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Understanding the outcomes of specialist nursing:

Findings from a qualitative study

Kate Gridley
Social Policy Research Unit
University of York
kate.gridley@york.ac.uk

https://www.york.ac.uk/spru/projects/admiral-nursing/
Aims and background:

- Wider study aimed to evaluate support for carers of people with dementia (Admiral Nursing as an exemplar)
- Qualitative interviews to identify outcomes to measure

What is Admiral Nursing?

- Specialist nursing service for carers of people with dementia (unique in the UK)
- Case-management approach
- Has not been externally evaluated on a large scale before

Service website: https://www.dementiauk.org/how-we-help/admiral-nursing/
Interviews and focus groups

35 carers of people with dementia:
- Interviewed or took part in a focus group
- 18 with AN
- 17 from areas without AN

Topic guide asked about the outcomes of:
- Information and advice
- Assessment/review of carers’ own needs and of the person with dementia
- Financial support
- Training
- Help in the tasks of caring
- Emotional support
- Support to remain in/take up paid work

Aim of qualitative strand:
- Outcomes of support from Admiral Nursing (AN) and other services
- Outcomes of not getting support
- How can we measure these?
Key theme: Confidence in caring

Interviewer

What ultimately … is the result or outcome of you having this Admiral Nurse?

Um, I think confidence is a lot of it, confidence that I can get help, confidence that I'm not alone, there's someone out there to help, who fully understands and who is trained in the specific illness.

Carer with Admiral Nurse [AN2C7]
Selected measure of confidence


Covers (for e.g.):

- Confidence in ability to handle any problems person with dementia has
- Certainty that you can find answers to questions about the disease
- Confidence to face the future
I just think I feel lost, because we've got a situation and I think I don't know how to handle this... At times I just feel I just don't know where to turn and what to do...

... it'd be nice for [there to be] somebody that, once you are diagnosed, they know you, [and] the person with it, and come and see you ... and as the illness progresses and deteriorates, you have this support that “Have you tried this?” or “Have you tried that?”

Carer without an Admiral Nurse [NAN2C6]
...once the illness takes over ... the support isn't always there, I've been trying for long enough to have the psychiatrist check my wife's illness and tell me, because I, I actually don't really know what stage she's in and I seem to be having quite a bit of problem of getting the doctor to look at my wife, to be honest
The thing about the Admiral Nurses is ... my mum would do something really random and I'd think "Is this part of it? Is this part of the disease, is this how it works?" They always, always had time to speak to me.

They always know what to say.

They just calm you down, and explain in a fashion that you understand.

From Focus Group 1 in Admiral Nursing Area 2
November and December were horrendous ...I don't think I could have done another 6 months of that without any help and support... Now, I do feel he's getting worse, but I do feel I can cope, and I now have a vision for the future that I know how it will go.

From Focus Group 2 in Admiral Nursing Area 2

But ‘confidence’ doesn’t cover everything....
Carer Quality of Life

Selected measure:

Covers (for e.g.):
- Isolation and control over your time
- Safety and self-care
- Feeling supported (the only measure that had this as an outcome in itself)
Isolation and control over your time

…it’s like you’re in this little bubble that he doesn’t want anybody [else] to be in … [and] I cannot make a choice to go out anywhere …’

…you become isolated with that person you're looking after…

For me that's the biggest thing…

…that can lead to carer breakdown so quickly…

From Focus Group 1 in Non-Admiral Nursing Area 2
Safety and self-care

- Examples of carers’ health (mental and physical) suffering from self-neglect
- Examples of physical threat
- The Admiral Nurses’ focus on the wellbeing of the carer could help carers to recognise unsafe situations:

  …she was one of the ones that said, “you know, you’ve really got to think of yourself too”

Carer with Admiral Nurse AN1C5
I said to her “Just knowing that you’re coming every month.” Because things change with [wife], and when they change they change quickly, so …it’s almost like a comfort blanket, you know someone’s coming.

It's two fold, they know you really well, but they're not in it... they can see what it's doing to you, they can see what you need, even when you can't yourself, and they can encourage and guide.
In summary:

Outcomes: 1. **Confidence in caring** (Carergiver Self-Efficacy Scale)  
2. **Carer Quality of Life** (ASCOT-Carer)

Key contributors:
1. Support coming from a **specialist** in dementia  
2. This specialist offering **continuous** support and  
3. Invests the **time** to get to know the families well

Anyone who's dealt with dementia can give you practical tips, but the Admiral Nurses properly get to know you, care for you, and provide the essential emotional support...somebody understands, and that, I think, is more important than anything…

From FG1AN2
Echoes previous York findings:

1. Factors promoting continuity of care for people with long-term neurological conditions

1. a single person or team co-ordinating support across boundaries
2. this person or team having specialist knowledge (of the disease and of available systems of support)
3. flexibility in how, when and where support is delivered
4. long-term involvement
5. proactive monitoring and/or follow-up

2. People with complex needs

'It was strongly felt that ongoing access to a designated key worker or case manager with specialist knowledge could improve access to, and continuity of, support.'
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