Title

When people living with dementia say 'no': negotiating refusal in the acute hospital setting.

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Abstract

A quarter of UK acute hospital beds are occupied by people living with dementia (PLWD). Concerns have been raised by both policy makers and carers about the quality of communication between hospital staff and PLWD. PLWD may experience communication impairments such as word finding difficulties, limited ability to construct coherent narratives and difficulties understanding others. Since much healthcare delivery occurs through talk, healthcare professionals (HCPs) and PLWD are likely to experience increased communication barriers. Consistent with this, HCPs report stress and reduced job satisfaction associated with difficulty communicating with PLWD. HCPs face these challenges whilst striving to deliver person-centred care, respecting the autonomy and wishes of the patient before them. However, best practice recommendations in the field tend not to be based on actual interactional evidence. This paper investigates recurring interactional difficulties around HCP requests to carry out health and social care tasks and subsequent reluctance or refusal on the part of PLWD. Using conversation analysis, we examined 41 video recordings of HCP/PLWD interactions collected across three acute inpatient wards. We identify both the nature of the refusals, and any mitigation offered, and explore the requests preceding them in terms of entitlement and contingency. We also explore the nature of HCP requests which precede PLWD agreement with a course of action. We conclude that several features of requests can be seen to precede acceptance, principally the use of higher entitlement requests, and the lowering of contingencies. Our findings underline the importance of examining the contextual interactional detail involved in the negotiation of healthcare, which here leads to an understanding of how design of HCP requests can impact on an important healthcare activity being carried out. They also emphasise the power of conversation analytic methods to identify areas of frequent interactional trouble in dementia care which have not previously been articulated.

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Keywords: UK; dementia; conversation analysis; patient-centred care; requests; refusals; healthcare of older people

Highlights

- Acute hospital staff need to make requests of their patients living with dementia (83)
- Hospital patients living with dementia may refuse important requests in direct ways (85)
- This creates a dilemma for staff wishing to deliver respectful and effective care (83)
- Some forms of requesting made direct refusal more interactionally relevant (77)
- High entitlement requests with lowered contingencies supported request acceptance (83)

Introduction

Dementia is a progressive neurological syndrome affecting memory and other thinking functions, such as reasoning, insight and language comprehension and expression. Dementia affects 5% of people over the age of 65, 20% of those over 80, and 25% of hospital inpatients in the UK (Prince et al., 2014; Royal College of Psychiatrists, 2013). Although a progressive, terminal condition, people may live with dementia for many years after diagnosis (Xie, et al., 2008). Recent UK policy frameworks have therefore emphasised the need for 'Living well with dementia' (Department of Health, 2009), moving away from a wholly negative conceptualisation of the condition. A narrow medical-model focus has been broadened to embrace more psychosocial perspectives on the social and relational aspects of living with dementia. Person-centred dementia care is now regarded as providing the underpinning principles on which good practice in dementia care in England should be based, wherever that care is delivered (NICE, 2018).

Despite the well documented difficulty of providing such person-centred dementia care in the busy, noisy and unfamiliar acute hospital environment (Goldberg et al., 2012; Houghton et al., 2016; Dewing and Dijk, 2016), PLWD will continue to require hospital admission because of urgent medical healthcare needs that cannot be dealt with adequately in community settings. Whilst in hospital PLWD may additionally exhibit behaviours which challenge staff, including agitation, aggression, disinhibition, exit seeking behaviours and repetitive activities (Goldberg et al., 2012). The inpatient management of both physical and mental health will involve a range of HCPs in healthcare activities such as clinical assessments, treatment, rehabilitation, planning and decision making, support with everyday care and emotional and psychological needs. All these activities are likely to require considerable communication between HCPs and PLWD.

However, PLWD are likely to experience difficulties with communication due to their condition, for example difficulties with word finding, understanding others, constructing and maintaining a coherent narrative and managing conversational topic (Hopper, 2007). HCPs in the hospital setting are therefore faced with the challenge of carrying out their usual healthcare activities in the context of a significantly altered communication environment. Although UK-based acute hospital staff recognise that communication with PLWD is particularly challenging, they report rarely receiving dementia-specific communication skills training (Griffiths et al., 2014).

A plethora of 'top tips' and general advice for communicating with someone with dementia is widely available (see for example, Alzheimer's Society, 2018; NHS Choices, 2017; Care UK, 2014) but these tend not to be based on robust empirical research and in some cases may conflict with the available evidence (Small et al., 2003; Tomoeda, et al., 1990; Wilson et al., 2012/2013). The recommended techniques are generalised, without specification of the particular social and interactional context. Recent systematic reviews of communication skills training in the dementia care context have not found any high quality study showing effectiveness for their intervention in the acute setting (Harwood et al., 2018; Morris et al, 2018; Eggenberger et al, 2013). None of the included hospital-based intervention studies used communication advice derived from empirical study of inpatient healthcare interactions with PLWD. There is a growing body of interactional work which examines talk between PLWD and conversation partners in other settings (see the reviews by Dooley et al (2015) and Kindell et al (2017)); however these reviews exclude hospital-based interaction.

