

Proceedings

INTERNATIONAL SYMPOSIUM „VOLUNTEERS AT THE HEART OF HOSPICE AND PALLIATIVE CARE“

Opportunities and Challenges 2030

25th May 2019, Berlin

Editors

- > EAPC Task Force on Volunteering
in Hospice and Palliative Care in Europe
- > German Association for Palliative Medicine
- > German Hospice and Palliative Care Association
- > Hospice Austria

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Women and Youth

*Volunteering is not an addition,
not an „add-on“, not a „nice to have“,
but part of the basis
of hospice and palliative care.*

EAPC President Christoph Ostgathe

25th May 2019, Berlin

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Preface

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**LEENA PELTTARI &
LUKAS RADBRUCH**

Initiated by the German Association for Palliative Medicine, the German Hospice and Palliative Care Association, Hospice Austria and the EAPC Task Force on Volunteering an international symposium „Volunteers at the heart of Hospice and Palliative Care – Opportunities and Challenges 2030“ took place on May 25th in Berlin, at the ESTREL Congress Centre. More than 300 participants from countries across Europe took part. It was the last day of the European Association for Palliative Care 16th World Congress in Berlin with more than 3.000 delegates from 100 countries.

It was with great pleasure that delegates were welcomed to the day by Mrs. Hartwig from the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany which very kindly provided the majority of funding for the event. Also part of the welcome committee were Professor Christoph Ostgathe, President of EAPC, Professor Lukas Radbruch, President of German Association for Palliative Medicine, Waltraud Klasnic, President of Hospice Austria, Anja Schneider, Vice President of German Hospice and Palliative Care Association and Leena Pelttari and Ros Scott Co-Chairs of EAPC Task Force for Volunteering on Hospice and Palliative Care in Europe.

The aims of the symposium were:

- to promote international development of volunteering in hospice and palliative care
- to raise awareness and understanding of volunteer hospice and palliative care work
- to share knowledge, experiences and ideas on an international level
- to network and learn from each other

The heart of the meeting was networking, sharing experiences and approaches and listening to one another. Volunteers in the field of hospice and palliative care, coordinators/leaders of volunteer hospice teams, managers of hospice organisations & associations, trainers and supervisors of hospice volunteers have participated.



Leena Pelttari



Lukas Radbruch

The day began with a keynote presentation from Dr. Rajagopal, considered to be the founding father of palliative care in India. He gave a moving and insightful presentation on Compassionate Communities in Kerala, India and the vital role played by volunteers in hospice and palliative care. Fatia Kiyange from The African Palliative Care Association then gave an overview of hospice and palliative care in Africa. Anja Schneider, DHPV, presented the results of a research study which explored Volunteering in Germany. These presentations were followed by a session on “My Volunteering Life”, a series of short presentations from volunteers from different countries giving an insight into their experiences of volunteering in hospice and palliative care.

For the first time, a chapter on volunteering was included in the EAPC Atlas of Palliative Care in Europe 2019, Carla Reigada gave an overview. A further discussion panel explored how hospice and palliative care volunteering was changing and included representatives from Austria, Belgium, France, Germany, Hungary, Italy, the Netherlands, Poland, Serbia, Spain, and the UK. Ros Scott and Leena Pelttari gave a joint presentation on “Voice of Volunteering” the EAPC Madrid Charter on Volunteering in Hospice and Palliative Care.

We are very grateful for the support of ERSTE Foundation for funding travel costs for participants from Eastern Europe Countries and for the generous support by the German Ministry of Family Affairs, Youth, Elderly and Women which made free participation and simultaneous translation possible!

Lukas Radbruch & Leena Pelttari

Programme

> 10 – 10:30

OPENING

Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, Germany

Christoph Ostgathe
President of EAPC

Lukas Radbruch
President of German Association for Palliative Medicine e. V.

Waltraud Klasnic
President of Hospice Austria

Anja Schneider
Vice Chairwoman of German Hospice and Palliative Care Association

Leena Pelttari and Ros Scott
Co-Chairs of EAPC Task Force for Volunteering on Hospice and Palliative Care in Europe

> 10:30 – 10:50

HEALTH CARE WITH THE PEOPLE: COMPASSIONATE COMMUNITIES IN KERALA, INDIA

M. R. Rajagopal, India

> 10:50 – 11:10

VOLUNTEERING IN PALLIATIVE CARE AND THE WIDER HEALTH SECTOR IN AFRICA

Fatia Kiyange, Uganda

> 11:10 – 11:30

VOLUNTEERING/CIVIC ENGAGEMENT IN GERMANY – GERMAN HOSPICE AND PALLIATIVE CARE ASSOCIATION RESEARCH PROJECT

Anja Schneider

> 11:30 – 12

STORY OF MY VOLUNTEERING LIFE

Volunteers from different countries presenting

> 12 – 13

LUNCHBREAK

> 13 – 14:20

VOLUNTEERING IN EUROPE

EAPC ATLAS OF PALLIATIVE CARE IN EUROPE 2019: VOLUNTEERING
Carla Reigada

HOW IS VOLUNTEERING CHANGING: OPPORTUNITIES AND CHALLENGES 2030

Karl Bitschnau, Austria
Mijodrag Bogicevic, Serbia
Chiara Caraffa, Italy
Anne Goossensen, The Netherlands
Leszek Pawlowski, Poland
Carla Reigada, Spain
Catherine Renard, France
Anja Schneider, Germany
Ros Scott, UK and Ireland
Steven Vanderstichelen, Belgium
Ágnes Zana, Hungary

> 14:20 – 14:40

VOICE OF VOLUNTEERING – EAPC MADRID CHARTER ON VOLUNTEERING IN HOSPICE AND PALLIATIVE CARE

Leena Pelttari und Ros Scott

14:40 – 16:30

WORLD CAFÉ

Lively discussions with colleagues from near and far to e. g. following themes:

- Training of Volunteers
- Training of Coordinators
- Quality Programs and Frameworks
- Changes in Volunteering / Challenges in Volunteering
- “Being there”
- Volunteers and Society
- Future of Volunteering

> 16:30 – 17

WORLD CAFÉ PLENUM AND CLOSING

Opening



SILVIA HARTWIG

Federal Ministry for Family Affairs,
Senior Citizens, Women and Youth



Dear Professor Ostgathe,
dear Professor Radbruch,
dear Ms Pelttari,
dear Ms Scott,
dear Ms Klasnic und Dr. Schneider,
dear ladies and gentlemen,

on behalf of the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth, I would like to welcome you here in Berlin and also to this international symposium. I would like to start by bringing you warm greetings from the Federal Minister, Dr Franziska Giffey, who would very much have liked to have been with you today, but the political times in Germany and in Europe are very turbulent right now and that means that she cannot be with you today.

Ladies and gentlemen, you will hear a number of very interesting speeches today. The first speaker is always in the comfortable situation of taking their time, and everyone else who comes after them has to hurry up. But I can assure you, I will make it brief and raise only two points. Firstly, safeguarding and further development of volunteerism in the care of the dying and in hospice work as a whole are very important concerns for the Federal Ministry of Family Affairs.

We know that hospice work and good palliative care are simply inconceivable without voluntary commitment. And we also know that volunteer work in Germany faces some very important challenges: It is about winning over new groups of people for commitment, and this at a time when in Germany many areas are competing for winning over volunteers. From our perspective, it is also a matter of developing or further developing other fields of voluntary work or commitment. I would like to mention, for example, the area of cooperation between committed staff and volunteers in inpatient facilities or wards in hospitals other than palliative care units.

And it's about securing the commitment on site. Aspects such as differences in urban and rural areas or volunteerism in regions with weak infrastructure, voluntary work in line with family tasks and professional requirements, but also the consideration of employer perspectives in today's world play an important role.

For all these questions we have launched a project with the German Hospice and Palliative Care Association. We hope that this will provide us with really good, new impulses for these questions. We are counting on the fact that the sponsors and the actors of hospice work and palliative care can be integrated into this project.

Secondly, further development, developing new ideas is not possible without exchange and without learning from each other. We in the Federal Ministry for Family Affairs are of the opinion that learning from an international perspective is both right and necessary. That is why we were very happy to support this symposium.

Dear Leena Pelttari, dear Ros Scott, we had planned something special for the EAPC Congress and also for the event here. I'm afraid things have changed. The Minister was unable to sign the European Charter today. But there is this Germany saying: postponed is not cancelled. And that should also apply to the EAPC Charter on Volunteering in Hospice and Palliative Care.

Dear ladies and gentlemen, let yourself be inspired today by the Charter on Volunteering in Hospice and Palliative Care. At a time when visibility determines impact, please let knowing about this effect guide your action. Therefore, I would like to encourage you to sign this charter today. It is important that it becomes visible and that you, your work and commitment, hospice care and palliative care also become visible.... For those who are here from Germany, of course also the request at the end: Please also sign the charter for the Care of the Severely Ill and Dying in Germany, a bedrock of our joint current and future work.

With this in mind, I wish you many fruitful discussions today and, of course, much success and good luck to the organisers.

Thank you!

>
CHRISTOPH OSTGATHE
President European Association
for Palliative Care



Dear Ms Hartwig,
dear ladies and gentlemen,
dear Volunteers ... it's you being in the focus of this day,

on behalf of the European Association for Palliative Care (EAPC), of which I have been President since yesterday, I am extremely pleased to welcome you all - also on behalf of the board - to this symposium of volunteers. I'm very pleased and believe it is fitting to have my first official appearance in the new office in the area of volunteerism. The EAPC is particularly proud that this important event will take place on the last day of the 16th World Congress for Palliative Medicine in Berlin with a good 3,000 participants. The EAPC is an association of almost 60 national palliative and hospice societies from 33 European and also non-

European countries with an estimated 50,000 associated members. It unites many who are active in hospice and palliative care as either staff or volunteers. The EAPC sees itself as a platform to promote high-quality hospice and palliative care for all age groups, from premature and newborn babies to the very old, through education, training and further education of those working in the field and the public, as well as through research, advocacy and evidence-based practice. Under the motto „One Voice – One Vision“, the EAPC wants to contribute to avoiding unnecessary suffering for people with life-threatening illnesses and their families or to reducing suffering where it arises and supporting everyone - no matter where they live in the world – to have fair access to hospice and palliative services as an integral part of the health system. Hospice and palliative care is very well developed in many countries in Europe and around the world; nevertheless - to this day - not everyone who needs it receives adequate care in these countries, including Germany.

The Atlas of Palliative Care at the End of Life presented at the congress shows impressively that there are still many countries in Europe where we are far from being able to offer hospice and palliative care to everyone.

Where people suffer from severe illness and the associated limitations, co-operation of staff and volunteers based on mutual respect is of particular importance for high-quality care. In recent decades, volunteering has increasingly become an important field of action for the EAPC. You will hear it today at this event; the „Task force on volunteering in hospice and palliative care“, together with the board of directors, has been extraordinarily active, creative, dynamic and, in the truest sense of the word, tireless in promoting the topic of volunteerism. In addition to the development of a white paper „Defining volunteering in hospice and palliative care in Europe: an EAPC White Paper“, the charter on voluntary work in „Hospice and palliative care in Europe“, which was initiated at the 2017 congress in Madrid, should also be mentioned here; more on this later by Leena Pelttari and Ros Scott.

The first sentence of the new English textbook for palliative care reads „Volunteers are key members of the hospice and palliative care team“. Volunteering is therefore not an addition, not an „add-on“, not a „nice to have“, but part of the basis of hospice and palliative care.

The EAPC board will continue to promote the cause of volunteers in the future. With this in mind, I wish you today - the core or key members of hospice and palliative care - a successful volunteer day. I would also like to combine this with thanks to the speakers of the Task Force Leena Pelttari and Ros Scott, the organising team, the German Association for Palliative Medicine and the German Hospice and Palliative Care Association, who fought for the event and prepared it so wonderfully. I wish you a wonderful day with fruitful exchange for all of you, you deserve it!

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LUKAS RADBRUCH
President German Association
for Palliative Medicine



As President of the German Association for Palliative Medicine, I am delighted to welcome you here. In Germany, too, as laid down in the European Textbook, voluntary work is indispensable in our work. Especially our experience, which we also made in Germany with 80,000 volunteers, is simply the way we can change society. As a doctor, I can do so much for patients in the context of palliative care, but if those affected and their relatives are not aware of palliative care options, if there fear that they will have to go to a hospice or a palliative care unit, because they believe that is only for those who are dying, then it is good to have volunteers who work with the patients affected, but also with their own families, with their colleagues at work as part of society, to ensure that we will talk about death and dying. And thus also spread the message that hospice and palliative care is not only something for the last hours or days of life, but can start much earlier. That this is about attitudes that are urgently needed in other parts of our society as well. This kind of change is only possible through the many volunteers in Germany and other countries. That is why I am particularly pleased that we have opportunities for exchange, because we repeatedly find that there are differences compared with neighbouring countries. In one of our research projects, for example, we found that voluntary work in southern European countries does not have the same significance, because this kind of care is done by the family. Voluntary accompaniment is practically a sign of disgrace, namely that the family cannot take over these tasks. How can we export our good experiences there or bring back from there community and family care into our societies?

This is the kind of exchange I'm hoping for today. Experiences, opportunities that we can use for ourselves and implement in our country afterwards. What a wonderful opportunity! And I am glad that we have so many people here who are interested in such an exchange, and I am especially looking forward to the further lectures today.

I would therefore like to pass on to Ms Waltraud Klasnic, President of the Austrian Hospice Association.

I am very pleased that you have made the long journey here today, and I am pleased that we can hold the symposium together, not only with the European Task Force, but also with the support of the professional societies in our two countries.

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WALTRAUD KLASNIC
President Hospice Austria



As chairman of the umbrella organisation Hospice Austria, I would like to extend a warm welcome to all those present, especially to the men present, who I would also like to encourage to continue being active and to invite more other males to this kind of commitment. I would like to thank all the volunteers who are here today.

Special thanks also go to our Chief Executive Officer of Hospice Austria, Leena Pelttari, without whom we would not be here today. Leena Pelttari made the decision at the EAPC Congress in Budapest in 2007 to work for volunteering at the European and EAPC levels, as she found that it was lacking representation.

Exactly ten years ago, in 2009, the first International Symposium for Volunteers in Hospice and Palliative Care was held in Vienna as part of the 11th EAPC Congress. „Being there in life“ was the motto. Hospice Austria, the EAPC and the Worldwide Hospice Palliative Care Alliance (WHPCA) were the organisers.

A particular highlight was the EAPC Charter on Volunteering in Hospice and Palliative Care, which was presented in plenary session at the EAPC Congress in Madrid in May 2017. The Charter is the fruit of an international Task Force on Volunteering in Hospice and Palliative Care in Europe, established at the end of 2013 at EAPC level and co-chaired by Leena Pelttari and Ros Scott, a UK scientist and hospice expert.

Today, thousands of volunteers in Austria and Germany are active in the field of hospice and palliative care for adults and for children, adolescents and their families, most of them in direct support.

In Austria, we have a treasure that enables us to do a lot: volunteers are trained according to a curriculum recognised throughout Austria by the umbrella organisation Hospice Austria and organised in hospice teams with a coordinator.

At the current EAPC Congress here in Berlin the new EAPC Atlas on Palliative Care in Europe was presented. In terms of the number of facilities per inhabitant, Austria is among the leaders. We are proud of this. We are also proud of a facility that is probably unique worldwide: in Graz, my hometown, there is an inpatient hospice for homeless people.

Flowers need sunlight and water to bloom, people need people. Volunteers in hospice and palliative are the people who are there for others, in responsibility and love.

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ANJA SCHNEIDER
Vice Chairwoman German Hospice
and Palliative Care Association



Ladies and gentlemen,
dear colleagues from near and far,

I would also like to welcome you to this symposium of volunteers. My name is Anja Schneider, I speak to you as deputy chairwoman of the German Hospice and Palliative Association.

I am very impressed by the overwhelming number of colleagues who have flocked to Berlin from all parts of the country and even the world. Some of you may have spent the last two days at the EAPC Congress, others have come especially for this symposium. Volunteering in hospice work and palliative care - this is of course also a central topic for us at the German Hospice and Palliative Association (DHPV), as our association emerged from a voluntary movement that had its beginnings in the 1980s.

Later on, I would like to report on a research project that DHPV has realised with renowned members of its scientific advisory board. Just so much in advance: This study is about the development of a systematic empirical foundation for the further development of hospice practice and culture, always with a view to its character as a citizens' movement and the importance of volunteering for our work. It is also about how we will be able to recruit younger generations of volunteers and become more heterogeneous and more colourful.

Dear Ms Hartwig, almost two months ago we had the common pleasure of getting to know almost a hundred young people working in hospice and bereavement counselling in person, which I will also report on.

My short lecture has been scheduled right after the talks of my colleagues Fatia Kiyange from Uganda and M. R. Rajagopal from India. Fatia Kiyange is programme director of the African Palliative Care Association, Mr Rajagopal „The Father of Palliative Care“ in India and was nominated for the Nobel Peace Prize in 2018. You'll understand that I am a little nervous - and that I am very much looking forward to the two lectures. That's why I don't want to speak for long. I wish you a gain of knowledge, exchange and networking and last but not least fun - in short: an inspiring day!

With a look at the programme, dear Leena Pelttari, dear Lukas Radbruch, it can't be any different. Many thanks to you and the whole team for the organisation and the invitation.



LEENA PELTTARI UND ROS SCOTT

Co-chairs of EAPC Task Force on Volunteering in Hospice and Palliative Care



Leena Pelttari



Dr. Ros Scott

Honoured guests, ladies and gentlemen,

We think today is such an amazing day, to see so many people from different countries gathered: volunteers and people who work in palliative care in many different disciplines. Together we can spend the entire day thinking about, learning about and exchanging experiences on volunteering in hospice and palliative care. We think there are very rare opportunities for us to do this, and we are also so inspired by the amazing international speakers that we will hear today. There was a great American guru in volunteering who spoke about volunteers and how they dreamed and made things happen. And if you think about the roots of hospice and palliative care services in many countries, they were started by volunteers who identified a need and drove them forward to where we are today. Volunteering is very much at the heart of hospice and palliative care! We both would like to welcome you all today to our international symposium on volunteering and we look forward to what we will share together today!

We would also like to say „Thank you“ to all, who have made this wonderful symposium possible! Ministry of Family in Germany and the ERSTE foundation in Austria, who had made it possible for many people from the south eastern part of Europe to participate. We would like to thank also our German colleagues who have been working very hard on this symposium: Lukas Radbruch as the president, Heiner Melching as the Chief Executive Officer of the German Association of Palliative Medicine and the whole team: Birgit Jaspers, Karin Dlubis-Mertens and Sabine Simon. Thank you so much and welcome all!

Talks

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**HEALTH CARE WITH THE PEOPLE:
COMPASSIONATE COMMUNITIES
IN KERALA, INDIA**

M. R. Rajagopal, India



Guten Morgen, ladies and gentlemen,
Lukas, Leena, and all organisers,

Very grateful for you to giving me this opportunity and I also thank the Floriani foundation for sponsoring me, travel and other expenses. Thank you very much, without all that support I could not have had the pleasure of seeing the growth of humanity through palliative care all over the world.

I come from Kerala which is in the southwest of India. It's a tiny state. As many of you know, there are a lot of us in India. We form one sixth of the global population. If you think that's overcrowding, look at Kerala which is thrice as dense in population as the rest of the country. We are all over the place. The overcrowding is indeed a huge problem and that adds to many issues including poor road conditions so that access becomes difficult, and health care becomes difficult because of poor access. In that state the common man has joined doctors and nurses, armed with the essence of care that is, ma'am (pointing to previous speaker) what you said, love. Doctors do not talk about that. There is no textbook chapter on love in medicine. We can't measure it. Unless it's measurable with clear indicators, we don't talk about it. It's not fashionable. And then the common man had to come in and show that health care has to incorporate humanity and love.

