British Journal of Neuroscience Nursing

Emotion-focused care requested by hospital patients with dementia: qualitative analysis of advance care planning documents using descriptive phenomenology

--Manuscript Draft--

Manuscript Number:	
Full Title:	Emotion-focused care requested by hospital patients with dementia: qualitative analysis of advance care planning documents using descriptive phenomenology
Short Title:	
Article Type:	Original research
Keywords:	Dementia; hospitals; nursing; emotions; qualitative approaches
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Abstract:	Background: This study responds to international pressures to improve hospital care for patients with dementia. Aim: To reach a concise overview of ways to improve the emotional wellbeing of patients with dementia when in hospital by exploring their personal care requests. Methods: Written advance care planning (ACP) documents completed by patients with dementia and their caregivers were retrieved from a UK hospital (n=21) and analysed using descriptive phenomenology. Findings: Care requests showed the changeable and personal nature of emotional distress and gave the responses that patients require from hospital staff. Responses included: attending to physical health, offering reassurance, being with the patient, treating the patient as a person and providing a different physical environment. Conclusion: ACP documents offered a structured tool for informing care with succinct, personalised requests of patients with dementia. Patient requests were consistent with extensive literature defining person-centred care. Increased use of ACP in hospitals requires evaluation.
Suggested Reviewers:	Claire Surr Professory of Dementia Studies, Leeds Beckett C.A.Surr@leedsbeckett.ac.uk Work widely cited in this field of research.
	Jan Dewing Head of Person-centred Research and Practice Development, Canterbury Christ Church University jan.dewing@canterbury.ac.uk Work widely cited in this field of research.
Additional Information:	

Question	Response
Please enter the word count of your manuscript **excluding references and tables**	1968

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Short Research Report

Title Emotion-focused care requested by hospital patients with dementia: qualitative analysis of advance care planning documents using descriptive phenomenology

Abstract word count 150

Manuscript text word count 1968

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Abstract

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Conflicts of interest

None.

Funding and sources of support

This work was supported by The Retreat York as part of S Petty’s PhD studentship. The funding source did not determine the study design, collection, analysis or interpretation of data, the writing of the report or the decision to submit the article for publication.

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Keywords Dementia; hospitals; nursing; emotions; qualitative approaches

Key points

- Hospital care for patients with dementia is a national priority because of concern when care is poorly tailored.
- In this study, patients with dementia communicated ways in which their emotional wellbeing could be improved when in hospital using written advance care planning (ACP) documents.
- A concise summary of care requests was of person-centred and holistic care in the hospital setting.
- Findings suggest the value of using ACP to make knowledge of ways to personalise care available to hospital staff within their routine working, suitable for the hospital setting.

Reflective questions

In what ways can advance care planning contribute to patient care?

What are some of the important things to ask about within advance care planning documents?

Please give examples of things that hospital staff can do to respond to patients with dementia when they show emotional distress, which are considered to be person-centred.

Introduction

Personalised hospital care

Person-centred hospital care in the UK requires healthcare professionals to understand the emotional wellbeing of patients with dementia and respond appropriately (National Institute for Health and Care Excellence 2018; Royal College of Psychiatrists 2017). Personalised care planning is important because hospital dementia care is often described as being inadequate (World Health Organization 2011), with nursing staff saying they have limited time and training to communicate with patients with dementia (Pecanac, Wyman, Kind and Voils 2018). If responses to patient emotional distress were to improve, implications could include more appropriate use of medication and reduced admission durations (Houghton, Murphy, Brooker and Casey 2016). Guidance of how patient emotional wellbeing can be achieved in hospitals is beginning to emerge (Petty, Dening, Griffiths and Coleston 2018a), but currently this omits the perspective of patients with dementia.

