Hospice volunteers: bridging the gap to the community?

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What is known about this topic

- Volunteers play a key part in the functioning of hospices and other end-of-life care organisations.
- Volunteering is changing.
- Most research about volunteers in end-of-life care has focused on the individual volunteer.

What this paper adds

- The cultural history of the hospice movement remains a driving force in England, with hospices conceptualised as discrete entities.
- Volunteers provide a degree of community engagement, but in an informal and ad hoc manner.
- Management could harness the closeness of volunteers to the community to promote more robust and inclusive community links.

Abstract

Current demographic, policy and management changes are a challenge to hospices to develop their volunteering practices. The study upon which this paper is based aimed to explore good practice in volunteer involvement and identify ways of improving care through developing volunteering. The project consisted of a narrative literature review; a survey of volunteer managers; and organisational case studies selected through purposive diversity sampling criteria. A total of 205 staff, volunteers, patients and relatives were interviewed across 11 sites in England in 2012. This article focuses on one of the findings – the place that volunteers occupy between the hospice and the community beyond its walls. External changes and pressures in society were impacting on volunteer management, but were viewed as requiring a careful balancing act to retain the 'spirit' of the hospice philosophy. Honouring the developmental history of the hospice was vital to many respondents, but viewed less positively by those who wished to modernise. Hospices tend to be somewhat secluded organisations in Britain, and external links and networks were mostly within the end-of-life care arena, with few referring to the wider volunteering and community fields. Volunteers were seen as an informal and symbolic 'link' to the local community, both in terms of their 'normalising' roles in the hospice and as providing a two-way flow of information with the external environment where knowledge of hospice activities remains poor. The diversity of the community is not fully represented among hospice volunteers. A few hospices had deliberately tried to forge stronger interfaces with their localities, but these ventures were often controversial. The evidence suggests that there is substantial scope for hospices to develop the strategic aspects of volunteering through greater community engagement and involvement and by increasing diversity and exploiting volunteers' 'boundary' position more systematically to educate, recruit and raise awareness.

Keywords: community engagement, end-of-life care, hospice, inclusion, volunteering

Introduction

The face of volunteering is changing. Innovative schemes are being developed and there are indications of shifting patterns in the nature and extent of volunteering and higher expectations from volunteers for appropriate support (Barron 2008, Brewis *et al.* 2010, National Council for Voluntary Organisations

UK Civil Society Almanac 2013). During the past decade, there have been well-documented trends towards increased professionalisation and formalisation of volunteer management (Howlett 2010, Hill & Stevens 2011). Policy focus has grown substantially during the same time, especially within public service delivery (Hardill & Baines 2011, Rochester 2013). In addition, Horton Smith (2013) provided evidence that

academic interest in studying volunteerism has grown since the 1970s. With increasing financial and demographic pressures, volunteerism in healthcare has become attractive to western policy makers. In the UK, the Department of Health (2011, p. 6) expresses an aim to 'nurture and release the capability, capacity and assets that exist within our communities'. Mundle *et al.* (2012) note that, from a societal perspective, volunteering has the potential to create services that are more responsive to local needs, engage seldom-heard communities, fill gaps and maybe even reduce the need for funded services.

Volunteerism has long been rooted in the hospice sector. Since its inception in the 1960s, the modern hospice movement has relied heavily on volunteers to help achieve its vision (Field & Johnson 1993). In England, local fund-raising was vital in establishing local services, usually in purpose-built hospice buildings. To this day, Independent Hospices remain located in these discrete buildings and account for the majority of hospice provision in England. Volunteers perform valuable roles in all aspects of their functioning, from ongoing fund-raising to the direct care of patients and their families. As Poulter et al. (2011 p. 25), wrote, 'the hospice movement is one of the UK's most successful models of community-led care and has developed ground-breaking services throughout its history'. However, despite their success, hospices are facing increasing social, economic, demographic and political demands in the 21st century, and the need for charity and volunteer action is likely to intensify. The Commission into the Future of Hospice Care (2013, p. 14) noted that hospices benefit hugely from their relationship with local volunteers, and that by being engaged with the hospice, communities can 'become increasingly informed, capable and confident in helping those who are living with serious life-shortening conditions'. While there is evidence that community engagement initiatives are of interest to hospices (Paul & Sallnow 2013), the historical relationships that hospices share with their communities may need to be re-appraised to consider how best to address changes in both society and in volunteering.

