

Communication and Comfort Measures for People with Dementia at End of Life: Effectiveness of Workshops for Care Home Staff

“When you’ve met one person with dementia, you’ve met one person with dementia”

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Abstract

As a consequence of an increasing elderly population, the incidence of those living and dying with dementia is growing [1] with demands for provision of quality care throughout the health and social care sector. This study assessed the impact of workshops to care home staff specifically for improving communication and comfort measures at end of life for people with dementia. It included an evaluation of the effects three months later, to assess whether these approaches had been embedded into practice.

The workshops enabled staff to develop confidence in appropriate strategies and approaches and crucially move towards a realisation that empathy and effective communication were at the core of compassionate care. The care home staff were empowered, individually and in teams, to provide effective multidisciplinary palliative care for their residents with dementia. This team approach ensured appropriate support was available within these care homes, where the person wished to be with familiar people and surroundings at end of life.

Keywords: *Dementia; Alzheimer; Workshops; Care*

Introduction

Kane [2] cites Brayne., *et al.* study (2006) with the stark figure that one in three people over the age of 65 will die with some form of dementia. Not surprisingly the care of people with dementia is described as a national challenge and delivering improvements in care and research is a government priority [1,3].

Advanced dementia is associated with a high symptom burden which Pace and Scott [4] suggest is not amenable to traditional models of palliative care services due in part to the decline in cognitive function. The emphasis at end of life should be in promoting stability and care in a familiar place with familiar people [2] with the avoidance where possible of referral for inpatient care to other establishments, including hospices. The input of carers who have developed a therapeutic relationship over a long period of time and who are able to provide stability and comfort is paramount. Support from palliative care services remains vital in promoting the confidence in carers to be able to fully support their residents with dementia until death, a concept which is strongly advocated by the Alzheimer’s Society [1].

This study describes the impact of two workshops which were developed and delivered for health and social care workers who provide care for patients with dementia nearing the end of life. A service evaluation followed utilizing semi-structured interviews within the employing organisations. Four of these who were private companies with two homes funded by the local county council. All of the homes

in the study had either completed the 6 Steps programme or the Gold Standards Framework accreditation so that end of life care was expected to be conducted within an established framework and so promote quality care at the end of life.

A scoping exercise was undertaken prior to the workshops and consisted of contacting five different residential and nursing homes from the ones included in the study. The purpose of this approach was to identify what was considered good practice in dementia care as recommended in policy documents and which was used to inform workshop content and evaluation [2,3].

Participant interviews formed the basis for an evaluation of the impact of these workshops in embedding the fundamental aspects of communication and comfort measures in end of life dementia care into practice. As a result of this evaluation practical changes were made in the care homes which included implementation of the Abbey pain scale and the use of memory boxes as well as updating of Best Interests policies and documentation.

Methodology

Semi structured interviews were conducted with carers who attended the workshops and who consented to be interviewed three months later, to analyse any changes in practice. The interviews were all undertaken in participants' places of work so as to minimise disruption to their services and reduce any anxiety.

Workshop one concentrated on communication measures with people with advanced dementia highlighting the effects of the disease on the brain which explained their progressive symptoms. Specific techniques were acted out, using role play, which the carers could use within their care home environments to promote interactions and assist in assessment of needs. Getting to know the person as an individual and the essence of the person was a constant theme throughout both workshops.

Workshop two concentrated on assessment of physical need and how to develop advance care planning. The importance and relevance of Best Interest documentation was demonstrated using case studies.

The focus of the research project was on communications and comfort measures at end of life with clients with dementia. These topics were deliberately avoided as a specific question in order to elicit whether these factors had indeed been embedded within respondents' approaches to caring for this group of clients. Eight workshop participants (44%) gave consent to be interviewed from a total of 18. Three of the participants who consented to the interviews had attended both workshops, the remainder had only attended workshop two.

Carer's Voices

The interviews were transcribed and themes were derived which are presented under the subsequent headings.

Listening and Understanding

This was a major theme which all participants discussed to some degree and is the basis of care for this group of residents.

