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“I want to get out... I’ve got a child at home”: intersubjectivity, reality disjunctures and distress in the care of people living with dementia in the acute hospital

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The pivotal role of language in achieving and maintaining intersubjectivity in interaction creates particular problems where one party has a medical condition affecting language use. Dementia can have significant impact on language comprehension, expression and memory; this creates challenges not only for people living with dementia (PLWD) but also those who care for them. In UK hospitals approximately 25% of beds are occupied by PLWD (Alzheimer's Society, 2009) and the need for improved care is widely acknowledged. One specific challenge is the issue of competing realities, where a PLWD may not be oriented to time or place, and may produce what appear to healthcare professionals (HCPs) to be inaccurate, untrue or even bizarre statements. As part of a wider UK-based study identifying ways to avoid, de-escalate or resolve distress for PLWD in the acute hospital setting, and prompted by their co-occurrence with distress, we used conversation analysis to examine interactions involving these 'reality disjunctures' (Pollner, 1975). We analysed 53 HCP/PLWD interactions collected across four acute wards in two large teaching hospitals. We found that responses to reality disjunctures fell into four categories across a continuum: challenging the competing reality expressed by the PLWD; diverting the interaction to an alternative aspect of reality that could be shared; finding a commonality in the PLWD's reality; and co-constructing the PLWD's reality. Our findings show similarities with Lindholm's (2015) analysis of 'confabulation' by a single PLWD in a day-care centre; however the range, distribution and detail of the practices differed in ways that reflected the contingencies of the acute care setting. Approaches in the middle of our continuum, which work to create some kind of shareable world or experience, are one way in which skilled staff support PLWD not only to manage distress, but also to maintain a social self rather than a subjective one. Identifying these approaches makes them available to others to improve patient care.

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Introduction

Intersubjectivity (defined here broadly as an understanding of thoughts, feelings or meanings shared between two people) is a phenomenon which has much exercised philosophers from Husserl onwards (e.g. Husserl, 1960). However, as a phenomenon which is central to human life, it is a practical problem as much as a philosophical one. Our experience of the world is not private but shared: this means the world of daily life is the world for *all* of us, as well as the world for each of us (Schutz, 1996:54). It follows that intersubjectivity is key to the life world, since it is the basis on which all social relationships are founded.

It is unsurprising then, that from the beginning of the 20th Century, sociologists have focused on the way in which a shared understanding of the world is achieved, and the fundamental role that social interaction plays in this. Goffman’s work on the ‘interaction order’ (1955; 1967) explicates how every person lives in a world of social encounters, involving face-to-face or mediated contact with others; from this it follows that “language is the wheelhouse of socially derived knowledge and the medium by which shared comprehension of the world is transmitted” (Trujillo 2018:8). As Raymond and Sidnell (2019) outline, over recent years there has been a growing focus, in the sociological subdiscipline of Conversation Analysis (CA) in particular, on epistemics as they manifest in interaction (over access and rights to knowledge and information) as an elementary form of social organisation. CA research has begun to unpick the specific details of the ways in which participants manage the use of putatively shared background (or, as Garfinkel (1967) describes, “common sense” knowledge) in talk-in-interaction (e.g. Raymond and Sidnell, 2019; Heritage and Raymond, 2005; Heritage and Raymond, 2012). Because the examination of talk-in-interaction allows access to intersubjectivity through “the display by participants that they each understand the other’s talk and

actions in the conversation” (Wilkinson 1999: 328), CA is an ideal approach to investigate how intersubjectivity is practically achieved. As Wilkinson (1999) goes on to point out, a major contribution of CA has been to show that these displays of mutual understanding are achieved largely implicitly in conversation, and are constructed over a series of turns.

The pivotal role of language in achieving intersubjectivity creates particular problems where one party to an interaction has a medical condition which affects their use of language, or as Garcia (2012:351) puts it, “medical problems where talk is the problem”. This descriptor does not reflect a view that the person with the condition *creates* this problem, but instead a recognition that interaction in support of assisting with the underlying condition may be more challenging for both parties. It is well recognised that dementia is one such condition, and that dementia can have significant impacts on communication abilities (Volkmer et al 2023). This may manifest in a range of ways, from word finding difficulties and repetition of questions, to lack of coherence, and, eventually, an inability to produce intelligible speech (Blair et al 2007; Kindell et al 2017; WHO 2023). Damage to the brain caused by dementia also affects the areas involved in creating new memories and retrieving old ones. This means PLWD can lose the ability to remember events or to fully understand their surroundings (NHS, 2024). Ordinarily, what is referred to as the ‘memory gradient’ means we tend to recall recent events more clearly, but as PLWD become unable to store new memories they are more likely to access older ones and so ‘time-shift’ (Gibbons et al, 2018). These communication issues create challenges not only for people living with dementia (PLWD), but also for those who care for them. It is anticipated that more than 1 million people in the UK will be living with dementia by 2025 (Prince et al., 2014), and in UK acute hospitals approximately one quarter of beds are occupied by PLWD (Alzheimer’s Society, 2009). Nursing staff and nurse managers report caring for PLWD to be challenging, and that they feel they lack sufficient training (Griffiths et al, 2014). The issue of competing realities is one particular challenge (2021 withheld). Lack of

orientation to current time or place may result in the production of what appear to healthcare staff to be inaccurate, untrue or “markedly bizarre” statements (Burgess, 1996:360). In this paper, we examine how such competing realities are managed by healthcare professionals (HCPs) in the context of the UK acute hospital setting. Our data come from a wider project aimed at identifying ways to avoid, de-escalate or resolve distress for PLWD in this acute care context (reference withheld). In our data, PLWD’s competing realities were often associated with distressed behaviour, where their reality was either a source of or a contributory factor to this distress. For example, competing realities over the presence of a healthcare need led to distress over what PLWD perceived as unnecessary treatment, and competing realities over time and place led to distress about not being able to leave hospital immediately upon request.

