

Dementia special interest group: shared learning across dementia, palliative and end-of-life care domains

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Received 3 December 2015

Revised 22 February 2016

Accepted 23 February 2016

ABSTRACT

There is a growing impetus to improve care for people with dementia at the end of life and facilitate better access to palliative care. Some settings and services are concerned that they are ill equipped to care for this group of people, in respect to environment and knowledge and skills. This article describes the launch of the 'Dementia in palliative and end-of-life care Special Interest Group', which was a joint venture between Dementia UK and Hospice UK. The group brought together practitioners and clinical leads keen, in the spirit of shared learning, to share knowledge and to provide high-quality palliative and end-of-life care for people and their families affected by dementia. A nominal group technique identified 13 themes, of which five were ranked as priorities in terms of addressing learning needs that could be met during future meetings. These were: communication in dementia; educating others; understanding and influencing policy; care in different settings; and pain assessment and management. Shared learning through the special interest group is a way of harnessing the expertise across the two care domains, with the common objective of improving the lives and deaths of people with dementia.

BACKGROUND

An ageing population

People aged 60 years and over make up the most rapidly expanding segment of the international population. By 2050 this group will treble in numbers from 605 million to 2 billion ([World Health Organization \(WHO\) 2012](#)) with increasing age being the strongest risk factor for developing dementia ([O'Connor 2010](#)). Of these older people it is estimated that, worldwide, 135.5 million people will have dementia by 2050 ([Alzheimer's Disease International \(ADI\) 2013](#)). While emerging evidence is suggestive of a

slowing of incidence ([Matthews *et al* 2013](#)), there are still an estimated 835 000 people currently living with dementia in the UK which will rise to over 2 million by 2050 ([Alzheimer's Society 2014](#)).

Dementia

Dementia is a term used to describe a syndrome; a collection of symptoms, including a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily living activities. These symptoms are caused by structural and chemical changes within the brain as a result of neurodegenerative changes. The cognitive changes arising in dementia are determined to a large extent by the areas of the brain that are affected by the underlying pathological processes. These processes include tissue destruction, compression, inflammation, and biochemical imbalances. In other words, the process of dementia is the end-stage manifestation of numerous brain disorders ([Wilcock *et al* 1999](#), [Piggot and Court 2008](#), [Fratiglioni and Qiu 2013](#)). Dementia is a degenerative disease and thus a life-limiting condition. Failure to recognise dementia as a terminal illness and that it is often accompanied by multimorbidity ([Sampson *et al* 2006](#)) with poor understanding and clinical recognition of when patients with dementia are entering the terminal phase of illness ([Ahronheim *et al* 2000](#)) has led to neglect in addressing end-of-life challenges for people with dementia (PWD) and their carers.

Dementia, palliative and end-of-life care

In recent years there has been a significant increase in policy and guidance, across many countries, which directly influences and promotes palliative and end-of-life care for non-malignant life-limiting conditions. In the UK the

To cite: Harrison Dening K, Cooper M. *End Life J* 2016;**6**:e000018. doi:10.1136/eoljnl-2015-000018

CLINICAL PRACTICE DEVELOPMENT

Table 1 Policy: dementia, palliative and end-of-life care

Publishing body	Year	Report
Department of Health	2001	National Service Framework (NSF) for older people
	2003	Building on the best
	2008	End of life care strategy
	2009	Living well with dementia: a national dementia strategy
	2010	Quality outcomes for people with dementia: building on the work of the national dementia strategy
	2011	Prime minister's challenge on dementia
National Institute for Clinical Excellence & Social Care Institute for Excellence	2006	NICE/SCIE guidelines for dementia
	2012	End of life care for people with dementia: commissioning guide
WHO	2004	Better palliative care for older people
	2004	Palliative care for older people: better practices
Care Services Improvement Partnership	2005	Everybody's business—integrated mental health services for older adults: a service development guide
National Audit Office	2007	Improving services and support for people with dementia
	2008	End of life
	2010	Improving dementia services in England—an interim report
Alzheimer's Society	2007	Dementia UK
European Association for Palliative Care (EAPC)	2013	White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the EAPC
National Council for Palliative Care (NCPCC)	2009	Out of the shadows

provision of palliative care services, irrespective of diagnosis or age, has been supported by a number of government reports (table 1). It is only following the publication of the NICE/SCIE Dementia Guideline (2006), where several best practice recommendations were made in respect of palliative and end-of-life care in dementia, have we seen a growing impetus for its access to families affected by dementia.

People with dementia (PWD), particularly those in the advanced stages, may experience poor end-of-life care because they are often not perceived to have a terminal illness, despite the fact that they are often bed bound, doubly incontinent and unable to communicate (Sampson *et al* 2011). A poor understanding of the pathophysiology of dementia among professionals is also suggested as a possible rationale (Thuné-Boyle *et al* 2010). Alongside this health and social care services may not be optimally configured to meet their complex needs; a Royal Commission report has highlighted how PWD are unable to access palliative care services (House of Commons Health Committee 2005).

