

Incontinence and Older People



**Is there a link
to social isolation?**

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**Research and report commissioned
by Help the Aged**

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Introduction

This report describes a study designed to capture the experiences of older people with incontinence and to explore the potential link between incontinence and social isolation. Incontinence is a common problem that can affect people of all ages, and while it is not an inevitable part of ageing, bladder and bowel problems are more prevalent in older people. Loss of normal bladder and or bowel control adversely affects the physical, psychological and social aspects of older people's lives. There are many studies that have measured the impact and prevalence of incontinence in older people, but few that have explored older people's experiences.

Social isolation and loneliness are often perceived as problems of old age, although the majority of older people do not consider themselves to be lonely or socially isolated (Victor, Scambler et al. 2000). There are many factors associated with social isolation, including personal characteristics, demographic factors, provision and access to resources and life events. This study explores the possible relationship between incontinence and social isolation. This new knowledge will provide better understanding of the impact that incontinence can have on an older person's life and can help to inform policy and practice recommendations.

The study's aims were to:

- understand the impact of incontinence on the quality of life of an older person in terms of its effect on behaviour, psychological and social health; and
- explore the potential link between incontinence and social isolation.

The key objectives were to explore:

- the impact of incontinence on quality of life, social contact, general well-being and self-esteem;
- the emotional and psychological effects of incontinence;
- how incontinence, urgency or fear of incontinence impacts upon older people's

ability or desire to engage in activities outside their home;

- the extent to which incontinence creates a barrier to engaging in the outside world and increases the risk of social isolation;
- the impact of incontinence on social activity and the reasons for such restriction;
- the aspects of the physical environment that exacerbate the impact of incontinence in terms of risk of social isolation; and
- whether environmental and other factors could be improved or put in place to reduce the impact of incontinence.

Background

Uncontrolled loss of urine or faeces is a common health problem in older people and is associated with significant psychosocial, physical and economic consequences. This section outlines what is known about the prevalence and impact of incontinence. The concepts of social isolation and loneliness are introduced and the policy context briefly reviewed.

Definitions of urinary incontinence vary but invariably relate to 'the involuntary loss of urine' (Corna, Cairney 2005). A more widely accepted definition is that it is an objectively proven condition in which involuntary loss of urine is a social or hygienic problem (Bates, Bradley et al. 1979). The latter definition is interesting because it makes no reference to the underlying pathophysiology or aetiology (Mitteness, Barker 1995) and by stating that it should be 'objectively proven' suggests that a medical affirmation of incontinence is more important than the incontinent person's understanding and experience of incontinence.

The classification of urinary incontinence is complex and emphasises the pattern of urine loss (stress, urge, overflow, mixed) (Diokno 1990). Stress incontinence is characterised by the involuntary loss of urine with effort or exertion, while urge incontinence is an involuntary leakage of urine associated with urgency (Norton, Brubaker 2006).

The prevalence and impact of incontinence on quality of life reported in the literature varies partly because of the different definitions used and the heterogeneous nature of incontinence. Defining faecal incontinence is also problematic as there is a lack of consensus (Steele, Campbell 2005). Although a simple definition is the involuntary loss of rectal contents through the anal canal, this can be more usefully elaborated to include incontinence of flatus, liquid, or solid stool, which has an impact on quality of life (Madoff, Parker et al. 2004).

Prevalence of incontinence

The reported prevalence of faecal incontinence in older people has varied considerably in the literature due in part to methodological differences between the studies. A more recent study has confirmed that faecal incontinence is a significant problem, given that it is more prevalent, more severe and more likely to have an impact on quality of life in older people.

Major incontinence, defined as soiling of underwear, outer clothing, furnishing or bedding several times a month or more often, was reported by 2.3 per cent of adults aged 65 years (Perry, Shaw et al. 2002). A systematic review of the prevalence of faecal incontinence in the community revealed that the rates of faecal incontinence (FI) were significantly higher in older people compared to younger people (Pretlove, Radley et al. 2006). The review was based on 29 studies (69,152 participants) and revealed that the rate of solid and liquid faecal incontinence among men over 60 was 5.1 per cent and 6.2 per cent in women over 60. The difference in rates between men and women was not statistically significant (Pretlove, Radley et al. 2006). Another review study also confirms that women and men seem to have a similar prevalence of FI (Stenzelius, Mattiasson et al. 2004).

There are variations in the prevalence rates of urinary incontinence reported in the literature reflecting different definitions of incontinence, target populations, sampling approaches and

data collection methods. For non-institutionalised older people living in the community the reported prevalence rates range from 16.4 per cent (65 to 69 years) (Maggi, Minicuci et al. 2001) to 36 per cent (over 70 years) (Temml, Haidinger et al. 2000) in women and from 4.6 per cent (65 to 69 years) (Maggi, Minicuci et al. 2001) and 20.9 per cent (over 65 years) (Ko, Lin et al. 2005) to 23 per cent (over 65 years) (Stoddart, Donovan et al. 2001) in men. A prevalence rate of 39 per cent (men and women over 65 years) was reported for a population of community-living older people (Peters, Horrocks et al. 2004).

A systematic review to derive age- and gender-specific rates of incontinence attempted to provide an accurate overall estimate from the cumulative data of 12 studies (Chiarelli, Bower et al. 2005). The pooled age-specific prevalences for females are 20.3 per cent (60 to 69 years), 23.5 per cent (70 to 79 years) and 28.4 per cent (over 80 years). The pooled age-specific prevalences for males are 6.8 per cent (60 to 69 years), 11.3 per cent (70 to 79 years) and 15.1 per cent (over 80 years) (Chiarelli, Bower et al. 2005). Review studies such as this confirm that the prevalence of urinary incontinence is higher with increasing age in both males and females and that urinary incontinence is more common in women (Stenzelius, Mattiasson et al. 2004).

However, simply reporting the prevalence of urinary incontinence may be misleading since urinary incontinence is not always perceived as bothersome by women. It is argued that the prevalence of incontinence that is problematic hygienically or socially would be more indicative of the need for health services since those women who do not consider their incontinence as troublesome may not seek treatment (Swithinbank, Donovan et al. 1999).

People with incontinence report significantly more health problems than those without incontinence and this is particularly true of those with combined urinary and faecal incontinence who are the most frail (Stenzelius, Mattiasson et al. 2004). The prevalence of double incontinence is also dependent on the different

definitions used, population samples and methods of data collection. In a community-based study the prevalence of double incontinence was reported to be 5.9 per cent in men and 9.4 per cent in women over 50 (Roberts, Jacobsen et al. 1999). However, a review study reveals that the reported prevalences of double incontinence do vary (Stenzelius, Mattiasson et al. 2004) reflecting differences in research design.

In summary, all types of incontinence are common among older men and women and the prevalence increases with age. Urinary incontinence is more common in women, while the prevalence of faecal incontinence and double incontinence is similar in both men and women.

Impact of incontinence

Incontinence is not life-threatening, but it can have a profound impact on the quality of life. The impact of both urinary and faecal incontinence is significant in terms of the costs to both individuals and the wider society (Avery, Gill et al. 2004). Most studies investigating the psychosocial issues of incontinence have measured the impact of incontinence.

Measuring the impact of incontinence on the everyday lives of older people is complex (Burgio, Ouslander 1999). Measures of quality of life are either generic or condition-specific (Dugan, Cohen et al. 1998). Generic measures are designed to be used across a range of conditions and populations (Hajjar 2004), but they may lack sensitivity to the distinctive features of incontinence and its effects on quality of life (Dugan, Cohen et al. 1998) (Heidrich, Wells 2004). Condition-specific measures relate to a specific disease and may be more sensitive (Hajjar 2004, Swithinbank, Abrams 1999). Several instruments have been developed that are specific for sub-types of incontinence, such as urge incontinence (Burgio, Ouslander 1999). There are other studies that include some measure of quality of life as part of

a general questionnaire (Swithinbank, Abrams 1999).

In the past 20 years a variety of condition-specific tools for urinary incontinence has been developed and tested. Comparisons between studies using different measures are difficult because of differences in research design, population samples, definitions and types of incontinence as well as differences in the factors measured (Hajjar 2004). These differences also account for variations in the reported impact of incontinence on quality of life.

In a large study to measure the prevalence and perceived impact of lower urinary tract symptoms, including incontinence, in women over 18 years, 61 per cent of women reporting incontinence found it problematic (Swithinbank, Donovan et al. 1999). Thirty-seven per cent of the participants considered their urine loss bothersome in a study that investigated the effectiveness of two quality-of-life measures for bothersome incontinence in older women (Robinson, Pearce et al. 1998). Another study revealed that of those women reporting incontinence, 44 per cent indicated that it had a detrimental impact on their quality of life (Vinker, Kaplan et al. 2001).

These and other studies suggest that the impact of incontinence is variable and that it is not inevitably viewed as problematic. A contrasting perspective is reported from a Canadian study comparing the impact of self-reported chronic conditions on health-related quality of life. This comparison revealed that urinary incontinence had a severe impact on health-related quality of life and that compared to other long-term conditions, urinary incontinence was reported as having one of the greatest effects (Schultz, Kopec 2003).

Despite the difficulties in comparing studies it is clear that most reveal that incontinence has a profound impact on psychosocial well-being (Hajjar 2004). However, the impact of urinary incontinence is highly subjective and variable and there are no universal statements about the social and emotional impact of urinary incontinence on older people. The factors

responsible for the varying impact also remain speculative (Johnson, Ouslander 2001). The impact experienced is reported in some studies to be variable according to the type of urinary incontinence, with urgency and urge incontinence having a more profound effect on quality of life than stress incontinence (Grimby, Milsom et al. 1993, Swithinbank, Abrams 1999).

The effects of both age and severity on the impact of incontinence on quality of life are also reported to be variable in different studies (Swithinbank, Abrams 1999). This possibly reflects the complex interplay between severity of urine loss, different interpretations of incontinence and a variable capacity to accept limitations on lifestyles. This complexity is illustrated in a Japanese study, which reports that the impact on physical health is greater in women in their 20s, while the impact on mental health is more pronounced in older women (Araki, Beppu et al. 2005).

Although most studies reveal that incontinence has a considerable impact on psychosocial well-being, reports of the impact of urinary incontinence on social activities vary among different studies (Hajar 2004). A Swedish study investigating the influence of urinary incontinence on the quality of life of older women using a generic measure and the Nottingham Health Profile Questionnaire revealed that women with incontinence were more socially isolated than their age-matched counterparts and that social isolation was correlated with all types of incontinence (Grimby, Milsom et al. 1993). This is confirmed in other studies that report that incontinence results in social isolation, anxiety, low self-esteem, depression and decreased satisfaction with life (Criner 2001) and additionally has a negative impact on travel and physical activity (Gallagher 1998).

The negative effect of urinary incontinence on activities is also confirmed by a study which sought to identify the most valid content areas for a new condition specific tool for incontinence (DuBeau, Levy et al. 1998). This revealed differences between the experts and

those with incontinence. Compared with expert-defined items from the literature, which tended to focus on the functional impact of incontinence, people with incontinence-defined items focused more on emotional well-being and on the interruption of activities (DuBeau, Levy et al. 1998).

There is a lack of research into the impact of faecal incontinence (Avery, Gill et al. 2004, Miner 2004) and there is an urgent need for more research that focuses on faecal incontinence, including its effects (Bliss, Krissovich et al. 2004). However, studies do suggest a significant association between faecal incontinence and high levels of anxiety and depression in older people (Deutekom, Terra et al. 2005, Edwards, Jones 2001) and faecal incontinence has a significant impact on usual activities (Deutekom, Terra et al. 2005).

Studies that address the psychosocial issues of incontinence have tended to focus on **measuring** the impact of incontinence on quality of life rather than **exploring** the impact of incontinence on the quality of life of older people. There have been relatively few studies exploring the psychosocial impact of incontinence in men (Burgio, Ouslander 1999, Moore, Gray 2004) and consequently there are gaps in our understanding of how incontinence affects them. This supports the need for research studies such as this, which explore the experiences of both older men and women with incontinence. In addition, the focus of many studies has been on urinary rather than faecal incontinence. Although there is some debate about the factors that are responsible for the varying impact of incontinence on the lives of older people, there is no consensus and they remain largely unknown.

Social isolation and loneliness

Since this study aims to explore the relationship between incontinence and social isolation, further deliberation on the terms social isolation and loneliness is appropriate. The concepts of social isolation and loneliness are

understood in a number of ways (Victor, Scambler et al. 2000); the terms are often used interchangeably and linked together, although there is no causal relationship between the two concepts (Wenger, Davies et al. 1996). Social isolation and loneliness are often perceived as problems of old age although the majority of older people do not consider themselves lonely or socially isolated (Victor, Scambler et al. 2000). Social isolation and loneliness are associated with a reduced quality of life and life satisfaction among older people (Victor, Scambler et al. 2000, Wenger, Davies et al. 1996) and the problem of social isolation in an expanding ageing population is therefore of growing concern (Findlay 2003).

A review of loneliness and social isolation in later life, which included British studies between 1948 and 1991, revealed that 2 to 20 per cent of people over the age of 65 were socially isolated (Victor, Scambler et al. 2000). More recently, a UK study of loneliness and isolation revealed that more than 12 per cent of people over 65 felt socially isolated (Owen 2001).

Social isolation can be viewed as the objective state of having minimal contact with other people, while loneliness describes the subjective feelings elicited by social isolation or a perceived lack of social contact (Victor, Scambler et al. 2000). Social isolation is an objective measure of social interaction, but since some older people may prefer to be alone, a lack of social interaction does not inevitably lead to the individual feeling lonely. Similarly, having an expansive social network is not synonymous with the absence of loneliness. A four-fold typology has been proposed which describes people as being not lonely and not isolated; isolated but not lonely; lonely but not isolated; and both isolated and lonely (Andersson 1986).

There are many factors associated with social isolation, including personal characteristics, demographics, resources and life events (Victor, Scambler et al. 2000). The relationship between these factors is unclear (Victor, Scambler et al. 2000, Wenger, Davies et al. 1996), although of

particular relevance to this study. It is clear that there is an association between isolation and living alone (Wenger, Davies et al. 1996), that the quality of social networks rather than quantity protects against isolation (Pinquart, Sörensen 2001) and that there is a clear relationship between isolation and poor physical and mental health (Wenger, Davies et al. 1996).

Social exclusion relates to social isolation and social segregation. It has many meanings, including those who are excluded from the labour market and those who are denied social citizenship status because of stigmatisation, restrictive legislation and institutional discrimination (Pinquart, Sörensen 2001).

Exclusion among older people is characterised by deprivation and the lack of access to social networks, activities and services, resulting in a poor quality of life. Age, sex, ethnicity, living arrangements, family structure, employment status, health, income and wealth are all factors involved in the exclusion facing older people (Social Exclusion Unit 2006).

Incontinence may be one of several aspects of an older person's life that contribute to social isolation.

Policy context

The framework for improving continence services for older people is provided by guidance and service standards in a number of policy documents including the *Good Practice in Continence Services* report (DH 2000), the National Service Framework for Older People (DH 2001a) and the National Service Framework for Long-term Conditions (DH 2005a). Management of urinary incontinence in women is also guided by a National Institute for Clinical Excellence guideline (NICE 2006). A review of continence services was instituted in 1998 and the working group was charged with updating the guidance on continence services originally issued in 1991 by the Department of Health (DH 1991). This led to the *Good Practice in Continence Services* (DH 2000), containing expert opinion and research-based evidence,

which stressed the need for integrated continence services and emphasised the importance of proper assessment and management. It also called for a regular audit of services and suggested potential quality indicators. However, while it provided guidance, it could be argued that it did not stipulate how good practice could be realised (Milne, Moore 2003).

The National Service Framework for Older People (DH 2001a), a ten-year strategy for ensuring fair, high-quality, integrated health and social care services for older people, set the requirement that service providers should establish integrated continence services for older people by April 2004.

Another report from the Department of Health, *Essence of Care* (DH 2001b), was initially launched in 2001 and revised in 2003. It provides a tool to help practitioners take a patient-focused and structured approach to sharing and comparing practice. The report includes benchmarks covering eight areas and two of these relate to continence care and preserving privacy and dignity.

The first national audit of continence care for older people in the UK set out to examine the quality of care, based on the standards set in the National Service Framework for Older People (DH 2001a) and the Department of Health guidance *Good Practice in Continence Services* (DH 2000). The audit, funded by the Healthcare Commission and undertaken by the Royal College of Physicians' Clinical Effectiveness and Evaluation Unit, examined the quality of care for 9,197 older people (65 years and older) with urinary and faecal incontinence in primary and secondary care, and 749 residents in care homes in England, Wales and Northern Ireland.

The results of this audit (RCP 2005) indicate a widespread failure to diagnose and manage continence problems. It reports that patients were often not examined thoroughly or were given routine assessments. The report also reveals there was limited effort to determine the underlying cause of incontinence and there is a continued emphasis on managing symptoms

rather than actively treating the problem. Additionally, the audit revealed a lack of written policies on continence, missing documentation about the problem, limited provision of staff training, high use of in-dwelling catheters in hospital settings and widespread rationing of incontinence pads.

Results of the second survey, carried out a year later by the Royal College of Physicians (RCP 2006), show little improvement. While the necessary basic infrastructure to provide continence services exists, the provision of true integrated services is incomplete. Some services have been reduced and there is still an emphasis on containment rather than cure. The rationing of pads leaves many patients having to fund their own supplies.

A joint report of the Healthcare Commission, the Commission for Social Care Inspection, the Audit Commission and Better Health in Old Age assessed progress five years into the ten-year government plan to improve services for people over the age of 50. This report, *Living Well in Later Life* (Chai 2006), found that while services have improved since the publication of the government's ten-year National Service Framework for Older People (DH 2001a), this progress was not consistent across the UK and improvement in some areas has been slow. None of the communities inspected had reached all the government-set milestones to enable them to meet the standards in the National Service Framework at the halfway stage of the plan.

The priorities for the second phase of the government's ten-year National Service Framework (NSF) for Older People are set out in *A New Ambition for Old Age: next steps in implementing the National Service Framework for Older People* (DH 2006a). The Government's ambition for old age revolves around the three main themes of dignity in care, joined-up care and healthy ageing.

There are ten programmes of activity under these three themes, which help to shape the policy context for the provision of continence services. The themes of joined-up care and

healthy ageing reflect the government's aspirations, set out in the White Paper *Our Health, Our Care, Our Say* (DH 2006b). This seeks to change the way services are provided and outlines four main goals: health and social services will provide better prevention services with earlier intervention; people will have more choice and a louder voice; more will be done to reduce inequalities and improve access to services; and there will be more support for people with long-term needs. A recent report, *A Recipe for Care*, highlights similar themes and stresses the importance of reconfiguring specialist services for older people so that long-term conditions are managed in the community by integrated health and social care services (DH 2007).

Some of these themes are also evident in the final report from the Social Exclusion Unit (Social Exclusion Unit 2006), *A Sure Start to Later Life: ending inequalities for older people*. The report details government plans to alleviate the exclusion, poverty and isolation experienced by older people. It emphasises prevention rather than crisis intervention and well-being through investment in local communities and support in older people's own homes. It moves beyond social services and promotes participation, leisure, education and better housing.

Improving participation and prevention are crucial elements in this and they echo the current policy emphasis on active ageing, which seeks to promote the benefits of physical activity as a cornerstone of the health, well-being and quality of life of older people. The concept of active ageing also embraces healthy living, volunteering, leisure, learning, and community participation (WHO 2002).

This brief overview of some key policy documents that have a direct bearing on the provision of continence services and the broader health and social care of older people, highlights a number of recurring government objectives. These aspirations include the development of local infrastructure and services that promote participation in activities to encourage health and well-being, better

prevention services, proper assessment and management of continence and the provision of integrated continence services.

Critical review of the literature

Rationale for review

The main purpose of the literature review was to explore any previously identified links between incontinence and social isolation. Additional aims were to discern general attitudes and experiences of older people living with incontinence and to inform the range of topics to be considered during in-depth interviews.

Search strategies

Searching for literature involved hunting through electronic databases and then a snowballing approach whereby key articles and authors were used to identify further literature. Relevant literature concerning incontinence and social isolation was identified by searching nursing, biomedical, behavioural and social sciences databases. A total of five research databases (British Nursing Index, CINAHL, MEDLINE, PsycINFO and ASSIA) were searched.

The development of the search strategy was an iterative process comprising initial thesaurus searching and then searching significant papers for key terms. In order to ensure that relevant studies were not missed, the search terms were developed to undertake a broad search that could then be refined to answer the questions posed by the project. The aim was to locate documents that related to the three areas under exploration:

- incontinence
- older people and
- social isolation.

