



This is a repository copy of *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 carers.*

White Rose Research Online URL for this paper:
<http://eprints.whiterose.ac.uk/81432/>

Version: Accepted Version

Article:

Lovatt, M.J., Lovatt, M.J., Nanton, V. et al. (6 more authors) (2015) 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 carers. *International Journal of Nursing Studies*, 52 (1). pp. 271-279. ISSN 1873-491X

<https://doi.org/10.1016/j.ijnurstu.2014.10.013>

Reuse

Unless indicated otherwise, fulltext items are protected by copyright with all rights reserved. The copyright exception in section 29 of the Copyright, Designs and Patents Act 1988 allows the making of a single copy solely for the purpose of non-commercial research or private study within the limits of fair dealing. The publisher or other rights-holder may allow further reproduction and re-use of this version - refer to the White Rose Research Online record for this item. Where records identify the publisher as the copyright holder, users can verify any specific terms of use on the publisher's website.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



eprints@whiterose.ac.uk
<https://eprints.whiterose.ac.uk/>

Accepted Manuscript

Title: 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 carers

Author: Melanie Lovatt Veronica Nanton Julie Roberts
Christine Ingleton Bill Noble Elizabeth Pitt Kate Seers Dan
Munday

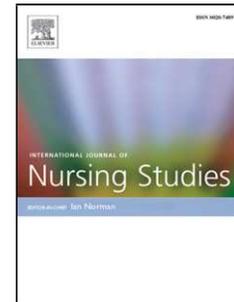
PII: S0020-7489(14)00271-5
DOI: <http://dx.doi.org/doi:10.1016/j.ijnurstu.2014.10.013>
Reference: NS 2464

To appear in:

Received date: 4-3-2014
Revised date: 23-10-2014
Accepted date: 25-10-2014

Please cite this article as: Lovatt, M., Nanton, V., Roberts, J., Ingleton, C., Noble, B., Pitt, E., Seers, K., Munday, D., 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 carers, *International Journal of Nursing Studies* (2014), <http://dx.doi.org/10.1016/j.ijnurstu.2014.10.013>

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.



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 carers

Melanie LOVATT, Veronica NANTON, Julie ROBERTS, Christine INGLETON, Bill NOBLE, Elizabeth PITT, Kate SEERS & Dan MUNDAY

Corresponding author: Melanie Lovatt – m.j.lovatt@sheffield.ac.uk

Author details

Melanie LOVATT: BA MA, Research Associate, School of Health and Related Research, The University of Sheffield, UK

Veronica NANTON: BA Msc PhD, Senior Research Fellow, Warwick Medical School, University of Warwick

Julie ROBERTS: BSc MA PhD, Research Fellow, School of Health Sciences, University of Nottingham, UK

Christine INGLETON: BEd PhD RGN, Professor of Palliative Care Nursing, School of Nursing & Midwifery, The University of Sheffield, UK

Bill NOBLE: MBChB MRCGP MD, Senior Lecturer in Palliative Medicine, Department of Oncology, The University of Sheffield, UK

Elizabeth PITT: RGN, SCM, D/N Cert, Former Service Lead of the Coventry & Warwickshire Partnership NHS Trust

Kate SEERS: BSc(Hons) PhD DSc RN . Director, RCN Research Institute, Warwick Medical School, University of Warwick, UK

Dan MUNDAY: MBBS MRCGP PhD FRCP, Honorary Associate Clinical Professor Palliative Medicine Division of Health Sciences, Warwick Medical School

Conflict of Interest

No conflict of interest has been declared by the authors.

Funding statement

This study received funding from Dimbleby Cancer Care

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

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.

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.

Keywords family carers, community care, emotional labour, health care assistants, palliative care, qualitative research

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 & 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 & Tuckey 2011; James 1992; Schell & Kayser-Jones 2007; Skilbeck & Payne 2003; Smith 1992; Yang & 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 & McIlpatrick 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 & 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.

The study

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 in community palliative care settings use emotional labour as part of their work; investigating whether family carers recognise and value the emotional care provided by HCAs; developing an understanding of whether the use of emotional labour by HCAs can facilitate the role of family members in caring for patients who wish to die at home.

