Petty, Stephanie ORCID logoORCID: https://orcid.org/0000-0002-1453-3313, Dening, Tom, Griffiths, Amanda and Coleston, Donna Maria (2020) Meeting the Emotional Needs of Hospital Patients With Dementia: A Freelisting Study With Ward Staff. The Gerontologist, 60 (1). pp. 155-164.

Abstract

Background and Objectives: People with dementia are vulnerable when in hospital, with serious risks to their physical and emotional wellbeing. Hospital staff are expected to understand and respond to the emotions of the patient; however, it is not known how this can be achieved. We provide a concise description of achievable emotion-focused care for patients with dementia.

Design and Methods: Exploratory qualitative interviews were conducted with a whole UK hospital ward providing dementia care, constituting 47 staff members. Staff responded to four questions using ethnographic freelisting. They listed: (1) all the ways they notice the emotional distress of patients with dementia, (2) the causes of emotional distress, (3) all the ways they respond and (4) the responses that seem to work. Cultural consensus analysis was applied.

Results: A single-factor solution for each question indicated a consensus approach to emotional distress. Emotional distress was noticed from agitation (Smith's saliency score, 0.418), crying (0.350) and increased mobilising (0.238). The main causes of distress were the unfamiliar hospital environment (0.355) and not knowing what is happening (0.313). The most effective ways to respond to emotional distress required knowing the person (0.299), talking (0.283) and being with the person (0.269).

Discussion and Implications: The findings expand what is understood of behavioural and psychological symptoms of dementia; these communicated emotional distress with well-understood causes. Prioritised ways of responding to emotional distress described person-centred care. The results offer a menu of options for providing emotionally-responsive care for patients with dementia in hospital. Future research should evaluate the care described.

Key words

Person centred care, qualitative research, ethnography

Introduction

Hospital dementia care

Patients with dementia are particularly vulnerable when in hospital. Admission can denote a crisis situation (Heath, Sturdy, & Wilcock, 2010), which is often followed by multiple and overlapping realities for the patient of being physically unwell, confused and in receipt of unsuitable treatment (Boaden, 2016; Digby, Lee, & Williams, 2017; Lyketsos, Sheppard, & Rabins, 2000; National Institute for Health and Care Excellence, NICE, 2018; Sampson, Blanchard, Jones, Tookman, & King, 2009). Furthermore, the environment within which patients feel unwell has been widely recognised as stressful (Boaden, 2016; Brooke & Semlyen, 2017; Cowdell, 2010; Dewing & Dijk, 2016; Goldberg, Whittamore, Pollock, Harwood, & Gladman, 2014; Heath et al., 2010). These are conditions for emotional distress. It is in this context that the care provided for hospital patients with dementia has been addressed as an international priority (World Health Organization, 2017). The scale and the complexity of meeting the needs of patients with dementia (Boaden, 2016; NICE, 2018) means that research is welcomed into how care can be improved in achievable ways.

Emotional distress in hospital

The research literature contains descriptive accounts of patients with dementia showing emotional distress in hospital (Boaden, 2016; Clissett, Porock, Harwood, & Gladman, 2013; Cowdell, 2010; Dewing & Dijk, 2016; Innes, Kelly, Scerri, & Abela, 2016; Scerri, Innes, & Scerri, 2015). These report that emotional distress is experienced but is infrequently understood or addressed. Within the third national audit of dementia care in hospitals, The Royal College of Psychiatrists in the UK (Royal College of Psychiatrists, 2017) reported that times of emotional distress, the causes of distress and the possible responses of hospital staff to distress are not well documented. This was also highlighted in a proposed theory of effective dementia care for the hospital context (Handley, Bunn, & Goodman, 2017). Hence, this is not currently a routine or prioritised aspect of care. The Royal College of Psychiatrists reported that overlooking this could have implications for the patient’s presentation, further challenge of hospital staff, the use of antipsychotic medication and increased healthcare costs. Consistent with these views, the available guidance from the UK’s National Institute for Health and Care Excellence (NICE, 2018) recommends that hospital staff understand and respond to emotional distress. This is an important component of integrated care, meaning that patients receive the care that they need (Boaden, 2016; Mental Health Foundation, 2013; NICE, 2018) and physical and mental health needs are not treated in isolation (Petty, Dening, Coleston, & Griffiths, 2018a; Petty, Harvey, Griffiths, Coleston, & Dening, 2018b; Royal College of Nursing, 2014). The available guidance does not yet detail how this can be achieved (NICE, 2018; Scerri, Innes, & Scerri, 2017).

