Title

Improving emotional wellbeing for hospital-based patients with dementia

Abstract

Purpose: Improving hospital care for people with dementia is a well-established priority. There is limited research evidence to guide nursing staff in delivering person-centred care, particularly under conditions where patients are emotionally distressed. Misunderstood distress has negative implications for patient wellbeing and hospital resources. The purpose of this study is to use the expertise of nurses to recommend ways to care for the emotional wellbeing of patients with dementia that are achievable within the current hospital setting.

Approach: A qualitative study was conducted in two long-stay wards providing dementia care in a UK hospital. Nursing staff (n=12) were asked about facilitators and barriers to providing emotion-focused care. Data were analysed using thematic analysis.

Findings: Nursing staff said that resources existed within the ward team, including ways to gather and present personal information about patients, share multidisciplinary and personal approaches, work around routine hospital tasks and agree an ethos of being connected with patients in their experience. Staff said these did not incur financial cost and did not depend upon staffing numbers but did take an emotional toll. Examples are given within each of these broader themes.

Implications: The outcome is a short-list of recommended staff actions that hospital staff say could improve the emotional wellbeing of people with dementia when in hospital. These support and develop previous research.

Originality: In this paper, frontline nurses describe ways to improve person-centred hospital care for people with dementia.

Research paper.

Introduction

Hospital care for patients with dementia is a priority in healthcare internationally (World Health Organization, 2017). In part this is because of the high demand and the associated costs of providing this care (Annear and Lucas, 2018, Cerejeira et al., 2012, Royal College of Psychiatrists, 2017), and in part because of the negative outcomes for people with dementia when their care is poorly tailored (Digby et al., 2016, National Institute for Health and Care Excellence, NICE, 2018). These are some of the important incentives for improving person-centred care in the hospital setting, defined as care that meets the holistic needs of the person, who shares the same value and humanness as any other person (Kitwood, 1997). As one important component of person-centred care, healthcare professionals are asked to care for the emotional needs of people with dementia (Institute of Medicine, 2001). We describe emotion-focused care as actions that are orientated towards the emotional wellbeing of patients, including promoting positive emotions as well as responding appropriately at times when patients show emotional distress (Petty et al., 2020a).

The experiences of people with dementia and healthcare staff working in hospitals suggest that the emotional wellbeing and the distress of patients is often missed, confused with physical illness or ignored (Dewing and Dijk, 2014, Petty et al., 2018, Crowther et al., 2018). This can mean that care interventions are not well-tailored, and, notably, this contributes to the use of ineffective medication, longer hospital stays and increased demands on nursing staff (Royal College of Psychiatrists, 2017; NICE, 2018). Times of high emotional distress present a particular challenge that nursing staff say they feel unequipped to respond to (NICE, 2018, Hessler et al., 2018, Galvin et al., 2010), though this is a routine part of their care work (Petty et al., 2020a, Petty et al., 2020b). Hospital staff have described having insufficient training, knowledge and skills when caring for patients with dementia (Griffiths et al., 2014, Dewing and Dijk, 2014) and they report being asked to care for the emotional needs of their patients without having sufficient direction (Clissett et al., 2013, NICE, 2018, Royal College of Psychiatrists, 2017).

Person-centred care is considered best practice for people with dementia, whereby each person is considered individually, can connect meaningfully with their caregivers and can inform their own care (Kitwood, 1997); however, person-centred care is not consistently delivered in real-world practice (Brooke and Ojo, 2017, Brooke and Semlyen, 2017, Dewing and Dijk, 2014). The needs of patients with dementia have been shown to be infrequently understood by hospital staff, in addition to there being competing priorities in a hospital ward that make delivering person-centred care more difficult (Brooke and Ojo, 2017, Samra et al., 2015). Hospital staff and patients have described how prioritised aspects of care, such as timetabled care tasks, can cause patients to resist care and mean that staff cannot respond positively to their needs (Featherstone et al., 2019).