Purpose/aim

Within this context of change, a team from the International Observatory on End of Life Care and the Institute for Volunteering Research have been researching volunteering in British hospices. The project examined volunteer management in end-of-life care (EOLC), with a specific focus on the challenges of involving volunteers. It used a case study methodology with 11

English hospices, and 205 people – volunteers, staff and patients and their families – were interviewed about their experiences. This article focuses on one of the findings – the place that volunteers occupy between the hospice and the community beyond its walls. The presence of volunteers can both bring the community into the hospice and take the hospice out into the community, but this usually occurs in an ad hoc way. It may be possible and desirable to harness this volunteer link with the community to educate, increase diversity, improve recruitment and to address the social positioning of hospice care.

Literature

Research into EOLC volunteering has generally focused on individual volunteers - their motivations, characteristics, coping, value and impact - and on organisational factors - volunteer roles, recruitment, support, training and the volunteers' place in the organisational system (Wilson et al. 2005, Morris et al. 2013). Modern EOLC volunteering is not homogeneous; it has grown up within geographical, political, cultural and economic constraints and varies considerably in different settings. For example, in England, volunteering usually centres around the hospice building (Davis Smith 2004), while in Canada and the USA, volunteers mostly operate within the patient's home. In low-income countries and remote settings, there is evidence of volunteer programmes that employ a community model to deliver a wide range of services (Decourtney et al. 2003, Gorospe & Bausa 2006, Fernandes et al. 2010). A study in Uganda by Jack et al. (2011) found that outreach 'deep into villages' was a vital aspect of the community volunteer role and provided a 'bridge to the hospice'. The theme of 'role boundaries' frequently figures, but tends to focus on the individual volunteer and the unique position that allows them to perform overlapping roles, such as friend, advocate, go-between and the issues that may arise from these (Payne 2001, Low et al. 2005, McKee et al. 2007, Berry & Planalp 2008, Weeks et al. 2008, Savery & Egbert 2010, Sevigny et al. 2010). However, very few studies specifically examine volunteering within and related to the wider community, although a recent article by Sallnow and Paul (2015) attempts to unpick and define the principles underlying community engagement in EOLC care.

In health and social care, volunteers are part of the 'mixed economy of care', alongside the formal, paid work of the statutory and independent sectors and the informal care offered by family and friends (Hoad 2002). Naylor *et al.* (2013) noted that defining

'volunteering' in this field is not without its challenges, but summarised formal volunteering as: 'unpaid work that benefits others to whom one owes no obligation via an organisation that supports volunteering in health and social care'. McKee et al. (2010, p. 103) wrote that EOLC volunteers inhabit a 'unique third culture of care that fuses elements of formal care with the informal visiting of friends and neighbours'. This appears to be particularly true for rural and small communities where volunteers are drawn from the locality. It has been argued that the social value of informal and formal volunteering differs in that informal volunteering 'bonds' social capital (i.e. creates social groups within society), whereas formal volunteering tends to 'bridge' social capital (i.e. creating societal social capital) (Egerton & Mullan 2008). Volunteers in EOLC services are often seen as having social proximity to the people who use services and thus may be an important factor in creating societal 'capital' by embedding services in the community (Hill et al. 2014).

Mundle et al. (2012) argued that involving volunteers in the delivery and design of services can help create powerful bonds with the local community. Drawing on available evidence, they suggested that volunteers can help to bridge gaps between services and patients/communities, open up channels for community knowledge to be fed back into strategic planning and service delivery, and facilitate greater patient engagement in local health services. Specifically in EOLC, volunteers can contribute to the creation of social bonds that foster a more humane and cohesive community around terminally ill patients (Sevigny et al. 2010). However, there are indications in the literature that there is a lack of diversity among people who use EOLC services (Evans et al. 2011) and also among EOLC volunteers. In England, for example, EOLC volunteers are neither representative of the British population nor the population of those who volunteer (Davis Smith 2004). Reese et al. (2004) suggested that having a more diverse set of volunteers can lead to a more diverse population of service users.

