Providing intimate continence care for people with learning disabilities

This study investigated continence care provided in residential homes for people with learning disabilities

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Abstract

Introduction: This report on a qualitative study of intimate and personal care for adults with severe and profound learning disabilities explores the implications of its findings on dignity in relation to bowel and bladder function.

Method: Participant observation in residential care homes, staff interviews and analysis of documents were used to ascertain the personal care experiences of six people with learning disabilities.

Results: Observations highlighted areas requiring improvement. These included respect for service users’ privacy and dignity, and the promotion of continence.

Discussion: Examples of good practice were observed but these standards were not always maintained. This may be because staff found it easier to carry out intimate care if the service user’s humanity was temporarily denied, or if they took a task-oriented approach to such care.

Conclusion: Intimate and personal care should be undertaken with respect for service users’ privacy and dignity in every care setting.

INTRODUCTION
Intimate and personal care is one of the most basic and fundamental human needs. It involves activities such as bathing, washing, cleaning teeth and shaving.

Most people take for granted their ability to carry out these tasks in private, and may not have considered the influence they have on their quality of life. But some groups depend on others to carry out intimate and personal care, and may have to expose and be touched on private parts of their body.

The way in which care is delivered can significantly affect quality of life (Mirfin-Velitch et al, 2004).

However, despite the importance of this area of care, it is one of the most overlooked in research, practice and policy.

Many people with severe and profound learning disabilities experience either urinary or faecal incontinence or both (Stenson and Danaher, 2005; Smith and Smith, 2003; von Wendt et al, 1990).

Incontinence is also common throughout the general population – other groups who require support in this area of care include older people, those who are physically disabled and people undergoing surgery.

While this study focused on care given to people with learning disabilities, the findings have implications for other patients in health and social care settings.

INTIMATE AND PERSONAL CARE

Intimate and personal care may involve

- being prompted to use the toilet, being cleaned and having continence pads changed. This care may be provided in a person’s own home or a healthcare setting.

Aims and Method

As there was no published research on the intimate and personal care experiences of people with severe and profound learning disabilities, an exploratory study was designed. This aimed to answer the broad question: ‘How do adults with severe and profound learning disabilities experience intimate and personal care?’

The participants had no verbal communication skills and depended on
others to meet all or most of their needs for intimate and personal care. Since they were unable to describe their experiences of receiving intimate and personal care, the methods used to investigate them were participant observation, interviews with staff and analysis of documents including support guidelines and organisational policies.

Strategies used to increase the validity and reliability of the study included reflexivity (reflecting on the results of the researcher’s involvement), triangulation (collecting data using multiple methods and sources) and keeping an audit trail.

Issues around the participants’ capacity to consent were complex, so detailed plans were drawn up to ensure that their well-being and rights were protected at every stage. Data was collected over 10 months, during which time the delivery of intimate and personal care provided to six service users by 17 social staff was observed in two residential homes.

Three service users experienced urinary and faecal incontinence and wore pads at all times, and three were able to use the toilet if prompted to do so at regular intervals.

Data was analysed using a combination of approaches from ethnography and grounded theory. This involved searching for themes in the data and grouping them with a coding system. Themes were then grouped into four categories, which formed the basis of an emerging theory. Data collection and analysis were carried out in stages, with each stage giving shape and direction to the next. In this way, the direction of the study can be guided by what is observed.

Two of the categories dealt with how intimate and personal care was carried out, and were labelled ‘doing’ and ‘communicating’. Within each category’s themes, there was variation in the extent to which dignity was being promoted. Other themes indicated reasons why there may have been variation in dignity and these were organised into the categories ‘attribution of humanness’ and ‘the meaning of intimate and personal care’.

This article presents the themes that relate to dignity in bladder and bowel function care.

**FINDINGS**

Data in the themes within the ‘doing’ and ‘communicating’ categories varied in terms of the extent to which dignity was maintained or compromised. Extracts from the data are provided as illustration. Names have been changed to protect confidentiality.

**Naked**

It was striking how often service users were left naked while sitting on the toilet, as the following observation illustrates:

Sally knocks on Barry’s bedroom door and we enter. Barry is in his en-suite shower room, and the door between this and the bedroom is open. Barry is sitting on the toilet with no clothes on.

One member of staff criticised this aspect of practice:

‘I don’t like leaving him on the toilet with no clothes on. I’d leave him with his pyjama top on or something. And I’d put a bath mat under his feet or leave his slippers on so he is warm. If he was wet, I’d put something on him, or put a towel over him and a towel over his shoulders so he’s covered up at least, and warm. I don’t like when people leave him sitting naked on the toilet. It winds me up.’

**Using the toilet as a seat**

Not only were service users often left naked on the toilet, but they were also asked to sit on the toilet while other aspects of their care were carried out. It is questionable whether it is dignified to be shaved or have teeth cleaned while sitting on the toilet.

Another potential problem with using the toilet as a seat was that service users were not always given the opportunity to sit on the toilet in private to urinate or defecate, without a member of staff doing something to them, as the following observation illustrates:

Gemma asks Elaine to move on to the toilet, saying: ‘Would you like to sit on here to get dressed? If you want to have a pee you can have a pee, yeah?’

It was possible that sitting on the toilet for other purposes than actually using it might lead to difficulties in associating the toilet with urinating or defecating, and this could contribute to incontinence. Problems with incontinence also increased when service users were left waiting to be taken to the toilet as can be seen in the following theme.