To illustrate what the volunteers can do, let me share with you this lady's story.

This woman (picture) is a single parent. She is in her thirties and has two teenage school-going girls. Her whole life revolved around her two daughters. A volunteer rang me up and said: There is this girl Tina (that's not her real name) who has advanced cancer and is now bleeding and in pain. But the cancer hospital is refusing to see her because she has lost her records. Can we do something?

We said: Bring her along. She came. Our social worker found that her story kept changing. It was never consistent. And there was clear suffering on her face. The social worker said: "Tina, there is something that you find difficult to talk about. Tell me. Allow us to help you".

And then the story came out. She did not have cancer. She had said cancer because she had wanted to tell us something that was shareable. What she really had was not easily shareable. What she had was a pregnancy. She could not bear the thought that her two daughters were finding out that she was pregnant. Pregnancy in an unmarried woman, a woman without a husband, is not something that our society takes lightly. We can be very moralistic and judgmental when it is about somebody else. And she was afraid that "if my daughters find out that a new baby is in me, if anybody finds out that I am pregnant, our life would be over".

Now we have an issue. We are palliative care people. We are a palliative care institution. Should we be seeing her at all? Guess who asked that question? Of course, the doctor. The doctor was digging in his mind ... palliative care definition ... life-threatening illness ... Pregnancy is not a life-threatening illness.... How can we see her?

The volunteer had no doubts and now said: Of course we cannot drive her out. We have to do something.

Actually, she had a life-threatening condition. Three lives were at stake. As it turned out, the fetus was already gone. She'd had an incomplete abortion. But her life and the two daughters' lives were at stake. She had actually bought poison. She said she thought she would kill the kids and kill herself. But then she thought: "They are my children! How can I kill my own children? I cannot do it! I don't know what to do."

Why am I talking about this story at a palliative care meeting? Because we in developing countries find that in the context of numerous primary health care issues we have to sometimes rise above definitions and do what a human being needs to do.

We said we are going to send you to a very kind gynaecologist who will see you and do the needful. She said: I cannot go to any hospital in this town. If somebody I know comes to know of this, my children's lives are finished. I won't go to any hospital. You do what you can here.

We rang up an obstetrician who was also a human being and that lady, by 7:30 in the evening after finishing her work drove down to see Tina. She found that Tina had an incomplete abortion which needed to be evacuated. But Tina would not go to a hospital. The gynaecologist arranged with a hospital in the next town and drove herself over. We arranged transport for Tina and the volunteer. They went there and had the uterus evacuated.

There were many questions. Suppose, something went wrong? Who'd take the responsibility? The hospital wanted a consent form. The volunteer and I signed the consent form as the closest relatives because there was nobody else to sign them.

Now, all this couldn't have happened, and those lives would not have been saved, if the volunteer had not identified the problem.

Here I bring in the concept of social capital. There must be many definitions of social capital, but I will not use any of them. Instead I will just say, let us for today call it the essence of goodness in the community. What has happened in society is that families are becoming more and more nuclear. That is the western disease which we have in micro portions in our country also now. The joint families are becoming less and less and families are becoming nuclear. The micro element of the social capital is becoming more micro and more micro. The macro element, the health care system, is becoming bigger and bigger; and the smaller hospitals are closing down. The town hospitals and the village hospitals are closing down, because they cannot survive. Unless they are in the government sector. And the government sector has always very overcrowded hospitals. The result is that the micro human being is becoming a total stranger in today's macro health care system.

Disconnection is growing, globally. What we are doing, what the volunteers are doing, is to re-connect them, bringing in the meso element of social capital, the goodness in the community that is coming together to connect the micro element with the macro element.

Would there be any community anywhere on the globe where there are no good people, kind people, compassionate people who get satisfaction out of helping others? They are there, everywhere. The only problem is they do not have an opportunity to help others because we professionals and politicians are managing health care. We only need to welcome them! And they will come and do what human beings can do.

So what do our volunteers do? It had started with one volunteer, 26 years back; next month there were three and then they started growing. What is their significance? It's in Cicely Saunders' concept of total pain. Really, the doctors and nurses are necessary only for one part of palliative care, the physical part. The social, the emotional and the spiritual domains of suffering need only human beings.

And that is the relevance the volunteers can or potentially can take on with dedication and commitment. Three-fourth of palliative care. And I will not stop there. Three-fourth of health care. If health care is to become what it should be.

But bringing the volunteers together does not happen spontaneously. So we actually have two social workers and three volunteers dedicated only to public awareness programs. They go and talk to people in schools, colleges, small village clubs, sports and arts clubs, Rotary Clubs and Lions Clubs, everywhere. Wherever people are willing to listen, we go there and do awareness programs, explaining to them about health-related suffering and what can be done. Inevitably there a few people who are interested. We try to get the people together and organise a meeting. Usually, typically, that will be a group of ten or twelve out of a hundred who come to an awareness program. Out of these, three or four will volunteer to undergo a training program. We insist on the training program. We are allowing lay people, armed with compassion but without understanding of health care to get into health care. It's easy to cause harm. It's easy to cause harm if you do not wash your hands and go and help another person. You can cause harm if with all good intentions if you speak the wrong words. So the training program is a must.

When groups get together and start functioning, we encourage them to form an organisation, initially informally, but then we encourage them to register as an independent charity. I think this is important. They should not be branches of my organization Pallium India; I believe they should have ownership of their own organisations. They should be able to take pride in what they do and have control over it. This is what the Astana declaration asks us to do. The Astana declaration asks all health care systems to give control and a role in strategy planning to the community as far as health care is concerned. The registration as a charity also brings in accountability. But then what do we do? We find that for several years they need hand-holding. For a long time we shall have to provide the service of professionals. Without that input, they cannot work. But eventually, there are many such organisations who themselves have employed doctors and nurses.

When we started something ten years back with eleven groups, two of them eventually employed doctors and nurses - full-time nurse and part-time doctor. And that's what they can do. But when they cannot get to that level, we assist them.

Over this last quarter of a century more than three hundred such organisations have evolved. More than two hundred of them are formally registered organisations. You must remember that in my world, that is my part of developing world that is one-sixth of the global population, primary care is minimal. We cannot expect to have what you can expect when you go to your hospital. So, in that context, say if that woman (picture) had a fractured femur, the hospital would do the surgery and send her out. No rehabilitation, no physiotherapy. If the volunteers had not have gone to her, we would not have seen her. (She did not have cancer. In a lot of places you have to have a particular disease to deserve palliative care.) Because the volunteers were involved and we were able to teach the volunteers how to help her, she learned to walk and now walks again. Actually now, she does her own tiny business. She makes brooms and goes around and sells them in her village.

The woman with advanced cancer living in that hut, (picture) was living in the porch because the three rooms were occupied by her three married children and their families. The volunteer, that young woman (picture), led us to her home. We found that she had had initial treatment for cancer, then she had to stop going for the cancer treatment, her disease was too advanced. We found that she didn't drink any water all through the day. She waits for late afternoon, because she cannot walk to the toilet. If she drinks, she has to go the toilet. So, she stopped drinking. In the evening, when the children and grandchildren come back from school, she starts drinking again. Now they can help her.

This kind of totally needless suffering could be avoided very easily. What the volunteer in the vicinity started doing was visiting her once daily. We visit only once a week, because we are traveling in different areas on different days. The volunteer would go there every day and visit. The volunteer organised a curtain which she could pull so that she could have some privacy. That curtain and a chair commode changed her life.

We further needed to give her morphine and treat her pain. But she was living again because of the volunteer. Of course, the volunteers and me together make sure that people like that would normally get their medicines free. And because palliative care is not only for the patient but also for the family, we do not forget the children.

One of the things that we have learned is that a serious disease in a family destroys generations. Children drop out of school, so their children also wouldn't have a good life. So our volunteers would make sure that no child would drop out of school because of catastrophic health expenditures of the family. Our volunteers together have started a program where almost three hundred children have their education supported in my city. And because the volunteers found that these children have very grey lives with all the disease and poverty in the family, everybody forgets to smile, the child never gets a hug anymore and there are no new clothes at school opening time et cetera, the volunteers organise a summer camp every year (picture). And all the high school kids are brought there; only the high school kids because the parents cannot come. And they have three days of fun, being together, exchanging mobile phone numbers, making friends and developing relationships.

The volunteers can take health care to heights that we professionals cannot. This (picture) was on world palliative care day which is on the second Saturday of October.

Our volunteers decided to give treat to people who were wheelchair-bound. Paraplegia in your countries may mean they learn to use a wheelchair to go to the super market and lead a normal life. Paraplegia in my country means that you are confined to four walls through the whole year. Their only outing is to the hospital. So, the volunteers decided to give a treat to everybody on a wheel chair, most of them with spinal cord injury. There were around forty people who wanted to come. That meant we needed one hundred and sixty volunteers. We needed four able-bodied men to pick up each person physically or carry them in a chair, carry them to a road that could be three hundred metres away, put them in a vehicle and drive them to the sea side. No problem. Two phone calls. Two phone calls to two engineering colleges made sure that one hundred and sixty young men got there, four went to one patient's home, and those four were the guardians of the patient for the whole day, with their family members. What does that mean? This was a once-in-a-lifetime experience for them. You see that girl in red and green, the second from this side (picture)? She is paraplegic; she does not have normal sensation in her legs. She said: "The waves touching my feet was the best experience that I have had in my whole life". This is health care, health being defined as physical, mental, social and spiritual well-being. That is the pinnacle of health care we professionals cannot achieve. We need human beings to do that. We professionals are too much of scientists.

The essential collaboration that has to evolve is the collaboration between the macro, the health care system, and volunteers. I am so glad to see that the ministry here was welcoming the volunteers, the professionals working with the volunteers. Astana declaration of 2018 asked to give control to the community. Let the volunteers also have a role in controlling the health care system, in strategising and in controlling. And I saw the same thing happening in Paris three days back, and this movement, I think, is going to transform health care to a health care of tomorrow - what it should be like.

But the relationship between governments and professionals on the one side and volunteers on the other is not easy. That means we professionals have to give up some of the power that we have. That also means that the volunteers who are full of good intentions also have to learn to work with the system. Systems are needed. They shouldn't be too restrictive, but you cannot work without systems. The volunteers have to accept and conform to a system which they have a part in creating. And this collaboration is essential.

Now, is this necessary only in primary care? The Astana declaration was mostly about primary care. I find that difficult to accept. Anywhere, this is necessary. I found about sixty volunteers working in the hospice in Paris. Why is there not an equal number in the hospitals? Where also is a lot of suffering? But then, the systems are more restrictive. The successful collaboration is something that has to evolve. Human beings are necessary to support human beings anywhere, not professional machines alone.

Could there be some problems in the volunteers' input into health care? Negative aspects of the social capital?

One of the things that we find in Kerala is that the professionals are sometimes turning away from palliative care; they feel palliative care is just for volunteers. They mistakenly believe they are not really needed. So, trivialisation of palliative care to only the psycho-social care and without the physical element is happening. This is something to be guarded against. We need the heart, but also need the brain.

The threat that social scientists are warning us about is the infiltration of vested interests. Palliative care becomes popular, volunteers' groups become popular, everybody sees that this is a nice thing. It may suit us in the next election, may be that is what the politician thinks. Infiltration of vested interests which may be political, or which may be religious which can be even harder to control - these are also potential threats to be guarded against. And we need to make sure that the volunteer is the not the most important person in the system. It has to continue to be the patient and the family.

The barriers that I expect are:

1. for professionals to give up the power that they have over hospitals and health care;
2. not enough public awareness.

The public doesn't know that they have a right to health care, proper health care; they don't know they have a role to perform in health care. So public awareness has to improve. Volunteers have to be willing to learn. This is a challenge sometimes. "Why, why do we need training to be compassionate?" They need to learn to listen, to talk less, just like us professionals, and they need to learn the fundamentals of health care also. Even if we do all that, without some ongoing mentoring by umbrella bodies - the EAPC or local organisations like Pallium India, small budding organizations will find it difficult to move forward. And of course, vested interest can destroy any new social innovative development. These are some of the barriers to be foreseen and to overcome.

Dr Richard Smith, former editor of the British Medical Journal, studying the Kerala model of palliative care, said: It does provide a feasible way of achieving Murray's vision (Dr. Scott Murray was at this EAPC meeting, giving a talk the other day), Murray's vision of palliative care covering all patients, all diseases, all nations, all settings, all dimensions.

Richard Smith also added: It is hard to see how else it will be achieved in another way.

What Richard Smith is saying is that without the volunteers' involvement, true health care for all patients, all diseases, all nations, all settings, all dimensions cannot be achieved.

And one suggestion that was brought in yesterday was that maybe all this is particularly relevant only to the developing world where primary care is very poor. I find that difficult to accept, because in western hospices I see something that I do not see in my country: so many lonely people. Oh, we are getting there also, we are also getting more civilised ... a lot of lonely people. They don't have to be lonely! There are lonely people in the hospices, there are lonely people out there in the villas outside who could get together, give companionship, and be together. I shall end with that message from that poet talking about people who are waiting forever in suffering, if not in pain then in the other symptom of loneliness. ("She waited..., Like a second ... suspended in time, Until her clock stopped ticking, For visitors who never came.") I have great admiration for what I have seen here. It was truly an enriching experience, and you are all so inspiring. I wish you all success in moving forward. What we do today is based on something that we learned from western medicine, and I hope we will be able to continue to learn from you.

Thank you so much.

> VOLUNTEERING IN PALLIATIVE CARE AND THE WIDER HEALTH SECTOR IN AFRICA

Fatia Kiyange, Uganda



Thank you for inviting me to this symposium. I thank the team who have organised this symposium, and I do sincerely thank the German Association for Palliative Medicine for inviting me to join you here today to share the African experience on this important topic. I also sincerely thank the Federal Ministry here, and also the ERSTE foundation that enabled the association to bring me here, to share the experience from Africa. I sincerely thank the EAPC Taskforce on Volunteering who have continuously involved us in the global movement and evolution of volunteering in hospice and palliative care.

I'm Fatia Kiyange and I work with the African Palliative Care Association. Our vision is that everyone in Africa who needs palliative care is able to access it, irrespective of where they are located, irrespective of their gender, irrespective of their socio-economic status. That's what we work for to achieve every day. We focus on creating awareness for palliative care, understanding of palliative care at different levels, at the policy level, at the health care provider level, at the community level and family level, also in academic institutions. We also work towards an integration of palliative care in mainstream health care systems. This is the only way we can sustain this discipline. So we do a lot to achieve that: development of policies, and supporting governments to do so. We focus on essential medicines for hospice and palliative care, and we do a lot to advocate for this working with governments, hospices and other institutions in different countries. We also support the development and implementation of hospice and palliative care education, and we work a lot with academic institutions as well. We also support quality improvement of service delivery, supporting hospitals to initiate and integrate palliative care services. We also promote palliative care research and evidence, which is very critical for influencing the policy makers, and also quality improvement.

So, largely, that is the focus of our work at the African Palliative Care Association.

I was invited to speak about volunteering in palliative care and the wider health sector in Africa. The focus of what I'm going to share is: a bit of background, the categories of volunteers in Africa, the models of volunteering in hospice and palliative care in Africa that we have, the added value that volunteers bring, challenges, opportunities and recommendations.

Hospices in Africa have done a tremendous job in terms of training volunteers and working with volunteers, and putting in place effective volunteer programs for their work. However, there are so many challenges currently, as you will hear, that we must work together to address. Of course, like any other continent, we've heard from India, caring for the sick is part of the African culture. Families do so much, the communities coming together to provide care for the sick and support their families. It's not new, it's part of the African culture. But as Dr Rajagopal mentioned, it's also starting to fade away. We are also becoming more civilised, so this very important value is being threatened right now. And of course, volunteering plays a big role in Africa because of the high burden of disease. As you may know, Africa has twelve percent of the global population, but we actually bear seventy percent of the burden of HIV and AIDS. So you can imagine. And we don't have enough trained professionals to meet the need for caring. There is high mortality, high morbidity rates, and this combined will accelerate the need for volunteerism on the continent. And I think we have, as Dr Rajagopal noted, a kind of volunteering that is more ad hoc, and informal.

We should be advocating for volunteering to become more formal in our governments. Because the Alma-Ata Declaration on the right to health care recognises the importance of community members in the provision of primary health care. And similar to the Astana Declaration they all speak about the role of communities. And that provides an important framework, a legal framework for us to formalize the role and the contribution of volunteers to our health care systems. And of course, the 2014 World Health Assembly resolution on palliative care also recognises the role of volunteers in the provision of hospice and palliative care services.

This gives us a very important global framework for us to promote volunteering in hospice and palliative care as a formal approach to service delivery and a formal contribution to health care systems. So we need to be advocating for volunteers to be recognised by health care systems because there are legal and policy frameworks that speak about their role. And of course, the World Health Organization has said so much and has written so much in all their documents and all their publications on volunteering being an integral part of palliative care teams. In Africa, of course, the human resources crisis in health care systems means that we desperately need well trained volunteers to support the professionals.

We have different categories of volunteers. We have professional volunteers, people who are professionals and have retired from their work and are giving time to hospices and palliative care programs. We do have very few indigenous people on our continent who actually do that. Even when people retire, they are still looking for survival, so there aren't many professionals that are giving their time to support hospice and palliative care work. The professional volunteers we commonly see actually come from the West, mainly from Europe, and the U.S.

Then we have the non-professional volunteers. These are the ones that Dr Rajagopal has been talking about. People from the community who are willing to support the provision of services. For today I will focus a lot on the non-professional community volunteers.

Then we have unpaid volunteers. And I am sure people are asking themselves, aren't all volunteers not paid? You will hear that actually some of the volunteers need to be paid for different reasons. And of course we do have paid volunteers.

We have different models of volunteers in hospice and palliative care and generally in the health sector. We do have volunteers that are being paid by the governments, for instance where I come from in Uganda we have a group of people at community level. They are called village health committees. They are actually associated with the government and are supporting the governmental in voluntary capacity and are not paid.

These are people who are well-trained at the community level to support households with health care issues.

Now, hospices and national palliative care associations have come in to train these government-linked volunteers, to give them the knowledge and the skills so that they include palliative care onto what they are already trained to do for the government. In some parts this is working well.

Then we have volunteer programs that are led by non-government organisations and civil society organisations, and this is where most hospice volunteers fall. The community volunteers are recruited and trained by hospice programs.

Then we have community-based volunteers that are linked to hospices and health facilities. These are largely volunteers in the community but linking and working together with hospices and health facilities. And do have a few site-based volunteers who come every day to the hospice and support patients within the hospices. And I've mentioned that we don't have many inpatient hospices in Africa because they are quite expensive. Except South Africa which has many of them, but in the rest of Africa the model that is commonly used is outpatient and home-based palliative care.

So, these volunteers would come to hospice, usually during day-care and support patients through the day, then return home.

Then we also have combined programs where as I mentioned government-led volunteers are also trained by NGOs and then include palliative care in what they provide. But we also have volunteers that are in disease-specific settings, for example, a tuberculosis program that has specifically trained some volunteers to just support compliance with the TB treatment. We also have volunteers with specific training for AIDS/HIV programs. So there are also disease and setting-specific volunteers in Africa.

Of course that complicates the formalisation and the structure for volunteers, and of course, we should recognise the importance and value addition that volunteers bring to health care.

Although it is mainly NGOs involved with volunteers I think it is very, very important that we advocate with governments to recognise the value addition from the work of volunteers. For instance, we have seen from India that volunteers are helping to facilitate the most vulnerable who wouldn't otherwise be reached by health care facilities to access services. Patients in remote areas can only be reached by the volunteers. And that's value addition, not just for us, but even for our governments, because it is their core responsibility to reach everybody with health services. Of course we do see that volunteers are reducing the work load of clinical teams. For Africa, I don't know what is happening everywhere, but most hospices are scaling down their services. Why? They are largely funded by donors. They are not supported financially by governments. Donor funding is going down each day, and most of them are scaling down.

