

## Abstract

**Background:** People living with dementia may call out repetitively, sometimes called disruptive vocalisation, or verbal agitation. In literature and policy, patients who call out repetitively are assumed to be expressing an unmet need, which should be met. Yet there has been little systematic study of this patient group in an acute hospital setting.

**Objectives:** To better understand patients who call out repetitively and to identify what care looks like in an acute hospital setting.

**Design:** Ethnography.

**Settings:** Ten acute geriatric medical wards in two hospitals.

**Participants:** 30 cognitively impaired patients who were calling out repetitively, and 15 members of hospital staff.

**Methods:** Semi-structured interviews with hospital staff, 150 hours of ward observations and informal conversations with staff, scrutiny of medical and nursing documentation, and measures of patient health status.

**Results:** Patients who called out were moderately or severely cognitively impaired, often had delirium, were very physically disabled, and many were approaching the end of life. Most hospital staff were found to hold contradictory views: that calling out represents distress or unmet need, but that nothing can be done to alleviate the calling out. During informal conversations, most staff also tended to say that they intuitively recognised when intervening was likely to alleviate calling out. During observations, many staff appeared to and spoke of the ability to 'block' calling out. As a result we argue that social, emotional and physical needs may get overlooked. We argue that some calling out of a need, represents a need that is unmeetable. We also found that while staff would

talk about strategies for identifying need, observations and hospital documentation did not support evidence of systematic attempts to identify potential need.

**Conclusion:** Calling out repetitively within a hospital setting is difficult for staff to understand and to respond to. This is because many of these patients are severely cognitively impaired, while also bed-bound and dependent on their professional carers. We argue that a form of socialised care futility gets communicated between staff and is used to rationalise becoming unresponsive to calling-out. We explain this phenomenon as resulting from two protective mechanisms: defence of staff's professional identity as competent practitioners; and defence of staff as having personal morality. Socialised care futility risks good quality care, therefore systematic strategies to assess and manage possible need should be developed, even if calling out remains irresolvable in some cases.

## Contributions of the Paper

What is already known about the topic

- People with dementia may call out repetitively, this is frequently observed on hospital wards, but there has been little systematic study of these patients in this setting.
- Calling out repetitively is commonly interpreted as a communication of distress or unmet need.

What this paper adds

- The unmet needs model of causation is difficult to operationalise in practice on acute hospital wards and may not represent a wholly adequate explanation.
- Staff learn socialised care futility, and rationalise inaction with patients who call out in an attempt to defend their professional identity and personal morality.
- These patient needs should still get identified and met, even if calling out repetitively continues.

## Keywords

Acute Hospitals, Agitation, Calling Out, Delirium, Dementia, Ethnography, Mixed-Methods Research, Needs

## Introduction

Half of people aged over 70 admitted to hospital as an emergency are cognitively impaired; 40% have dementia, 30% have delirium, and some have both (Sampson et al. 2009; Whittamore et al. 2014). Some of these patients call out repetitively (McMinn and Draper 2005, Goldberg et al. 2014; Inkley and Goldberg, 2016; Nagaratnam et al. 2003); this is also termed persistent or disruptive vocalisation, or vocal or verbal agitation (Barton et al. 2005), and is often included under the umbrella term 'agitation' (Cohen-Mansfield and Martin, 2010).

Behaviours that challenge, including calling out, are commonly interpreted as a communication of distress or unmet need (Jamie, 2011; Jackman and Beatty, 2015; Livingston et al. 2014; Kitwood, 1997; Miranda-Castillo et al. 2010; Schölzel-Dorenbos et al. 2010; Cohen-Mansfield & Werner, 1995); such as being in pain, or needing the toilet, although some needs may not be easily ascertained or interpreted (Kupeli et al. 2018). Dysexecutive syndrome (disinhibition), personality, and self-stimulation are additional potential explanations (Algase et al. 1996; Barton et al. 2005). Kitwood (1997) argued that the all-encompassing psychological need for people with dementia was to be loved and fulfilled via five fundamental needs, for: inclusion, attachment, comfort, identity, and occupation. Distress was hypothesized to result from disregard of, or failure to meet, these needs.

Calling out is associated with a general decrease in quality of life (Hurt et al. 2008) and poor patient outcomes (Dewing and Dijk, 2014). Care quality can rapidly deteriorate around the patient, with frustration, avoidance and overt disregard for their psychological (and sometimes physical)

needs (Goldberg et al. 2014). Calling out can also significantly increase the cost of care (Murman, 2005), due to increased use of pharmaceuticals to control or suppress the behaviour.

Staff report that they find it distressing or frustrating when a patient is calling out and they are unsure of what to do to calm them, staff may also take vocalisations personally, further increasing feelings of frustration (Barton et al. 2005). This produces feelings of workplace dissatisfaction, heightening stress and staff burnout (Cooper et al. 2018). A patient calling out could add to staff workload, as they may feel they are required to attend to the patient more often, giving them less time to see other patients under their care (Brodaty et al. 2003).

