'End of life could be on any ward really': A qualitative study of hospital volunteers' end-of-life care training needs and learning preferences

Lisa Jane Brighton[1], Jonathan Koffman[1], Vicky Robinson[1], Shaheen A Khan[2], Rob George[1,2,3], Rachel Burman[1,4] and Lucy Ellen Selman[1,5]

Abstract

Background: Over half of all deaths in Europe occur in hospital, a location associated with many complaints. Initiatives to improve inpatient end-of-life care are therefore a priority. In England, over 78,000 volunteers provide a potentially cost-effective resource to hospitals. Many work with people who are dying and their families, yet little is known about their training in end-of-life care.
Aims: To explore hospital volunteers' end-of-life care training needs and learning preferences, and the acceptability of training evaluation methods.
Design: Qualitative focus groups.
Setting/participants: Volunteers from a large teaching hospital were purposively sampled.
Results: Five focus groups were conducted with 25 hospital volunteers (aged 19–80 years). Four themes emerged as follows: preparation for the volunteering role, training needs, training preferences and evaluation preferences. Many described encounters with patients with life-threatening illness and their families. Perceived training needs in end-of-life care included communication skills, grief and bereavement, spiritual diversity, common symptoms, and self-care. Volunteers valued learning from peers and end-of-life care specialists using interactive teaching methods including real-case examples and role plays. A chance to 'refresh' training at a later date was suggested to enhance learning. Evaluation through self-reports or observations were acceptable, but ratings by patients, families and staff were thought to be pragmatically unsuitable owing to sporadic contact with each.
Conclusion: Gaps in end-of-life care training for hospital volunteers indicate scope to maximise on this resource. This evidence will inform development of training and evaluations which could better enable volunteers to make positive, cost-effective contributions to end-of-life care in hospitals.

Keywords

Volunteers, hospital volunteers, qualitative research, education, terminal care, palliative care

---

What is already known about the topic?

- Although most people use inpatient services in the last year of life, and over half of all deaths occur in hospitals, quality of end-of-life care here remains sub-optimal.
- Hospital volunteers contribute hours of their time free of charge, across wards that include elderly patients and those with life-threatening illness, and their families.
- Little evidence exists to inform volunteers' training in end-of-life care.

---

[1]King's College London, Cicely Saunders Institute, Department of Palliative Care, Policy, and Rehabilitation, London, UK
[2]Guy's and St Thomas' NHS Foundation Trust, London, UK
[3]St Christopher's Hospice, London, UK
[4]King's College Hospital NHS Foundation Trust, London, UK
[5]Bristol Randomised Trials Collaboration, School of Social and Community Medicine, University of Bristol, Bristol, UK

Corresponding author:
Lisa Jane Brighton, Cicely Saunders Institute, King's College London, Bessemer Road, London SE5 9PJ, UK.
Email: lisa.brighton@kcl.ac.uk

What this paper adds?

- Training in advanced communication and listening skills and education in other aspects of end-of-life care (e.g. grief and bereavement, spiritual diversity, common symptoms, and self-care) would allow volunteers to better help patients and families towards the end of life.
- Volunteers prefer training that is diverse and uses interactive teaching methods, drawing on real-life case examples and role plays. They also want opportunities to refresh and consolidate learning.
- Volunteers are open to the effects of training being evaluated using their own self-reports or observed behaviours, but highlighted potential limitations of patient, family and/or staff feedback as a form of evaluation owing to their sporadic contact with each.

Implications for practice, theory or policy

- Policymakers and managers responsible for improving end-of-life care in hospitals must not overlook the role of hospital volunteers in end-of-life care, including their training and support needs.
- Hospital volunteer managers and coordinators should use the findings of this study to develop evidence-based end-of-life care training for volunteers and evaluate its outcomes in collaboration with researchers.

Introduction

Over 70% of people use inpatient services in the last year of life,[1,2] and over half of all deaths in middle- and high-income countries occur in hospitals.[2,3] Despite this, evidence suggests that quality of end-of-life care (EoLC) in acute settings internationally is sub-optimal,[4] with patients and families reporting instances of uncompassionate care that lacks dignity.[5,6] A growing and ageing population is placing increasing demands on already stretched resources.[7,8] Identifying innovative and cost-effective ways to provide quality EoLC is now an international priority.[9–11] Improving EoLC provision by non-specialists in palliative care is central to these efforts.[12–14]

Across the globe, governments are promoting public engagement in health and social care through volunteering.[15–17] In England, a volunteer workforce of approximately 78,000 people contribute over 13 million hours per year to acute hospital trusts.[18] Roles include visiting and befriending on hospital wards, providing signposting services and supporting hospitality and activities (e.g. help with meal-times or drinks trolley services). Many volunteers work in settings where patients are likely to be elderly and/or facing life-threatening illness.[18,19]

Research regarding volunteers' contributions to EoLC in specialist palliative care settings has shown benefits for patients, families and staff. For patients, interaction with volunteers has been related to improved psychological well-being[20] and survival.[21] Among families, the support of volunteers is appreciated,[22–25] and those receiving more volunteer hours have rated quality of EoLC higher.[26] Staff report that volunteers' support to patients and families can make their role easier.[27] Such volunteering services cannot exist without adequate resourcing to support their management and training. However, with an estimated £11 return for every £1 hospitals invest in volunteering,[18] maximising the utility of volunteers in relation to EoLC is likely to contribute cost-effectively to improvements in patients' and families' experiences. Such implications are crucial in the context of financially challenged healthcare systems.[28]

While researchers have explored the experiences, training needs and impact of volunteers in specialist palliative care settings,[29–31] little is known about the specific needs of those volunteering in hospital settings.[32] Consequently, the EoLC challenges faced by volunteers and how volunteers can be better served through training and support remains poorly understood. Similarly, no research has explored hospital volunteers' preferences for learning and how acceptable different training evaluation techniques would be to them. This information is critical in developing evidence-based training and appropriate methods to evaluate such interventions. This study therefore aims to explore hospital volunteers' training needs and learning preferences in relation to EoLC and identify acceptable training evaluation methods in this population.

