

# Defining volunteering in hospice and palliative care in Europe: an EAPC White Paper

In 2013, a Taskforce on Volunteering in Hospice and Palliative Care was created within the European Association for Palliative Care (EAPC). Among other endeavours, it has worked on a White Paper containing a shared definition and typology of hospice and palliative care volunteering, and exploring its role, position, identity and value. This White Paper is presented here by **Anne Goossensen, Jos Somsen, Ros Scott** and **Leena Pelttari**

The hospice movement, which is akin to a civil rights movement, is partly based on volunteer work.<sup>1</sup> Hospice and palliative care (HPC) volunteers are active in almost every country in Europe, and many services depend on their contributions to deliver the range and quality of care they provide.<sup>2</sup> The numbers of volunteers, the tasks they perform and the development of their organisations vary greatly. In some European countries, volunteers have had a long involvement in the hospice movement, in some cases even starting it. In others, volunteering has only recently started and HPC pioneers are looking at other countries for inspiration and practical information to help develop volunteering in medically dominated care environments. Depending on the country, HPC volunteering can be well organised, with

concepts and theoretical frameworks that clarify its meaning and value.<sup>3</sup>

In November 2013, a Taskforce on Volunteering in Hospice and Palliative Care was launched by the European Association for Palliative Care (EAPC); this followed on from the first symposium on HPC volunteering, which had taken place at the EAPC Congress in Prague in May/June 2013 and had attracted 110 delegates.<sup>4</sup> A second symposium with over 160 participants from 12 European countries (volunteers, volunteer managers, researchers and other professionals) was held in April 2015 in Vienna; reports from a number of countries and early findings from a European study on volunteering<sup>5</sup> were presented and the position of volunteering in Europe was discussed.

Until recently, studies on volunteering have often investigated questions such as why volunteers do what they do,<sup>6</sup> what common problems they face,<sup>7</sup> why they choose to stay or go<sup>8</sup> and the boundary issues they experience.<sup>9</sup> However, insights emerging from the work of the Taskforce indicate that there is still much that we do not know about HPC volunteering in Europe. So far, there is no shared definition and a lack of clarity about the roles and tasks of volunteers. Basic information about numbers, roles, management and training is often missing or based only on estimates.<sup>4</sup>

This EAPC White Paper presents a consensual definition and typology of HPC volunteering, and clarifies its role, position, identity and value. It considers the unique position and identity of care-focused volunteering, in an attempt to address the ambiguities and tensions that exist in this

## Key points

- The Taskforce on Volunteering in Hospice and Palliative Care (HPC), created in 2013 within the European Association for Palliative Care (EAPC), presents a White Paper on the definition, typology, role, position, identity and value of HPC volunteering.
- This EAPC White Paper is based on a literature review, focus group discussions and a Delphi-like consultation of six European experts.
- Consensus was reached, among others, on the fact that volunteering in care-focused roles is best understood as a relational activity and that the contribution of volunteers in such roles lies in 'being there' and creating value through encounters.
- The concept of 'being there' used by volunteering organisations in several countries seems to offer a good base from which to research the theoretical framework of HPC volunteering, as well as develop training, supervision and self-reflection.

particular area. By exploring these topics in more depth, we hope to aid the work of volunteers with patients and those close to them, and help address attunement issues in the fields of formal and family care.

## Methods

A range of methods were used to produce this White Paper, including a literature review of published and unpublished research and 'grey' reports, an analysis of the outcomes of focus group discussions organised by the Taskforce, and an analysis of minutes taken at Taskforce consensus meetings at the EAPC congresses in Prague and Lleida.

The literature search focused on scientific publications in English language. The databases Medline, PubMed, Applied Social Sciences Index and Abstracts and Google Scholar were searched using the terms 'volunteering', 'palliative care', 'hospices' and 'volunteers'. Only articles published in scientific journals in the last decade were included. Several review articles were included and reference lists were searched for further sources ('snowballing'). For some authors – for example, Claxton-Oldfield – all retrieved publications were included because of their high relevance. Grey reports included material from an international study conducted as part of the Opicare9 project,<sup>10</sup> which was shared at the symposium in Prague.