In an acute hospital setting, there will be many patients on a ward at any time, and many of these will be disturbed by calling out, especially at night. It may increase stress levels of other patients, and disrupt their daily activities and their sleeping patterns (Older People's Commissioner for Wales, 2011). Calling out could also produce feelings of fear in other patients, be overwhelming or overstimulating, or evoke feelings of anxiety. This could potentially increase length of stay due to the inability to properly rest and recover (Knapton, 2016).

There is no clearly established treatment for calling out, and therapeutic approaches are likely to be multi-faceted (Barton et al. 2005; Von Gunten et al. 2008). An international Delphi study found a consensus among a panel with expertise in behaviours that challenge, that care should commence by identifying underlying causes and that person-centred care should be attempted ahead of pharmacologic treatment (Kales et al. 2019). UK Policy echoes an **assumption that behaviours that challenge must be the result of 'unmet needs'** (Algase et al. 1996). NICE guidelines on dementia state:

People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan (NICE, 2019).

How to deliver person-centred care within a hospital setting for a population with cognitive and communication impairment, where actual needs may be different from expressed needs and where needs may be any combination of physical, social or emotional, presents considerable challenges for caregivers (Clissett et al. 2013). We undertook a scoping review, and found there were very few studies of patients who call out repetitively in an acute hospital setting (Honda et al. 2016; and Inkley and Goldberg, 2016), and no ethnographies. With an ageing population, care for this patient group is a research priority area (James Lind Alliance Priority Setting Partnerships 2019).

This paper reports on an aspect of our findings from an ethnographic study, which set out to better understand patients who call out repetitively and to identify what care looks like in an acute hospital setting. Within the ethnography, formal and informal staff interviews identified that staff held contradictory views, that calling out repetitively was expression of an unmet need, but also that calling out repetitively may not represent need or that needs were unmeetable. This paper reports on this element of our ethnography.

## Methods

An ethnographic study of 30 patients who called out repetitively was conducted across ten acute geriatric medical wards in two hospitals. A multi-sited ethnography places focus on process where “local realities are produced elsewhere, through dispersed relations and agencies” (Marcus, 2011). While practice and process in wards and hospitals will be subject to distinctive and local culture, they are also highly regulated arenas subject to national agencies seeking uniformity in care. We therefore adopted a nomothetic approach to identify regularities derived from within and across several acute ward cultures (Baszanger and Dodier, 1998). The researcher (JB) was a female PhD student and psychology graduate, not otherwise involved in the care of patients. Data collection took place over 12 months from February 2017. The study was approved by Yorkshire and the Humber-Bradford Leeds NHS Research Ethics Committee, and the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee.

Prior to entering the field, the researcher received ESRC accredited methods training including ethnography and interviewing workshops. She then began developing links and connections with senior ward staff who enabled her to familiarise herself with the environment, facilitated staff introductions, and to become accustomed to ward routines. Once in the field, participants who called out were selected for observation. The researcher asked ward staff to identify recently admitted patients who called out repetitively, checked inclusion and exclusion criteria (*Table 1*), and contacted a family member to request agreement for the patient to participate. The research ethics committee requested that we only recruit patients who lacked mental capacity, to avoid possible distress in someone with capacity who did not realise they had been calling out; in the event no-one was excluded on this criterion. Posters were displayed on the wards, notifying patients, staff and family that an observational study was being conducted, with an invitation to notify the researcher if they did not want to be included. We had a Patient and Public Involvement (PPI) group consisting members of the public with an interest in, or carers of, people with dementia who contributed to the design of the study. We also had a Steering Group of 4 clinical academic professionals in dementia and one physician (a physiotherapist, physician, occupational therapist, specialist dementia nurse, and psychiatrist) as well as one PPI member who had cared for parents with dementia. We presented anonymised preliminary findings to this group.

*Table 1:* Inclusion and exclusion criteria for participants

Inclusion Criteria	Exclusion Criteria
Acute admission to a geriatric medical ward	Clinical team considered patient likely to die within a week
Cognitively impaired (MoCA <sup>1</sup> <20/30) or a diagnosis of delirium or dementia in the medical notes	Consultee agreement to participate not given.

Lacking mental capacity as assessed by the requirements of the English Mental Capacity Act (2005).	
Score of 1-4 on the Pittsburgh Agitation Scale – Aberrant vocalisation.	

<sup>1</sup>MoCA Montreal Cognitive Assessment (Nasreddine et al. 2005)

Patients were assessed 1-3 days after recruitment using measures of health status, including: the standardised Mini Mental State Examination (sMMSE; Molloy et al. 1991), the Delirium Rating Scale (DRS-R-98; Trzepacz et al. 2001), Barthel Activities of Daily Living Index (Barthel ADL; Collin et al. 1988), Neuropsychiatric Inventory (NPI-NH; Wood et al. 2000), and the Pain in Advanced Dementia observational scale (PAINAD; Warden et al. 2003). The characteristics (frequency and severity) of the calling out was assessed using the Pittsburgh Agitation Scale (Rosen et al. 1995), and the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1991).

