The role of a clinical nurse consultant dementia specialist: A qualitative evaluation
Fleur M Duane, Dianne P Goeman, Chris J Beanland and Susan H Koch
Dementia published online 27 August 2013
DOI: 10.1177/1471301213498759

The online version of this article can be found at:
http://dem.sagepub.com/content/early/2013/08/22/1471301213498759

Published by:
SAGE
http://www.sagepublications.com

Additional services and information for Dementia can be found at:

Email Alerts: http://dem.sagepub.com/cgi/alerts
Subscriptions: http://dem.sagepub.com/subscriptions
Reprints: http://www.sagepub.com/journalsReprints.nav
Permissions: http://www.sagepub.com/journalsPermissions.nav

>> OnlineFirst Version of Record - Aug 27, 2013

What is This?
The role of a clinical nurse consultant dementia specialist: A qualitative evaluation

Fleur M Duane
Royal District Nursing Service, Altona, Victoria, Australia

Dianne P Goeman, Chris J Beanland and Susan H Koch
Royal District Nursing Service, RDNS Institute, St Kilda, Victoria, Australia

Abstract
Delay in diagnosis and difficulties in accessing appropriate health care services plague dementia care delivery in the community setting, potentiating the risk for misdiagnosis, inappropriate management, poor psychological adjustment and reduced coping capacity and ability to forward plan. We evaluated a clinical nurse consultant role with a speciality in dementia to provide person-centred pre-diagnosis support in the community. Clients, with a six-month history of cognitive and functional decline in the absence of delirium but no formal diagnosis of dementia, were recruited from a Home Care Nursing Service and an Aged Care Assessment Service located in the Western Suburbs of Melbourne, Victoria, Australia. The role of a clinical nurse consultant was highly regarded by clients and other health professionals. This paper discussing the CNC role and the outcomes of the role suggests it was successful in providing timely assistance and support for consumers and support for other health professionals.

Keywords
dementia, qualitative evaluation, home nursing service, cognitive impairment, nurse-led intervention

Introduction
About 12 million people worldwide have a diagnosis of dementia, and this is expected to increase to 25 million by 2040 (Burns & Illife, 2009). The management of dementia is complicated, it is a progressive disease and the impact increases with the severity of the
condition. As well as memory impairment, people with dementia will usually experience psychological and behavioural symptoms, such as psychosis, depression, agitation, aggression and disinhibition at some time during the course of their illness creating a substantial social and economic burden (Brodaty, Green, & Koschera, 2003).

The impact of the reliance on health and aged care services, dubbed the ‘Dementia Health Threat’, has led to a rapid need for strategic and cost-effective measures to manage the impact on the community (Australian Medicines Industry, 2012). Consequently, in 2009 in the United Kingdom, there was a call for dementia to be determined a national priority, funding to be increased for dementia research, improved skills in dementia care, development of community support and support packages for carers, a national debate on who pays for care and the development of comprehensive dementia care models (Burns & Illife, 2009).

Similarly, in Australia, dementia is a leading cause of death and burden of disease with escalating demands placed on informal carers and health service providers (Australian Institute of Health and Welfare, 2012). Exacerbating these issues are misdiagnosis, delayed diagnosis and lack of information and services for people with dementia and their families (Bamford et al., 2004; Stokes, Combes, & Stokes, 2012) potentiating the risk for inappropriate management, crises, poor psychological adjustment to the diagnosis, reduced coping capacity and ability to forward plan (Pond et al., 2012). Difficulties accessing suitable health care services and information have also been found to be significant factors for stress and burden (Gardand, Dew, Eazor DeKosky, & Reynolds, 2005; Koch, Marks, & Hofmeyer, 2002; Wackerbarth & Johnson, 2002). In order to develop strategies to reduce the burden associated with dementia, in 2012, the Australian Federal Government declared dementia a national health priority (Australian Institute of Health and Welfare, 2013).

There is a growing body of evidence that ‘timely’ diagnosis promotes psychological wellbeing for the person with dementia as well as the carer (Aggarwal, Vass, Minardi, Ward, Farfield, & Cybyk, 2003; Koch, Marks, & Hofmeyer, 2002; Prince, Bryce, & Ferri, 2011; Wackerbarth & Johnson, 2002). ‘Timely’ being a response to patient and carer concerns rather than proactively screening for dementia (Philips, Pond, & Goode, 2011). We therefore developed and refined the role of a clinical nurse consultant (CNC) with a speciality in dementia to provide person-centred pre-diagnosis support to address the growing need for assistance by those experiencing cognitive changes, as well as their families and carers.

