Colourful Lives of Volunteers in Hospice and Palliative Care in Europe

Final Report on the work of the first EAPC Task Force on Volunteering in Hospice and Palliative Care

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1. Introduction

This report gives an overview of the work and achievements of the EAPC Task Force on Volunteering (TF) in Hospice and Palliative Care (HPC). The EAPC Task Force on volunteering began in December 2013 and brought together practitioners, volunteers and researchers. Our approach involved both research and the sharing of practice and experience. The Steering Group comprised seven professionals and volunteers from Austria, Germany, Italy, Netherlands, Germany, UK and Poland and the TF had a wider membership of 32 people from 13 countries.

Findings from the work of the TF demonstrated that volunteers play a diverse and vital role within HPC services. With a demand for HPC steadily increasing in many countries, volunteers will continue to play a vital role in the future care of patients and their families.

2. Context for the work of the Task Force

Volunteers play an important role in a civil society and have had a long involvement in hospice and palliative care services in many countries in Europe. In some circumstances it has been volunteers who have identified a need for and set up services. Many HPC services depend on volunteers to enable them to deliver the range and quality of services that they provide. This includes both emotional and practical support to patients and families in hospices, hospitals, patient’s homes and in care homes. In some countries, volunteers also provide valuable support to the wider organisation through administration, fundraising and awareness raising. They have an important role to play and bring a unique quality to the care of patients and their families. However, it is clear, that despite a history of involvement in HPC, volunteers, are not always acknowledged as a part of the team around the patient and family, or their skills and expertise recognized.

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3. Aims and Activities

The overarching aim of the work of the TF was to develop a greater understanding of volunteering in the field and influence the development and improvement of practice. Informed by a series of group sessions held at the Symposium “Colourful Lives of Volunteers in Europe” at the EAPC Congress in Prague in May 2013, the specific aims were to explore:

- The roles undertaken by volunteers in HPC in Europe
- How volunteering is managed
- What training is offered to volunteers
- What the challenges are for volunteers, managers and organisations
- The numbers of volunteers involved in each participating country

Activities

There were five main areas of work:

1. A baseline survey of volunteering in HPC in Europe to explore numbers, roles, management, training and challenges.

2. The development of an EAPC White Paper on the contribution, position, identity and value of volunteering in HPC in Europe.

3. The development of a charter for hospice and palliative care volunteering in Europe

4. A stories project gathering the experiences of volunteers and volunteer managers in their own words

5. International symposium in Vienna in April of 2015 and a Series of Open Task force meetings where volunteers, paid staff and researchers engaged in sharing knowledge, practice and ideas through focused presentations and workshops.

These are discussed in more detail below.

4. Outcomes from activities

4.1 Baseline Study of Volunteering in Europe

This study explored the numbers, roles, management, training and challenges faced by volunteers and volunteer managers. Led by Professor Lukas Radbruch and Dr Katharina Pabst, from the University of Bonn. A total of 366 participants from 36 different countries took part, including 144 volunteers and 44 volunteer co-ordinators. Early results include:

- **“Typical Volunteer**: women above 50 years old: 50-80 years mainly in Northern and Western Europe, 20-50 years in Eastern Europe and 20-40 and 50-60 years in Southern Europe.
• **Main motivations** according to volunteers are altruism and giving back to the community, rather than self-promotion and personal gain.

• **Common tasks** are emotional assistance like talking, listening and being there for the patients and their families as well as preforming creative activities. Medical tasks are the least common.

• **Compensations**: Some Volunteers receive provision of transport, travel expenses or meals, only very few receive financial compensation.

• **Recruiting** is easy or very easy for almost half of the coordinators and difficult for a fifth of the coordinators.

• **Trainings** mostly take place before the first assignment and/or regularly. Median of training hours is 20.

• **Training topics** are very often structure and processes of care including communication skills and PC.

• **Time management**: Volunteering mostly once per week in the last months of life of the patient.

• **Recent developments** describe a change of the volunteer profile (younger, employed, less time resources, more demands and less commitment). More general interest and public presence of volunteering, PC, hospice, dying and death.