Advance care planning

Advance care planning (ACP) is an established process within hospitals of reaching a shared understanding of a patient's needs, with the patient, their family and healthcare providers, to create a written statement of care (Piers *et al.* 2018; World Health Organization 2011). It can help healthcare professionals to achieve person-centred care, whereby the patient expresses what is most relevant to them. In the UK and USA, ACP often occurs on admission to hospital (National Institute for Health and Care Excellence 2016; NHS Improving Quality 2014) thus offering a means of systematically designing hospital care in line with best practice; however, ACP tools are mostly used to document decision-making around crisis medical procedures only (Detering, Hancock, Reade and Silvester 2010; Dixon, Karagiannidou and Knapp 2018) and patients with dementia are infrequently involved (Pecanac *et al.* 2018). Therefore, ACP could be a tool for detailing person-centred hospital care in ways beyond its current use.

When the care preferences of people with dementia have been sought in previous research, their priority has been for care that addresses their emotions (Dening, Jones and Sampson 2012a). Family members of patients with advanced dementia within UK nursing homes have also prioritised emotional support using ACP (Brazil *et al.* 2017). In a hospital setting, the perspectives of multidisciplinary staff suggest that the management of emotional distress is a routine aspect of UK hospital care (Petty *et al.* 2018a), but to our knowledge, research has not directly asked what hospital patients with dementia require when they are emotionally distressed. ACP documents can pose this question explicitly.

This article presents an exploratory study of the content of ACP documents that ask hospital patients with dementia about their care needs when they are emotionally distressed.

Methods

Participants and data collection

All available ACP documents within a hospital in the UK were retrieved by the first author between September and November 2018. Patients who had completed the documents were aged over 55 with a diagnosis of dementia, of any type and severity. ACP documents had been completed collaboratively by the patient and their personal and professional caregivers upon admission. Patients were admitted for a long-term hospital placement because of behaviour described as challenging. The setting was chosen in an attempt to find solutions where care delivery was complex (National Institute for Health and Care Excellence 2018) to ensure that any recommendations made were fit for real world practice.

The ACP document was created in 2010 by the hospital in consultation with service users. It had the following subheadings: family, friends and carers; arrangements for people or pets in their care; home, plans and finances; how the patient wishes to be treated day-to-day; named advocates. The written responses to one item were collated: '*How I wish to be treated: if I become upset and distressed and am unable to say what I need please refer to the following: …*'

Within the hospital’s routine practice, the capacity of patients to inform their care was not formally assessed prior to completing ACP documents; care planning followed best practice guidelines, was flexible in recognition of fluctuating capacity (Piers *et al*. 2018) and patients were supported by caregivers who were able to communicate effectively with them (Piers *et al*. 2018; World Health Organization 2011).

Ethics

All procedures were performed in compliance with relevant laws and institutional guidelines and the appropriate institutional committee approved them. Only anonymised data were accessed by the researchers. [*Details removed for blind review*]

Data analysis

Descriptive phenomenology was used to analyse the retrieved documents and reach a concise description of the care requested by patients with dementia collectively. The method aims to reach a summary of all that is essential from across different descriptive accounts (Colaizzi 1978) and is used when there is little existing research and when personal accounts are limited. Steps of the analysis as outlined by Colaizzi (1978) were followed closely by the first author. In brief, these were: all original documents were read multiple times; significant statements that were of direct relevance to the research question were extracted, here most data could be extracted in full given its brevity; significant statements were considered collectively as a means of moving to a representative description of all of the care requests; an exhaustive description was written that offered an overview of the essential content of all care requests; all documents were read in full and were used to verify whether patients’ experiences were captured.

To improve the trustworthiness of the analysis, all stages were detailed in an audit trail and all data were reviewed by the full research group. Three staff members working on the wards in the hospital reviewed the analysis to further reduce researcher bias and ensure that the findings were close to the original data. The first author was female and employed as a Chartered Clinical Psychologist and PhD researcher; they did not have a relationship with any participant and only anonymised data was retrieved for the purposes of the study.