A CNC is a nurse with a high level of expertise and specialist knowledge in their chosen field who is able to provide clinical expertise, clinical planning and management, education and leadership (Bloomer & Cross, 2011). The CNC dementia position is a Grade 4 district nursing role, which is the most senior level clinical role within the nursing organisation involved and requires a Master in Nursing degree.

**Methods**

Our qualitative study, conducted over a 12-month period between November 2011 and November 2012, utilised participatory action research (PAR) method (Meyer, 2006) to refine the role of a CNC specialist in dementia. Case studies are used in this project to describe details of the client and carer and delineate their journey (Keen, 2006). Case data were developed by the CNC following the experience of the participant; and informal conversations with them at regular intervals throughout the journey.
Setting
Clients from a Home Care Nursing Service (HCNS) and an Aged Care Assessment Service (ACAS) located in the Western Suburbs of Melbourne, Victoria, Australia.

Participants
Clients over the age of 65 years, with a six-month history of cognitive and functional decline but who had no previous diagnosis of dementia and cognitive impairment in the absence of delirium were included. Clients with cognitive impairment and no carer, undergoing palliative care, experiencing psychiatric issues or who needed an interpreter were excluded.

Recruitment
Participants were recruited from a HCNS site over a 10-month period and from ACAS over a six-month period. Referral to the project was triggered when the HCNS or ACAS assessor identified eligible clients. Written informed consent was provided by participants and/or carers.

Ethics
Ethics approval to conduct the study was obtained from the Royal District Nursing Service Human Research Ethics Committee.

Data sources
Field Notes. The CNC used reflective practice methods to document her experiences and observations following each client visit (Bulman & Shutz, 2008; Emerson et al., 1995). Participant responses to assistance from the CNC were discussed at reflective meetings with members of the research team and with colleagues.

Interviews. Semi-structured interviews with participants and or their carers were conducted at the end of the study to ascertain client perceptions of the role of the CNC, and what benefits, if any, it had provided (Tyrell, 2007). Quotes from participants have also been included to support themes (with any words added for clarity appearing in square brackets).

Focus groups. Focus groups were undertaken with HCNS and ACAS staff to evaluate staff perspectives on the value of the CNC role to both clients and to themselves as a community service provider.

Data analysis
Interviews and focus groups were recorded and transcribed. Field notes and interviews formed narratives of the client/carer journey (Kohler Reissman, 1993). Client/carer and staff focus group data were thematically analysed by the research team using a constant comparative approach (Lincoln & Guba, 1985). Transcripts were initially read by the authors, and emergent themes were discussed and interpretations compared. Analysis of the interviews with clients/and or carers and the focus groups are presented separately.
Results

Participants

One hundred and six participants were identified as potentially meeting the project recruitment criteria. Of these, 71 were deemed ineligible and 26 declined assistance from the CNC at the present time. See Table 1 for reasons for exclusion or non-participation. Nine clients were appropriate for inclusion and completed participation in the study. Participant demographics and referral information is included in Table 2.

Clients and/or carers evaluation of the CNC role

The findings are discussed using the major themes that emerged from the interviews: The qualities of the relationships with the CNC; the confidence participants developed in knowing how to approach managing cognitive changes and its progression and issues related to systemic processes.

Relationship with the CNC. The first theme that emerged from the data related to the qualities within the relationship participants had with the CNC. For older people and their carers, the relationship with the CNC was integral to their journey of adjusting to changes in their cognition. Underlying the perceived importance of the relational aspect of the CNC role was the many benefits this position was perceived to bring; including having face to face contact with the CNC, having an opportunity to explain their needs and concerns in a manner of their preference and the CNC herself having skills and attributes they identified as being essential in the delivery of care as these quotes attest:

‘She’s got such a soft manner and yet... she is quite efficient you know, good at her job
...Some people are abrasive you know. Talk at you instead of to you. It makes a lot of difference...’ (Louise)

