

A narrative literature review of the contribution of volunteers in end-of-life care services

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Abstract

Background: Volunteers are integral to the history of hospices and continue to play a vital role. However, economic, policy and demographic challenges in the twenty-first century raise questions about how best to manage this essential resource.

Aim: This narrative review explores the recent literature on end-of-life care volunteering and reflects upon the issues pertinent to current organisational challenges and opportunities.

Design: The parameters of the review were set deliberately wide in order to capture some of the nuances of contemporary volunteer practices. Articles reporting on research or evaluation of adult end-of-life care services (excluding prison services) that use volunteers and were published in English between 2000 and 2011 were included.

Data sources: Seven electronic databases, key journals and grey literature databases.

Results: Sixty-eight articles were included in the analysis. The articles were drawn from an international literature, while acknowledging that volunteer roles vary considerably by organisation and/or by country and over time. The majority of articles were small in scale and diverse in methodology, but the same topics repeatedly emerged from both the qualitative and quantitative data. The themes identified were individual volunteer factors (motivation, characteristics of volunteers, stress and coping, role boundaries and value) and organisational factors (recruiting for diversity, support and training and volunteers' place in the system).

Conclusions: The tensions involved in negotiating the boundary spaces that volunteers inhabit, informality and regulation, diversity issues and the cultural specificity of community models, are suggested as topics that merit further research and could contribute to the continuing development of the volunteer workforce.

Keywords

End-of-life care, hospice care, narrative review, palliative care, volunteers

Background

Hospices and specialist palliative care services (SPCS) are facing the twin pressures of increased demand and declining volunteer applicant numbers for volunteer involvement. While volunteers are integral to the history of hospices and continue to play a vital role,^{1,2} the economic, political and demographic challenges of the twenty-first century raise questions about how best to manage this essential resource.

The purpose of this article is to review the recent literature in light of these issues and to identify challenges and existing good practice.

Demand for end-of-life (EOL) care is growing at the same time as reductions in overall resources are taking place. The demographics of death in relation to the age profile of the population, cause of death and place of death

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have changed radically over the course of the past century. For example, in England and Wales, the annual numbers of deaths are expected to rise by 17% from 2012 to 2030,³ and the majority of deaths in developed countries at the start of the twenty-first century follow a period of chronic illness.⁴ Government policy is also driving a higher demand for specialist EOL care services. The 10-year EOL care strategy for England states that 'hospices will continue to have a pivotal role'.⁴ Across Europe, there are agreed standards that acknowledge the contribution of volunteers to maintain hospice and palliative care services.⁵

With the global economic downturn, government funding for SPCS and hospices is likely to be negatively affected. Indeed, in 2010, the UK National Health Service (NHS) is already limiting funding to a large number of hospices,⁶ and a sense of 'urgency imposed by the current financial position' is discussed in the report of the United Kingdom's EOL care strategy.⁴ The charitable sector is also affected; falls in charitable donations have been reported in the United States and United Kingdom.⁷ Similar economic pressures have been reported in a number of countries, including Canada.⁸ In addition, an ageing workforce in the hospice sector looks likely to cause recruitment and training problems in the future.⁹ Strategies for improving the cost-effectiveness of services may be essential in the coming years, as demographic changes, health-care reforms and policy pressures combine with the economic slowdown.

The early twenty-first century is a time when the changing context of EOL care is meeting the shifting needs and aspirations of volunteers. At the same time, as EOL care services are going through changes, so is volunteering more generally, with higher expectations on the part of volunteers for appropriate support.¹⁰ The supply of volunteers is declining as a result of wider changes in gender roles and female employment patterns, as women are working longer due to economic pressures, reduced pensions and later retirement age.¹¹ As women are more likely to volunteer in EOL care,² this is likely to have an impact. In addition, new volunteering opportunities are opening due to policies that encourage volunteering, such as the 'Big Society' in the United Kingdom, which aim to encourage people to play a more active part in society.¹²

