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- Testimonies of patients and nurses on NHS continence pad provision
- Repercussions of inadequate continence pad provision on informal carers
- Five proposed standards for the provision of continence pads

Continence pad provision: meeting patients' fundamental care needs

Key points

For people with urinary and/or faecal incontinence, effective containment of leakage is fundamental to quality of life

A lack of adequate continence pads can have disastrous consequences for patients and carers

NHS services do not always provide pads of appropriate design and/or in sufficient numbers

Interviews with 21 patients and nurses reveal a deliberate rationing of continence pads

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Abstract For people with untreatable bladder or bowel incontinence, effective containment of leakage is fundamental, but do they always receive enough continence pads to meet their needs? We interviewed 10 home-dwelling patients (or their carers) and 11 nurses at two trusts in England to explore their experience of NHS provision of absorbent pads. A majority said provision was inadequate, with negative repercussions on health, independence and dignity – not just for patients but also for their unpaid carers. Nurses described a worrying picture of restrictions on the quantity and type of pads provided. We have developed five standards for the provision of continence pads and urge service providers and commissioners to use these, so that people living with incontinence receive adequate and equitable care.

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Urinary and faecal leakage has a negative physical and psychosocial impact on patients and their unpaid carers, negatively influencing quality of life and causing major disruption to daily activities (Browne et al, 2015). Poorly managed incontinence places a high burden on carers (Santini et al, 2016); is associated with an increased risk of falls (Noguchi et al, 2016); increases the likelihood of care home admission (Morrison and Levy, 2006); can impair skin health (Beeckman, 2017); and increases the risk of pressure ulcers (Lachenbruch et al, 2016). Many diseases are associated with increased rates of incontinence, including dementia (Skelly and Flint, 1995), some cancers (Sacco et al, 2006), stroke (Wilson et al, 2008), multiple sclerosis (Murphy et al, 2012) and type 2 diabetes (Lifford et al, 2005).

Although continence assessment – and where possible treatment – should be the primary goal, for many people the

prevention of leakage is not achievable, in neither the short nor the long term (Riemsma et al, 2017). In these circumstances, the effective containment of leakage is fundamental to patients' and carers' quality of life (Santini et al, 2016). The most commonly used containment device is a disposable absorbent pad.

In its 2011 guide for commissioners, the All Party Parliamentary Group for Continence Care states that the benefits of an integrated continence service include the "cost-effective provision of optimal product for management/containment where required" (Wells et al, 2011). Despite this, continence product rationing is widespread and there is considerable variation in the choice and quantity of products provided (Harari et al, 2013).

To date, the impact of severely restricting continence pad provision has not been described in the literature. In this article, we discuss the findings from a qualitative study exploring the provision

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of continence pads to home-dwelling people living with incontinence, and propose five standards to guide commissioners and service providers in their decisions regarding pad provision.

Methods

Semi-structured interviews were undertaken in 2017 at two NHS trusts in England to elicit the opinions and experiences of patients and nurses on the provision of absorbent disposable continence pads. Ethical approval was provided by an NHS research ethics committee. Thematic analysis was used to analyse the data.

To participate, patients had to be aged 18 years or over, live in their own homes in areas with diverse socioeconomic populations, and have received absorbent pads for bladder and/or bowel incontinence for at least six months. All eligible patients were invited to participate via a letter either sent to their homes or given to them at a continence clinic; all accepted the invitation. If a patient was unable to take part, an unpaid carer providing day-to-day care for them could be interviewed instead. Interviews took place in the patients' homes.

Nurses were invited via a letter sent by email by a local collaborator at each trust. All nurses at the two trusts who regularly assessed patients' needs for continence products via the home delivery service were eligible and invited to participate; all agreed to be interviewed. Interviews took place in the nurses' place of work.

In total, 21 participants were recruited: 10 patients (two of whom were represented by their carers) and 11 nurses (nine community nurses and two continence specialist nurses). With the exception of one patient who was in her 30s, all patients and carers were over 65 years of age. Seven patients had urinary incontinence only, one had faecal incontinence only, and the two represented by their carers had both

urinary and faecal incontinence. The eight interviewed patients split equally between men and women, while the two interviewed carers were both male.

Findings

Only three of the 10 patients and carers believed the pads provided were meeting their needs. Provision was generally limited to three pads per day and a very narrow range of designs. Nurses confirmed that the needs of many patients were not being optimally met. These limitations had a negative impact on participants' health, independence and dignity, as further described below.