In England, the majority of hospices have developed alongside the NHS, but remain largely independent in terms of funding and management. It has been argued that one function they perform is to sequester 'the taboo processes of bodily deformation and decay' and thus reinforce contemporary western cultural values of individualism and self-containment (Lawton 1998, p. 121). They are places 'away from the world', where the individualism characteristic of western society extends into dying, with choice, control and self-determination the expected hallmarks of the 'good

death' (Seale 1995, Field 1996). Hence, hospices can have an ambivalent relationship with the 'community' from which they have arisen, both part of it, but also hidden. Recent calls for more openness have resulted in initiatives, such as 'Dying Matters', that aim to tackle taboos about death and dying (National Council for Palliative Care 2011). As noted, volunteers occupy a 'boundary' position in hospices, between patients and staff, but they are also placed between the hospice and the community and offer a link to the outside world. This article asks whether and how they provide such a link, and considers whether volunteers could be involved in supporting a wider dialogue about EOLC.

Methods

This research employed a mixed methodology, including a survey, organisational case studies and deliberative workshops. These methods have been used in EOLC studies and are recommended in 'real world' research where randomised controlled study designs are not feasible (Ritchie *et al.* 2003). The research took place in 2011–2013 in English EOLC organisations. An advisory group of experts in both volunteering and hospice care supported the research.

Phase 1 – online survey

An online survey was disseminated to all British hospices to collect information on current and planned volunteer involvement (n = 191 of 290 UK adult palliative care organisations that involve volunteers, 67% response rate). Volunteer roles, examples of good practice and the challenges facing the management of volunteers were explored and are reported elsewhere (Burbeck *et al.* 2014). The survey results, along with a literature review (Morris *et al.* 2013), helped inform the sampling matrix for the selection of case studies in phase 2 of the research and in the development of data collection areas of interest.

Phase 2 – case studies

Eleven EOLC organisations in England were purposively selected as in-depth case studies to ensure a variety of organisational and service settings in which volunteers are involved. Each case study used a variety of methods, including in-depth interviews, focus groups, non-participant observation and the collection of documentary data. Participants were recruited with the help of a link person in each organisation and drawn from the following adult groups: mem-

bers of staff, volunteers and patients or relatives of patients. The study gained ethical approval from the NHS National Research Ethics Service (11/NW/0630). All participants provided formal written consent with our researchers prior to taking part.

The analysis of the organisational case studies was informed by Yin's (2003) approach, transcribed and entered into a qualitative data analysis package (QSR NVivo 10). Further analysis involved cross-case comparisons to identify thematic factors associated with the challenges and successes of engaging volunteers. Each case study was written up as a single report and made available to the participating organisation for comment. Our previous research into hospice bereavement services demonstrated that this is a strong inducement to participate and is highly valued (Payne et al. 2007). Following the analysis, we conducted two deliberative workshops with selected participants from each case study site to refine and explore the practical relevance, feasibility and possible implications of the findings.

Findings

The case studies consisted of 205 interviews over 11 case study sites in the North West and South East of England, with 14–24 interviews at each site. All the interviews took place in 2012. Table 1, Boxes 1 and 2 provide an overview of the interviewee characteristics and roles.

The interviewees had an age range of 21–88 (age data were missing for 20 of the sample), with an overall average of 60 years. The average age of staff was 50, that of volunteers and family carers was 62 and 63 respectively, with patients' average age slightly older at 67 years. The time that participants had been involved with the hospice ranged from 2 months to 23 years.

The project explored all aspects of volunteer management. One of our coding framework themes was: 'relationship with the external environment', and it is the results from this strand of the work that we concentrate on in this article. In our initial survey of hos-

Table 1 Gender of the sample

	Staff	Volunteers	Patients	Carers/ relatives	All sample
Male	14	22	13	2	50
Female	58	74	16	12	155
Total	72	96	29	14	205

Six people in the sample had dual roles, e.g. carer and volunteer.

