Journal of Tissue Viability 34 (2025) 100925

Contents lists available at ScienceDirect

Journal of Tissue Viability

journal homepage: www.elsevier.com/locate/jtv

Exploration of current practice and context for the prevention and treatment of incontinence associated dermatitis for adults living in care homes and community settings: a qualitative study

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ARTICLE INFO

Keywords:
Incontinence associated dermatitis (IAD)
Social care
Incontinence
Qualitative
Care homes
Home care

ABSTRACT

Aims: This study aimed to explore current practice and context for the prevention and treatment of incontinence associated dermatitis (IAD), identify challenges and solutions, current prevention and treatment strategies, and products used.

Materials and methods: Using a qualitative cross-sectional approach online focus groups were conducted with stakeholders including experts by experience of IAD (n = 5) and health/care professionals (n = 16). Verbatim transcripts were coded independently by two researchers and analysed using framework analysis.

Results: Four themes and two sub-themes were identified: (1) Impact of IAD: "significant" damage could occur in a short space of time; (2) Uncertainty, is it IAD? Correct diagnosis of IAD was challenging, especially in people with black skin. Uncertainty was underpinned by a lack of education and clear guidance on skin inspection. (3) Lack of resources (sub-themes human resources and product resources): Lack of human resources related to the number of staff available, deficiency of knowledgeable and skilled staff, and limited leadership. Lack of availability of pads was a challenge and carers reduced the number of pad changes to "conserve pads"; (4) Variation in practice, both for cleansing skin and applying a leave-on 'barrier' product.

Conclusion: Care for adults with incontinence to prevent and/or treat IAD is challenging in the social care sector. Wide variation in practice exists and there is a need for educational interventions in the sector, targeting an international and transient workforce.

1. Introduction

Incontinence is commonly experienced by older people living in long-term care (LTC) facilities (43–77 %) [1] or at home (35 %) [2]. Incontinence Associated Dermatitis (IAD) is an irritant contact dermatitis caused by prolonged and repeated exposure of the skin to urine, faeces or both [3]. It is characterised by localised erythema and maceration. In some cases, skin loss, swelling, bullae and/or skin infection may occur [4]. There are few and variable prevalence and incidence estimates for IAD among adults receiving LTC, with no estimates from the UK [3]. Global prevalence reports range between ~5.5 % [5,6] to 30 % [7] in LTC facilities and 41 %–51 % [8,9] among people living at home. The economic impact of IAD in the UK is unknown, but it is likely to contribute to the development of pressure ulcers [3,10] which cost the National Health Service (NHS) over £1.4 billion annually [11] The exact contribution of IAD to pressure ulcer development is currently unknown.

Alongside continence promotion and appropriate use of pads and appliances, effective prevention and treatment involves skin cleansing and application of protectants (barrier products) [3]. Numerous products are available and while many people use them successfully, identifying the product(s) most likely to meet individual needs can be challenging [12]. Many people are involved in providing this care including informal carers, paid carers and nurses, although

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https://doi.org/10.1016/j.jtv.2025.100925
Received 15 January 2025; Received in revised form 27 April 2025; Accepted 30 April 2025
Available online 30 April 2025

evidence-based guidance is not easily available and anecdotal reports suggest use of skin protectants in LTC facilities may be "patchy". Using preventative measures almost halves (46 %) the risk of developing IAD [6] and reduces associated costs [10,11]. Products and procedures for both prevention and treatment of IAD are similar [3,13].

It is known that IAD is a common problem in LTC facilities, but how this is assessed and managed and the challenges faced within these settings are currently unknown. A qualitative approach was selected for preliminary in-depth exploration of this context to underpin co-design of an intervention to guide care for IAD. This paper reports on stakeholder focus groups during the first phase of a study to develop and assess the feasibility of implementing a manual of care for the prevention and treatment of IAD. This phase aimed to explore current practice and context, to identify challenges and solutions in dealing with IAD, current prevention and treatment practices, and products used.

2. Materials & methods

This qualitative cross-sectional study conducted online focus group interviews with stakeholders including both experts by experience of IAD and health professionals.