Background

This paper focuses on the empirical exploration of one particularly challenging aspect of communicating with PLWD in acute hospital care which arose out of the dataset: reluctance and refusal from PLWD in response to HCP requests to carry out important health and social care tasks. Such tasks in our dataset included assisting with eating, drinking and personal care tasks, giving medication, supporting rehabilitation or monitoring-related tasks. Refusal of care (also referred to as 'resistance to care' in the literature) is an acknowledged phenomenon in dementia care. It has been described across care contexts, including in residential settings (Konno et al 2014) and acute hospital contexts, where is was found to be ubiquitous (Featherstone et al 2019). Acting against a patient's will, for example in pursuit of patient safety, has been reported as a source of stress by nurses, provoking feelings of guilt and uncertainty for them about what actions are for the best (Edberg et al 2008). When PLWD refuse a HCP's request, the HCP is presented with the dilemma of how to complete such tasks in the best interest of the patient (e.g. to prevent dehydration or pressure sores, to reduce pain or to optimise mobility), whilst respecting the autonomy and wishes of the patient before them. Not completing important health and social care tasks has the potential to impact on the PLWD's health and well-being significantly, by delaying recovery and readiness for discharge home, increasing painful symptoms or even (in the case of refusal of food and drink) precipitating their death. In the specific context of dementia care in the UK, the action may have been agreed as being legally in the patient's best interest under the Mental Capacity Act (2005) but the frontline clinician is still left with the dilemma of how to deliver such care tasks respectfully if the PLWD refuses. A detailed examination of how HCPs make requests and deal with patient reluctance therefore has real importance for healthcare delivery and for the understanding of person-centred dementia care in practice.

There is an existing conversation analytic (CA) literature on the practice of requesting, in which we situate this analysis. Definitions of requests vary, but typically they are utterances designed by a speaker to ask something of the recipient, such as 'Can you pass me the salt?'. Requesting that another person does something (or allows something to be done to them) is a delicate interactional matter, because the person making the request impinges on the autonomy of the recipient by asking that they carry out an action of the requester's volition rather than of their own (Curl and Drew, 2008; Kent, 2012). The level of imposition is influenced by the social and institutional roles of the requestor and recipient, such as adult-child, teacher-student, or resident-carer (Antaki and Kent, 2012). Requesting may therefore be done in ways which reveal sensitivity to this imposition and attempt to mitigate it. CA research suggests that requesting is a dispreferred action (Pillet-Shore, 2017). Interactants orient to this by using strategies such as prompting an offer, delaying a request, or mitigating in other ways (e.g. Levinson 1983).

Refusals in response to requests have also been identified as dispreferred actions (e.g. Pomerantz, 1984; Schegloff, 2007; Pomerantz and Heritage, 2013; Pillet-Shore, 2017). When rejection of a request does occur, speakers will typically hesitate before responding and then carry out interactional work to mitigate the refusal, such as giving explanations or 'accounts' that clarify the reasons for their failure to comply and offering apologies or compliments which soften the refusal (Pillet-Shore, 2017; Kitzinger and Frith, 1999). To give an immediate or unmitigated refusal of a request is rare and likely to be treated as accountable by the requestor. It may be perceived as rude or hostile (Heritage, 1984), although this depends on the interactional context (Kitzinger and Frith, 1999) and the full interactional competency of both requestor and recipient. Unmitigated refusals may be more commonly seen, for example, in the talk of children when requested to perform actions by parents (Kent, 2012). Active refusal of a request (as opposed to passive resistance to a recommendation) is particularly uncommon in healthcare, where the entitlement of a health care professional to ask a patient to do something is reinforced by their institutional role (Stivers, 2006).

CA study of requests, across a range of datasets including social care interactions, has established that requests can be analysed in terms of the concepts 'entitlement' as initially espoused by Lindström (2005), and 'contingency' (Heinemann, 2006; Curl and Drew, 2008). A speaker displays, by the format of their request, how entitled they claim to be to ask the recipient to do something (their entitlement). In addition, the speaker acknowledges how difficult (or easy) they perceive the task will be for the recipient to carry out and what the relevant barriers are for the recipient (the contingencies).

In this study we designate the term 'request' to identify talk where the healthcare professional attempts to get a patient to carry out an action themselves (such as 'lift your leg'), and also for utterances that ask permission for the healthcare professional to conduct an action involving the patient (such as 'can I lift your leg?'). Compliance with or acceptance of a request can take the form of an immediately embodied response (e.g. patient lifts their leg) or it can be a purely verbal response, or a combination of both.

In summary, the CA literature on requests indicates that refusal to comply with a request is interactionally dispreferred, and that active refusal is uncommon in general healthcare interaction. However, initial observations of our dataset did not bear this out. Using CA, this paper therefore investigates refusals by PLWD in response to requests from HCPs, considering both the nature of the refusals and the requests preceding them. We also consider HCP requests that are followed by a PLWD complying with a course of action, either verbally or non-verbally. We identify the interactional practices used in this setting which result in successful accomplishment of health and social care tasks, and suggest that these have wider relevance for the acute dementia care context.

Methods

Wider Study

This work is part of a wider study funded by the UK National Institute for Health Research, Health Services and Delivery Research (project number 13/114/93; Harwood et al., 2018). The study objective was to design and evaluate a communication training intervention for HCPs caring for PLWD in acute hospitals (O'Brien et al., 2018). Ethical approval was granted by the Yorkshire and Humber - Bradford Leeds Research Ethics Committee (15/YH/0184). Previous study findings related to the closing of encounters with PLWD, drawing on the same dataset, have been published in this journal (Allwood et al., 2017).