The situation is further complicated by the fact that EOL care volunteer roles vary considerably by organisation and/or by country and over time. It is delivered throughout the world in a wide range of settings, such as purpose built hospices, people's homes, the wards of a hospital, day-care units and nursing homes.⁵ Different countries have different general models of delivery, which have grown up over time and in relation to the context and culture of that society and are subject to change as the context within which they operate shifts and changes.¹³ Historically, there have been restrictions on what hospice volunteers can do in direct patient care, which is related not only to risk management issues but also to traditional practices.¹⁴ So, while it is

estimated that 90,000 volunteers are active in hospices in the United Kingdom,¹⁵ the majority work in hospice shops and in fundraising and others provide support to the running of hospices. Few volunteers provide direct patient care, and those who do are mainly in bereavement or complementary therapy services, and 9 in 10 hospices impose restrictions on what volunteers can do, mostly in the area of nursing care.² This is in contrast to the United States, for example, where volunteers mostly assist in direct patient and family care and support.¹⁶

One possible solution to these dilemmas is to use volunteers in innovative ways. In the United Kingdom, this may mean an increase in direct volunteer involvement in direct patient and family EOL care and more community outreach. There is some evidence that volunteer managers believe that there is scope for developing volunteer roles in UK hospices.² Wilson et al.¹⁷ note that 'role diversity raises the issue of whether each EOL care organisation uses volunteers to their best advantage or their clients' best advantage'. In order to take advantage of opportunities for change, hospices are likely to benefit from support and guidance. Although there are some resources,¹³ very little evidence-based guidance is available to help negotiate the organisational challenges of expanding the scope of volunteer activity. Previous reviews indicate that the research evidence available on this topic is limited and that most studies are small scale in design.¹⁷

Aims

This narrative literature review forms part of a 2-year study into volunteer management in EOL care, which aims to examine the specific challenges of involving volunteers in roles that require direct contact with patients or their families in UK hospices. The review explores the recent literature on volunteering in palliative care services in order to reflect upon the issues pertinent to the organisational challenges and opportunities in engaging and managing volunteers in the current climate. It aims to highlight factors in the involvement of volunteers that may facilitate or hinder the ultimate aim of supporting the delivery of high quality care at the EOL.

Design

The purpose of the review was to take in as wide a range of research and recommendations as possible. It was anticipated that the available evidence would be of variable quality and diverse methodology. However, it was believed that there would be value in seeking an overview of the issues faced by volunteers and those who manage and support them in order to raise awareness and promote discussion. Hence, an inclusive narrative review approach was taken, with the parameters set deliberately wide in order to capture some of the nuances of contemporary EOL care volunteer experience and deployment. All reports of data from

volunteers, or about volunteers, were included. Themes were identified through a content analysis in order to provide a framework for discussion.

Data sources

The following databases were searched in August 2011 using OneSearch: EMBASE, MEDLINE, CINAHL, PUBMED, PsycINFO, Web of Science and AHMED. In addition, particular attention was paid to selected key journals: *Palliative Medicine*, *Journal of Palliative Medicine*, *Health Services Management Research*, *Nonprofit and Voluntary Sector Quarterly*, *Voluntary Action*, *The Journal of Voluntary Sector Research*, *Voluntary Sector Review* and *International Journal of Sociology and Social Policy*. The grey literature that could be accessed through SCIRUS and NHS Evidence was also included, and the *Institute for Volunteer Research's Evidence Bank* and the *International Observatory on End of Life Care's* Library databases were also searched.

The search terms used were as follows: 'palliative care', 'terminal care', 'hospice', 'dying' and 'end of life'. These terms were combined with the keywords 'volunteer*', 'manage*', 'support*', 'train*' and 'unpaid worker'.

Inclusion/exclusion criteria

The main criterion for inclusion in the review was that the data provide information relevant to the main aim of identifying how good practice in the involvement of volunteers in services that require direct contact with patients or their families can enable organisations to meet the current economic and social challenges facing EOL care organisations. The inclusion criteria were that the article was written in English; set in adult SPCS or hospices, including hospice at home; and published between 2000 and 2011 in order to focus on contemporary issues. We excluded children's services and prison services, as these are highly specialised environments and merit separate investigations. We included the following types of research participants: volunteers, volunteer managers or coordinators, SPCS or hospice staff, patients and relatives of patients. All types of study and outcome measure were included. We concentrated on research reports and excluded books, conference papers and unpublished dissertations.