Harm to health

Skin damage was the most commonly cited physical problem caused by inadequate pad provision. One wheelchair-reliant patient with heavy urinary incontinence stated that she was not given enough pads and, therefore, often kept them on for too long.

"That causes problems as well for itchy skin, soreness, rashes, infections - I get loads of infections because I'm just sat in wee." (Patient 6)

A patient with faecal incontinence highlighted the unacceptability of keeping a pad in place after bowel leakage.

"If I can't change a pad straight away, within about 10 minutes my skin starts to burn." (Patient 4)

Several patients and carers commented that having inadequate or insufficient pads at night could negatively affect sleep. One man caring for his wife (who had multiple sclerosis) said the 'insert' pads they received - which are designed to be inserted into specially designed underwear or used with close-fitting normal underwear - meant that her occasional diarrhoea caused considerable disruption at night.

"One and a half hours later, I went back to bed after changing the sheets, cleaning [wife's name], putting all the stuff in the washing machine and thinking how can we prevent this happening again? I was shattered, and with MS you're tired a lot of the time anyway, so to have all this happening it was much worse for [wife's name]." (Carer 1)

That carer found that a 'pull-up' pad with elasticated legs would contain bowel leakage more efficiently, and therefore, substantially reduce his wife's care needs during the night. However, his request to receive one pull-up pad for night-time use and two insert pads for day-time use (instead of the three insert pads they were receiving) had been declined.

Limited independence

Several nurses reported that they no longer had the option to offer 'pull-up pants'. They commented that this decision was detrimental to some patients, as the design was perceived to improve people's ability to self-care. One nurse said:

"It took the independence away from people with learning disabilities, dementias and physical disabilities, because they could manage these [pull-ups]." (Nurse 5)

Many patients and the two carers commented that the inadequate provision of pads caused substantially more work for carers. One patient said:

"The time it takes my poor husband - he's my carer - to change my bed and change my sheets and wash my clothes and the amount of knickers and trousers I go through is like nobody's business." (Patient 6)

Patients reported distress caused by the fact that they received fewer pads than the number of visits by paid carers, each of whom would change the patient's pad. One carer reported going through the rubbish bin to see whether any old pads could be re-used. He said:

"Three pads a day [...], with the girls coming out four times a day, means we run short." (Carer 2)

Many patients bought pads, either to supplement those provided by the home delivery service or to ensure they had products of an acceptable design. In addition to the cost of buying pads, patients mentioned the cost of damaged clothing and

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furniture and laundry. Patients and carers also spoke of the indirect costs of poorly managed leakage. One carer commented:

"It means they [paid carers] have got to clean up beds and everything where they shouldn't really have to, quite frankly, for the sake of a few coppers."
(Carer 2)

Battle for dignity

Three participants among the 10 patients and carers were satisfied with the pads they received, but most spoke about the battle to persuade their NHS provider to meet their needs. They described long journeys until they were finally provided with the appropriate pads and spoke of putting up with inadequate products, often for many years. One patient said:

"They [the pads] were not very successful, I had about eight or 10 years of that." (Patient 10)

Another patient described how he used to manage when he had to buy his own pads.

"I used to stuff them with toilet paper. I was making one last several days when we were buying them." (Patient 8)

Some had eventually managed to get the pads that best met their needs; others were still trying, while some had given up and were now buying their own. Some were unaware of the range of products available that could potentially improve the containment of leakage.

Several patients mentioned social barriers caused by inadequate pad provision. One remarked that her faecal incontinence would have a substantial impact on her social life if she only used the three pads provided by the local continence service and did not buy additional pads to give her the 10 she needed per day.

"It would be socially embarrassing, yes, I think it would be horrendous."
(Patient 4)

Another described the consequence of the lack of provision of high-absorbency pads.

"I'm wetting the bed, I'm wetting the seats, I'm wetting everything if I'm coughing." (Patient 6)

Patient 6 had started to limit family visits because she was concerned about the smell.

Patients described delays caused by clinicians interested in treating their incontinence, but not in helping them contain leakage if treatment was unsuccessful.