The study adhered to the Consolidated criteria for Reporting Qualitative research (COREQ).

Results

Overview of ACP documents and care requests

A total of 21 ACP documents were retrieved, from a possible 44 patients admitted with a dementia diagnosis (47%); not all patients had completed the document. Patients were mostly male (male n=13; female n =8), with a mean age of 75 years (SD 7.98). All patients had an ICD-10 diagnosis of dementia but the subtype was inconsistently documented. The mean duration of hospital placement was 2.43 years (SD 2.06).

85 significant statements were extracted from the care requests made in the ACP documents and were grouped beneath three themes: holistic care requests, personalisation and distress as changeable, as resented in Table 1. A theme refers to a description or observation of the dataset as a whole; the first theme captures the content of care requests and the further two themes qualify the ways in which care requests were made. A concise summary, or ‘essential description’, of all care requests is then presented.

Essential description of the care requests

The care requests made by patients with dementia for when they experience emotional distress in hospital did not form a simplified description of care that would meet the needs of all patients. There was no typical request made to hospital staff. Patients made multiple requests for others to respond to them, which varied with the type and extent of emotional distress that they felt. Personalised care, for physical health, social and spiritual needs, were concisely described for each patient using ACP documents, meaning that the detail of how their emotional wellbeing could be improved within hospital was easily accessible.

Discussion

The results are consistent with research showing the comprehensive and personal accounts of emotional distress of people with dementia (Petty, Harvey, Griffiths, Coleston and Dening 2018b). The findings also complement the reports of multi-profession staff within UK hospitals who have recognised that the causes of emotional distress for patients with dementia are numerous and that the most effective ways to respond depend upon knowing each patient personally (Petty *et al.* 2018a). ACP requests in this study replicate the findings of Dening *et al.* (2012a) who explored preferences for end-of-life care of people with dementia in a community setting, and the main need was for personalised care. Therefore, the findings from this study show that the extensive literature into person-centred care for people with dementia (Kitwood, 1997) is consistent with what was requested personally by patients with dementia as part of their hospital care in this study. The findings from this UK hospital setting agree with previous research (Houghton *et al.* 2016; Petty *et al.* 2018a) in suggesting that hospital patients with dementia cannot be prescribed a ‘one size fits all’ care intervention. Therefore, the findings have significance beyond the UK.

Importantly, requests for care to improve the emotional wellbeing of patients with dementia were made succinctly by patients personally via ACP documents and this detail was missing from existing research literature and healthcare guidelines (National Institute for Health and Care Excellence 2018; Royal College of Psychiatrists 2017). This is important because hospital staff have reported having limited time and training to communicate with patients with dementia (Dening, Greenish, Jones, Mandal and Sampson 2012b; Pecanac *et al*. 2018), with difficulty understanding their emotional needs in particular (Annear and Lucas 2018), which can result in care being described as sub-optimal (Digby, Lee and Williams 2016). This suggests the value of ACP in making this knowledge of personalised care available to staff in a structured way within routine hospital practice.

Strengths and limitations

ACP has been mostly used in hospitals to inform crisis medical care and often omits the patient's perspective; this study contributes the patient's perspective of their holistic care needs and shows patients with mild-to-severe dementia being involved in care planning, which is considered to be a strength of the design. Data were retrieved retrospectively to capture real world practice, suggesting the applicability of the findings to healthcare. The number of documents retrieved was consistent with prevalence estimates of ACP across a range of care settings (Dixon *et al*. 2018; Triplett and Black 2008), suggesting that a representative sample was achieved. The setting was thought to be a further strength, with most research into ACP being previously located in the USA and in care homes (Dixon *et al.* 2018; van der Steen *et al.* 2014).

