

## **Is there a role for a Carer Support Nurse?**

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Key words: carers, specialist role, community nursing

Main text: 1,921 words

No conflicts of interest

## Abstract

Carers play a vital role in supporting family and friends with health conditions, particularly long-term health conditions. This impacts on their own health and well-being. The NHS is committed to supporting carers, and community nurses are well-placed to identify and support them, but changes in the workforce and the patient population mean that nurses' time is limited: their focus is on meeting patients' needs. We propose a solution: a Carer Support Nurse role, dedicated to the needs of carers. We would welcome your views on this proposal.

## Background

Informal carers are "lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotion management" (Thomas, 2001). They play a crucial role in providing care to relatives and friends with support needs (Morris et al, 2015), and reduce formal care costs (Round et al, 2015). There are 1.4 million people in the UK providing 50 or more hours of unpaid care per week, and by 2037 there will be 9,000,000 individuals with caring roles (Carers UK, 2014).

Carers enable care (and death) in patients' place of choice. But this caring role comes at a cost: there is pressure on carers' finances, they experience psychosocial distress, and the physical and psychological health impacts of caring (including premature death) are well known (Morris et al, 2015; Schulz and Beach, 1999). These effects have huge implications for health care professionals in terms of identifying and meeting carers' support needs. Despite the vast number of studies focused on the burden and impact on carers of taking on the caring role there is remarkably little research on interventions or ways to support them (Candy et al, 2011), including nurse-led interventions.

## What do carers do and what do they need?

Carers provide complex personal care as well as practical and emotional support. They may be needed at any hour of the day, and even overnight (Bergs, 2002; Spence et al, 2008). Much like health care professionals they have multiple roles – but, unlike health care professionals, these are roles for which they are very rarely trained. Many experience feelings of uncertainty, feel ill-prepared in the caring role and lack confidence in caring tasks and situations (Spence et al, 2008; Gerrish, 2008). This can cause anxiety and can impact on their ability to ask for help (Whitehead, 2012). Carers are patients too (Stajduhar et al, 2008) but are often ambivalent about their own needs, putting the needs of their patient first, neglecting their own health (Bergs, 2002). They lack knowledge of professional services and lack access to those services (Bergs, 2002; Spence et al, 2008). They can remain unnoticed or invisible to health care providers (Burns et al, 2013), only seeking their help during acute episodes or crises (Spence et al, 2008).

## How should carers be supported?

The Department of Health (DoH) Carers' Strategy (DoH, 2010) states that carers should be universally recognised, valued and supported, and that carer support should be tailored to individual need. The DoH's mandate to NHS England acknowledged the importance of carers

to the NHS, and those they provide care for, recommending the NHS becomes dramatically better at supporting carers as well as patients (DoH, 2014). NHS England responded by setting out priorities on how it would support the NHS to deliver what carers have said is important to them: including raising their profile, delivering person-centred and well-coordinated care, and commissioning carer support (NHS England, 2014).

Person-centred care, which is central to the NHS, is based on four principles which can be applied just as equally to carers as to the patients they support (The Health Foundation, 2014):

- 1) affording people dignity, compassion and respect;
- 2) offering coordinated care, support or treatment;
- 3) offering personalised care, support or treatment; and
- 4) supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life.

The Nursing and Midwifery Council (NMC), in response to the challenges that the ageing population will bring to the nursing profession, published guidance for the care of older people (NMC, 2009). Care and Respect Every Time was written after consultations with older people, carers and other stakeholder groups in the UK and contains essential principles to help nurses interpret their professional Code of Conduct as it applies to older people (NMC, 2009). The guidance is for community nurses such as district nurses, health visitors and community matrons, who are involved with people who have caring responsibilities. It includes advocacy and effective communication such as helping carers to access relevant health and social care information and support (NMC, 2009). Identifying carers is the first step in offering them support but carers are rarely acknowledged, or supported, by healthcare systems (Laing and Sprung, 2014).

#### Current formal support for carers

Four sources of formal support for carers currently exist:

- 1) local authorities
- 2) charities
- 3) private services, and
- 4) the NHS

Local authority funded support workers address carers' social needs – they do not have a role in carer health, or in carer education on managing patients' symptoms and health care needs. Charities can offer advice if they are accessed by carers. And private care (formal carers) can be employed to help with caring tasks (and must be where patient assets exceed £23,000) but they can sometimes add to the burden of the informal carer who has to organise and manage them while they themselves are still trying to meet the patient's needs.

Within the NHS, carer support comes mainly through GPs and community nurses. The Royal College of General Practitioners (RCGP) introduced 12 GP Carer Champions with expertise in

supporting and identifying carers: the aim was to increase awareness of carers and their support needs, rather than to give direct support to carers themselves (RCGP, 2014). The rationale was that if carers were supported this would help them support patients, which may then reduce NHS costs e.g. through less frequent hospital admissions and less unnecessary primary care appointments. But this was not a national scheme and, although the RCGP recommended that Clinical Commissioning Groups spearhead local carer initiatives with communication between local carer support organisations and community nursing teams, it did not go as far as recommending nurses directly deliver support. Instead it suggested that support could be provided by different staff working within a GP practice, including receptionists (RCGP, 2014). This approach may offer a solution to carer identification and support at a basic level, but carers want to be supported by professionals with expert knowledge about the patient's condition, and with whom they can establish a relationship (Farquhar et al, 2014).

