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Penile hygiene: puberty, paraphimosis and personal care for men and boys with an intellectual disability

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Abstract

Background Supporting men and boys with an intellectual disability (ID) to meet their penile hygiene needs is perhaps one of the least acknowledged but most confronting issues facing care staff. The delivery of intimate hygiene can be a challenging topic particularly as it has been drawn into the emerging sexuality discourse and the ongoing abuse narrative. Compounding this challenge is the lack of guidance in intimate care for support staff. In addition, whereas the male with an ID outnumber the female, female care staff greatly outnumber male staff. Whether this situation affects outcomes for men and boys with an ID is unknown but it is an issue which should be examined.

Method This paper reports data from two separate studies, one quantitative the other qualitative, which sought to explore penile hygiene as a male health issue.

Results Results show the practice of care staff to be inconsistent, the views and values of care staff to be divergent. Some patterns and contextual differences were identified depending upon the gender of care staff. An emerging dialogue described some of the positive contributions that male staff make to men and boys with an ID.

Conclusions The penile health needs of men and boys with an ID are being compromised by a lack of guidance, training, knowledge and limited gender-sensitive care.

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Introduction

Approximately 57–60% of people with an intellectual disability (ID) are male (Australian Institute for Health and Welfare (AIHW 2003), yet there has been limited recognition to date of the distinctive health needs of this group (Wilson 2005; Servais 2006). Research exploring hypogonadism and testosterone deficiency has started to emerge

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(McElduff & Beange 2003; McElduff *et al.* 2003), yet this emerging body of work stands isolated from broader health promotion initiatives such as testicular examination and prostate screening. Patja *et al.* (2001) identified an increased incidence of testicular cancer in the male with an ID, yet testicular screening is virtually absent from the ID literature. While the issue of penile hygiene has been raised, it has been in the wider context of exploring support with personal and intimate care (Cambridge & Carnaby 2000; Carnaby & Cambridge 2002).

Penile hygiene is a significant male health issue, particularly for men and boys who are uncircumcised and also require the support of others for daily personal care. Conditions such as urinary tract infections, cancer of the penis, acquired phimosis, paraphimosis and candida infection (thrush) can result from poor hygiene. Adequate penile hygiene confers all of the benefits of circumcision without the risk of surgery (American Academy of Pediatrics taskforce on circumcision 1999), yet practice standards for this task are particularly elusive within vocational frameworks. As routine neonatal circumcision is increasingly uncommon, an understanding of adequate penile hygiene and associated issues becomes more pressing. For example, two separate cases of paraphimosis known to the first author have caused utmost distress for the boys, their families and staff. Both cases involved male teenagers found to have an extremely swollen penis during incontinence pad changes with the foreskin also swollen and stuck behind the glans. Both cases required timely intervention by health-trained personnel to return the foreskin to its original position and prevent any serious complications.

Adequate penile hygiene is daily retraction of the foreskin during bathing from puberty onwards (Santucci *et al.* 2005). In boys up to about 6 years, adhesions (which gradually detach from 6 years onwards) mean that the foreskin cannot and should not be fully retracted (Watters & Carroll 2001). Between the age of six and puberty, gentle rinsing without full retraction is recommended (Santucci *et al.* 2005).

Care staff need to be aware of the following:

1 How to perform adequate penile hygiene;
2 When retraction of a foreskin is not appropriate;
3 How to respond to an erection;
4 How to respond if a tight foreskin will not retract over the glans (head) of the penis (phimosis);
5 How to respond if, once retracted, a tight foreskin gets stuck behind the glans (paraphimosis);
6 Recognising indicators of infection and appropriate responses; and
7 The risks associated with poor penile hygiene.

Carnaby & Cambridge (2002) suggest that cleaning under the foreskin of an uncircumcised male is a practice risk not only for practical reasons but also as it confronts both client and staff sexuality (Cambridge & Carnaby 2000). While a brief opportunity during bathing for some males to enjoy some time free of incontinence aids presents part of this sexual confrontation, the chance to masturbate and enjoy sexual exploration of course should not be denied. However, the right to such sexual exploration has to be framed within the parameters of a risk assessment in relation to the vulnerability of both the male client and the staff member supporting him. With this in mind, male staff face particular issues which become heightened during the delivery of intimate care; McConky *et al.* (2007) report how male care staff often felt 'at risk' because of the stereotypical assumption that being male makes you a potential abuser. Unfortunately, when abuse becomes the dominant theme of intimate care, there is perhaps a greater risk of neglect because delivering adequate penile hygiene is rendered a less important issue.