Where I come from in Uganda, the largest hospice that has done extremely well for Uganda and the rest of Africa recently, two months ago, cut their staff by eighty percent. So what does that mean for patients? And it has a lot of implications also for volunteers. Volunteers are reducing work, but also we have to be careful, as Dr Rajagopal mentioned here, that the clinical staff, the professional staff, are now leaving their responsibilities to these volunteers.

They bring services close to patients and families and they spend more time with them, we've seen that from India. We also have to note that they contribute to national health and palliative care goals as a resource. So they actually save money even for governments. This is not documented, this is not researched. We know that they are saving governments' money, so their contribution should be recognised.

It is only through volunteers, that palliative care can reach the community at family level. We've seen that from India. Volunteers are also recognised by the WHO as a mechanism, an approach for engaging communities in health matters. We saw Dr Rajagopal presenting about the pregnant woman. Yes, volunteers are delivering palliative care, and are actually helping communities to participate in other health-related matters.

They are increasing community awareness in hospice and palliative care in many parts of Africa who don't know about hospice and palliative care, at all different levels.

Volunteers are helping a lot in terms of creating that awareness at family and community levels. And of course they are contributing to the uptake of services. Some people have been reluctant to take up hospice and palliative care services for many different reasons, and we see volunteers playing a key role to convince them to access services.

But there are so many challenges. We have individual, institutional and system-related challenges. At the individual level, some patients have no family care givers, even in Africa. What is happening is that it becomes the sole responsibility of the volunteers to look after these patients with no family care giver. And that's a huge burden placed on volunteers.

It is very common in Africa for volunteers to find patients with no food. Even patients on ARVs (antiretroviral treatment programs) – we know they must have good nutrition to be able to sustain and comply to ARVs – but many of them do not have the food. So volunteers have to face this challenge, don't have the means to provide nutrition, and yet they must help these patients to comply. They are facing overwhelming needs of the patients and their families.

And then patients prefer to go to traditional healers. This is very common. I was part of a team that visited a patient in Mozambique who preferred not go to the formal health care system but preferred to stay at home, and she had gone to see the traditional healers. And she was cut, everywhere, because they believe if they cut the body, the disease goes out. Her body was cut, she was comfortable at home, so if there are no volunteers who reach out to her she would never be reached by the health care providers.

It is very difficult for volunteers to convince such patients to actually go to health care facilities.

Some patients are too sick to walk to hospitals, and sometimes the hospitals are very far away; there are very long distances. The patients don't have transport to get there, and also the volunteers don't have the means and the transport to help the patients reach the hospitals. And that's a challenge. Also, the roads are bad in most of the places I am talking about.

Again, those are the patients that volunteers are seeing in the homes, very sick patients, not even willing to go the health facilities. Some of them have given up. Some of them are simply tired after having been everywhere and nobody had been helping them, so they prefer to stay in their homes.

Volunteers are therefore supporting the most vulnerable members of society. Poverty among the volunteers is a reality in Africa. So these people are volunteering but are not able to meet their own health needs.

What is happening now, which is different from eight years ago, the hospices used to support their volunteers if they got sick. Currently the hospices are all running on very thin budgets and have cut this support out. So, if a volunteer gets unwell you have no means to actually enable them to also access health care services. That is very difficult. It means that these volunteers expect some little facilitation from the hospices because they also have to meet their own needs.

Of course, they also have to look for a living, so then the time they give to a hospice is also a challenge. I talked about transport for volunteers and patients. The volunteers are trained to do all their best with the limited means they have.

At the institutional level (hospice level) activities of volunteers are mainly funded by donors, as I mentioned –they have proved not to be sustainable. The hospices are closing, for example in Zambia more than five hospices closed down, because they were supported by a donor which removed palliative care from their priorities. Most of the hospices closed down, others actually changed their direction and are only focusing on HIV/AIDS.

They are not taking in any other patients, because they are following the funding. The reduction of funding has led to the collapse of many volunteer programs, so the hospices are struggling to maintain their small clinical teams and they are letting go of these volunteers that have been trained, have a wealth of experience, but cannot sustain them.

There is a lack of supplies. Of course, some hospices are giving supplies such as the home care kit to the volunteers, but they can no longer afford to give this facilitation and the supplies. That is also a challenge at the institutional level. But also there is lack of standards and guidelines in terms of recruitment, role definition, motivation and capacity building of volunteers. Every health institution and hospice is doing it their own way. Then there is inadequate clinical staff to supervise and mentor volunteers.

At the health system level, there is no national data captured on volunteer contribution to services. We know they are contributing, but there is no data to quantify their contribution. That's really not helping health systems to consider the integration of the volunteer role in the mainstream systems.

Their contribution has remained very informal in most of the countries, apart from countries like Ethiopia that have made real serious steps, for formalising the role of volunteers and we see that they are doing very well in terms of primary health care. We have other countries like Zimbabwe, where the government is now considering being the coordinating body and in charge of volunteers. So we see more countries are coming up to learn from Ethiopia, but the role of volunteers has remained informal in most of the countries.

There isn't much investment in the work of volunteers at the national level and we need to be advocating for governments to invest in the role of volunteers. We are not asking them to pay them, but they can be facilitated to do this work well, they can be facilitated with guidelines and policies so that it's all part of the health systems, because they are contributing to meeting the national health goals.

There is no advocacy movement for volunteers in hospice and palliative care in Africa. This is something I'm learning more and more from Europe, this organization of volunteers, I think, is a lesson that needs to come to Africa. Everybody is doing it in their own way, and I think we just need to come together and use the collaborative opportunities to mobilise and have a strong volunteer movement for hospice and palliative care in Africa. I am assuming that the EAPC and all of you can support us to have a similar movement in the region.

Parallel volunteer programs I have mentioned, are both government and NGOs, they are competing. Some volunteers will move from hospices to go to another NGO because the other NGO has a lot of funding. They keep moving from one NGO to another, depending on where the funding is, which makes it difficult to sustain their role within hospices. And of course, there is inadequate research on activities of volunteers, and that means no data.

But of course we do have opportunities. For example, currently many governments are looking at re-engineering their primary health care. And we can advocate that the role of volunteers gets integrated into this re-engineering of programs. This is to sustain the role of volunteers, the good work and contribution in our nations.

Then, many nations are now developing plans and programs for Universal Health Coverage (UHC). Every government in Africa is now thinking how they can realise UHC. It's an opportunity for us to ensure that the volunteers are not left behind within UHC. New government programs are coming up on community health extension workers. I think it's very important to formalise the role of volunteers through new government programs that are focusing on primary health care.

Many governments in Africa are thinking about national health insurance schemes, and it's important that volunteers are not left out in these programs. There are also feasible and effective models for volunteering in hospices, also in countries such as Ethiopia, so we are not coming from zero. Countries can be supported to learn from other.

As a way of developing an active volunteer movement for hospice and palliative care, internal, regional and national conference such as the Sixth International African Palliative care conference which is normally presided by an African minister of health, can include deliberate sessions on volunteers.

We need to partner with you and everybody to advocate for the needs of volunteers within mainstream health systems. The more they are left to NGOs, the more they become very unsustainable. There is need to continue with advocacy for the formal recognition, planning and integration of the role of volunteers in hospice and palliative care by governments.

Governments need to acknowledge and recognise that volunteers are contributing significantly to achieving national health goals and give support to them. We need to develop champions who are volunteers in hospice and palliative care. I see in Europe you have achieved that. I think we can also mobilise and have some champions for this important issue.

We need more research and documentation of the contribution of volunteers to have evidence for governments that these volunteers are saving a lot of money. Then we need to advocate for the development and implementation of guidelines and standards, also in terms of ensuring patient safety. And then, of course, we need to continue building capacity and mentorship.

In terms of sustainability, the model from India, really getting communities to lead and to own initiatives for volunteers, could be another way to sustain the programs rather than hospices continuing to carry the burden to sustain them. I also think that we need to bring professionals in Africa on board, especially those who are retired. It's not their culture, they are reluctant to volunteer, but I think we need to mobilise professionals as well to come on board to volunteer in hospice and palliative care.

I'll leave you with these quotes from Mozambique, from volunteers.

"I appreciate the training on pain and palliative care. Now I know how to classify the level of pain using the pain ruler and know how to take care of palliative care patients. We also have a very good relationship with hospitals through our work with the hospital focal point person." Lidia, Palliative care volunteer, Mozambique

So again that's a volunteer, the link between the voluntary and the formal health system is very critical.

This is from a traditional healer in Mozambique:

"I do not do what I am not supposed to do. I got a patient last week with a problem in the private parts. I put him in my car and took him to hospital. I would like to sensitize other traditional healers in Africa so that they do the same as myself." Eve, a traditional healer trained on palliative care.

So even traditional healers can be trained and empowered to work closely with health care systems in Africa.

I thank you, and I'd like to invite you in September 2019 for that important 6th International African Palliative Care Conference in Kigali, Rwanda.

Thank you!

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**VOLUNTEERING/CIVIC ENGAGEMENT IN GERMANY,
GERMAN HOSPICE AND PALLIATIVE CARE
ASSOCIATION RESEARCH PROJECT**

Anja Schneider



As I had already announced earlier I was looking forward to the lectures of Fatia Kiyange from Uganda and M. R. Rajagopal from India, both were very moving. Many thanks again.

Dear colleagues, perhaps you have already had the opportunity to take a look at the poster exhibition. My lecture is about the presentation of some key results of the study „Volunteering and civic engagement in hospice work - characteristics, developments and future perspectives“. Here, directly at the entrance, you can see a poster where we present the study, and also give a short overview of the hospice development in Germany. Let's take a brief look at how hospice work in Germany developed before talking about the study.

It is thanks to the commitment of a large number of people that the first hospice initiatives were launched in Germany in the 1980s. Without a legal framework and above all without financial support, people looked for new ways of dealing with seriously ill and dying people and their relatives, who had not had a lobby before, especially in the then purely curative health care institutions. In 1995 a new law (§39a Social Code Book V) came into force, contributing to the institutional development of hospices as well as to the financing of voluntary hospice work.

In the last thirty years a lot has happened and today there are various kinds of palliative care and hospice services, which all have their basis in outpatient hospice services. There are inpatient hospices, there are hospitals with palliative care units and a steadily increasing number of hospital support. And now, nationwide, in early stages of establishment, day care hospices. We at the German Hospice and Palliative Care Association are very active in supporting these developments.

In Germany there are also the separate, but of course corresponding, I would probably rather say specialised inpatient, outpatient and home care services and facilities for children and adolescents.

I would like to illustrate this with a few figures, especially the number of outpatient hospice and palliative services in Germany has more than tripled since 1996. In the last ten years it has leveled off at around 1,500 outpatient hospice services. These 1,500 include approximately 150 hospice services for children and adolescents.

Of these 1,500 hospice services, about 900 are supported by the health insurance funds and 600 work purely on a voluntary basis. The latter are hospice services and initiatives that have decided not to have paid staff for coordination, but that do the same work in this form of organisation as the sponsored institutions.

The number of inpatient hospices and palliative care units, as you can see, also increased significantly between 1996 and the beginning of April 2016. Whereas in 1996 there were only 28 palliative care units and 30 inpatient hospices, today we have about 250 inpatient hospices and thus about an eightfold increase.

The first children's and youth hospice was opened in the city of Olpe in 1998. Today there are about 17 inpatient hospices specially equipped to meet the needs of children and young people with life-shortening illnesses. There are also palliative care units for children and adolescents in Germany, located at the three centres for palliative care for children, adolescents and young adults.

I also found this very interesting: A right to Specialist Palliative Home Care (SAPV) and its funding by statutory health insurance schemes was legally established in 2007. We have about 800,000 dying people in Germany every year. Referrals to SAPV are just under 120,000 p.a., which is quite an impressive figure. Although one must always bear in mind, of course, that this number is not equivalent to the number patients, because there may be multiple referrals per patient. But nevertheless, you can see there is a continuous and dynamic development.

The increase in physicians with the sub-specialty palliative medicine is also very encouraging, and since 2014 medical students who take their second state examination have had to provide binding proof of performance in pain and palliative medicine. For the mandatory tuition of palliative medicine at medical schools and the establishment of a sub-specialty, we had fought for a relatively long time, especially the German Association for Palliative Medicine.

The number of physicians with the sub-specialty palliative medicine, particularly among general practitioners, has risen continuously over the years and totaled 11,440 in 2017. So you can see that development is progressing continuously, and I think this is a very good sign.

Not only legislation and society are developing, but also DHPV. We started in 1992 as a Federal Working Group (BAG) Hospice, and the BAG was founded at that time by sixteen individuals and fifteen institutions. Today, the Hospiz- und PalliativVerband is the umbrella organisation of 25 supraregional hospice and palliative care associations and organisations and stands for over 1,200 hospice and palliative services and institutions in which more than 120,000 people are involved on a voluntary, civic and staff basis. That is an enormous number.

You have to imagine the organisation in such a way that we represent the regional associations as an umbrella organisation; this includes organisations of all sixteen states of Germany, individual members and supra-regional organisations, e.g. Malteser, TABEA, OMEGA.

Hospice work started over thirty years ago without financing and without a legal mandate. What does it look like today? Without going into the details of the individual laws again, here is a very brief overview of all the laws that have to do with hospice work and palliative care. Some were passed with the Act to improve hospice and palliative care, some lead to changes in already existing laws.

All these numerous changes, mostly improvements in the care of seriously ill and dying people, which this act has brought with it, lead to a very important question: Now that we have so many legal foundations, so many service providers, funding, and so many professional groups involved in the care of seriously ill and dying people, do we still need volunteers?

Yes, we do! And in quite different ways. In addition to medical and nursing care, the possibility of remaining in contact with other people than professionals in the health care sector, is of central importance for the dying. And here the volunteers bring a completely different approach: Time, being there, and above all empathy. I think most of you know exactly what I am talking about.

On the other hand, these people have an impact on society through their voluntary work - a very central aspect. Especially against the background of the ongoing discussions about euthanasia and assisted suicide, the volunteers stand for lived solidarity with seriously ill and dying people in our society.

There are quite different places and tasks involuntary hospice work, on the one hand of course in direct accompaniment, but also in public relations, bereavement support, administration, coordination and board work.

I now come to the volunteer study. Let me make it quite clear once again that voluntary work is the core of hospice and palliative work here in Germany. Please, keep that in mind. In order to take the new developments and changes into account and to be able to continue to inspire volunteers to accompany the dying and support the bereaved, DHPV has carried out a large collaborative study through its scientific advisory board. The picture you see here stands on the one hand for the focus of the study, to take a close look at where volunteering stands, how it is perceived. In a figurative sense, however, it is also an indication that we must initiate long-term development and shape the future of volunteering in hospice work if we do not want to have to look for volunteers with a magnifying glass at some point, as shown here.

What is the aim of the research? The development of a systematic empirical foundation for the further development of hospice practice and hospice culture with regard to the importance of volunteering and its history as a citizen movement. Key questions were how the commitment can be strengthened and how new forms of integration of volunteers engaged in the hospice sector can be guaranteed or improved. In addition, it should be clarified how the potential of people who are generally willing to volunteer can be achieved for the hospice movement.

Here are some original slides I brought. Basically 17 % of the population could imagine an engagement in the field of care for the dying, West Germans rather than East Germans (why, we don't know exactly), and women far more than men - this is probably based on tradition. Of these potential volunteers, significantly more would be willing to provide care at the dying person's home (70%) than, in particular, in a hospital (33%). However, many potential volunteers also face strong barriers to such involvement. Of course, the lack of time (45%) or incompatibility with requirements of their working life (29%) are at the top of the list. If all those are excluded who are potentially interested but affected by serious obstacles, the achievable potential is reduced to no more than 3% of the population. And that is too little. The most likely characteristics for potential involvement are: West German, female, persons in advanced stages of life, especially older single mothers, middle or working class, and people close to the church.

But who's volunteering today? The landscape of outpatient hospice services in Germany is essentially characterised as a female - no wonder - middle-class organisational practice, which is still predominantly carried out by women in the late employment or post-employment phase.

According to the coordinators we interviewed, on average the majority of volunteers across all services are female (ratio 6:1) and most are aged between 51 and 70 (education: secondary school, university of applied sciences entrance qualification, or Abitur). This means that hospice work is quite homogeneous - and that is also a problem.

This means: We need more heterogeneity and openness in voluntary practice. Much more than the previously committed can imagine an honorary post in the care of the dying. This potential needs to be further enhanced, including the importance of neighbourhoods and friendships, as well as opening up activities and opportunities for engagement to different population groups and social classes. In plain language this means: We need more men, we need more people with migration experience, and above all we need more young people in hospice and palliative care volunteering.

And that brings us to the head of our poster. When I say that we have to win more young volunteers, it doesn't mean that there aren't already some. In the current issue of *Bundeshospizanzeiger* [Federal Hospice Gazette], which you can see here, we have invited some projects by and for young people in hospice work and bereavement support to introduce themselves. I would like to emphasize the Malteser project of Dirk Blümke, which is a wonderful project, especially focused on the recruitment of young volunteers.

As already mentioned earlier, at the beginning of April we were able to meet almost a hundred impressive young volunteers up to the age of 30 at a joint event with the Federal Ministry of Family Affairs. „Letzte Wege begleiten. Mehr als ein Ehrenamt [Accompanying at the end of life. More than simple volunteering]“, Federal Minister for Family Affairs Dr Franziska Giffey honoured 95 young hospice and palliative care volunteers from work for their commitment.

The volunteers received certificates honouring their commitment as a reference of their acquired skills and commitment, that can be used for applying for trainings, a university place or a job.

It was a great event, with such impressive young people. We also felt that the Federal Ministry for Family Affairs clearly appreciated the commitment of volunteers.

Let me show you two quotes from young volunteers:

„I've always found working with people fascinating. You learn so much from encounters and shared moments. So it is all the more wonderful when you can spend time with people who often get the short end of stick to give them at least a little pleasure. We turn a blind eye to so many things and against many things one seems to be relatively powerless, but if you help at least with small things, it contributes to something „big“.“

That's amazing, considering that this is a person who probably doesn't have so much life experience yet - a very fascinating statement.

„I have developed a very great reverence for life. It is always touching when people put their trust in you. In addition I have made the resolution to live my life in such a way that I can let go when it's time. I want to make sure that my relationships with other people are open and honest, and that everything will be sorted out before it's too late.“

The DPHV would like to use this momentum, therefore we have organised two exchange meetings following this great event, because we see the young volunteers as experts in their own cause - and as shown in these quotes - whom we take very seriously as a source of ideas for the further development of hospice work. At these meetings with young people in particular, we also want to learn which topics are currently of interest for young volunteers in hospice work. How and where can young adults become active in hospice work? How should this topic be communicated to society and to young adults? And, of course, education must be appropriate for young people and the way they'd like to work.

For example, young people are project-oriented. Perhaps we will have to become more project-oriented? Young volunteers may not plan to stay with us forever, they take on certain tasks, and then they may leave again. That's where I think we need to adjust.

Thank you.



STORY OF MY VOLUNTEERING LIFE

Volunteers from four countries tell about their experiences.



Ms Prof. Dr. Monika Niedermayr, Austria
Ms Blazenka Eror, Croatia,
Ms Ewelina Legowska, Poland,
Mr Boldiszár Toth und Ms Orsolya Toth, Hungary
Facilitator Mag. Leena Pelttari MSc.

What do you do as a volunteer and what does it mean to you?

Monika Niedermayr:

I'm from Innsbruck. For seven years now I have been with Tiroler Hospizgemeinschaft. I started with tasks quite different from those of today. I used to have a puppy whom I trained for therapy work. Sadly, he passed away last year, but we have done many visits together. Meanwhile, I feel very connected with Hospizgemeinschaft. Once a week, fitting the stereotypical volunteer profile by being female and fifty something, I will visit the dementia ward on the fourth floor of a care home in Innsbruck. During my time as a volunteer I have been taking on more and more organisational tasks, probably due to my professional background as a lawyer working at the University of Innsbruck. For Hospizgemeinschaft, I also do some oral presentations on legal implications of end-of-life matters. What's important for dying patients and their family? How can they prepare for the end of life? Sometimes also discussions on whether or not they want or will need to prepare for the end of life because of their family situation. These are the issues of my volunteer work.

