary symptoms to be a severe problem and having a lot of impact on their quality of life

than women who were not anxious. These women were also more likely to report a family history of problems with urinary symptoms and feel they needed help.

Despite these differences in perceptions, women who were anxious were no more likely to have spoken to a professional about their problem than those who were not anxious. There was some indication that professionals may treat these groups differently, as those with incontinence who were anxious were slightly less likely to have received treatment than those who were not anxious (16.4 % and 17.2% respectively).

4.7.0 Summary

This chapter addressed each of the research questions in order to better understand the relationship between anxiety and depression and urge incontinence. Descriptive and univariate statistics provided useful information on the distribution of symptoms across different groups. Multivariate models enabled further exploration of these associations and temporal relationships, whilst adjusting for other significant variables. Anxiety and depression were both significantly associated with urge incontinence, though the association was not specific to this urinary symptom in the cross-sectional data. However, of the urinary symptoms entered into multivariate models to predict incident cases of anxiety and depression, only urge incontinence and frequency were significant.

Whereas depression appeared to be a response to urge incontinence, the relationship between anxiety and urge incontinence was more complicated. Thus, anxiety was widespread, its severity was related to the severity of incontinence and it appeared to be both a predictor and a consequence of urge incontinence and the presence of urinary frequency strengthened this association. Women with urge incontinence who were also anxious were more likely to perceive their urinary symptoms as a problem and in need of help, but they were less likely to receive treatment for their symptoms than those women with urge incontinence who reported they were not anxious.

The final chapter will relate these findings to the specific research hypotheses. It was proposed that symptoms of anxiety and depression have different causal relationships with urge incontinence. Thus, it was hypothesised that depression was a response to urge incontinence, in line with the quality of life evidence for Proposition 2, and anxiety interacted with and maintained symptoms of urge incontinence, in line with cognitive and behavioural models, which support

Proposition 3. The chapter will critically examine the extent to which it has been possible to answer the research hypotheses.

Chapter Five

Discussion

5.0.0 Introduction

This chapter will begin with a summary of the key findings and how these relate to the specific research hypotheses. Results from the study will also be compared and contrasted with the empirical evidence reviewed in the first two chapters. The methodological strengths and limitations of the study will be considered. A large part of the chapter will discuss the theoretical implications of the research findings. In particular, a psychological model of urge incontinence, which takes into account the roles of anxiety and depression, will be proposed. The relevance of these findings to clinical practice will be discussed in terms of assessment and treatment protocols. Suggestions will be made regarding the role of clinical psychology in the management of incontinence. The chapter will finish with recommendations for future research.

5.1.0 Relating the results to the research hypotheses

A summary of the main research findings in relation to the specific hypotheses is shown in Table 5.0. The first four hypotheses were based on cross-sectional baseline data and the last three on longitudinal follow-up data. Six out of the seven hypotheses were confirmed or partially confirmed.

The results chapter presented a detailed picture of the prevalence of anxiety and depression among women with urge incontinence. Hypothesis 1 was only partly supported. The majority (56.6 per cent) of women with urge incontinence reported symptoms of anxiety, and a minority (37.6%) reported depression. Anxiety was most common in the youngest age group (40-49 years of age), reported by 66.5 per cent, and depression in the oldest age group (80+ years), reported by 55.1 per cent.

There was also evidence to support Hypothesis 2. As predicted the prevalence of anxiety and depression was positively associated with the severity of urge incontinence and the reporting of other urinary symptoms (i.e. frequency and/or urgency) alongside urge incontinence.

Table 5.0 Summary of the research findings in relation to specific hypotheses

Hypothesis	Confirmed (✓) / Not confirmed (✗)	Research findings
❶ A minority of women with urge incontinence will report symptoms of anxiety and depression.	✗ (anxiety) ✓ (depression)	56.6% of women with urge incontinence (UI) reported anxiety and 37.6% reported depression
❷ Symptoms of anxiety and depression will be positively associated with the severity of urge incontinence and the presence of multiple urinary symptoms associated with urge incontinence.	✓	Anxiety was reported by 54% of women leaking several times a month to 61% leaking several times a day and depression ranged from 27% to 47%. 52% and 32% of women with UI only reported anxiety and depression respectively compared to 62% and 46% with multiple urinary symptoms.
❸ Symptoms of depression will be associated with many urinary symptoms and this association will be no stronger in urge incontinence than in other symptoms.	✓	Prevalence of depression was significantly higher among women with UI only (34.0%) compared with those with stress incontinence (SI) at 27%, but multivariate analyses demonstrated depression was associated with all urinary symptoms and not specific to UI.
❹ Symptoms of anxiety will be associated with many urinary symptoms, but the association will be strongest in urge incontinence.	✗	The prevalence of anxiety was similar among women with UI only and SI only at 49%. Multivariate analyses showed anxiety was associated with all urinary symptoms and not strongest for UI.
❺ Incident cases of depression will be predicted by symptoms of urge incontinence at baseline.	✓	Incident cases of depression were predicted by long-term illness, urge incontinence, frequency and anxiety, but not age, stress incontinence or urgency.
❻ Incident cases of anxiety will be predicted by symptoms of urge incontinence at baseline	✓	Incident cases of anxiety were predicted by decrease in age, long-term illness, urge incontinence, frequency and depression, but not stress incontinence or urgency.
❼ Incident cases of urge incontinence will be predicted by symptoms of anxiety, but not depression, at baseline	✓	Incident cases of urge incontinence were associated with increasing age, long-term illness, stress incontinence, urgency, frequency and anxiety, but not depression.

The prevalence of anxiety and depression was compared across three groups: women with urge incontinence only, stress incontinence only and women with mixed (i.e. urge and stress) incontinence. Univariate analyses indicated that anxiety and depression was significantly more prevalent in women with mixed incontinence. The prevalence of anxiety was similar among women with stress or urge incontinence only, but the prevalence of depression was significantly greater among women with urge incontinence only. When possible confounding variables (i.e. age, long-term illness and other urinary symptoms) were controlled for in a multivariate analysis, however, a different picture emerged. There was evidence to support Hypothesis 3, in that all the urinary symptoms entered in to the model were similarly associated with depression. Hypothesis 4 was not supported, as anxiety was not most strongly associated with urge incontinence compared with other urinary symptoms.

Analyses of the cross-sectional data revealed significant associations between urge incontinence, anxiety, depression, stress incontinence, urgency, frequency, age and long-term illness. The next step was to assess which of these variables predicted the emergence of incident cases of urge incontinence, anxiety and depression. Results from multivariate logistic regressions models provided support for Hypotheses 5, 6 and 7. Thus, urge incontinence was a significant predictor of incident cases of depression and anxiety, along with another urinary symptom, frequency. Additionally, anxiety was a predictor of incident cases of urge incontinence, but depression was not.

In Chapter Three a number of propositions were made regarding causal associations between urge incontinence and emotional factors (see Table 2.2). Results from this study supported propositions 2 and 3. Proposition 2 describes the association between urge incontinence and depression. There was evidence that urge incontinence predicted incident cases of depression, but depression did not predict incident cases of urge incontinence. Urge incontinence, then, had a significant impact on women's mental health in terms of feelings of depression. This proposition is in line with the quality of life and mental health literature reviewed in Chapter 2, Section 2.4.

Proposition 3 describes the association between urge incontinence and anxiety, whereby urge incontinence predicted incident cases of anxiety and vice versa. Additionally, severity levels of anxiety and urge incontinence were closely associated. It seems that anxiety, urge incontinence and frequency interact and

exacerbate each other. This proposition is in line with the behavioural and cognitive models of incontinence reviewed in Chapter 2, Sections 2.1 and 2.3.

The association between anxiety, urge incontinence and frequency was explored further. The severity and stability of urge incontinence and frequency were closely related to the severity of anxiety. Additionally, women with urge incontinence who were also anxious were more likely to perceive their urinary symptoms as problematic and feel in need of help than those who were not anxious. Although there was no significant difference between these two groups in terms of help-seeking behaviour, the former were less likely to receive treatment for their symptoms.

5.2.0 Interpretation of results and comparison with empirical evidence

These results have yielded some surprises and provided a more complete understanding of the association between emotional variables and urge incontinence in women. In this study 26 per cent of women reported urge incontinence in the last 12 months, which is similar to that found in many other community surveys (see Table 1.2, Chapter One). A smaller percentage (15 per cent) reported urge incontinence that occurred several times a month or more often. As in other studies, the prevalence of urge incontinence increased with age.

No other study has reported on one-year incidence rates for urge incontinence among women. This study found a one-year incidence rate of 8% among the sample. Herzog *et al.* (1990) reported a one-year incidence rate of 22 per cent, but their study dealt with any symptom of urinary incontinence at any level of severity among women aged 60 years or more. Nygaard and Lemke (1996) investigated urge incontinence specifically, reporting a much higher incidence rate (19 per cent). However, their study had a different time frame (follow-ups every three years), was based on an older sample (65 years or more) and referred to any severity of incontinence.

Despite these differences in methodology, all three studies found urge incontinence to be a fairly stable condition for most women from one year to the next. In this study 72 per cent of women incontinent at baseline were still incontinent at follow-up. Herzog *et al.* (1990) found that 89 per cent of women in their sample were still incontinent at a one-year follow-up and Nygaard and Lemke (1996) that 62 per cent were still incontinent at a three-year follow-up.

In this study, 39.0 per cent of women aged 40 years or more reported symptoms of anxiety and 20.3 per cent depression. These figures are slightly higher than that reported by Crawford *et al.* (2001), who also administered the HADS to a non-clinical sample (n=978) and reported prevalence of anxiety at 33.2 per cent and depression at 11.4 per cent among women. This difference may be partly explained by differences in sample characteristics, with their sample being younger (18 years or more) than this study's sample. Their sample was recruited from work, community and recreational centres, but is unclear how representative they are of the general population.

Spinhoven *et al.* (1997) used the HADS on random samples of patients on general practitioner lists and consecutive patient attending various clinics (n=6165) and reported a mean anxiety score of 5.1 and mean depression score of 3.4 for men and women aged 18 to 65 years (n=199). Again the equivalent scores for this study were slightly higher, with a mean anxiety score of 7.0 and 4.0 for depression (see Table 4.0). There is consistency across all three studies in that anxiety was found to be more prevalent than depression. However, it is important to point out that this study was based on a much larger sample size and the sample was representative of the population. It is likely, then, that the results from this study are more reliable than those already published. Only Mykletun *et al.* (2001) have used the HADS, in a Norwegian community survey, with a larger sample size (women: n= 33 070) than this study's sample. To date they have focused on the psychometric properties of HADS and concluded that it is a robust measure across a wide spectrum of sub-samples, with or without somatic symptoms.

This study demonstrated conclusively that symptoms of anxiety and depression were more prevalent among women with urge incontinence compared to those without this symptom. No previous study has reported on the prevalence of anxiety among women with urge incontinence specifically, so it is not possible to make comparisons with other studies. However, in a community study carried out by Vetter *et al* (1981) using a different measure of anxiety, 18 per cent of older adults (men and women aged 70+ years) with urinary incontinence were reported to be anxious. In this study more than 50 per cent of older women reported anxiety.

There is also limited opportunity to compare this study's findings regarding depression with other studies. Melville *et al* (2002) reported major depression in 3, 21 and 26 per cent of women with stress, urge or mixed incontinence respectively. In this study, 27, 34 and 39 per cent of women with stress, urge or mixed incontinence

reported depression. This study's prevalence figures followed a similar pattern across symptoms, but were much higher, probably due to a wider definition of depression.

Watson *et al* (2000) used the HADS in a study of women attending urodynamics in a urogynaecology clinic. They found that 57 per cent of these women reported anxiety, which is the same as that reported in this study, and 25 per cent depression, which is lower than this study. The figures from the urodynamic study, however, included women with different diagnoses (i.e. symptoms of stress, urge or mixed). It is impossible to make direct comparisons across studies, as there are major differences in the populations sampled and the measures of anxiety, depression and urge incontinence used.