A review of current evidence shows that any recommendations made for improving dementia care in hospitals, including ways to respond to holistic and emotional needs, must recognise existing priorities of demonstrating quality medical care and managing risk (Brooke and Ojo, 2017, Handley et al., 2017) and must be sensitive to resource constraints that vary by ward. Therefore, this study asks nursing staff to describe the circumstances under which it is possible for them to attend to the emotional wellbeing of their patients with dementia within routine practice in an exploration of the facilitators and barriers.

Methods

Setting and participants

The study setting was two wards within an independent hospital in the UK offering long-term placements for patients diagnosed with dementia and mental and physical health comorbidities. The setting was chosen because of the wards' routine care for people with complex clinical presentations and high distress and was sampled in attempt to find solutions to inform hospital practice more widely (NICE, 2018). Patients were admitted because of behaviour found to be challenging. Mean patient age was 75 years (SD 7.98); mean duration of stay was 2.43 years (SD 2.06) for 27 beds. A multidisciplinary team supported nursing staff and included a consultant psychiatrist, clinical psychologist and occupational therapist; physiotherapy, dietetics and social work involvement required referral.

Participants were employed as Registered General or Mental Health Nurses or nursing assistants for a minimum of three months, and were recruited using non-random convenience and volunteer sampling. The number of participants was determined by the analysis method; 12 participants were recruited in attempt to reach stable interview responses and find the main response themes (Guest et al., 2006).

Data collection

Face-to-face interviews were conducted using a semi-structured interview guide. Nursing staff were asked to keep in mind their routine working with people with dementia and were asked to describe their role, the hospital context, their own and colleagues' practice, and the facilitators and barriers to emotion-focused care provision. Interviews took place in a confidential room on each of the wards within staff working hours; interviews lasted 9-24 minutes (mean duration 15 minutes) and were audio-recorded. Staff then provided demographic information. The first author, who was a clinical psychologist and academic researcher with no role on either ward, conducted all interviews and transcribed them in full.

Data analysis

Authors undertook thematic analysis of the interview transcripts following an established protocol (Braun and Clarke, 2006). The transcripts were read, re-read and coded line by line so that the details in the text that explicitly answered the research question were found and labelled. Text could be retained beneath more than one code. All themes originated from the data. A coding scheme was drafted by the first author and developed in consultation with all authors over three iterations. An independent auditor with relevant experience examined the code framework and code descriptions. Three transcripts were coded independently by the auditor and first author to improve the reliability and validity of results; recommendations made by the auditor were adopted. Data saturation was deemed to be achieved when the final two interviews did not generate new codes. The consolidated criteria for reporting qualitative research (COREQ) were used for transparency (Tong et al., 2007).

Ethics

The study was approved by hospital directors and the University of Nottingham (School of Medicine, Division of Psychiatry and Applied Psychology Research Ethics Committee, 0242). All participants volunteered to take part and gave written consent.

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Results

Participants

Eight of 12 participants were nursing assistants; four were registered nurses, one with senior status. Most were female (n=7), White British (n=10) and mostly aged 25-44 (n=8). This broadly reflects the ward's full staffing and that of other UK hospitals (Royal College of Psychiatrists, 2017). Mean length of time working with people with dementia was 11 years (SD=10.8, range 1-40).

Facilitators of emotion-focused care

Three themes emerged, shown with accompanying subthemes in Table 1.

** Table 1 here **

Theme 1: Interpersonal factors

Personalising care

A barrier that staff said they had to overcome was the lack of a consistent method to relieve upset for all patients. Therefore, staff said they needed to know the patient as a person to meet their emotional needs, including how each patient expressed their emotions.

> *'they communicate and show their emotions in different ways so you can't just say 'Right this is a great way' because it might work for one person but it won't work for another' (P12)*

> *'what I try and do is try and understand who they once were, try and find out who they are now and blend that together' (P7)*

They needed access to information provided by the patient, their families and health professionals and to know that useful information existed and how it was stored. A barrier was at the point of patient admission when relevant information was seldom readily available, presented concisely or in an agreed format.