Design

The research presented in this paper draws on findings from a study which took place in 2011-12, entitled 'Receiving end of life care at home: experiences of the bereaved carers of cancer patients cared for by health care assistants' (funded by the UK Charity, Dimpleby Cancer Care). The research took place across three different settings: a city in the middle of England with an NHS funded home care service for terminally ill patients, led by an experienced community clinical nurse specialist, funded by a cancer charity; a hospice at home service provided by a voluntary hospice based in a small town with a rural catchment in the middle of England; an urban area in the north of England with a palliative home care service provided and coordinated by a NHS trust together with a national charity. In all of these settings HCAs cared for patients in their home alongside family carers, supporting and being supported by community generalist and specialist nurses and general practitioners.

As this was exploratory research, we wanted to elicit rich descriptions of both the experiences of HCAs providing the palliative care services and the experiences of the family carers who were recipients of it. We argue that in order to understand the role of emotional labour in facilitating effective community palliative care, it is important to consider the viewpoints of care-givers (HCAs) and care-receivers (family carers); therefore both perspectives were sought. Dual-perspective studies in health research are an effective way of investigating the attitudes of service providers and users to healthcare services, and can highlight barriers and facilitators to the effective use of these (Campbell *et al.* 2011; McPherson *et al.* 2014). To this end we conducted the study within a qualitative research design, and developed two semi-structured interview schedules for the HCAs and bereaved family carers.

Participants

Participants were recruited and interviewed between December 2011 and August 2012. Eight HCAs across the three sites were interviewed (see Table 1) and selected with the assistance of the three service leads. The sampling strategy for recruiting bereaved family carers was discussed with each of the three service leads, and services identified eligible family carers. Family carers were eligible to participate if they were aged over 18 and had been bereaved between three and nine months. We asked service leads only to exclude family carers if they were known to have had a further bereavement, be in poor health or judged unlikely to be able to take part in the research. It had

been intended to use a purposive sampling frame at each site to enable a spread of family carers to be interviewed (in terms of age, gender, relation to patient and ethnicity), but it became apparent that the numbers of bereaved family carers who met the inclusion criteria were relatively small. We therefore changed our strategy to that of convenience sampling, and invitations were sent to all eligible bereaved family carers. Bereaved family carers were only contacted once by post. They were sent an information sheet and covering letter from the service lead explaining the nature of the study and requesting their participation in an interview lasting 45 minutes to one hour. In total 160 invitations over the three services were sent out, and 33 bereaved family carers responded positively (21% response rate). All of these family carers were recruited and information on their relationship to the patient can be seen in Table 2.

[Table 1 here]

[Table 2 here]

Data collection

Semi-structured interviews were conducted with the HCAs and family carers by members of the research team (ML, VN, JR). HCAs were asked to describe their duties and their relationships with the patients and the family carers. In particular, the interviewers asked the HCAs about the emotional support they provided, and asked them to provide examples. Family carers decided on the interview location, with most choosing to be interviewed in their own homes. Most interviews lasted between 30 minutes and 1 hour, and were audio-recorded and transcribed verbatim. Family carers were asked about their experiences of caring for the patient at home, with particular focus on their experiences of receiving support from HCAs, and the extent to which they thought the HCAs provided emotional support.

Ethical considerations

As our research involved asking bereaved family carers to talk about a very difficult time in their lives, we gave ethical issues great consideration. Following previous research, we judged that carers who had been bereaved between three and nine months prior to being invited to take part in the study would be able to recall the time in sufficient detail, without our invitation taking place so soon after the patient's death as to be insensitive (Koffman et al 2012). Detailed information sheets, which included the contact details of the charity Cruse Bereavement Care, were sent to participants before they agreed to take part, and informed consent was obtained by the researchers before the interviews began. Participants consented to the interviews being audio-recorded, that they would be anonymised when transcribed, and that all audio recordings and transcripts would be stored

securely on password-protected computers or in locked filing cabinets. Ethics approval was granted by the Warwickshire NHS Research Ethics Committee, (11/WM/0106).

