Is it time to create a new nurse role dedicated to helping carers?

Informal carers provide unpaid care for relatives or friends who need support (Morris et al, 2015), thereby reducing formal care costs (Round et al, 2015). In the UK, 1.4 million people provide 50 hours or more of unpaid care per week; it is projected that by 2037 there will be 9 million informal carers (Carers UK, 2014).

Carers provide complex personal care and practical and emotional support, and may be needed at any time of day or night (Spence et al, 2008; Bergs, 2002). They have multiple roles for which they have rarely been trained, and consequently many feel ill-prepared and lack confidence in their ability to care (Gerrish, 2008; Spence et al, 2008). This causes anxiety and reduces their ability to ask for help (Whitehead et al, 2012).

Improved life expectancy for people with long-term conditions means more carers will be needed for longer periods. Carers of patients with advanced non-malignant disease face a long, uncertain and complex role (Aasbø et al, 2017; Bove et al, 2016; Morris et al, 2015); for example, the Living with Breathlessness study identified a median caregiving duration of seven years for carers of people with chronic obstructive pulmonary disease. Carers had higher anxiety and depression scores than the general population; they also had unmet support needs – both for themselves and to help them provide care – and were unprepared for many aspects of the caring role (Farquhar et al, 2014).

Carers often neglect their own health, putting the needs of the care receiver first (Bergs, 2002). They lack knowledge of, and access to, professional services (Spence et al, 2008; Bergs, 2002), and can remain invisible to healthcare providers (Burns et al, 2013) until they seek help in an acute situation (Spence et al, 2008). Despite many studies examining the burden of caring,
there is little evidence on how to support carers (Candy et al, 2011). Identifying carers is the first step, but they are rarely acknowledged, or supported, by healthcare systems (Laing and Sprung, 2014).

**Principles of carer support**

The Department of Health states that carers should be universally recognised, valued and supported, and that support should be tailored to individual need (DH, 2010). The DH’s 2014-15 mandate to NHS England acknowledged their importance and recommended that the NHS dramatically improves its support (DH, 2014). NHS England responded by setting priorities on how it would help deliver what carers said was important to them (Box 1) (NHS England, 2014). Nursing and Midwifery Council guidance on caring for older people (mainly nurses working in the community who are often in contact with carers) recommends advocacy, effective communication and helping carers access information and support (NMC, 2009).

**Current formal support**

Four sources of formal support for carers currently exist: local authorities, charities, private services, and the NHS. Local authorities fund support workers to address carers’ social needs, but these do not look after carers’ health or teach them how to manage patients’ healthcare needs; they are also only funded if the patient’s assets do not exceed £23,000, while charities offer advice. Although private carers can be hired to help with caring responsibilities, they sometimes add to the burden of the carer, who has to manage them on top of their other tasks, and this can be an expensive option.

NHS support for carers comes mainly from GPs and community nurses. While the Royal College of General Practitioners introduced GP carer champions in England (RCGP, 2014) this was not a national scheme. Although the college recommended clinical commissioning groups foster communication between local carer support groups and community nurses, it suggested support could be offered by other general practice staff, including receptionists. This may help identify carers and provide basic support, but carers want support from professionals with expertise with whom they can establish a relationship (Farquhar et al, 2014).

**Role of community nurses**

Community nurses are well placed to identify carers and respond to their needs (Carduff et al, 2014). Two recent studies stress the potential benefits of nurse support for carers: Dunn et al (2014) found that contact with community nurses reassured carers and improved confidence, while Borland et al (2014) found they appreciated the involvement and advice of hospice specialist nurses.

Community nurses face the challenges of a continuous decline in their number as well as rapidly changing demographics (Queen’s Nursing Institute, 2014). The number of district nurses has fallen by 44% since 1999, and more leave the profession than are being trained (National Nursing Research Unit, 2013). In addition, the skill mix in community teams has shifted: in 2005, qualified nurses made up 20% of all community NHS staff, but this fell to 12% in 2012 (National Nursing Research Unit, 2013). This makes district nurses’ dual role of supporting both patients and carers more challenging.

Ewing et al encouraged community nurses to use a formal assessment tool, the Carer Support Needs Assessment Tool (Ewing et al, 2015), but uptake was low (personal communication); this may be because, although their role is theoretically dual, district nurses focus on patients (Gerrish, 2008).

**A new nursing role?**

One solution would be to create a new role defined by two principles:

- It would be a nurse role;
- It would be dedicated to carers.

The role would have to be a nursing one because carers’ physical and psychological health needs are not covered by current support from local authorities. It would need to be dedicated to carers to overcome their known reluctance to ‘bother’ health professionals and use what they see as patients’ time for themselves (Spence et al, 2008; Bergs, 2002). A dedicated role would also address the fact that nurses still focus more on patients (Carduff et al, 2014).

**Box 1. What carers want**

- Recognition
- Information circulated to them as well as to professionals
- Signposting to information
- Help linking professionals together
- Flexible care available when it suits them
- Acknowledgment that they may need help in their caring role and with their own health and wellbeing
- Being involved and treated as experts in care
- Respect, dignity and compassion

Source: Adapted from NHS England (2014)

**Box 2. Principles of person-centred care**

- Affording people dignity, compassion and respect
- Offering coordinated care, support or treatment
- Offering personalised care, support or treatment
- Supporting people to recognise and develop their own strengths and abilities to enable them to live an independent and fulfilling life

Source: Health Foundation (2014)
This ‘carer support nurse’ role could be modelled on the community matron role: identifying and supporting carers would remain the remit of all health professionals, while the carer support nurse would manage more complex cases. A key aspect of the role would be education of other health professionals, to raise their awareness of carers and carers’ needs; this would help prevent the de-skilling of general nurses that can occur when specialist roles are introduced (McKenna et al, 2014).

This role would apply the principles of person-centred care (Box 2) by:

- Supporting carers according to need, circumstances and preferences;
- Showing compassion when the person they care for is approaching death;
- Enabling them to develop their strengths through recognition and education;
- Delivering personalised care through carer-led assessments;
- Ensuring care is coordinated through interprofessional liaison.

The role could deliver on the policy rhetoric of supporting carers by supporting them in practice. It could raise awareness of carers and their needs; promote identification, assessment and support; deliver health promotion and education; and help prevent crises by direct intervention, signposting or referral.

Both the literature and exploratory conversations with existing carers (and the people they care for) suggest that such a role is warranted. The carers and patients we talked to liked the idea of a community nurse dedicated to carers.

Collaborative research

The new role needs to be co-designed with carers, health and social care professionals, and commissioners, and to be formally evaluated. We are currently seeking funding to conduct collaborative research involving carers, patients and professionals to find out:

- Stakeholders’ preferences for the role and its remit;
- Core components and competencies of the role;
- How it might fit into existing services;
- Barriers and facilitators to its implementation;
- How to evaluate it.

To help inform that study, we would welcome the views of readers on this proposed new role of carer support nurse. Additional resources on carer support are listed in Box 3.

References


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