Background

The occurrence of competing realities in talk between a PLWD and conversational partners is often termed ‘confabulation’ (see Alzheimer’s Society, 2024). Lindholm (2015) provides an overview of this literature and some of the problems associated with it: in her work she refers to ‘parallel realities’, and defines confabulations as “incorrect beliefs presented by a person who is unaware of their incorrectness” (Lindholm 2015: 178). In the wider literature on confabulation a distinction is made between plausible or mundane confabulations and fantastic or bizarre confabulations (e.g. Burgess, 1996). Plausible confabulations may at face value be sensible (Lindholm gives the example of “I had porridge for breakfast yesterday”) and Burgess (1996: 360) describes them as “real memories not in their proper temporal context”. This distinction has been further elaborated by Koppelman (2010: 15), who identifies the phenomenon of spontaneous confabulation: confabulation which occurs without apparent motivation, and comprises a “persistent unprovoked outpouring of erroneous memories”.

However, these distinctions proved to be problematic in the dataset we present here. The competing realities present in our data were often real memories relating to a PLWD's childhood, younger adulthood or prior occupation, such that they were both actual, persistent and unprovoked, but also self-evidently not true at the current moment in time. For this reason we prefer the term 'competing reality' to Lindholm's (2015) 'parallel reality', because in our data it was generally impossible for the two realities in question to be held as true at the same (current) time. As in our previous work (ref withheld) it is important to note that we do not categorise the talk of PLWD presented here as 'errors'. Instead, our focus is on how competing realities can lead to breakdown of shared understanding, and attendant distress, which is then a practical problem to be resolved. The type of 'memory out of place' competing reality that was common in our data also makes problematic the link proposed in some psychological literature between motivation and confabulation (see Fotopoulou, 2010), where the suggestion has been made that confabulations promote positive self-presentation and self-enhancement by containing more positive self-representations than 'true' memories. In our data, as noted, these competing realities were often a significant source of distress.

For these reasons, we do not frame our analysis here in terms of 'confabulation', but instead in terms of 'reality disjunctures', on the basis that this more accurately represents the phenomenon found in our data. In his foundational ethnomethodological work on mundane reason, Pollner describes how a reality disjuncture occurs when two persons present two contradictory experiences of the world that both claim are true (Pollner, 1975: 411). This term is also used by Hydén and Samuelsson (2019) in their analysis of a single case of a woman with Alzheimer's disease participating in an hour-long conversation with two family members. Through their analysis, they explicate how a "disjunction challenges the common ground of the conversationalists and they must deal with this challenge" of not being in the same world (Hydén and Samuelsson 2019: 2663). In Pollner's original work, he describes how, in ordinary circumstances, we adjudicate between

apparently contradictory experiences through our accumulated knowledge of what counts as possible events in the world. He gives the example of seeing what appears to be a fuzzy road traffic sign: since we know that road signs are typically produced for maximum clarity and visibility, we assume that the problem is with our eyesight rather than the sign, thus resolving the disjuncture for ourselves. Hydén and Samuelsson (2019) expand upon this by drawing on Levinson (1983) in arguing that managing a reality disjuncture is not just a question of knowing facts but also about existential presuppositions. Given that participants to an interaction jointly assume that they live in and talk about the same world, these presuppositions underpin what we take to count as *possible* events in this world (cf. Levinson, 1983). Trujillo (2018) puts this another way when he observes that intersubjectivity is also a learned phenomenon: only a fraction of one's stock of knowledge originates from personal experience, and the bulk is socially derived.

These ontological and epistemological questions can take on a very practical form in communicating with PLWD. As Hydén and Samuelsson (2019) describe, in some conversations involving persons with Alzheimer's disease, the participants may have to deal with the difficulty that they do not share a common ground in terms of not only who is alive or dead, but more fundamentally, who could possibly be alive in a particular context. Hydén and Samuelsson's (2019) analysis is of a single conversation between a PLWD and their relatives, taking place in the individual apartment in the residential home where the PLWD lives. This context likely has implications for the focus of their analysis on face work (Goffman, 1955; 1967) and the ways in which reality disjunctures can threaten the faces of participants. A lack of shared understanding of who in a family is alive or dead has implications for the roles and positions of all family members, and not just a PLWD. However, the 'face threat' to a HCP enacting a professional role is likely to be less significant than the 'face threat' to a relative in this context; the reality disjuncture is less likely to directly threaten memories or

shared experiences that have a significant bearing on the HCP's sense of self. For HCPs, reality disjunctures are less an affront and more a practical problem to be managed in the delivery of care.

Returning to the work of Lindholm (2015), her analytic setting is the institutional environment of a day-care centre. As with Hydén and Samuelsson, her data comprise interactions with a single PLWD, though these span 30 hours of talk between the PLWD, other elderly individuals, different types of care professionals and a volunteer. Her analysis of how parallel realities are responded to in this setting illustrates co-participants choosing between acquiescing to the PLWD's reality, being non-committal with regard to it, or correcting the speaker. She argues that being non-committal is undesirable because it does not acknowledge and respect the PLWD as a full co-participant; additionally as (reference withheld) have shown, minimal responses that are judged less-than-adequate for the context may be picked up on by PLWD themselves. Acquiescing to the PLWD's reality can also be undesirable because the co-participant may then be agreeing with an untrue view of the world. The extensive debate on the use of the 'therapeutic lie' in dementia illustrates the moral complexities implicit in this approach (see e.g. Seaman and Stone, 2015; James et al., 2006; James, 2015; Kirtley and Williamson, 2016), though as Lindholm (2015) notes, much of this literature is based on hypothetical examples rather than empirical observation. As for challenging or correcting the PLWD, CA research has long established that other-initiated repair of this kind is both delicate and dispreferred (Schegloff et al., 1977; Schegloff 1992) precisely because it presents a challenge to a "world known and held in common" (Drew et al., 2013:93). Drawing attention to and discussing a reality disjuncture might therefore imply particularly severe and face threatening criticism of the other participant (Hydén and Samuelsson, 2019).