Data analysis

Transcripts of the eight interviews undertaken with the HCAs and 33 interviews with bereaved family carers were analysed according to the principles of grounded theory (Glaser and Strauss 1967) where data was coded to identify emerging categories, which were later grouped into key themes. Examples of emergent themes included when participants mentioned the relationship between the HCA and family carer, or the circumstances of a patient's death in the home. The transcripts were read through several times, and a constant comparative technique was used, in which emerging themes and concepts were continually checked against the transcripts to ensure a close fit between the data and our interpretation of it (Bryman 2008). The HCA and family carer transcripts were initially analysed separately, and following this, themes from both datasets were compared, with particular attention being paid to themes concerning emotional support which were common to both datasets. As shown in the results section, our three major themes were found across all sets of transcripts.

For the bereaved family carer interviews and HCA interviews, initial analysis was undertaken with the sets of interviews for each site individually. For each site disconfirming examples were sought to test the robustness of emergent themes. All interviews were analysed by the researcher responsible for the interviews at a particular site (ML and VN) with 20% analysed by the second researcher (ML and VN) as a further method of enhancing rigour. Comparison of emergent themes across all three sites was made by the whole research team, thus enabling patterns of cross cutting themes to be identified.

Results

It was apparent from our research that HCAs regarded the provision of emotional support as a key aspect of their role, and that the bereaved family carers recognised and valued this. We identified the following key themes: HCAs developing and maintaining relationships on the professional/personal boundary; the ability of HCAs to negotiate clinical/domestic boundaries in the home; HCAs and family carers working together to enable the patient to die at home. Each theme will be considered in turn.

Theme 1: HCAs developing and maintaining relationships on the professional/personal boundary

HCAs displayed great sensitivity and skill in developing relationships with patients and their family carers. Family carers appreciated HCAs for the genuine, friendly and caring manner in which they went about their work:

because they were really friendly and you know they genuinely cared it was a close relationship it was really. Er, I wouldn't say formal, cos you know they were all pretty laid back and friendly and I would like to say they genuinely seemed they weren't like somebody just coming through doing a job and then going. You know they genuinely they did genuinely care you know they you could see that, and so I would say the relationship was very, er very close (CYM08 – son of male patient).

Some family carers noticed a difference in the attitude of 'regular' HCAs employed directly by the community palliative care services, to those employed by agencies, and agency HCAs were occasionally criticised for their uncaring manner:

I think the difference was the ones that we had, they actually cared, you know, there was just those little touches, you know, things like brushing her hair and things like that. Whereas from the agency, the bank ones, is for a lot of them I think it was just... well it's an easy... you know, "I just have to sit here for 8 hours and read my book, I don't really need to" ... oh it sounds awful doesn't it, but it didn't feel as if they cared. (AYF18 – daughter of female patient).

Family carers spoke of the apparent ease with which HCAs were able to get along with patients and talk to them about aspects of their life which were not connected with their medical condition. The 'emotional' support of chatting to patients accompanied the 'physical' support of caring:

I think she loved it. Yes, you know, she got to know them well and um... the wife's a very outgoing person, would talk to anybody and could find all sorts of things to talk about, and she said, you know, there were people that came to... the carers were people that came to see her and she could just have a good chat with them while they were caring, you know. (BYM21 – husband of female patient)

In the same way that the family carers welcomed the HCAs conducting 'normal', everyday, non-medical conversations with the patients, they commented upon and valued the same sorts of conversations that they had with the HCAs.

They never made me feel low, they [always] talked about their family and their children, and I talked about my children and it were quite nice and comforting that we were like talking about something other than aches and pains, and pills and medication and you know cancer and things like that. It was nice. Nice conversation. (CYF11 – wife of male patient)

This worked both ways, with the HCAs also appreciating the 'normalising' conversations they had with family carers:

Like you can walk in and like the families accept you; you don't feel like you're in the way and it's part of their family I think sometimes. Especially if we've been going to them for a while and yes they treat you like that. They talk to you about everyday stuff and you know, ask you, "did you go out at the weekend" and we talk to them about stuff.Because they ask you bits about your life as well, and you don't mind saying because you feel like you've known them for a long time (BXF04 – female HCA at site B).