• **A challenge** for the volunteers is the cooperation with professional staff and confrontation with suffering.

• **Boundaries** are medical tasks and nursing”7.

The study suggests that volunteering is well established in many HPC services in Europe. Findings indicate that there is a desire to see volunteers accepted as having a separate and unique role alongside paid staff and family caregivers. It appears that the number of volunteers is growing, however, their expectations are also changing. They have less time to give and have higher expectations of how their time will be used.

In Southern and Eastern European regions volunteering is less common than in Northern and Western areas. Whilst it is not clear why, this may be related to the different role of family caregivers in these countries.

A key finding to emerge from this study was that very few countries collected data on volunteer numbers and activity. This means that it is challenging to monitor changes and trends and this will be a focus of the Second Task Force on volunteering.

The study is currently being written up with a view to publication in 2018.

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7 Pabst, Pelletari, Scott, Loth, Radbruch and the EAPC Task Force on Volunteering (2017) Poster Presentation EAPC 16 World Congress, Madrid
4.2 **White Paper on Volunteering**

One key focus of the TF was to explore and define the role of volunteers, clarifying the position, identity and value of volunteering in HPC in Europe with the intention of producing a White Paper.

The approach included:

- Analysis of existing literature
- Gathering information from workshops at two international symposia on volunteering
- Focus group and consensus discussions at task force meetings at the EAPC Congresses in Prague in 2013, Lleida, 2014 and Vienna, 2015.
- The development of discussion texts on the definition, typology, roles and position of volunteers.
- The circulation of discussion texts to experts in Austria, Germany, Ireland, Italy, Netherlands, Poland, Portugal, Romania, and the UK which enabled a consensus to be reached.

The White Paper “Defining volunteering in Hospice and palliative care in Europe” was published in the European Journal of Palliative Care in 2016. The EAPC White Paper defines Volunteering in Hospice and Palliative Care as “the time freely given by individuals, with no expectation of financial gain, within some form of organized 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)”.

4.3 **The development of an EAPC Charter on Volunteering**

The development of the Charter was closely linked to the work leading to the White Paper. The aim of the Charter is to

- “Promote the successful development of volunteering for the benefit of patients, families and the wider HPC community.
- Recognise volunteering as a third resource alongside professional care and family care, with its own identity, position and value.
- Promote research and best practice models in the recruitment, management, support, integration, training and resourcing of volunteers”.

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The four key messages are:

1. Recognise the important role of volunteers in the sustainability of HPC services.
2. Promote volunteering in the direct support of patients and families
3. Ensure the effective management of volunteering including clearly defined policy on roles, careful recruitment, selection, training and development.
4. Ensure effective support for volunteering at organisational, local and national levels.

Information for the Charter was gathered in a number of ways:

- Initially an international symposium volunteering in hospice and palliative care in Prague in May 2013.
- Further data were collected through feedback on draft versions of the Charter, at workshops at a second international volunteering symposium in Vienna (April 2015), at the EAPC Congresses in Copenhagen (May 2015) and Dublin (June 2016).
- Email-consultation was also undertaken with researchers, volunteers, paid staff and EAPC Board members.

Feedback and ideas from people from 13 countries (Australia, Austria, Belgium, Croatia, Germany, Hungary, Ireland, Italy, Netherlands, Poland, Portugal, Romania and UK) was incorporated into the Charter. The Charter was subsequently accepted as an EAPC Charter and was launched at the EAPC 15th World Congress in Madrid in May 2017.

There were a number of launch activities including 1) a Charter stand where delegates could access information and sign the Charter, 2) an Open TF Meeting to discuss the Charter and 3) a launch presentation at the closing plenary session.

The Open TF meeting comprised a presentation of the Charter key points with a discussion on the significance of the Charter with a panel of international HPC leading experts including Prof. Philip Larkin as EAPC president, Dr. Julie Ling as CEO of EAPC, Prof. Catherine Walshe, EAPC Board member and liason to TF, Dr. Stephen Connor, Dr Roberto Wenk, past president of IAHPC as Executive Director of WHPCA. This was followed by small group discussions on taking forward the implementation of key points. The panel discussed the importance of volunteering to hospice and palliative care, recognising that in low-income countries palliative care could not be delivered without volunteers.