The researcher then observed patients and their care, made structured and unstructured field notes, and examined a patient's medical and nursing records. She also interviewed health care professionals about their knowledge, beliefs and practice of working with cognitively impaired patients who call out repetitively.

Each participant was observed for calling out every one to three days or nights for the first two weeks, and then every three to seven days or nights until they were discharged. Structured two-hour non-participant observations were undertaken during a range of times during days, nights and weekends, with and without family visiting. Some observations took place when the doctor was visiting the patient, some without. 50 hours of structured observations took place. For three minutes every twenty minutes the researcher recorded whether the participant was calling out, what they said, staff responses, what the patient was doing, facial expressions, mood and what was happening around them. The researcher developed a checklist based upon the Chiseri-Strater and Sunstein

(2001) guide and included the nature of the calling out, social stimulation and observable impacts on others. It also included specific words, insider language, and impressions from sights, sounds and smells.

These structured observations were supplemented by unstructured observations also during a range of times throughout the day and night, while family members or doctors were there and when they were not. Initially the researcher tried observation, by sitting close to the patient to facilitate interaction. However, she found non-participant observation from a position that enabled her to overlook the whole bay helped with discrete note-taking and enabled her to capture both detailed interactions and a switch of focus to staff or other patients as activity arose (Creswell 2007). During these unstructured observations 'thick description' was captured using a pen and note-book to record what she saw and heard (Lincoln & Guba, 1985). She also made notes about the atmosphere on the ward (e.g. relaxed chatter with visitors, relative calm, or busyness among staff). Following a period of observation, the researcher typed up fuller notes over the next 24 hours. In total, she did 100 hours of unstructured observation. Medical and nursing documentation were also systematically scrutinised for the ways in which assessments and interventions related to calling out were recorded and referred to.

Fifteen staff members who worked regularly with patients who call out were recruited from within the wards being observed (*Table 4*). Staff who agreed to participate gave informed consent. Semi-structured interviews were then undertaken with staff about the calling out, what it meant and how it was responded to, using a topic guide which was reviewed by the PPI group. Interviews were conducted at the staff's workplace in private rooms. They were recorded on a digital audio recorder, transcribed verbatim, pseudonymised, and stored and managed in QSR International's NVivo 11 qualitative data analysis software.

Field notes were made after each **interview** to capture initial impressions. Interview data and field notes which included medical nursing documentation were transcribed and typed up in



order to be entered into NVivo 11. To ensure rigour an initial transcript was coded separately by each co-author to support the development of open coding within NVivo. JB also repeatedly listened to the interviews and read field notes to gain familiarity with the data (Braun and Clarke, 2006). Following the identification of key codes through open coding within NVivo, more focused coding involved printing and then the manual sorting of open codes. This gave rise to a number of themes which were then recorded within NVivo. Analysis was an iterative process occurring alongside and after data collection, and allowed for the interview topic guide to evolve, (Kerssens-van Drongelen, 2001). Themes were then presented and refined with the Steering Group and the co-authors met throughout to refine and challenge the findings. Theoretical data saturation occurred approximately two thirds into data collection (Bryman, 2004).

## Findings

On site one, the seven wards were all similarly configured. There were four bays with six beds in each. They were open-plan and each bay was single-sex. These wards also had two to four side rooms each. The feel on these wards were similar in that they were quite noisy because if someone was shouting in one bay it could be heard in all the bays. Mobile patients also moved outside their own bay onto other bays. Nurses and doctors tended to walk, often hurriedly, across the top of the bays. One ward was a specialist medical and mental health unit, and this ward had some brightly coloured walls and at times received visits from entertainers and musicians. The other six wards were neutrally painted and did not appear to have any externally delivered therapeutic activities. On site two, the three wards were also similarly configured to one another, but were very different in design. The bays were smaller with only four beds, and there were walls and doors between each bay. There were 12 side rooms each with their own door. These wards were quieter, and staff could be observed shutting doors if patients were particularly noisy. The corridors between bays and side rooms were larger than on site one, and mobile patients tended to move around these corridors, and were less likely to go into a bay that was not their own. Because observations on site two took place within a

closed bay or side room, the movement of doctors and nurses was less apparent. One ward at site two, was decorated to emulate the home. The floors were wood effect, and the seating was less institutional. The other two wards were more neutral and hospital-like. Across all 10 sites, there was usually one nurse and one health care assistant (HCA, unregistered nursing assistant) on each bay. Every 12 hours there was a staff handover. Doctor’s rounds occurred each morning. Visiting times were 11.00h until 20.30h (site one) and 11.30h until 19.00h (site two). Observations took place over a year, and sometimes a ward would feel light and upbeat and other times a ward would feel stressed and difficult. The different feelings generated within a ward might be to do with the staffing mix, and or the configuration of patients who were more or less vocal.

