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Title

The importance of personal and professional experience in providing person-centred care for patients with dementia in hospital: a freelisting interview study with ward staff

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Study concept and design: S Petty, T Dening, A Griffiths, DM Coleston. Acquisition of data: S Petty. Analysis and interpretation of data: S Petty, T Dening, A Griffiths, DM Coleston. Drafting of the manuscript: S Petty. Critical revision of the manuscript: S Petty, T Dening, A Griffiths, DM Coleston.

As guarantor, S Petty accepts responsibility for the conduct of the study, had access to the data, and controlled the decision to publish.

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Data sharing

The authors will share relevant data on which the analysis, results, and conclusions reported in the paper are based on reasonable request from BMJ Open.

Competing interests

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years and no other relationships or activities that could appear to have influenced the submitted work.

Abstract

Objective: To detail how personal and professional caregiving experiences of hospital staff changes the care provided for patients with dementia, in order to make practical recommendations for practice.

Design: Cross-sectional qualitative interviews with a purposive sample.

Setting: A UK hospital ward providing dementia care.

Participants: A complete hospital ward staff team, constituting 47 hospital staff from 10 professions.

Methods: Hospital staff were asked to list their approaches to emotion-focused care in individual, ethnographic freelisting interviews. Cultural consensus analysis was used to detail variations in approaches to dementia care between staff subgroups.

Main outcome measures: The most salient listed descriptions of care emphasised by staff members with personal experience of dementia caregiving when compared with staff members without such experience, and descriptions from staff newer to the profession compared with staff with more years of professional dementia caregiving experience.

Results: Subgroups of hospital staff showed different patterns of responses both in how they noticed the emotional distress of patients with dementia, and in prioritised responses that they deemed to work. Hospital staff with personal experience of

dementia caregiving and staff with fewer years of professional experience prioritised mutual communication and getting to know each patient.

Conclusions: Subgroups of hospital staff with personal caregiving experiences and fewer years of professional care experience were more likely to describe person-centred care as their routine ways of working with patients with dementia. It is recommended that personal experience and the novice curiosity of hospital staff be considered as valuable resources that exist within multidisciplinary staff teams that could enhance staff training to improve the hospital care for patients with dementia.

Strengths

- We sought to discover the existing expertise within routine hospital care using the ethnographic freelisting method.
- The study builds upon prior research recommendations to minimise future investments in interventions that rely on theoretical models of care.
- We sampled a representative hospital ward staff team that included different professions.

Limitations

- The approach described by hospital staff does not necessarily equate to care delivered for all patients at all times.
- The findings require more robust testing and replication.

Introduction

In the field of dementia care, there are initiatives to ensure that personal experience of caregiving for somebody with dementia makes a substantial contribution to professional care.[1] This is because a personal perspective can tailor care to address what matters most for the patient and can therefore improve health outcomes.[2] These benefits are urgently needed in hospital care for patients with dementia, which has been addressed as an international priority[3,4] and has been criticised for being task-orientated and falling short of person-centred care.[5,6] By person-centred care, we mean that which meets the holistic needs of the patient as a person, who shares the same value and humanness as any other person.[7,8] Finding ways to communicate with patients with dementia personally is particularly important because of the known difficulties with involving patients directly in their care.[9,10] There are serious implications of poor treatment compliance and wastage of care efforts when the patient's needs are not known.[2]

Whilst personal experience of caregiving can be integrated into dementia care in hospitals by having family members present,[1,11] this is limited by the physical and emotional demands on family members[3] and the hospital priorities of managing risk and delivering medical care that fall within professional roles.[5] Therefore, multidisciplinary hospital staff are required to deliver person-centred care.[10]

Quality hospital care has been evidenced but is variable[12] and successful interventions to enhance person-centred care have been time- and resource-intensive and with variable outcomes.[13] An outstanding question remains as to how person-centred care can be achieved consistently by hospital staff.[3,5,14]

We designed the current study in response to the call for research that explicitly seeks achievable solutions for routine practice and that recognises the existing skillset of hospital staff.[3,5] This paper aims to detail the different, prioritised ways of working of hospital staff with varying personal and professional experiences of caregiving for patients with dementia. We seek to offer suggestions for enhancing care provision within the constraints of existing resources. Here we focus specifically on the relationship shared with the patient at times of emotional distress as a component of person-centred care because of the challenge for both the patient and hospital staff at such times.[15]

Methods

This study presents the analysis of intracultural variations in the approaches to dementia care across different subgroups within a hospital staff team. Specifically, we investigated whether either personal experience of caregiving for a person with dementia or length of professional experience affected staff approaches to care.

Participants

47 hospital staff members constituted a whole ward staff team over a three-month period, which included bank and temporary staff members and all shifts. Staff members were recruited from one assessment ward providing dementia care within a teaching hospital in the UK. All participants volunteered to take part and gave informed consent. Ethical approval was granted by the Health Research Authority (ref 18/HRA/0221).

Patient and public involvement

Hospital staff were involved in the design of the content and format of the interview through discussion at pilot, hence they contributed to the outcome measures. The hospital ward manager facilitated recruitment, assessed the burden of participation and facilitated dissemination of the findings.

Data collection

Face-to-face, individual, ethnographic freelisting interviews were conducted with all staff members in the ward team. In the interview, staff were asked to keep in mind their working with patients with dementia and list as many items as they could to describe: (1) how they notice when a patient is emotionally distressed; (2) what they think causes patients to be emotionally distressed; (3) all the ways they respond when a patient is emotionally distressed; (4) of the ways to respond, all the things that seem to work. Interviews were audio-recorded.

Data analysis

Staff subgroups overview

Cultural consensus analysis[16] was used to determine how different subgroups of staff described their approaches to care. Two sets of subgroups were created as follows. Personal caregiving experience: the list data of staff members who reported personal experience of dementia caregiving, such as having a family member or friend with the diagnosis (n=18), was compared with the list data of staff without personal caregiving experience (n=29); this formed datasets for two staff subgroups. Professional caregiving experience: the list data of staff members who had worked in a professional role with people with dementia for more than 15 years (n=15), was

compared with the list data of staff who had worked with people with dementia for less than 5 years (n=18). This formed data sets for two further staff subgroups.

Cultural consensus analysis

ANTHROPAC analysis software was used.[17] First, recode and consensus procedures were used to apply factor analytic methods to determine whether each staff subgroup reached a shared domain description in response to each of the four interview questions. Consensus was shown by a single-factor solution, where the eigenvalues of the first factor and second factor formed a ratio of greater than 3:1. Second, each staff member's agreement with the consensus description of the subgroup was given by a knowledge score; this was each staff member's loading on the first factor, with a maximum loading of 1.0. This analysis showed whether different staff subgroups formed a consensus in their approach to care and how much each individual staff member agreed with the consensus.