Box 1 Roles of the interviewed members of staff

Volunteer manager/co-ordinator	10
Chief executive officer	8
Medical director/doctor	4
Other manager	14
Nursing	15
Administration	3
Supportive services (counselling, bereavement, creative, complementary, family support)	13
Chaplain	2
Chef	1
Social worker	1
Research fellow	1
Total	72

Box 2 Roles of the interviewed volunteers

Day care unit	32	
Supportive services (counselling, creative/psychological or		
complementary therapies, family support)		
Inpatient unit	14	
Bereavement services	12	
Reception and administration	8	
Driver	7	
Chaplain	1	
Total	96	

pices, 28% of respondents cited volunteer impacts related to community issues. These included contributing to the community atmosphere within the hospice, helping promote the services of the hospice within the community and acting as ambassadors for fund-raising within the community. More detailed responses in the case studies echoed and expanded on these issues. Most discussion of the theme occurred when we asked about changes, both recent and planned, and also about volunteers and the community. It was mainly staff who talked about this theme, especially volunteer managers and chief executives, but volunteers also mentioned aspects of the hospice's links to the external environment.

One of our participants (bs5) provided a useful way of summarising the theme of hospice and community in the phrases 'bring[ing] the community into the building' and 'taking the hospice out into the community', highlighting the two-way nature of the relationship between the hospice and its environment. The idea that there was an 'inside' and the community was 'outside' was constituted in these phrases, reiterating the notion of English hospices as secluded places apart from mainstream life. The processes by which the world outside the hospice grounds affected volunteer activities within, and the ways the hospice was taken out into the community by volunteers are explored in the analysis that follows.

Bringing the community into the building

Making it a more professional service

The wider healthcare community and the world of volunteering, as well as societal pressures, impinged on the hospices we studied. Wider societal changes, such as economic pressures and demographic fluctuations, affect the flow of volunteers and their characteristics. Changes to the National Health Service and other governmental policies in England were seen as impacting on volunteering, and potentially 'distorting and abusing' the basis of volunteering (bs1) through a demand for professionalisation of the service and the volunteers within it. The 'volunteer' journey was affected and the management of volunteers was changing. Fears were expressed regarding the danger that over-formalisation would not only deter some volunteers but also stifle the distinctive contribution and unique position of volunteers within palliative care services. Accommodating changing times and requirements was often described as something of a balancing act, where national policy guidance had to be followed while retaining the 'spirit' of the hospice movement and charitable funding. Volunteers were perceived as highly relevant to the future and as 'strategic' in maintaining the original hospice philosophy in this context. The history and autonomy of the hospice were evoked within the context of national directives and charitable status, but there were differing opinions on the value of the professionalising changes:

We have to be seen to be spending that money wisely, quite rightly. I think back to the things we used to do and it's almost comical..., but you were left to your devices more before, which wasn't to say that we weren't doing things properly. (sj05)

Just because it's been long-term practice, doesn't necessarily make it right. (srs6)

The ancient model

Typically, hospices had mostly been set up through local fund-raising efforts, most usually led by volunteers. The history and future of the organisation and hospice movement were linked through reference to the importance of volunteers.

Historically, independent hospices have relied heavily upon volunteers; indeed, we could not survive without our team and as the services at [hospice] continue to evolve, the volunteer role will continue to develop alongside that of the paid staff. (Volunteer handbook bp)

It seemed clear from many comments that the history and 'roots' of the hospice continued to be a strong point of reference. This could be interpreted in

both positive and negative terms. For some it was the 'ancient model' (bs4) of caring for strangers that defined the uniqueness of hospices, while others experienced it as a limitation that hindered change and more modern practices. The public perception of the hospice 'myth' involved volunteers and 'how it couldn't change' (cs25).