The main limitations are discussed here. It was not possible to quantify the extent to which patients had determined the content of their ACP documents, which capture collaborative care planning; this is important because patients and caregivers have been shown to differ in their preferences for end of life care (Dening *et al.* 2012a). Furthermore, interpretation of how the care requested by patients was translated into care delivered by hospital staff was beyond the scope of this study and raises important questions for future research. The sample was limited to one care setting, limiting the generalisability of the findings; the findings require replication beyond a single hospital site in the UK.

Currently, there is too little evaluative research into the use of ACP to make further recommendations for its use (Dixon *et al*. 2018), though ACP has the potential to increase patient satisfaction with care and reduce emotional distress for families (Detering *et al*. 2010).

Relevance to clinical practice

Existing recommendations suggest that training for healthcare staff in the purposes and legal standing of ACP could promote its more consistent use (Beck, McIlfatrick, Hasson and Leavey 2017; van der Steen *et al*. 2014). We add a further recommendation that training in ACP emphasises holistic care planning (Beck *et al*. 2017), such as asking what could improve the emotional wellbeing of patients with dementia. In this way, nursing staff can easily access information on how to personalise patient care.

Conclusion

Hospital care for patients with dementia is an international priority because of concern when care is poorly tailored. When patients are emotionally distressed, care is particularly challenging. This study presents a concise description of the care requested by a sample of hospital patients with dementia for when they are emotionally distressed, as captured within ACP documents. ACP provided a structured intervention to inform person-centred care, suitable for the hospital setting. In this regard, the study presents the perspective of patients with dementia that is mostly missing from usual care planning in hospitals.

References

Annear MJ, 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. https://doi:10.3384/ijal.1652-8670.17344

Beck ER, McIlfatrick S, Hasson F, Leavey G. 2017. Health care professionals' perspectives of advance care planning for people with dementia living in long-term care settings: a narrative review of the literature. *Dementia. 16*(4): 486-512. https://doi:10.1177/1471301215604997

Brazil K, Carter G, Cardwell C, Clarke M, Hudson P, Froggatt K . . . Kernohan G. 2017. Effectiveness of advance care planning with family carers in dementia nursing homes: a paired cluster randomized controlled trial. *Palliative Med. 32*(3): 603-12. https://doi:10.1177/0269216317722413

Colaizzi PF. 1978. Psychological research as the phenomenologist views it. In: Valle RS, King M, editors. *Existential phenomenological alternatives for psychology*. New York: Plenum. p. 48-71.

Dening KH, Jones L, Sampson EL. 2012a. Preferences for end of life care: a nominal group study of people with dementia and their family carers. *Palliative Med. 27*(5): 409-17. https://doi:10.1177/0269216312464094

Dening KH, Greenish W, Jones L, Mandal U, Sampson EL. 2012b. Barriers to providing end of life care for people with dementia: a whole-system qualitative study. *BMJ Support Palliat Care. 2*(2): 103-7. https://doi:10.1126/bmjspcare-2011-000178

Detering KM, Hancock AD, Reade MC, Silvester W. 2010. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ, 340:* (c1345). https://doi:10.1136/bmj.c1345

Digby R, Lee S, Williams A. 2016. The experience of people with dementia and nurses in hospital: an integrative review. *J Clin Nurs. 26*(9-10): 1152-71. doi:10.1111/jocn.13429

Dixon J, Karagiannidou M, Knapp M. 2018. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. *J Pain Symptom Manag. 55*(1): 132-50. https://doi:10.1016/j.jpainsymman.2017.04.009

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. *Int J Nurs Stud. 61:* 104-16. https://doi:10.1016/j.ijnurstu.2016.06.001

Kitwood T. 1997. The experience of dementia. *Aging Ment Health. 1*(1): 13-22. https://doi:10.1080/13607869757344

National Institute for Health and Care Excellence. 2016. Transition between inpatient mental health settings and community or care home settings. NICE Guideline [NG53]. London: National Institute for Health and Care Excellence.

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.

NHS Improving Quality. 2014. *Capacity, care planning and advance care planning in life limiting illness: a guide for health and social care staff*. London: NHS Improving Quality.