Symptoms of anxiety and depression were very prevalent among women with urge incontinence. However, multivariate analyses confirmed that anxiety and depression were common to many urinary symptoms and not unique to urge incontinence. Additionally, the relative contribution of each urinary symptom to the occurrence of anxiety and depression was very similar. The suggestion, then, that urge incontinence, unlike other symptoms of incontinence, is a psychosomatic disorder (see Chapter 2, Section 2.2), was not supported. Disseminating this result will be extremely important, as there is a prevailing belief among some influential specialists in the field that emotional factors underpin the development of urge incontinence or detrusor instability:

The actual cause [of detrusor instability] is unknown, and in most women is idiopathic, possibly occurring as a sequel to poor bladder training in childhood or when the bladder escapes voluntary control in adult life. Emotional or other psychosomatic factors are often associated. (Cardozo, 1991, p.1454)

This belief is misplaced and it would be more accurate to reiterate the findings from this study. That is, symptoms of anxiety and depression were not specific to urge incontinence, but general to a number of urinary symptoms. However, anxiety may play an important contributory role in maintaining symptoms of urge incontinence and frequency.

A distinction is often made between sufficient and necessary causes and risk factors (Beaglehole *et al.*, 1993). A sufficient cause is an event, condition, characteristic or a combination of these factors that inevitably initiates or produces a disease, whereas a disease cannot develop in the absence of a necessary cause. Risk factors, on the other hand, are not sufficient or necessary to cause a disease. Instead, they indicate factors positively associated with the risk of developing a disease. For example, multiple sclerosis is a risk factor for incontinence, but the condition itself

does not inevitably result in incontinence. The modest likelihood ratios found in the multivariate analyses used to predict incident cases of anxiety and urge incontinence suggest that neither is a sufficient nor necessary causal factor for the other.

Nevertheless, women with urge incontinence and frequency are significantly at risk of developing anxiety and depression. Likewise, women with anxiety are significantly at risk of developing somatic symptoms, such as urinary symptoms. Most diseases are the result of many factors interacting with each other (e.g. biological, biographical, familial and environmental, standard of living and level of health care). Although, researchers and clinicians have become increasingly aware that health and illness are dependent on a whole host of systems working and interacting with each other at micro (e.g. cell) and macro (e.g. community) levels, it is appreciated that one does not need to tackle all the systems to alleviate distress. Attention to one factor (e.g. levels of anxiety or depression) can have repercussions on the whole system and lead to changes in health status (e.g. alleviation of urinary incontinence). The important point is, whether these changes to the system are enough of a difference to health status to improve a person's quality of life and whether these changes are long lasting.

The author does not wish to psychologise illness in the same way a doctor may somatize or a politician socialise it (Meikle, 2002). As yet, there is no good evidence available to support or refute interventions that attend to the emotional and cognitive characteristics of urge incontinence. Most interventions have focused entirely on the physical and behavioural aspects of this symptom. It may be beneficial to have a more integrated model of urge incontinence that investigates how each of these factors (physical, behavioural, cognitive and emotional) interact with each other and maintain incontinence.

5.3.0 Methodological strengths and limitations

There were three main strengths to this study which together made it unique in terms of the research that has been published to date: firstly, it was based on a community rather than clinic sample; secondly, it was longitudinal rather than cross-sectional in design; and thirdly, it differentiated between symptoms of incontinence and controlled for other urinary symptoms when examining the role of anxiety and depression.

Thus, problems with selection bias associated with clinical samples were overcome by surveying a random sample of women within a geographical region.

This was important, as there is strong evidence (see Chapter Two, Section 2.3) that only a minority of women with urinary incontinence seek help. The large sample size of the study and its prospective nature also enabled the author to observe the development of new symptoms, to identify factors associated with them and make confident statistical predictions. Lastly, attention was given to different urinary symptoms so that similarities and differences between symptoms could be properly explored. As a result of these features, this study has provided a more detailed and comprehensive understanding of the association between anxiety and depression and urge incontinence than any previous study.

Attention must also be given to some important shortcomings of the study, which relate to problems with selection and information bias and measurement error. In terms of selection bias, response rates to the postal survey were lower than anticipated at 65 per cent for the baseline sample, though it improved in the subsequent mailing to about 78 per cent. People who completed the postal questionnaire at baseline, then, were likely to participate in further mailings. Generally, though, the response rate to the postal survey was comparable to other large postal surveys on health using similar sampling procedures (Harrison et al., 1999).

The sensitive nature of many of the health questions in the questionnaire may have deterred some people from participating or they may have felt this survey was not applicable to them if they were in good health. Results from the non-responder study indicated that there was little evidence of non-response bias. However, response rates tended to be the lowest in the oldest age group (80+ years) and older non-responders were more likely to report urinary symptoms. It is likely, then, that prevalence rates are underestimated for the age group that is most vulnerable to health problems. Additionally, this study did not include people living in residential and nursing homes, where disability and ill-health are common.

Longitudinal studies have an additional problem with selection bias in that as the years pass the cohort decreases in size (i.e. deaths, migration, loss of interest in the study) and becomes increasingly selected. For example, 12,568 women completed that baseline postal questionnaire, compared with 9596 at FU1. There was evidence that those reporting anxiety and depression at baseline were less likely to participate in the follow-up mailing. This study is likely to err on the conservative side regarding estimates of the prevalence and incidence of urge incontinence,

anxiety and depression, as the most vulnerable drop out or are excluded from the study.

The ability to classify participants as cases or non-cases accurately is dependent on the quality of measurements used. The measures used in this study were known to have good validity and reliability. It must be reiterated that this study measured symptoms of urge incontinence, anxiety and depression rather than clinically diagnosed conditions (e.g. detrusor instability or mood disorders). It is recognised that the HADS is a useful screening tool for anxiety and depressive states, rather than a case-identifier for psychiatric disorders (Spinhoven *et al.*, 1997). Thus, it was not possible to make more precise predictions about the association between urge incontinence and specific emotional disorders, such as anxiety, somatoform or compulsive-obsessive disorders. Similarly, it was not possible to investigate whether women with motor or sensory urge incontinence presented with different emotional profiles. It would have been useful to have followed up a small group of women with urge incontinence and a matched sample, in order to carry out a more detailed clinical assessment of their mental health and continence status. Unfortunately, this was not possible within the remit of this study.

The measures used focused on symptoms only, but their time frames were not entirely compatible. The HADS asked respondents to report on symptoms that occurred in the past week, whereas the urinary symptom questions asked respondents to report on symptoms that occurred in the past 12 months. It is likely that recall is less reliable when subjects are asked to report on the frequency of symptoms over a one-year period than they are for symptoms occurring in a one-week period. The urinary questions also addressed the relative stability of symptoms over one year, whereas the HADS focused on current status (i.e. past week) only.

Despite these differences case definition for incontinence, depended on symptoms occurring several times a month or more often. In other words, episodes of urge incontinence had to occur generally on a weekly basis or more often, which was a similar time frame for the HADS. As the weekly occurrence of symptoms was of particular interest it would have been much more informative to collect such information on a weekly or monthly basis, rather than annually, as in this study. Unfortunately, more frequent follow-ups would have required very motivated participants and been financially costly. Such an approach would be more appropriate for a smaller-scale and more in-depth study. In this way, weekly

fluctuations in urinary symptoms could be captured and compared to fluctuations in emotional symptoms along with time delays in the presentation of symptoms.

The strengths of the study, however, outweigh the limitations. The results from this study provide good quality evidence regarding the associations between emotional variables and urge incontinence and whether these are unique to this urinary symptom.

5.4.0 Theoretical implications

Much attention has been given to the biological basis of urge incontinence (i.e. bladder physiology and function) and the impact of incontinence on an individual's quality of life. Less attention has been given to how psychological factors may maintain or exacerbate symptoms or impede interventions that require highly motivated clients. Conservative interventions have tended to be based on behavioural models that focus on symptom elimination and changing toilet behaviours. Such an approach is crucial in helping women with incontinence, but its benefits may be limited if attention is also not given to the cognitive and emotional aspects of the symptom and the context against which incontinence occurs, within and outside the health system.

Figures 5.0 and 5.1 illustrate a provisional psychological model of both continence and incontinence, which attempts to integrate the behavioural, cognitive, emotional and social aspects of this bodily function. The top two thirds of the diagram incorporates a cognitive behaviour therapy formulation of anxiety disorders, and includes the distinctive 'vicious circle' (Wells, 1997). Within this model, cognitions (i.e. interpretations, beliefs and schemas) are involved in the aetiology and maintenance of disorders, and safety behaviours exacerbate such cycles. Thus, in the vicious circle of urge incontinence (see Figure 5.1), dysfunctional schemas or beliefs occur at two points: firstly in terms of appraisals of threat in response to a specific situation or trigger; and secondly, in terms of misinterpreting bodily symptoms. An overestimation of the danger associated with a situation or symptom and an underestimation of one's ability to cope with such events result in anxiety and somatic symptoms. The cycles of continence and incontinence represent a continuum, but the former is based on fairly flexible and realistic interpretations and the latter on rigid and dysfunctional beliefs with catastrophic outcomes.