The difficulty of responding to reality disjunctures is, then, a concrete example of one of the issues that HCPs find challenging as they care for PLWD. With this in mind, the analysis we present here is

informed by Lindholm's (2015) and Hydén and Samuelsson's (2019) previous work, but, as we will show, the acute care context and presence of distress lead to some important differences. In previous research in this setting, we have noted (reference withheld) that family or day care settings for PLWD are generally more oriented to providing a social and stimulating environment, and so there is usually less of a focus on completing tasks in a time-sensitive way. By contrast, in the acute hospital, patients are not admitted because of their dementia, but instead for medical reasons such as fractures following a fall, or unresolved infections. This means that there are specific care tasks that need to be carried out by specific staff with scheduling limitations, and these staff may have only limited access to biographical knowledge about the patient that would assist in establishing the basis for the presentation of a competing reality. Following other conversation analytic work that has shed light on interactions between PLWD and their co-participants in a range of settings (e.g. Webb, 2017; Dooley and Barnes 2022; Jones et al., 2016), our approach here has been to use CA to focus on the interactional management of our phenomenon of interest in this specific context. We also extend our conclusions to offer points of learning to support the future training of HCPs in the context of the acute hospital environment.

Methods

Wider Study

The data presented here are taken from a wider study, the aim of which was to develop and evaluate a training intervention to support acute hospital staff in avoiding and resolving distress in the context of caring for PLWD (reference withheld for peer review). This project built on a previous project where CA-based training resources were successfully developed and disseminated nationally using a train-the-trainer model, and the current project adopted this same approach (see (reference withheld) for details). The project was funded by (withheld). Ethical approval was obtained from (withheld).

For the purposes of this project, distress was interpreted broadly. The terms 'challenging behaviour' or 'behaviours that challenge' are sometimes used in this context, but in line with Cohen-Mansfield (2000) and James et al (2020), our analysis was underpinned by an unmet needs perspective on the relationship between distress and behaviours. These authors propose that expressions of distress arise from physical or psychological needs; therefore behaviours reflect a signal of a need, an attempt to meet the need, or are a sign of frustration that the need is not being met. Examples of distress we incorporated in our analysis included physical agitation (such as repetitive movements, kicking or hitting out, throwing things and breaking items such as windows) and verbal agitation (such as shouting and swearing, repetitive questioning or vocalisations, and crying). These were not exclusive categories: often distressed behaviour combined several of them, so for example repeatedly seeking an exit from the ward might be accompanied by repetitive questioning and/or verbal aggression.

Data Collection

Data were collected across four older persons' wards in two acute NHS hospitals in the UK. As previously noted, PLWD admitted to these wards have immediate clinical needs to be attended to. Ninety-six healthcare practitioners (HCPs) were recruited, including nurses, healthcare assistants, doctors and allied health practitioners. The distribution of gender and ethnicity of HCPs was representative of wider NHS diversity data. Fifty-four of the recruited HCPs were included in one or more recording, when interacting with an eligible patient. Patients were eligible for recruitment if staff reported they had a diagnosis of dementia and had displayed distressed behaviours during their admission. Twenty-six patients were recruited, with one providing their own consent and the other 25 through a process of consultee agreement. Twenty-two patient participants were subsequently recorded during their interactions with HCP who had also consented, up to a maximum of three times each. Many of our recordings involved more than one HCP, reflecting the fact that many

healthcare procedures (e.g. transferring a patient from a bed to a chair, delivering personal care to someone who is bed bound) require more than one member of staff. These multi-party interactions often involved HCPs from more than one professional group.

Table 1 shows the breakdown of recordings by HCP professional group.

Table 1: Recruitment and recording of HCPs by professional group.

Professional group	Number recruited Phase 1 VOICE2	Number recorded Phase 1 VOICE2
1. Nurse (all grades including staff nurse, ward manager, student nurse)	41	20
2. Healthcare assistant (including rehabilitation support worker, clinical support worker)	24	15
3. Doctor (all grades including consultant, registrar, medical student)	11	7
4. Allied Health Professional (AHP) (including Speech and Language Therapist, Occupational Therapist, Physiotherapist)	11	7
5. AHP support staff (Physiotherapy assistant)	2	0
6. Advanced clinical practitioners (ACP) (in our sample all nurses by background)	3	2
7. Other (including ward activity coordinator, clinical support trainer, mealtime assistant)	4	3
TOTALS	96	54 HCPs recorded at least once

Recordings were scheduled with ward staff around times or events when distress had previously occurred or might be expected to occur for a particular patient (such as around personal care or painful procedures such as cannula insertion) or during ongoing expressions of distress, such as exit

seeking behaviours or repetitive calling out. However, no recording was made if patient participants reacted negatively in any way to the recording device or the presence of the researchers. Audio (rather than video) recording was used for intimate care or wherever necessary to preserve dignity.

Over a period of six months (April-September 2022) a total of 54 healthcare encounters were recorded, of which three were audio only. The average length of recording was 11:03 minutes, with a range from 1 to 68 minutes, giving a total of 586 minutes of data.

Conversation analytic method

We analysed the data using CA, which has been widely used to study healthcare interactions in a range of settings (e.g. Heritage and Maynard, 2006; withheld) and which we used in a prior study of acute care on which this work builds (refs withheld). Video recordings were transcribed using standard CA procedures (Jefferson, 2004) and subjected to repeated close examination, using the transcripts as an adjunct to the videos. Following Sidnell (2013) our analysis was conducted in three stages: observation of the dataset; identification of the phenomenon of interest and collection of all examples from across the dataset; then use of both single encounters and comparison across multiple examples, to describe the practice. Our initial analytic findings were presented at frequent group data sessions attended by all authors. These data sessions were used to develop and refine the analysis. Comparison was also made with data from the previous study in the same setting (reference withheld), to identify further relevant data for the collections and analysis.