Also, together with two others, I am part of the body that organises and teaches at the last help courses, developed by Dr Bollig. Each year there will be five to six four-hour courses in rural areas. We'll introduce people to matters concerning the end of life and dying, including physical, psychological, mental and spiritual issues, and – to a great extent – bereavement.

Photos: Florian Willnauer

That's quite lot of volunteer work. How do you find enough time for your professional life?

Monika Niedermayr:

I have to allot my time carefully, and I must say I don't give it away easily. Therefore, I am very happy that the care home where I volunteer is only in two minutes walking distance from my home which is great.

Well, as we have heard, there's something like multi-tasking volunteering. Thank you.

Blazenka, you come from Croatia. Can you tell us a bit about your organization and what you do there? How is your volunteer career?

Blazenka Eror:

We are a non-governmental organization (NGO). We are helping palliative patients and their families by visiting them in their homes. In Croatia we have a few hospices, in Zagreb we don't have any. And so, our palliative patients have to stay at home or are living in care homes. We started to reorganize hospices to have a few beds for palliative patients, that's our strategy in Croatia.

For us, the main activity in our association is to help palliative patients to spend their last days of their life at home with their families. We employ a social worker, she coordinates volunteers and also provides help and assistance for patients and families concerning social issues.

Personally, I am an economist. It's not usual to have an economist in palliative care, I work in the finance industry, am a volunteer and president of our association. As president of our association, I have to undertake a lot of activities that are helpful for the survival of the association, such as management, administration, fundraising, and reporting - and also encouraging volunteers and others. We have 25 volunteers, mostly women, one or two men occasionally join us and then leave very quickly... I hope this will change. I can see men here in the audience, and I hope that we will find ways to encourage men to become volunteers in palliative care in Croatia.

I am also engaged in designing and implementation of projects and activities establishing cooperation and partnerships with other stakeholders in palliative care.

As NGO we want to cooperate with all professionals in palliative care in hospitals and in primary health care, promoting the needs of palliative patients. In Croatia, volunteering and civil engagement is not as developed as in other countries, therefore we have to promote volunteering. We have to collect money to pay the salaries of our employees and the expenditures we have. From time to time I am also involved in helping patients and their families, but mostly providing them with assistance in administrative and financial matters, as I am an economist.

Thank you so much. As we are saying in the Task Force, you are a board member and working in administration, and you are also working directly with the families. I think, that's a good combination as well. Thank you.

Now we have Ewelina Legowska. You come from Poland. What do you do as a volunteer there?

Ewelina Legowska:

Maybe I tell you from the beginning, because I have been a volunteer since I was seven years old, that's a long time, about twenty years, I am twenty-seven now.

My parents were building a day care facility for children in a small village near my home. I was just playing with the kids, after that I started to join school clubs. In 2011 my volunteer work as a leader of high school volunteer clubs was awarded by a foundation in Poland as one of greatest volunteers in 2011. In our country it's a very big competition when each year they will choose eight of the greatest young volunteers in our country.

I am a medical physicist and I am working as a teacher teaching physics. I am including a new kind of work for bereaved children. I am working for a hospice foundation in Gdansk, Poland. They are taking care of adults and also children. We are taking care of family caregivers. That's a new part of our work. We have a lot of hosts, and now we are focusing our work on bereavement. In my part, now as a PhD student thanks to my supervisor Ros Scott, I am including science as a new support for bereaved children. This is quite interesting because no one in Europe is doing it right now.

What else can I do in this hospice foundation? I am collecting money, for example, as a coordinator of a lot of actions in our town. I am also a medical volunteer, taking care of ill people during day care.

For me, it is not a hobby, it is a part of my life.

In my country, you know our Polish Pope Jon Paul II, the motto of our volunteering staff is: We are all like a treasure, we are all worthy, but we are as worthy as we are giving ourselves to other people.

Thanks a lot.

Thank you very much. Now we are getting new ideas about what we can do as volunteers.

I am very happy to have you here, and you are from Hungary. You are both working as volunteers, young volunteers as we can see – how old are you, Boldiszar?

Boldiszar Toth:

I am 16.

And you, Orsolya?

Orsolya Toth:

I am 18.

Can you tell us what you do as a volunteer and what it means to you?

Boldiszar Toth:

We, me and my sister, together with other volunteers, usually help out at public events and in preparation for these public events. We usually make gifts and cookies which we then sell at the event. Also we collect donations, hand out flyers, and help with anything else we are asked to do.

Orsolya Toth:

Actually, I am doing exactly what my brother does. We haven't been in direct contact with patients yet because of our age. But we have been doing this kind of voluntary work since we were very young. I love preparing for these events very much because I think this is so important to help other people in any way you can. It doesn't have to be directly.

In the future I want to help people, too. I'd like to become a psychologist or something. But if you can help people by collecting money or maybe just give them a smile, that's a really good thing too. So, in my opinion, you should do just anything to can to make people happier.

What does volunteering mean to you?

Boldiszar Toth:

Volunteering means a lot to me, because my mother also works a hospice, and I see her always working for this purpose. I know it's important to her, and I wanted to help out in her job.

Blazenka Eror:

Volunteering in palliative care has become my life, a big part of my life. It also helps me to grow as a person, think about priorities in life, and have a fulfilled life and a purpose.

Monika Niedermayr:

Every person I encounter offers me an opportunity to see a reflection of my own behavior and thinking. When I experience difficulties when meeting other people I know that's something I have to work on myself. So I will profit as much as the other person from these encounters. I think we need each other to become more human.

Thank you all for your great work in your country.

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**EAPC ATLAS OF PALLIATIVE CARE
IN EUROPE 2019 – VOLUNTEERING**

Carla Reigada



Thank you very much. It is a pleasure to be here. Life stories are powerful.

What I will be presenting here is the chapter on volunteers of the European Atlas of Palliative Care. It is the first time that the European Atlas presents this chapter on development of hospice and palliative care volunteers in 15 European countries. It was written together with Leena Pelttari, Lukas Radbruch, and Ros Scott. Thank you for your support.

We also would like to thank the other experts identified by the EAPC and national associations. Some of them are here today. This work wouldn't have been possible without your help, giving us all the data to make it possible.

This study includes information from 28 national experts and represents 15 countries. We sent a survey with 17 questions to at least two experts per country. The respondents were 28 national experts on volunteering in hospice and palliative care: Ten belonging to the EAPC Task force on volunteering, four from national/local hospice and palliative care volunteer associations, four with publications on volunteering. The remaining ten experts are palliative care professionals, representatives of hospice and palliative care associations, and academicians.

In the first step we identified the seven main indicators on volunteering:

- The number of volunteer hospices;
- The number of people involved as volunteers in hospice and palliative care services;
- Systems to track hospice and palliative care volunteers;
- Training programmes for volunteers;
- Funds;
- Compassionate communities;
- Formal representation in the national palliative care association.

The majority of the countries reported not to have data on the number of volunteers in hospice and palliative care. However, it is estimated that in Austria, Belgium, France, Germany, Italy, the Netherlands, Poland and UK there are over 1000 volunteers involved in hospice or palliative care provision (slide 5). The Czech Republic, Hungary, Portugal, Serbia and Armenia register lower numbers of volunteers (less than 500/country).

We also asked the experts about training programmes at national, regional, local and specific (care setting) levels. The response was that training is widely provided in Europe but may differ between countries with regard to the context/level of training. Almost all countries reported that they have mainly local, regional training. Usually, this training is performed by the local organisations.

Seven countries reported that they don't have any system to record the activities of volunteers. Experts from eight countries reported about such systems, but mainly on the level of the respective services. Volunteer activity is increasingly recognised as an important part of care, therefore we should promote systems to record volunteer activities. Society is changing and so is volunteering. There are new models, such as compassionate communities. This is a social movement to remind and prepare the society for the topic of end-of-life care and suffering. There are no compassionate community models in Belgium, the Czech Republic, Poland, Portugal, Romania, Serbia and Switzerland. Coming from Portugal myself, I can tell you that we will start working on compassionate communities.

There is some funding of volunteers, but not on the same level across countries.

European countries get funds mostly from donations (12 countries) or grants (9 countries). While Portugal and Belgium do not report receiving any type of funding to support volunteers' activities, countries like Austria, France, Germany, The Netherlands, the United Kingdom, Switzerland, and Czech Republic report that their respective government sponsors some of the volunteering activities or to train volunteers.

The EAPC Task Force on Volunteering in Hospice and Palliative Care, as you may know, has been working on the recognition and the development of volunteer activities. Our final message is to encourage everyone here – I know there are many coordinators in the audience – to continue this work, we need to start to register data covering the above mentioned indicators. We need to have formal data. There is no doubt about the value of volunteering, but we do need evidence too. We hope that in five years we will be able to present a beautiful chapter on volunteering in Europe with strong data.

You can download the EAPC Atlas from twitter, check out the EAPC blog.

Thank you very much.

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**HOW IS VOLUNTEERING CHANGING –
 OPPORTUNITIES AND CHALLENGES 2030**

Discussion with

Mirodrag Bogicevic from Serbia, Carla Reigada for Spain and Portugal, Anne Goossensen from the Netherlands, Leszek Pawlowski from Poland, Karl Bitschnau from Austria, Catherine Renard from France, Ros Scott for UK and Ireland, Steven Vanderstichelen for Belgium, Agnes Zana for Hungary, Chiara Caraffa from Italy, and Anja Schneider from Germany.

Facilitators: Leena Pelttari and Lukas Radbruch



Mirodrag Bogicevic



Dr. Carla Reigada



Prof. Dr. Anne Goossensen



Leszek Pawlowski, PhD



Dr. Karl Bitschnau



Catherine Renard



Dr. Ros Scott



Steven Vanderstichelen



Dr. Agnes Zana



Chiara F. R. Caraffa



Dr. rer. cur. Anja Schneider

We do have representatives from a large range of countries on the stage which is necessary to show the scope of volunteering in different countries. This also means we will not be able to ask everybody the same questions, but will pose different questions to different people. The first questions is on what the volunteering situation is in your country, because in previous research we found differences between north and south of Europe. We would like to start with Carla Reigada, asking about the situation in Portugal and in Spain.

Carla Reigada:
 We don't have a system to record volunteering in palliative care in Portugal. I cannot say how many volunteers we have. We don't have hospices, but do have palliative care units, acute palliative care units. But the volunteers come from other organisations, for example the Portuguese League Against Cancer. We try to train them for end-of-life issues, but there is few, we don't have a system implemented. We are starting now with compassionate communities in two cities. The national commission for palliative care of the government is now putting their strategy for volunteering in action. About Spain: Spain is a huge country, very complicated in terms of health care politics. Each community has their own laws. In some there are palliative care programmes considering volunteers and they will train their volunteers, but some communities have nothing.

Although the EAPC slogan is "one voice, one vision", unfortunately in practice we often noticed that there are some differences between the francophone and the anglophone areas, at least, and we often neglect the fact that there are large parts of Europe where English is not the first language.

So maybe, differences are related to cultural issues as well. Therefore, we'd like to ask Catherine Renard: What's the situation in France? And could you also please briefly introduce yourself?

Catherine Renard:
 The situation in France is quite comfortable, because volunteering has been addressed in the law for twenty years. A palliative care unit in a hospital must have a contract with volunteer services. Volunteers are there "to listen", that means to be there but not perform other tasks. This is great to some extent, but I think maybe it's time that volunteering in France could open up a little bit to helping with other tasks which may lead to an increasing recognition.

In Italy, what kind of challenges you do have, Chiara?

Chiara Caraffa:
 In Italy, volunteering in palliative care is tradition, because we have volunteering activities since 1986, that's more than thirty years. Our situation is that we have a second generation of volunteers, therefore we have different challenges than other countries. We would like to have just one programme. In 2010 the ministry of health together with the Italian society for palliative care defined a programme that is not used all over the country. Our challenge is to identify needs and to cover those needs in our country. You know that Italy is long and narrow, and people in different regions have different needs. Everyday life may differ extensively, people lead a different life in Milano where I live or, for example, in Sicily. We need to undertake a mapping and have just launched a survey to collect big data on what we are doing. In a few months, these data will be evaluated, and we let the Task Force know about the results.

We have more than 6,000 volunteers. We thought this was quite a good number, but after this morning we know we have to put more effort into recruiting volunteers, as this is quite a low number compared to Austria and Germany.

Well, you are doing a great job in Italy. There's the number of volunteers, but there's also the quality and the training. Thank you! Anne Goossensen, how do you see the challenges in the Netherlands?

Anne Goossensen:
 In the Netherlands we have been developing volunteering in hospice and palliative care since the 1980s. I have been studying this as a professor in volunteering. We do have a special kind of hospice, called "almost-at-home home". There is only one paid coordinator, and all the others are volunteers that are active in direct patient care. Sometimes eighty to one hundred volunteers are caring for people at the end life in hospices with four to beds. In the Netherlands we do have good training programmes, we actually have waiting lists for people who want to become volunteers, although this is decreasing a little bit. When we are talking about challenges – in the morning we heard about India and the challenges that are being faced there – I think part of the solution is opening up and sharing practices and stories. There is a lot of knowledge within our practices, but this is often only in our own language. We should open up and describe our practices and the stories, the narratives, in a precise and maybe scientific way, make them available across borders and

learn from each other, because although we all perform “being there” or “Da-sein” or “active listening” there are differences in doing so and we can learn from each other. We launched a little booklet today, one of our studies has been translated, you’ll find flyers here ... It’s about “being there” in the Netherlands with many quotations from volunteers.

Thank you, Anne. As mentioned, Anne is a professor for volunteering in hospice and palliative care which I think is unique, at least in Europe.

Ros, what do you think? I know you know a lot about the differences in the different countries being a co-chair of the task force and having published a book about this, but what are the challenges in the UK?

Ros Scott:
I think it’s a very exciting time for volunteering in the UK. I think it’s never been as high on hospices’ agendas as it is today, and partly that’s because we are seeing – like many other countries – huge increases in people who within an ageing population are going to need palliative care. And hospices are saying that the only way we can see to this and work towards this in the future is to involve more volunteers in doing this. Something exciting that is happening is that compassionate communities have inspired our hospice volunteering. I think we are seeing a move to more community programmes, slightly less formal approaches for volunteers who are working in the community, although as Dr Rajagopal said everybody needs to be properly selected and properly trained.

Challenges – well, volunteering is changing. The people of my generation or slightly beyond my generation, the pre-baby boomers and the baby boomers are becoming much, much older, and the younger generations have different expectations with different impact on their lives, more moves in different directions, and see volunteering quite differently. So we have to adapt and we have to change if we want to engage the future generations to support us.

Thank you. I really like it that the challenges sound like opportunities when you are talking about them. To take that idea forward, let’s not talk about challenges. So what are the new chances you see for volunteering I’d like to give that question first to Leszek Pawlowski from Poland.

Leszek Pawlowski:
It’s difficult to say. In May, we conducted a survey among hospice coordinators in Poland which 14 coordinators answered. They told us about difficulties in volunteering. The main difficulty is cope with death and dying (one third); the second is to maintain the volunteers in the organization because the frequent resignation from the volunteers is a real problem. One of the main problems is to recruit volunteers because some of the hospices don’t do anything to invite volunteers, they are waiting and volunteers are not coming. The hospices that are organising courses to promote volunteering are going to schools, to clubs or to other institutions, non-governmental organisations are trying to collect huge groups of volunteers.

In our survey we have organisations that co-operate with 2,000 volunteers, but also have organisations with only a few volunteers. So the situation of volunteering in Poland depends on the respective units. Volunteering is associated with organisations in the hospice sector, organisations with the most volunteers are hospices themselves. Organisations with training for volunteers have more volunteers than those who don’t offer training. Promotion of training programmes, opportunities to join the training programmes would be good opportunities to recruit new volunteers. Some volunteers stay for a long time, some for only a short time.

Being proactive, dissemination, information is the challenge, I think that’s become very clear, thank you very much. Karl, would you like to add something to this from Austria?

Karl Bitschnau:
Society should stay human. We just heard from India this morning that they have troubles getting pain killers in the amount needed, but people are also having other pains, because people don’t care for each other. The counterprogramme to that is volunteering. So the changes are exactly there, we need volunteering very, very much. That’s the chance for society, and it’s the chance for everybody who is volunteering to get something back, and these chances are very high. I did quite some volunteering myself, and I know that otherwise I wouldn’t do it. The third thing that has to be said is that it is a great chance for organisations.

Organisations without volunteers tend to be self-satisfied and don’t grow anymore, don’t take on real challenges. If you don’t keep an open mind you tend to become narrow-minded.

Volunteers will give you some solid ground to stand on. Thank you very much. Same question, new chances, Steven, what about Belgium?

Steven Vanderstichelen:
We’ve talked about this during the whole conference and during this morning in the lecture by Dr Rajagopal, it’s an issue of power, an issue of ownership. I think a great chance for volunteering is a move towards a more hybrid model of volunteering. Volunteering is no longer a model of ownership where volunteers only belong to the organisation which to some extent is limiting is what volunteers can do and are allowed to do, reducing them to a very narrow professionalised role. In order to preserve humanity and keep sustainable we think we should move to a model of partnership where health services and the entire society see volunteers as equal partners in care provision.

That’s a big opportunity, a big chance for our society to move forward in palliative care and in care in general. Another chance, or maybe a bit more of a challenge is our employment market and the health care system itself. It needs to evolve towards a systems where informal care in general, including volunteering is more valued. What I mean by that is that of course we value the human aspect but we tend to trivialize it or we ignore it because it is not fashionable, so we also devalue it.

What I mean is if they chose to take up care for a community member or a family member and give up their job, partly or entirely, they are suddenly invisible regarding the gross domestic product in their country. Their country doesn’t care, they don’t notice the value they are creating, because it doesn’t show in the figures. This is a very essential flaw in our health care systems and employment market. It’s a big challenge, and I don’t know how this can be solved quickly, but I think we need to work on that and find ways to value this informal care and human element in our care provision.

Thank you, Steven. The next question is to Agnes from Hungary: How do you see the future of volunteering?

Agnes Zana:
I hope there will be a lot of youth in the system. There is already a tendency towards this. Usually, volunteers come from those who have retired but now many high school and university students, nurses, medical students, and others are in the system. That’s a very good chance. For the future my hope is a new team culture where the volunteer will be a team member. I also hope there will also be more non-family caregivers, as in the Austrian model, for example the Kardinal König Haus in Vienna. We also hope that death and dying will be no longer taboo subjects in society.

Mijodrag, you come from Serbia. Can you tell us about your thoughts about the future of volunteering?

Mijodrag Bogicevic:
My opinion is that volunteering needs to be developed. We will have to change some models of volunteering and adopt them to the new generation. It is also our responsibility to make sure the new generation will understand the value of volunteering.

That's important for patients but also for volunteers because it will provide them with the opportunity for personal, social, emotional, and spiritual growth. We have different models in Europe, different training programmes, different activities in which volunteers are engaged.

We need to talk with each other, to share our experiences, to help each other and to help new initiatives and new activities on local levels. Of course, we need to understand that there are regional, cultural and local differences, but we need to support all different volunteer activities.

I agree totally. Anja, you were already talking to us about the situation in Germany. How do you see the future of volunteering?

Anja Schneider:
I have already said a few things about the development in Germany. We have a very comfortable situation in Germany and we represent all countries through the Federal Association, for which I am very grateful. I was talking about homogeneity earlier. It will be the challenge for us to achieve more heterogeneity, to see how we can develop. We will also have to see to it that, as in India, we move more into neighbourly structures, that the value of friendships will be included to a greater extent. There are already some models in different regions. As a federal association, we are also promoting similar curricula for training of volunteers. If someone is volunteering in Hamburg and moves to Munich, he must be able to continue working there without barriers because the training and qualifications are comparable.

