



Challenges associated with using continence management products: Qualitative study set in India, Papua New Guinea and Romania

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ABSTRACT

Background: Effectively managing urine and faecal leakage is essential to maintain quality of life for people living with incontinence. Most people affected by long-term incontinence use continence management products (purchased or homemade). These products can have both positive and negative consequences. Globally, people living in lower and middle income settings often do not have access to products or only very limited options, but availability is increasing. Understanding the challenges of product use is important to support product decision making. The aim of this study was to identify and describe challenges associated with using continence management products for adults and young people living with incontinence in India, Papua New Guinea and Romania.

Methods: We used a qualitative exploratory design and participatory action research approach in this study. Data were collected using semi-structured interviews with 63 people (continence product user $n = 42$, parent/carer $n = 21$) who took part in a total of 54 interviews in India, Papua New Guinea and Romania. Secondary analysis of the data was undertaken using a framework approach to address the study aim.

Results: Participants used products namely, indwelling urinary catheters, disposable absorbent products and homemade products (e.g. bottles or blankets). Experiences varied widely and depended on individual characteristics and circumstances. Four themes were used to categorise the key challenges associated with continence product use (i. Physical side-effects, ii. Cost and impact on access, iii. Engagement in day-to-day activities and iv. Psychological and social effects). The large majority of participants reported one or more negative consequences of use, with skin damage, infection, embarrassment, smell, difficulties using or disposing of the products and cost dominating, varying by product type. Some challenges were relatively minor, but others (such as wounds or needing to move out of their home) were potentially life changing.

Conclusion: Most participants reported an overall benefit from using products, but many also experienced significant challenges. Some did not appear to be using an appropriate product to meet their needs or were using products incorrectly (e.g. not changing them frequently enough). Ensuring a range of products to meet individual needs will help mitigate against unintended harms. To optimise the benefits of product use, policy makers and service providers seeking to improve continence product provision should consider local and individual contexts, and ensure personnel are trained to support product selection and correct fit and usage.

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1. Introduction

Hundreds of millions of people around the world cope with incontinence on a daily basis [1–3]. Ideally, continence problems should be treated and cured, but this is not always possible and many people live with long-term symptoms. For these people, reliable containment using continence products is necessary to maintain health and continue with daily activities [4].

Commonly used continence products are disposable absorbent products (DAPs), indwelling urinary catheters (IUCs) and to a lesser extent urinary sheaths and washable absorbent products (WAPs). However, a survey of 35 countries undertaken by the World Health Organization (WHO) reported only around a quarter of people requiring continence products had access to them [5]. Where specifically designed products are not available or accessible, people make them using household items such as old clothing or blankets, bottles, plastic bags or other household materials. [6,7]. The global continence care market (catheters, catheter accessories, incontinence & bowel management) continues to grow rapidly. Valued at USD 19.68 billion in 2024, it is anticipated to grow at a rate of 7.49 % from 2025 to 2030. Manufacturers are pursuing markets in lower and middle income countries (LMICs) as populations age, health systems mature and awareness of incontinence increases [8].

In 2016, WHO introduced the Priority Assistive Products List to support its work to improve access to high-quality, affordable assistive products in all countries; this list included continence products [9]. Whilst the benefits of using specially designed continence products such as DAPs and IUCs outweigh the disadvantages for many people, all continence products have challenges. The negative effects of continence products have been reported for higher income settings [4,10,11] and it has been emphasised that more attention needs to be paid to the balance between the beneficial and negative treatment effects [4,10]. Downsides to DAPs include skin damage, problems changing the products, anxiety about smell, leakage and lack of discreetness [4,10]. Harms associated with catheters include infection, blockage, pain, trauma and spasm [11]. Challenges associated with urinary sheaths include skin/tissue damage, accidental dislodgement and discomfort [12–14].