Staff said they asked patients about their emotional needs within their routine interactions; they viewed this as ideal.

> *'speaking just to the actual person, because they'll be able to tell you something, even if it is only a tiny little thing, that tiny little thing could make their life a lot easier' (P12)*

Alternatively, information could be from personal books prepared prior to admission, which relied less on patients' verbal abilities. Staff accessed information about sources of enjoyment and comfort generated by previous care teams and family members, particularly about:

> '*all their likes and dislikes, little tips and hints. It's about getting to know them as a person' (P7)*

By knowing the patient personally staff said they could anticipate reasons for different emotions, which prevented high levels of distress being reached and prevented rapid changes in emotion; this was a particular condition that made emotion-focused care possible. Half of the participants said it was challenging to calm somebody when their level of emotional distress was high, such that the patient became distraught and distracted. Tailored responses, employed when personal information was available, included adapting communication by preparing visual aids.

The emotional toll of care interactions

Within interactions with patients, staff said they could pause and notice patient emotions, allow the patient to experience their thoughts and feelings without trying to change them, offer touch and share positive emotions. They could also hold the patient in mind when away from them.

> *‘I suppose you, you’re almost feeling it with them, it’s kind of empathy… I think you almost have to enter into what that person’s feeling to be able to support them’ (P1)*

Staff described feeling emotions themselves in order to identify with patient experiences. They chose to be with and talk with patients, and imagine the patient’s perspective.

> *‘you can’t imagine what the experience is like for the person with dementia but you can at least try to imagine what it’s like’ (P9)*

Some staff said they entered into being confused and attempted to understand visual misperceptions and hallucinations.

Some staff said it was important not to offer superficial reassurance and tell patients that everything was OK when it wasn’t.

> *‘I think a lot of the time people like to make things better for people and smooth over and go ‘Oh it’s ok’ but actually it’s not. It’s really sad’ (P1)*

Staff chose words carefully to explain their actions, to let the patient know that somebody was there to look after them and that they were in a safe place; these were carefully chosen responses to overcome giving false reassurance. Staff used nonverbal communication to portray patience and understanding, offering touch and sitting close at hand to help when patients misunderstood verbal language.

The barrier most discussed across all interviews was the unspoken requirement for nursing staff to bear emotional upset. Staff described the effort required to recall personal information when with the patient and to keep the patient ‘in mind’ when away from them. This was especially important when patients withdrew from expressing themselves. Many said the impact of keeping patients in mind carried a cost of feeling upset and disappointed in their role.

> *'you feel really awful because you can't sit with them there and then, but it's the case of, you've got to go around and you've got other things that need to be done' (P12)*

This condition was not easily overcome.

Staff said they sometimes made a decision to use humour and emphasise the happy side of things. They found sharing positive emotions to be rewarding, making sustained emotion-focused care possible.

> *'I think the thing about positive emotions is that you make a connection, a really strong connection with people, and it's really lovely (...) and it feels like you've reached the person that's inside, that's really valuable' (P1)*

Theme 2: Service design

Service prioritising of emotion-focused care

Emotion-focused care was said to be facilitated by shared motivators of duty, respect and honouring patients' human rights, and by an organisational ethos of leaders giving permission to promote emotional wellbeing alongside other prioritised tasks.

Staff said that valuing the person as a human being, the same as before the illness, with the same need for emotional comfort as any other person, was the reason for them getting to know the person, and treating them and their belongings with care.

> *'you know you've got to look after them. They're a human being. It's their right to be cared for' (P4)*

> *'treat them like they are a person, which they are, like you'd want to be treated yourself. They are still the same person, aren't they? It's just they have this illness and they didn't choose to have it' (P8)*

Many said that hospital leaders needed to model emotion-focused behaviours and judge them to be positive, because this way of working was difficult to describe and difficult to enforce but was obvious when it was present; a condition described was that senior staff members must spend time with patients.