Responses to emotional distress by hospital care staff

Patients with dementia rely upon hospital staff to maintain their wellbeing (Brooke & Semlyen, 2017; Dewing & Dijk, 2016; Digby & Bloomer, 2014; Edvardsson, Sandman, & Rasmussen, 2011), though the skills required of hospital staff are not demonstrated routinely or consistently (Cowdell, 2010; Dewing & Dijk, 2016; Digby et al., 2017; Goldberg et al., 2014; Griffiths, Knight, Harwood, & Gladman, 2014; Handley et al., 2017; Moyle, Borbasi, Wallis, Olorenshaw, & Gracia, 2010). It is not known how the widely-recommended emotion-focused approaches (Brooker & Surr, 2006; Feil, 1993; Kitwood, 1997) translate into hospital care (Dewar & Nolan, 2013; Edvardsson et al., 2011; Scerri et al., 2015); in part this is due to the complex systems of rules and order within hospitals (Street & Coleman, 2012) and the priorities of managing risk and delivering medical care (Brooke & Ojo, 2017;

Handley et al., 2017). In a review of all dementia care training interventions for hospital staff, Scerri et al. (2017) found an absence of emotion-orientated training and reported that the wellbeing and emotions of patients were not evaluated as an outcome in any study. Additionally, in an earlier review of hospital care for patients with dementia, Dewing & Dijk (2016) criticised the over-emphasis on theoretical recommendations and asked what care is achievable specifically in this context.

The purpose of this study is to outline how hospital staff can notice, understand and respond to the emotional distress of patients with dementia within routine practice.

Design and Methods

Exploratory qualitative interviews were conducted with multidisciplinary hospital staff using freelisting methodology (Weller & Romney, 1988), an ethnographic method used to capture the viewpoints of people inside a culture.

Cultural consensus is a means to examine whether the responses given by individuals in a group share an underlying definition, and the extent to which there is shared cultural knowledge (Romney, Weller & Batchelder, 1986). The concept was used here to determine whether a single description was reached that was agreed by all hospital staff for each question, hence whether the responses conveyed a cultural consensus about emotional distress.

Participants

Staff members were recruited from one ward within a teaching hospital in the UK. The ward was a member of Dementia Action Alliance, which connects over 150 national organisations in the UK, including hospitals, royal colleges and Government bodies, who show a commitment to improving dementia care in England. This setting was chosen in attempt to produce findings generalisable to other hospital settings, and in recognition that there is no recommended design of hospital services for patients with dementia in Europe (Hermann, Muck, & Nehen, 2015). A total of 47 hospital staff members constituted the whole ward staff team over a three-month period, as determined by the staffing duty roster, and included bank and temporary staff members and all shifts including night shifts. There were no exclusion criteria. The whole ward was sampled in recognition of the skills of the whole hospital workforce (Ashton & Manthorpe, 2017; Boaden, 2016; Innes et al., 2016). The number of participants was determined by the analysis method (Weller, 2007) and was in line with previous studies (Barg et al., 2006; Martinez Tyson, Castaneda, Porter, Quiroz, & Carrion, 2011; Schrauf & Sanchez, 2008).

All participants volunteered to take part and gave written consent. Ethical approval was granted by the Health Research Authority (18/HRA/0221).

Data collection

The first author collected spoken lists within individual, face-to-face interviews. Hospital 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 somebody is emotionally distressed; (2) what they think causes them to be emotionally distressed; (3) all the ways they respond when somebody is emotionally distressed; (4) of the ways to respond, all the things that seem to work. The researcher then asked staff to provide demographic information. The interview was audio-recorded.

Data analysis

Each interview was transcribed in full. List items were taken from each transcript and each unique listed item was given a code, summarised as three-letters. A code book was used to document each code, its description and all verbatim words and phrases that contributed to that code (see Supplementary Table S1). In creating the code book, the aim was to retain all unique list items. The researchers did not attempt to group items by theme. Therefore, as many unique terms were retained as possible in case participants used different words to express different things. This process was iterative and required reference back to the original recordings and transcripts to ensure that the meaning of each participant was retained. To improve the reliability of coding, the code book for each question was reviewed in full by all authors and edited through group discussion; a sample (10%) of transcripts was coded independently by two reviewers. The codes for list items became the dataset for analysis. Each list was written in ASCII computer language and analysed with ANTHROPAC software (Borgatti, 1996).

The ANTHROPAC freelist procedure was used to calculate: the total number of times that each item was listed (frequency), the average position in a list when listed (average rank) and the salience of each item, using Smith's saliency score. Salience is a measure of how important an item is and is calculated using both the frequency and rank of an item; an item with higher salience will have been mentioned more frequently and earlier in lists. Salience scores were plotted as a scree curve; breaks in the curve showed the difference between items that were culturally shared and those that represented individual responses (see Supplementary File S2). Only items with higher salience and items mentioned by at least 20% of respondents will be displayed in the results table for each question, as these criteria serve to mark the boundary of the cultural definition (Barg et al., 2006).

ANTHROPAC recode and consensus procedures were used to organise the data into a matrix with rows representing staff members and columns representing list items (a participant-by-item matrix); cells contained a 1 if an item was listed and a 0 if it was not. Factor analytic methods then used a participant-by-participant correlation matrix, with staff members represented as rows and columns, to indicate agreement between staff members. The analysis used participants as the variables in factor analysis.

