

Barriers to providing end-of-life care for people with dementia: a whole-system qualitative study

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ABSTRACT

Objectives People with dementia may experience poor quality end-of-life care. The complex health and social care system may not meet their needs. The authors' objectives were to identify perceived and real barriers that prevent people with dementia and their carers receiving end-of-life care of acceptable quality.

Methods A whole-system qualitative study as part of a rapid participatory appraisal. The authors used semistructured interviews and focus groups with recently bereaved family carers of a person with dementia and a wide range of health and social care staff (50 participants). Thematic content analysis was used to analyse data and to identify barriers.

Results Five areas were identified as barriers to providing good end-of-life care: impact of hospitalisation, care pathways, advance care planning, impact on carers, staff skills and training. A wide range of health and social professionals provided end-of-life care to people with dementia but with little coordination or knowledge of each other's activity or remit. Care was fragmented and ad hoc leading to crises and inappropriate hospital admissions. Staff lacked confidence and requested more training. Many of the identified barriers were underpinned by feelings of uncertainty regarding disease trajectory and the perceived futility of interventions. Areas of good practice were specialist nurse support to family carers and 'in reach' to nursing homes.

Conclusions Qualitative methods of service evaluation facilitated a broader and deeper understanding of a range of perspectives, which, with other components of rapid participatory appraisal, generated potential solutions to improve care.

INTRODUCTION

Caring for a person who is dying with dementia can be demanding for both families and professionals. Their experiences may differ in important features from caring for those with other terminal diseases.¹ Medical and social care staff may lack the skills required to understand and manage the unpredictable nature of disease progression. Family carers often suffer significant levels of distress, burden and in particular 'anticipatory' or 'pre-death' grief.² They are expected to act as 'proxies' having to make difficult and emotionally demanding choices at the end of life, for example, regarding resuscitation.³ Therefore, improving end-of-life care for people with dementia requires a multidisciplinary and holistic approach.⁴

We conducted a rapid participatory appraisal (RPA) across a whole health and social care community (see accompanying paper). This methodology

originated in developing countries to gain insight into a community's own perspective of its needs⁵ and is a systems approach, where information is obtained from different sources and methodologies in the study community (qualitative interviews, patient pathway analysis and observation of services). RPA may, in itself, facilitate change and thus is a form of 'action research'. Qualitative data collected as part of RPA may enhance our detailed understanding of the more complex interactions occurring between the person with dementia, their family carer and health and social care providers as the end of life approaches.⁶ In this paper we present the qualitative data.

Aim

Our aim was to identify barriers to people dying with dementia and their carers receiving good end-of-life care, and to identify good practice that might inform improvements in care.

METHODS

Data were collected from recently bereaved family carers of persons with dementia and health and social care professionals who were involved in care for people with dementia towards the end of life. Health service ethical approval was sought; however, the committee categorised this as service evaluation and further approval was not required. The study was endorsed by the local council. Signed informed consent was obtained from all participants. The study was set in the health and social care system of a London borough (Haringey). For further details, see accompanying paper.

Carers

We defined carers as relatives or friends who had provided care on a regular, unpaid basis to people who had died with dementia. Using purposive sampling from the mental health trust caseload and local authority day centres, we aimed to recruit participants of different ages, genders and a range of cultural and economic backgrounds representative of the local population (all were English-speaking as we did not have funds for interpreters). Carers were approached between 4 and 11 months after bereavement to maximise recall but avoid the anniversary of the death.

Staff

A 'snowballing' technique was used to identify health and social care professionals. We included a range of staff to reflect all services involved in

the care of people with dementia: ambulance manager, district nurses, care home managers, care home assistant, hospice staff, adult social service care managers, admiral nurses (nurses who support carers of people with dementia), acute hospital nurses and doctors.

Procedures and data collection

Focus groups and qualitative interviews with professionals

Each focus group comprised of staff from one professional group, was led by a researcher with clinical experience in this field and lasted approximately 1 h. A second researcher co-facilitated and took field notes. Sessions were also recorded. When a professional was unable to attend a focus group, an hour-long one-to-one interview was offered. A structured topic guide was developed with the steering group and from a toolkit that has been used for other palliative care populations.⁷ This provided headings to prompt the focus group moderator or the individual interviewer (box 1).