Focus group discussions between the wider Taskforce membership had taken place during the 2013 and 2014 EAPC congresses in Prague and Lleida (see Box 1 for a list of participating countries). These were opportunities to exchange views and information on volunteering practices and the development of HPC volunteering in Europe.

Initial data from the literature review and focus group minutes were discussed in 2014 at Taskforce Steering Group meetings in Lleida and Utrecht. In February 2015, a draft paper was circulated among Taskforce Steering Group members (see Box 2). Six European experts in the field were also consulted and a Delphi-inspired approach was used to elicit their views and reach final consensus.

The White Paper is divided into four sections:

- defining HPC volunteering
- a typology of HPC volunteers
- the unique contribution of volunteers
- position and identity of HPC volunteers in care-focused roles.

- Box 1. Countries participating in the Prague and Lleida meetings**
- Countries participating in the symposium on hospice and palliative care volunteering in Prague in 2013: Australia, Austria, Belgium, the Czech Republic, Denmark, Germany, Ghana, Hungary, Ireland, Israel, Italy, Japan, Kazakhstan, the Netherlands, Nigeria, Norway, the Philippines, Romania, Russia, Serbia and Montenegro, Slovakia, Slovenia, Spain, Sweden, Tanzania, Turkey, Uganda, Ukraine, the UK and the USA
  - Countries participating in the Taskforce meeting in Lleida in 2014: Austria, Germany, Ireland, Italy, the Netherlands, Portugal and the UK

- Box 2. Taskforce Steering Group**
- The members of the Taskforce Steering Group are: Leena Pelttari (Co-chair, Austria), Ros Scott (Co-chair, UK) Rosalma Badino (Italy), Piotr Krakowiak (Poland), Sheila Payne (UK), Lukas Radbruch (Germany) and Jos Somsen (Netherlands)

## Defining HPC volunteering

The scientific and grey literature provided a number of descriptions and definitions of volunteering in general and HPC volunteering in particular. A general definition of volunteering comes from a European Parliament Library Briefing.<sup>11</sup> This document recognises that volunteering is understood differently in different countries and that a number of countries have their own, distinct definitions; however, some shared characteristics also emerge from it.

- Volunteering is undertaken of one's own free will.
- Volunteers are not motivated by financial gain.
- Volunteering benefits the individual volunteer, communities and society as a whole.
- Volunteering is often carried out in support of non-profit organisations or community-based initiatives.
- Volunteering refers to all kinds of voluntary activity, formal or informal.
- Volunteering does not replace professional, paid employment.

Reflection within the Steering Group and during the Delphi-inspired consultation shows that there are at least two aspects of this definition that are not shared by all participating countries. In the Netherlands and Romania, for instance, there is no distinction between 'formal' and 'informal' volunteering. In the Netherlands, following changes taking place in the healthcare system, volunteering is

now expected to replace paid employment in some areas. The Dutch Association for Volunteer Organisations has formulated conditions that must be met to ensure that the specificities of volunteering are maintained when it replaces work that was traditionally done by professionals.

An attempt to overcome differences between countries was made in the Grundtvig II project on HPC volunteering, which involved six eastern and western European countries in 2006–07.<sup>12</sup> One of its conclusions was that ‘volunteering is the whole of activities done without payment by a volunteer for another person, group (without any blood ties), or the society as a whole within an organization and without any obligation’. Here, expressions such as ‘without any blood ties’ and ‘within an organization’ clearly distinguish volunteering from family care.