Data Collection

A spread of healthcare professionals (HCPs) from medical, nursing and allied health professional (AHP) groups were successfully recruited (n=41) from across six of eight Healthcare of the Older Person wards at one large acute teaching hospital in the UK. Of these 41 HCPs, 26 were actually filmed for the study, because of the need for them to be recorded working with a consented patient. Some HCPs were recorded more than once, but none more than three times.

	Number of HCPs recruited	**Number of HCPs recruited and then filmed**	**Number of films collected, by professional group**
Nurses	19	11	19
AHPs	11	6	10
Doctors	11	9	12
Total	41	26	41

Table of Healthcare Professional Participants: Recruitment and Data Characteristics

Twenty-seven patients were recruited to the study, 17 women and 10 men, of whom 26 were filmed, some more than once. Patient participants had a diagnosis of dementia documented in their medical notes and were considered by staff on the ward to display some level of communication difficulty in their interactions. Patients were excluded if they had an additional diagnosis of Parkinson's disease, they did not use English in their interactions or medical staff deemed them to be in their final week of life. The recruitment process included an initial assessment of the patient's mental capacity to consent to being included in the study. This was conducted by the first author and a research assistant who were both experienced clinicians (speech and language therapists). If the patient lacked capacity in this regard, an unpaid carer such as a family member was asked to act as a personal consultee under section 32 of the Mental Capacity Act (2005). All patients recruited to the study lacked capacity to give informed consent for the study.

Over a three-month period (September-November 2015) a total of 41 routine healthcare encounters were video and audio recorded, with an average length of 9.24 minutes (ranging from 2 minutes to 31 minutes). No limit was set on the length of each recording, since the aim was to record the interaction as it would naturally have occurred. Any encounter between a consented HCP and PLWD could be filmed, provided the interaction would have been occurring anyway and did not include any intimate care. Encounters were filmed based on the convenience and agreement of all participants. All interactions were initiated by the HCP because of the planning involved in setting up the equipment and ensuring the PLWD was comfortable with the camera presence. No participants were filmed more than three times, to avoid overburdening any individuals.

For each recording, patients' interactions were classified by the researcher-clinicians as mildly, moderately or severely communication impaired, and an effort was made to gather some spread of data across these broad categories (27% mild; 54% moderate; 19% severe).

Conversation Analytic Method

Conversation analysis (CA) is a research method whose aim is to study the structure and order of naturally occurring talk in interactions. The method has been widely used to study healthcare interactions since the early 1980s (e.g. Heath, 1981; Heritage and Maynard, 2006; Pilnick et al., 2010). CA relies on the close and repeated examination of recordings along with detailed transcripts of those recordings. To this end, recordings were transcribed using standard CA procedures (Jefferson, 2004). Paralinguistic features such as intonation, volume and rate of speech were noted throughout the transcriptions. Non-verbal features were added where relevant to the unfolding action. The recordings and transcriptions were used together to support the analysis. The method of analysis followed the conventions of CA as laid out by Sidnell (2013), involving the three steps of: observation of the data by the analytic team; identification and collecting of the phenomenon of interest from across the whole dataset; and then the description of the practice, using both detailed analysis of a single encounter and comparison across multiple examples.

Initial observation of our data showed HCPs conducting a range of health and social care tasks with a PLWD including: medical examinations, such as listening to the chest; nursing ‘observations’, such as taking blood pressure; assessment and rehabilitation tasks, including standing, transferring, walking and making a cup of tea; and support with the taking of medications, food and drink. Further observations of the recordings revealed that these tasks were achieved through the HCP making multiple requests of patients, with over 600 requests occurring across 39 of the 41 encounters. Only two encounters contained no requests, being entirely focused around discussion and involving no examinations. Patients responded with some level of refusal, often repeatedly, in 28 of the 41 recordings. Collections of refusals were made and organised around emerging themes. We then analysed the nature of HCP requests which preceded refusals, before comparing these with other requests. These data were analysed in monthly group data sessions attended by all authors, to guide further analysis and in order to increase robustness and reliability (Sidnell 2010). Data sessions are a recognised part of the conversation analytic method, involving collaborative and repeated viewing of a recording with the transcript, which support the development of a ‘sharable and shared understanding’ (ten Have, 1999, p123) and help to avoid individualised interpretations.

Findings

Analysis will cover: refusal, requests preceding refusals and requests preceding acceptance.

Refusal

Refusals were categorised as overt refusals, mitigated refusals and ambiguous responses. Non-responses from patients were classed as ambiguous responses, where neither the HCP nor the analyst could discern whether the patient was deliberately rejecting the request or was unable to respond to the request either verbally or non-verbally or had not understood the request. For this reason the analysis of these is not presented here.

i) Overt refusals

In this data set, 13 episodes across nine encounters were found in which PLWD refused verbally, without the usual mitigation, usually by just saying ‘no’. These were termed ‘overt refusals’. Extract 1 is an example of an overt verbal refusal occurring in line 9.