One family carer also acknowledged that the patient may have confided in the HCA when perhaps she didn't feel able to talk to her own family:

Perhaps she was worried, I don't know, about things that she didn't want to talk to me about. People do talk to somebody that's slightly on the outside that you can trust. (BYF22 – daughter of female patient)

The above example also effectively summarises the 'insider-outsider' status of the HCA and relates to the ambiguity of their role. On the one hand the HCA was a trusted, capable person who spent many hours, and often many nights in a patient's home developing a close relationship with them. On the other hand, they were not a family member, but a paid care worker. This ambiguity in their role enabled them to 'fit in' to individual homes and family settings where they could be accepted as a 'friend' whilst retaining a sufficient professional distance which allowed them to receive confidences that the patient might find difficult to share with close family or qualified staff with whom the patient was less familiar.

Negotiating the boundary between becoming 'one of the family' and maintaining a professional distance involved experience, skill and emotional work, as described by HCAs:

So you can become part of the family really, they look upon you and they trust you, and you know, you're there as comfort to them, as company. A lot of time at night it can be company. So yes the relationship, although we don't change our working relationship with them, they do look to us to be part of their family and probably trust us as much as they would a member of their family. Although we have to keep that... you know, if we get too emotionally involved you can't make the right decisions with what maybe the patient needs. So we kind of have to still keep that on a professional level (AXF19 – female HCA from site A).

Theme 2: the ability of health care assistants to negotiate clinical/domestic boundaries in the home

The ambiguity of the HCAs' role allowed them to not only negotiate the personal/professional boundary in terms of their relationships with family carers and patients, as described above, but also allowed them to act as 'go-betweens' for the family carers and other health professionals. This was commented on by one family carer who described the HCAs as like,

the liaison between us and the medical people and it worked very well (CYF07 – wife of male patient).

The HCAs were also conscious of this position:

you are somebody they depend on because you're there, you're there, and you're the contact with getting other people as well, you know. They might have... some of them have really good relationships with their GP's [general practitioners], which is fine, so it's less on you. Some don't get on with their GP's, you know, some don't get on with the nurses [laughs]. Some like the nurses that come in, some don't like the nurses that come in. So you're a buffer between all the different people because you're there. It's nothing more than you're simply the one that spends the most time with them (BXF13 – female HCA, site B).

HCAs were also aware that, to the family carers, the medical 'paraphernalia' such as equipment and medicine that was brought into the home could be unfamiliar and cause them to feel anxious, and so worked to reassure them and explain what such equipment was for.

Because it's frightening, a syringe driver to a lot of people means someone's going to die that day, and diamorphine or even oromorph, so a lot of it is counselling of the family, to talk to them and explain everything. And we have the times to do that where maybe district nurses and doctors haven't. So they do look to us for a lot of support, emotional support (AXF19 – female HCA, site A).

While the above example shows how the sheer length of time HCAs spent in the family carers' homes allowed them to become trusted 'go-betweens' with regard to the family carers and other health professionals, it is important to recognise that this was not inevitable, and that the HCAs had to work hard to fit in to individual, domestic environments. One of the ways they did this was to assess each situation individually and fit in with or 'get on with' whatever needing doing – even if this was not always a requirement of their job:

They emptied my washer and my tumble drier and folded it all up. I could have kissed them, I think I probably did. Because they said 'well we are here all night if he's asleep we can do whatever' and they emptied my dishwasher and did strange things like that which I would never in a million years have asked anybody to do, but it was lovely that they did it. (CYM20 – son of male patient)

It was also important for the HCAs to gain the trust of family carers as this allowed the family carers to perform normal, everyday tasks within the home, safe in the knowledge that while the HCA was present to oversee the clinical care, they could 'switch off' a bit and perform domestic tasks:

it gave me the chance to get out and get shopping and... and also, you know, and you know that when you're not there there's somebody there and you know there's somebody there responsible who knows what they're doing (BYM14 – husband of female patient)

Theme 3: HCAs and family carers working together to enable the patient to die at home

Enabling patients to die at home was regarded by HCAs and family carers as the most important outcome of the service, and this outcome was a product of the HCAs and family carers working together. HCAs were careful not to exclude family carers from caring for the patient, but instead provided them with the appropriate knowledge to allow them to care, and reassured them that they were doing the right thing:

they still want to help and be there and help you change and help you feed. Sometimes they are like that, they still want to be involved with the caring which is only natural because they have probably been caring for a long time without any help. And then we come along and you don't want them to feel pushed out (BXF05 – female HCA from site B).

This was clearly appreciated by the family carers:

they had the book and I used to read that book every day and they used to write in it and put observations in every night. So I knew at least what had happened over night, err, so yes it was just nice, nice to know (CYF09 – daughter of male patient).