Of the thirty patients recruited, two-thirds had a prior diagnosis of dementia. Most (73%) patients were severely cognitively impaired and 88% had features of delirium. They were very severely physically impaired, mostly unable to undertake basic activities of daily living, and had evidence of mild or moderate pain. Mean length of stay (29 days) was longer than for patients nationally in the same age range (12 nights; Stevenson et al. 2018). One third died within the 90-day participation period. Calling out was mostly persistent; patients who stopped calling out did so when delirium resolved (n=2), or when approaching the end of life (n=2) (Tables 2 and 3).

Table 2: Clinical characteristics of the patients included in the study

Sex	20 female, 10 male
Age	Mean 82 years, range 63-96
Prior residence	18 (60%) home, 12 (40%) care home
Prior diagnosis of dementia	19 (63%; 5 vascular, 4 Alzheimer’s, 10 unspecified)
Length of index hospital stay	Mean 31 days, range 6-90
Days spent calling out	Mean 25 days, range 2-90
Readmissions within 90 days of recruitment	11 (36%)

Deaths within 90 days of recruitment	10 (33%; 1 during index admission, 9 after discharge)
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*Table 3: Participants' baseline health status*

Cognitive impairment (standardised Mini-Mental State Examination /30)	Mean: 5.8/30, Standard Deviation: 6.0 0-10 (severe): 22 (73%). 11-19 (moderate): 8 (27%)
Categorical delirium (Delirium Rating Scale-1998 revision, DRS-R-98)	24 (88%) likely to have delirium Mean score: 24.2/46, Standard Deviation: 6.1
Activities of Daily Living (Barthel ADL index/20)	0-5 (very severe impairment): 22 (73%); 6-10 (severe impairment): 6 (20%); 11-15 (moderate impairment): 2 (7%)
Observational pain rating (Pain in Advanced Dementia scale, PAINAD)	None: 4 (13%) Mild: 11 (37%) Moderate: 13 (43%) Severe: 2 (7%)
Behavioural and psychological symptoms (Neuropsychiatric Inventory/144)	Mean: 28.3/144, Standard Deviation: 10.3 Aggression/agitation 88%; anxiety 76%; apathy 76%; irritability 72%; hallucinations 60%; depression 56%; disinhibition 52%; motor behaviour 40%; delusions 36%
Executive function (Frontal Assessment Battery/18)	Mean: 2.5/18, Standard Deviation: 3.8 100% had executive dysfunction, using cut-off score of 12 or lower

Fifteen interviews were conducted with staff members (10 female, 5 male). Staff had from 10 months to 30 years' experience working with older people (Table 4).

Table 4: Staff Interview participant demographics.

Staff Interviews			
Pseudonym	Role	Experience (years)	Length of Interview (min:sec)
David	Consultant	21	30:26
Carlos	Mental Health Nurse	2.5	26:27
Sandra	Junior Doctor	0.8	27:37
Judith	Registered Nurse	5	11:40
Beth	Discharge Coordinator	2	20:48
Jenny	Occupational Therapist	4	29:55
Marco	Deputy Charge Nurse	16	18:55
Issac	Healthcare Assistant	14	13:50
Deena	Registered Nurse	16	22:38
Philip	Consultant	8	19:13
Marianne	Assistant Practitioner	10	24:02
Olivia	Healthcare Assistant	2	18:31
Katherine	Deputy Charge Nurse	1.5	12:43
Violet	Registered Nurse	11	12:07
Tami	Healthcare Assistant	1	17:09

During observations, calling out repetitively could manifest in a number of ways. The most common form was repetitions of a single word or phrase: *“help me, help me”*, *“mum!”* or a name. Some would call out a tangible need: *“a peepee!”* or *“can I have a drink please?”*, but once the need had been met, would either continue to call out the same word or words or incoherent phrases or words: *“I hope to goodness that you’ve found somebody out ... why ... and I mean this ... FIIIVE!!!”*. Some expressions of need were understandable, but impractical: *“This isn’t my house, get me home!”* Sometimes calling out was accompanied by banging on the table, attempting to get out of bed, or throwing things. On occasions, effective person-centred care was implemented by staff, and did appear to reduce calling out; for example, a tablet computer was used to show a patient pictures of the country where he grew up, and another had a favourite song sung to them by staff.

However, analysis of the data highlighted a contradiction within the accounts of staff around causation: that calling out repetitively is due to an unmet need and conversely that it is unrelated to need. Failure to identify causation and alleviate the calling out was explained in a number of different ways by staff, and staff sought to make sense of the tensions and contradictions involved. These tensions between staff accounts of causation, together with data derived from observations, illuminated both significant gaps in our understanding of the behaviour, which in turn gave rise to significant gaps in suitable care for this population.

