

Notes of 2nd Symposium The Colourful Life of Hospice Volunteers in Europe: Volunteering in Hospice and Palliative Care

9th April 2015 Vienna

1. OPENING

Rudolf Hundstorfer, Minister of Social Affairs, Austria opened the conference welcoming delegates and stressing the Austrian Government's commitment to hospice and palliative care. He also spoke of the valuable and important work undertaken by volunteers.

Prof. Herbert Watzke, President of OPG-Congress, Austria also welcomed delegates and highlighted the importance of the work of volunteers in Hospice and Palliative Care and thanked Hospice Austria for the excellent organisation of this important international symposium.

Harald Retschitzegger, President of OPG (Austrian Palliative Care Association) welcomed all volunteers and volunteer managers and thanked Hospice Austria for the excellent co-operation.

Waltraud Klasnic, President of Hospice Austria welcomed delegates, spoke of the government's commitment to hospice and palliative care and the important contribution from volunteers.

Prof. Sheila Payne, President of EAPC gave a welcome by video, outlining the work of EAPC and highlighting the role of Task Forces and the great work of the EAPC Task Force on Volunteering

Ros Scott and Leena Pelttari, Co-Chairs of EAPC Task Force for Volunteering on Hospice and Palliative Care in Europe gave an overview of the structure and purpose of the Task Force and a brief summary of current projects. Leena Pelttari, welcomed delegates from Austria, Germany, UK, Poland, Portugal, Italy, Hungary, Romania, Netherlands, Belgium and Croatia.

Karl Bitschnau – Vicepresident of Hospice Austria also welcomed delegates and spoke of the importance of the day devoted to the discussion of volunteering and of looking to the future in Europe.

2. FUTURE OF VOLUNTEERING IN EUROPE - HOW IS VOLUNTEERING CHANGING: CHALLENGES AND CHANCES **Summary of key points**

The following section is a summary of key points from the presentations.

Full presentations and country- posters are available at the homepage of Hospice Austria: www.hospiz.at

UK and Ireland : Ros Scott

Thank you to: Geralyn Hynes Associate Professor in Palliative Care and Frances Ryan Associate Professor Lecturer, School of Nursing and Midwifery, Trinity College, Dublin for their contributions to this presentation.

- The place of volunteers: Initiating and developing hospice services, as trustees of hospices, practical, social and emotional support to patients and families, supporting staff, supporting the organisation.
- Models of volunteering UK and Ireland: Formal hierarchical service-delivery model, hundreds of volunteers in each organisation, volunteers with specific roles, overall management by Volunteer Managers, local line management by professional staff, some managed by other volunteers.
- Statistics UK Estimates: 160,000 volunteers, 23 Million hours of time every year, Economic value approximately £150 Million
- Standards and Training: No legal definition of 'volunteer', legislation affects directly and indirectly, regulatory care standards and volunteers, investing in Volunteers – national UK standard optional, no national palliative care volunteering standards, training provided by individual organisations.
- Challenges: Changing society, increasing demand for hospice and palliative care services, funding difficulties, changing volunteer expectations, more interest in short term opportunities, more choice of how to spend leisure time, increased competition for volunteers.
- How is volunteering changing? Skills now more effectively utilised, empowerment of volunteers, volunteers more interest in care focussed roles in Ireland, development of community models- led by volunteers, volunteers more involved with patients at home, UK resources for development.
- Opportunities: Engagement with patients and families in identifying new ways for volunteers to support, moving away from 'business' approach to management, full recognition of the role and place of volunteers, better training for staff in working with volunteers, community models of volunteering, national framework for training.

Poland and Eastern Europe: Piotr Krakowiak

- In the beginning of palliative care in Poland in 1981, all work was undertaken by volunteers with help from Western Europe.
- Once the structure of hospice and palliative care became more developed, after socio-economic changes in 1989, it became dominated by professionals and volunteers numbers have decreased.
- Since 2004 national projects involving volunteers and stressing the importance of social support for end-of-life care have been developed (see more: www.hospicja.pl)
- Now Poland is returning to the roots of hospice and palliative care. Guides for volunteers and for volunteer co-ordinators have been developed as

- textbooks available for hospices and general public.
- Volunteer Co-ordinators were once all volunteers but are now paid. Proper coordination ensures success with volunteering, but there is no funding for this in many Palliative Care teams.
 - The textbook regarding end-of-life issues and volunteering is used in kindergarten through to secondary schools, universities and in the community to explain hospice and palliative care volunteering.
 - Getting hospice and palliative care and volunteering accepted by government ministers has not yet been successful.
 - Volunteers often have a key role in spiritual care and often patients prefer to talk to a volunteer.
 - School pupils and university students get special points if they volunteer in Poland. Many Palliative Care centers use these mechanisms to invite pupils and teachers to work together in charitable events and fundraising.
 - Poland needs to involve volunteers in Palliative Care because of limited resources compared to Western Europe. The situation is similar in other Eastern European countries.