Points were raised highlighting the importance that was placed on getting to know individual clients with dementia. Participants 6 and 7 strongly advocated the importance of getting to know individual clients, their likes and dislikes and who they are as individuals. Participant 6 stated:

"Especially with dementia you've got [participant's emphasis] to know their history and life story".

This was used not only as a means of assessing for symptoms at end of life but as a means of supporting the individual. These points were further endorsed by all of the participants who all highlighted some means of getting to know their residents on an individual basis.

Participant 6 further stated:

“You have to know them as an individual as this is how you support them, bring them back when they’re having a bad day, if you don’t know them then you can’t do that!”

Participant 3 added:

“If you know them in some respect it’s easier to pick up the change in them and find out what’s wrong”.

These points further confirm the in-depth relationships these carers have to develop in order to be able to provide effective care on admission, which also assists them when end of life care is required through building on their skills and personal knowledge of the individual.

Participant 2 suggested that you can communicate with individuals with quite severe dementia once you get to know them and cited the low staff turnover in the home as a key factor which assisted in maintaining these relationships and strong links with individual carers who understood their residents.

Participant 8 specifically highlighted the use of the video on workshop 2 which related to validation therapy and the means of communicating with end stage dementia residents. This was a highly emotive video clip which underlined the importance of developing therapeutic relationships through getting to know individuals on a very personal basis.

“It was very intimate but showed you how to communicate even when they were really bad [advanced dementia]”.

Peer Support

Many of the participants stated that they felt they benefited from listening to others on the workshop and their ideas and problems which they could understand but also their solutions.

Participant 6 stated:

“I found getting other people’s opinions on things and their experiences, I think you learn by that” which was a common statement amongst participants.

Participant 1 could be seen to endorse this approach as she suggested;

“...it just really highlighted your role in end of life care and the support you can give to people. There’s lots of little things you can do to improve end of life care for people I felt and that sort of thing [the workshops] brings it all home”.

With participant 5 stating;

“It’s hearing other people’s take on how everybody should aim for a nice death, a peaceful passing” which endorsed the approach this care home had taken by incorporation of the Gold Standards Framework which had been implemented within the home.

Support from managers and colleagues were specifically identified as being significant for the participants with participant 5 stating:

“It’s that support from the office that’s crucial”.

When asked specifically what type of support was important participant 7 stated:

“It’s just listening to you and giving you that little bit of time out so you can have whatever feelings you’re feeling at the time, if you’re upset if someone is really ill at the end”.

This identifies an essential element required in the environment in which these participants work. If there is not a supportive culture then this could have a negative impact on the carers trying to provide quality end of life care.

All of the participants stated that they felt supported by their peers and also their managers which they viewed as essential in this care environment.

There was also a consensus amongst the participants that they all did receive training in end of life care within their own work environments.

Empowerment and Confidence

A number of topics in the workshops assisted in development of confidence in individual carer's abilities to care effectively for residents with end of life needs. The Abbey pain scale was one specific tool mentioned by name which was discussed and modelled in the workshops with one participant suggesting:

"It empowers the carers though they feel they have made an assessment and it's more likely to be taken seriously [by the doctor]" suggesting additional benefits and growth in clinical confidence when using an evidence based tool in practice.

Participant 1 also endorsed the effect on carers (as opposed to trained staff) as:

"...it helps them [support staff] to understand why they [the residents] are behaving like that". This statement suggests that the Abbey pain scale is a useful and practical tool with benefits to both carers and residents and specifically contributes to the comfort of the resident at the end of life.

Participant 3 specifically stated that the session on Best Interests and Advanced Care Planning specifically stood out for her with the reason stated below;

"It was new to me, hadn't seen anything about it before". This point perhaps highlights the importance of ongoing workshops and other educational training in providing updates for the carers.

Participant 7 described how caring for someone at end of life with dementia was

"Massive".

This related to her perception on staff ability to be able to care for someone in their preferred place of care ie the care home, rather than them having to be moved. This ability had been tested following completion of the 6 Steps programme with participants 6 and 7 suggesting it:

"Gave us the confidence to be able to do that whereas we wouldn't before they would have to go somewhere else" and participant 6 stating:

"I felt comfortable enough to answer their questions rather than having to say to go to the office".

