



The full range of Volunteering

Views on Palliative Care Volunteering from seven countries as gathered in March 2014 in Bonn, Germany

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Preface

According to the history of hospice care as a citizens' movement, voluntary work is an essential part of palliative care in Germany and it is regulated by law in §§37b and 39a SGB V. The development of networks and services has led to more specialisation and professionalization. Hospice and palliative care were limited to cancer patients in the beginning. Meanwhile also neurological (Parkinson's disease, dementia, ALS), cardiovascular and pulmonary diseases have come into focus of hospice and palliative care. In addition to the change in epidemiology the demographic change is a big challenge for society. There is a rising number of elderly and multimorbid patients, who need access to palliative or hospice care. All these changes may require a revision of the role of volunteers in palliative and hospice care.

The study week, 'Volunteer work in hospice and palliative care – sustainable concepts for the future?', was held from 31 March to 4 April 2014 at the Malteser Hospital Bonn and was funded by the German Ministry of Education and Research (Bundesministerium für Bildung und Forschung, BMBF). In a multiprofessional and interdisciplinary discourse we wanted to discuss normative, legal, political, health - care, spiritual and social aspects of voluntary work, and also identify interdisciplinary needs for research.

The study week aimed to provide the opportunity to identify challenges, exchange experiences, elicit needs for research and open up international discussion. Thirteen scholars from five countries participated and presented their projects dealing with different aspects of volunteering, such as the challenge of an ageing society; motivation, attitudes and characteristics of volunteers and how volunteers cope with grief and spirituality. In addition, eight renowned international experts gave talks, enriched the discussions and enabled an open discourse with the participants: Fatia Kiyange (APCA – African Palliative Care Association), Werner Schneider (professor of sociology, University of Augsburg, Germany), John Ellershaw (professor of palliative medicine, University of Liverpool, UK), Piotr Krakowiak (director, Hospice Gdansk, Poland), Yvonne Engels (assistant professor, Radboud University Nijmegen Medical Centre, the Netherlands), Thomas Klie (professor of public law and administration, University of Freiburg, Germany), Ros Scott (EAPC Task Force on Volunteering) and Leena Peltari (EAPC Task Force on volunteering, Hospice Austria).

The discussions throughout the week, and across the continents and settings, demonstrated that there is a need to focus on at least three fields of interest:

Terminology – What does it mean when we talk about volunteers, voluntary work, professional volunteers, civic engagement?

Guidelines – There seems to be a need for guidance, for example with the definition of standards and guidelines - but how much do standards impede the flexibility that is a core element of volunteer work in hospice and palliative care?

Core competencies – What are the core competencies of volunteers in hospice and palliative care – across settings and healthcare systems?

Experts and participants of the study week contributed to this publication to give insight into the different approaches to volunteering in their country.

Our thanks go to the German Ministry of Education and Research (Bundesministerium für Bildung und Forschung BMBF) for funding this week. Furthermore we want to thank the experts for their talks, their discourse and their contribution to this publication. Last but not least we want to thank the scholars for the vivid discussions, the good collaboration and their support to publish and share their experiences of the study week.

To structure this publication you find at first the expert's talks and second the contributions of the scholars which are arranged to main themes. In addition we distinguished between research projects and research findings. Due to the nature of contributions you will find overlapping information especially given in introduction or background parts. We decided not to shorten the texts and we do not take any responsibility for the content of the articles.

Bonn, May 2015

Letter from the Editor

I am working in pain management and palliative care for more than 20 years now, and have been in contact with volunteers continuously throughout this time, including volunteering as president of the small volunteer hospice service in my home town for three years now. Throughout these years I have noticed some changes in the profile of hospice and palliative care volunteering in Germany. This included in one direction the increasing emphasis on appropriate training and supervision, leading to some sort of professionalization of the volunteers. And curiously enough, this has led to some restrictions in the range of activities.

For example, volunteers will no longer agree to supervise the patient's medication and certainly will not apply subcutaneous injections, which some of the volunteers had done in the early years. With the training they have learned that these are not volunteer tasks, that there may be liability issues and that they just should not get involved with the medication and the symptom management. Similarly, some volunteers will not do household work or shopping for the patient, as they have learned that their volunteer focus is psychosocial support. So with the ongoing development volunteers become more professional, but there is a cost of this with loss of flexibility, as volunteer work gets narrowed down and streamlined.

At the same time, I noticed that the development of hospice and palliative care in Germany and the implementation of general and specialized palliative care in the health care system in some cases has alienated the volunteer services and the rest of the care providers. For example, general practitioners, oncologists, but also nursing home staff get interested and start working in palliative care, but often do not know about the range of support nor about availability of volunteer services in the region.

I did get very different impressions on volunteer work from congresses and other visits in other countries. A man stood up at the congress of the African Palliative Care Association and wanted to talk about his problems with volunteering in an African country. He felt severely stigmatized, working as a male volunteer in a caring role, something that traditionally is considered a woman's role.

Later on, I visited hospice and palliative care services where volunteers were used as community health care workers, or for case finding, roles that are very different from those of volunteers in our German setting.

These experiences led to the idea of the research workshop on the roles and functions of volunteers in hospice and palliative care. The results of the workshop with contributions from invited experts and from participants are presented here, depicting the rich experience that volunteers have and what they can contribute to the care of the severely ill and dying patients and their families.

I hope that this will offer new insights to the reader, and that it may be useful as a sampler with new ideas, each of which the reader can take and test for his own setting, whether it might offer something new and worthwhile to add to range of options in the care of the patients.

Bonn, 24th April 2015 Lukas Radbruch

Lectures

F. Kiyange:

Volunteers in palliative care in Africa

My focus is on volunteers in palliative care in Africa. I want to characterize several facts: First, Africa's disease burden to better understand the role of the volunteers there. Furthermore the volunteer models and their categories are described. Other topics are the patients' level and health systems related outcomes associated with voluntary work, motivation issues and legal, political, health care, spiritual and social implications. Also lessons and recommendations and research areas are part of my speech.

Africa's disease burden.

Africa's total population is about 1.033 billion which is about 12% of the global population. Its average life expectancy is with 53 years way below the world's average of 67. An important fact about Africa is that 70 % of the HIV patients live in Africa, and in 2010 70 % of all new infections globally occurred in Sub-Saharan Africa. So most of the people dying due to AIDS live in Sub-Saharan Africa. That is why HIV in Africa is contributing to a very big number of patients needing palliative care. Some countries in Southern Africa like Swaziland even have HIV prevalences of 20 %, among which are many children.

Other illnesses leading to death in Africa are non-communicable diseases (NCDs) such as cardiovascular diseases diabetes and cancer. Nowadays they are the number one cause of death worldwide. The WHO suspects that in Africa NCDs will increase immensely in the next 20 years. Cancer being generally presented very late in Africa leads the need for palliative care. Unfortunately there is no accurate data. Anyway, due to the lack of health facilities, some people in for example Uganda never see any health worker in their life.

Both HIV and NCDs are interplaying with each other, thus HIV associated cancers like Kaposi Sarcoma have increased. Other HIV associated illnesses are mental and neurocognitive disorders; diabetes, renal disease, cardiovascular diseases etc. Some patients are even developing all of the HIV-associated diseases. In African oncology units about 65 % of the patients are HIV positive. Another interplay between an infectious disease and a NCD is the one between Hepatitis B and Liver Cancer. So the palliative care and also the health care in general needs an integrated approach covering both NCDs and infectious diseases particularly HIV and cancer. Hence African governments are trying to support integrated services being also able to care for children rather than highly specialized or parallel systems.

Also emerging issues like the role of palliative care in disease prevention arise. In Africa there is no separation between hospice care and palliative care: Palliative care and treatment starts right after getting the diagnosis. For instance, some patients will be on a palliative program for months, but some will be there for years. One reason for the combined care is the lack of the

health insurance schemes in most of the African countries.

African researchers are now focusing on finding solutions for a long term care for HIV patients. It is a chronic illness with increased numbers of people on anti-retro-viral therapy (ART). Due to this therapy HIV patient's longevity is increased, so the focus is on adherence and retention in care. Also the effects on the young populations living, e.g. 30 years with the virus are unknown until now. Another emerging issue is the acquaintance with HIV patients taking their treatment for several years. Also the role of psychosocial approaches in care is one of the focus areas where improvement is required, and a better access to integrated services needs to be established, too. The volunteers in palliative care are facing these emerging issues as well.

Of the 50 countries globally having critical shortages in health human resources 36 are located in Africa. So the doctor and nurse /population ratios are very low compared to the global one. One of the reasons for that is the 'brain-drain' phenomenon meaning that educated and skilled health workers emigrate to either other African countries or the West to work there because of higher salaries.

Volunteer models.

In Africa the holistic approach of palliative care has to consider the cultural context, especially with the role of volunteers. On the one hand palliative care starts immediately when someone comes in with a life-limiting illness but also patients often see the doctor very late. From 2004 until 2006 there was a palliative care development baseline made in Africa. There were only four countries which were integrating palliative care in their health systems, eleven countries had initiated capacity building. There were eleven countries with localized provision of palliative care and 21 countries had no hospice or palliative care at all. But we have moved on since 2005. In 1979 the first hospice in Africa was built in Zimbabwe. After 2005 lots of other countries came on board; currently there are just over 20 countries realizing programs for palliative care.

In general the history of palliative and hospice care has a lot to do with voluntarism. Also in Africa volunteering and caring for the sick is part of the culture; Ubuntu which means caring for each other, derived from human kindness and compassion. So even without having contact to the so called "palliative care" in Africa people would care for the sick. The voluntarism could be part of the solution for the lack of human resources for health in Sub Saharan Africa.

For volunteers there are various models used. For example, there are the community based volunteers who part of the community and are based in the community. Other examples are site or facility based volunteers, volunteers who come to a certain place like a hospice to work as a volunteer. They do their part and then they go home. Thus community-volunteers operate from their communities although linking with facilities while site-specific volunteers operate from the sites/facilities.

Again there are disease or intervention specific models of volunteers for example TB or ART adherence supporters who are specific to a disease condition or an intervention.

Also there are volunteers covering wider areas of health based on allocation of households, for

example each volunteer is allocated to 25 homes. So this volunteer is responsible if there is malaria, or somebody with cancer, or someone with HIV. Thus their scope is wider than the one of facility based volunteers’.

In terms of categories there are professional volunteers on the one hand and non-professional ones on the other hand. Both of them may operate at the community level or at a site level.

The terminology being used for volunteers all over Africa is manifold. Even within one country there are several terms for “volunteer”. In Ugandan governmental programs, for instance, they are called “village health committees”. Those working for NGOs are called differently. In one country you can find up to five terms for these volunteers. Thus the unstandardized level of terminology shows the unstandardized approach and level of volunteers.

But who are the volunteers? In general, volunteering is traditionally associated with using ones knowledge and skills to provide a service without expecting a pay in return. This is working when it comes to professionals, and not only in Africa. When it comes to non-professional volunteers, this it does not work. One of the definitions for non- professional volunteers is the following:

“A Community Health Worker (CHW) is any health worker who performs functions related to health care delivery; has trained in some way in the context of the intervention & has no formal professional or paraprofessional certificate or degree in tertiary education.” (Lewin et al, 2010)

This person doesn’t necessarily need any kind of school education.

Another definition, especially used in palliative care is the following: “A community care provider (CCP) is someone providing care for the patient and their family, with supervision from professional care providers, but who does not have a professional qualification recognized by the Ministry of Health, e.g. community health workers, community volunteers, lay care givers, nursing aides. They will, however, have had some training to prepare them for their role.” (APCA Standards, 2011)

In contrast to the CHW the CCP have to be trained in some sort of way.

Another question to be answered is the identification of the volunteers, so how would community members know of the volunteers being responsible for them. In the beginning even NGOs identify their volunteer with the help of the community or the local leader which is the most important way of identification. So every community will have a local counselor on the village level. Thus volunteers are recruited by NGOs with the help of local leaders due to their experience. It is also possible that family members care for their loved ones and then get motivated and become volunteers for others, too. The third possibility are expert patients or clients that are identified by their service providing institution or community leaders. They usually have a lot of experience to share.

The needs of volunteers basically revolve around the motivation. All of them need to have the knowledge and skills, also the supervision and the mentorship have to be clear. Another important item is the facilitation, for example the transport by bike or a motorcycle or another

conveyance has to be provided. Giving the example of two local districts she recently visited, Ms. Kiyange emphasizes the importance of the political and other forms of recognition for volunteers, in terms of being sponsored or giving an extra speech in front of communities. Another important need is providing required supplies e.g. protective gear like the gloves, especially in areas with a high HIV burden.

Furthermore role clarity is a basic need of volunteers because sometimes the expectation of volunteers and their sending organization differ very much. That is why roles have to be clear from the start.

Volunteers sometimes pay costs of carriage or phone calls for people they are caring for out of their own pockets. For that they need to be reimbursed. For reporting and data collection volunteers need to have access to very basic tools like reporting templates, referral forms etc. They also appreciate having contact with their health facilities. Yet, there are exceptions: In a group of HIV positive volunteers in Namibia, volunteers are connected to each other but not to their main facility. This constitutes a challenge to full access to clinical services.

A report on the role of community based volunteers from 2008 looking into clinical, social, psychological, nutritional, spiritual, financial and income generation aspects, shows the following results:

One of the critical points is to identify patients with needs for palliative care and to make appropriate referrals for patients and families to access services. In Uganda, 58 % of the people never meet a health worker, thus identifying palliative patients is a very critical point. Others are providing basic health and hygiene support; or accompanying patients to health facilities.

Even though the activity of supporting patients in accessing and taking medications is very critical, once volunteers are trained it works very well, especially for HIV treatment and pain management. The volunteers visit patients at home, for example just to remind them to take their medication.

Another task of the volunteers is linking patients with clinical teams when patients under their care experience serious symptoms including emergencies. Thus patients alert their health care volunteer whenever there is a problem.

In the volunteer's training there is a lot of basic counseling and information on emotional support.

Something else the volunteers provide is organized community based activities for patients and their families, e.g. day care programs which do not necessarily need to be at a hospice or health facility site, but can also be situated in a community church, for instance.

Education, awareness, health promotion and fundraising activities are also among volunteers' duties. For patients living alone, volunteers help out a lot in the house hold. For example, they cook, get water and in Zimbabwe, for example, they also need to search for fire wood.

In Africa children often have to care for their sick parents. So volunteers provide support for

them, for instance by giving them a ride to provide medication for the sick parents. After the parent's death the children live alone and child-headed households arise. Volunteers often help out then. The largest home-based care program in Namibia is a Catholic one which identifies child-headed households and supports them. In Uganda there is a home visiting program in which patients are visited by volunteers on motorcycles who bring them medication.

Also there are patients who don't have access to care and who are not even thinking about getting it. So often volunteers identify them and organize their care or their transport to a hospice or health facility.

In addition volunteers sometimes also navigate facilities, so that patients can be helped to find certain departments in a hospital.

Other tasks of volunteers are: gardening, organizing social activities e.g. day care, playing, feeding and educating children, filing and recording, coordinating and organizing psychosocial and spiritual support. Of course they do a lot of discharge related support and also triaging work at the clinical site and in external settings. This helps to reduce waiting times for patients and the workload for nurses.

It is getting clearer which patients need which kind of help, different patients have different needs. Some patients can be only cared for at home for a certain time, so they don't actually need to come to the facilities.

Patients' outcome

There have been some studies around patient's outcomes arising from the work of volunteers.

- In one of the largest programs in Uganda using expert patients as volunteers, it is called "integrated palliative care- Kitovu mobile homes", 82 % of clients enrolled on ART (Anti-retroviral treatment) were retained with adherence level of more than 95 %.
- Another effect is reduced waiting time for patients at facilities and outreach clinics, due to triaging.
- There are also stronger community linkages, referral mechanisms and solidarity among fellow clients. There is also increased access to HIV counseling and testing (HCT) services being provided by volunteers as a result of positive living by expert patients, who become volunteers too. Thus there is already a lot of counseling on the community level happening a lot in Uganda and Malawi. Patients usually even feel more comfortable to share their concerns with someone who is suffering from the same illness.
- There is also a potential to change the behavior e.g. widow inheritance in Kenya, improved disclosure in South Africa, Ethiopia and Uganda. Volunteers who are

very well-trained can even give better counseling in some cases. In Malawi and South Africa, quality of counselling by community health care workers was comparable or better than that by health care workers.

- Volunteers also increase the uptake of health services. In Malawi, for instance 806 PLHIV were screened by Community Health workers and 161 were diagnosed with smear positive TB.
- Volunteers can increase the adherence to medications through the adherence counseling which is proved to be very evidential.
- There is evidence that volunteer contribution is reducing viral suppression in HIV; also the risk of deaths decreases because volunteers get patients earlier. As a result therapy can start in an earlier stage.
- Volunteers are contributing to dignity and quality of life since they offer a sense of belonging and companionship to the patients.
- Children, who are especially vulnerable, also profit from volunteers by being trained in income generating activities like tailoring, e.g. in Malawi.

Health care system related outcome.

Volunteers also achieve outcomes on the health care system level.

- In Malawi reduced waiting times and improved patient flow at facilities was a relief to professional health care workers.
- Even a reduced need for patient visits to facilities is observed because volunteers can manage certain patient needs at home. As a result, patients don't need to visit the facilities.
- Health workers in Africa are really overwhelmed by their workload. Fortunately the volunteers task shifting reduces the workload of health workers in Zambia, Uganda, and Malawi.
- Moreover, volunteers are bridging the gap between patients and health workers by linking health facilities.
- Volunteers also improve patient provider communication and help out in filling in forms.

Volunteers' motivation.

Another aspect is the motivation of the volunteers. Some studies indicate that people just feel good to get some new knowledge and skills for self-care, family and community care. This is mainly a motivation of HIV positive volunteers. They often had very good care of a loved one who has passed away, so out of empathy people decide to become a volunteer. In Uganda

respect from communities and status enhancement is very important and volunteers have a higher status in the community. Ideally they are identified as part of the medical team which gives them a lot of pride.

- Volunteers also receive transport facilitation e.g. bicycles.
- Other motivations are the reimbursement of costs incurred and spiritual fulfilment and humanitarian contribution.
- A small monthly stipend for their inputs is paid sometimes, usually USD 30 – 70 which is mostly common in Southern Africa region.
- Some volunteers are motivated by the fact that they have previously benefited from services of volunteers being patients themselves.
- The opportunities to access simple organizational jobs, like cleaning and catering, increases.
- Also the availability of home based care kits like drugs including ART, gloves, detergents and a mosquito nets are a source of motivation.
- Another motivation is peer-involvement and reduced stigma, meaning that sometimes when other community members observe someone working as a volunteer they also want to participate. For PLHIV it is empowering to be respected by communities arising from their volunteer and expert role in HIV.
- The promotion of gender equality can also motivate volunteers. Traditionally in Africa men are not meant to provide care but nowadays there is a lot of change. Especially in Eastern Africa the gender ratio among volunteers is nearly equal, while in Southern Africa it is still mainly women giving care. This inequality contributes to a lot of issues like different information and treatment compliance levels of both men and women concerning HIV.

Motivation issues.

- There are still a lot of challenges volunteers are facing; one is the lack of recognition by the main stream health systems. It is visible that it is very painful for volunteers not being recognized even though they have done a good job.
- Also working without payment in the face of poverty becomes very difficult. They work and they come home with empty pockets, yet some of them are patients themselves.
- Too much shifting of responsibility from the health workers roles to volunteers occurs, such as filling complicated monitoring and evaluation tools, unfortunately work tasks are not standardized yet.

- Furthermore there is a lack of guidelines or standard operating procedures and an inconsistency in paying volunteers, causing challenges of retention. That contributes to a lot of imbalance, as some NGO affiliated volunteers are paid while others including those affiliated to Governments are not. This varies from one country to another.
- High expectations and demands from patients and families are a challenge for volunteers too. Some patients expect volunteers to give them money and food. This can sometimes frustrate volunteers.
- In many cases home based care kits, uniforms, protective clothing are not accessible by volunteers.
- In some parts volunteers are seen as the second line group; so there is a lack of belonging to operating teams.
- The volunteer role is mainly taken on by women in most countries due to cultural expectations. Men doing voluntary work are often pressured and stigmatized. That creates a barrier, too.

Further implications.

- On the institutional basis there are also some challenges.
- The expectations for accountability without payment differ a lot. Sometimes volunteers don't have any kind of contract with these institutions.
- Also role conflicts with the professional staff are a problem. Thus physicians for example are sometimes protective when it comes to their compartment. Some people even think that volunteers and social workers are doing the same job and that is why they prefer to employ volunteers instead of professional who would need to be paid much higher.
- Another issue is the differentiation between the declared intention and the actual one. For instance the volunteer's motivation is to get a certificate but in the beginning he or she pretends to have spiritual motivations.
- Another challenge can arise by high expectations from volunteers. Some of them put very high demands on the institution that has recruited them.

Moreover institutional related challenges, legal ethical and political, are discussed.

- An ethical controversy is that volunteers are generally poor and often HIV patients themselves and additionally they are working without payment.
- Another point is the lack of regulatory frameworks governing the work of volunteers. For instance the responsibility if something goes wrong is not clarified.

Even the accountability is difficult, e.g. if there are no binding contracts.

- Many of the volunteers are poor and bring food from their recruiting programs to patients. Thus food security is not always guaranteed.
- Sometimes voluntary work results in political votes from communities; some volunteers have even become famous politicians.
- Volunteers sometimes feel helpless because of the patients' expectations, especially when patients ask for things volunteers don't have.

In the health care, several implications of the voluntary work can be observed. Task shifting or sharing is made with professional health workers, for instance because health workers can't do everything, especially with increasing demands and complicated health issues. This goes along with an appropriate training, mentorship and supervision of the volunteers which is required for quality services. A lot of times volunteers work without anybody tracking the quality of services they are providing.

- Sometimes there are positive things like career path management and support. Some community volunteers begin as community health workers, and through support and education enter a cadre of professional health workers.
- Another positive result is the enhancement of the social status of volunteers, who are respected as important members of society. However volunteer work is to an extent society's expectation to help as part of African culture and the spiritual fulfilment.
- Since volunteers have psycho-social issues, as well, another type of question is: "Who meets the psycho-social needs of volunteers, like stress management?" Some are clients and some have experienced loss in their own families.
- Having so many patients, volunteers themselves allow voices of patients to be heard and priorities to be considered by the communities and politicians.
- Another issue which was already mentioned is that care giving is perceived as a feminine role thus a barrier to involvement of men arises.

Lessons and recommendations.

At the end of the speech some lessons are presented. In some areas only limited research was possible and there is a need for more interdisciplinary research. Another aim would be to explore and better utilize the non-monitory approaches for motivating volunteers.

Parallel voluntary systems are causing competition among institutions, for instance between NGOs and the government. A harmonized coordinated system is desirable. The use of expert clients/patients as volunteers has obviously enormous benefits. Within the institution it is

important to have a staff coordinator and another among the volunteers for the volunteer work.

Some of the recommendations are to include volunteers in formal institutional and national structures, something that has already been realized in Southern Africa. Also establishing standards and policies for their operations would be important, especially contracts with the institutions.

Other recommendations would be defining reasonable work packages for volunteers and providing them with ongoing technical support, supervision and mentorship. In Uganda the use of retired professionals has been tried, but at the end of the day in South Africa the retired nurses asked for money.

Furthermore the support and reinforcement during regular supervision, training and annual retreats and income generating activities for volunteers are recommended.

Then of course activities that are attractive should be also available for men. This can be realized by training them in groups consisting only of men and allocating them with tasks that they are excited to do, such as driving.

Research areas.

Some research studies and systematic reviews have been carried out in Africa. They cover areas such as:

- Volunteers in home care services
- Contribution of volunteers in end-of-life care services
- Role of volunteers in community-based life care service (such as driving, treats, asking for money for the own family)
- The role of a volunteer in specialist PC care service
- Roles and outcomes of volunteer work in HIV care service

However, limited research has been carried out in areas such as costing, gender and populations at risk (including children, prisoners and the disabled people among others.)

- The question for a sustainable model is not clarified yet. Thus it needs to be examined how a sustainable and good practice model for volunteering should look like, and whether an integrated model that combines public facilities and community programs could work best. It is also important to explore how such a model could be replicated.
- Another issue which may be explored is an appropriate terminology for volunteers as there are so many different ones in each country.
- Other research priorities are tensions involved relating to boundaries of

volunteers; informality and regulation; diversity issues and cultural specificity of community models. Furthermore the expectations of volunteers and the average length of time people are able to volunteer on a regular basis need to be investigated.

Finally I want to thank the team for inviting me to share the African experience.

Contributors.

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W. Schneider:
**Voluntary work in the context of Palliative Care –
challenges today and for the future**

Introductory reflections.

Sociology studies observe how this modern and still modernizing society has radically changed its relationship with death and dying, starting in the 1970s/80s.

Three theses capture this radical change regarding death and dying:

- We live in a society in which we are (once again) continuously being familiarized with the proper handling of dying and death, of dying and dead persons.
- Dying, the apprehension of one's death, becomes a project, to be shaped primarily (autonomously and providently) by the individual (for) him- or herself.
- With this culture of concern and recognition of one's own death, a form of 'good dying' (in the sense of dignified, because self-determined and free of pain) becomes institutionalized as the final phase of life. Relatively little is known about the conditions of and effects on social difference of this shift. Within individualized and heterogeneous societies, dying becomes increasingly risky.

Within this social shift, the hospice movement, as a form of citizens' movement, has played and continues to play a central role – I go so far as to claim that how society will deal with death and dying in future will hinge upon the development of hospice care as a citizens' movement.

Accordingly, the basic question of this presentation is: What are the challenges for palliative care and for the hospice as a form of citizens' movement, today and in future?

I start with a short, cursory look at the past and present state of the hospice movement.

Hospice movement: past and present.

The comprehensive institutionalization of 'good dying' since the 1980s can be regarded in large part as an achievement of the hospice movement. With its offer of volunteer-based hospice care, the movement – in the spirit of a true popular movement – has contributed to the fact that today almost 90 % of the German population have an understanding of the label "hospice", and 66 % can even define it correctly (Ruprecht 2013 ,p.6-9, see also DHPV e. V. 2010).

These numbers can be seen as indicative of hospice culture as an idea, coupled with a concrete understanding of the hospice, entering into common knowledge. Thereby "hospice" conveys a message that extends beyond death and the realm of dying: People, in this society, may expect and rely on unconditional help and support from others in situations of existential crisis. It appears important to me that the credibility of this message is in no way based solely on a

professionalized, standardized and 'assured' promise of care, but particularly on its links with volunteering. Hospice culture and palliative care, on this understanding, is inconceivable unless sustained by a variety of people in the form of voluntary, civic engagement.

This is why it seems crucial to me, from a cultural and socio-political perspective, that the defining characteristics of the idea of the hospice, namely unconditional care and support for dying persons and their relatives provided in a specific 'hospice attitude' and in the form of voluntary work, are not displaced and eliminated by the official paradigm of medical palliative care. Medical palliative care towards the end of one's life is a legal entitlement, which assures all individuals equally of the required medical treatment on a professional level, according to their specific needs – even if their situation requires a specialized form of treatment like SAPV. In contrast, it is only under certain circumstances that the specific needs of an individual who, alongside her relatives, is in a situation of existential crisis towards the end of her life can be gratified, that such an individual can be provided with comprehensive, everyday practical support reflecting her wishes; there can be no legal guaranteed of such care. Such support is notably provided by means of voluntary work. Legally guaranteed palliative care fails to accompany in that sense.

The significant change that hospice care is currently undergoing is particularly evident in the field of voluntary work. This can be illustrated by briefly comparing the hospice movement as it presented itself in the past, still in its initial phase, to the hospice movement today.

In the recent past, the period from its emergence in Germany in the 1970s/80s to its establishment in the last decades, the goal and practice of the hospice movement still seemed clearly defined. The task was to foreground dying and the dying person and his relatives, to salvage them from the social obscurity into which they were pushed by the great success of the modern, medical-scientific health regime. It seemed clear against who or what the campaign needed to be directed: against the institutional order of modern clinic, in which there was no place for dying due to the concentration on healing. Therefore death and dying had no place in the modern clinic, because in a way these phenomena were incompatible with the regular procedures of the modern clinic. Furthermore, the object of critique was a society that charged dying with moral import – especially at the margins of society, concerning marginalized groups like people who suffer from HIV, whose dying was misused within the political discourse as a legitimation for devaluing the lifestyle of these groups and for stigmatizing their members. And it was quite clear how this fight had to look: The point was to support dying persons and their relatives with their needs, concerns and fears, and to show them that they remain, despite their existential crisis situation, an esteemed part of this society, that especially towards the end of their lives, their voices would be heard. Thus – thanks to the success of the hospice movement – dying was (once again) fundamentally dehospitalized within our way of thinking and at the same time privatized, by giving its definition and organization over, as far as possible thanks to support, to those directly affected.

Even though the objectives are more valid than ever, maybe precisely because the hospice idea constitutes such a success story, it needs to be pointed out that on this level the hospice movement has arrived at the heart of society! Nevertheless, or rather therefore, hospice practice

today seems to be far less characterized by such certitude and clarity. From the perspective of the actors on site – especially from the perspective of voluntary workers – their everyday experiences are rather shaped by uncertainties, contingencies and partly manifest, partly latent contradictions, which I will briefly examine hereafter. In this context, I believe there are four core aspects that underlie the diagnosis of increasing uncertainty, contingency and inconsistency of voluntary hospice work:

- The hospice movement is currently undergoing an age-related generational displacement, in the course of which the ‘founding generation’ in Germany is withdrawing from hospice practice and valuable experience-based knowledge thereby threatens to be lost.
- At the same time, this generational shift enables and requires a fundamental discussion and possibly a conceptual extension of the voluntary structures, orientations and characteristics ‘of doing hospice care’.
- This debate on principles and extension is unavoidable in the light of the general social change since the 1980s and the associated effects on voluntary work and civic engagement (catchword: new forms of voluntary work).
- As a consequence, the crucial concern for cultural sociology and from a socio-political point of view is the question of social disparity within the process of dying, or more precisely of the social range of the offer of hospice care: To what types of people (with which social characteristics) is and will hospice care be available in the future? And closely linked to that: What type of people (again with which social characteristics) will engage in voluntary work within hospices in the future? In short: Who enables whom to have a ‘good death’, accompanied by hospice care?

To pursue these four aspects, it is necessary to take a closer look at the current situation of hospice voluntary work in palliative care – its challenges, problems, dangers, contradictions.

Just a short preliminary note concerning the German terminology in the field of hospice care, which is shifting from ‘Ehrenamt’ (honorary office) towards ‘Freiwilligenarbeit’ (voluntary work), because the wording signifies the social change that I want to further examine. Language produces reality – our terms mark and shape the ways in which we perceive and think about the world we live in.