> *'I think having it engrained in the day-to-day running, making it be ok to just sit with somebody and talk to somebody and hold their hand and give them that reassuring comfort' (P2)*

Staff described a barrier as being the difficulty identifying specific actions that were emotion-focused. They said emotion-focused actions were commonplace, such as being flexible with timings of care interventions, communicating with the person throughout interventions and spending time with the patient following interventions. When additional time was needed, staff would make effort to find small increments of time, of a few minutes. They said they persisted in making this effort in the context of having insufficient time to spend with patients.

> *'we do make time and we do fit that extra bit in even when people would be like 'I can't possibly fit that in I'm too busy'' (P8)*

Staff said they worked with, rather than against, routine care tasks, such as providing food and completing documentation, because such tasks were important and provided essential daily structure.

Staff team composition

Team working, valued contributions from different multidisciplinary professions and personal caregiving experience were reported as existing team resources that enabled emotion-focused care.

Team working, through attending meetings, attending supervision and observing colleagues to learn from them had the purpose of sharing approaches to care that worked. This was thought particularly valuable because times of increased patient need were difficult to predict and team working did not depend upon staffing numbers; however, staff agreed that emotion-focused care was facilitated by a service designed with sufficient and consistent staffing.

> *'if I can't do it personally, get somebody else, do you know if someone else isn't busy, just say 'can you just go and spend five minutes with them' (P12)*

Multi-disciplinary working supported staff in responding appropriately to complex presentations, which included physical ill health and end of life care.

> *'also work colleagues you know, watching how colleagues, whether they're nurses, nursing assistants, therapists, psychologists, psychiatrists, just watching how they interact and learning what works' (P7)*

Staff described benefits of having team members with more personal experience of dementia-caregiving, which they said often taught them how to provide emotion-focused care that was missing from their formal training. This was a fortuitous solution to a barrier said to be caused by professional training curricula.

Use of therapeutic resources

Involving family and friends in care was said to be important, as was using therapeutic activities and community connections. Staff said they invited family to participate in hospital events or made telephone contact so patients could speak with family members.

> *'get the family involved… if you need to ring her daughter you know the family can help' (P4)*

Staff also said they asked for pictures and memories of family as ways to maintain family connection in their absence and deliver emotion-focused care.

Recommended therapeutic activities included reminiscence (said to be with the aim of promoting happiness, competence and inclusion), music, sensory resources (with spaces where sounds and scents could be adapted), dolls and animals, which could promote positive emotions or offer distraction from emotional distress. Visiting community events and being visited by external agencies were examples of community involvement. These were ways to counter emotional distress caused by patient status and the dominance of the hospital structure and environment.

Theme 3: The hospital context for emotion-focused care

Staff described the hospital environment as intense, overstimulating, busy, undignified and regimented. Over half of the staff members described the hospital context as being frightening for patients with dementia. This was due to patients not having a solid construct to hold on to that helped them make sense of who they are and where they are. Staff said patients feel threatened by the behaviour of their peers. Staff said patients could feel fear, sadness and anger.

Staff described their attempts to reduce the negative impacts of the hospital setting by being present in the environment, by being physically there and by including patients in conversation, to enhance belonging.

> *'exchanges between staff and patients can normalise a situation, cause more of a homely environment rather than an institutional one' (P6)*

Staff said patients benefitted from things that made the hospital environment more familiar and provided associations with their life, having access to outside spaces and spaces that offered low stimulation.

In summary, nursing staff said that the barriers to delivering emotion-focused care in hospitals are: high intensity and rapidly changing emotional distress for patients with dementia that often reflects the reality of their situation, an intense hospital environment, the requirement for nursing staff to bear emotional upset and persist in achieving brief moments of personal connection, there being no single way to relieve patient upset, missing or inconsistent ways of sharing personal information about patients at the point of admission, emotion-focused actions being difficult to describe and enforce and emotion-focused care being missing from formal nurse training. In this context, recommended actions for improving the emotional wellbeing of patients with dementia are given in Table 2.