2.1. Sampling and target population

Purposive sampling was through professional networks of the research team and patient organisations (Supplementary file 1). We aimed to recruit 30 expert stakeholders with breadth and diversity of experience caring for community-dwelling adults/LTC facility residents with urinary and/or faecal incontinence and with or without IAD.

- 10–15 health professionals from LTC facilities, home care agencies, community nursing teams, continence advisory services, tissue viability services, other community and primary care services (e.g. community pharmacists, General Practitioners), hospital nurses caring for older people.
- 10–15 clients/residents, informal carers and family members, patient representatives with experience of urinary and/or faecal incontinence, with or without IAD.

2.2. Data collection

Participants attended a 2-h online focus group via Microsoft TEAMS. Following introductions, stakeholders were divided into breakout groups with clinicians and experts by experience interviewed separately. Participants were asked about their experiences based on a topic guide developed with our patient and public representatives (Supplementary files 2 and 3).

This work was underpinned by the MRC Framework for developing complex interventions [14] and enhancements suggested by Bleijenberg and colleagues [15] addressing the first three steps of intervention development:

(i) problem identification,
(ii) determination of needs and
(iii) examination of current practice/context.

During the focus groups contextual challenges of settings, current practice (which products/procedures were used) were discussed and barriers/facilitators to change in practice were explored. Each group was facilitated by an experienced member of the research team, trained in qualitative interview techniques (CN, SW, PW), and another taking notes. Discussions were digitally video and audio-recorded via TEAMS and professionally transcribed verbatim.

2.3. Data analysis

Transcripts were anonymised, coded independently by two team members (SS, SW) and patient representatives (HG, FK), using framework analysis [16]. Themes were explored and agreed. This structured the qualitative analysis to include the key areas identified, with scope to identify new themes. This method is particularly useful where several researchers, especially patient representatives, are involved in data analysis [17].

2.4. Ethical approval

All participants gave written informed consent. Ethical approval for the study was obtained from the King's College London Ethics Committee (Ref: HR-19/20–17478). The protocol study was prospectively registered (ISRCTN26169429).

3. Results

Participants (n = 21) comprised 16 health professionals (Table 1), three people with incontinence (two males, both white) and experience of IAD and two family carers (both female, one white/one Asian) of someone who developed IAD. One family carer was previously known to the research team. All healthcare participants had at least one year experience in caring for people with IAD. The clinical experience of nurse participants was extensive, ranging from 12 to 37 years.

Four themes and two sub-themes were identified: (1) Impact of Incontinence/IAD; (2) Uncertainty – is it IAD? (3) Lack of resources (subthemes human resources and product resources); (4) Variation in practice.

3.1. Impact of Incontinence/IAD

Incontinence and IAD affected not only the person, but also family carers. Participants reported the anxiety that resulted from fear of incontinence and how loss of independence "*ground her [mother] down*". The indignity of not being able to keep oneself clean as well as being hoisted and then told to pee or poo in a pad was distressing and associated with family guilt if IAD developed.

> "*Not being able to have control over your bladder and your bowel had so many ramifications … she didn't want to drink because she didn't want to wet the pad … then seeing her gradually becoming depressed.*"
>
> (Family carer of LTC facility resident)

The speed with which IAD can develop was reported and "*significant*" damage could rapidly occur if faecal incontinence was not cleaned within 30–60 min, with diarrhoea being more problematic. Lack of public toilets made it more difficult to change pads in a timely manner for those able to leave home.

Accepting personal care was challenging and there was a need to "*feel clean*" through bathing as well as to be physically clean. Any residue on the skin could cause soreness. The impact of requiring personal care was also recognised by health professionals, especially for those with dementia, who were unable to tolerate it due to the "*whole indignity*". Providing sensitive care was just as important as providing good clinical care.

> "*So, it's not just about doing it [cleansing] well. It's about how you manage the psychological distress to someone.*"
>
> (LTC facility provider)

3.2. Uncertainty – is it IAD?

Participants agreed that diagnosis of IAD was challenging, with many voicing concerns that this was often mis-diagnosed as a pressure

Table 1
Health Professional Participant Characteristics (all female, five black/11 white).