"The nurses reported a deteriorating picture of decreasing formularies and increasing restrictions on pad provision"

One commented:

"He [a surgeon] didn't do anything about the actual incontinence, the pads or anything like that, he didn't seem interested in that." (Patient 10)

Most delays, however, were caused by system limitations and deliberate rationing. The nurses that were interviewed described tactics to avoid providing pads, with patients waiting many weeks for an initial assessment and then treatment before pads were provided, even if treatment was unlikely to be successful.

One nurse highlighted how the rigid protocol of attempting to treat incontinence before providing pads meant that patients with dementia-associated incontinence were required to complete a programme of pelvic floor exercise before receiving pads.

"We are supposed to be doing a three-month exercise programme even for people with dementia now; our manager is very keen for them to be on a programme prior to giving them any containment." (Nurse 4)

In another case, all pad provision had been halted until the new financial year almost four months later.

"They're not actually processing the orders at the moment until April."
(Nurse 2)

Another nurse explained that pads to prevent heavy leakage were no longer available.

"We [no longer] do a maxi pad, which was taken away for financial reasons, yet we are a moderate-to-heavy continence service." (Nurse 1)

The two specialist continence nurses identified the lack of knowledge among non-specialist nurses about continence products as a barrier to adequate provision. The process for choosing products varied within and between the two trusts. In some areas, specialist continence nurses advised patients on product choice, but in others the task was undertaken by community nurses. One of the specialist continence nurses observed:

"Generally, nurses don't see it as a high priority, so they don't really know too much about it do they? Even not so much the products themselves, but just the different types of products that you can use at different times – they see someone as incontinent and just give them a pad." (Nurse 6)

Discussion

Patients and carers in our study faced a range of difficulties due to the inadequate provision of continence pads (whether insufficient in number and/or inappropriate in design). These included lost sleep, reduced independence, skin infections, increased carer workload and social isolation. Nurses reported a deteriorating picture of decreasing formularies and increasing restrictions on pad provision, and expressed frustration at being unable to meet their patients' needs.

Restricting the provision of continence pads can have unintended consequences that conflict with proclaimed healthcare

Box 1. Proposed standards for the provision of continence pads

NHS services should provide appropriately designed continence pads in sufficient quantities to:

1. Do no harm

- I. Avoid skin or tissue damage
- II. Avoid reducing functional ability (for example, ability to use the toilet)
- III. Protect dignity

2. Contain incontinence

- I. Avoid leakage
- II. Provide appropriate designs for day or night use

3. Promote independence

- I. Allow people to carry on with their everyday activities
- II. Support people to be self-caring

4. Facilitate care

- I. Consider care provision (for example, number of paid carer visits)
- II. Minimise workload of unpaid carers

5. Manage moderate and heavy urinary incontinence and all faecal incontinence

- I. Provide pads in case of moderate or heavy urinary incontinence (that is, which cannot be contained by a sanitary towel-sized pad)
- II. Provide pads for all types of faecal incontinence

priorities and result in significant health and social care costs. Most people receiving pads from community trusts rely on a carer for their daily needs. The inadequate provision of pads can make carers' role more difficult. The strain of managing incontinence is known as a 'tipping point' after which home-based care breaks down and the person is admitted to residential care (Schulter et al, 2017; Friedman et al, 2005).

Current guidance (Association for Continence Advice, 2017; Wells et al, 2011) recommends that providers supply products that meet patients' clinical needs, but does not give any detail on how to achieve this. The provision of continence products varies considerably between trusts (Royal College of Physicians, 2010) and is complicated by the funding mechanism. Unlike other items used to manage bladder and bowel problems that are available on prescription (such as urinary sheaths or stoma products), pads are usually paid for by individual providers, so are in direct competition with other community services.

We know that most people with incontinence will not be cured (Riemsma et al,

2017). Meeting their clinical needs goes beyond the current practice of estimating urine output and providing three or four pads per day to contain that volume. Patients need pads that are well-fitting, easy to use, comfortable and discreet, that limit malodours, promote dignity and independence, and allow people to undertake their daily activities.

Meeting fundamental care needs

The adequate provision of containment products can improve the physical, psychological and social wellbeing of both patients and carers, even if leakage remains severe. Conversely, inadequate pad provision can unnecessarily cause skin damage, affect sleep, lead to social isolation, increase carers' workload and adversely affect people's dignity. The majority of participants in this study thought the provision of continence pads by NHS services was inadequate.