Study selection

Titles and abstracts of studies to be considered for retrieval were recorded on an EndNote database. Abstracts were assessed according to the agreed inclusion criteria and selected articles were retrieved and critically assessed by members of the project team independently. A table of selected articles was created with the information on country,

method, sample and results for each reference (supplementary table).

Results

The initial literature search identified 176 possible articles. On examination of the abstracts, 103 full-text articles were retrieved. Our final selection included only articles that reported on a research study or evaluation and examined a topic relevant to our aims. The analysis reported here included 68 articles, of which 2 were literature reviews and 3 were reports.

The results are presented under two overarching themes:

1. Individual volunteer factors, constituted the following: (a) motivation, (b) characteristics of volunteers, (c) stress and coping, (d) role boundaries and (e) value;
2. Organisational factors, constituted the following: (a) recruiting for diversity, (b) support and training and (c) volunteers' place in the system.

The implications of theme 1 fed into theme 2 and their importance for the future management of volunteers in EOL care are discussed.

Theme 1: individual volunteer factors

Motivation to volunteer in EOL care. The motives for becoming an EOL care volunteer have been widely discussed in the literature and, despite being numerous, appear to follow similar patterns even in different settings and countries. Claxton-Oldfield et al.¹⁸ specifically looked at motivations, reviewing British and American studies and carrying out further interviews to compile a list of 22 reasons for volunteering. They grouped the responses into four motivational themes: altruism, civic responsibility, leisure and personal gain, adding self-promotion as a further category more recently.¹⁹ Studies have also suggested that motives vary with age, as younger volunteers report stronger career motivations, while stronger social motivations are reported by older people.²⁰

As many volunteers have had an experience with EOL care and death of a member of their family or a friend,²¹ becoming a volunteer in this field can also be driven by deeply personal experiences and desires. Andersson and Ohlen,²² taking a phenomenological hermeneutic approach, examined the existential meanings of being a volunteer within hospice or palliative care. They suggest that volunteers feel rejected if their 'need for meaning and for belonging to the hospice' is not satisfied and that a longing for 'fellowship' is often a motive (p. 607). Planalp and Trost²⁰ also suggest that making connections and feeling valued are important in starting and continuing to volunteer. Freedom, and choice to use their time and contribute 'as whole

persons' in a flexible way, was cited as an important aspect of deciding to and continuing to volunteer among volunteers from three diverse palliative care settings (p. 18).²³ Using a motivational approach, Finkelstein²⁴ studied older hospice volunteers in the United States and suggests that whatever the motivations for helping, satisfaction depended on the volunteer experience fulfilling their particular goals. As Guirguis-Younger and Grafanaki²³ indicate, 'volunteerism is a dynamic negotiation between the individuals who choose this role and their selected setting' (p. 21).

Characteristics of EOL care volunteers. Several researchers have addressed the question of whether people who volunteer in EOL care are different from volunteers in other spheres. Egbert and Parrott²⁵ found that hospice volunteers differed from other health-care volunteers in having significantly higher scores on an empathic concern subscale. Personality tests were used by Claxton-Oldfield and Banzen²⁶ on female hospice volunteers and compared with adult females in general. Empathic concern was again significant, and they also found that the hospice volunteers scored significantly higher on the traits of agreeableness, extraversion and openness and significantly lower on the trait of neuroticism.

Volunteers are also likely to differ from employed members of the EOL care team in their attitudes and needs. When compared with employed staff, hospice volunteers were less positive about extending hospice care to non-cancer patients, restricting care to patients with specialist palliative care needs, and less negative about euthanasia.¹ A study by Low et al.²⁷ suggested that volunteers may be more resistant to change than professionals, while an examination of ethical issues that sampled patients, families and non-medical staff by Towers et al.²⁸ found that volunteers were the group most open in voicing concerns and often spoke as advocates.