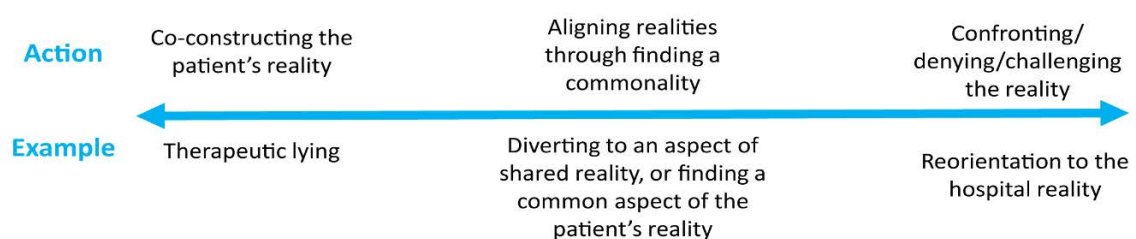
Analysis

Our focus here is specifically on how HCPs deal with reality disjunctures in the context of distress. An initial viewing of our data showed that sometimes the patient's competing reality was a distressing one in and of itself (for example a PLWD who believed their young child was left at home unattended), whilst on other occasions exit-seeking behaviour or non-cooperation with necessary

healthcare tasks were grounded in the fact that the PLWD did not recognise that they were in hospital or had any attendant clinical needs. It was also clear that in the context of competing realities set alongside wider communication difficulties, it could be challenging for staff to work out what a patient’s unmet needs might be, in order to provide any kind of solution.

In Lindholm’s (2015) work on confabulation, she describes co-participant responses as occurring along a continuum, from acquiescing at the one end to open challenges at the other. She notes that practices at either end of this continuum are rare, and that instead co-participants, particularly those who are more experienced in dementia care, tend to use non-committal responses such as minimal acknowledgements (e.g. ‘mmm’) which acknowledge the contribution to interaction that the PLWD has made but remain ambiguous as to whether they express agreement or simply listening. A broadly similar continuum of practices was found in our data, as we represent below (Fig 1). In the analytic sections that follow, we unpack the different positions on this continuum and reflect on the consequences of these in responding to distress.

Fig 1:



In the six examples that follow, we present extracts from interactions between three different patients (denoted in the transcripts as PN) and a variety of hospital staff (denoted as HN, or for student staff, ON). The problem of reality disjunctures was widespread in our data set, but we have selected the examples below to illustrate the range of ways in which staff responded to them, and to

show as clearly as possible the ways in which some of these response types appeared to be effective in resolving distress.

1. Challenging/confronting the reality of a PLWD

Just as in Lindholm's (2015) data, we found that while this approach was present in our dataset, it was used only rarely: there was very little of what could be categorised in Jefferson's (1987) terms as 'exposed correction'. However, there was one notable exception to this. For some patients, their reality did not encompass the fact they were in a hospital setting, or in need of medical care. Some HCPs attempted to deal with this disjuncture by trying to reorientate the PLWD to the hospital reality.

Extract 1 shows an example of this. A PLWD (PN07) is being visited by her son (FN01), when two Healthcare Assistants come to the bay where they are sitting. Only HN39 speaks at this moment, and proposes making a visit to the toilet at the end of the ward.

Extract 1:

PN07_HN39

```
33 HN39: ((places hand on PN07's arm)) [we just] need to walk you to the
34 FN01:                                     [↓mu:m?]
35 HN39:         toi↓let [that's] all we're going do
36 PN07: ((shakes head))[ no ]((shakes arm off)) N↑O
37         (1.8)
38 PN07: I don't want anybody ↓n↑ow in my house
39         (0.3)
40 FN01: you're ↓just going to go for a ↑wee [ mum ]
41 HN39:                                     [you're] in hospital at the
42         minute
43         (1.2)
44 PN07: ((looks at FN01 then as speaking turns to HN39)) no (.) no (.)
45         no.
46         (1.2)
```

In this extract, the proposed visit to the toilet is strongly imperative in character: "we just *need* to walk you", though this is mitigated by the use of 'just' and the subsequent minimisation of the action "that's all we're going to do" (reference withheld). However, the patient resists this proposal both verbally and non-verbally, shaking off the HCP who has touched her on the arm and then repeating

but increasing the volume of her initial 'No'. Her initial responses (line 36) do not indicate a reason for the refusal, but her subsequent turn, "I don't want anybody in my house" makes clear that she is not oriented to the current reality of the hospital ward. Her son responds by reformulating the purpose of the proposed necessary healthcare action in everyday terms, centring the patient's own actions in this and again using the mitigator 'just'. One of the HCPs then overlaps with the end of this utterance, (line 41) in an attempt to reorient the PLWD to the reality of the hospital. In Lindholm's (2015) terms, this is an open challenge: it is done explicitly, drawing attention to the challenge, and it also stops progress of the interaction and creates a side sequence (Jefferson, 1972). However, this challenge does not result in a resolution of the disjuncture; instead the patient turns first to her son, then back to the HCP, repeating 'no' emphatically.

Throughout our dataset, direct attempts at reorientation did not work to resolve reality disjunctures related to location in hospital and/or need for medical assistance. Nevertheless, it is understandable both from an interactional and an institutional perspective why HCPs attempt them. The practice of reorientation is explicitly recommended in some healthcare circumstances, for example where patients have delirium (NICE 2023). And interactionally, in everyday talk, problems of understanding are generally dealt with through the well-documented process of 'repair' – so that when trouble occurs in understanding each other, participants work to reach a shared or mutual understanding (Schegloff et al 1977; Schegloff 1979; Drew 1997), meaning that instigating repair may be an instinctive response. However, the process of repair generally assumes that participants have shared referents for their interactions. As Garfinkel (1967) argued and as Raymond and Sidnell (2019) further explicate, a refusal to 'make sense' of what a subject says, where assumed shared background knowledge is not used to make sense of other people's actions, can quickly provoke moral outrage. It is perhaps unsurprising then that reorientation attempts were so fiercely resisted in this context, appearing to lead to heightened distress.

In accounting for the scarcity of open challenges in her data, Lindholm (2015) makes a moral argument. Drawing on Shakespeare's (1998:52) assertion that "if a repair is not required of a participant who has made a noticeable error, then he or she is not being treated as a full participant", she suggests that the lack of these challenges in her data demonstrate that PLWD are commonly treated as less than full participants. However, it has also been argued that avoiding repair can treat a co-participant as a full participant who can be understood despite language differences (2021 withheld). An assertion of moral failings also becomes more problematic in the context of a task-focused environment like the acute ward. Previous CA work has shown how participants generally orient to progressivity and the need to get a job done through interaction (Schegloff 1979; Stivers and Robinson, 2006). But progressivity is not a binary or dichotomous variable, and participants constantly balance this with intersubjectivity in the service of particular contexts (C.W Raymond 2016). Privileging intersubjectivity over progressivity will delay a next action. In the specific case of acute healthcare, failing to carry out the necessary task promptly may leave an HCP open to criticism, but it may also leave a patient in discomfort or even danger.

