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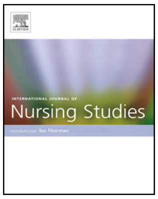

The provision of emotional labour by health care assistants caring for dying cancer patients in the community: A qualitative study into the experiences of health care assistants and bereaved family carers

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ABSTRACT

Background: While previous research has suggested that health care assistants supporting palliative care work in the community regard the provision of emotional labour as a key aspect of their role, little research has explored the experiences of family carers who are the recipients of such support.

Objective: To explore the emotional labour undertaken by health care assistants working in community palliative care from the perspectives of both health care assistants and bereaved family carers.

Design: We conducted a qualitative interview study in 2011–2012 with bereaved family carers of cancer patients who had received the services of health care assistants in the community, and health care assistants who provided community palliative care services. Transcripts were coded and analysed for emergent themes using a constant comparative technique.

Settings: Three different research sites in the United Kingdom, all providing community palliative care.

Participants and methods: Semi-structured interviews were conducted with 33 bereaved family carers and eight health care assistants.

Results: Health care assistants view one of their key roles as providing emotional support to patients and their family carers, and family carers recognise and value this emotional support. Emotional support by health care assistants was demonstrated in three main ways: the relationships which health care assistants developed and maintained on the professional–personal boundary; the ability of health care assistants to negotiate clinical/domestic boundaries in the home; the ways in which health care assistants and family carers worked together to enable the patient to die at home.

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Conclusion: Through their emotional labour, health care assistants perform an important role in community palliative care which is greatly valued by family carers. While recent reports have highlighted potential dangers in the ambiguity of their role, any attempts to clarify the 'boundaries' of the health care assistant role should acknowledge the advantages health care assistants can bring in bridging potential gaps between healthcare professionals and family carers.

What is already known about the topic?

- Health care assistants (HCAs) are a key part of the workforce in providing community palliative care.
- The provision of emotional support is an aspect of HCAs' role.
- The number of family carers caring for terminally ill patients in the community is growing.

What this paper adds

- HCAs work with great skill to provide emotional support to palliative care patients and their family carers in the community, helping end-of-life cancer patients to die at home.
- Family carers value HCAs for their emotional support and ability to 'fit in' to the home.
- HCAs act as an important liaison service between family carers and health and social care services.

1. Introduction

Health care assistants (HCAs) were introduced as part of the 1990 National Health Service (NHS) and Community Care Act in the United Kingdom (UK) (Department of Health, 1990). The position of HCA is comparable to that of (health) care aides, found for instance in Canada and Australia (Aoun et al., 2012; Berta et al., 2013; Mallidou et al., 2013). HCAs require no formal training or mandatory qualifications, and the grade was originally created with the intention of supporting qualified nurses and allowing them to spend less time on ancillary duties, and more time with patients (McKenna et al., 2004). While their specific duties vary according to individual settings and services, their role has evolved such that as well as undertaking ancillary duties, they also now provide direct patient care and perform tasks which were previously undertaken by their qualified colleagues (McKenna et al., 2004). HCAs now make up around a quarter of the NHS workforce (NHS, 2013), yet despite their widespread involvement in supporting the delivery of palliative care in the community, little research to date has considered HCAs' role in this setting, and the perspective of family carers who receive such services in their homes has been largely overlooked.

A recent systematic literature review of the role of HCAs in providing palliative and end-of-life care in the community has identified that the provision of emotional support is a key aspect of their role (Herber and Johnston, 2013). Originally defined by Hochschild (1983) as 'the management of feeling to create a publicly observable facial and bodily display,' (Hochschild, 1983, p. 7) the concept of emotional labour has been applied to nursing (Bartram et al., 2012; Gray, 2009; Hayward and Tuckey, 2011; James, 1992; Schell and Kayser-Jones, 2007; Skilbeck and Payne, 2003; Smith, 1992; Yang and Chang, 2008) in general, and more specifically to HCAs involved in community palliative care work (Munday, 2007; Ferguson et al., 1998). Emotional labour involves consciously working to present emotions that enable a person's job to be performed effectively, and sometimes requires a person to suppress their inner emotions in order to do this. For instance, a nurse might actively demonstrate a caring attitude and take time to listen and talk to a patient, even if they have had a bad day and are inwardly feeling tired and irritated (Gray, 2009). Previous research has indicated that emotional labour performed by HCAs includes listening to the patient and family carers, offering guidance on what to expect during the course of the illness, and being a reassuring presence up to, and at the death of the patient (Clark et al., 2000; Denham et al., 2006).

In many developed countries, the number of patients with life-limiting conditions who are choosing to die at home is increasing (Flory et al., 2004; Gomes et al., 2012; Neergaard et al., 2011; Wilson et al., 2009). In the UK, the End of Life Care Strategy for England (Department of Health, 2008) emphasised the need to provide appropriate community health and social services to support patients and their family carers to enable this to occur. While previous studies have found that HCAs supporting palliative care work in the community regard the provision of emotional support as a key aspect of their role (Clark et al., 2000; Devlin and McIlfatrick, 2010; Ingleton et al., 2011), little research has considered the experiences of family carers in receiving such support. Given that there is widespread awareness of the potential emotional burden on family care givers caring for a patient at home (Harding et al., 2012; Jack and O'Brien, 2010) and recent research from New Zealand suggests there is still work to be done in improving the 'interface' between health professionals and family carers (McPherson et al., 2014), we highlight the importance of researching family carers who receive emotional support, and how this affects their experiences of caring for patients at the end-of-life.

2. The study

2.1. Aim

The aim of this study is to explore the emotional labour undertaken by HCAs in community palliative care settings from the perspectives of both HCAs and family carers caring for cancer patients at home. The study addresses three main objectives: exploring the ways in which HCAs