Salience of list items

For each staff subgroup, the freelist procedure was used to calculate the listed items that were highest in salience for each of the four questions. Salience is a measure of how important an item is; an item with higher salience will have been mentioned more frequently and earlier in lists.

Group comparisons

Two main comparisons were made: between (1) staff members with personal experience of dementia caregiving compared with those without, and (2) staff members with more years of professional caregiving experience compared with those with fewer years of experience. For each comparison, the salience scores of items

produced by one staff subgroup were subtracted from the salience scores of items produced by the second staff subgroup. This gave a list of difference scores ranging from positive values (items with higher salience for the first staff subgroup) to negative values (items with higher salience for the second staff subgroup). The list items at each end of the continuum show the emphasis of one group relative to the other.[18] Qualitative differences in the items listed were then considered.

Results

Participant overview

The full ward participated. The following professional roles were represented: health care assistant (n=20), nurse or student nurse (n=12), occupational therapist, physiotherapist or therapy assistant (n=4), doctor (n=3), manager or deputy manager (n=3), domestic (n=2), volunteer (n=2), ward clerk (n=1). The majority of hospital staff were female (70%) and White British (75%). The mean length of time working with people with dementia was 11 years (range 3 months to 37 years).

Comparing approaches to dementia care: personal experiences of caregiving

Shared domain descriptions

Both staff subgroups produced a single, consensus domain description in response to each of the four interview questions. Both subgroups listed an equal number of items for all four questions; no comparison of mean number of items between staff subgroups for the four questions reached statistical significance. Therefore, neither group was more or less able to describe their approach to responding to the emotional

needs of patients with dementia; however, meaningful differences were revealed in the amount of agreement between staff and in the different items listed.

Staff agreement

Knowledge scores showed that staff with personal experience of dementia caregiving showed less agreement with each other as a subgroup than they did with the whole staff team in their responses to all four questions, as shown by lower mean knowledge scores: ways to notice emotional distress ($t(63)= 4.21$, $p< .001$); causes of emotional distress ($t(62)= 4.16$, $p< .001$); responses to emotional distress ($t(63)= 2.41$, $p= .019$); responses that seem to work ($t(63)= 2.96$, $p= .004$). In contrast, staff without personal experience of dementia caregiving did not differ significantly in their level of agreement with each other when compared with the whole staff team. Therefore, personal experience was influential when forming a consensus approach. This means that hospital staff with personal experience of dementia caregiving showed more variety in how they noticed, understood and responded to patients with dementia.

Comparison of list items

Tables 1a-d show the list items with the greatest difference in salience between staff with personal caregiving experience as compared with staff without for all interview questions.

Staff with personal experience of dementia caregiving had a greater expectation that the patient would communicate their distress verbally or nonverbally through their facial expression or their body language. They emphasised that the staff member needs to know the patient as a person to be able to notice their emotional distress and their way of communicating. In their responses to emotional distress, this staff

subgroup was more likely to empathise, to talk, to listen and to mirror the patient. They were more likely to say that sometimes it is not possible to understand fully or respond helpfully. This suggests an approach to care that is responsive to each individual and is personalised. This subgroup also placed stronger weighting on the hospital being a cause of distress, including being with strangers, being in an unfamiliar environment and feeling upset by the manner of hospital staff.

In contrast, hospital staff without personal experience of dementia caregiving placed more emphasis on the role of a patient's family in maintaining their wellbeing: they recognised that a patient might ask for their family when distressed and recognised that causes of distress included being away from loved ones and wanting to go home. This subgroup also stated they would be more likely to respond to emotional distress by contacting a patient's family for a telephone call or visit. They showed more caution in how to respond to emotional distress: they were more likely to state that their response would depend on the level of distress or would depend on the circumstances and they were more likely to say that a wide range of responses to distress work at different times.

The approach described by all staff was nurturing, reassuring and comforting.

Comparing approaches to dementia care: professional experiences of caregiving

Supplementary Tables S1a-d show the list items with the greatest difference in salience between staff with more and fewer years of professional caregiving experience for all interview questions.

Shared domain descriptions

Both staff subgroups produced a single, shared domain description for each question; however, staff members with more years of professional experience listed significantly more items for ways to respond to emotional distress (mean 13.13, SD 4.94) than did staff with fewer years of professional experience (mean 8.33, SD 4.14) ($t(31)= -3.04$, $p= .005$), suggesting an accumulation of possible ways to respond to patients. They did not list significantly more responses for the fourth question when listing responses that they deemed to work.

Comparison of list items

Personalised care was more prevalent across responses to all questions for the staff subgroup with fewer years of professional experience. They were more likely to say that they noticed distress through easily visible cues, such as from a patient's face, or through their body language. They expected patients to voice their distress. They were more likely to say that they needed to know the patient as a person and that they would listen to the patient. In contrast, staff with more years of personal experience were more likely to use surmised terms when describing emotional distress; they listed agitation, aggression and anxiety, which might suggest a shorthand developed over time.

Discussion

Principal findings

Hospital care for patients with dementia requires improvement and would benefit from clear recommendations that apply to routine practice.[3-5] This study explored how existing resources of personal and professional caregiving experience could

differentiate between the approaches of hospital staff when patients showed emotional distress. The results show that different staff subgroups emphasised varying features of person-centred care.

Staff members with personal experience of dementia caregiving prioritised knowing the person, achieving reciprocal communication and showing an understanding of the patient's perspective. The second staff subgroup comparison revealed complementary findings, whereby hospital staff that were newer to a professional care role were more likely to notice each patient as a person and notice their individual communication. These findings make two notable contributions to the research literature. First, the approach described by the two staff subgroups mirrors person-centred care[7,8] and exemplifies the most positive aspects of hospital care described in the research literature.[11] Second, these staff said that they communicated with the patient, hence they involve patients in their care; such involvement is required as a fundamental standard of person-centred care and is particularly lacking for patients with dementia when in hospital.[9] We therefore recommend that the personal caregiving experiences and the novice curiosity of hospital staff be considered as an existing resource to enhance person-centred care in hospitals for patients with dementia. These resources could be drawn upon within staff training interventions and be given merit by management.

It is possible that personal experience of dementia caregiving contributes knowledge, confidence and a positive attitude to professional working, as has been described elsewhere.[19,20] We also speculate as to whether career longevity promotes knowledge, but fosters a 'professional' approach to dementia care whereby technical expertise and shorthand are valued for the purposes of documentation and risk management.[6] In this

study, staff with more years of professional experience tended to describe behaviour as agitation or aggression and were more likely to list medical causes of emotional distress such as infection or delirium, which suggests an approach that overlooks the complexity of a person beyond diagnostic criteria.[21] This interpretation does not dismiss the dedication of staff who sustain a career in working with patients with dementia, as was shown in the compassionate responses of all hospital staff in this study. Instead we aim to recognise the variations in approaches within a team.