The term ‘Ehrenamt’ represents the civil modernity of the 19th and 20th Century. It is an additional office, which a reputable citizen occupies in his community and through which he acquires symbolic gratification: even more honour – he enhances his symbolic capital. For the civil woman volunteering is even more interesting, because it constitutes the only possibility of abandoning her place at home, in the private sphere, which civil gender roles allot to her, and to thereby emerge into the public sphere without her husband by her side. For modern society, ‘Ehrenamt’ hence has a dual function: Volunteering integrates those who engage in it, or rather

strengthens their integration – and it integrates those who are addressed by volunteering or saves them from completely dropping out of society. The concept of civic engagement already marks the ‘reflexive’ process of modernization of modernity along progressive individualization: From the middle of the 20th century, beginning in the 1970s, an office is no longer occupied but is engaged as an individualized citizen within civil society. No office is conferred; instead, what matters is a more or less intense and costly commitment, which each individual has to determine for him- or herself. In normative terms, the charitable aspect of volunteering is replaced by a political one, or if not wholly replaced at least complemented. While the double integrating effect endures, the rewards of such commitment for society and for the committed individual become diversified, more nuanced. Now voluntary work in the sense of ‘Freiwilligenarbeit’ above all connotes two aspects: *Voluntariness*, which all of a sudden appears explicitly within the concept and marks the act of decision for or against the work. And this aspect of decision is needed, because now, volunteering is about *work*. Since the 1970s, we detect a tendency for society to subsume more and more aspects of life and domains of social relations (besides gainful employment) under the concept of work. Relationship work within marriage, partner relationships, educational work within the parent-child relationship, grief work, work on one’s self (coaching) and so forth – surely soon there will be ‘friendship work’ and so on...

This suggests that more and more aspects of life are submitted to active social regulation, normalization and figuration ‘as work’ – and that (like in modern gainful employment) the individual cannot simply be active in these areas, but has to activate, to inform, to organize and to qualify himself. With the concept of work, these areas are newly processed for individualized ‘self-organization’.

Hospice volunteering in a state of flux: Challenges, difficulties, perils, contradictions.

First of all it should be noted that hospice volunteering in palliative care – both within in- and out-patient treatment – is highly diverse and contingent upon the organizational structure and culture of the service, as well as on the infrastructural networks (up to the relation between AAPV and SAPV) within which the voluntary worker is situated. Tasks range from psychic-spiritual relief and acts of basic support, care and help in the sense of psychosocial relationship work to information, consultation, management and coordination or public relations activities.

The general social development is shaped by two global trends (plus economization, bureaucratization):

- Pluralisation/diversification of the life worlds of the population (pluralizing of private, familial life forms)
- Individualization: The organisation of life is definitively attributed to the individual (even children and adolescents) – right up to autonomy, self-determination etc.

These two trends effect two changes in volunteering: The catchword ‘change of volunteering’ or ‘new volunteering’ points to – first – a change within the personnel: In future, the individuals – still predominantly women – who hold voluntary office within hospice work will be younger, with

greater vocational and family responsibilities, distinctive individual motivations depending on their specific life stage and relation to the project, and will therefore be less flexible. At the same time the pluralizing of volunteering offers great opportunities, to implement the movement's orientation towards the specific needs of patients more definitely: Diversity as a chance. The more heterogeneous the 'dying worlds' of patients and their relatives become, the more important for the success of hospice care it will be to find suitable approaches for this purpose, through the help of voluntary workers who are familiar with these diverse 'life and dying worlds'. Only such voluntary workers are able to honour that comprehensive 'promise of safety' in the daily routine of the final phase of life at the patient's home, promoting a 'normalizing everyday-framing' that – alongside the indispensable palliative pain treatment – makes dying at home possible.

Secondly, volunteering is changing on a functional level. In transforming hospice care from simple terminal care to a more encompassing life care approach, that as an offer shall include as many of the patient's areas of life as possible, in stressing life care at the end of one's life instead of organizing death and dying (in order to distinguish it even more clearly from euthanasia), the tasks and responsibilities of voluntary workers become more diverse. Volunteering is no longer merely about keeping watch at night, but increasingly about all kinds of organizational day to day duties, which have to be arranged.

This inevitably means: A comprehensive commitment can decreasingly be expected and warranted, on average more voluntary workers will have to be appointed per patient and the coordination of voluntary commitment will become increasingly difficult and costly for the service as a whole.

The potential fields of application will once again be distinctly enlarged. The overt problem consists in an impending overextension of volunteering and of hospice care as such, through the danger of dissolution of boundaries, an externally and self-imposed overload, the excessive commandeering of voluntary workers at the expense of their freedom and voluntariness.

Thirdly, volunteering is changing with regard the demands it makes on the knowledge, and hence the qualifications of volunteer. In the light of new challenges on the part of the patients (mental deficiency, but especially dementia), current ways of conceptualising the relation between volunteering and professionalism must be questioned. With the increased demands arising within care for individuals affected by dementia, the knowledge required to act competently and securely also increases. Such qualitatively demanding care will have to be increasingly linked with 'professional' knowledge. Nevertheless volunteering still has to be defined per se voluntarily and 'non-vocational'. This means that voluntary workers were, are and shall remain people from next door, who can decide for themselves if and in which field they want to improve themselves.

Thus in the future – besides the already implied distinction between terminal care and life support – there will probably be another differentiation: a professionalized structurally open type of volunteering on the one hand, and a structurally conservative laicized type on the other. The one type would be a voluntary worker in the sense of a 'professional helper from next door', who

wants to exchange views on a par with the other actors in the field. The other type is a voluntary worker who deliberately, in the sense of a distinct intention of a 'non-professional' (not following vocational expertise), gives help in matters of everyday life without any presuppositions, just like a neighbour, as a rank and file citizen. The hospice movement will need both types – just like terminal care and life support.

Eventually – fourthly and following the already said – in future, volunteering in hospice care will especially have to fundamentally change its relation with full-time work. Away from the differentiated, functional specificity of the full-time professional and the functionally vague everyday-social competencies of the voluntary worker as a lay person – towards a full-time, generalist-holistic professionalized case manager and a specialized voluntary worker occupied with everyday-functional matters, who is equipped with his own expertise and professionalism. Therefore it will be necessary to recruit more people from different social areas and milieus, with diverse capabilities, skills and expertise, of varying ages and sex for voluntary work in hospice care. And this is already happening in various quarters!

A danger of this inevitable change of volunteering is that in these roughly outlined contours hide certain contradictions, for instance that between the profile of the voluntary, multifunctional and flexible life companion at the end of one's life and the notion of an intense, intimate, biographically individualized form of support during the final phase of a person's life, which is being retained. Another danger could be that those un-communicable differentiations are associated with diverse symbolic valences and could finally lead to disparities between true hospice workers and pure auxiliary workers, professionals and dilettantes, valuable and less valuable commitment, good and bad work.

To put it as clearly as possible: in this case one can perceive nothing but socially defined, culturally produced contradictions! Concretely: On the one hand, volunteering is to be protected by clear profiling, by concrete descriptions of operations or even target agreements, but also by knowledge and expertise transfer, on the other hand, its liberty, voluntariness, openness and spontaneity must remain uncut. It is not supposed to be socially co-opted (for instance as a way to reduce cost) but at the same time it is to remain socially significant or become even more socially significant, for instance as a corrective for revealing institutional abuses. Volunteering within hospice care is to be positioned even more broadly and nevertheless it is not to become a comprehensive 'wish-fulfilment' regarding dying. To ensure all of that, appropriate, structurally fixed framework conditions are needed, which may however rather impede hospice care as a citizen-driven practice.

Adding to that, the desired liberty, voluntariness and openness of volunteering, inevitably leads to diverse values on the part of the voluntary workers, underlying the overarching values of humanity, holism and orientation towards patients and their relatives, which have to be addressed internally in exchange with the different hospice actors (for instance right up to divergent attitudes concerning euthanasia).

These contradictions are structurally and culturally determined – and thus socially determined. Therefore they cannot be solved by the hospice movement alone. Hospice culture and hospice

practice resemble, due to their base in a citizens' movement, a portrayal of processes of change of society as a whole: individualization of people, pluralisation of life worlds and increasingly abstract core values, which in their normative implementation become increasingly ambiguous, disparate and contradictory.

It seems important to me that the credibility of this message is primarily based on the conjunction (!) of voluntary and full-time work. Even more: hospice culture and palliative/hospice care, on the understanding adopted here, are unthinkable unless they are sustained by a variety of people from a sense of voluntary commitment, but at the same time they need to exhibit a certain form, which guarantees stability of structure and thereby signals reliability in a dual sense, reliability of the presence of the offer and reliability of the experienced care itself. In other words: volunteering always produces full-time work – and full-time work ensures the presence and reliability of volunteering. To put it bluntly, volunteering would no longer be volunteering if it didn't present itself as a form of neighbourly help of normal people like you and I, but the organized dealing with volunteering within hospice practice has to be – on the basis of a transparent, strict separation between volunteering and full-time work – professional. The hospice movement as a citizen movement indeed finds its strength and innovative energy in a constantly changing society only at the bottom, within the daily routine of people – but at the same time it needs to hold a powerful position within organizations and political structures.

Conclusion.

Overall, against the backdrop of the stated, I see two possible future scenarios for the hospice movement: Either the hospice movement will vanish sooner or later – just like citizen movements come and go, because they vanish when they are unsuccessful as well as when they are successful – like the hospice movement. Or – and that seems to be the more probable possibility (or at least that is my hope) – the hospice movement will continue to develop, it will remain flexible and resistant and above all it will remain socially innovative, which means that it will continue to reinvent itself. Companies often advertise with this notion of reinventing oneself, but usually they cannot do so due to their organizational characteristics; citizens' movements however are able to keep reinventing themselves! In the future the hospice movement will remain at the heart of society, where by this time it has arrived – and at the same time it will have to move to the margins of society and take action there, because in the future these margins will become more diverse, more complex, and more difficult – and above all they will grow.

Thereby we should consider: Volunteering is not(!) – like Thomas Rauschenbach remarked sceptically in 1995 – „one of these seldom ingenious discoveries in the history of mankind (...), from which everyone always seems to benefit” (Fischer 2011 ,p.10, see also pp.246). A fairly new social-scientific study shows that for upper milieus volunteering is per se of peculiar benefit, because it enhances the individual resource and capital endowment and at the same time legitimizes their claim to be the leading social milieus, by means of accomplishments that are seen as promoting the general welfare. In short, the socially predominant 'gentlefolk' of the educated middle class reinforce their distance to the 'lesser folk', not exclusively but also

through voluntary work, which functions highly selectively with regard to who practices it as well as who receives it (Fischer 2011).

In the hospice movement, valuable civic engagement was primarily performed by older women of the upper middle class – the hospice movement seems to be one of the most successful women's movement that ever existed. Especially because of that it is very important to extend this commitment and to make it more heterogeneous concerning the characteristics of the people who engage in it: younger persons, also males, from diverse cultures and milieus of origin, so that the hospice movement can be seen as reflective of social diversity and heterogeneity. The health system of our society functions highly selectively in a social regard. Sickness/mortality is especially differentiated through the social gradient, and one should not assume that this is any different in the accompaniment of dying persons. The more palliative care is integrated in the health system as a formal provision, the more it will reproduce the social disparities of our society. It will be the same in hospice care – if volunteering fails to represent a social diversity.

The shift towards the so-called 'new volunteering' offers the chance to minimize the sociocultural selectivity of hospice care and to enhance its social range in an increasingly pluralized world, in which the 'dying worlds' of people also become more diverse. Thereby it is not about replacing the one with the other, or about either restoring the hospice movement to a grassroots movement or dissolving it into the health system. Rather we need both! For instance we need nocturnal watches as well as the voluntary street worker who is familiar with the margins of society. It is not about either/or, but about as well as!

I conclude: To the question, what would be the greatest harm for him, Ernst Bloch answered: „To die before I am done living!“ Modern man, the individual within modern society, bases his self-conception on the assumption that he will never be done with his own life, that there is always another life in the temporal tomorrow, which he already bears in mind. We have no problem with growing old, as long as we are still able to live this 'own' life; we don't even have a problem with dying, as long as we are able to operate this 'own' life within dying – this is why we care so much about dying. Apparently what we want to save is nothing else than our own life, even in dying. Klaus Schroeter uses, with a critical intent, in another context the term 'maximization of life' – this is the credo of the health-society with its great health. And the almost hallowed saying of Cicely Saunders, to give more life to the remaining days, can precisely be (mis-)understood in that sense. I find that pretty alarming!

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J. Ellershaw:
**Some context around palliative care in UK,
and aspects of volunteering linked with that**

Introduction.

The UK model of palliative care

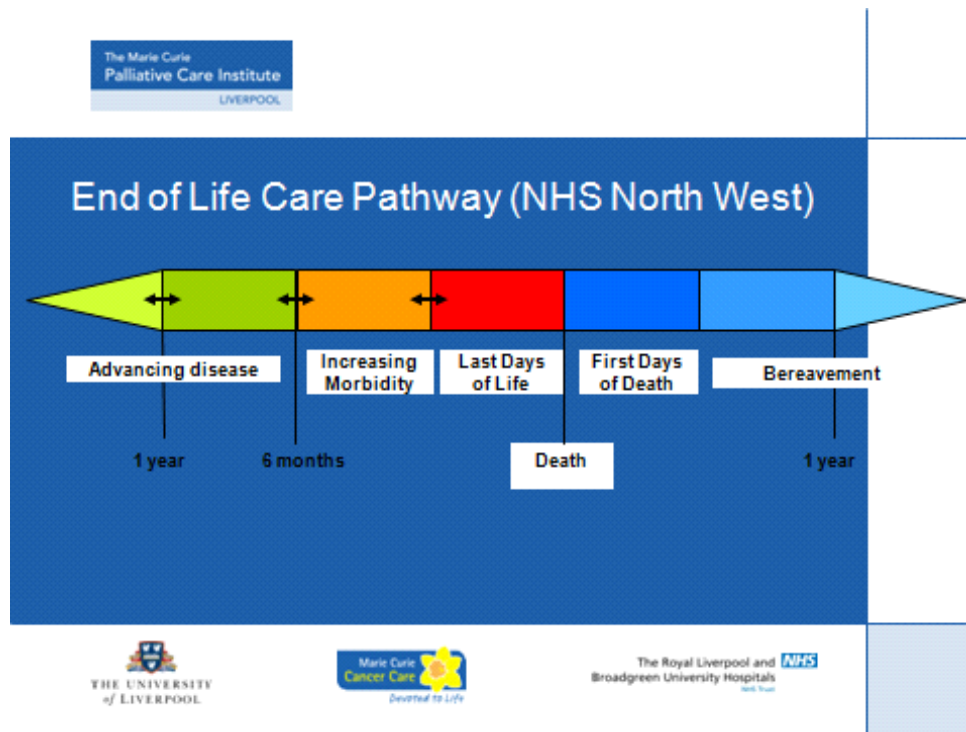
The Marie Curie Palliative Care Institute is based at the Cancer Research Centre in Liverpool and has two clinical sites, a 30 bed hospice and the Royal Liverpool University Hospital which has 900 beds. The vision around these two clinical sites and the work we have there is to be a leader in taking forward the best care for the dying patient. We will talk more about their last hours and days of life when I get to one of the European projects. Somebody has mentioned Cicely Saunders already, and it's quite interesting because some of the founding principles of hospice medicine built in our country were linked with Cicely Saunders' vision. And she said that you matter because you are you and you matter till the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die. I think we talked quite a bit about language in palliative care and I kind of find the WHO definition of palliative care a little bit long and definition by committee. But I like this as a definition for palliative care, as it doesn't deny death. A lot of people want to talk about palliative care but try to avoid saying that somebody dies. But then it can be so much about death and dying that it kind of puts people off, so I like the language about living until you die and that people matter till their last moment of life. And I think that it's those values and principles that underpin what we do.

Palliative Care Development in England

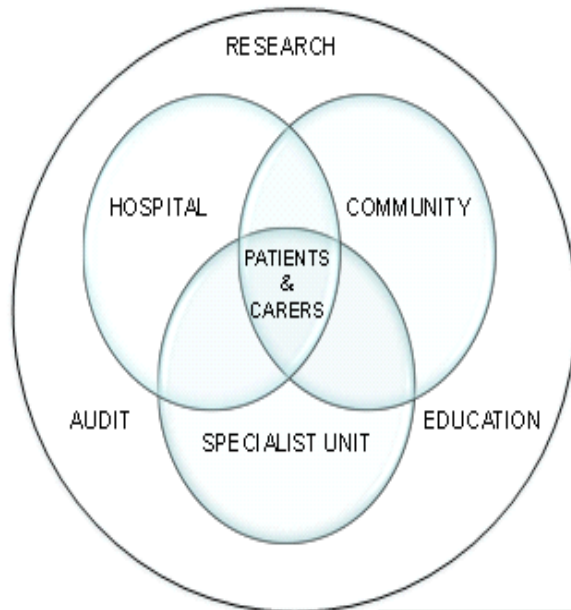
St. Christopher's Hospice was founded by Cicely Saunders in 1963. She recognised that the kind of philosophy and values that she wanted for people who were dying couldn't be developed within mainstream NHS at that time, and so she wanted to take forward her own vision of what could be done. She had worked at different organisations, like a hospice run by nuns in London, and she'd seen how they cared for their dying patients. She wanted to create that vision alongside the health care service. So she ended up with St. Christopher's in South London, and she started the building without enough money to finish it. She was a lady with strong faith and she believed that God would give her the money to finish the hospice, and indeed somebody did give her the money and the building did get finished. Palliative care has always had a tradition of volunteering. Interestingly, some of the volunteers early on were health care professionals. Some of her doctor friends that she trained with and who shared her vision went and did volunteer work in the hospital on top of their day job, just so that the whole concept could get

going. Sometimes when we think of volunteering we like to be quite narrow in our country now.

Our model of palliative care is not particular dissimilar from other countries, but I think it has taken a long time to evolve into this in our country. So patients and carers are in the centre, supported by a specialist palliative care unit together with hospital and community services because you need palliative care wherever patients and carers are. And surround that by research, audit and education.



MODEL FOR PALLIATIVE CARE



This is another model which I thought might be interesting in regard to our discussions; it shows how we describe palliative care in a hospice.

Palliative care reaching out

In the lecture this morning we talked about how the word 'hospice' had a clear message, and sometimes having a clear message is quite helpful because people know what you're talking about. The lecture this morning said then, from a clear message it has now become diffuse and permeating into society. I think this is a problem and it is an opportunity, but it is a challenge if your message isn't clear, because the people you are trying to communicate with about what you do and what you want to do are trying to understand something that is not as clear as it was. We are having a transition phase in our country at the moment about how palliative care goes into lung cancer, and affects more lung cancer patients, how we get palliative care earlier in the disease, how we get into all care settings, how do we get into all specialities. The palliative care approach and the hospice approach should be the approach of the health care system. So where does this hospice and palliative service fit into that? Where is this positioning in the service delivery as opposed to the philosophy of care? These are some of the things that are challenging in the system.

Of course linked with that is how the volunteers link and support the philosophy of care and link with the service delivery. So one of the things that we worked on in the UK was about how to describe to people what we do in palliative care. These phases I think are helpful, because they are the last days of life. About six months before their deaths people recognise they are getting less well. In our country, six months from death they are entitled to a benefit, some money. In

our country six months from death is a prognostic point, which is important because people get more funds. The majority of patients are in their last year of life, and that helps us think about commissioning services, because if you would say we were palliative care for heart failure patients and ask: 'how many of those are in palliative care?', you can refer to the people in commissioning services and ask: 'how many people died of heart failure last year?' 'We had 500'. So suddenly you can quantify the things you do and it helps to talk about what we are doing.

This is showing how many palliative care services we have across the UK and Ireland. One extensive lay of services, and certainly in my area, too, where we have a hospital, we have a hospice, the hospital will have a consulting team, there'll be hospice inpatient units and then there will be a community service. That is what you'll expect to find anywhere in the UK.

So this is the hospice. We have some four bedded rooms and two bedded rooms. Some people actually do like the company of people around them instead of staying in a one-bedded room. With our inpatient services we have around twelve admissions a week into our 30 beds; half of the patients die and half of the patients go home. An average stay is around 14 days. We have more than 3000 patient appointments each year. In daycare we have ten places and a bereavement service with 30 % uptake within our service.



One patient's story

Here is a family lady with advanced lung cancer, together with her sister and her son Jamie. This lady was two weeks from death when she was admitted to the hospice. We were talking earlier around the lunch table about people accessing services and being able to be kept at home. But this lady has not been wanting to talk about her disease whatsoever at all, until in fact she got to the point where she couldn't move off her sofa where she was sleeping and the GP said: 'you can no longer be here, we can no longer take care for you here, you have to go to the hospital or hospice'. She agreed to come to the hospice, but she hadn't done any preparation at all. She hadn't spoken to her son about how ill she was, made no planning for his future care, no discussion within the family. So this is somebody who has dealt with the situation in a certain way. But it also meant that there was a lot of discussion to be held in the last two weeks of life.

Outline

So just a little bit of context there, because certainly people come from different countries, different continents, and we've already heard there are cultural differences and certain different social norms in these different areas. I thought what I'm going to do specifically around volunteers, is just to look at a survey of volunteers in palliative care in the UK, which has been done and published recently in Palliative Medicine. The hospice that I work at is one of the ten hospices that is part of the national charity: Marie Curie Cancer Care. I will just give you examples for what happens in volunteering in palliative care. I touch upon the EU research project OPCARE 9 particularly around the volunteer work and some of things we found in there and then just finish with volunteer's voice.

Volunteers in specialist palliative care - a survey of adult services in the UK.

'Volunteers in specialist palliative care - a survey of adult services in the UK' has been sent to 290 UK adult hospices specialist palliative care services. It has a response rate of 67 % and the data regarding the volunteers is: Numbers, roles, settings. This figure is quite interesting as it shows that in palliative medicine there are 1.5 volunteers for every paid member of staff in the UK. So in our hospice in Liverpool there are around 140 volunteers. In our hospice we rarely advertise for volunteers, as we get more people walking into our hospice asking to become a volunteer than we can actually manage in our system. This means there are a lot of people out there that are keen to volunteer in this sector. There are some challenges in the way volunteering is growing up in the UK.

I think the most common involvement can be seen in the creative diversional therapies, which refers to volunteers for example working in our day centre where they support the people coming from the community by doing artwork and other different activities during the day. It is a social interactive environment and a lot of volunteers do their work in that area. As an alternative some volunteers do complementary alternative therapy within palliative care settings. In the counselling area, particularly in bereavement counselling linked with hospices, volunteers are often the main work force all over the UK. In some ways it's quite interesting that we've engaged volunteers far more in bereavement work than in the work with the living, before people die. In our hospices quite often the interaction is rather superficial for volunteers. They work in the shop, on the reception, or they take the teas and coffees around, B'but they don't often get involved in direct patient care or conversation. It is less common than what we found on the research around Europe. We also have volunteers linked to pastoral faith-based service, which is more patient-orientated.

The study revealed how many services had volunteers linked to them – 90 % daycare, 79 % bereavement services, 74 % inpatients, 56 % outpatients and 32 % home care. If you look at this within the national charity Marie Curie Cancer Care and the volunteers, there is a real kind of diversity of goals. We have fundraising shops for our hospice, which is an odd dimension because a lot of other European countries don't have fundraising around their services. Probably around 60 % of the funding of our hospices in our country comes from fundraising, from the

community. So we get 40 % from our health care system and have to generate a lot of money from charity and society to run our hospice services. We sell daffodils always through March and so they had nine million daffodils made for this month of March, so it is a quite big fundraiser.

There is a group of expert voices, which consists of volunteers who work to give a voice to a patient and carers. I think including patients and carers is an initiative almost mandated in our health care service. The group of expert voices helps to advice and guide the charity in its direction. These people go out to big organisation asking for big amounts of money. People help with different events. Right into the executive level we have a volunteer on the board and sitting on the committees within the charities. So in a sense the volunteer work force goes from board-level right down to the service-delivery-patient level and fundraising.

Marie Curie Helper Service.

The Marie Curie Helper Service is a new idea. It was started by our chief executive, who had a young friend that received a diagnosis of metastatic cancer and wasn't going to recover from it. He didn't know where to go to and who to talk to. The coordination sign posting part of the world didn't really exist for him. So the chief executive at that time thought this would be a good thing to develop. As you can see it's not quite what he thought, but things do not always turn out the way you think they are going to. The service here is around filling the gap in meeting the emotional support needs of terminal patients and their carers, enabling carers to cope better in their caring role, reduce social isolation and support people throughout the terminal illness. That is normally the last twelve months of life, so this service is aimed for the people in their last year of life. In some ways, for a hospice service we don't get that many referrals before twelve months. It's more the the last twelve to six months, so this is being more engaged within the community with these patients in their last year of their life.

There is a whole structure that supports all this, with a coordinator, and they recruit up to 60 volunteers to work with them. They have to commit to a minimum three hours a week for at least one year, so that there is this minimum responsibility thing going on quite strongly. As you can see it costs around 80,000 pounds to run this service linked with 60 volunteers. So this is kind of all the people in the orange boxes who can refer people in.

Defined Outcome

The Helper Service operates in five locations, and Liverpool, where I work, is one of them. The core elements are really interesting here, in the context of the "non-kin-carer" language. In some respects the helper is almost like the "non-kin-carer", but it is a volunteer. Because what they do is to provide some companionship, emotional support, practical support, short carer respite, information provision and bereavement support for up to three months. So they cover a quite wide range of support here. Somebody said that volunteer roles are getting more specific and

narrow and the professional roles bigger. I don't think that this is actually the case in our country. The helper has got a wide variety of potential roles. The outcome that we are looking for is emotional well being, reduced carer strain, reduced fear and isolation, increased knowledge of and access to local services, and increased confidence to cope now and in the future.

I think one of the things that we do all the time in our country now is that we have a focus on outcomes. If you are doing services or if you are running a service, people want to know 'what are your outcomes?', so we have an outcome based language and culture. If you put a new service in, than you might see a hundred patients, which is great, but actually what difference will it make? What are the outcomes? And at times that's quite hard in palliative care to measure, also it is hard in health care to measure at times. But the outcomes-language is helpful because it articulates what you think over here and what we should deliver over here. You can then start to measure some of your outcomes. I think it's good.

When you were setting up these volunteer time schemes, you put in lots of work and bureaucracy behind the scenes to get it into your system, into your governance. It is a lot of thinking and time. You can see here these volunteers get three days' training in their programme.

Matching process

What they have is interesting; we have a matching with the volunteer and the family who they are going to work with. So the coordinator knows the volunteers and when somebody is referred the coordinator is going to meet the patients and the people around him. They then match the volunteers with the patients and the family. Instead of just randomly sending somebody there, they actually allocate somebody who may best meet their needs. And this is interesting because we have that kind of concept of the middle-aged woman with the honorary positioning. I think what we're doing in our country with this kind of volunteer programme is expanding the types of volunteers and people we get to work voluntarily and their roles. At the hospice, when we have our team meeting and are talking about a patients who may be suitable for this service, our health care professionals tend to gate-keep. This is because we think the volunteer would like a nice patient, a nice family in a nice home, so when he sees them they'll all be nice together, it's all gonna be nice, but actually the world isn't like that. When we get the coordinator to come into the meeting, we hear about a complex, difficult family with a difficult home situation. When we engaged him and said: 'What about help there?', the nurses said: 'Oh, you cannot send a volunteer in there'. The coordinator replied: 'Well, actually we've got a retired social worker; we've got a retired specialist nurse from palliative care.' This shows that we have within our helper services, also within our volunteers, different levels of knowledge and skills that can be matched with these people, because if you put a lifelong social worker in a complex family situation, a lot of skills are put and transferred into this situation. Sometimes we have to stop ourselves gate-keeping the services we are developing. There is a whole complex thing going on here, but it is about accessing and supporting people who do have complexity of lifestyle, of relationships and of social conditions as well. The kind of things we will be talking about, and I

think the fact that you can create that kind of generic volunteering role that moves into that kind of patient-family situation and can support people on the way, is interesting and inimitable in our country. Anyway once people have done enough with one family they can move to the next family. These people can build their expertise up and become an expert helper as they move forward.

Patients' voices

These are some quotes from the patients:

'I don't like the prospect of having suddenly to come to terms with the fact that I may be dying and having somebody intelligent and sympathetic to chat about these things is a great help.'

Quite a lot of research has been done about families and patients at home. Patients know that they are dying but they don't talk to their family and friends much because when they do they get upset, and then their family and friends get upset, and this is difficult for them. But actually talking to somebody else about it or coming to the day unit where a lot of people are in the same situation, you can have a talk about it without getting upset and emotional. This is helpful and therapeutic for people. I think this kind of conversation doesn't mean that people aren't talking to their family or their family doesn't know; it's just that it helps people talking to someone outside of the family.

'I used to go golfing three times a week and I had my golfing friends, my men friends, and it was chaps' time together, so for me it has replaced that gap which appeared in my life'.

'She's actually taking me shopping, she's been taking me to hospital. It is lovely because I feel independent; you know it feels like you are just going with a pal'.

So that sort of close association has a lot of resonance with your stories.

Some of the challenges around the Helper Service are the balance of supply and demand, and how we do that. How do you get a service going and understood in the community? Getting the model right. And here we are, we got the idea of boundaries for the world. The costs and the fact that volunteers, just like most human beings, can't fix everything. If you put Marie Curie Cancer Care Helper into Google you'll get some work about the evaluation of the project and what the helper service looks like.

OPCARE 9.

Methodology

A bit more now about the EU research project. OPCARE 9 was a support and coordination project, led from Liverpool with nine other countries, including seven European countries, Argentina and New Zealand. It looked specifically at care in the last hours and days of life. One of the work packages was looking into the volunteer's role in the last hours and days of life and how volunteers interface with this part of care. They were looking around service provision, roles, education and training. If you take a look at the literature, and this is around the last hours and days of life, there were only two case reports from the US. So with that grey literature here, which was part of our work, we did an initial survey - systematic review in English and thematic review in the eight native languages. Trying to find literature in academia about volunteers is difficult. There is not a lot, so the work we are doing with the research studies is great, because it's going to add to the academic background, research knowledge and evidence we've got. In the UK at the moment there is a lot more interest in formally researching volunteer services. I think people are recognizing the importance of having formal evaluation of volunteer services, and the research and academic work is growing in this area, for example the papers that have been published in Palliative Medicine about what volunteers are doing in the UK. There was a lot of time spent on looking at literature. There is an article written on this, which is a waiting publication at the moment, so I can't give you a reference for that, but it is on its way.

Findings

Here are the articles, and in fact the main articles came from all English speaking countries - UK, US, Canada, Australia. The articles have been published in the corresponding native language in order to address to the people of interest, which sit in their home country rather than in the global community. I think accessing this is one of the challenges.