For more information on the Charter please see:

For more information on the Background information to Voice for Volunteering: The EAPC Madrid Charter on Volunteering in Hospice and Palliative Care please see:
4.4 The Story Project

Recognising that too often we speak about volunteers and their work rather than learning directly from them about their experiences in their own words, the TF developed the Stories Project. The aim of the project was:

- To understand more about why volunteers do what they do
- How they experience volunteering
- What it means to them to be a volunteer in HPC
- To understand more about the role of volunteer managers and what working with volunteers means to them.

The research questions was ‘What does volunteering mean to volunteers and volunteer managers?’

Key contacts in eight countries were approached to identify five volunteers from their country, who were willing to write a short story of their experiences (maximum 500 words). Volunteers were given two questions to help to frame their story:

- What do you do as a volunteer?
- What does volunteering mean to you?

In addition, stories of a similar length from two volunteer managers in each of the eight countries were also collected. Volunteer managers were given three questions to help to frame their story:

- What tasks does your role as a volunteer manager involve?
- What do volunteers mean to your organisation?
- What does working with volunteers mean/bring to you?

A total of 37 volunteer and 13 volunteer manager stories were received from eight countries; Austria, Finland, France, Germany, Italy, Netherlands, Poland and UK. The stories were translated into English and a small team undertook the analysis using a qualitative framework approach. Early results suggest that:

- Most volunteers (34) were involved in providing practical, emotional and social support to patients and families.
- Many volunteers had more than one role
- Most respondents (32) were involved in different adult HPC settings including patient’s homes, hospices, hospitals and care homes.
- Two volunteered in children’s palliative care services
- Two provided bereavement support to families.
- Volunteers often had more than one role and were involved in a range of activities including taking patients out, shopping for patients and families, driving them to medical appointments, providing emotional support, listening to patients’ and families’ needs, sitting with those who were dying, and offering bereavement support.
It was clear that volunteers find significant meaning in what they do. For many it is an important part of their life and their values. Volunteers often spoke about the ‘privilege’ of being with patient and families at such a precious time. They told of how much they learned from encounters around death and dying and the importance of ‘being there’ for patients during this period in their life. Others describe the challenges that they faced working in HPC and how hard this can be at times. Many felt that their lives were enriched by their experiences.

Once the analysis has been completed, the findings will be written up for publication. Findings will be presented in an oral presentation at the EAPC Research Congress in Bern in May 2018. It is also planned to make the stories available electronically in both in the original written language and in English.

The analysis of the Volunteer Managers stories has still to be undertaken.

4.5 International Symposia and Open Task Force Meetings

International Symposia

**Prague 2013.** The idea for the TF was launched at an international Symposium on volunteering, “Colourful Life of Hospice Volunteers” held at the EAPC Congress in Prague. Around 100 delegates from 32 different countries attended the event and included volunteers, volunteer managers, palliative care professionals and researchers. As outlined in the introduction, this event was used to gather information on HPC volunteering in Europe, recruit members and identify the key areas of work for the proposed TF.

The day produced a rich source of information and feedback was very positive. It was agreed that we should continue to run similar events, if funding was available.

**Austria 2015.** Costs and lack of funding prevented a repeat of this in Copenhagen, however, the TF was pleased to be invited to hold a second Symposium: “Colourful Life of Hospice Volunteers” at the Austrian Palliative Care Congress in Vienna on 9th April 2015. This was held in partnership with Hospice Austria, who also funded this event. Over 160 delegates from 12 countries attended and delegates again comprised volunteers, volunteer managers, palliative care professionals and researchers. The aim was to continue to gather information on volunteering in HPC from different countries to inform the work of the TF and to discuss the development of the Charter. Networking between European countries, learning from each other and recognition of volunteers were also important goals.

Learning from the discussion groups at this event suggested that there were similarities across a number of countries including:

- A growing demand for HPC volunteers
- A change in volunteering as a result of ageing populations and later retirement, increase in women in paid employment
- A rise in the ‘the new volunteer’ who has less time available, volunteer for shorter periods of time with more interest in project work.
Motivations are changing with volunteers interested in personal development, offering specific skills with increased expectations of their volunteering.