Nurses
- District nurse (n = 1)
- Tissue viability nurse (hospital based) (n = 3)
- Tissue viability nurse (integrated Trust) n = 1)
- Continence nurse specialist (hospital based) (n = 1)
- Continence nurse specialist (community based) (n = 2)
- LTC facility provider (n = 1)
- Product advisor/educator (industry) (n = 2)

Care staff
- Home care agency manager (n = 1)
- Care staff (care home) (n = 3)
- Care staff (home care agency) (n = 1)

ulcer or an allergic reaction to a topical product.

"*People don't know how to diagnose IAD, they see it as an allergy to a product … there's still a lot of people that unfortunately don't know how to recognise the difference between IAD and a pressure ulcer*."
(Community continence advisor)

All redness was treated as pressure damage, especially in home care where carers described "*working blindly*" with asynchronous access to a community nurse for advice. Correct identification of IAD was particularly challenging for people with darker skin tones:

"*It's very easy to notice a pressure sore or IAD in a white person … how to identify pressure sore, or IAD in a black person … it's not easily noticed*"
(Carer 1, LTC facility)

Uncertainty was compounded by lack of education and clear guidance about which products to use. Participants highlighted that there was a "*lot of education to do*". Bedside teaching had been used successfully, but there remained cases where differentiation between pressure damage and IAD was challenging:

"*Sometimes the damage done is a combination of both and not one or the other*"
(Tissue viability nurse)

A simple "*one page pathway*" for staff to facilitate differentiation was reported to be useful. The emphasis was usually on reacting to skin breakdown rather than proactively identifying risk of IAD. Creams were kept "*on standby*" for those who were known to be prone to IAD, but were not used for others.

3.3. Lack of resources

3.3.1. Human resources and leadership

Lack of human resources related to staff availability, deficiency of knowledgeable and skilled staff, and limited leadership. The lack of staff or time to take people to a toilet was reported so staff were said to "*whack a pad*" in place as the "*default"* solution, which may increase the incidence of IAD. IAD was considered inevitable by some participants. LTC facility staff were aware of the need to empathise with residents.

"*It's so uncomfortable and you try to imagine if this is happening to you*."
(Carer 2 – LTC facility)

At home, clients had to manage their bladder and bowels around carer visits and were "padded up" between visits. Lack of available care in the community was challenging for hospital discharge planning. Inadequate staffing in LTC facilities was reported to be widespread. LTC facility carers felt this was down to managers not ensuring adequate staffing. Poor leadership was said to contribute to poor practice, which was "*learned by example*". Conversely good practice could be disseminated via "*word of mouth*", good leadership and role modelling of best practice.

"*Word of mouth can sometimes educate more than one presentation*"
(Community continence nurse)

LTC facility staff failing to perform personal hygiene at pad changes was raised and some staff were unsure what to do, although one carer pointed out that carers need to take responsibility to review care plans.

"*Every resident or service user has a care plan. You go to the plan … and that's how you know how to care for them*".
(Carer 2– LTC facility)

Carers generally wanted to do the right thing but needed support. Carers recognised they were skilled, but that this was not always valued by managers. Staff who had received training were perceived as a vehicle for change and "knowledge is power" when it came to providing person-centred care.

"*It's caring as a human being that we care for each other and then empowering with that little bit of education*."
(District nurse)

Where LTC facility staff were highly skilled and turnover was low, carers who "*know their residents*" were an important element of skincare provision. However, there was a disconnect between those who planned and those who delivered care. Specialist staff were only called when skin was in a "*horrendous state*" for crisis management While their intervention may lead to improvement in IAD they recognised they were not doing anything to treat the root cause and IAD would often recur. LTC facilities needed access to expert resources, but "*all the expertise is in [hospitals*]" and that this was "*back to front*".

Carers who did not have English as a first language along with high staff turnover was a challenge for staff training to develop a skilled workforce.