In the service provision there is a huge diversity of what people did, but I think what is also interesting are the financial structures. In some countries the volunteers got their expenses, in some countries the volunteer coordinator's costs are covered and there are some countries where there is public funding attached to volunteering. If we are trying to disaggregate countries who are funders or non-funders of volunteers it becomes a bit complicated when you look from country to country. I just got this quote from Claxton-Oldfield: 'Nurses report overwhelming positive attitudes on the impact of volunteers in supporting their role'. Yet they are quite unaware of that their current training goes kind of behind that world of volunteering. It is almost in this mystical area outside health care. The actual interface between health care and volunteering is a grey area. Certainly in our country volunteering has been very common in hospices, but until about ten years ago you wouldn't find many volunteers in hospitals. Anyway now in our country there are many volunteers doing many different types of roles in big general hospitals. This was

another theme about whether volunteers were spending time with patients who are dying. One of the interesting things is that actually you start with the small beginnings as the helpers often do, you end up with the emotional attachment and then the whole dying phase, which you probably never imagined you might be in when you started with your small beginnings. The education and training needs to take into account that you might be linked with a very special time of people's life which you may not have experienced or encountered before.

Distinction of volunteers

When we looked around the countries that were involved in OPCARE-9, there were three countries that had some aspects of training to be or sit with dying patients. One of the places we came to was Cologne, just down the road. One interesting feedback from volunteers sitting with dying patients was that they would do things that staff members would never do. When we think of volunteers we often think of them of doing things, if we weren't so busy we would do them, but we haven't got time so it is good that the volunteer is here, like shredding the paper or photocopying. But actually we shouldn't be thinking of volunteers as of mini health care professionals, but more as the community having a presence with our patients. The volunteer we met in Cologne told us how often she sits with the relatives when the patient was dying. She realized how hard the situation was for the relatives and so she talked to them about the patient in the bed, telling them stories and reliving some of their memories. Hearing this from a stranger or a person who was interested makes sense for them because they would never have such conversation with a nurse or a doctor. These things that volunteers bring into this caring environment are complementary to what the health care professionals are doing as opposed to replacing them. One must think of those paradigms of how we use volunteers and their skills. I think we shouldn't be thinking they can do the things we are too busy to do. They are bringing in another dimension of how to care for patients.

Living Community Presence for the Dying

We were keen at the end of all this to think whether we could bring together the learning to develop a course aimed specifically for the care of dying patients. A European who volunteered in 2011 notes that a critical role of volunteering is lifelong learning, allowing individuals to develop. Those two sides of the coin are about the volunteer volunteering to do something but also benefiting from doing what they do. So there are two sides to volunteering. The important thing is that the EU recognising it as the year of volunteering, saying this is an important part of our society, and how our society is going to maintain and sustain itself into the future.

On the back of the learning from the European project we received funding, a quarter million pounds, to create a programme called the Living Community Presence for the Dying. Again the title of this project is really good because this project is about volunteers coming in to our big hospitals of 880 beds, and to sit with dying patients they never met before. They are there if the

patient is dying alone, or the relatives want someone to be with the patient, or the relatives want a time out. It's about bringing the community into the hospital. If patients can't die at home, how about bringing the community to them? That was based on the work from OPCARE-9 and we trained in total around 20 volunteers to do this. Interestingly they have range in age from 18 to 80, a wide range of people. One of our biggest concerns was getting the right people to do this because it was getting emotionally challenging, they would have to be responsive when we needed them in the hospital. To get the right kind of people we did get out to seek these volunteers and didn't just pick them from our internal volunteers. We got out and sought these volunteers with adverts in various places. One of the biggest surprises was what kind of people came forward to do this. It actually attracted an amazing group of people. Some of them actually had experience in palliative care but most hadn't. The 18 year old was actually a medical student and she had quite a spiritual background, a strong faith and was very impressive to most people who met her because of her whole persona and how she valued the opportunity of being involved in this piece of work. I think this has been a surprise where we are still running and evaluating the programme. So far our work has been a success and in our hospital now it hasn't just been in six wards, it has been rolled out to the rest of the hospital and we are recruiting more volunteers to it. For us within the hospital it is now a part of a volunteer service we are delivering.

Linguistics

It is interesting when we talk about the language. English at times is an awkward language; I don't think there are enough words. Other languages have these words that have a lot more meaning when it comes to palliative care and end of life care. An example from New Zealand is 'Mahi aroha' - a term that closely translates the concept of voluntary work, unpaid activity performed with sympathy and caring for others rather than working for financial reward. 'Tohu aroha' is an expression that incorporates the spiritual aspects of volunteering. 'He tohu aroha' is an expression or manifestation of love, sympathy and caring. The Maori tradition around death, dying and rituals is very significant; it's a huge community activity. You go back to your house, your mother house, which is a huge hub and the whole community gather and is there with you. Your family consists almost of the whole tribe, and it is a big tradition in Maori culture. They have such a strong culture and a language to describe something that we would struggle with in English. It would be great to have time to develop new English words around this. But I think when you look at other languages and civilizations, you see how they grow from development, it is just part of their culture.

Concluding words

I thought we should finish with volunteers, since we are here for volunteers. So I'm about to show you these four little extracts from a rather long video, from two of the volunteers who are working for Living Community Presence for Dying People in our hospital.

These are some empowered people doing some remarkable things. They value the interaction with humanity, being with people, and it is a special time for them, they get real value and reward from doing it. So this I wanted to present to you - some different aspects of volunteering, and I hope it did make some sense. Thank you!

Piotr Krakowiak:

Hospice-palliative care volunteering in the changing society of Poland

Introduction.

I would like to start this lecture with a fragment of our educational movie, just as a small multimedia introduction. It's called "Hospice seen from inside" (Karbowski 2007) and has been directed by a professional who has been working as a volunteer and taken an active part of the daily care in the hospice in Gdansk. Because the patients knew him he was able to show the real daily life of the place, which relies in major aspects on volunteers. You can see, there are some workshops that are done by the volunteers. There you can see our lady-patient, who was really good at singing. We had discovered that when we did the workshops. Even though she had cancer on her back with metastases, she sang us a few concerts, and part of one has been recorded. She couldn't really lie on her back and singing while lying on your belly with pain in your back is not easy. I showed you a short clip to introduce hospice team in Gdansk. You can see the full movie and many other multimedia materials in Polish, with English subtitles - at: www.hospicja.pl/en

After this let me tell you a little bit about myself. I've been part of the hospice movement in Poland since 1990 and involved in end-of-life care for more than 20 years in various roles. I started as volunteer while studying theology as I'm from the religious order of Pallottines and a Catholic priest since 1993. After time of volunteering I became a chaplain in a hospice, doing also the work of a volunteer coordinator. By working with patients and their families in home care, I soon realized that I need to do some other special training, a part of theology. I studied psychology in Italy with doctoral dissertation in the US. When I came back to Gdansk in 2000, I was able to start the volunteering program with all the good practices that I'd learned abroad, in the US and the UK as well. In the following years I worked as chaplain, psychologist and volunteer coordinator in the hospice in Gdansk. In 2002 I became managing director of this center, which I ran until 2011. In 2003 I became national chaplain of hospices, nominated during the Bishops Conference of Poland and I've started to introduce a new approach towards volunteering. Many hospice-palliative care programs in Poland are based on the faith institutions, mostly from the Catholic Church (few of Protestant and Orthodox Churches, too). The role of national chaplain of hospices gave me an access to many of these places. I'm going to tell you more about that in a moment.

In the beginning, allow me one methodological clarification. I like to use the terms "hospice care" and "palliative care" together, like combining two activities. Whereas hospice care is more on a voluntary basis and palliative care on a university, medical, professional level. The combination of the two allows you not to lose anything and include all (Krakowiak 2012a). At the end of this

introductory part - I'm very glad to be here and to be able to share our experiences from Poland here in Germany with international participants.

Short look at history of modern hospice movement in Poland and the role of volunteers.

It's difficult to understand the current role of volunteers in hospice-palliative care without seeing the history of the modern hospice movement. It will be shown in briefly. Soon also a textbook will be published in English, as first attempt to share the unique story of the hospice movement which has developed in Poland together with the Solidarity Movement.

Voluntary based hospice teams 1981-1990

The first modern hospice in Poland started in 1981 in Cracow, so we have more than 30 years of history - more than most other European countries. Dr Cicely Saunders from London's St. Christopher's Hospice became a close friend with one of her first patients, the Polish Jew and holocaust survivor David Tasma. He offered her all his savings "for the window in the house for dying", and she called him "the first inspirational person for modern hospice movement". Dr Saunders is the founder of modern hospice movement, and with her husband, a Polish artist from Krakow, she visited Poland in the difficult period during the communist era. Her meetings and lectures in the 1970's were the first inspirations for the hospice movement in Poland. There were already volunteers doing some work for terminally ill in the Catholic Church structures. Those visits and meetings had empowered them and some of them went to London to see how a modern hospice operates (Krakowiak 2012b).

The first modern program in Krakow started in 1981 and was based on the inspirations from St. Christopher's in London. In the difficult Eastern-European reality in these times it took 15 years to finish the hospice house project in Krakow, as it was a difficult time at the end of the communist regime and the Solidarity Movement (Krakowiak et al. 2007). In the meantime in 1983 we created a hospice home-care-system in Gdansk. Home care has been started by the parishes with groups of volunteers and some equipment donated from the West. Those teams were able to do hospice home care efficiently (Krakowiak et al. 2013). In 1987 the Pope John Paul II came to Gdansk and in his homily he was saying that he admires the work of the volunteers. He helped to promote hospice care. He encouraged existing teams to continue their work, and after his message the bishops were encouraged to support hospice care as well. At that time I was a student and had heard about the hospice movement for the first time, as many others and throughout society.

Home care in Poland proved to be very successful, and in 1989 we had over 90 programs of this kind, which were mostly connected to the Catholic parishes. The national chaplain of hospices was in charge, because most of these programs were close to or within the church structures (Krakowiak and Stolarczyk 2007). All the medical and non-medical activities were performed by volunteers, who would help seriously ill and their families apart from their professional placements. With growing numbers of patients this voluntary based structure needed changes,

which came in time of democracy in Poland.

Development of hospice-palliative care in Poland: 1990-1998

For around ten years there were only volunteers in hospices in Poland. Nobody was paid for his/her activities: doctors, nurses, psychologists, social workers, chaplains. Everything was on voluntary basis, which I think is quite unusual in comparison to other programs in Europe. We had a lot of support from the church and also help from abroad. We had a lot of foreign help and assistance during that time - solidarity support and charitable transports with drugs and equipment, which we have used in our home care. In some way we might be able to say that many parishes and other organization from Western Europe (Germany, Austria, France, Belgium, Holland and Scandinavia) were in some way co-founders of our modern hospice movement. Most of the equipment and drugs were donated by them to our teams. Our teams often exchanged some drugs and equipment for hospitals with other stuff available, which was necessary for our home care for dying.

Along with democratic changes since 1989 in Poland and the rest of Eastern Europe, there were changes in the end-of-life care and a national consultant of palliative medicine has been nominated since the 1990's. We have had a hospice and palliative care cooperation with the joint commission created by the minister of health in 1992 (Krakowiak and Janowicz 2013). Professionals from palliative care clinics and volunteers from voluntary based hospices have been invited to elaborate a future work program. It was the time most involved medical volunteers (physician, nurses) had the opportunity to do paid work full-time or part-time. This way providing a very important continuity of care. The transition from the voluntary system into paid jobs was not always easy, but with time professional standards have been implemented into most of our teams. Some of them have refused regular employment for a long time and remained employed solely on a voluntary basis, as they considered it a part of hospice philosophy.

Hospice-palliative care implemented into health care system in Poland: 1998-2004

In 1998, when the national program for hospice-palliative care was implemented into the health care system an important step had been made in Poland (Ministry of Health, Poland 1998). The strategy was composed of spiritual-religious recognition, emotional support and voluntary activities in the structures of hospice-palliative care. So this was also a result of the work provided by the joint commission. Not only from the professional level but also from the voluntary level. In addition, everything that was not medical was considered as well. But gradually since 1998, volunteers started to diminish in different kinds of care. In some of them they even stopped volunteer training and involvement completely, focusing more on the clinical and medical side of hospice-palliative care (Krakowiak 2012b). This situation has been reported as a lack of holism, in which apart of professional competence the good will and enthusiasm of

volunteers play a major role. Some of our hospice-palliative care institutions were professional but there was no "home-like atmosphere", which is usually created by volunteers in institutional and home care. There was a need to return to the roots of the hospice movement and social education was the first step.

Social education about end-of-life care and invitation for volunteering: 2004-2014

Public education on modern hospice movement in Poland has been done mainly by teams from Cracow and Gdansk. Hospice volunteers were publishing in many magazines and books regarding end-of-life care and volunteering (Krakowiak and Stolarczyk 2007). In the field of hospice-palliative care for children most professional education for Poland and Eastern Europe have been provided in the hospice for children in Warsaw. Most of its publications are available online in Polish and English, for those of you who would like to see palliative care for children in details. With gradual professionalization and medicalization of hospices -palliative care publications and books on the professional level did not reach the general public. This has led to less public education efforts and consequently in less candidates for volunteering, as well as less support from local communities. Since 2004 we have a special nationwide educational programs called "Hospice is also a life" in order to establish social education about hospice-palliative care, and promoting voluntary involvement. In 2007 another nationwide program, specifically designed to promote hospice volunteering in our local centers, called „I like helping” has been launched in Poland. Today, according to the recent EAPC Atlas 2013, we have more than 450 hospice-palliative care units in Poland, which is quite impressive. It puts us in the fifth place in Europe and on the first place in Eastern Europe (EAPC Atlas Centeno et al. 2013). That is also the result of the common efforts of the volunteers and the professionals, of the faith communities and other people. Even though faith communities are supporting and helping us, we are not only open for the faith communities. Everybody is welcome. Here we can see the part of the church’s activities in our hospice-palliative care activities. We have asked Pope Benedict XVI for the blessing of our "I like to help" program and he has granted it for us, sending greetings to all hospice-palliative care volunteers and professionals in Poland (Krakowiak and Janowicz 2013). I believe in using all possible forces in promoting our activities, and religious support is still important factor in our society. We have new challenges which I will describe shortly for you.

Structure and current challenges of hospice-palliative care in Poland.

What do the structures of hospice-palliative care in Poland look like today? We mostly do home-care and inpatient-care in independent hospice houses or in bigger hospitals. Our nationwide project has started with invitation of representatives of both fields to join and to work together in social education and promotion of volunteering. We made a website www.hospicja.pl which was at that time very important to unite everybody, to inform all of the institutions there are. In 2004 it was something new and also proved to be very successful as tool uniting professionals and volunteers, as well as patients and their families and the general public (Krakowiak 2012a).

In the mass media you didn't have to go that much into detail anymore as you could just refer to the website. The website had so many visits after the first national campaign ten years ago. This website was awarded 1st price of charitable websites in 2005 while it was created by volunteers, and run by volunteering students. We understood the impact of TV when ten million people saw programs and reports regarding hospice-palliative care and volunteering in the TV at prime time. Many of those who saw it went to the website afterwards, so we had to improve and enlarge that tool quickly.

The impact factor of the mass media was very important. So what we were trying to do, and I think we were really successful doing it was to change the stereotype that hospices are horrible places to think about, to visit and even to talk about. It's one of the taboos which society is not talking about. I noticed that. At that time I was the managing director of the Hospice in Gdansk, and I could see, that when employees were presenting themselves outside they would not gladly say "I work in a hospice". It was something negative, so I said: "No, no, no, we need to think about it in a positive way. We are a team working at the end of life-care and we are professionals who should be proud of that." Changing the image from this black and white cliché to something positive was crucial, creating an image which would help and involve people to help our caring teams. So this is why we did these colorful campaigns with a positive message regarding end-of-life care (Krakowiak 2012b).

Did we achieve that goal? To some extent yes. Now people in Poland working in palliative care are presenting themselves openly and they are proud of what they do. I think it is an important factor in this. Another factor is the public opinion, which has changed with time and I could say that the idea of hospice care is well promoted in Poland. We've had a visitor from Switzerland, and she made a private survey and published it on the EAPC blog. She was saying that she was asking random people if they would know about hospice and palliative care and she was surprised how much people from the street knew about that (Schmidlin 2013). I think that it was the result of the campaigns of this social education that have been ongoing since 2004 every November with thousands of media events in the TV, in the radio, and in the newspapers (Krakowiak 2012a).

Every year we make the spots on our own and we need to prepare all of the media coverage, which is also done by volunteers. Our beginning was very humble and nowadays we do that with more professional flavor because it needed to be improved. When we started, our friends from the Hungarian Hospice-Palliative asked us if they could use our spot with their own language and we gladly agreed. They put it out in their media, and got good response in supporting their organization as well as their volunteering. The message is that people should have the choice in the way to get involved. It's not always necessary to go directly to the patient's bed but there is also so much to be done from another perspective. This has been achieved in our nationwide educational campaigns and one can see more of this in my action research on this topic presented during the EAPC conference in Prague in 2013. The research was published earlier in Poland. One of the results of the educational campaign was also the gain of educational tools which I will shortly present to you in next part of my lecture.

Resources for volunteering and the general public's opinion about end-of-life care and volunteering.

Preparing every nationwide campaign, and inviting experts from hospice-palliative care in Poland we were also preparing several books and multimedia resources for volunteers and for the general public. Those books have been distributed for free to all centers of hospice-palliative care in Poland. The books were also distributed in the general public and in schools.



We have started in 2005 with a book regarding the mode of communication in end-of-life care. The accessibility and simplicity attracted many readers, and the book's success has encouraged us to review and update it as a practical textbook for professionals and volunteers (Krakowiak et al. 2014). In 2007 the textbook regarding grief, mourning and bereavement was published, as a guide for volunteers and the general public (Krakowiak 2007). It was used to create the bereavement groups in our hospice and palliative care units. Having no public funding for that kind of activities in our hospices, we prepared social workers, chaplains, and psychologists to be leaders in those bereavement groups. We've also given them training and advice about how to find money to run these institutions. Today over 100 hospice-palliative care centers in Poland do bereavement support for adults, using our books and multimedia tools. Parts of these activities are done by volunteers, often psychology and social work students, who are adequately prepared for these activities.

Since 2007 all efforts of my team in the Hospice Foundation were dedicated towards voluntary activities. An important achievement in 2008 was a handbook for volunteer coordinators (Krakowiak et al. 2008a) prepared by a team involved in the "I like helping" educational campaign. For the first time we've united the experiences that have been developed in different places in Poland in one book. The book is not just for one program, but for several programs existing in Poland. So that you are given the freedom to choose how you can get involved. A version of the textbook for volunteer candidates has been also prepared (Krakowiak et al. 2008b) and sent free of charge to all hospice-palliative care centers in Poland as teaching material for volunteers. The following year we were discussing multidisciplinary teams and different skills needed in end-of-life care teams. We have prepared consequently a handbook about non-medical aspects of hospice-palliative care (J Binnebesel et al. 2010). In this textbook there is important information regarding fundraising and cooperation with the media for local centers and volunteer coordinators.

After conclusion of "I like helping" nationwide campaign in 2010 there was a number of research and publication regarding all the achievements on the local, regional and national level. The first one has described most of the three years activities by the Hospice Foundation and the opinions of volunteer coordinators from participating centers. The following has been published as an action research regarding changes in volunteering activities and social education about end-of-life care (Krakowiak 2012a). Another publication has been based on those findings and was designed as a proposal regarding further developments in end-of-life care and involvement of volunteers (Krakowiak 2012b). Apart of the above mentioned books few educational films have been prepared and distributed for free among all hospice-palliative care institutions as well as among the general public through online platforms. I would like to describe more broadly in the next section the educational activities in schools regarding one of our books containing four movies.

Practical use of hospice tools in educational practice in Poland.

The textbook for teachers (J. Binnebesel et al. 2009) has been prepared in 2008 and is especially interesting when it comes to the education on end-of-life care and volunteering. It shows in a practical way how to talk about end-of-life issues and volunteering with students, with pupils, with teenagers and with adults. This book was prepared together with teachers which we invited during our workshops across Poland. Those who were cooperating with local hospices were writing from their educational experience. The book includes also four educational movies: for children with easily understandable cartoon animations; for teenagers considering hospice volunteering; for students and for teachers. We've received a recommendation of the Polish Ministry of Education, as we are the only ones that did a textbook about these kinds of topics. It's still much of a taboo in the education system. If you look at your countries, there is a lot on that topic.



This textbook has been translated into Italian (J Binnebesel et al. 2011) and soon it will be translated into Romanian and Hungarian. So maybe there will be the chance for other translations, at least for a part of that book. Half of this book consists of lesson-scenarios for teachers, with practical indications. Prepared by the teachers it answers questions what to do

when a parent of a pupil is dying. Teachers were telling us in the workshops that they'd avoid the problem. Some would say that they don't know what to say. Others are overprotective so that they only talk to this specific child and the others are left alone. So it was the teacher's experiences that helped us to set up a kind of "first aid kit" for these kinds of situations. In the books there are lessons and scenarios ready to use. The ministry of education in Poland gave the grant to distribute this textbook to every school in Poland, and there were lots of positive answers from the teachers. We've got a lot of requests from individual teachers who also wanted that book. Lesson- scenarios and educational movies are used both in crisis situations and while talking about volunteering to different age groups in schools.

In the above mentioned and all of our other books and educational campaigns we repeat that everyone can do something for a hospice. You can be part of the national campaigns or you can do something to support your hospice with your artwork. For children in kindergarten and school for example we have this daffodil initiative, which represents a sign of hope. We took that idea from Scotland, from Edinburgh. It is very popular in Poland, because it involves schools with even small children. The program is called "Fields of hope" . Together with all the members from local communities, the schools can also participate in a series of various events. Usually they prepare and give the daffodils to the pedestrians in the streets, walking with flowers and boxes asking for money for the hospices.



It is happening all over Poland and I think it is a very good promotion and source of fundraising. The children feel responsible for those seriously ill people, and they feel proud that they, as children, are helping. For those children the preparation of this event is often the first time that they visit a hospice and meet with team members. You might talk to some volunteers and in the future you might consider yourself to be a volunteer. Even the young kids during "Fields of hope" tend to say: "I'm a hospice volunteer." Furthermore young children often arise the interest of their parents and families - we have profited a lot from people's involvement after their children's report from meetings in hospices.

We also have motivational mechanism for teenagers in the gymnasium. In the gymnasium the

students need to collect points in order to reach the next level of scholastic education. They can gain these points by working as a volunteer in hospices. Some say: "Well, it's artificial. They are only coming for the points and the commitment doesn't come from the heart. But I say: Come on, it's a chance. They can come, we can talk to them and some of them stay. Especially those who go for the subjects of helping professions like psychology, social work, medicine" (Krakowiak et al. 2008a).

In Poland we start promoting hospice volunteering as early as in kindergarten, as we have children from kindergarten involved in volunteering. Of course we won't expose them to dying patients but we won't exclude them from visiting the facilities. They come at Christmas and are singing Christmas carols which they've prepared at school, and our patients are happy to see the children performing. In the hospice in Gdansk we have cooperated with 70 schools and we have almost 70 requests for performing Christmas carols in our hospice. One needs to be careful not to "kill" our patients with all the carols. While too much of those activities might be a form of euthanasia, which is not a hospice approach to dying with dignity. Usually our nurses know who among our patients is ready for the concert, and if possible somehow the patients do participate gladly. For the children and their teachers it's a special gift for seriously ill and their careers. They feel like having done something important and especially children often talk about it with their parents.



The word spreads through our children-volunteers, and often the parents are also donating to the organization in which their children perform. Sometimes we also receive phone calls from worried parents: "What are you doing? You are sending our children to the dying." We respond that we are just teaching them about life, which has its natural beginning and its natural end. Explaining to parents that it's not about exposing their children or showing them dying patients but letting them enter gradually into end-of-life issues. I believe this approach has a great educational value, and this book prepared by a team of professionals, volunteers and teachers who practically cooperated with hospices could be used and be adopted to other languages and cultures across Europe.

Challenges and chances for better end-of-life care in Poland.

At the beginning of XXI century we started a series of common initiatives for all hospice-palliative care institutions in Poland, which has been described above. When hospice-palliative care became more and more professional all the standards were necessary, computers were necessary and financial sustainability was necessary because we were receiving money from the Ministry of Health. If the volunteers existed, they were left alone, being often seen like something old from the past. On the one hand we were saying "volunteering is crucial for hospice-palliative care" but in reality it was something non-existing. If somebody comes towards you with a lot of energy and you try to hire him as a volunteer and then there is nobody to take care of him, this person will never come back to you. He will think that you try to tell him one thing but then you do something else. A crucial effort to improve volunteering standards in Poland has been the investment in volunteer coordinators, which has proven to be a success in many caring centers. As I presented above, there has been a lot of work done to improve and professionalize voluntary service and voluntary coordination in Poland. There are many other challenges, as for example new task assignments of professionals and volunteers, which will be presented briefly.

From religious into spiritual care

Another thing that derives from this experience of volunteering is the involvement of volunteers in spiritual care. Somehow volunteering and spiritual care is combined in palliative care, as one speaks about team work and spirituality there. In other places in our system there is no spiritual care at all. There is spiritual assistance, you have a chaplain. 20 years ago I started as a chaplain. At that time in the hospices, there was hardly anybody that did not want to talk to the chaplain or receive the communion. After 25 years I went to the hospital where I was chaplain before. There was hardly anybody who wanted to talk to me anymore and those who wanted the communion wanted to ask questions first and have a chat with me. I think you have had the same development in your countries as well. A lot of people in church do not practice the old traditions and sacraments anymore. The margin will be on the edge of people who are traditional Catholics, Orthodox or whatever. The group of traditionals still exists, but I think the numbers of those who do not care about such matters anymore are growing. We used the good practices we acquired over time to launch a school. To this school we invited men and women to work together in teams (Muszala et al. 2011). The biggest resistance we had during the establishing of the school came from priests - chaplains, who often seem to be afraid of cooperation in teams. There are good practices originating from the volunteering tradition in hospice-palliative care when it comes to teamwork. We are integrating those good practices into the health care, social care and home care in Poland.

Volunteers in home care for elderly and chronically ill

With ideas we had from working with volunteers and the improvement of their coordination,

we've tried to move forward and create a new project: "From hospice-palliative care towards end-of-life care". We asked the Catholic Caritas, the Protestant Diakonia and the Orthodox Eleos if they could do something for the end-of-life care education. It is also about taking these good practices and competences we've developed for hospices to other institutions, e.g. home care and institutional care. So we started a common program with Caritas, Diakonia and Eleos. Here you can see the book we've published in 2011 carrying the title "Home care for seriously ill patients" (P. Krakowiak 2011). It's a textbook with a lot of easy-to-use information and an educational movie that helps people who are in difficult situations with their relatives at home. We've realized that there are more and more people who do family care, informal care and non-kin care. In Poland, there are many people who emigrate to the west, so the elderly stay alone and somebody has to care for them. This textbook is the first step to help those people. We do workshops as well. We follow the example of the national strategy on end-of-life care that started in the UK and Ireland. I think this is something we should adopt, in order to deal with the growing problems of demographical changes. We already adapted some of our books to the home care for elderly and chronically ill, as well as for chronically ill children and their parents and siblings (J. Binnebesel 2012). Some other literature is in progress together with Caritas.



Prisoners as hospice volunteers

Could you imagine prisoners, convicts to be hospice volunteers? It is now happening since ten years in Poland. We have started in Gdansk but now we do this in more than 30 hospices and over 100 nursing homes in Poland. And of course you might ask yourself how did this happen? It's a cooperation between the psychologists and sociologists in the prison and our team. We told them we need the best of the best in the prison, the people who really want to change. We don't seek serial offenders but first time convicts. Sexual convicts are excluded. We have people though who killed somebody because they drove drunk, as for example a doctor who still had alcohol in his blood after a party. He was a pediatrician and told me that he would do anything in order to stay out of prison as long as possible. So I said to him: "Let's create a program to train prisoners for volunteering." We started to develop a program for volunteers by cooperating with a group of preselected people ready to get involved in hospices as volunteers. We have published an article on this project in English in the EAPC Journal (Krakowiak et al. 2012).

Usually there are very efficient and happy to work in the team. They are appreciating the fact that they are a member of the team, wearing the same t-shirts as other volunteers. The first thing they do when they receive the t-shirt after finishing the program is taking a picture and sending it home. "I'm not a criminal anymore, I'm a volunteer." They have children, they have a wife and they have moms and dads. They're all not very happy about them being in prison. I see it might be shocking to you, but it's a resource and with this project we've also discovered another resource. The youngsters who are at risk are often young first-time-offenders, who can avoid prison with community service in hospice. Of course the voluntary coordinator needs to be well prepared for that but if they are able to handle the situation, it's very fruitful. Because the people who are in this risk group, they will most likely never be good at school. They happened to be born in a bad neighborhood. Usually after alcohol and drug abuse they won't be good in sports anymore but they can still be good volunteers. They can have an achievement and success in their life. For example we've had these youngsters from this risk group that were taking care of our cars in the hospice. The cars get used and you need to repair them. Some of them had a driver license and were driving our nurses to the homecare. That's how we've started with voluntary drivers in our hospice in Gdansk. The nurses are happy because now they can do telephone calls and paperwork in-between their visits as they don't need to drive. So these are the resources that are possible, if you have a well prepared volunteer's coordinator and a team which accepts this kind of cooperation.



Multigenerational volunteering

Another group of volunteers that we have discovered during this nationwide program was the 50 years plus, 60 years plus, 70 years plus volunteering. In Szczecin (Stettin), not far from here, the head of the volunteering group in one of the hospices is an 80+ retired captain of big ships that were going around the world. He is a volunteer coordinator and he is working with his voluntary team like he was used to work as a captain with his crew members. It is very interesting as he is over 80, and still very active. In Poland there is still this cliché that volunteering is only for young people and in the west of Europe it's different. For example in the UK the hospice system consists mostly of adults. In Poland this was not the case but within promotional efforts the medical volunteers over 50 has tripled and the non medical volunteers over 50 have quintupled

in a short time. Just by telling them you can also be a volunteer, and your competence, your maturity, your willingness to help, your possible financial stability is welcome.

What happens with the young volunteers? They migrate very often: from one city and school to another. Nowadays it's the fact that volunteers are going abroad and are working in different places in Europe and the world. So the adults are a very secure resource. And I'm very glad to see the blending of the youth with the 60+, 70+ generations. It is very fruitful for the effectiveness in our teams. The cooperation with the mass media was very positive in promotion of hospice volunteering of adults and elderly people. Why? Because the media want to talk positively, they will not repeat that people are dying over and over again, as well as telling bad news about the poor financial security of caring institutions. They liked the idea of investing in volunteering, that's why media helped a lot with better understanding the principles of hospice care in both, the local environments and in the general public. The program also helped to establish contact to other hospices and makes the communication easier. In hospices that took part in our program there is also a better bereavement support, which is due to the fact that their financial situation is better.