Earlier, a lady rightly drew my attention to the fact that I was talking about the differences between East and West Germany, so I would like to take this opportunity to explain that this was meant as a reference to tradition. I myself come from East Germany, from Dessau just around the corner, so I know the situation. We started much later. I would like to apologize again for any inconvenience, it was not meant to be discriminatory.

I would also like to highlight another aspect, namely the focus on young volunteers. I have already mentioned that there are a number of initiatives in this area, but I would like to say once again that diversity is important. We do not only want to turn our attention to young people – we want them, and we want more of them, but we are also still interested in the older volunteers. Without them, we would be unable to go on with our work.

Thank you very much. Coming to the end of this round we would like to put one question to the whole panel which is: If you had one wish for a good development of volunteering what would you wish for?

Agnes, would you like to start and then pass on the mic?

Agnes Zana:
My first wish is for good fundraising, media and marketing support for multicenter charity associations in Hungary are very important. Also, the taboo of addressing death and dying in the community needs to be tackled.

Anja Schneider:
Ich denke, dass wir in Deutschland schon ganz gute soziale und gesetzliche Unterstützung haben. Was ich mir wünsche, ist Sprachfähigkeit. Die Menschen sind nicht sprachfähig, in den Familien ganz besonders. Die Familien unterhalten sich nicht über dieses Thema. Wir haben keine entsprechenden Worte, – auch wieder aus der Tradition her – uns fehlt das Wort. Auch da ist der Hospiz- und PalliativVerband auf dem Weg durch die Projekte „Hospiz macht Schule“ und „Hospiz lernen“ zu helfen, dass die Gesellschaft in Zukunft zu diesem Thema sprachfähig sein wird.

Steven Vanderstichelen:
To make use of the existing social networks and communities that exist, the general community but also the marginalised communities that often have very strong internal networks. They could be used and added for care provision, instead of being replaced or built on top of. We should move away from the paternalistic model towards a partnership model.

Karl Bitschnau:
I wish that for years to come there will be still enough men and women touched by the faith of dying people and ready to get involved, and to find structures to do what their heart will tell them to do.

Ros Scott: My dream for volunteering is to be fully recognized for its importance, to be recognized as a unique resource in its own right alongside family caregivers and professionals throughout the world.

Chiara Caraffa:
I would like to have enough volunteers for any person in need of volunteers.

Leszek Pawlowski:
In my opinion well-trained coordinators could improve the situation of hospice and palliative care volunteering.

Catherine Renard:
I am very proud to be part of this huge family and I think we all do the same with all our heart. Days like today are extremely inspiring and I am very happy to go back to France after this wonderful day.

Anne Goossensen:
My wish is to further clarify “being there” practices and explore boundaries. For example, in the Netherlands we are taking part in a European study with four other countries.

Carla Reigada:
I have two wishes: One is to have more data in five years' time, so, let's work on that. And I wish that all schools should have a palliative care campus and teach students about the importance of caring for each other.

Mijodrag Bogicevic:
I would like to wish every person facing serious illness to be able to live the rest of their lives with dignity, and of course, for all those who will need it, access to volunteer services.

Thank you all very much. I am sure that for the good fairy or whoever will be responsible to fulfill all these wishes, this will be quite a tough task. I can specially relate to the wish for young volunteers so that there will be someone young there for me when I will need them.

>
**VOICE OF VOLUNTEERING –
 EAPC MADRID CHARTER ON VOLUNTEERING
 IN HOSPICE AND PALLIATIVE CARE**

Leena Pelttari und Ros Scott



Leena Pelttari



Dr. Ros Scott

Leena Pelttari:

We have been talking about the charter many times today, and you can still sign it at the table of the German Hospice and Palliative Care Association. But what is this charter about?

When we started with the task force six years ago after a symposium on volunteering at the 15th EAPC World Congress in Prague we wanted to work on and have a charter that promotes the successful development of volunteering in Europe and maybe in the whole world. It is also important to recognise volunteering as the third resource, and many other things that have been written down in the charter have been mentioned today already. So actually we know we are on the right way because we hear it all the time. It took us about two years to complete the charter as it is, because we have been negotiating with many people from different countries.

What does “third resource” mean? Yesterday Steven Vanderstichelen presented their survey on volunteering, showing that volunteers have their own role. They are not part of the family and they are not part of the professional or the paid team; therefore they are called “third resource”. In promoting research and best practice models, I think we are getting better. At this congress there were very many talks about volunteering and also many posters on volunteering.

We have four main messages, and they are on

- sustainable hospice and palliative care,
- direct patient care,
- effective management,
- and effective support.

Volunteers play an important role in the total care of patients and their families. They are also helping organisations with fundraising and administration or in being board members and chairs.

But volunteers do not replace professionals or family carers! In Europe we don't want the volunteers to replace professionals, this may be different from Africa.

“Being there” for the patient and family is the core contribution of volunteering in direct patient care. This is very true in many countries already, but there are some countries in Europe which are just starting to build volunteering services on the concept of “being there”.

Volunteering also needs effective management with clearly defined policy on roles, careful recruitment, selection, training and development. We, of course, will also need sensitive collaboration between volunteers, family and professionals. This is vital for good quality and sustainable volunteer services in our countries. Also, national best practice guidance, training and quality programmes to support volunteering are necessary and needed in different European countries.

For effective support, funding is necessary for effective management, training, quality and for costs incurred by volunteers.

Volunteering should become an important area for research so that we know more about volunteering.

And it's not only that, it's also that we want to be on the same eye level with others. It not just that we want to know, it's also about recognition. We have been working on accurate data for each European country and we will need all your help. We also want to influence legislation and policy advocating for hospice and palliative care volunteering. For example we were told today that France has a law on volunteering in hospice and palliative care.

What did we do the last two years with this charter? I had the great pleasure to introduce it at the plenary session at the EAPC World Congress in Madrid. In the meantime, it has been translated into twelve languages with your help. We had some national launches, presentations at different conferences, we have been circulating it through networks. Avril Jackson from the EAPC has helped us with the social media. We had some blogs and used LinkedIn, Facebook, and Twitter.

Ros Scott:

Although it is still early in our work with the charter, so far we have 3,400 signatures both electronically and on paper from 50 countries, not only from Europe but throughout the world including Surinam, Mauritius, Qatar, Japan, South Africa and the USA. If you haven't had the time to sign it yet, please take a moment to do so. You've heard from Carla; we were so delighted to have been able to collaborate with the EAPC Atlas team towards the inclusion – for the first time – of a Chapter on Volunteering in the EAPC Atlas of Palliative Care

We've also been able to collaborate through a colleague, Anne Goosensen, in a European project focused on training for volunteers supporting people in hospital at the end of life. And because we are so committed to volunteering we have started our own small project to develop a minimum data set on hospice and palliative care volunteering. We also wanted to undertake a survey to assess the awareness and the impact of volunteering. The aims of this impact survey were to assess the awareness of charter, its reach and its impact, and its usefulness as an advocacy tool.

The study design was a mixed methods cross-sectional survey design, using an online survey containing closed and open-ended questions. It was sent to all 55 EAPC member organisations, other regional and national organisations providing palliative care and volunteer organisations involved in palliative care across Europe. The survey has been circulated through the EAPC Newsletter, EAPC Task Force contacts and social media platforms.

We received 64 responses from 11 countries, 56% (n=36) of which were from hospice and palliative care organisations, 14% (n=9) national organisations, and 30% (n=19) from individuals from hospice and palliative care teams.

In terms of awareness levels and use, 64% of respondents (n=41) had heard of charter, 26 out of 39 (67%) had not yet used it, but we were delighted about those who had.

We then asked the participants about the charter's role in advocacy and improvement. They told us it had a role in advocacy in three key ways: These were at European level, at government level, as well as at the national and local organisational level and in making global connections.

One respondent [from Austria] said: “The charter can be helpful in all discussions about financing – with governments and policies. It has more power in all public discussions.”

And in making improvements to the charter people suggested that we could have some specific descriptions of what is happening and happened in different countries to give examples if people want to think about what they might do. And people were very keen for us to continue with efforts on publicity to develop global awareness.

It was also suggested by one respondent that the charter could be used “(...) as a tool for creating national standards, by-laws and programmes, which will have to include volunteerism as an inseparable part of hospice and palliative care.” [Serbia]

The survey tells us that there is little room for complacency and much work still to be done in promoting the charter. It is striking, for example, that, although 72% of respondents had heard of the charter, many had not yet used it. The reasons for this are not clear - is this because respondents were mainly from countries with well-established volunteering culture and frameworks? Or is the opposite true: Is it because people do not recognise the importance of the charter because they do not have well-established volunteering programmes?

But are we being over-confident about volunteering? Not only palliative care is impacted upon by changing society and demographics; volunteering is also subject to this and so to ignore this is to leave our services open to risk...

So, finally, I would ask you: How are YOU using the charter in successful development of volunteering? How are you using it in recognising volunteering as a third resource? And how in promoting research and best practice models?

For example: Do you know how many volunteers you have in your organisation, your region and country? If you don't - why do we really need this data? Because without it we cannot plan and will have no evidence of how volunteering is changing, if there are any trends, if there are any possible shortages we might need to be aware of, shortages that may impact on services.

What impact do volunteers make in your organisation and your country? Do you need this evidence? Because how can we develop volunteering effectively without evidence to support practice?

And what about quality – how do we ensure that volunteers give the best quality of support to patients and families? Volunteers are motivated by and want to know what impact they make. They also want to know that they are working in the best way possible.

Volunteers are such an amazing and important resource – we owe it to them, to our patients and families to recognise their unique and important role. There is, therefore, still much for all of us to do in order to embed volunteering as a third resource, and this was very much the work of our task force as we move forward.

However, the charter is the result of a great deal of work by many people. We cannot thank all of them here but we would just like to say a huge thank you to

Philip Larkin, President EAPC 2014-2019; Julie Ling, CEO EAPC; Avril Jackson EAPC, the EAPC staff team - they have been a tremendous support to us and encouraging our work. We also like to thank our partners of the International Association of Palliative Care (IAHPC) and the World Hospice and Palliative Care Association (WHPCA); everyone who have contributed to the development, all those who have signed! And many thanks to the task force for its continued passion, commitment and belief in the importance of this work.

I'd also like to thank my colleague and co-chair Leena, we talk together a lot, the Skype line between Scotland and Austria burns hot. I don't think we would have gotten where we are without working with you.

But I just like to say too, that many of us here today are volunteers from different backgrounds – I volunteer myself -, different countries and involved in many different activities. I'd like you to think for a moment about a world without volunteers.

There is so much that would not happen. And in palliative care, what we've heard today and throughout the congress is, fewer and in some countries no people would receive palliative care; patients and their families would not benefit from the practical, social and emotional support that volunteers bring.

Volunteers truly are at the heart of hospice and palliative care. So we would like to end this presentation by asking you to recognise and thank all of you here today and Volunteers in hospice and palliative care everywhere no matter what they do ...

Thank you.

World Café

World Café



BIRGIT JASPERS



Dr. Birgit Jaspers

World Café is a format in which participants from different countries discuss specific topics and share their experiences in small groups formed according to their interests.

The participants were asked to choose a topic from the following:

- Training of Volunteers
- Training of Coordinators
- Quality Programs and Frameworks
- Changes in Volunteering
- “Being There”
- Volunteers and Society
- Future of Volunteering

For each topic, tables were prepared for discussions in English or German, where interested parties could meet. A moderator entered key points of the discussion and first results into a form - and after the end of the discussion the moderators presented their results and recommendations on stage to the audience.

A total of 10 discussion groups were formed.

Table 1: Training of volunteers/English

Group:
Participants from the Czech Republic, Germany, Hungary and the Netherlands

Discussion:
Mentorship by experienced volunteers

Results & Recommendations:
Experienced volunteers are needed for mentorship of volunteers and should be included in the development of training programmes

Table 2: Training of coordinators/English

Group:
Participants from Germany, Poland, Scotland/UK

Discussion:
Training for coordinators should include:

- General knowledge in hospice and palliative care
- Practice in coordinating
- Interprofessional communication between coordinators and trainers

Results & Recommendations:
A core curriculum (multi-professional, international and/or national) for training of coordinators is needed; there's also a need of training organisations for volunteers, and organisations may benefit from access to international trainers.

Table 3: Volunteers and Society/English

Group:
Participants from Croatia, Germany, Hungary, Italy and Spain

Discussion:
Social media should be used for recruitment of volunteers and making volunteering more visible in society

Barriers/challenges:

- Society does not want to talk about death and dying
- Parents of sick children are part of society and may find it difficult to speak about death

Facilitators:

- o Social media may reach out to persons with experience in palliative care, spiritual/religious persons,
- Grief can be the drive to start volunteering
- Promoting events
- Talking about life, not just death
- Talking about values
- Laws supporting volunteering

Results & Recommendations:

- Telling stories and talking about values is the key
- Cultural events may rise awareness of volunteering in hospice and palliative care
- Programmes for schools – we need different trainings for different target groups
- Send positive messages to society: It's not about death, it's about life
- Commitment and good leadership

Table 4: Future of Volunteering/English

Group:
Participants from France, Germany, the Netherlands and Scotland/UK

Discussion:

- In some countries there is a problem with volunteering at patient's homes
- People prefer to work in hospices or hospitals
- Roles of volunteers in the home setting are less clear
- We need more flexibility in order to find young volunteers
- We should use social media more and talk about volunteering in schools
- We should involve young people in shaping volunteerism
- People have less time for volunteering, have more demands on their time, bringing up their children, looking after elderly parents

Results & Recommendations:
We need a bottom-up approach – asking volunteers what they can and want to do for us
Stop trying to fit volunteers into our structures, our ways of working
We need to look more imaginatively into the virtual world, to think about opportunities for virtual volunteering – f.e. help with online training

Table 5: Quality Programmes and Frameworks /German

Group:
Participants from Austria, Germany and Uganda

Discussion:

- Voluntary work in hospital not known; hypothesis: subject matter is difficult
- Comparison of the situation with Africa
- Challenge: competition
- Clarification of tasks for voluntary work („only“ accompanying or also other tasks)
- How can many different professions/services act as „one team“?
- To whom does the patient „belong“?
- Building bridges
- Dealing with former volunteers

Results & Recommendations:
Proactive and structured networking between hospice services and institutions is needed to better meet patients' needs
We should not wait for this to happen by accident

Table 6: Being There /English

Group:
Participants from Austria, Belgium, France, Germany, Italy, Poland and Scotland/UK

Discussion:

- Being there is about listening, helping, dignity, human connection, has a personal element
- It is not reducing people to their diagnosis
- Challenges are: Facing your own mortality, difficult situations and ethical issues, dealing with silence and putting yourself last, learning to follow the patient's lead

Results & Recommendations:
Provide supervision, guidance and reflection: Volunteers should not work alone at the end of the day, should have some to turn to and reflect on difficult experiences
Don't avoid or escape the difficult questions patients may ask, but acknowledge their experience and explore what the patients wish to share, respect their view

**Table 7:
Being there /German**

Group:
Participants from Austria, France and Germany

- Discussion:*
- Attitude, emptying yourself - without prejudices
 - Challenge and opportunity
 - Wash hands before - as a ritual
 - Being there - the greatest miracle of this activity
 - Being there as a human being, in the moment, without past, without future
 - Attune to the breathing of the dying person

Results & Recommendations:
Being there – wonder and challenge

**Table 8:
Volunteers and Society/German**

Group:
Participants from Austria and Germany

- Discussion:*
Perception in society:
- Volunteering has the privilege of having time
 - Raise awareness/visibility in society
 - Society should be better informed
- What do we want?
- Improve regional awareness
 - Networking (the wheel does not have to be reinvented)
 - Transparency/visibility in the media (e.g. public media/TV)
 - Integrate umbrella organisations more closely into society/raise public awareness

Results & Recommendations:
Hospice and palliative care movement in 2030:
The man on the Clapham omnibus knows that „hospice“ is not about “spices”

**Table 9:
Training of volunteers/German**

Group:
Participants from Austria, Germany and Serbia

- Discussion:*
- Additional special training desirable
 - Self-reflection and self-awareness are important
 - Process-oriented training over several weeks enables the volunteers to get to know each other

Results & Recommendations:
Compulsory basic training, standardised at European level
We need some standardised programmes on a higher level, recognised by national and hospice organisations.
For example, if a volunteer from Austria wants to work in Germany, the volunteer should have some knowledge and skills that are needed everywhere in Europe
Specialised training for organisations with special needs can be built upon standardised programmes

**Table 10:
Quality Programs and Frameworks /German**

Group:
Participants from Austria and Germany

- Discussion:*
- How can we ensure quality without getting bogged down in regulations and standards?
- Our suggestions are:
- The core and heart of volunteering is trust and the relationship of the patient, their family and the volunteer
 - Whatever endangers trust, is not good for ensuring quality
 - None of us challenged that the team, coordination, training and supervision are necessary
 - If healthcare professionals also work on a voluntary basis, they do so with their human, not their professional specialisation

Results & Recommendations:
Assuring quality means doing everything to ensure that trust will grow and can remain
If you have standards, leave room for transgressing the standards

Closure

Lukas Radbruch

Thank you all very much.

It's always the balance between standardisation and openness – as we heard before. We need some kind of standards, but how can we adopt them to individual needs? When we talk to medical students and tell them: “You would need 80 hours of training within six months”, they won't do that. So, can we have less training for this group, is that feasible or does it hurt the principle of standardisation? I think, that's one of our challenges, isn't it?

A big applause for the moderators and participants of the groups! Thank you all for your contributions, and for presenting the results of your discussion and your recommendations.

I am really impressed. What I learned is that obviously there are two dimensions of what we are doing: One is somehow inwardly, which means that we should probably be more self-aware, think about our attitudes, take ourselves back, empty ourselves – we have to be very careful about a lot of things. The other dimension is more outwards towards society, and we have to make ourselves visible, show what volunteers are doing and what they can achieve.

We will try to follow up what we have done here, we will try to work with the messages that you have given us, put together a booklet about this symposium and make it available online. We hope we can give you back something that you all contributed to this symposium. Für den Abschluss darf ich jetzt an Leena Pelttari übergeben.



Lukas Radbruch



Leena Pelttari

Leena Pelttari

Finally, I would like to thank everyone very, very much for being here and for your contributions. For us as the EAPC Task Force, this is the capital with which we will work. Thank you all very much, and also for the voluntary work you do in your institutions and for our societies throughout Europe.

Thank you very much for coming. I think this has been a great day for all of us! We are going to think about everything we have heard here today, also in the European Task Force on Volunteering, and will discuss what kind of projects we may start, taking into account what you presented today.

Thank you so much, and have a good and safe trip back home!

Appendix Presentations

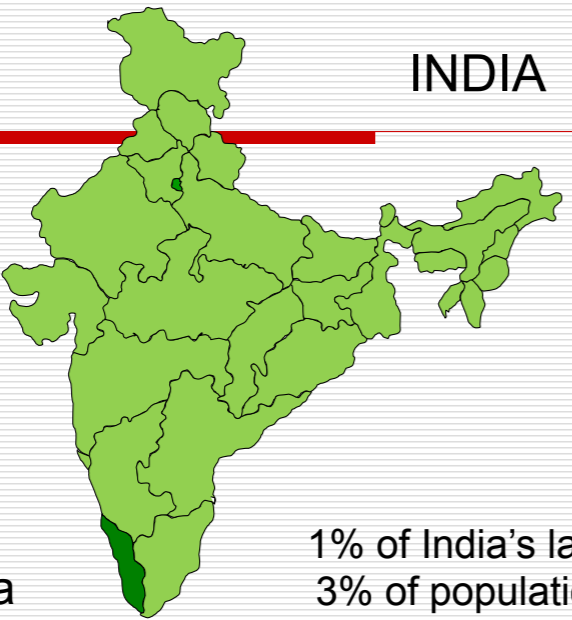
Healthcare **with** the people: Compassionate Communities in Kerala, India

M R Rajagopal
chairman@palliumindia.org

28.06.20

www.palliumindia.org





INDIA

Kerala

1% of India's land.
3% of population.