Extract 1: 133_206 (Nurse)

```
5      HCP:                                          I ↑was ↑just
6            ↑wondering if I could help you with (0.4) relieving some
7            ↑↑pressure on ye:r ↑botto:m
8            (1.0)
9      PAT:  °°no::°° hhh
```

Overt refusal could also be accomplished entirely non-verbally, where refusal was embodied and no verbal mitigation was offered. These occurred in a further six encounters, often repeatedly. Examples included the patient closing their mouth to an approaching spoon or pulling their hand away from a blood test needle.

ii) Mitigated refusals

Fourteen of the encounters contained mitigated refusals, with multiple instances occurring in 11 of these. Patients offered three clear types of mitigating account for their refusal: lack of ability, lack of willingness, and lack of perceived need.

Lack of ability to carry out a task (or lack of confidence in one’s ability) is perhaps unsurprising amongst PLWD in hospital, given the likely impairments arising from their ill-health, and may account in part for their reluctance to comply. Extract 2 is an example of a refusal involving a mitigating account referencing inability following the physiotherapist's request.

Extract 2: 124_203 (AHP)

```
30     HCP:  ↑can I have a ↑little↑look at >these legs first can you
31           just< march them up and do:wn
32     PAT:  °how ↑could I?° (.) because I hurt me bo↑ttom when they
33           made me sit in that ↑chai:r this morni:ng,
```

On other occasions patients referenced a lack of willingness, explicitly stating that they did not want to carry out the requested action, as in the extract below where the patient is being asked by a speech and language therapist to try a teaspoon of yoghurt to assess his swallowing:

Extract 3: 122_220 (AHP)

```
227    HCP:  ↑try a little bi:t
228    PAT:  I don't really want to do ↑tha::t
```

In the third type of mitigated refusal patients accounted for their reluctance by explicitly expressing a lack of perceived need, displaying that their perception of their healthcare needs did not match that of the HCP, as in this case, where the patient's arm was in plaster:

Extract 4: 117_227 (Nurse)

```
34     HCP:  mary (0.4) can I  have a look at your ↑a::rm (0.8)
35           at [thi:s]
36     PAT:     [↑(1 syllable)] WHY what's up with i:t (0.4) my arm
37     HCP:  you ↑broke i:t
```

38 PAT: I ↑’aven’t broke ↑i:t,

Requests preceding refusals

The examples above demonstrate the presence of both overt and mitigated refusals in our dataset. To shed light on the recurrence of refusals in this context, we next analysed the types of HCP requests preceding both overt and mitigated refusals. This analysis draws on the concepts of entitlement and contingency, both of which can be conceptualised on a continuum from high to low. In most cases of refusal, we found healthcare professionals had displayed low- to moderate-entitlement in their requesting. This lowered entitlement displays an orientation to a possible lack of willingness or ability to comply on the part of the patient, as we will consider in more detail below.

(i) Low entitlement, high contingency requesting

In sequences containing overt refusal, HCPs sometimes displayed extremely low entitlement to make requests of PLWD. In Extract 5, lines 5-7 (an extended version of Extract 1 above) a nurse uses the ‘I was wondering’ format described by Curl and Drew (2008) in calls to out-of-hours general practitioner services. She asks permission to help the patient with the task of ‘relieving some pressure on your bottom’, meaning the patient needs to stand up. This initial request for permission results in a considerably delayed but unmitigated ‘no’ from the PLWD in line 9:

Extract 5: 133_206 (Nurse)

1 HCP: ↑hello ↑Mau↑↑ree::n,

2 PAT °hello°

3 HCP: ↑how are ↑you:?

4 PAT: not too: bad,

5 HCP: not too bad, (0.6) good good (0.4) **I ↑was ↑just**

6 **↑wondering if I could help you with (0.4) relieving some**

7 **↑↑pressure on ye:r ↑botto:m**
8 (1.0)
9 PAT: °°no::°° hhh
10 HCP: no::?

By referring to her own ‘just wondering’, the HCP displays potential doubt about whether the patient will grant the request. The HCP’s ‘wondering’ suggests she anticipates contingencies limiting the patient’s ability or willingness to grant the request. Framing her proposal as an offer to help with a task (line 6) also displays a consideration that the patient might not be able to complete the task alone. It can be argued that through the use of low entitlement and high contingency in her requesting, the HCP makes relevant to the patient the option and possibility of refusal.

In framing her request in this way, the nurse demonstrates a positive orientation to patient choice, empowerment and autonomy, consistent with current ‘best practice’ thinking about person-centred dementia care (Kitwood, 1997). However, whilst low entitlement requests may appear respectful of patient autonomy, they also present a clear interactional opportunity for refusal. This can be problematic where the action proposed is necessary for best-practice care delivery.

Other overt refusals in our data set were preceded by low-entitlement ways of requesting that were structured with the permission-seeking prefaces ‘Is it alright if I…?’, ‘Is it okay if I…?’ or ‘Do you mind if I..?’, as in Extract 6 below, in which a doctor wishes to examine a patient’s chest during a routine ward round:

Extract 6: 143_227 (Doctor)

50 HCP: °↑all [ri::ght] Mary° (.) **is it o↑kay if I have a=**
51 PAT: [huh huh]
52 HCP: **=↑↑listen to your che:st**
53 PAT: ↑NO:::: I didn’t know th’t

54 HCP: no::,

Here the permission-seeking question ‘Is it okay if I have a listen to your chest?’, uses the conditional ‘if’ and again allows for the possibility that it will not be ‘okay’ with the patient, who may be unwilling to grant the requested permission. This framing of the request suggests there are possible contingencies which might render the activity not ‘okay’, and the patient does indeed refuse.

