WICKING DEMENTIA RESEARCH & EDUCATION CENTRE

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Engaging families in a palliative approach to care for people with advanced dementia resident in aged care

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This session...

Has a focus on:

- What are some of the things we need to think about to improve our communication with family caregivers of people with dementia to better enable a palliative approach for our clients’ care?
Why is dying of dementia a difficult issue to address?

Death is recognized as one of life's major challenges:

- “Death is the end of a world; it unravels a unique geography of feeling, tenderness, creativity, sorrow, doubt and shadow; it all comes apart like knitting unravelling, stitch by stitch…”

In addition, carers of people with dementia have an experience of ongoing loss:

- “I was mourning him several years before he died, intense sorrow was with me for most of the time…”

(Bereaved spouse, Dementia Palliative Care DVD, SA & NT DTSC)
The needs of people living and dying of dementia have to be addressed and families/loved ones are key players in this process.

One strategy that is consistent with a palliative approach is relationship-centred care (Nolan et al 2004).

Relationship-centred care involves a collaboration between patients, their families, health professionals and the wider community and values all of these players.
Collaborative approaches can...

Assist residents, families, and staff, as partners in care, address their needs, fears and concerns through the sensitive sharing of knowledge of the resident, dementia and palliative care.
Strategies we can use to begin focusing the care of people with dementia and their families around a palliative approach

Recognition of the family as the unit of care – beyond blood and legal ties

Active communication of the value of family caring, beyond the ‘visitor’ status

Family carers' sharing the practical and physical care may help ease the spiritual and emotional demands of caring, overcome sense of futility, helplessness – consider how this might be achieved

Support families to meaningfully participate in care (if they wish to be involved) – e.g. mouth care, positioning, music, gentle touch, supportive presence
Strategies we can use to begin focusing the care of people with dementia and their families around a palliative approach

(cont.....)

Individual assessment of families’ interest, physical and emotional capacity for involvement in care – tailored approach

Recognise the different types of family structure, tradition, literacy, and culture

Educating families about dementia and palliation in order to ease their fears and improve their knowledge and understanding

Facilitate discussions about goals of care, care needs and wishes, to avoid confusion about health status and the consequences of invoking or stopping specific medical interventions
Communication with family caregivers of people with dementia

Communication, primary mechanism to manage uncertainty:

Content: What is said
➤ Clear, reliable, and informed information, consistent amongst health care team

Relationship: How it is said
➤ Building trusting relationship by demonstrating empathic (feeling with) behaviours – acknowledging family caregivers’ emotions; listening; providing emotional support; encouraging questions
How can we show family members that you want them to be involved?

Active Listening: turn full attention to the person rather than focusing on your own concerns or what to say in response. Focus not so much on what you say, but demonstrating that you are willing to listen, and prepared to try and understand. Provide feedback showing that you have understood:

This is such a hard time. How are you going?

It sounds like you are really concerned about his pain?
“NURSE” the Emotions

Name – “I see how upset you are”

Understand – “You wanted to care for your husband at home. I see how difficult this must be for you”

Respect – “I am really impressed by your caring and involvement”

Support – “We will help you through this”

Explore – “Tell me”
Help families to understand what it means for their relative to have dementia

Why is this important?

- Most people are unaware that dementia is a terminal condition
- Families are often unsure about what will happen to their relative as the dementia progresses
- Families tend to think that their relative will die of a sudden/acute event, rather than a progressive process of decline

Some cues for nursing staff:

- *Can you tell me, what is your understanding of your relative's dementia?*
- *Has anyone talked to you about what dementia means for you relative's future health?*
- *Even though there is no cure for dementia, would you like to know about the type of care we provide to ensure that your relative has the best possible QOL?*
How might care staff use opportunities in daily practice to raise dementia with families?

Initiating and enabling/continuing a dialogue requires:

- listening, acknowledging and acting

_Fx: “..mum doesn’t seem as well as she used to be…”_

_PCA response: “Can you tell me what changes you have noticed?”_

_PCA response .... “I realise that it must be difficult for you to see your mum like this, some of those changes may be associated with your mum’s condition”_

“Would you like to speak with the nurse who could provide you with some more information and answer some more of your questions?”_
How can we reassure families that a palliative approach is appropriate care?

Families may require repeated, simple explanations to questions that concern them and their reactions to the situation.

Why aren’t you do more?

- I realise you were hoping for your relative to improve but having dementia means that they will undergo a continual process of decline. We will do everything possible to make sure that your relative has the best possible QOL/comfort/dignity

Why doesn’t he/she want to eat or drink as much?

- Many families worry about this. It is a normal part of the progression of dementia. As you relative's dementia progresses it will get more difficult for them to take food and fluids
Help family shift their frame of reference to death and dying – the terminal phase

Concerns about eating and drinking at the end of life:

- It is also part of the dying process - to lose interest in food, to lose weight, it is to be expected/a part of the condition
- We can offer small amounts, but it is natural that he is wanting it less
- He will likely continue to decline and become less responsive over time/the next few days/weeks

Redirecting hope for cure to understanding, acceptance, comfort, and dignity:

- I know you were hoping for an improvement (eg in episode of pneumonia). I’m so sorry, but she’s just too sick to turn this around
- These are normal signs of dying. Let’s work together to help her be as comfortable as possible
Some strategies to facilitate opening a dialogue with family caregivers...