Figure 5.0 Provisional psychological model of adult continence

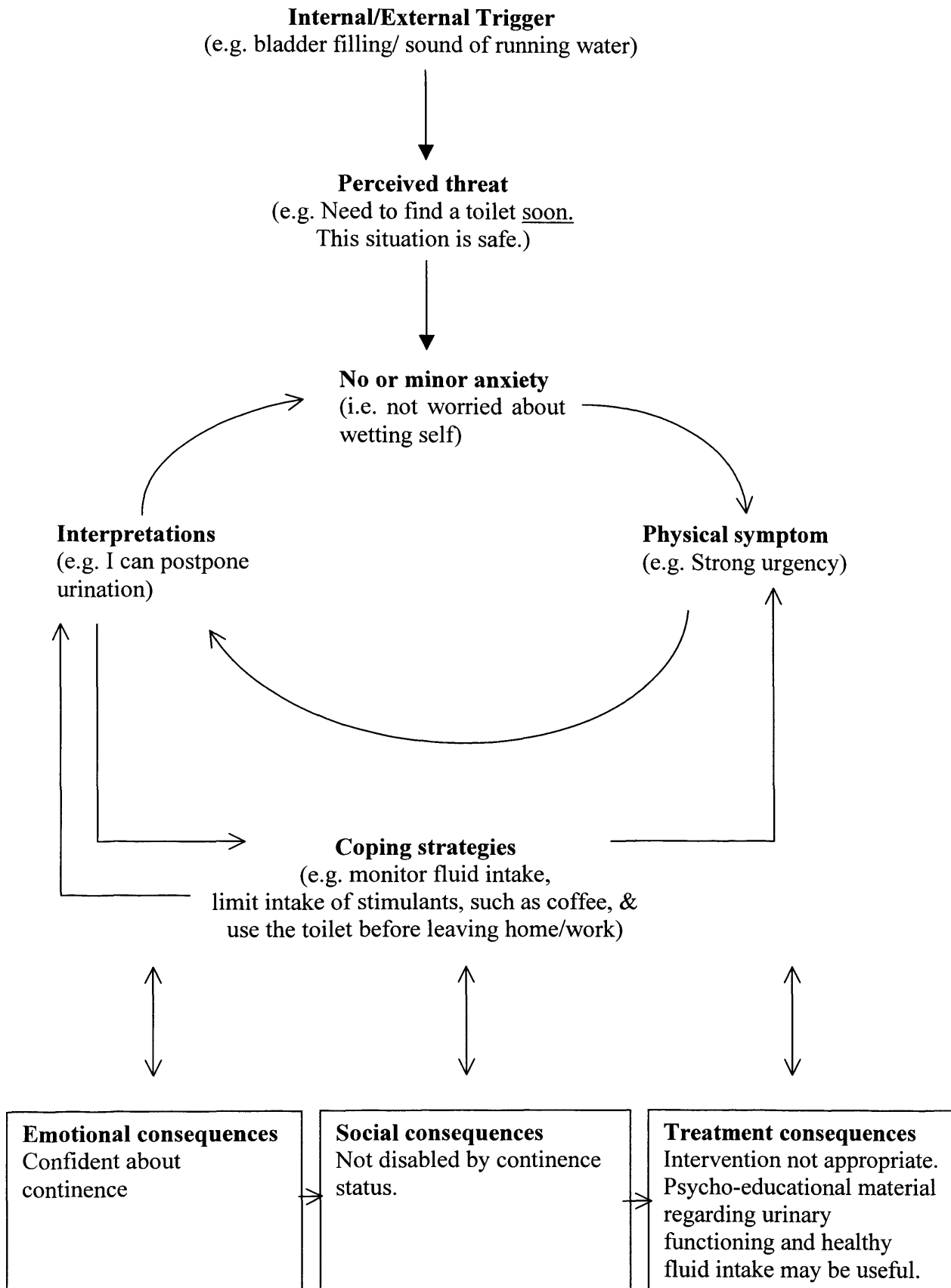
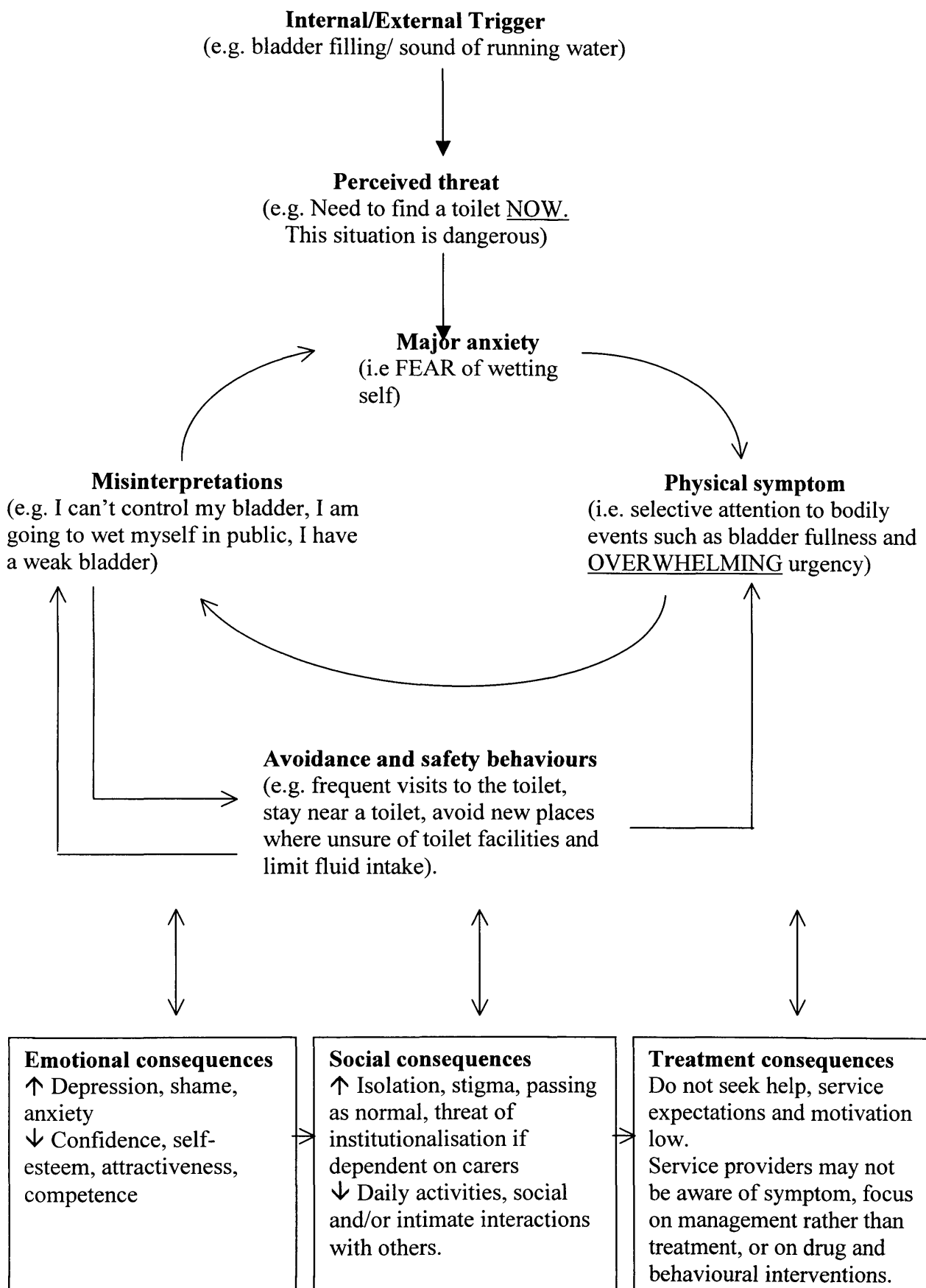


Figure 5.1 Provisional psychological model of urge incontinence



The bottom sections of these two diagrams, representing the emotional, social and health service consequences of such anxiety cycles, is more systemic in orientation. It illustrates the repercussions of anxiety cycles on other systems both internal (i.e. how a woman may feel about herself and not just her symptoms) and external (i.e. the degree to which she participates in everyday activities, relates to others and risks disclosure to health professionals). It also illustrates how these systems, in turn, reinforce anxiety cycles. For example, failure to promote continence within the health service can reinforce an individual's belief that their incontinence is a normal part of the ageing process for which little can be done.

The advantage of such an integrative model is that it provides a basic structure from which the idiosyncrasies of each woman's experience of incontinence can be described and explained. Such a model could be used to explore which parts of the cycle or systems are particularly important or difficult for the individual (e.g. fear of wetting or worries about impact on carers) and need to be prioritised if an intervention is going to have positive outcomes for the client. Indeed, some of the repercussions of incontinence may provide important incentives or goals, which will help to motivate clients when they are carrying out mundane behavioural programmes. Alternatively, such a model may identify serious problems, such as depression or social isolation, that need to be addressed before any interventions for incontinence are recommended.

The psychological model of urge incontinence, illustrated in Figure 5.1 can also be adapted and used to describe the development and maintenance of other urinary symptoms (e.g. frequency, urgency and stress incontinence). Urinary symptoms may have an organic basis and this should be investigated, but so should the psychological components of any somatic disorder, especially when they have an impact on the quality of life and mental health of individuals and their families. Waddle (1998), in her book on the growth of personality discusses the

...complex intimacy of the links between cognitive and emotional deficit, between organic impairment and affective disorders, between functioning of the brain and of the mind. This issue is not that the brain affects the mind, but that the mind affects the brain. (p.239)

In the same way, continence is not simply determined by the characteristics of the bladder wall – its stability, compliance, sensations and capacity. It is also dependent on a woman's perceptions, beliefs, assumptions and expectations about her ability to control urination; her level of motivation and confidence about

(re)learning new skills; her ability to face her fears and cope with failures; and the level of support and resources she has available to her. Behavioural models have focused on relearning or imitating good toilet behaviour. What it has not recognised is the fact that imitation in itself does not necessarily instil confidence and the ability to deal with different situations competently. A woman may still believe she has a weak bladder and limit rather than broaden participation in social activities. The evidence has already shown us that women are excellent at ‘passing’ as continent and normalising time-consuming self-management regimes (see Chapter Two, Section 2.3).

Whether a woman perceives herself to be continent or incontinent and the extent to which she is distressed or not by her continence status is as dependent on her perceptions and feelings as on the actual severity of her symptoms. Behavioural models focus on changing behaviours and learning more appropriate toilet habits. This level of intervention may be appropriate for some women, but others may also need to address how they think (i.e. cognitions) and feel (i.e. affect) about their incontinence if they are to learn how to deal with somatic symptoms better, in the long-term and in different contexts.

The provisional psychological model described here provides choices for women and health professionals. Women with incontinence may wish to focus on changing their toileting behaviours, but it is important that realistic goals are set and these reflect values that are important to them and they are not simply complying with treatment protocols devised by health professionals. Thus, feeling confident in social situations may be more meaningful than being ‘dry’ for long periods of time. The fear of wetting in public may be more evident than the actual experience of wetting in public. In other words feelings of shame may be more apparent than incidences of public humiliation. Interventions, then, need to acknowledge the feelings associated with incontinence as well as changing behaviours and physiology. It is essential that health professionals do not make their own assumptions about what is the most important for a woman seeking help and how they feel about their incontinence.

5.5.0 Clinical implications

Urinary incontinence is frequently identified as a very common disability that is costly to the National Health Service and easy to treat if properly identified and assessed (DOH, 2000; The Continence Foundation, 2000). Urinary incontinence

consistently appears in policy documents relating to health care for older people: *Fit for the Future: the prevention of dependency in later life* (Prophet, 1998); *Nursing home placements for older people in England and Wales: a national audit* (Millard, 1999); *National Service Framework for Older People* (DOH, 2001a); and *Care homes for older people: National Minimum standards, 2000* (DOH 2001b). Across all client groups (child, young mothers, older people, people with learning and/ or physical disabilities) there is an emphasis on providing ‘integrated’ continence services in terms of co-ordinating services across primary, community and hospital settings with continence nurse specialists and specialist continence physiotherapists taking a lead in the delivery of care (DOH, 2000, 2001a).

Findings from this study would emphasise that ‘integrated’ services should embrace not only the physical and social aspects of incontinence, but also the psychological. The importance of anxiety and depression in women’s experience of urge incontinence suggests that training packages for nurse specialists and other primary care staff should be broadened to include the cognitive and emotional dimensions of somatic symptoms. Behavioural programmes, such as bladder training, may also benefit from additional and more up-to-date training in psychological interventions (see Chapter Two, Section 2.1.1 for suggestions). Such training could form become part of individuals’ planned programme of Continuing Professional Development (DOH, 1999, 2000).

The results from this study have significant clinical implications in terms of the assessment and treatment of the urinary symptoms. These implications, however, need to be debated and are presented as proposals only. The evidence to support such new directions is largely based on epidemiological and qualitative research, rather than clinical data which has conclusively demonstrated the superiority of one model or intervention over another. The section will focus on the clinical implications for primary care staff and specialist nurses. However, it will end with a discussion of the relevance of this research to clinical psychology services.

5.5.1 Clinical assessment

Recently, the Department of Health (DOH, 2000a) has outlined the key components of continence assessment in their document on good practice guidelines in continence. These components are listed in Table 5.1. Currently, clinical assessment is very symptom orientated, with an emphasis on excluding aetiological factors that may be affecting continence (e.g. urinary tract infection). Cheater *et al.*

(1998) has produced a more detailed assessment protocol, which reviews the research evidence, provides specific “Must Do” and “Should Do” performance criteria and methods for identifying patients and collecting information. The Royal College of Physicians (1998) has also produced an audit scheme for the management of urinary incontinence generally, which includes: 1) single patient audit – comprising of a comprehensive checklist of good practice; 2) multiple patient audit – providing an overview of the extent to which good practice is being achieved; and 3) facility audit – assessing policy and procedures, staff education and the promotion of continence.

Table 5.1 Key components of an initial continence assessment identified by DOH and additions proposed by this study

DOH (2000) guidelines
• Review of symptoms and their effects on quality of life; • Assessment of desire for treatment alternatives; • Examination of abdomen for palpable mass or bladder retention; • Examination of perineum to identify prolapse and excoriation and to assess pelvic floor contractions; • Rectal examination to exclude faecal impaction; • Urinalysis to exclude infection; • Assessment of manual dexterity; • Assessment of the environment, e.g. accessibility of toilet facilities; • Use of and ‘Activities of daily living’ diary; • Identification of conditions that may exacerbate incontinence e.g. chronic cough.
Additional guidelines, based on results from this study
• Clinical history of patient’s general health, previous contact with services and interventions regarding urinary symptoms; • Measure of mental status and health (e.g. Mini-Mental State Examination, HADS); • Assessment of motivation; • Functional analysis of urinary symptom (e.g. ABC chart); • Patient’s management of urinary symptoms and coping skills; • Social support and resources (i.e. involvement of carers); • Identification of patient’s priorities and goals • Agreed measures of successful outcome to intervention;

These types of assessment protocols are essential if good practice is to be encouraged in continence services, but they do not provide a complete clinical history, especially when possible aetiological factors have been excluded. In these circumstances, the clinician is left with minimal information on the history of symptoms (not just current) and use of previous treatments; the patient’s

understanding of her symptoms and how she copes with them; her own priorities and goals; and most importantly, her current mental health and how this might impact on her ability to cope with urinary symptoms and treatment programmes.