One respondent described with a sense of nostalgia how her grandmother had volunteered by just coming in to sit with patients or:

...make cake and bring it in. You can't do that now, it's all CRB checks and signing a form to say you've made a cake. (iv8)

Talk about changes was frequently imbued with a sense of loss, particularly by volunteers:

We're a business now: we were a family. And that's my opinion, and a lot of the older volunteers feel the same. (bpv6)

Yet, it was also clear that the informal arrangements that had held sway in the past were no longer sustainable, and staff tended to be much more positive about increasing attention to safety and regulation with regard to volunteers. There was evidence that the strategic response of the organisation and new people in management positions could impact strongly on volunteering arrangements.

Bringing the world in

The day-to-day activities of the hospice volunteers provided value in many ways. A repeated theme was the way that volunteers could bring the 'normality' of the outside into the hospice:

But they also bring the community into the building and I think that's perhaps important for patients. They bring normality, they bring a change of conversation away from the focus on the illness. (bs5)

In addition, volunteers were perceived as involved in the flow of information from the local community into the hospice:

Our Chairman is a great believer in the volunteers. He listens to them, when he's walking his dog round – because we're very parochial [...] and he comes back with loads of information for me. 'Has So-and-so told you this?' and 'Has So-and-so told you that?' Everybody's got an opinion and it's great. (ros5)

However, there were perceptible challenges with regard to the kind of outside world that volunteers were bringing in. The issue of diversity was raised and frequently acknowledged as somewhat lacking among volunteers in terms of age, gender and ethnicity, although some hospices were now doing more outreach with schools, care homes and 'a whole variety of local churches of all faiths and all kinds of persuasion' (cs1). There was also some indication of a greater acceptance of diverse volunteers:

The majority of our volunteers from ethnic minorities are youngsters, which is interesting [...] But I feel differently now than I did 5 or 6 years ago. I think we do have a more diverse group of volunteers and I do think staff welcome diversity. (bs4)

Volunteers were seen by staff as a conduit to the outside world, but volunteers were often more attached to the 'old ways' and found change difficult. For example, several of our case sites had made the decision to forge a stronger interface with the locality, either in the form of a physical space, such as a cafe open to the public, or providing a venue for business and other meetings, somewhere the community could use 'to support the hospice' (us2) and enter it. Volunteers were perceived by some staff as 'unwelcoming' and epitomising the closed face of the hospice. The symbolic value of opening up the hospice to the public could be an enormous change, both structurally and in terms of mindset:

There was something about the physicality of it that opened up possibility in other ways. (cs7)

Taking the hospice out into the community

Services in the community

In terms of expanding or maintaining services, especially ones that reached out into the community from the hospice building, the pressures of regulation and funding were often uppermost in respondents' minds. Several hospices had, or were about to start, a type of hospice at home. It was clear that developing a service in the community had its anxieties and resource implications, with much planning and careful thought involved. Most hospices that had developed these community services only sent employed staff into people's homes. However, several were considering expanding the service to include volunteers in the future, if they could organise it safely:

The questions in our heads are: what are all the systems and structures and legal obligations and liabilities and insurance and protection for patients and families and the volunteers? What do you need to put in place before you can allow a volunteer into somebody's home? (bps1)

Where non-clinical befriending schemes involving volunteers had been developed, the importance of training and supervision was highlighted, with associated time and cost implications. In one instance, a hospice had secured a grant to set up the service, but

was reliant on the extra commitment of paid staff to manage and sustain it. These schemes were often attractive to the NHS Commissioners as a way of preventing avoidable hospital admissions. Some respondents saw the need for such services as a sign of the times, but were regretful, echoing other concerns about the passing of a more informal time in hospice care and the community:

It's a sad scheme to me – they view it as a hospice neighbour scheme. [...] And it's the sort of stuff that, a generation ago, you'd have expected your neighbours to do. (us2)

Some outreach volunteer innovations were linked to funders and other hospices and charities, such as an aim to develop a 'volunteer bureau - a bit like a volunteer jobcentre kind of thing, but having processes in place that other hospices can potentially tap into' (ps1) or a 'volunteer handyman bank' (sc1). But there was little evidence of links across hospices, and all our case studies operated as individual entities with few collegiate mechanisms. Several respondents also talked about networking, learning and sharing with the wider community of palliative care. A sense of isolation was felt by some volunteer managers who sought out links with those in a similar role. Several volunteer managers attended two deliberative workshops related to this study, and on the feedback forms, the opportunity to meet with colleagues and discuss was widely valued. It was also notable that any links and networks that were cited related to hospices and palliative care; we found little evidence of links with more general volunteering organisations.