Netherlands and Belgium: Jos Somsen

Belgium

- More is known about volunteers in Flanders than in the Walloon region. The last survey on PC volunteering in Flanders dates from 2005, new numbers are currently being collected.
- Volunteers in Flanders are involved in 'being there', grief counselling and non-direct tasks.
- There is growing demand for volunteers,
- Clients are becoming more critical.
- Volunteering in general seems to be changing in the same way as in the Netherlands (see below).
- The main motivation for HPC volunteering seems to be changing from a focus on doing good to others to a focus on one's own spiritual and personal growth.
- There is a growing need for role clarification in relation to formal care.

Netherlands

- 88% of HPC volunteer hours is spent in care-focused roles, strong points of the Dutch situation include an extensive national curriculum for volunteers, coordinators and board members, a national organization for HPC volunteering and government funding for HPC volunteering, which covers 62% of the costs for the volunteer and hospice organisations.
- Major demographic and social developments that influence HPC volunteering include the ageing population and later retirement, increase in women in paid employment, 'the new volunteer' (less time, shorter commitment to organization, interested in personal development, offering specific skills).

- Big political changes are causing a move from formal to more informal care and from residential to extramural care.
- These developments lead to an expected increase in demand for HPC volunteers in home and hospice settings, and an increasing supply of potential volunteers. From 2040 onwards we expect volunteer shortage, because of a decrease in the supply of volunteers with a still increasing demand for HPC volunteering (peak in 2050).
- Care is becoming increasingly complex because of less availability of formal care and conditions such as dementia.
- Boundaries between professional and volunteer care may be changing. This calls for careful discussion, attunement with formal and family care, clear policy and good training of volunteers. Quality indicators are being developed and a new post of Professor for quality of HPC volunteering is in preparation.
- Volunteering is developing in new settings such as nursing homes, however funding is necessary to support this work.

**German speaking countries: Austria, Germany and Switzerland:
Leena Peltari**

Figures

	Austria	Germany	Switzerland
Volunteers	3.283	ca.80.000	ca.2.000
Volunteer Teams	156	1.500	122
Time (h)	385.596	ca. 3.040.000	
Patients	11.022		

Organisation

- Organized in teams with (paid) coordination
- In Austria important part of graded Hospice and Palliative Care System
- In Germany regulated in law § 39 a SGB V
- In Switzerland as groups of formal volunteers (sometimes with coordination)
- Volunteers work with patients and their families at home, in hospices, palliative care units, hospitals and nursing homes
- Volunteers help in the organization, administration, PR and media work and fundraising
- Many board members in hospice and palliative care organizations work on voluntary basis

Training

Austria

- Austrian wide Curriculum by Hospice Austria with 80 hours of theory and 40 hours of practical training
- Curriculum for additional training in childrens hospicework with 40 hours of theory and 40 hours of practical training

- Curriculum for bereavement counselling with 80 hours or 110 hours
- 8 hours training per year compulsory
- Supervision compulsory

Germany

- 50 hours theory and 50 hours practical training in 6 – 12 months
- Ongoing training and supervision compulsory

Switzerland

- Courses between 2 days and 120 hours
- Most similarities in curricula between Caritas and Red Cross Switzerland with minimum of 50 hours, ongoing training recommended

Funding

Austria

- No general public funding, varies by region
- Sponsoring by Erste Foundation and Sparkassen

Germany

- § 39 a SGB V is the law which regulates public funding

Switzerland

- Public and private funding

Changes

- Hospice movement has gained strength, has become more selfconfident and is growing
- Volunteers have become part of the health and social system – more structure with new challenges
- Volunteers have less time available and volunteer less for shorter periods of time, more interest in project work
- Motivation has changed - people wanted to help, now people want more to develop themselves personally and to help their professional work
- Older people with dementia are becoming a new area of work for hospices
- Children's hospice work and bereavement are also growing areas for hospice volunteering.
- More young volunteers and more men are volunteering

Challenges and Opportunities

- Co-operation between volunteers and paid staff: same eyelevel is needed
- Sometimes too many “helpers” with competition
- Culture of volunteering often needs acknowledgement and new fire
- Standards and organisation vs. Freedom of volunteering
- More and more administration through public funding
- More research about volunteering is needed for the further development
- Professional care givers need to know more about what volunteer care givers provide

- The demographic developments influencing hospice and palliative care and volunteering are similar to those in the UK
- There is a need to recruit more volunteers and retain them
- Integration of hospice approach in the society, e.g. schools
- Hospice culture is an expression of human values: solidarity and community caring
- In both Austria and Germany there are positive political processes, and high media interest relating to hospice and palliative care.