Informal carer and family qualitative interviews

A topic guide (box 2) similar to that for the focus groups was used to lead semistructured interviews, allowing a natural flow of conversation while ensuring comprehensive data collection. Interviews were conducted in a place of the carer's choice, usually their own home, lasting approximately 1 h. Interviews were recorded and field notes were taken by a second interviewer. If participants became upset, they could end the interview and they were offered support through the Admiral Nurse Service.

Data analysis

The tapes and field notes of focus groups and one-to-one interviews were transcribed verbatim, preserving participant anonymity. The data were then pooled and coded manually using content thematic analysis. This involved detailed reading of each transcript by two researchers (WG and KHD) who independently identified distinct units of meaning and then collected similar units together. Initial themes describing the barriers to providing good quality end-of-life care were generated by both researchers who then combined units and labelled categories, as necessary through an iterative process. The final emerging themes were then independently triangulated by ELS who checked and verified the themes by re-examining the original data.

RESULTS

Study participants: carers

Nine carers of people with dementia were approached and seven agreed to take part (one carer was not interested and the second not available during the data collection period) (table 1).

Study participants: professionals

Six focus groups were held. Participants were district nurses (five), the palliative care team (five), admiral nurses (four), care home managers (five), hospice staff (four) and adult social services care managers (three). Individual interviews were held with two local general practitioners (GP), two senior acute hospital nurses, one geriatrician, one ambulance manager, one doctor from the primary care out of hours service, one old age psychiatrist, one private care agency manager, two social services day care and care home managers, a community matron, advocates and two with staff from an Asian carers support group.

Box1 Healthcare professionals: focus group topic guide

- ▶ Their role in the delivery of services to people with dementia.
- ▶ How they receive referrals and their criteria for referral
- ▶ Source of referrals and method of prioritisation
- ▶ Links with the district nurses/key worker and other health and social professionals
- ▶ Formal channels of communication with other professionals in the community
- ▶ Level of information received about each person with dementia and its adequacy
- ▶ Methods of assessment and recording of a person's needs
- ▶ Out of hours services available to a person with dementia and their carer—and whether these services meet the person's needs
- ▶ Their level of contact with a person with dementia and/or carer
- ▶ The impact of the role of the carer
- ▶ Particular issues for providing palliative care to people with dementia
- ▶ The major barriers that prevent people with dementia from dying in the place of their choice
- ▶ How community services could be improved to provide better palliative care for people with dementia
- ▶ Examples of where there has been a 'good' and 'bad' death and the components that have caused these outcomes
- ▶ Bereavement support available to carers

Themes

Five areas were identified as barriers to providing good end-of-life care for people with dementia:

- ▶ Pathways of care
- ▶ Impact of hospitalisation
- ▶ Advance care planning
- ▶ Impact on carers
- ▶ Skills and training of staff.

Pathways of care

People with advanced dementia had complex medical and social needs requiring input from a number of agencies, but the coordination was poor. The need for out-of-hours (OOH) care, outside the Monday to Friday '9 to 5' period, presented difficulties for staff who were often not fully aware of the severity of a person's dementia. In particular, ambulance services responded to emergency calls at night when other support services were unavailable, this would often lead to hospital admission as alternatives were limited:

A palliative care crisis intervention team is needed...to prevent unnecessary end of life admissions. (Ambulance Manager)

A significant factor for OOH staff was that they could not contact a patient's GP and did not have access to primary care records. This was even a difficulty for OOH GP services:

There is insufficient information to enable (OOH) GP to say that death was expected and therefore they have to contact the police. (OOH GP)

We are frequently required to attend the home of patients in the evening when things go wrong. (District Nurse)