"*We're finding we're having to train our staff differently because they've been brought up in a health system that's very different to the NHS. Then you've got changing care providers with care homes or even care agencies and the turnover of staff is huge and it's school leavers. It's people that have just maybe become unemployed and going to give it a go. It's … hard to sustain a level of education*."
(LTC facility provider)

3.3.2. Product resources

Lack of availability of pads was challenging and carers either had to reduce the frequency of pad changes to "*conserve pads*" or if pads were the incorrect size carers resorted to using multiple pads.

"*They buy these very small pad sizes, so carers tended to use … up to like three pads [at a time], but it doesn't work … most of the bed sheets are wet*."
(Carer 3 – LTC facility)

Using multiple pads was common practice, but it was recognised that these were "*not designed to soak through*" and the rationale for this was unclear. Carers were also unaware of products, especially cleansers, that could be used to provide personal care and only used products if they were prescribed.

"*Most times we're advised to use soap and water*"
(Carer 3 – LTC facility)

Where providers tried to eliminate soap and water for cleansing, those leading the change faced resistance and were asked to provide evidence to support this.

> "*It's obviously the business model and the management who think, 'Well let's do soap and water. That should do fine. There's no evidence to say it's not good enough'*".
>
> (LTC facility provider)

Shifting focus from treatment to prevention of IAD through use of correct products was advocated. Incorrect use of products, such as application of too much product or too frequent applications could also deplete stocks and lead to lack of availability of products. Additionally, a "*bottom full of cream*" can make skin assessment more difficult. While products were important, being proactive with a "*toilet first*" approach was needed alongside a comprehensive continence assessment to determine the cause, which was the "*missing piece*".

3.4. Variation in practice

Variation in practice was reported, both for cleansing skin and applying a leave-on 'barrier' product. People receiving care at home reported variation as different carers had "*different ways*" or ideas about how to care for skin. In LTC facilities some staff used wipes, while others used soap and water. Products would appear in a resident's room only to disappear and for another to take its place. These variations were perceived by family members to be down to both time and staff preference and described as "*very patchy*" and there was "*no clear policy*". People with experience of IAD had identified what helped them through trial-and-error – some pads were felt to cause more abrasion and some creams felt unpleasant and "*gloopy*". IAD was often not discussed at continence appointments and with experience clients learnt to be more proactive at preventing IAD.

> *"I'd like to have known about all these things years ago because I struggled …. I now manage reasonably well, but this has taken 10 years*!"
>
> (Male with incontinence)

One continence specialist had audited cleansing products used, finding a "*whole array*" that included shower gels, scrubs and shaving gel. Community prescribing guidelines included many product choices. Wide product availability led inevitably to variability in products used, but assessment and selecting the right product for the right person was important. Patient involvement in decision making was vital.

> "*We need them [clients/residents] on board because if not, …it's not going to work and they're not going to comply [with treatment*]."
>
> (Community continence nurse)

Involvement of family carers was also important in maintaining consistency between different carers coming into the home. The lack of evidence supporting the use of one product over another was problematic:

> "*It's very difficult when you're looking at products, though, because there's no evidence to support one over the other and there's so many of them. So as a clinician, where do you start in making those decisions*?"
>
> (Tissue viability nurse)

For clients, access to products was variable. Some products were purchased by family members both at home and in care homes or were preferred by carers over others due to perceived superiority. Where evidence was lacking, nurses resorted to trial-and-error to inform clinical decisions, while cost was also a factor for some. All products on the market were felt to "*do the job*" so decision-making came down to making it easy for staff to remember what to use and when: to "*keep it simple*" and restrict product choice. Participants reported this made it easy to educate and some suggested a stepwise protocol with variations for those at increased risk of IAD had proven useful.