When we looked for a HPC-specific definition of volunteering, we considered Scott’s proposition that it is ‘the time freely given by individuals, with no expectation of financial gain, to support hospice patients, their families or those who care for them and local communities with the intention of improving the quality of life of adults and children with life-limiting conditions’.<sup>13</sup>

Discussions within the Steering Group and during the Delphi-inspired consultation led us to adopt a consensus definition of HPC volunteering in Europe which features in Box 3. Volunteering is always defined as an activity with no financial counterpart, which is expressed by formulas such as ‘time freely given’ and ‘with no expectation of financial gain’; we reached consensus on the point that this means more than simply not receiving any money for the work performed. A deeper understanding of this principle must also take into account the values of volunteering, such as those laid down by the International Association for Volunteer Effort, which states that ‘volunteering brings to life the noblest aspirations of humankind – the pursuit of freedom, opportunity, safety and justice for all people. It is a means by which human values of community caring, service and participation are sustained and strengthened. Individuals exercise their rights and responsibilities as members of communities and connections are made across differences which otherwise can push us apart’.<sup>12</sup>

Volunteering in hospice and palliative care is defined as the time freely given by individuals, with no expectation of financial gain, within some form of organised structure other than the already existing social relations or familial ties, with the intention of improving the quality of life of adults and children with life-limiting conditions and those close to them (family and others)

### Box 3. Consensus definition of volunteering in hospice and palliative care in Europe

### A typology of HPC volunteers

Different scientific publications,<sup>3,14</sup> and the 2013 symposium in Prague, have stressed the importance of clarifying roles and contributions as a crucial step in the development of HPC volunteering. This would help improve collaboration, not only between informal and formal carers, but also between different types of volunteers.

At the Prague symposium, based on her research within the Opcare9 project,<sup>10</sup> Smeding proposed a subdivision of HPC volunteers into three categories: ‘D-volunteers’, ‘C-volunteers’, and ‘B-volunteers’.<sup>15</sup>

D-volunteers are disciplinary-based volunteers; that is, professionals who work within their discipline without being paid. There seem to be many D-volunteers in countries where HPC volunteering is in its early days. This is the case, for example, in Poland, where the first home care hospice team was formed in 1983 with support from the Church; as Krakowiak explains, ‘it became a model for creating more than 100 home care programmes in Poland based on the voluntary work of physicians, nurses, chaplains, and others.’<sup>16</sup> A Taskforce member reporting on the situation in Ireland suggested that professionals taking early retirement may engage in disciplinary-based volunteering.

C-volunteers are community-based volunteers; that is, members of the local community who offer their time, bridging normal life and professional care. The Steering Group suggested that C-volunteers could be further divided into those who work in care-focused roles and those who work in indirect, facilitative roles. In care-focused roles, C-volunteers are regularly involved with patients and those close to them. This is sometimes called ‘direct patient care’. In indirect facilitative roles, C-volunteers

support the organisation or the clinical team, performing tasks such as office duties, fundraising, domestic services, gardening, catering and transport.

B-volunteers are unpaid board members of HPC services<sup>17</sup> and are prevalent in many non-profit organisations. They are often seen quite differently to other volunteers and carry significant responsibility for the organisation's strategic direction and effective management.

These subdivisions help to understand the substantial variations within and between European countries regarding volunteers' tasks and roles. In the UK for example, the percentage of HPC volunteers involved in direct patient care at the very end of life is smaller than in some other European countries. In Romania, only a minority of volunteers work in direct care roles and over 70% of volunteers are young people – mainly university students. This contrasts starkly with the situation in Germany, Austria, Italy and the Netherlands;<sup>3,10</sup> in the Netherlands, 88% of HPC volunteers' time is spent in care-focused roles;<sup>18</sup> in Austria the figure is 65%.<sup>4</sup>

Although all work done by volunteers is equally valuable, regardless of role, the focus of this White Paper is mainly on care-focused roles in HPC volunteering because of the challenges faced by organisations and professionals in this particular area.

### The unique contribution of volunteers

Before exploring the position and identity of volunteers in care-focused roles, it is important to consider the wider context of HPC volunteering. The literature considers volunteering through a number of different theoretical lenses. Broadly speaking, these can be divided into three categories:

- societal – social action, equity and community engagement<sup>1,19–22</sup>
- organisational issues – management models and approaches including recruitment, cost and benefits, impact, selection, training, support, retention and dismissal<sup>23–27</sup>
- individual characteristics of volunteering and volunteers – for example, their motivations, roles and tasks and relationships with paid staff.