Strengths and weaknesses

Strengths: primarily, we sought to discover the existing expertise within routine hospital care using the ethnographic freelisting method. This is important given the manifold barriers to hospital staff implementing best practice dementia care, such as having limited time.[5,12,13,20] We built upon prior research recommendations to minimise future investments in interventions that rely on theoretical models of care to increase the real-world impact of the research.[3] The findings offer some guidance as to how person-centred approaches could be enhanced, and how patients with dementia could be involved in their care.[2,10] We sampled a representative hospital ward staff team that included different professions. Limitations: the approach described by hospital staff does not necessarily equate to care delivered for all patients at all times. Whilst we have detailed the knowledge of staff, we have not directly observed their behaviour. The findings require more robust testing and replication.

Implications for clinicians and policymakers

We intend the findings to influence staff training interventions, specifically, hospital staff have repeatedly expressed the value of collaborative learning with peers that these findings would encourage.[19,22] We also recommend that the person-centred approaches detailed here be given merit by management to enable change in the hospital culture.[5,22] Possible benefits to sharing expertise amongst multiple professions include building a reliable skillset that is more resistant to staff turnover and is valuable when family members are not consistently available.

Unanswered questions and future research

These findings require follow-up in three ways: first, replication beyond a single UK hospital ward; second, further exploration of how patient, staff and the hospital system variables interact to complicate the delivery of person-centred care; third, evaluative studies of how personal experience and professional curiosity can be prioritised in practice.

The lead author affirms that this is an honest, accurate, and transparent account of the study.

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Tables

Tables 1a-1d. Top six list items with the greatest difference in salience between hospital staff with and without personal experience of dementia caregiving for each of four interview questions.

Table 1a. Interview question: how to notice emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
The person will tell you: Patients are able to say that they are distressed, such as describing an emotion.	-0.221	*Withdrawn*: Included being quiet, disengaged or subdued; patients were described as being distressed within themselves.	0.107
Body language or posture: Including descriptions of a patient waving, pointing or putting hands to their head.	-0.197	*Asking for family or friends*: Included asking where family are, whether family are safe, whether family know where they themselves are.	0.105
Face or facial expression.	-0.160	*Easily visible*: Distress was visible and seen by looking at somebody; or distress is obvious; 'it's not hard to tell'.	0.104
Seeking, searching, looking for someone or something: Didn't always describe what was being searched for.	-0.118	*Anxious or frightened.*	0.103
Behaviour or actions: Sometimes described as a change for the person.	-0.093	*Repeated questions*: Included patients not feeling reassured.	0.101
Knowing the person: To be able to notice distress; the patient not being their usual self, something being different.	-0.082	*Wanting to leave*: Included attempting to leave; asking to go out or for doors to be unlocked, trying exit doors, banging doors, absconsion, calling for a taxi, asking about the train station.	0.081

Table 1b. Interview question: causes of emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience

Not knowing where they are: Disorientation, asking where they are and not knowing that they are in hospital.	-0.176	*Being orientated or contradicted*: Included descriptions of others not understanding a person's reality, questioning them and what they see or not giving an answer that a patient wants to hear.	0.122
Strangers: Unfamiliar or unknown people, unfamiliar faces and voices and patients not knowing who is around them.	-0.145	*Wanting to go home*: Missing home, asking to go home.	0.112
Hunger or thirst.	-0.134	*Being away from loved ones*: wanting to see family or friends, looking for them and thinking about them, not being with them, awaiting or not receiving visitors and not knowing where family are. Specific family members, such as 'mum' or 'husband', were mentioned. Descriptions also included feeling left or abandoned by family.	0.085
Expression difficulties: Patients being unable to express what they want to say or not being understood by others; included being unable to verbally express pain or emotions.	-0.124	*Frightened, scared or fearful*.	0.077
The hospital environment: An unfamiliar, new or foreign setting; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	-0.109	*Infection*.	0.063
Upset by staff: Included descriptions of the attitude, skills and manner of staff and the way people were spoken to causing distress; included staff being impatient and not understanding how to talk to somebody.	-0.102	*Rumination, remembering the past*: Included patients replaying past scenarios, experiencing flashbacks of earlier life.	0.060

Table 1c. Interview question: responses to emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
Empathise: Trying to understand, tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	-0.164	*It depends on the level of distress*.	0.134
Distraction: Sometimes distracting from the person's thoughts or mood; changing topic; distracting for a short time.	-0.136	*Activities*: A range of games and puzzles were listed, including jigsaws, draughts, bingo, skittles crosswords and word puzzles, flower arranging and building.	0.109
Listening: Included telling the patient they are listening.	-0.103	*Contact with family*: Enabling contact with family included speaking with family on the phone, allowing family to visit at flexible times or stay longer.	0.093

Sometimes can't help: Staff said they sometimes couldn't help or couldn't fully understand; not every time; included stating that they don't know the patient well.	-0.100	*Reassurance*: Giving reassurance generally was listed without further description.	0.092
Mirroring: Mirroring the person, their actions or volume; described building off each other.	-0.097	*It depends on the circumstances*.	0.063
Talking: Sharing conversation and stories; included talking whilst walking.	-0.096	*Comfort*: Included descriptions of being calming or nurturing.	0.058

Table 1d. Interview question: responses to emotional distress that seem to work.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
Sometimes can't help: Staff said they sometimes couldn't help, sometimes nothing works or a response doesn't work; responses that work are never guaranteed.	-0.110	*Reassurance*: Giving reassurance generally was listed, including reassurance not to worry or that problems would be resolved.	0.174
Empathise: Trying to understand, putting self in their place; telling them they understand.	-0.101	*It depends on the level of distress*.	0.082
Knowing the person: Staff described having to know or get to know the person; included each person being different/unique; being person-centred; being patient-led; different responses working for different people.	-0.088	*Contact with family*: Enabling contact with family included speaking with family on the phone, allowing family to visit at flexible times.	0.076
Comfort: Included descriptions of calming somebody, being nurturing or giving emotional contact.	-0.077	*Allowing space*: To pace or let their anger out.	0.073
Change the member of staff: Included changing to a more familiar staff member or changing to a male or female staff member.	-0.072	*Listen*: Included telling and showing the patient they are listening.	0.062
Consult colleagues: Included consulting with and learning from multidisciplinary colleagues.	-0.067	*All/any responses*: Anything, everything or all of them was listed.	0.058

Supplementary table

Supplementary table S1a-d. Top six list items with the greatest difference in salience between hospital staff with more years of professional experience and fewer years of working experience for each of four interview questions.