** Table 2 here **

Importantly, emotion-focused care was achieved by using existing resources optimally, working with care tasks and drawing upon shared team expertise. Solutions described were informed by personal experience and aspirations to provide humane and person-centred care. These solutions required personal effort and persistence.

Discussion

In this study, hospital nursing staff described the conditions under which they are able to care for the emotional needs of patients with dementia. The descriptions of the facilitators and barriers to improving person-centred dementia care are important because they provide the direction needed for further investment in this area, by being informed by the frontline staff who understand the context of hospital care.

The findings bring together in one place what has been mentioned indirectly or partially in the research literature previously. Collectively, studies from the UK and Sweden have described things that care staff can do to promote the emotional wellbeing of people with dementia (Crowther et al., 2018, Edvardsson et al., 2011, Finnema et al., 2000, Handley et al., 2017, Schneider et al., 2010). Nursing staff in this study agreed with each of these recommendations and expanded upon their descriptions, which include: accessing information about the person’s usual self and their ways of communicating, investigating reasons for different emotions, entering the patient's experience largely through being with the patient, communicating nonverbally to offer comfort using manner and touch, sharing daily activities, being guided by principles of dignity, respect and pride in care delivery, leaders modelling a culture of caring for emotional wellbeing around routine care tasks, working as a multidisciplinary team and valuing experiential learning, involving families in care, using therapeutic and community activities and reducing negative impacts of the hospital environment. The agreement across studies suggests that a shared description of good practice is emerging in the research literature.

Importantly, these findings suggest that emotion-focused care is possible under certain conditions. First, in all studies, attending to the emotional wellbeing of patients was achievable only if it occurred alongside other care priorities, such as timetabled activities of administering medication or managing mealtimes (Featherstone et al., 2019), which is an important condition for any suggested intervention for improving practice. Emotion-focused interactions were not discrete activities, but formed a culture of care, and required moments throughout the day of emotional comfort to be integrated within tasks. These were supported and modelled by leaders.

Second, achievable ways of attending to the emotional wellbeing of patients required minimal outlay (Brooke and Ojo, 2017, Houghton et al., 2016). For example, staff said they needed personal information about each patient and this needed to be presented in concise formats that are quickly accessible: rather than introducing procedures for information gathering, personal books and advance care planning documents prepared with family members are recommended tools that support patients with dementia to make their care needs known (Petty et al., 2020a). These can be shared through computerised systems and made easily accessible (Griffiths et al., 2014). As another example, expertise of staff members, including expertise of multidisciplinary colleagues and knowledge that staff have developed through building personal relationships with people with dementia, can be shared through experiential learning (Griffiths et al., 2014, Handley et al., 2017, Petty et al., 2019). Team-based learning where staff members share good practice, reflect and turn to each other for support when needed, have been recommended for nursing practice (Bridges et al., 2017). Of note, staff interviewed in this study said that team working did not depend on staffing numbers; this is a valuable finding, requiring further study.

Third, and not previously recognised in research literature, staff in this study said they allow patients to experience their thoughts and feelings without dismissing them and they feel emotional distress with them. These actions are not easily measureable and, importantly, they require personal effort for nursing staff in their pursuit of improving patient care (Dartington, 2007; Matthews and Sunderland, 2019). These actions describe a shift in orientation from the usual hospital care priorities, whereby hospital staff have described depersonalised patient care because of having too little time to think beyond their to-do list (Digby et al., 2016). In this study, nursing staff described their efforts to maintain a human connection with their patients. Therefore, the greatest barrier to caring for the emotional wellbeing of patients with dementia described in this study was the unspoken request for nursing staff to bear emotional upset. It is therefore necessary to provide the support structures they require to maintain their own wellbeing. This warrants further study to ensure that management and supervision arrangements address the emotional toll of dementia care. Sharing of positive emotions with patients is little discussed in hospital dementia care and is one partial contribution that could improve patient and staff satisfaction and manage the toll on staff of sharing distress (Brooke and Ojo, 2017, Crowther et al., 2018, Griffiths et al., 2014). However, it is important not to over-simplify the needs of patients with dementia, including their upset, even though this can reduce the demand on the care systems (Bartlett et al., 2017).