Development of bereavement services

In recent years the campaigns and tools have been created to support bereavement groups for adults, in Poland. Recent activities have focused on additional groups for bereaved children. I think the people are very responsive when it comes to the needs of the children and the financial situation. So sometimes people promote their bereavement system for children and adults but use the funds only on adults. That's the reality. I speak open about how it is, while from my experience it is difficult to find money and volunteers for bereavement support of adults only. Generally speaking - at least from my experience - it is much more difficult to find money for adults than it is to find money for children. Fortunately it is not such a huge problem to have bereavement support for children, so we combine adults and children and create some kind of two programs with one fundraising project. Soon the nationwide website and call center will be created to support families and bereaved children. The British model of "Winston Wish" has been adopted and our own resources have been added to this project, which will be run by the Hospice Foundation mostly with trained volunteers (Krakowiak 2007).

Conclusions.

For three years in Poland more than 100 hospice-palliative care centers have taken part in the "I Like to help" program. Others were invited but didn't accept the conditions. Those who accepted the conditions of our program have received a lot of practical resources for volunteering. Most of those centers have grown up with this program and the number of volunteers has developed significantly. This is shown in detail in the action research of this project (Krakowiak 2012a). Many hospice managers have refused to take part in the project because they were saying they will be losing money on volunteering. The action research shows the opposite - all the centers

which have developed volunteering have improved also their cooperation with local sponsors. The financial security of hospices with volunteers is twice as big when you invest in volunteering compared to if you don't. Investing in volunteering might cost you some money, but the volunteers than again are able to raise money themselves. They promote the cause and help the people in their local environment to better understand the principles of hospice-palliative care. And that's the most precious resource when it comes to medical and non-medical staff, and also for managers of caring institutions. But the most important reason for preparing, recruiting and training volunteers is that they are close to the patients and their families, helping to fulfill the mission of good quality care towards the end-of-life.

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**Y. Engels:
Volunteers in Palliative Care -
A Comparison of Seven European Countries**

Introduction.

Good afternoon to all of you. I'm Yvonne Engels, I'm from the Netherlands. I work at the expertise center for palliative care of the Radboud University Medical Center in Nijmegen. I'm 55 years old. I was a midwife for 15 years, which was very rewarding, and gave a lot of positive energy, being involved in such an intimate moment of new parents. Probably you know that in the Netherlands a midwife is fully responsible for the delivery of the child. She's doing home deliveries and I did that for 15 years, as well in hospitals and at home. Then I started studying again. I did health sciences in Maastricht. I started to do research. I did my PhD on the organization of primary care in the Netherlands and in Europe.

After I finished my PhD in 2005, the expertise center for pain and palliative care in Nijmegen just started and professor Kris Vissers was looking for a senior researcher. It seems a contradiction, but already when I was a midwife I was very interested in palliative care. It might sound strange but there are so many similarities between the beginning of life, being a midwife and being involved in palliative care at the end of life. I'm not a clinician anymore. As well around birth as around death, medical ethical aspects play a role, pain is a dominant symptom, and professionals don't have a nine-to-five mentality.

Now I am a researcher in palliative care and cancer pain management since 2006 and one of the first projects for which I received funding was a European EU co-funded project. In this project, called Europall, seven countries participated: Germany, the Netherlands, Belgium, England, Poland, France and Spain.

Literature review on volunteering in palliative care.

On Pubmed, the combination of 'palliative care' and 'volunteering' resulted in about 150 publications, most of them from the USA, Australia, some from the UK, focusing on specific settings (emergency department) or patient groups (children), but hardly any focused on organisational aspects of volunteering, except for a review of the volunteer movement in EACP countries from 2001 by Fusco-Karmann et al., and a German book of Gronemeyer et al. on palliative care in Europe. Most papers we found on this topic were about the reason to become a volunteer, the role of volunteers and on the impact of being a volunteer. In this presentation I will focus on these four aspects: reason to become a volunteer, the role of the volunteer, problems volunteers face and the influence of volunteering on their lives.

Reasons to become a volunteer in palliative care

The most important and prominent reason to become a volunteer appears to be to help ease the pain of those living with a life-threatening illness. Five different categories of motives for becoming a hospice palliative care volunteer have been described: altruism, civic responsibility, leisure, self-promotion, and personal gain. Altruistic motives were the most influential reasons for choosing to join hospice; personal was the least influential reason for becoming a hospice volunteer. Altruism was found to be a significant predictor of volunteers' length of service to the hospice.

The role of a volunteer in palliative care

Several studies explored the role of volunteers, also in comparison to professionals. Three theme clusters were found: the distinctness of the volunteer role as compared to the role of the (paid) professional, the characteristics of the role, and the volunteer experience of the role. Literature suggests that the role of volunteers is distinctive as compared to professionals. The volunteer may act as a mediator between the patient and the staff. However, we also found some contradictions. Volunteers also appeared to have temporary surrogate family-type relationship roles. They also take over some of the characteristics of a paid professional. The second cluster concerns the essence of the role. Literature showed that the dominant feature of the role is social. The third helps to explain aspects of the role from the point of view of volunteers themselves. This third aspect highlighted that volunteers consider the role as flexible, informal and sometimes peripheral. Some volunteers find this stressful.

Reasons why volunteers liked volunteering and continued to work as a volunteer most often appeared to be enjoying it, feeling adequately prepared/trained to perform their role, and the fact that they learn a lot themselves from patients' experiences and listening to their patients' life stories. Being recognized (e.g. pins for years of service or being profiled in the hospice newsletter), receiving phone calls/cards from their volunteer coordinator on special occasions, and being reimbursed for out-of-pocket expenses appeared less important aspects.

The influence of volunteering on their own life

It has been shown that volunteering not only helps the patients, but it also has an influence on the volunteers themselves. A lot of volunteers experience personal growth in some way, have learned to keep things in perspective and to do different things to prevent compassion fatigue. In general it has changed their look on life. They describe their job as very rewarding.

Problems related to volunteering

Problems that volunteers are facing are mostly having had insufficient training and insufficient

coordination from their 'employer'. Furthermore they are not medically trained and are not knowing enough about end-of-life symptoms.

Europall: Volunteering in Europe.

One of the goals in palliative care in Europe is to further improve the quality of palliative care by evaluating its current level and standardizing routines and methods based on evidence and expertise. In order to assess current good practices in palliative care different organisations from seven European countries (the Netherlands, Belgium, Germany England, Poland, France, Spain) have carried out an international study. For this research four aspects concerning volunteers in palliative care in seven European countries were studied: 1. involvement of volunteers in palliative care; 2. the organisation of volunteers; 3. legal regulations concerning volunteers, and 4. training and education of volunteers (2014 Woitha, Engels et al.).

We followed three different steps to answer these four research questions: a scientific literature search, a grey literature search, and interviews with national experts in the seven participating countries. These experts needed to have at least five years of experience in palliative care and to be acknowledged on a national level (professors in palliative care, professional caregivers, policy makers).

Figure 1 gives an estimation of the number of volunteers that are involved in palliative care in these seven countries. Yet, it is not clear how valid these figures are. What you see is that particularly in Poland and Belgium, with 0.07 volunteers per 1,000 inhabitants and 0.06 volunteers per 1,000 inhabitants the estimated number of volunteers seems very low.

	Home care	Palliative care unit	Nursing home	Hospital	Day care centre	Hospice	Care home
Belgium	+	+	+	+	+	+	-
Germany	-	+	-	-	-	+	-
Spain	+	-	+	+	-	-	+
France	+	-	-	+	-	-	-
Netherlands	+	-	+	+	-	+	+
Poland	-	-	-	-	-	+	-
England	+	+	-	+	+	-	-

Country	Number of Inhabitants	Number of volunteers	Volunteers/ 1.000 inhabitants
Belgium	6,000,000	354	0.06
Germany	82,046,000	80,000	0.98
Spain	46,661,950	14,203	0.3
France	65,073,482	4,169	0.45
Netherlands	16,493,156	8,300	0.5
Poland	38,153,389	2,500	0.07
England	60,587,000	70,000	1.16

Closely

related to the number of volunteers is the question in which kind of settings they work. In Belgium, the Netherlands and the United Kingdom, volunteers are present in most type of settings. In Germany, this seems restricted to hospices and palliative care units, in France to hospitals, and in Poland to hospices (figure 2).

Country	Training	Mandatory	Supervision	Internship	Qualifications
BE	Flanders: 1, 2	yes	+	+	-
DE	1, 4		+	-	-
ES	5		+	+	-
FR	1, 3	yes	+	+	-
NL	1, 4		-	-	-
PO	6	yes	-	-	-
UK/ GB	1, 4		+	-	+

Only in Germany, France and the Netherlands, national organisations for the coordination of palliative care volunteers exist, and in all countries but Germany there are regional organisations.

When comparing Belgium, Germany, Spain, France, Netherlands, Poland and Great Britain, one can see that only in Spain no basic training is needed for volunteering. In Germany, the Netherlands and Great Britain, in addition to basic training additional courses are demanded. In Belgium refresher courses and in France continuing or advanced courses are needed for volunteering. In Spain online courses are offered; in Poland preparation courses are offered.

Since last year, an EAPC taskforce on volunteering in hospice and palliative care exists.

“This task force will explore the role of volunteers in hospice and palliative care in Europe, the different approaches to management and training and any barriers to their involvement in care. The Task Force will involve practitioners in volunteer management in hospice and palliative care, managers of hospice organisations, volunteers themselves and academics drawn from different European countries. The Task Force will also involve networking at a European level. A small number of contributors with specific expertise may also be drawn from other countries. The

approach will involve a mixture of research and evidence from practitioners and volunteers and the outcomes are intended to influence and develop knowledge and understanding and to improve and develop practice.” (Taken from the EAPC-[homepage](#).) Hopefully, this taskforce will succeed in giving more explicit figures on the organisation of palliative care. If they manage to get a better overview of this, in combination with more insights in the needs of volunteers, they might be able to improve training and education of volunteers. Best practices can be shared. Preferably, also volunteers, family members, patients and professional caregivers will cooperate in this taskforce, or have an advisory role. They can help to plan the agenda for an international training and education plan, to put volunteering on the policy agenda.

More insight in, better coordination, better training and better international coordination of volunteering in palliative care, will eventually contribute to a better quality of life of all palliative patients.

T. Klie:

Volunteering in palliative care- indispensable but please don't exploit

Hospice movement.

Hospice work developed from a civil society movement. Inspired by Cicely Saunders in England women and men in many countries are engaged for the circumstances for human beings to die with dignity.

Mortifying conditions in hospitals as well as the desertion and the loneliness of dying people at home gave the reason for their commitment. To bring back dying into the middle of our society, to develop a new culture of communion with the dying; that is what the hospice movement stands for as well as for the commitment and requirement of professional adequate company of the dying. The civil advocacy is its characteristic. To enable dying in relationship with human beings estranged from each other and to confront the delegation of dying in institutions, constitutes a cultural challenge in a pluralistic society. By that the hospice movement also sets an example against the economization of the public health system and public care which are threatened by losing sight of the human being in his dignity, in his vulnerability and as our fellow men.

Mixed Care.

The work of volunteers in hospice work and in palliative care is always integrated in a welfare mix of care: Professionals guarantee palliative medical and specialized care company; social workers care for the involvement of relatives and the use of legal assistance. Relatives live their communion and in the everyday life of hospice work volunteers complement the work of others with their time, with their talents, with their competences and empathy. Thereby voluntary hospice work in different cultures and countries has different faces: While in England and Scotland volunteers campaign for the financial and administrative support of the institution; care for fundraising and gardening and take responsibility for the whole administration; the voluntary work of the Palliative Care Teams in Kerala is focused on day-to-day support of life and survival of the dying men's families.

In Germany psychosocial company is to be found as a characteristic of the volunteers. They accompany the dying and their families. They give their support and relieve relatives and professionals.

Professional's and volunteers.

In the beginning those who actually launched hospice work were volunteers, meanwhile they are integrated in a palliative care work which is regulated by law. They get qualified, instructed and assigned to the "full-time occupation". While they were once the principals, today they are assistants, while they were once the initiators, today they are wanted as volunteers. They are integrated in the logic of palliative care service- including the quality management efforts. The zze study in Bavaria about hospice work shows that volunteers nowadays gladly engage in

inpatient health care and while the engagement in the domestic sector rather decreases. At the same time hospice work extends - in the direction of grief attendance in regard to the target group of people with dementia and their relatives.

The financing of hospice work according to § 39a SGB V has changed the role of volunteers and has influenced the culture of hospice work: professionals dominate, are involved in quality assurance. That contributed to an expansion of hospice work. Not until palliative care rose in many regions in Germany. Thereby volunteers have to “entrust” quality specifications and structures and logics of palliative care.

The special quality in voluntary work.

Professional and voluntary work complement each other. This applies for the sector of palliative care in a particular way. While professionals demonstrate their specific know-how, their reliability, their hermeneutic assessment of the health state; know how to abate pain, prevent wearing situations, assure the arrangement of the overall situation; thus volunteers embody the solidarity of the society especially for vulnerable people demonstrated by the time volunteers give, the attitude they face dying people and their relatives. A caring society realizes a culture in which human beings are aware of being jointly responsible for their fellow citizens beyond the logic of payment and family membership; and with the conviction that a society would not be a good one otherwise. Volunteers bring along their specific competences, their talents and their empathy and at the same time educate themselves and continue their education to be able to react in a professional appropriate way. Here they gain competences; learn and win for their own lives - as the case may be for a professional occupation- important experiences and skills. Their tasks are different from the ones of a professional occupation. It is not necessarily the grade of obligations which differs volunteers from professionals; also voluntary fire brigades act complementarily and extinguish a fire at the time when it burns and not when volunteers like it. But their scope of duties is another.

Assignment profile.

It can be tasks like simply keeping the company of sick people. This might be a relief to relatives: be it in the household or in the organization of every-day life. It can be the offer to drive somebody to places or the presence in the house or a room which provides security. In residential hospices it can also be tasks that are not closely related with the patient and which are typical for volunteers in hospices in England or Scotland: Taking charge of fundraising of public relations or administrative tasks. Thereby for hospice work also applies: volunteers get involved with different intensity. For instance, in the project “engagement sets an example“ being time-limited young people look into the concept of a hospice for a limited period of time.

Others commit themselves to responsible roles for a long-term period. The spectrum of engagement is wide and this is a good thing. In hospice work it is important and a requirement for the public sponsorship that volunteers are qualified. The tasks are ambitious; tasks that require a spectrum of know-how. Being in the company of a dying person demands a certain empathy and openness. It has to be assured that hospice work is not used to realise missionary concerns. For volunteers themselves the companionship of dying persons is linked to experiences that need to be handled. It is advisable to offer and use supervision and it is

essential to be integrated in a team. - If the volunteer's task is the direct companionship of the dying. The specific voluntary tasks though should never get lost: the obstinacy, the motivation to do something for yourself, for others and for a just world on a small scale. That is also why it is important that voluntary activities are not monetarised, are not interweaved with economic purposes which put other motives, that might for example be business like forward. Of course charges have to be refunded but please do not reimburse relating volunteers by to the hours. That is what distinguishes volunteers from middle class people, who are also want to do lot of 'good' but they are certainly not looking for paid work.

No functionalizing and no exploitation.

The financing of hospice work is closely linked to the inclusion of volunteers. Hospice services need volunteers. This should not lead to volunteers doing the work of professionals, having to hold out for financial stability of palliative care services. The future of care for vulnerable people, to which especially the dying belong, lies in the mix of care, in the intelligent cooperation of relatives and professionals, professional activities and volunteers. In the ideal constellation everyone contributes what is appropriate to him or herself. Volunteers do not serve professionals; it is rather the opposite: Full-time employees have to support the motivation, the „need to help others“ and the willingness, the search for a reason, the realization of many different talents and the willingness to care. They are in demand especially where there are people being ready for engagement anyway. It is the middle class that gives hospice work its characteristics. Insofar it seems especially important to support people from different social groups and different origins in their willingness to campaign for and support vulnerable people; to give them a framework in which they can get involved with their abilities, their willingness to learn, with their empathy. That can be elaborate. Herein lies the cultural task, the requirement to create a culture of care in a modern society even without having the confidence of being cared for oneself and if we cannot count on the help of a family, good friends or neighbors. Ideal is, for example, what is happening in the Indian federal state Kerala: Meanwhile there are 60,000 volunteers acting in palliative care. Nearly all the neighbourhoods in the cities and communities know palliative care teams which set themselves the task to support vulnerable people, dying people and their families. By that they show that the culture of a society lives from the ability of compassion; the ability of sympathy for others. That's what volunteering in palliative care stands for, to be honest and co-productive.

Unpayable but not available for free.

Volunteers are not wanted for the hospice service but for the hospice idea which promises to dye where I live and belong to and in in connection with the community and family. This requires frame conditions. In Germany we can be happy that there are (limited) public aids; the confession that voluntary support also requires frame conditions to make them reliable and open for as many people as possible: Honorary appointment and volunteers are unpayable but not available for free.

R. Scott:

Volunteering in Hospice and Palliative Care – a UK Perspective

Introduction.

Volunteers have historically been involved in hospices in the UK since the movement began. Indeed, many if not all, independent hospices were founded by volunteers who identified a need for this care and set about making it a reality in their local area.

This paper explores volunteering in hospice and palliative care in the UK and is set out in three parts. The first section gives an overview of hospice and palliative care volunteering in the UK, the second part considers how and why this is changing and the final section reports on research undertaken which explores the relationship between volunteering and independent hospice sustainability in the UK.

UK hospice volunteering today

Before moving on to explore the role and activities of volunteers in more depth it is helpful to consider definitions of volunteering generally and of hospice volunteering in particular.

The National Council for Voluntary Organisations defines volunteering as:

“Any activity that involves spending time, unpaid, doing something that aims to benefit the environment or someone (individuals or groups) other than, or in addition to, close relatives. Central to this definition is the fact that volunteering must be a choice freely made by each individual.” (NCVO)

In considering a definition specific to hospice and palliative care volunteering, Scott (Scott 2013) defined this as:

“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” (p. 17).

With these definitions in mind it is worth considering the extent of volunteering in hospice and

palliative care in the UK today. It is estimated that there are approximately 125,000 volunteers involved in hospice and palliative care in the UK (Help the Hospices 2006) although figures from Scott's recent research study (Scott 2013) suggest that this figure might be closer to 160,000. Volunteers donate over 18 million hours per year with an economic value in excess of £112m (Help the Hospices 2006).

Volunteering models tend to be formal and hierarchical where volunteers are involved in helping to deliver a range of services and supporting the staff team. Overall responsibility for management of the voluntary service normally sits with a Volunteer Manager. In addition professionals also provide line-management to volunteers who are part of their team.

Volunteers are involved in a diversity of roles from providing psychosocial support to patients and families, administrative and practical support to the organisation, fundraising and helping in hospice shops.

Standards and Training

In the UK, there are definitions of volunteering, but these are not legal definitions. Legislation affects volunteers both directly and indirectly as do regulatory care standards. There is an optional national standard for volunteering investing in Volunteers, but currently there are no national palliative care volunteering standards. Training is provided by individual hospice organisations and is tailored to the role of the volunteer. For care focussed roles, this can be intensive and used as part of the selection process to assess the suitability of the volunteer.

Volunteering, hospices and a changing environment

Findings from the Commission into the Future of Hospice Care (Help the Hospices 2012) suggest that hospices need to change if they are to be able to meet increasing and changing demands of patients in the future. With an aging population, hospices will experience ever-increasing demands from an elderly population living with complex conditions. Additionally, hospices must consider the palliative care needs arising from the frailty of this population. All this is set alongside the challenges of funding and service commissioning.

For a number of years now, there has been growing recognition of the vital role of volunteering in supporting hospices in the future. Evidence from the literature and from the Commission suggests that volunteers have a key role to play in hospice strategy (Help the Hospices 2012, Scott 2013). The Commission (Help the Hospices 2012) also suggested that "volunteers offer a sustained caring connection to people with life-shortening illnesses in all settings" (p. 8) and that hospices must enable them "to play a full role in the work of the clinical team" (p. 6).

Various studies (Burbeck et al. 2013, Carling et al. 2013, Scott 2013, Pastor 2010) suggest that

the majority of volunteers are not involved in care. However given the significant numbers of volunteers involved and the wide range of roles, this is perhaps not surprising. A more recent study of volunteers working only in care found that volunteers were involved in diverse range of roles including sitting with dying patients (Burbeck et al. 2014). In a study of children's hospices Burbeck et al. identified key role for volunteers in transition of young adults. Scott (Scott 2013) identified a clear commitment to the further development of volunteering in care.

Together for Short Lives (Together for Short Lives 2013), the national association for children's hospice and palliative care services identified that many organisations have no strategic view of volunteering and do not recognise the key role that they may play as part of the workforce. They suggest that services "need to consider volunteering strategically and invest in the development of new approaches" and also consider using trained volunteers in the direct delivery of care.

Naylor, C., Mundle, C., Weeks, L., & Buck, D. (Naylor 2013) researching the future of health and social care recommend that:

"Volunteering needs to be seen as a high-value activity in health and social care and volunteers as an important part of the workforce. As such, service providers and commissioners should take a much more strategic approach, with a clear vision of how volunteers will help meet organisational objectives and benefit patients and the local community" (p. 34), and that

"Volunteering should be used as a means of improving quality rather than reducing short-term costs. The management of volunteering and supporting infrastructure should be adequately resourced or there is a risk it will not achieve its potential." (p. 34)

All this points to significant opportunities for the further development of hospice and palliative care volunteering and our experience in this field puts us in a good position to capitalize on this.

Volunteers and hospice sustainability

It is not uncommon in UK hospices for hospices to say that they are dependent on volunteers in order to deliver their services. However, there is little research evidence to support this view. Therefore a research study Volunteers Strategic Asset or Optional Extra was undertaken to explore this area (Scott 2013).

Using a theoretical model developed from a review of the literature the purpose of the research was to:

Test the applicability of the theoretical model in both adult and children's hospices in UK by:

- Exploring the influence of volunteers on four key organisational sustainability

factors: governance, service delivery, hospice economy, and community engagement;

- Gaining insight into how volunteering is understood by senior staff, volunteers and trustees;
- Considering the relationship between volunteering and independent hospice sustainability.

Methods.

The study had a strategic focus and involved senior staff, trustees and volunteers. A self-administered online survey was sent to three senior staff, three trustees and ten volunteers in each hospice. In all 267 completed questionnaires were received from 32 hospices located in England and Scotland and giving a good geographic spread. Ethical approval was received from the University of Dundee Ethics Committee.

Data analysis was undertaken across respondent group, country and hospice type and categorised hospices by size using the number of beds. The relationship between the number of beds, staff and volunteers was considered but no strong trends emerged.

Findings.

Findings can be grouped into four key areas

- Volunteers and strategy
- Volunteers and service delivery
- Volunteers and community involvement
- Relationship between volunteers and hospice sustainability

Volunteers and strategy

It was clear from the findings across all groups that volunteers are recognised as a strategic resource but conversely there was little evidence of planning for volunteering within the service. There was little recognition of the significant involvement of volunteers in governance in their role as trustees.

Trustees perceived themselves to have a good level of engagement with volunteers and staff. However, the perceptions of staff and volunteers did not support this.

Volunteers and service delivery

Findings from trustees, staff and volunteers suggested that volunteers were important in enabling the delivery of a range of services to patients and their families and also in improving the quality of services. Volunteers were also considered to be integral to the professional team and important to the care and support of patients and families. Volunteering also had a vital role

to play in fundraising and in helping services to achieve more with less funding.

Volunteers and community involvement

Hospices in the UK depend heavily on their local communities for fundraising, staffing and volunteers. In exploring the role of volunteers in this context findings indicated that volunteers were important to community engagement and in educating the public about hospices, death, dying and bereavement.

However, volunteers themselves questioned the abilities of local communities to sustain ever-increasing demands for volunteers. In considering why hospices involve volunteers, volunteers saw their role mainly as saving the hospice money and in supporting staff, enabling them to concentrate on the specialist nature of their role. There was also a clear commitment from all groups to develop volunteering further in care.

Volunteers and hospice sustainability

In exploring the relationship between volunteering and hospice sustainability there was strong agreement across all respondents with a number indicating that their services would not be able to continue without volunteers. The findings are summarised in Table 1.

Table 1 Key sustainability findings

Key sustainability findings	Percentage of respondents
Volunteers contribute to financial success.	100%
Volunteers are important to patient care	88%
Volunteers help to make our services sustainable	100%
Unable to provide services without volunteers	100%
Would need to close without volunteers	12%

It is clear from this study that independent hospices need to recognise the strategic significance of volunteering and their dependence on volunteers for sustainability. At both a national and local level, volunteers need to be recognised as a key strategic asset and consideration given to

planning and resourcing this effectively.

Conclusion.

Hospice and palliative care volunteering in the UK is attracting significant interest at present and there are many innovative initiatives at local and national level. New models of community led volunteering are emerging along with more care focussed volunteering roles. National initiatives include: a guidance document on making the most of volunteers in hospice and palliative "Volunteers Vital to Our Future" commissioned by Help the Hospices and Together for Short Lives (Scott 2014), there are also plans to consider palliative care competencies and training.

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L. Pelttari:
**Experiences in volunteer hospice and palliative care work in Austria and the
EAPC Taskforce on Volunteering**

Background.

Let me introduce myself: My name is Leena Pelttari. I come from Finland but I have been living in Austria for almost 24 years and have been working in hospice and palliative care for more than 15 years – from very early stages through different phases of the development.

Austria is in size about 1/10 of Germany and has about 8.5 million inhabitants. The country is usually well known because of its beauty and its arts, its historical sites and good food and wine.

I am the Chief Executive Officer of Hospice Austria, the nonprofit independent national umbrella organisation of about 290 hospice and palliative care institutions. Our office team consists of six paid staff and nine volunteers. Hospice Austria started very small. In the beginning it was just a president and me. We were both volunteering for Hospice Austria. So we have actually grown very much in the last couple of years.

What are these nine volunteers doing in a national umbrella organization? We have two men working as volunteers for us, one of them was a lawyer; he is helping us in transportation and also gives us legal advice, being “our legal department”. Furthermore we have a former policeman and a former secretary who send living will forms on demand to people all over Austria. A former social worker, a former teacher and two retired doctors are consulting people on establishing living wills. Hospice Austria offers this as a special service to people of the region. They can also establish their living will with us when no further legal service is required. Finally we have volunteers who come when and where it is needed; our current president is also doing her job on a voluntary basis.

The main goal of Hospice Austria is the implementation of nationwide hospice and palliative care with long-term financing provided. Hospice and palliative care should be accessible and affordable for all those who need it. We face – as most do - challenges when it comes to financing hospice and palliative care in Austria. Hospice Austria is also striving to implement hospice and palliative care in nursing homes, general hospitals and for children, teenagers and young adults.

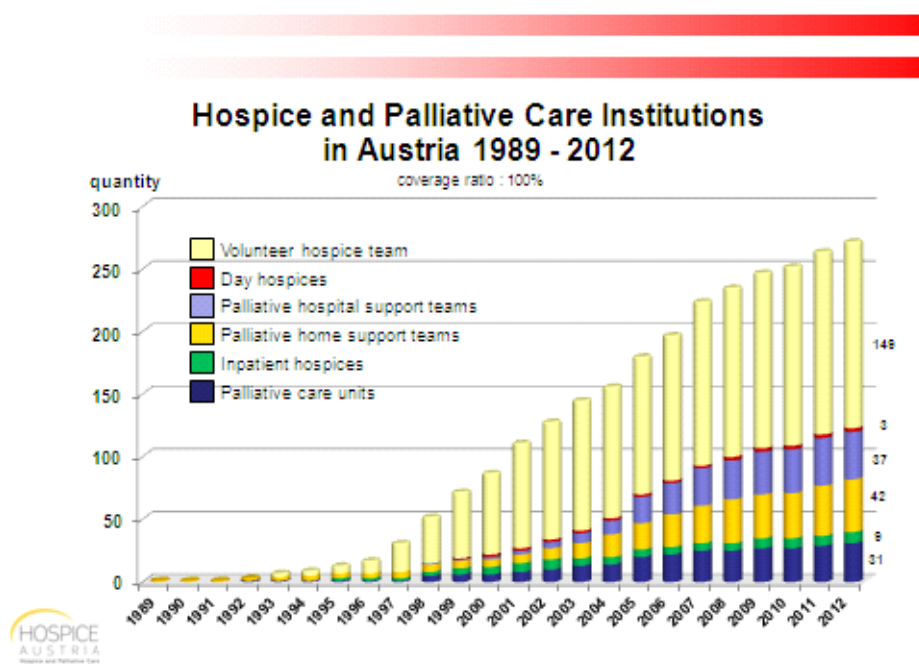
A glimpse of history

Hospice Austria was founded more than 20 years ago, in 1993, by Hildegard Teuschl, who was also our first president. She was the most important pioneer of the hospice movement in Austria. Hildegard Teuschl belonged to the congregation of Caritas Socialis Sisters. Her approach to

starting hospice work was by starting adequate trainings. I had the joy to work with her for more than ten years and also had the privilege to accompany her until she died from breast cancer in February 2009. - The Austrian Hospice movement started as a voluntary based movement. Sister Hildegard Teuschl and some other people founded the first hospice service in Vienna, a mobile team for support at home. Doctors and nurses were all working on a voluntary basis. The team started to grow and is today one of the biggest home palliative care support teams in Austria. In 1992 the first Austrian palliative care unit was established, which actually was an inpatient hospice at that time and was then turned into a palliative care unit because of financial reasons.