These participants within this particular care home felt so comfortable that they stated:

"We actually promote their last wishes" highlighting a resident who had been admitted to hospital but they knew through their interactions with her that this was the last place she wanted to be. They fought to get this resident back with them stating:

"...we managed to get everything in place, get her back here and this is where she'll be". Again participant 7 described this as follows;

“For us that’s massive! At the end of the day what’s the point of us doing this training if we can’t do it [care for people at the end of life]. We’re not just here for the best bits, we do all of it. It all falls into one package. It’s not a case of bring them into us when they’re mobile and self-caring but as soon as they’re end of life then they have to go, NO! [participant’s emphasis]”.

As participant 2 stated;

“This is their home, no difference [than their choice if they were still in their own home] whatsoever”.

Communication

The focus in workshop one was to encourage carers to develop different ways of communicating with their residents specifically to meet the needs of the residents and their differing stages of disease.

A direct result of attending the workshops was the placing of memory boxes within the care home. These were situated outside each resident’s room with mementoes within. These were installed with mixed reactions from the residents but the intent was to have a focus for communicating with each resident and which had been identified as good practice in policy documentation [2,3].

Participant 6 highlighted that most were agreeable to having them but one resident suggested it was an invasion of her privacy. A further resident stated that she was just there temporarily so would not need one despite being a long term resident. This perhaps reflects the very nature of the disease. Participant 7 stated that you needed to remind the resident that the box was there with participant 6 stating:

“Resident A uses the box but that’s because as you walk down the corridor her bedroom is directly in front of you so she can’t miss it as you are going forwards. She does look into it each time she goes into her room so you have something to talk about, focus on for her”.

Participants highlighted the benefit of the Abbey pain scale which was discussed within workshop one but specifically related to communication techniques. Participant 2 stated;

“it’s what we would do anyway when assessing someone whether they’re in pain or not, it might be from a urine infection or a chest infection, their behaviour changes and you have to recognise what they are normally like because then you can see they’ve altered in some way”.

Participants 3 and 4 agreed with participant 7 stating;

“Facial expressions, the way they react I think we’ve got a better understanding with that [Abbey Pain Scale]”.

Participant 3 stated;

“The pains scale was good for them [the residents] especially without capacity or who are not particularly good at articulating. I’m more aware of it now”, which suggests an aspect of the workshop which may have been incorporated into practice.

Making an early start

Leading on from the theme above is the concept of making an early start in the communication process in order to maximise opportunities to get to know the resident in order to adequately be able to support the resident. This was achieved through a variety of methods.

Getting to know the person and how this was communicated to the rest of the team in the care environment was seen as a key element of the workshops. The interviewer probed further in order to elicit how this was done in practice. Many of the participants stated that this started from the admission process, getting to know the person as an individual through their likes and dislikes which are all documented within their notes.

Within the care home of participants 6 and 7 a proactive approach was taken through the use of one page profiles on individual residents. These documented the individual's likes and dislikes from food and drinks to what they like to watch on the television to the music they listened to. These profiles together with a photograph could then be used with new staff who did not know the resident, to assist them in getting to know that person and understanding their behaviour. This enabled all the staff to help support the resident better on a day to day basis in achieving the things the resident liked to do but also as end of life issues arose.

As participant 6 stated:

"It all rolls together, your one page profile, your memory boxes, your end of life care pathways and the training you've had ...and because we've done the 6 Steps it all rolls into one, it follows on, it's great!"

However, it was proposed by the participants that this process should start as soon as the person was admitted to the care home and participant 1 even suggested earlier before any capacity had been lost at all.

"This discussion needs to take place before perhaps they've even got here [the residential care environment] because if they have more severe dementia then we won't be likely to get that information from them unless the relatives know which might not be strictly accurate...the earlier the better".

Building Trust

Participant 7 discussed the importance of building trust through communication with family carers who may have been looking after the individual prior to their admission and be experiencing guilt and disempowerment as a consequence. This communication with family members and other carers was viewed as equally important by participant 6 who suggested; "...any information that can help you support them better, you've got to do it [communicate with relatives]".