### Calling out repetitively is due to unmet need

Almost all staff during interview stated that the reason that patients call out repetitively was “*unmet need*” (David, Consultant) or that they were communicating distress, agitation, or anxiety caused by the presence of a need: “*It could be that they need a bed pan, it could be that they are wet, that they've been incontinent. It could be that they want water, that they are dry. It might be pain*” (Philip, Consultant).

Staff reported that they usually felt able to ascertain patients’ needs, and that most patients were able to communicate their needs, and that meeting patients’ needs was achievable: “*on the whole, most of them tend to know what they want*” (Judith, Registered Nurse). However, if the patient could not verbalise their needs, staff reported that the situation became more uncertain, “*There might be something they can't express. They might be wanting a drink but all they can say is help*” (Violet, Registered Nurse). Identifying the unmet need was reported to be “*difficult*” (Carlos, Mental Health Nurse), necessitating the need for a “*mental checklist*” (David, Consultant) to discover what the cause might be: “*Usually by non-verbal cues if they can't make their needs known. You can tell by facial cues or the way they're behaving*” (Deena, Registered Nurse). Calling out repetitively then, is viewed as an intentional if unclear verbal expression designed to meet a need.

## Calling out repetitively is unrelated to need

Evidence from observations, interviews, talking to staff informally, and nursing documentation however, suggested that ward staff also held the contradictory view that calling out could be unrelated to need. *“Claudine is calling ‘help’ loudly (...) The HCA sitting watching the cohort bay [constant observation bay for patients at high risk of falling] ... said to me that Claudine calls out all the time, for no reason - she said there was nothing staff could do to stop her calling out and said ‘It’s just how she is. She is who she is’. (Field notes).*

*“Just because somebody’s shouting out it doesn’t mean that there’s something wrong necessarily”* (Katherine, Deputy Charge Nurse).

Staff spoke of how the patient had *“no real issue, no ‘nursing’ issue”* (Carlos, Mental Health Nurse), and *“we know that every need has been attended to but they are still shouting out”* (Katherine, Deputy Charge Nurse). A common belief was that *“some people will just continue to shout no matter what you do”* (Issac, HCA), and that for these patients intervening would be futile because *“there is a group who are genuinely intractable”* (David, Consultant).

It was clear from observation that even after the expression of a tangible need, and an attempt to meet the need, the patient would often continue to call out. If expression was incoherent, or calling out continued after an initial attempt to meet a need, we observed that attempts were neither repeated nor documented. Some need was often almost impossible to assess, especially if a patient had severe cognitive impairment, as was often the case. However, staff often concluded that there was no need, and went on to rationalise this in a number of ways.

### *“It’s part of the dementia”*

Some staff used a diagnosis of dementia to rationalise the absence of need: *“it might be more easy to ignore the people that are calling out if you know that it’s part of dementia”* (Sandra, Junior Doctor).

*"It's a phase"*

Some stated that patients could call out and then stop for no apparent reason: *"Often it's like a phase, isn't it? And then an hour later they'll be fast asleep and fine"* (Jenny, Occupational Therapist).

*"They like doing it"*

Another suggestion was that calling out was a form of self-soothing or self-stimulation: *"they might just not want anything. They're just calling because that's how they feel comfortable"* (Judith, Registered Nurse). This idea was more common in situations in which the calling out was not perceived to be an expression of tangible need, but was used to explain when, for example, the behaviour was *"just counting"* or *"singing"*. *"Sometimes they just want to hear their own voice and I think that is the comfort they have, I suppose"* (Philip, Consultant).

*"It's normal for them"*

Staff implied that if a patient called out repetitively prior to admission, it represented their *"usual behaviour"* (nursing notes) and should therefore be tolerated: *"if that's a normal thing for him then you have to accept it"* (Marco, Deputy Charge Nurse). Staff referred to calling out repetitively as habitual or inadvertent: *"they're not even aware, they don't realise, it's become a habit"* (Judith, Registered Nurse).

*"It's attention seeking"*

The concept of 'attention seeking' was also employed to explain calling out. *"They're doing it for attention"* (Olivia, HCA), was used to imply patients were exhibiting childish or selfish behaviour. There was also a view, that if staff responded too readily to calling out, the patient would become overly dependent on them. *"A staff member called me [researcher] over and said Antonio is becoming too reliant on staff, therefore they are trying to not go over and sit with him and talk to him. She said 'we're not ignoring him'"* (field notes). The nurse said this because she did not want

the researcher to interact with the patient, and the researcher felt the nurse was explaining why, despite the patient calling-out, they were not attending to him.

### *Resistance to futility*

Only one staff member resisted the notion of futility, holding instead to the notion of unmet need. She said “I’d never say there’s nothing you could do. [...] that is again lack of understanding. It’s just a case of, is anybody bothered to read about them, can you pick up a phone and ring a relative?” (Marianne, Assistant Practitioner). She acknowledged however, that futility was a widely held assumption.