Suitable terms that related to the concept of social isolation and which enabled us to access the relevant literature were explored before agreeing a final set of search terms. This process resulted in a number of key words, which were linked together in the following search string: ((urinary or fecal or faecal) and incontinence and (old* or elder*)) and (('quality of life') or (social or psychological or emotion*)).

The search was limited to English publications from 1998 to October 2006 to ensure that contemporary research was obtained. Relevant

articles were also identified by checking the citations of papers identified through the electronic databases and following up articles by key authors.

Search results

Retrieval of references

Abstracts of 33 papers were retrieved from the ASSIA database and 526 from the combined search of British Nursing Index, CINAHL, MEDLINE and PsycINFO databases. This large number reflected the broad and inclusive search. At this stage, only 24 articles were related to faecal incontinence. The abstracts were read to assess their relevance to the three areas under exploration and this yielded 17 papers from the ASSIA search and 69 from the combined search of the other databases. Twenty-seven abstracts were removed at this stage because they were repetitions. The remaining 59 papers were considered relevant.

Inclusion criteria

The 59 articles were sought but one was unobtainable from the British Library. The remaining 58 papers were read to determine their fit with the inclusion/exclusion criteria. Papers that reported empirical research and those that reviewed the literature and discussed theoretical concepts were included. Inclusion criteria for articles were those that:

- focused on older people and incontinence and
- explored the impact of incontinence on quality of life and/or psycho-social well-being.

Exclusion criteria were studies that

- reported on quality of life and/or symptoms scores/correlates of UI but
- lacked exploration of patients' perspectives, experiences or attitudes.

After the articles were reviewed independently by two researchers, 20 articles were considered to fit the inclusion criteria. Snowballing yielded a further six articles that were considered relevant and met the criteria. The 26 articles included papers that reported both qualitative and quantitative research studies (Table 1) and included four papers concerning faecal incontinence.

Table 1: Types of articles in the 26 papers

Type of research	Number of studies	Surname of first author
Survey (mainly quantitative data)	10	Bertera, Dugan, Deutekom, Edwards, Fultz x 2, Iglesias, Lee, Newman, van Oyen
Literature review	7	Bradway, Edgley, Hajjar, Miner, Shaw, Steeman, Wilson,
Qualitative study	8	Chelvanayagam, Collings, Bradway, Brown, DuBeau, Horrocks, Robinson, Shapiro
Case study	1	Paterson

Critiquing the studies

The articles were appraised using the Critical Appraisal Skills Programme (CASP) 2006, although this was to develop familiarity with the papers in order to facilitate data extraction rather than to eliminate unsuitable papers. Elimination of papers could have resulted in loss of important data (Sandelowski 1997). Relevant data were extracted and themes developed.

Of the 26 articles, 19 were research-based and seven were literature reviews. A total of 21 studies focused on urinary incontinence, reflecting the scarcity of literature that explores older people's experiences of faecal incontinence. Only four research-based articles about faecal incontinence met our criteria and one literature review focused on both urinary and faecal incontinence.

Sample sizes ranged from three to 2,818. The studies that were collecting quantitative data about the prevalence and impact of incontinence tended to include both continent and incontinent respondents and had large sample sizes, whereas the qualitative studies included only people with incontinence and the samples were smaller, ranging from three to 38. The sampling strategies were very variable and the variations in the demographics reflected this. Of the 19 studies, seven were exclusively exploring women's experiences while only one study was wholly concerned with men's experiences of incontinence. The age range was variable and

some of the large studies surveyed adults across the entire adult age span. Only 14 of the 26 papers dealt specifically with older people and in studies that claimed to have older people as their specific focus, some included people aged 60 and over while others included people aged 65 or older.

Findings

The search of the literature on older people and incontinence confirms that there is little reported data that helps to illuminate the personal impact of incontinence, and what there is largely focuses on urinary incontinence rather than faecal incontinence (Chelvanayagam, Norton 2000, Miner 2004). Many of the studies in the broad search were eliminated because they focused on measuring the impact and/or prevalence of incontinence rather than exploring older people's experiences of incontinence. This resonated with the view that experts tend to focus on the functional impact of incontinence while those with incontinence more often allude to the impact of incontinence on their emotional well-being and participation in activities (DuBeau, Levy et al. 1998). This review also reaffirmed that much of the literature on urinary incontinence is related to women (Wilson 2004) and that there are few studies that focus on men (Edgley 2002).

Eight key concepts emerged from the articles reviewed: conceptualisation of incontinence,

identity and self-esteem, being in control or out of control, coping and management strategies, negative feelings, depression and anxiety, social interactions and activities.

Conceptualisation of incontinence

The prevailing beliefs and interpretations held by older people about incontinence give insight into the meanings they attribute to it. A recurring theme in the literature is that women consider urinary incontinence a consequence of ageing (Hajjar 2004b, Horrocks, Peters et al. 2004, Robinson 2000, Shaw 2001). In one study, 56 per cent of respondents thought incontinence was normal and a part of ageing (Newman 2004). In the same study, the older women with incontinence appeared to belong to one of two groups: those who felt incontinence was a normal accompaniment of ageing and who were not embarrassed to tell their doctor, and another, smaller, group that was reluctant to seek medical help and was uncomfortable discussing incontinence. The latter group was more likely to feel that incontinence had a negative impact on their lives (Newman 2004).

In a qualitative study of 20 older people living in the community, which sought to explore what prevents older people from seeking treatment for their incontinence, attitudes to ageing and beliefs about the cause of incontinence seemed to be influential in how participants reacted to their incontinence. In this study most participants accepted incontinence and its effects as a normal consequence of ageing (Horrocks, Peters et al. 2004).

Lay beliefs and interpretations of incontinence are important factors in the illness behaviour of people experiencing incontinence (Shaw 2001) and in shaping the therapeutic partnership (Wilson 2004). Despite this, there is little in the literature that explores the meaning urinary incontinence has for older people.

A recent study, in which 17 community-dwelling women were interviewed about their experience of urinary incontinence, suggested that the women's narratives were of three main

types (Bradway 2005). The quest narrative encompasses a matter-of-fact response to incontinence, the development of strategies to manage it, accepting it and getting on with life. The restitution narrative is typified by an individual who does not focus on the negative impact of incontinence but learns to live with it and makes favourable comparisons with others who are worse off. The hallmarks of the victim narrative are that the woman feels unable to resolve the problems associated with incontinence and blames the incontinence on external factors (Bradway 2005). The women in this study described differing experiences and this may partly reflect their diverse age ranges (28 to 86, mean 65 years) and the heterogeneous nature of urinary incontinence (Bradway 2005).

Another way of conceptualising the meaning of incontinence is to consider it as being somewhere between a disorder and a disease. The significance of this is that a disorder is often managed as a social problem while a disease is regarded as a medical problem (Steeman, Defever 1998). A disease can be treated while a disorder embodies negative aspects, such as labelling, blame and unacceptable behaviour (Steeman, Defever 1998). If incontinence is viewed somewhere along this continuum it may not be considered treatable but instead managed with a range of strategies so that it remains concealed (Steeman, Defever 1998).

Differences in the way older people explain their incontinence are highlighted in the literature. However, whether older people experience and understand incontinence differently if it is related to a medical condition, such as multiple sclerosis, rather than to more ill-defined causes, is not explored in the literature.

The explanatory style that older people use to explain how and why they are incontinent is considered to be an important mediator of the impact of incontinence on their quality of life (DuBeau, Levy et al. 1998). Three domains – locus of blame for urinary incontinence (external or internal), duration (transient or

ongoing) and specificity (specific or global) – were used to code the explanatory statements made by participants in focus groups and ultimately the statements were coded as positive, negative or mixed, depending on the domain elements. For example, a statement that was coded as internal, ongoing and global was considered negative while a statement was considered positive if it was coded external, temporary or specific (DuBeau, Levy et al. 1998). Analysis of the explanatory statements used in the focus groups revealed that most were positive-style comments. There was a significant correlation between the negative explanatory style and six specific urinary incontinence-related quality of life items: sense of inevitability, poor self-concept, concern that urinary incontinence is a psychological rather than physical problem, association with women's biology, fear of ageing and shame. The authors suggest that these items reflect a sense of inescapable destiny that is consistent with a general feeling of helplessness (DuBeau, Levy et al. 1998).

There is a dissonance in the acknowledgement that a social construction of urinary incontinence exists, yet much of the understanding of incontinence comes from studies that are designed to exclude the social context (Paterson 2000).

Identity and self-esteem

In cultures where continence is a tacit precondition for being socially acceptable, urinary incontinence with its connotations of self-neglect, lack of hygiene or poor self-discipline may be considered as confirmation of social incompetence. This may contribute to the negative impact of incontinence on self-esteem in older people (Wilson 2004). However, cultural attitudes to urinary incontinence vary and it is suggested that in most Western cultures incontinence is increasingly regarded as a medical illness (Wilson 2004) and so the linkage to incompetence is weakened. Other aspects of incontinence that are reported to affect self-esteem adversely include the stigmatisation of

incontinence (Edgley 2002) and the loss of control over the bladder and bowel with the concomitant threat to cleanliness (Miner 2004).

Although some studies indicate that urinary incontinence has a major impact on well-being, a study of continent and incontinent respondents revealed that while a minority reported adverse consequences, the majority did not report that urine loss affected their self-esteem (Fultz, Herzog 2001).

The threat to self-esteem may be minimised by a range of strategies that enable the older person to adjust to the problem rather than dealing with the problem of incontinence itself (Steeman, Defever 1998). Self-management of urinary incontinence helps to maintain self-esteem when other disabling conditions dominate older people's lives (Horrocks, Peters et al. 2004).

A collective case study of three men over 60 years with post-prostatectomy urinary incontinence revealed that the stigma experienced affects public and private identity (Paterson 2000). Since they wanted to portray themselves to the public as being continent of urine, the men employed concealing devices or tactics to protect their public identity and they were constantly fearful of public detection of their incontinence. Although their public identity was preserved, their private identity was threatened. The men indicated that their experience of urinary incontinence was as an interaction between body and self and that they had to reconfigure a sense of self that accommodated their leaking body. This reconfiguration of self was achieved by a rejection of cultural attitudes to incontinence, which was facilitated by their knowledge of anatomy and physiology, family history and life events (Paterson 2000).

Low self-esteem is also a significant aspect of the experience of faecal incontinence. In a study of women with faecal incontinence, focus group discussions contained repeated references to low self-esteem and confidence (Chelvanayagam, Norton 2000).

Being in control or out of control

Gaining bladder and bowel control are symbolic in the move from childhood to independence and loss of control over these functions as an adult threatens the autonomy and independence of the individual (Edgley 2002) and causes psychological stress (Miner 2004). Being or appearing to be in control is also necessary for being viewed as a competent performer in society (Paterson 2000). This is illustrated by women with faecal incontinence, who expressed the need to be in control and who had a fear of losing control (Chelvanayagam, Norton 2000).

In a study of 65 women with urinary incontinence (primarily with urge symptoms), the most commonly cited references in focus group transcripts that related to functioning and well-being were about loss of control. This loss of control was exemplified by women who reported loss of bodily functions and feeling like a child (Brown, Subak et al. 1998). Being in control is an important mediating factor in the impact incontinence has on quality of life (Steeman, Defever 1998) and being in control involves developing strategies that enable the person to accept their incontinence and minimise its significance (Steeman, Defever 1998).

Coping and management strategies

Although the literature indicates that many older people with incontinence do not seek help, there are variations in the prevalence of help-seeking behaviour reported in studies (Shaw 2001). In one study, 65 per cent of respondents sought professional advice concerning urinary incontinence (Newman 2004).

The severity of incontinence can affect behaviour by mediating the individual's appraisal of their situation as being a threat to health. Appraisal of a situation as a health threat depends on the person's constructions of what constitutes a medical condition or illness (Shaw 2001). Since urinary incontinence is often viewed as a usual consequence of ageing, it is not

credited with an illness label and is not deemed worthy of discussion with health professionals (Bertera 2002, Shaw 2001). Other people may not seek help because they believe there is no cure for their symptoms (Shaw 2001).

This is reinforced by others who suggest that incontinence may be viewed by older people with incontinence and health professionals as somewhere between a disorder and disease and therefore, rather than being treated, it is managed (Steeman, Defever 1998). This lack of disclosure to health professionals was highlighted in a study of older people living at home with faecal incontinence – of 78 people with incontinence, 54 per cent had not discussed it with a health professional (Edwards, Jones 2001).

There are many factors that influence an individual's appraisal of the situation and their decision to act on the symptoms and these include an appraisal of their ability to cope (Shaw 2001). A range of strategies may be employed as part of the individual's coping plan and these may or may not include asking for medical help (Shaw 2001). Management strategies include developing comprehensive knowledge of the location of toilets when going out and carrying a change of clothes (Miner 2004). Other strategies include self-imposed daily routines, regular visits to the toilet, restrictions on drinking and choice of clothing, and well-judged use of continence pads (Horrocks, Peters et al. 2004). Much is invested in behavioural strategies adopted in response to incontinence and this can severely deplete the older person's time and energy for other activities (Bertera 2002).

Older people may manage their symptoms in isolation and secrecy to avoid societal censure (Bradway 2003, Wilson 2004). Negative feelings towards incontinence play a part in older people concealing their incontinence problems (Horrocks, Peters et al. 2004) and this secrecy is a psychological strategy designed to minimise negative feelings older people have about themselves (Bradway 2003).

The theory that emerged from a study of nursing home residents' perspectives of urinary incontinence using grounded theory methodology was focused on elucidating a process called managing urinary incontinence (Robinson 2000). The six strategies used by residents to manage their urinary incontinence revealed by in-depth interviews and participant observation were: limiting, improvising, learning, monitoring, speaking up and letting it go (Robinson 2000). Managing urinary incontinence included limiting activities and behaviours and improvising with a range of tactics to avoid inappropriate urine loss or its effects (Robinson 2000). The consequences of managing incontinence depended on the extent to which the strategies were employed to the satisfaction of the resident and supported by others (Robinson 2000).

In a study of women with faecal incontinence, coping strategies identified by the women included restricting activity, denial, knowing the location of toilets when going out and the use of pads (Collings, Norton 2004). Another study also indicated that some women coped by planning their activities carefully (Chelvanayagam, Norton 2000).

People employ a range of coping and management strategies to minimise the risk of accidents. These strategies, while protecting their public image, may reduce the time they have to engage in activities. Keeping incontinence secret to avoid societal disgrace may cause older people to isolate themselves.

Negative feelings

Urinary incontinence is widely reported to cause emotional distress (Bradway 2003) and a prevailing view is that the embarrassment associated with incontinence has a significant effect on the psychosocial well-being of people's lives (Edgley 2002). In a study of the experiences of older women with incontinence, 50 per cent (126) worried about being embarrassed or humiliated (Shapiro, Setterlund et al. 2003). Anger and frustration may also be expressed by

people with incontinence (Miner 2004). Other negative outcomes include fear of leakage (Bertera 2002). These negative feelings were echoed in a study exploring women's experiences of faecal incontinence where the women revealed negative feelings, including stress, anger, shame and embarrassment (Collings, Norton 2004).

In a study of older people in Hong Kong, those with incontinence reported they were easily angered and had feelings of stress. They also worried that incontinence would have a negative impact on their usual social interactions and activities. Older men testified to more negative psychological effects than older women (Lee 2004).

In a study by Brown, Subak et al. (1998) in which 65 women with urinary incontinence – primarily with urge symptoms – participated in focus groups, the women's experiences were allocated to three broad domains: feelings, relationships and activities. Most of the words used by the women were allocated to either feelings (52 per cent) or activities (40 per cent) with only 8 per cent associated with relationships (Brown, Subak et al. 1998). Within the domain of feelings, the most cited were about loss of control while feelings connected with lowered self-esteem were expressed less often (Brown, Subak et al. 1998). The study also revealed that women under the age of 70 more frequently identified low self-esteem and feeling unattractive compared to older women (Brown, Subak et al. 1998).

In a study by DuBeau, Levy et al. (1998), 30 older people with urge urinary incontinence living in the community participated in focus groups in which they were asked to discuss their experience of incontinence, including which aspects of their daily lives were most affected by their incontinence (DuBeau, Levy et al. 1998). Transcripts from four focus groups identified 32 urinary incontinence-related quality-of-life issues and, of these, more than half had not previously been reported in the literature. The study reported that the impact of incontinence on coping with negative feelings about

themselves, such as embarrassment, was greater than the impact on performing activities (DuBeau, Levy et al. 1998). The issues defined by the participants and indicative of negative feelings included shame, fear of public embarrassment, considering urinary incontinence a psychological rather than physical problem, constant preoccupation, stress from anticipation of urinary incontinence and loss of dignity (DuBeau, Levy et al. 1998).

Twenty older people living in the community were interviewed to explore primarily what prevents older people from seeking treatment for their incontinence. A range of reactions were reported, including embarrassment, shame and disgust (Horrocks, Peters et al. 2004). These negative reactions were partly responsible for older people concealing their incontinence from family, friends and health professionals (Horrocks, Peters et al. 2004).

In a study of older people from a rural Spanish population, about half of the subjects with incontinence (330) reported negative feelings connected to their urine leakage (Iglesias, Caridad y Ocerin et al. 2000). In this study 43 per cent reported psychological distress, but only 10 per cent considered that their lives were significantly affected by their incontinence (Iglesias, Caridad y Ocerin et al. 2000). Only a quarter of the older people with incontinence felt that it significantly affected their lives, indicating that interpreting the impact of incontinence on quality of life is complex (Iglesias, Caridad y Ocerin et al. 2000).

Depression and anxiety

Incontinence can have negative psychological effects, including depression, which may further impact on the quality of life of older people (Bertera 2002). A national health survey of Belgian adults revealed that the prevalence of reported mental ill-health was greater in subjects with incontinence (Van Oyen, Van Oyen 2002). Both anxiety and depression are more likely in people experiencing urinary incontinence (Miner 2004) and, in a study

exploring the impact of faecal incontinence in men and women aged 65 or older, it was also revealed that they were more likely to experience anxiety and depression (Edwards, Jones 2001). This study also suggests that women more often reported anxiety and depression than men (Edwards, Jones 2001), although the converse was true in another study in which older men reported more negative psychological effects than older women (Lee 2004). A more recent study investigating the association between faecal incontinence and anxiety and depression revealed that there was a significant relationship between incontinence severity and frequency of reported anxiety and depression (Deutekom, Terra et al. 2005).

Sadness and depression are allied to the loneliness that may occur because of the loss of contact with others (Miner 2004). A study of 986 older adults with urinary incontinence reveals that the association between incontinence and depression is significantly related to the behavioural changes that are adopted in response to incontinence, particularly the avoidance of activities such as walking, using stairs, reaching, bending, stooping and lifting (Bertera 2002).

Social interactions

Continence can be construed as a precondition for social acceptance (Wilson 2004). Incontinence leads many people to withdraw from social contact in an effort to manage their condition by always keeping close to a toilet (Miner 2004) and to avoid the shame and embarrassment of making frequent trips to the toilet when away from home (Bertera 2002). In general, studies that report the consequences of incontinence on social well-being give varying accounts of the magnitude of the impact, possibly reflecting different populations of people with incontinence (Edgley 2002).

While social support is important in mediating the impact of incontinence and helps adaptive coping, the stigmatisation of incontinence inhibits people from seeking support strategies (Shaw

2001). The isolation that may be experienced as a result of incontinence can be either self-imposed or created by the response of others (Miner 2004). The adaptations made to urinary incontinence may have both negative and positive consequences, in that while fear and embarrassment may be minimised there is a concomitant restriction in activities and social withdrawal (Bertera 2002).

In a study of people with and without urinary incontinence, both condition-specific measures of psychosocial impact and generic measures of depression, loneliness and sadness were used to investigate the social and emotional impact of urinary incontinence. Respondents with incontinence reported being more lonely, sad and depressed than those who were continent, although the majority of those with incontinence did not report that their self-esteem or participation in activities was diminished by urine loss. When other variables were controlled, loneliness was the only outcome that was significantly associated with incontinence (Fultz, Herzog 2001). Being male and losing greater quantities of urine were associated with being more socially restricted (Fultz, Herzog 2001). A national health survey of Belgian adults, which sought to investigate the prevalence, the correlates and the psychosocial consequences of urinary incontinence, revealed that a low appreciation of social contacts and a low functional content of social contacts were greater in subjects with incontinence (Van Oyen, Van Oyen 2002).