'Cause they were doing what we wanted, no what they want. Not one of them did it said, "no, it's got to be done like this". It were what, it were what we wanted, and that's what it should be like at end of life (CYF14 – wife of male patient).

By being on hand to provide emotional support and reassurance whenever it was required by family carers, HCAs were able to fulfil the requests of patients who wanted to die at home, and family carers who wanted to care for their loved ones at home.

It's also that knowing that there is a lot of people wouldn't be able to cope having loved ones at home in last stages when they are dying, if they didn't have other support from services like ours. Er, so that there is that satisfaction of knowing that like you are helping that patient be where family, where they all want to be together in their own home er, and we are providing that support to enable that to happen. (CXF03 – female HCA from site C)

me aunty got to pass away where she wanted to pass away, she didn't want to be in hospital room. So is that, that for me is a real positive you know. And not having to do that on your own, I couldn't have done it on my own. Know I couldn't so I'd have gone to pieces probably. (CYM10 – nephew of female patient).

I think we were much more relaxed as a family because we had got the [HCA] around and were much more relaxed after that first night about caring for her, during the day time er, and that she talked to us about the signs and about you know what we may see happening to mum. And I think that we felt that we were more prepared yes (CYF18 – daughter of female patient).

The death of the patient was a particularly challenging time, not just for the family carers, but also the HCAs who had to carefully balance the emotional needs of the family, and give them the necessary support and space, while also ensuring that the specific duties associated with a patient's death were carried out in a timely manner. That the HCAs balanced these potentially competing responsibilities successfully is attested to by the family carers.

The night he died... she was so...just kind and er, "when you are ready I will inform everybody, just tell me when and er, who are you going to have for undertaker?" and she just cleared off and we went and said to her, "yes we are ready now. Let everybody know" and er, I realised then I couldn't we couldn't have coped without her because well you panic don't you, you don't know oh what shall I do? What shall I do, er, and she, they were lovely. Really are nice girls. (CYF17 – wife of male patient)

In some cases, HCAs were obliged to fulfil the roles which would usually be filled by family members:

And I did happen to be there when he passed. Um, and I went to get his wife who didn't want to sit with him, she was frightened, so I sat with him and held his hand while he passed away (AXF19 – female HCA at site A).

Discussion

This study sought to increase understanding of the emotional labour used by HCAs in community palliative care, how it is received by family carers, and the implications for facilitating the preferences of patients who wish to die at home.

The findings of our research demonstrate that HCAs regard emotional labour as a key component of their role, and that this is recognised and appreciated by family carers. As previously identified in a study with nursing staff within the hospice setting (James 1989), emotional support was not distinct from the physical support but both were given to patients simultaneously. Furthermore, in our study the emotional support which HCAs provided, underpinned and informed all aspects of the HCAs' role and earned them the trust from family carers which allowed them to care for the patient, and give the family carers a break. HCAs displayed great skill and sensitivity in 'fitting in' to family carers' homes and forming relationships with family carers and patients. That the HCAs were able to swiftly and skilfully appraise each new situation, form relationships with a range of individual family carers, and fit in to a range of different home environments illustrates an important aspect of the professional role of HCAs. Our findings support those of previous studies which have highlighted the important role unqualified health care staff perform in improving the quality of life in community palliative care patients (Aoun *et al.* 2012; Ingleton *et al.* 2011).

Davies (1998) defined three types of care: 'professional caring,' undertaken by trained nurses; 'care work,' the semi-skilled role of low paid care workers such as HCAs and domestic 'home helps' and 'caregiving,' a role occupied by family and friends, where there is no division of labour – the carer doing all necessary tasks (caring, domestic work, shopping etc.). The results from this study show that HCAs although classed as 'care workers' undertook some professional caring roles (reassuring families, interpreting clinical situations and taking a lead e.g. after the patient's death) and also taking on a caregiving role (domestic chores). As well as this professionally ambiguous position, HCAs' work environment is also ambiguous where the private space of the patient's home is converted into a semi-public clinical area. The HCA works to mitigate these effects by normalising the environment, ensuring that it remains the patient's home.