### *Hierarchy of need*

Although staff suggested that in some cases calling out was intractable, they expressed discomfort about the possibility that an, as yet, unidentified need may be the cause of the calling out. Staff also took the view that even if the behaviour was an expression of need, not all needs could be met within the context of an acute hospital ward. They acknowledged the possibility that need could be social or emotional rather than physical, but that this was harder to identify.

Staff spoke of time pressures being a problem for identifying and meeting social and emotional needs: *“But yes, you really feel bad when you can’t go and sit with somebody, and see all they need is somebody to sit with them. But everyone’s being so efficient that they don’t have that spare five minutes anymore to go and sit with somebody. That’s really sad”* (Jenny, Occupational Therapist). Prioritisation was used to rationalise determining what needs could and could not be met: *“you have to put your professional hat on, and you prioritise what you need to be doing”* (Judith, Registered Nurse). Prioritisation inevitably meant social and emotional needs were seen as a lesser priority: *“as far as you’re aware there’s no real issue, no ‘nursing issue’. There’s no ... they just want someone to talk to. They are gonna be at the bottom of the list for priorities, unfortunately”* (Carlos, Mental Health Nurse). The view was that if staff were to cater for these needs then they would neglect more ‘important’ needs: *“if you’ve got to one-to-one somebody who is calling out ... then you tend to not have time to look after your poorly ones”* (Marco, Deputy Charge Nurse).



When wards were observed to be busier, several staff conversationally referred to the challenges of needing to prioritise their care. One charge nurse in an informal conversation with the researcher described needing to be like an octopus.

The tension between the view that calling out repetitively is on the one hand the expression of an unmet need and on the other is intractable making attempts to alleviate futile, was recognised. This cognitive dissonance left staff uncomfortable.

### Feelings of discomfort

Staff were keen not to be seen as incompetent or uncaring. A consistent theme from informal conversations with staff was references to finding it *“distressing”* (Sandra, Junior Doctor) or *“heartbreaking”* (Jenny, Occupational Therapist) when a patient was calling out repetitively and they felt unable to do anything about it: *“It does drain you emotionally”* (Judith, Registered Nurse). Staff members repeatedly spoke about themselves and their colleagues being *“good”* (David, Consultant), *“specialist”* (Carlos, Mental Health Nurse), and *“efficient”* (Jenny, Occupational Therapist), and reiterated how *“busy”* (Deena, Registered Nurse) they always were, and how hard they had to work. Staff were eager to assert that even though they did not always respond to calling out they and their co-workers were still moral agents. Beth speculates: *“If I had all the time in the world, I would talk to every patient, every day”* (Discharge Coordinator), and emphasised that *“everybody that works here are here because they care about people”* (Jenny, Occupational Therapist).

### ‘Knowing’ when and how to respond to calling out repetitively

This discomfort led staff to assert a form of tacit knowledge about when they could and when they could not effectively intervene. Such tacit knowledge got passed on .

Staff spoke of not knowing how to respond to calling out when they first started the job, and seeking advice from more experienced staff. One HCA was told: *“Just sit there and watch him he’ll be all right’ (...)* They [senior staff] calm you down quite quick because there’s no worry in their face or panic, it’s just, ‘it’s the way they are, it’s the condition’” (Issac, HCA).

Staff spoke of gaining expertise for *“knowing when to intervene, and when to just let it roll”* (Sandra, Junior Doctor), *“you soon get to learn”* (Olivia, HCA), sometimes very rapidly *“within half a shift”* (Olivia, HCA). More junior staff thought that senior colleagues could identify more quickly when intervention was not needed, and were better at recognising ‘real’ need. Observation revealed, however, that although staff sometimes tried to address repetitive calling out, this was not done systematically or recorded: *“Patient has been awake all night and constantly calling out. Would keep quiet for a few seconds when asked to stop, and then carry on again with constant calling out”* (nursing notes). Staff reported knowing when a patient was expressing a tangible need: *“I think sometimes, especially the ones who need the bathroom or need changing, you can notice a change there with them. Especially if you’ve worked with that patient more than once and then you get to know them more and you see the signs that are specific to them”* (Tami, HCA).

However, this ‘knowing’ was tacit and meant that staff did not check and recheck the possibility that new need might have arisen.

### Missed identification of need

Staff members spoke of their ability to create a *“shield”* (Sandra, Junior Doctor) to *“block the sound”* (Philip, Consultant) of patients who call out. Patients were observed on occasion to be communicating a tangible need, with no staff intervention: *“Frances has been calling out for about 10 minutes for someone to cover her feet up (6 or 7 times) “please can you cover my feet up, they’re ever so cold”, “wrap my feet up please”, no-one has covered her feet up yet. Frances’ feet are uncovered and the window is open, I feel this is a legitimate need. She is also calling out things like “Can you tell Andy he’s spilt yoghurt all over him”, and repetitively calling “Vicar!” so I can understand why the staff are drowning it out - they may not even be hearing that she has a legitimate request as it is getting buried”* (field notes).