The impact of incontinence on social interactions is complex. While social support can help to alleviate the impact of incontinence, older people may avoid social interaction as a way of coping with incontinence, thus denying opportunities for support from others.

Activities

Studies in which condition-specific quality of life tools for urinary incontinence have been used to investigate the impact of urinary incontinence indicate that older people with incontinence

experience interference with their social activities. Such activities include travel, shopping, recreational activities and entertainment events outside the home (Hajjar 2004).

There are reports that different symptoms have a differential effect on social activity, with urge symptoms having a greater effect compared to stress incontinence (Shaw 2001) and that the volume of urine loss may be more critical than the frequency of loss (Fultz, Herzog 2001).

In a study of 65 women with urinary incontinence, primarily with urge symptoms, references in focus group transcripts that related to functioning and well-being were frequently about activities (Brown, Subak et al. 1998). This study revealed that the effect of incontinence on activities showed a strong correlation with self-reported urinary frequency, nocturia and number of protection changes rather than the number of incontinent episodes or years of incontinence (Brown, Subak et al. 1998).

The effect of incontinence on activities was illustrated by quotes from the women, which indicated that their participation in activities was restricted by their fear of leakage and by having to plan activities around the availability of toilets. They also operated to self-imposed time limits that constrained involvement in activities, and certain activities were avoided because of their physical or public nature (Brown, Subak et al. 1998).

In a survey of 435 older adults with incontinence, one of the health predictors significantly associated with quality of life outcome variables, measured by incontinence-specific quality of life and generic quality of life questionnaires, was having activities restricted. The others were feeling less well than usual and having mobility problems (Dugan, Cohen et al. 1998). The impact on daily life measured with incontinence-specific questionnaires was greater for those who were younger with severe urine loss, suggesting that older people may have other co-morbidities affecting their quality of life and that they adapted psychologically and behaviourally to their incontinence (Dugan,

Cohen et al. 1998). Another study also revealed that not only younger respondents but males were more likely to report psychosocial distress (Fultz, Herzog 2001). In this study, men with urinary incontinence reported more restrictions on social activities compared with women (Fultz, Herzog 2001).

A study exploring whether urinary incontinence affected middle-aged and older women's time use and activity patterns compared women with incontinence and those without. It revealed that incontinence affected women's participation in a range of activities (Fultz, Fisher et al. 2004). Compared to their continent counterparts, women with incontinence were less likely to undertake activities such as walking, shopping and attending a movie or cultural event (Fultz, Fisher et al. 2004).

Incontinence can disrupt and interfere with activities. The interference older people describe is variable and this is likely to be the result of a range of factors, including the nature of their symptoms and their age. There are indications in the literature that men report more curtailment of their social activities than women as a consequence of incontinence.

Conclusion

This literature review has identified eight themes that reflect the experience of older people with incontinence, namely:

- conceptualisation of incontinence
- identity and self-esteem
- being in control or out of control
- coping and management strategies
- negative feelings
- depression and anxiety
- social interactions and activities.

The majority of studies focus on urinary incontinence rather than exploring older people's experiences of faecal incontinence and a disproportionate number of studies explore women's experiences of incontinence rather

than men's. The studies indicate that older people have differing experiences and this may, in part, reflect the heterogeneous nature of incontinence.

The impact of incontinence on individuals' lives is also variable and a number of factors are purported to mediate the effects of incontinence. The factors that are variously reported to heighten the impact of incontinence are being male or being female – depending on the aspects studied; being younger; and severity of urine loss. The consequences of incontinence on social well-being are complex and variable. Withdrawal from social contact may be used by some older people in an effort to manage their incontinence.

The study: design, data collection and analysis

The perceptions and experiences of older people with incontinence and its impact on behaviour and psychosocial health and well-being were explored in this study. Both incontinence and social isolation are sensitive topics and participants were likely to feel vulnerable. Choosing the right approach to data collection was critical. In-depth interviews, conducted in the individual's own home, were the most appropriate way of capturing the lived experiences of older people with incontinence. Participants were also asked to record a personal account of their experiences in a diary for three days.

Ethical considerations

The study was conducted according to principles set out in the research governance framework for health and social care (DH 2005b). Ethical approval was gained from the University Ethics Committee and from an NHS local research ethics committee. The project was also approved and registered by the research and development departments of the trusts in which data were collected. All participants were provided with written information during their recruitment to the study and were asked to sign consent forms.

Sample

A purposive sample of 20 people (men and women) aged 65 years or over with incontinence (urinary, faecal or both) was drawn from two primary care trusts. The trusts serve urban areas and semi-rural suburbs in south-east Bristol and north Bristol and rural areas and semi-rural suburbs in north Somerset. Although Bristol is more diverse than other areas in the South West, it has a smaller ethnic minority population than the national average. The sample reflected this and all participants were white and all were British-born apart from one.

The socio-economic profile of these areas is quite diverse, with traditional residential areas some of which abut onto the Downs, Bristol's

inner city green belt, and large estates of social housing in more socio-economically deprived areas. The sample contained older people from a range of socio-economic backgrounds living in their own homes.

Recruitment

Potential participants were identified by continence advisers or community nurses at community-based continence clinics. A total of 62 recruitment packs containing a letter of participation and participant information guide were given out to older people who met the inclusion and exclusion criteria. The recruitment strategy aimed to capture older people who had sought help and were willing to discuss their incontinence and to preclude older people who may be socially isolated because they were housebound as a result of multiple co-existing conditions. The rationale for this strategy was to attempt to reduce the influences of factors other than incontinence on social interaction.

The criteria for inclusion were participants who were 65 years or older, were currently accessing community-based services for management of incontinence (urinary, faecal or both urinary and faecal incontinence), had the ability to communicate in an interview and a willingness to share experiences with the researchers. Since the focus of the study was to capture older people's perspectives of incontinence, the cause of incontinence was not a criterion in the recruitment strategy, nor was it a topic specifically raised in the interview. Older people who were interested in participating in the study were contacted by the research associate, who discussed the project with them and obtained written consent.

Data collection

In-depth interviews lasting between 45 and 90 minutes were conducted in the participant's home. During the interview, open-ended questions were used to elicit the participant's experience of incontinence and their

perceptions of the effects of incontinence on their lives.

Discussion topics were partly based on themes emerging from the literature review. However, the interviews were directed by what the participants wished to disclose about their experiences rather than being driven by specific questions. Triggers to aid discussion in the relevant areas were used to encourage honest and frank accounts.

Following the interviews, the research participants were invited to keep a diary over three days, in which they recorded events, feelings, interactions, activities participated in and activities avoided. The handwritten accounts were very variable, ranging from brief notes made as an itinerary of the day's events to more detailed personal and reflective accounts in which feelings were described.

Data analysis

All but one of the interviews were digitally recorded. One interviewee preferred not to be recorded. Both interview and diary data were subjected to thematic analysis. The qualitative data analysis program, NVivo7, was used for handling data and coding. Words and phrases used by participants were coded according to meaning and these concepts were then grouped into categories based on shared characteristics. Themes were identified by examining and grouping these categories. Once the themes and categories were identified, the data was again examined and further categories and themes searched for. This process was repeated until no further themes emerged.

Findings

Twenty older people between the ages of 65 and 87 with incontinence were interviewed about their experiences and 11 of them completed and returned diaries. The sample consisted of five males and 15 females, of whom 16 had urinary incontinence, two had faecal incontinence and two had both faecal and urinary incontinence (see Table 2). The participants were drawn from a range of socio-economic groups and from urban and semi-rural areas in Bristol and more rural areas in North Somerset.

Table 2: Sample profile

	Male	Female	Total	Age range (years)
Urinary incontinence	4	12	16	66–87
Faecal incontinence	1	1	2	73–86
Combined urinary and faecal incontinence	0	2	2	65–67
Totals	5	15	20	65–87

During the interviews, many participants offered their interpretations of incontinence and explained their beliefs about the causes and the meaning it had for them. A variety of coping and managing strategies were revealed and diary entries and effective management of incontinence enabled the older people to maintain their sense of well-being and self-esteem. The reported impact of incontinence on the quality of life was variable and there were many examples of how it impinged on the interviewees' psychosocial well-being. The degree to which incontinence contributed to social isolation appeared variable and was mediated by a number of factors. Some were protective and seemed to reduce the likelihood of social isolation as a consequence of

incontinence, while others seemed to make this link more inevitable.

The five key themes emerging from the interview and diary data are:

- interpretations of incontinence;
- coping and managing strategies;
- impact of incontinence;
- mediating factors in the relationship between incontinence and social isolation; and
- social withdrawal.

These themes, together with their sub-themes or categories, will be presented in detail in this section.

Interpretations of incontinence

Although they were not asked to explain the causes of their incontinence, most respondents did offer some explanation, reflecting a desire to make sense of their incontinence. A number of concepts and categories emerged, which gave insights into both their understanding and the meanings they attributed to incontinence.

Table 3: Interpretations of incontinence

Category	Concepts
Making sense of their incontinence	Trying to understand Meaning of incontinence
Beliefs about incontinence	Association with ageing Women's problem Male experience is different
Explaining their incontinence	Feeling like a child Feel responsible Incontinence linked to life events May be psychological Taboo subject

Making sense of incontinence

Many of the older people needed to understand

the physical basis of incontinence and in **trying to understand**, several interviewees analysed the patterns of their incontinence and considered what influenced these patterns.

Interviewee 15: *I did say to this lady down the clinic, I said, 'I went to bed the other night and I got up four times and I could not believe the amount.' It wasn't just a trickle, do you know what I mean? I actually went and I said I couldn't believe I could have all that in my bladder during the night.*

Interviewee 3: *For some reason there are some times when you want to go a hell of a lot although you haven't drunk anything. That's what makes me wonder where it all comes from. That's what I haven't had a satisfactory answer for. I asked the doctor once and he said: 'Oh, your bladder is dripping all the time from your kidneys,' but he still didn't say where it all came from.*

They expressed a desire to understand what made their incontinence better or worse, so that they could act to manage or improve their symptoms and the consequences.

Interviewee 7: *But I think you'll find most people would say the same. It doesn't help, lifting heavy stuff, that doesn't help. I find if I lift anything I start leaking more and the one thing I've got to do here is to do my washing. I've got to take it either down to the next floor or down again. I've got the lift but you know, I mean – it's not that far, but it's still lumpy to carry it down so I do try to do my washing quite frequently so that I don't have a lot.*

Interviewee 3: *I don't know where it all comes from. The urine... where it comes from. It's funny to me. I stopped drinking a couple of times. I thought, right I won't have anything after 8 o'clock. The doctor said about that, he said... that's years ago, that is, he said: 'Don't have anything after 8 o'clock in the evening' and I started doing that. I still... you know... I measured once, three pints in the night.*

The older person's understanding of the **meaning of incontinence** changed with personal experience.

Interviewee 11: *I feel that incontinence, I used to take – you know when you're young, you*

take the mickey: 'Oh, look at her wetting herself; you know. But it's not funny, not when it happens to you. You know it's not. It's damned disgusting and horrible and nasty.

Interviewee 8: *I never ever thought about people being incontinent, you know. You don't, do you, unless you know someone who's like it? I never thought. No, I didn't realise. I thought maybe it was just going to the toilet often and maybe coming out of the toilet and having to go back in because they didn't empty their bladders. That sort of thing. I had no idea it was coming away all the time.*

Interviewee 6: *In addition to that urinary trouble, I get a... I don't quite know how to describe it, a slight trouble with... I suppose what is it, a relaxed anus or something. It's not incontinence but I am inclined to dirty my pants.*

Beliefs about incontinence

A few of the older people expressly linked incontinence with old age, but even though the **association with ageing** was recognised as a common perception, it did not necessarily match their own beliefs.

Interviewee 6: *Well, what I meant was, I think men don't realise. They think this is something that comes with old age. I've just got to put up with it and other people have got to put up with it. It's not bad but there it is and no, I think it's very sensible to do what I did, or what my doctor said. There's this specialist nurse who knows all about these things and may be able to help you, which indeed I think she is doing.*

In telling their experiences, several older people supposed that incontinence was a **women's problem**.

Interviewee 13: *And then, you know, gradually she told me and I said: 'Well, Mum, I get it.' So she said: 'I think all women get it.' She said: 'Because I'm not the only one that I know that has got it.' That was Mum. So really she highlighted it better ... [laughter].*

This may contribute to some men assuming the **male experience is different**.

Interviewee 5: *People don't realise what incontinence means. If it's just a teaspoon of leakage there's nothing to worry about. Huge pads are something else. Women have been wearing some sort of protection, there's a difference in the mind-set, the psychology. What it means for a man to wear pads, well – it depends on the man. It does not faze me. Some are paranoid.*

Interviewee 5: *It's the male psyche. Women menstruate. A girl is familiar with sanitary towels and tampons. For a man, you don't expect it. You grow up expecting to be the same.*

Explaining their incontinence

In giving their personal account of incontinence, only one interviewee understood their incontinence in terms of **feeling like a child**.

Interviewee 12: *I used to have towels on the bed. Oh, I used to hate to go to bed. You know, I'd sort of gone back to [being a] child again, you know. I'm not so bad now as I was but I used to hate going to bed, for that one reason: I'm going to wet the bed.*

The same interviewee drew an analogy between a bereaved adult and a neglected child, suggesting that, for her, incontinence may be connected with feeling neglected.

Interviewee 12: *Well, you wet yourself, just like a child. If a child is not looked after properly and, you know, it doesn't get the love and comfort, there's something wrong there when you find a child of probably seven or eight still wetting the bed. They want love and compassion, they want family round them. Probably there's only one parent and it can't give that child all that it desires. So it's the same with a person who's lost her partner, like me, or even a spinster, you know. She's probably had friends but they've probably disappeared on her, so she's on her own and she doesn't want to go out and then when she doesn't go out it's 'I can't be bothered to go upstairs', you know.*

Some of the older people seemed to **feel responsible** and blamed themselves for their condition.

Interviewee 13: *Well, I didn't think, I mean, I don't know what I thought, to be quite honest. I thought I was the only one with a problem because you don't talk about it and don't say anything, but I thought I was the only one and that I must have done something wrong to have that problem.*

Interviewee 2: *Of course, they tell you to do these exercises and stupidly I didn't keep it up. I don't know why I didn't.*

Incontinence linked to life events was recounted by several older people. They linked the start or worsening of their incontinence with events such as the death of relatives or close friends, moving house or retiring.

Interviewee 2: *I did not seem to have much of a problem then. It seems to be worse since he died. I don't know why that is... I know it's got worse in the past eight years since he died.*

Interviewee 6: *It's difficult to remember exactly. More like five years, I think. Probably since my wife died. It was the sudden urgent need to urinate and the inability to control it during the last few seconds.*

One interviewee traced the progress of her urinary incontinence to several life events in which bereavement featured twice.

Interviewee 12: *She put me on some tablets and said use some towels and I had to send away for them. Tena, you know. You had to buy them yourself and all that. Okay, I was quite happy for a while then suddenly I got worse and in the last... I think it's since my husband's been dead, you know. He's been dead 15 years, and I think the shock of that... because he had a tumour of the brain and I was in and out of hospital with him and it really threw me.*

It was all right for a while until about four years ago, I suppose, and I lost my friend and his wife within two years and then, while I was in hospital this time, I lost my sister. She had cancer and luckily I did manage to get out to see her in the home and then within six months I lost my brother-in-law. So all the shock of that, I was coming back to square one again.

Many respondents expressed the view that they felt there may be **psychological dimensions** to their incontinence.

Interviewee 11: *Anyway, we decided to go for a walk and I said to [name]: ‘I don’t know, I don’t think I ought to come.’ That’s how it is. I hadn’t thought about it before but as soon as he said ‘go out’, I decided I probably wanted to go to the toilet. I’m sure it’s psychological, some of it, now. I don’t know but anyway...*

Interviewee 13: *No, I was all right after that because I didn’t even wet it. You know, it was one of those times that I didn’t. Maybe it’s psychological. Maybe that’s what it is. Maybe you think, well, hang on, I want to go and then when you get there, you know...*

Interviewee 9: *I was seeing her about my problem and she did seem... she gave you confidence, that’s it. Which is psychological, I think. A lot of this is psychological. Like when we go out somewhere, I’ve got to be near a toilet.*

Interviewee 7: *Sometimes I think it’s psychological because I can go out for a good three hours and it doesn’t bother me, but as soon as I put the key in the door I’m desperate, you know. And it’s sort of really taking over my life. I find it worrying, irritating. I’ve always got to be thinking about it, to make sure that I’m okay if I go out or anything.*

Interviewees varied greatly in their openness and willingness to confront their incontinence and discuss their condition, but all affirmed that incontinence continues to be a taboo subject.

Interviewee 2: *It’s just that this problem... [pause] it isn’t a thing you talk about, is it? I’m a bit... I’m embarrassed, that’s what... You see I get embarrassed if I’ve got to talk to people about it... because I think it’s, well, it’s not a very nice thing to talk about, is it?*

Interviewee 6: *Well, I mean normally it’s not a subject you want to... I don’t say to people, well, I’ve got a ... in the same way as I might say I’ve got arthritis in my knee, I’ve got incontinence in my stomach or wherever it comes from.*

Coping and managing strategies

People developed a range of strategies to keep control over their bladder and bowels in order to maintain their integrity in public. They ranged from practical actions to cope with the uncontrolled flow of urine or faeces to psychological strategies that enabled the older person to redefine their understanding of what constitutes being ‘normal’ in relation to control over their bladder and bowels.

The interview and diary data yielded numerous concepts, which were grouped into categories based on shared characteristics.

Table 4: Coping and managing strategies

Category	Concepts
Minimising problems	Minimising problems Getting used to it Positive comparison with others Normalising incontinence Rationalising incontinence
Concealing strategies	Limited confiding Being discreet Vigilant about cleanliness
Talking strategies	Degree of openness Euphemisms Talking helps Humour
Being prepared	Equipped to go out Using pads Pre-emptive toilet trips Toilet mapping Resort to buckets Forced to use public places as toilets
Keeping control	Taking control Being independent
Maintaining activities	Importance of going out Keeping occupied
Responding to advice	Doing pelvic floor exercises Recommended drinking or diet
Self-imposed restrictions	Reducing activities Limiting travel Rush outings Thrifty use of pads Monitoring drinks

Minimising problems

Participants learned to live with their incontinence using a range of psychological strategies aimed at minimising problems and rationalising their incontinence so that what could be considered a problem becomes 'normal'.

Some respondents demonstrated the capacity of minimising problems and stated that incontinence was not much of a problem at all.

Interviewee 1: *I really bury my head in the sand, you know, because I ... um... I've got lots of other worries, you know. That's a very little one.*

Interviewee 2: *I expect you think I'm different to everyone else because I've got no real problems with it.*

Believing that nothing can be done to help them with their problem, some participants describe **getting used to it** as a way of coming to terms with their incontinence.

Interviewee 10: *It's not very nice but I've learned to live with it because I had to live with it.*

Interviewee 3: *I've got used to it now, though. That's the trouble. But it's still a damn nuisance. That's the way to think of it.*

Another strategy was to make **positive comparison with others** and to use this as a way of adjusting to incontinence. Irrespective of the respondents' perceived severity of their own incontinence, almost all mentioned others in a worse condition.

Interviewee 6: *But compared with some people I must be much better off. I mean, I hear of some men who say: 'Oh, I have to get up eight times in the night.'*

A striking example was one interviewee who spends much of his time at home in his underpants.

Interviewee 3: *When at home I live in my underpants unless I'm expecting visitors. It allows me those extra few seconds to reach the toilet. I'm so used to it I take no particular notice now.*

He nevertheless could still say:

There's a lot of people with it. Some are worse off than me. More often.

Others felt that in comparison to other health problems, incontinence was less of a concern.

Interviewee 7: *I mean, I don't talk about any other of my problems. I'm not that type of person. I just get on with it. I think there are other people far worse than me, with other illnesses and things. I don't discuss, I mean. Nearly always, if they ask me how I am: 'Yeah, I'm not too bad,' you know, even if I'm dying.*

Interviewee 14: *Leaving out things like cancer or anything like that, I haven't got problems with hips or knees. My eyesight is something that, you know, is under control. I can cope with that. And I'm just very lucky to have just this to cope with. I think so. I'd rather not have it, same as anybody, but it's a minor consideration really.*

Several participants adjust by **normalising incontinence** and trying to live a normal life despite incontinence.