As with other assistive products, effective use of continence products is “highly context sensitive in terms of an individual user’s environment” [15]. Poor matching of product and person can be actively harmful, and only subtle differences in context can make the difference between success and failure [15]. It cannot be assumed that the continence product challenges faced by people in higher resourced settings are the same as those elsewhere. In LMICs, whilst there is a moderate body of literature on the often devastating impact of living with incontinence [7, 16,17], reporting on the challenges of using continence products for non-infants is sparse with the limited body of relevant literature mostly focuses on the cost and lack of availability of products [16,18]. As large-scale changes in access to continence products in LMICs are currently taking place [8], it is an important time to address this knowledge gap. Individuals, personnel and policy makers in healthcare systems would benefit from clear information on the downsides as well as the benefits of continence products.

The opportunity to examine this topic was provided via a recent WHO study exploring the provision and use of WAPs (absorbent products designed to be worn, washed and re-used). These products are not widely used for non-infants in any settings but might be an effective option for many [19,20]. In this context, in 2022, WHO launched a new online training resource *Training in Assistive Products (TAP)* with the goal of building health service capacity to provide a range of simple assistive products, including WAPs. As part of the project, the WHO team worked with partners in India, Papua New Guinea and Romania to train service providers to provide WAPs using TAP. The project included the provision of WAPs to around 100 adults and children (aged 7+), and follow up with these individuals. The individuals were asked to try the products and then (as part of a research study) invited to take part in

interviews to describe their experiences. The primary aim of the study was to gather data on the perceptions of adults and children receiving washable absorbent products and service providers (people working in the local health facilities who had direct involvement in providing products) on the usability and acceptability of washable absorbent continence products. A paper reporting the primary analysis of this study is available [21]. The challenges of using WAPs are fully covered in that paper and are not included in the secondary in-depth analysis reported in this paper.

In the interviews, before the participants were asked about their views and experiences with the WAPs, they were asked how they previously managed their continence problems and about their experiences with continence products. Participants’ responses to those questions were the focus of the secondary in-depth analysis reported in this paper. Our aim was to identify and describe challenges associated with using continence management products for people (age 7+) living with incontinence in India, Papua New Guinea and Romania.

2. Methods

A full description of the study and methods used is reported elsewhere [21]. Briefly, a qualitative exploratory design and participatory action research approach [22] was used to undertake semi-structured interviews to gather data within three partner countries: India, Papua New Guinea and Romania. The Consolidated criteria for reporting qualitative research (COREQ) checklist was used to appropriate reporting of findings [23]. Ethical approval was gained from the University of Southampton (ERGO 63891) and local country level. Data collection took place from January 2022 to January 2023. The partners in this research were the WHO Access to Assistive Technology Team, Country Partners (Mobility India; the Rural Development Trust, India; Indian Institute of Public Health; National Department of Health, Health Facilities Standards Branch and National Orthotics & Prosthetics Service, Papua New Guinea; National Capital District Provincial Health Authority, Papua New Guinea; Eye Care and Port Moresby General Hospital Eye Clinic (logistics); Motivation Romania) and the University of Southampton. Participatory action approach principles, including collaboration, inclusivity, empowerment and reflexivity [24] were used to support working between all members of the research team throughout the study. For example, partners participated in multiple workshops to guide finalising the research objectives, writing the protocol, designing the interview topic guide and interpret the data. The University of Southampton researcher led on gaining overall study ethical approval, Country Partner personnel led on obtaining local ethical approval and data collection and the WHO team facilitated the online meetings. All partners supported data analysis and dissemination of findings.

Semi-structured interviews were used for data collection. Interviews took place in a range of rural, urban and suburban settings in India, Papua New Guinea and Romania with participants aged 7+ who were living with long-term continence problems. Carers or parents also participated if the product user was unable to participate alone. Everyone who received washable products as part of the wider project (n = approx. 100) was invited to take part. Participants were provided with study information at least four weeks prior to the interview and verbal consent was audio recorded. Local personnel were trained to take informed consent and undertake the interviews, including audio recording. The country partners identified and trained a local translator who transcribed the data verbatim. Data was transferred and securely stored on Microsoft OneDrive. The interview topic guide included the following prompts regarding their original method of continence management.

- How was incontinence managed before using the washables?
 - o What sort of products used?
 - o How well did they work? Any problems?

- o How easy or difficult is it to access the products?
- o If no products were used – did you know about the different products that were available? Have you ever tried any?
- Do you need help to manage your products (e.g. changing the products)?

