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Improving the experience of young men with continence problems

Key points

One in 10 young people and children in the UK experience bladder and bowel problems but the issue is often hidden, particularly in young adults and teenagers

Young men are particularly vulnerable because of a lack of recognition of male continence problems

Due to the stigma associated with continence issues, many young men are not accessing the help available

Most nurses have little training or experience in continence issues, which can cause them to make unhelpful assumptions

Staff need to help young men feel comfortable disclosing such information, and facilitate shared decision-making between patient and clinician

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Abstract About 900,000 children and young people are affected by bladder and bowel problems in the UK but, because of the stigma attached, many hide the issue and do not access the help they need. Young men are particularly vulnerable as there is little recognition of male continence problems. A survey of young people showed that almost half would feel “uncomfortable” talking about their continence problems to relatives and friends, and almost two-thirds would be embarrassed to see a doctor. This is compounded by a lack of early intervention, gaps in specialist children’s bladder and bowel services, and lack of support in the transition from child to adult services. Healthcare staff often have little training in continence issues and poor awareness of its impact on young people. This article reports the experience of one young man with continence problems, while two continence specialists – a nurse and an occupational therapist – explain how staff can improve the experience of care for young people with incontinence.

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It is commonly assumed that incontinence does not affect younger people but nearly 900,000 children and young people aged <19 years in the UK experience bladder and bowel problems (NHS England, 2015). A report by the All-Party Parliamentary Group (APPG) for Continence Care (2018) found that because of the “significant stigma that exists around bladder and bowel issues, many young people are not accessing the help that is available and some services are facing challenges in providing the support these young people need”.

A quarter of young people surveyed believed bladder and bowel issues only affected older people, almost half would feel “uncomfortable” talking about such problems to relatives and friends, and nearly two-thirds of those aged 18-24 years said they would be embarrassed to see a doctor.

The report labelled as “painfully slow” the implementation of NHS England’s

(2015) *Excellence in Continence Care* and called for a renewed focus on children and young people. It found:

- A lack of early intervention in diagnosing and treating bladder and bowel conditions in young people;
- Regional variation and gaps in specialist children’s bladder and bowel services;
- Insufficient support in the transition from child to adult services.

This was having “a wide-ranging impact on young people’s day-to-day lives; acting as a barrier in their social interactions and holding them back from achieving their aspirations” (APPG for Continence Care, 2018).

Male incontinence

Young men can be particularly vulnerable because continence problems in men are less recognised. Although men are less likely to report continence problems than women – and the problem tends to be age



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related when they do – bowel and bladder problems can still affect men at all stages of life. As an example, in a large community study in Leicestershire 8.9% of men complained of urinary incontinence and the prevalence steadily increased with age (Perry et al, 2000). The causes can range from neurological injuries to obstructive problems such as an enlarged prostate (Moore and Lucas, 2010).

QUICK FACT
900,000
Number of under 19s in the UK with bladder and bowel problems

Male incontinence is often related to prostate surgery. One study estimated that around 10-15% of men treated for prostate cancer experienced persistent urinary incontinence. It showed that men preferred to manage their incontinence using a mix of devices and pads to meet their lifestyle needs, but there was a need for better information and skilled advice on how to use medical devices (Bit.ly/ProstateContinence).

Effects of incontinence on young people

University of Bristol research on continence problems in young people aged 11-20 years showed that embarrassment, fear of bullying and stigmatisation, and lack of understanding meant that some went to great lengths to conceal bladder and bowel issues, thereby risking:

- Serious distress;
- Social isolation;
- Underlying conditions going untreated (Whale, 2016).

The social assumption that continence problems only affected very young children, women or older adults caused participants to feel abnormal and misunderstood. A small number told friends, but all hid it at some level, and many did not want anyone to know. This led to worry about “being discovered”, at a time of development when fitting in with peers and society felt particularly important (Whale et al, 2018). However, many found effective ways of coping (APPG for Continence Care, 2018) and those who told friends reported positive experiences and a sense of relief (Whale, 2016).

In terms of the healthcare experience, participants wanted to be supported to self-manage, reporting positive treatment experiences when there was good rapport with clinicians and they felt fully involved in decision-making (Whale et al, 2017).

Box 1. Case study: a young man's story

Jamie Gane^{*} is in his early twenties. As a teenager he had complex regional pain syndrome in his foot, confining him to a wheelchair. At 15, he developed continence problems after spinal surgery. He eventually had his leg amputated and now uses a prosthetic limb. Today he is a para-athlete, competing in martial arts and various endurance races, which include mud and water obstacles.

“When I first noticed my continence problems I kept it to myself as I didn’t understand what was going on. I had a catheter after surgery and I assumed it’s what happens when the catheter is first taken out. But after a few weeks I thought: ‘Maybe this isn’t right’. I mentioned it to a friend’s mother, who was a nurse, and she suggested some products.

“I was too embarrassed to tell my parents, or talk to the specialist with my mother present. It felt like a really horrible and dirty secret, and on a practical level it was very difficult. I managed to hide it with products from the pharmacy hidden in my bag at school, but it was stressful – and expensive.

“It wasn’t until university when I was really broke that I told my specialist and was referred to a specialist continence service. The nurses assumed I was still struggling to come to terms with it, but I was 19 years old and had been dealing with it for four years. I had worked out my own management plan and was doing fine. I had even told my university friends, which was a huge relief. I just wanted some financial help.