At the other end of the continuum from openly challenging the patient's reality are responses which co-construct it. It is to examining these kinds of responses that we now turn.

2. Co-constructing the patient's reality

In her data, Lindholm (2015) identifies the presence of what she describes as 'acquiescing' to the confabulation: where participants' responses develop and, as a result either implicitly or explicitly confirm the patient's reality. In our data, we see a similar phenomenon, though with some important differences in the ways and extents to which HCPs actively align with a patient's reality and/or build on it, as we shall unpack below. Extract 2 shows a PLWD who is repeatedly seeking an exit from the ward. However, in order to meet her care needs, she is the subject of a Deprivation of

Liberty Safeguarding Order (DoL) issued by a UK Local Authority, meaning that staff cannot let her leave.

Extract 2:

In this extract the PLWD (PN02) is walking along the ward corridor. A HCP (HN14, a Healthcare Assistant) has been walking and talking with her, and they then encounter a student nurse (ON02) who is addressed by the patient.

PN02_HN14

183 PN02: I want to get out of here and get home
184 (1.3)
185 ((gestures to HN14)) [he won't let me]
186 ON02: [if you- if you] follow this gentleman
187 here
188 PN02: [pardon]
189 ON02: [he will] show you the way
190 (0.3)
191 PN02: pardon
192 ON02: ((gesturing to HN14)) [this] gentleman over here- look over
193 here
194 HN14: [huhuh]
195 ON02: Valerie (.) he's going to show you the way
196 PN02: #(oh really) he l↑ives here#
197 ON02: he do:↑:esn't↓
198 HN14: feels like it sometimes
199 PN02: he li:ves here I live Placeington
200 (0.9)
201 ON02: yeah he lives in Placeington but he came today to just take
202 care of you
203 PN02: ((signs and frowns))

In the extract, the PLWD addresses her question about getting out of the ward to this second HCP, indicating through her gesture and talk (line 185) that she believes the first HCP to be the reason why she is unable to leave. However, the second HCP begins to produce a response before this blame has been attributed, and suggests that HN14 will in fact show the patient the way out. Given the DoL, the HCP who produces this statement may know this is untrue, though we cannot be certain she is familiar with the patient. However, the way in which it is responded to by the patient suggests that she is also sceptical of its truth. After some trouble hearing and requests for ON02 to repeat herself, ultimately, in line 196, the PLWD rejects this proposal (and underlines the reality

disjuncture) by stating that the first HCP 'lives here'. While the second HCP directly rejects this assertion, this rejection is responded to only by the first HCP, while the PLWD goes on to restate it, upgrading her rejection by contrasting the 'here' of the ward with the name of the city where she lives. A final attempt in line 201-202 by the second HCP to frame the first HCP as the person who can help her is rejected non-verbally by the PLWD, who sighs and frowns.

In Lindholm's (2015) terms, the suggestion that a member of staff will help the patient leave is an 'elaborate confirming response'; it not only confirms the contents of the reality disjuncture (that the patient is not in hospital for necessary care and free to leave), but elaborates upon it. Lindholm notes that in her data this type of response is produced only by the researcher, who is less experienced in the day centre environment. It is also rare in our data, and it is worth noting here that the HCP in this instance is a student nurse, and so also likely to be less experienced. However, as we have previously suggested, this kind of response which addresses a reality disjuncture by going along with the patient's version of reality is likely in many circumstances to be time-limited.

Elsewhere in our data we have an example of a patient reluctant to be cannulated for drug treatment who asks whether the HCP has 'already done' the other patients in the ward; when she is told yes, she allows the procedure to commence. In this example, then, going along with the patient's proposed reality is successful, but the patient will not reasonably discover the lie. However, this approach is unlikely to be sustainable as a way of resolving distress where the competing reality which is causing the distress cannot ultimately be delivered and this will quickly be evident; in this instance the PLWD cannot be allowed to leave at this time, whoever she believes she is going home to. More experienced staff may therefore make a judgement that any immediate interactional benefits of this approach are outweighed by potential consequences of heightened distress when a request or promise is not subsequently fulfilled. The general lack of occurrence of this phenomenon in our data may also reflect the fact that staff can be uncomfortable with deception as a principle, particularly if this deception has to be repeated multiple times in response to repetitive questioning.

Recent debates on ‘therapeutic lying’ have concluded that since lying disturbs the general principle of honesty to patients, lying to PLWD should ideally only occur as a last resort, should be well-thought out and documented as in their best interest, and should also be delivered consistently (James et al., 2006; James, 2015; Kirtley and Williamson, 2016). Instead, it is suggested that caregivers should consider looking for alternative meaning (such as unmet physical or emotional needs), or attempt to distract the PLWD (Hertogh et al., 2004; Kirtley and Williamson, 2016).

Thus far, we have focused on responses at either end of the continuum presented in Fig 1, noting that, as in Lindholm’s (2015) data, these are less common in our recordings. We turn next to responses that occupy the middle ground. Lindholm (2015) observes that in her data, a common way of dealing with the competing reality presented by a PLWD is through minimal responses. As she describes, responses such as ‘mm’ are ambiguous in character, in the sense that they can be used and interpreted either to express agreement, or simply to show that someone is listening. Thus, they acknowledge the PLWD’s contribution to an interaction, without either confronting or confirming this contribution. Interestingly, however, we have little of this minimal responding in our data. As well as our previous observations that minimal responses are a time-limited approach (withheld), we also suggest that this scarcity is likely to be related to our context: when someone expresses distress, these kinds of ambiguous responses are far less likely to be received as appropriate from the outset. In terms of the framing of our paper, they do little to acknowledge or support the ‘social self’ of the distressed PLWD. We outline below the practices that occurred more commonly in our setting and which are more effective in bringing this acknowledgement or support about.

