the psychosocial impact of incontinence on older people: a review

Although incontinence can inhibit or ruin a person’s life, research into its psychosocial impact has, in recent years, been limited. That situation needs to be put right, says Joanne Edgley

The psychosocial impact of incontinence on older people is a relatively poorly recognised area of continence care, especially in care settings where incontinence is not a primary concern. Although continence care is fundamental in almost all areas of nursing practice, it can be something about which nurses become complacent. Psychosocial considerations can be overlooked in favour of the practicalities of toileting, catheter-bag emptying or pad-changing, and older people can be left feeling not only embarrassed and insecure but also that they are a burden (Athlin et al 1993). The prevalence of incontinence is likely to increase with an ageing population, and the psychosocial impact on older individuals therefore needs to be given greater consideration. In reviewing the literature on the psychosocial impact of incontinence on older people, this article aims to offer insight into the experiences of sufferers and to emphasise the importance of truly individualised care.

available knowledge

In order to review the literature, a ‘snowballing’ strategy was employed. Keywords such as ‘incontinence’, ‘elderly’, ‘psychosocial’ and ‘psychological’ were used to search databases such as CINAHL and Medline. Browsing books and journals and surfing the internet also proved to be valuable.

There are many studies demonstrating that incontinence has a negative impact on a person’s social and emotional well-being (White 1997, Athlin et al 1993, Kelleher 1995, RCP 1995, Harris 1999, Keller 1999, Grimby 1993, Dowd 1991, Gallagher 1998, Smith 1998, Macaulay 1987, Norton et al 1988, Norton 1986). There is, however, a lack of research available which focuses solely on the psychological impact. This review, therefore, investigates the impact of incontinence on quality of life. Due to a lack of research into faecal incontinence, the review focuses solely on urinary incontinence. It was also noted that few studies focused on men, possibly because more women than men experience incontinence (Thomas et al 1980).

definition of terms

Authors use different terms and definitions of incontinence for their studies. The term ‘continence’ is currently preferable to ‘incontinence’ and people are described as experiencing ‘continence problems’. The range of terms can lead to some ambiguity in presenting and reviewing research findings.

Incontinence is not a disease but a symptom (White 1997, Alexander et al 2000). Continence is ‘ having the ability to store urine in the bladder or faeces in the bowel and to excrete voluntarily where and when it is socially appropriate … any deviation from this is seen as incontinence’ (White 1997).

Quality of life is a difficult concept to define. It incorporates many different aspects such as age, cultural values and beliefs, and also self-concepts, all of which are dependent on the individual’s intrinsic values (Kelleher et al 1995). A study by Farquhar (1995) investigated older people’s definitions of quality of life. Farquhar (1995) found that for the older person at home there was more to life than health. Family relationships, social contacts and activities were all valuable components of a good quality of life. These issues will all be taken into consideration when evaluating the effect on quality of life.

prevalence of incontinence in older people

It is widely recognised that people are at greater risk of developing problems with continence in later life (Norton et al 1988). However, epidemiological research by Thomas et al (1980) and the Royal College of Physicians (RCP 1995) has shown that the number of sufferers is far greater than is reported to healthcare professionals.

When considering prevalence, it is important to look at the definitions that each researcher has used, and to consider the method of inquiry (RCP 1995). In addition, it is often contended that incontinence is greatly underestimated due to the taboo surrounding the issue. Indeed, it is still a subject that people of all ages find difficult to discuss. Therefore, due to the inherent embarrassment, face-to-face inquiries may result in under-reporting (RCP 1995). Gathering, collating and interpreting data from 26 sources, the Royal College of Physicians (RCP 1995) estimated the prevalence of both total and regular urinary incontinence in older (over 65 years of age) people living at home to be 10-20 per cent in women and 7-10 per cent in men. The prevalence in both men and women living in residential homes was estimated to be 25 per cent; in nursing homes 40 per cent; and in hospital long term care 50-70 per cent. Keller’s (1999) study in the USA reported a prevalence of urinary incontinence in approximately two thirds of its 120 respondents, women aged 55 and over.

general psychosocial effects

While the physical effects of incontinence may not be clinically life-threatening, the symptoms can have a devastating effect on the...
Grimby in other studies (Athlin 1993). The psychosocial impact did not seem as great as it has been demonstrated in some studies. In this sample, the single respondent deemed it to be a major concern. In this sample, the social isolation due to the fear that an ‘accident’ might happen (Dowd 1991). Embarrassment is one reaction commonly experienced, causing a lack of disclosure to others and thereby a potential for misunderstanding. They may also want to avoid the feeling of stigmatisation.