Interviewee 5: *I've hardly been prevented from normal activities. I go hill-walking – Mendips, Lake District, etc. – and all I've had to do is carry six pads and change them behind a bush. You can see I've made quite an effort to normalise things and not let it prevent me from leading a normal life.*

Others feel normal because their public behaviour appears acceptable.

Interviewee 16: *I don't actually find that I need to go to the loo more than other people do. Or if I go on an oldie expedition on a coach, you know, the loo stops are built in because there's loads of people who need to go to the loo who may not be incontinent but who need to go. [laughter]. So it's not actually an issue, you see.*

Another related strategy was **rationalising incontinence**; some respondents were able to cope by viewing incontinence as a consequence of factors beyond their control.

Interviewee 10: *I'd been complaining for quite a time about the waterworks, but the doctors I saw just said: 'You're on the water tablet so you've got to go more often.' If you leave the water*

tablets off you get fluid on the chest, so I was in limbo and didn't.

Concealing strategies

The effective management of incontinence involves appearing normal to other people. This is achieved by a range of concealing strategies, including practical steps to conceal the loss of bladder or bowel control or its consequences. In addition, there are psychological strategies aimed at concealing incontinence from others.

All interviewees had strategies for concealment. Even those who were more open about their incontinence would be discreet in their management of it, carrying spare pads in a rucksack or unobtrusive bag, for example. Changing pads and washing frequently to avoid telltale signs of smell was a strategy used by all.

All participants used a strategy of **limited confiding**, although the extent to which each person concealed their incontinence varied. They each had their own parameters as to whom and how much they were prepared to reveal to partners, family, friends and professionals. One interviewee reported not telling her husband she has faecal incontinence, despite having had major operations; however, she does talk frankly to one very close friend.

Interviewee 15: *I don't tell anybody. I don't even think I tell my husband. Don't think he knows. He knows that I've got a problem but we don't discuss it. It's my problem and it's embarrassing. I suppose I'm old-school, really. We don't. I mean I can remember last time I had this prolapse and I said to him: 'There's something wrong with me,' and he went: 'What do you mean, something wrong with you?' And I went: 'Well, I haven't got a hole.' [laughter] And I didn't know how to describe it and he went and he laughs and went: 'Oh, sex is out, then.' [laughter] He's joking. I mean when you've been married as long as us, I went, 'Tut' – and that was it. That was the end of discussion. He knew I had a problem. We didn't, we never bothered with sex after that. We just, you know, we knew that it wasn't comfortable. It wasn't and that was that.*

Interviewee 15: *Now my best friend, I tell her everything, I've got no embarrassment with her at all, I mean we're more like sisters, we had our babies together and everything and I can tell her absolutely anything, I could tell her more than I could tell my husband.*

The majority were more likely to confide to family in the first instance, although the disclosure was circumscribed to varying degrees.

Interviewee 10: *I tell the wife what I want her to know, more or less.*

As a rule those who confided little to their families were more disinclined to confide in friends.

Diary entry from interviewee 8: *Other than my family and close friends I would not like anyone else to know what has happened.*

Interviewee 2: *Oh yes, they're good friends but I wouldn't tell them that.*

Being discreet about incontinence was another strategy some people employed to conceal their incontinence.

Interviewee 12: *You see that bag there is where I keep my STs and that and a towel for the chair... and I always take it with me so it's not noticeable. It's just an ordinary little bag you go out with, you know. Who's not to know it's a handbag or purse or what thing really?*

Fear of smell was a universal concern and concealing possible smells by being **vigilant about cleanliness** and changing pads was a strategy invariably employed, although the benchmark for personal hygiene was variable. All interviewees report washing themselves and keeping their immediate environment clean.

Diary entry from interviewee 1: *I worry all the time if I smell although I don't think I could be more hygienic in any way. Shower, dress, open the bedroom windows wide to get fresh air in, bed folded right back. I always feel terribly worried in case people can smell my urine problem. I keep washing myself during the day, often have to change my briefs during a day because in spite of always wearing a Tena it is sometimes too much.*

Talking strategies

Although participants with incontinence had their own restrictions on whom they confided in, many reported that having someone to talk to helped them to cope with incontinence both in avoiding potential embarrassment and in coming to terms with it. Often talking about incontinence revealed that others also shared the problem and this made them feel more normal. However, opportunities for discussion in their immediate circle of family and friends could be constrained by people's embarrassment. This seems to be exacerbated by the fact that incontinence remains a taboo subject.

Incontinence is not yet openly debated in public, unlike many other medical conditions. Discussion was often clothed in humour or euphemisms.

Participants varied in their degree of openness to talking about incontinence. Having at least one confidant helped; one interviewee spoke to no one except the continence adviser about incontinence and found it helpful.

Two participants found talking helpful and had a particularly open approach to discussing their incontinence.

Interviewee 5: *Most people in my various walks of life know. I've not attempted to keep it a secret because I don't think it's anything to be ashamed of. It's a purely physical result of an operation I've had and I have to deal with it in the way that I do.*

Interviewee 12: *If anybody wants to know anything, I mean, my neighbour up there, I talk to her... she comes down, sometimes I'm upstairs. In fact, when I came out of hospital she said to me: 'If you want anything done, call me.' So one day I phoned her up and said: 'Do you mind coming down a minute?' and she said: 'Why? What's gone wrong?' 'Just come down.' So she came down and I said, 'I can't get my brassiere off.' So she undid my brassiere, and she said: 'Look, every night I'll come down and take your bra off. How about your pants?' I said: 'Yeah.' I used to have to wear something at night so I take*

it off and she'll help me pull the pants up at night and she knows there's the bags in there that you put the pads in and she folds them up and puts them straight in the bin and she said: 'Don't worry.' And I said to her, 'You don't mind, do you, you know, helping out?' She said: 'I am your age. I am not quite so bad as you in incontinence but I know what you're going through, you know.'

Other interviewees displayed a less open approach to talking about incontinence by using **euphemisms**. These interviewees often employed euphemisms both to the interviewer and in reporting how they discussed incontinence with others. When interviewees described how they broached the subject with a family member or friend for the first time it was clear that they employed euphemisms to break the ice.

Interviewee 1: *I did tell her that I was a little bit... er um... it wasn't very good [laughs] and she said: 'Oh, that's Mother's problem.'*

Various euphemisms were used by the interviewees during the interviews.

Interviewee 10: *But I'd been complaining for quite a time about the waterworks.*

Interviewee 6: *In addition to that urinary trouble I get a – I don't quite know how to describe it – a slight trouble with I suppose what is a relaxed anus or something. It's not incontinence but I am inclined to dirty my pants, and that's embarrassing.*

One interviewee tried to keep her incontinence secret for nearly 40 years and described how once the ice was broken with her friend it was much easier to accept an invitation to tea.

Interviewee 13: *I think I was coming from [name] and she was out on the gate and she asked me to come in for a cup of tea and I wasn't going to go in 'cause of my problem, and I didn't say anything and then she looked up and said she'd got a catheter fitted and I said: 'What's that for?' and she said for her water, like, you know, her water, so I said: 'Oh, what – do you wee yourself like I do?', 'cause it was natural, wasn't it? It's a natural thing, like. She said: 'I've had a bit of an operation on me and I've had to have this',*

and she said, 'Look', and she pulled down her skirt and showed me it like, you know. And she had a bit of bag, only a small one but it's there and I said: 'What happens to that?' and she said: 'Well,' she said, 'I don't need to go to the toilet like you do.'

...in the end I went and she said: 'It's all right, come on in.' She said: 'You ain't going to...' She said: 'I've got a leather three-piece, you won't wet it. You might wet your dress, but not that.' So I said: 'I got a thing on', I said, 'you know – to stop it.' So she said: 'Come on in, come and have a cup of tea.' She said: 'Behave yourself.' Yeah, that's what I've done.

Many interviewees found that **talking helps** and that discussing incontinence could provide some relief.

Interviewee 6: *So it is a relief for somebody like me to be able to discuss it with somebody like you, or a nurse or a doctor with whom there is no embarrassment whatever. The thing that is troubling is the other people's embarrassment, really, and if they're not embarrassed, then you're not embarrassed yourself.*

Talking about incontinence with those around them could also help the older person to reach the toilet in time and avoid accidents.

Interviewee 3: R: *And are you open with your sons about it?*

Oh, they know all about it. 'Cause [name], they got a toilet downstairs that they never use – they've got bags of potatoes down there. But when I used to go up there they used to clear that out for me. Yes, he knows about it all.

There was some recognition that public awareness of the issue was limited and that talking about incontinence may lead to better public understanding.

Interviewee 14: *Although I'm quite happy chatting about it, it's not the sort of thing that you do tend to bring up, maybe because you know a lot of people are, maybe most people are... I don't know, aren't happy talking about it, which is a pity, I think. I almost feel it's in the same situation as Alzheimer's was for so many years*

and that's now out in the open. I think incontinence is in the same sort of field, in some ways.

... and fair enough, you can understand it in some ways but I think it's a pity it doesn't come to a stage where it's something you can just chat about.

Broaching the subject tends to encourage others to talk about their similar experiences and reinforces how common incontinence is. This seems to help people to feel less alone.

Interviewee 7: *She was quite helpful and I think it helped me in some ways talking to her, that helped, yeah. It helped me to, you know, I thought well, you know, I'm not the only one; it's not so drastic.*

Many older people used **humour** to defuse the situation when talking about incontinence. Humour was used as a strategy to make light of incontinence and to make incontinence more acceptable to themselves and those around them.

Interviewee 3: *Oh yes, we used to say about making a real splash... we used to say, we can't see how far up the wall we can go now. [Laughs]*

R: *Make jokes?*

Yeah, making jokes, that was the thing... when we were kids and young... and all that... we used to see how far up the wall we could go... and now you have a job to get it into the urinal! [laughing] Oh, it was all quite open.

Being prepared

The older people invested a considerable amount of effort and planning to make sure they were prepared to cope with their incontinence at home and when they ventured out of the house. These strategies were aimed at preventing accidents and ensuring they were protected against leakages.

Making sure they are **equipped to go out** becomes an integral part of life and allows them to engage in activities outside of their homes. If

they feel they are properly equipped, they go out.

Interviewee 5: *I've had some accidents. I change the pads to make sure. It's about management. You learn how to calculate. It's not the chore it sounds.*

Interviewee 15: *Well, erm, I mean, it is embarrassing. I mean, I wouldn't go out without a spare pair of pants and a pad in my handbag, you know.*

Some of the older people reported **using pads** as a sort of insurance policy; it enabled them to carry on with their usual activities with a safety net in case of accidents.

Interviewee 12: *I always took them with me. A pad, yes, just to make sure that if I did have a leak I could have support down there at the same time, you know. It's usually a pair of knickers and one pad and that controls me for the day usually now.*

Some interviewees initially used pads as an alternative to seeking professional help.

Interviewee 6: *I did a bit of self-treatment. I got some sort of incontinence pads and things and tried to but, well, eventually, I thought it was silly not to seek advice.*

For many older people the most important aspect of being prepared to effectively manage their incontinence is **toilet mapping**. Every interviewee knew where the toilets are in the areas they frequent. Their activities, including the timing and their itineraries, are dictated by toilet location. For many it is the first consideration in planning an activity and can be a deciding factor in choosing where to go.

Interviewee 15: *And I like to go to places where I know where the toilets are. And I always say to her when we get somewhere: 'Let's go and have a cup of coffee first', 'cause I know that wherever we go for a cup of coffee or a cup of tea, there'll be a loo so that before we start doing anything I can go to the loo.*

Interviewee 5: *We know all the toilets that are local. We have to plan. Got to know where they all are.*

Interviewee 11: *I don't mind going out so much when I know where the toilets are and I can shop when I'm about near the toilets. That's not too bad.*

As well as toilet mapping, interviewees report making **pre-emptive toilet trips** before any outing or activity to reduce the likelihood of being caught in public without access to a toilet.

Interviewee 7: *There are loos there. I mean, sometimes I go to the loo before the service starts but I nearly always go afterwards because I have to wait about, you know, for them to take me back in the minibus and not necessarily come straight home because we're dropping other people. So I need to sort of make sure I'm okay.*

Interviewees place themselves strategically in public places to ensure quick access to toilets.

Interviewee 10: *If I went to like the AGM we have or reunions, well, I have to sit at the back because I know I'm going to have to go out once or twice and to try and go. 'Cause if you just move and there's something important being done, then everybody seems to stare at you so you have to try to go if they're talking about something.*

They also recognise that they mustn't delay and need to act quickly at the first signal.

Interviewee 12: *But I've got to think positive. I've got to say to myself, you know, if you want to go to the toilet you've got to go. You don't leave it, not leave it five minutes. If you want to go, go. So if you feel the urge, you know, go. And that's what I've got to do. I haven't got to worry about anything.*

Many of the older people have been forced to **resort to buckets**, jars and jugs in order to avoid an accident in public or in the privacy of their own homes.

Interviewee 7: *I use a cheap plastic jug, 'cause I did buy one of these that you can get, you know, for women. I didn't get on with it very well. And I get on fine with that.*

R: *So you've found a way?*

Yes, you'd be surprised how you find a way, you know.

Interviewee 3: *To be quite honest, I keep a bucket just beside the door.*

Interviewee 10: *I got the jar to carry around with me, not so much now I'm on these tablets. But if I go from here to Bath, I go to the toilet before I go and by the time I get to Bath I want to go again. But the toilets are locked. The first two toilets I pass are locked so then we have to park up and I've got my bottle and I have to sit in the car which – there's no other way of doing it, you know. Do it in a jar and then I can pour it out.*

Some interviewees report other measures.

Interviewee 13: *Well, for waterworks I'd tear up an old sheet and put it between... I've done all sorts. I'll tell you. I mean I put stuff in me drawers.*

Diary entry from interviewee 3: *If I'm out for a while, the pads can get bulky. That's when my trousers can get wet. When at home I live in my underpants unless I'm expecting visitors. It allows me those extra few seconds to reach the toilet.*

The final resort is being **forced to use public places as toilets**.

Interviewee 10: *You know, relieving yourself in public places, well, everywhere out in the street is public. But if there's an alley or somewhere I can go, then I have to. Otherwise I'll just wet myself and then you've got that to contend with for the rest of the time you're out.*

Interviewee 11: *I either manage to hang on or else I get behind a tree and go. At one time I thought that was [the] most disgusting thing anybody could do, really. You know, all right if you want to spend a penny, yeah, but nothing else, that's disgusting. But now I think, well, it's necessary. And you do it, you know.*

Keeping control

Keeping control by not letting incontinence dominate their lives was crucial for many interviewees. They strove to keep control over their bodies and also their minds. Several spoke

about mind over matter and commented on the importance of not letting thoughts about incontinence and its management become all-encompassing. This strategy of **taking control** was an important way of coping.

Interviewee 6: *It doesn't dominate my thinking all the time.*

Interviewee 5: *We get on with it. What's the alternative? If you get depressed or despondent about it and then you let it get you down, it's the tail wagging the dog.*

Interviewee 12: *I always put one of the pads on the seat when I get in the car. You know, they take a pillow with them so it's my pillow that gets wet really, but I don't worry because I know full well I'm in somebody else's car and not to do it. So it's mind over matter.*

Taking control was related to **being independent**; the degree to which this was achieved was variable although the attitude was common.

Interviewee 15: R: *Tell me, a difficult question... can you think what it is that makes you sort of – stop it taking hold of your life? What is it about you or your circumstances?*

I think it's independence. Yeah, I think it's because I don't think I could not be... I couldn't be dependent on anybody.

Maintaining activities

One way in which some respondents kept control over their incontinence was to remain engaged in activities. Many older people recognised the importance of **going out**.

Interviewee 7: *I do try to make myself go out; I'm going out tomorrow morning. I'm using Dial-a-ride to take me shopping, which is a very good service so I can do my own shopping. And if I want to go up to the precinct, then I use a firm called [name] and they just take me up. Then I can just wander around and then they'll bring me back, you see.*

Some of the respondents also recognised that **keeping occupied** was key to managing incontinence.

Interviewee 12: *What I was doing to stop that was to put your mind on something else. I was in hospital and one of the girls in there, one of the ladies, was knitting scarves. So when the girls came in they said about knitting scarves. But I was doing it at night-time, not thinking about down here, and I could go to bed quite happy.*

Responding to advice

Taking responsibility for their own improvement was an important aspect of managing incontinence and keeping control. Interviewees were generally avid for advice from professionals, especially continence advisers, about what they could do to aid their own recovery or manage their incontinence more effectively. Following professional advice by doing **pelvic floor exercises** regularly and keeping to any **recommended drinking or diet** was part of the self-help regime.

Interviewee 7: *Well, I suppose it's sort of go on, try and persevere to do what they tell you. Because they tell you that doing these floor exercises, pelvic floor exercises, it does take at least three months or even more, you know, to get a real effect and the lady I saw yesterday, she said I was doing them really well and some days I think to myself, oh well, it does seem a bit better and then the next day I think, oh no. Well, how to control it, isn't it? That's the main thing. I mean, when once you've got control of it, you know life would be so much different.*

Interviewee 15: *And I went to him for years and he sorted my diet out and one thing and another. And I wouldn't take anything apart from what he said and I got it under control. It never went away but I got it what I thought was under control.*

Self-imposed restrictions

Interviewees report numerous self-imposed restrictions to their lives in order to manage their incontinence and avoid accidents. Restrictions range from rationing drinks and pads to limiting the time spent away from home. Interviewees also report **reducing activities** outside the home as a way of coping with incontinence and limiting the possibility of accidents.

Interviewee 6: *I had a bout in hospital about a month or six weeks ago and I came out and I was having to visit the loo to urinate every hour, day and night. Not easy. And I couldn't go out. I daren't leave this flat really to go to church, to visit friends, to go shopping or to do anything.*

In some cases, activities were also compromised in the home, although some people seemed to be resigned to leaking when doing household activities.

Diary entry from interviewee 8:

Christmas day I prepared lunch sitting on a stool. This seems to stem any leakage. But as soon as I get up, it starts again and I have to hold myself until I reach the bathroom.

Diary entry from interviewee 16: *Sat on low sofa. Baby plays on floor rug with great contentment. I am aware of slight leakage as I bend to lift her on to sofa.*

Partly the reduction in activities is to do with **limiting travel**.

Interviewee 13: *Yeah, did stop me. Like, say, travelling too far or if I go to a new place and I'm not sure, you know. I'm frightened to sit down in case I wet when I get back up.*

In cases of improved condition, interviewees feel they can lift their restrictions.

Interviewee 11: *It's a bit worrying sometimes but it's not as bad as it was. I couldn't have gone last year this time, no way. But I think I could manage coach trips. I could manage a coach trip now.*

When they do go out, many interviewees report restricting their time away from home and describe having to **rush outings**, as a way of

managing their incontinence and keeping control.

Interviewee 9: *Well, she likes shopping. I don't. So she takes a lot longer to go down than I would and that's when I begin to get a bit agitated, although I know that there's a toilet there. I think, well, come on, I've got to get going. I can't...that's it.*

Diary entry from Interviewee 15: *Had a moment when I thought I might need a loo so got shopping needed. Didn't browse and took bus home. Only two stops but just in case.*

Another self-imposed restriction was the **thrifty use of pads**, which was because of their expense. The number of pads used in a day became a preoccupation for some.

Interviewee 8: *As soon as I'm on my feet, it's like I keep changing. So what I would do is cut up pads and put extra lining in the proper pad. That's not very comfortable.*

Interviewee 13: *Well, because I never had enough to go round [laughter] obviously. I never had enough so I used to be sparing with them.*

For those with urinary incontinence, **monitoring drinks** to avoid excessive fluid intake is another restriction employed. Most are aware that it is important to drink, so they engage in a balancing act of drinking enough to avoid infection, but not so much that they leak or have to make toilet trips more frequently than usual.

Interviewee 7: *Well, I think I've only had about two cups of coffee for three months and I cut down on my tea drinking. Although I still have about three cups of tea, I don't drink so much. I don't fill up the cups. I always have big cups of tea usually. Don't like little ones. But I don't fill them up so much and I don't drink all of it, so that's another psychological thing. You're not denying yourself tea but you're not drinking so much.*

For some, the self-imposed restriction on drinking was severe.

Interviewee 1: R: *So when you visit friends, what happens with your management?*

I try not to drink anything [laughs].

Interviewee 13: *I found a lot of it is to do with drinking as well. Drinking tea. Like, you know, if I was to have a lot of tea one day, I would have a problem. But if I didn't drink, like say I may not have a drink now till I get up in the morning, then I find I won't... yeah. I probably might not have a drink now.*

Impact of incontinence

Interviewees' accounts of their daily activities both inside and outside their home revealed a range of recurrent worries, consequences and constraints.