Hospice and Palliative Care services in Austria			
Primary Care		Specialised Hospice and Palliative Care	
Providers of General Care		Counseling and support	Care
Acute inpatient care	hospitals	Volunteer Hospice teams	Hospital Palliative Care Support Teams Palliative Care Units
Long term care	Nursing Homes	Home Palliative Care Support Teams	Inpatient Hospices

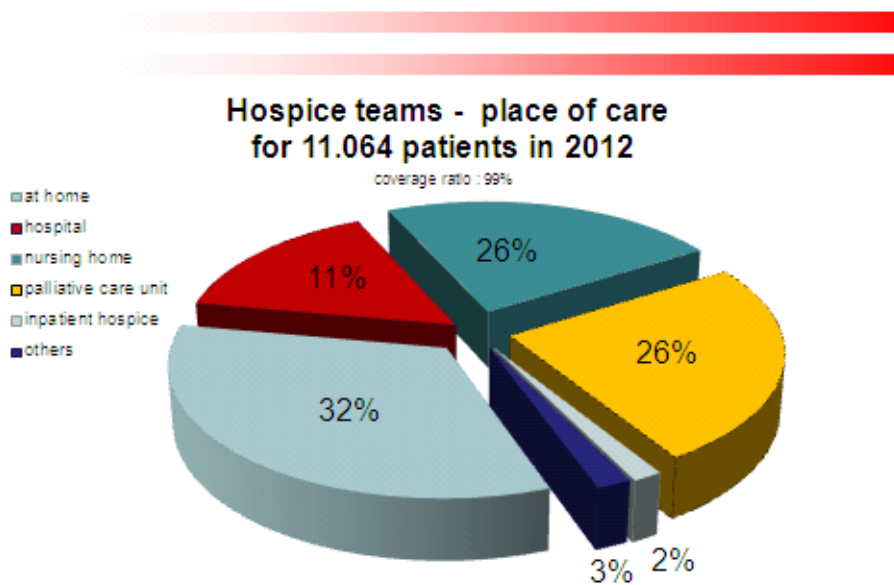
Hospice and Palliative Care Services in Austria



Austria has a 3-level-system of hospice and palliative care. The first level is the primary health care setting with hospitals, nursing homes and home care. The second level is support care provided by specialists and involves hospital palliative care support teams and home palliative care support teams. On the third level specialized care is provided in palliative care units, inpatient hospices and day hospices. Hospice volunteers work in all these contexts.

The diagram above shows the development of hospice and palliative care institutions in Austria over the last 20 years. The biggest growth concerns voluntary hospice teams.

Hospice Volunteers in Austria.



In 2012 Austria had 3,263 volunteers in hospice and palliative care. They are organized in teams, in 2012 there were 149 hospice teams. The great majority of the volunteers work in cooperation with the other specialized hospice and palliative care services, but they also start to work in primary care institutions like nursing homes. It will still take some time before volunteers can work in hospitals apart from palliative care units.

Place of Care

In 2012 hospice volunteers took care of 11,064 patients. The patients' families – volunteers also care for them - are excluded in this number. The diagram above lists the places where volunteers offer their care: 32 % were at the patients' home, 11 % in hospitals, 26 % in nursing homes, 26 % in palliative care units, so volunteers are working in all palliative care settings. The low number with inpatient hospices - only 2 % - is a result of the fact that Austria actually has

only nine inpatient hospices in three out of nine federal states. The reason is a lack of funding. Palliative care units on the other hand are as hospital wards part of the Austrian health care system with accordingly clear funding.

Organisation of hospice volunteers

As mentioned before hospice volunteers are organized in teams. This was a big change in Austria, because in the very beginning we had volunteers here and there, mostly working on their own in inpatient hospices and home palliative care support teams. With the introduction of the graded hospice and palliative care-system in 2004 we started to build more and more volunteering teams. A hospice team was defined as a group of ten to twelve volunteers qualified according to the curriculum of Hospice Austria with a (paid) coordinator (50 % full time equivalent). Volunteers need to participate in team meetings, they need to have supervision, they need ongoing training, at least eight hours per year and they need to document what they are doing.

The hospice team *organization* provides the accident insurance, the refunding of travelling and telephone costs or other costs the volunteers have. The organization also provides possibilities for training and further education. The concept of the graded hospice and palliative care-system suggested at least one team for 40,000 inhabitants in Austria. We have been revising these numbers lately: one team for 30,000 – 40,000 inhabitants. According to plan we would need around 210 hospice teams in Austria. In 2012 we had 149 equaling coverage of about 71 %.

Training of volunteers

Who are the volunteers in Austria? They are people with different backgrounds, different motivations, different life experiences, different age and most of them (88 %) are female. All volunteers in Austria have to qualify for the challenges in hospice work. Hospice Austria issued an updated Austrian-wide curriculum in 2012, which includes 80 hours of theory and 40 hours practical training before volunteers are allowed to work. This applies for all volunteers involved in direct patient and family care. If volunteers are working in an office they don't have to have this training, yet it is recommended.


The main aim of the curriculum is to convey a certain mindset. The appropriate attitude is the main instrument of care as a volunteer. So it is the person herself/himself that is very important. The educational principles of learning are 1) an open process with strong links to practice, b) small groups, c) learning by doing and d) learning by examples. These principles are followed in the four fields of contents: Biography, communication, information and spirituality. Whoever wants to become a hospice volunteer in Austria has to write an application stating why they want to become a volunteer.

Hospice Austria is also part of the Bundesarbeitsgemeinschaft Trauerbegleitung (National

Working Group on Bereavement Support) developing a new Austrian wide curriculum for grief support. There are two ways to get the qualification: 1) anyone already qualified as a hospice volunteer can add the grief support qualification of 80 hours. 2) Or you start with the grief support qualification of 110 hours without being a hospice volunteer before.

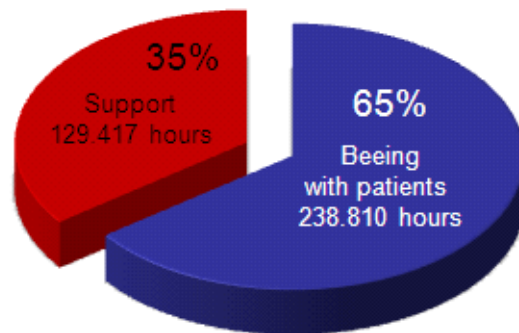
The role of the volunteers in hospice and palliative care

What volunteers contribute is probably similar almost everywhere: having time, being there sitting and listening, talking about life, awaking memories, taking a walk or offering a ride. Volunteers bring the normality of daily life to the patients and support their families and loved ones. In nursing homes they also carry out activities like music, seat dancing, reading to residents. Volunteers are also involved in planning and organizing charity events, fundraising and motivating new people for hospice work.



Volunteers Expenditure of Time 2012

(total: 368.227 hours)
coverage ratio : 95%



The diagram above shows the volunteers' expenditure of time in 2012. It's a total of 368,227 hours. 65 % of the hours were spent being with patients and families and 35 % for support and administrative tasks.

New developments

Three to four years ago Hospice Austria started a project for children's hospice work. Austria didn't have much children hospice work at all until then. After looking at other countries like Germany and the UK Hospice Austria decided to develop an Austrian-wide concept. The aim

was to achieve a good quality in children's hospice work. Together with the Ministry of Health and the Austrian Health Agency (GÖG/ÖBIG) Hospice Austria set up a concept for hospice and palliative care for children, teenagers and young adults. This concept was approved in 2013. Children's hospice volunteer teams are one of the four levels of care who are supporting families at home and in hospitals. The others are home palliative care support teams for children, inpatient hospices for children and palliative care beds for children in pediatric wards in hospitals. We estimate that we need one or two inpatient hospices for children. We also created a new Austrian-wide curriculum for qualifying children's hospice volunteers. The curriculum provides for already qualified hospice volunteers an additional training of 40 hours specializing in palliative care for children and their families. Hospice Austria plans to create another curriculum for people who want to be working only with children (and without qualifying for adult hospice volunteer work before) which will probably be around 80 hours. The first children's hospice volunteer teams are just being built, for example in Lower Austria, Vienna, Salzburg and Styria. Styria has implemented an own comprehensive concept of children's hospice and palliative care according to the official concept.

A word about finances.

Financing for hospice and palliative care institutions in Austria is a problem because Austria does not have an equivalent to the German §39a (SAPV Regelung). We have public funding, but it is different in all nine federal states. As a result financing of the hospice and palliative care work and the availability of its services is depending on the federal state where it is organized. That creates a great need for private funding and fundraising.

In 2007 Hospice Austria started a co-operation with the Austrian Savings Bank Group with the focus in supporting the work of hospice volunteers. In most of the federal states there are projects where hospice teams are supported by local branches of the Austrian Savings Bank Group. The support covers a wide range of forms from providing financial support to providing an office and basic infrastructure or support in PR and event management. The cooperation with the Austrian Savings Bank Group also contributes to financing Hospice Austria. For Hospice Austria this is an important source of funding as it is not easy to finance an umbrella organization. It is also very important to empower hospice work and the qualification of volunteers, so the financial resources received in this cooperation are also used for support training, supervision, events and team coordination.

Quality and research in hospice and palliative care.

Hospice Austria, the Paracelsus Medizinische Privatuniversität and the conference center St. Virgil in Salzburg are organizing and hosting the postgraduate master course "Universitätslehrgang Palliative Care". 78 Masters of Palliative Care and 142 Academic Palliative Care Experts have graduated so far. One master thesis and six theses for the academic palliative care expert degree were written about volunteering.

The Austrian Health Agency (GÖG/ÖBIG) and Hospice Austria developed together a Quality Management Manual which accounts for all of the six different institutions of hospice and palliative care and so also for volunteer hospice teams. It deals with process quality and supports hospice and palliative care organizations by suggesting which actions have to be taken when and in which order, for example when a patient calls. The manual describes the processes from the very first contact until the final steps after ending care. As far as we know it is the only quality manual covering *all* kinds of hospice and palliative care services and therefore quite unique in Europe.

Challenges.

The cooperation between professionals and volunteers to build a multiprofessional team is a challenge also in Austria. Other challenges are the role of volunteers in the society, in the health care system and in the social system and new settings for volunteering. Examples for new settings are children's hospice work and hospice volunteers in nursing homes.

Hospice Austria is organizing a nursing home project (called HPCPH) in Austria with the goal of implementing hospice and palliative care in all nursing homes. The project is a quality management program combining an organizational development process with training of at least 80 % of ALL staff in Palliative Geriatrics. There are around 800 nursing homes in Austria. By the end of 2012, 60 of these nursing homes had implemented hospice and palliative care according to this project. The Austrian Ministry of Social Affairs approves of the project and would like to implement hospice and palliative care in all nursing homes within the next ten years.

We also need more volunteers. A challenge here is the funding but also keeping up the "Hospice Spirit" in the health care system.

Susanne, a hospice volunteer, received the following letter from Margot, after Margot's husband Steffen had died. The letter sums up what it's all about and wonderfully describes the gift of hospice volunteering: being there.

Dear Susanne, an unforgettable moment for me, you at my door, you bright sunshine! Susanne, you cannot possibly imagine what you meant to us. I could go on writing line after line to thank you, to praise and to honour you for your dedication and to tell you how helpful and good it was for all of us that you were with us! My tears still flow because we have lost Steffen. It is so painful and yet, it is the way it is. I thank you from the bottom of my heart!

Margot

A new EAPC Task Force on Volunteering in Hospice and Palliative Care.

The situation of volunteers involved in hospice and palliative care varies greatly between European countries. Volunteers often play an important part in the care of patients and families, but also in a variety of other tasks, including fundraising and administration. Many hospices

depend on volunteers to be able to deliver the services they provide.

The EAPC Task Force on Volunteering in Hospice and Palliative Care was officially set up in November 2013 and its steering group first met in December that year. Co-chaired by Leena Pelttari and Ros Scott, it aims to explore:

- The numbers of volunteers involved in hospice and palliative care in Europe
- The roles undertaken by volunteers
- How volunteering is managed
- What training is offered to volunteers
- What the challenges are for volunteers, those who manage them and the organizations they work for.

The new EAPC Task Force is also interested in differences in approaches to the management and training of volunteers, as well as in any barriers that might stop them from getting involved.

The work of the Task Force will rely on networking at European level. Practitioners in volunteer management, hospice managers, volunteers and academics will all contribute.

The approach will be a mixture of research and direct evidence gathered from both professionals and volunteers. The general goal is to expand the knowledge and understanding of hospice volunteering in order to develop and improve practice.

With demand for hospice and palliative care steadily increasing, volunteers will certainly continue to play a significant role. It is thus important to explore the current situation of hospice and palliative care volunteers in Europe, and to identify ways of improving and increasing their involvement, which is what the new EAPC Task Force has set itself to do.

Participants Research

Motivation, attitude and characteristics of volunteers

This chapter puts the individual volunteers in the center of interest: Who are these people? Why do they do what they do? How do they feel about it? Those were some of the questions asked by the participants.

Three research projects are presented in the following section. Katrin Caro goes back in time to demonstrate the changes of volunteer's characteristics in Germany and England during the past decades, Katharina Pabst presents a survey-based methodology to research volunteering across Europe and Carolin Loth explains how this methodology was adapted to explore volunteering across Africa.

K. Schamböck-Caro:

The understanding of volunteerism
in the modern hospice movement
– from the beginning to future

Background.

The modern hospice movement began with the engagement of Dame Cicely Saunders, nurse, social worker and physician, in the second half of the 20th century. She was the first who looked after the needs of the dying at the end of life (Saunders 1999). Saunders realized that we have to look at all this pain. Dying people feel; we have to be the advocate of their belongings and we have to stay with them until the end. As also being a doctor, for Saunders pain reducing was essential for getting better conditions for life until the end.

For pain management and pain control she conducted scientific research, and there she developed her own new understanding of how to handle pain in this end of life situation: „constant pain needs constant control“ (Clark 2005, p.9). Anyway for Saunders pain didn't have not only this medical dimension, pain has a physical, emotional, social and spiritual dimension. For this phenomenon Saunders created a new term: total pain (Clark 2014, Saunders 1964b, Saunders 1964a).

From the beginning on she included volunteer work (Saunders 1999, p.119).

For Saunders volunteers need a specialised training, but she also said that volunteers cannot handle (medical) crisis (Saunders 1999, p.57). So at that time volunteers were mainly engaged in fundraising, house keeping, gardening, transports, shopping or things like that (Draper et al. 2014). The number of those who take care of the dying themselves is low. In the UK, if you compare it to Germany, palliative care and hospice became very early part of the public health

system, but they don't receive the money they need. That is the reason why a very high percentage of volunteers work in the field of fundraising. But British volunteers nowadays more and more want to take care of the dying for example as sitting at the bed of the dying (Draper et al. 2014).

In the eighties of the last century, deeply influenced by the British movement, the Germans began within different groups and movements to look at dying people and their needs. „Volunteers did that on their own...“ wrote Josef Roß (2001, p.5). Hospice units worked like grassroute movements, that meant operated they without any head (top) or official organisations. Inspired by Cicely Saunders they wanted to accompany dying people and their families, they wanted just to be there and wanted to show their needs in the public (Müller 2012, Roß 2001). In the beginning hospice movement worked as a home based civic movement only with volunteers. Today home based hospices are part of the German health system, their services are partially or totally paid by the system. In Germany around 100,000 volunteers in hospice are a crucial element of hospice services.

During the process of becoming part of the public health system, hospices had the problem to accept the rules of this system and that they had to be medically oriented. This is why economic aspects became important. Dying now got rules (Gronemeyer et al. 2007), volunteers had to learn standards and to get qualified (DHPV e.V. 2014). For Reimer Gronemeyer, in this new system volunteers were putted to the edge of the hospice movement (Gronemeyer 2013). Within the rules for the „specialist home-based palliative care services“ for example we find mostly physician-centered services, volunteer services will now only be part of the care if patients ask for them. Gronemeyer and Heller name volunteers in this context „clerus minor“ in palliative medicine (Gronemeyer and Heller 2007, p.584).

If we look to the future of hospice care in Germany and the UK we can recognize similar civil, demographic and medical challenges. They will have influence on the way we will die and how volunteers will work in the future (von Hayek et al. 2009, p.14, Keil 2013, p.26). Aging societies, shortage of nurses, financial problems of the health system, changing family structures, new roles for women, the discussions about active, passive and assisted euthanasia, changes in motivation of hospice volunteers, civic engagement as society's task – all these subjects will influence the two European societies.

In both countries the demand of support will rise. Regarding to Dörner, in Germany we are on the way to the greatest helping demand in human history (Dörner 2012) which we cannot solve with professional work. Our financial resources for that are too low (Burbeck et al. 2014).

„Here it is very important that volunteer work will survive.“ (Gronemeyer 2013, p.27)

Since the eighties of the last century Dörner foresees already an upward trend to new ways of staying home until death (Dörner 2012). And in his opinion this will only possible with the support of volunteer work. UK also faces these problems. British studies and publications refer already nowadays to the economic aspect of volunteers work in hospice and palliative care (Burbeck et al. 2014).

In aging societies, also the number of people with dementia rises. In Germany for example the number of people who need dementia care in 2009 reached 1.76 million people, for 2050 a number of 2.3 million is estimated (Stat. Bundesamt 2009). Also in that area home based volunteers get involved (Kuklau 2014) and they face the challenge.

Another problem will be that because of the increasing number of working woman there are fewer families who will take care of their old relatives. They cannot accompany them until death. Together with the civil movements we also realize a new understanding of volunteers work. Although there are no international studies available, we assume that most of the volunteers are female (Reitinger 2014). As mentioned above, the number of working women is increasing. In Germany 80 % of women between 27 and 40 years without children and 69 % of those with children go to work (Statistisches Bundesamt). That means their time for working as a volunteer is decreasing. On the other hand, when working as a volunteer the work must make sense to them (von Hayek et al. 2009).

In the beginning of the hospice movement in Germany the founders were leaded by their own concerns, many of them had lost a loved one. Because of their personal experience they wanted to do something to enhance the situation for the dying (Heller et al. 2013, p.29). Today volunteers are also looking for personal gain and self-promotion.

In Great Britain, a country with a long tradition in volunteering, we can also see a change in motivation for being a volunteer. Besides altruism and civil-responsibility, people are nowadays, like in Germany, looking for self-promotion and personal gain (Draper et al. 2014). In Great Britain volunteers now also just want to sit at the bed of the dying, listen to them and not only work in the administration or do other jobs (Burbeck et al. 2014).

Objective.

As above mentioned we realize a change in working as a hospice and palliative care volunteer. I want to describe the changes that happened from the beginning of the modern hospice movement until now, and I will also describe the change that is still going on. The second issue is to find out which activities volunteers in palliative care will carry out in the future, which part of the palliative care team they will fill out, how their role will be defined. Within that study I will look at the differences and similar tasks that volunteers cover in Britain and/or Germany. If volunteers in both countries face common problems the various solutions or ideas for that are to be described.

Design.

The objective contains different steps of investigations. Because of that I will use the mixed-methods-design (Mayring 2007, Flick et al. 2013, p.313).

The first step will be a literature research on volunteers' role at the beginning of the modern hospice movement in Germany and in Great Britain.

Step two is to look at volunteers' role today and to compare the differences and the common issues between the two countries.

Beside the volunteers' role also the influence of the social circumstances in both countries has to be considered.

A third step will identify the social circumstances and structures of society for the future and try to define the parameters for the future roles and activities of the volunteers in palliative care. To find these parameters I will interview experts in that field in Europe, mainly in the UK and Germany.

In this study I will mainly look on volunteers' work outpatient at home.

Method.

A questionnaire for volunteers has to be developed. Volunteers will be asked about their activities, about their part within the team, about their motivations to begin to stay or to leave in volunteer work.

To work out the parameters for future volunteers' work I will interview four to five experts in palliative care in Germany and in Great Britain. Asking for future development, the interviews will be formed as a narrative interview (Flick 2011, p.215).

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Background.

The complex requirements in the care of persons suffering from an incurable, life-limiting disease and their relatives can only be met with the aid of a multiprofessional and multidisciplinary team (Aulbert et al. 2012, p.1, p.77-78, Radbruch L 2011, p.263). It is the core aim here to achieve the best quality possible of life for patients and their relatives. Due to a holistic approach both the treatment of pain and other symptoms as well as the support in mental, social and spiritual issues are of primary concern (WHO 2013a). Volunteers uniquely contribute to provision of care (Aulbert et al. 2012 ,p.1278), can respond to the specific needs of patients and patients' relatives (Sabatowski et al. 2005, Morris et al. 2012) and have a significant influence on several sub-aspects of their quality of life. This is why they are an essential part of the multidisciplinary team and a constituent element (Wissert et al. 2004a) in palliative medicine and hospice work.

In spite of the volunteers' central position and increasing relevance, until now only limited data exists concerning their internal motivation and their role.

Hence, the following aspects of voluntary work will be explored comparing the European countries:

- Location (e.g. hospice)
- Activities (e.g. mental support, help with practical tasks)
- Time frames
- Role (e.g. as protector, trusted friend or advocate in patient care)
- Internal motivation and original reason for the voluntary commitment
- Training
- Boundaries, problems and challenges
- Changes in the past years

Methods.

This study is planned and carried out as a part of the work programme of the European Association for Palliative Care (EAPC)'s Task Force on Volunteering (EAPC 2013). The Task Force's Steering Group is involved in every step of the preparation and realization.

Furthermore, a close cooperation with the African Palliative Care Research Network (APCRN) of

the African Palliative Care Association (APCA) is planned, as a similar study with the same methods and the same questionnaires (with some minor adjustments to the regional setting) will be used in Africa.

The study is carried out in two phases. Initially, three different questionnaires are created. In a first phase, these questionnaires are reviewed and optimized based on expert consultation. In a second phase, the three questionnaires are distributed.

Experts for the expert interviews during the first phase are chosen among members of the EAPC's Task Force on Volunteering and among participants of an international study group in Bonn (on volunteers in palliative care). The interviews serve as medium in order to evaluate the draft questionnaire's effectiveness.

In the second phase, the questionnaires are distributed to board members of the national associations of Hospice and Palliative Care, to volunteer coordinators and to volunteers.

One questionnaire is sent to the approx.. 550 board members of the 56 national associations of Hospice and Palliative Care that are collective members of the EAPC. They come from 32 different countries of the European Region (by WHO definition, WHO 2013b). A link to the online-questionnaires (created with SurveyMonkey) is sent to them via the EAPC's Task Force on Volunteering. A response rate of at least 30 % is expected. A second questionnaire is sent to volunteer coordinators or volunteer managers. One to two of these coordinators in each of the participating countries are identified either by the EAPC's Task Force on Volunteering, the national organisations or participants of the study group in Bonn and asked for their cooperation. They are asked to complete the questionnaire referring to their own institution and act at the same time as contact persons to volunteers at hospices or in palliative care. Through the coordinators, five volunteers per country are identified and asked to fill out the questionnaire for volunteers.

Questions concerning the volunteers' activities are developed based on a structured and systematic review of the contents of the voluntary work, that has been developed by the German Hospice and Palliative Care Organisation (DHPV) and the Institute for Applied Research (IAF) (Wissert et al. 2004b ,p.81-94). Questions concerning the volunteers' motivation are designed on the basis of the Inventory of Motivations for Palliative Care Volunteerism (IMPCV) by Claxton-Oldfield et al. (2010, 2011).

Questionnaires are available in English, German, French, Spanish and Portuguese and can be accessed via an online link or as a pencil-paper version. Answering the questionnaires ought to take ten to 15 minutes on average.

Results.

The data collected from the questionnaires will be stored in an electronic database. Descriptive and evaluative evaluation will be performed with this data, using the SPSS program.

The obtained information will be used to determine structures and requirements for volunteer work. The data will also be used to identify differences between countries and to formulate

hypotheses concerning why this is the case. The study will then identify opportunities to improve practice, with an emphasis on practices that promote and support the expansion of volunteer work.

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C. Loth:
The role and motivation of volunteers
in hospices and palliative care in Africa

Introduction.

The study “Palliative care volunteers in Africa”, led by APCA (African Palliative Care Association) is running simultaneously with the European study described by K. Pabst. The aim is to gather and compare information about the service of volunteers in various African countries. Therefore participants in 34 countries will be addressed. During the pilot phase of the study questionnaires have been tested in Uganda and adapted with help of the findings. The underlying methodology can be found in K. Pabst’s contribution (“The role and motivation of volunteers in hospices and palliative care in Europe”), while this text treats topics that have caught my interest when I was working in Uganda and describes these aspects from a European perspective.

The aspects “Language” and “Inclusion Criteria” have already had a direct influence on the study design, while the aspects “Sustainability”, “Spirituality”, and “Unemployment and Poverty” address issues that will be of interest in the analysis.

Study design.

Language

Among the most obvious challenges with such an international research projects are language barriers. Looking at the example of Uganda alone, you will find about 70 different languages. Consequently, translating the questionnaires into all relevant mother tongues is not possible. Instead there will be translations into the most spread official languages in Africa: English, French, Arabic and Swahili. The professional service managers or volunteer coordinators will understand both, the official language and the local language. Thus they are able to interview volunteers, taking the questionnaires as a guideline and complete them on their behalf. This form of oral interviews enables non-literate volunteers and volunteers who do not understand any of the official languages to participate in the study.

Inclusion Criteria

Another question occurring during the pilot phase of the study relates to the definition of a palliative care service: Who should we interview for our research? In Africa, palliative care is often integrated within basic medical care and not a clearly distinct offer. Moreover, palliative care is still in a start-up phase in many countries, mostly in the francophone eastern and northern region. Defining palliative care by the services offered would risk excluding volunteers who are devoted to the idea of palliative care. This exclusion would also mean missing a chance

of gathering information about the start-up phase, which is often labour-intensive with few paid team members and many volunteers involved. Basis for our participant selection are therefore experts opinions. In concrete terms, we have gathered contact addresses e.g. with help of APCA staff, Hospice Africa Uganda and the palliative care institute of Mulago University Hospital.

Points of interest for analysis.

Sustainability

As volunteers' labour is naturally associated with little costs only, their involvement is especially attractive in resource-poor settings. Often it is essential to run a sustainable organisation. This was one of the topics often mentioned in the interviews. Of interest will now be whether this image of "low-cost labour" upgrades the role of volunteers or not.

Spirituality

Spirituality seems to be almost a synonym for religiosity in Uganda, and both are noticeably visible in public life. This reflects also on the everyday work of volunteers, as spiritual needs are addressed more open than e.g. in a German setting: A weekly meeting to give cancer patients and opportunity to exchange, for instance, starts with a long prayer and includes a bible reading. The panafrican study is going to show whether spirituality has a strong standing within palliative care in other countries as well.

Unemployment and Poverty

The official unemployment rate in Uganda was 4.9 % in 2010. Yet, this percentage does not reflect the – in reality much higher – number of people looking for a job, because everyone working at least one hour a week is counted as "employed" (Ugandan Bureau of Statistics 2010). Finding an employment is difficult for people with all levels of education, including university graduates. This is relevant for our research, since many young people volunteer up to 40 h/week to gain job experience and to build up a network in their future profession. Furthermore the widespread poverty leads to even small allowances being an incentive for volunteering. With the help of the index for motivation in Hospice and Palliative Care Volunteerism by Claxton-Oldfield et al. (2011) the questionnaire asks for the influence different factors had on the decision to be a volunteer. This way the importance of the search of work can be objectified.

Summary.

From a European point of view, there are especially two factors that had influence on the study design: First, the use of standardised questionnaires is complicated by the heterogeneity of local languages and the incomplete literacy of volunteers. This situation required the involvement of

the local coordinators. Moreover, curative and palliative care are often offered by the same service. Therefore experts' opinions are the basis for recruiting participants and not a static list of inclusion criteria.

Literature research and experts interviews have shown some aspects in which volunteering in Uganda strongly differs from volunteering in Germany. These aspects are: Sustainability efforts and their influence on the role model of volunteers; Spirituality as a frequent field of volunteer activity; and the relevance of Unemployment and Poverty as a motivation for voluntary work. They will be of special interest when analysing the questionnaire data.

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Volunteering in an aging Society

People are getting older and there are challenging factors linked with disease like dementia, multimorbidity and also linked with social issues like loss of family structures. All these changes may require a revision of the role of volunteers in palliative and hospice care. Three of the researchers worked on research projects linked with this subject. Paulina Wosko looked at older people living alone, Margit Gratz looked on implementation of palliative care in nursing homes. Here you can find as an overview the contribution of Katharina Klindtworth. Her research project asks for the special needs of elderly patients.

K. Klindtworth:

Volunteering in the context of palliative care - and beyond?!

A view of the care of older people

Background.

Against the background of demographic developments, an increasing number of very elderly, multiply morbid and chronically ill patients are found in German society. Many of these have to deal with various stresses and ailments related to their disease(s) and their age. Physical limitations pose a particular challenge. This is especially the case when undertaking familiar, but increasingly cumbersome, aspects of everyday life. Frequently there is a lack of personal support that is only intermittently fulfilled by the efforts of care services. More importantly, given the increasing isolation in society and the consequences of this for the care of those that require it, is the need for support during everyday life that goes beyond mere care, household chores and organizational aspects, such as the coordination of services – frequently exceeds supply. Those affected frequently lack sufficient doctor-patient contact time to meet those needs that go beyond medical care. Even the deployment of a care service can only meet these needs partially. The patient is thrown back onto his own personal social network i.e. family, neighbours and acquaintances – as far as they are (still) available. Other services would have to be purchased for a fee. Familial and other informal care arrangements may, in many cases, no longer, or only inadequately, meet these needs. Moreover, building up such as support network is no longer possible for many elderly people if they have not been able to provide one in advance. The consequence is insufficient care.

Interviews with elderly people.

Among the findings made by a qualitative, longitudinal project undertaken on older people with severe heart failure towards the end of life, a great need for human companionship has been revealed. In the absence of available people in the immediate personal environment, this need is then generally placed with the family doctor or other available caregivers. In many cases this leads to long lasting patient discontent as well as excessive demands on medical and nursing support (Klindtworth et al. 2012).

The project was based on repeated in-depth interviews with people older than 70 years with severe heart failure (NYHA stage III/IV) towards the end of life. Interviews were analyzed according to grounded theory. The definition of the term 'end of life' was based on the estimation

of the attending physician on the basis of the 'surprise question' (Schneider et al. 2011). Every three months over a period of 18 months (up to seven interviews per patient), interviewees were visited in their home environment and asked about their views and needs in terms of medical, nursing and psychosocial care. The longitudinal aspect helped to build trust, so that deep insights were possible into patient life. Personal, even intimate, issues could be addressed.

This longitudinal aspect could also illustrate that processes of aging, being and remaining-unwell, as such, the 'chronification' of illness takes time - time to adjust and time to come to terms with the change in circumstances (cf. Schaeffer et al. 2008, Corbin et al. 2004). This phase may be associated with increased doctor contact as patients try to meet a need that is not medical in origin. Here, some people lack psycho-social support during the aging process and in their adaption to physical changes and limitations that cannot be adequately addressed from a medical perspective.

Triangulized Interviews: Patient, family, doctor.

Comparable results were obtained in a further longitudinal study, conducted recently by the same research group. This study used a similar research design to assess the care needs of older people with frailty (Muller-Mundt et al. 2013). In this project, the patients themselves, their caregivers and their family physicians were interviewed every six months for a period of 18 months. These interviews sought to capture the situation regarding supply [of care] and the needs of the affected people from three perspectives.

The demand for non-medical support is enormous. Despite this need, there are clearly still situations where support from third parties is rejected. The patient worries of losing the own independence, leading to a reluctance to allow strangers into their personal sphere predominates. This also requires a process of contention and coming to terms with the increasing loss of independence.

