An ongoing study has found that perceived stigmatisation causes feelings of shame in children with continence problems and results in them avoiding social activities.

Effects of continence problems on children

In this article...

- Current understanding of childhood continence problems
- Preliminary findings on the effects of childhood continence
- Coping strategies used to keep continence problems secret

Keywords: Continence/ Long-term conditions/Childhood continence

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Abstract
A study looking at the outcomes and risk factors associated with continence problems in young people aged 11-20 highlights the significant effects these problems have on the daily lives of young people. The study is being used to develop online resources for helping adolescents living with bowel or bladder conditions, and will be made available online.

Continence problems (daytime wetting, bedwetting, constipation and soiling) are among the most common long-term conditions of childhood, and their impact on quality of life is comparable to paediatric patients with other long-term conditions, such as asthma and epilepsy (Bachmann et al, 2009). The stigma associated with these problems leads most young people to conceal their problem and results in considerable 'hidden disability'.

Despite their prevalence and impact, continence problems remain a poorly researched public health issue. Evidence-based knowledge of the impact of continence problems on young people is lacking and this is significantly hindering the development of support and interventions to address their complex needs.

National guidance on the management of nocturnal enuresis in children and young people (National Institute for Health and Care Excellence, 2010) identifies a strong need to examine the psychological impact and quality of life of children and young people with continence problems. In addition, urinary incontinence issues were identified as a research priority by the James Lind Alliance, an organisation involving patients, carers, and clinicians in research priority settings (Bit.ly/JLA Continence).

In 2014, a Medical Research Council (MRC) grant was awarded to Carol Joinson to perform work aimed at increasing understanding of risk factors and outcomes associated with continence problems in children and adolescents. Based at the University of Bristol Centre for Child and Adolescent Health, this study includes both analysis of longitudinal quantitative data, previously reported in Nursing Times (Joinson, 2016), and an in-depth qualitative interview study run by Katie Whale.

The qualitative work aimed to explore the impact of continence problems on young people’s everyday lives, such as:

» Mental health;
» Education/school;
» Social and romantic relationships;
» Social activities;
» Goals;
» Aspirations for the future.

This study not only provides an insight into how continence problems affect young people, but also addresses serious gaps in information on their needs. Its results are being used to inform the development of empirically based and age-appropriate online resources, which will be available on the website of Education and Resources for Improving Childhood Continence (ERIC) (www.eric.org.uk) and will give participants much-needed information and advice from other young people with continence problems.

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5 key points

1. Continence problems can have a negative impact on the quality of life of children and young people
2. There is lack of evidence on the psychological impact of continence problems on children and young people
3. The results of a qualitative study gave an insight into the effects of continence problems on this group
4. Participants reported feelings of shame and stigmatisation
5. Strategies for concealing continence problems included avoidance of a range of social activities
The study

Participants were recruited from paediatric continence clinics across the UK and through an online advertisement. Patients were eligible for inclusion if they were:

- 11-20 years old;
- Experiencing continence problems (daytime wetting, bedwetting, constipation and soiling or a combination);
- Able to speak English;
- Able to give informed consent or assent.

Participants could be interviewed via Skype, telephone or, for the local participants, face to face. Interviews were audio recorded and later transcribed verbatim; transcripts were analysed using inductive thematic analysis (Braun and Clarke, 2006). A total of 20 participants were interviewed, nine female and 11 male. Of these, six experienced bedwetting, six daytime wetting, five both daytime wetting and bedwetting, and four had soiling problems; 11 were interviewed by Skype and nine by telephone. Table 1 provides a full overview of participant demographics.

Preliminary findings

Children and young people experienced a wide range of secondary impacts associated with their continence problems. One of the most salient issues they faced is the stigmatising nature of this condition. This not only has a significant negative impact on individual wellbeing and quality of life, but is also the root cause for many other secondary impacts. Three main themes were identified relating to the stigmatising nature of continence problems:

- The origin of stigma;
- The hidden nature;
- The personal impact of living with stigma.

The origin of stigma

Many participants described a dawning realisation that being incontinent was problematic and no longer acceptable for their age group. This realisation came from social comparison with friends and siblings, or from parents.

"When I was a kid I never really thought of it as a problem... I suppose I just assumed it happened to everyone... and it was maybe about, when I was nine or so, maybe slightly younger and when you start to realise that, no actually it’s not something that everyone does, and that’s when it becomes a problem." (Participant 12, male, age 19, night wetting)

Much of the stigma of incontinence is tied to societal views on age-appropriate behaviour and the myth of control.