Participant 3 stated;

"You can ask yourself and you can ask carers [family and friends] and all together you can work out what is wrong".

This was tempered with comments from participants 2, 5 and 6 that families can often be the source of problems if they themselves are having difficulties in accepting the prognosis of their loved one's condition. Consequently, participants did emphasize the need to develop a trusting, open, honest dialogue with the families as well as the residents.

Not all issues could be resolved through general discussion, when there was a conflict of interest, and Best Interest discussions were also mentioned as a means of resolving some of the issues that may arise in end of life care, demonstrating how this aspect of the workshops has also been incorporated into some of the care homes. Participant 7 viewed these Best Interest meetings as follows:

"...just to keep the family up to date with what's going on and the situation; that we would expect that to happen [physical changes at end of life] but they [the family] don't. If they need to know anything else then there is another chance to ask" and "We don't want anything to be a shock".

The Wider Team

Participant 3 found other community teams could be a useful source of information highlighting district nursing teams, community mental health teams and home carers who may also have had the opportunity to get to know individuals over a period of time and could therefore inform the care staff of preferences.

This could not have been achieved without the help and support from other teams such as community mental health teams, district nursing teams, specialist dementia staff, palliative care specialist teams and the GPs who attended the residents. The majority of the participants described this input as "brilliant" and "fantastic".

Participants 6 and 7 highlighted the way they worked round increasingly demanding behaviour, utilising community teams and their specialist assessment and support offered. In this way as participant 7 stated:
“...they gave us ideas or another option on how to support them”.

What the participants liked about this support was that:

“They said we’re not here to take over...and how we can help”, highlighting a sense of partnership in care with these teams but also their commitment to caring for their residents at the end of life.

Participant 6 stated:

“...we’re here to do a job to give them the best care and if we’re finding difficulties it’s trying to find something that fits in for them”.

Obtaining outside assistance was acceptable, even advocated by some carers.

Documentation Processes

Participant 2 talked about the documentation process and how preferences were documented throughout their stay and not solely during the admission process.

“You can’t just write ‘had a good day!’ It has to be more in depth than that...you have to write if they express a wish to us we have to put that in and everything they have done throughout the day is written down”. Although this was not linked by the participant to the discussions within the workshop on Best Interests this method of documentation is advocated with this document and seen as good practice.

Participants 6 and 7 highlighted how the resident’s preferences for end of life were documented from admission as did all of the participants. However, this was qualified by participant 4 who suggested that asking questions very early on can cause unnecessary anxiety in the resident so has to be taken on an individual basis. As participant 5 stated:
“You don’t want to scare them off!”

Participant 2 felt the majority of residents got their wish of staying within the home at end of life rather than going into hospital. This factor was attributed to using the Preferred Priorities of Care documentation for all of the residents, which was addressed at admission.

This point further highlights the importance of getting to know the resident and having such discussions early on in the care trajectory before choice becomes lost. The quality of the early discussion is a key factor in promoting choice at end of life in dementia.

Discussion

The aim of this small study was to evaluate the impact on the provision of communication and comfort measures in end of life care following two educational workshops. It is clear from the above conversations that the commitment to caring is vital to these carers with the ideals of communication and comfort all wrapped into the notion of patient centeredness. As Kane [2] suggests each person with dementia is different and therefore the need for individualised care is paramount. The participants all espoused this approach with the emphasis being on getting to know that person as an individual through effective communication techniques. This was viewed as the only authentic way of supporting those residents and ensuring their day to day comfort as well as at end of life.

The ability to care for residents with dementia at end of life is built upon the established therapeutic relationships developed between residents and carers. This relationship promotes choice for the individual through this in-depth knowledge of the individual and their preferences in care thereby enhancing quality of care through this heightened knowledge and awareness of end of life care needs.

The concept of a “good death” includes comfort measures such as being pain free and seeming calm rather than agitated and distressed. These desirable outcomes outlined in the Department of Health End of Life Care Strategy [5] were echoed by all the participants highlighting the intrinsic nature of caring which seeks to provide comfort to the vulnerable.