Table S1a. Interview question: how to notice emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Crying: Descriptions include crying, tears and weeping.	-0.400	*The person will tell you*: Patients are able to say that they are distressed, such as describing an emotion.	0.168
Agitation: The words 'agitation' or 'agitated' are used; verbal or physical agitation is described.	-0.384	*Body language or posture*: Including descriptions of a patient waving, pointing or putting hands to their head.	0.159
Unsettled, fidgety, not relaxed, fiddling: Being unsettled was described; descriptions include fiddling, fidgeting, fussing with items, tearing items, pulling at clothing or equipment, being flustered or unable to settle.	-0.320	*Face or facial expression*.	0.130
Aggression: The terms 'aggression' or 'aggressive' were used without further description. Descriptions included.	-0.250	*Easily visible*: Distress was visible and seen by looking at somebody; or distress is obvious; 'it's not hard to tell'.	0.111
Anxious or frightened.	-0.207	*It is different patient to patient*: state distress is shown differently by different people; can include distress depending on the person's life experiences.	0.105
Knowing the person: To be able to notice distress; the patient not being their usual self, something being different.	-0.142	*Behaviour or actions*: Sometimes described as a change for the person.	0.097

Table S1b. Interview question: causes of emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
The hospital environment: An unfamiliar, new or foreign setting; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	-0.242	*Lots of different things*: staff said there are lots of/a variety/a myriad of things that cause distress; the causes can change; the reasons for distress need to be worked out or analysed.	0.151

Infection.	-0.153	*Being confused.*	0.117
Frustration.	-0.143	*Strangers*: Unfamiliar or unknown people, unfamiliar faces and voices and patients not knowing who is around them.	0.113
Delirium.	-0.129	*Being too hot or too cold.*	0.098
Missing belongings and objects: being without familiar things such as a teddy bear and sleeping in a different bed.	-0.129	*Hunger or thirst*.	0.096
Not knowing where they are: Disorientation, asking where they are and not knowing that they are in hospital.	-0.112	*Memory problems:* forgetfulness, forgetting having their questions answered, forgetting reassurance, being unable to recall their date of birth or items on a cognitive screening tool.	0.091

Table S1c. Interview question: responses to emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Space: staff listed offering a different or preferred environment, room or space. This included using the café away from the ward.	-0.221	*Comfort:* Included descriptions of being calming or nurturing.	0.167
Reassurance: listed without further description.	-0.144	*Ask the person:* asking what the matter is or why they are distressed, asking what they would like.	0.093
Empathise: Trying to understand, tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	-0.137	*Talking*: Sharing conversation and stories; included talking whilst walking.	0.091
A cup of tea.	-0.130	*Leave them:* included allowing space for the patient to let off steam or wind down, being hands off, allowing them liberty, not stopping somebody from wandering, staff keeping their distance for the safety of colleagues or patients.	0.091
Touch: included holding a person's hand or offering a hug.	-0.127	*Mirroring*: Mirroring the person, their actions or volume; described building off each other.	0.069
Body language: listed without further explanation, meaning staff used their body language in their response.	-0.123	*Identify the cause or reason for distress*: identifying the problem or the need; fathoming, working out or getting to the grounds of the distress.	0.057

Table S1d. Interview question: responses to emotional distress that seem to work.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Space: offering a different or preferred environment,	-0.280	*Knowing the person*: Staff described having to know or get to know the person; included each person being	0.271

room or space. This included quiet and still spaces.		different/unique; being person-centred; being patient-led; different responses working for different people.	
Touch: descriptions of touch included holding a person's hand or offering a hug.	-0.133	*It depends on the circumstances.*	0.174
It depends on the level of distress.	-0.126	*Listen*: Included telling and showing the patient they are listening.	0.148
Sitting with, being with, engaging with. Included descriptions of giving attention and being a person without uniform or equipment.	-0.099	*Change the member of staff*: Included changing to a more familiar staff member or changing to a male or female staff member.	0.117
All/any responses: Anything, everything or all of them was listed.	-0.076	*Talking*: sharing conversation, chatting, communicating.	0.114
Activities.	-0.067	*Sometimes can't help*: Staff said they sometimes couldn't help, sometimes nothing works or a response doesn't work; responses that work are never guaranteed.	0.093

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The importance of personal and professional experience for hospital staff in person-centred dementia care: a cross-sectional interview study using freelisting in a UK hospital ward

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Abstract

Objective: To detail how hospital staff with differing personal and professional caregiving experiences approach the care of patients with dementia, in order to make practical recommendations for practice.

Design: Cross-sectional qualitative interviews.

Setting: A UK hospital ward providing dementia care.

Participants: A complete hospital ward staff team, constituting 47 hospital staff from 10 professions.

Methods: Hospital staff were asked to list their approaches to emotion-focused care in individual, ethnographic freelisting interviews. Cultural consensus analysis was used to detail variations in approaches to dementia care between staff subgroups.

Main outcome measures: The most salient listed descriptions of care emphasised by staff members with personal experience of dementia caregiving when compared with staff members without such experience, and descriptions from staff newer to the profession compared with staff with more years of professional dementia caregiving experience.

Results: Subgroups of hospital staff showed different patterns of responses both in how they noticed the emotional distress of patients with dementia, and in prioritised responses that they deemed to work. Hospital staff with personal experience of

dementia caregiving and staff with fewer years of professional experience prioritised mutual communication and getting to know each patient.

Conclusions: Subgroups of hospital staff with personal caregiving experiences and fewer years of professional care experience were more likely to describe person-centred care as their routine ways of working with patients with dementia. It is recommended that personal experience and the novice curiosity of hospital staff be considered as valuable resources that exist within multidisciplinary staff teams that could enhance staff training to improve the hospital care for patients with dementia.

Strengths

- We sought to discover the existing expertise within routine hospital care using the ethnographic freelisting method.
- The study builds upon prior research recommendations to minimise future investments in interventions that rely on untested theoretical models of care.
- We sampled a representative hospital ward staff team that included different professions.

Limitations

- The approach described by hospital staff does not necessarily equate to care delivered for all patients at all times.
- The findings require more robust testing and replication.