Conclusion

Perhaps the most significant finding of this study is the list of suggested solutions for improving the emotional wellbeing of patients with dementia as described by nursing staff who understand the challenges of hospital care. These provide an alternative perspective to the hopelessness and barriers to delivering tailored hospital dementia care (Crowther et al., 2018, Dewing and Dijk, 2014, Digby et al., 2016, Scerri et al., 2017, Surr et al., 2016). Supported by prior research, these begin to suggest practice that could inform hospital policy with a person-centred ethos, in this complex area of care delivery. The emphasis of clinical practice and research going forward should be to evaluate the cost and gain of embedding these recommended actions.

Strengths and limitations

A small participant sample from long-stay wards within a single hospital limits the generalisability of the findings, including how the findings might suit acute hospital settings; the sample was mostly nursing assistants and of White British ethnicity. There is no recommended design for dementia services, so staffing and resources vary widely across wards (Hermann et al., 2015; Royal College of Psychiatrists, 2017). Ward priorities and available resources in this setting are likely to differ from acute wards. The findings need replication with a larger sample from across different hospital sites. Participants volunteered to take part in the interviews, therefore, bias might have been introduced from a non-representative sample, meaning the findings could represent a limited viewpoint. Finally, the descriptions of emotion-focused practice given here need to be evaluated against objective outcomes, including patient wellbeing and medication use (Handley et al., 2017), before they inform changes made to hospital practice. The study had a number of strengths: interviews were conducted within the hospital during ward shifts to improve the applicability of the findings to real-world practice; multiple coders of the interview data and the use of independent audit strengthened the analysis and attempted to improve the reliability and validity of the findings. The findings are presented as recommended actions for hospital staff, as described personally by nursing staff, as has been missing from the literature (Dewing and Dijk, 2014; Crowther et al., 2018, Innes et al., 2016, Surr et al., 2016).

Declaration of Conflicting Interests

The authors declare that there is no conflict of interest.

References

Annear, M. J. & Lucas, P. (2018). Dementia in a regional hospital setting: contextual challenges and barriers to effective care. *International Journal of Ageing and Later Life***,** 1-29. DOI: 10.3384/ijal.1652-8670.17344

Bartlett, R., Windemuth-Wolfson, L., Oliver, K. & Dening, T. (2017). Suffering with dementia: the other side of "living well". *International Psychogeriatrics, 29*, 177-179.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology,* 3**,** 77-101. DOI: 10.1191/1478088706qp063oa

Bridges, J., May, C., Fuller, A., Griffiths, P., Wigley, W., Gould, L., Barker, H. & Libberton, P. (2017). Optimising impact and sustainability: a qualitative process evaluation of a complex intervention targeted at compassionate care. *BMJ Quality & Safety,* 26**,** 970-977. DOI: 10.1136/bmjqs-2017-006702

Brooke, J. & Ojo, O. (2017). Elements of a sustainable, competent, and empathetic workforce to support patients with dementia during an acute hospital stay: a comprehensive literature review. *The International Journal of Health Planning and Management,* 33**,** e10-e25. DOI: 10.1002/hpm.2448

Brooke, J. & Semlyen, J. (2017). Exploring the impact of dementia-friendly ward environments on the provision of care: a qualitative thematic analysis. *Dementia,* 0**,** 1-16. DOI: 10.1177/1471301216689402