In addition to respect for gender, the risk of abuse during intimate care has encouraged some authors to argue for a same gender service system (e.g. McCarthy & Thompson 1996). However, such arguments also need to be analysed and discussed within the context of female care staff greatly outnumbering male care staff, often by up to 95% (McConky *et al.* 2007). Although the reality of men and boys with an ID being surrounded by women has started to be explored (e.g. Folkestad 2004), the potential of a feminised health environment has yet to be acknowledged. Just as the provision of expert and gender-sensitive supports for the health needs of females with an ID is well established, the same gender-sensitive supports are no less of a right for the male.

A limited male-specific research outline has surfaced in the literature that could not yet be called an emerging agenda. Although some male-specific

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needs are being explored, there remains a virtual hiatus in most areas. This paper will report on selected results from two separate research projects which will contribute towards the creation of a male-specific research agenda. Both these projects are focussed on the practices, views and the context that care staff play in the lives of the male with an ID. The first research project conducted in the UK between 2001 and 2003 comprised a descriptive survey to determine the practices of care staff while supporting men and boys with penile hygiene (Wilson 2002). The second research project, currently being completed in NSW Australia, is an ethnographic study investigating the sexual health needs of men and boys with an ID.

Research project 1: descriptive survey

Method

Sample

The National Care Standards Commission database of all registered accommodation facilities for adults with an ID within a county district in England was used to randomly select 15 providers from a list of 40. In addition, one domiciliary (supported living) provider was randomly selected from a list of seven for the district. Of the 16 organisations (survey sample) contacted, only seven (participant sample) agreed to participate (six residential care providers and one domiciliary care provider), five private organisations, one village community and one domiciliary provider. Some 88.3%, or 53 surveys, were returned. Demographic data show the participating staff members ($n = 53$) consisted of 41 females (77.4%), 11 males (20.7%) and one non-gender aligned (1.9%). Participants had a mean age of 37.6 years (median 38 years) within a range of 19–67 years. A total of 41 participants identified themselves as care staff (77.4%) with three (5.6%) and eight (15.1%) participants identifying as managers and care supervisors respectively.

Instrument

A descriptive survey was designed on six main topics identified in literature review (Wilson 2002): consent, abuse, touch, health promotion, staff practice and training. Reliability was determined by a test–retest by three care staff where a percentage agreement of 66.6% was considered acceptable; no modifications were made.

Procedure

Each facility was contacted first by letter, then by phone, followed by face-to-face meetings to discuss the project further and leave surveys for collection at a later time.

Ethical considerations

At the time fieldwork was completed in the UK, ethical committee approval was not required for research involving interviews with care staff not employed by health services. Agreement was obtained from each Registered Manager prior to leaving any surveys. Consent was implied by the free choice to participate. All data were stored in accord with the requirements of the Data Protection Act (UK).

Results

Data were analysed using a coding framework designed for SPSS v10.0. Where appropriate, data were analysed using chi-squared and correlation analysis to evaluate the significance of responses to actual care practice; a P-value of less than 0.05 was used for statistical significance.

Training

When asked if the participants had received any specific training in how to retract and wash under the foreskin of a male unable to wash independently, 73.6% ($n = 39$) answered ‘no’, while 24.5% ($n = 13$) answered ‘yes’.

Adequate penile hygiene

Participants were asked to state how often they believed a foreskin should be retracted and cleaned selecting from daily, weekly, monthly, never and do not know. A total of 92.5% stated daily ($n = 40$) or weekly ($n = 9$), the remaining 7.5% stated never ($n = 1$) and do not know ($n = 3$). Despite this, 33.9% ($n = 18$; male, $n = 1$, female, $n = 17$) of those who responded daily or weekly actually reported that they do not practice this, choosing instead to

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Table 1 Influence of policy and training on care practice

Policy and training	Penile hygiene practice			
	Do not retract foreskin	*Retract foreskin		
		No	Yes	Nil
Written policy				
No	14	1	17	
Yes	4		13	2
No response			1	1
Training in foreskin retraction				
No	16	1	20	2
Yes	2		11	
No response				1