3. Aligning realities through finding a commonality: achieving an aspect of the reality that can be shared

In our data, practices in the middle of the continuum were united by one aspect: HCPs worked to create some kind of shared understanding or experience or feeling; in other words to achieve

some degree of intersubjectivity. As we will show, this striving for intersubjectivity can work to reduce the patient's distress by creating the possibility of interaction that is meaningful and accessible to both the HCP and the patient. Through creating this shared social connection, it may be possible to respond to the patient's emotional need without directly addressing the reality disjuncture.

In Extract 3 below, two healthcare assistants (HN39 and HN40) are accompanying a PLWD (PN07) to the toilet. This is the same patient seen in Extract 1 and is a continuation of that interaction, The patient has with her in hospital a cuddly toy ('Sarah') that she interacts with as though it is a small being that needs taking care of. As they embark on the walk along the ward to the toilet, the patient begins to protest the absence of Sarah.

Extract 3:

PN07_HN39

85 PN07: ((walking and looking around)) I am n↑ot going anywhere now
86 without my little ted
87 (0.3)
88 HN39: right I'll ↑go get her- she's ↑h↓ere look
89 HN40: Sarah's here ((stroking bear under her arm))
90 HN39: we ↑brought her ↑with ↓us (.) [she's st]retchin-
91 PN07: [↑I know↑]
92 (0.3)
93 HN40: she's stretching her l↑egs with us in't ↓she
94 (3.4)
95 shall we leave her outside the toilet though=
96 PN07: =no
97 HN40: ↑no okay

Here, the first HCP responds to the patient's declaration in line 88 by offering to fetch the cuddly toy, before HN40 reveals she is carrying it. Both HCPs then draw the attention of the patient to the fact that Sarah is with them, with the second HCP expanding this to state "she's stretching her legs with us in't she". In this way, the HCPs acknowledge the emotional importance of the toy for the PLWD. Whilst the utterance in line 93 could be interpreted as giving Sarah agency, the fact that the HCP is carrying the toy as she speaks underlines that Sarah cannot be understood in any

reasonable/meaningful way to be stretching her own legs, and this is instead a figure of speech representing the fact that she has been brought along for the journey. The subsequent utterance “Shall we leave her outside the toilet though” clarifies this, as if the toy were being actually treated as a small person by the HCP it would not be appropriate to leave her outside alone. Thus, in this example the HCPs do not challenge the patient’s reality nor entirely enter into it, but instead work towards an aspect of it they can share which encompasses the importance of Sarah for the patient. As a result, a connection is built which shows interest and concern for the patient’s world.

A similar approach is shown in Extract 4 below, which shows the same patient (PN02) as in Extract 2. She is displaying agitation that she is unable to get out of the hospital ward, stating that the reason that she needs to leave is because she has a child and a pet waiting for her at home. (Previously, she has also stated that she needs to leave before it gets dark as she does not like to drive home in the dark). Also present here is the same Healthcare Assistant (HN14) and the researcher (RES) who is making the video-recording.

Extract 4

PN02_HN14

165 PN02: I don't care how
166 HN14: [((to RES)) what's her] son's name Mike
167 PN02: [safe I am in here](.)
168 PN02: [I've got a child at home]
169 RES : [erm her her nephew Harold]
170 HN14: [Harold]
171 PN02: [and a] pet (0.4) and a child (0.3) I can't leave them on
172 their own all night long
173 HN14: Valerie
174 PN02: ((turns to HN14))
175 HN14: you know Harold (0.7) your [nephew]
176 PN02: [yes]
177 HN14: .h he's looking after your ca:r and everybody else
178 PN02: (11.0)((looks around then walks back towards a student nurse))

Before responding to the patient’s utterance beginning at line 165, the HCP here turns to the researcher to establish the name of the male relative who has recently visited the hospital.

Overlapping with this, the patient presents an explicit rationale for what her previous utterance left

implicit: that a child and a pet cannot be left on their own at home at night. In response, using her name to attract her attention, the HCP uses his newfound knowledge first to ask the patient to affirm the identification of Harold, thereby establishing a joint referent, and then (line 177) to propose a reason for why the patient need not be distressed: 'he's looking after your car and everybody else'. By using this formulation, the HCP orients to the source of the distress and provides a potential resolution. However, by naming only the car specifically, and 'everybody else' generically, he avoids explicitly aligning with the reality of a child and pet who have been left at home alone. As G. Raymond (2023) has noted, using indexical references or vague formulations designed for non-specificity are a way of avoiding identifying or problematising a specific referent, thereby enabling another participant to think they share the same reality.

Extract 5 below shows a similar approach. This extract is taken from an interaction between a nurse and a PLWD (PN15) who has previously exhibited physical aggression, for example by taking a shoe from another patient and using it to crack a window on the ward. Immediately prior to this extract, he has been walking with the HCP (HN67), talking about being asked to be Prime Minister, and about the need for war, and his talk and tone have shown distress. At line 319 he introduces this topic again.

Extract 5:

PN15_HN67

319 PN15: If they went to war (1.5) to protect their own people (0.5) I'd
320 go to war with them and I'd be on the front line (.) and I'd
321 ~fight em to the death~ (.)((emotional voice))
322 HN67: ((nodding))
323 PN15: but I can't run the country (.) I can't tell them what to do=
324 HN67: ((hand on patient's hand))
325 you don't have to [run the country daniel]
326 PN15: [=when I don't know meself]
327 HN67: you don't have to ↑run the country
328 PN15: don't try and convince me when I'm an idiot (.) I know you
329 love me and I know that you're kind
330 HN67: yea:h but you don't have to do tha:t (.) you haven't got to run
331 the country we have got some other idiot doing it (1.0) you
332 don't have to do tha:t
((Patient shifts topic to discussion of a local fishing tackle shop))

The HCP's initial response in this extract is to nod, but as the patient's utterance comes to an upshot statement (line 323) about his inability to run the country, she places her hand on his and offers explicit reassurance: 'You don't have to run the country Daniel'. As in the example above, the HCP is responding to the PLWD's emotional tone (withheld). This initial reassurance does not stop the distress, and HCP restates it again at line 327. Following this restatement the PLWD explicitly rejects her response, though the second part of his turn appears to orient to the reassurance/shared emotion that has been offered, by acknowledging the HCP's kindness. From line 330 the HCP restates her position for a third time, but this time expands her statement to include a concrete reason for the reassurance: that there is no requirement for Daniel to take on the role because it is already filled.