(ii) Moderate levels of entitlement and contingency

Other instances of overt refusal from patients followed requests which used questioning, modal verb formats, such as ‘Would you…?’ and ‘Can you…?’. Previous CA research identifies these as having higher entitlement compared to ‘wondering’ requests (Curl and Drew, 2012). However, the use of modal verbs will/would and can/could still invoke a patient’s willingness or ability (respectively) to engage with the request, and therefore display moderate rather than high entitlement.

Prior to the exchange in Extract 7 below the nurse has spent many minutes walking with a patient who chose not to sit, trying to verbally encourage and physically support the patient to eat his lunch. An example of a ‘would you’ request format then follows:

Extract 7: 103_225 (Nurse)

398 HCP: **↑↑would ↑↑you ↑↑li:ke a↑↑nother spoon[fu]l Da↑vi::d?**
399 PAT: [n-]
400 PAT: no no no (0.4) no don’t make me any mo::re
401 HCP: ↑↑that’s ↑↑fine

The interrogative format of this request opens up the interactional space for either a ‘yes’ or ‘no’ type-conforming response, and in this case the patient chooses to emphatically decline a further spoonful. As well as the question format clearly highlighting the optionality of granting the request, the HCP has also offered ‘not liking’ as a possible contingency on which basis the patient might decline, and this declination is accepted in line 401. Other overt refusals in our dataset were prefaced by ‘can you’ requests, with the modal verb here referencing the patient’s *ability* to grant the request. Extract 8 below is taken from an encounter where the doctor is holding a stethoscope and attempting to listen to the patient’s chest:

Extract 8: 140_211 (Doctor)

202   HCP: **>can you< [take a] ↑deep breath in and ou:t my dear**

203   PAT: [u::::h]

204   PAT: no::

205   HCP: just try

206   PAT: no:: I don’ think c’n

As Curl and Drew (2008) assert, although the ‘can you’ formulation technically references ability, it is used normatively to ask someone to do something, not to enquire about ability. The HCP’s request at line 202 is thus ordinarily understood as a request for the patient to start taking deep breaths. In this case the patient’s initial unadorned ‘no’ does not clearly differentiate whether she is unwilling or unable. The HCP treats the response as if it had been declined on the basis of ability by suggesting the patient ‘just try’ (line 205). The patient’s turn at line 206 clarifies that her refusal was based on her likely inability, possibly due to the back pain she has reported. By using the format ‘Can you do X?’ the HCP has introduced the possibility of refusal that may reference either ability or willingness.

In summary, the analysis in the sections above has demonstrated that patient refusals were often preceded by HCPs using formats for requesting that allowed for and made relevant the option of refusal. Requests preceding overt refusals were found to be frequently (although not exclusively) formatted in ways which displayed a low or moderate entitlement to make the request. Requests preceding mitigated refusals were frequently delivered in ways which referenced the patient’s ability or willingness to comply and were therefore referencing moderate levels of entitlement and contingency. Issues of willingness or ability were often reflected in patients’ mitigation for refusal.

Requests preceding acceptance

Given these findings, a working hypothesis was formed that higher entitlement requests may be more likely to lead to acceptance, all other things being equal, because they project acceptance responses and do not explicitly provide interactional space for a refusal response. We next searched the dataset for requests formatted to display higher entitlement. We found four types of request formats that displayed higher entitlement to ask, all of which preceded instances of acceptance in our data.

(i) Announcements of future action

Some HCPs announced future action and intent through the use of the formats ‘I will’ or ‘I’m/we’re going to’, such as ‘we’re gonna sit you up a bit’ or ‘I’ll just pop some tape on’. Announcements were often followed by a checking, permission-seeking question such as ‘is that okay?’ or ‘alright?’ as in the swallowing assessment by a speech and language therapist shown in Extract 9:

Extract 9: 111_212 (AHP)

HCP: o:kay (0.4) **↑I’m ↑↑just ↑↑gonna ↑↑give ↑↑your ↑↑mouth a**
little ↑wipe (0.6) you have some white just around your
lips **is tha o↑ka::y,** (0.4) .hh and then that’ll be us all
done (2.6) is that o↑ka: [::y,]
PAT: [↑yea]::h,
HCP: yeah?
PAT: °yeah°
HCP: all right

The HCP announces the action she intends to carry out 'to' or 'for' the patient, in this case to wipe the patient's mouth (line 266-267). This announcement displays a high entitlement to ask. The HCP is stating that the action is going to happen, and not providing an interactional space for the patient to decline (or indeed to verbally accept) the activity.

Despite the lack of interactional space this formulation offers, acceptance of a course of action pronounced in this way is typically pursued (Stivers, 2005). This can be seen here in line 268-9, where the permission-seeking, or checking, question 'Is that okay?' is repeated at line 269 in her pursuit of a response. Still, this form of question strongly prefers an affirming response, and the request format 'announcement + checking question' is followed by assent in every case in our dataset. However, there are other features present in the example above which serve to soften this highly-entitled request. Firstly, after a 0.6 second pause in which no patient response is forthcoming (line 267), the HCP explains why this action is needed with her account of the 'white' round the patient's lips, demonstrating sensitivity to the dispreferred nature of such requests and providing an account or explanation for the activity (Schegloff, 2007).