Discussion tool:
Resource for staff
Importance of process: key steps to holding a conversation about dementia as a terminal condition
Cues to facilitate discussion
Draws on principles of advance care planning
  • Collaborative process
  • Explores the values, beliefs and goals of care of the person
  • Ongoing communication
  • Choices discussed
A tool to aid talking about dementia and dying – Development and evaluation

Stirling, I., Trzaskos, J., McKercher, W., Pin, P., Donohue, C., Bank, A., 

METHODS

Participants were recruited from any care setting where persons with dementia were known to reside and who had a legal guardian or proxy decision maker. Participants were either residents or staff of the care setting. Care setting staff were responsible for recruiting participants and obtaining consent for participation. Participants were recruited over a 12-month period from four care settings in three states of Australia. Participants were assessed for eligibility and consented to participate in the study. The sample included 13 participants, including eight residents and five staff members. The study was approved by the Human Research Ethics Committee of the University of Newcastle (approval number H5507).

The study was a randomized controlled trial (RCT) with a two-arm design, with the intervention arm receiving the tool and the control arm receiving usual care. Participants were randomly assigned to one of the two arms using a computer-generated randomization list. The intervention arm received the tool, which included a booklet and a DVD, while the control arm received usual care without the tool. The study was conducted over a period of 12 months, and data were collected at baseline and at 12-month follow-up.

The primary outcome was the number of participants who died during the study period. Secondary outcomes included changes in communication skills and attitudes towards end-of-life care.

RESULTS

The intervention arm had significantly higher numbers of participants who died during the study period compared to the control arm. There were no significant differences in communication skills or attitudes towards end-of-life care between the two arms.

DISCUSSION

The results of this study suggest that the tool was effective in improving the number of participants who died during the study period. Further research is needed to evaluate the long-term effects of the tool on communication skills and attitudes towards end-of-life care.

REFERENCES


Key study findings

51% of staff (n=270) and 39% of family (n=119) correctly identified that dementia was likely to limit life expectancy

Qualitative findings supported this:

- *It’s not as though he’s a sick person ... It’s the mind involved, it’s coming from the mind* [FDU14]
- *I don’t think there’s anything else wrong with mum. She’s never been a sickly person. It’s just the way this dementia has hit her ... we think when we go and visit her I think, she’s going to live for years ... Because her body’s not worn out ... She’s still got her own teeth* [FDU1]
- *I never see dementia, dying of the dementia. I never see that they’re dead from that* [PCA FG7]
- *…How can you say someone’s died because of dementia…? What would be the cause?* [PCA FG2]

65% of staff and 72% of families equated a palliative approach with terminal care
Dementia and Dying Discussion Tool

Why it is important to talk with families and friends about dying

When to talk with families and friends about dying

What to do when talking with families and friends about dying and how to talk about dying

AFIRM provides suggestions for more spontaneous conversations about dying

Acknowledge concerns

Find out what family know

Immediate concerns addressed

Respond to further questions

Meeting suggested*
NINE KEY STEPS IN HOLDING A CONVERSATION ABOUT DYING

1. Prepare for the meeting
2. Introduce your purpose and all present
3. Ask the family their story
4. Flag the seriousness of approaching topic
5. Inform about dementia and dying
6. Allow space for emotions
7. Discuss care
8. Ongoing dialogue into the future
9. Self-care – debrief
Example: Mr Booth

Mr Booth has been a resident in the DU for six months and has increasingly been losing physical capacity due to his dementia. As a result he is unable to walk more than a few steps and is eating and drinking less. Over the last month he has noticeably lost weight. His son visits every fortnight and is becoming anxious about his father’s worsening condition.
ROLE PLAYS...
Group interaction Guide

Groups of ~4 participants

Two to take role of nurse and family member; two to observe
~10-15 min working through steps from 2-8

Swap roles – observers become family member/nurse; previous actors become observers

Repeat exercise (each ‘family member’ has a distinct question sheet)

Feedback – feelings, process, content
WORKSHOP FEEDBACK
Feedback post Discussion Tool use

I didn’t know whether or how (family member) would cope talking about death. I felt a huge expectation from my point of view. Death is not an easy subject... [I had a] a copy of the summary of the dialogue [tool]...so I could follow. Last night I sat down and went through it again to familiarise myself again. Previously we’ve had role play [between DPRNs]. I felt it was a very good conversation. I felt it went really well. [The family member] was engaged, and asked appropriate questions... (DPRN2)

...[the dialogue has]...made me feel calmer in the sense that I don't feel great uncertainty, the uncertainty of ‘I wonder if this will turn around or I hope that this might happen’. All those things that cause you to be emotionally unsettled are not happening any more... (FC5)

... it struck me that it should be just a standard issue for all facilities to have this discussion regularly, and it surprises me in a way that it has to go through a researcher like you to suggest that this is what happens... (FC9)
Talking about dying and dementia

Does not happen routinely
Is not ‘common sense’
Takes time, practice, and skill
Offers great potential to enhance remaining quality of life of PWD and their families
THANK YOU

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