Embarrassment Unsurprisingly, embarrassment has been shown to be a major psychosocial impact on incontinent people’s lives. A study by Norton et al (1988) investigated 201 women aged 16 to 86 undergoing an initial urodynamic assessment at clinics in two London hospitals. A questionnaire containing open and closed questions was used, followed by a brief interview. The findings showed that embarrassment and a reluctance to discuss the problem with general practitioners caused delay in seeking help, commonly for over a year.

Misconception In the USA over 50 per cent of 120 women aged 55 agreed, incorrectly, with a questionnaire statement that urinary incontinence is a normal part of the ageing process, and one-third that urinary incontinence develops in most people by the age of 85 years (Keller 1999). These findings, and those of Norton et al (1988), showed that many women delayed seeking medical advice due to the misconception that their symptoms were normal.

Older people can also delay seeking help because of the misconception that surgery is the only cure (Norton et al 1988). There were other misconceptions; once continence was lost, control could not be regained; and little or nothing could be done to treat or cure the problem (Keller 1999).

Social isolation Social isolation has been shown to be far greater for people with incontinence than an age-matched control group of continent people (Grimby et al 1993). One-quarter of a survey sample (Norton et al 1988) avoided other people and avoided going far from home or using public transport due to the incontinence symptoms or the threat of symptoms.

Dowd (1991) also found that women who could not control symptoms admitted to staying at home and limiting their social contacts to avoid the embarrassment and low self-esteem occurring after an accident. Gallagher (1998) used an ‘incontinence impact questionnaire (IIQ), previously tested in other research for validity and reliability, with women aged 60 and older living in the community, whose urinary incontinence symptoms occurred at least once a week. Results confirmed the significant relationship between incontinence and a change in physical activity and social relationships. There is a particularly strong correlation between physical symptoms such as obstruction or discomfort and psychological symptoms of low self-esteem, stigmatisation and reluctance to travel (Athlin et al 1993, Grimby et al 1993, Dowd 1991).

By contrast, for 81.9 per cent of Keller’s (1999) respondents in the USA incontinence posed only minor limitations on their lives and not a single respondent deemed it to be a major concern. In this sample, the psychosocial impact did not seem as great as it has been demonstrated in other studies (Athlin et al 1993, Grimby et al 1993, Dowd 1991, Gallagher 1998, Macaulay et al 1987). This could be due to the differing methods of sample selection. For example, the Norton et al sample (1988) consisted of women already attending continence services, whereas Keller’s sample was identified using random names and addresses of individuals.

Macaulay et al (1987) disagreed with Keller’s findings. In response to the question ‘generally how troubled are you by your bladder problems?’ (on a scale of 0-8, where 0=‘untroubled’, 8=‘making life not worth living’), half of the 190 patients sampled tended towards the midpoint and about one-third chose 7 or 8. When undergoing psychological assessment, using a ‘phobic subscale’, one-quarter of subjects found ‘life not worth living’. Macaulay et al (1987) concluded that ‘these patients were as anxious, depressed and phobic as psychiatric inpatients’ and argued that, because incontinence is longstanding and distressing, depressed mood in sufferers is understandable, although they tend not to experience depressive illness as such. The authors also stated that people with urodynamic disorders are unusually anxious and score highly on depression scales.

The Macaulay et al (1987) study also investigated the effectiveness of psychotherapy (including support, encouragement and reassurance) as an intervention. Different aspects were valued by different individuals and some simply valued the mere presence of support. This suggests that, when individuals isolate themselves due to their incontinence, they may be withdrawing from the very support systems that could be of value. Farquhar’s study (1995) showed that, for older people, social contact was one of the most influential factors in achieving good quality of life.