Recognising the importance of volunteers in spiritual care

Initial and ongoing training and supervision of volunteers is essential for quality work.

A number of challenges and opportunities were also common to different countries including:

- The need to improve relationships between volunteers and paid staff.
- Volunteers today want to be seen more as equal partners.
- Paid staff need to understand more about what volunteer care givers provide.
- Acknowledging the importance of the culture of volunteering.
- Getting the balance right between standards and organisation and the freedom of volunteering.
- The challenge of retaining volunteers after training.
- The need for more HPC volunteering research to inform development.

Once again lack of funding prevented a similar Symposium being held in Madrid. However, funding is being sought and plans by the Second Task Force on Volunteering are underway for such an event to be held on 22 May 2018 in Berlin prior to the EAPC 16th World Congress.

Open Task Force Meetings and Presentations

Task Force meeting in Lleida
The first open meeting of the TF was held at the EAPC Congress in Lleida in 2014. Members from Ireland, Netherlands, UK, The Azores, Austria, Italy and Germany attended. This provided an opportunity to discuss the proposal for the stories project and White Paper on volunteering.

EAPC Congress in Copenhagen
The TF delivered a Meet the Expert Session attended by over 30 delegates in Copenhagen. Presentations gave a brief overview of early outcomes from the Task Force work and covered similarities and differences in volunteering in different countries including factors that influence volunteering and their impact, roles, training and legislation, the changing nature of volunteering and the challenges and opportunities. Presentations also considered values, principles and definitions of volunteering, the unique role that volunteers play, and considerations for organisations as they develop volunteering. This also provided an opportunity for further discussion of the Charter.

EAPC Congress in Dublin
The TF held a second open meeting at the EAPC Congress in Dublin in June 2016. This meeting included an update on Task Force progress from Leena Pelttari and series of short presentations on approaches to volunteering research including:

- Professor Anne Goossenssen “A Care Ethical Perspective on HPC Volunteering – the consequences for designing research”.
- Professor Catherine Walshe gave an overview of the “Training of Volunteer
Managers and Volunteers as part of the research team” and
- Dr. Ros Scott spoke on a “Theoretical Model of Volunteering and Hospice Sustainability”.

Subsequent discussions took place considering the different approaches to volunteering research and there was an agreement there should be a volunteering research interest group within the Task Force. This group is now established and held a first meeting at the EAPC Congress in Madrid. This interest group will be a focus of the Second Task Force on Volunteering.

5. Reflections

The work of the first TF was successful in achieving most of the aims. It has helped to develop a clearer understanding of HPC volunteers in Europe; their activities, management and training and the challenges facing volunteers, volunteer managers and organisations. The profile of volunteering has been raised through the Charter, symposia, publications and blogs.

It is clear that there are many similarities across Europe in volunteering and there is strong agreement on the importance of volunteers in contributing to the holistic care of patients and families.

It proved impossible, however, to gather accurate data on the numbers of volunteers involved as only a small number of countries collect such data on an annual basis. It is clear that this is an area that needs to be addressed.

Throughout the life of the Task Force, new contacts, alliances, networks and friendships have been made which empower and strengthen joint working across countries in the further development of volunteering.

6. Next Steps

Much has been achieved and there is still much to do. The work of the First TF has formally come to an end. However, second TF had recently been approved by the EAPC Board which will ensure the completion of the European Survey and Stories project in addition to focusing on the implementation and evaluation of the impact of the Charter.
Appendix 1

Publications and blogs

Papers


Blogs


EAPC Blog 3 August 2016 EAPC White Paper: Goossenssen, A., Somsen, J., Scott, R., Pelttari, L. Understanding volunteering in hospice and palliative care

EAPC Blog April 25 2016 Scott, R., Pelttari, L. In their own words – The colourful lives of hospice and palliative care volunteers in Europe.

EAPC Blog March 2015 Scott, R., Pelttari, L. Colourful lives of hospice volunteers in Europe 2.