Table 5.1 also outlines the sort of psychological information that would be useful to collect during the assessment process in order to exclude or incorporate psychological factors in the development and maintenance of incontinence. The collection of such information would encourage a more collaborative approach between the clinician and patient. It would also ensure that both clinician and patients have a shared understanding of the current problem. Some of the tasks can help to motivate the patient (and carers if relevant) to understand better her symptoms and the impact they have on her life. In a sense the assessment process itself introduces the patient to how the intervention will be carried out if it is to be successful. Thus, the treatment will need to be tailored to each patient's circumstances, but it requires the patient to be an active participant rather than a passive recipient of treatment.

5.5.2 Clinical Interventions

The most disappointing aspect of the Department of Health's guidelines for continence services (DOH, 2000) is the lack of attention to treatment protocols. Thus the 'implementation of bladder and bowel training regimens' is recommended (p13), but no details are provided on how to do this effectively and exactly what such regimens entail. Systematic reviews of the literature regarding the effectiveness of behavioural interventions for incontinence have concluded there is only weak evidence to suggest that bladder training is more effective than no treatment (Berghmans *et al.*, 2000; Roe *et al.*, 2000). This is largely a result of methodological flaws, one of the most common being insufficient details on how behavioural interventions were actually carried out (see Chapter 2, Section 2.1.1).

There are no audit protocols for the delivery of bladder training, equivalent to those found for the assessment of incontinence. Table 5.2 outlines what a behavioural protocol might include. The intervention itself is not complicated. A written protocol, however, ensures that it is carried out systematically, but not uniformly. The success of such a programme is individualising it, thus ensuring it is 'person-centred' rather than treatment-centred.

Table 5.2 Protocol for a behavioural intervention for urinary incontinence

Steps	Description
1. Monitor symptoms	Completion of continence diary for one week (baseline data)
2. Monitoring of sequences and identification of self-management strategies.	Completion of ABC charts (e.g. triggers, incontinence episodes and consequences)
3. Patient education and support	Discussion of bladder functioning and behavioural models.
4. Identify treatment goals and intermediate steps.	Agree on outcomes and how these can be evaluated.
5. Identify rewards (reinforcers) and how they will be administered.	Education on types of rewards and the importance of immediacy, strength, attention and consistency.
6. Specify a target behaviour	Decide exactly what it is you want to change.
7. Carry out a task analysis	Break down the target behaviour into small steps and agree on how this will be monitored and successes rewarded.
8. Provide feedback	Regularly view progress with tasks and agree on pace of intervention. Set a time-table.
9. Attend to motivation	Openly discuss relapses and the expectation that these will occur and how best to deal with them.
10. Review progress	Discuss preferred strategies and alternative techniques (e.g. desensitisation hierarchy, relaxation, cognitive restructuring).
11. Evaluate progress	Completion of continence diary for one week and collect outcome measures.
12. Maintenance of continence	Generalisation of progress to other contexts. Assess personal and professional resources and schedule follow-ups.

Currently, behavioural interventions tend to be delivered on a one-to-one basis (nurse or physiotherapist with patient), but there may be many benefits to organising group therapy in this area. Group work programmes in health settings have encouraged people to share their experiences and expertise and provide important sources of social support and motivation in terms of peer role models (Tovian *et al.*, 1996). Unfortunately, there is little evidence of supportive group work in continence services in this country, although *Incontact*, (an organisation of people affected by continence problems and their carers), is a useful source of information and support.

Additionally, health policy (DOH, 2001c) is promoting the concept of ‘expert patients’ and ‘Chronic Disease Self-Management Programs,’ as a new approach to chronic illness (in particular, arthritis, diabetes, manic depression and multiple sclerosis). Such models of service delivery have received little attention in the field of urinary incontinence, though they are very relevant. It is possible that women with urinary incontinence, with proper instruction and supervision, may be as effective as professionals in delivering basic behaviour and cognitive interventions or can support professionals in this capacity. Much is written about women’s skills in managing incontinence (see Chapter Two, Section 2.3.0), but there is little evidence of professionals and patients sharing their respective areas of expertise in order to provide more comprehensive and flexible person-centred interventions. Such a shift in working would empower patients and encourage openness about treatment choices and limitations.

The psychological model outlined in Figure 5.1 could be used to investigate the roles of anxiety and depression and other feelings in women’s experience of incontinence and how such feelings can interfere with behavioural programmes. A nurse could draw a personalised incontinence flow chart or incontinence cycle with a patient in order to prioritise treatment options. For example, if feelings of shame predominated, attention to self-esteem or assertiveness training may be important; if anxiety is a problem, cognitive behaviour therapy may be the most effective option; if low mood is evident, motivation is likely to be a significant factor; and if hygiene is a concern, better self-management strategies could be promoted. These types of intervention can run alongside bladder training regimens.

Primary care staff and nurse specialists, who provide frontline treatments for incontinence, must consider their own level of expertise to assess whether they can carry out these types of interventions or whether they need further training and the opportunity to consult with or be supervised by specialists (e.g. clinical psychologist or qualified therapists). If a woman’s incontinence appears to be a complex psychological problem, it may be more appropriate to refer her to specialist services (e.g. clinical and health psychology) or to work jointly with other professionals. Access to more specialist help, then, should include access to psychological therapies and not only investigative facilities and surgical services.

The psychological model presented in Figure 5.1 also draws attention to the treatment consequences of incontinence. It highlights the effects of continence on others: not just the immediate family and carers, but health systems and professionals

too. It is essential that professionals address their own assumptions about incontinence and appropriate toileting behaviours and recognise that these may be different to patients' and to their colleagues. This is particularly relevant when there is so much confusion about incontinence in the literature. Chapter One presented the ongoing debates concerning definition and classification, prevalence and natural history, the role of different causal factors and the effectiveness of different treatments for incontinence.

Against this context, patients should be informed of the good news (i.e. what we can do and do know about incontinence) as well as the bad news (what we can not do or do not know about incontinence), so that expectations about treatments are not exaggerated and professionals do not feel pressurised into 'curing' incontinence. Raising awareness of incontinence and promoting continence are important targets, but so is encouraging a dialogue between interested parties to ensure that everyone is properly informed of the facts, as they stand. If too much emphasis is put into promoting continence, failure to achieve continence can create a blaming culture: the patient is blamed for not trying hard enough or not complying with treatments and nurses, in turn, are accused of oversimplifying problems and not being sensitive to an individual's circumstances. Such a climate is disappointing for patients and specialists and likely to have a detrimental effect on morale.

5.5.3 The role of clinical psychologists

This study has demonstrated the relevance of emotional factors in women's experience of urge incontinence. Although, the author would encourage nurse specialists to deal directly with the emotional aspects of incontinence, she would also encourage clinical psychologists to recognise the relevance of somatic symptoms when working with women with mental health problems, such as anxiety and depression. In older people, in particular, it is often difficult to untangle mental health problems from concerns about physical health, loss of function and disability. If clinical psychologists routinely asked clients about common physical symptoms, such as headaches, pain and incontinence, it might help people to talk more readily about a symptom they are too embarrassed to seek advice for, that might contribute significantly to their mental health problems. Good practice guidelines for continence services have stipulated the importance of 'raising awareness of professionals to the problems of continence' (DOH, 2000). As health professionals, clinical psychologist should be included in any promotion material and training in this area.

Clinical psychologists could also become more actively involved in continence services, as trainers, consultants or practitioners. As trainers, clinical psychologist, along with other qualified therapists, could provide basic training in behavioural and cognitive models or provide refresher and advanced courses. They could also provide some education on minor mental health problems, such as symptoms of anxiety and depression, and how they might maintain symptoms or have an impact on treatment outcomes. As a consultant, they could provide advice or supervision in terms of developing treatment protocols, which attend to psychological factors. Clinical psychologists are likely to be a good resource for literature on psychological interventions and have access to clinical and research tools (e.g. questionnaires, diaries, relaxation tapes and recording charts). As a practitioner, they could work directly with clients with more complex psychological problems who need help with their incontinence or those clients a nurse specialist is finding difficult to engage with using standard treatment approaches.

Currently, it is rare for a patient with incontinence to be referred to a clinical psychologist. This may well be appropriate, but it is likely that better use could be made of clinical psychology services in terms of training and improving the quality of continence care provided. Although behavioural interventions are standard first line treatment for urge incontinence, it is unclear what training specialist nurses receive, how this is monitored and how frequently it is updated. Clinical psychologist could make a significant contribution in this area.

5.6.0 Recommendations for future research

This study has demonstrated the significance of emotional factors in women's experience of urinary symptoms and urge incontinence in particular. These findings have generated new ideas for research in diverse areas, including:

- Epidemiological - e.g. screen for mental health problems, such as anxiety somatoform and obsessive-compulsive disorders, among women with different urinary symptoms;
- Experimental – e.g. conduct single-case design studies or detailed case studies to establish the benefits or not of specific components of behavioural therapy;
- Educational – e.g. survey continence nurse specialists to identify their training needs and knowledge of basic psychological models, such as cognitive behaviour therapy;

- Clinical – e.g. compare and contrast treatment outcomes for women receiving different interventions (e.g. cognitive therapy vs. bladder training, individual vs. group programmes).
- Audit – e.g. assess patients' satisfaction with continence services and their own treatment goals and service needs.
- Qualitative – e.g. to better understand why women with urge incontinence who are anxious may be less likely to receive treatment than women with urge incontinence who are not anxious.

This study has focused on women's experience of urge incontinence. It would also be valuable to investigate the experiences of men, those living in residential and nursing homes and to make comparisons across different ethnic groups. The Leicestershire MRC Incontinence Study has a wealth of survey data and the potential for secondary analyses to address some of the gaps in the literature is enormous. This study has demonstrated one possible avenue for research, there are many more.

5.7.0 Conclusions

Until fairly recently scientists had a fairly negative impression of emotions: they were 'messy', unruly and got in the way of rationality and intelligent behaviour (Evans, 2001). They preferred to focus instead on behaviour and cognitions, which appeared easier to manipulate and control. In the 1990s, such ideas were seriously challenged and emotions were championed as central to survival and morality. Thus, not only did emotions affect our autonomic nervous system, which in turn controls such involuntary bodily functions such as heart rate, immune response, digestion and bladder functioning, they also underpinned the way we behaved towards other:

...emotions, rather than being the antithesis of rationality, greatly aid thinking. People can reason and deliberate as much as they want, but if there are no emotions attached to the various options in front of them, they will never reach a decision or conviction. This is critical for moral choice, because if anything, morality involves strong convictions. These don't – or rather can't – come about through a cool Kantian rationality; they require caring about others and powerful gut feelings about right and wrong. (de Waal, 2001, p.349)

Rather than separate feelings from thoughts and behaviour, scientists have become increasingly interested in how these different systems interact with each other. For example, people can be passionate about their beliefs and behave in a certain way and also have well thought out reasons for their feelings and behave in another.

Within incontinence services emotions have not been ignored, but all too often they are treated as natural responses to physiological dysfunction only: very simply, our bodies fail us, we get upset, what do you expect? Rather than deal with the ‘upset’ bit of the equation, clinicians have focused on fixing the body or changing the behaviour, with the expectation that success in these areas is easier to accomplish and that managing the emotions will not affect the bladder or toilet behaviour. Thus, much is written about the bladder’s sensations, capacity, compliance and stability, and much less is known about the patient’s perceptions, abilities, motivations and emotional status. Consequently, interventions are preoccupied with controlling the bladder. The simplicity of dealing with bladders and behaviours only is appealing, but ignoring the head and the heart, so to speak, is bound to limit the effectiveness or scope of any intervention.