Here again, the HCP is offering reassurance that can sit within the reality of the PLWD. Her responses do not dispute his belief that he has been asked to take on the running of the country, but instead whether it is necessary for him to take on the role. Since this possibility is making him very anxious, attempting to remove it is responding to his emotional need. As in Extract 4 above, the problem that the patient proposes is met with an alternative solution. These responses are distinct from what Lindholm (2015) (drawing on Jefferson (1987)) identifies as 'embedded challenges', because they do not attempt to confront the reality disjuncture per se. Instead, they propose an alternative way to deal with patient beliefs, while remaining agnostic about the belief itself. Other examples in our data show similar instances of staff responding to the patient's 'emotional tone' (withheld 2021), rather than, for example, challenging PLWDs' beliefs that deceased family members are still alive.

4. Diverting to another topic or activity

The final approach we found in our data involved diversion. Other researchers have noted the use of diversion or distraction in managing distress exhibited by PLWD (Hertogh et al 2004), and

anecdotally members of our Experts by Experience group who contributed to the project and who were themselves carers for PLWD also reported using these in their own caring practices. Lindholm (2015) does not identify these as a separate category in her data, though there are instances of, for example, a staff member commenting on a PLWD's use of cutlery when they produce a confabulation while eating. We have used the term diversion rather than distraction because in our data HCPs were generally attempting to purposefully engage participants with a new but shareable topic or reality, rather than simply stopping engagement with the old one. Often these diversions involved the reality of the here and now, enabling HCPs not only to shift the focus from distress but also to support the social self of the PLWD in a shared understanding of an aspect of the current moment, but this was not always the case.

In the wider literature, diversions are reported as successfully drawing the person towards something less distressing than their current state of mind. James and Gibbons (2019) suggests that the diversion ideally needs to be towards something that is more powerful and rewarding than where the person is now, and this may involve knowing the patient's background and carefully planning activities and resources. However, while this may be best practice in an ideal scenario, it is not always possible in the context of a busy acute setting, where background knowledge and resources such as photographs or music may not be available. Nevertheless, we still find examples in our data of diversions working to draw people from their distress.

In our data we found three different categories of diversion: environmental diversions (where HCPs topicalise visible objects or aspects of the environment such as the view from the window); proposals of alternative activities (such as going to get a cup of tea); and purely interactional diversions (where, in the absence of any other resources to hand, HCPs simply introduce another conversational topic). For reasons of space, we will show only an example from the final category here.

4.3 Interactional diversion

In the example below, the PLWD (PN02) who has been shown exit-seeking in Extracts 2 and 4 walks into an office where an Advanced Clinical Practitioner is completing records on a computer. Having expressed her desire to leave to the HCP (HN13), the HCP responds as follows:

Extract 6

PN02_HN14

271 HN13: [where]- where were you from
272 PN02: Placeington
273 HN13: whereabouts
274 (2.1)
275 PN02: Townington
276 HN13: ↑oh not fa:r↑ then
277 PN02: no (0.3) far enough when it gets dark
278 HN13: mmh that's true
279 (1.1)
280 I don't e- I don't even know your na:me
281 (0.3)
282 PN02: (ellor) what
283 HN13: I don't even know your name
284 PN02: Valerie Carrington
285 HN13: ah hello
((PN02 quiet for 2 mins whilst HN13 resumes typing))

In this example, the HCP responds to the patient's desire to leave by asking her where she is from (and by implication where she is trying to get back to). She follows this up in line 173 with a question designed for the patient to specify a specific part of the city, and then on receipt of the answer, producing an assessment that this is 'not far'. However, the patient's response to this assessment (line 277) is dispreferred, and alludes to what she has previously stated to other members of staff: that she needs to leave now in the daylight, because she does not like driving in the dark. This utterance by the PLWD, then, indicates a potential recycling of the topic which has been causing her distress. After acknowledging the patient's assessment (line 278), the HCP subsequently introduces an entirely different topic, by asking her name. The patient produces this, and after a further acknowledgement by the HCP, she sits in silence for two minutes while the HCP continues with her task at the computer.

In this instance, then, the HCP introduces a new conversational topic as a diversion. This is a conversational topic that can be shared in the absence of any other resources or knowledge about the patient (and in fact exploits that lack of knowledge). While such diversions were not necessarily long-lasting, a temporary diversion of this kind can provide a 'break' in the interaction which subsequently shifts a PLWD to something longer lasting like sleep, a positive conversation, or a meal. Whilst co-constructing a patient's reality could potentially also provide a break in distress, the use of diversions also avoids the need to deceive the PLWD or agree to something which will quickly prove undeliverable.

Discussion

In this paper we have examined the ways in which HCPs in an acute care context respond to reality disjunctures produced by PLWD which are associated with distress. Whilst previous research has suggested different ways of categorising these reality disjunctures, however they are categorised they present a practical problem for healthcare staff. We have shown four approaches that HCPs use to respond: challenging the competing reality expressed by the PLWD; co-constructing that reality; finding an aspect of the reality which can be shared which enables the HCP to respond to the distress whilst remaining more generally agnostic about the source of it; and diverting to a new topic or activity.

We shown how, although our findings exist on a similar continuum from challenge to confirmation found by Lindholm (2015), as represented in Fig 1, the distribution and detail of responses along that continuum is different in ways that are related to both the specific contingencies of the acute care context and the presence of distress. When aspects of PLWDs' realities are sources of distress, then minimal or non-committal responses at best do nothing to alleviate this distress and at worst risk exacerbating it. It is therefore unsurprising that these types of responses are rarely seen in our data.

Equally, co-constructing a patient's reality not only goes against ordinary norms of practice in healthcare but is also not likely to be effective beyond the short term. It may appear to alleviate immediate distress but is unlikely to work beyond that, e.g. when a HCP is unable to help the PLWD leave the ward and return home.