Table 5: Worries and consequences

Category	Concept
Being worrisome	Constant worry Constant presence Being vigilant Taking over life Feeling defeated Perception of severity
Aggravating consequences	Discomfort of urgency Constant wetness Sleep disturbance Time-consuming Difficulty using public transport Expense of incontinence
Diminished activity	Physical activity makes it worse Stairs are a problem Reduced physical activities Reduction in social activities

Worry

Many of the older people reported **constant worry** about incontinence and the need for quick access to a toilet wherever they were. This interfered with their enjoyment of activities.

Interviewee 11: *So it is... it ... it is... not nice and it's very debilitating. You know because you constantly... you go out and you think, 'I wonder where there is a loo'. [laughs] I used to go to lots of concerts and shows but I don't do that now.*

The same interviewee was conscious of her spouse's worry on her behalf, and his driving too quickly to reach a toilet made her worry even more.

Interviewee 11: *He's always on edge in case I want to go to the toilet. Not so much now but before, if he did manage to get me out I'd only have to say 'Oh'. "What's the matter, do you want the toilet?" and I said, 'Oh my gosh', and then he'd have to make a mad dash and I'm frightened to death he's going to drive too fast and get caught, you know. Because he does tend to, you know, go a little bit speedy to try to get me home in time. Now he's not so bad. He knows I can hang on for a bit, but, you know, it's going round the shops.*

A few wondered whether worrying aggravated their urgent need for a toilet.

Interviewee 3: *It's on your mind all the time, thinking about it. And if you could forget about it... like I said before, at odd times I've forgotten all about it and I'll be all right and then all of a sudden I think, I haven't been to the toilet for a while and that starts a chain reaction and off you want to go.*

One interviewee's account of her incontinence reveals it as a **constant presence** and constant worry. In order to address the worry of smell, she is often in the toilet or changing pads.

Interviewee 8: *I am spending half my time in the toilet because as soon as I get up and walk around I can feel the urine coming away from me and I know my pad's going to be wet, unless I go into the toilet. And I might just save it, then, you know, save the pad. Then ten minutes later the same thing happens. I'm in the toilet on and off all day. It's better at night actually. This morning I woke up at 2am and went to the toilet and changed my pad and went back to sleep and woke up at 5am and then I changed my pad again and then I was all right until 8am when I got up. So it's worse during the day than it is at night. If I'm visiting anyone I am always afraid to get up. I have got to hold myself instead of just letting it go.*

This interviewee was most concerned about leaking urine and the smell associated with it.

Interviewee 8: *Well, it's the constant losing water and the smell. If I didn't change my pad frequently I know it would smell. It does smell.*

Being vigilant about avoiding wetness was a way of life for all the interviewees with urinary incontinence, both day and night. This was evident during the interviews, which were frequently paused so that the interviewee could go to the toilet.

Interviewee 16: *Well, it has affected me in the sense that I feel I have to check, like I haven't leaked doing that cough, you see. So I don't always.*

Interviewee 7: *Well I've never had a sort of real accident where I've got wet or anything, like outside, not that. I've always been very, very careful.*

Two of the respondents were conscious of incontinence **taking over life**. One felt that it had done so; the other was determined it should not do so.

Interviewee 7: *I suppose it's annoying really and yes, it's like taken over my life. I've got to be thinking about it all the time.*

Interviewee 15: *I'm determined it's not going to take over my life. I think: 'I'm only 67. I got a lot of living to do yet.' No, I'm not going to let it affect my social life, not as long as I can help it. I think it's mind over matter. I think you've just got to be determined.*

A small minority of older people believed their incontinence stopped them engaging in enjoyable activities. The belief that nothing could be done to improve their condition appeared to leave them **feeling defeated**.

Interviewee 2: *I wouldn't go to the doctor special for that problem because I think, well... it's not a problem... what can they do about it?... they don't do nothing. They can't do anything, can they? There's no help at all for people like that who have got my problem, not in that way, not for doctors to help you. I mean there's nothing they can do.*

Interviewee 9: *Pretty lousy. Sometimes I feel I don't want to go on, you know, carry on. Why?*

Because there's no pleasure, is there, if you can't go anywhere or do anything? I think well, why bother, why bother to get up in the morning?

Older people measured their incontinence in terms of frequency, urgency, number of pads used, number of accidents, the degree of control they had and how confident they felt about going out. Some measured intake and output meticulously. Their **perception of severity** was expressed in terms of those measures and often in comparison with previous experiences and/or with what they would expect on the basis of what they had recently drunk.

Interviewee 10: *Well, when I say frequently, I wouldn't expect to have to go three or four times after having a cup of tea or, what do you say, possibly once things had settled down a bit it would be every hour which, to me, was a lot up to what it used to be. Even now – I mean, I could have a cup of tea now and as soon as I stood up I would be desperate to go, but that has gradually eased a bit now 'cause of the medication. They've changed the medication again so...*

Interviewee 3: *I measured once three pints in the night. One of my buckets in there, I measured the level on the outside and then topped it up with water up to that level 'cause you could see through the bucket. Yeah, three pints! I thought, blooming heck, where did that all come from? But I must admit, now, since I stopped taking those tablets there, I don't do half of that.*

Like the above interviewees, who perceived some improvement in the condition, others measured severity in terms of a worse past.

Interviewee 9: *Things were beginning to improve. I wasn't going so frequently. I still had to protect myself but it wasn't so frequent.*

R: *When you say not so frequently, you didn't have to go to the toilet so often?*

Not so often, no.

R: *But in terms of accidents, as it were, was that more or less frequent?*

Well, less frequent then.

One interviewee measured severity by the number of knickers used.

Interviewee 11: *Millions of pairs of knickers. Because pads didn't seem to contain it, you know. Yeah, anyway, it's better now. It's getting better anyway.*

Severity is frequently assessed in terms of the degree of control.

Interviewee 10: *I just have to go, you know, if and where I can. It's that bad.*

Aggravating consequences

Older people describe the emotional and physical **discomfort of urgency**, which is particularly intense for those with faecal incontinence.

Interviewee 11: *I just got to the toilet in time. I was sweating. Actually I did have a tiny... I started to have a little accident before I got there but it was all right, you know. I managed most of it but then went there, got back in the car, only got half way up and I said: '[Name], you'd better hurry up.' He said: 'Oh, not again!' and I had to run into the toilet.*

I went back to the car and sat down and all of a sudden I wanted to go to the toilet and there were several cars. And then I thought, oh God, what can I do? I was sat there and I was really, really in pain with it, sweating and cussing to myself and hanging on and hanging on. Anyway the cars went and I thought, that's it, and I had to nip out and rush over and go behind a tree. But I think I'd have to have gone even if the cars had been and there'd been a dozen people around. You know, it was that bad. It made me feel really ill. I was trying to hold on but you get, it's just one of those things, you just can't. If you want to go, you go. It's so terrible. I did manage a little bit then, but I couldn't have lasted much longer. I had to go. It's dreadful. It makes you feel so horrible.

The unbearable nature of urgency was also expressed by those with urinary incontinence.

Interviewee 18: *Well, I always think if you've got a shopping area and if you're going to shop and you're going to do your shopping for at least two hours, you need a loo. Most women need a*

loo and so, I mean, if you haven't got one you're looking quickly to get back into the car and get back home. And if you do suffer like that, I mean, it can be unbearable to just stand there and sit there.

Some interviewees experienced **constant wetness** and found this the most difficult aspect of incontinence.

Interviewee 8: *If I'm standing up, I would need to change about more than every half hour really. I'm losing water all the time.*

Interviewee 7: *It just seems to be sort of dribbling all the time, you know.*

Many people spoke about the discomfort of being wet.

Interviewee 18: *It can be smelly if you're not a clean person and it's not very nice to sit down in the chair and all of a sudden feel you've got something wet under your bottom. And so you've got to get up and you think, oh, you know, I've got to change again.*



Sleep disturbance is a commonly mentioned aspect of incontinence with people having to get up frequently during the night to urinate.

Diary entry from interviewee 3: *Late getting up. Urge to urinate deciding factor. Six times in the night.*

Interviewee 19: *It just makes it uncomfortable for me of a night-time because if I'm lying in bed and I'm sleeping and all of a sudden I can feel water running from me and I'm lying there and I'm thinking to myself, I hope I don't wet the bed, I hope I don't wet the bed. Now when I woke up this morning and got up, I had – I had a slight accident in the bed so I had to get up.*

Diary entry from interviewee 1: *Woke up just after 06:00 desperate to go to the toilet and wanted to go back to sleep. I was still very tired. Up five times during the night.*

Diary entry from interviewee 2: *At about 3 o'clock in the night was woken needing to spend a penny. Didn't quite make it to the toilet. Had to change my towel. This happens quite frequently, having to get up in the night. Consequently I am awake then for nearly two hours.*

The **time-consuming** nature of managing incontinence was particularly illustrated in the diaries.

Diary entry for interviewee 5: *Slept well. Dreamed of flooding. Had a pee at 4.45am. Back to sleep. Felt comfortable. Rose at 7.30am, had pee and changed pad. Pelvic floor exercises (1) during breakfast. Drank cup of tea, glass of cranberry juice. 10.30 changed pad. Walked to local shops and back. Some leakage. Not too bad. Home 11.50. Cup of coffee. Pelvic floor exercises (2) at midday. Changed pad at 1pm. Glass of water with lunch. Had pee at 1.45pm. Cup of tea at 3.15pm. Pelvic floor exercises (3) at 3.30pm. Changed pad at 4pm. Changed pad at 6.15pm. Pelvic floor exercises (4) at 6.30; after dinner. Off to pub 7.30. Pelvic floor exercises (5). 8pm. Two pints. Changed pad 10.15. Bus home at 10.30pm. Pelvic floor exercises (6). Catheter 11.15. Okay. Bed midnight.*



Photo: John Cobb

Summary: *All in all a pretty good day but rather too many pad changes still.*

Other participants similarly report how much of their daily life is spent using toilets in the quest to avoid accidents.

Interviewee 15: *Since I started eating healthily again, back to eating healthily, my bowel's up the creek. I'm on the toilet all the time.*

Interviewee 8: *I am spending half my time in the toilet because as soon as I get up and walk around, I can feel the urine coming away from me and I know my pad's going to be wet, unless I go into the toilet. And I might just save it then, you know, save the pad. Then ten minutes later the same thing happens. I'm in the toilet on and off all day.*

For some people the **difficulty of using public transport** is so great that it is not a travel option.

Interviewee 2: *I got to keep running to the loo all the time and I wish that I could get out more*

but I'm afraid to go too far. Although if I want to go any more, now I got to take a taxi. There's a lane where that lorry is that goes out to [place] and the bus stop is at the top of [place]. But if I have to stand there for long, I don't think I could do it.

Interviewee 8: *And before I went into hospital, I was catching the bus to wherever – to hospital, to the supermarket. I had no problem at all. Now I can't do that.*

Others were prepared to use public transport but only with careful planning.

Interviewee 15: *It's got to be a good day. I must admit it's got to be. I've got to be really confident it's a good day 'cause it's an hour on the bus and I can get that bus at the end of the road... never do that, never. I go to that end of the road. I catch a bus to town and then I get a bus to the mall so that if I, and I've never admitted it to myself, but I know that if I want to go to the loo, I can go to the loo before I get on that bus again.*

Interviewee 14: *I certainly like to sort of, you know, know where, on the train, where the toilets are, that sort of thing.*

Interviewee 19: *I thought, I've been in this pad all day yesterday and all night. I've now got to go and change but I couldn't go on the toilet on the bus, you see. There was a toilet on the bus but I couldn't go in it because I didn't know whether they'd have a tin in there where I could put my used pad. And I'm very funny. That's one thing I don't like. That's the only thing that gets me, is if I go somewhere I got to make sure they got somewhere for me to put my used pad. And sort of put it in a bag or something and put it in there to get rid of the smell and that...*

Many interviewees drew attention to the expense of pads and the resulting **expense of incontinence**.

Interviewee 10: *Well, if people had the information where they could go to one of these disabled shops, mobility shops and you can buy them, like I can buy them, but to get 20 for £5 or 28 for £5 is a hell of a lot better than getting 10 for £4.49.*

Some interviewees had a limited number of pads supplied to them or had a special allowance for decreased mobility, but they were very aware of the expense.

Interviewee 8: R: *What sort of things do make it better, because I think you mentioned good and bad days?*

Having plenty of pads, 'cause you're short of pads. I know you can buy them yourself but it would cost me a fortune if I had to buy my own pads.

Interviewee 7: *I have the [name] pads and of course they're very expensive. I mean they're almost £7 for 12 and I use about... sometimes I've used three a day but I've got down to about two. Fortunately I do get Attendance Allowance because of my not getting about, so that helps quite a bit obviously. Otherwise I don't think I could afford to do it. But then they've never offered me any. I did ask at the surgery, you know, if I could get any pads and they said no, they didn't supply.*

Interviewees who were not using enough pads to be concerned about the expense anticipated it could become an issue if many pads were needed daily.

Interviewee 14: *I've got no problem with paying for pads, etc. Again that could be a problem. I imagine it could be later on, certainly.*

Diminished activity

In the experiences of many older people, **physical activity makes incontinence worse**. Even minor, everyday, physical actions can aggravate the incontinence.

Interviewee 16: *I suppose I feel a bit self-conscious about that. But you know I just use very slimline sanitary towels because, I mean, I can go all day just with one really, you know, unless I do something really unexpectedly, like bend down and undo my shoe laces with a very full bladder.*

Interviewee 3: *That's the trouble. If you're quick enough. And the trouble is I'm sitting here and can be here for ages perhaps and then I get up to do something and I got to go straight away, as soon as you move. And in bed it used to be like that. As you turned in bed you'd want to go.*

One of the most commonly cited everyday actions prompting leakage was getting up from a sitting position.

Interviewee 8: *When I get up now, I hold myself because I know my urine is going to come away from me until I get into the toilet.*

Interviewee 6: *My problem is, for instance, the way I am feeling at the moment. If I stood up I would need to urinate very quickly, but I am all right while I'm still prone or semi-prone.*

Many participants reported that **stairs are a problem** since going up or down prompted voiding.

Interviewee 13: *The times I've done it coming down on the stairs or walking round through here trying to get to the ... 'cause I'm not very fast, like.*

Diary entry from interviewee 1: *Stairs are always a problem regarding my bladder. Drove*

home with one of my friends. Problems on the stairs again. Rushed into my bedroom to throw my coat etc. on the floor. Loo next door. Quickly wash to get back to my friend.

Those who were not necessarily affected by minor physical actions, such as standing up, nevertheless reported that slightly more strenuous actions, such as walking, pushing a trolley or lifting laundry, aggravated their incontinence.

Interviewee 5: *I have good and bad days. The more active I am, gardening, bending, the more I'll use due to leaking.*

Interviewee 7: *It's lifting heavy stuff that doesn't help. I find if I lift anything I start leaking more...*

For many, but not all, older people, knowing that exertion caused leakage led to **reduced physical activities**.

Interviewee 8: *I can't see myself dancing now. I can't see myself dancing. All of a sudden I start dribbling or something like that because there's no guarantee it's not going to come just flooding out.*

Interviewee 1: *I used to go to keep-fit once a week. It's to do with the university – over-60s. I used to go to that. I don't go there now.*

R: *Is that because of the bladder problem or other reasons?*

Um, well, it's that as well as... I can't walk as fast, you see... it always starts with walking around quickly... I can't do that any more... I feel ashamed because I can't do it.

Interviewee 17: *I couldn't go swimming any more, which was sad. That was the biggest sadness for me, not being able to go swimming. I stopped because I was having to get out of the pool right in the middle of a lesson and toddle all the way to the toilet. And then by the time I got back it was... so it was a nuisance. When my swimming went, my aerobics went.*

Curtailment of physical activities involving being with other people also deprived the older person of social activity. A **reduction in social activities** was reported by several interviewees.

Interviewee 11: *Well, I stayed in most of the time. I didn't go out hardly at all. I didn't want to go out. I didn't like the idea of going out. I'd go round to our friends. They only live round the corner and I'd be in and out the toilet. Well, you don't want people coming and visiting you. I mean, in and out the toilet all the time. And I didn't like them coming round here because I had to keep going out.*

Interviewee 6: *Not easy and totally that I couldn't go out. I daren't leave this flat really to go to church, to visit friends, to go shopping or to do anything.*

Mediating factors in the relationship between incontinence and social isolation

The findings from this study suggest that incontinence has the potential to be a contributory factor in social isolation. However, there are many factors linked to social isolation, such as increasing age, living alone, restricted social network, life events and ill-health (Victor, Scambler et al. 2000). So when an older person with incontinence is becoming socially isolated, it is likely that a range of factors are involved in addition to incontinence.

The impact of incontinence on continued participation in activities and social interactions was variable. While incontinence was a likely precursor to social isolation, the relationship was not inevitable. The extent to which incontinence may be a significant contributor to social isolation depended on a number of mediating factors. Some factors were protective and reduced the likelihood of social isolation as a consequence of incontinence, while other factors seemed to make the progression to becoming socially isolated more predictable.

Table 6: Factors affecting social isolation

Category	Concepts
Self-esteem	Feeling embarrassed Threat to their dignity Shame
Attitudes	Personal attitude Others' attitudes Unsympathetic public attitude People understanding Lack of interest by professionals
Professional care	Did not seek professional help Listened to by professionals Limited professional help Knowledgeable professionals Positive help and support
Support	Marital support Support from family and friends
Adequate information	Sharing information with peers Information from professionals Consistent and accessible information
Compelling interest	
Toilets	Lack of toilets Access problems in toilets Hygiene Male problems in toilets
Mobility	Personal mobility
Transport	
Finances	

Self-esteem

With a few exceptions, all the older people mentioned instances of threatened self-esteem.

Feeling embarrassed or the fear of being embarrassed was the most often quoted negative feeling about incontinence.

Interviewee 15: *I think that's the worst. It's the embarrassment, isn't it?*

Two older people with faecal incontinence recalled particular instances that caused them to feel very embarrassed.

Interviewee 11: *It's going round the shops. [laughter] You go to the toilet. If you want to go to the toilet, you go to the toilet and you rush out and it's just so bloody embarrassing, you know. Really and truly it is. You look at people all*

normal and then you think to yourself, oh God, they're all right, they're not going to the toilet, like, you know. And it's awful when you just can't stop it.

Interviewee 13: *It would go straight through me like, you know. I went up to the post office to pay some bills and I was way up to the counter getting served and it just came and I thought, what can I do? What can I do? You know, I didn't know what to do. So I waited for my money and just got out of there as fast as I could. And, of course, by the time I got down to the park and I went into the park and cleaned myself up best I could in the toilet in the park, and then I walked. I wasn't getting on the bus and I wasn't going to get a taxi because I knew what I had done like, you know. So I walked all the way from there.*

Older people with urinary incontinence recounted specific events when they were embarrassed.

Interviewee 10: *Yeah, when I started the radiotherapy. But one of the biggest problems I had was I'd go somewhere to have a wee, sort of thing, and I couldn't go. Then all of a sudden it would just come out and hit the back of the urinal and go everywhere. That was so embarrassing because you couldn't leave it just as it was 'cause there'd be bloody muck everywhere like, so you had to try and clear it up the best you could, and then you wait for next time.*

Interviewee 4: R: *So what made you go and get help?*

Because I felt so embarrassed. I went out with [name] one time and... er... I couldn't get to the toilet fast enough and I wet my trousers... I said: 'This is ridiculous.'

Many respondents described their ongoing fear of being embarrassed and this can be associated with various circumstances and situations.

Interviewee 15: *Well, erm, I mean, it is embarrassing. I wouldn't go out without a spare pair of pants and a pad in my handbag. Everywhere you go you've got a spare pad and a... And when we went shopping on, was it Saturday, and I thought when I looked in my*

handbag, I thought, oh I haven't got a pair of pants and a pad in this handbag and I panic and I'm thinking I probably won't need it but it's still this panic. There's still this thought that you might need it. You might embarrass yourself.

Interviewee 17: Well, it's embarrassing if you have to do it regularly in church now.

Interviewee 17: I was using huge pads and I thought, 'These show', and I was a bit embarrassed with them.

Talking about incontinence was also embarrassing to many of the older people.

Interviewee 8: I haven't sort of spoken a lot about it. It's embarrassing to me.

While embarrassment is the most commonly experienced feeling, several interviewees expressed other feelings relating to their own self-image. Some intimated a **threat to their dignity**.