Cultural consensus, and the coherence of the cultural domain, is shown by a single-factor solution and stronger agreement between staff is shown by a higher ratio between the first and second factor. A large first eigenvalue relative to the second eigenvalue, with a ratio greater than 3:1, shows that a single domain exists (Handwerker & Borgatti, 1998). Knowledge scores represent each staff member's awareness of a domain by showing the level of agreement of each staff member with the cultural consensus, or each staff member's loadings on the first factor, where the maximum value is 1.0.

The analysis was repeated separately for each of the four interview questions.

Results

Participant characteristics

Participant demographic data is shown in Table 1. The majority of hospital staff were female (70%) and White British (75%). The professions with the highest representation were health care assistants (43%) and nurses (26%). The mean length of time working on the ward was six years (SD = 7.4, range 1 week to 28 years). The mean length of time working with people with dementia was 11 years (SD = 9.4, range 3 months to 37 years).

Responses to freelisting questions

For each of the four questions, the most salient list items, their frequency and average list position are given in Tables 2-5. Collectively, multidisciplinary hospital staff produced a single, shared description of how to notice, understand and respond to the emotional distress of patients with dementia. This reflects a comprehensive and shared understanding of how to address the emotional needs of patients with dementia when in hospital.

Question (1) How to notice emotional distress

A total of 67 unique descriptions of distress were listed. The mean list length was 8.3 items (SD = 3.4). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 29.4 and 1.5 respectively, with a ratio far greater than 3:1 (Handwerker & Borgatti, 1998). The average knowledge score was 0.8 (SD 0.1). The most salient items for ‘how to notice emotional distress’ (with Smith’s saliency score) were: agitation (0.418), crying (0.350), mobilising more (0.238), restlessness (0.235), facial expression (0.215), body language (0.209), aggression (0.170), being withdrawn (0.169), disorientation or confusion (0.169), anger (0.155), verbal aggression (0.154) and calling out or shouting out (0.150). ‘Agitation’ was listed by 53% of participants and on average was given third in a list. Agitation was the list item with the highest saliency score across all four questions, showing the high prevalence of its use. ‘Crying’ was listed by 51% participants and tended to be ranked lower. Whilst ‘being withdrawn’ was listed by the next highest number of participants, 36%, it tended to be ranked below sixth, suggesting that being withdrawn was a less immediate way of noticing distress. See Table 2 for the 12 most salient items listed.

Question (2) Causes of emotional distress

A total of 97 unique causes for emotional distress were listed. The mean list length was 8.3 items (SD = 4.2). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 33.1 and 0.7 respectively. The average knowledge score was 0.8 (SD 0.1). The most salient items for ‘causes of emotional distress’ were: the hospital environment (0.355), not knowing what is happening (0.313), being away from loved ones (0.288), not knowing where s/he is (0.268), pain (0.150), wanting to go home (0.143), confusion (0.136) and strangers (0.124). Although ‘being away from loved ones’ was listed by the highest number of participants, 52%, on average it was listed fifth, whilst the hospital environment was listed third on average and was the most salient item. See Table 3 for the eight most salient items listed.

Question (3) Responses to emotional distress

A total of 104 unique responses to distress were listed. The mean list length was 10.7 items (SD = 5.6). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 31.9 and 0.8 respectively. The average knowledge score was 0.8 (SD 0.1). The most salient items for ‘all the ways to respond to emotional distress’ were: reassurance (0.357), talking (0.306), sitting with or being with (0.260), distraction (0.255), comfort (0.247), asking the person about their needs (0.191), a cup of tea (0.167), empathising (0.167), identifying the cause (0.166), knowing the person (0.148), listening (0.140), touch (0.137) and offering space or a different environment (0.133). The highest total of list items were given in response to this question; this question also produced the highest number of culturally shared items as shown by the scree curve plot and over 13 items being listed by more than 20% of participants. See Table 4 for the 13 most salient items listed.

Question (4) Responses to emotional distress that seem to work

A total of 70 unique items were listed. The mean list length was 5.6 items (SD = 2.1). One coherent, bounded cultural domain was represented: the first and second eigenvalues were 32.2 and 0.8 respectively. The average knowledge score was 0.9 (SD 0.1). The most salient items for ‘ways to respond that seem to work’ were: knowing the person (0.299), talking (0.283), sitting with or being with (0.269), trying all of the responses listed (0.258), reassurance (0.176) and a cup of tea (0.126). ‘Trying all of the responses listed’ was ranked highest when listed, first or second on average, but was listed by fewer participants than other list items, 28%, suggesting that a subset of staff feel well-resourced in responding to emotional distress. Most participants, 43%, said that talking to the person worked at times of distress. Knowing each person as an individual was the most salient item for this question. See Table 5 for the six most salient items listed.