General practitioners involved in the supply of primary care see it as an obvious aspect of their medical work to provide psycho-social care and to be available for consultation on issues that go beyond medical issues. However, with multi-morbidity, very elderly people increasingly must face their mortality. Delineation is needed here; a striking demonstration is provided by a general practitioner with his statement: "I only treat medical problems. I'm a doctor, not a pastor." Regardless of the professional attitude of the physician, it remains questionable to what extent patients need to talk to a pastor at this stage in their life and indeed, whether pastors should fulfill this task at all. Another colleague tried to solve this recurring problem in their family practice via internal contacts within the practice itself. Connections between patients who are more mobile and robust and those that require support are made in order to promote mutual support services within the neighborhood.

This is an encouraging approach, which can however only provide limited support. A more desirable system would be a widespread support structure in a whole district. The need for interpersonal and organizational monitoring could be addressed by the use of another service that is not aligned to the medical or nursing services. As a consequence, the doctor - patient relationship could be relieved and subsequently focused on needs-based medical care.

Necessity of volunteers.

At this point we require a further form of personal care and support that can be provided to patients at a low threshold and at low cost or which can be taken up by [the patient] and which is uncoupled from their medical and nursing needs. The use of volunteers in the town/in the district is not new, although in today's environment it would be worth considering the extension of this approach. Within the framework of the further evolution of voluntary work, an expansion of the target groups, a broadening of the scope of duties offered, as well as the coordination of available personal resources could be employed.

In the past, volunteers have been involved in the care of older people within the context of their community service or as part of a volunteer social year organized by the church and non-profit organizations such as the Caritas or Malteser. Since 2011, the Federal Voluntary Service has taken over this role. Although the supply available can only fulfill specific needs and cannot meet demand.

Within the framework of a palliative context, the expansion of voluntary service is conceptually urgently desirable with volunteers already providing important contributions in many Specialized Palliative Care teams (SAPV) (Burbeck et al. 2014). In addition, such an expansion should extend beyond the specialized hospice and palliative context to include General (Palliative) Care (AAPV), a requirement which is usually met by general practitioners.

For many people, the need for support increases with very old age and comorbidity without them being taken up by palliative care structures. For example, outpatient-based palliative provision for patients with cardiac insufficiency is very rarely available even in advanced stages (Hess et al. 2014, Kavalieratos et al. 2014). The transition to specialized palliative care provision could, if necessary, be supported by the early use of volunteer helpers in the process of care. In this way the requirements of the European Association for Palliative Care (EAPC) and the European Union Geriatric Medicine Society (EUGMS) for the deployment of palliative care early in the development of chronic diseases could be met (WHO 2012).

Example of volunteering in a home-based setting.

Individual examples based on voluntary commitments in their own living space show the possibility to counteract this gap in the system.

For example, preventive home visits to the very elderly and the chronically ill in the small Bavarian town of Rödental, where systematically trained volunteers visit people in need on a weekly basis (Hibbeler 2014). With the collection of defined medical parameters, a worsening of condition can be quickly detected. Crises, and the threat of hospital admissions or home visits which result, can thus be detected early and, if possible, overcome without the need for hospitalization.

Preventive home visits represent a useful opportunity to meet the clinical needs of the very elderly and the chronically ill and, if required, to provide assistance in the case of an impending emergency. At the same time, preventive home visits bring together two people who both benefit from the reciprocal exchange and sympathy of the encounters.

In Lower Saxony, scattered community projects offer support services via voluntary helpers - sometimes for a small fee. These can be either supportive measures in the household or organizational matters as well as social time. Target groups are vulnerable people living alone for whom little or no help is available from other sources. Information regarding this offer is often passed on via the family doctor practice. The practice personnel are aware of these communal services and suggest them to the elderly patients or their relatives.

In this way, patient desire to remain in their familiar home environment can be fulfilled. In many cases, older people have become used to living alone following the death of their partner many years previously and wish to continue living in this way (Klindtworth et al. 2012). Often no viable network of relatives and friends is available who can be reached in the case of an emergency. In many cases, knowing that someone can be called - and not necessarily present - is sufficient to address the fears and concerns of these people (Bleidorn et al. 2012). Participation in the life of others and having a contact person available in case of emergency, can in many cases be enough to prevent recurrent emergency doctor visits and hospital admissions.

Conclusions.

The projects outlined are scattered, voluntary initiatives within the context of care of older people and are generally very well received by the parties involved. However, they remain inaccessible to many needy people because of a shortage of supply or lack of access. Furthermore, it should be stressed that these support services should represent longer-term arrangements, which allow a relationship to be built up and are thus able to meet the growing need for assistance as the patient steadily grows older and frailer.

Other initiatives are regionally distributed across Germany. All share a communal, spatially-constrained approach. Consequently, existing municipal structures should be used and expanded. It is conceivable that communal voluntary associations (equivalent to SAPV teams) can be combined with available GP surgeries.

The initiative can be started by the doctor who is directly in contact with the patients. They can often assess the secondary (non-medical) care needs and instruct practice workers (such as medical assistants) to direct patients to the volunteer network contact. Similarly, relatives or acquaintances of the patients who are familiar with their situation can establish contact. Should the health care needs of the elderly patient subsequently move into the palliative area, a rapid 'transfer' to specialized care can be arranged by the GP.

This approach relies on a good and viable interaction between those involved and requires care and commitment. The financial aspects also need to be regulated if surgeries become involved to a greater extent. All too often such initiatives are dependent on the commitment of individuals and independent financing, not infrequently based on donations. The connection of volunteering to existing outpatient medical care structures could facilitate the transition from individual projects to a comprehensive and lasting care for the elderly and chronically people.

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Society and volunteers

The young scholars dealing with these themes came from Austria, Poland and Ukraine. Sonja Schrey's research project deals with the necessity of volunteers. The Polish researchers Malgorzata Olszweska and Magdalena Urlińska describe their experience about tasks of volunteers and look on needs of training, supervision and support. Alexander Wolf from Ukraine shows that volunteering has no history and no culture in the former Soviet republics, and he elicits the special benefit of civil engagement in contrast to governmental approaches.

S. Schrey:

Volunteer support in the in-patient hospice: discourses and practices or: how indispensable are volunteers?

During my first week as a highly motivated volunteer in an inpatient hospice, I had my own experience with "distinction": At the door which I wanted to enter was written: "No volunteers, please." I found this very irritating. My first thought was: Are we, the volunteers not indispensable?

Objective.

My research questions are therefore: Volunteer support in the inpatient hospice - discourses versus practices. Or: How indispensable are the volunteers in an in-patient hospice? From the perspective of patients? From the perspective of the professional staff? From their (volunteers) own point of view? What needs do the patients have?

Did the role of volunteers change due to issues such as: shorter length of stay in hospices, professionalization, and institutionalization processes? (see also chapter 4).

Field of investigation and methodology.

The subjects of my investigation are two hospices:

- One in Lower Austria (Austria): the existing hospices are integral part of the nursing homes (in the ownership of the municipalities). The patients of the hospices are external.
- One in North Rhine-Westphalia (Germany). This hospice is sponsored by a Christian organisation.

In addition, a survey in a state nursing home with integrated hospice – and palliative care culture is planned, which has no volunteers at all (Lower Austria, Austria).

In a first step, I would like to explore the organizational embedding of volunteers in the hospice organisation (total number, diversity, length of service) as well as statistical data of the hospice itself (date of foundation, etc.). The following surveys per hospice are planned:

- One group discussion with **volunteers of the hospice** (AT/Ger): On the basis of various

discursive stimuli two or three topics will be discussed. With semi-structured individual interviews one to two volunteers, who work in the hospice, will be interviewed. Depending on the outcome of the group discussion before, changes may arise here.

- One group discussion with **full-time employees** (AT/Ger): After the individual interviews with the volunteers a group discussion with professional staff of the interdisciplinary team (five to six individuals) will be held. Topics are: expectations and experience of professional staff towards volunteers. Depending on the outcome of the group discussion, there will be also one to two semi-structured individual interviews.
- **Four individual interviews with patients (AT/Ger):** In order to explore the expectations of the patients towards the volunteers, semi-structured individual interviews with four patients are planned.

The special vulnerability of this group has to be considered. Therefore, the selection will be made only after consultation with the respective caregivers. Of course, the entire survey is preceded by an ethical clearance process. Where possible and appropriate an individual interview can then take place.

A potentially influencing factor to consider is that many of the hospice guests were housed in hospitals with six-bed rooms and very little personal attention before coming to the palliative care unit. In my opinion, when questioning this group of people, the satisfaction of patients would always be very high, solely due to fact that more attention and care is provided due to the increased number of staff.

Therefore, it is planned to interview patients only if they are longer than seven days in the hospice, in order to get a more meaningful result. This point, however, will be reconsidered on site.

- After the interviews and group discussions in the hospices, **one to two individual interviews with full-time staff in a state nursing home** in Austria will be conducted: In some of the state nursing homes in Austria, in which the integrated hospice and palliative culture was introduced, there are no volunteers. It is interesting to ask one or two staff about the process of accompanying terminally ill patients and how they do it, without the support of volunteers. The questions for these interviews also depend on the results and discussions of the previous interviews, so I have no specific questions here so far.

Scientific Discourses.

The research project is embedded within the following scientific discourses. The relevant literature refers however mainly to Germany. The extent to which developments can be transferred to Austria is still to be examined:

Shorter length of stay

Rochus Allert describes the downside of the success of the hospice movement in Germany. In

particular, the strong expansion of the outpatient-hospice teams which has a direct impact on the inpatient-hospice and palliative care units. "If we manage today even better (...) to guarantee that terminally ill people remain as long as possible in their own homes (...) this implicates on the other hand that (...) the remaining time in the inpatient-hospice decreases down to very few days." (Allert 2011 ,p.7) "Personal relationships to volunteers or full time staff are therefore almost impossible." (Allert 2011, p.7) (*Quotations are originally in German.*) In my research project it is also interesting if this trend is also applicable to the hospices in Austria; and if so, how volunteers deal with this changed situation.

Professionalization

Another influencing factor is the steady professionalization, i.e. the functional differentiation, both on the part of the volunteers but also on the part of the full-time staff (Watts 2012). In an interdisciplinary team there are, besides nurses and doctors, at least also chaplains, psychotherapists, social workers, and physiotherapists (DHÖ 2013). Further, there may be students, interns and men doing their non-military service.

Will the hospice work, because of this, be a task only for professionals? What role or what niche do the volunteers have? And what are the needs of the patients in terms of companionship, conversation, or support? Are there perhaps too many "supporters" on the last journey?

Institutionalization process

Another issue is the organizational development of the hospice area. "In Austria, too, the hospice movement gets a bit long in the tooth" (Heller 2012, p.147) writes Andreas Heller. "The warmth of the open fire of the early years was (...) tends to be replaced by central heating systems" (ibid.). He explains the institutionalization process of the hospice movement.

Marie Luise Bödiker describes the three stages of organizational development in the hospice area in Germany (*quotations are originally in German*): "Following the first 'innovative phase', there is the 'consolidation phase' and finally – at present - the 'regression phase' ". "*The purpose of the engagement is that the social / political goal is achieved - or at least in sight. (...) The commitment declines - the complaints about a lack of dedication rise, and the volunteers set off for new tasks... The hospices complain about a growing mismatch between active and passive members.*" (Bödiker 2011 ,p.52-53) So how will this development affect the work of volunteers? What is today the expectation and motivation of volunteers?

Status quo of literature review.

The literature on volunteers in hospices mainly describes the importance of volunteers in this area. Starting with the foundation of hospices, where it would have been impossible without volunteers to bring the hospice idea to life, until today, where they provide an indispensable contribution in hospices as "experts of everyday life".

Most of the publications on the topic "volunteers" are in the English-speaking world, mainly in Canada by the couple Claxton-Oldfield (2009, 2007, 2011).

A further focus of the literature deals with the motivation of volunteers. One of the first studies in Germany on this topic is the study "dying where one feels at home ..." - organization and practice of death companionship in outpatient-hospice care" by Julia von Hayek, Christine Pfeffer and Werner Schneider (2009).

My research project would like to join there and explore the question of how the volunteers are perceived by terminally ill people and by professional staff.

Next steps and Time schedule.

The analysis of the surveys and the results will be reported back to the hospices, as well as to the state nursing home. Taking their critical opinions into consideration, this work should lead to suggestions for improving the work with volunteers or confirm the existing way of working.

Field work:

Group discussions and individual interviews in Germany and Analysis

November 2014 - February 2015

Group discussions and individual interviews in Austria

February 2014 - April 2015

Finalisation:

September 2015

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M. Olszweska:
Światło Hospice: Volunteer programs and volunteers' voices

Volunteer programmes.

The aim of the supportive treatment, which is essential in palliative care, is to maximize life quality and make the patients' activity as optimal as possible. It is carried out by interdisciplinary staff, which is focused on the somatic, psycho-social and spiritual needs of the patients (Grądalski, p.128).

In the team mentioned above – consisting of doctors, nurses, psychologists, physiotherapists and priests – equally important roles are fulfilled by volunteers. They complement the work of the professionals by supporting patients and their families. The crucial thing is to be aware and recognize the patient's needs.

The volunteer engaged in palliative care enhances interpersonal bonds.

Matie de Hennezel, *Seize the Day*, Macmillan, 2012:

“...the last interval before death can also be the culmination of the shaping of the human being, even as it transforms everyone else involved. There is still time for many things to live themselves out, on a different plane, more interior and more subtle, the plane of human relations. Even when one enters final helplessness, one can still love and feel loved, and many of the dying, in their last moments, send back a poignant message: Don't pass by life; don't pass by love.”

A constant contact with death requires psychical maturity, emotional balance, inner composure, peace and patience. The candidates are selected by voluntary coordinators according to principle that the main aim is to help others and not themselves (Ostrowska A 2005 p.184).

The essence of volunteering is to accompany and to offer their time and attention. “Time spent with a dying person is priceless”, says a volunteer. Uniqueness of time, situation, gesture is a deep truth of life. The truth which is particularly easy to discover especially in a hospice (Bartoszewska, p.11).

Hospice reality is an area which frightens people throughout the society. The fear is caused by ignorance, stereotypes and indefensible anxiousness. It is very crucial to get common people closer to the subject of incurable disease and death. This is a matter which no one can avoid and all of us will face them sooner or later. It is very important to talk about it openly and to take away the fear. Volunteering is the perfect opportunity to deal with that problem, to get to know hospices and to deal with the subject.

The Palliative Care Complex Hospice “Światło” has existed for more than 20 years. Last September we celebrated its 20th anniversary.

Voluntary work in Hospice "Swiatlo" is the inherent component of its activity from the very beginning. Our volunteers are people in various ages (from students to seniors), people of many professions, interests and life experiences. They are connected by their involvement helping suffering patients, giving their hearts to people in need. Every volunteer is a priceless part of our professional hospice staff.

Voluntary work in our hospice can be divided into two aspects:

- direct contact with a patient (medical care)
- no direct contact with patients (non-medical care)

Recruitment processes for the first group are much more expanded and complex than for the second one and include psychological interview and diagnostic tests among others.

Nowadays our hospice collaborates with 30 volunteers, involved both in direct and indirect forms of care. It is worth mentioning that only adult candidates can participate in medical care.

The main tasks in voluntary work as a direct form of care are: help in daily routines (meals, bath, nursing help), conversations, reading, strolling, small shopping trips, appropriate games and exercises, contact with family.

Recruitment to the non-medical voluntary work is very similar, although psychological tests are not required. The non-medical volunteers help in cleaning the area around the hospice building, gardening, windows washing, tidying the hospice chapel etc.

Most of the non-medical volunteers, but not only them, are committed in a wide range of activities in the Hospice "*Swiatlo*" *Association* (non-governmental organisation set up by hospice workers to support the institution financially and educationally (www.facebook.com/StowarzyszenieHospicjumSwiatlo)).

"Corks" is a campaign that is assisted by more than 30 schools and institutions in the town and region, involving hundreds of pupils, students, employees and individuals. Apart from arousing pro-ecological attitude and responsibility for our planet the main aim is to popularise the idea of palliative care.

Another campaign for schools and non-medical volunteers is 'Give high five to Hospice "Swiatlo"'. That economic project is supported by many Polish pop stars. It is an opportunity for the local community to support our hospice by small regular payment. Everyone who wants to help Hospice Swiatlo in that way can give us 5 PLN every month from their bank account.

The new idea to popularize the palliative care and raise awareness for terminal patients needs is zumba lessons. A few days ago we performed the first lesson and the admission tickets were small items we use in every day care.

Both medical volunteers and the rest of supporters can take part in every form of qualification. Our hospice experts run many educational lectures on psychology, relations between patient and their family, communication with patients, general palliative care and first aid. Last December people interested in hospice subjects took part in a complex training "A volunteer as a patient's assistant". It included specialists' lectures, psychological workshops, nursing, physiotherapy and medical guardian exercises and practice on the ward. All costs were underwritten by local authorities.

We are very open and enthusiastic towards people who wish to be a part of creating hospice reality by commitment in our voluntary work.

Volunteers' voices.



Norbert Orlowicz

The experience of hospice volunteering enriched me extremely. Each time I go home, hospice workers thank me for the time I offered. However, the truth is that I am thankful that I can be there to help, to learn. Helping someone on the ward gives me a lot of strength, joy and satisfaction. Each time, even though I do not show it, I have a hard time when I come to the hospice, see a funeral car knowing that one of the patients has died.

I have to admit that before I started to engage in voluntary hospice service I had a very bad opinion about hospices. I perceived this place solely through the prism of suffering and death. Being in need of palliative care seemed to be a death sentence to me. Now I know that it is a consequence of a very wrong and unfair stereotype inherent in human thinking. Today I know that in hospice people work normally and that the patients enjoy the rest of their life. It has a familiar atmosphere and each patient gets professional help.

If anyone reading my words reflects on whether it is worthwhile to be a volunteer then my advice is this: come to the hospice and get involved! Volunteering in hospice adds strength and joy to your life and the own problems of everyday life become less burdensome.



Karolina Majorowska

My 'adventure' with volunteering started in the first year of study (I am now in the third year). Back in junior high school and high school I was thinking about volunteering, but when I came to Toruń, I managed to make my dream come true. In my hometown Ostróda there was no hospice or similar facility. Therefore, just as soon as I learned about hospice 'Light', I decided to engage in volunteering. The first conversation with the volunteer's coordinator made me even more certain that it is a good decision.

I would like to share the feelings which arise in me when I enter the walls of the hospice and when I leave. Each time I enter, I feel uncertainty, hesitation, curiosity, and that hasn't changed even after nearly three years of commitment. Leaving after few hours which I spent with the patients I feel joy, meaning of fulfilled mission, sometimes slight sadness. It is also a chance to reflect on one's life and to forget own cares and troubles, which now seem trivial



Karolina Kordowska

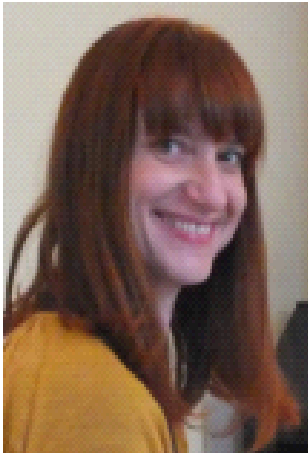
For almost two years I learned a lot. And I still keep on learning all the time. At the end of 2013 a series of workshops was held. I'm not starting with the assumption that it is only me who gives something to others. Sometimes I come to the conclusion that it's rather me gaining something.

As a volunteer I have learned to tolerate all kinds of human characters, respect other people's habits. I've become more patient. Conversations on difficult subjects are still challenging. I think

that not everyone has the predisposition for that.

A hospice is also a place to make friends whether it's patients or volunteers. Sometimes it's hard, sometimes it's sad, but yet, life is not only about surrounding yourself with wonders.

Is it worth it? YES IT IS.



Aleksandra Glowacka

Coming to the ward I wasn't sure what to expect, but I had a great desire to help people. Sometimes only by feeding and saying nice words I had the impression that my presence brings relief. I came to the hospice with the idea that I can help and this thought accompanied me as I talked to the patients and fed them. Everyone was different, had a different character, different temperament, and often they were in different stages of disease. I treated them as healthy persons. Visiting them, I was talking about prosy matters, about life, about everyday problems. Many people began talking and I saw the change in their mood. A man lying in bed all day long, a bedridden patient, wants to talk about everything else but the disease.

My motto is, to keep going and to think positively. I'm trying to bring a good word and smile to the patients. I believe that it allows the patients to leave the sorrow, pain and from what is inevitable, even if it is only for a short moment.



Beata Przystas

A volunteer is such an 'earthly guardian angel' who makes that difficult reality become easier and more joyful. A day in hospice is much longer than one filled with the daily duties, therefore, the sick have a lot of time for, not always positive, thoughts. A volunteer is there in order to stop, as far as possible, thoughts not beneficial for the health and make every day a little different, to bring some variety in the bed reality. The secret lies in the simple things which bring a fresh breath from the outside world to the world of suffering and human misery and, hence, remind the world before the disease. These simple things are for example a cup of hot tea, ordering a pizza, daily newspapers, painting nails, reading books, listening to the memories. Despite difficult situations everyone would like to integrate with the outside world, and the world that gives hope. This is why it is so important to support patients in their fight against the disease.

Marta Kolodziejska



My cooperation with Hospice 'Light' started in March 2013. At the beginning it was mainly about helping with the meals and keeping company with the patients, which included gossip during strolls around beautiful landscapes. Over time, the conversations became deeper, which was probably due to the fact that we got to know each other better. My tasks also include making a cup of tea/coffee, going for walks, or changing bedclothes.

I completely agree that volunteering brings many intangible advantages. For me, the most

important thing is to feel that patients trust me. They talk about their feelings, about their suffering, their longing for the past and for their home. I feel needed, I raise my self-esteem.

*I would recommend volunteering to all those who have lost the meaning of life, lament over their life situation, have nothing to do with their free time, feel unnecessary, alienated, abandoned, indifferent to everything that surrounds them. Perhaps in volunteering they may find what they haven't found elsewhere. For all those who consider such way of using their time, I would like to refer to a saying by Seneca the Younger, which is my life motto: *Alteri vivas oportet, si vis tibi vivere* (You should live for another if you would live for yourself).*

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M. Urlińska; A. Janowicz:
The role of coordination
in the creation and development of volunteering
in institutional and home end-of-life care in Poland

Background.

In the era of demographic changes and inevitably aging population, it has become a burning issue and necessity to prepare the public to quality health-related changes. The number of people with chronic diseases increases with aging populations. This issue is becoming a significant problem, not only in medical, but also social dimension. Patients require assistance from both the medical services as well as social and welfare. There is a growing number of aid institutions, but simultaneously there is also a need to develop support for the chronically ill and the elderly in terms of home care. The necessity of community involvement in helping the growing number of dependent elder and individuals at the end of life must be associated with the use of a social force of volunteering and the care for family caregivers. Hospice and palliative care in collaboration with volunteers developed a successful model of team care for patients at the end of life and their families (P Krakowiak 2012).

The main concerns of people at the end of life is pain, social isolation and loneliness. Teams of caregivers respond to these fears through holistic care implemented by employees and volunteers. Healthcare professionals care for relief of physical pain. Spiritual, religious and emotional unrest is eliminated by a chaplain and a psychologist. Problems of social and living conditions of the patient and his family are solved by social worker. Team care professionals provide support to patients and their families in the field of their specialization, also being sensitive to their other needs. Adequately prepared volunteers effectively complement this support by taking, commitment and sharing their time. Volunteers with the time to listen, talk and be with people at the end of life and their loved ones, they can help reduce patients' sense of loneliness and prevent social exclusion of families caring for a seriously ill.

Forms of voluntary commitment.

There are various volunteer opportunities for action inside the team of hospice and palliative care. It is primarily a direct help for the sick adults and children and their families, but also a lot of activity in the non-medical volunteer or support for people in mourning. Adults, who will take the theoretical and practical course of hospice volunteer, provide direct help for the sick in the terminal stage of the disease and their relatives, in close cooperation with the staff team. The tasks of the volunteers, among other things, is to help with care in collaboration with nurses and care workers, in support of patients and their families, helping to relieve minor tasks in home care.

Another group of volunteers are health care professionals. This kind of volunteering is open for experienced staff of medical professionals who participate in hospice volunteer after retirement or take part in volunteer in addition to its full-time work. The advantage of this type of volunteers is experience and belief in maintaining basic medical procedures in difficult situations, which is

not lacking in care at the end of life. Volunteers usually perform duties similar to their profession, but also very different tasks assigned to them by the volunteer coordinator. They may be a valuable support for full-time staff of the center, becoming guides for other medical volunteers in the team. Their share in stationary and home care and palliative hospice is a significant force in many centers for the care worker teams, although an important task is to remind the volunteer coordinator about their auxiliary role to the full-time employees.

Beside direct patient care volunteers may also engage in all kinds of non-medical activities. Such possibility is given by the volunteer capital, in which minors and adults can be involved. It consists of occasional participation in organizing and conducting various types of charity events for the center, occasional meetings and celebrations. Pupils and students are usually involved in such type of actions. For children volunteering mainly takes the form of participation in charitable activities for the benefit of hospice (participation in fund raising, but also, for example, the preparation of performance for patients), combined with a visit to the hospice center and education in the field of end of life. Speaking of hospice the subject of severe illness, death and mourning must be mentioned. The knowledge given in the appropriate age group during a charity action can help "tame" the taboo, and even affect the way of experiencing illness or loss. Youth volunteering starts usually from action, but the educational meetings with staff and volunteers are encouraged to participate in future training for volunteer medical or continuing non-medical assistance.

Students can volunteer to acquire experience with the directions of their studies (e.g. medical or psychological), but it is also an invitation addressed to representatives of other disciplines so that education about care at the end of life is available to all who wish to face important existential questions and want to help the needy. Another possibility is to support the hospice administrative and order team (in administration, reception, cleaning activities), voluntary education (preparation and conduct of the department of educational activities in schools, universities, parishes and local community). There are also volunteer teachers and educators who serve as volunteer coordinators, special interest groups in school and work closely with the volunteer coordinator or others in hospice (see: J. Binnebesel et al. 2009, Kosiedowska 2006).

Volunteers also play an important role in public education about palliative and hospice care and volunteering. Through the testimony of its commitment to become promoters of the idea of hospice and volunteer, presenting various forms of its activity centers, setting an example and an inspiration to others. There is also a large group of economically active volunteers who support palliative and hospice centers by offering their time and a free loan of professional competence, a valuable support for the daily functioning of the institution. Volunteering in this group may be composed of representatives of the various professional disciplines and professions, transferring their skills and professional knowledge to the center, its pupils and the whole team of employees and volunteers.

A special group in a team of volunteers are people aged 60-70+. They bring to the team their experience and wisdom. Usually they are people with a stable situation, so that they can engage longer than younger people who will experience a lot of changes. Multigenerational teams are also a source of mutual support, when the experience, prudence adults and elders meet with

enthusiastic young people.

Volunteering alongside professionals.

This brief overview of the various forms of voluntary commitment to palliative-hospice care team shows how important roles they can play and how specific and varied support the team and above all the patients and their families can get from volunteers. Both in direct care, as well as other work related to the center or by charities linked to social education, volunteers are an important part of the team. They also emphasize the importance of the Council of Europe Recommendations: "Palliative and hospice care is a multidisciplinary activity, which involves professionals from various fields, usually made up of a team of doctors, nurses and other health care professionals [...]. Volunteers are an important part of the team. They do not take the work of professionals, but have their own contribution and expertise in care. "

Multidisciplinary care team of volunteers do not provide in most other institutions caring for people at the end of life in health care systems and social assistance. No team care and commitment of volunteers to exercise leads to a sense of loneliness at the end of life, as well as social isolation and exclusion of families caring for a seriously ill, especially in home care (The Council of Europe ,p.9).

An increasing number of chronically ill people in their homes and overload informal carers confirms our observations that an essential element of the system of aid is the person of the volunteer coordinator. The experiences of projects related to the development of volunteering in Poland show that one of the basic conditions that volunteering was created and develop further, is the presence in the team volunteer coordinator. Coordination of volunteering is a guarantee of good cooperation between the properly trained volunteers and professionals in of stationary and home care. Coordination of volunteering is also support for those volunteers who, through commitment to helping people at the end of life are experiencing fatigue, discouragement and burnout.

The volunteer coordinator's role.

The coordinator is usually responsible inter alia for: recruitment of volunteers (which consists of many elements), the proper preparation and introduction to the team and motivate ongoing formation, organization of work, solving difficult situations. To be successful in these activities, he/she should have certain skills and knowledge. Usually, in practice or literature, attention is focused on the tasks and the role of volunteers, but more emphasis should be spend on the role or the roles of the volunteer coordinator.

In society each individual unit is defined by some social roles that are a reflection of social expectations that relate to their position in the society. Same as the reality the social role is a dynamic process, and it is constantly changing. However, an important issue is the individuality of a unit, its individual way of playing a role (an actor on society scene) which is conditioned by its personality, temperament, adopted system of values, attitudes and behaviors. Category social role is very popular among researchers in many scientific fields such as psychology, sociology, education and anthropology. It is an issue that "is accompanied by describing social

reality from both the social macro and microstructures and analysis of human behavior. Popularity is probably due to its wide possibilities of using it to describe and explain the social situation of the individual, based on the inevitable necessity of cooperation in the framework of the existing social arrangements. It is a kind of bridge between the personality, culture and social structure." (Białyszewski 1967)

Social role is defined in the literature as a system of social activities, the pattern of social behavior, the group's expectations arising from the participation of the individual in a particular social group. There are various definitions depending on the approach of the authors, however, we can distinguish in all of them some significant points for the social role: the location of the individual in a particular social environment, socially established patterns of behavior and self-esteem of individuals, bundle of rights afforded to individuals by the group, set of responsibilities expected by the group and imposed on entity, and the interdependence of roles (Jakubczak 1966,p.83).

R. Linton defines social role as "the sum of the overall cultural patterns associated with a particular status. Therefore includes attitudes, values and behaviors that society assigns to each animal possessing the status" (Linton 1975 ,p.92). In the work of G. H. Mead role is a two-way interaction between society and the individual, staff of relationships and interactions between entities. Accepting the role of the "other" consists in identifying the personality of another, with thanks to him self-conscious. Mead (1975,p.350-351) reflects the role of norms and attitudes adopted by society. On the one hand, accepting the role is dependent on individual ability, on the other hand, it is institutionalized by the existence of the obligation to adjust their own actions to the actions of others (E.W. Bielajew, D.N. Szalin 1978, p. 109). The volunteer coordinator is the key person to run the project, with an extremely wide range of competencies.