Methods

Design

Qualitative focus group study.

Setting

Hospital volunteers were recruited from a large tertiary teaching hospital in London, which has approximately 1000 volunteers in total. Volunteers have a minimum commitment of 3 h/week, with roles such as hospital guides, chaplaincy volunteers, ward visitors and assisting with discharge to home. Data collection took place from December 2014 to March 2015.

Sampling and recruitment

Eligible participants were hospital volunteers aged 18 years or over, with at least 3 months of experience. Focus groups were advertised via posters and flyers in the volunteering office, at existing volunteer meetings, and using invitations circulated via email by the hospital volunteer manager. Volunteers interested in taking part were invited to contact the researchers. Sampling was purposive to represent different volunteer roles (chaplaincy and non-chaplaincy), a variety of wards and differing degrees of experience volunteering. Recruitment continued until saturation was reached, that is, analysis resulted in no new emerging themes.[33]

Data collection

Semi-structured, face-to-face focus groups were facilitated by a researcher (L.J.B. or J.K.) with experience in qualitative techniques and palliative care research. Neither researcher had prior relationships with the study participants. Focus groups were held offsite, and refreshments were provided. The facilitator began each focus group by explaining the rationale for the research to participants and the ground rules for the focus group, and answering any questions they had. The topic guide explored the following issues: (a) participants' experiences of working with patients with serious, life-threatening illness and their families; (b) views on their training; (c) their perceived training needs; (d) how they liked to learn; (e) views on mentoring and/or supervision and (f) their opinions regarding training evaluation methods (Appendix 1). When discussing training needs, participants were provided with a list of potentially relevant topics to prompt their discussion (Appendix 2), developed based on the existing literature[34] and a local training course for non-specialists in EoLC.[35] Each focus group was digitally recorded and transcribed verbatim. A researcher (L.J.B.) or administrator (L.K.) took field notes on the setting and recorded non-verbal communication for each focus group.

Analysis

Inductive thematic analysis[36] within a minimal realist paradigm[37] was conducted. Specifically, the language used by participants was treated as directly reflecting their experiences and meanings while acknowledging the inevitable influences of interpretation by the researcher during analysis. Thematic analysis was deemed most suitable to formulate a descriptive account of patterns in the data and was conducted using following steps: first, a draft coding frame was inductively constructed by L.J.B. following familiarisation with the data. Second, the coding frame was revised and refined with input of the multidisciplinary project team (L.S., J.K., V.R., S.A.K., R.G.). Third, the coding frame was applied to all data (L.J.B.), with independent dual coding of a selection of the transcripts (J.K., S.O.) to maximise analytical rigour.[38] At all stages, discrepancies were discussed to reach consensus. Fourth, a narrative summary of findings was written, paying attention to non-confirmatory cases[39] and how themes related to participant characteristics (e.g. role, years of experience). Field notes were referred throughout to better understand the focus group dynamics and where particular issues were emphasised by participants' non-verbal cues (e.g. tone of voice). Analysis was managed in QSR NVivo 10.[40]

Ethical approval

This study had ethical approval from King's College London's Research Ethics Committee (BDM/14/15-11). Volunteers gave written informed consent prior to focus group participation.

Results

Participant characteristics

Five focus groups lasting a median of 1 h 25 min were conducted with a total of 25 participants (Table 1). Participants ranged in age from 19 to 80 years (median: 50), the majority were women ($n = 19$), and they had been volunteering for a median of 1 year 3 months (range: 3 months–18 years). Eight were chaplaincy volunteers, whose roles spanned multiple wards and focused on spiritual support. The remaining 17 volunteers were primarily based in a single ward or department (but may have worked on other wards during their training period), with a range of wards represented. Their roles were primarily keeping patients and/or families company. The participants were of diverse ethnicities: White British ($n = 8$), African ($n = 6$), Caribbean ($n = 3$) and mixed White and Black African, Irish, Bangladeshi, British Guyanese, Filipino, Canadian and Polish (all $n = 1$; one participant did not disclose their ethnicity).

Themes

Of the 25 participants, 20 described encounters with patients with life-threatening illness or those approaching the end of life, and their families. While the remaining participants did not mention specific instances of working with the dying, their experiences and discussions of the broader challenges they faced working with people who were unwell were relevant and are included. Four themes emerged from the analysis: (a) preparation for their volunteering role, (b) EoLC training needs, (c) learning preferences and (d) evaluation preferences.

Preparation for their volunteering role. Mandatory volunteer training included both in-person sessions (a 6-h induction, with an additional 2 h on communication skills and 2.5 h on

Table 1. Participant details.