Introduction

In the field of dementia care, there are initiatives to ensure that personal experience of caregiving for somebody with dementia makes a substantial contribution to professional care.[1] This is because a personal perspective can tailor care to address what matters most for the patient and can therefore improve health outcomes.[2] These benefits are urgently needed in hospital care for patients with dementia, which has been addressed as an international priority[3,4] and has been criticised for being task-orientated and falling short of person-centred care.[5,6] By person-centred care, we mean that which meets the holistic needs of the patient as a person, who shares the same value and humanness as any other person.[7,8] Finding ways to communicate with patients with dementia personally is particularly important because of the known difficulties with involving patients directly in their care.[9,10] Prevalence estimates suggest that patients with dementia can occupy over a third of hospital beds in the UK;[11] there are serious implications of poor treatment compliance and wastage of care efforts when the patient's needs are not known.[2]

Whilst personal experience of caregiving can be integrated into dementia care in hospitals by having family members present,[1,12] this is limited by the physical and emotional demands on family members[3] and the hospital priorities of managing risk and delivering medical care that fall within professional roles.[5] Therefore, multidisciplinary hospital staff are required to deliver person-centred care.[10]

Quality hospital care has been evidenced but is variable[13] and successful interventions to enhance person-centred care have been time- and resource-intensive and with variable outcomes.[14] An outstanding question remains as to how person-centred care can be achieved consistently by hospital staff.[3,5,15]

We designed the current study in response to the call for research that explicitly seeks achievable solutions for routine practice and that recognises the existing skillset of hospital staff.[3,5] This paper aims to detail the different, prioritised ways of working of hospital staff with varying personal and professional experiences of caregiving for patients with dementia. We seek to offer suggestions for enhancing care provision within the constraints of existing resources. Here we focus specifically on the relationship shared with the patient at times of emotional distress as a component of person-centred care because of the challenge for both the patient and hospital staff at such times.[16]

Methods

This study presents the analysis of intracultural variations in the approaches to dementia care across different subgroups within a hospital staff team. Specifically, we investigated whether staff with either personal experience of caregiving for a person with dementia or more years of professional experience than their peers approached care differently.

Participants

47 hospital staff members constituted a whole ward staff team over a three-month period (October to December 2017), which included bank and temporary staff members and all shifts. Staff members were recruited from one ward for the assessment of older people within a teaching hospital in the UK. The ward was a member of Dementia Action Alliance, which connects 150 UK organisations through their commitment to improving dementia care; otherwise, the hospital had no dementia specialty such as consultation or liaison services and was not a dedicated

dementia ward. The setting was chosen because of its similarity with hospital services for patients with dementia across Europe.[17] All ward staff who interacted with patients within their working role were invited to participate, in an attempt to recognise whole system working.[18] Study information was made available to all staff by the ward manager. Participants were informed of times when the researcher was available; all participants volunteered to take part and gave written informed consent prior to interview, after reading the study information. The hospital ward manager approved the study. The authors had no prior relationship with any participant. The lead author is a Clinical Psychologist, experienced in working with people across the age range with mental health diagnoses, and their support networks. Ethical approval was granted by the Health Research Authority (ref 18/HRA/0221).

Patient and public involvement

Staff from a second hospital in the UK were involved in the initial design of the content and format of the interview through discussion with the lead author to ensure that it was appropriate for use.

Data collection

Face-to-face, individual, freelisting interviews lasting approximately 15 minutes were conducted with all staff members in the ward team. Freelisting is an ethnographic method and provides the theoretical underpinning for the analysis.[19] In the interview, staff were asked to keep in mind their working with patients with dementia and list as many items as they could to describe: (1) how they notice when a patient is emotionally distressed; (2) what they think causes patients to be emotionally distressed; (3) all the ways they respond when a patient is emotionally distressed; (4)

of the ways to respond, all the things that seem to work. The type and severity of dementia was not specified. Interviews were audio-recorded and transcribed in full. The transcripts were reviewed by all authors and list items were extracted through group discussion; 10% of the transcripts were reviewed independently by two authors.

Data analysis

Staff subgroups overview

Cultural consensus analysis[19] was used to determine how different subgroups of staff described their approaches to care. Two sets of subgroups were created as follows. Personal caregiving experience: the list data of staff members who reported personal experience of dementia caregiving, such as having a family member or friend with the diagnosis (n=18), was compared with the list data of staff without personal caregiving experience (n=29); this formed datasets for two staff subgroups. Professional caregiving experience: the list data of staff members who had worked in a professional role with people with dementia for more than 15 years (n=15), was compared with the list data of staff who had worked with people with dementia for less than 5 years (n=18). This formed data sets for two further staff subgroups. The year boundaries chosen were a means of comparing staff with relatively more and fewer years of professional experience based on the demographic data in this study.

Cultural consensus analysis

ANTHROPAC analysis software was used in the following ways,[20] with close reference to example studies.[21,22] First, recode and consensus procedures were used to apply factor analytic statistical methods to determine whether each staff subgroup reached a shared domain description in response to each of the four interview

questions. Consensus was shown by a single-factor solution, where the eigenvalues of the first factor and second factor formed a ratio of greater than 3:1. Second, each staff member's agreement with the consensus description of the subgroup was given by a knowledge score; this was each staff member's loading on the first factor, with a maximum loading of 1.0. This analysis showed whether different staff subgroups formed a consensus in their approach to care and how much each individual staff member agreed with the consensus.

Salience of list items

For each staff subgroup, the freelist procedure was used to calculate the listed items that were highest in salience for each of the four questions. ANTHROPAC applies Smith's salience index[23] to measure how important an item is; an item with higher salience will have been mentioned more frequently and earlier in lists.

Group comparisons

Two main comparisons were made: between (1) staff members with personal experience of dementia caregiving compared with those without, and (2) staff members with more years of professional caregiving experience compared with those with fewer years of experience. For each comparison, the salience scores of items produced by one staff subgroup were subtracted from the salience scores of items produced by the second staff subgroup. This gave a list of difference scores ranging from positive values (items with higher salience for the first staff subgroup) to negative values (items with higher salience for the second staff subgroup). The list items at each end of the continuum show the emphasis of one group relative to the other.[24] Qualitative differences in the items listed were then considered.

In addition, the mean number of items listed for each question was compared for staff with and without personal caregiving experience, and staff with more and fewer years of professional experience, using independent sample t-tests.

Finally, mean knowledge scores of each staff subgroup were compared with the mean knowledge score for the whole staff team for all four questions using paired sample t-tests; this shows the amount of agreement over the approach to care between members within a subgroup as compared with the full hospital ward.

The lead author performed all analysis.

