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Given an opportunity to talk, family carers have much to say about the importance of continence and toilets.

Liz Forbat explains why knowing more about these basic features of care can alert professionals to the difficulties carers may be experiencing, and of the need to support them

KEY WORDS

**Continence
Carers
Dementia**

Listening to carers talking about the subjects of continence and toileting

the door being used. Rather than a concern about wandering, usually associated with dementia, the carer needed to be sure her father-in-law was toileting appropriately.

This issue of space connects with the next theme – demonstrating competence.

Use of toilets as indicating competence This theme was common in the interviews both in terms of appropriate use of the toilet indicating competence and inappropriate use indicating incompetence (for example, not being able to locate the toilet).

A frequent retort by carers was: ‘She didn’t know where the toilet was.’ Similarly, not recognising the need to urinate/defecate away from public areas of the home implied a lack of competence.

‘There was times when mum couldn’t go to the toilet, she was just getting out of the bed and just doing it, floor of the bedroom’ (Mrs F, who cares for her mother-in-law and father-in-law).

Conversely, the appropriate use of toilets was used to indicate that the person with dementia was competent. Indeed one interviewee commented that her mother’s ability to use the toilet and interact on a superficial level was used as evidence by a visitor that there was not a large need for care. She recounted one episode:

‘...and at that particular moment in time [mum] could get up and go to the loo do what ever is necessary and [the visitor said] ‘she looks fine to me’ [they] go away thinking well maybe it’s just this person can’t cope or she’s making a big thing about it because she thinks that she doesn’t want to look after her’ (Mrs F).

The importance of her mother being able to use the toilet was recruited into the visitor’s account. Appropriate use of the toilet is used to challenge the mother’s need for care, and the carer’s own difficult position.

Being attentive to conversations about toileting is vital not just for recognising the importance of the spatial organisation of people’s homes, but also to highlight how toilet use influences relationships and is even seen to validate or invalidate the need for care. Mrs L talks of her relative’s own lack of insight into her incontinence: *‘She doesn’t realise she hasn’t cleaned herself, she thinks she’s been to the toilet, come back some on her clothes.’*

Other interviewees noted that the level of continence would inform their decision about moving their relative

of physical space and clothing:

‘He got food poisoning, it was there I know that, because it was mushrooms that came out and I’m not joking. I have never seen him do that ever. I clean him four times within twenty minutes and the mess he made, luckily he was in the bathroom on the floor. Oh my God it was like a tap. And I cleaned it with my own hands. You know the mess’ (Mr K, who cares for his father).

Mrs L spoke of a similar experience with her mother’s continence, including the effect this had on Mrs L’s own children.

Mrs L: She’s smelling and people don’t want to go near her when she smells. But she gets used to the smell, she doesn’t think she is smelling.

Interviewer: Sure.

Mrs L: And before I put her in my car in the morning, I have to make sure I’ve changed her clothes, I have to give her a good old wash before I can put her in the car, because the car smells, my kids won’t get into it.

These discussions about cleaning up were often articulated with an air of annoyance and frustration. However, although the next theme was also often accompanied by similar feelings, the remaining talk about incontinence was largely warm and sympathetic to the relative’s needs and feelings.

The changing nature of space in the house Many carers spoke of the need for structural changes in their homes to enable their relative to use the toilet as much as possible. This ranged from minor changes such as fitting grab rails and modifying toilets, to major structural alterations such as building new ground-level bathrooms.

The following quote is taken from an interview with Mrs I who cares for her husband. The interview was conducted in Urdu with an interpreter.

Interpreter: You know he needed a [grab rail] for the, when he peed in the toilet and he can grab and get up and get up and everything, they didn’t put one of them in.
Interviewer: So you have to help?

Interpreter: Yes she has to help him all the all the while.

The lack of grab rails referred to by the interpreter leads to the carer having to physically help her husband each time he needs to use the toilet.

Mrs F’s father-in-law often urinated outside the house. This was such a concern that the carer felt the need to fit an alarm to the front door, to alert the household that

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Toilets and continence play critical roles in the lives of people who care for a relative at home. Issues around toileting are central to the relationship between the carer and the person being cared for, with the bathroom often becoming the most important place in the house.

This article explores some assumptions about toilets and continence, drawing on interviews with carers. It outlines some of the ways that carers spontaneously talked about toilets and continence in interviews that were set up to explore family-care relationships. The study investigated the experiences of people from minority ethnic communities who care for a family member who has a diagnosis of, or suspected, dementia.

Research indicates that people with this diagnosis are more likely to be incontinent (Hellstrom et al, 1994). The quotes in this article are from interviews with 11 people who identified themselves as being from a South Asian or Afro-Caribbean background.

The link between incontinence and dementia is developed in this article, as the interviewees were all looking after a family member with dementia. The interviews are drawn from a larger study of the impressions of carers who look after a family member with a diagnosis of dementia (Forbat and Nar, 2003).

Methodology Interviews were held to hear about difficulties arising in the family as a consequence of caring, and to connect the findings with recent policy relating to adult protection and race relations. The topic of continence emerged from the interviewees, rather than from the interviewer.

The interviews were tape-recorded (apart from one instance where the interviewee preferred not to be recorded). They were then transcribed and analysed. Most of the interviews were in English; others – conducted with the aid of interpreters – were in Urdu and Mirpuri.

People were recruited primarily through community support groups for South Asian and Afro-Caribbean elders. These groups acted as the gatekeepers to potential respondents. Further details on the methodology have been published elsewhere, highlighting the difficulties in accessing this client group (Forbat, 2003).