Table 1. Reason and number of people excluded from the project

<table>
<thead>
<tr>
<th>Reason for exclusion or non-participation</th>
<th>Number of people</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clients/carers declined CNC assistance with arranging diagnosis</td>
<td>26</td>
</tr>
<tr>
<td>Clients discharged from HCNS services prior to CNC review</td>
<td>21</td>
</tr>
<tr>
<td>Diagnosis of cognitive impairment (dementia or other) already present</td>
<td>15</td>
</tr>
<tr>
<td>Clients already reviewed or to be reviewed by Aged Care Assessment Service or Cognitive Dementia and Memory Service</td>
<td>14</td>
</tr>
<tr>
<td>Clients requiring use of interpreter</td>
<td>10</td>
</tr>
<tr>
<td>Long-term RDNS client without diagnosis</td>
<td>4</td>
</tr>
<tr>
<td>Client had other psychosocial/psychiatric issue making it not appropriate to recruit</td>
<td>3</td>
</tr>
<tr>
<td>Clients were only receiving HCNS Home and Community Care (HACC) response service or palliative care (emergency callouts only)</td>
<td>3</td>
</tr>
<tr>
<td>Client deceased before review</td>
<td>1</td>
</tr>
</tbody>
</table>
Table 2. Participant demographics and reason for referral for home nursing care

<table>
<thead>
<tr>
<th>Case</th>
<th>Referred need</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Case 1:</strong> Ernie and wife Edna (carer). Both Australian born; Ernie is 88 years old.</td>
<td>Ernie was identified with cognitive impairment by the CNC after he had experienced a three-year history of memory decline, reducing ability to reason and a reduction in insight. Edna had observed this decline in Ernie and was concerned about the extra assistance he needed and would need in future if this decline continued. Following meeting through an admission visit for HCNS services, Ernie was recruited into the project.</td>
</tr>
<tr>
<td><strong>Case 2:</strong> Louise (no carer). Australian born and 81 years old.</td>
<td>Louise was referred for continence management; however, on admission she also presented with early changes of cognitive decline. She lives alone with her only son living in the country. Her elderly sister Nicole and brother in law live in the house next door. Louise was experiencing memory loss and word finding concerns, particularly relating to maintaining appointments and managing her house and bills. Following referral for CNC services, two visits were made to Louise to provide service information until formally recruited into the project.</td>
</tr>
<tr>
<td><strong>Case 3:</strong> Betty (no carer). Australian born and 80 years old.</td>
<td>Betty self-referred to RDNS for assistance with continence management. She mentioned during her assessment that she had a strong family history of Alzheimer’s Disease, and that she has experienced a recent decline in her memory and word finding, and that she was worried about her future. Following referral for CNC services, Betty was keen to be recruited upon the first visit made by the CNC.</td>
</tr>
<tr>
<td><strong>Case 4:</strong> Robert, Margaret and son Brett (carer). Australian born; Robert is 84 years old.</td>
<td>Brett is the live in carer and son for his parents Robert and Margaret. HCNS have been visiting Robert to manage his chronic leg ulcer since April. Brett reported having concern about both of his parents’ cognition. As Robert was an HCNS client, he was referred to the CNC, the Cognitive Assessment Tool (CAT) was attended and revealed significant cognitive decline. Following referral for CNC services, one visit was made to provide service until formally recruited into the project.</td>
</tr>
<tr>
<td><strong>Case 5:</strong> Sally (carer daughter Sarah). Australian born; 82 years old.</td>
<td>Have been seeing Sally and Sarah since June, Sally was referred by an ACAS assessor. She was initially referred to ACAS via her GP, to arrange extra support in light of her decline in cognition. Sarah was agreeable to CNC assistance from the first visit.</td>
</tr>
<tr>
<td><strong>Case 6:</strong> Hillary and daughter/carer Denise. Hilary is 102 years old.</td>
<td>Hillary was assessed by ACAS in home support (home help and hygiene assistance – which she was refusing help with). She was identified as having an undiagnosed cognitive impairment by the ACAS assessor who referred her to the CNC. Denise was agreeable for the service at the first visit.</td>
</tr>
<tr>
<td><strong>Case 8:</strong> Henry and Nina; Henry is Australian born and 83 years</td>
<td>Henry has experienced significant cognitive impairment with severe memory loss, poor insight and judgement. Nina observed these changes over the last 12 months and sourced support via their GP, who referred them to ACAS. ACAS referred them to the CNC for review. Henry and Nina were agreeable for the service at the first visit.</td>
</tr>
</tbody>
</table>
The face to face interaction within the delivery of care had the capacity to provide social contact for the person, as well as time to access information and support:

‘Yeah she came very regular... As often as we wanted to talk to her about something she would come back’. (Sarah)

For many participants, there was a strong preference for face to face contact:

‘I reckon personal, its better, because you can sit down and talk about stuff’. (Brett)
‘...spend an hour, half an hour talking to you and...from general conversation find out if there is anything troubling you.’ (Ernie)

The bedside manner, that is, the non-verbal communication of the CNC also helped the participants’ gauge if they’ve been ‘understood’:

‘...She said ‘don’t worry, we will see what we can do but don’t worry’ that was good because you do worry...’ (Louise)
‘...its safe to talk to her about all sorts of things. She understood you know’ (Edna)

Confidence in managing the disease and its progression. This second theme from the interviews ‘confidence in knowing how to approach managing disease and its progression’ stemmed from the participants newly acquired knowledge and awareness of what was happening and why (information), and the CNC providing responsive co-ordination of care needs (management strategies) and future planning. A couple of participants expressed how the assistance of the CNC reduced their worries:

‘It’s a very, very, very big help. It’s eased my worries. It’s [been] too much thinking what’s going to happen in the future and the dementia...’ (Nina)
‘...gave me a lot of confidence...’ (Louise)

Table 2. Continued

<table>
<thead>
<tr>
<th>Case</th>
<th>Referred need</th>
</tr>
</thead>
<tbody>
<tr>
<td>Case 9: Ronald and Edith (carer).</td>
<td>Ron was referred by an ACAS clinician and was diagnosed as having mild cognitive impairment by a geriatrician prior to CNC review. He is a former cabinet maker, now retired, living with his wife. He has supportive adult children who live nearby. Ron has memory loss but otherwise is mostly independent. His wife Edith supports him by managing household bills and Ron's medical appointments. Ron and Edith were agreeable for the service at the first visit.</td>
</tr>
<tr>
<td>Case 10: Milly (son Adrian-carer).</td>
<td>Milly lives alone. She was referred to ACAS by her GP. She has no insight into her memory loss and is easily confused with changes in routine. She is very reluctant to receive services. ACAS referred to the CNC for input and assistance. Adrian was agreeable for the service at the first visit.</td>
</tr>
</tbody>
</table>

*aTo protect the identity of participants pseudonyms have been used.*
Specifically, it was the ability of the CNC to source and provide information that was appreciated:

‘…she would look into it and then meet up with us a week or two later with the information that we were looking for.’ (Sarah)

The CNC was also perceived as being able to clarify information and gave advice relating specifically to the participant’s journey and experience of cognitive changes:

‘…I think it’s a good idea because it keeps us up with what’s going on…also if anything should go wrong with either of us there’s someone to give us a bit of advice and that sort of thing….’ (Ernie)

The CNC also delivered the information in a manner which best suited people of culturally and linguistically diverse backgrounds:

‘and also very good she send me the paper in Spanish about dementia.’ (Edith)

Management strategies. Inherent in all discussion with participants was a focus on working with the person to maximise their independence and how they may prepare and continue to manage as changes progress. The strategies identified as being of particular value in this journey included both products such as calendar clocks, and referral to other services:

‘[Most helpful was] how to deal with the onset of dementia and the strategies I should consider’ (Adrian)
‘…because he not very good with hearing, she find me, give me some paper about the special telephone … So I said to [the CNC] try to find me please and she did…’ (Edith)
‘…the sticker for the window (do not knock) that was another thing [the CNC] did for us. Care Alert, she did that, Home Help ….Oh and Webster pack she organised that….’ (Sarah)

Systematic processes. As well as sharing and sourcing information for participants, the CNC proved beneficial in navigating the health care system and the multitude of services available and referring the participant to the appropriate services for general health and wellbeing.