Secondly, at line 266 the HCP downgrades the task with the use of the minimisers 'just' and 'little'. These items work to display the task as less intrusive for the patient (or in other examples, where the task is in the patient's domain of action, as less onerous for them). Practices which act in this way, to lower the contingencies of a request, are very common in our dataset, orienting to the possible challenges in completing the request from a patient perspective. This contrasts with Antaki and Kent's (2012) explication of 'bald imperatives', where the requestor takes no account of these.

It is important to note that in the above extract, the context was an encounter in which the goals of the patient and HCP appeared mostly aligned. However, our dataset also contains examples of this mode of requesting in situations where a patient had previously indicated reluctance to comply with a proposed activity. Extract 10 is taken from an encounter with a patient who earlier that morning had declined to be shaved, following a proposal from a different nurse (not recorded for our study).

The subsequent encounter captured a different nurse with the same patient. The following interaction occurs as they walk together down the ward:

Extract 10: 114_225 (Nurse)

```
20    HCP:  u:::m, (0.6) okay we’re just gonna ↑use this ↑bathroom
21          he:re we’ll have a, (0.6) a ↑quick sha:ve (0.6) and get
22          you ready for the day is ↑that al↑right?
23    PAT:  yeah
24    HCP:  ↑yeah?
25    PAT:  [yeah]
26    HCP:  [good] ma:n. (0.6) ri:ght
```

Here the HCP uses the announcement formulation (lines 20-21) ‘we’re just gonna’ to present the activity as about to happen, with the minimisers ‘just’ (line 20) and ‘quick’ (line 21). An account is given for the relevance of the activity (‘get you ready for the day’), before adding the permission seeking question ‘is that alright?’. Again, the HCP displays an awareness that the task might seem onerous to the patient, but is attempting to minimise this. Despite the context of previous refusal, the patient appears to accept the activity at this point, without reluctance being displayed.

(ii) Proposals

Healthcare professionals also formatted requests as proposals for joint activity using formats such ‘Let’s’ and ‘How about’ which invite the collaboration of the patient (cf Stivers et al., 2018) as in Extract 11:

Extract 11: 142_220 (AHP)

```
95    HCP:  let’s have another go ↑shall ↑↑we::? (0.6) you were going
96          >to have a ↑little< ↑drink for ↑↑me::,
97    PAT:  ↑yeah
98    HCP:  ↑here ↑we ↑go
```

In the encounter from which this extract is taken, the speech and language therapist has been encouraging a PLWD to have a drink. The utterance ‘Let’s have another go’ is made in the context of the previous (repeated) attempts at the activity, and the use of ‘let’s’ presents the activity as shared. As this patient is no longer giving himself food or drink independently, the HCP has been supporting the patient with the activity of drinking, for example, using a ‘hand over hand’ technique to take the cup to the patient’s mouth. In this sense the activity of drinking has indeed become a joint enterprise for the HCP and patient. Using ‘let’s’ here demonstrates high entitlement requesting, so that an agreeing response is strongly preferred. However, West (1990) argues that the projection of an activity as a shared one gives the ‘let’s’ format an ‘invitational flavour’, which she suggests proposes a less asymmetrical relationship between interactants. As such, it is an example of a more highly-entitled way of requesting that maintains a sense of respect for the patient.

(iii) Statements of need

On occasion, HCPs formulated a request through presenting an announcement of their own needs or the needs of the patient. In Extract 12, the nurse produces repeated statements of need (at lines 61 and 66) followed by a permission-seeking question, ‘Is that alright?’ in line 68. This question suggests that in this instance, the statement of the nurse’s need was issued as a request for permission to act on the patient:

Extract 12: 1_133_215 (Nurse)

```
61     HCP:  I ↑need yea:h I ↑need to put something over tha:t (0.4)
62           to    [stop it]
63     PAT:        [there's] (↑it) it's plaster the:re  (0.4)
64           [that's ] where it is
65     HCP:  [I ↑nee-]
66     HCP:  I ↑need to wrap it up,
67     PAT:  mm an- [(?)]
68     HCP:          [and] give it a ↑↑clea::n is that ↑alri:ght?
```

This type of formulation, which justifies the request of an action in the patient's interest through the personal need of the HCP, indicates extremely high entitlement. West (1990) characterises this formulation as an 'aggravated directive'. In her dataset this was seen in (mostly male) GPs instructing patients as to what they 'ought to' or 'needed to' do and her analysis showed this was more likely to trigger an 'aggravated response'. However, our example has important differences: in Extract 12, the HCP has packaged the entire activity as one that she needs to carry out *but also* requires the patient's permission to do, and she does not pursue this until permission has been given. The high entitlement is softened here by the HCP's deference to the patient's authority to allow or not allow the activity to proceed, as demonstrated through the question in line 68.