### Volunteers' motivations

There is a significant amount of literature on volunteers' motivations, both in general and in HPC. Rochester *et al* suggest that volunteers' motivations can be grouped into three categories:<sup>20</sup>

- civil society (activism, addressing social issues, community engagement)
- volunteering within a structured organisational context (the 'dominant paradigm')
- volunteering as serious leisure (where volunteers seek to gain knowledge and/or experience or develop new skills).

Nissim *et al*<sup>28</sup> and Planalp and Trost<sup>29</sup> suggest that HPC volunteers' motivations are largely comparable with those of volunteers in general, a view supported by Claxton-Oldfield *et al*;<sup>30</sup> their 'inventory of motivations for hospice palliative care volunteerism' divides these motivations into five categories: altruism, civic responsibility, self-promotion (for

example, to acquire a status or feel needed), leisure, and personal gain; Claxton-Oldfield *et al*'s research focused on volunteers in Canada and the UK, and suggests that HPC

volunteers are strongly motivated by altruism and civic responsibility.<sup>30</sup>

Morris *et al* found that motivations were broadly similar in all settings and countries, but suggest that they can vary according to age, younger volunteers being more motivated by career aspirations.<sup>14</sup> In a comparative study of German and US HPC volunteers, Stelzer and Lang conclude that German volunteers are more motivated by career aspirations than their US counterparts.<sup>31</sup>

Andersson and Ohlén say that HPC volunteers are motivated by the fact that they help others and support causes they believe in, but also by their own experiences of bereavement, a wish for personal development and an aspiration to understand more about life and death.<sup>32</sup>

The six experts consulted in the Delphi-like process were in broad agreement that all the motivations outlined above are relevant; however, they thought it important to include, in addition to the motivations of pensioners seeking a social activity, the motivations of unemployed people wishing to acquire experience and personal benefit with a view to finding paid employment.

**HPC volunteers are motivated by the fact that they ... support causes they believe in**

They also thought it important to take into account that, in some countries, volunteers might be motivated by a religious calling. Finally, culture and tradition were identified as factors that influence people's motivations: some countries have strong volunteering traditions, others do not.

Hustinx *et al* consider the complexities of volunteering and suggest that volunteers may be driven by several motivations.<sup>33</sup> Guirguis-Younger and Grafanaki explain that, for volunteering to be sustainable, there must be interdependence between the needs of the volunteer and those of the organisation.<sup>24</sup> Therefore, for HPC volunteering to be effective, it is important to understand why people volunteer and ensure that their motivations are taken into account when allocating roles and planning support or development.

#### *Volunteers' contribution*

Volunteers in health- and social care have been recognised as playing an essential role, improving patients' experience of care.<sup>22</sup> Morris *et al* suggest that the context within which HPC volunteers work will influence the roles they undertake;<sup>14</sup> however, these will also

be influenced by society, culture and the structure and traditions of the healthcare system.

Woitha *et al* found a diversity of HPC settings in which volunteers were involved in

Europe, including hospitals, palliative care units, hospices, home-care teams, day-care centres and residential care homes.<sup>3</sup>

Organisations that involve volunteers may have been created and be run by volunteers or by professionals. Volunteers may work within a separate team or as part of the same team(s) as paid staff.

The EAPC highlights that volunteers make 'an indispensable contribution to palliative care'.<sup>1</sup> Radbruch *et al* add that volunteers play a key role in contributing to the psychosocial well-being and quality of life of patients and their families, in addition to promoting palliative care to the general public.<sup>1</sup> Scott supports this view, and highlights that volunteers have a crucial part to play in community engagement.<sup>2</sup> Additionally, she found that the viability of a number of charitable hospices in the UK depended on the contribution of volunteers.

