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CRITICAL REFLECTION ON PRACTICE DEVELOPMENT

Using a practice development approach to support Admiral Nurses with end-of-life care

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Abstract
Background: The use of a practice development approach to support Admiral Nurses in caring for persons with dementia at end of life and their families.
Aim: This article is an exploration and reflection on how supporting the learning of specialist nurses in dementia care can ensure their development is person-centred, innovative and valuable.
Conclusions: A practice development approach towards learning and development is available to Admiral Nurses and enables the development of a supportive learning culture. As a result, the nurses are more able to provide families with specialist support when it is needed.
Implications for practice:

- A collaborative approach to practice development with shared values and goals is essential to achieving person-centred learning
- Practice development must be supported by a sustainable model and skilled facilitation
- End-of-life care can be complex and emotive so nurses need appropriate support to enable them to be more reflective in and on practice

Keywords: Practice development, Admiral Nursing, dementia, end of life, peer reflection processes, facilitation, learning culture

Introduction

There is growing political and government awareness of dementia, which has resulted in plans to implement better care (Department of Health, 2013; 2015). With more than 850,000 people now living with dementia in the UK and more than 220,000 developing it each year (Alzheimer's Society, 2018), the need for effective care over the trajectory of the disease is absolutely essential. As overall life expectancy increases, more people are living with a range of conditions and disabilities (Matthews et al., 2013), and people with dementia are among the main users of health and social care as they move towards the end of their lives (Kulmala et al., 2014). There are concerns around their unmet palliative care needs (Dempsey et al., 2015), with urgent calls for better provision for people with end-stage dementia and better support for the person and their family through their experience (Lillyman and Bruce, 2016).

Palliative care and dementia

The paucity of palliative care provision in dementia is worsened by the fact that it is not always recognised as a terminal or life-limiting condition (Middleton-Green et al., 2017). This leads to a

failure to recognise and respond to specific end-of-life needs. However, while there is little reference to palliative and end-of-life care for people with dementia in recent NHS policy (NHS England, 2017), there is an acknowledgement of the increasing complexity of care in dementia and recognition of the need for improved training and development of staff as a way of achieving better care.

Admiral Nurses have been developing their approach to meet the ongoing and palliative care needs of families affected by dementia over several years (Harrison Dening and Wharrad, 2010; Harrison Dening et al., 2012; Evans et al., 2018). Admiral Nurses are specialist dementia nurses (see box 1), who use a range of psychosocial, educational and practical approaches to support families living with dementia (Bunn et al., 2014). There are approximately 250 in the UK, based in a variety of care settings including the community, acute hospitals, care homes and hospices. Historically, and also in response to NHS England's intended transformation of dementia services, Dementia UK supports the professional and practice development of this specialist nursing model of case management.

Dementia UK has long recognised the benefits of clinical supervision for individual Admiral Nurses, organisations that employ them and, most importantly, affected families. The charity offers such support on the premise that professionals providing person-centred care for families require equal consideration to enable them to nurse and care effectively. Smith (2012, p 202), in her discourse on emotional labour, concludes: 'For patients to feel safe and cared for, the staff who care for them must also feel safe and cared for.' Actively supporting group supervision can be a way for organisations to demonstrate they also care for their staff and to promote nurse resilience (Delgado et al., 2017; Driscoll et al., in press).

Box 1: The role of the Admiral Nurse (Rahman and Harrison Dening, 2016)

Admiral Nurses are specialist dementia nurses, who:

- Focus on the needs of the whole family affected by dementia, including psychological support to help the person with dementia and their carers understand and deal with their thoughts, feelings and behaviour, and to adapt to the changing situation
- Use a range of specialist interventions that help people live as well as possible with the condition, and develop skills to improve communication and maintain relationships
- Work with families at particular transition points of difficulty in the dementia journey, including diagnosis, when the condition progresses or when tough decisions need to be made, such as moving a family member into residential care
- Help families cope with feelings of loss and bereavement as the condition progresses
- Provide case management and advice on referrals to other appropriate services, and liaise with other health professionals on behalf of the family

Evans et al. (2018) explored the role of the Admiral Nurse in providing end-of-life care for families affected by dementia. Their findings show that family carers cope better when they have consistent professional advice on various aspects of care, including the emotional and practical challenges they encounter. As well as highlighting the positive impacts of Admiral Nurses on family carers, Evans and colleagues also acknowledge the emotional impact on the nurses themselves of providing such intensive support and appreciate the need for skills, such as advanced communication and reflective practice, to sustain such demanding practice. This paper discusses the part professional and practice development can play in supporting Admiral Nurses with delivering end-of-life care.