Italy: Rosalma Badino

- There have been many changes in last 10 years.
- The number of volunteers is now up to 7,500.
- Volunteers are involved in therapy, music and drawing.
- There are now more young people and more women than men.
- Men offer social support or reading to patients but find more difficulty with emotional tasks. There is a need to attract more men to support male patients.
- Young people are motivated by gaining new skills or experience for work.
- New volunteers are motivated both by altruism and personal gain.
- With an ageing population demand for hospice and palliative care will increase and we will continue to need new volunteers.
- We also need to convince new volunteers of the importance of ongoing training to reduce the risk of burnout.
- We also need to address communication difficulties with professionals who see the role of volunteers as peripheral.

Discussion

During the discussion areas such as training for volunteers, working more closely with schools and palliative care volunteering as part of medical, nursing and social work training was discussed.

Hungary has student education for those at high school who need to volunteer whilst they finish high school. Hospice volunteers undertake a 40 hour training course and they volunteer with patients after training. Volunteering is compulsory for young people in Hungary.

In Romania most volunteers are young people. We also have to consider how we approach short-term volunteering. Piotr Krakowiak suggested that from experience in Poland short term volunteers are involved as drivers and to repair cars. The involvement of prisoners as volunteers has been very successful in Poland.

3. STORY OF MY VOLUNTEERING LIFE

Ros Scott introduced the Stories Project planned by EAPC-Task Force. We always talk about volunteers and about volunteer managers but it is important to

hear about their experiences in their own words. The project plans to invite stories from volunteers and volunteer managers and to make these available electronically both in the original language and in English so that we can share experiences and ideas. Whilst the project process still had to be finalised by the Task Force, it was recognized that the start of the project was in this session today.

Karl Bitschnau then invited the delegates to speak to the person or people next to them and to tell their story of volunteering or of volunteer management. After a period of lively discussion amongst delegates, they were invited to write their story on coloured card and hang them on the strings provided around the room. There were many touching stories displayed in the room highlighting the colourful life of volunteers.

Two volunteers chose to share their very touching stories with all delegates. Both were very moving and highlighted the important role of volunteers in providing care and support to individuals and service to society.

4. WORKSHOPS

After lunch provided by Hospice Austria, delegates had the choice of attending the opening of the Austrian Palliative Care Congress or to take part in one of four workshops:

- 1) Spiritual Care: Margit Gratz (Germany) and Piotr Krakowiak (Poland)
- 2) New Aspects and Challenges of Volunteering
Ros Scott (UK) and Beatrice Manea (Romania)
- 3) Management and Coordination
Christof Eisl (Austria) and Sabine Janouschek (Austria)
- 4) Open Discussion: Topics defined by participants
Karl Bitschnau (Austria)

A summary of the outcomes from the workshops are listed below:

4.1 Spiritual Care

The differences between spiritual care and religious assistance were underlined in the context of people with religious traditions and those outwith the faith communities.

Practical ways of involvement of team members and volunteers in spiritual care were also discussed.

Participants raised many practical issues based on their experiences, asking for tools and advice to enhance spiritual care.

Information regarding curriculum for training volunteers in spiritual care was presented and the possibilities of its translation from German into other languages were explored.

The workshop also enabled an exchange of good practice in spiritual care. Involving volunteers was encouraged, as it is an important aspect of holistic palliative care.

4.2 New Aspects and Challenges of Volunteering

How is volunteering changing?

- Hospice care for children in Austria and Hungary
- Growing numbers of patients and volunteers
- Growing number of young people as volunteers largely as a result of national initiatives in Poland and Italy
- Competition less now between volunteers and professionals
- New groups of volunteers: prisoners, disabled people, silver power, pupils
- Political and economic changes - losing communism, austerity
- More 'selfish' volunteers
- New law in Romania prevents pupils under 15 years volunteering

Challenges

- Volunteering seen as Patriotic work prior to democracy (Romania)
- How much medical information do volunteers need about patients
- Challenge to keep/ retain volunteers with organisations
- Difficult to attract men as volunteers- men prefer practical tasks
- Spontaneous volunteers - to help with specific tasks
- Challenges in attracting young volunteers
- Increasing competition for volunteers
- Matching volunteers with patients
- Intercultural communities
- Volunteers have different tasks in different countries
 - Difficult to keep volunteers in some roles.
- Retaining volunteers after initial training
- Not obligatory to have supervision - leads to volunteer burnout

4.3 Management and Co-ordination

The workshop began with an extensive round of introductions with everyone talking about him/herself, the tasks and the duration of the volunteer engagement. Key issues in coordinating volunteers quickly became clear. The group had a mix of delegates – some came from inpatient institutions as well as

home care. Some were experienced and some had just started, some were working in a supportive surrounding, some had to take over “a mess”.