ID	Gender	Time volunteering	Current ward
1	F	1 year, 9 months	Elderly care
2	F	2 years, 4 months	Intensive care
3	F	1 year, 5 months	Medical assessment
4	M	(Not disclosed)	X-ray
5	M	10 months	Liver outpatients
6[a]	F	1 year, 6 months	Oncology
7	F	4 months	Maternity
8	F	3 months	Discharge
9[a]	F	2 years, 9 months	Stroke
10	F	6 months	Elderly care
11	M	4 years, 3 months	Accident and emergency (A&E)
12[a]	F	3 months	Surgical
13	M	1 year, 3 months	Multiple (chaplaincy)
14	F	3 years, 3 months	Multiple (chaplaincy)
15	F	18 years	Multiple (chaplaincy)
16	F	1 year, 2 months	Multiple (chaplaincy)
17	F	5 months	Multiple (chaplaincy)
18	F	3 months	Multiple (chaplaincy)
19	F	10 years, 6 months	Multiple (chaplaincy)
20	F	1 year	Multiple (chaplaincy)
21[a]	F	1 year, 6 months	Discharge
22[a]	M	1 year, 1 month	Neurology
23	F	1 year, 6 months	Orthopaedics
24[a]	F	4 months	Surgical
25	M	1 year, 3 months	Phlebotomy

F: female; M: male.
[a]Volunteer had background experience in healthcare.

respecting privacy, dignity and assisting with eating and drinking) and online modules (1.5 h each on manual handling, confidentiality, safeguarding children and safeguarding vulnerable adults). Participants believed this training was good but would always have gaps owing to the individuality of their different roles: 'I think you can't really specifically train someone for a certain area. So you need to do this kind of umbrella, coverall kind of training' (V1, Elderly care). For non-chaplaincy volunteers, role-specific gaps in training were filled by their ward or department manager. This ranged from formal discussions: 'I sat down with the nursing sister, which was very good, very formal. And we went through a ward description, job description' (V6, Oncology), to far briefer encounters: 'They just go, "There is the toilets. There's where you put your handbag or that's where you don't put your handbag"' (V2, Intensive care).

Chaplaincy volunteers attended 10 h of formal, face-to-face training on communication skills, self-care, spirituality and cultural competence, in addition to the mandatory training. This was thought to have an added value relevant to EoLC: 'It is those kinds of things that the chaplaincy training was able to open up to us. That it's about making the patient feel valued and making sure that they know they are being listened to' (V16, Chaplaincy).

EoLC training needs. Participants identified five distinct training needs related to working with patients and their families towards the end of life: communication skills, understanding grief and bereavement, understanding spiritual diversity, understanding common symptoms at the end of life, and volunteers' self-care.

Communication skills. Communication, particularly listening, was considered by all participants to be central to their volunteering role: 'Listening is the most important thing we do as a volunteer' (V11, A&E). Half explicitly stated a training need in this area. Of the remaining half, all but four participants described how working with seriously ill patients could involve encountering difficult and emotionally charged interactions. One volunteer recounted her first upsetting interaction with a cancer patient and her concern about how to respond to his emotions: 'So I just said, "Hi, how are you doing today?" Like that. And then, he started crying' (V18, Chaplaincy).

Communicating with families who were understandably distressed was also worrying for six participants, for example,

> You are the first person they see, sometimes they are just ready to kill you basically. You know, it is like it is all your fault. (V2, Intensive care)

Others were keen to know how to behave or what to say in the presence of emotional relatives. One volunteer remarked,

> And [the patient] was in one of the rooms where you have to wear extra protective clothing as well, and I remember his children there. And they were really upset, and obviously me and him were having … He is telling me about times he went to Jamaica, and we're talking, but I could see that his children were visibly upset. So I asked them if they wanted me to leave, and they were like no, no, no. But I felt … I didn't really know what … To them, they are seeing their dad, someone who has looked after them, in an ill position, but I didn't really know what to like, say to them. (V24, Surgical)

The difficulty of these situations and conversations was amplified when volunteers were not privy to background information about patients and their families. For example, one participant, who was unaware of a dying patient's prognosis, spoke evocatively of a difficult interaction:

> Uh, it was just … had I known how serious the prognosis was, I would have handled the situation much differently. So, you know, it is very difficult going in cold sometimes because you can end up really putting your foot in your mouth. (V14, Chaplaincy)

Understanding grief and bereavement. Partly as a consequence of such interactions, volunteers clearly recognised the emotional impact of life-threatening illness and end

of life on patients and families. Five participants believed they would benefit from an improved understanding of grief and bereavement:

> I think additional training on understanding grief, on providing support for family experiences, I think we should have more training on that. (V3, Medical assessment)

One volunteer felt this was particularly relevant to their role accompanying patients home, as sometimes their service worked specifically with patients who have little support around them as a result of bereavement:

> That's why [the volunteer discharge service] goes there. So having that kind of support and knowledge on how to support them … is very important. (V7, Discharge)

Understanding spiritual diversity. All volunteers recognised the increasingly multicultural nature of the hospital population and the diversity of religious and spiritual beliefs associated with this. Non-chaplaincy volunteers, in particular, believed more knowledge about the roles of formal religion and individual expressions of spirituality in the context of serious illness would help them to respect diverse beliefs and avoid causing offence:

> [It's] such a diverse community and such a multi-racial and multi-ethnic hospital, we have no idea of what culture and what religion a lot of the patients are. We don't want to say anything wrong or insult any family members. We don't want to start taking a guess at what people are, um, because there are so many different religions in every ward. (V9, Stroke)

> The one that stood out for me the most is understanding spiritual, cultural and environmental aspects of dying because nowadays we are living in a society where people are very religious. And even though there may be some patients that aren't religious, you just have to respect what somebody believes. (V10, Elderly Care)

Few chaplaincy volunteers reported needing more training in this area, but all agreed this knowledge would be very relevant to non-chaplaincy volunteers: 'I think even the active listening and even some of the spirituality kind of training, I think it would be quite beneficial to any volunteers' (V16, Chaplaincy).

Understanding common symptoms at the end of life. Volunteers also saw basic knowledge of the common symptoms associated with life-limiting conditions as potentially useful in ameliorating anxiety, whether their own, or that of patients or families:

> It means that you have the opportunity to say to a family member who is quite distressed, 'Actually, it is okay. This is all that's happening', and that can be the most powerful thing

you can possibly say, to know that actually that's okay. It is not anything out of the ordinary. (V16, Chaplaincy)

Others suggested knowledge of symptoms would help them distinguish between clinically important events and those normally expected within the context of the patient's illness:

> I actually thought he was dead because he didn't say anything for a while, and I was like 'Oh no, what am I going to do'. So I went and got a nurse, and he was not, I was just thinking. I was like had I known. Because he had really heaving breathing, I don't know what was actually wrong with him. But like I think like air would get caught in him and it seemed like he was choking, so I went and told the nurse straight away. And she was like, 'No, don't worry'. (V24, Surgical)

Volunteers' self-care. Participants often ruminated over the difficult interactions encountered in their volunteering role, particularly when their patients died: 'He died a few days after, but I just kept thinking in my mind, I hope that last conversation that I had with him, it was good' (V24, Surgical). Volunteers also spoke of feelings akin to grieving when they had developed meaningful relationships with patients and their families:

> It does it affects you at times when you know someone, you may be seeing them – so for example, during two weeks or three weeks you get to know them, and then they are gone. (V4, X-Ray)

and of the emotional impact when death occurred in close proximity:

> We both work in situations where people die. They die in front of us, and it is very difficult. (V2, Intensive care)

This participant suggested such situations had previously resulted in resignations by volunteers unprepared for what lay in store for them: 'We have so few volunteers [in Intensive care], because they either don't stay because it is a very traumatic situation, or it is not what they were expecting' (V2, Intensive care). In addition to clear preparation and guidance on self-care for potential encounters with death and dying, non-chaplaincy volunteers felt they would benefit from more pastoral support. Although they reported that they could find a member of staff to talk to informally if needed, there was no formal system or protocol in place, and some participants suggested a key point of contact would be beneficial:

> Like for example, every six months or every year, whatever, for that individual to help them to cope with the situation because we all - the family, now the family, we have empathy for the family, but when it comes to the staff or the volunteers, we tend to neglect. (V4, X-Ray)

This need was less present for chaplaincy volunteers, who spoke of a more structured support system of debriefing following visits:

> But when we do come back and we feedback on our visit, quite often, um, the chaplains will give their own input as well as to a situation that you have talked about. They might say what did you do about that, how did you feel about that. (V16, Chaplaincy)

Learning preferences

Teaching methods. When questioned about the most appropriate mode of training and teaching EoLC, participants emphasised the need for a variety of interactive methods. One volunteered stated, 'A mixture of everything … because you need the practical experience to deal with the situation like that and you need also the theoretical aspect of it all' (V5, Liver outpatients). Seven participants expressed that they were in favour of using real-case examples to illustrate situations they would likely encounter: 'If I know that it actually happens and this was the scenario that someone actually faced, it makes it seem more than just an exercise. [Sounds of agreement]'(V16, Chaplaincy). Role plays were also seen as an acceptable and effective way to learn; two participants in discussion with one another said,

> I think role play is probably one of the best ways. (V14, Chaplaincy)

> So do I, because it puts you on the spot. (V17, Chaplaincy)

E-learning, however, was not an approach any participants chose to endorse, regardless of age group: 'I don't think that is the sort of thing you can really teach on a computer really' (V11, A&E). Mentoring by experienced volunteers was also viewed favourably, as a role that could increase confidence and provide pastoral support early in their volunteering career.

Teachers. In addition to learning from experienced peers, volunteers were enthusiastic about being taught by highly credible staff working in the field, for example, palliative care specialists or staff from the bereavement office:

> I think both [staff and volunteers], because you will get the professional experience or the professional knowledge of the situation and they might have been dealing with in it for years and years, so their training, and then a bit from the volunteers because they are hands on also. So I think both is important. (V3, Medical assessment)

Optional versus mandatory training. Participants also discussed whether training in EoLC should be optional or mandatory. Participants gave three key reasons for preferring optional training. First, the highly sensitive nature of

EoLC meant not all volunteers would want to work in the area: 'Some people aren't of that makeup' (V9, Stroke). Second, owing to the diverse range of wards volunteers worked on, not all would necessarily require this specialist knowledge set. Finally, it was suggested that since volunteers chose to offer their time, there should be some recognition that any training offered should be on their terms:

> To say that this should be compulsory is like you are forcing them to do something that they don't want to do. (V10, Elderly Care)

One volunteer initially disagreed saying EoLC training should be compulsory on the basis that 'End of life could be [on] any ward really'; however, after further discussion they felt satisfied that even if optional, 'There would be a very, very high take up of it' (V11, A&E).