* No, does not return foreskin; Yes, does return foreskin; Nil, no response.

wash around the genital area and not retract the foreskin. These data suggest that male staff are more likely to practice adequate penile hygiene. The remaining participants ($n = 35$) do retract and wash under the foreskin. The age of a male when foreskin retraction should occur was answered with 7.5% ($n = 4$) stating at the onset of puberty, 75.5% answered at birth ($n = 40$), the remaining 17.0% answered at the age of five ($n = 9$). These data highlight the risk in children's services of acquired anatomical abnormalities, either phimosis or paraphimosis, from care staff retracting the foreskin when it is not recommended for this age group. Participants were also asked if they were aware of any policy with respect to penile hygiene; 60.4% ($n = 32$) stated they were not aware of any written policy. Table 1 highlights a significant association between policy, training and staff practice ($P = 0.001$ and $P = 0.040$ respectively); the presence of policy and training was more likely to influence the provision of adequate penile hygiene.

Health promotion

Participants were asked to rate whether they felt retracting and washing under a foreskin was less, more or equally as important a health promotion issue as breast, testicular and cervical screening. Responses show ratings of 86.8%, 90.6% and 77.4%, respectively, that foreskin retraction was considered equally as important.

Touch

Although only limited Table 2 represents a slight, non-significant trend towards feeling 'uncomfortable' the more independent the male becomes: 9.4% for profound ID, 17.0% for any level of disability but with good communication. Conversely, the data show a non-significant trend towards feeling 'comfortable' the more dependent the male becomes 30.2% for profound ID, 24.5% for any level of disability but with good communication.

Bathing practice

Bathing practice showed 49.1% ($n = 26$) of participants provided personal care to male and female clients. Only 3.8% ($n = 2$) reported a same gender bathing practice. Male clients were supported by staff of either gender 32.1% ($n = 17$) but female clients were supported only by female care staff. Table 3 summarises what the participant reported that they would do if the male client sustained an erection during intimate care; no significant association was found between staff gender and response to an erection ($P = 0.407$).

Consent

Participants were asked whether their client group had ever been assessed for their capacity to consent to examination or treatment; 45.3% ($n = 24$) stated 'no' while 43.4% ($n = 23$) stated 'yes'

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Table 2 Staff feelings towards performing penile hygiene at different levels of dependence

	Level and type of clients' disability			
Staff feelings of comfort	**Profound ID and physical disability**	**Profound ID but no physical disability**	**Borderline ID, not independent with intimate care**	**Any level of disability, good communication**
Very comfortable	7.5% ($n = 4$)	9.4% ($n = 5$)	5.7% ($n = 3$)	7.5% ($n = 4$)
Comfortable	30.2% ($n = 16$)	28.3% ($n = 15$)	28.3% ($n = 15$)	24.5% ($n = 13$)
Neither	43.4% ($n = 23$)	41.5% ($n = 22$)	37.7% ($n = 20$)	35.8% ($n = 19$)
Uncomfortable	9.4% ($n = 5$)	11.3% ($n = 6$)	15.1% ($n = 8$)	17.0% ($n = 9$)
Very uncomfortable	9.4% ($n = 5$)	9.4% ($n = 5$)	13.2% ($n = 7$)	13.2% ($n = 7$)
No response				1.9% ($n = 1$)

ID, intellectual disability.

Table 3 Care staff response to an erection during penile hygiene

Response	**Female (*n*)**	**Male (*n*)**
Carry on regardless	13	2
Stop bathing immediately	0	1
Wait for erection to subside then continue	16	2
Ensure safety then leave room for 5 min	14	7

(six participants gave no answer). Of those who stated 'yes', 74.0% claimed this extended to assessment for ability to consent to the performing of intimate care tasks. However, when it comes to the delivery of intimate care, only 7.5% ($n = 4$) stated they would go ahead and talk to the client as the procedure was undertaken. The remaining participants stated they would talk to the client before the task (66.0%, $n = 35$), try to gain some form of consent before proceeding (17.0%, $n = 9$) or both (9.4%, $n = 5$). Significantly, 96.2% ($n = 51$) felt that where a client cannot give consent regarding intimate care, an entry regarding this should be made within their care plan.