28.06.20 www.palliumindia.org **PALLIUM INDIA**


Tina, single parent, 37, mother of 2 teenage school-going girls

A volunteer says Tina has advanced cancer, Pain & bleeding PV. Lost medical records; so cancer centre is refusing to treat her.



28.06.20 www.palliumindia.org **PALLIUM INDIA**


Elements of health-related suffering



28.06.20 www.palliumindia.org **PALLIUM INDIA**

Tina, single parent, 37, mother of 2 teenage school-going girls

Our social worker finds her story inconsistent, lays a hand on her hand and says, "There is something that you are finding difficult to talk about. Tell me; let us help you."



28.06.20 www.palliumindia.org **PALLIUM INDIA**

Tina, single parent, 37, mother of 2 teenage school-going girls

What Tina had was a pregnancy; not cancer. She could not bear the thought of her girls finding out and being shamed.

Should the palliative care team treat her?



28.06.20

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The relevance of social capital



Micro



Macro

28.06.20

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Tina, single parent, 37, mother of 2 teenage school-going girls

She had bought poison to give to the girls and consume herself; but could not bring herself to kill the girls.



28.06.20

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The relevance of social capital



Micro



Meso



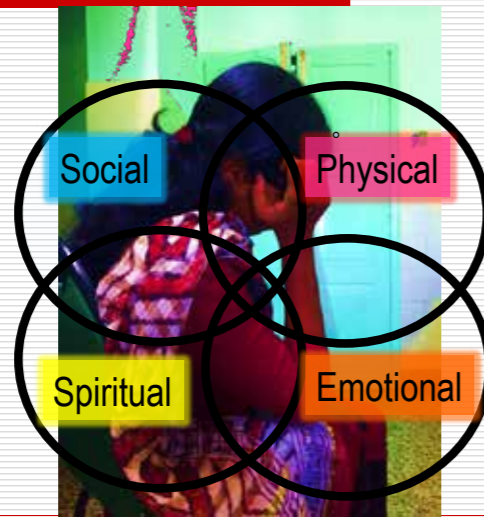
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Elements of health-related suffering



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PALLIUM INDIA
CARE BEYOND CLINIC

Facilitation of community involvement - the process

- Awareness program.
- Meeting of the interested.
- Volunteers' training program.
- Formation of an organization.
- Registration of the organization.
- Periodic review with umbrella organization.



28.06.20

www.palliumindia.org

PALLIUM INDIA
CARE BEYOND CLINIC

More than 300 community-based organizations in Kerala



28.06.20

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PALLIUM INDIA
CARE BEYOND CLINIC

Care reaches her in her home including free medicines



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PALLIUM INDIA
CARE BEYOND CLINIC

Support for children's education: Kids' Collective



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PALLIUM INDIA
CARE BEYOND CARE

The essential collaboration

- ❑ "Meso" element of the social capital
- ❑ Public -NGO partnership
- ❑ Integration of palliative care in tertiary centers -referral hospitals, Medical Colleges etcetera.

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PALLIUM INDIA
CARE BEYOND CARE

The elements of the social capital - volunteers



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PALLIUM INDIA
CARE BEYOND CARE

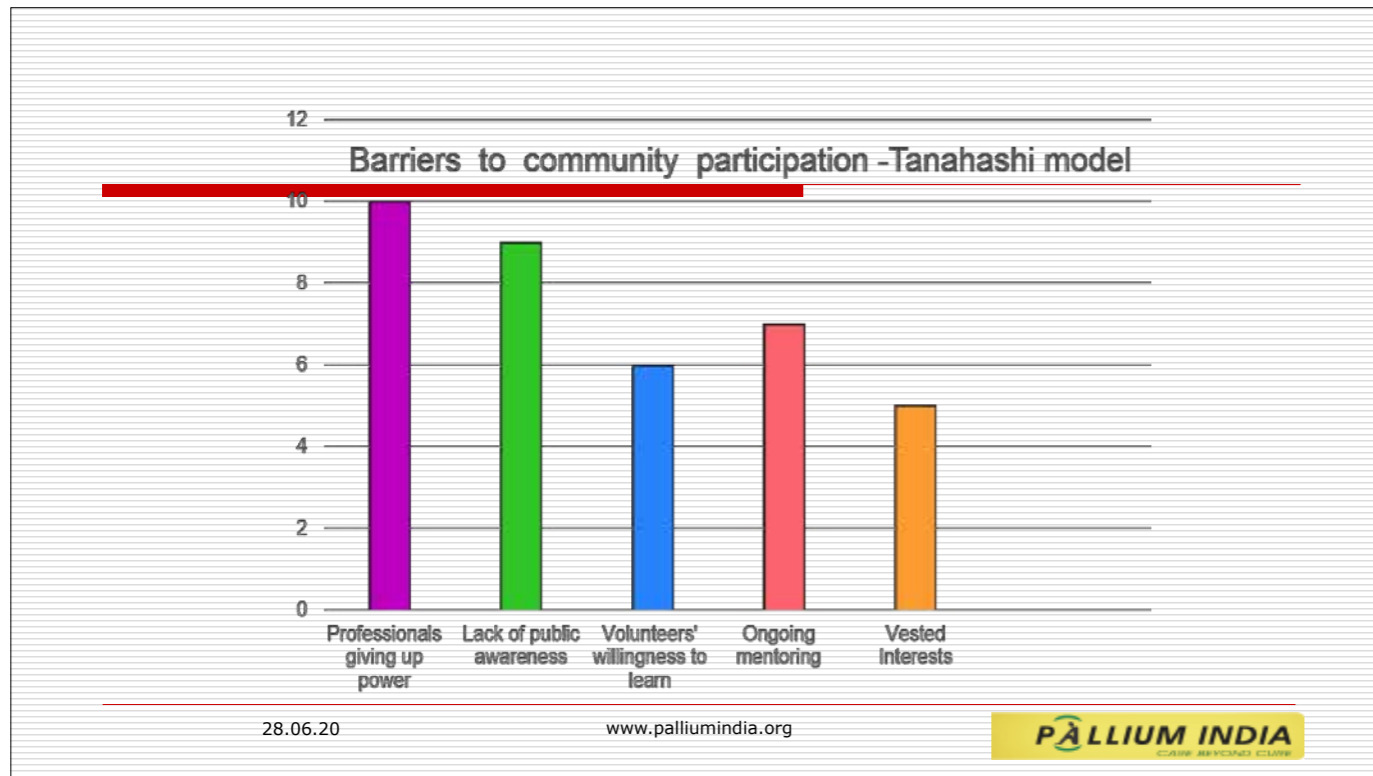
The negatives

- ❑ Routinization & trivialization of palliative care; we need both the science and compassion.
- ❑ Potential threat: vested interests in the community.

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PALLIUM INDIA
CARE BEYOND CARE



Is social capital relevant in high-income countries?

“She waited...,
Like a second
suspended in time
Until her clock stopped
ticking
For visitors who never
came.”



Frances Shani Parker <https://hospiceandnursinghomes.blogspot.com/2010/12/poem-about-loneliness-in-older-adults.html>

28.06.20 www.palliumindia.org **PALLIUM INDIA**
CARE BEYOND CURE

Richard Smith; The BMJ opinion

The Kerala model does provide a feasible way of achieving Murray's vision of palliative care covering "all patients, all diseases, all nations, all settings, and all dimensions." It's hard to see how it will be achieved in another way.



<https://blogs.bmj.com/bmj/2012/06/25/richard-smith-a-way-to-provide-palliative-care-globally/>

28.06.20 www.palliumindia.org **PALLIUM INDIA**
CARE BEYOND CURE

THANK YOU

28.06.20 www.palliumindia.org **PALLIUM INDIA**
CARE BEYOND CURE



**INTERNATIONAL SYMPOSIUM
“VOLUNTEERS AT THE HEART OF
HOSPICE AND PALLIATIVE CARE”
Opportunities and Challenges 2030**

**Volunteering in palliative care and the
wider health sector in Africa, 25th May
2019, Berlin**

Fatia Kiyange, Programmes Director, APCA
fatia.kiyange@africanpalliativecare.org

The presentation

- Background to volunteering in hospice & palliative care and health sector in Africa
- Categories of volunteers
- Models of volunteering in hospice & PC in Africa
- Value addition from the work of volunteers
- Challenges
- Opportunities
- Recommendations

Overview of volunteering in the health sector in Africa (I)

- Caring for the sick is traditionally part of African culture
- The high burden of disease, high mortality & mortality rates have accelerated the development of volunteerism on the continent.
- The Alma Ata Declaration recognizes the importance of community members in the provision of primary health care

Overview of volunteering in the health sector in Africa (2)

- The 2014 World Health Assembly resolution on PC recognizes the role of volunteers in the provision of hospice and PC services
- Volunteers are integral to PC teams & help address the human resources crisis in health care systems in Africa

Models of volunteering in Africa

- Government led
- NGO led
- Community based & linked to hospices or health facilities
- Site based
- Combines Government and NGO model
- Setting or disease specific volunteers

Categories of volunteers

- Professional volunteers
- Non-professional volunteers
- Unpaid volunteers
- Paid volunteers (stipend)

Value addition from the work of volunteers

- Facilitate the most vulnerable & remote patients to access PC services
- Reduce work load for the clinical teams
- Bring services close to patients and families and spend more time with them.
- Contribute to national health and PC goals as a resource – savings to Governments

Value addition from the work of volunteers

- PC service provision at the community and family level
- Volunteers delivering PC are central to the engagement of communities in health matters, a key recommendation of WHO
- Increase community awareness on hospice and PC
- Contributing to increased uptake of services



Trained volunteer in Mozambique leading patient care with support from Mozambique PC Association

Individual challenges for volunteers

- Some patients with no family care givers
- Patients with no food, even those on ARVs
- Patients preferring to go to traditional healers
- Patients are too sick to walk to the hospitals, which are sometimes too far, yet without transport to take them there



Trained volunteer in Mozambique leading patient care with support from Mozambique PC Association & Pain Without Borders (DSF).

Individual challenges for volunteers

- Poverty among the volunteers themselves – unable to meet their own needs & of their families – financial expectations
- Time commitment versus other responsibilities
- Transport challenges to reach patients – means, infrastructure etc
- Volunteers doing their best with the limited knowledge, skills and resources

Institutional challenges

- Activities of volunteers in hospices & PC programmes mainly funded by donors – not sustainable
- Reduction of funding leading to collapse of well developed volunteer programmes
- Lack of supplies – home care kit
- The lack of standards/guidelines – recruitment, role definition, motivation, capacity building etc
- Inadequate clinical staff to supervise & mentor volunteers

System related challenges

- No data captured on volunteer contribution to services
- Contribution has remained informal in most countries
- Not much investment in the work of volunteers at national level
- No advocacy movement for volunteers in Hospice and PC in Africa
- Parallel volunteer programs – Government & NGOs, leading to competition for resources & high attrition rates among volunteers
- Inadequate research on activities of volunteers

Opportunities

- Integration in efforts for re-engineering Primary Health Care
- Integration in plans and programmes for Universal Health Coverage
- New Government programmes e.g. Community Health extension workers
- National health insurance schemes
- There are feasible and effective models e.g. in Ethiopia providing lessons, and in hospices

Recommendations

- Partnership to advocate for the needs of volunteers within health systems
- Advocacy for the formal recognition, planning and integration of the role of volunteers in hospice and PC.
- Developing champions who are volunteers in hospice and PC
- More research and documentation of the contribution of volunteers to hospice and PC
- Advocating for the development and implementation of standards
- Capacity building & mentorship

Volunteers feel confident to undertake the provision of care and support to patients and families when well trained and supported:

“I appreciate the training on pain and palliative care. Now I know how to classify the level of pain using the pain ruler and know how to take care of palliative care patients. We also have a very good relationship with hospitals through our work with the hospital focal point person” Lidia, Palliative care volunteer, Mozambique

“I do not do what I am not supposed to do. I got a patient last week with a problem in the private parts. I put him in my car and took him to hospital. I would like to sensitize other traditional healers in Africa so that they do the same as myself.” Eve, a traditional healer trained on palliative care.

References

- Scott, R., & Howlett, S. (Eds.) (2018). The Changing Face of Volunteering in Hospice and Palliative Care: An International Perspective.
- Kiyange, F., (2015). Lessons learned from Mozambique’s model of community volunteers. Available from: https://ehospice.com/international_posts/lessons-learned-from-mozambiques-model-of-community-volunteers/
- Radbruch, L., Hesse, M., Pelttari, L., Scott. R., (2014) *The Full Range of Volunteering: Views on Palliative Care Volunteering from Seven Countries as Gathered in March 2014 in Bonn, Germany.*Bonn: Pallia MedVerlag
- World Health Assembly (May, 2014) Sixty-Seventh World Health Assembly. *Strengthening of palliative care as a component of comprehensive care throughout the life course.* [pdf] Available from: http://www.oeci.eu/Attachments%5CA67_R19-en.pdf
- World Health Organization (2008) *Summaries of Country Experiences on Primary Health Care Revitalization.* Report of the International Conference on Primary Health Care and Health Systems in Africa. Available from: <http://www.afro.who.int/en/health-policy-and-service-delivery/>

2019 Conference

6th International African
Palliative Care Conference

Palliative Care and
Universal Health Coverage

17-20 SEPTEMBER 2019

Kigali, RWANDA



HOSTED BY
African Palliative Care Association and the
Ministry of Health of the Republic of Rwanda



African Palliative Care Association

P.O.Box 72518

Kampala

Uganda

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+256 393 265 978

E: info@africanpalliativecare.org

W: www.africanpalliativecare.org

Stand und zukünftige Entwicklung der ehrenamtlichen Hospizarbeit in Deutschland

Dr. Anja Schneider
Stellv. Vorsitzende des Deutschen Hospiz- und PalliativVerbands e.V.

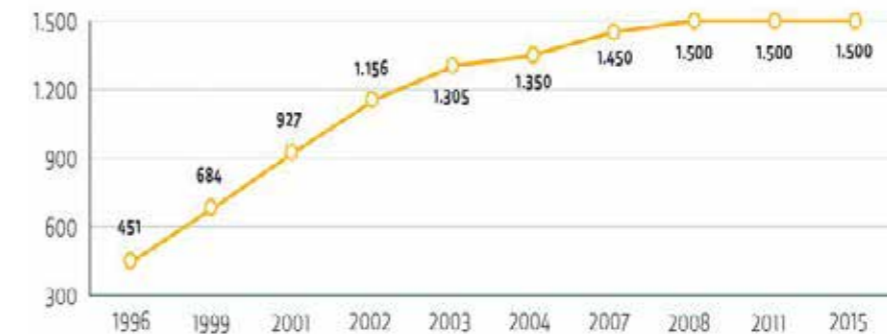
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Die Anfänge

- 1971 strahlt das ZDF den Film „Noch 16 Tage“ über das St. Christopher's Hospice in London aus
- 1983 Gründung der ersten Palliativstation an der Universitätsklinik Köln
- 1985 Gründung des ambulanten Christophorus Hospiz Vereins (CHV) München, des Hospizdienstes in Halle (Saale) und von OMEGA – mit dem Sterben leben e. V.
- 1986 Eröffnung der ersten stationären Hospize in Aachen und Recklinghausen
- 1990 Gründung des Deutschen Kinderhospizvereins e. V.
- 1991 Gründung des Bayerischen Hospiz- und Palliativverbandes e. V. als bundesweit erster Landesverband
- 1992 Gründung der BAG Hospiz, heute Deutscher Hospiz- und Palliativverband (DHPV), als bundesweite Interessenvertretung der Hospizbewegung sowie zahlreicher Hospiz- und Palliativeinrichtungen in Deutschland

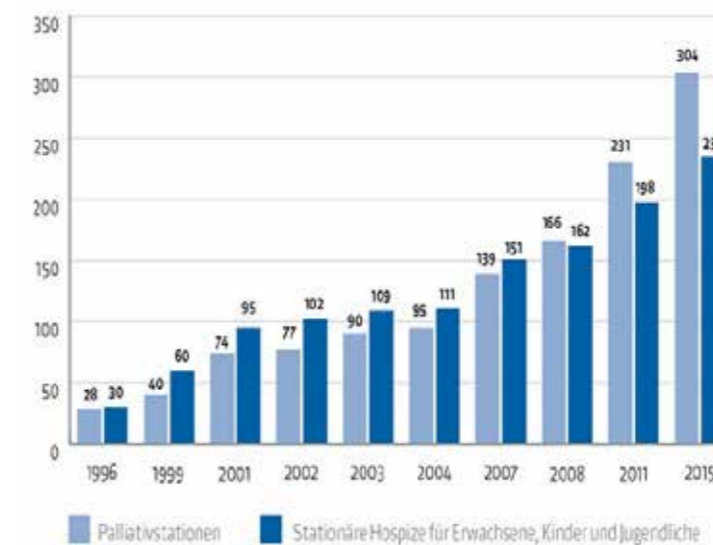
Die Entwicklung

Ambulante Hospiz- und Palliativdienste für Erwachsene sowie Kinder und Jugendliche



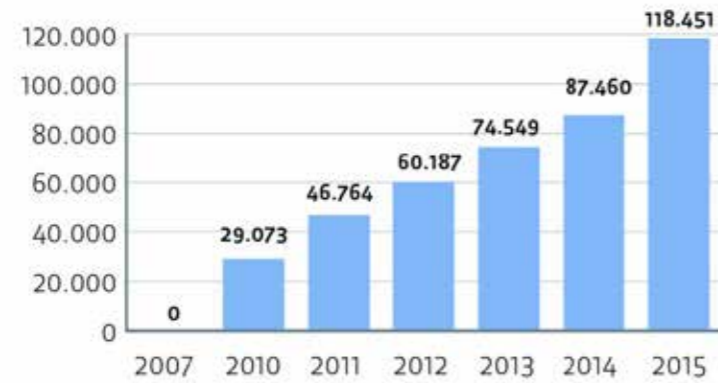
Quelle DHPV: https://www.dhpv.de/service_zahlen-fakten.html

Anzahl der stationären Hospize und Palliativstationen



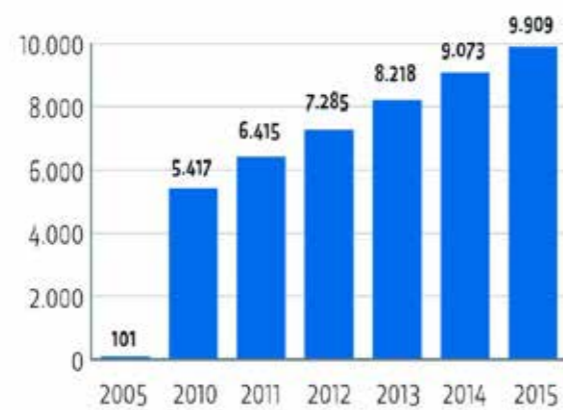
Quelle DHPV: https://www.dhpv.de/service_zahlen-fakten.html

Verordnungen SAPV (Spezialisierte ambulante Palliativversorgung)



Quelle DHPV: https://www.dhpv.de/service_zahlen-fakten.html (aus: www.gbe-bund.de)

Ärzte mit Zusatz-Ausbildung Palliativmedizin



Zahlen 2016: www.gbe-bund.de

Der Deutsche Hospiz- und Palliativverband e.V. (DHPV) ist seit über 25 Jahren die bundesweite Interessenvertretung der Hospizbewegung sowie zahlreicher Hospiz- und Palliativeinrichtungen in Deutschland. Unter seinem Dach engagieren sich heute in 1.200 Hospiz- und Palliativdiensten und -einrichtungen mehr als 120.000 Menschen für schwerstkranke und sterbende Menschen, die meisten davon ehrenamtlich.