Shared learning to improve care

In 2011, Hospice UK established the Commission into the Future of Hospice Care (Help the Hospices 2013)

to explore the key challenges facing hospices in the future. In order to address significant shifts in demography and disease, palliative and hospice care will need to become more agile in responding to a changing profile of people seeking palliative care. The report identified dementia care skills as a specific technical area that needed to be developed by hospice professionals as they seek to support increasing numbers of PWD, as well as older individuals with multiple conditions and frailty, and the related needs of family carers.

Similarly professionals working in the field of dementia care have long been aware of a growing need to ensure PWD and their family carers receive the best possible care as end of life approaches for the person with dementia. Dementia UK established a special interest group for palliative and end-of-life care in 2008 to scope the practice development needs of Admiral nurses to be better able, in knowledge and skills, to meet the needs of families affected by dementia (Harrison Dening and Wharrad 2010). What became apparent during this project was that knowledge and skills in this area often spanned the specialties of dementia and palliative care and while joint working could be facilitated in complex cases, there needed to be focused practice development for both groups of specialist staff groups.

To this end Dementia UK and Hospice UK held an event, inviting professionals from dementia care and palliative and end-of-life care, to establish a special interest group that had as its focus the sharing of practice, knowledge and expertise in their respective fields to support *shared learning*. At the inaugural meeting delegates participated in a nominal group to collectively identify their learning needs from the special interest group.

Aim

This paper describes the use of a nominal group technique (NGT) (Delbecq and Van De Ven 1971) to examine the learning and development needs of clinical staff from fields of dementia, palliative and end-of-life care and those working in practice that entails both.

Participants

The day was attended by 35 experts from the fields of dementia care (n=5), palliative and end-of-life care (n=17) and those who worked across both fields (n=6) and from a variety of care settings: hospices, acute hospitals, care homes, mental health assessment wards and community services of different kinds.

METHOD

The NGT (Delbecq and Van De Ven 1971) is a structured evaluative methodology, developed to facilitate group or team problem identification, solution generation and decision-making. It can be used in groups of varying sizes but where everyone's opinions are taken

into account. NGT facilitators encourage the sharing and discussion of thoughts and ideas made by each group member, thereby identifying common ground, and a plurality of ideas and approaches. This diversity often allows the creation of a hybrid idea (combining parts of two or more ideas), often found to be even better than those ideas being initially considered (O'Neil and Jackson 1983). It has also been used in healthcare settings for those with impaired language, understanding and capacity (Harrison Dening *et al* 2012).

Conduct of the groups

To ensure consistency, the NGT was conducted according to a predetermined schedule, which included an introduction to the purpose and process of NGT in developing an understanding of the educational and knowledge needs of attendees at the special interest group. While this process did not require ethical approval, written consent was obtained from participants for purpose of sharing the data gained from the process.

Stage 1: generation of ideas (15 min)

Participants were asked to consider what their individual knowledge and educational needs were in relation to dementia and/or palliative and end-of-life care and to write a word or short statement for each onto a 'post it' note. Although all contributions were anonymous, each participant was asked to indicate their 'speciality' in the upper right hand corner of the post it; E indicated palliative and end-of-life care specialist, D indicated dementia specialist and B indicated a specialist who worked within a service that entailed both. The number of ideas they could generate was not limited. This stage aimed for silent generation of ideas.

Stage 2: discussion (20 min)

This involved a structured and time-limited discussion of all ideas generated. This was to clarify ideas, explore the underlying rationale and add further items that emerged through discussion, ensuring each participant felt their contributions were valued. Ideas were placed on a flip chart paper in full view of all participants.

Stage 3: further generation of ideas (10 min)

Participants were asked to consider any additional ideas arising after hearing those of others.

Stage 4: discussion and generations of themes (10 min)

All contributions were discussed to generate common themes. This group activity ensured face validity of themes.

Stage 5: ranking (10 min)

Ranking of themes was then undertaken collectively to determine the group's priorities for educational

topics on which to focus in up and coming sessions of the special interest group meetings. Participants were each allowed two votes to use in ranking their top priorities. This enabled the group to collectively identify the five top priorities to take forward. Field notes were taken by KHD and MC of group discussions to add richness and context to the NGT processes.

RESULTS AND DISCUSSION

In total 15 themes were developed where the members of the group identified learning needs. Of these, five themes were ranked highest by the participants in terms of their perceived need for developing their knowledge and skills in palliative and end-of-life care in dementia:

- ▶ Developing skills to enable better communication as they care for the person with dementia;
- ▶ Meeting the educational needs of the wider team regarding dementia care;
- ▶ Understanding and influencing policy and strategy for palliative and end-of-life care in dementia;
- ▶ Understanding issues for dementia care in different settings;
- ▶ Pain assessment and management in dementia.