This study demonstrated that the majority of women aged 40 years or more with urge incontinence reported symptoms of anxiety or depression. These symptoms were also associated with other urinary symptoms, such as stress incontinence, urgency and frequency. The longitudinal data suggested that anxiety and depression were often a consequence of urinary symptoms, but also that urge incontinence was often a consequence of anxiety. When specialist nurses struggle to promote continence using traditional bladder retraining techniques, attention to the feelings (their own and their patient’s) may lead to a better understanding of the problem and result in improved outcomes.

To finish on a personal note, my own memories of my ‘accident’ on the bouncy castle when a young girl, are pretty vague in terms of how much I actually leaked, my consequent behaviour and the reactions of those around me. The feelings associated with the event, in contrast, are vivid and have, in a sense, maintained my interest in incontinence. Similarly, it is often the personal stories patients tell doctors and nurses about their incontinence that motivate professionals to fight for better continence services and improve the quality of care offered. Women have a lot of expertise in managing their symptoms; the difficult part might be in dealing with their feelings. It is hoped that this research project has raised the profile of emotional factors in women’s experience of urge incontinence; provided conclusive evidence regarding the positive association between anxiety and depression and urinary symptoms; and discussed how emotional factors can be addressed realistically in clinical practice.

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Appendix One

Literature search on the stigma associated with urinary incontinence

The author carried out a review of the literature to investigate whether there was good evidence that women felt stigmatised by urinary incontinence. A literature search was conducted on the database 'PsychInfo' for the years 1984 to 2001, using the search terms "exp urinary function disorders/ or exp urinary incontinence/ or urinary disorders.mp." AND "psychol\$.mp.". This search produced only 107 hits, of which 26 were discounted because they were commentaries on papers, duplicate references or reports of rare diseases (e.g. Koro syndrome and Maple syrup urinary disease) or other urinary disorders. Of the remaining 81 papers, 49 (60%) were related to enuresis in children, and the remaining papers were on incontinence in adults. However, only 9 of these papers were on psychological responses to incontinence and only 3 of these were based on experimental data to investigate the psychosocial impact of urinary incontinence on older adults.

It was decided that the search strategy would need to be broader covering urinary disorders and 'quality of life' as a generic term. Health related quality of life is a multidimensional concept that encompasses the perceived impact of illness on physical health, well-being, daily activities and social functioning (Bowling, 1995). This yielded 693 hits for the same period of time, this time on the Medline database. Many of these papers were epidemiological in nature. Papers reporting impact on well-being were selected. This led to the identification of 9 papers dealing with feelings of shame, embarrassment, fears of smelling and loss of confidence (see Table 1.6). Five of these papers related to older people only and four assessed a wider age range. In total, 6/9 papers included men in the sample, but only 2 studies provided separate data for men.

In terms of the characteristics of the sample, 6/9 studies were based on a random community samples (which include people who have sought clinical help) and 3/9 were clinical samples only (i.e. those people in receipt of treatment for urinary incontinence). This last distinction is important because clinical sample are probably not representative of people with urinary incontinence generally: a review of the literature concluded that about one quarter to one third of women with urinary incontinence report they have sought help for their symptoms (Hampel *et al.*, 1997). Consequently, averages for all 9 studies will be compared to averages for studies based on community populations only. It must also be remembered that there is little consistency between the studies in their definitions of incontinence and shame. This is probably further complicated by the fact that the papers are international and there

are likely to be problems with translating such abstract terms as well-being and shame.

Table 1.6 A review of quantitative studies that have investigated the prevalence of shame among adults with incontinence

Author Year Country	Sample details	Symptoms	Dimension of shame investigated	Percentage reporting impact on well-being
Norton, 1982 GB	F, 22-78 years Clinical N=55	Incontinence	Fear of smell restricts activities	30
			Fear of embarrassment restrict activities	44
Yu, 1987 USA	F, 77-87 years Nursing home & clinical N=30	Incontinence	Outcast	63
			Ashamed	79-90
			Feel guilt	79
			Worthless	79
			Embarrassed	63
Ju <i>et al.</i> , 1991 Singapore	M & F 65+ years Community N= 35	Incontinence	Ashamed	26
Lagro-Janssen <i>et al.</i> , 1992 Netherlands	F, 20-65 years Community N=110	Stress urge and mixed incontinence	Shame	60 (50 with stress and 68 for urge and mixed)
Brocklehurst, 1993 GB	M & F 30+ years Community N=422	Incontinence	Embarrassed	30
			Smelly	10
			Ashamed	8
Fonda <i>et al.</i> , 1995 Australia	M & F 60+ years Clinical N = 73	Incontinence	Embarrassed	52
Jitapunkal & Khovidhunkit, 1998 Thailand	M & F 60+ years Community N= 114	Incontinence	Ashamed	M 60 F 56
			Loss of confidence	68 60
			Afraid of going out	76 40
Iglesias <i>et al.</i> , 2000 Spain	M & F 65+ years Community N=296	Incontinence	Embarrassed, concerned, upset, distressed	M F 27 28
			Shame	16 11
Ueda <i>et al.</i> , 2000 Japan	M & F 40+ years Community N=606	Incontinence	Embarrassing condition	63

M=Male, F=Female

Feelings of shame and embarrassment were reported in six studies. The percentage of people with incontinence reporting shame ranged from 8-90% with a mean of 45% and median of 52%. Shame was less prevalent in the community sample (mean = 30%, median = 26%). The percentage of people reporting embarrassment ranged from 27-63% with a mean of 51% and median of 44%. Embarrassment was less prevalent in the community sample (mean = 37%, median =

29%). Feelings of fear, mainly of smelling, were reported in 4 studies, ranging from 10-76% with a mean of 39% and median of 35%. Only two studies report on feelings of inferiority:

To summarise, the evidence seems to indicate (from the community surveys), that about one third of people with urinary incontinence report feelings of shame, embarrassment and are fearful of smelling in social situations. Only one study made a distinction between different symptoms of incontinence, and found that women with urge and mixed incontinence reported more distress than those with stress incontinence (Lagro-Janssen *et al.*, 1992).

The evidence suggests that feelings of shame and embarrassment and the fear of being stigmatised are frequently reported by women with urinary incontinence, but only by a minority, albeit a significant minority. There is no doubt that for these women, urinary incontinence has a detrimental effect on their perceptions of themselves. Very few published papers have actually addressed the nature of this stigma and the extent to which people with urinary incontinence experience it. It is not possible to conclude from the literature whether feelings of shame are influenced by demographic variables and/or symptom characteristics.

Appendix Two

Summary of conservative treatments for urinary incontinence.

Health education

In brief, the focus on health educational material tends to be lifestyle factors, such as weight loss, restricting heavy lifting, cessation of smoking, caffeine reduction and fluid management, relief of constipation and postural changes (Wilson *et al.*, 2001). These interventions are not specific to urge incontinence. Sometimes, simple advice, such as reducing the number of cups of coffee a person drinks, can have dramatic results, but such cases are rare. These interventions focus on raising people's awareness and educating them on how the urinary system functions.

Little mention is made of the role of motivation in changing some of these lifestyle habits, which is unfortunate as it is crucial if patients are going to adhere to behavioural programmes. There are likely to be problems with compliance if such lifestyle changes disrupt daily routines, result in little positive feedback and improvements are only achieved in the long rather than short-term. Indeed support for these types of interventions is often based on the fact that lifestyle factors are associated with urinary incontinence. There is very little evidence that changing any of these behaviours has clinical benefits in terms of continence status, except when dealing with serious problems (e.g. obesity) (Wilson *et al.*, 2001).

Physical therapies

Improvement of pelvic floor muscle tone is important because it contributes to the action of the external sphincter, thus maintaining urethral closure. Physical therapies include pelvic floor muscle training (PFMT), biofeedback, vaginal cones and electrical stimulation. Less will be said about physical therapies, as they are the main intervention for women with stress incontinence. Basically, they entail training a woman to contract her pelvic floor muscles voluntarily and comply with specific exercise regimes. In this way, muscle strength, power and endurance is improved, but these effects are only sustained if adherence to the exercise programme is maintained on a daily basis (Haslam, 2002). Indeed, it is recognised that high motivation and compliance are crucial to the success of physical therapies.

A systematic review of randomised controlled trials (RCTs) of conservative treatment for stress incontinence found that PFMT reduced symptoms (Berghmans *et al.*, Bo *et al.* 1998) and was better than no treatment. There is also evidence that such interventions reduce symptoms of urge and mixed incontinence (O'Brien *et al.*,

1991). However, for women with urge incontinence, it may be more appropriate to offer PFMT in combination with other behavioural therapies (e.g. bladder training).

Biofeedback techniques have been used to improve PFMT (Haslam, 2002). Basically, biofeedback entails using equipment (e.g. monometry and surface electromyography) to monitor the activity of pelvic floor muscles. Changes in activity are displayed on a dial or graphically on a screen so that women can see the effects of their actions on muscle activity. This increases their awareness of muscle activity, how to regulate such activity and monitor any progress. In this way, women are trained to control specific responses (i.e. contraction of external sphincter) they thought were outside voluntary control. At this stage there is inconclusive evidence regarding the superiority of PFMT with biofeedback techniques as opposed to PFMT alone (Wilson *et al.*, 2001).

Behavioural therapies

Behavioural interventions in this field are often referred to as bladder training, re-education, drill or discipline. This is the recommended initial treatment for adults with urge incontinence. It consists of patient education, scheduled voiding and positive reinforcement (Fantl, 2001). The focus is on patients regaining control over their bladder. A number of RCTs have produced consistent results, indicating that bladder training is better than no treatment for women with urinary incontinence (Berghmans *et al.*, 2000; Roe *et al.*, 2000). However, the quality of the evidence is fairly weak and behavioural interventions tend to reduce rather than eliminate episodes of incontinence, although this may be sufficient to improve a person's quality of life. There is some evidence that women with sensory urgency respond better to behavioural therapies than those with motor urgency (Wilson *et al.*, 2001).

It has also been suggested that the placebo effect plays a major role in bladder training programmes (Aitchison, *et al.*, 1989; Sandvik, 1995). Patients may benefit greatly from the opportunity to discuss their symptoms openly with another person, the reassurance and supervision received during assessment and treatment phases and the impact of positive feedback on their perception of their problem. As in the case of physical therapies, compliance to behavioural programmes is important and many people may do well to begin with, but relapse in the longer term when positive reinforcement from professionals is no longer available or as accessible (Holmes *et al.*, 1983). Behavioural interventions will be discussed in greater detail in Chapter Two.

Pharmacotherapy

When behavioural bladder training programmes are not effective in reducing or curing urge incontinence, drug therapy is frequently administered. Anticholinergic drugs (e.g. oxybutynin and tolterodine) and tricyclic anti-depressants (e.g. imipramine) are recommended and work largely by inhibiting detrusor contractions (Thakar & Stanton, 2000). Unfortunately, most of these drugs have unwanted side-effects, such as dry mouth, blurred vision, drowsiness and gastrointestinal symptoms, which might outweigh the benefits they have in reducing incontinence. There are no pharmacological agents that are purely selective and act on the lower urinary tract only.

Findings from RCTs indicated large variations in cure or improvement rates as well as side-effects and dropouts (Rovner & Wein, 2001). Thus, it is now believed that although significant improvements can occur with drug therapy, complete restoration of normal functioning is seldom achieved. The idiopathic and relapsing and remitting nature of urge incontinence make it difficult to establish the long-term effectiveness of treatment programmes and relapse rates are often unrecorded. More recently, it has been suggested that “complete elimination of symptoms and “cure” are not realistic for most patients” and that “patients may have unrealistic expectations regarding therapy outcomes” (Davila & Neimark, 2002). The expectations of health professionals are likely to be of equal importance.