Cerejeira, J., Lagarto, L. & Mukaetova-Ladinska, E. (2012). Behavioral and psychological symptoms of dementia. *Frontiers in Neurology,* 3**,** 73-93. DOI: 10.3389/fneur.2012.00073

Clissett, P., Porock, D., Harwood, R. H. & Gladman, J. R. (2013). The challenges of achieving person-centred care in acute hospitals: a qualitative study of people with dementia and their families. *International Journal of Nursing Studies,* 50**,** 1495-503. DOI: 10.1016/j.ijnurstu.2013.03.001

Crowther, G. J. E., Brennan, C. A. & Bennett, M. I. (2018). The barriers and facilitators for recognising distress in people with severe dementia on general hospital wards. *Age & Ageing,* 47**,** 458-465. DOI: 10.1093/ageing/afx198

Dartington, A. (2007). *Where angels fear to tread. Idealism, despondency, and inhibition in thought in hospital nursing.* London: Karnac.

Dewing, J. & Dijk, S. (2014). What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia,* 15**,** 106-124. DOI: 10.1177/1471301213520172

Digby, R., Lee, S. & Williams, A. (2016). The experience of people with dementia and nurses in hospital: an integrative review. *Journal of Clinical Nursing,* 26**,** 1152-1171. DOI: 10.1111/jocn.13429

Edvardsson, D., Sandman, P. O. & Rasmussen, B. (2011). Forecasting the ward climate: a study from a dementia care unit. *Journal of Clinical Nursing,* 21**,** 1114-1136. DOI: 10.1111/j.1365-2702.2011.03720.x

Featherstone, K., Northcott, A. & Bridges, J. (2019). Routines of resistance: an ethnography of the care of people living with dementia in acute hospital wards and its consequences. *International Journal of Nursing Studies,* 96**,** 53-60. 10.1016/j.ijnurstu.2018.12.009

Finnema, E., Dröes, R. M., Ribbe, M. & Van Tilburg, W. (2000). The effects of emotion-oriented approaches in the care for persons suffering from dementia: a review of the literature. *International Journal of Geriatric Psychiatry,* 15**,** 141-161. DOI: 10.1002/(SICI)1099-1166(200002)15:2<141::AID-GPS92>3.0.CO;2-5

Galvin, J. E., Kuntemeier, B., Al-Hammadi, N., Germino, J., Murphy-White, M. & Mcgillick, J. (2010). "Dementia-friendly hospitals: care not crisis": an educational program designed to improve the care of the hospitalized patient with dementia. *Alzheimer Disease and Associated Disorders*, 24**,** 372-379. DOI: 10.1097/WAD.0b013e3181e9f829

Griffiths, A., Knight, A., Harwood, R. & Gladman, J. R. (2014). Preparation to care for confused older patients in general hospitals: a study of UK health professionals. *Age & Ageing,* 43**,** 521-527. DOI: 10.1093/ageing/aft171

Guest, G., Bunce, A. & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods,* 18**,** 59-82. DOI: 10.1177/1525822X05279903

Handley, M., Bunn, F. & Goodman, C. (2017). Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review. *BMJ Open,* 7(7)*,* e015257. DOI: 10.1136/bmjopen-2016-015257

Hermann, D. M., Muck, S., & Nehen, H. G. (2015). Supporting dementia patients in hospital environments: health-related risks, needs and dedicated structures for patient care. *European Journal of Neurology,* 22**,** 239-245.