‘…from the start we didn’t have a clue, yeah so [the CNC] came in, she spoke to us about a lot of different services available to us. She sent out referrals for us for them to get in touch with us, which they have…’ (Sarah)
‘[the CNC] has been able to arrange for Joanne to come out to give Mum sponge baths and also to do house cleaning’ (Denise)
‘Something that she did do was that was very helpful was that she put you on to a dietician.’ (Edna)

Repetition of assessment. The length of the assessments conducted during the diagnostic process at the hospital was highlighted as being an issue for some of the participants. Louise explained she was tired from the number of medical appointments she had so expressed a reluctance to go to the hospital to see the geriatrician:

‘…I wouldn’t go over there. [The CNC] said if I didn’t want to go over there she would get someone to come to me…’ (Louise)
Edna also expressed that the diagnostic process had duplication within it:

‘Oh yes, they were excellent and they put a lot of time in... but well I got exhausted too because it’s so repetitive.’

For Sarah, it was keeping track of the service providers who were referred after the hospital review that proved challenging:

‘...we have had a lot of meetings over the past four months. That is why it is so confusing trying to think now which was which, everyone of them we have had contact with...’ (Sarah)

Some of the strategies suggested as an outcome of these assessments were not ‘person-centred’ and were perceived as inappropriate in some instances:

‘I think about the social group things they are [only] for me... and I would have to leave [Edna] at home on her own and I don’t think that’s right.’ (Ernie)

The overall sentiment of the interviewees in regard to efficacy of the CNC role was perhaps best summarised by Ernie, who said:

...[The best way was] like [the CNC] was doing, come spend an hour, half an hour talking to you and you should be able to from general conversation find out if there is anything troubling you' (Ernie)

**HCNS and ACAS staff evaluation of the CNC role**

In contrast to the themes raised by older people, the focus group discussions with care staff had three overall themes: improved client outcomes from the CNC role, addressing the educational needs of HCNS staff and streamlining of health care processes.

**Improved client outcomes from the CNC role.** Discussion highlighted that the CNC was perceived to optimise the positive outcomes for the client through being responsive to requests for assistance with client care:

‘I very much thought that [the CNC] was part of the team and she came to case conferences... as a clinician and we would discuss... some of our follow ups and her feedback was very reassuring, very knowledgeable and very skilled.’ (ACAS)

‘[the CNC] being at case conference she... was able to be involved in the plan’ (ACAS)

HCNS staff also found the CNC to be responsive and able to spend time with them to listen to their concerns and plan care:

‘...There are a lot of times that you can’t get people to listen and you might have concerns that other people don’t have. So to bring someone out that has the time to go into everything, to see every problem that you are bringing up. That was really helpful, it makes us, our lives a lot easier.’ (HCNS)

There was emphasis placed on the time spent discussing proposed care plans with the referrer and the positive outcomes from this:

‘...it was good for [the CNC] to pass on all the available services and organisations involving the client and the family. So I guess she was taking on the extra step that we don’t do that side of it as
well... it was good to know that she was there through the whole process and informing them[the client] as much as possible...’ (ACAS)

‘I don’t think that there was a time when she couldn’t give me an answer or put me onto a resource and she was just an absolutely invaluable resource for information and support. She would go out and double with me and at the end of it not have to shoot off but sit with me for 45 minutes afterwards sometimes. It was really, really good to have those resources available.’ (HCNS)

Prompt and regular communication between the CNC and the assessor or nurse was also seen as providing good outcomes for both clients and staff:

‘...The family were interested in a diagnosis but along the way they decided that wasn’t needed because [the CNC] strategies worked really well so...and this family found very difficult to have services coming into the house and clearly she worked with the family really well’ (ACAS)

‘Well both having a discussion and finding out whether they were suitable for her to go out and see. What you were worried about, concerns and to look at other things...The resources to do what she could do and so for me I found it quite valuable.’ (HCNS)

Staff were particularly forthcoming with examples of interventions that were implemented and seen as appropriate and beneficial to clients

‘...one my clients drives his wife crazy he is always pressing remote controls and she would say why don’t you watch your favourite show and he would press all the controls like crazy...[the CNC] found one that could be used for everything and we supported her and advocated for services from the local council and this made a huge difference and so the wife is much happier now and feels she can continue to care for him more than she did before’ (ACAS)

‘...she certainly came up with different strategies and I suppose that flexibility about being able to fit into what was required.’ (ACAS)