Stigma Almost half of the 201 females in the study by Norton et al (1988) reported feeling ‘odd’ and ‘different’ from other people because of their incontinence, and the trauma of being incontinent appears to function as stigma (Athlin et al 1993, Grimby et al 1993, Fonda et al 1995). On the other hand, if the sufferer can be confident in managing to stay dry and odour-free, he or she can feel more ‘normal’: Dowd (1991) argued that effective continence care is therefore a necessary, but not always sufficient, pre-requisite to maintaining a desired lifestyle, and that individuals can alter their perspectives to view incontinence as just another life event. In this way, it becomes part of normality and can be coped with accordingly. The sense of being ‘normal’ reduces the risk of social exclusion. According to Dowd (1991), although feelings of stigma are noted in all age groups, feelings of ostracism by others because of incontinence seem to increase with age.

Self-esteem Low self-esteem may, in itself, result from feeling stigmatised by others and seems to be a common occurrence among older people with continence problems. Macaulay et al (1987) found that women appeared to experience significant low self-esteem and low self-confidence, and this is supported by the conclusions of other researchers.

For many people, the major threat to self-esteem can be of an ‘accident’ occurring in public followed closely by the fear of odour, even non-visible accidents (Dowd 1991). Dowd (1991) argued that in order for self-esteem not to be threatened, the feeling of ‘being in charge’ was essential among the women studied. This involved deciding which protection to wear, how often to toilet, being prepared...
and ready to implement their plan and organising activities to include time and place for implementing the routine. Harris (1999) also showed that mastery over urinary incontinence and raised self-esteem correlated with lower depression levels and a sense of a better quality of life.

A small, in-depth qualitative study with a sample of six women in long-term care settings (Athlin et al 1993) revealed that being independent and in control of one’s bladder was of vital importance to these women’s perceptions of themselves but those who were incontinent saw themselves as dependent. One woman’s inner experience of her intrinsic value and autonomy depended on acceptance, control and knowledge of incontinence and also a belief that the future could be positive. Dowd (1991) similarly stated that, for women to accept incontinence and still feel good about themselves, they had to believe that their current circumstances were at least as good as they could be. Although not generalisable, the small study by Athlin et al also highlighted the ways in which nurses interacted with sufferers and, for example, while tending to their continence needs, determined whether the sufferers felt good or bad about themselves. These attitudes and reactions directly affected the patient’s experience of incontinence related to comfort or discomfort, high or low self-esteem, independence or dependence.

Dependence Independence and autonomy are very important factors in every adult’s life. Continence is usually gained in childhood and is the first step to gaining independence; hence bowel and bladder control are, for most, symbols of moving away from childhood to independence. As independent adults, control of these functions occurs without much thought or anxiety. When an individual loses this skill, a major part of what it means to be autonomous and independent is also threatened. Independence is especially threatened in institutional settings when toilet arrangements are governed by staff convenience, as opposed to individual residents’ needs (Athlin et al 1993). This in turn can cause a distressing degree of anxiety (Norton et al 1988, Stevenson 1989).

Sadly, physical frailty alone leads to dependence on others, and may be the cause of subsequent incontinence (Stevenson 1989).

Norton (1986) highlighted how environmental factors can affect a person’s independence. Good walking aids and easily adjustable clothes to allow quick removal and replacement can be important factors to consider. These have the potential to be the difference between dependence and independence, as does the correct height of the lavatory seat to allow leverage to move from sitting to standing. It is essential to take such factors into account and to realise how making even small adjustments can dramatically improve quality of life.

Conclusion

The potential for incontinence to destroy or inhibit older people’s lives is undeniable and it is vital that they receive the care and support they deserve. The input of specialist services is essential and individual ‘packages’ of support must be developed specifically for each individual’s requirements and circumstances (Athlin et al 1993). It is therefore essential that a thorough assessment is conducted of the factors affecting an individual’s life and resources implemented to help improve the quality of life of these sufferers. Although the psychosocial impact of incontinence on older people has not been completely ignored in nursing research, much of this took place in the 1980s and early 1990s and has been lacking in recent years. In order for health care to be truly evidence-based and for practice to change, more research and education of the public, doctors and nurses needs to take place (RCP 1995). Aspects such as the impact of continence services on the quality of life of older individuals is particularly needed.

At the conclusion of this review of the literature, it is salutary to read the Royal College of Physicians’ (1995) statement that, although there is a need for public awareness about the high prevalence of incontinence and its management, there is an ‘ethical dilemma in raising public expectations when in reality many health professionals are not sufficiently competent at assessing and treating incontinence to obtain optimum cure and improvement rates’.

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References