Responses to these prompts were used in the secondary analysis of the data that is presented in this paper. Themes were identified based on the objectives of the research using a Framework approach [25]. All research team members contributed to the interpretation of the data.

Table 1
Overview of interview participants.

Participant (I=India, R = Romania, PNG – Papua New Guinea)	Product-user (PU) or carer (C)	Age bracket	Sex	Rural/urban/semi-urban	Carer dependent?	Incontinence (urinary/faecal/both)	Stated cause of incontinence
I1	PU	60+	M	Semi-urban	No	Urinary	Low bladder capacity
I2	PU	20–39	F	Rural	No	Both	Spinal cord injury
I2C	C	40–59	F	Rural	N/A	N/A	N/A
I3	PU	20–39	M	Rural	No	Both	Spinal cord injury
I4	PU	20–39	M	Rural	Yes	Both	NK
I5	PU	20–39	M	Rural	Yes	Both	Spinal cord injury
I6	PU	20–39	F	Rural	Yes	Both	Spinal cord injury
I7	PU	20–39	M	Rural	Yes	Both	Spinal cord injury
I8	PU	40–59	M	Rural	Yes	Urinary	Spinal cord injury
I9	PU	20–39	F	Rural	No	Urinary	Postpartum
I11	PU	40–59	M	Rural	Yes	Urinary	Spinal cord injury
I12	PU	20–39	F	Rural	Yes	Urinary	Spinal cord injury
I13	PU	20–39	M	Rural	Yes	Urinary	Spinal cord injury
I14	PU	7–19	M	Semi-urban	Yes	Both	Spinal cord injury
I14C	C	N/K	M	Semi-urban	N/A	N/A	N/A
I15	PU	20–39	M	Rural	Yes	Both	Spinal cord injury
I16	PU	7–19	M	Rural	Yes	Both	Spinal cord injury
I17	PU	7–19	F	Rural	Yes	Both	Illness
I18	PU	40–59	M	Rural	No	Both	Spinal cord injury
I19	PU	20–39	M	Rural	No	Urinary	Spinal cord injury
R1	PU	40–59	M	Rural	Yes	Urinary	Spinal cord injury
R2	PU	40–59	F	Rural	N/A	N/A	N/A
R3	C	40–59	F	Urban	Yes	Both	Disability
R5	PU	20–39	F	Rural	NK	Urinary	Surgery
R6	PU	7–19	F	Urban	Yes	Urinary	Disability
R6C	C	40–59	F	Urban	N/A	N/A	N/A
R7	PU	20–39	M	Urban	Yes	Urinary	Disability since birth
R8	PU	7–19	M	Urban	Yes	Both	Disability since birth
R8C	C	N/K	F	Urban	N/A	N/A	N/A
R9	PU	40–59	F	Urban	Yes	Both	Disability from infection
R10	PU	N/K	M	Urban	Yes	Urinary	Spinal cord injury
R10C	C	N/K	F	Urban	N/A	N/A	N/A
R11	PU	40–59	M	Urban	No	Urinary	Disability since birth
R12	PU	7–19	M	Rural	Yes	Urinary	Disability since birth
R12C	C	N/K	F	Rural	N/A	N/A	N/A
R13	PU	7–19	F	Rural	Yes	Urinary	Disability since birth
R13C	C	N/K	F	Rural	N/A	N/A	N/A
R14	PU	60+	F	Rural	Yes	Both	Neurological disorder
R15	PU	60+	F	Rural	Yes	Urinary	Neurological disorder
R16	PU	20–39	M	Urban	Yes	Both	Disability since birth
R17	PU	60+	F	Rural	No	Both	Neurological disorder
R18	PU	7–19	F	Urban	Yes	Urinary	Neurological disorder
R19C	C	NK	F	Urban	N/A	N/A	N/A
R20C	C	NK	M	Urban	N/A	N/A	N/A
R21	PU	20–39	M	Urban	Yes	Urinary	Neurological disorder
R21C	C	NK	F	Urban	N/A	N/A	N/A
R22	PU	20–39	M	Urban	No	Urinary	Spinal cord injury
R23	PU	20–39	M	Urban	No	Urinary	Spinal cord injury
R24C	C	NK	F	Urban	N/A	N/A	N/A
R25	PU	7–19	NK	Urban	Yes	Urinary	Disability
R27	PU	7–19	NK	Rural	Yes	Urinary	Disability
R27C	C	NK	F	Rural	N/A	N/A	N/A
PNG1C	C	NK	F	Urban	N/A	N/A	N/A
PNG2C	C	NK	F	Urban	N/A	N/A	N/A
PNG3C	C	60+	F	Rural	N/A	N/A	N/A
PNG4C	C	NK	F	Rural	N/A	N/A	N/A
PNG5C	C	NK	F	Rural	N/A	N/A	N/A
PNG6C	C	40–59	F	Urban	N/A	N/A	N/A
PNG7	PU	60+	M	Semi-urban	No	Urinary	Spinal cord injury
PNG8	PU	20–39	F	Semi-urban	Yes	Urinary	Infection
PNG9C	C	NK	F	Semi-urban	N/A	N/A	N/A
PNG10C	C	NK	F	Urban	N/A	N/A	N/A
PNG11C	C	60+	F	Urban	N/A	N/A	N/A