Hessler, J. B., Schäufele, M., Hendlmeier, I., Junge, M. N., Leonhardt, S., Weber, J. & Bickel, H. (2018). Behavioural and psychological symptoms in general hospital patients with dementia, distress for nursing staff and complications in care: results of the General Hospital Study. *Epidemiology and Psychiatric Sciences,* 27**,** 278-287. DOI: 10.1017/S2045796016001098

Houghton, C., Murphy, K., Brooker, D. & Casey, D. (2016). Healthcare staffs' experiences and perceptions of caring for people with dementia in the acute setting: qualitative evidence synthesis. *International Journal of Nursing Studies,* 61**,** 104-16. DOI: 10.1016/j.ijnurstu.2016.06.001

Innes, A., Kelly, F., Scerri, C. & Abela, S. (2016). Living with dementia in hospital wards: a comparative study of staff perceptions of practice and observed patient experience. *International Journal of Older People Nursing,* 11**,** 94-106. DOI: 10.1111/opn.12102

Institute of Medicine. (2001). Crossing the quality chasm: a new health system for the 21st century. Washington DC: National Academy Press.

Kitwood, T. (1997). The experience of dementia. *Aging & Mental Health,* 1**,** 13-22. DOI: 10.1080/13607869757344

Matthews, N., & Sunderland, N. (2019). Listening with feeling: emotional labour and digital storytelling in dementia care education. In B. Avieson, F. Giles, & S. Joseph (Eds.), Still here: memoirs of trauma, illness and loss (pp. 115-128). London: Routledge, Taylor and Francis Group.

National Institute For Health And Care Excellence. (2018). Dementia. Assessment, management and support for people living with dementia and their carers. NICE Guideline [NG97]. London: National Institute for Health and Care Excellence.

Petty, S., Coleston, D. M., Dening, T., & Griffiths, A. (2020a). Emotion-focused care requested by hospital patients with dementia: qualitative analysis of advance care planning documents using descriptive phenomenology. *British Journal of Neuroscience Nursing*, 16(1), 2-6.

Petty, S., Dening, T., Griffiths, A. & Coleston, D. M. (2020b). Meeting the emotional needs of hospital patients with dementia: a freelisting study with ward staff. *The Gerontologist*, 60(1), 155-164.

Petty, S., Dening, T., Griffiths, A. & Coleston, D. M. (2019). The importance of personal and professional experience for hospital staff in person-centred dementia care: a cross-sectional qualitative interview study using freelisting within a UK hospital ward. *BMJ Open*. DOI:10.1136/bmjopen-2018-025655

Petty, S., Harvey, K., Griffiths, A., Coleston, D. M. & Dening, T. (2018). Emotional distress with dementia: a systematic review using corpus-based analysis and meta-ethnography. *International Journal of Geriatric Psychiatry,* 33**,** 679-687. DOI: 10.1002/gps.4870

Royal College Of Psychiatrists. (2017). National audit of dementia care in general hospitals 2016-17: third round audit report. London: Royal College of Psychiatrists.

Samra, R., Griffiths, A., Cox, T., Conroy, S., Gordon, A. & Gladman, J. (2015). Medical students' and doctors' attitudes toward older patients and their care in hospital settings: a conceptualisation. *Age & Ageing,* 44**,** 776-783. DOI: 10.1093/ageing/afv082

Scerri, A., Innes, A. & Scerri, C. (2017). Dementia training programmes for staff working in general hospital settings: a systematic review of the literature. *Aging & Mental Health,* 21**,** 783-796. DOI: 10.1080/13607863.2016.1231170

Schneider, J., Scales, J., Bailey, J., & Lloyd, J. (2010). *Challenging care: the role and experience of health care assistants in dementia wards.* Southampton: Queen's Printer and Controller of HMSO.

Surr, C. A., Smith, S. J., Crossland, J. & Robins, J. (2016). Impact of a person-centred dementia care training programme on hospital staff attitudes, role efficacy and perceptions of caring for people with dementia: a repeated measures study. *International Journal of Nursing Studies,* 53**,** 144-151. DOI: 10.1016/j.ijnurstu.2015.09.009

Tong, A., Sainsbury, P. & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care,* 19**,** 349-357. DOI: 10.1093/intqhc/mzm042

World Health Organization. (2017). Global action plan on the public health response to dementia 2017–2025. Geneva, Switzerland: World Health Organization.