This was a small study and its findings might not be generalisable across settings, but we have found evidence that current provision often fails to meet the most fundamental of care needs. We believe service commissioners and providers have largely ignored the potential consequences of rationing continence products. All cases of incontinence should be fully assessed and, where possible, treated. However, while treatment is ongoing or when it has failed, the provision of the right quantity and type of pad is fundamental to the health, dignity and quality of life of people living with bladder or bowel leakage and their carers.

We have used current evidence (Brown et al, 2018; Cottenden et al, 2017; International Organization for Standardisation; 2017; Murphy et al, 2012) to develop five standards for the provision of continence pads intended for service providers and commissioners (Box 1). We urge them to consider these standards when making decisions about pad provision for people living with incontinence, to ensure adequate and equitable care. **NT**

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References

- Association for Continence Advice (2017) *Guidance for the Provision of Absorbent Pads for Adult Incontinence: A consensus document*. Bit.ly/ACAGuidance2017
- Beeckman D (2017) A decade of research on incontinence-associated dermatitis (IAD): evidence, knowledge gaps and next steps. *Journal of Tissue Viability*; 26: 1, 47-56.
- Brown J et al (2018) Selecting absorbent

- continence pads for people with dementia. *Nursing Times* [online]; 114: 5, 26-29.
- Browne C et al (2015) Bladder dysfunction and quality of life for people with multiple sclerosis. *Disability and Rehabilitation*; 37: 25, 2350-2358.
- Cottenden A et al (2017) Management using continence products. In: Abrams P et al (eds) *Incontinence* (6th edn). Bristol: International Continence Society.
- Friedman SM et al (2005) Characteristics predicting nursing home admission in the program of all-inclusive care for elderly people. *Gerontologist*; 45: 2, 157-166.
- Harari D et al (2013) *Continence Care Services. England 2013. Survey Report*. All Party Parliamentary Group for Continence Care. Bit.ly/APPGContinenceSurvey2013
- International Organization for Standardisation (2017) ISO 15621:2017 - Absorbent incontinence aids for urine and/or faeces - General guidelines on evaluation. iso.org/standard/65740.html
- Lachenbruch C et al (2016) Pressure ulcer risk in the incontinent patient: analysis of incontinence and hospital-acquired pressure ulcers from the International Pressure Ulcer Prevalence Survey. *Journal of the Wound, Ostomy and Continence Nursing*; 43: 3, 235-241.
- Lifford KL et al (2005) Type 2 diabetes mellitus and risk of developing urinary incontinence. *Journal of the American Geriatric Society*; 53: 11, 1851-1857.
- Morrison A, Levy R (2006) Fraction of nursing home admissions attributable to urinary incontinence. *Value in Health*; 9: 4, 272-274.
- Murphy A et al (2012) Prevalence of stress urinary incontinence in women with multiple sclerosis. *International Neurourology Journal*; 16: 2, 86-90.
- Noguchi N et al (2016) Lower urinary tract symptoms and incident falls in community dwelling older men: The Concord health and ageing in men project. *Journal of Urology*; 196: 1694-1699.
- Riemsma R et al (2017) Can incontinence be cured? A systematic review of cure rates. *BMC Medicine*; 15: 1, 63.
- Royal College of Physicians (2010) *National Audit of Continence Care: Combined Organisational and Clinical Report*. Bit.ly/RCPContinence2010
- Sacco E et al (2006) Urinary incontinence after radical prostatectomy: incidence by definition, risk factors and temporal trend in a large series with a long-term follow-up. *British Journal of Urology International*; 97: 6, 1234-1241.
- Santini S et al (2016) Impact of incontinence on the quality of life of caregivers of older persons with incontinence: a qualitative study in four European countries. *Archives of Gerontology and Geriatrics*; 63, 92-101.
- Schulter PJ et al (2017) Urinary incontinence, but not fecal incontinence, is a risk factor for admission to aged residential care of older persons in New Zealand. *Neurology and Urodynamics*; 36: 6, 1588-1595.
- Skelly J, Flint AJ (1995) Urinary incontinence associated with dementia. *Journal of the American Geriatric Society*; 43: 3, 286-294.
- Wells A et al (2011) *Cost-effective Commissioning for Continence Care: All Party Parliamentary Group for Continence Care Report. A guide for commissioners written by continence care professionals*. Bit.ly/CostEffectiveContinence
- Wilson D et al (2008) Urinary incontinence in stroke: results from the UK National Sentinel Audits of Stroke 1998-2004. *Age and Ageing*; 37: 5, 542-546.



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