Guirguis-Younger *et al* found that volunteers bring a unique human approach to the care of people at the end of life in very medical environments, playing an important role in bridging the gap between professionals and patients.<sup>34</sup> Claxton-Oldfield supports this and says that volunteers provide valuable social and emotional support to patients.<sup>35</sup> Through listening to patients' concerns and anxieties and helping them to engage with their interests and hobbies, volunteers can help reduce feelings of isolation.

Once again there was broad agreement on these ideas among the six European experts. They suggested that we must consider what the needs are, rather than what volunteers can do or want to do. The concept of 'being there' was recognised as central. One expert stressed that volunteers can have an impact on both policy and service development; for example, when they are pushing for a new service, such as a hospice, to be created. Not only does this have implications for service development, but it can also become important politically.

#### *Benefits of volunteering*

Anecdotal evidence suggests that those who observe the work of volunteers seem convinced of their benefit; however, the benefits of volunteering remains an under-researched area. These benefits can be considered at different levels: societal, organisational, individual. Here we focus on the individual benefits, both for the recipients of the support and the volunteers themselves.

Candy *et al* found some evidence that volunteers in care-focused roles improve the well-being of patients and families.<sup>36</sup> Claxton-Oldfield suggests that patients and families benefit from the practical and emotional support provided by volunteers, in addition to the social benefits of companionship.<sup>35</sup> In an earlier study by Claxton-Oldfield *et al*,<sup>37</sup> family members reported high levels of satisfaction with volunteers, valuing the fact that they give their time, the emotional support they provide and their help in getting respite from caring. This is confirmed by a study from Block *et al*, in which patients reported higher levels of satisfaction with services that had greater volunteer involvement.<sup>38</sup> Herbst-Damm and Kulik found evidence suggesting that patients who were supported by volunteers lived much longer than those who were not.<sup>39</sup>

### **Volunteers provide valuable social and emotional support to patients**

## Position and identity of HPC volunteers in care-focused roles

The involvement of volunteers in care-focused roles is one of the more challenging areas in HPC volunteering. Reasons for this can include staff concerns about the skills of volunteers, the management of task boundaries and the impact on the quality of care. If volunteering is to be further developed, there needs to be a clearer understanding of volunteers and their place within the team. Some studies describe the position of volunteers in care-focused roles as characterised by ambiguity and flexibility, being somewhere between paid staff and friend, between informality and regulation; this results in uncertainties when performing tasks and stress regarding the boundaries of their roles.<sup>40</sup>

In the process of writing this White Paper, we found that there was a consensus for seeing volunteering as existing next to family care and professional care, and having its own position, identity and value. Some qualitative studies help to investigate the essence of this identity; for instance, Andersson and Ohlén have conducted a phenomenological analysis of the experience of being a hospice volunteer: they identify volunteers as ‘valuing encounters’ and ‘building relations’, and describe volunteering in care-focused roles as a relational activity. Volunteers described their essential experiences as ‘an encounter with the hospice (atmosphere, community) and encounters with patients (understanding needs, imagining their situation)’.<sup>32</sup>

Other papers confirm that there is value in understanding the identity of volunteering as relational.<sup>28,41</sup> A review and thematic synthesis of qualitative studies identifies volunteering as social in nature – providing support, just being there, and just listening.<sup>40</sup> The six consulted experts agreed that a relational view of volunteering helped to express what it can bring to patients and society.

If care-focused volunteering is essentially to be understood as a social activity with a focus on quality encounters, which concepts can help us clarify the position of the volunteers and their benefits? In a critical reflection on palliative care philosophy, the term ‘Asklepian tradition’ is introduced as opposed to the ‘Hippocratic tradition’.<sup>42</sup> The Hippocratic

tradition stands for an analytic and scientific approach where every disease is viewed as having a cause which can be discovered and as being curable by an external intervention. The focus is on knowledge of illness and symptoms that can be generalised.