Box2 Carer interview topic guide

Illness belief and expectations	Decision making
▶ Illness identity (symptoms)	▶ Difficulties
▶ Illness and treatment control	▶ Influences
▶ Any side effects or consequences	▶ Living will/awareness of patients wishes
▶ Time-line (how long the illness lasted)	▶ Attitudes towards end of life treatment
Carers/family needs	Important areas of care
▶ Physical needs	▶ Influences of previous experiences
▶ Psychological needs	▶ Confidence in health care professionals
▶ Emotional support	▶ End of life treatment preferences
▶ Social/practical needs	Attitudes towards palliative care principles
▶ Practical support	▶ Thoughts about quality vs quantity of life
▶ Spiritual/existential needs	▶ Beliefs about benefit of palliative care principles
▶ Spiritual support	▶ Awareness of palliative care services
▶ Barriers on support uptake	Other
Communication	▶ Anything not mentioned
▶ Communication re. illness course	▶ Bereavement support
▶ Understanding of situation	▶ Future hopes
▶ Clarity of information given	
▶ Information needs	

Residential and social care staff often felt unsupported during OOH periods and unclear as to what alternatives they had to acute hospital admission.

Lots of people working in a residential home will not come from a nursing background and therefore the critical thing is 'back up' from services when you need it. (Social Services Manager)

Both family carers and professionals were unsure when a person with dementia was entering the terminal phase of the illness. They found it difficult to manage uncertainty; this would lead to inappropriate or reactive care:

...difficulty in enabling staff carers and GP to acknowledge that the person with dementia is in the terminal phase and when it is not clear, there is a tension about what to do or not to do in the event of a sudden change in the persons condition. (Community Matron)

It is difficult to predict when a resident is going to die—those who you expect will return following an admission, do not and those that you think you will not see again, come back. (Care Home Manager)

Family carers also had to live for many years with uncertainty regarding prognosis and the disease trajectory:

Death had been expected for many years but not more so that week than any other. I had a prayer in my bag every time I was away—just in case—the possibility was with you all the time. (Carer)

Table 1 Informal carer characteristics

Carer characteristics	Total (n=7) n (%)
Gender (male)	2 (29%)
Employment	
Working	4 (57%)
Retired	3 (43%)
Ethnicity	
White British	6 (86%)
Other	1 (14%)
Carers role	
Full-time	4 (57%)
Lived with person with dementia	4 (57%)
Relationship	
Wife	2 (29%)
Daughter	3 (43%)
Son	1 (14%)
Other	1 (14%)

...he was admitted to (hospital) six times in the last year...on the last occasion...they indicated he was fit for discharge...on the Wednesday...and (then he) died on the Thursday. (Carer)

After the person with dementia had died, family carers and staff, particularly those in care homes described a lack of support from services during the initial stages of their bereavement.

Impact of hospitalisation

Both family carers and staff discussed the negative impact of hospital admissions for the person with dementia towards the end of their lives. Frequently there were several admissions, at increasing frequency, each seen in isolation with a failure to consider alternatives. Primary care staff and family carers knew that acute hospitals were not always the best place for people with dementia and were aware of the potential negative impact of admissions:

Send an elderly patient with dementia to hospital and they will probably die. A&E is not the place for palliative dying patients. (GP)

Every time he went into hospital he deteriorated. (Carer)

In particular, people with dementia were often discharged from hospital in a worse state than when they had been admitted; hospital acquired infections, bedsores and worsening of behavioural problems were described. Acute hospital staff wanted to provide good quality care but felt they did not have the necessary skills or resources to manage. Some felt helpless when faced with

...patients who have no capacity to get themselves better. (Hospital Nurse).

It is very difficult you watch a patient deteriorate and there is not much you can do. (Hospital Nurse).