As our analysis also shows, the management of reality disjunctures in interaction is a delicate undertaking. Raymond and Sidnell (2019: 191) describe, drawing on Garfinkel (1967), how "Persons in interaction...are...not only entitled to know things, they are also obliged to know and use shared knowledge about themselves, their interlocutors and their joint circumstances in forming and making sense of actions". It follows that frustration and anger can be a product of the implication that one should have known the thing that one is asking about. These foundational interactional principles help to illustrate just why dealing with this phenomenon in PLWD is so difficult; they also shed light on why the issue of "therapeutic lying" is fraught not just from a moral perspective but also an interactional one. Whilst we would not want to suggest that responses at either end of the continuum are always inappropriate, it is nevertheless easy to see why they are rarely used in this context.

What we see instead is that HCPs in this setting do subtle and nuanced interactional work. In interactions with PLWD, they work hard to create some kind of shared aspect of world or experience; this enables supporting a patient in their distress experience without necessarily entering into it. Finding a commonality enables positive interaction to continue, thereby supporting the social self of the PLWD. It can also produce useful resources for delivering care, by giving information about a need or identity that could be met or supported in a hospital setting. As Boyle and Warren (2015) have argued, because research has centred on self-identity and subjectivity, this has led to a neglect of PLWDs' capacity for intersubjectivity. Here we have shed some light on some

of the practical ways in which PLWD might be supported to maintain a social self rather than a subjective one (Burkitt, 2008).

At the conclusion of her work, Lindholm (2015), notes different responses to confabulation by those with less experience of dementia care, and proposes that further research is needed to account for the effect of professional training on dealing with confabulations. We suggest here that this can be approached from a different angle: how HCPs can actively be trained to respond in this scenario. As in our previous work, (refs withheld) our underlying premise is that the expertise of skilled practitioners can be made explicit through the study of real-life interaction. What our analysis shows is the immense interactional skill with which some HCPs are already approaching the issue of reality disjunctures; by presenting and analysing these interactions in detail we are able to make this available to others in order to improve patient care³. By identifying and orienting to an aspect where intersubjectivity can be achieved, skilled staff can work to manage or reduce the distress associated with the patient's reality.

Conclusion

To our knowledge, our analysis draws on the first data set comprising video recorded interactions between PLWD and HCPs in the acute hospital care setting. Our findings align with some existing recommendations for interaction with PLWD (James and Gibbons, 2019); however, what we have presented here is an empirical basis for these recommendations which has previously been lacking. We have illuminated the interactional rationale for why some of these recommendations may work more or less well in different contexts, and have demonstrated specific approaches to enact these more general recommendations in an acute care-based setting. We recognise that the contingencies of delivering care to PLWD in other contexts, such as care homes or longer-stay rehabilitation facilities where there are more established relationships with staff and less urgent clinical need, may

be different. Therefore, while it seems likely that some of these approaches may have more general applicability, it is also possible that different specific practices would be found in other settings.

In the context presented here, HCPs are more able to change their communication patterns than PLWD can, and the ways in which they interact make a difference to how distress is managed. No one way of communicating will always alleviate the distress that can be associated with a reality disjuncture, and our data show that different approaches may be used with the same PLWD at different times (for example Extracts 2, 4 and 6 show the use of co-constructing a reality, finding a commonality, and producing an interactional diversion, all in response to the same PLWD's continued exit-seeking and distress over not being able to leave the ward). It is also possible that repeated use of a particular approach with the same PLWD (for example repeatedly producing a diversion) could render it less effective. Our methods do not allow us to speculate on *why* staff might choose a particular approach at a particular time, assuming they could articulate this. However, in terms of fostering an ability to respond to reality disjunctures in this setting, an awareness of a possible range of responses can help staff to fit their approach to the local interactional context and provide them with alternatives to try if a first approach is not successful.

We have also demonstrated two additional findings. The first is that, while it might be best practice for HCPs to know patients as well as possible, the reality of acute care is that staff will not always have as much information as they would like, or have an existing relationship with patients. However, even in this scenario it is possible to bring about positive interaction to minimise distress.

The second is that respite from distress may be temporary rather than permanent. However, respite and breaks are part of the institutional response to this challenge; temporary (or even momentary) respite from distress can be valuable for the person with dementia, other patients and staff.

Additionally, since negative interaction can in itself cause or exacerbate distress, avoiding this can in itself be viewed as success.

We have framed this paper in terms of intersubjectivity. However, as we have noted above, drawing on C.W.Raymond (2016), intersubjectivity and progressivity are always in balance in an interaction. Participants may therefore accept a less precise level of intersubjectivity in the interests of moving on with an interaction. What we have shown here is that, in the context of caring for PLWD, this less precise level may involve a focus on shared emotions or feelings as well as shared experiences of the world. Establishing such commonalities are a means through which, even in the context of a busy acute care ward, PLWD can be supported to maintain a social self.

1. An approach occasionally seen in our data was to ask the patient if they knew where they were. A negative response gives the HCP permission to explain (though this explanation may also be contested).
- 2 Lindholm notes that in her data, the PLWD who confabulates often does so in a different, softer voice, with some degree of nonverbal disengagement from the co participants- she describes this as a mode somewhere between other-directed and self-directed talk. This phenomenon is not apparent in our data.
- 3 Training resources developed from the project can be found here: (withheld).

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Professional group	Number recruited Phase 1 VOICE2	Number recorded Phase 1 VOICE2
Nurse (all grades including staff nurse, ward manager, student nurse)	41	20
Healthcare assistant (including rehabilitation support worker, clinical support worker)	24	15
Doctor (all grades including consultant, registrar, medical student)	11	7
Allied Health Professional (AHP) (including Speech and Language Therapist, Occupational Therapist, Physiotherapist)	11	7
AHP support staff (Physiotherapy assistant)	2	0
Advanced clinical practitioners (ACP) (in our sample all nurses by background)	3	2
Other (including ward activity coordinator, clinical support trainer, mealtime assistant)	4	3
TOTALS	96	54 HCPs recorded at least once

Research highlights

'Reality disjunctures' present challenges in communicating with people with dementia.

Challenging or co-constructing PLWDs' realities seem to be unhelpful in acute care.

Skilled care staff find ways of achieving a shared aspect of reality or experience.

Identifying the practices staff use means they can be explicated and trained.

Some practices support people with dementia to maintain a social self.

Ethical approval

This study received UK NHS ethical approval (reference numbers withheld for anonymity during peer review).