Consolidating learning. Seven participants stated that an opportunity to attend training more than once, or attend 'refresher' training at a later date, would be helpful to reinforce their ongoing learning:

> I kind of wish I did the training again, like a freshen up, because when I actually got onto the ward, it was different to when we were sitting down and just talking about it. (V24, Surgical)

Evaluation preferences. The final area of discussion concerned methods that might be used to evaluate the effectiveness of volunteer training in EoLC. Volunteers stated that they would be happy to self-report perceived changes as a result of training or potentially be observed in their role; the latter appeared more instantly acceptable to those with previous healthcare experience (e.g. V9 and V12). Volunteers reported the acceptability of evaluations was dependent on how it was presented: evaluation should be presented as aiming to test training effectiveness, rather than to judge their work:

> I think as long as they are aware that that they weren't being assessed and it was just an assessment of the training and not their abilities … (V11, A&E)

Participants were mindful of the benefit of patients, relatives and staff providing feedback on their role and contributions. However, they also foresaw difficulties due to the sporadic nature of their contact with these individuals: 'On my ward, I mean I go and visit [patients] and then by the next week they have gone home' (V15, Chaplaincy), 'I work from 11 until 2 and the families are not allowed to come in until two o'clock. So I never meet them' (V23, Orthopaedics). In terms of asking staff to assess volunteers, concerns were raised in relation to burden: 'They have a lot of paperwork already to do and to add an extra one on of a volunteer that isn't employed by the NHS

whatsoever, I can imagine them looking at me as if to say, pardon?' (V16, Chaplaincy).

Discussion

In this first in-depth study of hospital volunteers' experiences, training needs and learning preferences in relation to EoLC, we found that volunteers frequently encountered patients with life-limiting illness and their families. They need additional training and support to deliver better EoLC, particularly in relation to communication skills, understanding grief and bereavement, spiritual diversity, common symptoms, and self-care, plus increased pastoral support. They reported that training must be diverse using interactive teaching methods such as role play and drawing on real-life case examples. To transfer classroom learning to practice, volunteers suggested that they learn from both expert professionals and each other, in addition to being able to refresh and consolidate learning at a later date. Volunteers discussed the emotional burdens of working in EoLC and highlighted the potential for harm suggested by volunteers leaving roles in intensive care. Participants' recommendation to provide adequate support for volunteers involved in EoLC and ensure it is signposted within volunteer training is therefore crucial. Volunteers also stated that any evaluations of training must test the training and not them, in order to be acceptable. Although deemed valuable, collecting evaluation data from patients, families and staff was seen as logistically difficult owing to volunteers' sporadic contact with each group.

Volunteer training needs in relation to communication skills,[41–43] grief and bereavement,[42] symptoms[44], and self-care and support[41,42] have been reported and responded to within specialist palliative care settings.[45,46] Yet, this has not been a priority in hospital settings. Most people who die, however, do so in hospitals. Considering the multidisciplinary, collaborative nature of palliative and EoLC, it is now timely for hospital volunteer training to be adapted from, or run in collaboration with, specialist palliative care settings. Where training for chaplaincy volunteers already exists, offering this to other interested hospital volunteers could help augment their knowledge and skills in communication and understanding spiritual diversity. Indeed, integrating training on palliative and EoLC into existing structures would be cost- and time-efficient.[32] Similarly, signposting volunteers to existing support structures (e.g. chaplaincy services or volunteer coordinators) or encouraging attendance at hospital-based initiative such as Schwartz Rounds[47–49] could provide much-needed support mechanisms. In the same way that feeling trained and supported is vital in the performance of paid staff,[50–53] ensuring education and support is available to hospital volunteers is essential.

The importance of making sure all those involved in care of the dying receive adequate training is recognised internationally.[54,55] In Canada, the Hospice and Palliative Care Association advocate for a nationally standardised training package for volunteers to improve quality of care.[56] The UK Department of Health also recommends training in communication for all those working in EoLC.[57] More recently, novel initiatives have involved training volunteers in hospitals for specific roles related to palliative and EoLC. For example, in the United States, Sanon et al.[58] trained hospital volunteers to support older people admitted to emergency departments, while in the United Kingdom, Germain et al.[59] trained volunteers for a Care of the Dying Volunteer Service (designed for wards with high numbers of deaths and palliative care referrals). However, our study findings highlight that hospital volunteers in general support roles also encounter many challenges related to EoLC. Policymakers and managers responsible for improving EoLC in hospitals therefore should not limit initiatives to paid staff: they must consider the role of volunteers as non-specialist providers of EoLC and harness their full potential by ensuring that they are adequately trained and supported members of the multidisciplinary team. With the increasing impact of a globally ageing population, supporting volunteers with EoLC should be high on the international agenda. Specifically, action is needed to identify the training and support needs of all volunteers with the potential to be involved in EoLC and seek appropriate ways of filling these gaps. However, all initiatives must be based on robust evidence; when this is absent, they must be rigorously evaluated for effectiveness and cost-effectiveness. Findings must then be shared to identify good practice internationally.