Results

Participant overview

All 47 members of the ward agreed to participate. The following professional roles were represented: health care assistant (n=20), nurse or student nurse (n=12), occupational therapist, physiotherapist or therapy assistant (n=4), doctor (n=3), manager or deputy manager (n=3), domestic (n=2), volunteer (n=2), ward clerk (n=1). The majority of hospital staff were female (70%) and White British (75%), with an even spread of ages from across five age brackets, from '25 years or under' to '55 years or over'. The mean length of time working with people with dementia was 11 years (range 3 months to 37 years). Demographic differences between staff subgroups were: both volunteers and three of four physiotherapists or therapy assistants had personal experience of caregiving; all other professions and genders were proportionately represented. The majority of staff without personal caregiver experience were aged 45-55 years; the majority of staff with personal caregiver experience were aged 55 years or over. There were no differences of note in the

representation of different professions or genders in the staff subgroups with more or fewer years of professional caregiving experience, however, all staff with more years of professional experience were aged 35 years or over and, collectively, were relatively older than staff with fewer years of professional experience, as might be expected.

Comparing approaches to dementia care: personal experiences of caregiving

Shared domain descriptions

Both staff subgroups produced a single, consensus domain description in response to each of the four interview questions. Both subgroups listed an equal number of items for all four questions; no comparison of mean number of items between staff subgroups for the four questions reached statistical significance. Therefore, neither group was more or less able to describe their approach to responding to the emotional needs of patients with dementia; however, meaningful differences were revealed in the amount of agreement between staff and in the different items listed.

Staff agreement

Knowledge scores showed that staff with personal experience of dementia caregiving showed less agreement with each other as a subgroup than they did with the whole staff team in their responses to all four questions, as shown by lower mean knowledge scores: ways to notice emotional distress ($t(63)= 4.21$, $p< .001$); causes of emotional distress ($t(62)= 4.16$, $p< .001$); responses to emotional distress ($t(63)= 2.41$, $p= .019$); responses that seem to work ($t(63)= 2.96$, $p= .004$). In contrast, staff without personal experience of dementia caregiving did not differ significantly in their level of

agreement with each other when compared with the whole staff team. Therefore, personal experience was influential when forming a consensus approach. This means that ward staff with personal experience of dementia caregiving showed more variety in how they noticed, understood and responded to patients with dementia.

Comparison of list items

Tables 1a-d show the list items with the greatest difference in salience between staff with personal caregiving experience as compared with staff without for all interview questions.

Staff with personal experience of dementia caregiving had a greater expectation that the patient would communicate their distress verbally or nonverbally through their facial expression or their body language. They emphasised that the staff member needs to know the patient as a person to be able to notice their emotional distress and their way of communicating. In their responses to emotional distress, this staff subgroup was more likely to report that they empathise, to talk, to listen and to mirror the patient. They were more likely to say that sometimes it is not possible to understand fully or respond helpfully. This suggests an approach to care that is responsive to each individual and is personalised. This subgroup also placed stronger weighting on the hospital being a cause of distress, including being with strangers, being in an unfamiliar environment and feeling upset by the manner of hospital staff.

In contrast, ward staff without personal experience of dementia caregiving placed more emphasis on the role of a patient's family in maintaining their wellbeing: they recognised that a patient might ask for their family when distressed and recognised that causes of distress included being away from loved ones and wanting to go home.

This subgroup also stated they would be more likely to respond to emotional distress by contacting a patient's family for a telephone call or visit. They showed more caution in how to respond to emotional distress: they were more likely to state that their response would depend on the level of distress or would depend on the circumstances and they were more likely to say that a wide range of responses to distress work at different times.

The approach described by all staff was nurturing, reassuring and comforting.

Comparing approaches to dementia care: professional experiences of caregiving

Supplementary Tables S1a-d show the list items with the greatest difference in salience between staff with more and fewer years of professional caregiving experience for all interview questions.

Shared domain descriptions

Both staff subgroups produced a single, shared domain description for each question; however, staff members with more years of professional experience listed significantly more items for ways to respond to emotional distress (mean 13.13, SD 4.94) than did staff with fewer years of professional experience (mean 8.33, SD 4.14), ($t(31)= -3.04$, $p= .005$), suggesting an accumulation of possible ways to respond to patients. They did not list significantly more responses that they deemed to work, as asked by the fourth question; this might suggest shared agreement between all staff of a limited number of effective responses.

Comparison of list items

Personalised care was more prevalent across responses to all questions for the staff subgroup with fewer years of professional experience. They were more likely to say

that they noticed distress through easily visible cues, such as from a patient's face, or through their body language. They expected patients to voice their distress. They were more likely to say that they needed to know the patient as a person and that they would listen to the patient. In contrast, staff with more years of personal experience were more likely to use surmised terms when describing emotional distress; they listed agitation, aggression and anxiety, which might suggest a shorthand developed over time.

Discussion

Principal findings

Hospital care for patients with dementia requires improvement and would benefit from clear recommendations that apply to routine practice.[3-5] This study explored how existing resources of personal and professional caregiving experience could differentiate between the reported approaches of hospital staff when patients showed emotional distress. The results show that different staff subgroups emphasised varying features of person-centred care.

Staff members with personal experience of dementia caregiving prioritised knowing the person, achieving reciprocal communication and showing an understanding of the patient's perspective. The second staff subgroup comparison revealed complementary findings, whereby ward staff that were newer to a professional care role were more likely to notice each patient as a person and notice their individual communication. These findings make two notable contributions to the research literature. First, the approach described by these two staff subgroups, staff members with personal experience of dementia caregiving and staff members newer to professional

caregiving, mirrors person-centred care[7,8] and exemplifies the most positive aspects of hospital care described in the research literature.[12] Second, these staff said that they communicated with the patient, hence they involve patients in their care; such involvement is required as a fundamental standard of person-centred care and is particularly lacking for patients with dementia when in hospital.[9]

In previous research,[25] hospital staff have expressed having more confidence in their working when they have personal experience of dementia caregiving. The current study adds to the literature by asking how staff with personal experience of dementia caregiving approach care when compared with their colleagues without such experience, using a cross-sectional design; the findings would support that personal experience of dementia caregiving contributes knowledge, confidence and a positive attitude to professional working as described elsewhere.[25,26] We also speculate as to whether career longevity promotes knowledge, but fosters a 'professional' approach to dementia care whereby technical expertise and shorthand are valued for the purposes of documentation and risk management.[6] This shorthand is consistent with expert thinking that has been refined over time, as compared with staff newer to the profession who make decisions more slowly and are influenced by more information,[27] such as that relating to each individual patient. Traditional training in dementia care has prioritised medical care,[5] which reflects the approach prioritised here by longer-standing staff. In this study, staff with more years of professional experience tended to describe behaviour as agitation or aggression and were more likely to list medical causes of emotional distress such as infection or delirium, which suggests an approach that overlooks the complexity of a person beyond diagnostic

criteria.[28] This interpretation does not dismiss the dedication of staff who sustain a career in working with patients with dementia, as was shown in the compassionate responses of all ward staff in this study. Instead we aim to recognise the variations in approaches within a team.