Practice development

Practice development is a way of being, working and learning that is person-centred and strives to enable each individual and each group to flourish (McCormack and Titchen, 2006; Manley et al., 2008). Reflecting on the history of practice development, there is evidence in the literature of attempts to give clarity to the term, with more recent work including views around human flourishing and integrating

supportive workplace cultures. The first of the nine principles of practice development (Manley et al., 2008, p 4) states:

> *'Practice development aims to achieve person-centred and evidence-based care that is manifested through human flourishing and a workplace culture of effectiveness in all healthcare settings and situations.'*

The literature finds practice development at the heart of person-centredness and the enablement of human flourishing (Manley, McCormack and Wilson, 2008). This view is supported by LeGrow et al. (2016), who state that person-centredness is an approach that views each individual as a unique being, and is underpinned by the values of mutual respect and individual right to self-determination. For nurses in specialist roles, this feels particularly poignant given that person-centred care is at the heart of their role working directly with carers (Quinn et al., 2012). In a recent study, Maio et al. (2016) found high levels of satisfaction experienced by family carers supported by Admiral Nurses; particular value was placed on their effectiveness in developing a rapport, establishing trust, showing compassion and understanding – all of which reflect the person-centred approach of the model.

Reflecting on practice development for Admiral Nurses

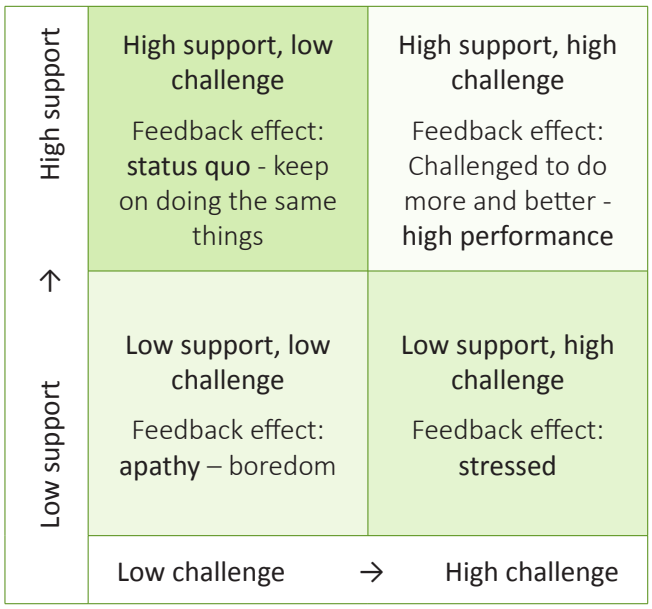
The model allows the nurses to have the support of a practice development approach to their learning, based on a competency framework developed by the University of Worcester (Carter et al., 2018). Admiral Nurses have a monthly day away from practice as a group to develop the appropriate skills and knowledge to support the people for whom they care, including those at the end of their lives. This group work begins with a values clarification foundation and agreed development plans.

Having previously worked in a more training-oriented role, it has been enlightening for me (CS) to see the benefits of emancipatory practice development (Manley et al., 2008) in progress, alongside some of the challenges of critical reflection. I now have a greater opportunity to reflect on learning with a practice development approach within the supportive and person-centred culture offered to Admiral Nurses. Using Rolfe et al.'s reflective model (2001) I have explored how such an approach to learning and development can enable the nurses to better support people with dementia at the end of life, and to consider topics and challenges that will inform their future learning. Rolfe's model – 'What, So What, Now What' – helps practice development facilitators towards an enhanced understanding of how practice development can enable Admiral Nurses in this work.

What?