“The staff at the clinic did not listen to my own recommendations of products that I had been using and tried to push their suggestions but, eventually, I received some decent products that made my life a lot easier. I wish they had



asked the right questions and listened to me, instead of assuming they knew how I felt and telling me what was best for me.

“Before my amputation, I was in and out of hospital. I ended up taking my own products and avoiding telling the nurses because I was tired of having to repeat the whole story and people trying to fix it for me. When I did find a nurse to confide in, suddenly the whole team knew and I had people I’d never met before asking me if I needed assistance. There was a lack of sensitivity.

“The nurses seemed to have no confidence in me and tried to put me into their routine. They gave me different products because they were the ones the hospital used. I would have a few horrible days trying to follow their routine and then when I got home it was hard to get back into my own routine. It was a ‘one-size-fits-everyone’ approach.”

*The patient’s real name has been used, with his permission.

However, many felt frustrated about a lack of continuity of care and poor understanding of the wider impacts of continence problems on their lives.

Most continence problems in young people are functional, but some are caused by an underlying condition (see case study in Box 1). Hospital admission can result in the disruption of long-standing self-care regimes, which can be particularly distressing for patients; non-specialist nurses

should recognise patients are often experts in their own care, and listen and work in partnership with them to minimise this disruption (Rodger, 2016).

Nurse’s view on the case study

Davina Richardson is children’s nurse specialist, Bladder and Bowel UK. “Children’s continence services are not universally available in the UK and adult continence services will not always see

Box 2. Common misconceptions and useful trigger questions

Common misconceptions/assumptions

- Young people do not have continence problems
- They will feel comfortable discussing intimate problems with parents, carers and/or health professionals
- They will want parents/carers present throughout, or feel able to ask for some privacy for all/part of the consultation
- Young people are not competent/informed enough to make their own decisions about managing their health needs
- They will not have tried different solutions to manage their problems

Useful trigger questions

- Do you ever experience any dribbling of urine or wetting?
- Do you ever experience any soiling or leakage of poo?
- Do you have any other concerns about your bladder or bowels?
- How do you manage the problems?
- Are you happy with these arrangements?

Source: Davina Richardson, children's nurse specialist, Bladder and Bowel UK

Box 3. Further information

- Association for Continence Advice
www.aca.uk.com
- Bladder and Bowel UK
www.bladderandboweluk.co.uk
Email helpline: bladderandboweluk@disabledliving.co.uk
Tel: 0161 607 89219
- ERIC – The Children's Bowel and Bladder Charity
www.eric.org.uk/about-the-teens-section
- Spinal Injuries Association
www.spinal.co.uk

local policy criteria, most services strive to try and meet individual needs. This usually involves providing as small or discrete a product as possible that meets the urinary loss of the individual.”

Conclusion

Mr Gane's account clearly illustrates the problems faced by young people and, in particular, young men who have continence problems. It is important that health professionals are aware that continence problems are not confined to groups such as older people and that they recognise that young men may have problems. Nurses must be confident asking patients vital trigger questions and work with them to find solutions to meet their needs. **NT**

- The patient's real name has been used with his permission.

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young people under 18 years. Transition from child to adult services is improving, but experiences for some young people remain poor.

“Most nurses and other healthcare staff have little training and experience in continence issues, particularly relating to young people. Mr Gane's experience highlights the need to treat intimate issues sensitively, ensure privacy for asking questions about personal care – particularly on hospital wards, and ensure young people understand that staff need to document information, and how and with whom this will be shared.

“Sufficient time should be allowed in consultations to build rapport with young people, and listen to and understand their perspective. They should be encouraged to have at least part of a consultation without a parent/carer so that intimate, personal or risk-taking behaviours can be discussed openly in a safe and non-judgemental way.

“Continuity of care, explaining all the options and understanding young people's preferences is important. Meeting these as far as possible – or, when it is not possible, explaining the reasons why – is helpful and contributes to positive outcomes.”

Common misconceptions and trigger questions to ask young people are outlined in Box 2.

Occupational therapist's viewpoint

Julie Vickerman is clinical specialist occupational therapist, Bladder and Bowel Service, Blackpool Teaching Hospitals Foundation Trust, Lancashire.

“Given Mr Gane's medical and surgical history, he would probably have been seen by an occupational therapist (OT), especially

after his initial spinal surgery. Despite his reluctance to discuss his continence problems with his spinal surgery specialist, it is disappointing that an OT did not identify these difficulties – toileting skills should be part of any initial functional assessment.

“Lack of coverage in undergraduate occupational therapy programmes means OTs can feel unqualified to identify continence problems or may not see them as their responsibility. In training sessions countrywide, I suggest therapy staff ask the right trigger questions as part of their holistic assessment. Multidisciplinary

“Part of a consultation should be without a parent so intimate or risk-taking behaviours can be discussed”

team members also need to know how to act on this information.

“The specialist continence service should have given Mr Gane a comprehensive continence assessment, including keeping a bladder diary and documenting his fluid intake, to offer an appropriate method of management that matched his urinary loss. This might include hand-held urinals, urinary sheaths, body worn urinals, bags, adaptive underwear and disposable pads.

“Where pads are considered most appropriate, the product recommendation should be based on the urine output chart, balanced with information on lifestyle, living environment, privacy and dignity factors, and include a discussion of the appropriate disposal of used pads. While pad provision in the NHS is governed by