Wider support was also important. When residents became terminally ill, the support from the multidisciplinary teams, including specialist palliative care teams, was also seen as invaluable in allowing residents to remain within their preferred place of care. This would address objective 12 of the Alzheimer’s Society report [2] which identifies the need to ensure that staff have the right support in place to allow them to care effectively for this group of residents. Communication could therefore be viewed as not just between carers and resident but also between teams to ensure that care was optimized. This would also meet objective 7 of the Alzheimer’s Society Report [2] which states that, regardless of setting, there should be equity of access to specialist palliative care services to meet individual needs. This equity did appear to be in place for these residents. The multi-disciplinary support would also tackle concerns raised by Pace and Scott [4] who suggested hospices may be overwhelmed with referrals to their service. Instead, input from specialist palliative care services did make a difference in those people with advanced dementia and therefore they should be part of the wider multidisciplinary team. However, this can only occur when carers are confident in the care they provide and the essential grounding of the development of a therapeutic relationship. Within this group health and social care workers, care appears to be based on these essential principles. This forms the foundation for the care that is provided and demonstrates that care is of equally high quality within these environments compared to other care providers.

The workshops also sought to embed some of the good practice demonstrated into individual participant’s practice areas. All participants worked within environments which had undertaken the 6 Steps programme or were GSF homes so there would have been substantial knowledge and a framework in place to assist in caring for residents at end of life. Philips, *et al.* [6] highlight the need for multi-faceted approaches to palliative care in order to promote and maintain a standard of practice and it is unlikely therefore that these discrete workshops would be expected to change approaches to care drastically if viewed in isolation. However, what they appeared to achieve was to confirm the good practice that was already taking place within these care environments and instil confidence into individuals that they were providing appropriate care. This was particularly important when it was difficult to get any direct feedback from residents on pain levels or feelings of comfort, due to the loss of communication skills in severe dementia and when nearing end of life stages.

The established knowledge and frameworks within the 6 Steps and GSF could be considered to provide a theoretical foundation, but evidence from participants suggests the workshops then build on this sound knowledge base. The carers within the workshops added to their already established knowledge base and promoted their confidence in providing care for this vulnerable group of people. Value for money from previous training can be seen to be evident with this spiral knowledge construction which assists in promoting an effective knowledge base and dissemination of good practice.

Ideas which were transferred into the participant’s working areas included use of the memory boxes. In one particular home which was solely for residents with dementia, this provided another focus for communication with the resident. Although within this particular home they were situated outside the rooms, this could perhaps be incorporated into other care homes by putting the box into the room for the resident, family and carers to go through and enable more easy access. This would also address one of the concerns of a resident who suggested it invaded her privacy.

The Abbey pain scale had already been implemented in some of the homes and this increased awareness amongst the participants of its suitability for their residents. During the workshops, it became apparent that they did not realize the tools they were already using in assessing their residents included the Abbey pain scale. They utilized a large proportion of the assessment areas within the Abbey pain scale and had been assessing pain and discomfort already through the communication techniques already established with their residents. Aspects such as change in behaviour, facial expressions and body language were all highlighted by the participants as being

essential in assessing the person and advocated by Cunningham, *et al.* [7]. However, this knowledge seemed to have been picked up intuitively, rather than formally taught.

Respondents reported that the scaling system was not used solely for pain measurement, but for any discomfort such as when a resident needed to pass urine and there was a resultant change in behaviour, or if a resident was suffering from other health problems such as a chest infection, this again changed an individual's behaviour. Developing a sensitive therapeutic relationship meant that behaviour change which might be linked to pain and discomfort was noticed and addressed earlier. Hence residents' needs were dealt with, comfort was enhanced and choice was maintained.

This highlights the importance of getting to know the individual and allowing carers the time for this vitally important one to one care. Communication is the essence of caring in dementia [1] and cannot be over emphasized. This also extends to family and friends and can be viewed as a means of promoting choice in end of life care through this individualised person centered approach.