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#199458174

Die Gesetzgebung heute

- § 39a Abs. 1 SGB V sowie Abs. 2 SGB V
- § 87 SGB V Bundesmantelvertrag / einheitlicher Bewertungsmaßstab (BQKPM)
- § 132d SGB V Spezialisierte ambulante Palliativversorgung
- § 37 Abs. 2a SGB V ambulante Palliativversorgung - APV
- § 27 SGB V Krankenbehandlung
- Krankenhausfinanzierungsgesetz und Krankenhausentgeltgesetz
- §28 SGB XI besagt Pflege schließt Sterbebegleitung mit ein
- § 114 SGB XI Verpflichtung zur Kooperation(-sverträgen) mit einem Hospiz- und Palliativnetz, Ärztenetz, Apotheken
- § 132 g SGB V Gesundheitliche Versorgungsplanung für die letzte Lebensphase

Bedeutung des Ehrenamtes in der / für die Hospizarbeit

Ehrenamtlich in der Hospiz- und Palliativarbeit Engagierte stehen für die gelebte Solidarität mit den schwerstkranken und sterbenden Menschen in unserer Gesellschaft.

Tätigkeitsfelder

- Begleitung Schwerstkranker und Sterbender sowie der An- und Zugehörigen
- Trauerbegleitung
- Öffentlichkeitsarbeit
- Vorstandsarbeit
- Verwaltung
- Koordinationsaufgaben

...

Einsatzorte / Aufgaben von EA in der Hospizarbeit

Der überwiegende Teil der ehrenamtlichen Mitarbeiter*innen ist in ambulanten Hospizeinrichtungen tätig. Weitere mögliche Tätigkeitsfelder sind stationäre Hospize, Krankenhäuser, Einrichtungen der Alten- und Eingliederungshilfe und weitere Lebensorte.



Studie „Ehrenamtlichkeit und Bürgerschaftliches Engagement in der Hospizarbeit – Merkmale, Entwicklungen und Zukunftsperspektiven“.

gefördert vom Deutschen Hospiz- und Palliativverband (DHPV), Leitung: Prof. Dr. Werner Schneider (Augsburg), Prof. Dr. Dr. Reimer Gronemeyer (Gießen), Prof. Mag. Dr. Andreas Heller (Wien), Prof. Dr. Thomas Klie (Freiburg)

Ziele der Forschung

Erarbeitung eines systematischen empirischen Fundaments für die

Weiterentwicklung der Hospizpraxis und Hospizkultur hinsichtlich der
Bedeutung von Ehrenamtlichkeit und mit Blick auf ihren Charakter als
Bürgerbewegung.

(Er-)Klärungen

- Wie kann das Engagement gestärkt und neue Formen von Assoziation der im Hospizbereich engagierten Ehrenamtlichen gewährleistet bzw. verbessert werden?
- Wie kann das Potential von Menschen, die generell zu freiwilligem Engagement bereit wären, für die Hospizbewegung erreicht werden?

Ein Sechstel der Bevölkerung könnte sich ein Engagement in der Sterbebegleitung vorstellen

Frage: "Einmal unabhängig davon, ob das Ihre jetzige Lebenssituation zulässt oder nicht: Können Sie sich grundsätzlich vorstellen, ehrenamtlich in der Sterbebegleitung tätig zu sein, oder tun Sie das bereits, oder können Sie sich das nicht vorstellen?"



Bas: Bundesrepublik Deutschland, Bevölkerung ab 18 Jahre
Quelle: Altersbooster Active, ID-Umfrage 11382, Februar 2018

© IFO Altbach

Profil der HospizhelferInnen

- nach Einschätzung der KoordinatorInnen mehrheitlich weiblich (Verhältnis 6:1)
- Alter zwischen 51 und 70 Jahren
- meistens mit Realschulabschluss (Mw. 38 %) oder Fachhochschulreife bzw. Abitur (Mw. 22 %) – niemand ohne Schulabschluss; Hauptschulabschlüsse und Hochschulabschlüsse nur selten

Fazit

Wir brauchen mehr Heterogenität und Offenheit in der ehrenamtlichen Praxis sowie in der hospizlichen Organisationskultur und -struktur. Für eine zukunftsfähige Hospizarbeit muss der Wandel hin zu einem ‚neuen‘, d. h. bunteren, vielfältigeren und flexibleren Ehrenamt voran gebracht werden.



Beispiel: Junges Ehrenamt



- „Junge Menschen in der Sterbe- und Trauerbegleitung: interessieren – stärken – beteiligen“, Malteser Hilfsdienst e.V.
- Trauerchats doch-etwas-bleibt.de, Hospiz Bedburg-Bergheim e.V., www.doch-etwas-bleibt.de
- da-sein.de | Die kostenlose Jugend-Onlineberatung für trauernde und sterbende Jugendliche - Stiftung Hospizdienst Oldenburg, www.da-sein.de



(c) Trutschel/photothek / BMFSFJ

Ich fand schon immer die Zusammenarbeit mit Menschen faszinierend. Man lernt so viel aus Begegnungen und gemeinsamen Momenten. Umso schöner ist es, wenn man die Zeit dann noch mit Menschen, die oftmals zu kurz kommen, verbringen kann, um ihnen zumindest eine kleine Freude zu bereiten. Es wird so viel weggeschaut in unserer Welt und gegen vieles scheint man relativ machtlos zu sein, aber wenn man zumindest in kleinen Dingen hilft, trägt das zu etwas „Großem“ bei.

Natalie Neumann, Ehrenamtliche im Kinderhospiz Regenbogenland in Düsseldorf

Ich habe eine sehr große Ehrfurcht vor dem Leben entwickelt. Es ist immer wieder berührend, das große Vertrauen zu spüren, das einem in den verschiedenen Situationen geschenkt wird. Außerdem habe ich für mich den Vorsatz gefasst, dass ich mein Leben so leben möchte, dass ich selbst einmal gut loslassen kann. Ich möchte mich darum bemühen, dass meine Beziehungen zu anderen Menschen offen und ehrlich sind und ich nicht noch etwas klären muss, wenn es möglicherweise schon zu spät ist.

Jakob Kamin, Hospizbewegung Münster e.V.

Dr. Anja Schneider
Stellv. Vorsitzende des DHPV
Geschäftsführerin
Anhaltische Hospiz- und
Palliativgesellschaft gGmbH Ein
E-Mail: anja.schneider@ediacon.de
oder a.schneider@dhpv.de



VOLUNTEERING in the EAPC ATLAS 2019

Sat, 25th May 2019 | 10.00 am – 5.00 pm
Estrel Congress Center, Berlin
INTERNATIONAL SYMPOSIUM
"VOLUNTEERS AT THE HEART OF
HOSPICE AND PALLIATIVE CARE"
Opportunities and Challenges 2030

Carla Reigada, LcSW, MSc, PhD
@ATLANTESPC
Institute for Culture and Society
University of Navarra (Spain)



Chapter 8 Development of Volunteering in Hospice and Palliative Care in 15 European Countries

Authors
Carla Reigada
Leena Pelttari
Lukas Radbruch
Ros Scott

NATIONAL EXPERTS COLLABORATING IN THIS CHAPTER

Armenia (Avetis Babakanyan), Austria (Leena Pelttari), Belgium (Karin Van Beek Staven Vanderstichelen, Suzy Van Ende Suzy), Czech Republic (Markéta Novotná), France (Renard Catherine), Germany (Lukas Radbruch), Hungary (Agnés Zana, Judit Schaffer, Miklos Lukacs), Italy (Stefania Bastianello), Poland (Piotr Krakowiak, Leszek Pawlowski), Portugal (Maria Teresa Flor-de-Lima), Romania (Beatrice Paring, confidential), Serbia (Miodrag Bogicevic, Katarina Sivčević), Switzerland (Sylvette Delaloye, confidential), The Netherlands (Anna Goossensen, Marianne Boone and Fleur Imming), United Kingdom (Ros Scott).

29/08/2019

Methods

- Interviews - EAPC Task Force leaders on paediatrics, long-term care facilities, primary care, volunteering, public health and cardiology.
- On-line surveys - to qualified national experts in their field (54 countries)

Additional databases on opioids (International Narcotic Control Board), professional activity (EAPC databases), and PC integration into oncology (ESMO databases, ClinicalTrials.gov and Scopus) were consulted

Development of Volunteering in HPC in 15 European Countries

17 questions - 7 main indicators on Volunteering

1. Number of volunteer hospices
2. People involved as volunteers in HPC services
3. Systems to track PC volunteers
4. Training programmes for volunteers
5. Funds
6. Compassionate communities
7. Formal representation in the national PC association

Data collection: 12/2018 to 3/2019 (4 months)

2

29/08/2019

Development of Volunteering in HPC in 15 European Countries

COUNTRY	VOLUNTEERS HOSPICES ORGANISATIONS	VOLUNTEERS	ANY TRAINING PROGRAMMES (OR CURRICULA) FOR VOLUNTEERS		ANY DATA COLLECTION SYSTEMS TO TRACK VOLUNTEERS ACTIVITY	
			YES	N/S	YES	NO
Armenia	0	0-10	○	○	○	○
Austria	184	>1000	●	○	●	○
Belgium	84	>1000	●	○	○	○
Czech Republic	12	100-500	●	○	●	○
France	NA	>1000	●	○	○	○
Germany	1316	>1000	●	○	○	○
Hungary	5	100-500	●	○	○	○
Italy	NA	>1000	●	○	○	○
Poland	20	>1000	●	○	●	○
Portugal	NA	100-500	●	○	○	○
Romania	NA	500-1000	●	○	○	○
Serbia	1	100-500	●	○	●	○
Switzerland	30	500-1000	●	○	○	○
The Netherlands	91	>1000	●	○	●	○
United Kingdom	NA	>1000	●	○	●	○

N/A: Not Accurate.
N/S: Not stated.

Development of Volunteering in HPC in 15 European Countries

"Volunteering in palliative care in France is part of the June 1999 Palliative Care law. This is the only volunteering registered by law which defines the model of volunteering in palliative care." (France)

"Hospice Austria conducts a yearly data collection for all hospices and Palliative Care services in Austria including volunteer hospice teams both for adults and children." (Austria)

"There is a good understanding for the need and importance of volunteers in Palliative Care among Palliative Care specialists in Armenia." (Armenia)

3

29/08/2019

Development of Volunteering in HPC in 15 European Countries

COUNTRY	COMPASSIONATE COMMUNITIES			VOLUNTEERS REPRESENTATION IN THE NATIONAL PC ASSOCIATION		GOVERNMENT FUNDING FOR PC VOLUNTEERING ACTIVITIES	
	YES	NO	N/A	YES	NO	YES	N/S
Armenia	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Austria	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Belgium	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Czech Republic	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
France	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Germany	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Hungary	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Italy	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Poland	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Portugal	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Romania	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Serbia	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Switzerland	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
The Netherlands	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
United Kingdom	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>

Development of Volunteering in HPC in 15 European Countries



“In UK, volunteering within hospices and Palliative Care services is funded by the services themselves. This would mainly be through charitable fundraising.” (United Kingdom)

“The volunteer service run by our department has also three part-time coordinators and around 60 volunteers. The volunteer services also do a lot of bereavement work, offering counselling, bereavement groups and cafes and other activities.” (Volunteering hospices model: an example from Germany)

29/08/2019

Development of Volunteering in HPC in 15 European Countries



1. Number of volunteer hospices
2. People involved as volunteers in HPC services
3. Systems to track PC volunteers
4. Training programmes for volunteers
5. Funds
6. Compassionate communities
7. Formal representation in the national PC association

Data collection: 12/2018 to 3/2019 (4 months)



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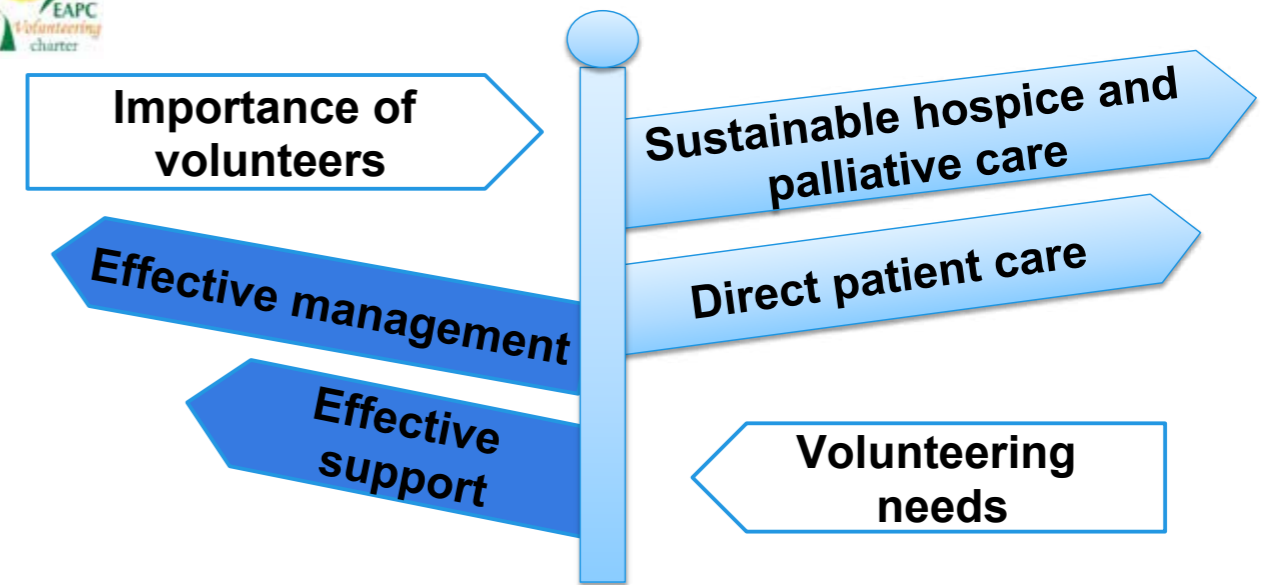
creigada@unav.es





Impact of 'Voice of Volunteering' EAPC Madrid Charter on Volunteering

Dr. Ros Scott, Mag. Leena Pelttari MSc
Co-Chairs EAPC Task Force on Volunteering



Please sign now! <http://bit.ly/EAPCVolunteeringCharter>



Charter Aims

- To promote successful development of volunteering
- To recognise volunteering as a third resource
- To promote research and best practice models

Please sign now! <http://bit.ly/EAPCVolunteeringCharter>



Key Message 1

Importance of volunteers:

Sustainable Hospice and Palliative Care

- Volunteers play important role in the total care of patients and their families and in
- Organisation of hospice and palliative care services

Please sign now! <http://bit.ly/EAPCVolunteeringCharter>



Key Message 2

Importance of volunteers: Direct patient care

- Volunteers have their own role
- They do not replace professionals or family carers!
- ‘Being there’ for the patient and family is the core contribution of volunteering in direct patient care.

Please sign now! <http://bit.ly/EAPCVolunteeringCharter>



Key Message 3

Volunteers need: Effective Management

- With clearly defined policy on roles, careful recruitment, selection, training and development.
- Sensitive collaboration between volunteers, family and professionals - Vital for good quality and sustainable volunteer services.
- National best practice guidance, training and quality programmes to support volunteering are needed in every European country.



Key Message 4

Volunteers need: Effective Support

- Funding necessary for effective management, training, quality and for costs incurred by volunteers
- Important area for research - evaluate the impact of volunteering
- Accurate data for each European country
- Influence legislation and policy advocating for hospice and palliative care volunteering.



Charter promotion

- Translation into 12 languages
- National launches
- Presentations: national/international conferences
- Circulation to networks
- Social media – blogs, LinkedIn, Facebook, Twitter





Outcomes



- Over 3,000 signatures (electronic and paper) from 50 countries
- Chapter on Volunteering in EAPC Atlas
- Collaborating - volunteer training research
- 'Minimum data set' project on HPC volunteering
- Survey to assess awareness and impact



Impact Survey

Aims

To explore:

- Awareness of Charter, reach and impact on volunteering
- Usefulness as an advocacy tool

Method

- Mixed methods survey - online questionnaire
- Sample population
 - 55 EAPC member organisations
 - Other regional and national HPC organisations
 - HPC Volunteer organisations across Europe



Results



- 64 responses, 11 countries
- 56% (n=36) HPC organisations
- 14% (n=9) national organisations
- 30% (n=19) individuals from HPC teams
- Awareness levels and use
 - 64% (n=41) heard of Charter
 - 14 out of 47 (30%) had used it



Advocacy and Improvement

Role in advocacy

- At EU and Government level
- At the national and local HPC organisational level
- Making global connections

Improvement

- Detailed international descriptions and examples
- Publicity to develop global awareness



How are YOU using the Charter

- In successful development of volunteering?
- In recognising volunteering as a third resource?
- In promoting research and best practice models?

Volunteering needs YOUR support and action

Please sign today at: <http://bit.ly/EAPCVolunteeringCharter>



Thank you...

- Philip Larkin, President EAPC
- Julie Ling, CEO EAPC
- Avril Jackson EAPC, EAPC staff team
- IAHPC and WHPCA
- All those who contributed to the development
- All those who have signed!
- Task Force – continued passion, commitment
- Volunteers in hospice and palliative care everywhere

Appendix
Poster Exhibition



Training Volunteers to Support Dying Patients, and their Families, in the Hospital Setting - iLIVE study

Goossensen, A.* , McGlinchey, T.**, Mason, S.***, Skorpen Iversen, G.****, Martin-Rosello, M.L.*****, Lunder, U. ***** , Bakan, M.*****, Kodba Čeh, H.*****, Simon, J.*****, Fischer, C.*****, Ellershaw, J.**

* University of Humanistic Studies, Utrecht, The Netherlands
 **The Royal Liverpool University Hospital, United Kingdom
 ***The Palliative Care Institute Liverpool, University of Liverpool, UK
 **** Regional Centre of Excellence for Palliative Care, Western Norway
 ***** Cudeca Hospice Foundation, Spain
 ***** University Clinic Golnik, Slovenia
 ***** Medical University Vienna, Austria

The iLIVE project includes a prospective 10-country cohort study to gain insight into 21st century experiences of dying patients and their formal and informal caregivers. The iLIVE project combines experimental studies on medication management to alleviate physical symptoms and on the development and implementation of compassion-based volunteer programme, with an observational study to better

understand the experience of death and dying.

The aim of the volunteer study is: to develop and evaluate an international volunteer (training) programme to support patients dying in the hospital and their families.

In five countries, patients with a life expectancy of one month or less, will be invited to participate in

the volunteer trial.

In this trial, we will evaluate whether the introduction of volunteers to support dying patients and their families in the hospital setting improves patients' quality of life in the dying phase, family bereavement and study cost-effectiveness.

The study started in January 2019 and includes the following tasks:

Task 1: Protocols

Development of detailed protocols (x5) to describe the study procedures, patient recruitment and data collection will be developed.

Task 2: Delphi study

A 3-round international Delphi study is underway to achieve consensus on the content of the international training programme.

Task 3: Prepare service

The infrastructure is prepared for the new volunteer service in the hospitals in the five participating countries.

Task 4: Learning Lab

A Learning Lab will be developed: a virtual forum in which Volunteer Coordinators (VCs) in all participating countries will exchange experiences with the programme and its implementation.

Task 5: Train-the-Trainer

A three-day international 'train-the-trainer' (TtT) course is delivered to two identified VCs per hospital site.

Task 6: Recruitment

Following the TtT-course, VCs screen and recruit a maximum of 20 volunteers per hospital and deliver the training programme.

Task 7: Data collection

For (cost) effectiveness evaluation data will be collected with several instruments, including: EQ-5D, ICECAP-CPM, ICECAP-SCM questionnaires, Hogan Scale, phenomenological in depth interviews and cost information.