Interviewee 11: *But these past couple of years have been awful really. It's not only for me. It's been for my husband as well. Because I can't see very well, he's had to go behind in the toilet and make sure that everything's all right and it hasn't always been all right when I haven't been able to get there quite in time, you know. It's not nice for a man to do things like that.*

Interviewee 15: *It's awful. It's degrading and I think have I got – am I going to be one of these smelly ladies that... I suppose really I am. I go over the top with hygiene because I don't want to be, you know, like...*

One interviewee felt a strong sense of **shame**.

Interviewee 1: *I don't know... I mean I feel ashamed.*

R: *Is that the worst thing?... what other feelings are there?*

I don't know [near tears, pause] I feel ashamed that it doesn't get any better.

Diary entry from interviewee 1: *I am ashamed to say I am always already wet.*

Attitudes

The older person's **personal attitude** towards life was an important mediator in their ability to cope with incontinence. Some people showed a degree of resilience.

Interviewee 19: *Other than that I don't have any problems with it at all. As I say, only if I go away anywhere I've got to make sure, like, if I go out anywhere. I go down Weston to my daughter's. I put a couple of pads in my green bags and tie the ends up and put them inside my handbag and take them with me to change. That's the only way I can. I just brought myself round it. I don't worry about it one little bit. It doesn't worry me at all.*

The attitude of other people towards incontinence can have a profound impact on the sensibility of the older person. **Others' attitudes** can make it easier for the older person to overcome the difficulties they experience with incontinence and enable them to maintain their activities and continue to socialise.

Interviewee 17: R: *I've picked up that your friends in the [name] make it easier for you because they know.*

Nobody says anything but that's the reason. I am more comfortable with them, yes.

It may be the fear of others' attitudes that may hamper the older person taking the risk of going out and socialising.

Interviewee 6: *I think there would be a danger if they notice that you have wet your pants, for instance, that... 'That's a bit careless of the old boy. He should have gone to the loo,' you know.*

Some older people remarked on the **unsympathetic public attitude** they experienced, which hindered their ability to maintain their activities outside the home.

Interviewee 2: *I was absolutely dying to go to the loo and I said to the assistant: 'Have you got a toilet I could use?' but the receptionist said: 'We have, but sorry, customers can't use it.' It was against the law or something. We're not allowed*

to let customers come in and use it'... And I had to sit there and suffer! As soon as I got outside that shop... Oh my Gawd, I thought, it ain't gonna work, I shall have to go up to the precinct again and go in there because they've got a loo in there. It wasn't too bad. I managed to get in there without much trouble, but isn't that terrible? No loo for people if they want to go. I mean... I suppose they don't keep people sitting that long like me... Oh, it was a long time. I sat there ages.

Others were more positive about **people understanding** their incontinence and their particular needs.

Interviewee 10: *It doesn't make a lot of difference. It hasn't made any difference to me, I don't think – 'cause I still chat with people, no matter – 'Well, I've got to go', and then they know I've got to go and they've gone on their way and the next time, 'Oh, how far did we get last time?'. No, it don't really. I don't think people shun me in any way. I don't think they... 'cause more or less they're just interested in how I'm doing. Concerned for how I'm progressing. That is what it's like.*

The degree to which someone else could understand the experience of incontinence was also queried.

Interviewee 11: *People sympathise with you but they don't really. It's like when somebody dies, everybody says: 'Oh yeah, I understand how you feel,' but nobody understands how you feel unless they've experienced it themselves. You can talk about it till the cows come home and people, you know, okay so they... and then you think, oh well, they're probably exaggerating, that couldn't possibly be as bad as all that. But they haven't been there. They don't know.*

Some interviewees were more confident of a positive response from other people.

Interviewee 9: *I'd be very upset about it but they would know that there was something wrong with me and probably expect something to happen. You know, I expect people are generally very sympathetic. They might not like it but they generally would be sympathetic with someone who has a problem.*

The fine balance between feeling appropriately supported by other people and getting too much of the wrong sort of help can leave the older person feeling patronised.

Interviewee 11: *I don't like to be thought of as somebody who's like that – got the runs all the time, you know. You got to be looked out for. It's like with my eyesight. I don't want people fussing over my eyesight. I mean, [name] is a bit of a pain because, 'Watch that! Mind that step! There's a bough there.' And while she's telling me, she's sliding down herself you know [laughter]. And well, that gets me a bit. But, you know, it's only done out of kindness.*

Very few interviewees commented disapprovingly on the attitude of professionals, but a **lack of interest by professionals** was experienced by a small minority and this left them feeling unsupported.

Interviewee 2: *I did mention it once to one of the doctors, but I don't think they were that interested. They said it was old age and I just took it as that... well, I got it, I got to stick with it I suppose... there ain't nothing that can be done.*

This perceived lack of interest could make the older person less inclined to persevere with seeking professional help.

Interviewee 10: *... but there was no follow-up so, of course, when you're telling the doctor every time you see them, then there's nothing happening, so you don't bother to tell them next time. You just go up with your chest or whatever else it is, 'cause every time you saw her ... I'd tell her what I'd come up about and then she'd say: 'Yeah, but what constrains you most?' And of course having a heart attack and pneumonia, that was... and I was fed up with telling them about my water works, so perhaps every two or three visits to the doctor, I would say and then it was always 'What are you most concerned about today?'*

Professional care

Many older people found it difficult at first to get the professional help they needed; this was

partly because of their reluctance to discuss incontinence. Although help and support were recognised as being important in helping the older person manage their incontinence and continue to participate in activities, some **did not seek professional help** for a long time, in one case several decades.

Interviewee 13: *I didn't tell him about the waterworks. I don't know why. Bit silly, I suppose. but I didn't tell him. I just felt, I don't know... I suppose embarrassment as well, that you've got to tell somebody else. I mean, now I'm more outgoing about it.*

Being **listened to by professionals** was an important factor in the older person feeling supported.

Interviewee 7: *I felt it was the right thing for me to discuss it with a lady doctor and she was quite helpful. She advised me to go to the clinic, and the lady I saw first of all, she was very, very nice. I wasn't so keen on the other lady I saw yesterday. She didn't seem to really want to listen but she was all right.*

Some interviewees felt there was **limited professional help** or advice when they first reported their problems.

Interviewee 5: *...but I am not sure that I was best advised early on.*

Interviewee 16: *Well yes, I mean, the doctor didn't say there was a continence adviser. I just thought like she... 'cause they don't have time to talk to you or find out who you are.*

Knowledgeable professionals made the older people feel more confident about managing their incontinence.

Interviewee 1: *She was very knowledgeable in her field. And extremely nice.*

R: *It helped that you felt that she knew?*

I had confidence that she knew.

Some interviewees commented on the **positive help and support** they received from professionals.

Interviewee 7: *Well, just that the advice she gave me, you know, to go to the clinic. Because as*

she said, it was better for me to go to somebody that really had studied, because after all they only know just the bare facts of it – well, of all illnesses really. And yes, I think the lady I saw was quite helpful and I think it helped me in some ways talking to her. That helped, yeah.

Several interviewees described examples of the practical help they received from professionals.

Interviewee 5: *I think the continence adviser straightened me out on the pelvic floor exercises. When she tested me, I was doing the wrong muscles. I think I'm doing them properly now. I want to do the test again to see if I'm doing them better.*

Support

The support that some older people received from partners, family and friends was critical in helping them to cope with their incontinence. For many interviewees, **marital support** was the most important source of both emotional support and practical help.

Interviewee 8: *It helps because he knows what happened to me and he knows what the problem is. With other people you have to go right through from the beginning and they really don't want to know, all about illness and goodness knows what. And he knows everything, so I don't feel embarrassed.*

Interviewee 4: *Oh, he's good, he's wonderful. I'm lucky. There are lots of people that don't get the same help as me. Well, we've been married for 50 years. He knows everything.*

R: *Yes, and you think that makes a big difference?*

Very much, yeah. I can talk to him about anything.

R: *About the bladder problem? Your feelings?*

Anything, yes.

The support of a partner was seen by some as crucial in enabling them to continue going out and therefore helping to ameliorate the likelihood of incontinence leading to social isolation.

Interviewee 5: R: *Do you think that there is a link between incontinence and social isolation?*

I feel very much included but yes, very much so. There must be social isolation for some. I am fortunate in having a wife of 40-odd years, a lovely family, great friends.

There must be people – widowed, for example – who feel far more the pressures of being incontinent. We can talk about everything. If you're on your own... two heads are better than one... A woman would accept it more. A man on his own, with his experience, must find it very hard.

The complexity of the support derived from a long-term partnership was illustrated by one interviewee, who despite acknowledging a lack of emotional support from her partner, was clear that the long-term partnership did provide comfort.

Interviewee 15: *I don't discuss my problem with my hubby. He would not understand. If I break wind, which I have no control over, he makes me feel ashamed and gives me the cold shoulder for hours. He does know I can't help it but still doesn't accept it. So I suppose I suffer in silence. He has never been interested in my personal problems.*

Interviewee 15: *No, no, it hasn't made any difference to our lives. You know we're still affectionate to one another and, you know, our feelings haven't changed... I don't think his feelings have changed, any different. Like comfortable slippers, isn't it? I suppose. I mean I do think now I'm older and less... oh God, if anything happened and I had to live on my own...*

While marital support seemed to be critical, several interviewees also spoke of the benefits of **support from family and friends**.

Interviewee 5: *In the family it's not a problem; they wish me well. It's the same with my friends. The ones I walk with and the ones I pub with. Yes, I think people are very understanding and supportive.*

There seemed to be two kinds of family support; that gained from confiding in family members and the supportive presence of a family who may or may not be aware of the incontinence.

Interviewee 14: *Well, you've got somebody you can chat to and talk about it and that makes a heck of a difference. If you've got a problem you're dealing with on your own, even if you've got a good doctor or whatever that you can go and talk to, as I have, it still makes a big difference if you've got family and friends.*

Interviewee 17: *They know I've got to spend pennies. Grandma's got this problem. I never told them but I expect, well – they seem to know.*

Adequate information

Sharing information with peers is seen as helpful, partly because it makes the older person with incontinence feel less alone with their incontinence and enables them to ask for help. Knowing that other people have incontinence is reassuring.

Interviewee 14: *It's not the sort of thing you're going to bring up with anybody else unless you feel that you can help each other or, you know, they can help you or you can help them. In which case I wouldn't worry about talking about it all but...*

Some interviewees expressed satisfaction with the **information from professionals**.

Interviewee 18: *So that's what she said, you know. She said: 'Come back to me.' But she said: 'You can ring up,' and I would if I wanted to, but she said: 'Come back to me and we can have another talk and go into it.' So I was very happy about that.*

Others felt that there should be more information available; and while reflecting that incontinence was a difficult subject to discuss with professionals, they seemed to imply that the onus was on the health professional to broach the subject and provide appropriate information.

Interviewee 12: *I don't think they get enough information about it. No. I mean you don't always sit next to a person talking about incontinence. And probably they're frightened to say to the doctor about it, but yet the doctor should ask if they've got any trouble: 'Are you worried about anything?'*

Interviewee 7: *I think doctors and anybody in the medical profession should take it much more seriously and be as helpful as they can, you know, and give people advice, you know.*

One interviewee also reflected upon the importance of receiving **consistent and accessible information** from health professionals.

Interviewee 5: *I knew that initially after the operation there would be incontinence, but this seems to be permanent. I feel I'm getting much better advice and help from the clinics. It's more immediate. I think it is a valid question: 'Why did the hospital from the start not put me in touch with the clinic? You have to put your trust in people. None of the information is in one leaflet. There is conflicting advice. When I see the surgeon or the urological nurse or the people at the clinic, is information shared? If the patient does not know who is dealing with what aspect of your problem, you do not know who to go to for a specific condition.'*

Compelling interest

Older people who had a strong sense of purpose or **compelling interest** seemed more resistant to withdrawing from activities and social events because of their incontinence. Their motivation to continue doing the same sort of things that they had always been interested in outweighed the power of incontinence to lead to social withdrawal.

Interviewee 14: *Activities as far as I can recall haven't changed from what happened before or what I do now. I'm still just about as active. I guess I obviously get more tired doing things now than I did, you know, way back before it started. But I've always [been] pretty active and I'm doing the same sort of activities, pursuing the same interests.*

Toilets

Toilet mapping is a prerequisite for older people with incontinence engaging in activities outside their homes. However, mapping is not simply concerned with the availability of toilets but also with their accessibility, their cleanliness, their washing facilities, and the privacy they afforded.

Interviewee 4: R: *When you're out, what makes the problem better?*

Being able to get to a toilet. That's the number one issue.

R: *In selecting a toilet, what are your selection priorities?*

Getting to it and making sure it's clean, I suppose.

R: *Is that a problem, the cleanliness?*

Sometimes it is. I'd try and find somewhere else if it was dirty.

Interviewees' experiences in accessing suitable toilets varied; some were upbeat about local provision; others less so. Several expressed concern over **the lack of toilets**.

Interviewee 10: *No matter where you go, the toilets aren't available. They should put more toilets there. And in Bristol, where I knew where the toilets were, you say: 'Oh well, I'll go round that way because I know there's the toilet.' But when you get round there it's locked. So then you're really in trouble 'cause psychologically you've told yourself you'll be going in the next two or three minutes, but then it could be ten minutes, quarter of an hour later. 'Cause by then you've started and there's not a lot you can do about that.*

Some interviewees intimated that limited public awareness of the needs of people with incontinence in part accounted for the lack of toilets.

Interviewee 18: *I don't think there are enough toilets around for people that do suffer like that, you know. No I don't, not really.*

Interviewee 15: *And I must admit I booked a holiday to Ireland and it was by coach and the*



first thing I said to her is: 'Have you got toilet facilities on your coach?' She said: 'Yes.' And when we got on the coach, they didn't. And I must admit I worried about it going to Ireland and I worried about it. I wrote a stinking letter to them. And I felt sorry. There were older people on the coach who were on water tablets, so how they managed I don't know.

While one interviewee's diary extract suggests that public awareness in Bristol is improving, it glumly reports that there are not many toilets left in the locality.

Extract from diary 3: *Just heard the corporation has a list of public toilets in Bristol or at least the ones they haven't closed. They didn't know where to get one so I shall have to find out. Two of them near here have gone, leaving just one in the car park.*

Another interviewee wondered whether there were more available toilets than the public were aware of and that it is a matter of publicising them better.

Interviewee 14: *I was in [place] because I bought the TV recently. I went into [name] to see what they'd got first and asked them. And you know: 'Yes, there's one at the back of the store.' There was no notice to say it was there but it made me wonder whether there aren't toilets in most big stores.*

A number of **access problems in toilets** were reported. One interviewee recounts her experiences at a wedding reception in a Bristol venue.

Interviewee 12: *They pushed me in a chair at the reception. I was going to the evening. They booked me in a room in the hotel and when I looked at the room, I said: 'No, I'm sorry I cannot stay in here.' They said: 'Why not?' I said: 'There's not a disabled.' They had one disabled. Isn't it ridiculous? One disabled room and that was already taken and this room, they took the door off the toilet but they had no high seat for me. I can't get down on those seats, you see, and the bed was too low.*

Another explains the predicament about not being able to visit the toilet discreetly.

Interviewee 17: *If it was round the back and you could creep out to the toilet, that would be all right but you've got to walk right up through the front and everybody can see you and I expect they say: 'What's the matter with her, then? Is she all right?'*

Another, who has acquired a RADAR key for access to disabled toilets, nevertheless describes the torturous process of using the key and the toilet.

Interviewee 3: *I use it along the precinct because they got an invalid one there. Trouble is, doors open this way. You've got on the scooter, you stick the key in the lock and then reverse the scooter to open the door. You go inside and there's another door in there and that opens this way but the scooter's in the way, so you back your scooter back, open that other door and go in there. But I must admit that once you're in there, there's plenty of room. You can sit down and give yourself a wash and everything, which is quite handy. But that's the only one around here that I ever use. I don't know of any others.*

The interviewee continues to explain the importance of toilet design inside the cubicle.

Interviewee 3: *But that's one thing at [place]. I can go in the men's toilet. The only thing bad in there is that the toilets are low down. I've got extended seating in there [referring to his own downstairs loo]. But I got a grab rail to help me up, which is what I need.*

R: *If you were designing loos ...?*

Yeah, wish they'd open out a bit. If you go in with your groceries in there, you don't want to be leaving them outside. So I open the door. I get partly in. I get off and work round and open the other door that opens the same way and I put my scooter in and shut the other door, the outside door.

Hygiene in public toilets, in terms of their cleanliness, washing and disposal facilities, was a

key issue – and for one person, determined whether she would go out at all.

Interviewee 1: *I don't like using public toilets. I'm a bit fussy. I wish the loos were a bit cleaner. That stops me from going anywhere because of the dirty loo.*

Cleanliness was also one of the **male problems in toilets**. Several men reported a dilemma between their need for a cubicle for its privacy and its sitting facility, and the fear of risking infection by sitting in an unclean environment. A disabled toilet is more likely than a public male toilet to provide both privacy and cleanliness.

Interviewee 5: *One of the things I've had to do is use a disabled toilet. I don't have to. I could go in the Gents, in a private cubicle – to change a pad. I have to do that when there is no disabled toilet but, where possible, I will go to the disabled toilet. More comfortable. If you're in major stores, they're [the gents' toilets] generally of a high standard, but if you're in a public gents it's not always clean and the floor is wet.*

R: *Why is that an issue?*

Bearing in mind I'm talking about sitting in a gents' toilet to change pads. I have to dispose of the pads. I'll always carry plastic bags – like for a baby's nappy. Ideal for rolling up a pad. If I'm out in public, I tend to go to a disabled loo where there is [a] proper receptacle for incontinence waste, whereas in the public ones I have to bring my used pads home. There's probably a greater risk of my picking up an infection because I have to spend longer in the toilet. I'm not paranoid. It's just an observation. Other men are just in and out.

Interviewee 10: *Public urinals, I used to have to sit down. I had to sit down because I had to strain so much, you know, 'cause you're getting from both ends. But if I stood up to try and do it, I know I would have had mucky pants, like. You know what I mean? 'Cause the effort, it was hard to pass the water and then it was the motion, like. But now it's not too bad now.*

Some interviewees were very positive about public toilet facilities and this seemed to

facilitate their leading active lives outside their homes. One interviewee reported having ‘finely tuned antennae for decent toilets’.

Interviewee 16: *I tend to use the designated disabled toilets because, of course, they always have wash hand basins so you can usually sit on the toilet and reach forward with a pad of paper and sort of give yourself a bit of a shower if you feel you need to change. So I found with the provision of toilets adapted for disabled use in most stores and places like that... I mean, I wonder if people really know about that because often people think if you've got a disabled adapted toilet that it is only for disabled people. They don't realise it's priority for disabled people or people with a problem. And I know where those are as I go around.*

Mobility

The impact of incontinence can be partially alleviated by being sufficiently mobile to reach a toilet when needed.

Mobility was explored both in terms of **personal mobility** – being able to move around in the house – and in terms of going out into the wider community. Limited personal mobility exacerbates the consequences of incontinence in terms of reaching a toilet in time. The older people were generally able to isolate incontinence from their other conditions and identify whether it was limited mobility or being incontinent that made going out difficult. Some believed recovery from temporary immobility would ease their management of incontinence and enable them to go out.

Interviewee 3: R: *Do you think that this bladder problem is making you isolated?*

Yeah. Sure it is. Although I must admit I've got this mobility problem, which helps or doesn't help, depending on which way you look at it. 'Cause that's the main thing. I reckon that I could cope with the toilet perhaps if I could move around a lot better.

Having to use stairs to reach a toilet is problematic. Walking up or down stairs can

aggravate a weak bladder and it is particularly difficult for people who have physical difficulties in negotiating stairs. One interviewee described the problem that arises if designated disabled toilet facilities on the ground floor are not easily accessible.

Interviewee 10: *Usually on a Monday we do shopping and then we go in [name] and have a meal. There's a disabled toilet downstairs but it's for pensioners or disabled. Well, then, one time they didn't have the lock. It just wouldn't close, so everybody in the bar was using it rather than going upstairs. So by the time you got up the first couple of steps, you'd started anyway.*

Interviewees were able to distinguish between the relative importance of immobility or incontinence being instrumental in them not going out.

Interviewee 7: *But that's not only because of my bladder. I don't think that stops me going out providing I'm protected. It's more or less because of my ability not to be able to walk very far. I mean, even if I am in town. I went the other Monday and I was walking around and I felt any moment now my back was going to give out, you know, and I have to sit down somewhere.*

Limited mobility also affects the ability to manage once inside the toilet.