**Being left waiting**

There were times when service users were left waiting to use the toilet, and sometimes this appeared to cause them to be incontinent. One strategy used to maintain continence was to take service users to the toilet at regular times, as illustrated in an extract from one man’s support guidelines:

Ask Barry if he wishes to go to the toilet when he gets up in the morning, after each meal and mid morning/mid afternoon (10.30am and 3pm), and before going to bed. However, guidelines were not always adhered to, and service users were left for long periods without being taken to the toilet. On the occasion described in the following extract, a service user’s

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incontinence might have been prevented if the guidelines had been followed:

At 5.45pm David is having a cup of tea and Gemma says she will take him to the toilet after he has drunk it. No one took David to the toilet and, after dinner, at around 7.30pm, I notice David is soaking wet and I tell Lorraine who changes him into his pyjamas.

Service users might also have been left waiting because they were unable to tell anyone when they needed support, or non-verbal communication was missed or ignored, as this observation illustrates:

It is 7.30am and Josie is reading a newspaper. I can hear Beth in the hallway making sounds. After some time Josie says she will attend to her.

Every morning one male service user was awake and sat up in bed when staff went to help him get up, as this excerpt illustrates:

7.45am. Barry is sitting up in bed, smiling and rocking when we enter his bedroom.

It is possible that Barry had wanted to get up earlier, but there were no strategies in place to enable him to communicate this.

At times, staff did respond to service users’ behaviour so the latter did not have to wait, as this observation illustrates:

Sally goes into Simon’s bedroom and asks: ‘Shall we put the radio on?’ She puts the radio on then starts to leave the room. Simon pulls Sally by the hand back into the bedroom. Sally says [to me]: ‘I am going to change him into his pyjamas and rocking when we enter his bedroom.

However, this meant another male service user had to wait to be helped out of bed, and Sally explained why this may have been a problem: ‘... left him too long, he might have wet the bed by now’.

Being watched
The policies and procedures in both homes highlighted the need to maintain privacy and dignity during intimate and personal care. However, while doors were always shut while care was delivered, other staff and service users often entered the room while someone was on the toilet or in the bath. On one occasion, when a man was on the toilet, at least three other people intruded.

This situation was exacerbated when service users shared bathrooms. On one occasion, a service user wanted to use the toilet. He went into the bathroom where another man was having a bath; a member of staff called him away angrily and said: ‘I’m sure Joe does not want to watch you have a crap...’

Despite efforts to maintain privacy by keeping doors shut during intimate and personal care and knocking before entering, the extent to which this was successful was limited because staff did not wait for a reply before entering and the person providing care did not attempt to cover the service user up, as this example shows:

David is in the bath and is being supported by Caroline. Rita knocks on the door, enters and immediately sprays air freshener.

Lack of discretion
The way staff discussed service users’ continence was often lacking in dignity. This occurred when they were indiscreet and talked about incontinence in front of or in the presence of other people. Although it may have been necessary to share this information on some occasions, it would be better to do so in private. Also, the words chosen showed a lack of respect for dignity, such as: ‘Barry was shitty this morning.’

Here is another example:

Two members of staff (James and Sally) are talking in the kitchen about Barry being incontinent that morning. James tells Sally that ‘there was fucking loads of it’.

DISCUSSION
This is been just a snapshot of the study findings. Within each of the themes, there were examples of both dignified and undignified practices. If it was possible to deliver care in ways that promoted dignity, why were standards not always maintained?

From data analysis, possible explanations emerged and were considered in the light of the weight of evidence as well as supporting theory and literature.

The themes ‘attributing humanness’ and ‘the meaning of intimate and personal care’ offered possible explanations. These suggested that the reasons for failing to maintain dignity may have been related to staff attitudes towards the people they were working with, and their understanding of the purpose of intimate and personal care. The conclusion reached was that, in order for dignity to be maintained, a service user must be seen as a human being and also that the goal of intimate and personal care must be to give a positive subjective experience, not just to ‘get the job done’.

Recognition of a person’s humanity is fundamental to a respect for dignity (Gallagher, 2004), so if a person is to be treated with dignity, they must be viewed as ‘fully human’. It may be easier to carry out intimate care by temporarily denying a person’s humanity and treating them as an object (Downs, 1998; Walmsley, 1989).

Staff sometimes approached intimate and personal care as physical care, and may have failed to consider the importance of the care-receiver’s experience. Therefore, indignity may have arisen not from malevolence but from staff carrying out care in a task-oriented manner.

The weight of evidence in this research indicated that, in the main, staff perceived intimate and personal care as a goal-oriented activity and felt pressure to complete tasks quickly. This meant this type of care was often rushed, which may have led to dignity being overlooked.

This research has identified certain factors that are necessary to maintain dignity:

● There must be enough staff and resources to ensure that service users are given the time and support they need;

● Staff must have a positive attitude towards the people they are working with, and see them as fully human rather than objects that need things done to them;

● Intimate and personal care must be seen as holistic care, not just as physical care.

The findings have direct implications for practice, including the need to keep doors shut, cover up service users and reduce exposure wherever possible, and refer to intimate and personal care in a dignified manner and in private.

CONCLUSION
The requirement for intimate and personal care to be carried out with dignity is equally applicable across all settings. This article has made recommendations for how this can be achieved in practice.

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