Questions (3) and (4) Comparison of responses and responses that seem to work

Hospital staff listed significantly fewer items on average for responses that seem to work than they did for all responses that they try (t(46)= 7.54, p< .001). Despite listing fewer items, staff showed slightly more agreement with each other for responses that seem to work, as shown by higher knowledge scores (t(92)= 2.27, p= .026) and showed the same high levels of agreement over the most salient items as shown by the ratio between the eigenvalues for the first and second factor and the spread of salience scores shown in Tables 4 and 5. This suggests a confident consensus over responses to emotional distress that seem to work.

Discussion

This study provides an illustration of how an entire ward staff team understands the emotional needs of patients with dementia as part of routine practice in a UK hospital setting. Consensus analysis of four questions showed that a shared cultural domain underlay the descriptions given by individual hospital staff members, with a high degree of consensus. The descriptions of emotional distress and care responses given by hospital staff were ordered by priority, with items of the highest salience reported. This provides an operational definition of compassionate hospital care. This study responds to the requirement for hospital staff to provide integrated care and emotion-focused care (Boaden, 2016; Mental Health Foundation, 2013; NICE, 2018).

The main ways of noticing emotional distress listed closely match what has been labelled as the behavioural and psychological symptoms of dementia (BPSD) (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). These include: agitation or restlessness, increased mobilising, low mood, aggression, irritability and aberrant vocalisations. Importantly, though, this study challenges these symptom labels in the following ways: first, the symptom labels were listed as ways that emotional distress is communicated, thus offering some understanding of their meaning; second, the causes thought to underlie these behaviours were described in equal detail and with equal confidence as the symptom labels, giving further remit for targeted interventions; third, over fifty additional descriptions of the ways to notice emotional distress were provided beyond the twelve most-used descriptions, meaning that there is a broader lexicon available to describe a person’s behaviour than this shorthand. For example, increased mobilising was more fully described here as getting out of bed, wanting to leave the ward and looking for or searching for somebody. The behaviour described was semiotic, or meaning-driven, because a person was upset about being in an unfamiliar place, without knowing what was happening to them. The listed descriptions of distress in this study are understood as usual reactions to circumstance, rather than the symptoms of a disease. Table 3 gives examples of what could cause emotional distress for any person, regardless of diagnosis. The findings restate that the range of behaviours shown by people with dementia are heterogeneous because they reflect personal and widely variable experiences (Cerejeira et al., 2012; Petty et al., 2018a; Petty et al., 2018b; Stokes, 2017).

The leading causes of emotional distress were considered to be the unfamiliar hospital environment and the patient not understanding what is happening. Supportive of these findings, the physical hospital environment is the focus of international intervention (NICE, 2018; Waller, Masterson, & Evans, 2017; World Health Organization, 2017). The need to improve a patient’s understanding of their placement in hospital also replicates findings from other studies (Digby, Moss, & Bloomer, 2012; Edvardsson & Nordvall, 2008). However, hospital staff did not describe responding to emotional distress by addressing the physical environment or increasing orientation to time and place. Addressing these factors could prove helpful in the prevention of emotional distress.

From the numerous possible responses to emotional distress, the responses thought to work described person-centred and validating care, which is widely recommended for people with dementia than when in a hospital setting (Brooker & Surr, 2006; Feil, 1993; Kitwood, 1997); this included staff having to know each person as an individual, talking, being with the patient as a person, offering reassurance that problems can be resolved and offering a cup of tea. What staff did to try to help the persons in distress was, in one way or another, involved engaging the person as a human being in need. When distress was felt for the reasons described in Table 3, the person was helped by having someone notice them, understand them and be humane with them. Beyond the diagnosis of dementia, treating the patient with dementia as a person was key. Consistent with what staff prioritised in this study, accounts of hospital care from patients with dementia and their families have established that relationships with care staff are of greater importance than the physical environment (Cowdell, 2010; Digby & Bloomer, 2014; Edvardsson & Nordvall, 2008). Staff showed strong agreement over these effective responses to emotional distress (Barg et al., 2006; Schrauf & Sanchez, 2008).

Strengths

First, this study provided the detail of achievable care, recognising the existing knowledge of hospital staff, and such research has been called for (Brooke & Ojo, 2017; Dewing & Dijk, 2016). Importantly, the findings offered are solutions from practice, which responds to prior criticism of an overemphasis on theoretical models of person-centred care for patients with dementia when in hospital (Dewing & Dijk, 2016). The understanding offered is helpful ahead of the implementation of interventions. Second, the sample featured all professions and demographics expected in a UK hospital setting (Dewar & Nolan, 2013; Griffiths et al., 2014). A major strength of the sampling was the multi-profession perspective, with greater representation of different professions than in previous studies (Griffiths et al., 2014; Innes et al., 2016). Third, freelisting was a novel method to explore the realities of everyday practice in a hospital setting and is praised for being simple, inexpensive and an efficient way to gather meaningful information (Fleisher & Harrington, 1998).