We shared experiences and insights how to attract and train volunteers starting from first contact until admission. We talked about ways of financing and how to turn the work experience, required as part of the training, into a success. Although there are Austrian standard guidelines for training and running a team the implementation varies greatly. All coordinators agreed that investing in the initial and ongoing training of volunteers is the significant contribution to achieve a high quality of work. Moreover the training presents an opportunity for self-development of volunteers and at the same time it is a sign of appreciation by the volunteer organisation.

We also shared much about volunteers' different areas of engagement and tasks and how to distinguish between hospice care and visiting, between volunteer tasks and paid services. Reports about asylum-seekers and prisoners as volunteers in community work were very interesting.

The (non)-cooperation between volunteer hospice teams and home palliative care support teams was also discussed. Experiences ranged from very supportive to highly competitive with palliative care teams “replacing” volunteers teams. Everyone in the group agreed that hospice and palliative care have to be seen as a whole and professionals have to be at the same eye level with volunteers. How this ideal is translated into reality often depends on the people involved and their personalities. What fosters and enables cooperation is a clear description of tasks, a knowledge of each other and of the mutual tasks. In some regions attracting and coordinating coordinators is a big challenge. Coordinating is a complex task, the degree of employment is often very low.

The participants' statements in the workshop made clear how valuable the volunteers' contribution is and how challenging the task of coordinating a team is with new challenges constantly arising.

4.4 Open discussion

This session covered:

- Helping activities and how to accompany a patient as a volunteer in hospices
- Models in place - how should volunteers work?
- Dying is a taboo - people don't want to know what volunteers do
- There is a need to raise awareness of volunteering
- The challenge of how to increase number of male volunteers
- How to define hospice and palliative care as it has different meaning in each country
- How to improve support for co-ordinators

5. FIRST RESULTS OF STUDY ABOUT VOLUNTEERING IN EUROPE###

Katharina Pabst and Michaela Hesse, University of Bonn

The aim of the study is to gather new findings about the numbers, role, motivation, training and challenges of volunteering and volunteer management in Europe. Three questionnaires were developed in different languages, one for national associations, one for volunteer managers (two per country) and one for volunteers (five per country). Volunteer Managers and Volunteers are still being recruited to the study.

Early results include:

- Largest numbers of responses were from UK, Germany, Ireland and Italy.
- Which tasks do volunteers do? - top five included creative activities, emotional attention, conversation, emotional support work with the patients family and sharing activities with patients.
- Volunteers undertaking medical tasks were very rare.
- Volunteers' motivation was altruistic and included: to help others, to give back, to care, to support.
- Only a small number of responses were about making a better impression, a hobby, being seen more positively or a duty. Selfish motivation was rare.
- Hours of training ranged from 2-160 hours, with the median being 20 h
- The advantages of volunteers reported included: time - they have more time, money - keep costs down so money can go to patients and extras - volunteers offer services not covered by professionals, individual attention which is really special.
- The greatest challenges included: co- operation between paid staff and volunteers, clarity about responsibilities, finding the right volunteer, differentiating between suitable and unsuitable people, preventing burnout
- It is important to create good framework so that volunteering can be properly supported.

6. EMPOWERMENT OF VOLUNTEERING – EUROPEAN CHARTER

Jos Somsen and Anne Goossensen

Anne introduced the EAPC Task Force's Position Paper and the methods by which this had been developed. Literature reviews had been undertaken, information from minutes of meetings had been used to build cornerstones of knowledge. A consultation using a Delphi inspired approach had then been used to gain consensus. One of the key points from the paper was that volunteering was important for relationships with professionals and families. Volunteering

makes a unique contribution – it is not little sister of the professional. Volunteering is about building relationships and the art of connecting with people.

Jos and Anne then ran an interactive session with delegates, introducing the ideas behind an European charter for hospice and palliative care volunteering, the key points of which had been taken from the position paper. Earlier in the day delegates had been asked to suggest key stakeholders in helping to promote and empower volunteering and these were then discussed. These included:

- Lobbying organisations for example Hospice UK.
- National organisations - however it was recognized that not all countries have these organisations.
- Current volunteers – we need to ask volunteers what the European charter should include.
- Family doctors and other professionals - if they are in favour they will recommend
- Connecting with young people from an early age - connection to death & dying and volunteering

There was almost unanimous agreement from all delegates on the stakeholders however it was recognised that it is not possible to include everything in a charter.

Jos Somsen then introduced the key points from the position paper and delegates were asked to indicate their approval or otherwise using green and red papers. There was unanimous agreement for all points.

7. Summary and close

Waltraud Klasnic, President of Hospice Austria then summarised the day and thanked the organisers, speakers, chairs of the day, workshop leaders and translators.

Ros Scott/Leena Pelttari
16 April 2015

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