Interviewee 12: *She said: 'Mum, do you want to go in there?' I said: 'Yes, I think I'd better get going in here before I get in the car.' And so I went into the convenience and she said: 'Can you manage?' and I said, 'I think so but I might call you in... in a minute,' which I had to, 'cause once I got out of the trousers I couldn't get the other one up, button it over. And that is, you feel if you're on your own, you will feel really, really awkward, you know. And I don't think I could manage on my own to be honest. Not yet. Not with this.*

Transport

Regardless of the degree of personal mobility, older people expressed unease about using public transport. There are concerns about the difficulty of using public transport; and that waiting around for buses or trains, especially if they are late, increases the risk of an accident.

Several interviewees commented upon the importance of travelling independently in a car. This was because they were in control over the timing of their activities and their access to toilets.

Interviewee 14: *Well, you're more in control in a car of how long you're there and where you can go. And if I was going on a trip and I was going to [place] and to [place] and wherever, I can rearrange things if I need to in a car, whereas if you're travelling by bus it's not quite so easy. But it's not a problem because I'm not out on the whole, you know, right away from the toilet in any situation for more than the time I need to be. If I wasn't a driver then it would be more of a problem, I think.*

Interviewee 11: *If there's a likelihood of me wanting to go, I stay in the car or I get parked by a loo and make sure I know where the loo is, so I can rush to the loo.*

Using a taxi removed the hassle of waiting for buses but incurred additional expense.

Interviewee 2: *Well, as I told you, I can go out in a taxi but it is rather expensive.*

Finances

Some older people acknowledged the importance of having sufficient finances to cope with the extra costs of incontinence and thereby lessen its impact. The expense of incontinence was identified by a number of older people. Many spoke about the expense of pads and how they used pads thriftily to reduce costs. Having the money to afford taxis, adequate pads, a car and privacy appear to tip the balance in favour of an older person with incontinence continuing with activities outside the home.

Interviewee 8: R: *What sort of things do make it better?*

Having plenty of pads, 'cause you're short of pads... I know you can buy them yourself but it would cost me a fortune if I had to buy my own pads.

Interviewee 14: R: *You were talking about the ways you cope and you said you could cope because you were physically mobile, drove your own car. So in transport you are independent.*

I haven't got any physical disabilities, you know, like hip problems or knee problems.

Economically, no problem. If we end up going away, the fact that I can afford to have a single room is a big advantage. I mean it's no problem sharing a room with a friend who understands, if you've got a really good relationship, but I'd be a bit more unhappy, perhaps a lot more unhappy, sharing a room with a stranger who didn't... just in case she was somebody who was, sort of, felt awkward about it or whatever. But it does mean that I do go for single rooms.

Social withdrawal

The preceding section introduced factors that can either attenuate or exacerbate the likelihood of incontinence contributing towards social isolation. Some aspects of the effects of incontinence on older people that may lead to a reduction in social activities have already been highlighted. The ways in which incontinence can affect a person's ability to remain socially active are likely to be complex and subtle. For example, difficulties using public transport, feeling tired and constant worry are all likely to have a damaging effect on the older person's inclination and capacity to engage in social activities. Other aspects of incontinence, such as fear of accidents, are likely to have a more direct and detrimental effect on socialising.

Some interviewees spoke of being **afraid to go out**.

Interviewee 11: *I think it's because I'm frightened, I'm literally frightened to go out because I'm afraid I'm going to get caught.*

Interviewee 2: *I've got to keep running to the loo all the time and I wish that I could get out more, but I'm afraid to go too far.*

Many older people identified specific examples of **social retreat** as a result of their incontinence.

Diary entry from interviewee 8: *This is the first Christmas day we have ever spent at home. Normally, the shops being open, we might have gone out for an hour, but I have lost the desire to go out and about as I did before I became incontinent. This problem has made a great difference to my way of life. This problem has restricted my normal way of life and I do not like mixing with other people while I am like this.*

Interviewee 10: *If you're home you can always change. So it affects your social life, although I'm not a big socialiser anyway with regards, you know, going up the pub with people and this, that and the other.*

Only one older person spontaneously spoke about **feeling isolated** and it seemed that several factors besides incontinence contributed to this. One factor was that she lived alone on an estate and had limited contact with the neighbours.

Interviewee 2: *I would love to go to... my daughter's mother-in-law is in a home... she's in this home and it's beautiful... and what I miss most is people... you know, I'm all alone here and I think if anything should happen to me I couldn't get in touch with anyone. But that [name] tried to get me to wear one of these alarms, but I'm not very keen on that.*

A second factor seemed to be lack of confidence about meeting new people, caused by a combination of deafness and worry about incontinence.

Interviewee 2: *Well, like I said, I'm a bit nervous about meeting people.*

R: *Is that more to do with the deafness...? Yeah, yeah.*

R: *...or the bladder problem?*

Well, both, really... I don't suppose the bladder would be a problem because they've got toilets there but um... I feel really isolated... you know what I mean? Especially in this weather... It drives me nuts.

A third factor was difficulties with transport.

Interviewee 2: R: *In what way do you feel isolated?*

Well, as I told you, I can go out in a taxi but it is rather expensive. I did try Dial-a-ride but when I phone they take ages to answer and when I do get through, they say: 'We've got no room' and I got fed up doing that so I thought, what's the point of that?... I think they've got people on their list every week and so they fill up with them.

But in conclusion, the respondent was ambivalent about whether incontinence really constrained her from going out.

Interviewee 2: R: *In what way do you think the bladder problem is making you more isolated?*

[Long, long think] Um, well, I can't think really. I don't suppose it's a lot of trouble to me, not to that extent, because if I want to go somewhere then I go. You know what I mean? I don't sit here and think, oh, I can't go out because I shall be wetting myself. No, I don't think that. It's um.... no it's just that, it's just that I'm so isolated and I get so miserable with life.

Towards the end of each interview, the older person was asked whether they thought there was a link between incontinence and social isolation. On each occasion the question was phrased in a way appropriate to the preceding dialogue. Some interviewees did admit to feeling more isolated.

Interviewee 15: *It does stop you. I got to be honest. I mean if I was having, if I'd made arrangements to go out, say, this week, with my sister-in-law, we might go to Street or something. We'd get on a bus and might go to Weston, you know. Or we get on a bus and go somewhere for a nice ride. If I was having problems with my bowel the day before, I wouldn't go.*

Interviewee 9: R: *I asked you if you felt it was isolating you?*

It is, because you can't go out to meet people and we don't want people to come here really 'cause it's too much for us when they come.

The majority of respondents denied feeling socially isolated but could easily extrapolate from their own experiences how incontinence could lead to social isolation under certain circumstances.

Interviewee 5: *I feel very much included, but yes, very much so. There must be social isolation for some.*

Interviewee 14: *I obviously realised the quantity you'll leak over any given period can vary enormously but I hadn't realised that, you know, it can be... literally haven't got any control over it then. Well, that must be awful. That could, I would have thought, pretty well kill any social life. It may not kill it, but it would certainly restrict it.*

Two interviewees, both in their 80s, robustly denied that they felt isolated. Both were very open with their families about the condition.

Interviewee 12: *Well, to the girls it didn't make any difference but my son-in-law, you know, he doesn't mind because [name] will say to him: 'I want to take Mum in the toilet a minute,' and he'll say: 'All right, go on and I'll walk on down.' He just took [it] in his stride. My grandson-in-law, you know, even though they'd only been married like nine months, she'd known him from the age of 15, ten years, and I've known him that length of time, they've come up here for a meal. 'Nan, what are you doing tonight?' 'Why?' 'Can we come up for a meal?' 'Yes, come on.' Even then I found I was all right. She said: 'We're not going to worry you,' 'cause they know worry is the cause of the trouble. And I said: 'No, you come up when you want. I'll cook the dinner and I'll set it out if you're not here.' And that's what I used to do. I didn't worry. Come as you find me.*

Interviewee 18: *It don't me. No, it don't me. I'm not worried at all because sometimes I think, oh gosh, you know, I felt that. And I will say to [name] or whoever, and I will make excuses, I'm*

going over to change me pants. I don't mind. We're very outgoing with one another – not in a nasty way, a very quiet way. And my granddaughters, we're all like that and I can say to [name] that was here this morning: 'Oh, hurry up! I've got to run to the loo, you know.' So no, I don't ever worry about that, no. But I think I would be very embarrassed if I were sat down drinking a coffee somewhere or a tea and I couldn't find a loo and I really wanted to go really bad.

Some older people answered the question about social isolation with the comment that they were intrinsically retiring people; they enjoyed the social interaction that they chose to pursue.

Interviewee 17: *Oh yes, people come in that I've known for years. Not that you have much of a social life, not when you're my age and living in the country, 'cause it is, I mean I'm isolated here and with no neighbours or anything.*

R: *Do you think the continence issue has made a difference to the sense of isolation?*

Not really. I was shy before. I am a retiring person and it's my business. So some people are outgoing. I'm not. Not that I haven't done it in the past. But it doesn't come easy to me.

Interviewee 7: *No, I don't feel isolated. No. Because it's my own choice, isn't it? I don't need to be isolated. I know I can go out and talk to somebody. It's my own choice that I prefer to live like I am.*

One person suggested that isolation triggered incontinence.

Interviewee 12: *I think if you're on your own, you get bored and you think a lot about it. And that is when you sort of do what you shouldn't be doing.*

R: *What's that then?*

Well, you wet yourself, just like a child.

Two interviewees commented on factors they thought might contribute to isolation.

Interviewee 14: *I don't know where or when things start. It's going to be more of a problem depending on their lifestyle and their financial*

situation obviously. Maybe it's going to be affected by the support, or, you know, the number of friends they've got, family or whatever. If it's somebody living on their own and having problems, it's going to be worse.

Interviewee 16: *Because you can have all the will in the world to do self-management, but you need the energy and you need money and you need facilities to do things to cope with a condition like that, don't you?*

To summarise, the findings reveal that older people strive to make sense of their incontinence and in doing so explain it in different ways. People developed and used a wide repertoire of coping and managing strategies, including a variable ability to reconcile their incontinence with their general philosophy of life and to minimise the problem. Other devices, include concealing strategies, talking strategies, being prepared and self-imposed restrictions, were employed by all older people towards the over-arching aim of avoiding accidents and public embarrassment. The degree of preoccupation with these strategies varied, as did the reported impact of incontinence on their lives. The effects of incontinence were described in terms of being worrisome, producing aggravating consequences and resulting in diminished activity.

The individual's decision to participate in activities outside the house was variable. For some, concealing the condition was such a dominant concern that they began to cut out opportunities for social interaction. Others, having equipped themselves as best they could, defied potential embarrassment and went out. The extent to which social withdrawal became a consequence of incontinence was shaped by a variety of mediating factors. These factors and other aspects of the relationship between incontinence and social isolation will be discussed in the following section.

Discussion

The findings from this study provide insights into the experience of older people with incontinence and reveal the complex ways in which incontinence may contribute to social isolation. The study findings reveal older people's interpretations of incontinence, the diverse range of coping and managing strategies they employ to lessen its impact and keep control, and an array of factors that mediate the effects of incontinence on social activity and well-being.

Interpretations of incontinence

The findings suggest that older people attribute different meanings to their incontinence and that incontinence is understood in different ways. The recurring belief about incontinence documented in the literature is that older people consider it a natural consequence of ageing (Hajjar 2004, Horrocks, Peters et al. 2004, Robinson 2000, Shaw 2001). While this was alluded to, a number of other beliefs and interpretations about incontinence were given more credence by the older people in this study.

Many of them linked their incontinence to life events and felt that the death of relatives or close friends, in particular, was related to either the start or worsening of their incontinence. Conceptualising incontinence as part of a larger life story emerges in other studies. In one study, women explain incontinence in terms of their personal histories and integrate incontinence into accounts of their lives (Peake, Manderson et al. 1999). In another study, three different narrative types used by women to tell their stories of incontinence were described (Bradway 2003). A 'victim narrative' was identified, in which women describe being a victim of men, family members or society.

In accounting for their incontinence, some older people in this study reported feeling partly responsible for their incontinence. This has some resonance with the 'victim narrative' in that incontinence is viewed as a consequence of something that has happened to them, although the older people believed they were the source

of the problem rather than a victim of someone else. This feeling of being responsible for incontinence has been reported by women who felt their incontinence was because of their inaction and their lack of control over diet, weight and pelvic floor exercises (Peake, Manderson et al. 1999).

Another forceful view was of older people perceiving a psychological dimension to their incontinence. Many thought that when they were distracted by activities, such as shopping, their need to use the toilet receded. Conversely, when their thoughts returned to incontinence or they arrived home, they had a desperate need to use the toilet. This Pavlovian-like trigger has been reported (Abrams 2006) and although it is acknowledged that there is often no specific trigger for urgency, activities such as hand-washing, answering the telephone or putting the key in the front door have been reported as provoking factors (Abrams 2006).

There is a dearth of literature about the experiences of men with incontinence and therefore little is known about men's beliefs about incontinence. One older man in this study felt that men experienced incontinence differently because, unlike women, they were unused to losing body fluids and wearing pads. He implied that it might be more difficult for men to cope with their loss of continence than women and that the effect of incontinence is more detrimental to a man's sense of identity.

A study investigating the gender differences and the psychological impact of incontinence on older people in Hong Kong revealed that older men reported more negative psychological effects than women (Lee 2004). The author suggests that the self-image and expectations of men in a Chinese society account for these differences. The impact of incontinence for men unused to dealing with body fluids or using pads may be particularly complex given the 'commercial feminisation of urinary incontinence' described by Wilson (2004) and may threaten their masculinity.

Management and coping strategies

How an older person interprets their incontinence and the meanings they attach to it shape the ways in which they manage it (Bradway 2005). Older people employed a range of strategies to conceal their incontinence. A number of these were psychological strategies aimed at minimising the problem. One of the ways in which the older people were able to reduce negative feelings about themselves was to compare themselves favourably with other people who were worse off, thereby making their own situation seem better. Social comparison theory proposes that making positive downward comparisons increases self-esteem (Dibb, Yardley 2006) and makes the older person feel better. Favourable comparison with others seemed to be possible irrespective of the severity of incontinence. One person who spent much time at home in underpants as a way of managing incontinence was still able to consider that others were worse off.

Older people use a variety of strategies to manage their incontinence so that they feel normal. This quest to normalise incontinence is reported elsewhere (Mitteness, Barker 1995, Skoner, Haylor 1993). Feeling normal meant being able to carry on with their usual activities and maintaining an outward public appearance of being in control of their bladder or bowel. Normalisation was achieved in several ways, including adapting to incontinence by being prepared to deal with accidental loss and reducing the risks of possible accidents in public.

Concealing incontinence is a crucial aspect of this normalisation and pivotal in the ability of older people to protect their public image, maintain their social position and self-esteem (Mitteness, Barker 1995). Three aspects of concealing described by older people in this study were limited confiding, being discreet and being vigilant about cleanliness. Managing symptoms in isolation and secrecy to avoid being rebuked by others is widely reported (Bradway 2003, Wilson 2004). What was striking in this study was the variation in the extent of

confiding exhibited by the older people, both in terms of how much they revealed and to whom.

Some older people found talking about their incontinence particularly helpful and had an open approach to discussing incontinence, while a smaller minority were much more guarded about discussing or revealing their incontinence. Talking about incontinence is difficult for many older people since they consider it a taboo subject. Humour and euphemisms were variously employed as tactics to overcome the embarrassment of discussing incontinence.

Different styles of communication exhibited by older people with incontinence have been identified (Cochran 1998). Older people with open communication styles and those with closed communication styles are likely to respond differently to public education about incontinence and older people with a closed communication style are less likely to disclose their incontinence during a routine health visit (Cochran 1998).

Increasing public awareness of incontinence and public education campaigns via the media were proposed by some older people in this study, who derived comfort and information about incontinence from the media. National awareness campaigns would perhaps encourage older people to raise the issue of incontinence with professionals and others (Cochran 1998) and also ameliorate an ill-informed individual trial-and-error approach to self-managing incontinence.

Practical steps older people took to manage their incontinence included wearing pads, keeping to strict daily routines, limiting the amount and types of food or drink they consumed, and scheduling activities around availability and proximity to toilets. These findings confirmed management strategies that have been widely reported (Mitteness, Barker 1995, Steeman, Defever 1998, Horrocks, Peters et al. 2004, Miner 2004). Much energy and effort was involved in planning ahead, devising travel arrangements and participating in activities in proximity to toilets. This investment, together with dealing with the consequences of

incontinence, such as buying and disposing of pads, frequent visits to the toilet and constant worry, not only depletes the older person's time and energy for other activities (Bertera 2002) but, as this study also reveals, can spoil enjoyment of activities.

Two tactics used by older people in this study to circumvent accidents, which do not appear to be reported elsewhere, are being forced to use public places as toilets and having to resort to using buckets, jars and jugs in lieu of toilets. Choosing these options shows the lengths people will go to to avoid accidents, but also demonstrates the loss of dignity incurred by incontinence. In addition, using public places instead of toilets is a health hazard (Greed 2006) and may be misinterpreted by others. Street urination has become a major nuisance in some cities and is viewed as anti-social behaviour (London Assembly, Health and Public Services Committee 2006).

Maintaining control is a recurring theme in the literature (Dowd 1991, Mitteness, Barker 1995, Steeman, Defever 1998, Koch, Kralik et al. 2001). One aspect described by some of the participants in this study was exerting control over the burgeoning thoughts and preoccupation with incontinence that could easily overwhelm them. Older people striving to control their minds as well as bodies, as a consequence of incontinence, is not something that appears in this literature.

Self-imposed restrictions on activities and behaviours as a way of managing and coping with incontinence is well documented (Brown, Subak et al. 1998, Hajjar 2004, Robinson 2000). However, the findings in this study suggest that the relationship between participation in activities and incontinence is particularly complex since many of the older people kept control of their incontinence by resolutely continuing to engage in activities and recognised that this was beneficial.

Impact of incontinence

The impact of incontinence was generally perceived as negative by older people in this study. The negative feelings associated with incontinence have been well documented (Brown, Subak et al. 1998, DuBeau, Levy et al. 1998, Collings, Norton 2004, Horrocks, Peters et al. 2004). The constant presence of incontinence touched the lives of all the interviewees. Even the most sanguine agreed they had to prepare well to avoid accidents and check regularly that they were not wet in the course of pursuing their normal activities.

There was emotional distress in terms of constant worry and the need for constant vigilance, as well as worry about the costs of incontinence. There was physical discomfort, the sensation of uncontrolled urination, urgency of bowel movements, discomfort from wetness and consequent soreness and fatigue from disturbed sleep. Tiredness and sleep deprivation associated with incontinence is alluded to (Grimby, Milsom et al. 1993, Brown, Subak et al. 1998, Chelvanayagam, Norton 2000), but not given prominence in the literature. Participants in this study revealed their sleep disruption with striking clarity in their diary entries. This supports the view that data from diaries can provide invaluable insights into the lives of older people. Handwritten diary accounts are suggested to have greater social significance than what is said in passing and are therefore an important method of investigating everyday life (Johnson, Bytheway 2001).

In addition to the negative feelings and consequences highlighted above, there was also the nagging knowledge that any encounter with stairs or even the simplest physical act could, and often would, end in wetness and another round of managing that. Despite these commonly experienced problems, only a minority of interviewees displayed the ongoing depression or underlying anxiety so widely documented elsewhere (Al-Shammari, Al-Subaie 1999, Edwards, Jones 2001, Bertera 2002, Van Oyen, Van Oyen 2002, Deutekom, Miner 2004, Terra et al. 2005).

The majority, while recalling times when they felt despondent, did not seem to dwell on negative feelings and did not report feeling depressed. Many older people indicated that they made conscious efforts not to dwell on incontinence and focused their energies on devising and implementing ways of managing their incontinence. More positively, because they actively monitored their condition each day, for example, in terms of number of leakages or nocturnal disturbances, they were well attuned to the improvements as well as to any setbacks. The constant monitoring or hyper-vigilance by older people (Mitteness, Barker 1995) can, over time, contribute to a drain on energy reserves.

Many commented that a change of tablets or pelvic floor exercises or change in drinking habits were making a positive difference, thus treating incontinence as a challenge to be met head-on (Mitteness, Barker 1995, Bradway 2005). Some people, owing to a variety of interrelated factors, are more successful than others in managing incontinence (Mitteness, Barker 1995). Three types of management were identified by the same authors in a study of older people with urinary incontinence: supercompetence, isolating competence and incompetence. The supercompetent were able to manage their incontinence very effectively; some were less competent but could still manage to maintain their self-esteem, sometimes at the risk of increased social isolation; and the incompetent failed to manage their incontinence in public and were subject to hostility (Mitteness, Barker 1995).