Limitations

An important consideration when applying the findings to future care design is whether the descriptions of care given are equivalent to the care that is routinely delivered. Additionally, there is likely to be variability in the care delivered at any one time, given what is prioritised on the ward, busyness, fatigue and demands on staff including aggression and the emotional toll of being with distress and illness (Ashton & Manthorpe, 2017; Goldberg et al., 2014; Griffiths et al., 2014; Handley et al., 2017; Moyle et al., 2010). In a previous study, hospital staff reported providing person-centred interactions with patients that were not supported by observation (Innes et al., 2016). In this study, the spontaneous listing task completed within a working shift and the strong agreement between staff suggest reliable knowledge, though the care described was not observed. Additionally, we explored ways to respond to distress once it is manifest, therefore, additional questions would be needed prior to recommending interventions to prevent distress. Finally, the findings would benefit from replication beyond a single hospital site as different staff teams might contribute to a more comprehensive set of responses and might appraise effectiveness differently; this study has limited generalisability due to the homogeneous nature of the sample, and the findings reflect aspects of the English culture that might not translate well to other countries, such as the value of a ‘cup of tea’.

Implications

Implications for practice

First, commonly used labels such as agitation and aggression should be understood as meaningful behaviour by patients with dementia that conveys an emotional reaction to the circumstance of being in hospital, rather than the symptoms of a disease. Second, it is of note that the skills to respond to emotional distress described in the literature to date have been variable in all settings (Clissett et al., 2013; Edvardsson et al., 2011; Griffiths et al., 2014; Nolan, 2006; Scerri et al., 2015). Training interventions designed for hospital staff have demonstrated that translating person-centred care into practice is challenging to achieve and resource-intensive (Innes et al., 2016; Surr, Smith, Crossland, & Robins, 2016). Here, staff produced a menu of possible ways to notice, understand and respond to emotional distress. The personal connection that was prioritised at times of emotional distress could suggest a skillset that is quick to draw upon and that is transferable to a range of care situations. The results are the prioritised interventions of hospital staff who are responsible for providing care in moments of the highest challenge (Boaden, 2016; NICE, 2018) thus showing the value of these aspects of care provision. Staff demonstrated relevant knowledge and experience; the emphasis of both clinical practice and research going forward should be the implementation of this knowledge into care delivery. We recommend that the findings are applied to clinical practice given the potential benefits to patient wellbeing and staff wellbeing, the reduced use of antipsychotic medication and reduced healthcare costs (Cerejeira et al., 2012; Royal College of Psychiatrists, 2017). Third, a comprehensive understanding was shared by the whole staff team; this has implications for person-centred care being delivered more consistently, beyond what volunteer or liaison services can achieve (Dewing & Dijk, 2016; Griffiths et al., 2014; Handley et al., 2017). This also recognises the valued input of cleaning staff (Ashton & Manthorpe, 2017). Finally, the findings support further development in addressing the physical environment (Digby et al., 2012; Waller et al., 2017) and campaigns to increase the presence of family members in hospital as preventions for emotional distress (Boaden, 2016) as these were described as the leading causes of emotional distress for patients with dementia when in hospital.

Implications for research

Future research would benefit from supplementing staff report with other outcomes of interest, including observations of care (Innes et al., 2016) and patient-report (Hung et al., 2017). This study poses questions as to whether emotion-focused care is consistently delivered and asks what the multiple impacts on the system might be were it to be delivered. For example, these might include changes in staff attitude and confidence, use of medication, length of stay, incidence of falls, patient aggression and family member wellbeing (Scerri et al., 2017). Research has shown that training programmes for multidisciplinary staff in a community care setting that prioritise knowing the person with dementia can achieve these benefits (Alonzo, Mitchell, & Knupp, 2015). This research would contribute to the limited evidence that is currently available to recommend emotion-focused approaches to care in hospital (NICE, 2018).

Funding

This work was supported by “blinded for review”. The funding source did not determine the study design, methods, subject recruitment, data collection, analysis or preparation of the paper.

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Tables

Table 1. Participant demographics

	N = 47

Female	33
Age	
less than 25 years	7
25-34 years	8
35-44 years	9
45-54 years	13
55 and more	10
Ethnic origin	
White British	35
Indian	5
Pakistani	2
White background other than British, Irish or Irish	2
Other	3
Professional role	
Health care assistant	20
Nurse or student nurse	12
Occupational therapist, physiotherapist or therapy assistant	4
Doctor	3
Manager or deputy manager	3
Domestic assistant/cleaner	2
Volunteer	2
Ward clerk	1
With personal experience of dementia	18
Years working with people with dementia	
0-5 years	18
6-10 years	10
11-15 years	5
16-20 years	6
20+ years	8
Training in dementia care	
No formal training	6
Mandatory training and online courses	12
Classroom teaching	26
Qualification in dementia care	3