Having spent most of my career in palliative and end-of-life care nursing, I acknowledged that people with dementia do not often access appropriate levels of support at the end of life. Working with nurses specialising in dementia, I reflected on how the innovative practice, support, skills and knowledge that Admiral Nurses offer could enable people with dementia to receive appropriate care. Also, in my practice development facilitator work, I saw that the use of the principles of collaboration, inclusion and participation (McCormack et al., 2013) to support the Admiral Nurses' understanding of end-of-life care seemed to be a key part of the process. High challenge with high support is a process used to raise awareness about what is happening in a situation and our role in it, balanced by support for the individual to take action on what they learn (Manley et al., 2008). This approach has required me to develop a more reflective perspective on my own role. In a study by Newman et al. (2015), using the support and challenge framework (see figure 1), nurse managers recognised the benefit of participating in facilitated peer discussion to critique their practice. Similarly, the Admiral Nurses have responded well to using high challenge/high support, enabling them to reflect on their work via practice development and to benefit from mutual support among peers in critiquing practice.

Figure 1: High challenge/high support framework

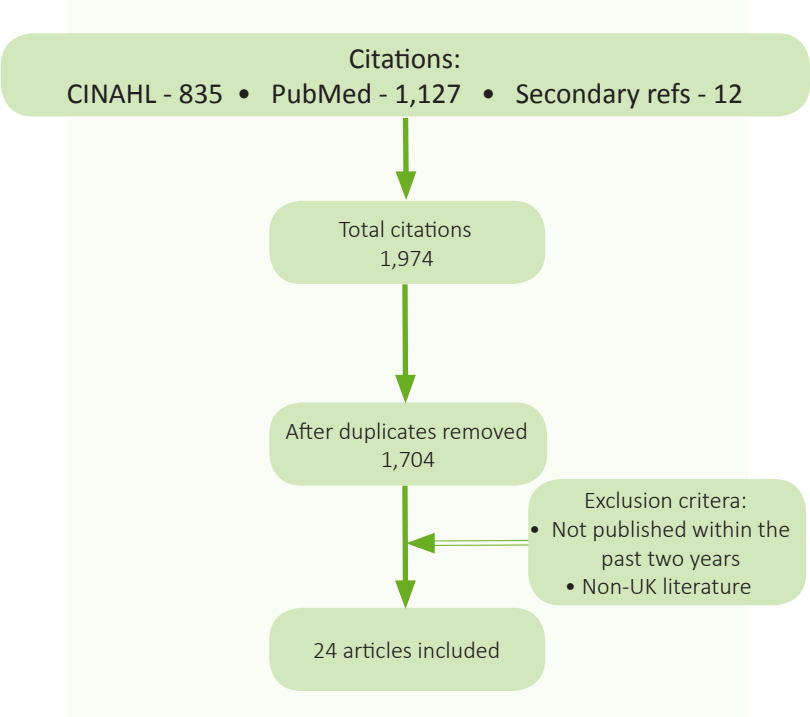


Given the emotive nature of end-of-life care and the varying levels of experience within the Admiral Nurse practice development groups, it was also vital to develop and enhance my facilitation skills. Manley et al. (2014) highlight the importance of practice development in establishing a person-centred and effective safe space that enables all participants to flourish. This reinforces the necessity to ensure all the nurses, regardless of level of experience, feel valued for their contributions.

So what?

Moving to the 'So what' phase of Rolfe's reflective model, I conducted a critical review of the literature to explore the evidence, themes and challenges relating to people with dementia at the end of life, and considered how Admiral Nurses might address those challenges. The literature search is summarised by a PRISMA flowchart (Moher et al., 2009) in figure 2.

Figure 2: PRISMA flowchart (Moher et al., 2009) – search method and retrieval criteria



When considering the challenges for Admiral Nurses when caring for people with dementia at the end of their lives, Lillyman and Bruce's literature review (2016) highlighted barriers faced by this group of people. The themes of their review were discussed as part of a journal club of Admiral Nurses to ascertain which were most challenging for them (see table 2).