There are a number of limitations that affect transferability of our findings. First, the study was conducted at a single site: a large tertiary teaching hospital in an inner-city setting with a well-established volunteering programme. Views of these hospital volunteers might differ from those at smaller hospitals, those in rural areas or those with less-established volunteering programmes, where training needs may differ and perhaps be more extensive. Second, the initial study advertisement informing potential participants about this study was primarily email and poster-based; we therefore cannot determine the number of non-responders. It is possible that the volunteers who chose to take part in the study were different from those who chose not to. However, if participants in the focus groups were those more interested in working with patients towards the end of life, their views are highly relevant. Moreover, our sample was diverse with regard to age, ethnicity, role and volunteer experience, allowing us to capture a range of views and representing the diversity of the hospital's volunteers. While there were more female participants than male, this reflects hospital volunteers generally in the United Kingdom.[18] Third, this study presents the training needs of hospital volunteers in EoLC only from their perspectives. As self-assessment of skills

and training needs may not always be accurate, studies exploring the role of hospital volunteers in EoLC from other perspectives (e.g. patients, families and staff) might add valuable insight and would be an interesting area for future research.

Conclusion

Hospital volunteers currently play an important role in patient and family care, including EoLC. To fully harness the commitment and benefit of hospital volunteers, policy-makers must match their promotion of volunteering with investment in adequate preparation and support structures. Our findings provide valuable evidence to inform the development of training and support for hospital volunteers, which should enable them to fully contribute to cost-effective, quality EoLC in the acute setting.

References

1. Bardsley M, Georghiou T and Dixon J. Social care and hospital use at the end of life. Report, The Nuffield Trust, London, 2010, http://www.nuffieldtrust.org.uk/sites/files/nuffield/social_care_and_hospital_use-full_report_081210.pdf

2. Goldsbury DE, O'Connell DL, Girgis A, et al. Acute hospital-based services used by adults during the last year of life in New South Wales, Australia: a population-based retrospective cohort study. *BMC Health Serv Res* 2015; 15: 1–14.

3. Ruth K, Pring A and Verne J. Variations in place of death in England: inequalities or appropriate consequences of age, gender, and cause of death? Report, National End of Life Care Intelligence Network, London, 2010, http://www.endoflifecare-intelligence.org.uk/search/variations+in+place+of+death

4. Al-Qurainy R, Collis E and Feuer D. Dying in an acute hospital setting: the challenges and solutions. *Int J Clin Pract* 2009; 63: 508–515.

5. Robinson J, Gott M and Ingleton C. Patient and family experiences of palliative care in hospital: what do we know? An integrative review. *Palliat Med* 2013; 28: 18–33.

6. Guo Q and Jacelon CS. An integrative review of dignity in end-of-life care. *Palliat Med* 2014; 28: 931–940.

7. Guerin B, Hoorens S, Khodyakov D, et al. A growing and ageing population – global societal trends to 2030: thematic report 1. Report, RAND Corporation, Santa Monica, CA, 2015, http://www.rand.org/content/dam/rand/pubs/research_reports/RR900/RR920z1/RAND_RR920z1.pdf

8. Juni MH. Ageing population: a public health implications. *Int J Public Health Clin Sci* 2015; 2: 93–103.

9. Canadian Hospice Palliative Care Association. Cost-effectiveness of palliative care: a review of the literature. Report, Canada, 2012, http://www.hpcintegration.ca/media/36290/TWF-Economics-report-Eng-final-webmar7.pdf

10. House of Commons Health Committee. End of life care, fifth report of session 2014-15. Report, House of Commons, London, 2015, http://www.publications.parliament.uk/pa/cm201415/cmselect/cmhealth/805/805.pdf

11. Radbruch L and Payne S. White paper on standards and norms for hospice and palliative care in Europe: part 1. *Eur J Palliat Care* 2009; 16: 278–289.

12. Hallenbeck J. Palliative care training for the generalist a luxury or a necessity? *J Gen Intern Med* 2006; 21: 1005–1006.

13. Quill TE and Abernethy AP. Generalist plus specialist palliative care – creating a more sustainable model. *N Engl J Med* 2013; 368: 1173–1175.

14. Shipman C, Gysels M, White P, et al. Improving generalist end of life care: national consultation with practitioners, commissioners, academics, and service user groups. *BMJ* 2008; 337: a1720.

15. Corporation for National & Community Service. Volunteering and civic engagement in the United States. 2016, https://www.volunteeringinamerica.gov/national (accessed 26 April 2016).

16. Woodhouse J. The voluntary sector and the 'Big Society', http://www.parliament.uk/business/publications/research/briefing-papers/SN05883/the-voluntarysector-and-the-big-society (2013, accessed 25 April 2016).

17. Australian Government Department of Social Services. Community visitors scheme policy guide 2013-2016, https://agedcare.health.gov.au/ageing-and-aged-care-older-people-their-families-and-carers-community-visitors-scheme/community-visitors-scheme-policy-guide-2013-2016 (2014, accessed 26 April 2016).