We therefore recommend that the personal caregiving experiences and the novice curiosity of hospital staff delivering dementia care are considered to be two areas of expertise within staff teams. For example, the approaches described in this study could contribute valuable content to staff training interventions; training in the format of learning with colleagues and embedding learning in routine practice has been reported to be more effective in improving personalised dementia care than formal training interventions, which are not always suitable in their content and are not available to all staff.[14,25] The current findings support future investment in models of training whereby colleagues who have differing expertise learn with and from each other. Flexible training formats,[14] which emphasise collaborative learning and the sharing of existing expertise are recommended.

The person-centred approach described could also be given merit by hospital management and clinical leaders. Hospital staff have expressed beliefs of having little authority or permission to influence routine patient care,[5] though their contributions to service development and delivery can be particularly valuable in the delivery of person-centred dementia care.[5,25] Hospital staff providing dementia care have asked that their existing knowledge and skills be recognised.[5] This study shows the potential value of developing a hospital culture of staff learning together and sharing approaches that work.

Strengths and weaknesses

Strengths: primarily, we sought to discover the existing expertise within routine hospital care using the ethnographic freelisting method. This is important given the manifold barriers to hospital staff implementing best practice dementia care, such as having limited time.[5,13,14,26] We built upon prior research recommendations to minimise future investments in interventions that rely on theoretical models of care only and have not been tested in a clinical setting; this is to increase the real-world impact of the research.[3] The findings offer some discussion as to how person-centred approaches could be enhanced, and how patients with dementia could be involved in their care.[2,10] We sampled a representative hospital ward staff team that included different professions. Limitations: the approach described by ward staff does not necessarily equate to care delivered for all patients at all times. Whilst we have detailed the knowledge of staff, we have not directly observed their behaviour. The generalisability of the findings is limited by the setting being a single hospital ward in the UK, and by the possible recall bias of participants when interviewed about their practice. The findings require more robust testing and replication. Future research would benefit from measuring staff knowledge, attitude and training in dementia care as possible confounding variables in the delivery of person-centred care, alongside measures of personal and professional caregiving experiences.

Implications for clinicians and policymakers

We intend the findings to influence staff training interventions, specifically, hospital staff have repeatedly expressed the value of collaborative learning with peers that these findings would encourage.[25,29] We also recommend that the person-centred approaches detailed here be given merit by management to enable change in the

hospital culture.[5,29] Possible benefits to sharing expertise amongst multiple professions include building a reliable skillset that is more resistant to staff turnover and is valuable when family members are not consistently available.

Unanswered questions and future research

These findings require follow-up in three ways: first, replication beyond a single UK hospital ward; second, further exploration of how patient, staff and the hospital system variables interact to complicate the delivery of person-centred care; third, evaluative studies of how personal experience and professional curiosity can be prioritised in practice.

The lead author affirms that this is an honest, accurate, and transparent account of the study.

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Tables

Tables 1a-1d. Top six list items with the greatest difference in salience between hospital staff with and without personal experience of dementia caregiving for each of four interview questions.

Table 1a. Interview question: how to notice emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
The person will tell you: Patients are able to say that they are distressed, such as describing an emotion.	-0.221	*Withdrawn*: Included being quiet, disengaged or subdued; patients were described as being distressed within themselves.	0.107
Body language or posture: Including descriptions of a patient waving, pointing or putting hands to their head.	-0.197	*Asking for family or friends*: Included asking where family are, whether family are safe, whether family know where they themselves are.	0.105
Face or facial expression.	-0.160	*Easily visible*: Distress was visible and seen by looking at somebody; or distress is obvious; 'it's not hard to tell'.	0.104
Seeking, searching, looking for someone or something: Didn't always describe what was being searched for.	-0.118	*Anxious or frightened*.	0.103
Behaviour or actions: Sometimes described as a change for the person.	-0.093	*Repeated questions*: Included patients not feeling reassured.	0.101
Knowing the person: To be able to notice distress; the patient not being their usual self, something being different.	-0.082	*Wanting to leave*: Included attempting to leave; asking to go out or for doors to be unlocked, trying exit doors, banging doors, absconsion, calling for a taxi, asking about the train station.	0.081

Table 1b. Interview question: causes of emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience

Not knowing where they are: Disorientation, asking where they are and not knowing that they are in hospital.	-0.176	*Being orientated or contradicted*: Included descriptions of others not understanding a person's reality, questioning them and what they see or not giving an answer that a patient wants to hear.	0.122
Strangers: Unfamiliar or unknown people, unfamiliar faces and voices and patients not knowing who is around them.	-0.145	*Wanting to go home*: Missing home, asking to go home.	0.112
Hunger or thirst.	-0.134	*Being away from loved ones*: wanting to see family or friends, looking for them and thinking about them, not being with them, awaiting or not receiving visitors and not knowing where family are. Specific family members, such as 'mum' or 'husband', were mentioned. Descriptions also included feeling left or abandoned by family.	0.085
Expression difficulties: Patients being unable to express what they want to say or not being understood by others; included being unable to verbally express pain or emotions.	-0.124	*Frightened, scared or fearful*.	0.077
The hospital environment: An unfamiliar, new or foreign setting; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	-0.109	*Infection*.	0.063
Upset by staff: Included descriptions of the attitude, skills and manner of staff and the way people were spoken to causing distress; included staff being impatient and not understanding how to talk to somebody.	-0.102	*Rumination, remembering the past*: Included patients replaying past scenarios, experiencing flashbacks of earlier life.	0.060

Table 1c. Interview question: responses to emotional distress.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
Empathise: Trying to understand, tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	-0.164	*It depends on the level of distress*.	0.134
Distraction: Sometimes distracting from the person's thoughts or mood; changing topic; distracting for a short time.	-0.136	*Activities*: A range of games and puzzles were listed, including jigsaws, draughts, bingo, skittles crosswords and word puzzles, flower arranging and building.	0.109
Listening: Included telling the patient they are listening.	-0.103	*Contact with family*: Enabling contact with family included speaking with family on the phone, allowing family to visit at flexible times or stay longer.	0.093

Sometimes can't help: Staff said they sometimes couldn't help or couldn't fully understand; not every time; included stating that they don't know the patient well.	-0.100	*Reassurance*: Giving reassurance generally was listed without further description.	0.092
Mirroring: Mirroring the person, their actions or volume; described building off each other.	-0.097	*It depends on the circumstances*.	0.063
Talking: Sharing conversation and stories; included talking whilst walking.	-0.096	*Comfort*: Included descriptions of being calming or nurturing.	0.058

Table 1d. Interview question: responses to emotional distress that seem to work.