Appendix Three

An overview of the Leicestershire MRC Incontinence Study

The Leicestershire MRC Incontinence Study was a programme of interrelated epidemiological and clinical studies that ran concurrently within a defined geographical population. The aims of the programme were to describe:

1. The prevalence of urinary symptoms, related need, use and effectiveness of services;
2. The effectiveness and cost of Specialist Continence Nurse Practitioner (CNP) service compared to the Primary Care Team, with and without the support of Continence Advisors;
3. The effectiveness and cost of imipramine, oxybutynin and HRT compared to placebo in the treatment of detrusor instability (DI);
4. The effectiveness and cost of pelvic floor exercises, weighted vaginal cones and HRT compared to placebo in the treatment of genuine stress incontinence (GSI);
5. The incidence, natural history and aetiology of incontinence and related need.

The programme was multidisciplinary and aimed to provide a complete package of guidance for developing and delivering cost-effective services across the country. The author was one of two academic psychologists, who worked mainly within the epidemiological studies. The clinical trials were led by medical and nursing professionals. No clinical psychologists were involved in the design and development of behavioural interventions. The programme began in 1995 and data collection was completed in 2002.

The programme received ethical approval from Leicestershire Research Ethics Committee (LREC) in 1995 (reference number 3650). This committee was notified of changes to procedures, method of contact, patient letters and information sheets, measures and clinical protocols during the course of the programme. Data is stored on computer databases within the Department of Epidemiology and Public Health at the University of Leicester according to regulations stipulated by the Data Protection Act 1998 and the Caldicott Review. Thus, appropriate technical and project management measures have been taken to protect the rights and freedoms of data subjects in relation to the processing of personal data. It is important to safeguard uses made of confidential information on subjects. This includes new analyses of data.

The Leicestershire MRC Incontinence Study was also monitored by a Steering Committee which is made up of team of experts in the fields of epidemiology, statistics, urology, gynaecology, health economics, nursing and physiotherapy, representatives from the Medical Research Council and a lay member who also has associations with a voluntary organisation representing the interests of people with urinary problems. The steering committee convened annually in order to review progress and timetables, management issues, changes and amendments to protocols and provided advice on any research related matters.

Dissemination of the findings from the study was ongoing: starting with the presentation of results from pilot and qualitative studies; followed by methodological and educational papers; and finally the main results from the epidemiological studies and clinical trials.

Appendix Four
Ethical Approval

The present study was approved by the Academic Office, University of Leicester, regarding procedures for submitting a research thesis as part of a doctorate course on data that has already been collected. It meets the stipulated criteria in that such work does not pose a problem as long as it entails:

1. New analyses of data
2. Does not involve replication of work which has already been submitted as part of a post-graduate qualification
3. The work is of psychological relevance.

Leicestershire Research Ethics Committee (LREC) was informed of the proposed further analyses of the data. It was noted that the data would be de-identified and that the purpose of the present study was in keeping with the original programme's aims. Approval was given to the amended application (reference number RFB 0064) in December 2002 (see copy of letter at the end of this appendix).

DIRECTORATE OF RESEARCH AND DEVELOPMENT

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Dear Dr S I Perry

RE: Project Number: RFB 0064 *[Please quote this number in all correspondence]*
Incontinence: A population laboratory approach to the epidemiology and evaluation of care

We have now been notified by Leicestershire Research Ethics Committee that they have approved the amended application which was enclosed with your letter of 21 November (please see the attached letter from the Ethical Committee).

I therefore have pleasure in confirming approval of these documents on behalf of the University Hospitals of Leicester NHS Trust and also confirm that, as this amendment does not alter the resources which you originally declared in your notification form, you are fully authorised to continue with the study.

The study remains covered by Trust Indemnity, except for those aspects already covered by external indemnity (e.g. ABPI in the case of most drug studies).

May we take this opportunity to remind you that we will be requesting annual and final reports on the progress of this project, both on behalf of the Trust and on behalf of the Ethical Committee.

In the meantime, in order to keep our records up to date, could you please notify the **Research Office** if there are any significant changes to the start or end dates, protocol, funding or costs of the project.

I look forward to the opportunity of reading the published results of your study in due course.

Yours sincerely



Anne-Marie Cannaby
Head of Nursing for Research and Development

Leicestershire, Northamptonshire
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Ethics Administration
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Dear Dr Perry

**Leicestershire MRC Incontinence Study – Incontinence: a population
laboratory approach to the epidemiology and evaluation of care – our ref:
3650**

I am in receipt of your letter of 21st November 2002 identifying further analyses to be carried out of the data from this study.

I note that the data will be de-identified and the purpose is in keeping with the original study aims.

By chairman's action approval for this amendment is hereby given.

Yours sincerely

**P G Rabey
Chairman
Leicestershire Research Ethics Committee**

(NB All communications relating to Leicestershire Research Ethics Committee must be sent to the Committee Secretariat at Leicestershire, Northamptonshire and Rutland Health Authority. If, however, your original application was submitted through a Trust Research & Development Office, then any response or further correspondence must be submitted in the same way.)

Appendix Five
Non-responder and validation study

Non-responder study

To assess whether responders were different to non-responders a random sample of 1050 non-responders stratified by sex and age group was follow-up by trained interviewers by telephone or home visit. Dallosso *et al.* (2003) provide full details of the non-responder study. Stratification ensured sufficient numbers in the oldest group were included, as this was where bias was likely to be the greater risk (i.e. smaller numbers, lowest response rates and greatest level of morbidity).

In brief, 99% of non-responders were traced in person or accounted for and 12% were identified as not eligible to be in the survey sample. The remainder were asked a number of questions from the postal questionnaire, regarding their health and urinary incontinence in particular. Half of the eligible group did not answer the interviewers questions: the main reason being disinterest, general unwillingness and poor health. Only a few people complained about the actual content of the questionnaire, indicating that they found the subject particularly sensitive.

When non-responders were matched with a sample of responders from the survey, few differences were found in answers given to questions in the postal survey. Only three statistically significant findings were found in logistic regression analyses: non-responders were more likely to report high frequency of micturition, poorer general health, but less likely to report long-term health problems. Separate analyses comparing the oldest age groups revealed many statistically significant differences, with older non-responders more likely to report a number of urinary symptoms (incontinence, urgency and frequency) and poorer health. It was concluded that there was little evidence of response bias in the group overall, but the greater reporting of urinary symptoms by older non-responders suggest that prevalence rates in this age group may be underestimated.

Validation study

The validity and reliability of some of the symptom questions (i.e. incontinence, urgency, frequency and nocturia) included in the postal survey were investigated in a validation study (Shaw *et al.* 2002). Subjects were recruited from the epidemiological and clinical programmes within the Leicestershire MRC Incontinence study and represented those with different levels of symptom severity (i.e. no symptoms to severe symptoms). In brief, test-retest and inter-rater reliability was good with agreement (using Cohen's κ statistic) in the good (0.61-0.81) to

excellent (0.81 – 1.00) range for all questions, and all were responsive to change in symptoms, showing significant differences before and after treatment in the randomised controlled trial of a continence nurse practitioner (CNP) service.

In terms of criterion validity, participants were asked to complete a 3-day urinary diary and 24-hour pad test as well as answer questions on the questionnaire. Thus, self-reporting of symptoms were compared with diary records and changes in pad weights. Again there was good agreement between the different measures (i.e. those who reported severe incontinence, recorded more incontinence episodes in the diary and had greater gains in pad weight) and little overlap in confidence intervals between categories. However, respondents tended to overestimate both frequency and nocturia in interviews compared to diary responses.

Pad tests and diaries did not provide reference standards for urgency, so construct validity was assessed by comparing self-reported symptoms to urodynamic diagnosis, for subjects who were offered secondary treatments (e.g. pharmacotherapy) in a further series of randomised controlled trials. Those with a diagnosis of detrusor instability were more likely to report more frequent and a strong to overwhelming sense of urgency (chi-square, $p = 0.01$ and 0.002 respectively).

The results from the validation study were encouraging and the questions used in the survey appear to be acceptable, sensitive and to discriminate between different levels of symptom severity. However, the administering of the questionnaire was different in the validation study, as subjects were interviewed rather than asked to self-complete a questionnaire. There was, then, less opportunity for subjects to misunderstand questions as the interviewer could aid in interpreting questions. On the other hand, subjects may have felt more comfortable disclosing symptoms in private when they used the self-completion questionnaire than when asked directly by an interviewer. Further testing of the questionnaire is needed to assess the significance of mode of administration.

Appendix Six

Postal questionnaire, covering letter and information sheets

Summary of the contents of postal questionnaire

Type of question	Number of questions	Source
Urinary symptoms	36	Leicestershire Incontinence Study
Bowel symptoms	4	Leicestershire Incontinence Study
Anxiety and depression	14	HADS (Zigmond & Snaith, 1983)
Positive and negative affect	10	Bradburn Affect Balance Scale (Bradburn, 1969)
Life satisfaction	1	Life Satisfaction Index (Andrews & Withey, 1976)
Self assessment of health	1	SF-36 Health Survey (Ware & Sherbourne, 1992)
Long-term illness	1	OPCS, 1992
Activities of daily living	13	SF-36 Health Survey
Physical activity	3	Activity and Health Research (1992)
Breathlessness	3	Rose <i>et al.</i> , 1977
Self reported height and weight	2	Leicestershire Incontinence Study
Cigarette smoking and passive smoking	3	OPCS, 1993
Alcohol intake	1	OPCS, 1993
Exposure to u.v light	2	Salamone <i>et al.</i> , 1994
Nitrogen dioxide exposure	1	Jarvis <i>et al.</i> , 1991
Current use of prescribed medicines and diuretics	1	Slimani <i>et al.</i> , 2002
Co-morbidities and somatic symptoms	24	Leicestershire Incontinence Study
Falls	2	Leicestershire Incontinence Study
Stroke	1	O'Mahoney <i>et al.</i> , 1995
Menstrual history	2	Leicestershire Incontinence Study
Obstetric history	4	Leicestershire Incontinence Study
Demographic details	7	OPCS, 1992
Proxy information	1	Leicestershire Incontinence Study

Confidential Survey on Health and Lifestyle

This health survey concerns some common problems that are not always mentioned to the doctor. Any information you give us will be treated in the strictest confidence. It is important that we collect information from everyone.

EVERYONE'S ANSWER IS IMPORTANT - EVEN IF YOU DO NOT HAVE A HEALTH PROBLEM

If you have difficulty in filling in the form, you may wish to ask a friend or relative to help you. If you have problems with any of the questions, please contact Mrs Lesley Harris, University of Leicester, Department of Epidemiology and Public Health, 22-28 Princess Road West, Leicester LE1 6TP. Telephone 0116 252 5426

**PLEASE RETURN THE QUESTIONNAIRE
IN THE ENCLOSED ENVELOPE.
NO STAMP IS NEEDED.**

This survey is part of a larger study taking place in Leicestershire funded by the Medical Research Council and the National Health Service. It is designed to find out more about health problems and how to improve certain services for the future. Taking part is voluntary and any information you give is strictly confidential and will not be seen by your doctor.

The questionnaire starts by asking you about your physical activity and fitness.

Q1. The following are activities you might do during a typical day. Does your present health limit you in these activities? If so, how much?

Please tick ☒ one box on each line

Are you limited:-	a lot	a little	not at all
carrying out vigorous activities , such as running, lifting heavy objects, participating in strenuous sports. Are you limited	☐	☐	☐
carrying out moderate activities , such as moving a table, pushing a vacuum cleaner, bowling or playing golf. Are you limited	☐	☐	☐
lifting or carrying , bags of shopping, groceries. Are you limited	☐	☐	☐
climbing several flights of stairs. Are you limited	☐	☐	☐
climbing one flight of stairs. Are you limited	☐	☐	☐
bending, kneeling or stooping . Are you limited	☐	☐	☐
walking more than one mile . Are you limited	☐	☐	☐
walking half a mile . Are you limited	☐	☐	☐
walking one hundred yards . Are you limited	☐	☐	☐
bathing or dressing yourself . Are you limited	☐	☐	☐
getting around the house . Are you limited	☐	☐	☐
getting in and out of a chair . Are you limited	☐	☐	☐
feeding yourself . Are you limited	☐	☐	☐

Please check that there is a tick ☒ on each line

Please tick ☒ one box only per question

Q2. Are you troubled by shortness of breath when hurrying on level ground or walking up a slight hill?