3. Results

Sixty-three people (product user $n = 42$, parent/carer $n = 21$) took part in a total of 54 interviews. Some interviews included both the product user and carer (Table 1). Twenty participants were in India, 11 in Papua New Guinea and 32 in Romania. The large majority of participants were aged under 60 ($n = 56$) and the majority had continence problems resulting from either spinal cord injury or other neurological issues. All product users lived with urinary incontinence and around half additionally had faecal incontinence.

3.1. Overview

For a small minority, the products they used were easy to access and worked well and they had few or no challenges, but the substantial majority faced at least some difficulties. This secondary analysis presents commonly found themes and experiences with the range of devices. The large majority of participants used an IUC or DAPs (some used both). The remainder using containers (such as drink bottles, cut-down tins or plastic bags) or homemade absorbent materials made from old blankets or clothing.

Most IUC users were in India. This is likely due to the recruitment of mostly spinal cord injury patients in India plus the relative affordability of IUCs compared with DAPs. In Romania, the majority of participants used DAPs and in Papua New Guinea a mixture of products were used. It was unclear whether IUC users were using the devices to manage urinary retention, bladder leakage or a combination of both. Some of the time, some participants did not use any products; this might be because they did not have reliable access to products or, in a small number of cases, either because they found using the products that they did have available so problematic that they would rather leak and clear up the resulting waste (*I have both my urination and defecation on bed. My grandmother removes everything and cleans it.* [I15]) or because they tried to use the toilet (*I used to go to the toilet once in 3 hours for urine crawling on the floor.* [I12]).

The challenges of using the various continence products were interpreted and allocated to four overlapping themes (i. Physical side-effects, ii. Cost and impact on access, iii. Day to day activities and iv. Psychological and social effects) each presenting results by product type.

3.2. Themes

3.2.1. Physical 'side effects'

3.2.1.1. IUCs. Most IUC users experienced physical side effects from their catheter and several participants stopped using catheters due to the physical side effects. These devices were reported to cause more physical problems (and more seemingly severe problems) than other product types. Commonly, skin problems and indications of infection (urinary tract infection or skin/tissue) were reported as illustrated by two participants in India.

- *I am using catheter, no other product. I get vomiting, fever and burning sensation in the urinary tract and back pain. I also get pain while fixing and removing the catheter.* (I2)
- *I didn't have any problems with the catheter except for pain and burning sensation and wounds. My wife applies powder and cleans. I still have the wounds ... I feel ok only when I am lying down. I get pain from the wound both while sitting and standing and walking. I can't sit continuously for more than 20 minutes* (I8)

Other symptoms possibly indicating catheter blockage or bypassing were also reported. These problems sometimes appeared to be exacerbated by lack of information on appropriate product use.

- *I did not know that I should change it every 20 days. As I was using it beyond 20 days, my stomach got swelling and it started bleeding. Therefore, I removed the catheter.* (I18)

3.2.1.2. DAPs. Although the physical side effects associated with using DAPs were less common than with IUCs, several participants reported skin and/or tissue damage and a number also declined to use these products due to these problems.