Developing skills to enable better communication as they care for the person with dementia

By far the largest number of participants ranked 'communication in dementia' as being the most important practice development need. In dementia communication can become increasingly difficult. For the person with dementia it can be as challenging to be understood as much as to understand the communication of others (Downs and Collins 2015). Poor communication can have a negative effect on the well-being of a person with dementia and thus it becomes the responsibility of those around them to ensure effective communication (Kitwood 1997).

NGT participants across dementia care, palliative and end-of-life care and those that work specifically with both, all expressed the need for further knowledge and skills in effective communication with PWD at the end of life. Those who were from the palliative and end-of-life care fields acknowledged that many had attended an 'advanced communication skills' course (eg, http://www.uclan.ac.uk/courses/connected_advanced_communication_skills_training.php) in relation to difficult conversations in cancer care but remained concerned that this would not help them make better 'connections' with the person with advanced dementia. They identified learning needs in respect of communication skills in dementia:

Skills in difficult conversations but...does that help?...
how to communicate and care for the distressed person
with dementia who is unable to co-operate... (E)

Those working in the field of dementia care wanted to develop their skills in communication about

end-of-life issues for families affected by dementia. Participants working across the combined specialties were also concerned about how best to communicate with family carers:

Communication in dementia is not straight forward anyway...everyone is different...how I communicate with one may not be the same for another. How does this fit with end-of-life care...? (D)

Not just about communicating with the person with dementia but their carer too... (B)

Communication, both verbal and non-verbal, is an essential aspect of living and is a means of expressing thoughts, preferences, emotions and opinions. The difficulties associated with communicating with PWD are not the same as the issues covered in educational courses about holding difficult conversations. Non-verbal communication is fundamental to communication in dementia. Tone of voice, facial expressions, body language and gesture are all essential elements of good dementia care and communication. We need to be perceptive of all of these elements of communication, alongside hearing the verbal communication. For example, we can pick how a person may be feeling through their tone of voice, irrespective of the content of speech (Powell 2000). It would seem from the views of NGT participants, irrespective of care setting or specialist background, that education and skill development in communicating with people with dementia is a strong and shared need.

Meeting the educational needs of the wider team regarding dementia care

The second highest ranked theme was how the NGT participants could develop the knowledge and skills of generalist practitioners with whom they networked through their roles. There are growing expectations for professionals to support those in other, associated fields, through the sharing of knowledge and skills. However, there was concern expressed that though this was accepted, it presented a challenge in that they perceived themselves as having fundamental learning needs to have confidence in doing so:

We each 'know what we know' but how do we get to know what we don't know...? (D)

[More people with dementia]...are expected to come into our hospice but how will [I] support the staffs' educational needs when I am not an expert in this... (E)

Some participants felt that it was not about what they knew but that it was more about how they could access education and supervision from others who had a certain expertise:

I may not have the answers, but I know where to get them... (B)

Great need for education...across organisations, professionals...help each other... (E)

You don't need a medical approach, just lots of training to empathise. (D)

Others recognised that other factors could enable development in each specialty:

How leadership rather than teaching is what will make a difference. (E)

Overriding the themes and discussions of participants was the agreement that they had much to gain from the shared learning that the special interest group could provide. Shared learning is the process of working collectively to achieve a common objective in a group; members can share knowledge and complement each other's skills.

Understanding and influencing policy and strategy for palliative and end-of-life care in dementia

As we have discussed earlier in this paper, policy and strategic approaches to facilitate better access to palliative and end-of-life care for families affected by dementia is not new. Since the first call for better end-of-life care for older people (Department of Health (DH) 2001) the policy and strategy drivers to include dementia (among other excluded illnesses) has gained momentum. However, participants in the NGT all expressed knowledge needs; not in understanding the messages within various reports and documents, but in how they can learn from other practitioners, from whichever specialist background, to use such policy and strategy to develop their services. Several participants sought learning on how they might influence funders and service setting management boards to develop better care for PWD:

[I want to understand]...ways to get management, clinical commissioning groups's on Board. (E)

[I would like]...training in effective business case preparation...[to make the case for access for people with dementia]. (B)

How to persuade those who define your hospice strategy that we must ensure we care for PWD equitably. (E)

Of equal concern across all practitioners was how extending their services and care to people affected by dementia would be funded and given equal weight to that of other life-limiting conditions:

[I] would like dementia to be as seriously funded and thought about as cancer. (B)

However, when considering policy and strategy within end-of-life care some participants did not welcome the drive to include PWD in main stream services:

Some people [in palliative and end-of-life care services] don't want to look after dementia patients with end-of-life care needs as they see them as being difficult to look after...resistance... (E)

Often policy and strategies are developed with little or no consideration to how, in this instance increased access for PWD to palliative and end-of-life care services, to ensure staff groups are on board to take change forward. The English national Dementia Strategy (2009, p. 61) simply stated within objective 12 that the principles enshrined within The End of Life Care Strategy (2008), be applied to PWD and that local work on end-of-life care needs to focus on the large numbers of people who will die with dementia. In addition, commissioners and providers were to ensure that effective end-of-life care for PWD can be made real, including the effective use of specialist liaison with palliative care providers and end-of-life nursing care.