The theory of individual social role by D. J. Levinson shows the entity who is capable of constructing its own social reality. It consists of structural role orders, which reflect the system of norms, values, requirements and orders of social and personality role definition, which is a component of an individual's personality (J. Szmacka 1989, p. 196). Playing the role depends on the individual interpretation of expectations and social orders. Within the concept of the role of D. J. Levinson singled: facilitating of the role (understood as the technical and cultural resources and working conditions, which help to understand the injunctions of the role) and the role's dilemmas (meaning problematic issues concerning the role of being the result of a conflict of interest the role-partners as well as the individual). Levinson's definition of the role of personality determines the individual unit as a creator of social reality, pursuing its own ways to adapt, who is expertly moving inside the system requirements. The individual is aware of his own place in the social structure, analyzes its position and selects the appropriate management strategy for itself which is adopted in relationships with the role-partners (role-partners are e.g. governmental and non-governmental institutions, volunteers, beneficiaries and their families). Mutual relations, in the context of social roles, are ascribed by certain expectations, rights and obligations of operators.

The concept of role is therefore an individual interpretation of the interaction between individuals, their determination of their own tasks and ways of functioning. Social orders and the concept of

role translate into a way of exercising the rights and duties, obligations and expectations associated with the role; this is called the role performing. Each individual unit has assigned several roles, called complex status, because of belonging to several social groups, but all of them interact with each other, running on the basis of feedback. The duties of the coordinator role involve important issue of status/position the individual occupies in society, which "determines the interactions between people, certain influences, elections, social roles, duties, rights, scope of knowledge" (K. Janus 2006). Status is synonymous with prestige, socially expressed respect for each unit, which are related to specific patterns of behavior, lifestyle, a system of values or symbols (e.g. life or professional experiences, meta-language, appearance, etc). The scope of volunteer coordinator of the complex status includes the following roles:

a) a *guardian (tutor) of the volunteers* is responsible for the recruitment, training and deployment of volunteers in the functioning of the object, determines their competence, integration with the team, support, motivate, coordinate and monitor their activities;

b) a *volunteer leader* - responsible for working with regional centers volunteering, schools, local authorities and non-governmental organizations, recruiting new volunteers, and changing attitudes towards this form of care in the environment;

c) an *advocate of volunteers* is responsible for the support and motivation of volunteers to prevent fatigue or burnout, resolves conflicts in a team of volunteers, working closely with the management team and the resort;

d) an *ambassador of hospice* is, along with volunteers, involved in breaking the stereotypical way of thinking, fear, end of life care;

e) a *local organizer* in a practical integrates and coordinates the care in the community, improving the quality of life of students and caring team, using available social forces to build public trust and recognition for volunteer work.

Both good practices concerning the coordination of volunteer hospice, available books, exchange of experience and cooperation culture of volunteers and professionals could become a model that can be transferred from hospice and palliative care for the land and domestic institutional forms of care at the end of life.

Implementation of these roles is associated with on one hand specific tasks, on the other hand the necessary knowledge and skills. Mentioned briefly the tasks above include a range of activities. Only that way the center is well working with multigenerational team of volunteers; the center and the idea of palliative and hospice care is known to the local community and supported by the community as well as by local institutions or companies.

The volunteer coordinator's work.

The starting point for action is recruiting coordinator, or the process of obtaining volunteers. But before starting the recruitment of the coordinator, the team should consider the classes in which volunteers will help and how many people are needed. Linked to this is to determine when and where volunteers will carry out their tasks. By identifying the needs of institutions in this regard, it

is easier to prepare well first, then direct the volunteers and their work. Before starting the recruitment the coordinator must think to whom the invitation is addressed to volunteering. Does the person have to be a student or retired person or age does not matter? Does that person have any specific skills or education? Having established the "profile" of a volunteer, it is easier to plan an effective recruiter. An important element of cooperation with volunteers is their proper preparation. Depending on the specifics of the center and the tasks that have been provided to the volunteer coordinator training plans, preferably containing a practical part. Candidates for volunteering need to know what situations they can meet before proceeding to perform the duties. Taught how to deal with the patient and how to talk to him, in what activities to help staff, how to become a valuable part of the team, and make them conscious of their responsibilities and rights. The task of the coordinator and provided good cooperation with a team of volunteers is also appropriate to introduce them to the center - to present him to show what's going on, presentation skills and powers of team members and to provide volunteers to staff. This will avoid confusion and will give volunteers a sense of security. One of the most important tasks of the coordinator is to organize and coordinate the work of volunteers. Regular meetings (for supervision, mutual support, lifelong learning and development) provide an opportunity to exchange experiences. This helps to highlight volunteer needs or problems that may arise in cooperation. On the side of the coordinator it is also a concern for proper documentation of the work of volunteers and to provide legal protection. Therefore, it is important that both the coordinator and volunteers have their place in the center.

Studies on the development of volunteering in palliative and hospice care have shown that the presence of adequately trained volunteers and their coordinator has significantly improved the quality of care, collaboration with local communities, organizations and the media, as well as the financial condition of the facilities. They were carried out at the end of the national project "I like to help", which aim was to create a professional volunteer centers in the hospice. The starting point for achieving this goal was the selection and preparation of the volunteer coordinators, or people who later formed the volunteer centers and managed them. The project lasted three years (2007-2010), and accounted for a large part of its educational activities: training and conferences for coordinators and volunteers, e-learning for coordinators and teachers working with hospices, manuals and guides for volunteer coordinators and volunteers. Accompanied by national campaigns "Hospice is also life", which, in cooperation with the media, promoted volunteering of different age groups and professions. The presence of the coordinators of the centers was a guarantee that any person who reports to volunteer will be duly taken, prepared and introduced to the team.

Publications on volunteer coordinators.

Three publications prepared for of hospice voluntary service coordinators and volunteers (Manual of hospice voluntary service coordinator (P Krakowiak et al. 2008a), Manual of hospice volunteer (P Krakowiak et al. 2008b), Non-medical aspects of hospice-palliative care (J Binnebesel et al. 2010)), have already been successfully used in developing voluntary service in health and social assistance in Poland. Their presentation, translation of innovative issues along with presentation of systems of training and online support for coordinators (forum, e-learning, workshops) can be an inspiration to of the existing of hospice volunteer centers in Germany and

means for institutional and home care that want to establish or expand cooperation with volunteers from different age groups.

“We wstępnie do Manual of hospice voluntary service coordinator” Prof. dr. Jacek Luczak, MD, President of Eastern and Central Europe Palliative Care Task Force (ECEPT) napisał:

“Writing an introduction to the Handbook for Hospice Volunteer Coordinator, I believe that it is step towards better use of good energy of volunteers in our hospice-palliative care centers. Their presence is primarily to help patients and their loving once, but also a concern for most daily needs of the ward or home care unit, interest in the shares of charitable help. Volunteers allow local communities the active participation in social education; known to us all under the banner of Hospice is Life, too. Thanks to this comprehensive interdisciplinary knowledge covered by this impressive textbook coordinators of volunteering, often working aside their basic responsibilities as social workers, nurses or chaplains, will have the precious help and support in the recruitment, training and collaboration with volunteers. This publication will also serve the volunteers and all people of good who want to help to develop hospices and palliative care centers in Poland.

Congratulating the team of Hospice Foundation, this important initiative, I am glad that I can in this way encourage both managers of care as well as entire teams to be more open a hospice volunteers. Cooperating together with adequately prepared coordinators we will be able to use full enthusiasm brought in our teams by volunteers. We can this way more effectively improve the quality of life of our patients and bring relief for very tired families, especially in home care services.

Textbook of hospice volunteer coordinators is important for the history of hospice movement in Poland, and I do hope that this publication will serve them well. I encourage all managers, employees and volunteers, as well as medical students of nursing, psychology, social work and theology, to use this manual showing the wealth of interdisciplinary cooperation for the sake of a seriously ill and dying, which requires common efforts and Christian and human assistance.”
(Łuczak 2008)

This guide, in addition to training and conferences, is a practical tool to facilitate the performance of coordinators and their roles. It shows, step by step, how to create and develop volunteering. It advises how to solve difficult situations, which sometimes lead to the termination of the agreement with the volunteer. It is an important tool which was created as part of the project was an online forum for coordinators. Composed of various thematic categories it allows coordinators to find answers to their questions. It also provides a platform for the exchange of experiences and mutual support. Coordinators exchanged in it their comments, advice and inspire each other; established a special community of people working in 96 centers throughout the country, in different communities in different teams and palliative hospice. All shared a common passion

and commitment to volunteering, showing courage in taking the roles which are not always easy. This passion of coordinators and volunteer support is now needed wherever there are elderly, self-reliant, chronically ill or lonely persons. Wherever there are people at the end of their life, both patients and their families need the presence of someone who without a rush will give them their time. The experience of educational projects carried out in Poland show that the involvement of volunteers is effective if it is properly prepared and coordinated. Many factors contribute to the success associated with the formation of volunteering. But without a doubt, one of the key persons is the volunteer coordinator.

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A. Wolf:
Perspectives of civil society activities and volunteering in palliative and hospice care in Ukraine

Introduction.

The urgency of the development of modern humanistic approaches of social policy towards terminally ill is to be explained by the fact that this social problem affects almost every family in Ukraine. Within 90 years of the last century and the first decade of the XXI century in Ukraine there is domination of extremely negative demographic trends, the most destructive is the unprecedented increase in mortality. According to our research, over the past five years every year in Ukraine died about 800,000 people, almost 90,000 of them from cancer. Thus, about 600,000 terminally ill patients in the final period of life need professional palliative and hospice care. In addition, family members of palliative care patients also need professional palliative care, because when the family faces the problems of terminally ill person, especially in end-stage disease, it causes a decrease in quality of life for the whole family and causes severe psychological, social and economic interruptions of family function. Thus, each year, in Ukraine there are about two million people in need of palliative and hospice care (Y. Gubski, V. Chaykovska, A. Tsarenko, 2010; A. Tsarenko, 2010, Y. Gubski, A. Tsarenko, H.A. Baranovska and al., 2011).

There are around 30 facilities called “hospices” in Ukraine to provide care which are mostly medical units, administrated by the Ministry of health and local health care authorities (Babiychuk et al. 2013). The constant paradigm for Ukraine is the struggle between two trends – grass-roots initiatives (where some hospices have been established with the support and on initiative of civil society) and “from the top” initiatives (when hospices are being established by the resolutions or recommendations of the Minister of Health in the frameworks of the health care reform). However, the headquarters’ resolutions do not have strong impact as most of them cannot be implemented (A. Wolf, 2012-2013).

This leads to the necessity of studying the civil society activities and volunteering in the process of development of palliative and hospice care in Ukraine.

It is worth mentioning that until now the topics of medical and public administration, sociological, psychological issues of palliative and hospice care are rather underdeveloped on the scientific level: in Ukraine, since 1991 there are just four PhD researches on medical issues of palliative and hospice care, one on public administration aspects of care to incurably ill, and one on making the state policy more human-oriented.

Short Methodology.

System analysis enabled us to determine the basic principles in the field of voluntary work for the terminally ill in Ukraine. Our research has been carried out in the form of semi-standardised observations and interviews with 25 volunteers active 1) in innovative hospice and palliative care program on the basis of elderly social center in Kiev and 2) in the support to severely ill children

on the basis of central children hospital in Kiev.

Results.

Our research shows that civil society has a leading role in shaping social policy for the terminally ill in Ukraine and around the world. This is evident from the fact that the first hospices in Ukraine have been established in the first years of independence, and it were civic society structures that pushed the government to recognize palliative care. In 2006, the Ministry of Labour and Social Policy declared that hospice and palliative care is the domain of just health care. In 2012-2013, following six years of advocacy work of civic society organizations, the ministry established a new type of social services – palliative care which is to be provided mostly at home.

One of the crucial points during this process was the advocacy voluntary campaign organized by the Association of Palliative and Hospice Care for development of the first home hospice care facility (on the basis of social center) within the structure of Ministry of Social Policy. For that, the special series of cultural events, mostly charitable concerts in Kyiv with the title “Artists support hospices” have been organized by volunteers. The purpose of the campaign was to attract additional financial resources (charitable donations) and volunteers for hospice and palliative care on the basis of social center in the Pechersk district. Materials of research suggest the following conclusions:

To organize an average charitable concert the group of artists (four to eight persons), designers (two persons), and volunteers (three to seven persons) spent about 100 hours. The preparation started two months before the event and one of the development stages was building a team of volunteers. Maximum operating time was devoted to the event advertising. Work was carried to attract, select and train volunteers who were collecting donations during the event.

In the frameworks of our innovative Pechersk program, the age of active volunteers who contributed to charitable concerts varied from 23 to 61, and they were mostly females.

We have interviewed 15 volunteers, aged 22 to 61, five males and ten females to study their motivation in voluntary activities. The motivation of participants was "to help seriously ill people" (nine answers), "compassion for these people" (two answers), "desire to participate in good event" (five answers) and "desire to help" (six answers).

The number of visitors of the concerts was about 130 people and about 420 people attended the performances. At the same time, the amount of donations in the concert was 3.5 times higher than in the performances. This can be explained by the fact that concerts have been attended by people of different ages, mostly of older age who donated more, and performances have been attended mostly by young people who donated rather symbolically.

The final goal of the event (collecting donations for the hospice in Pechersk district) did not influence the sum of donations raised. In addition just one person out of 420 event visitors agreed to become a palliative and hospice care volunteer (2010-2014). From this we can assume that the main motivation for the audience of the event was rather satisfying spiritual

needs than support hospice movement. Desire to support hospice care program was the secondary need.

The special support had been provided through the NGO which supports former drug-addicted persons. Participation and voluntary support for these persons meant additional psychosocial rehabilitation. However, the decision about the volunteering for hospice charitable concert was supported mainly by the coordinator of the rehabilitation program, so we can not draw any conclusions about the motivation of the volunteers from this service.

All volunteers stated that they do need to undergo special trainings where they could increase their communication and administrative capacities. The Association of Palliative and Hospice Care does not offer such a training for volunteers.

Evaluation of fundraising programs has shown that volunteers are the crucial point to support the innovative program. In 2010-2013 the program has been developed with the support of volunteers. They have helped to raise funds, attract public attention, and keep interest to the program. The list of institutions involved in assisting the terminally ill and their families has been expanded in four years. The program included the local organization of the Red Cross (coordinates patronage nurses involved in the program), Association of Palliative and Hospice Care (helps to find volunteers, attracts additional funds for the implementation of the project) and the Synodal Department of Ukrainian Orthodox Church (coordinates providing spiritual care to palliative patients).

The realization of the project in the 2010-2014 showed some difficulties associated with the voluntary service in the field of palliative and hospice care. As mentioned above, hospices, including those in Kiev, are “medicalized” institutions that do not have social workers and volunteers. This immediately reduced the possibility of an exchange of experience between the hospices and the new program, which started to operate on the basis of the social center.

The program demonstrated an unwillingness of clients to accept volunteer assistance. Clients at home hospice programs are elderly (65 years and above) who are very wary of new people. Even the coordination of the social worker and the psychologist did not help to establish a regular home support. Thus, more than ten volunteers from the local church community were not able to provide the services they offered.

Another difficulty was connected to the fact that in 2012 the law about volunteering was passed in Ukraine. Its content, according to experts of the YMCA and other NGOs, suggests that it was adopted hastily, in order to strengthen state control over the NGO and volunteers which might be suspected to be “the foreign agents”. It raises a number of barriers (e.g. obtaining the status of the “volunteer” organization), but, on the other hand, does not provide the mechanism to monitor the implementation of this policy.

At the same time, the Association of Palliative and Hospice Care implemented the program of support for severely ill children who are in the central children hospital in Kiev. It has shown that volunteers in children's hospitals, who work in departments treating palliative care patients (dialysis department, blood cancer, AIDS / HIV) are significantly more active. It should be noted

that in Ukraine there is neither children's hospice nor palliative care for children. Although mortality in the aforementioned departments is very high, these units are not considered to perform palliative care and have no special rights, responsibilities and privileges. Volunteers in these offices operate in two areas: the organization of raising funds for medicines and other necessities as well as psychosocial support.

Discussion.

Thus, one of the main principles of human-oriented policy is a multidisciplinary and multisectoral approach when professionals with medical education, social workers and psychologists, representing various agencies and facilities as well as representatives of civil society unite in order to alleviate the comprehensive physical, psychological and spiritual suffering of the terminally ill and his family. Volunteers can play essential role in making the care to the dying more human-oriented and humanised. Accordingly to Krakowiak, (personal communication), volunteers are the "salt of hospice movement". Volunteers can provide psychosocial support of the dying and their caregivers, in some cases preventing euthanasia (Engels, personal communication), providing bereavement support and emotional support to dying patients and their caregivers. The role of volunteers can be crucial in raising financial and material resources. Being representatives of the community, volunteers can get other stakeholders involved in the support programs thus being the key factor of the success. Volunteers can be regarded as an active and essential part of civic society which pushes the civic society "from idea to action".

The study into realization of the mentioned innovative program in Kiev helps us to conclude that because of the lack of the strong motivation, training, and other forms of support for volunteers, more volunteers prefer to devote themselves to activities such as charitable actions and fundraising aiming to either support of elderly or children, rather than to regular patient care.

In consequence a better solution to encourage volunteering for Ukraine could be the development of options to organize different actions. This could be the field where volunteers can be active and trained, with less attention for volunteering at bed-side of severely ill person facing the challenge of incurable disease.

In general, the study of implementation of the volunteer program in 2010-2014 showed that the volunteers at the hospice are a sign of the openness of the institution. In Ukraine, hospices, as a product of the overall health system, are not open to collaboration, so there are no organized groups of volunteers, their coordinator, social worker and supervisor within the hospices. The most promising form of organization of the volunteer movement in palliative and hospice care in Ukraine is action volunteering, helping to raise funds and draw attention to the issue of palliative care.

Further studies should be done on the issues of motivations of volunteers (e.g. do they have religious background?), their expectations, and possibilities of trainings.

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Dealing with grief and spirituality

Bereavement support is often given by volunteers. How do volunteers deal with grief? Alexandra Vogt presents study results looking into the mechanisms of grieving and as well on volunteers' and professionals' need for bereavement support. Patients confronted with life limitation are often looking for meaning. Margrit Gratz introduces a newly developed curriculum on spirituality, which was designed to prepare volunteers dealing with spiritual aspects in patient care.

A. Vogt:

The use of volunteers

in regards helping grieving people in Nursing-homes

The baseline scenario.

In the field of nursing homes are emotional demands, which bring mainly dealing with suffering, illness, death and dying and the grief experience with it, very strong and calls by employees working an intense and immediate confrontation with the theme of "dying, death and bereavement" (Simon et al. 2005, p.19). Looking at the current and future demographic and social change both a numerical and percentage increase in very old people is noted, and thus to determine an increase by dying people every year (cf. Statistisches Jahrbuch 2012, p.28). In this context, the patient long-term care is becoming increasingly important as today already emerges a "shift to professional care in nursing homes" (Pfaff 2013, p.6). Sooner or later the employees are inevitably confronted with work-related grief feelings (Gerken et al. 2002, p.16). However: due to the lack of culture of the conscious of dealing with death and dying they are left alone and the employees grief on their own (Anderson et al. 2004 ,p.61).

The information is based on a research project, started in 2011 and ran for about 2 ½ years. It was funded by the German ministry for Education and Research, in cooperation also with the University Clinic Bonn, Alpha Rheinland and others.

The project was looking at the efficacy of grief support - as to: how people manage the complex process of grieving; emotionally and socially. The main focus of this project was, among others:

- a) The subjective experience of distress while grieving. What are the factors that influence the process of bereavement?
- b) What role does bereavement support have on people grieving, and what kind of support is effective for the people suffering? Means: Which kind of support actually works for people?
- c) Another focus was on the professional people working in nursing-homes: How do they cope with the day to day issue of dying, death and bereavement? (cf. Wissert 2013).

Consequently, the research study looked at both sides: at the carers, supporting the dying and

the grieving, as well as the people receiving support while dying and grieving.

Data collection and sample

To the data we collected in 2010 and 2013 by means of questionnaires:

- *Data collection in 10 Facilities in residential long-term care (N = 259)*
 - social statistical data
 - occupational background
 - experience burden in relation to dying, death and grieving
 - framework and resources for dealing with death and bereavement
 - demands and needs for a good deal with death and bereavement
- *Nationwide data collection „Effects of grief counseling“*
 - Grief counselors (N = 319)*
 - Social statistical data
 - Framework
 - Effect ranges
 - Areas of competence

Mourners with and without grief counseling (N = 682)

Data was also collected from 682 people who had grieved: 503 of which had professional support and 170 of people who had not:

- social statistical data
- relationship to the deceased
- circumstances of death
- forms of support
- grief experience
- effective ranges

In detail, it was looked at: what kind of treatment and what kind of effective ranges would have helped grieving people? The questions on the grief experience were made retrospectively for the weeks immediately after the death and at the current time, this means at the time of the questionnaire survey (cf. Wissert 2013).

Both parts of the research indicated important effects which were apparent in the structure and the quality of the work. This is significant and needs to be recognized for future volunteer or charity works in the area of palliative care.

Presentation of results.

- ***Results from the questionnaire survey in nursing homes of the difficulties that carers experience, when confronted with dying, death and bereavement***

In the study, every relevant group of staff was asked and data was collected.

Figure 1: Distribution by occupations or functions (N = 257)

In particular the study looked at the so called “hands-on workers”, who do the nursing part consisting of the body and mind work (staff in social care, nurse and nursing assistant and health care workers in nursing homes). The hands-on group is the biggest group altogether.

The “non-hands-on workers”, such as administration, catering service and others were also asked because people working in these fields, also have contact with the dying and grieving residents.

To be able to validate results, a control-group was obtained. This means that: apart from the data collected by ten nursing-homes, a hospice group was also surveyed. This control group was chosen because they work strategically different compared to nursing-homes. For example, they use different approaches in regards to their goal settings, areas of work, as well as the guidelines they work with.

All staffs were asked with a scale from 0 (not at all) to 10 (very strong) about the degree of perceived distress due to be witness of dying, death and bereavement on a daily basis.

The amount of perceived distress lies for all workers together in the statistical mean of 4.4. Looking at this result in more detail, three points become obvious: with a mean of 3.4, there seem to be the least perceived distress for carers in a hospice setting, workers that have a non-hands-on function (administration, catering service and so on) the mean lies at 4.0.

The highest degree of perceived distress, with a mean of 4.7, seemed the hands-on-worker, working only in a nursing-home setting.

The results in relation to the support given by carers in the last days of the people’s lives are of great importance in many respects. However, due to financial and personal restrictions, this support is not always given, much to the carer’s disappointment. Generally the work in nursing-home settings amount to more than just basic nursing. More importantly, carers perceive, is the individual and emotional support for people, whilst going through the process of dying.

Following factors depends with the stress, which is experienced by the employees in dealing

with dying, death and bereavement:

Gender context: Women (n = 217) experience with $x = 4.6$ a significantly higher burden of dealing with dying and bereavement than men (n = 27) with an average burden by $x = 3.2$. Statistically there is a significant correlation ($p = 0.003$) between gender and the level of general burden.

Occupation context: Whereas employees with the occupations "care for the elderly" and "care assistants" have an average experience burden of $x = 4.9$ or 5.0 respectively, is this in "nurses" with an average burden experience of $x = 3.7$ significantly lower.

Duration of employment: the duration of the nursing activity has a statistically significant influence on the burden experience of the employees in dealing with death and bereavement: the longer the employees are involved in the care, the higher they experience their burden ($p = 0.019$).

In the survey it became clear that the support of residents in the last days has a high priority for the employee and, when the time available to them is not sufficient for this purpose, they do this also over the collective working hours. Almost every fifth employee has stated.

How the content areas for the individual time management for the "care of the deceased" and the time for the "accompanying relatives" is, is shown in figure 2.

Figure 2: Time for „care of the deceased“ and time for „accompanying relatives“ (after dying of the residents) of hands-on employees in nursing homes (noted in %)

Figure 2 shows the time spent to support and care for the deceased residents in the nursing-home and the support for the grieving family members. In particular, just over 65 % of the hands-on workers (as revealed in the last red columns) say they would often spend time to support the deceased residents, as opposed to a very small amount of workers who don't manage to make this time.

Even though carers are under immense time pressure in order to look after the dying and deceased persons well, 87 % of hands-on workers report to deliver that sort of support already.

The intensity and the high work load reduces proportionally, when supporting the people grieving. Nearly 27 % of the carers point out that they have little or no time to support family members. While over 28 % of the carers say they try to make time, about 45 % say they would make time for it often.

Looking at the scores of distributions, last mentioned “caring for the deceased” shows that nearly three quarters ($\frac{3}{4}$) of hands-on workers indicated that they do take the time to support. However, the scores for the “support of family members grieving” are different, only half of the workers reported, managing to take the time.

And: the more time carer spend on supporting grieving family members the higher their perceived distress levels (as opposed to people who do not take the time). This result could also indicate that perceived distress is connected to the relationship they form with their patients. This is confirmed also throughout many other effects in this study, for example every 5th worker mentioned the relationship to the dying person to be a strong factor of high level of distress. Equally were the outcomes for the support of family members, where every 6th carer made the comment.

The evidence suggests that if workers develop a strong personal relationship to the people, they may pay a big prize for it once the residents die.

Another part of the study concentrated on which resources and help of networks they used. In detail it was looked at in regards ***to supporting the dying***, and in ***the process of bereavement***.

The staff could indicate on a four-level Likert scale the frequency of using resources. The ordinal-scales of these categories were designed in such a way that the scores were shown in the bar graph: 1 meaning ‘never’ and 4 meaning ‘always’, out of which the statistical mean was calculated.

Figure 3: Arithmetic means of the use of resources in support for the dying and dealing with grief (all staff)

Figure 3 demonstrates in detail the nature of support used by workers in both respects; the care of the dying and the process of bereavement.

Here it becomes apparent, that the available resources are mostly used when caring for the dying. In particular, about 50 % of the respondents used the **outpatient-hospice services** for this. Of similar importance was the use of **spiritual support**. Also other **charity groups** (for example church communities) with a mean of 2.0 were still used frequently, whereas inpatient Hospice, support-groups and SAPV-Teams (**special outpatient palliative care team**) are used rather seldom.

Compared to the results, these resources seem less frequently used when it comes to the **process of bereavement**, whether for oneself or for others. The statistical mean of 1.6 (shown in the bar chart: hospice and spiritual support) would indicate this, and are used only seldom to not at all.

For the network partners remain the same which are used in supporting the dying, yet less so in regards to supporting the grieving. This indicates strongly that this is not due to the fact that the workers don't know these resources or that they don't exist. The resources, usually provided by volunteers are available; however, they may be unsuitable for the support of bereavement, or there may either be internal or external reasons for this.

It follows: The burdens due of the experience of grief are high. It also follows that the usage of resources provided by volunteers, especially in the areas of experiencing bereavement and the dealings with grief in long-term-care is generally one that is neglected.

b.) Results of the Questionnaires that is concerned with the efficacy of the support with bereavement

In addition to the survey of 319 carers who supported the grieving, a total of 682 mourners also attended. Of these, 503 have taken an accompaniment and 170 people experienced bereavement, but made no accompaniment.

Figure 4 shows the results of the labor regulatory framework of the surveyed grief counselors.

Figure 4: Work legal framework of grief counselors (multiple answers)

Figure 4 shows the importance of grief counselors volunteer: 143 people, this are 41 % of the workers asked, were volunteers. This compares to the overall (only) 30 % of the 319 people who were paid workers (**salaried employees**), the 16 % who were self-employed, and the 10 % of people who get paid on reward.

In general there was no difference in respect to workers professional's basic education. In other words: all kinds of professional qualification were present by volunteers; most of them had a health and educational background.

Figure 5 illustrates the amount of hours done weekly, first, by the professional - and charity support-workers, for their individual work on their patients, and second, for their organization.

*Figure 5: Average weekly hours for accompaniment and organization of support:
Comparison main and volunteer grief counselors Arithmetic means of the use*

The full-time professional support-workers, working over 50 % in their job, said that they would work weekly an average of 10.5 hours for the actual work with the patient, and about the same amount of hours on organizational duties.

An important point to mention would be that there is little difference between the part-time professional workers, working under 50 %, and the volunteers in regards to their weekly hours spent with the patient and the organizational work done. This suggests that charity workers work structurally much the same as part-time professional workers do.

It seems that the amount of hours working is the most important factor when it comes to the intensity of support, and not whether the supporter is a professional or a volunteer.

All workers asked were highly experienced in regards to support-work (Figure 6)

Figure 6: Experience of support work of grief counselors in months: statistical mean

The average months of experience in supporting the grieving, lies at about 69 months (about six years, this can be seen in the blue columns). In regards to the occupational structure of the supporters, the workers, paid by hours, have most experience with an average of almost 88 months. This is followed by the volunteers with an average of almost 82 months.

This means that volunteer support-workers, with an average of almost seven years of experience, bring a lot of knowledge into the job.

One reason why the full-time professionals and the self-employed support-workers indicated less time of experience compared to the volunteer workers, is that 'support-work' as such is only a new profession. This is now provided by the full-time professional support workers and a common characteristic in the outpatient-hospice-service.

In relation to the types and the amount of hours spent supporting the grieving, whether on a one-to-one basis or a group situation or in other ways, such as meeting others in a Café, that is especially available for grieving people, is operationally irrelevant. Similarly, it makes little difference as to what kind of workers had done the work - volunteers or other professional support workers.

Overall the result of this study was that there were no differences in the efficacy of support by volunteers for the grieving compared to the full-time professionals.

When focussed on the charity groups in respect to dying, death and bereavement in in the nursing home setting, a few points can be mentioned:

Summary.

In summary it can be emphasized that with regard to the theme of volunteering in dealing with dying, death and bereavement in nursing homes settings

- the daily experience of workers dealing with dying, death and bereavement in the nursing home setting is highly distressful.
- volunteers are frequently used to help out in care-services to **support the dying** people.
- however: When **dealing with grief** (their own and of the survivors) the resource of (voluntary) grief counseling is seldom used.
- in bereavement support nearly 50 % of the accompanying are volunteers.
- the efficacy of support in bereavement was statistically significant, compared to the control group: grieving people receiving no support.

Conclusion.

Volunteers are a specific and very efficient source of support in bereavement, which however, are not often used in nursing home settings.

The main question therefore is how resources available, meaning the volunteering support-workers for the grieving, can be better integrated in nursing homes.

For opening up nursing-homes for charity groups, possible options and questions could be:

Using volunteers as means to support survivors (for example family members) and possibly to support carers in the process of grief in nursing-homes.

One possible result of ***using volunteers to survivors*** is that carers may be relieved of the pressure they are in.

Still it must be mentioned that there is a personal and conceptive division for the support of the dying, as opposed to the grieving process; plus the volunteers may need specific skills in order to be able to work in a nursing-home and to support the grieving people

In regards to the ***support of the carers***, working in nursing-homes, it may be asked whether they need/should be qualified to cope with their own grief. If this is so, could that be supplied by the volunteer workers? Or could volunteers give support directly to the workers (individually and in group settings)?

The issue here could, however, lie in the acceptance and the organisational procedures.

In conclusion, it can be said, that volunteer workers have great potential and are an effective source towards the palliative care in nursing-homes – nevertheless, it does generate many questions in regards as to how it is put into action.