(iv) Direct instructions

HCPs also used direct instructions or 'bald imperatives' (Antaki and Kent, 2012) as requests. These were constructed with no subject, such as 'keep turning' or 'deep breath in'. In our dataset these were found as a later part of a sequence of instructions, once an activity was already in progress, as the extract below from an encounter with a physiotherapist illustrates:

Extract 13: 124_211 (AHP)

153 HCP: ↑we:ll done

154 PAT: u::↑::::h hu::::h (0.6) °↑a:::h ha ha°

155 HCP: **nice and steady rou:nd,**

156 PAT: °↑a:::::h ha::::h° (0.4) °°uh huh huh°° (.) °°uh huh huh°°

157 (0.4) °a:::h ha ha°

158 HCP: .hhh ↑**keep hold of the fra:me els↑ie:,** (0.4) **turn round**

159 **with the frame** (0.6) that's ↑it,

160 PAT: °u::h° (.) °huh huh° (0.4) °u:::h huh huh°

161 HCP: **use the fra:me turn all the way round**

162 PAT: °a::h ha ha° (0.6) °uh huh huh °

163 HCP: that's it

164 PAT: °uh huh°

165 HCP: **slowly do::wn,**

166 PAT: ↑o:::::h hhh

167 HCP: o::kay

168 PAT: oh go:::d.

169 HCP: ↑well done,

In this encounter, the physiotherapist has assisted the patient to walk down the ward and return to her bedside, where the patient now needs to turn around using her frame before lowering herself into her chair, with support and guidance as necessary. The instructions or 'commands' illustrated here display very high entitlement to ask, where the patient is offered no option to decline. In existing CA research, these formulations are typically considered to lack sensitivity to the recipient's contingencies, and to emphasise the speaker's entitlement to make the request (Antaki and Kent, 2012).

However, as the example above illustrates, the local context of these formats in this setting serve to soften the high entitlement. These instructions are generally issued during an ongoing, 'agreed to' activity (in this case, walking up and down the ward) where agreement has already been gained for the overarching activity. Once this agreement has been obtained, these kinds of instruction sequences may be produced without further need to negotiate each instruction with reference to patient choice.

Where imperatives occurred elsewhere in our data, they were generally constructed with reference to contingencies, in particular using the words 'try' and 'just' and followed by some orientation (by either speaker) to potential difficulty carrying out the task. In Extract 14 below, a speech and language therapist is attempting to encourage the patient to drink more. Following one successful sip, the HCP continues:

Extract 14: 142_220 (AHP)

```
127   HCP:  how was that

128   PAT:  ↑not ba:d

129   HCP:  not ba:d try a bit more
```

This was followed by:

```
136   HCP:  >little bit< spilling ou::t (1.4) try ↑one ↑mo:re

137   PAT:  yeah
```

A request from a HCP asking for a patient to ‘try’ orients to a patient’s potential lack of ability or difficulty in carrying out a task, and presents effort rather than success as the object of agreement. In addition, the use of ‘just’ was frequently observed in direct requests in this setting, as in lines 138 and 144 in the example below, which formed part of a speech and language therapist’s assessment of the patient’s swallowing:

Extract 15: 111_212 (AHP)

136 HCP: good, oka:y let’s try another one (0.4) okay it’s my
137 hands here (17.6) ↑no::w, (1.4) that was goo:d, (0.6)
138 feels good and stro::ng. (0.6) **↑just ↑say ↑↑a::::h,**
139 PAT: A::::H
140 HCP: e:xcelle:nt (0.6) feels nice and stro:ng (0.4) >will we<
141 try ↑one ↑mo::re
142 PAT: if you want to:
143 HCP: ↑yeah? (0.4) well >as ↓long as< ↑you ↑want to::, (0.6)
144 **just one mo:re** (1.6) ready?

The use of ‘just’ in direct requests was common in our data set, including other examples such as ‘just stand up tall’, ‘just come this way’ and combined with ‘try’ in ‘just try and go for it’. The use of ‘just’ in this way minimises or downgrades the requested task, suggesting it may not be as difficult or onerous as the patient might conceive. As we have demonstrated, this use of ‘just’ also softens the use of highly entitled direct requests, thereby displaying the HCP’s continuing sensitivity to the potential contingencies for the patient.

Discussion

We have presented examples of refusal by PLWD in response to requests from HCPs, in the context of an acute hospital setting, and considered both the nature of the refusals and the requests preceding them. We have contrasted these with HCP requests that resulted in a PLWD complying with a course of action. Strikingly, despite the dispreferred nature of explicit refusal to a request, particularly in healthcare settings, such refusal was a relatively commonplace response by PLWD in this dataset. The CA literature on requesting assumes the involvement of two competent interactional partners, which may in part explain the ordinarily dispreferred nature of refusals. However, communication impairments associated with dementia may make explicit refusal more likely in the same way that refusals appear more common in the talk of other partnerships where one speaker's interactional competence could be considered less than the other's (Kent, 2012).

We have shown that HCP requests in this context can be usefully analysed in terms of the framework of entitlement and contingency developed by Lindström (2005), Heinemann (2006) and Curl and Drew (2008). Through this analysis of the recurring practices of requests and refusals, we see a common theme of interactional trouble in the context of low entitlement requesting. Our data from the wider study demonstrate that a PLWD may be uncertain about why they are in hospital (or indeed that they are in hospital), and unclear who the HCP interacting with them is. Given this context, a low-entitlement request may fail to convey the urgency or importance of an intervention; additionally it may fail to identify the requester as an expert professional making a judgement about the need for such an intervention. This means that the consequences of refusal may not fully be appreciated by PLWD. Our analysis suggests, despite the apparent 'person-centred' nature of requesting in a low-entitled way, the unintentional consequence may be that a patient infers that the action is not necessary or important and/or that the HCP does not have an appropriate level of expert and confident authority in suggesting the action. This may make a refusal more likely, since it may seem less consequential.