- *I used diaper for a long time. But I was having rashes and wounds. I stopped using the diaper.* (I15)

The most common problems with DAPs were with leakage and smell, often with both being experienced together.

- *The diapers from the store does smell, yeah. Yes, it smells and leaks. If he urinates once or twice, it is okay but when he urinates more than once then it smells and leaks. For instance, at night, If I do not change is diapers, it leaks and smells.* (PNG11C)
- *I had small problems, leaks, they were not good, they did not sit properly. They did not have a very high absorption capacity.* (R11)
- *Diapers when it is still being worn for the whole day and you go, you will want to vomit too.* (PNG2C)

It appears that these issues could exacerbated by the participants not having products with the correct absorbency or not changing the products frequently. This links to the next theme of Access to the product and cost.

3.2.2. Cost and impact on access

3.2.2.1. IUCs. Some participants (varying within and between countries) were provided with indwelling urinary catheter by their local healthcare provider. Others needed to buy both the catheter and accessories (e.g. drainage bags). In some cases, cost was a determining factor with continuing catheter use or how frequently they change the device. For some, it was cheaper to use DAPs.

- *I stopped catheter because it is expensive. After those 8 months, I used the use and throw diaper.* (I15)
- *I change the catheter once in 15 days. The hospital people instructed my mother on how to insert, remove and change the catheter. The catheter set that is used for a fortnight costs Rs.3000/- [approx. US\$34].* (I16)

Some participants also found obtaining (whether self-purchased or provided without direct cost) IUCs to be burdensome.

- *I was initially using one catheter for one month. Later, doctor advised me to change it every 15 days. I find it difficult to go to Anantapur to buy and get catheters. I have to spend Rs.20/- [approx. US\$0.23] to go to Anantapur.* (I2)

3.2.2.2. DAPs. Almost all participants who used DAPs commented on the high cost of the products and only a very few (mostly in Romania) were provided with the products without direct cost. For some people, they only managed to buy DAPs with considerable difficulty.

- *They are not overly expensive, but not cheap. We can afford them because we have to afford them.* (R12C)
- *Financially they are quite expensive because we use at least 2 or 3 a day. Well, considering that I have an income of 1800 RON [approx. US \$376], 300 RON [the monthly expenditure on DAPs] is about a sixth of the pension.* (R20C)

In some cases, DAPs were only used intermittently as budget

allowed.

- *When I have money, I go and purchase them and when I do not have money, I relied on my children to purchase it for their father. (PNG11C)*
- *I had to go to the town travelling 18 Kilometres to buy them. My brother-in-law used to bring it for me. My uncle was helping to buy it. After that, I stopped using it. (I5)*

Reliable access to DAPs was an issue particularly in Papua New Guinea.

- *It is very difficult. After purchased shop diapers run out, it is very difficult to get new shop diapers (PNG3C)*
- *When there was fighting in the city, and we could not go to get the adult diapers. (PNG1C)*
- *I had to go to the town travelling 18 Kilometres to buy them. My brother-in-law used to bring it for me. (I5)*

3.2.2.3. Homemade products. In both India and Papua New Guinea, some participants did not have reliable or affordable access to purpose designed products. This led to improvisation using household items to help manage.

- *At nights, I was keeping a plastic bag near my bed. (I18)*
- *I keep a bowl in the night. The bowl is a cut bottle. I wash the bottle and use it again. My wife washes it. I get urine 3 times in the night but it depends on the amount of water I drink. (I11)*
- *We use the laplaps or blankets that we do not really use (for our beddings) (PNG5C)*

3.2.2.3. Engaging in day to day life (including carers' lives)

The use of continence products impacted on users' lives in a range of ways. Both IUCs and DAPs influenced people's daily activities and also sometimes their longer-term decisions such as living arrangements, employment or education.