The tension between the various forms of possible need, and the eventuality that even within the context of someone with intractable calling out a new meetable need might arise, meant that staff developed blocking coping mechanisms as well as theories of futility. The absence of

regular re-assessment of patients, even where calling out is believed to be intractable, meant that meetable care needs were going unnoticed.

## Discussion

Our data show that people living with dementia who call out repetitively are severely medically, cognitively and functionally impaired, and may be approaching the end of life. Staff expressed a widespread belief that calling out repetitively was driven by unmet need, but simultaneously spoke of there being no 'real' need, or that need was social or emotional, something unmeetable within the context of a hospital ward. Given the time pressures and competing priorities of a busy medical ward, the inability to meet such needs meant attempts to identify possible need were prejudged to be futile. 'Knowing when to intervene' was considered a skill, but there was little evidence that this was established by systematic clinical assessment. 'Real' need, amenable to intervention was assumed to be identifiable especially among more experienced staff. When it was not easily identifiable, post-hoc rationalisation applied. Such views were collectively held by a diverse group of staff, across different wards and two hospitals. Some calling out was observed in circumstances where need was not easily determined, or feasibly met. In such instances staff were observed to be 'blocking' or ignoring calling out. A consequence was that 'real', tangible and meetable needs, perhaps unassociated with the nature of the calling out, may have been neglected. We have constructed a theoretical typology of needs and wants, involving possible scenarios and outcomes to illustrate the difficulty surrounding care needs for this population in an acute setting (*Table 5*).

*Table 5:* Theoretical typology of possible needs and wants in patients who call out repetitively and potential staff responses

Presence of a need	Presence of a want	Patient able to communicate need or want	Staff able to meet need or want	Example
Yes	No	Yes	Yes	Patient is thirsty, asks staff member, who responds
Yes	Yes	Yes	No	Patient is anxious, tells staff member they have to go home, staff cannot let patient leave
Possibly	Possibly	Possibly	No	Staff block calling out, need is not heard
Yes	Possibly	No	Possibly	Patient is distressed, cannot communicate why, staff member has to deduce from body language, or use trial and error strategy
Possibly	Possibly	No	No	Patient is unable to communicate, staff member cannot determine if there is a need or not

We have called the tendency to assume that nothing can be done to meet needs when someone is calling out repetitively, ‘socialised care futility’. This propensity potentially inhibits good care of patients who call out; firstly because assessment is often superficial and not systematic or recorded, but gets tacitly passed on; secondly because legitimate day-to-day needs may be missed through ‘blocking’; and thirdly because the contradictory ideas around causation, mean little is done to try to alleviate the apparent distress shown by these patients. Futility is ‘socialised’ because the belief is collectively held and communicated between staff members, endorsed by senior colleagues and becomes normative with professional socialisation. It may be more likely in environments where there are time pressures associated with heavy workload, understaffing, and the need to address multiple competing priorities, especially urgent physical healthcare needs where patients are acutely unwell. Staff used a variety of rationalisations to explain why intervention might be futile.

The data suggest that socialised care futility acts as self-protection. Staff seek to protect their own perceptions of their professional identity as competent practitioners as well as their personal morality as carers. Health professionals draw their professional identity from their public image (Hoeve et al. 2014). A system of thought rationalising that some patients cannot be helped,

may allow staff to repair negative perceptions of their professional identity, and to resist internally labelling themselves as insufficiently competent or caring. Hospital staff will often work in particular specialities due to professed personality characteristics (Mann and Cowburn, 2005), validated by seeing the difference they can make in patients' lives. Such 'sentimental work' is necessary to good care (Strauss et al. 1982). Successful encounters between patients and staff depend on both parties collaborating to play their role, including interpretable responses from the patient. Staff in this study expressed distress about the struggle of caring for patients who call out repetitively. In patient groups who neither respond to treatment nor behave according to 'normal' social rules, there is a risk that staff find attempts to care unrewarding. Patients who call out repetitively may be an extreme case of 'rubbish patients' who risk being framed as 'attention seeking' (Jeffery, 1979).

Hospital staff are continuously scrutinised to ensure they are doing their jobs properly (Harding, 2014). Neglect of an older patient who calls out, may get seen as an example of discrimination (Galloway, 2011). Regulators perceive calling out with no response from staff as an example of poor care (CQC, 2012). Similarly, visitors to hospital wards may also see a patient calling out as an example of failure of staff care. Such perceptions damage public perceptions of health care (Gregory, 2015; Pecci, 2015; Triggle, 2014). Such judgements do not acknowledge the challenges associated with caring for a patient group where calling out may be intentional or unintentional, may relate to meetable or unmetable needs or wants and yet may simultaneously mask 'real' need, all within an acute setting with a range of competing priorities. A more nuanced understanding of calling out repetitively is urgently required, so that staff are better supported and patient care within this population can be improved.