- ☐ yes
- ☐ no
- ☐ never walk uphill or hurry

Q3. Do you get short of breath walking with other people of your own age on level ground?

- ☐ yes
- ☐ no
- ☐ never walk with other people in this way

Q4. Do you have to stop for breath when walking at your own pace on level ground?

- ☐ yes
- ☐ no

Q5. Compared with other people of your age would you describe yourself as

- ☐ very physically active
- ☐ fairly physically active
- ☐ about the same
- ☐ not very physically active
- ☐ not at all physically active

Q6. If you think of vigorous activity as something that makes you out of breath or sweaty, (for example brisk walks, hard work in a job, the home or garden, participation in a vigorous recreation or sport) how many times do you take part in this type of activity for at least 20 minutes during a typical week?

- ☐ unable to take part in this level of activity
- ☐ never take part in this level of activity
- ☐ very occasionally take part in this level of physical activity
- ☐ take part once a week
- ☐ take part twice a week
- ☐ take part three or more times a week

Q7. We are interested in how active you are on a typical day. Which of the following do you think best describes your typical day? Please tick ☒ only one box

☐ most of the day spent in **light sitting activities** (e.g. light office work, reading, watching TV, driving)

☐ most of the day spent in a mixture of **sitting and standing activities** (e.g. light housework and gardening, shop assistant, teacher, hairdresser)

☐ large part of the day on your feet working with **reasonable physical effort** (e.g. heavy housework and gardening, walking, non sedentary employment)

☐ large part of the day engaged in **vigorous leisure or occupational activities** (e.g. manual labourer, construction worker, frequent vigorous sporting activities)

Please tick ☒ one box only per question

The next questions are about some aspects of your general lifestyle

Q8. Are you now or have you ever been a cigarette smoker?

- ☐ never smoked
- ☐ ex-smoker
- ☐ current smoker

Q9. On average how many cigarettes do you smoke or did you smoke a day?

- ☐ never smoked
- ☐ very occasional smoker
- ☐ less than 10 a day
- ☐ 10 to 19 a day
- ☐ 20 plus a day

Q10. Is there anyone in your household who smokes more than 10 cigarettes a day?

- ☐ yes ☐ no

Please tick ☒ one box only per question

Q11. Which of the following describes your usual alcohol intake? By alcoholic drinks we mean a glass of wine, measure of spirits or half a pint of beer/lager.

- ☐ have never drunk any alcohol
- ☐ drank alcohol in the past but no longer do so
- ☐ less than 1 alcoholic drink a week
- ☐ 1-6 alcoholic drinks a week
- ☐ 7-14 alcoholic drinks a week
- ☐ 15-21 alcoholic drinks a week
- ☐ more than 21 alcoholic drinks a week

Q12. During the summer months how often do you spend at least 30 minutes outside?

- ☐ most days
- ☐ some days
- ☐ seldom

Q13. During the summer months how do you dress on a warm sunny day?

- ☐ usually wear clothes which expose my arms
- ☐ seldom wear clothes which expose my arms

Q14. What kind of hob (ie, rings for boiling and frying) is used in your kitchen for cooking?

- ☐ gas
- ☐ not gas

Q15. In this question we want to find out how you feel about your life in general. Circle the number that represents where you are on the scale - 7 means you are very satisfied with your life at the moment and 1 means you are very dissatisfied with your life at the moment.

Very dissatisfied

Very satisfied

						
-----Please circle the number below which best represents how you feel at the moment-----						

1

2

3

4

5

6

7

These questions ask about your general health and medical history

Please tick ☒ one box only per question

Q16. In general, how would you rate your health?

- ☐ excellent
- ☐ very good
- ☐ good
- ☐ fair
- ☐ poor

Q17. Do you have any long term illness, health problem or handicap which limits your daily activities or the work you can do?

(include problems which are due to old age)

- ☐ yes ☐ no

Q18. Has your doctor ever told you that you have any of the following?

Please tick ☒ one box on each line

high blood pressure (hypertension)	☐ yes	☐ no
angina	☐ yes	☐ no
heart attack (including myocardial infarction or coronary thrombosis)	☐ yes	☐ no
blocked arteries in the legs	☐ yes	☐ no
deep vein thrombosis	☐ yes	☐ no
Raynaud's disease	☐ yes	☐ no
diabetes	☐ yes	☐ no
Parkinson's disease	☐ yes	☐ no
dementia or Alzheimer's disease	☐ yes	☐ no
depression	☐ yes	☐ no
multiple sclerosis	☐ yes	☐ no
spinal cord injury	☐ yes	☐ no
epilepsy	☐ yes	☐ no
rheumatoid arthritis	☐ yes	☐ no
osteoporosis	☐ yes	☐ no

Please check that there is a tick ☒ on each line

Please tick ☒ one box only per question

Q19. Have you ever had a stroke? (sometimes known as cerebral haemorrhage, cerebral thrombosis, brain haemorrhage, subarachnoid haemorrhage, cerebrovascular accident, or a mini-stroke or TIA)

☐ yes ☐ no

Q20. Has pain or stiffness in your joints caused you problems in the last year? (for example in walking or dressing)

☐ a lot
☐ a little
☐ no

Q21. Do your ankles swell?

☐ a lot
☐ a little
☐ no

Q22. Have you broken any bones as a result of a minor fall (rather than a major accident) since you were 30 years old?

☐ yes ☐ no

Q23. Have you had any problems with your balance or dizziness in the last year?

☐ a lot
☐ a little
☐ no

Q24. How many times have you fallen in the last year?

☐ have not fallen
☐ once
☐ twice
☐ three or more times

Q25. Do you have any problem with your eyesight that is not fully corrected by wearing glasses?

☐ a lot
☐ a little
☐ no

Please tick ☒ one box only per question

Q26. Do you have any problem with your hearing?

- ☐ a lot
- ☐ a little
- ☐ no

Q27. Do you sometimes have difficulty remembering things? We are interested here in your recent memory, for example what you did yesterday, rather than things you did many years ago.

- ☐ a lot
- ☐ a little
- ☐ no

Q28. Do you suffer from any of the following allergies?

Please tick ☒ one box on each line

asthma	☐ yes	☐ no
hayfever	☐ yes	☐ no
dermatitis or eczema	☐ yes	☐ no
allergy to any food	☐ yes	☐ no
allergy to any medication	☐ yes	☐ no
allergy to elastoplast	☐ yes	☐ no

Please check that there is a tick ☒ on each line

Q29. Are you currently taking diuretics or water tablets (eg. burinex, frumil, bendrofluazide, frusemide)?

- ☐ yes
- ☐ no

Q30. Have you had any episodes of urinary infection or cystitis in the last year?

- ☐ yes
- ☐ no

Q31. Has your doctor ever told you that you have problems with your prostate gland?

- ☐ yes
- ☐ no
- ☐ not applicable (female)

**The questions on this page are for women only.
We would like to know about your menstrual cycle and any
children you may have had.**

Please tick ☒ one box only per question

Q32. When did you have your last menstrual period?

- ☐ not applicable (had a hysterectomy)
- ☐ less than three months ago
- ☐ about 3 to 11 months ago
- ☐ about 1 to 5 years ago
- ☐ more than 5 years ago

Q33. Are you currently on hormone replacement therapy (HRT/Oestrogen)?

- ☐ yes
- ☐ no

Q34. How many children have you had (excluding early miscarriages)?

- ☐ none
- ☐ one
- ☐ two
- ☐ three
- ☐ four
- ☐ five or more

If you have had any children, please answer the following questions.

Q35. Was the delivery of any child assisted by forceps or Ventouse?

- ☐ yes
- ☐ no

Q36. Was the delivery of any child by Caesarian Section?

- ☐ yes
- ☐ no

Q37. Were any of your children over 9lbs at birth?

- ☐ yes
- ☐ no

These questions are for men and women and ask about some common urinary and bowel symptoms. Please answer each question thinking about any symptoms you have experienced in the last 12 months

Please tick ☒ one box only per question

Q38. Do you ever leak any urine when you don't mean to?

(this means anything from a few drops to a flood during the day or night)

- ☐ continuously
- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q39. When you leak urine are you usually:

- ☐ soaked
- ☐ wet
- ☐ damp
- ☐ almost dry
- ☐ no leakage

Q40. Does any urine leak when you laugh, cough or exercise?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

If you have this symptom, how old were you when it started?

years old

Q41. Do you have such a strong desire to pass urine that you leak before reaching the toilet?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

If you have this symptom, how old were you when it started?

years old

Answer each question thinking about any symptoms experienced **in the past 12 months**.

Please tick ☒ one box only per question

Q42. Do you leak urine without feeling it happen or realising?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q43. Do you dribble or leak urine immediately after you feel you have finished urinating?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q44. Do you leak urine because you have difficulty going to, or getting on or off a toilet or commode?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q45. Do you leak urine when you are asleep?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q46. During the daytime, how often do you usually go to the toilet to pass urine?
About every:

- ☐ half hour
- ☐ hour
- ☐ 2 hours
- ☐ 3 hours
- ☐ 4 hours

Answer each question thinking about any symptoms experienced **in the past 12 months**.

Please tick ☒ one box only per question

Q47. How often do you usually feel the need to get up at night to pass urine?

- ☐ 4 or more times a night
- ☐ 3 times a night
- ☐ twice a night
- ☐ once a night
- ☐ not usually

Q48. When you need to pass urine, how strong is the urge usually?

- ☐ overwhelming
- ☐ very strong
- ☐ strong
- ☐ normal
- ☐ weak
- ☐ never have this sensation

Q49. How often is the urge to pass urine very strong, making it difficult to delay urination?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q50. Do you feel any pain in your bladder?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q51. Do you feel any pain or burning when passing urine?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Answer each question thinking about any symptoms experienced **in the past 12 months**.

Please tick ☒ one box only per question

Q52. Do you have to strain to pass urine?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q53. Do you feel that your bladder has not emptied completely after you have finished urinating?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q54. Does your urine stop and start several times when urinating?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q55. Is your urinary stream weak?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q56. Do you have to wait for the stream to begin?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Answer each question thinking about any symptoms experienced **in the past 12 months**.

Please tick ☒ one box only per question

Q57. Do you use any pads or padding for your urinary symptoms?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely
- ☐ no urinary symptoms

Q58. Do you use a catheter?

- ☐ yes
- ☐ no

Q59. Do you use any other aids or appliances to help with your urinary symptoms?
(eg commode, plastic sheets, waterproof pants, urinal, bedpan)

- ☐ yes
- ☐ no
- ☐ no urinary symptoms

Q60. Do you feel you need any help with your urinary symptoms?

- ☐ yes
- ☐ no
- ☐ unsure
- ☐ no urinary symptoms

Q61. Have you spoken to anyone about your urinary symptoms in the past 12 months?

You may tick ☒ more than one box

- ☐ GP
- ☐ nurse
- ☐ family/friends
- ☐ hospital doctor
- ☐ other
- ☐ no
- ☐ no urinary symptoms

Q62. Have you had any treatment for your urinary symptoms in the past 12 months?

- ☐ yes
- ☐ no
- ☐ unsure
- ☐ no urinary symptoms

Answer each question thinking about any symptoms experienced **in the past 12 months**.

Q63. How much of a problem would you say you have with your urinary symptoms?