Research project 2: ethnographic study

Method

Sample

Three non-Government organisations providing community group home accommodation within a region of NSW were approached; two responded favourably. Across three settings 18 staff agreed to participate in the study consisting of three male and 15 female staff. Setting A provided accommodation for one male client and four females, setting B two males and three females, setting C two males and one female.

Instrument

Data were collected from interviews with care staff using a semi-structured interview schedule based upon topics identified within the literature: sexual health, masculinity, gender, staff gender, policy and training. Additional data were collected during participant observation sessions over a 12-month period.

Procedure

Having read an outline of the research project, individual staff were invited by their service managers to meet with the researcher to establish if they wanted to be involved. Participants were interviewed individually using a digital voice recorder, transcription of interviews occurred as soon after each interview as possible. Each participant was provided with a copy of the transcription and was invited to respond to the content; one female participant requested for her interview to be excluded from the study because of concerns she had with the confidentiality of her thoughts. Participant observation sessions occurred mainly in the evening and weekends when clients were at home.

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Ethics

Approval was granted from the University of Sydney ethics committee in 2005. Participants were supplied with a participant information schedule plus a written consent form to sign. Because of the level of ID, where all males had a moderate to profound ID, capacity to consent to conduct the study was gained from service boards. Assent from clients in the group homes was used as an indicator of approval for the researcher's presence; no clients or participants indicated verbally or through their behaviour unhappiness with the researcher's presence during data collection.

Results

Analysis

Qualitative data were analysed using the constant comparative method (Strauss & Corbin 1998).

Training

No participants could recall any formal gender-specific training or policy other than several staff in setting C discussing an 'unwritten house policy' that no male staff provided personal care to a female client:

> . . . just the unsaid one about females only supporting females . . . She (a female client) will grab men on the crotch . . . policy is for male staff benefit.

Adequate penile hygiene

Participants were asked during interviews what they thought the sexual health needs of their male clients might be. One participant, a female enrolled nurse, in relation to the dependent client group in her care, felt penile hygiene was an important sexual health measure.

> They can't look after themselves so most important thing is, I guess, their [penile] hygiene . . . kept really clean, you gently push the foreskin down . . . the boys get mucous from being in nappies . . . they're sweaty . . . you really gotta make sure you wash them properly.

Participants from community group home C staffed solely by females, while discussing penile hygiene expressed a range of emotional responses in relation to penile hygiene:

> Participant: There is a cream that [male client] has to have on his foreskin and [some of the female staff] are freaking out about it . . . I say it's his cream and put it where you have to.

> Another participant suggested: Some staff do this, some staff don't . . . female staff might get embarrassed – young female staff who don't want to see that and they are quite within their rights to say no but it does not help [the male client].

> Health and safety concerns were also an issue:

> Participant: We have to pay particular attention as he is obese and gets lots of rashes and sores [penis and groin] – lots of staph infections – he picks his sores – staff do not want to get staph off him.

One participant felt the gender of care staff may influenced the adequacy of penile hygiene:

> Interviewer to participant: If there were more male staff would this (penile hygiene) improve?

> Participant: Yes, the female staff are fastidious with the female client.

Health promotion

Only one participant mentioned male clients may need prostate screening and testicular examination was not mentioned once by any participant.

Touch

Participants expressed a range of fears related to the issue of touch but not specifically when performing intimate hygiene. Male staff reported a general 'fear of accusation' and female staff reported a general 'fear of male strength'. One male participant deliberately distanced himself out of fear:

> I am terrified of someone saying . . . that looked a bit funny . . . how do you then protect yourself when I need clearance for my future career? He [male client] loves physical affection and I don't encourage it.

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A young female participant expressed a

> . . . fear of males and [male] violence being in that situation before in my life.

The same basis for a fear of males was expressed by an older female participant:

> . . . [male] sexual things might worry me because I have seen a lot and I have been through a lot over the years . . . I don't trust any man unless I have known them for a long long time . . . I find it hard to trust – a lot of things have happened to me in my life.