It is notable that the participants in these and other studies were predominantly female. In 2004, the 'typical' hospice volunteer in the United Kingdom was 'likely to be 55 or over, retired, female and white' (p. 3).² Whether this is changing is difficult to ascertain, as specific data on the numbers and profile of EOL care volunteers are scant.¹³ It must also be remembered that volunteers include professionally qualified people, who offer their services for free, such as counsellors, therapists and trustees. The literature does not provide much insight into their specific characteristics, motives and needs, as few studies make this distinction, tending to group all sampled volunteers together. Turner and Payne²⁹ suggest that trustees are 'hidden' volunteers and are predominantly older, retired, white British men from professional backgrounds. They reported tensions between established older trustees and the new 'professional' generation of trustees and indicated their importance in organisational change.

Limited diversity among volunteers is frequently mentioned as an issue in the literature.^{30–32} A few studies have

looked at how men^{33,34} or younger people³⁵ might be encouraged as EOL care volunteers. Although there are studies that look at 'cultural competence' among volunteers,^{30,32} none were found that examine the lack of volunteers from ethnic minorities.

Stress and coping among volunteers. Unpaid volunteer workers are involved in a social, rather than a business, transaction; this can allow freedom and flexibility, which is reported as highly valued by volunteers.³⁶ Nevertheless there are tensions and challenges reported in the literature; studies of stress and coping in EOL care volunteers are common, and similar themes arise. Perceived stressors include the following: poor communication, lack of emotional support, need for training and information, dealing with patient's family members, dealing with death and dying, being underutilised, being placed with a patient too late in the patient's illness, feeling undervalued by some members of the medical staff and not being able to do more to help patients and their families.^{37–40}

Clearly, the system and setting in which volunteers work are likely to have an effect on volunteer stress. A UK study compared volunteer and professional caregivers across three settings – NHS, hospice and community based – and found differences in reported stress levels between settings and between caregiver types.⁴¹ The timing of stressful feelings is not constant and has been reported as temporary, related to the start of volunteering or to challenging events, and many volunteers report few feelings of stress.^{38,42} In trying to explain low reported stress, it has been suggested that people who are emotionally robust self-select to volunteer in EOL care.^{26,43} The coping strategies of volunteers have also been investigated and include the following: keeping an emotional distance from patients, looking at guidelines, problem-focused coping (such as seeking advice from members of the hospice interdisciplinary team, or talking with other volunteers), emotion-focused coping (talking with others, going to funerals), meaning making through appraisal (religious beliefs and values, perceiving death as a merciful release and a necessary process) and physical techniques (walking, deep breathing).^{21,38,42,44} Some authors go further than 'coping' and suggest that volunteers achieve personal growth through their encounters with hospice,^{21,22} and there are several reports in which volunteers describe 'getting more back than they put in', enjoying their jobs and generally feeling valued.³⁸

Role boundaries. The roles that volunteers take on in EOL care are frequently listed in the literature but depend on the context within which they are working, for example, in the United Kingdom, the roles centre around the hospice building and fundraising,² while in Canada and the United States, volunteers mostly operate within the patient's home. In less-developed countries and remote settings, innovative volunteer programmes focus on a community model,

drawing on the willingness of local volunteers, who may deliver a wide range of services.^{45–48} A study in Uganda by Jack et al.⁴⁹ found that outreach ‘deep into villages’ was a vital aspect of the community volunteer role and that the initiative provided a ‘bridge to the hospice’ in identifying patients and was well received.

It is widely reported that volunteers are placed uniquely in services and can perform overlapping roles, such as friend, advocate and go-between.^{27,31,44,50–54} McKee et al.⁵⁵ write that volunteers inhabit a ‘unique third culture of care that fuses elements of formal care with the informal visiting of friends and neighbours’ (p. 103). This appears particularly true for rural and small communities where potential volunteers are drawn from the local community. The relationship between volunteers and paid providers can become ‘hazy’ in this context.⁵⁶ In more structured settings, the roles may be clearer, yet, while generally good working relationships between volunteers and staff are reported, some concerns over professional boundaries have been found.^{28,31,57,58}

The value of volunteers. Volunteers provide their time for free, but there are some monetary costs associated with their deployment. In a study into the cost-effectiveness of volunteers in hospices in the United Kingdom, each pound put into supporting and managing volunteers was found to yield a return of between £7 and £9 in the value of the volunteers’ work.¹⁵ Differences in the organisation of volunteering and the roles for volunteers did not substantially affect the level of return, and the ratio was higher than that found in most other organisations.

