Urine screening for clients with learning disabilities

Authors
Melanie Chapman, BSc, MRes, is research associate; Jenny Price, BSc, RNLD, is community nurse; Andrea Barber, RNMH, previously community learning disability nurse; all at Manchester Learning Disability Partnership, Central Community Learning Disability Team, Manchester.

Abstract

This article describes a study carried out to explore how common urinary tract infections are among adults with learning disabilities who use continence products. The study also evaluated the use of a product to assist urine sample collection with this client group.

Incontinence affects the lives of many people with learning disabilities. A number of studies highlight the prevalence of continence needs in the population of people with learning disabilities, with figures ranging from 47% (Lennox et al, 2003) to 59% (Bland et al, 2003). Symptoms of incontinence increase with the severity of cognitive impairment. While the prevalence of encopresis (soiling), diurnal (daytime urinary incontinence) and nocturnal enuresis (night-time urinary incontinence) for adults with mild intellectual disability is within the range reported for the general population, prevalence rates are substantially higher in those with a profound learning disability (Smith and Smith, 2003; Smith and Smith, 1998). People with a learning disability may also be affected by long-term consequences of constipation, which can lead to intestinal obstruction (Jancar and Speller, 1994). Deaths from this condition occur more frequently and at a younger age among those with learning disabilities than would be expected when compared with the general population (Jancar and Speller, 1994).

It has been suggested that urinary tract infections (UTIs) are a potential cause of incontinence. In addition to the health implications outlined above, incontinence can have financial implications, and a wider impact on self-esteem, independence and quality of life for both people with learning disabilities and their carers. Indeed, incontinence may be a major reason for the breakdown of the caring relationship which can lead to admission to residential or nursing home care (Department of Health, 2000).

Medication prescribed to people with learning disabilities for epilepsy, mental health and behaviour may also lead to bowel problems (De Silva et al, 1992).

The DH's (2000) Good Practice in Continence Services identified people with learning disabilities as a 'discrete group' who may experience continence problems and difficulties accessing services. The document states that everyone presenting with incontinence should be offered a detailed assessment, and receive a management/treatment plan and periodic reviews. However, the report focuses on those people who develop symptoms of incontinence and neglects the needs of adults who have never acquired continence. Although monitoring and auditing of services is recommended, there is a lack of guidance for learning disability services.

More recently, the white paper Valuing People (DH, 2001a) emphasised the importance of good health and health action plans. The white paper points to the low uptake of screening services in general and the higher prevalence of undetected health needs among people with learning disabilities. Continence is identified as one of the nine key health issues affecting people with learning disabilities.

The Essence of Care provides benchmarking tools for 11 areas that services should be aspiring towards in the area of continence (DH, 2001b). These benchmarks should equally apply to people with learning disabilities.
The literature search revealed that generally, approaches to incontinence focus on assessment, investigation and treatment of symptoms, or rehabilitation. In contrast, for adults with learning disabilities, incontinence is often viewed as an inevitable consequence of the learning disability (Stenson and Danaher, 2005; Smith, 1994; Bradley et al, 1995). Although the incidence is higher in those with profound learning disabilities, approximately half of the people in this group acquire bowel control, and approximately a quarter diurnal and nocturnal continence (Smith and Smith, 2003; Smith and Smith, 1998).

There is a scant evidence base on continence and people with learning disabilities (Smith and Smith, 2003). People with learning disabilities may be excluded from research into the effectiveness of continence services on the grounds that they have specific needs (Pyne and Stott, 1996). Some studies focus on the impact of environmental and lifestyle changes. For example, Jolly and Jamieson (1999) found that through improving nutrition in a group of people with severe learning disabilities, a range of symptoms improved, including faecal continence.

The majority of studies focus on behavioural approaches rather than examining alternative explanations for incontinence (Smith, 1996, 1994; Smith et al, 1994). Such behavioural approaches assume that a failure to learn how to be continent causes incontinence, rather than recognising that there may be underlying health conditions, functional problems or maladaptive learning, which may hamper the acquisition of continence. Stanley (1997) points out that behaviour management is only one aspect of a broader approach to promoting continence, and functional analysis may assist the understanding of reasons for incontinence which may not be health-related.

Research with people with learning disabilities and continence issues tends to focus on children (Stanley, 1997; Bradley et al, 1995; Bliss and Watson, 1992; Hyams et al, 1992; McCartney, 1990; Konarski and Diorio, 1985), involve small samples or single case studies, and lack long-term follow-up. Earlier studies were often based in hospital or institutional settings, rather than community settings, and more recent large-scale community studies have been hampered by poor response rates and sampling limitations.

Promoting continence for adults with severe learning disabilities is a neglected area and therefore, there is little in the literature to guide nursing practice.

Background to this study

This study developed as a result of the findings from a previous study exploring the process of continence assessments for adults with learning disabilities (Barber and Chapman, 2002). The earlier study found that most adults with learning disabilities who used continence products had not received an assessment. Those people who had been assessed had often not had a urine sample screened. The study found that 67% of adults with learning disabilities who received continence products had both urinary and faecal incontinence. People who have both urine and faecal incontinence are at higher risk of developing UTIs (DH, 2000).