Getting that message across

Hospices usually serve a local prescribed community and are embedded in it through their history, fundraising and services. Yet, hospices tend to be set apart and the general public often have poor knowledge of their location or activities unless they have been directly involved with a patient:

A friend of mine died here unfortunately and a lot of my group came to see him and a lot of them didn't realise that hospices are charities, and I thought that was quite shocking. (rov3)

In the interviews, there were many comments about the importance of volunteers in linking out into the community, both in a philosophical sense and a practical way of giving information and promoting fund-raising. Some hospices had 'Friends groups' that fund-raised and got the 'message across of how important it is to do your bit for the community' (bps6). It was suggested by some that 'using'

volunteers 'gives the wider community a foothold or a sense of ownership or commitment to or support' (ps3).

Volunteers were often described as vital in informally spreading the word in the local community. Terms that were used of volunteers included 'ambassadors', the 'public face of the hospice', 'informal marketers', 'face on the street' and 'spokespeople'. They were seen as having an impact on fund-raising, recruitment of volunteers and the hospice's reputation by staff:

They bring a really positive reflection into the hospice and I think that reflects outwards as well because they're our marketing people really in lot of ways. (srs6)

Many of the volunteers spoke about correcting people on the outside about the hospice, which was widely assumed to be a place where you 'go to die' and a difficult and sad place to work:

I tell everybody that it's the happiest place. (bvc5)

However, the question of representing the hospice caused some anxiety among staff, due to its informal and unspoken nature, despite guidelines and volunteer handbooks. While it was expected that volunteers would promote and defend the hospice, concern was expressed over the lack of control management had regarding volunteer utterances and their understanding of what was appropriate publically.

You can't always control the message. [...] We just have to hope that we give them enough information about what we do in the right way, that they don't ever say the wrong thing. (bs1)

Discussion

Hospices in England have a singular history and are usually located as discrete physical entities, situated outside the formal healthcare system. Arising from local fund-raising, hospices have their base in the local community, but remain somewhat 'hidden' from the general public (Mellor & Schilling 1993). This paradoxical boundary position was visible in our data, as participants talked of the challenges of interfacing with the national healthcare context, the hospice movement and other hospices, and the local community. The tensions generated were highly relevant to volunteers within these hospices (The Commission into the Future of Hospice Care 2013).

Within the context of the national healthcare system and related to a general move towards revising and expanding volunteerism, driven by policy makers and a changing economic climate, hospices, along with other voluntary sector organisations, are being

challenged to modernise their practices and expand their services. However, hospices provide an example of volunteering caught between the informality of their roots and the increasing formalisation of the current climate. As Howlett (2010, p. 357) indicated, there are 'distinctive challenges involved [in managing] the variety of circumstances under which volunteering takes place'. Rochester et al. (2009) suggested that the model operating within hospices and palliative care is characterised by structured processes and hierarchical systems where volunteers work alongside paid staff in very clearly defined roles. This approach often evolves because of the legislative and regulatory framework that surrounds the field of work. This was apparent in our study with the increasing professionalisation of volunteer management, and discussion on costs and pressures to expand services into the community across all our case sites. However, a few of our case studies were moving beyond this into developing a more professionalised volunteer management system and providing specialised training for volunteers. This new model is closer to the 'corporatist' model indicated by Fyfe and Milligan (2003), where welfare is delivered by a professionalised workforce of paid staff and highly trained volunteers. However, the authors are critical of this model in terms of its failure to encourage active citizenship and for lessening the opportunities for 'interaction with clients and communities' (Fyfe & Milligan 2003, p. 2071).