This situation is interesting in the light of concerns raised about the lack of definition and regulation of the HCA role. HCAs' position as unqualified and non-regulated staff has recently been highlighted in the Francis report into the failings at the Mid-Staffordshire Hospital (Mid Staffordshire NHS Foundation Trust 2013) in the UK. This has led to proposals from the UK Government for a clearer definition of their role, statutory training and regulation (Department for Health 2013), and in May 2014 Health Education England and the UK Nursing and Midwifery Council commissioned a review into the education and training of nurses and health care assistants (Health Education England 2014). However, HCAs in this study used the ambiguity of their role to prevent the alienation of patients and families within their own homes. It is unclear how heightened regulation might affect this important aspect of the role of HCAs in providing emotional support within the home of dying patients.

As paid, yet unqualified carers, concerns have been raised that HCAs operate in a confusing and blurred state, where they may be undervalued by qualified nursing staff, while being expected by informal carers to perform tasks which they are not qualified to do (Devlin & McIllfattrick 2010), leading to the possibility of stress (Fleming & Taylor 2007). While recognising problems arising from

the variation in HCAs' roles in the UK, (Bach *et al.* 2008), our study shows that HCAs are able to work with the ambiguity of their role by 'getting on with whatever needs doing', thus enabling them to develop relationships with family carers and act as liaisons between family carers and health professionals. This supports recent research from New Zealand, which emphasises the importance of formal care providers being able to respond flexibly to the needs of informal carers in individual contexts (McPherson *et al.* 2014).

By including the perspectives of both HCAs and family carers, we have attempted to develop a more comprehensive understanding of how emotional labour is provided and received within the context of community palliative care. In their recent study of the interaction between formal and informal carers, McPherson *et al.* found a 'mismatch' between the support which formal caring services said they could offer, and the support which informal carers received (McPherson *et al.* 2014). By contrast, our results suggest a good alignment between, on the one hand, what HCAs judge that patients and family carers need and they see as their role in providing and, on the other, what family carers acknowledge they have received and appreciate.

Limitations

We recruited fewer participant family carers than we had planned to, though the difficulties of recruiting this particular sample group are well acknowledged (Grande and Ingleton 2008). While we were unable to recruit a purposive sample, our convenience sample yielded a balanced sample in terms of the age, gender and relation to patient of the family carers. We are aware that the gatekeeping role might have skewed the sample (Grande and Ingleton, 2008), but it was considered ethically important to allow service leads to exclude family carers if they thought their inclusion was likely to impose an unacceptable burden on them.

Although the data for this study was collected in 2011-12, there have been no statutory changes to the roles of HCAs in intervening years, and so it is unlikely that the experiences of HCAs providing community palliative care services and family carers receiving their support will have changed significantly since the data was collected.

Although this study was undertaken only in the UK, it is likely to have applicability in other countries where grades exist comparable to health care assistants. For example, Certified Nursing Assistants in North America, who are also involved in care of dying patients (Chicin *et al.* 2000), care aides working in community palliative care in Australia (Aoun *et al.* 2012) and health care aides working in older people's residential care settings in Canada (Mallidou *et al.* 2013). Therefore we believe the study's contribution has international relevance.

Conclusion

A fundamental aspect of the work of HCAs providing home care for dying patients is emotional labour. Accounts of their work by bereaved family carers in this study and the positive responses reported, indicate the skills these HCAs possess in providing this type of work.

Previous research has highlighted the poorly defined role boundaries of HCAs, and calls have been made to clarify their roles. However, while this study demonstrates that HCAs work on the boundary between professional health workers and family carers, from the family carers' perspective, this was

clearly a strength, and not a weakness. The bereaved family carers we spoke to valued the HCAs as health care workers for their knowledge and skill in supporting the provision of end of life care, whilst simultaneously 'fitting in' to family homes at a very difficult time. Present attempts to clarify the role boundaries and professional status of HCAs should therefore take this into account, to ensure that HCAs can continue to provide valued and flexible physical and emotional support to family carers.

Acknowledgements

We would like to thank all the family carers and staff who participated in the study, and Dimbleby Cancer Care for funding the project.