Guidance suggests that everyone who is incontinent should be screened for UTIs during routine assessments (DH, 2000) and supported to have a continence assessment every six months (DH, 2001b).

In practice, anecdotal evidence suggests it can be difficult to collect urine samples with people with learning disabilities who may be unable or unwilling to cooperate. A range of methods of sample collection have been evaluated (clean catch, sterile adhesive bags, suprapubic stabs, disposable nappies, sanitary towels, catheter, cotton wool, urine collection pads). However, in common with research on the effectiveness of continence services referred to above, research on collecting urine samples tends to focus on younger, ill children (Liaw et al, 2000; Feasey, 1999; Vernon, 1995; Vernon et al, 1994) or older people (Ouslander et al, 1995a; Ouslander et al, 1995b). There is a lack of research evaluating urine collection methods with adults with learning disabilities.

Aims and objectives

The overarching aim of the study was to improve screening for urine infections with adults with learning disabilities. Study objectives were:

- To identify undiagnosed UTIs;
• To measure the prevalence of UTIs in adults with learning disabilities who receive continence products;
• To explore the usefulness of carrying out screening of urine samples;
• To evaluate the utility of a urine collection product.

Method

The study involved the collection and testing of urine samples and a questionnaire study.

It was carried out in a PCT within a large British city. Continence assessments for people with learning disabilities are carried out by district nurses or community learning disability team nurses. The local PCT's guidelines state that assessments should include urinalysis.

Ethical approval was obtained from the local NHS research ethics committees. Gaining ethical approval was particularly important as the research involved NHS staff and concerned a vulnerable group.

Forty-six potential participants who were eligible for local learning disability services were identified from a local PCT continence database. Of the potential participants, 26 (57%) were female and 20 (43%) were male. They were sent a letter explaining the research and inviting them to take part. This included:

• An information sheet about the study;
• The urine collection pack;
• A consent form;
• A 'best interests' form for use where people were considered unable to consent but where it was in their best interest to have a urine sample tested (DH, 2001c);
• A questionnaire to provide information about using the pack, urinalysis results and follow-up treatment.

The postal invitation to take part was followed up by a telephone call by the research nurse to answer questions about the research, the process of urine collection and analysis. The research nurse offered support to collect the urine sample if necessary.

Data collection and analysis

Urine samples were collected from the participants using traditional methods or the Euron (Uricol) Newcastle Urine Collection Packs. Participants chose which method they wanted to use. Urine samples were collected from participants with support from family carers, support workers, nursing assistants and the research nurse if necessary. The samples were then taken to the participants' GP practices where they were tested by practice nurses using a reagent strip. Samples were then sent for microscopy, culture and sensitivity testing at the microbiology laboratory.

The people with learning disabilities or the person providing them with support were asked to complete a questionnaire which contained questions about using the pack, urinalysis results and follow-up treatment. The questionnaire used closed questions with fixed response items and some space for participants to elaborate further if required.

Data from the questionnaires was entered on to a database and descriptive statistics were carried out using the Statistical Package for the Social Sciences (SPSS, 2001).

Results

Thirty-three people with learning disabilities had urine samples tested as part of the study (a 72% response rate). All of the people with learning disabilities who took part were incontinent of urine. Sixty-four per cent were female. Thirty-three per cent lived in a family setting; 66% lived in supported housing.

Nine people had a UTI detected (27%). Of these, one person had blood in urine detected: when followed up, this person was found to have prostate problems. The research nurse followed up all of the people who had a UTI detected to ensure that they had received the appropriate treatment.
Feedback on the urine collection process was received from 22 people. Twelve people returned a questionnaire, while 10 people who did not return the questionnaire were contacted for verbal feedback guided by the questionnaire items.

Thirteen people chose to use the pack to collect the urine sample. Four of the remaining people used a bowl, jug or other household receptacle; two people used a urine pot (information was not provided about how the urine samples were collected for three people).

The pack was used with 10 women and three men and 10 of these people said that they could not have obtained the sample without the pack. Only one person reported a problem using the pack but they had a urinary catheter in situ so use of the pack was inappropriate. Five of the people who used the pack had UTIs detected.

Ten people provided information on the length of time taken to collect the sample when using the pack. It took less than half an hour to collect the sample with five people. For three people it took between one and two hours and for two people it took over two hours.

Conclusions

UTIs were detected in approximately a quarter of the people who were screened (n =8; 27%).

This demonstrates the importance of screening people with learning disabilities who receive continence products.

The pack evaluated in this study can provide a useful method of collecting a urine sample. During the study it became clear that some carers and support workers had limited knowledge of how to obtain a sterile sample and the importance of preventing contamination of the urine sample (for example, by using a pack that had been open for some time or using a pad that had been dropped on the floor). To ensure effective use of the pack, support workers and carers need to be informed about the importance of maintaining a sterile environment when using the product.

Further work with a larger sample size is needed to replicate the study and to identify those people most at risk from UTIs.

References


Footnote
This study was supported by a research award from the ACA. Research support was funded by the Department of Health Priorities and Needs Funding. Ontex provided the Euron (Uricol) Newcastle Urine Collection Packs. The authors would like to thank Claire Holden and Sue Pattinson who helped collect the urine samples.