“On the outside looking in”: Developing nursing practice around a palliative approach for people with dementia – family members’ understandings

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Research Question

How can nursing practice be developed around a palliative approach, for people with advanced dementia in a residential special care unit (SCU)?
Background

- Dementia incidence & prevalence
- Impact on residential aged care services.
  - Estimated: 30% low care and 60% high care residents have some form of dementia
  - Almost 87% residents separate RACFs via death (Andrews-Hall et al. 2007).
- RACFs are increasingly required to focus care on palliative approaches
Research: palliative approach improves QOL, is more cost effective and provides support for families.

Considered a best practice approach
Supported by the Australian Government
Commissioned the development of “Guidelines For a Palliative Approach in Residential Aged Care”.
Palliative Approach

- Promotes principles of palliative care philosophy - beyond specialist setting

- Independent of the illness, stage or setting of care.

- Early identification, assessment and treatment of symptoms.

- Focus on early planning and collaboration with family and client where possible.
Project Aims

- To describe how a palliative approach is or is not currently provided for residents on the unit and their family members.
- To identify barriers in providing a palliative approach.
- To develop interventions that will facilitate nursing practice around a palliative approach to improve care provision.
Project Setting and Design

- 30-40 bed, dementia SCU.
- 35-40 staff members.

Guided by an action research approach
Intense collaboration with staff from the dementia SCU (action research group).
Staff members → change agents.
Phase 1: Preliminary Investigation

Phase 2: Four action Plans – Initial Data Collection

1. Action Research group meetings
2. Questionnaires
3. Stakeholder Interviews
4. Documentation Audit

Phase 3: Action Plans

Implementation and evaluation
Family Interviews

- 8 Interviews – family members
  - Time since admission of the person with dementia: < 6 months – 3 years.
- Semi-structured
- Duration 45-1hr
- Audio taped
- Transcribed
- Thematic analysis
Central Themes – Family members

- Understanding dementia: “learning along the way”.

- Dementia as a terminal condition: “no major ailment”.

- Decision making: “signing forms”

- Being involved: “on the outside looking in”.
Understanding dementia: “learning along the way”

Family members:
- Limited understandings about dementia.
- Limited engagement with formal resources or support services.
- At best casual discussions with staff on the SCU re: dementia.
- Informal process of learning while journeying with a relative who has dementia.
Marion: ...what goes on in the brain has nothing to do with reality... her brain is overcrowded and just short circuits.

...the only difference between Alzheimer’s and dementia, is Alzheimer’s patients get physically and verbally abusive and mum doesn’t so she’s got dementia. I figured that out for myself, I had to, as I said no-one explained anything to me.
Understanding dementia

Peter: I’ve found out [about dementia] basically along the way... got bits and pieces [of information] ...and learnt bits and pieces.
... we know the basics, he [dad] hasn’t got a memory, he hasn’t got a mind really.

...Oh yeah we’d (staff) have a chat sort of thing but you don’t go right into it.

Carol: ...I think I have learnt (about dementia) as I’ve gone along ...when I’d ask them (staff) a question they’d say “well it is a dementia ward you know!”
Emma: I was reading up a lot on dementia ... and I just tried to talk about it as much as possible with people that I knew. [I read about] about what dementia was and how it can affect the individual, because every patient is quite different, it gave me that understanding of what could happen.
Dementia as a terminal condition: “No Major Ailment”

- Dementia largely not considered as a disease process contribute to death.

- Death more likely to occur from a sudden, catastrophic health event.

- Somewhat invisible trajectory.

- Traditional understandings of palliative care - (dying, right at the end, dying of cancer, final stages)
Dementia as a terminal condition?

Emma: no, no not at all and had I informed myself as much as a possibly could… I never put those two together.

Emma: cancer you do, heart disease you do you know there are a whole list of things that lead to palliation but dementia, nup.
Dementia as a terminal condition?

Jackie: you see there is nothing wrong with mum, she’s not on any medication, so apart from her mind, which is probably not real, real bad at the moment, I could see mum living for another 10 years ...there would have to be another cause [of death] like pneumonia or stroke.

Someday, ten years down the track
– consider dementia as a condition, requiring palliation.
Robert: he’s [Dad] got no medical problems, he’s never had heart problems, … no major ailments, … so he could live for a bloody long time, … I mean he could have a stroke tomorrow and die, but as far as I know he has never had high blood pressure still doesn’t…

Robert: Dying of dementia, I’d like to know more about that. …How can you die of dementia? All the neurons in your brain decide not to function?
Dementia as a terminal condition?

Invisible trajectory:

Lydia: ...no not really...i mean you look at someone with cancer you can sort of see them deteriorating where as dementia, no...i don’t think mum will die of dementia, I think she will die from a heart attack or stroke or something.
Decision Making: “Signing forms”

- Related to family member wishes for future care.
- Decisions contextualised with reference of a sudden health event.
- Signing forms = decision making
- Deferral of decision making
- Uncertainty of some family members re: course of future care.
Lydia: I think I did sign something to say that if mum had a heart attack, they’d sort of treat her there [at the facility] not send her to hospital... I think if she had sort of a stroke they’d still whisk her off to hospital I assume they would...

Robert: I think that I have signed some stuff about that yeah; they [staff] make the decision if he has whatever, a stroke and if he dies ...I can’t remember discussing it with anybody, certainly not staff
Decision Making

Peter: they [staff] went through all that, if Dad did have a major fall, if he had to be resuscitated would you want him to be...we had to sign some forms...it was mainly for if he had a bit of a heart attack would you want to let him go...

Re: transfer to hospital - ...Peter: I think they [staff] just do it anyway and told us that he’s gone to hospital, I don’t think they actually asked.
Tom: ...something to think about when the time comes.

Marion: Nothing like that has ever been mentioned and I haven’t bought up the subject.
Being involved: “outside looking in”

- Family members did not feel adequately involved in care of their relative.

- Absence of ongoing dialogue.

- Family having to actively seek out information about their relative.
Tom: they [staff] don’t really discuss, they don’t really come to us and say anything...they don’t come and say well mum had a bad night last night or anything like that.

Robert: not much [discussion] at all, I mean they rang up when dad fell over...basically apart from that nothing.
Being Involved

Marion: …I’m on the outside looking in and it really gets to me… I have to keep myself in it.

Emma: …More of an outsider… I can understand that they [the staff] are run off their feet and they do a tremendous job … the families I think tend to be a bit forgotten.
What does all this mean?

Action research group reflection on the data:
Key considerations:
- How can staff support family members to better understand dementia and key issues associated with the dementing process?

What are the possibilities for improving communication processes with family members, to facilitate discussion around future care planning and increase family involvement in decision making?
Towards Change...

- 2 action plans devised
- Implemented by members of the action research group.
- Consistent with palliative approach
1. Distribute an information booklet to family members of residents on the SCU – “Information of families and friends of people with severe and end stage dementia.”

2. Trial of an advance care planning process with family members/ ‘person responsible’.
   - Processes of ongoing communication