References

- Aoun, S., O'Connor, M., Skett, K., Deas, K. & Smith, J. (2012) Do models of care designed for terminally ill 'home alone' people improve their end-of-life experience? A patient perspective. *Health and Social Care in the Community* 20 (6), 599-606.
- Bach S., Kessler I., Heron P. (2008) Role redesign in a modernised NHS: the case of health care assistants. *Human Resource Management Journal* 18 (2), 171-187.
- Bartram T., Casimir G., Djurkovic N., Leggat S. & Stanton P. (2012) Do perceived high performance work systems influence the relationship between emotional labour, burnout and intention to leave? A study of Australian nurses. *Journal of Advanced Nursing* 68 (7), 1567-1578.
- Berta, W., Laporte, A., Deber, R., Baumann, A. & Gamble, B. (2013) The evolving role of health care aides in the long-term care and home and community care sectors in Canada. *Human Resources for Health* 11 (1), 25.
- Bryman, A. (2008) *Social Research Methods Third Edition*. Oxford University Press, London.
- Campbell, C., Scott, K., Madanhire, C., Nyamukapa, C. & Gregson, S. (2011) A 'good hospital': Nurse and patient perceptions of good clinical care for HIV-positive people on antiretroviral treatment in rural Zimbabwe—A mixed-methods qualitative study. *International Journal of Nursing Studies* 48 (2), 175-183.
- Chicin E., Burack O.R., Olson E. & Likourezos A. (2000) End-of-life ethics in the nursing assistant. New York: Springer.
- Clark D., Ferguson C. & Nelson C. (2000) Macmillan carer schemes in England: results of a multicentre evaluation. *Palliative Medicine* 14 (2), 129-139.

Davies C. (1998). Caregiving, carework and professional care. In: Brechin, A., Walmesley, J., Katz, J. & Peace, S. (eds.) *Care Matters: Concepts, Practice and Research in Health and Social Care*. London: Sage.

Denham S.A., Meyer M.G., Rathburn A., Toborg M.A. & Thornton L. (2006) Knowledge of rural nurses' aides about end-of-life care. *Family & Community Health* 29, 229-241.

Department of Health (1990) NHS and Community Care Act. Her Majesty's Stationery Office (HMSO), London.

Department of Health (2008) End of life care strategy: promoting high quality care for adults at the end of life, London.

Department of Health (2013) The Cavendish Review: an independent review into healthcare assistants and support workers in the NHS and social care settings, London.

Devlin M. & McIlpatrick S. (2010) The role of the home-care worker in palliative and end-of-life care in the community setting: literature review. *International Journal of Palliative Nursing* 15 (11), 526-532.

Ferguson C., Nelson C., Rhodes P. & Clark D. (1998) The role of the Macmillan carer in a new community care service. *International Journal of Palliative Nursing* 16 (4), 6-13.

Fleming G. & Taylor B.J. (2007) Battle on the home care front: perceptions of home care workers of factors influencing staff retention in Northern Ireland. *Health and Social Care in the Community* 15 (1), 67-76.

Flory J., Young-Xu Y., Gurol I., Levinsky N., Ash A. & Emanuel E. (2004) Place of death: U.S. trends since 1980. *Health Affairs* 23, 194-200.

Glaser B. & Strauss A.L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine.

Gomes B., Calanzani N. & Higginson I. (2012) Reversal of the British trends in place of death: time series analysis 2004-2010. *Palliative Medicine*, 26 (2), 102-107.

Grande G. and Ingleton C. (2008) Research in Palliative Care. In Payne S, Seymour J and Ingleton C (Eds) *Palliative Care Nursing: Principles and Evidence for Practice*. OUP: McGraw-Hill

Gray, B. (2009). The emotional labour of nursing—defining and managing emotions in nursing work. *Nurse Education Today*, 29(2), 168-175.

Harding, R., Epiphaniou, E., Hamilton, D., Bridger, S., Robinson, V., George, R., Beynon, T & Higginson, I. J. (2012). What are the perceived needs and challenges of informal caregivers in home cancer palliative care? Qualitative data to construct a feasible psycho-educational intervention. *Supportive Care in Cancer*, 20(9), 1975-1982.

Hayward, R. M., & Tuckey, M. R. (2011). Emotions in uniform: How nurses regulate emotion at work via emotional boundaries. *Human Relations*, 64(11), 1501-1523.

Health Education England website 2014. <http://hee.nhs.uk/work-programmes/shape-of-caring-review>. Accessed 7 August 2014.