Addressing educational needs of staff. The CNC was not only viewed as being responsive to client needs, but also responsive and sensitive to staff educational needs and knowledge about dementia, with time spent assisting teaching and guiding staff:

‘My knowledge base has increased threefold [due to the CNC]...’ (HCNS)

[The CNC] being here when we rolled out the cognition assessment tool, all the resources, information and brochures that we needed to complement that [The CNC] has developed. So we’ve got stuff about tracking wandering clients, about safety things and stuff that we never had before so it’s been good timing that she was here when we rolled out that dementia model of care.’ (HCNS)

Systemic processes. The risk for multiple assessments by different health professionals was identified by one assessor:

‘...you need to be careful with that because like I saw a lady yesterday and that was the same thing. She’d had so many calls and so many people coming from council etc that in the end they are not clear who is who anymore and so I can certainly see for you as HCNS it is a terrific role really and I certainly think with the geriatrician its good but my note of caution is that you must be aware that you don’t want to add too many layers’ (ACAS)
However, other staff recognised that the CNC was in fact able to streamline processes with ACAS:

‘I think for me she was very respectful of the ACAS process and she was very respectful about not wanting to reinvent the wheel, and so all the information we gather, we gather a lot of information, not wanting to have to go through all that again with the clients, you know, coming to speak to us about what is our concern. How did I find the client? What kind of questions would the family have for her. Things like that. Very responsive.’ (ACAS)

And also the relationship between ACAS and HCNS:

‘...that link between ACAS that was really good, we had better client outcomes [the CNC] could articulate the issues better verbally than we could in written referrals.’ (HCNS)

‘...my experience is that [the CNC] has been able to provide, like streamline things so that the client, nurse and herself have continued on from me flagging that there might be something and then [the CNC] has sort of streamlined it with ACAS to make it better for the client, continuum for the client’. (HCNS)

‘...[the CNC] was able to guide me as to what specific blood tests... could be requested from a GP that ACAS [could] do their assessment... that was really useful to reduce the wait.... I wouldn’t have known that those particular blood tests would have been relevant prior to that’. (HCNS)

Discussion

We utilised a participatory action research model that sought feedback from clients/carers and staff to develop and refine the role of a specialist CNC dementia nurse. The resulting CNC model of care addressed client needs and concerns, provided assistance to gain a timely diagnosis, access to suitable resources, referral to appropriate services, assistance with navigating the health care system, reduction in duplication of assessment among services and as a consequence an improvement in the quality of life of those affected by cognitive decline.

In our study, as well as the specific outcomes of the CNC role discussed already, the CNC also functioned within the organisation to provide support, advice and education for community care aides, enrolled nurses and Grade 2 and 3 registered nurses.

Similar district nursing services operate in the UK and USA. Within the United Kingdom, district nurses work to provide acute care, complex care and end of life care in the home using a model of care that includes a mix of nursing staff, with senior nurse role perhaps mirroring the CNC position in our study (Royal College of Nursing, 2013). In the United States, community nurses work within a multitude of areas and specialties, but similarly to the consultant role, this may include provision of complex care in the home environment (Meadows, 2009).

In the United Kingdom, however, Admiral Nurses specialising in dementia, work with family carers and people with dementia in the community and other settings. While Admiral Nurses seek to improve the quality of life for people with dementia and their carers through a broad range of interventions they differ in their role to that of a CNC dementia (http://www.dementiauk.org/what-we-do/admiral-nurses/what-admiral-nurses-do/, accessed 15 May 2013)

Our CNC dementia not only sought to improve the quality of life for people with dementia and their carers, but was regarded as a senior nurse with a high level of expertise and knowledge in her chosen speciality, who not only provided clinical expertise,
education and leadership but was a role model who worked independently and autonomously.

Evaluation of this model by clients and staff provided evidence of its benefit to those living with cognitive impairment and/or their carers and families in addition to HCNS and ACAS staff providing support to such people in the community setting. The findings also highlight important stages within the experience and how the benefits extended to including improved understanding and awareness of dementia.

**Strengths and weaknesses**

Previous research has revealed that General Practitioners often diagnosis dementia some considerable time into the course of the disease resulting in delays in anti-dementia medications that may slow the disease progress, referral to support services that could assist families to help understand and adjust to the impact of the disease and insufficient time to plan for the future while competent to do so (Boise & Kaye, 2004; Brodaty & Green, 2002; Valcour, Maskai, Curb, & Blanchetter, 2000).