Continence problems are seen by many as something that only happens to babies and small children, or much older adults, and are therefore not acceptable in this age group. Due to their age, participants talked about being expected to control their bladder or bowels.

"I think some people just don’t get it. I think people think, ‘Oh, you must be able to help it. Just go to the toilet.’ People think it’s that simple. And I’m like ‘Well if it was that simple, I wouldn’t be still sitting here 17 years later, still on medication, still panicking about things.’" (Participant 18, female, age 17, night wetting)

Negative social judgements were often reported. The expectation that they should be able to control their bladder or bowels led to the belief that accidents must be due to the individual choosing to do it, and that they could stop if they wanted to. This led participants to feel misunderstood and frustrated.

At an interpersonal level, participants spoke about feelings of disgust and shame. Being incontinent and having a dysfunctional relationship with their bladder and bowels led them to articulate feelings of disgust with themselves and their bodies. Participants talked about feeling ashamed and disgusted with having accidents and being incontinent.

The hidden nature

Due to the stigmatisation of continence problems and negative social judgments, all participants reported feeling the need to hide their problem at some level. Choosing whether or not to tell people was a highly important decision. While a small number of participants had told friends about their problem and reported positive experiences and a sense of relief, many others did not want anyone to know. These latter participants articulated worry about negative judgement, being treated differently, being embarrassed and being picked on or bullied. As a result, they had developed a range of strategies to conceal their problem; the most common were avoidance of certain situations, such as sleepovers or school trips, excuses for numerous toilet trips, adapting clothing choices to better hide pads or accidents and social avoidance.

A consequence of the desire to conceal their continence problem was participants’ fear of being discovered. Many participants constantly worried about people noticing their problem and about being thought of as ‘smelly’, especially if they had an accident.

"What happens if they can smell me? What do I do when, because I’m at a different house, I’ve got nobody, like my..."

TABLE 1 PARTICIPANT DEMOGRAPHICS

<table>
<thead>
<tr>
<th>Participant no.</th>
<th>Gender</th>
<th>Age</th>
<th>Continence problem</th>
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<td>Day and night wetting</td>
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mum or my dad there? How am I going to get changed without them knowing?”
(Participant 19, male, age 13, soiling)
The fear of being discovered centred mainly on the uncertainty of what would happen and how people would react.

Personal impact of living with stigma
Living with a stigmatised health condition that engendered a need to conceal it had a significant personal impact on participants. The social assumption that continence problems only affected very young children or older adults caused many to feel abnormal.

The fact that most young people with continence problems hid it from their friends and engaged in behaviours to keep it secret, caused them to feel socially and emotionally isolated.

“It kind of makes me feel adrift because I can’t tell anyone else. Say me and my friends are talking about our secrets, I want to say it but I know I can’t because who knows what they could say.”
(Participant 9, female, age 11, day and night wetting)

A common strategy for concealing the problem was avoidance of social activities, such as playground games, going out at weekends and sleepovers. Not only did this have a negative impact on social relationships and wellbeing, but it also reinforced feelings of isolation.

“It makes me feel really embarrassed and quite sad because if they’re all playing a game together, and I have to go away from it because I don’t want them to notice anything, I’ll be a bit lonely.”
(Participant 13, female, age 11, soiling)

Due to feelings of isolation and lack of social support, participants frequently expressed a desire to be able to talk to other young people with the same problems. Even those who had told friends about their problem felt these friends could never truly understand their experiences, as they had not gone through it themselves. They felt that talking to other young people with continence problems would not only provide much-needed emotional support, but would also offer a rare opportunity to discuss practical strategies to manage their continence problem.

Conclusion
Living with a stigmatised health condition that promotes the need to hide the problem can have a significant negative impact. The perceived lack of social understanding or shared experience can lead individuals to feel emotionally and socially isolated. Strategies commonly used to conceal the problem, such as avoidance of social activities, can further reinforce these feelings.

Negative social judgments based on a lack of understanding relating to the cause of continence problems are common. The social assumption that continence problems affect only very young children or older adults can cause individuals to feel abnormal and misunderstood.

Children and young people with continence problems express a desire for shared support and understanding through being able to talk to other young people with the same conditions. Not only would this provide them with much-needed emotional support and connection, but also provide a forum for discussing practical strategies to manage their continence problem.

Future directions
Analysis and dissemination of the qualitative findings are ongoing. Other areas of analysis include clinical experiences, including attending appointments and undergoing treatment, and the impact of the school environment on continence problems. The findings of this research will be presented at ERIC’s Paediatric Continence Care Conference “Right time, Right place, Right care” on 12 October 2016.

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References