- ☐ severe problem
- ☐ moderate problem
- ☐ mild problem
- ☐ no problem
- ☐ no urinary symptoms

Q64. Do your urinary symptoms:

Please tick ☒ one box on each line

	a lot	a little	not at all	no urinary symptoms
bother you?	☐	☐	☐	☐
cause you any physical discomfort?	☐	☐	☐	☐
interfere with your daily activities?	☐	☐	☐	☐
interfere with your social life?	☐	☐	☐	☐
affect your relationships with other people?	☐	☐	☐	☐
upset or distress you?	☐	☐	☐	☐
affect your sleep?	☐	☐	☐	☐
affect your overall quality of life?	☐	☐	☐	☐

Please check that there is a tick ☒ on each line

Q65. If you were to spend the rest of your life with your urinary pattern just the way it is now, how would you feel about that?

- ☐ delighted
- ☐ pleased
- ☐ mostly satisfied
- ☐ mixed - about equally satisfied and dissatisfied
- ☐ mostly dissatisfied
- ☐ unhappy
- ☐ terrible

Q66. As far as you are aware, have any of your close relatives (parents, brothers or sisters) suffered from any urinary problems?

- ☐ yes
- ☐ no
- ☐ don't know

Answer each question thinking about any symptoms experienced **in the past 12 months**.

Please tick ☒ one box only per question

Q67. Do you ever leak from your bowels when you don't mean to?
(during the day or night)

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q68. If you leak from your bowels when you don't mean to, is there usually:

- ☐ soiling of furniture or bedding
- ☐ soiling of outer clothing
- ☐ soiling of underwear
- ☐ minor staining of underwear
- ☐ no leakage

Q69. Do you have difficulty in delaying a bowel movement once you feel the urge to go?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q70. Do you have to strain when you have a bowel movement?

- ☐ several times a day
- ☐ several times a week
- ☐ several times a month
- ☐ several times a year
- ☐ never/rarely

Q71. These are some questions about your general feelings. Please concentrate on how you have been feeling during the past week.

Please tick ☒ one box per question

Do you feel tense or wound up?

most of the time

a lot of the time

from time to time,
occasionally

not at all

☐☐☐☐

Remember to concentrate on how you have been feeling in the past week

Do you still enjoy the things you used to enjoy?

definitely as much

☐

not quite so much

☐

only a little

☐

hardly at all

☐

Do you get a sort of frightened feeling as if something awful is about to happen?

very definitely and quite badly

☐

yes, but not too badly

☐

a little, but it doesn't worry you

☐

not at all

☐

Can you laugh and see the funny side of things?

as much as you always could

☐

not quite as much

☐

definitely not so much

☐

not at all

☐

Do worrying thoughts go through your mind?

a great deal of the time

☐

a lot of the time

☐

from time to time, but not too often

☐

only occasionally

☐

Do you feel cheerful?

not at all

☐

not often

☐

sometimes

☐

most of the time

☐

Can you sit at ease and feel relaxed?

definitely

☐

usually

☐

not often

☐

not at all

☐

Do you feel as if you have slowed down?

nearly all the time

☐

very often

☐

sometimes

☐

not at all

☐

Do you get a sort of frightened feeling like 'butterflies' in the stomach?

not at all

☐

occasionally

☐

quite often

☐

very often

☐

Have you lost interest in your appearance?

definitely

☐

you don't take as much care as you should

☐

you may not take quite as much care

☐

you take just as much care as ever

☐

Do you feel restless as if you have to be on the move?

very much indeed

☐

quite a lot

☐

not very much

☐

not at all

☐

*Remember to concentrate on how you have been feeling **in the past week***

Do you look forward with enjoyment to things?

as much as you
ever did

☐

rather less than you
used to

☐

definitely less than you
used to

☐

hardly at all

☐

Do you get sudden feelings of panic?

very often indeed

☐

quite often

☐

not very often

☐

not at all

☐

Can you enjoy a good book or radio or TV programme?

often

☐

sometimes

☐

not often

☐

very seldom

☐

Q72. These are some more questions about your general feelings. This time we want to know more about the past 4 weeks.

Please tick ☒ one box on each line

During the past four weeks did you ever feel:

often

sometimes

never

particularly interested in something?

☐☐☐

so restless that you couldn't sit long in a chair?

☐☐☐

proud because someone complimented you on something you had done?

☐☐☐

very lonely or remote from other people?

☐☐☐

pleased about having accomplished something?

☐☐☐

bored?

☐☐☐

on top of the world?

☐☐☐

depressed or very unhappy?

☐☐☐

that things were going your way?

☐☐☐

upset because someone criticised you?

☐☐☐

Please check that there is a tick ☒ on each line

The questionnaire finishes with some questions about you and your home.

Q73. Please indicate whether you are:

☐ male ☐ female

Q74. What is your date of birth?

				1			
d	d	m	m	year			

(For example 21 June 1917
would be entered as)

2	1	0	6	1	9	1	7
---	---	---	---	---	---	---	---

Q75. Approximately how tall were you when you were 20 years old?

feet	inches	

don't know

Q76. What do you weigh now?

stones		lbs	

don't know

Q77. Do you live alone?

☐ yes ☐ no

Q78. What best describes your accommodation?

- ☐ rented from the local authority (Council)
- ☐ rented from private landlord, Housing Association or Trust
- ☐ owned or mortgaged
- ☐ sheltered housing with warden
- ☐ residential home, nursing home or hospital ward
- ☐ other _____

Q79. How many cars are normally available for use by you or members of your household (other than visitors)?

☐ none ☐ one ☐ two ☐ three or more

Please tick ☒ one box only per question

Q80. Which of the following best describes your current employment?

- ☐ retired
- ☐ working full-time (over 30 hours per week)
- ☐ working part-time (30 hours per week or less)
- ☐ on a training scheme or in full-time education
- ☐ unemployed and looking for work
- ☐ unable to work due to long-term sickness or disability
- ☐ at home not looking for paid employment (i.e. tending to house or family)
- ☐ other _____

Q81. How would you describe your ethnic origin?

- ☐ White
- ☐ Indian
- ☐ Bangladeshi
- ☐ Pakistani
- ☐ Black-Caribbean
- ☐ Black-African
- ☐ Black - other _____
- ☐ Chinese
- ☐ other _____

Q82. Did you need help to complete this form?

- ☐ no
- ☐ yes, help from someone in the household
- ☐ yes, help from someone outside the household

Any comments:

Thank you for completing this questionnaire.
Please check you have answered all the questions
and return it in the envelope provided -
no stamp is needed.

«fAdd1»

«fAdd2»

«fAdd3»

«fAdd4»

«fAdd5»

«fAdd6» «fAdd7»

«NAME»

«rHouse»

«rStreet»

«rAddress1»

«rAddress2»

«rAddress3»

«Postcode»

«StudyID»

19 October 1998

Confidential Survey on Health and Lifestyle

Dear «PName»

On behalf of all the doctors in our practice, I hope you will help with a health survey which is being carried out by the University of Leicester. The survey is contacting people over forty years of age who live in Leicestershire and asking them questions about their health and lifestyle. By completing the enclosed questionnaire, you will help to improve local health services in the future, and of course the information you give will be treated in the strictest confidence.

Further information and instructions are given on the front page of the questionnaire and if you have any concerns please contact Lesley Harris at the University on 0116 252 5426.

Thank you for your help.

Yours sincerely

Dr «GPSname»

«NAME»
«rHouse»
«rStreet»
«rAddress1»
«rAddress2»
«rAddress3»
«Postcode»
«StudyID»

19 October 1998

Confidential Survey on Health and Lifestyle

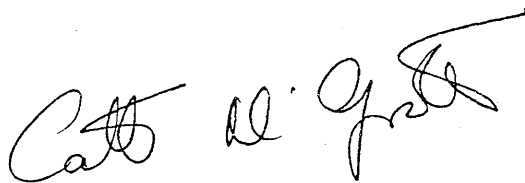
Dear «PName»

We hope you will help with a health survey which we are carrying out with the support of your general practitioner. We are contacting people over forty years of age who live in Leicestershire and asking them questions about their health and lifestyle. By completing the enclosed questionnaire you will help to improve local health services in the future, and of course the information you give will be treated in the strictest confidence.

Further information and instructions are given on the front page of the questionnaire and if you have any concerns please contact me or Lesley Harris on 0116 252 5426.

Thank you for your help.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Cath McGrother', with a stylized flourish at the end.

Dr Catherine McGrother
Community Physician

The Leicestershire Health and Lifestyle Survey

What is The Leicestershire Health and Lifestyle Survey?

The survey is part of a large project at Leicester University Medical School and has your general practitioner's support. The main focus is on urinary symptoms and possible links with health and lifestyle factors. We aim to investigate how these symptoms develop and change over time and to find clues to their causes and prevention. This type of research in the community has led to important discoveries in health and disease, for example the causes of heart disease. In the same way we hope to find the causes of some very common and often distressing urinary disorders.

What is the point of filling in the questionnaire when my health hasn't changed over the last year?

We are following up a group of people who completed the questionnaire a year ago. For our research to be successful we need to have information on a true cross-section of the community. It would be misleading if we only heard from people with poor health which had deteriorated over the year. Therefore it is essential to collect answers from everyone, old and young, with and without health problems.

How will any personal information I provide be safeguarded?

We go to exceptional lengths to protect any information you provide. All participants are given a unique identification number and accompanying barcode. As a result, names and addresses are never seen alongside answers to the questions. We operate under strict rules imposed by the Data Protection Act, Leicestershire Health Authority, the local Research Ethics Committee and the Medical School.

What if I don't want to fill in the questionnaire?

Although we offer complete confidentiality, some people may prefer not to answer the sensitive questions and we respect their wishes. Thank you again for the help you have provided.

If you have any queries, please contact Lesley Harris on 0116 252 5426 at the University of Leicester, Department of Epidemiology and Public Health, 22-28 Princess Road West, Leicester LE1 6TP

Health and Lifestyle Survey

part of the
Leicestershire MRC Incontinence Study

What?

Why?

How?

Why me?

Again?

Taking part is voluntary and any information you give is strictly confidential and will not be seen by your doctor. If you have any queries, please contact Lesley Harris on 0116 252 5426 at the University of Leicester, Department of Epidemiology and Public Health, 22-28 Princess Road West, Leicester LE1 6TP

Inside we have answered some of the questions you may have about this survey

What is the Leicestershire MRC Incontinence Study?

This is a large project studying urinary incontinence and related problems. The Leicester University Medical School set up the project in 1995. The Medical Research Council and the NHS are funding it.

The project is made up of a number of studies. These are looking at different issues, such as:

- how many people have urinary problems?
- what are the causes?
- how do urinary problems affect individuals' lives?
- what are the most effective treatments?
- what health services are needed?
- what are the costs to individuals and to the NHS?

Where do I fit in?

You are taking part in the **Health and Lifestyle Survey**. This is a study of patterns of urinary problems over time. We want to know how these relate to a person's health and lifestyle.

This is the largest survey of its kind in the UK. You are one of 23,000 people who have completed our postal questionnaire about urinary problems and other aspects of your health and lifestyle. Some of you have also completed a questionnaire about your diet. Others have taken part in interviews.

How was I chosen to take part?

We are studying men and women aged 40 and over who live in the community. We chose people at random from the Leicestershire Health Authority's list of patients. Your GP gave consent for us to contact you.

What about confidentiality?

The Data Protection Act 1998 and Human Rights Act 1998 protect you. We follow their strict rules about confidentiality. We only use your name and address when we post you a questionnaire. Your personal details will never be revealed in the results we publish.

Why do I need to fill in another questionnaire?

We are studying changes in health over time. So we need to contact you at least twice. Last year 75% of the original 23,000 participants returned their questionnaire. This year we hope even more of you will do so.

The success of the survey depends on how many people take part. *Even if you have only filled in one questionnaire before, the information you give us now will be useful.*

Do I need to fill in a questionnaire even if I don't have any health problems?

Yes please, most definitely! It is important that people in our survey are representative of the whole population. It would be misleading if we only heard from people with poor health or whose health had got worse in the last year. We need to hear from everyone, young and old, with and without health problems.

What has the project found so far?

Urinary problems are common in the community. 22% of men and 35% of women aged 40 or more have some kind of urinary problem. These problems are more common in older people. But effective treatments do exist.

The project is still ongoing. It is not yet possible to give detailed results. These will be published once the project is completed.