Volunteers also have value in other ways. Their roles are thought to be complementary to those of professional staff.³⁸ Volunteers, especially those working in people’s homes, are considered to provide a valuable in-between role³⁴ and help to keep the dying person in the community.⁵⁵ Family caregivers appreciate the emotional support, availability, sustained relationships and respite that volunteers can give.^{59,60} A report of a Philippine initiative suggested that local volunteers provided culturally sensitive care, such as spotting undisclosed anxieties and pain and validating family dynamics. Two studies attempted to measure the impact of volunteer services on patients or families: Herbst-Damm and Kulik⁶¹ studied patient records in the United States and, controlling for baseline health status, found that patients receiving volunteer support survived significantly longer than did unvisited patients; Block et al.,⁶² using a secondary data analysis, found that, after controlling for various factors, the higher the direct volunteer hours, the higher the family rating of quality of care.

Theme 2: organisational issues: enhancing the management of volunteers

This review has been considering recent research and its relevance for the changing circumstances that EOL care

organisations are encountering. Given the financial, demographic and changes to volunteers expectations, what might EOL care organisations, particularly those in the United Kingdom, need to consider in order to maintain and enhance their services through the use of volunteers? In the following section, some of the salient issues that have been identified as current concerns in the literature will be examined in relation to these questions.

An organisation that uses volunteers needs to manage them, and many of the studies cited here provide recommendations for management based on their findings. Issues related to recruitment and retention are most often discussed, but the volunteers’ place in the system, communication with other members of the multidisciplinary team and their training and support needs also figure.

Recruiting for diversity. It has been acknowledged that EOL care volunteers are mainly drawn from a small section of the community and are not representative of the population at large.² The recent literature suggests that volunteers have certain characteristics and life experiences that foster self-selection in what is considered an emotionally demanding setting. Changing demographics make diversity an important issue to address and could also help serve a more diverse client population. Reese et al.³² found that the presence of diverse staff or volunteers predicted a more diverse patient population that suggested that the directors of EOL care organisations should provide leadership to encourage diversity. Voluntary Service Managers anticipate recruitment becoming more difficult over the next years, which may force EOL organisations to change the way this is done. Davis Smith² argues that hospices need to do this if they are to fully reflect the profile of the communities in which they operate, and that ‘a diverse volunteer (and indeed paid) workforce says something very powerful about the nature of the organisation and the market it is aiming to reach’ (p. 19).

A few studies have tried to explore why men or younger people are less well represented in EOL care. For example, Claxton-Oldfield et al.³³ make suggestions for attracting more men based on their ‘preferred tasks’ – the opportunity to promote EOL care services to the wider community and to provide practical support – which could be highlighted in advertising for more volunteers. The involvement of volunteers from ethnic minorities in developed countries is a topic that is hardly touched on in the literature, despite evidence that they are less likely to volunteer or make use of EOL care.^{63,64} A study that focused on the needs of current volunteers for ‘cultural competency’ training mentioned that attracting a more diverse, multilingual and representative set of volunteers would be an ‘effective “word-of-mouth” strategy to encourage other minorities’ to use palliative care services in Canada.³⁰

However, just targeting increasing numbers from diverse groups may not take into account the ‘need to screen volunteers

for personal suitability for palliative care work, and legal issues such as the need for police checks' (p. 254).¹⁷ Volunteer managers face challenges in addressing reduced numbers of volunteers (through demographic change and increased competition for volunteers from other agencies), a desire to increase diversity and the potential to expand the roles volunteers undertake in EOL care. A more formal and regulated approach to volunteers may need to be developed but may be seen as a loss by some who value a more informal and flexible approach. In the context of the twenty-first century, differences between 'what is called "classic volunteerism", this being characterised by long-term and regular service in an altruistic context, and 'new volunteerism', which is characterised by shorter or time limited service within a more reciprocal relationship' are highlighted (p. 2).⁶⁵