The Asklepian tradition stems from the practice, in ancient Greece, that saw the incurably ill visit the temple of Asklepios. In this metaphor, healing would come from within, aided by the attentive gaze of the snakes present in the temple. The snakes’ gaze has become a symbol of the carer’s attention, waiting and listening, honouring the patient’s integrity. Here the focus is on seeing the human being in its entirety.

Both these traditions are reflected in Dame Cicely Saunders’ original approach to HPC, which combined expert pain and symptom relief with holistic care to meet the physical, social, psychological and spiritual needs of patients, family and friends.<sup>43</sup>

The contribution of community volunteers does not lie in the ‘expert symptom relief’ characteristic of the Hippocratic approach. They have much more to offer – their time, their attention – within the Asklepian tradition. The Asklepian tradition is in line with the concept of ‘being there’, which, in the Netherlands (*er zijn*) and in German-speaking countries (*Dasein*), was chosen as the core concept for HPC volunteering. Different theories<sup>44–46</sup> can help to clarify the quality of ‘being there’. The value of HPC volunteering lies in this precious thing of just ‘being there’ and creating value through an encounter. HPC volunteers deal with ordinary life and focus on lived experience rather than on illness. They give attention, are receptive, identify concerns and do what can be done.<sup>47</sup>

In our Delphi-like consultation, it appeared that the concept of ‘being there’ was of value to all. Some participants fully embraced the concept, while others reflected further on the relationship between ‘being there’ and performing tasks. Perceiving the identity of HPC volunteers from this perspective is not in opposition with the performance of tasks, but situates the latter within the context of relationship-building. What is at stake for each patient and what can be done becomes clear through a quality encounter and relational attunement. The concept of ‘being there’ used

### The value of HPC volunteering lies in this precious thing of just ‘being there’

by volunteering organisations in several countries seems to offer a good base from which to research the theoretical framework of HPC volunteering, as well as develop training, supervision and self-reflection.

### Reflections and conclusion

We have attempted to build a common understanding of what HPC volunteering is, the common types, contributions and benefits of volunteers in Europe, as well as their motivations, identity and position. To this end we organised two European symposia on volunteering, reviewed minutes from the EAPC Taskforce meetings and relevant literature, and organised a Delphi-like consultation with experts from six European countries, seeking to achieve consensus. The results of our work show that there are no significant differences between participating European countries regarding the position, contributions and identity of volunteering.

Among the wider Taskforce membership, all agreed that care-focused volunteering is a relational activity. When positioned as such, HPC volunteering has a lot to offer, not only to people with life-limiting conditions and those close to them, but also to healthcare organisations and paid staff: volunteers may have different views than paid medical staff and detect different signals from patients, which they can then pass on to paid staff. For society, HPC volunteering is an expression of the caring community; it shows a connection between society and the terminally ill. Further theoretical analysis of the contributions of volunteers would be welcome.

While the concept of 'being there' was embraced by all members of the Taskforce Steering Group as well as the six consulted experts, some interesting reflections emerged. Clearly, the concept does not capture the whole extent of volunteer activity; for example, volunteers who mostly support an organisation through fundraising or administration will have a more task-oriented understanding of their role. Some volunteers would be more comfortable with the concept of 'being there' because it suits their personality, while others would prefer to think about their role as focused on performing tasks. This could be an interesting topic for

further research. Some hospices – for example, in the UK – have a business-oriented approach to volunteer management and focus on numbers and tasks, rather than valuing them 'being there'. Using 'being there' as a concept for volunteering in caring roles might help volunteers recognise the importance of this.

Further theoretical and empirical elaboration is required; it may well show that the theoretical approaches of 'presencing' and of 'performing tasks' are not as contradictory as they may seem. The six experts suggested that the Asklepan dimension of care may be important for all involved in HPC. There may be merit in exploring to what extent the Asklepan dimension has value when assessing the quality of care provided by paid staff. Empirical studies on this topic would be helpful to contribute to the debate on the quality and value of volunteering in HPC.

#### Declaration of interest

The authors declare there is no conflict of interest.

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