18. Galea A, Naylor C, Buck D, et al. Volunteering in acute trusts in England: understanding the scale and impact. Report, The King's Fund, 2013, https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/volunteering-in-acute-trusts-in-england-kingsfund-nov13.pdf

19. Naylor C, Mundle C, Weaks L, et al. Volunteering in health and care: securing a sustainable future. Report, The King's

Fund, London, 2013, https://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/volunteering-in-health-and-social-care-kingsfund-mar13.pdf

20. Schulz R. Effects of control and predictability on the physical and psychological well-being of the institutionalized aged. *J Pers Soc Psychol* 1976; 33: 563.

21. Herbst-Damm KL and Kulik JA. Volunteer support, marital status, and the survival times of terminally ill patients. *Health Psychol* 2005; 24: 225.

22. Claxton-Oldfield S, Gosselin N, Schmidt-Chamberlain K, et al. A survey of family members' satisfaction with the services provided by hospice palliative care volunteers. *Am J Hosp Palliat Care* 2010; 27: 191–196.

23. Luijkx KG and Schols JM. Volunteers in palliative care make a difference. *J Palliat Care* 2009; 25: 30.

24. McGill A, Wares C and Huchcroft S. Patients' perceptions of a community volunteer support program. *Am J Hosp Palliat Care* 1990; 7: 43–45.

25. Weeks LE, Macquarrie C and Bryanton O. Hospice palliative care volunteers: a unique care link. *J Palliat Care* 2008; 24: 85–93.

26. Block EM, Casarett DJ, Spence C, et al. Association of hospice use of volunteers with bereaved family members overall rating of the quality of end of life care. *J Pain Symp Manag* 2010; 39: 502–506.

27. Claxton-Oldfield S, Hastings E and Claxton-Oldfield J. Nurses' perceptions of hospice palliative care volunteers. *Am J Hosp Palliat Care* 2008; 25: 169–178.

28. Karanikolos M, Mladovsky P, Cylus J, et al. Financial crisis, austerity, and health in Europe. *Lancet* 381: 1323–1331.

29. Burbeck R, Candy B, Low J, et al. Understanding the role of the volunteer in specialist palliative care: a systematic review and thematic synthesis of qualitative studies. *BMC Palliat Care* 2014; 13: 1–12.

30. Pesut B, Hooper B, Lehbauer S, et al. Promoting volunteer capacity in hospice palliative care: a narrative review. *Am J Hosp Palliat Care* 2014; 31: 69–78.

31. Candy B, France R, Low J, et al. Does involving volunteers in the provision of palliative care make a difference to patient and family wellbeing? A systematic review of quantitative and qualitative evidence. *Int J Nurs Stud* 2015; 52: 756–768.

32. World Health Organization. Palliative care for older people: better practices. Report, WHO Regional Office for Europe, World Health Organisation, Copenhagen, 2011, http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf

33. Saumure K. Data saturation. In: Given LM (ed.) *The SAGE encyclopedia of qualitative research methods*. Thousand Oaks, CA: SAGE, 2008, pp. 196–197.

34. Pulsford D, Jackson G, O'Brien T, et al. Classroom-based and distance learning education and training courses in end-of-life care for health and social care staff: a systematic review. *Palliat Med* 2013; 27: 221–235.

35. Selman L, Robinson V, Klass L, et al. Improving confidence and competence of healthcare professionals in end-of-life care: an evaluation of the 'Transforming End of Life Care' course at an acute hospital trust. *BMJ Support Palliat Care* 2016; 6: 231–236.

36. Braun V and Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101.

37. Seale C. Quality in qualitative research. *Qual Inq* 1999; 5: 465–478.

38. Armstrong D, Gosling A, Weinman J, et al. The place of inter-rater reliability in qualitative research: an empirical study. *Sociology* 1997; 31: 597–606.

39. Mays N and Pope C. Assessing quality in qualitative research. *BMJ* 2000; 320: 50.

40. QSR International Pty Ltd. *NVivo qualitative data analysis software, version 10*. QSR International Pty Ltd, 2012, http://www.qsrinternational.com/support/faqs/how-do-i-cite-nvivo-10-nvivo-9-or-nvivo-8-in-my-wo

41. Brown MV. The stresses of hospice volunteer work. *Am J Hosp Palliat Care* 2011; 28: 188–192.

42. Dein S and Abbas SQ. The stresses of volunteering in a hospice: a qualitative study. *Palliat Med* 2005; 19: 58–64.

43. Deodhar JK and Muckaden MA. Continuing professional development for volunteers working in palliative care in a tertiary care cancer institute in India: a cross-sectional observational study of educational needs. *Indian J Palliat Care* 2015; 21: 158.

44. Wee B, Coleman P, Hillier R, et al. Death rattle: its impact on staff and volunteers in palliative care. *Palliat Med* 2008; 22: 173–176.

45. Claxton-Oldfield S, Crain M and Claxton-Oldfield J. Death anxiety and death competency: the impact of a palliative care volunteer training program. *Am J Hosp Palliat Care* 2007; 23: 464–468.

46. Brock CM and Herndon CM. A survey of hospice volunteer coordinators: training methods and objectives of current hospice volunteer training programs. *Am J Hosp Palliat Care*. Epub ahead of print 12 January 2016. DOI: 1049909115625961.

47. Pepper JR, Jaggar SI, Mason MJ, et al. Schwartz Rounds: reviving compassion in modern healthcare. *J R Soc Med* 2012; 105: 94–95.