In addition to staff feeling that they needed more training and support, the acute hospital and its systems were recognised as providing barriers to good quality care:

...hospital environment is not conducive to supporting patients with advanced dementia...we do not treat or provide care differently to patients with dementia. The hospital layout does not lend itself to wandering or agitated patients. (First Response Nurse)

...the emphasis is on rapid treatment and discharge—with lots of people looking after each patient, preventing continuity of care. (Hospital Nurse)

Carers described how acute hospital staff struggled to provide basic care. Carers perceived a lack of understanding, little compassion and low staffing levels. This led to high demands being placed upon families:

...one day I came and found him with no clothes on his bottom half, no slippers and stood in a pool of water... (Carer)

He was agitated and frustrated in hospital...he didn't know where he was, why he was there and was aggressive a couple of times...he wandered and when (they) tried to get him back he hit out. They got security in, sedated him and he slept for 24 hours with no food or drink...that was in the last three months of his life. (Carer)

I would find the tablets in a pot by his bedside; he was obviously unable to take them himself. The staff looked to me to care for him when he was in hospital. (Carer)

For some family carers, the demands placed upon them were more burdensome than if the person with dementia was still at home:

They had no skills or awareness of dementia...staff called me day and night when they had problems. I was called at 2 am one morning...he could not understand why they were doing these things to him. He had no dignity...no one helped him to eat or drink.(Carer)

Advance care planning

There was variable awareness of advance care planning among family and professional carers. Social care staff feared censure from regulatory authorities if they did not call emergency services during a crisis. This situation was of concern to ambulance staff who have a duty to act if there are no directives to the contrary:

If we had prior knowledge...then a resuscitation attempt would not have been attempted. Where there is a properly constituted AD [advanced directive] then it will be honoured...people still call the ambulance, emotions go to pot in a crisis. (Ambulance Manager)

Advance decisions...nervous about their consequences. A resident requested she not be resuscitated...the daughter was shocked that she had signed such a document. (Social Services Manager)

There was little evidence that people at any stage of dementia were asked about their wishes. Carers therefore often have to make complex decisions for their relative, with little support or information:

We had to make important decisions... we found this hard and needed help...they thought he might need a tube to feed or another treatment that I cannot remember. Three different doctors said three different things... they said 'you have to decide'. (Carer)

Despite these negative perceptions, if advance care plans were in place then more appropriate care could be given:

...important to get GPs to embrace the Gold Standards Framework and Liverpool Care Pathway—if patients are reviewed in a structured way other benefits will follow. (Ambulance Manager)

Impact on carers

Family carers described how little happened routinely; they had to initiate and then “push” for services to be provided, these were unpredictable and fragmented:

I had to request her annual review...no automatic follow up...no routine visits ... I had to ring up the surgery to

request a visit to the home for the flu vaccine. She was on (medication) for years and received a continuous prescription without reviews. (Carer)

Carers described the physical and emotional demands of caring over long periods of time, incontinence, lack of sleep and behavioural problems were particularly difficult to manage. However, professionals noted that even though carers are often exhausted and physically burdened by their caring role they often delay seeking help and neglect their own health:

The stoicism of ... carers is remarkable...I am always shocked at how far it has got before they seek help. (GP)

Her own health (carer) is deteriorating but she will not have treatment as she is unwilling to leave her husband (person with dementia) in the care of others. (GP)

Care home staff felt that their feelings of loss when a resident died were not acknowledged.

Skills and training

During their day-to-day practice, a wide range of health and social care staff came into contact with people dying with dementia. Many, particularly hospice, ambulance staff and district nurses acknowledged they had received little or no training in dementia, in particular concerning communication and managing behavioural problems.

Dealing with people with dementia is not part of the crew's training package. It is touched on but it is not sufficient. (Ambulance Manager)

Staff at the hospital need to have more knowledge and skills to care for people with dementia....I found three nurses trying to restrain him in a corridor, one was hit by him. It was not his fault; he couldn't understand why they were doing these things to him. When I cared for him they said 'oh he is like a baby with you'. (Carer)

However, there were inherent difficulties in ensuring that investment in workforce education was effective:

The staff turnover is high in residential care homes and therefore investment in training is difficult and needs to be constantly ongoing. (Community Matron)

Good practice

We found some areas of good practice. The Admiral Nursing service supported people with dementia and their carers throughout the illness trajectory and beyond to bereavement:

The Admiral Nurse was very supportive; I do not know what I would have done without her. (Carer)

'In reach' services which worked to improve staff confidence were particularly valued; particularly the Community Matron supporting care homes in dementia care and end-of-life care and the Gold Standards Framework:

...it is the greatest improvement in residential care in the last few years. (Care Home Manager)

However, high levels of staff turnover and service re-organisation were identified as barriers to best practice. Valued services were often viewed with 'caution' in case they were withdrawn.