Stress and coping – support and training for volunteers. Suggestions for improving the experience of volunteers, and thereby retaining their services, are common in the literature. The value that volunteers get from continuing to volunteer include personal feelings, such as a sense of commitment and connection (to the hospice and people), and being valued as a caring person.^{20,22} Managers and organisations can help foster these feelings through providing a welcoming and inclusive environment for volunteers and providing support, training and appreciation. The relationship between volunteers and between them and the volunteer coordinator or manager is important. Several studies indicate that contact and talking with other volunteers is helpful in terms of stress and learning and that ongoing contact with the coordinator is very important.^{42,66} Volunteers like to know they are valued by the professionals and managers.^{40,67} Although there is no evidence of animosity toward volunteers by staff, there are hints in the literature that volunteers are not always considered full members of the multidisciplinary team,⁶⁸ that communication can be lacking^{27,39} and that power differentials are enforced with subtlety.³¹ Educating staff to understand the volunteer contribution better, especially in situations where this might be changing due to current pressures, is a strategy that could enhance volunteer experience, information sharing and retention.

The training of volunteers is highly recommended in the literature and asked for by volunteers.³⁷ A wide range of topics is mentioned, such as communication, ethics, the reasons behind guidelines, death, disfigurement, listening skills, cultural competency, complementary medicines, non-verbal communication and managing negative feelings and conflict.^{20,38,44,69,70} Clearly, the list could be very long and will be most useful where it is related most closely to the setting and the expectations on volunteers. Resources are also needed, and the issue of providing a more professionalised system for volunteers is also implicated. The issue of training merits further investigation and a detailed systematic review of its own.

Role boundaries – volunteers' place in the system. Questions related to who the volunteers are and how they are supported as individuals within the organisation are important for the future of volunteers within EOL care. But there are also questions about where they are located in the system and whether they are most effectively placed. The 'boundary position' of volunteers, especially those who provide direct patient or family care, has been noted in the literature. This can be seen as a unique positional strength and complementary to professional care, but Sévigny et al.⁵² note that this position may leave volunteers less likely to be integrated into seamless care. There is a tension here between the flexibility of 'informal' volunteering and increasingly pressures to formalise the volunteer role in order to attract new and more diverse people in a changing 'market'. How far to go down the road of 'formalising' volunteers remains a question for managers to answer in regard to their particular setting and service. Decourtney et al.,⁴⁵ for example, suggest that in a remote community setting, it is impossible logistically to impose formal hospice protocols but that traditional culture can be incorporated through local community volunteering.

Conclusions

This article has reviewed the recent literature on volunteers in EOL care settings, with particular attention to the organisational challenges and opportunities involved in engaging and managing volunteers at a time of financial and demographic change. The articles were drawn from an international literature, while acknowledging that EOL care volunteer roles vary considerably by organisation and/or by country and over time. The majority of articles were small in scale, but the same topics repeatedly emerged from both qualitative and quantitative data, indicating their importance. These topics were grouped for discussion under two main themes – individual volunteer factors and organisational issues.

The review has brought together the kind of issues and questions that EOL care organisations are likely to face in the future, such as increasing diversity and more formal regulation of volunteers. The tensions involved in negotiating the boundary spaces that volunteers inhabit – between professional and friend and between informality and regulation – influence their experiences and satisfaction. The literature suggests that those who support and manage volunteers need to handle these issues sensitively in order to make the most of this important resource. Research into the effects of increasing regulation on the volunteer workforce would be valuable in assisting managers to negotiate the changing arena of volunteerism.

The literature also highlights the need to address diversity issues in order to reach a larger 'pool' of potential volunteers and to support diverse clients. Although there are some evidence-based recommendations on attracting more men and younger people into EOL care volunteering,

research is lacking on volunteers who come from ethnic minorities. In addition, some studies explore a 'community-driven' model of volunteering, which is often culturally specific and which merits further investigation as a way of developing new answers to the current dilemmas. In many countries, such as the United Kingdom, engaging with volunteers in innovative ways could involve an increase in direct volunteer involvement in EOL care and more community outreach.

Conflict of interest

The authors declare that there is no conflict of interest.

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