### Role of nurses

Community nurses are well placed to identify carers and to identify, assess and respond to their support needs (Carduff et al, 2014), but community nursing is challenged by rapidly changing community demographics (Queens Nursing Institute, 2014) and a continued fall in District Nurse numbers (by 44% since 1999): the number of District Nurses leaving the profession or retiring from practice now exceeds the number in training (National Nursing Research Unit, 2013). In addition, the balance and skill mix of community staff groups has shifted: in 2005, qualified nurses accounted for 20% of all community NHS staff – a figure that fell to 12% by 2012 (National Nursing Research Unit, 2013).

This makes District Nurses' dual role of providing both patient and carer support much more challenging. Ewing et al attempted to introduce a formalised carer needs assessment to the dual District Nurse role (the Carer Support Needs Assessment Tool: CSNAT (Ewing et al, 2015)) but uptake was low (personal communication): District Nurses' focus is patient need (Gerrish, 2008). However, two recent studies support the potential for nurses working with carers and the benefits this can bring to both carers and patients. Dunn et al found that contact with community nurses reassured carers, improving their confidence in caring (Dunn et al, 2014), and Borland found involvement of hospice specialist nurses helped carers to perform their role: carers saw the nurse as a confidante, appreciating their acknowledgment and prioritisation of their needs, and their expert advice (Borland et al, 2014).

Improved life expectancy for people with long-term conditions means more carers will be needed and for longer periods of time. Carers of patients with advanced chronic non-malignant diseases face important challenges given the long duration of their caring role (Morris et al, 2015), along with its uncertainty and complexity (Funk et al, 2010; Bove et al, 2016; Aasbø et al, 2017). Our longitudinal study of need in patients and carers living with advanced chronic obstructive pulmonary disease (the Living with Breathlessness study) identified an average (median) caregiving-duration of seven years (Farquhar et al, 2014). These carers had higher average (mean) scores for anxiety and depression than the rest of the population, they had unmet direct support needs (support for themselves) and enabling support needs (support to help them in their caring role), and they were unprepared for

many aspects of the caring role, particularly accessing services and information (Farquhar et al, 2014).

#### Possible solution – the Carer Support Nurse:

One solution to these problems might be the development of a new carer-dedicated nursing role: the Carer Support Nurse. Two core principles define this potential new role: (1) it is a nursing role, and (2) it is dedicated to carers.

It is a nursing role because of the need to focus on carers' physical health and psychological support needs – areas of need which current local authority carer support does not cover. And it is dedicated to carers due to carers' known reluctance to "bother" health care professionals (Bergs, 2002), particularly in non-emergency situations (Bergs, 2002; Spence et al, 2008), during what they see as the "patients' time". A dedicated role would also address the challenge nurses currently face in supporting carers within their dual, but patient-focused, roles (Carduff et al, 2014). A key aspect of the role could be education, not only education of carers themselves but education of other health care professionals to raise their awareness of carers and the need to identify, assess and support them: this could help prevent de-skilling of generalists that can occur with the introduction of specialists roles (McKenna et al, 2014). Carer identification and support would remain the remit of all health care professionals but with the Carer Support Nurse managing more complex cases (i.e. modelled on the Community Matron role, but focused on carers).

The Carer Support Nurse role could deliver the four principles of 'person-centred' principles by:

- 1) supporting the carer depending on need, circumstances and preferences, and demonstrating compassion when working with carers of patients approaching death;
- 2) ensuring care is streamlined and coordinated through inter-professional liaison;
- 3) delivering personalised care through carer-led assessments; and
- 4) enabling carers to develop their strengths through recognition and education.

This new role could deliver on the policy rhetoric of supporting carers – it could help deliver carer support in clinical practice. It could benefit both carers and patients by delivering person-centred care to support carers in the crucial role they play. It could raise awareness of carers and their needs, enable better carer identification, assessment and support, deliver carer health promotion and carer education, and help prevent crises by direct intervention, signposting or referral-on to existing resources.

Both the published literature and exploratory conversations we have held with existing carers (and their patients) suggest the development of a Carer Support Nurse role is warranted and would be welcomed. Carers and patients liked the idea of support from a community nurse dedicated to carers. It is important that this new role is co-designed with carers, as well as with health and social care professionals and commissioners. It is even more important that it is formally and robustly evaluated.

We therefore need to find out:

- carers', patients', health and social care professionals' and commissioners' preferences for the role and its remit
- core components of the role, and competencies
- how the role might align with existing services
- potential barriers and facilitators to the implementation of the role, and
- how to evaluate the role.

We are currently seeking funding to address this knowledge gap through a collaborative research study involving carers, patients and health and social care professionals. To help inform that study we would welcome the views of readers on this proposed new role: the Carer Support Nurse.

To share your thoughts with us please email [M.Farquhar@uea.ac.uk](mailto:M.Farquhar@uea.ac.uk) using the subject heading: Carer Support Nurse (Nursing Times)..

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