Herber O.R. & Johnston B.M. (2013) The role of healthcare support workers in providing palliative and end-of-life care in the community: a systematic literature review. *Health and Social Care in the Community* 21 (3), 225-235.

Hochschild A.R. (1983) *The managed heart: the commercialization of human feeling*. University of California Press, Berkeley.

Ingleton C., Chatwin J., Seymour J. & Payne S. (2011) The role of health care assistants in supporting district nurses and family carers to deliver palliative care at home: findings from an evaluation project. *Journal of Clinical Nursing* 20, (13-14), 2043-2052.

Jack B., & O'Brien M. (2010). Dying at home: community nurses' views on the impact of informal carers on cancer patients' place of death. *European journal of cancer care*, 19(5), 636-642.

James N. (1989) Emotional labour: skill and work in the social regulation of feelings. *The Sociological Review* 37 (1), 15-42.

James N. (1992) Care = organisation + physical labour + emotional labour. *Sociology of Health and Illness* 14, 488-509.

Koffman J., Higginson I.J., Hall S., Riley J., McCrone P. & Gomes B. (2012) Bereaved relatives' views about participating in cancer research. *Palliative Medicine* 26 (4), 379-383.

McKenna H. P., Hasson F. & Keeney S. (2004) Patient safety and quality of care: the role of the health care assistant. *Journal of Nursing Management*, 12, 452-459.

McPherson K.M., Kayes N.K., Moloczij N. & Cummins C. (2014) Improving the interface between informal carers and formal health and social services: a qualitative study. *International Journal of Nursing Studies*, 51 (3), 418-429.

Mallidou, A. A., Cummings, G. G., Schalm, C. & Estabrooks, C. A. (2013) Health care aides use of time in a residential long-term care unit: a time and motion study. *International Journal of Nursing Studies*, 50, 1229-1239.

Mid Staffordshire NHS Foundation Trust 2013. Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry. London: Crown Copyright.

Munday D. (2007) *Exploring complexity in community palliative care: a practitioner based approach to research and development*. PhD Thesis, University of Warwick.

Neergaard M.A., Jensen, A. B., Sondergaard, J., Sokolowski, I., Olesen, F., & Vedsted, P. (2011). Preference for place-of-death among terminally ill cancer patients in Denmark. *Scandinavian journal of caring sciences* 25(4), 627-636.

NHS 2013. Monthly NHS Hospital and Community Health Service (HCHS) Workforce Statistics in England – June 2013, Provisional Statistics. London: National Health Service.

Schell, E. S., & Kayser-Jones, J. (2007). "Getting into the skin": Empathy and role taking in certified nursing assistants' care of dying residents. *Applied Nursing Research*, 20(3), 146-151.

Skilbeck J. & Payne S. (2003) Emotional support and the role of Clinical Nurse Specialists in palliative care. *Journal of Advanced Nursing* 43 (5), 521-530.

Smith P. (1992) *The emotional labour of nursing: its impact on interpersonal relations, management and the educational environment in nursing*. Macmillan Education, Basingstoke.

Wilson D.M., Truman C.D., Thomas R., Fainsinger R., Kovacs-Burns K., Froggatt K. & Justice C. (2009) The rapidly changing location of death in Canada, 1994-2004. *Social Science & Medicine*, 68 (10), 1752-1758.

Yang, F. & Chang, C. (2008) Emotional labour, job satisfaction and organizational commitment amongst clinical nurses: A questionnaire survey. *International Journal of Nursing Studies*, 45, 879-887.

Accepted Manuscript

Summary statement

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.

Table 1: Health care assistants by research setting

<u>Organisation Identifier</u>	<u>Number of Health Care Assistants Interviewed</u>
A Hospice	2
B NHS Service	4
C Supportive Care at Home	2

Accepted Manuscript

Table 2: Sample group by setting and relationship to patient

Setting	Wife caring For husband	Husband caring for wife	Daughter caring for mother	Daughter caring for father	Son caring for mother/ father	Other	Total
A	4	0	0	0	0	0	4
B	5	5	3	2	0	0	15
C	7	1	1	2	2	1	14
Total	16	6	4	4	2	1	33

A	Hospice at Home
B	NHS Service
C	Supportive Care at Home