48. Goodrich J. Supporting hospital staff to provide compassionate care: do Schwartz Center Rounds work in English hospitals? *J R Soc Med* 2012; 105: 117–122.

49. Lown BA and Manning CF. The Schwartz Center Rounds: evaluation of an interdisciplinary approach to enhancing patient-centered communication, teamwork, and provider support. *Acad Med* 2010; 85: 1073–1081.

50. National Nursing Research Unit. *Does NHS staff wellbeing affect patient experience of care?* Policy plus evidence, issues and opinions in healthcare, 2013, https://www.kcl.ac.uk/nursing/research/nnru/policy/Currentissue/Policy-Plus–Issue-39.pdf

51. Cimiotti JP, Aiken LH, Sloane DM, et al. Nurse staffing, burnout, and health care-associated infection. *Am J Infect Control* 2012; 40: 486–490.

52. Poghosyan L, Clarke SP, Finlayson M, et al. Nurse burnout and quality of care: cross-national investigation in six countries. *Res Nurs Health* 2010; 33: 288–298.

53. Ramirez AJ, Graham J, Richards MA, et al. Mental health of hospital consultants: the effects of stress and satisfaction at work. *Lancet* 1996; 347: 724–728.

54. Department of Health. Delivering high quality, effective, compassionate care: developing the right people with the right skills and the right values, http://hee.nhs.uk/wp-content/uploads/sites/321/2013/05/29257_2900971_

Delivering_Accessible.pdf (2014, accessed 26 April 2016).

55. Neuberger J, Gutherie C, Aaronovitch D, et al. More care, less pathway: a review of the Liverpool Care Pathway. Report, Department of Health, London, 2013, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf

56. Canadian Hospice Palliative Care Association. Synthesis of recommendations from national reports on hospice and palliative care. Report, Canada, 2012, http://www.hpcintegration.ca/media/36246/TWF-Macdonald-report-Eng-feb2013.pdf

57. Department of Health. End of life care strategy – promoting high quality care for all adults at the end of life. Report, Department of Health, London, 2008, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf

58. Sanon M, Baumlin KM, Kaplan SS, et al. Care and respect for elders in emergencies program: a preliminary report of a volunteer approach to enhance care in the emergency department. *J Am Geriatr Soc* 2014; 62: 365–370.

59. Germain A, Nolan K, Doyle R, et al. The use of reflective diaries in end of life training programmes: a study exploring the impact of self-reflection on the participants in a volunteer training programme. *BMC Palliat Care* 2016; 15: 1–11.

Appendix 1

Focus group topic guide

Introduction

- In your role as a volunteer, how often do you work with people with serious, life-threatening illness and their families? *Prompt: Is this frequent/infrequent, challenging/not challenging?*
- We understand that you all receive training when you become a volunteer. What did you think of this training? *Prompt: Did it prepare you for your role? Is there anything it did not prepare you for?*

Training needs [refer participants to topic list handout (Appendix 2)]

- Are there any topics that you feel would be particularly helpful in an end-of-life care training course for hospital volunteers? Why?
- Are there any topics that you feel would not be helpful or relevant to you? Why not?
- Are there topics we haven't mentioned that you think should be included in an end-of-life care training course for volunteers? Why do you think this would be helpful/is important?

Preferred course format/time/delivery

- How long do you think a course should be? *Prompts: Would you prefer shorter sessions over multiple days or fewer longer sessions? Minimum or maximum length?*
- When should it be held? *Prompt: Are particular times of day best?*
- Who should attend? *Prompt: Would you prefer a course attended by hospital volunteers only or by other groups of people, for example, non-hospital volunteers, staff members?*
- Who do you think the course should be taught by? *Prompt: Hospital/community palliative care staff? Other volunteers?*
- How should it be taught? *Prompt: In-person versus online, as lectures versus interactive skills training. What about a mixture of in-person and online resources?*
- Where should it be held? *Prompt: At the hospital where you volunteer? Local to the hospital but not necessarily the hospital itself? At a hospice?*

Mentoring/ongoing supervision techniques

- Do you think that ongoing mentoring or supervision would be useful alongside an end-of-life care training course? *Prompts: If yes, what do you think would be the best way to provide this (e.g. in person supervision sessions, booster training session after a particular time period, online support from senior staff member, online peer support from other volunteers). What are your views of mentoring by an expert by experience, that is, patient/family member? If you don't think mentoring/supervision would be helpful/appropriate, why not?*

Training effectiveness assessment

- How would you feel about us assessing the effectiveness of the training course by …
  - … videoing or audio-recording your encounters with patients or families?
  - … using patient or family satisfaction measures?
  - … using 360° appraisals from colleagues, managers, patients and family members?
- *Prompts: Are any of these methods particularly preferable or not preferable? Why?*

Appendix 2

End-of-life care training topic prompt list

- Understanding patients/families priorities in end-of-life care (EoLC);
- Dealing with death and dying (volunteer self-care, coping and resilience);

- Understanding common symptoms in dying patients;
- Understanding spiritual, cultural and environmental aspects of dying;
- Having difficult conversations with patients and families;
- Advanced communication and listening skills;
- Understanding grief and providing support for family experiencing bereavement;
- Resources available for patients/family support;
- Managing uncertainty;
- Volunteer role and boundaries;
- When to seek assistance and who to go to.