The research aimed to involve either small group discussions or individual interviews. The use of vignettes enables speakers to talk about care generally without the need for personal/private stories. This is important when the discussions are about the more difficult areas of caring relationships.

As Brechin et al (2003) note, there is a need to find

methods which enable people to 'talk about potentially damaging aspects of caring without making carers guilty, fearful or defensive. Admitting to difficulties in caring is not easy'.

The gatekeepers to potential respondents for this research indicated that conversations with South Asian and Afro-Caribbean carers were likely to be limited to public accounts, drawing on vignettes to illustrate issues, because personal accounts would generally not be forthcoming. This turned out to be far from what happened.

Findings of the study

Toilet talk Many carers spoke at length about continence, and more generally about the difficulties in getting their relatives to the toilet or having appropriate facilities. Much of this talk began without any specific prompts from the interviewer.

Much of the talk did not stem from vignettes, and case studies were not even used with all interviewees. For one carer, the important role that toilets held in their lives was mentioned in the first two minutes of conversation:

'He had a couple of falls. Mum had a fall, and [unclear]. And on top of that he used to wet himself a lot. I had a commode put in their room, but it wasn't just using it for passing water and all that they were using it for, they were using it for their motions and stuff. It wasn't very good...' (Mrs F, who cares for her mother-in-law and father-in-law).

Toilets and continence were so important in the speakers' worlds that they started talking about them without reassurance that this was appropriate.

Themes that emerged from conversations about continence and incontinence Four key themes were evident in carers' talk. Each of these will be briefly discussed alongside illustrative quotes from the interviews.

Clean-up operations Toilet talk was often based on accounts of 'clearing up'. The importance of managing continence and the appropriate use of toilets was driven home by the great burden placed on the person responsible for cleaning up. For one carer, continence was meaningfully related to huge washing tasks:

'Sometimes when he gets in a mess and he changes clothes, have to sit outside, soaked and washed, and sometimes I can't even put them in my own machine I have to take them to the laundry. I take them to the laundry' (Mrs F, who cares for her mother-in-law and father-in-law).

Often accounts would reflect the process of ensuring the person being cared for was clean, as well as issues

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practices is potentially troublesome and culminates in them often staying at home.

Mr K: You go out somewhere, because you don't know where you are, if you go out to someone's, people's homes and things you know he, he might you know not realise. Something like that you ought to really stay at home.

Interpreter: Mmm.

Mr K: And that's one of the other reasons you don't go out much.

Interpreter: Right.

Mr K: You know because in case he wants to go into the loo and things like that.

Discussion Continence has received much attention from researchers in recent years, focusing particularly on older adults. Reports include associations with quality-of-life indicators (Robinson et al, 1998) and the cultural meanings of continence, focusing particularly on stigma (Mittens and Barker, 1995).

Other research calls for greater professional awareness of the impact of continence and a movement towards more effective care (Stoddart et al, 2001). Twigg (2000) also noted the importance of continence in community care.

Her study focused primarily on the accounts of people receiving intimate care from care assistants who come from minority ethnic backgrounds.

Much of the talk focused on care assistants not wanting to engage in intimate tasks concerning continence. There is a perception among family carers that talking about incontinence is often inappropriate. However, the research outlined in this article has identified that, given minimal prompts, carers will discuss intimate personal care in great detail.

This kind of intimate support is often at the heart of caring, so for carers to be able to talk about their needs and experiences is therefore vital.

Conclusion Analysis of the interviews indicated that continence is a component of family care that is seen as very important. Awareness of how continence impacts on care and caring relationships can enable practitioners to respond more effectively to carers. ■

into residential care.

'If she is wearing trousers she manages, [...] Lifting a skirt and pulling her knickers down she can't do. And even outside if you are outside sometimes have to adjust her clothes. So that sort of thing is ok, but I think the day she can't go to the toilet or do her own bath... that is what is in our minds []that's when we need to consider it for her health' (Mrs G, who cares for her mother-in-law).

This extract underlines the potential meaning of incontinence and its implications for care. The indication of levels of self-care is highly significant for family carers, and also for nurses working with family carers, in order to understand the stressors and strains that may lead to a decision about residential care.

Embarrassment about incontinence Embarrassment among the carers and the people they care for was indicated as an important component of how family members experience incontinence. However, this embarrassment did not extend to the interviews, as carers talked at length about issues they had marked out as being difficult.

Embarrassment was not only seen in relational terms but also on an individual level. Incontinence was particularly problematic for people who had been fastidious about their appearance throughout their lives, and who felt ashamed at being unable to stay continent.

'If she has a slight bit of wet in her pants she throws it away. So we have a dustbin bag now, we don't throw rubbish in, just have the dustbin bag and we know ... usually because she is desperate to go to the loo and hasn't get there in time. She won't put it in the wash, or... because she is embarrassed about it she will throw it away. She will throw her whole clothes away as well. But no she is hygienic, very hygienic, likes to keep herself clean and tidy' (Mrs G).

The embarrassment also restricts socialising for the carer and the person with dementia:

'I want her to be as independent as possible ... we have to remind her to go and have a bath, we have to remind her to go to the toilet before we go or if we've gone somewhere before we come back, because if she gets desperate she tends to have accidents. And then she gets upset, and it's a vicious circle' (Mrs G).

Mr K supports this opinion over several minutes of talk. He notes that his father's lack of insight into his toilet

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