Table 2. Salience information for the top list items for interview question (1) how to notice emotional distress

List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
Agitation	The words 'agitation' or 'agitated' were used; verbal or physical agitation was described.	25	53	2.9	0.418
Crying	Descriptions included crying, tears and weeping.	24	51	3.6	0.350
Mobilising more	Descriptions were of more movement, including wandering, pacing, running, standing to move and getting out of bed.	16	34	4.3	0.238
Restless	Being unsettled was described; descriptions included fiddling, fidgeting, fussing with items, tearing items, pulling at clothing or equipment, being flustered or unable to settle.	14	30	3.3	0.235
Facial expression	A person's face or facial expression shows distress. This includes descriptions of anxiety, strain, upset, anger or pain showing on their face, or a change in expression.	13	28	2.8	0.215
Body language	Body language or posture was listed; descriptions included waving, pointing or moving hands or putting hands to their head.	12	26	2.7	0.209
Aggression	The terms 'aggression' or 'aggressive' were used without further description.	14	30	4.7	0.170
Withdrawn	Being withdrawn, quiet, disengaged or subdued were described. Individuals were described as being distressed within themselves.	17	36	6.4	0.169
Disorientated or confused	Confusion or disorientation were listed; included a person not understanding where s/he is, not understanding what s/he is doing or having poor attention.	15	32	6.0	0.169
Anger	'Anger' or 'angry' were listed, sometimes with explanations for the anger.	10	21	3.3	0.155
Verbal aggression	Verbal aggression was listed or descriptions of swearing, bad language or arguing were given.	11	23	4.3	0.154
Raised volume	Staff described an increase in the volume of speech. Descriptions included shouting, calling out or	14	30	5.4	0.150

crying out.

Table 3. Salience information for the top list items for interview question (2) causes of emotional distress

List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
The hospital environment	Descriptions of the environment included descriptions of an unfamiliar, new or foreign setting or the hospital setting explicitly; this included descriptions of an intrusive environment and descriptions of hospital bays and beds.	20	43	3.1	0.355
Not knowing what is happening when in hospital	Meant a person not understanding why s/he is in hospital; descriptions included asking why s/he is in hospital, denying the need for hospital and not knowing the duration of hospital stay.	20	43	3.4	0.313
Being away from loved ones	Included descriptions of 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.	24	52	5.1	0.288
Not knowing where s/he is	Disorientation to place included descriptions of a person not knowing where s/he is, asking where s/he is and not knowing that s/he is in hospital.	17	37	3.3	0.268
Pain	Pain was listed.	11	24	4.7	0.150
Wanting to go home	Staff described a person missing home, wanting to go home and asking to go home.	11	24	4.3	0.143
Confusion	'Confused' or 'confusion' were listed as single words without further description.	9	20	3.6	0.136
Strangers	Strangers, unfamiliar or unknown people, unfamiliar faces and voices and individuals not knowing who is around them were described.	9	20	4.7	0.124

Table 4. Salience information for the top list items for interview question (3) responses to emotional distress

List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
Reassurance	Giving reassurance was listed, such as ‘reassure them’, without further description. It was used to mean telling a person verbally that things would be OK.	20	43	2.5	0.357
Talking	Talking; sharing conversation and stories; talking whilst walking.	21	45	4.8	0.306
Sitting with, being with	Included descriptions of being with the person in their distress and offering company.	20	43	5.9	0.260
Distraction	Distraction was sometimes described as providing distraction from the person's thoughts or mood; changing topic; distracting for a short time.	20	43	6.2	0.255
Comfort	The word ‘comfort’ was used. Descriptions of giving comfort also included descriptions of being calming or nurturing in manner.	16	34	3.9	0.247
Ask them	Responding by asking the person; this included asking what the matter is or why s/he is distressed; asking what s/he would like.	15	32	6.2	0.191
Cup of tea	A cup of tea or cup of tea with biscuits was listed. Described as a comfort and described as allowing time together.	18	38	8.8	0.167
Empathising	Trying to understand; empathising. Descriptions included tuning in to what is troubling them, getting into their mind-set or universe; telling them they understand.	12	26	5.0	0.167
Identify the cause	Responding by identifying the cause or reason for distress, identifying the problem or the need; included descriptions of fathoming, working out or getting to the grounds of the distress; not assuming.	11	23	5.6	0.166
Knowing the person	Staff described having to know or get to know the person; included each	10	21	6.0	0.148

	person being different/unique and different responses working for different people.				
Listen	Listening was listed. Also included telling the person they are listening.	12	26	5.8	0.140
Touch	Descriptions of touch included holding a person's hand or touching their shoulder, arm or knee; offering a hug; allowing them to rest their head.	11	23	6.7	0.137
Space	Staff listed offering a different or preferred environment, room or space. This included using the café away from the ward.	14	30	8.3	0.133