While variations in the ability of older people to manage their incontinence were apparent, more evident were fluctuations in an older person's symptoms and their ability to control them. The interviewees reported good days and bad days. This has been reported elsewhere (Koch, Kralik et al. 2001), but the older people in this study also described how they often knew in advance whether they were in for a good or bad day and arranged their day accordingly. Many reported that when they were having a good day or felt more confident about their control, they resumed their social activities.

Social well-being and social isolation

The view that incontinence leads people to withdraw from social contact in an effort to manage their incontinence is commonly reported in the literature (Dowd 1991, Bertera 2002, Hajjar 2004, Miner 2004). Women suffering all types of urinary incontinence were more socially isolated than their age-matched counterparts (Grimby, Milsom et al. 1993) and in another study loneliness was the only outcome that was significantly associated with incontinence (Fultz, Herzog 2001).

Of the 20 participants in this study, three broad experiences of incontinence and its impact on social well-being could be identified. There was a small minority of older people who dwelt on their shrinking social involvement and seemed to regard it as permanent, talking of limited friendships, limited mobility and limited belief that there was much to expect from professional help. One of these spontaneously confessed to feeling socially isolated.

The majority of respondents said there were circumstances in which they were afraid to go out because their symptoms seemed so severe and beyond their control. Some were in that state at the time of the interview and admitted that it was restricting activities outside the house and with other people. Others could recall specific instances or a period in their lives when they would temporarily withdraw from activities and social interaction, but then resume them when they had regained control and found a new routine and ways of coping. The temporary or spasmodic nature of people's withdrawal was generally not a consideration in the studies, which found reduced social interaction (Fultz, Herzog 2001, Bertera 2002, Van Oyen, Van Oyen 2002, Miner 2004) or diminished activities (Hajjar 2004), but it may account for the apparent ambivalence among some participants as to whether their incontinence was leading to withdrawal.

A third group of respondents were determined to carry on with life as near as possible to

normal. They employed a range of strategies to achieve this, including padding up and planning their outings in meticulous detail.

Mediating factors in the relationship between incontinence and social isolation

The severity of urine loss and type of incontinence are factors reported in the literature that are thought to account for the variable impact of incontinence. In one study, being male and losing greater quantities of urine were associated with being more socially restricted (Fultz, Herzog 2001). However, the significance of aetiology and symptom severity being important predictors of the impact of incontinence are variously reported (Hajjar 2004b) and the factors responsible for the varying impact also remain speculative (Johnson, Ouslander 2001, Shaw 2001).

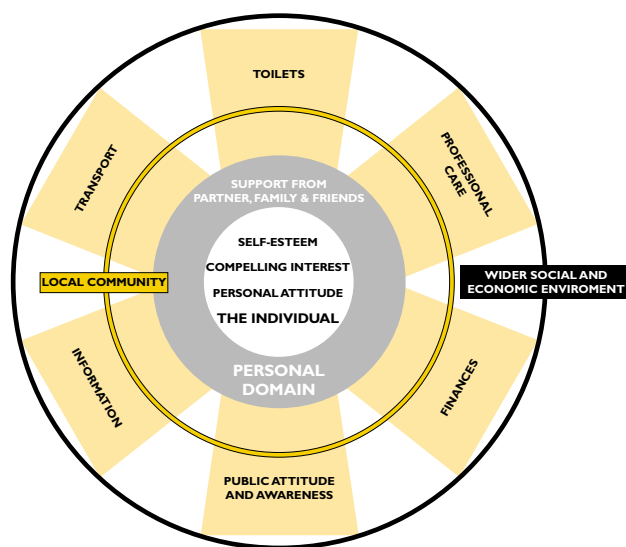
In the present study, severity of urine loss did not appear to be the most significant factor in the link between incontinence and social withdrawal. Some of the older people in this study, both male and female, who were most afflicted with urinary incontinence and those with faecal incontinence, which is reported to have a greater impact (Miner 2004), were among the most determined not to let it take over their lives. This group of older people did not report being socially isolated.

Many mediating factors in the relationship between incontinence and social isolation have been revealed in this study (see Figure 5.1), but the key factors which appear to determine the extent of social involvement seem to be a personal attitude that refuses to allow incontinence to defeat them, the quality of support from family or friends and the presence or absence of compelling interests.

Few studies have assessed the impact of personal attitude on the psychosocial well-being of people with incontinence. However, there are

some indications in the literature that personality types respond differently to incontinence (Shaw 2001, Bradway 2005). The influence of personal attitude in mediating the impact of incontinence is an under-researched aspect.

Figure 7: Mediating factors in the relationship between incontinence and social isolation



This study suggests that the involvement of partner, family and friends is an important influence on an individual's management of their incontinence and capacity to continue engaging in social activities. Such support mitigates the likelihood of incontinence leading to social withdrawal and isolation. Little has been reported in the literature that explores the effects of social support on adaptation to urinary incontinence (Shaw 2001), although the number of close friends is reported to be related to seeking professional help (Burgio, Matthews et al. 1991). In a study of women with faecal incontinence, wider social networks were influential in shaping an individual's ability to live with faecal incontinence (Collings, Norton 2004).

A more recent study, which investigates the role of social support in the relationship between urinary incontinence and psychological distress (Corna, Cairney 2005), highlights the complex interplay between social support and impact of

incontinence. Four measures of social support – tangible support, affection, positive social interaction and emotional/information support – were investigated for their influence on psychological distress. None was found to have a mediating effect, although a significant interaction between tangible support and urinary incontinence was reported (Corna, Cairney 2005). Surprisingly, tangible support (practical support available with someone to help with meals, visits to doctor, daily chores) is associated with lower psychological distress in older people who are continent, but not those with incontinence. Furthermore, those with urinary incontinence reported higher levels of distress at higher levels of tangible support.

These counter-intuitive findings reflect the complex effects of social support. The authors suggest that receiving social support that is not needed may have a negative impact on the older person and their levels of distress by eroding their perceived independence, autonomy and sense of control (Corna, Cairney 2005). While this study was not exploring the role of social support in the relationship between urinary incontinence and social isolation, it does serve to illustrate the complexity of the factors that are likely to be involved in this relationship.

A partner's support was viewed by some of the participants as being critical in enabling them to continue with activities in and out of the home. In a study of older people with urinary incontinence, married individuals were significantly less likely to experience 'feeling blue' compared to widowed or divorced people (Bertera 2002). However, the same study revealed that married individuals were not significantly less likely to experience depression compared to widowed or divorced people (Bertera 2002). No comparison was possible with single people who had never been married or in a partnership since they were not represented in the sample. The relationship between support from a partner and social isolation in older people with incontinence warrants further investigation.

The factors involved in an older person becoming socially isolated are complex (Victor, Scambler et al. 2000) and living alone is not the same as being alone. There is a clear relationship between isolation and living alone, in that while not everyone who lives alone is isolated, the majority of those who are isolated live alone (Wenger, Davies et al. 1996). The number of participants living alone or with a partner was evenly spread and of the 20 participants in this study, eight were widowed and two were divorced. The majority of older people who lived alone were well supported by family and friends.

Many participants in this study, whether living alone or not, repeatedly described instances in which family and friends effectively impelled them to go out and, more often than not, accompanied them. This inducement, combined with carefully planned itineraries, timing and pre-emptive precautions, appear to overcome the barriers. In the event of mishaps or potentially embarrassing situations, friends and family are frequently reported to help save the situation.

Most of the older people in this study derived social and emotional support from family and friends, often a chosen few. Four participants had confided only in family, and one in a best friend, but not family. Those living alone and without a supportive family or network of friends were more likely to report that incontinence interfered with their social lives.

Having a compelling interest also seems to act as an inducement to people's continuing social involvement. Many respondents reported going on day trips, holidays and an unchanged involvement in hobbies. The motivation to continue being actively engaged in activities was a powerful incentive to go out and be with others.

The importance of this in warding off social withdrawal does not contradict findings that people set a high priority on avoiding public embarrassment (DuBeau, Levy et al. 1998). The older people continued to go out and engage in activities but were able to avoid public embarrassment by putting considerable effort into stringent precautions. Reports of

interference with activities are variable (Hajjar 2004), although it is widely reported that incontinence affects participation in a range of activities, such as shopping, hobbies and travel (Dugan, Cohen et al. 1998, Fultz, Fisher et al. 2004, Hajjar 2004). While incontinence has the potential for restricting activities, having a compelling interest that leads to participation in activities is significant in preventing an older person with incontinence becoming socially isolated. These findings suggest that facilitating older people's active participation in absorbing activities could be an effective strategy for preventing incontinence leading to social isolation and would support the principles of the active ageing policy (WHO 2002). Irrespective of incontinence, active participation in activities, particularly those which are collective and active, has benefits in terms of increased social relationships and well-being (Social Exclusion Unit 2006).

The three factors that have emerged as being most significant in ameliorating the likelihood of incontinence leading to social isolation are personal attitude, support from family or friends and having a compelling interest. These factors relate to the personal domain and are, on the whole, beyond the control of outside agents. The participants with these characteristics adapted to living with incontinence and continued to lead active and fulfilling lives. However, nearly all participants in the study reflected on factors outside the personal domain and how they could be instrumental in the decision to withdraw from social activity or could enable them to engage and enjoy their various pursuits.

These additional mediating factors were particularly critical in those older people who were figuratively poised in the middle ground, somewhere between leading active lives and withdrawing to the extent of becoming socially isolated. The most important of these external mediating factors were:

- the financial ability to meet the costs of incontinence, especially purchasing pads;
- the quality, as well as availability, of toilet facilities;

- the degree of public awareness of incontinence;
- the quality of professional support;
- the quality and accessibility of information; and
- the range of transport options and their facilities.

The expense of incontinence was frequently raised in relation to the price of pads, although several people also referred to other costs, such as taxis and the extra cost of a single hotel room with en-suite facilities. Wearing an effective pad was a prerequisite for going out. Those not entitled to free pads or those whose limited number of free pads was viewed as insufficient for their needs were at risk of rationing their pads and restricting their ventures out. The connection between an incontinent person's ability to pay for sufficient pads to enable them to feel comfortable and sufficiently confident to go out does not appear to feature in studies exploring the impact of incontinence on social activities. References to the economic cost of incontinence generally relate to the direct and indirect costs of incontinence on public finances, with only passing comment on private expenditure (Van Oyen, Van Oyen 2002, Miner 2004).

Widespread pad-rationing was highlighted in the audit of continence care (RCP 2005), which was based on the standards set out in the *National Service Framework for Older People* (DH 2001a) and the Department of Health guidance *Good Practice in Continence Services* (DH 2000). This rationing does not comply with the principle that continence products should be provided according to the individual's continence needs (DH 2000). The issues of costs, supply and disposal of pads are likely to become more contentious with the current agenda pressing for more biodegradable products.

The availability and quality of toilet facilities had a powerful influence on older people's activities outside of the home. Toilet mapping of local areas, in terms of knowing the location of every public toilet, is well documented (Steeman,

Defever 1998, Shaw 2001, Collings, Norton 2004, Miner 2004). The older people in this study were equally focused on the quality of the toilets, such as cleanliness, accessibility and privacy. The importance of this is less well documented in the literature, although it has been raised by women with faecal incontinence (Chelvanayagam, Norton 2000). Several older people reported ceasing activities where toilets were either non-existent or inadequate.

The specific difficulties faced by men using public toilets were powerfully told in this study and do not appear to have been reported hitherto. The male perspective on incontinence in the literature is sparse and focuses more on the psychological implications for men. Men with incontinence required access to cubicles, both for privacy and to be able to sit down rather than use a urinal. Male toilets were considered to be particularly unclean and the lack of cubicles, together with the unsanitary conditions, was a disincentive to men feeling comfortable using public toilets.

The importance of public toilets in sufficient numbers and of a high standard, in terms of design and cleanliness, are not just a prerequisite for older people with incontinence to venture out. Anyone who is out and about during the day in public places and using public transport needs access to toilets. Older people, people with disabilities and women accompanied by children may all be deterred from going out because of a lack of toilet provision (Greed 2006).

Recognising that incontinence is something that other people experience and being able to talk to other people with incontinence was considered helpful by older people. However, talking about incontinence was still considered to be taboo by many; this was partly attributed to a lack of public awareness. Advertising continence products on television and in magazines and being able to buy continence pads in supermarkets were considered helpful in bringing incontinence into the public domain. Increasing public awareness of incontinence can help to encourage open discussion and enable people to seek professional help.

The interviews revealed many insights into the subtle effects of other people's awareness. Increased awareness enabled friends to understand the difficulties faced by an incontinent person, while a lack of awareness, such as a group of people not making it easy for a person to withdraw discreetly to a toilet, could leave the older person feeling uncomfortable and embarrassed. Such small acts of understanding could make or break a person's willingness to join in an activity. Women with faecal incontinence considered public attitudes to be a serious obstacle to coping effectively (Chelvanayagam, Norton 2000).

Attitudes, beliefs and knowledge about incontinence have been influenced by increased exposure in the media and this publicity is an important factor in influencing older people's access to continence services (Horrocks, Peters et al. 2004). Raising public awareness and knowledge of incontinence is imperative because not only does it influence people to seek help, but it may also alter health professionals' response to incontinence (Mittiness, Barker 1995, Palmer 1995).

The quality of professional support was reflected upon by the interviewees. Health professionals were seen as a source of emotional support and several older people commented on the benefits of being able to discuss incontinence without embarrassment. A striking finding was that, for some older people, the professionals were their only confidant or their first confidant.

Being listened to with empathy was highly prized, as was the impression that something could and should be done about the condition. Some people with incontinence choose not to ask for help and the reasons for this are complex (Shaw 2001). Others report not being asked about incontinence when seen by health professionals (Horrocks, Peters et al. 2004). In this study some participants felt that although they had tried to talk to their doctor and other health professionals about their incontinence, they perceived that they were not given enough attention and that little action had been taken.

Despite not always seeking help about their incontinence, many older people were very keen to find out as much as they could about it. Several older people commented on the difficulties in accessing consistent information when they needed it. Some reflected that information about cheaper pads and alternative treatments to aid their recovery and management could have been more forthcoming and would have enabled them to adapt and resume their usual activities more quickly. A lack of awareness of the availability of treatments is a barrier to seeking help (Edgley 2002, Horrocks, Peters et al. 2004, Steeman, Defever 1998).

Continence advisers were highlighted as being an important source of information and support by older people in this study. Continence advisers and other nurses have an important advisory role regarding appropriate symptom management for older people with incontinence (Steeman, Defever 1998). Not only were older people avid for information and advice about incontinence, they diligently followed the guidance given. Acting on advice was another way in which participants could be in control and manage their incontinence. Being in control helps them to adapt to their incontinence (Chelvanayagam, Norton 2000, Mitteness, Barker 1995, Steeman, Defever 1998).

Using public transport was often hazardous for the older people in this study because they lost some control over their access to toilets and carefully planned timing of toilet visits. Some participants would travel only by car, because this allowed them to remain in control. The chief concern for older people when travelling was to get to their destination in a short time unless toilet facilities were assured on the transport. Older people indicated that this affected their decision to go on a short trip to church or the shops, as well as long-distance train, plane or bus journeys.

Loss of mobility is detrimental to well-being and although it is accepted that there is an important relationship between travel and quality of life, this relationship is not well defined (Metz 2000). The reduction in travel consequent to

incontinence is not widely reported in the literature but, given the findings of this study, requires further research. Transport has a key role in enabling older people to participate in social activities and exclusion from transport is a major factor in social isolation (Social Exclusion Unit 2006). Toilet provision within the public transport system is poor (London Assembly, Health and Public Services Committee 2006), and thus makes travel impossible or compounds the difficulties people with incontinence have in travelling.

The findings from this study provide valuable insights into the experience of older people with incontinence and highlight the importance of personal and external factors that are instrumental in preventing or promoting the likelihood of social isolation. The experiences and perceptions of the older people captured here resonate with some of the themes in the critical review of the literature. However, this study has revealed some notable differences and many instances of subtle variation or elaboration of established views and ideas about older people's experience of incontinence and the relationship between incontinence and social isolation.

Conclusion and recommendations

Three broad experiences of the impact of incontinence on social well-being could be identified. First, there was a small minority of older people who dwelt on their shrinking social involvement and seemed to regard it as permanent. Secondly, a majority of older people emerged who felt there were circumstances in which they were afraid to go out because their symptoms seemed so severe and beyond their control. Thirdly, a group existed who were determined to carry on normally, as far as possible, and who achieved this by using a range of strategies to manage their incontinence.

Three factors that emerged as being most significant in ameliorating the likelihood of incontinence leading to social isolation are personal attitude, support from family or friends and having a compelling interest. Most participants in the study, irrespective of the degree to which they felt incontinence affected their social activity, were able to identify additional factors outside the personal domain which could be instrumental in preventing or promoting the likelihood of social isolation. These included their own personal finances, quality and availability of toilets, public awareness of incontinence, professional support, access to information and transport provision.

Help the Aged recommendations for policy and practice

Some factors that affect the ability of an older person with incontinence to participate in activities and remain socially engaged are unique to the experience of incontinence, while others are more generic and affect all older people.

The approaches to social inclusion highlighted in *A Sure Start to Later Life* (Social Exclusion Unit 2006) include the provision of integrated services that focus on the older person's needs; these include health and social services, benefits, housing, transport, leisure, community safety and learning. Similar principles are reflected in the *National Service Framework for Older People*, which

advocates the promotion of person-centred care, fitting services around people's needs and promoting older people's health and independence (DH 2001a, DH 2006a). The approaches and policies outlined in these and other documents also actively promote privacy and dignity and advocate always treating older people and their carers with respect and dignity (DH 2001a; DH 2001b).

Older people with incontinence wish, above all, to appear normal. The provision of public services should therefore be well designed and accessible for all older people, so that older people with incontinence are not unduly marked out by other people. One of the principles of *Sure Start* is to deliver non-stigmatised services that support dignity for individuals (Social Exclusion Unit 2006). This should guide the provision of quality services that promote social inclusion of all older people, whether they have incontinence or not.

Public awareness of incontinence and access to information

We will:

- raise awareness of the impact of incontinence on people's lives by bringing the subject into the open and breaking taboos;
- encourage older people who are experiencing incontinence issues to seek help and advice from health professionals, recognising that in many cases incontinence can be cured or improved; and
- encourage a co-ordinated local approach to the provision of comprehensive and localised information.

Quality and availability of toilets

We will:

- encourage local authorities to prioritise the provision of public toilets and to set it as a best-value performance indicator;
- recommend that the Government commits to commissioning a regular national mapping exercise to ascertain where toilet facilities are declining. This exercise used to be undertaken by the Audit Commission and since it stopped campaigners estimate that the provision has spiralled downwards;
- encourage the provision of accessible and well-designed toilets with adequate numbers of cubicles, and hand-washing and disposal facilities, which are cleaned regularly and well-maintained.

Personal finances

It is vital to ensure that older people who need incontinence pads have access to a sufficient supply.

We will:

- call on PCTs to ensure that everyone who needs incontinence pads has access to a well-designed and adequate supply;
- urge manufacturers, retail and supply chains to produce and market affordable and well-designed pads; and
- campaign to tackle pensioner poverty.

Professional support

We will:

- support the development of best practice in continence services by disseminating information and research; and
- raise awareness among those who work with older people of the impact of incontinence on older people's lives.

Transport provision

We will:

- call for adequate and affordable public transport, which is accessible and appropriate for all older people to enable them to participate fully in society; and
- encourage the provision of adequate, accessible, well-maintained and equipped toilets with the necessary disposal facilities for pads at all bus, coach and railway stations and facilities on coaches and trains.

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Help the Aged publishes a free advice leaflet: *Bladder and Bowel Weakness: managing incontinence*, which is available from the Information Resources team (advice leaflets@helptheaged.org.uk. or telephone Help the Aged), from libraries, CABx, Help the Aged shops or on the Help the Aged website, www.helptheaged.org.uk.

As well as reviewing existing literature on the subject, *Incontinence and Older People* captures the first-hand experiences of a group of older people who spoke in private, one-to-one, with researchers. The findings highlight the impact of incontinence on older people's quality of life, their resourcefulness in terms of coping strategies, and the dearth of advice and support currently available to many of them.

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