## Reflexivity

When JB began this study her belief was that if patients who call out repetitively were closely observed, this behaviour could be understood and alleviated. Like her participants, she too held the assumption that this behaviour was the result of an unmet need. It was when she closely probed staff interviewees and observed practice on the ward, that she recognised that this

behaviour was more complex. As her data collection evolved, her sympathy for nursing staff grew as the intractability of the behaviour became more evident. It was critically interrogating her own psychology training and the literature that she reviewed that enabled her to challenge the suitability of the unmet needs model for care of this complex population.

## Conclusion

Calling out repetitively has been described as one of the most challenging behaviours for carers and staff (McMinn and Draper, 2005). Socialised care futility makes sense of a behaviour within a system in which it is easier to attribute explanations and blame to individuals rather than address systemic problems associated with understanding and meeting the 'real' needs or even wants of a complex patient population. Such needs and wants may even be incompatible with traditional hospital care.

However, we also argue that the unmet needs model alone is inadequate as an explanation for calling out repetitively among older people living with dementia. Ascertaining needs and meeting them may be impossible, may require a skill set not common amongst acute ward nurses (as opposed, for example, to mental health or care home nurses) (Camp et al. 2002) or might require a depth of knowledge of the person, which takes time to develop, which is not possible during a brief admission. Acute healthcare professionals and hospital organisations typically prioritise physical and safety needs over the emotional and psychological (Tadd et al. 2011). As a result staff often struggle to apply person-centred dementia care in these settings (Clissett et al 2015). Multiple forms and causes of distress that may occur within an individual at any one point in time, which can be difficult to recognise or explain and may or may not be associated with calling out. The individual may be afraid, angry, bored, disorientated, feeling abandoned, and attempting to communicate a specific physical need all at the same time (Algase et al. 1996). Our inability to identify need, and to distinguish between various causes of distress, does not mean that needs that can be alleviated may not be present, or that calling out is always intractable, but equally it is possible that some calling

out does not reflect a 'need' (strictly defined as the ability to benefit from an intervention). The inability to distinguish between these possibilities, draws our attention to the possibility that these patients have a poor quality of experience (Hurt et al. 2008) with associated poor outcomes (Dewing and Dijk, 2014), and that staff may suffer with the emotional labour associated with cognitive dissonance.

Socialised care futility is a risk for this patient group. We argue that to prevent this from occurring, **staff need** to remain open-minded and aware of the tendency to hold contradictory beliefs. We encourage, instead, reflection upon and an interest in challenging the assumptions that are made about a patient who is calling out repetitively (Cordon, 2013). Staff may be correct that calling out repetitively cannot be resolved for a given individual, but should be cautious in assuming this or that no new need will arise. Instead, care should be based upon thorough and regular assessment, and therapeutic trials, as might be expected in mental health nursing practice (Keady et al. 2003).

Several potential limitations in this study are acknowledged. First, the field researcher has a psychology rather than a nursing background, and therefore has limited expertise in the delivery of clinical care. This represents both a strength and weakness; the researcher was able to observe staff and patients without the lens of professional socialisation contributing to or affecting the interpretation of events. However, staff may have been unwilling to be open to an 'outsider' compared with a healthcare professional researcher. Equally, staff may have changed the way they behaved, or the things that they said, in the presence of an 'outsider' (Draper, 2015). In practice, the field researcher reported feeling well accepted, and she found staff were remarkably candid. Second, while a relatively small number of staff were interviewed, the data was rich and illuminating, and findings from these interviews were triangulated by extensive unstructured and semi-structured observational data, informal conversations, and systematic inspection of nursing and medical documentation. Third, participants were recruited via staff recommendation, which

could have skewed selection towards the more severe and persistent cases and so our data may not be representative of the population of patients who call out as a whole. While our actual understandings of causation remain uncertain, our data points to widespread tacit assumptions among a range of staff across several settings about causation. We contend therefore, that our findings about such tacit assumptions in this patient population, are likely to be transferable to a range of medical settings both nationally and internationally. Our research points to the need for rethinking this territory for both patient and staff benefit.

We argue for a more nuanced understanding of the care of this patient group, by making the case that calling out repetitively be simultaneously detached yet linked to questions of causation and the possibility of unmet need. We emphasise that patients with cognitive impairment who call out repetitively within the hospital setting are complex. There is still little known about why patients call out, or how to manage it effectively, but our study suggests that calling out repetitively may be an attempt to communicate a need or a want that may or may not be met, or it may not be an attempt to communicate need. Equally we show that intractable calling out may be accompanied by a new need arising. To meet international policy objectives, so that optimal physical health and psycho-social care is delivered, and to best support staff so they are not left at best frustrated and at worst blamed for poor care, we argue that these patients require regular and repeated assessment, that must be recorded and an environment that anticipates social and psychological needs.

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