3.2.3.1. IUCs. Several participants found the need to have their IUC frequently changed was disruptive to their lives.

- *During this one year and a half, they were changing my catheter in the hospital once in a fortnight. My mother, sister and brother-in-law used to accompany me to the hospital. We used to go by auto-rickshaw. (I6)*

Some catheter users reported that their catheter limited their ability to leave the house and continue with normal activities.

- *I insisted to remove the catheter as it is inconvenient for me to work in the shop. (I6)*
- *When I was using the catheter, I had to come back home every 4 hours from wherever I was, as I had to empty the catheter again. Otherwise, my stomach would swell. (I17)*

One participant reported that the catheter meant that they needed to live by themselves (within a communal house) in order to manage their IUC without embarrassment.

- *They provided a bed for me in the outside part of the house. But I was feeling embarrassed there ... I rented a separate room and living here as I have difficulty there while using catheter and other appliances in the apartment. This is a separate rented room. This is convenient to me although I am alone. (I2)*

3.2.3.2. DAPs. Disposal of these products caused problems to participants in all countries, but was particularly reported in Papua New Guinea where rubbish collection services were often unavailable or

unreliable. In some cases, this led to digging pits to dispose of the products.

- *Yes, with the adult diapers, in terms of the waste, I have to do a lot. I have to wrap it up properly and worry about how to get rid of it. Sometimes the rubbish truck is very late in coming (to collect rubbish) and sometimes it does not come at all. You all can see my mother's rubbish is still there (pointing to small shopping bags that are used as garbage bags hanging on the fence). Hopefully, they will be coming this afternoon. (PNG1C)*
- *Yes, there is a pit that we dug. We do not know, maybe it is an unhealthy practice due to the smell from the diaper, but we have to do it so we take it with our bare hands and throw it away. (PNG3C)*
- *For the disposable, we had to find areas to dig and bury. (PNG10C)*

The need to frequently change the products also caused challenges for some users, particularly if they had leaked.

- *So, we had to double our work. One is to change the diapers and one is to change the beddings. (PNG3C)*
- *I can change myself, but I also need help many times because I can't stand for too long, and I can't put them while I'm in bed, I can't fix them well. (R14)*

A few participants explained that these issues led to them changing the amount that they drank in order to minimise the burden of changing products or managing leakage, particularly at night.

3.2.4. Psychological and social effects

The impact of products can be not just physical or practical (e.g. on day-to-day activities), but also psychological and social. Stigma associated with all products caused some participants to change management strategies or adapt their lives to avoid embarrassment and the products could be a cause of tension within the home.

3.2.4.1. IUCs. Fear of their catheter being seen by others was a reason for changing management strategies for some.

- *I must say that I was also feeling embarrassed to move around with catheter. That is why, I insisted with the hospital people, that they must remove my catheter.... Now I don't have the embarrassment of the catheter hanging behind me visible to the others. (I6)*

3.2.4.2. DAPs. Disposable absorbent pads were often associated with babies or small children and this could exacerbate the stigma of incontinence.

- *Maybe it was a bit bulky, but she always wears her top on as I do not like my grandchildren to come and see her with the diaper The granddaughter is fine, but the grandson teases her and say my baby grandmother (PNG2C)*

One participant noted that the children in the family home should not be made aware of the problems and therefore the DAPs could not be kept in the home.

- *Since she is an adult, we could not keep them where children live. (PNG5C)*

3.2.4.3. Homemade products. Improvised products could also lead to tension in households.

- *When I urinate in it, sometimes my children complain. They say, you remove it. It smells! [coke bottle] (PNG7)*

4. Discussion

To our knowledge, this is the first paper reporting on the experiences of using of continence management products across multiple LMIC settings. Whilst these products can have specific positive effect on people's lives, it is clear there can be wide-ranging and often severe downsides to their use.