Understanding issues for dementia care in different settings

Care settings for PWD and how palliative and end-of-life care can best be facilitated was a strong theme. For palliative and end-of-life care staff there was a need to understand their role in caring for PWD, how best to provide this in their respective settings, such as, hospice, care home or acute hospital. Of particular concern was in caring for a person with dementia who was distressed and the perception that this may require not just knowledge and skills but also extra staffing resources; some participants sought to understand optimum staffing ratios:

Do we have enough staff? Do dementia patients need more staff? (E)

In contrast those working in dementia care or across both specialties were more concerned about understanding what resources were available in any care setting that could be accessed by families affected by dementia towards the end of life, for example, volunteers and befrienders. A particular tension around funding and capacity was who should care for PWD if they are unable to stay at home and hospital admissions are to be avoided; hospice or care home?

[There needs to be a] shared ethos between hospices and care homes. Care homes are businesses...hospices are 3rd sector and struggle for funds therefore there needs to be shared understanding of which each other can offer... (B)

Pain assessment and management in dementia

Pain is common in people with advanced dementia and is often undetected and undertreated (Scherder *et al* 2009). McCarthy *et al* (1997) reported that significantly more patients with dementia experience pain in the last 6 months of life compared with those with cancer and that pain control was often inadequate: this again may be due to a failure to

recognise pain or assess it in PWD. NGT participants from all groups of staff expressed a need to learn more about pain in dementia:

Understand how to assess and manage pain...in advanced dementia. (E)

All three groups also expressed a need to be able to differentiate between distress behaviours related to pain and physical causes as opposed to those associated with the behavioural and psychological symptoms of dementia (BPSD):

Pain management should be a part of care management for distressed behaviours and...BPSD. (D)

[Pain]...managing people with dementia. (B)

Pain education...not just seeing 'agitation' and treating 'agitation'... (D)

Pain can often manifest as behavioural change such as agitation, distress, social withdrawal, depression or resistive behaviour (Scherder *et al* 2009), and such changes in behaviour are at risk of being interpreted as psychological or psychiatric problems associated with dementia if pain and physical discomfort is not considered as a possible cause of the distress. Participants from the field of dementia care seemed to have a greater awareness of the behaviours being viewed negatively as a symptom of dementia; sharing knowledge and skills in the field of pain assessment and management alone could be a significant and powerful outcome of the special interest group.

Methodological issues of NGTs

A major advantage of NGT is that it is a process that is supportive of participation. Some members of such a group, where two distinct areas of specialist practice come together might make group members reluctant to suggest ideas because they are concerned about being criticised, or are reticent and shy. Chapple and Murphy (1996), in evaluating students learning experiences found this not to be the case with NGT overcoming such problems and having the advantage in ensuring relatively equal participation. Other advantages include producing a large number of ideas and in allowing higher numbers of participants than in other group methods, such as focus groups.

However, a disadvantage might be that an individual's priorities for personal education needs may not be ranked as highly as they would wish in addressing their own, pressing, professional development needs.

Clinical implications for the special interest group and sharing knowledge and skills

The special interest group in palliative and end-of-life care in dementia has the potential to develop into a forum that can facilitate shared learning and development to meet practice and knowledge gaps in practitioners working in this challenging field of care.

There are plans to develop the interest group enabling members to gain the advice and support of others outside of the formal education meeting of the group; for example, a dedicated website (attached to Hospice UK site) to 'ask a colleague' online discussion group, signposting to other learning resources, links to relevant evidence and journal articles with an online journal club.

CONCLUSIONS

The national special interest group in palliative and end-of-life care in dementia is in an embryonic stage, however, the power of shared learning through the vehicle of such a forum is not to be underestimated. This NGT is the first stage in understanding the key learning priorities for the group participants from the fields of dementia and palliative and end-of life care. Shared learning through this approach, it is hoped, will achieve the common objective of improving the lives and deaths of PWD, and is a way of harnessing the expertise across the two care domains.

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Acknowledgements The authors acknowledge Dementia UK and Hospice UK in their support of the national special interest group in palliative and end-of-life care in dementia.

Competing interests None declared.

Provenance and peer review Not commissioned; externally peer reviewed.

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End Life J 2016 6:

doi: 10.1136/eoljnl-2015-000018

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