Pecanac KE, Wyman M, Kind AJ, Voils CI. 2018. Treatment decision making involving patients with dementia in acute care: a scoping review. *Patient Education and Counseling. 101*(11): 1884-1891. https://doi:10.1016/j.pec.2018.06.017

Petty S, Dening T, Griffiths A, Coleston DM. 2018a. Meeting the emotional needs of hospital patients with dementia: a freelisting study with ward staff. *Gerontologist.* https://doi:10.1093/geront/gny151

Petty S, Harvey K, Griffiths A, Coleston DM, Dening T. 2018b. Emotional distress with dementia: a systematic review using corpus-based analysis and meta-ethnography. *Int J Geriatric Psych. 33*(5): 679-687. https://doi:10.1002/gps.4870

Piers R, Albers G, Gilissen J, De Lepeleire J, Steyaert J, Van Mechelen W . . . Van den Block L. 2018. Advance care planning in dementia: recommendations for healthcare professionals. *BMC Palliat Care. 17*(1): 88-104. https://doi:10.1186/s12904-018-0332-2

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

Triplett P, Black BS. 2008. Content of advance directives for individuals with advanced dementia. *Journal of Ageing and Mental Health. 20*(5): 583-596. https://doi:10.1177/0898264308317822

van der Steen JT, van Soest-Poortvliet MC, Hallie-Heierman M, Onwuteaka-Philipsen BD, Deliens L, de Boer ME . . . de Vet HC. 2014. Factors associated with initiation of advance care planning in dementia: a systematic review. *Journal of Alzheimer's Disease. 40*(3): 743-757. https://doi:10.3233/JAD-131967

World Health Organization. 2011. *Palliative care for older people: best practices*. Copenhagen: World Health Organization.

Table 1. Themes of person-centred care requested by patients with dementia when emotionally distressed within written advance care planning documents in a UK hospital.

Personal requests for emotion-focused care when in hospital
Theme 1. Holistic care requests Requests were for care of the whole person and their holistic needs, which included: basic care interventions such as being offered food, being supported to access the toilet or with washing; being physically comfortable or warm; medical interventions including monitoring of blood glucose levels, possible constipation or infection, assessing for pain and administering medication; communication, such as explaining what is happening and offering reassurance, using a calm and caring manner, ‘listen to me and allow me to express my feelings’ (P15); being treated with dignity, respect, kindness and gentleness, asking to be seen as a person; to be with, hear the voice of or talk about family members or significant others, including advocacy or hospital staff; for somebody to make sure that family members were being looked after; touch, including holding hands; relaxation, being peaceful, listening to soft music, having a bath or going for a walk; activities, including distraction with beauty activities or listening to the radio, a cup of tea or coffee; aloneness or space; a different physical environment, which included low stimulation, minimal noise or crowding.
Theme 2. Personalisation This theme describes the detailed nature of care requests, which made care personal to each patient. For example, one patient requested a cup of coffee with two sugars and one biscuit only when calming down from feeling agitated (P12); a second patient gave a phrase for staff to use as their preferred way of being spoken to. Patients asked for different responses from different named people. Patients also asked for personalised care explicitly by saying ‘please see me and not my behaviour’ (P14). No single request was made by a majority of patients.
Theme 3. Distress as changeable Care requests varied with the type and intensity of emotional distress, and there was right timing for different responses. In half of the documents (52%), patients added qualifiers as to when different responses were appropriate, such as for when they were upset, agitated, aggressive, frightened, scared or depressed, very agitated or when calming down. Eighteen documents (86%) had more than one request listed; the number of requests ranged from one to nine (mean 3.76, SD 2.36), for example: ‘Relaxation techniques. I like my own space. Going for a walk. When upset I would rather not be left alone’ (P01). When one request was made, this was to be treated with respect or understood as a person (P10 and P16).

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Cover letter