Whilst a person-centred and goal-oriented approach to care is not new, in fact it is reflective of the Victorian Government Active Service Model (ASM) (Department of Health, State Government of Victoria, 2013), we believe that our novel person-centred nurse-led positive dementia practice intervention is a workable inclusive model of pre-diagnosis community nursing support delivered in the home setting to address the problems associated with delay in a diagnosis of dementia for clients and their carers and families.

Throughout the duration of the project, the CNC was consulted by colleagues and asked to provide advice or at home consultation for clients with complex, specific needs related to cognitive impairment. The CNC supplemented this need by collating dementia-specific resources to support direct care staff; with both online and hard copy information made available. The need to support staff in all aspects of dementia care, learning requirements and understanding of resources is crucial and therefore the CNC addressing these needs was an unexpected benefit of the model.

The contact the CNC had with families following visits by the ACAS assessors and geriatricians also demonstrated an unexpected benefit for clients and carers as the CNC was able to clarify points of discussion from these meetings. It also allowed for additional needs to be identified and addressed and referrals and strategies to be formulated outside of those relating specifically to cognitive impairment.

As the CNC service aimed to meet the needs of participants, the process and delivery of service was done at a time and pace that suited the individual or dyad requiring care. We underestimated the length of time that a person-centred approach would take and consequently due to the 12-month time frame of the study, this lead to a low number of study participants.

One staff member expressed the CNC may add another layer of complexity; however, this view was not shared by the other focus group participants. In fact, many explained that provision of services may be streamlined within this role, as information related to the client may be shared between agencies more easily. It was also highlighted that positive outcomes may in part have been related to the fact the position was not subject to the normal workload of a community nurse.
Conclusion

Our CNC nurse-led positive dementia practice is novel and outcomes suggest that the independence and the quality of life of people with dementia can be enhanced through this inclusive model of community nursing care for people with cognitive decline and their carer’s. Integral to the journey of adjusting to changes in their cognition was the importance of the relational aspect of the CNC role which included face to face contact with the CNC and opportunities to explain their needs and concerns in a time and manner of their preference.

Our study revealed greater insights into the experience and journey of older people with cognitive changes and dementia. We recommend further research into service provision and evaluation should be undertaken. Ideally replication of this project would consider the results of our work, expand the length of study to improve recruitment numbers and be inclusive of non-English speaking older people and carers.

Acknowledgements

We would like to thank Liz Brewer and staff from the Aged Care Assessment Service. We also appreciate the assistance of the staff from the Cognitive, Dementia and Memory Service (CDAMS), Alzheimer’s Australia Victoria and the Consumer Reference Group.

Declaration of competing interests

The authors report no conflict of interest.

Funding

This study was funded by an Ian Potter Foundation Research Grant.

References


Royal College of Nursing. (2013). District nursing-harnessing the potential: The RCN’s UK position on district nursing. London: Royal College of Nursing.

Author Biographies

Fleur M Duane completed her Master of Nursing in 2008. She worked as a researcher for over two years with particular interest in the area of Dementia and aged care and as part of team researching medicine management in the community. Fleur currently works as a community Clinical Nurse Consultant Dementia as well as under taking further studies to qualify as a Nurse Practitioner.

Dianne P Goeman is a medical sociologist and Senior Research Fellow at the RDNS Institute. Dianne has extensive experience in mixed-methods research. She has a special
interest in dementia, medicines management, the health literacy and the priorities of people living with chronic illness, as well as health professionals’ delivery of care.

**Chris J Beanland** is a registered nurse and physiologist. Christine’s research interests have primarily been in using clinical trials methodologies to evaluate new nursing interventions and in the development of tools to assess a person’s ability to self-administer their medicines; initially in an acute inpatient setting and currently in the community.

**Susan H Koch** is the Director of the RDNS Institute. She is currently Chair of the Australian Government Minister’s Dementia Advisory Group, a Fellow of the Royal College of Nursing, Australia and Fellow Australian Association of Ageing. Susan’s research has its focus on practice issues including restraint use; elder abuse; care for people living with dementia and medicine management.