Discussion

Research project 1 is the first study to focus solely on penile hygiene for men and boys with an ID. Combined with data from research project 2, this paper brings together quantitative and qualitative data in an attempt to generate a solid basis for future practice. Both these studies have confirmed that care practices to support the penile hygiene needs of men and boys with an ID are inconsistent. Table 1 shows where training and policy in penile hygiene exists, poor practice while not eliminated, is reduced. Data from study 2 concerning the application of creams to a foreskin together with the two cases of paraphimosis mentioned in the introduction highlight some of the negative outcomes of poor practice and limited knowledge. Both studies have identified a widespread lack of policy, training and professional guidance for penile hygiene.

Both studies echoed other findings where female care staff greatly outnumber the male in most settings. Gender dynamics during intimate care mirrored those discussed, among others, by Cambridge & Carnaby (2000). The data from both studies suggest that the gender of support staff may directly impact upon adequate penile hygiene; however, this would require deeper analysis to reach firmer conclusions. While male care staff should not be the gate keepers of male health needs, the data recognise a positive value base for the male. It offers a starting point to frame why more male care staff working in the sector should be a sector wide goal. There may well be a relationship between male staff and positive outcomes for male clients, a finding also reported by McConky *et al.* (2007).

The data on touch also illuminated some more gender-specific fears extending beyond penile hygiene: the fear of male physicality, male interaction and male violence. Based upon a combination of individual belief systems, duty of care and perceived professional boundaries, these are interdependent and deeply complex issues. The literature has acknowledged some of these gender-specific issues for support staff (Thompson *et al.* 1997; McConky *et al.* 2007); however, a wider appreciation of masculinity theory and its potential for understanding gender-relations and gender-hierarchies is absent.

The need to focus on training care staff to understand and practice adequate penile hygiene has been recognised. Like most other health-related tasks, formalised competency-based training in penile hygiene is non-existent for the disability sector in Australia. Even in the UK where training and professional standards are formalised, competency-based training (national vocational qualifications) does not focus on intimate hygiene in any detail. It has been suggested that tensions between care staff performing health-related tasks such as penile hygiene and the legislative framework governing service delivery have not left people with an ID better off (Mott *et al.* 2007). The provision of adequate penile hygiene, which requires some appreciation and acknowledgement of health promotion, should not be a great challenge. With the inclusion of some basic information into competency frameworks such as that described in paragraph three of this paper, together with some gender-specific mentoring, the risks associated with poor penile hygiene could be decreased.

This paper illustrates the importance of exploring sexuality when discussing intimate care, in particular the concept of asexuality. Data in Table 2 suggest care staff do not automatically assume an erection which has a sexual connotation. Another perspective suggests those participants who would leave the room saw the erection as sexual. While the survey did not ask participants to attach a sexual rating to the meaning behind an erection, it is possible that the participants who would 'carry on regardless' either saw the client as asexual or saw

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the erection as perhaps more a biological reflex to touch during bathing. In addition, it is also possible that some of these responses were borne out of safety considerations where leaving a client unattended was not possible. Data from research project 1, however, support the findings of both Thompson *et al.* (1997) and Edwards (1998) of an increase, albeit minimal, in the perceived sexual nature of touch the more independent the male client becomes. The data from study 2 concerning touch help to contextualise the findings in study 1.

There remain, however, some limitations of the results, the principal one being the absence of the voice of men and boys with a moderate to profound ID. A major limitation concerns the fact the two studies were not directly related, participants were different, and therefore the qualitative data fail to directly illuminate the quantitative data. However, as the two studies were conducted in different countries and contexts, this is also a strength as a deeper contextualisation of the issues has been possible. Furthermore, as the first author was the sole male researcher, it is possible that some element of 'male bias' was introduced to the research. Conversely, it could also be argued that a male researcher exploring male issues to positively influence the lives of men and boys with an ID is a significant strength.

Future research needs to focus on evaluating training on health-related tasks. Health issues including basic anatomy, pathophysiology, health and safety, and sexual health provide a sound starting point. Furthermore, the intersection of masculinity and ID and the fact that a large number of men and boys' with an ID experience life within an asymmetrical gender dynamic is another important issue. The following quote from a female participant in project 1 exemplifies why penile hygiene should be a more important issue:

> I have never in my whole time in care work ever had my attention drawn to this area of care . . . all staff should be aware of procedures to follow with each client in order to protect the client and themselves.

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Conflict of interest

No conflicts of interest are declared.

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