Just as you are getting used to a service ... it is gone again. (GP)

...but now she (Community Matron) has left and we were just starting to feel more confident... (Care Home Manager)

DISCUSSION

This study is unique in that we took a whole systems approach to identify barriers to providing end-of-life care for people with dementia, from the perspective of family carers and professionals. Many staff had similar concerns regarding the quality of end-of-life care that they are able to provide to people with dementia. Recent reports have consistently called for better coordination of services but we found that end-of-life care for people with dementia frequently involved a wide range of professionals with little coordination or knowledge of each other's activity or remit.^{8 9} Some, such as ambulance staff, are not perceived to be part of the 'dementia workforce' but they are often involved at times of crisis. A range of professionals, from GPs to care home staff, described problems in managing the unpredictable trajectory of advanced dementia and identifying when the person with dementia was entering the dying phase. This made it difficult to make decisions regarding appropriate care. In addition, advance care planning was not occurring routinely. This has been widely advocated as a way of increasing autonomy and improving the quality of care at the end of life.¹⁰ We identified numerous barriers to this including insufficient time and staff resources to engage in necessary discussions. There were concerns regarding staff confidence in adhering to advance care plans and fears of censure by the regulatory authorities.

Underpinning many of the barriers we identified were feelings of uncertainty, the perceived futility of caring for someone with dementia and the need for education and training. For example, ambulance staff receive little specific dementia training and yet they are called when an OOH crisis occurs. While 40% of older people admitted to the acute hospital have dementia and many die during admission,¹¹ acute hospital staff often felt helpless. Staff working in the community and care homes, including district nurses, whose core workload is with frail older patients, described a lack of confidence. The need to improve training in dementia care for the health and social care workforce has been highlighted by the National Dementia Strategy.⁹ Our work illustrates that this needs to be facilitated by ongoing support such as the 'in reach' work provided by community matrons to care homes.¹²

Family carers were key in supporting people with dementia at the end of life and took on a variety of roles both at home and in other settings: from providing basic 'hands on' physical care to initiating referrals and requesting medical reviews. Family carers were implicitly involved in decision making for the person with dementia throughout the illness but in keeping with previous research we found they were ill prepared to make decisions regarding end-of-life treatments.³ The burden and stress experienced by carers of people with dementia has been well described.¹³ Our work highlights how, in addition, this occurs against a background of increasing uncertainty regarding the trajectory and prognosis of advanced dementia.

Despite including numerous health and social care staff, none of our data suggested a clear need or role for specialist palliative care that focuses on people with complex care needs.¹⁴ Many of the barriers we identified were system-related or associated with education, training and the uncertainty of disease trajectory.

Strengths and limitations

We interviewed a full range of health and social care providers and also included bereaved caregivers of people with dementia. It was a relatively large sample for a qualitative study. Previous research has focused on care homes and the acute hospital but

we took a whole systems approach and included ambulance staff, community nurses and primary care. Our focus groups, with on average four participants in each, were smaller than usual. This was due to difficulties in staff taking time from work to participate. Despite actively seeking male family carers and those from ethnic minorities to participate, our sample was still predominantly female and white British. Although our findings may not represent a wider national perspective, our findings concur with previous work from the UK and further afield.^{10 15}

CONCLUSIONS

All staff were keen to provide better quality end-of-life care to people with dementia and were acutely aware of the limitations, both in their own knowledge and skills and in the health and social care system within which they were working. Many of the barriers were associated with lack of inter-agency communication, not having a clear dementia care pathway and a sense of helplessness. However, none of these are likely to require specialist palliative care interventions. The qualitative data have informed the RPA and suggested practical areas in which we can improve care.

Contributors KHD, WG, LJ, UM and ELS designed the study, wrote the protocol and managed the study. All authors collected and analysed data, interpreted the findings and wrote the final draft.

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