Our data also suggest that, when HCPs used formats which displayed a higher entitlement to make requests, this appeared to support cooperation. Higher entitlement approaches included announcements of future action (‘I’m just gonna’), proposals of joint activity (‘let’s’), and statements of need (‘I need to do X’), with these three methods often accompanied by a permission-seeking question (‘is that alright?’). Direct instructions (‘take a step’) were also used, but in specific contexts within longer sequences. By delivering a request in a manner that communicated expert authority, we suggest that HCPs emphasised the importance of the request for the patients’ health and wellbeing. Higher entitlement requesting was also used in combination with an orientation to potential contingencies (or difficulties) for the patient, and HCPs could explicitly lower these by using expressions to minimise the task size, duration or frequency, such as ‘just’, ‘a little’ and ‘quick’, and by asking the patient to ‘try’. In doing so the HCP oriented to the potential challenges facing the PLWD and demonstrated their intent to make the activity as undemanding and straightforward as possible. By using this approach, HCPs owned their authority to make requests but did not communicate an absolute right to demand the actions of patients.

As we have already noted, the prevalence of refusal in our data highlight the difficulties HCPs face in practice, when trying to provide person-centred care to PLWD (Kitwood, 1987; Brooker, 2007) alongside ensuring a patient’s basic needs are met and best interests are recognised. Person-centred care places value on the individual’s personhood and autonomy, including wishes around their healthcare choices. However, and particularly in this context, the patient may have an incomplete understanding of an action or its consequences for their health or welfare, which impacts on their ability to make an informed decision. A HCP’s awareness of the impact that refusal may have, and of the fact that the patient may not fully understand this, means that the HCP needs to balance encouragement of the patient to co-operate with a course of action with respect for that individual’s right to choose to accept or decline. Whilst no form of requesting will guarantee a recipient will comply, our findings suggest that more entitled ways of requesting, softened by reference to lowering of contingencies, mean an unmitigated refusal is less likely. However, the importance of professional and ethical practice by HCPs remains undiminished by identifying what language can be used to encourage compliance in this context.

A contrast is often made in the literature between ‘person-centred’ care and ‘task-centred’ care (Grainger, 1993; Cowdell, 2010; Tadd et al., 2011). However, it is our contention here that achieving important health or social care tasks and person-centred dementia care need not be mutually exclusive. The HCPs in our dataset do considerable interactional work to attempt to achieve eventual agreement with their patients around completing important tasks which have been deemed in their best interest. Failure to complete such tasks might be seen as both neglectful and a failure to acknowledge the person-centred principles of the human value and individual needs of a PLWD (NICE, 2018). When an activity is deemed to be in a PLWD’s best interest, and where absence of that activity might lead to neglect or a deterioration in health and well-being, it is likely that the supporting person, whether professional or family member, will persist in attempting to negotiate, motivate and encourage acceptance of a request. The Patient and Public Engagement Representatives involved with this project confirmed that as former carers of PLWD they too had regularly faced similar challenges of dealing with refusal around important tasks such as eating, drinking or offering pain relief. Our analysis has sought to explicitly identify what variety of interactional approaches might be used when requesting in this context, and to reflect on their relative effectiveness, without suggesting one approach should always be used with PLWD.

No manner of verbal requesting will ultimately override a patient’s free will and ability to exercise their agency. In this dataset, PLWD repeatedly succeed in completely refusing aspects of healthcare despite HCPs’ repeated efforts. For example, even those with the most advanced dementia, whose interactions consist only of embodied responses, continue to display their agency by successfully refusing medication and drinks. There is no single way of requesting which will always lead to an acceptance or agreement, given the patient’s agency. However, in identifying what requesting practices ‘do’ in these interactions, it is hoped that HCPs can be made aware of such practices in order to better inform their encounters with PLWD (O’Brien et al., 2018).

Conclusion

In summary, our data suggest that, in contrast to the more usual pattern in healthcare communication, requests made by HCPs to PLWD receiving acute care are often met with refusal, and that this refusal is sometimes unmitigated. In their requests, HCPs show awareness of different levels of entitlement to make a request, and orientation to contingencies affecting completion of the requested action. The manner in which requests are constructed appears to influence acceptance or refusal in this setting. Several features were found to precede acceptance of requests: asking in a more highly entitled way, lowering contingency by making a task sound smaller or shorter, or asking a PLWD to ‘try’. Practices that explicitly invoke patient agency, and therefore highlight the philosophy of person-centredness in relation to specific requests rather than the holistic context, also create a more ready interactional opportunity to refuse healthcare. In this setting, this may create difficulties for patients with cognitive impairments who may not fully understand the consequences of refusing a health and social care request which is made in their best interest or in accordance with best practice in healthcare. This highlights the challenge for HCPs in acute settings between seeking to treat PLWD as full agents who can collaborate in their healthcare through ordinary interactions, and adapting communicative practices to account for impairment.

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