Evidence Brief

University of Southampton

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What makes it difficult for patients to ask for help in hospital?

Failures in fundamental care of hospital patients can have serious consequences, including patients dying unnecessarily. NHS policy and nursing theory emphasise shared decision making by staff and patients. However they do not consider what prevents nurses providing care as they would wish, nor the difficulties patients can face in alerting staff to missed care.

Researchers from the University of Southampton interviewed 20 patients and six focus group members about their experiences of involvement in fundamental care decisions in hospitals, including whether they raised missed care with staff and if not, why not. This evidence brief presents our findings, taken from our recent paper. (1)

Patients' role in decisions about fundamental care

Fundamental care in hospitals consists of helping patients with personal cleansing, eating, drinking, dressing, toileting needs, rest, sleep, mobility, comfort and safety [2]. When this care is not provided, it can have serious consequences, including avoidable deaths and other poor health outcomes [3-5]. However when nursing workload exceeds staffing capacity, emotional support and some aspects of fundamental care can be missed while medical care is prioritised [6].

Patient involvement in healthcare can lead to better health outcomes [7] and patients might be able to flag missed care to avoid adverse outcomes [8]. Researchers have previously described the patient's role in nursing staff-patient interactions. These existing conceptualisations have not considered patients' efforts to avoid being seen as difficult, for example by not asking for support when needed [9].

This study aimed to explore the patient's role in nursing staff-patient interactions around fundamental care omissions in acute hospital settings.

Interviews and focus groups

This was part of a wider study testing the feasibility of an intervention to increase patient involvement in fundamental care decisions. We interviewed twenty patients from four inpatient medical and/or surgical wards participating in the study. To obtain a wide range of perspectives we selected the sample to have varied ages, genders and hospital stay lengths [10]. We also ran three patient focus groups with six people who had been in hospital within the last two years who had registered their interest in participating in local healthcare research.

In interviews and focus groups we asked patients about their experiences of receiving and negotiating appropriate fundamental care in hospital. Data was recorded, transcribed and analysed together using the thematic analysis method described by Lofland and colleagues [11]. Full details are given in our original paper [1].

What patients told us

Patients described working to avoid making a nuisance and to present as 'good' patients who would not be disruptive. This was reminiscent of patients in Goffman's work on Total Institutions [12] where inpatients and prisoners focused on 'staying out of trouble'. This involved scrutinising nurses' 'performances' to assess whether they could ask for care without compromising their impression as a'good patient'.

Engaged nurses – 'Nothing is too much trouble'

When patients assessed staff performances as believably caring and available, they described being able to make care requests without fear of being seen as a difficult patient. Nursing staff would take time to chat or joke with patients and appeared interested in them as a person, not just a patient, and would personalise care.

It sounds genuine whereas sometimes it's sort of like, 'Are you okay?' and they walk off before…yes. They don't seem to do that on B2. They actually seem to listen (Interview 17, Ward B2).

This participant was paraplegic and standard pressure ulcer prevention techniques (using a pillow to prop up ankles) did not work for her:

one of the nurses has come up with a good solution now which is much better using something smaller [a rolled up towel] (Interviewee 7, Ward A2).

Distracted nurses – 'They mean well but they are very busy'

'Distracted' nurses were assessed by patients to be caring but unavailable, for example while carrying out a routinised task like taking vital signs observations. Patients avoided asking for support, even if they needed physical assistance to carry out fundamental care.

I wouldn't say [it's] easy [to talk to a nurse] because they're you know, they're in and out, aren't they? 'Just coming to do your blood pressure. Just coming to do that.' (Interview 16, Ward A2).

He don't eat chicken. […] They put a note up above his bed [saying he says 'yes' to everything] and it's like all agency people that's coming in, yes, and they're just going, 'Roast chicken', they're going, 'Ching' [mimes ticking box], like that and they're not looking at that

(Interview 1, Ward A1)

obviously I've got a tongue in my mouth, I can ask, you know, which I usually do say, 'Can I do my teeth?' and it's not a problem. But I think there were a few days at the beginning when I didn't get them done and I didn't ask
(Interview 7, Ward A2, who was unable to leave her bed unassisted).

Dismissive nurses – 'the nursing staff don't listen to you'

Staff who were 'distracted' were seen as caring though unavailable due to their workload. However, 'dismissive' staff were perceived as deliberately withholding their time and attention from patients or ignoring their requests for help.

last night, I had some chocolate buttons […] and I asked [a frail, 'muddled' patient] if she wanted one [in the morning]. And she was like, 'Yes, yes.' So I said to the staff member this morning: 'Can you give one to her? She wants it.' She went over and she went, 'Oh, don't worry, she'll have forgotten that she asked you for one.'

(Interview 2, Ward A1)

I described it to my surgeon as feeling like a piece of meat on the slab and there were occasions when that was reinforced on the ward because I ceased to be a person. I didn't have a name anymore; I was just a bed, I was a body in a bed that needed things doing to it.
('Roger', second focus group)

Care inequalities

Patients who had greater physical autonomy and were recognised as possessing mental capacity were able to protect their and staff 'faces' more easily through carrying out some aspects of their own fundamental care, although they were sometimes unsure what they were 'allowed' to do for themselves. Patients who had difficulty communicating their needs or who required physical support to carry out fundamental care tasks were at greater risk of fundamental care omissions, such as failing to get enough nutrition or not being given the equipment to brush their teeth.

Conclusions

Patients can find it hard to ask for the care they want unless they believe staff are both caring and available (engaged). However it can be hard for staff to present themselves as 'available' when they are under significant pressure due to workload. While this is a complex situation with no simple solutions, we hope that this research alerts nurses to how difficult it can be for patients to request care from nurses who do not appear both caring and available. Patients who are most in need of their support may be most disadvantaged, experiencing poorer health outcomes.

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