Table 5. Salience information for the top list items for interview question (4) responses to emotional distress that seem to work

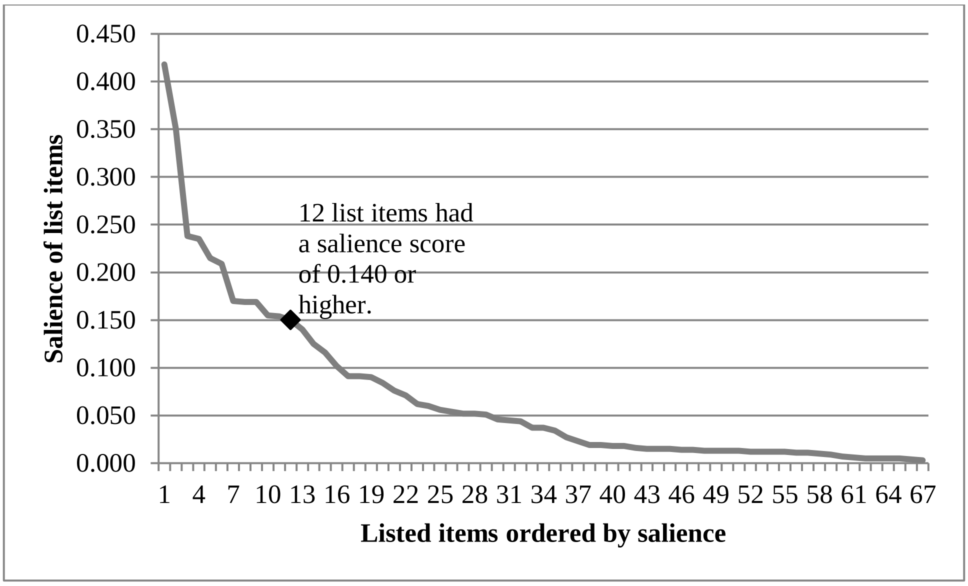
List item	Description of list item	Frequency	Listed by (%)	Average rank	Salience
Knowing the person	Staff described having to know or get to know the person; included each person being different/unique; being person centred; being patient-led; different responses working for different people.	19	40	3.1	0.299
Talking	Talking; included sharing conversation, chatting, communicating.	20	43	3.2	0.283
Sitting with, being with	Sitting with, being with, engaging with. Included descriptions of giving attention and being a person without uniform or equipment.	19	40	3.9	0.269
All of them	'Anything', 'everything' or 'all of them' were listed; sometimes any in combination.	13	28	1.9	0.258
Reassurance	Giving reassurance generally was listed, including reassurance not to worry or that problems would be resolved.	12	26	2.9	0.176
Cup of tea	A cup of tea or cup of tea with biscuits was listed.	11	23	4.6	0.126

Supplementary Table S1. A brief excerpt from the code book of all unique list items generated from the freelisting interviews

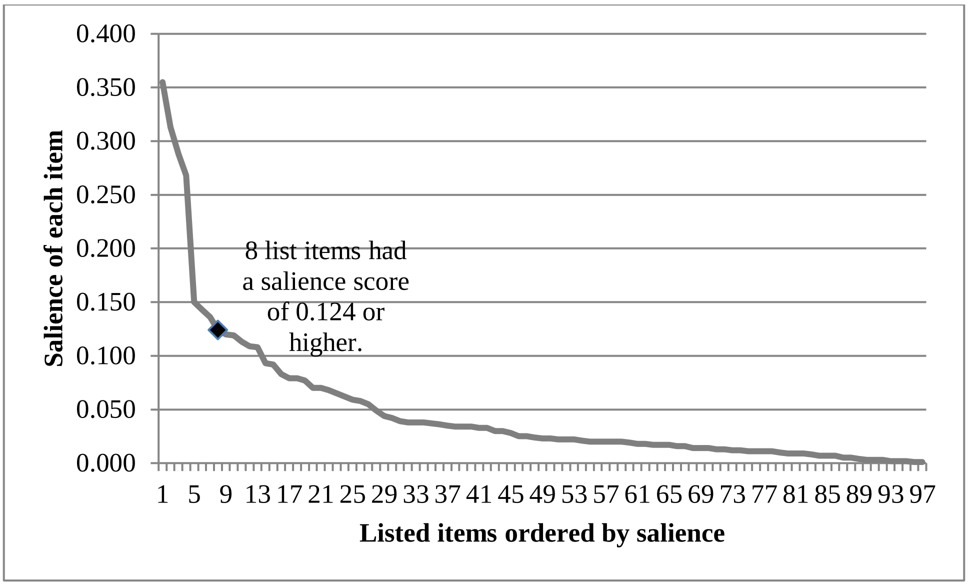
Code	Code explanation	Code content	Code summary
REA	Reassurance	'reassure', 'reassurance', 'reassure everything is fine'	Giving reassurance generally was listed without further description.
SIT	Sitting with, being with	'sit down', 'keep company', 'little bit of time', 'be with them in their distress'	Sitting with or being with included descriptions of being with the person in their distress and offering company.
TAL	Talking	'talk it through', 'talk to them about it', 'conversation, stories, chat'', 'talk whilst walking'	Talking; included sharing conversation and stories; included talking whilst walking.