4. Discussion

This study is the first to our knowledge to explore current practice to prevent and treat IAD in LTC facilities and home care. The analysis revealed four themes and two sub-themes which centred around the experiences of IAD, diagnosis, care resource and variations in practice. Little is known about the perspective of adults receiving care at home and in LTC facilities about quality of care in this context [18]. This study revealed significant challenges to providing high quality care and proactively preventing IAD which has a significant burden on individuals and their families, consistent with previous studies that have demonstrated similar carer burden [19]. Indeed, the impact of incontinence and IAD on individuals and family carers extends beyond the physical effects to emotional health and wellbeing. The need to feel clean and bathe, although extremely painful, may lead people to override professional advice not to use traditional soap and water or shower gel. It may be that support with personal hygiene when needed is lacking. When gaps in the system exist, family carers may feel compelled to step in Ref. [20].

Care staff were not confident to identify IAD and distinguish this from other types of skin damage, such as pressure ulcers, especially in people with dark skin tones. Erythema in the early stages of IAD may not be as obvious in those with darker skin tones [21]. It is known that nurses find it difficult to correctly identify IAD [22,23] so it is unsurprising that the same is true for a social care workforce. Inability to differentiate IAD from other skin damage may lead to inappropriate and ineffective interventions [24] and highlights the need for effective development of the care workforce [25], which is known to be a variable and long-standing issue [26,27]. Decision making around product use was highly variable and depended on several factors including product availability, costs, previous experience and prescribing practice locally. This is consistent with findings of previous studies [21]. Our Cochrane review [3] found no evidence to support the benefit of one leave-on product over another for prevention of IAD. It is likely, therefore, in the absence of such evidence that this variation in practice will continue. Clinical guidelines based on the best available evidence may reduce variation in practice [28] and support the need to develop an intervention to guide practice in LTC-facilities.

The need to provide dignified care was acknowledged, consistent with the literature [29], but care may be compromised by resources available, including staffing levels and skill mix. Growth of the care workforce in the UK is not meeting current demand, with more than 131, 000 vacancies across the sector in 2023/24 [25] and turnover rate of 28.3 % in 2022/23 [30]. An increasingly international workforce has implications for development of educational interventions to improve care for IAD. Leadership was also identified as a factor influencing high quality care and was often linked with staffing levels. Investment in leadership development is needed to improve care. Leadership is an important element in the provision of good quality care [31] and was identified as such by our participants. Leadership is potentially an attribute of all care staff, and a leadership qualities framework has been developed for social care in the UK [32]. These factors were incorporated within the logic model that was developed to underpin the co-design of a manual for the prevention and treatment of IAD that followed this study.

4.1. Limitations

While we achieved participation from a wide variety of health and care professionals, this study is limited by a lack of recruitment of care recipients and their family carers. Participants may have been those with highly positive or negative experiences of care limiting transferability to the wider social care sector. However similar themes emerged from both groups of participants. The themes may not be transferable to other LTC settings in different regions and countries where staffing and care provision may vary.

4.2. Clinical and research implications

Clear and simple evidence-informed guidelines are needed for care staff to effectively prevent/treat IAD, underpinned by training materials accessible to an international workforce. Care plans need to be readily accessible and include instructions for skin cleansing and application of barrier products. Research is needed to explore the clinical and cost effectiveness of implementing guidelines and training of the care workforce in prevention/treatment of IAD.

5. Conclusions

Care for adults with incontinence to prevent/treat IAD is challenging in the social care sector. Variation in practice exists and research is needed to provide a sound evidence base for product selection. Educational interventions are needed for the sector, targeting an international workforce, so that skin care product use and care practices can be enhanced. Investment in the development of the care workforce and its leadership is essential to improve care for people with IAD.

Funding

This study is funded by the NIHR [Health Technology Assessment programme (NIHR128865)]. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

Declaration of interest

CN declares the following conflicts of interest: Speaker fees from: Janssen, WebMD, Medscape, Merck Pharmaceutical; Tillotts Pharma UK, Lilly. Pfizer advisory board.

CC declares the following conflicts; Attends UK Ltd - presentation funding, Clinisupplies UK Ltd - presentation/conference funding, SW; TG; SS; MF; JF; HG; RH; FK; PW no conflicts.

Acknowledgements

The authors would like to thank those members of the public and health professionals who gave so generously of their time as stakeholders to support this study.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.jtv.2025.100925.

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