The majority of the participants found use of the Best Interests documentation useful, with this document being new to some of them. None of the participants viewed this documentation as a tool to assist in complex decisions once capacity had been lost by the resident. It seemed to be another aspect of the paperwork to complete rather than anything else that could have an impact on their practice. However, this documentation needs to be viewed as another way of promoting choice when capacity is lost, as careful documentation of preferences can be used as evidence of these wishes when capacity is lost.

The need to ensure effective means of getting to know the individual and documenting this from admission appeared to be established. Documentation was kept either as one page quick summaries especially useful for new staff but also within the records when new ideas, likes and dislikes were expressed. Staff were required to complete these on a daily basis. However, how readily this was retrieved and passed on to other staff when a summary was needed, was unclear and is an area of practice which could be improved, upon especially within the larger care homes.

The wider consequence of developing these in-depth relationships should also be acknowledged. During the course of a research interview in a care home, the researcher observed both the GP and district nurses visiting to support carers in looking after a resident who was dying. One of the carers within the home was visibly upset at the forthcoming death of a resident with whom she had become close. The team accepted that close relationships form and indeed allowed these to flourish as they were seen as beneficial for the care and comfort of their clients. This was a great strength within this home. What was also evident was that these individuals were allowed time to be able to support the resident more closely but they also had the support of their colleagues to do this. Thus, when they were feeling emotional at this sad time they felt comfortable to be able to express these feelings.

This is vital if care is to be truly compassionate and to enable the ideals of the End of Life Care Strategy [5] to be realised. However, this is reliant on a supportive culture within individual environments. If the prevailing culture does not value staff as a resource or recognise that the quality of care partially rests with the support it provides for staff, then the staff will be less likely to invest spending quality time and emotions with their clients. This would have potentially negative consequences on the quality of communications which affects the total care of the individual [8]. It is this practice of quality care that can provide intrinsic reward in caring work [8] but it needs the right environment and culture for this to thrive.

Conclusions

The objectives of the study can be seen to have been attained through the provision of training for a group of health and social care workers followed by an in-depth evaluation of practice. Current practice was established through the scoping exercise which identified a number of principles for good practice as well as a system of quality measures. This included the need to develop holistic, individualised

care for the person with dementia and utilisation of frameworks to help the person with dementia at the end of life as advocated with the Gold Standards Framework (GSF) for End of Life Care.

Good practice was defined through the scoping exercise and endorsed by the carer's evidence supplied in the interviews so ensuring that individual's needs are elicited in order to help support the person with dementia on a day to day basis. This knowledge can then critically affect quality of life at the end of life. The person centred approach cannot be emphasised enough: the time needed for carers in these homes to be able to get to know their individual residents, their likes, dislikes and also end of life preferences. Future work to evaluate good practice could also incorporate peer/researcher observation, and feedback from line managers, residents and their families.

Recommendations

The findings from this study suggest that in order for comfort and communication measures at end of life to be fully implemented the following key requirements need to be met

- Time needs to be spent in the process of getting to know the individual resident so that the person feels safe within this care environment. It is essential that managers of these care environments acknowledge that this is time well spent and allow processes to ensure this occurs through sufficient staff ratios to meet these individual needs.
- Effective means of documentation are required that encourages carers to document very early on expressed preferences, to promote choice when care is needed at end of life.
- A supportive culture is also required within any caring environment but especially as these are relationships which could potentially be long lasting.
- The effect on carers needs to be considered when the resident is at end of life, and care taken with staff that have supported these individuals over a long period of time and who may have become close. This is the nature of any caring relationship where there is a need to develop empathetic and compassionate approaches to care.
- End of life preferences need to be established when the person has capacity and before much of this is lost by the time they are admitted to a care home. There is a need to develop more robust methods of developing and ensuring these conversations occur at a much earlier stage of the illness and even possibly at diagnosis before capacity is lost any further. This would avoid the need for Best Interest discussions which can be distressing for the family and those who care for them but also more importantly, promote choice for the individual in deciding on how and where they would like to be cared for and their preferences at end of life.

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Conflict of interests

None.

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