Box 2: Barriers faced by people with dementia and their families (Lillyman and Bruce, 2016)

Admiral Nurses cited the main challenges faced when caring for persons at the end of life as:

- Diagnosis of dying phase
- Timing of referral to specialist palliative care services
- Ethical decisions in relation to medication and nutrition at end of life
- Environmental factors
- Undertreatment, overtreatment and burdensome interventions
- Carer involvement
- Collaborative working
- Family needs
- Advance decision making

Within the group discussion, acknowledging a diagnosis of the dying phase was considered the most important factor, alongside the challenge that dementia must first be recognised as a life-limiting condition (van der Steen et al., 2014). Admiral Nurses work closely with families of people with dementia, but there has been little research into the extent to which they actually understand the nature of their family member's condition (Andrews et al., 2015). Andrews and colleagues found the majority of family members did not recognise dementia as life-limiting, and so failed to make a connection between dementia and death.

In order for Admiral Nurses to address this disconnect they need to be allowed space to explore how they feel about their own mortality in a safe environment. The professional and practice development days are an opportunity to explore their own attitudes towards death and dying, and to identify and develop the skills and knowledge needed to support families.

Another important point discussed in the journal club concerned nutrition and hydration, an issue often raised by families. People with dementia often develop swallowing difficulties as the disease progresses and enteral feeding is often raised as a treatment option (Sampson et al., 2013). Managing these discussions involves good assessment and advanced communication skills, as well as collaboration with other healthcare professionals. A Cochrane review (Sampson et al., 2009) explored enteral feeding and found inconclusive evidence that nasogastric feeding offers people with dementia any benefits in terms of nutrition, mortality or reduced pressure ulcers. However, discussions with Admiral Nurses demonstrated that the emotive and ethical concerns around this sensitive issue, rather than the evidence for clinical outcomes, make it the main area of concern for the professionals and the families they support; this seems particularly evident with feeding issues towards the end of life. However, a focus on individual nurses' learning needs and outcomes is needed to assess the ability of practice development to help build their skills, practice and knowledge in this area.

It was evident from the review of the literature that good care is underpinned by prioritising the holistic and person-centred care needs of the person with dementia (Kupeli et al., 2016; Middleton-Green et al., 2017). Also important are developing therapeutic relationships with family members and working within a multidisciplinary team to ensure sustainable high-quality care is available (Harrison Dening, 2016). When considering the challenges for Admiral Nurses and possible areas for development, one distinct advantage to the model is the extended time they spend with families of people with dementia – this familiarity is of particular value when the end of life approaches. Carers can feel alone in their role and so benefit from empathetic understanding and support from professionals (Middleton-Green et

al., 2017); providing families with such psychological support is an essential ingredient of the Admiral Nurse approach (Harrison Dening, 2016).

The work can be complex, requiring highly skilled practitioners to work at an advanced level of practice. With the support of a practice development approach the nurses are expected to continually develop their knowledge and skills. A refreshed version of the Admiral Nurse Competency Framework (Carter et al., 2018) enables them to develop and maintain evidence about their practice in a productive and meaningful way, using peer support during practice development days for mutual high support and high challenge.

Now what?

Considering 'Now what', with a focus on how ongoing practice development can enable Admiral Nurses to offer end-of-life care has been a key focus of this work. Reflecting on sustainability and continued learning using a practice development approach should be seen as integral to this.

A well-established Community of Practice (CoP) on end-of-life care involving two charities, Dementia UK and Hospice UK, brings together palliative care and dementia specialists to share practice and learn together (Harrison Dening and Cooper, 2016). Communities of practice have been defined as groups of people who share a concern or a passion for something they do and learn how to do it better as they interact regularly (Wenger and Wenger-Trayner, 2015). More recently, a CoP for the growing number of Admiral Nurses working in the hospice setting has been developed as part of the Dementia UK practice development approach. The members of this community are keen to share their work with each other and also to generate new learning that could result in a shared model of practice for Admiral Nurses working in this speciality. Having a group of hospice-based nurses who are able to give advice and support to colleagues in other health and social care settings will be an excellent resource.

Conclusion

To support nurses, and other health and social care professionals, practice development facilitators are required to gain a better understanding of the most effective ways to apply practice development approaches to learning. In this respect, it is essential to have knowledge of the target population for whom the nurses care, the care setting and the main evidence and factors that can influence good care. Undertaking a collective approach to consider the broader educational and development needs of a specific community of practice has been an empowering experience. On a personal level the process has enabled me to draw on previous end-of-life care experience and to support Admiral Nurse colleagues to explore their own knowledge and skills base in dementia and expand it to embrace end-of-life care

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