The limited body of literature on product related challenges is largely set in high income countries and we found some differences, but also some striking similarities with the challenges reported in our study. Stigma associated with the products themselves (not just the underlying incontinence) appears very common in all settings [16,26,27]. In all societies, people prefer to keep continence products hidden from public gaze, often including family members. DAPs in particular are widely associated with babies or old, incontinent people [28,29]. IUCs (or drainage bags) reveal urine that most people in all contexts would rather hide [30]. Similarly, particularly with IUCs, the potential for physical harms such as infection and skin damage are also found in all settings [11]. However, where products (and associated health services) are easily available it is perhaps easier to avoid or effectively treat these issues at least some of the time. For example, antibiotics to treat infections and adequate changes of DAPs to help avoid skin breakdown from incontinence associated dermatitis rely on consistent access to health personnel, essential medicines and continence products. Furthermore, IUCs are widely seen as a continence management method of last resort [31], but if alternatives such as DAPs are inaccessible, IUCs are likely to be used more frequently. It is also easier to avoid unnecessary and inappropriate IUC use if diagnostic equipment such as a bladder scanner is available to assess urinary retention. It was sometimes unclear whether participants in this study were using catheters for reasons other than urinary incontinence in which case intermittent catheters might have been a more appropriate management option.

Products often have practical challenges, but again these can be exacerbated by the lack of available infrastructure or organisational systems. The clearest example of this was the need to dig pits to dispose of DAPs in rural areas of Papua New Guinea due to the lack or unreliability of rubbish collection services. Limited infrastructure had previously been found to be a challenge with the washable products, specifically lack of readily available running water [21]. Participants reported that continence product associated challenges often extended beyond the individual user to additionally impact their carers or families. Again, this supports previous findings where it has been observed that the choice of product can influence the time required and the physical demands associated with caring [32].

Overall, for many participants, the balance between the advantages and disadvantages of using the various products varied considerably. For a minority, the disadvantages were such that using the products became untenable. However, a similar minority used their products almost problem free. This highlights that, just like other assistive products, multifaceted context of use is crucial to the usability and acceptability of continence products. This in turn emphasises the need for holistic assessment by trained personnel to understand the continence problem within the individual's context, advise on the most appropriate management and products, and guide on the correct use. Together with access to essential diagnostic equipment, medication and a range of continence products, this will help mitigate against unintended harms and allow people to continue with their daily activities so far as possible. To support this goal, the Continence Product Advisor website (www.continenceproductadvisor.org) is an evidence-based, independent website hosted by the International Continence Society providing guidance on the pros and cons of different continence product options.

This work is exploratory in nature. To better support future policy and decision-making, further work is now required to gain a more nuanced understanding of 1) how to assess for continence product needs and advise on product use in different settings, 2) both the pros and cons

of using a range of continence products in varied settings, including identifying strategies to mitigate harms 3) understanding the variation in needs between male and female product users, different groups of carers (e.g. spousal or adult child) and product users with varying comorbidities.

This study has a number of limitations. Firstly, it is a secondary analysis of data from a study of participants who had been provided with WAPs and this was the focus of most of the interviews. Greater depth of understanding on the pros and cons of participants' original method of continence management might have been achieved if it had been the sole focus. The generalisability of the findings might be limited by a number of factors; 1) many of the people who were provided with products in this study were living with incontinence due to spinal cord injury or other neurological issues, 2) there were fewer older people than they might be in the general population, 3) there was far more discussion on the management urinary rather than faecal leakage, partly because half of participants experienced urinary incontinence only.

5. Conclusion

Whilst most people had an overall benefit from using continence management products, almost everyone also experienced side effects and challenges with their use; some minor, but others potentially life changing. Some people were either not using an appropriate product to meet their needs or were using an appropriate product incorrectly (e.g. not changing it sufficiently frequently). Experiences varied widely and depended on individual characteristics and circumstances. Getting the right products to meet individual needs together with appropriate advice on how to use them will help mitigate against unintended harms. To optimise the benefits of product use, policy makers and health personnel seeking to improve continence product provision should consider local and individual contexts, and ensure personnel are trained to support product selection, fit and use.

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Registration of research studies

<http://www.researchregistry.com/ClinicalTrials.gov>

1. Name of the registry:
2. Unique Identifying number or registration ID:
3. Hyperlink to your specific registration (must be publicly accessible and will be checked):

Ethics approval

<https://www.equator-network.org>

The authors declare that this study involves Humans and the ethics approval statement is as follow:

Ethical approval was gained from the University of Southampton (ERGO 63891).

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Cathy Murphy reports financial support was provided by the Government of Germany. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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