Supplementary File S2. Scree curve plots showing the number of listed items with the highest salience for each of the four freelisting tasks.

Interview question (1) how to notice emotional distress

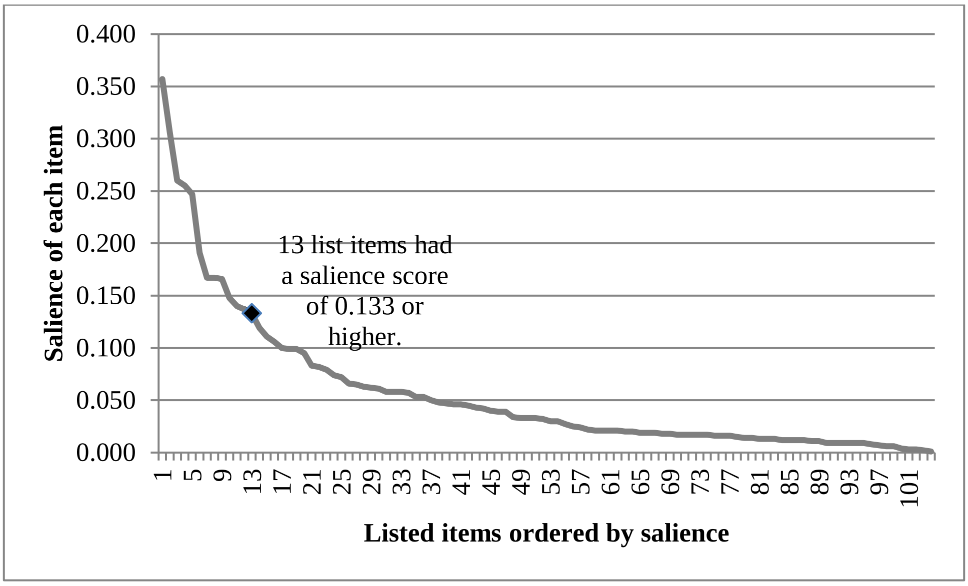


Interview question (2) causes of emotional distress



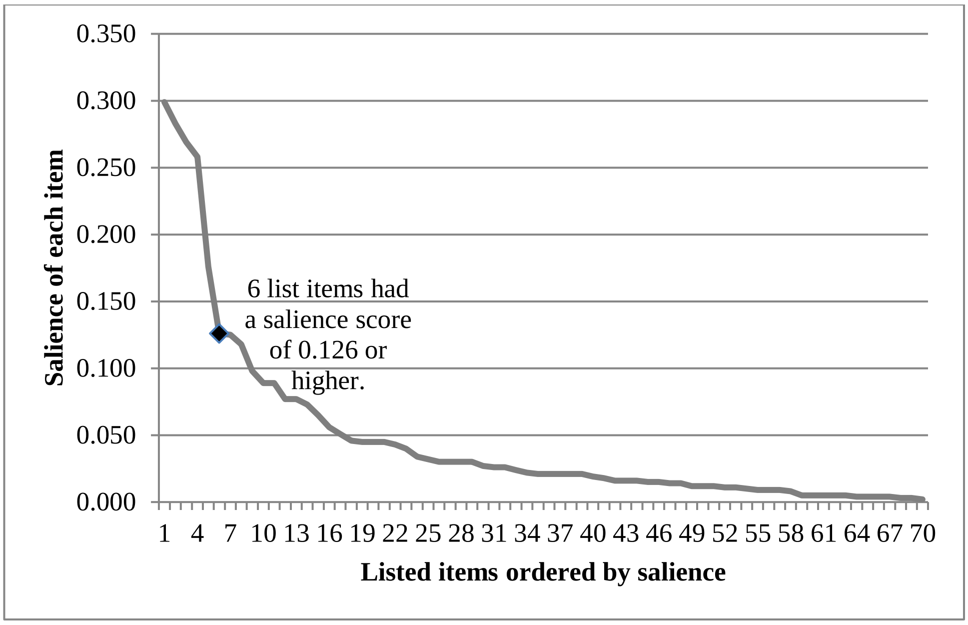
8 list items had a salience score of 0.124 or higher.

Interview question (3) responses to emotional distress



13 list items had a salience score of 0.133 or higher.

Interview question (4) responses to emotional distress that seem to work


0.350
0.300
0.250
0.200
0.150
0.100
0.050
0.000
Salience of each item
6 list items had a salience score of 0.126 or higher.
1 4 7 10 13 16 19 22 25 28 31 34 37 40 43 46 49 52 55 58 61 64 67 70
Listed items ordered by salience