Higher salience items for staff members with personal experience of dementia		Higher salience items for staff members without personal experience of dementia	
List item	Difference in salience	List item	Difference in salience
Sometimes can't help: Staff said they sometimes couldn't help, sometimes nothing works or a response doesn't work; responses that work are never guaranteed.	-0.110	*Reassurance*: Giving reassurance generally was listed, including reassurance not to worry or that problems would be resolved.	0.174
Empathise: Trying to understand, putting self in their place; telling them they understand.	-0.101	*It depends on the level of distress*.	0.082
Knowing the person: Staff described having to know or get to know the person; included each person being different/unique; being person-centred; being patient-led; different responses working for different people.	-0.088	*Contact with family*: Enabling contact with family included speaking with family on the phone, allowing family to visit at flexible times.	0.076
Comfort: Included descriptions of calming somebody, being nurturing or giving emotional contact.	-0.077	*Allowing space*: To pace or let their anger out.	0.073
Change the member of staff: Included changing to a more familiar staff member or changing to a male or female staff member.	-0.072	*Listen*: Included telling and showing the patient they are listening.	0.062
Consult colleagues: Included consulting with and learning from multidisciplinary colleagues.	-0.067	*All/any responses*: Anything, everything or all of them was listed.	0.058

Supplementary table

Supplementary table S1a-d. Top six list items with the greatest difference in salience between hospital staff with more years of professional experience and fewer years of working experience for each of four interview questions.

Table S1a. Interview question: how to notice emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Crying: Descriptions include crying, tears and weeping.	-0.400	*The person will tell you*: Patients are able to say that they are distressed, such as describing an emotion.	0.168
Agitation: The words 'agitation' or 'agitated' are used; verbal or physical agitation is described.	-0.384	*Body language or posture*: Including descriptions of a patient waving, pointing or putting hands to their head.	0.159
Unsettled, fidgety, not relaxed, fiddling: Being unsettled was described; descriptions include fiddling, fidgeting, fussing with items, tearing items, pulling at clothing or equipment, being flustered or unable to settle.	-0.320	*Face or facial expression*.	0.130
Aggression: The terms 'aggression' or 'aggressive' were used without further description. Descriptions included.	-0.250	*Easily visible*: Distress was visible and seen by looking at somebody; or distress is obvious; 'it's not hard to tell'.	0.111
Anxious or frightened.	-0.207	*It is different patient to patient*: state distress is shown differently by different people; can include distress depending on the person's life experiences.	0.105
Knowing the person: To be able to notice distress; the patient not being their usual self, something being different.	-0.142	*Behaviour or actions*: Sometimes described as a change for the person.	0.097

Table S1b. Interview question: causes of emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
The hospital environment: An unfamiliar, new or foreign setting; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	-0.242	*Lots of different things*: staff said there are lots of/a variety/a myriad of things that cause distress; the causes can change; the reasons for distress need to be worked out or analysed.	0.151

Infection.	-0.153	*Being confused.*	0.117
Frustration.	-0.143	*Strangers*: Unfamiliar or unknown people, unfamiliar faces and voices and patients not knowing who is around them.	0.113
Delirium.	-0.129	*Being too hot or too cold.*	0.098
Missing belongings and objects: being without familiar things such as a teddy bear and sleeping in a different bed.	-0.129	*Hunger or thirst.*	0.096
Not knowing where they are: Disorientation, asking where they are and not knowing that they are in hospital.	-0.112	*Memory problems:* forgetfulness, forgetting having their questions answered, forgetting reassurance, being unable to recall their date of birth or items on a cognitive screening tool.	0.091

Table S1c. Interview question: responses to emotional distress.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Space: staff listed offering a different or preferred environment, room or space. This included using the café away from the ward.	-0.221	*Comfort:* Included descriptions of being calming or nurturing.	0.167
Reassurance: listed without further description.	-0.144	*Ask the person:* asking what the matter is or why they are distressed, asking what they would like.	0.093
Empathise: Trying to understand, tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	-0.137	*Talking*: Sharing conversation and stories; included talking whilst walking.	0.091
A cup of tea.	-0.130	*Leave them:* included allowing space for the patient to let off steam or wind down, being hands off, allowing them liberty, not stopping somebody from wandering, staff keeping their distance for the safety of colleagues or patients.	0.091
Touch: included holding a person's hand or offering a hug.	-0.127	*Mirroring*: Mirroring the person, their actions or volume; described building off each other.	0.069
Body language: listed without further explanation, meaning staff used their body language in their response.	-0.123	*Identify the cause or reason for distress*: identifying the problem or the need; fathoming, working out or getting to the grounds of the distress.	0.057

Table S1d. Interview question: responses to emotional distress that seem to work.

Higher salience items for staff members with more years of professional experience		Higher salience items for staff members with fewer years of professional experience	
List item	Difference in salience	List item	Difference in salience
Space: offering a different or preferred environment,	-0.280	*Knowing the person*: Staff described having to know or get to know the person; included each person being	0.271

room or space. This included quiet and still spaces.		different/unique; being person-centred; being patient-led; different responses working for different people.	
Touch: descriptions of touch included holding a person's hand or offering a hug.	-0.133	*It depends on the circumstances.*	0.174
It depends on the level of distress.	-0.126	*Listen*: Included telling and showing the patient they are listening.	0.148
Sitting with, being with, engaging with. Included descriptions of giving attention and being a person without uniform or equipment.	-0.099	*Change the member of staff*: Included changing to a more familiar staff member or changing to a male or female staff member.	0.117
All/any responses: Anything, everything or all of them was listed.	-0.076	*Talking*: sharing conversation, chatting, communicating.	0.114
Activities.	-0.067	*Sometimes can't help*: Staff said they sometimes couldn't help, sometimes nothing works or a response doesn't work; responses that work are never guaranteed.	0.093

Standards for Reporting Qualitative Research (SRQR)*

http://www.equator-network.org/reporting-guidelines/srqr/

BMJ Open Manuscript ID bmjopen-2018-025655

The importance of personal and professional experience for hospital staff in person-centred dementia care: a cross-sectional interview study using freelisting in a UK hospital ward

	Page/line no(s).
Title and abstract	
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1, line 3
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 5, line 10
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Page 7, line 6
Purpose or research question - Purpose of the study and specific objectives or questions	Page 8, line 3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/ interpretivist) is also recommended; rationale**	Page 9, line 44
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 9, line 20
Context - Setting/site and salient contextual factors; rationale**	Page 8, line 48
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 8, line 44

Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 9, line 17
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Page 9, line 40
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Page 9, line 40
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 8, line 44
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 10, line 6
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 11, line 19
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 10, line 8

Results/findings

Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 16, line 25
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Page 25, line 5

Discussion

Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Page 17, line 18
Limitations - Trustworthiness and limitations of findings	

Other

Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 19, line 27
Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 3, line 21

*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:
O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388