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M. Gratz:
Preparing Hospice Volunteers
for Dealing with the Spiritual Dimension of Dying People

Background.

Since the beginning of the hospice movement the work of hospice volunteers has deeply changed. Volunteers do play an important role in the context of palliative care (Seeger 2014, p.19, Planalp et al. 2011, p.483-486). This role is basically seen as psychosocial support for the seriously ill, dying, and their relatives. But hospice volunteers regularly also come in contact with spiritual resp. religious concerns (Gratz et al. 2014, p.174-179). This is no surprise considering the fact that volunteers are involved in existential situations in very different ways. In some instances, patients or family members express spiritual resp. religious aspects (e.g. resources, needs) directly. At other times, they can also be mentioned implicitly so that volunteers have to read between the lines. The spiritual resp. religious dimension may be important to a seriously ill or a dying person, but this may go unnoticed as the patient doesn't give a hint of this need at all (Büssing et al. 2006, p.82). Hospice volunteers are in need to develop competency of perception and skills to deal with spiritual issues. They are considered to be persons of confidence for issues at the end of life; as much as professional caretakers, hospice volunteers need to understand that spirituality resp. religiosity is an important resource in times of seriously illness, if they want to follow the concept of whole-person care (Weiher 2009, p.45-52, Ferrell et al. 2013, p.431-437). A hospice volunteers' training in Germany should encompass at least 100 lessons (Bundesarbeitsgemeinschaft Hospiz e.V. 2005).

It is undeniable that hospice volunteers are an important factor in spiritual care. It is unclear, however, if hospice home care services employing volunteers regard spiritual care as their mandate and how they train volunteers for this challenge in terms of themes and methods.

Aim.

Hospice Volunteers are primarily considered as people who give psychosocial support. Seriously ill and dying people as well as relatives ascribe them – either consciously or not – the role of a companion, often enough including spiritual issues. The aim of our research project is to enhance hospice volunteers' abilities in the provision of spiritual care within palliative care. This is not only a matter of training but also a matter of consolidating honorary work. It is important that hospice volunteers are not only appreciated for their work and appointed, but well prepared to fulfill the tasks assigned. There is a need for training as well as for continuously sensitizing of employees in different professions within hospice and palliative care.

Collaboration with pastoral care is important because spiritual care by hospice volunteers is limited. For this reason, training programs have to include information about the specific activities of providers of pastoral care or chaplaincy services, and how they can be involved as part of a multiprofessional and team approach to palliative care.

To succeed in this aim, we took several steps and defined partial aims:

- Data collection about the spiritual care training situation in Germany and the collaboration of hospice home care services with pastoral care services
- Discussion on what training themes, aims, and methods are most important to be included in a spiritual care curriculum.

Developing a spiritual care curriculum for hospice volunteers' education in detail including precise sequences of all themes, literature, training aims for each theme, and a separate volume of teaching material for trainers

- III. Train the trainer: Training for spiritual care trainers to make them apply the spiritual care curriculum in their hospice home care services and evaluation of this training
- IV. Implementation and evaluation of the hospice volunteers' spiritual care training performed by the spiritual care trainers trained in step III.

This way it is possible to put a practice-based research project into effect and return the results back into practice in order to test its efficiency and feasibility.

Methods.

The different research steps require different methods. At time of publication step IV is in progress. For steps I to III, results are available. The study and questionnaire apply to the standards of research ethics of the University Hospital of Munich.

Step I

An online-survey was performed in July 2012 to all hospice home care services for adults in Germany (n = 1,332). The questionnaire was pretested and improved before launching.

Step II

Eight experts were invited to a focus group interview in October 2012. They were either full-time coordinators of hospice home care services or experienced spiritual care trainers. A semistructured interview guideline was used; the group discussion was digitally recorded and transcribed. After transcription the text was analyzed qualitatively following the instructions of thematic content analysis (TCA), allowing us to identify those training themes, aims, and methods that participants considered most important.

The results of the TCA were processed into an ordered spiritual care curriculum with details concerning single sequences of all themes and methods. Based on specialist literature, a volume of teaching material for trainers was developed.

Step III

The first version of the curriculum was evaluated by 21 home care service coordinators resp. spiritual care trainers by organizing a training for these trainers (train the trainer workshop) in March 2013. Participants were asked to fill out a questionnaire before (t 1) and after the training (t 2) to get information about the feasibility and potential for improvement.

Step IV

An enhanced version of the curriculum was mailed to all 21 persons in August 2013 who had participated at the train the trainer workshop. They were asked to perform spiritual care training for their hospice volunteers in their service following the instructions of the curriculum provided. A questionnaire is to be filled out before (t' 1) and immediately after (t' 2) the training as well as three months later (t' 3). This way, personal, useful, and professional benefits for participants gained by the spiritual care training will be evidenced. Step IV in our project is currently under way.

Results.

Step I

The survey was answered by n = 332 (24.9 %) hospice home care services. All of them confirmed that they consider training participants to reflect on their own spirituality to be important.

Training concepts vary in the way spirituality is integrated: nearly one third of all responding participants take spirituality as basis of the whole training. One third applies a specific teaching unit to spiritual matters consisting of a number from two to 20 (average 5) lessons. About 20 % report to occasionally mention spiritual issues within other themes. All in all, the conceptional approach to spirituality issues in hospice volunteer training is very different. There are only few services who state that they don't discuss spiritual issues in volunteer training at all.

Participants also vary in terms of their understanding of spirituality. Some use the working definition that was developed and published by the German Association of Palliative Medicine (Deutsche Gesellschaft für Palliativmedizin 2007) . Others work with the working definition of the task force on spiritual care of the European Association for Palliative Care (Nolan et al. 2011, p.86-89). Some use individual concepts developed by their hospice home care service. Some providers of volunteer training invite external teachers for spiritual care issues allowing them to make use of their own concept. A fifth of the participants not uses any specific definition or understanding of spirituality at all.

In two thirds of the hospice home care services, aims for spiritual care training are defined by the supervisor of the program. A quarter of services declares the hospice home care service to be responsible to decide about training aims. A quarter leaves it to the trainer assigned. Half of the respondents say that their trainer is an external person.

Preparing hospice volunteers to be able to deal with spiritual issues at the end of a patient's life concerns the responsibilities of two separate professional groups and academic disciplines: pastoral care and the field of theology / science of religion, and hospice work and the field of palliative care and palliative medicine. However, the trainers' professional background most often belongs to only one of these fields. Less than half of the trainers are familiar with both subjects. Either spiritual care trainers were religious experts (i.e. pastors and religious leaders)

with a lack of experience in end-of-life-care, or they were experts in hospice work with no practical experience in professional spiritual care.

All hospice home care services participating considered spiritual care as an important part of volunteering. They discuss spiritual care in general quite often, but they don't work out in detail which tasks are associated with volunteer spiritual care.

Cooperation and networking takes places to a mean degree only.

Step II

The focus group interview revealed several themes, training aims, and methods that participants considered most important to be covered by a spiritual care training curriculum.

Interview participants regard spiritual care as a training theme that needs special didactical considerations. Competency in spiritual care cannot be achieved by attending lectures, but needs a variety of methods including techniques to enhance self-reflection and practical skills. Training aims vary also. Methods and aims cover the wide spectrum of knowledge, skills, and attitudes.

Theme 1: understanding / definition of spirituality
Theme 2: spiritual needs, distress, hopes, and resources
Theme 3: spirituality in existential situations and crisis
Theme 4: spirituality and meaning of life
Theme 5: belief systems and cultural issues
Theme 6: spirituality and coping / dealing with suffering
Theme 7: introduction into practical spiritual care
Theme 8: spiritual care: presence and communication
Theme 9: spiritual care: „being present and endure“
Theme 10: spiritual care: referral to pastoral care service
Theme 11: spiritual care: rituals and creativity

The themes singled out by the focus group interview were put into a further process to identify and prioritize eleven spiritual care training themes:

Literature for each theme was provided to support trainers to prepare for the lessons; teaching material for teachers are added and put together in a separate volume of the curriculum. The first version of the curriculum developed at this stage of the research process was not ready for publication, but put to test and evaluation:

Step III

The test run with 21 spiritual care trainers resp. hospice volunteers training coordinators led to several findings enabling us to rewrite the curriculum. First of all, participants were asked to do a

global evaluation by answering two questions (five possible answers with a range between “I agree completely” and “I don’t agree at all”). Firstly, they confirmed that all in all, training themes and methods were suitable to prepare hospice volunteers for their tasks in spiritual care. Secondly, the curriculum was also considered to be suitable to support trainers preparing and executing course lessons.

Every training issue sets another impulse and follows a different perspective. All participants were requested to describe the training aims for each theme in their own words, based on their knowledge of their own hospice volunteers and their own experience in hospice care. Analyzing their answers allowed us to identify a number of experience-based training aims that could be incorporated into a reworked curriculum. The aims cover the full spectrum of knowledge, skills and attitudes.

Theme 2: spiritual needs, distress, hopes, and resources
Theme 8: spiritual care: presence and communication
Theme 9: spiritual care: „being present and endure“

It is assumed that training courses of most of the hospice home care services will not cover all eleven themes in the volume described. For this reason, all participants were asked to prioritize themes for inclusion by deciding which three out of the eleven themes they regarded as the most important. As the most important are considered:

Further questions on each theme were: how do you evaluate the content of each theme, methods used, and recommended lesson volume? Possible answers included “constructive” resp. “appropriate” or not. Participants were asked to suggest areas for improvement. Answers showed that improvement suggestions were restricted primarily to methods of teaching. This potential was tapped by creating a new version of the curriculum to prepare it for step IV. The curriculum at this stage of development spans about 15 hours of teaching

Step IV

Results of the test run with hospice volunteers that is executed by the participants of step III are not available yet. They are expected in 2015.

Discussion.

Step I

Apparently, spiritual care provided by hospice volunteers plays an important role in whole person care for severely ill patients and their families. The reason for preparing them in very different ways and for not clearly working out the tasks might be the diversity and individuality of spirituality and of the scope of duties. A guideline for pain treatment (Schmitz et al. 2014, p.67, see also: S3 Leitlinie Palliativmedizin) is much easier to develop. It is a challenge to create a curriculum that prepares hospice volunteers for dealing with the most important needs (Hampton et al. 2007, p.42-48) by regarding the variety and openness of spirituality. This requires

extensive knowledge of the trainers about the field of action of hospice volunteers in general and about their needs for their daily work. To teach spiritual care also requires to be familiar with the field of spiritual and religious issues resp. pastoral care (Hagen et al. 2011, p.28). Spirituality is what the patient says it is and what a patient says is helpful (Roser 2011, p.45-56, Pargament 2013, p.8-16). This definitory openness of spirituality makes it necessary that hospice volunteers have reflected their own notion of spirituality as well as their own spiritual life (Raab 2005, p.60-61) long before they turn towards to someone seriously ill.

The openness and the variety as central characteristics of spirituality could be the reason for hospice home care services not to name the spiritual care tasks in detail and not to work on them in the training. This is why specifications of training aims gain importance. By phrasing training aims it is easier to ensure good training results. As long as decisions about training aims are differing between the supervisor, the institution, and the trainer it is helpful to provide a list of training aims. The moderate integration of pastoral care has to be seen against the background of the different distribution of the religions and denominations (Statista 2011) in the federal states. Offers of the hospice home care services (Heller 2014, p.87-92) have to be expressed and to be brought into a cooperation agreement to involve pastoral care. Clarifications include questions like “what can pastoral care provide at the end of life?”, “what does pastoral care provide concerning parishioner and people who abandoned the church?”, “what are the hospice home care service’ offers in detail in the area of operation?”.

Step II

The themes generated by the focus group interview cover training in terms of knowledge, skills, and attitude (Marr et al. 2007, p.169-177). A wide spectrum of methods named by the interview participants correlates with this broad spectrum of themes. The results disclose that hospice volunteers are confronted with great demands. This gives an idea that professionalism is not a matter of being an employee or a volunteer only (Burbeck et al. 2014, p.568-574, Guirguis-Younger et al. 2005, p.143-144). It is rather a matter of the role that is filled with specific tasks and that the persons get prepared by education or training. Dealing with seriously ill or dying people requires a qualification specially tailored for the tasks in each role.

Training arrangements have to be enhanced over the years (Deutsche Gesellschaft für Palliativmedizin 2014) alongside the challenges that employees and volunteers meet in their field of work.

To create a curriculum out of the results of the focus group discussion mandates a certain readiness to rewrite and rearrange. Our project is based on practical experiences; we hope to review practice by scientifically sound methods in order to enhance future practice through theory. This succeeds if research knowledge and practical experiences complete one another (Nauck et al. 2014, p.89-90) with the meaning of an evidence-based approach. Practical experience is a composition of the coordinators working experience as well as the trainers resp. supervisors spiritual care teaching experience. Both have to impact the development of the

curriculum to meet the requirement of practical relevance. At this stage of the research process the researching results and practical experiences interlock.

Step III

The test run with 21 spiritual care trainers resp coordinators brought confirmation in two respects. Firstly, the development of the curriculum based on research and practical experience led to a version that was evaluated as adequate. Secondly, a potential for improvement (especially in terms of methods) could be identified which will increase the feasibility for the trainer and as well as learning value for hospice volunteers. The improvement could be made very accurate because the potential for improvement (in terms of content, methods, and duration of the lessons) was queried for every single theme.

The training aims were determined qualitatively. In particular, they offer the opportunity either to read the curriculum as a stimulation in order to think about the own training aims and / or to give a strong mandate to a trainer. It seems to be enriching that a curriculum not only contains detailed contents and methods for each theme. Training aims are beneficial because they indicate why a theme is recommended and what is supposed to be achieved by teaching a theme. This facilitates an individual adaptation and a variation (regarding content and methods) or a creation of a distinct training concept (Müller et al. 2014, p.31-38)].

Step IV

Statements about the effects of a spiritual care training with hospice volunteers can't yet be made. Results will be available in 2015.

Conclusions.

The research process has shown that hospice home care services are interested in a spiritual care curriculum and that they need assistance in creating lessons. It became clear that a curriculum should offer proposals concerning themes and methods. It also has to remain open for different understandings and definitions of spirituality and concepts of spiritual care of hospice home care services as well as of hospice volunteers. Flexibility within a curriculum is possible because, on the one hand, the training aims described stimulate individual priorities. And, on the other hand, themes and methods can be replaced by themes and methods that are especially developed in the hospice home care service.

The training aims were generated by the test run participants regarding the requirements hospice volunteers face in their work. By taking a glance at these training aims it may create the impression that volunteers and employees differ according to the type of employment but not according to the required degree of competence.

The curriculum including the teaching material was based on the results of the focus group interview. To organize a test run and a review by the coordinators resp. spiritual care trainers

was important because a cognitive approach is not suitable and should be replaced by interactive methods.

A curriculum should not only rely on a research process but also on practical experiences of coordinators resp. spiritual care trainers. The practitioners queried within the research project confirmed that the challenges in hospice volunteers' work require a spiritual care training. They also confirmed that the collaboration with pastoral care is indispensable. It is one out many other spiritual care tasks to involve providers of pastoral care.

Spiritual care can be taught in different ways. In the hospice home care services spiritual care will be as different as the patients' expectations of hospice volunteers. For this reason, a curriculum can only offer support. Hospice volunteers play an important role within palliative care beyond their psychosocial focus because they are addressed on the spiritual level directly or indirectly. Hospice volunteers are important and competent partners in situations of existential situations and crisis. It would be a loss to ignore this in the multidisciplinary (i.e. professional) approach of palliative care. Which gain in competence can be achieved by organizing spiritual care trainings for hospice volunteers will be revealed by the evaluation of the last research step.

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Participants Experiences

By Samuel Guma

Introduction

In African tradition, the philosophy of caring for all members of the community is well described by the term Ubuntu, which is the capacity in African culture to express compassion, reciprocity, dignity, harmony and humanity in the interests of building and maintaining community with justice and mutual caring (Nussbaum, 2003). It was therefore the responsibility of the entire community to care for the sick people within their community, and neighbours are expected to support the affected family by bringing food, helping to take care of the sick by bathing them, feeding or helping with other house chores. This culture may be under threat in modern Africa due to wide spread poverty and underdevelopment.

Personal experience

In July 2007, I and a group of other devoted health professionals started a community based non-profit organization – Kawempe Home Care - to provide comprehensive care for patients with HIV/AIDS, Cancer and Tuberculosis. The community we cover comprises three large urban slums on the outskirts of the capital city. The members of this community are immigrants from all over the country who come to the city in search of jobs. They live in basic shelters with total strangers as their neighbours. The majority of the slum dwellers work in the city as casual labourers or market vendors. They do not have any structured social support system and survive on what they earn on a daily basis. The struggle to survive in a capitalist economy and hardly any government social support system makes people in this community very vulnerable to poverty and disease. When we started working in this community we found many patients dying of AIDS in their homes and many of them hardly had any food or money to seek medical care or buy medicines. Their neighbours were not able to offer them any support due to their similar vulnerable state, and so their chances of survival despite the medication that our team provided were very slim. We decided to develop a number of interventions that could provide psychosocial support for the patients and this included establishment of a community network of carers i.e. local people from the community who were identified and trained on how to provide home based nursing care, medication adherence support, counseling services etc. Other projects to eradicate poverty and provide education for their children were set up.

In Uganda volunteering in Palliative care has been mainly taken up by church communities and community owned resource persons who have been trained by health care organisations. The general public still has not yet caught up on the spirit of caring and supporting other people. The one week interdisciplinary meeting at the department of palliative medicine, University of Bonn shed light on some very interesting aspects of volunteering in palliative care in Europe especially the experiences of the United Kingdom, Germany and Poland.

Lessons learnt

The experiences of volunteering in palliative care in the United Kingdom, Germany and Poland were very enlightening. The most remarkable lesson was how hospices and palliative care organisations have got their communities involved in volunteering. This could be in form of working for the hospice i.e. casual work like gardening, washing, cooking, reading books for the patients and keeping them company etc. Other ways of volunteering are like fundraising at schools, churches, in clubs e.g. Lions or Rotarian clubs etc. Members of the community provide their time and various skills to support their local hospices.

The lessons learnt from Poland revealed the power of mobilization for a cause using already existing structures e.g. the church. The hospice movement in Poland developed a mass mobilization strategy and with the support of the Catholic Church they reached all ages of their citizens. The wide spread advocacy for palliative care for the entire population has ensured nationwide support for the movement. The palliative care leaders also identified the opportunity of working with the Pope to bless the works of the movement and also urge the citizens to get involved in supporting the cause. The Pope's involvement in the hospice movement was a great boost to getting more Catholics to support the drive for hospice care in Poland.

In Uganda, volunteering in Hospice and palliative care services is mainly done by students who have completed their tertiary education and are looking for employment opportunities in organisations, and so they volunteer with the hope of getting employed in the organization. Other categories of volunteers are groups of "good Samaritans" who are members of local churches. These groups of people, who are mainly women, provide food, clothing and various kinds of support for the sick people in their communities.

Conclusion

The lessons learnt from the experiences in the United Kingdom, Germany and Poland present a great opportunity to mobilise the citizens of Uganda to get involved in supporting the palliative care movement. Reaching out to the middle class, the religious institutions, political groups, corporate organisations, institutions like schools and universities etc. would guarantee increased human, material and financial resources that will help to improve the quality of life of patients with life limiting illnesses and their families.

By Sonja Schrey

During the seminar week in Bonn, among other things, the subject of "Tasks / core competencies of volunteers" with examples from Uganda, Poland, Ukraine, Austria and Germany were discussed.

Particularly exciting for me was an example from Uganda. The discussion started here already with the definition of "volunteers": While in Germany and Austria mainly of "volunteering" and "volunteers" is spoken, in Uganda there are up to 80 different terms e.g. "community helpers", "social counseling", etc.

A participant from Austria told us that there are many elderly people in Austria who have drifted apart from their family or carry unsolved disputes to their grave. Here, the tasks of the volunteer staff is to visit or to accompany the dying people: listen to them, read, shop, walk with them.

A participant from Uganda asked quite irritated, "Why do the volunteers not help to unite the families, to bring them somehow together? In order to have good death, it is most important, that the family is together! The care for the dying must ensure that all are reconciled before death." This objection from the participant in return was quite an awakening for the participants from the other countries.

In Austria, as well as in Germany, an important competence which is expected from the volunteers is that they are able to set clear boundaries in their role. This means that they are not actively involved themselves in family quarrels unless they are asked. Keeping an appropriate distance from the people concerned is therefore a key issue which is practiced and discussed in supervision over and over: How can I distance myself? How can I manage that personal issues do not affect me too much?

An explanation for this misunderstanding lies in the basic attitude of the people in Uganda called "ubuntu", which can be translated with humanity and kindness. This "ubuntu" goes far beyond what we understand under accompanying dying people. For the volunteers in Uganda, it is self-evident that they can and should actively take part in the family affairs of the dying. According to the Ugandan participant, they see it as their task to do everything to contribute to a "good death". This also includes making sure that the family gets together, and that they reconcile.

For me and my research project, I learned that the expected core competences of volunteers strongly depend on the cultures and is not the same everywhere: this can reach from clear distance from the people up to active involvement in family affairs. It is important to clear the expectations in order to accompany people from different cultures in a good way.

By Katharina Klindtworth

Participation in this study week was an impressive and memorable experience. People from different countries and continents came together in a group to share and discuss their ideas about volunteering in a palliative context. From a German perspective it was also interesting to gain an understanding of volunteering in palliative care in other cultures.

Particularly impressive was the lively engagement of young participants from the Polish hospice movement. This movement is not regionally restricted to individual hospices and cities, but is country wide, and is effective in its use of media such as television and radio (Father Krakowiak). Contrary to the structures in Germany, which relies more on middle aged people, it is mainly young people who are engaged in Poland – although the tendency is also getting younger here.

But it was also clear that each movement has a heart that generates the drive and keeps it going. This makes the transfer to other regions and countries difficult. Beyond that, it was also clear that the activities undertaken by volunteer workers differ not only in terms of countries, but also because of religious backgrounds, cultural characteristics and institutional arrangements. It is worth addressing the integration of many of these aspects into our own structures. There is certainly potential for many learning and developmental opportunities.

By Katharina Pabst

At the study week in April 2014 in Bonn people with a variety of different ideas and different backgrounds came together. This included various cultures, nationalities and approaches. But what we all share is a focus on the work with volunteers in palliative care. Versatile lectures and constructive discussions enabled us to share experiences and open up new perspectives. As this was my first time to take part in a study week on volunteers in palliative care, I was able to benefit greatly from the experiences and knowledge about volunteering which were shared both from scientific as well as from personal point of views. My study “The role and motivation of volunteers in hospices and palliative care in Europe” contains an intra-European comparison. Therefore I had a great interest in meeting and forming new contacts with people from different European countries such as Poland, the UK, the Netherlands, or the Ukraine. This also included the pleasant encounter with Leena Pelttari, an Austrian member of the EAPC’s (European Association for Palliative Care) Task Force on Volunteering, with whom a close cooperation is planned. The study week allowed us to establish a first personal contact and exchange ideas about the study.

Overall, I was able to gain impressions of volunteers in palliative care and their work in different countries. I could gather new ideas and inspiration and hope to implement these in my study.

By Carolin Loth

Soon after the start of the “Palliative care volunteers in Africa“-study I heard of the BMBF studyweek “Volunteers in palliative care“. As the study was not only my first research project, but also my first close contact with the topic, I benefited twice from my participation: Firstly, the other participant’s presentations taught me a lot about constructing and performing sociological studies. Secondly, the various angles, from which volunteers in palliative care were presented, helped me widen my knowledge.

Samuel Guma’s presentation and Fatia Kyange’s talk were certainly of special interest for me: both spoke of their experiences in Uganda, as well as in other parts of Africa. These expert reports gave me a better understanding of original papers on palliative care in resource-poor settings, I had read before. Also, the reports were of great help to me in the later course of the study, for example during interviews I conducted in Uganda.

The international conversations, inside and outside of the seminary room have been a lively example for the way people working in palliative care can benefit from communicating with their colleagues from abroad. Alexander Wolf’s presentation, in which he stated to learn especially from Poland, as the country is not only geographically but also historically and economically closest to Ukraine. This motivated me: I hope, that the results of the comparative study on volunteers in Africa will facilitate the regional, intra-African exchange.

By Magdalena Urlińska

The study visit within the project prepared by the German Ministry and the Department of Palliative Medicine in University of Bonn was a great opportunity to create an international discussion panel that gathered around a table experts, academics and practitioners from around the world, giving them the opportunity to exchange views, opinions, share results of their research and observations. In my opinion workshops were not only the form of activation, but also allowed us got to know the specifics of voluntary activities and a system of palliative and hospice care in different countries. Mainly they have mobilized us to share thoughts and develop joint solutions based on our good practice.

In the social consciousness of Poles volunteering is still perceived as a very narrow form of civic activity, limiting to actions in the face of tragedy, natural disasters or large promotional or charities campaigns. Poles are faced with the problem of the low level of involvement in voluntary work, mainly because it is treated as an activity imposed from above, they don't see the benefits of such activities. For the most part, volunteers (mostly volunteers time actions) in Poland are young people, a minority are adults and seniors. The problem is that for Polish young generation voluntary work is (unfortunately) often a trendy way to spend time. They don't see that thanks to this form of activity they have opportunity for full personal development, they conquer new skills and competences, which make them in the future more attractive in the labor market. Poland is struggling with a lack of comprehensive approach to the management of volunteers, often the knowledge and skills of coordinators and animators make their actions are limited to a particular sector (hospice volunteer, student, sports).

Volunteering is rather a temporary aid than a dynamic social activity. Due to the fact that volunteering is work performed voluntarily and free of charge, providing assistance to people in need is not only the idea of spending free time, but most of all it is a form to acquire knowledge, skills and experience through the contact with another individual. Voluntary work is valuable for both sides - volunteers and people benefiting from support. A crucial element is to improve the quality of the involvement of volunteers, development initiatives in support of volunteering, which may change the attitudes of people towards development assistance activities. It is necessary to intensify the promotion of the value of volunteering, make that it will become a permanent element of active citizenship, through which an individual has the ability to help others and be an active participant in social life.

The extraordinary atmosphere, open-minded participants, substantive discussions and exchange of experiences - often carried out long after the meeting - allowed me to re-look at the problems associated with the issue of volunteering in institutional and home palliative care. The workshops were a source of inspiration for me, forcing me also to look for new solutions or even redefine some of the issues and look at them from a different perspective.

During the workshop a number of issues related to volunteering has been raised. Together we reflected on the definition of the role of volunteer support system, taking into account volunteers' needs, including spiritual awareness and social responsibility. There have been appeared opinions regarding challenges posted to the volunteers, inadequacy of the system and lack of transparent relationships between entities. Regardless of country, common problems of volunteering is lack of funds, excessive workload and the high expectations of patients and their families to the volunteer. Some ideas to create a common global standards came up, but after long debate the participants seemed not quite convinced of that. They approached with reserve to this idea, stating that the cultural differences existing in different countries can become problematic.

Many times during our debates and discussions in the corridors there were voices that still too little attention and space in publications is dedicated to the work of volunteers, especially their emotional and organizational. Participants stressed that the volunteers suffer from a lack of support not only organizational but primarily psychological. Often they are unable to cope with their own but also with others emotions. They feel discouragement, fatigue, sometimes burnout. In contemporary European society still operates a stereotypical way of thinking about volunteering, hospice and palliative care, what effectively discourages people to become more involved in work for another person. For me personally an extraordinary example of public accountability for each individual was the idea of Ugandan Ubuntu. In Africa it is synonymous with prestige and unselfish concern for another human being. Another problem was the issue of accompaniment in mourning, while the presence of experiencing sadness and grief and reasonableness of the actions taken by volunteers in the work of those who have lost loved ones.

Summary of experiences allowed participants to combine theory with practice. What is more, create an international platform for mutual understanding the issue of volunteering and palliative care in the wider international context. I had the feeling that together we had the great opportunity to celebrate the time, which we spent on sharing our knowledge, skills, exchanging experiences and remarks, sometimes it was a voice of constructive criticism. Weekly debate confirmed my firm belief that in each of individuals is a source of (creative) potential that can and must be used for the good of society. Study meetings, such as those in which I had the great pleasure to attend, are the best way to go beyond the schematic thinking about problems, look for innovative solutions in the good practices and experiences of other researchers and experts.

By Alexander Wolf

The BMBF study week on volunteering in hospice and palliative care was interesting, and I got the possibility to learn more about organization of voluntary movement in the world.

It was especially interesting to learn about the African experience, and, of course, about life in Uganda and various aspects of its life. I learned about Ubuntu. In my opinion, mutual aid is a basic principle of life in Africa. In Ukraine, I do not think there shall be such forms of assistance, but of course the volunteer movement shall continue to develop. In our country, unfortunately, in the 20th century religion and faith have been cruelly persecuted, so most people are not used to volunteering, which, of course, through the ideas of humanism and altruism is associated with Christianity

In Poland, volunteering is very highly developed, too. According to my observations, this is also related to the work of the church, a fairly high morality and general high development of civil society. People tend to unite and to social issues feel that they are community, and therefore understand that they are responsible for solving social problems. Very much on the subject has been mentioned in the presentation of Rev. Peter Krokovyak. As he pointed out, a strong impetus to the development of palliative and hospice care gave the Pope of Polish descent. I think Ukraine will also rise the level of altruism and humanism, and the flagship in this process will be the Catholic and Protestant churches in Ukraine, because they have experience in dealing with the Western world.

However, the culture of giving and culture of humanity will be confronted by indifference and nihilism of people who do not believe in high ideals. Unfortunately, life in Ukraine has confirmed that human life is not valued here. This is peculiar to the Asian culture where thousands of lives or deaths are nothing.

Also at the meeting in Bonn, it struck me that people over 50 from Germany are also volunteers, and also working in the field of HIV/AIDS. It also speaks to the high development of civil society and mentality.

I think that such meetings should be held regularly and as often as possible. They are necessary because young scientists necessarily need to share experiences and ideas. However, it is very important that these ideas are put into practice, that they stay not just ideas. After all, people in need - seriously ill, the elderly and children - are waiting for real help.

I would like to thank organizers of the BMBF study week on volunteering in hospice and palliative care for their preparations and work.

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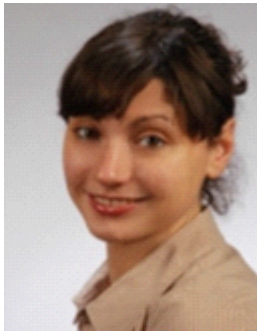


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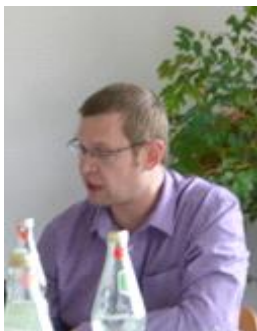


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