The current dilemma for British hospices in terms of their volunteer force revolves around change – moving from the 'ancient model', where informal caring is paramount and a sense of 'family' is created, to a more innovative use of volunteers. A general move to greater regulation of volunteers was evident in all sites, and where more radical, and often contested, change was taking place, there was a drive to 'professionalise' the volunteers. The boundary position of volunteers as an interface with the local community was one which sometimes caused anxiety to management, but was valued as the face of 'normality' in the hospice. However, although volunteers were perceived as representatives and ambassadors, these roles were not exploited in a systematic way to bring the hospice closer to the community. For example, diversity among volunteers tends not to reflect the diversity in the community they serve. Except in a few cases, this was a neglected issue in our case studies, despite recommendations that EOLC organisations should provide leadership to encourage diversity (Reese et al. 2004).

Alongside increasing regulation, the national policy context also encourages a greater emphasis on openness, with members of the public increasingly

involved in healthcare service decisions and research. While British hospices have their roots in community action and fund-raising, ongoing community engagement in the development of hospices was rare, perhaps in part due to the tradition of community 'elders' among trustees (Turner & Payne 2008). Volunteers were consulted in some hospices, particularly around changes, but there were few formal attempts to reach into the community more widely and acquire their input. The Commission into the Future of Hospice Care points out that engagement is 'more than fundraising and the use of volunteers; it is also about asking people in the community to work with the hospice to influence future services' (The Commission into the Future of Hospice Care 2013, p. 47). In our study, staff believed that volunteers provided an informal educative role in the community, both with regard to de-stigmatising hospice connotations, and in terms of promotion and reinforcing the hospice reputation locally. Mundle et al.'s (2012) suggestion that volunteers can act as a 'bridge' between services and communities is borne out by our data, but only in a limited way and with ambiguity about the role of volunteers in representing the hospice to the community.

Sallnow and Paul (2015) defined community involvement as a spectrum ranging from informing to empowering, depending on the tenor of the dialogue between the community and the organisation. At a simple level, hospice engagement with community could build capacity and address issues to improve the experience of end-of-life and bereavement. Our research revealed widely held perceptions among our participants that volunteers were closer to the 'people' and that they held a symbolic value that linked the hospice to both the community and the cultural history of the hospice movement. However, this history has tended not to be fully inclusive and the lack of diversity among volunteers is reflective of a more general issue that has been recognised in the hospice movement (The Commission into the Future of Hospice Care 2013). This also links to the way that hospices have developed a more 'corporatist' model of volunteering, where volunteers are seen as involved in service delivery, rather than as community representatives.

McCurley *et al.* (2012) suggested that few organisations really make the most of their volunteers. Most British hospices grew up through the dedication of local volunteers, but only some hospices have begun to use their resources to change the way volunteering happens and few have made steps towards a community engagement strategy. The decision to invest in these activities may be difficult in the current economic

climate and with policy pressure to deliver services that reduce state hospital usage. In our study, volunteers were generally seen as a link to the community, but in an ad hoc, individualistic way. Yet, the advantages of a targeted engagement strategy have the potential to create services that are more responsive to local needs, engage seldom-heard communities, fill gaps and potentially reduce the need for funded services (Mundle et al. 2012). Furthermore, an engagement strategy involving volunteers could have an impact on the organisation, including improved access from under-represented groups, more appropriate use of services and better links with other community organisations, thus addressing issues of isolation. In addition, there can be a benefit for the community in building social capital and community knowledge and increasing skill, capacity and resilience (Scott 2014).

Volunteers have always been vital to the existence of hospices and it is important that they remain so (Help the Hospices Commission into the Future of Hospice Care 2012). Their 'boundary' position between the hospice and the community is one which offers the potential for closer community engagement, but has not been carefully exploited by British hospices. This seems to be partly due to the unique history of hospices and the sensitive, sometimes taboo, nature of their activities, as well as some reluctance to change. In the current context, hospices are beginning to consider issues such as diversity, openness, transparency and engagement. Scott (2014, p. 11), writing for hospice organisations, describes volunteering as 'a significant strategic organisational asset' which 'requires effective consideration, planning and resourcing'. The findings of our study support this view as well as suggesting that it is the position on volunteers between the hospice and the community that could prove particularly valuable in developing an open dialogue and shared sense of purpose with the community.

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Conflict of interest

The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

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