Task 8: Focus Group

The lived experience of volunteers caring for a patient in the last days of life will be explored through a focus group interview per country. The experience of staff will also be explored through focus groups.

Task 9: Implementation

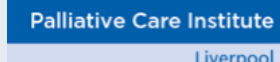
In depth interviews and focus groups will also be used to explore factors that influence the implementation of a new hospital volunteer service for dying patients.

Volunteer services will be organized in hospitals in:
 - UK: Liverpool, Royal Liverpool University Hospital
 - Netherlands: Rotterdam, Maastad Hospital
 - Norway: Bergen, Haukeland University Hospital
 - Spain: Malaga, Cudeca Hospice
 - Slovenia: Ljubljana, University Clinic Golnik



iLIVE is financed by the European Union under an EU Framework Programme for Research and Innovation - Horizon 2020-SC1-BHC-23-2018. Project ID 825731

Acknowledgements:
 - Agnes van der Heide (project leader), ErasmusMC, Netherlands
 - Dagny Faksvåg Haugen, Norway
 - Inmaculada Ruiz-Torreras, Spain



STORY OF MY VOLUNTEERING LIFE

WHAT DO I DO? WHAT DOES IT MEAN TO ME?



Ashla Rani

Volunteer of Pallium India (<https://palliumindia.org/>) – a national registered charitable trust formed in 2003 with a vision to integrate palliative care in all health care so that every person has access to effective pain relief and quality palliative care along with disease-specific treatment and across the continuum of care.

LIFE STORY



Born and brought up in a rural village of Kerala, India



Worked as a full-time software engineer for 4 years



Met with an accident, sustained a spinal cord injury and became quadriplegic



4 years of hospitalization for physiotherapy after the acute treatment



Search for something meaningful to do in life resulted in becoming a volunteer at Pallium India

WHAT DO I DO AT PALLIUM INDIA?

- Executive Assistant to Dr M R Rajagopal – Chairman, Pallium India
- Counsellor at Half-Way-Home, a project aimed at helping the spinal cord injured people to come back to life
- A friend in need for children in Unarv – the bereavement support group
- Advocacy for palliative care and accessibility
 - Awareness programs at schools and colleges
 - Meetings with government officials
 - Workshops for people with disabilities

WHAT DOES IT MEAN TO ME?

- Sharing my smile with someone who has forgotten how to smile
- Listening to people in the most vulnerable time of their lives
- Using life experience to help similarly placed people to live with dignity
- Creating opportunities for improving quality of life for people with disabilities
- Giving a purpose for my life

VOLUNTEERING IN HOSPICE AND PALLIATIVE CARE IN CZECH REPUBLIC

VOLUNTEERS IN CZECH HOSPICE CARE

- Volunteers are spending time with patients. (reading, walking, talking to)
- Volunteers in Czech republic often help with organizing public events, beneficent and fundraising activities.
- Volunteers can also help with administrative work in hospices.

From survey (2010) follows (Association of Hospice Palliative Care Providers - 25 member organizations):

- Most of hospices have introduced volunteers program.
- More than 270 volunteers work in these programs.
- Most of organizations have special volunteer trainings.
- More than a half of organizations have special position - volunteer coordinator.

VOLUNTEERING IN CZECH REPUBLIC IN GENERAL (DATA 2016)

According to Czech statistical office - number of hours worked by volunteers increased in 2016 to 46,1 millions hours (year to year increase about 2,2 %)

Number of volunteers in Czech republic is about 2 millions.



The Development and current state of Volunteering in Hospice and Palliative Care in Africa

Fatia Kiyange African Palliative Care Association, Kampala, Uganda
fatia.kiyange@africanpalliativecare.org

Introduction

- Caring for the sick is traditionally part of African culture
- The high burden of disease, high mortality & mortality rates have accelerated the development of volunteerism on the continent.
- The Alma Ata Declaration recognizes the importance of community members in the provision of primary health care
- The 2014 World Health Assembly resolution on PC recognizes the role of volunteers in the provision of hospice and PC services
- Volunteers are integral to PC teams & help address the human resources crisis in health care systems in Africa

Categories of volunteers

1	Professional volunteers
2	Non-professional volunteers
3	Un-paid volunteers
4	"Paid volunteers" (stipends)

Models of volunteering

- Government led
- NGO led
- Community based & linked to hospices or health facilities
- Site based
- Combines Government and NGO model
- Setting or disease specific volunteers



Trained volunteer in Mozambique leading patient care

Opportunities

- Role in re-engineering primary health care
- Role in Universal Health Coverage
- Role in national health insurance schemes
- New government health programmes
- Models exist for replication

Value addition from the work of volunteers

1	Access to hospice & palliative care services by the most vulnerable people
2	Reducing work load for clinical teams
3	Bringing services close to the patients and patients and spend more time with them
4	Contributing to national health and palliative care goals as resources saving Governments money
5	Makes it possible to provide palliative care services at the community and family level
6	Make it possible to engage communities on health matters
7	Increase community awareness on hospice and palliative care
8	Contribute to uptake of hospice and palliative care services

Challenges of volunteering

Individual level:

- Some patients with no family care givers
- Patients with no food, even those on ARVs
- Patients preferring to go to traditional healers
- Patients are too sick to go to the hospitals
- Poverty among the volunteers themselves
- Time commitment versus other responsibilities
- Transport challenges to reach patients
- Volunteers doing their best with the limited knowledge skills and resources

Institutional level:

- Volunteer programmes heavily dependent on donor funding – not sustainable
- Collapse of established programmes due to reduced funding
- Lack of supplies – home care kit
- Lack of standards/guidelines
- Inadequate supervision & mentorship

Systems level:

- No national data & not much research
- Remained informal
- Limited investment at national level
- No advocacy movement for volunteers
- Parallel volunteer programs

Recommendations

- Partnerships for advocacy of volunteers roles, recognition & Government support
- Developing champions – volunteer movement
- Research & documentation
- Developing & implementing standards
- Capacity building and mentorship

Hospice Volunteering in the UK

Dr Ros Scott, University of Dundee,
EAPC Task Force on Volunteering



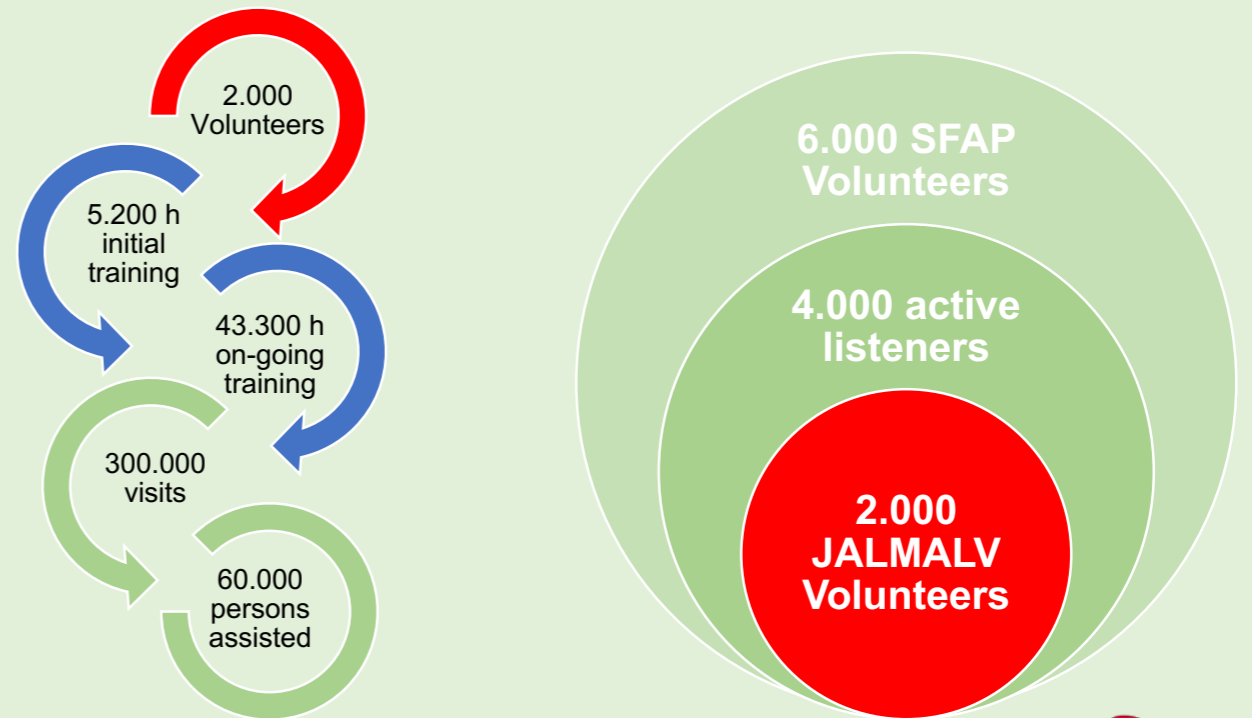
CHOOSING ONLY TO LISTEN

JALMALV (Jusqu'À la Mort, Accompagner La Vie – Passing Away, Accompaniment Life) is a French association created in 1983, during the early years of the AIDS crisis, in order to represent the civil society in hospitals.

Values: dignity, active presence, solidarity, respect

Commitment:

The majority of the association in the SFAP (French Society For Support and Palliative Care) have made the choice of only active listening to patients.



To be multiplied **x 2** in the next **4 years**

Focus

The increasing number of volunteers shall help to meet the growing demand of the French citizens to be able to pass away at home. One of the pioneers in home care support, JALMALV seeks to develop the palliative culture by accompaniments in hospitals, hospices and at home.



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- Developing & implementing standards
- Capacity building and mentorship

VOLUNTEERING IN THE HOSPICE AND PALLIATIVE CARE IN POLAND - 2019

Leszek Pawłowski¹, Piotr Mróz¹, Iga Pawłowska², Monika Lichodziejewska-Niemierko¹

¹ Department of Palliative Medicine Medical University of Gdańsk, Gdańsk, Poland

² Chair and Department of Pharmacology Medical University of Gdańsk, Gdańsk, Poland



Legal status of volunteering in the hospice and palliative care in Poland

Table 1. Legal regulations concerning volunteering in Poland

Act of law	Content
Act of 24 April 2003 on Public Benefit and Volunteer Work	General act of law related to volunteering in Poland. Definition of volunteer and volunteers' rights. Conditions of agreement between volunteer and organization.
Act of 6 November 2008 on Patients' Rights and Patients' Rights. Ombudsman	Duties of patient-facing volunteers Poland.
Act of 15 April 2011 On Medical Activity	Professionals working as volunteers.

Volunteers' rights:

Volunteers' rights according to the Act of 24 April 2003 on Public Benefit and Volunteer Work include the right to:

1. Information about the performed services
2. Information about rights and duties
3. Information about the risks to health and safety as well as protection
4. Work in a healthy and safety environment
8. Obtainment a certificate confirming voluntary activities
9. Resignation from volunteering
10. Reimbursement of traveling costs
11. Accident insurance (in the case of an accident, each volunteer can benefit from insurance, which is ensured by the country or by the centre - depending on the period for which the agreement was signed).

Legal definition of volunteer:

Volunteer is a natural person who provides services voluntarily and without remuneration, under the provisions specified in the Act (Act of 24 April 2003 on Public Benefit and Volunteer Work).

Questionnaire survey on volunteering in the hospice and palliative care in Poland

Aim

The aim of this study was to identify the current state of volunteering in the hospice and palliative care (HPC) in Poland.

Methods

A cross-sectional survey was applied. Volunteer coordinators from Polish HPC centers were asked to complete the online questionnaire.

Results

14 volunteer coordinators from 14 Polish HPC centers participated in this survey.

Table 2. Background characteristics of volunteering in the HPC centers in Poland

Respondents:	Volunteer coordinators	n=14
Number of all volunteers in the hospice:	- average	228
	- median	50
	- range	20 – 2082
Number of patient-facing volunteers:	- average	28
	- median	22
	- range	4 - 82
Average age of volunteers in the hospices (years):		36
Most of the volunteers are:	- working persons	64,3 %
	- pupils and students	28,6 %
	- retired and pensioners	7,1 %
Pre-training in patient care for volunteers (number of hours):	- average	43
	- median	40
	- range	11 - 100
Number of patient-facing volunteers trained in 2018:	- average	21
	- median	18
	- range	0 - 60
Knowledge about: "The Voice of Volunteering" The EAPC Madrid Charter on Volunteering in Hospice and Palliative Care:	- yes	28,6%
	- no	71,4%

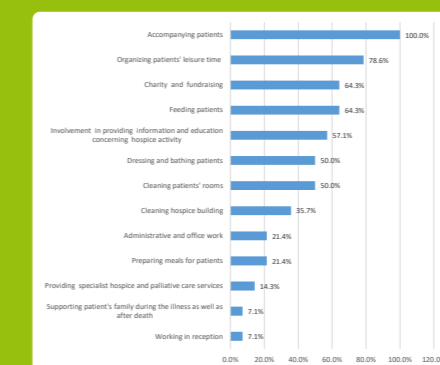


Fig. 1. Volunteers' activities in the HPC centers

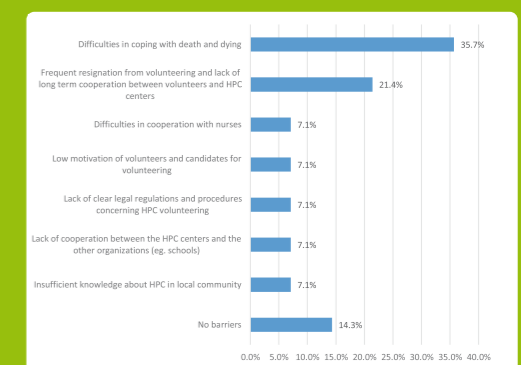


Fig. 2. The major difficulties and barriers in activity of the HPC volunteering

Conclusion

The current status of volunteering at Polish HPC is diverse with respect to the number of volunteers, their job activity and training. On the other hand, volunteers from various HPC provide similar services related to the patient care. The most common barriers in activity of the HPC volunteering include difficulties in coping with death and dying and resignation from voluntary work.

The authors declare no conflict of interest.
Contact: leszek.pawlowski@gumed.edu.pl

Croatia

development and current state of volunteering in palliative care



Current state of volunteering

- framework is set according EAPC standards as it is stated in White paper
- usually NGOs are the volunteer organizers
- some NGOs are specialized for palliative care only and some have palliative care among their other activities
- NGOs provide psychosocial support to patients and families, organize education, lend orthopedic aids, organize activities for public information and advocate for palliative care
- the scope of activities is different among NGOs
- there is plenty of room for development

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Development and current state of Volunteering in hospice and palliative care in Italy

The Federation of Palliative Care



Geographical distribution of the 93 NPOs part of FCP

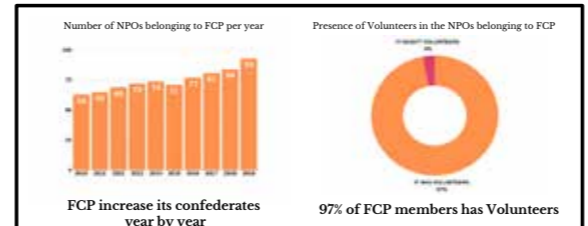
The Federation of Palliative Care (FCP) is a second-level organization of the Italian third sector that represents the network of Non-Profit Organizations (NPO) operating in the field of palliative care of the country. 93 Non-Profit Organizations are currently members of the FCP gathering more than 6.000 Volunteers.

The FCP, active in helping and assisting people with an evolutionary and incurable disease with poor prognosis, was established in 1999 with the aim of promoting and developing palliative care, spreading its culture and preserving dignity of the person, also guaranteeing the right not to suffer.

The Federation of Palliative Care (FCP) is in constant relationship with the NPOs associated and maintains ongoing close working relationships both with the Italian Society of Palliative Care (SICP) and with a significant number of external NPOs.



Law February 26th 1999, No. 39	Law March 15th 2010, No. 38	Law December 22nd 2017, No. 219
"Provisions to ensure urgent action to implement the 1998-2000 National Health Plan"	"Provisions to guarantee access to palliative care and pain therapy"	"Rules on informed consent and Advance Health Care Directive"
The Minister of Health [...] adopts a program on a national basis for the realization, in each autonomous region and province, in consistency with the objectives of the National Health Plan, of one or more structures, located in the territory in order to allow easy accessibility for patients and their families, dedicated to palliative care and support primarily for patients affected from terminal neoplastic disease requiring care aimed at ensuring a better quality of their life and that of their families.	[...] Having heard the main scientific societies and non-profit organizations operating in the palliative care and pain therapy sector, homogeneous training courses are defined throughout the national territory for the volunteers who work in the two networks (Federation of Palliative Care – FCP and Italian Society of Palliative Care – SICP).	The time of communication between doctor and patient constitutes cure time.



The role of the Volunteer in Palliative Care

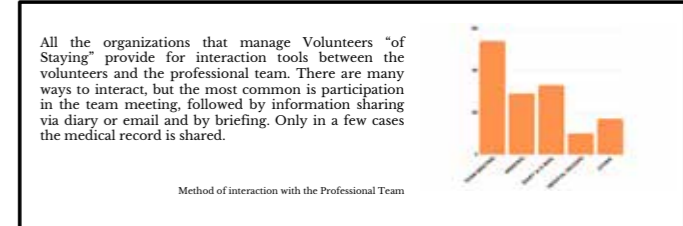
VOLUNTEERS BRING THEIR PRESENCE
 This happens in a context in which "being there" is revolutionary; the volunteers are present where suffering, loss of autonomy, death prospectus lead to risk of loneliness and isolation.

VOLUNTEERS ALLOW MOMENTS OF NORMALITY
 The presence of volunteers alongside the sick person promotes the sharing of daily life activities, allows the proposal of recreational initiatives, promotes the maintenance of personal interests, offers a relationship not necessarily linked to disease problems and concerns.

VOLUNTEERS OFFER SUPPORT AND EMOTIONAL SHARING IN RELATION TO UNCHANGABLE DISEASE
 A prepared volunteer knows how to "stay" in a conversation even when it concerns sickness, death, suffering, concern for the future of the sick or of family members.



Our concrete response, realized in collaboration with the Italian Society of Palliative Care, is a tool.



All the organizations that manage Volunteers "of Staying" provide for interaction tools between the volunteers and the professional team. There are many ways to interact, but the most common is participation in the team meeting, followed by information sharing via diary or email and by briefing. Only in a few cases the medical record is shared.

Method of interaction with the Professional Team

Although aware of not having solutions or answers, the volunteer can make a very important contribution through listening, welcoming and through emotional participation in the history of people to whom he has freely chosen to dedicate time.

VOLUNTEERS PERFORM A SOCIAL ROLE
 The volunteer, together with his Association, represents a member of the community capable of bringing the outside world to places of care, overcoming physical barriers linked to lodging or, in any case, reduced mobility. In the same way, the Association, through the volunteers, can transfer information, sensitivity, values such as gratuitousness matured with experience, helping to grow local communities that can give support, capable of expressing closeness and inclusion also to sick people.



The Federation has always been committed to collecting data related to the associated NPOs and to all those active on the national territory, this with the purpose of providing the citizen who needs care or information direct contacts with the organizations operating in their geographical area.

The Federation has collected the data of the associated NPOs in 2012 (69 NPOs), in 2015 (71 NPOs) and it is currently processing the recently acquired data about 93 NPOs, not yet available.

Needs of Palliative Care in Italy. An FCP-SICP document
 Italian population - 60 million 494 thousand residents
 In 2017, approximately 647.000 people died in Italy
 Needs of Palliative Care
 Prevalence: 1-1.4% of the adult population Estimate: between 524.000 and 733.000 people
 Incidence: 72%-80% compared to the number of deaths / year
 Estimate: 465.000 – 517.000 people every year

Parliament Report on implementation status of law No. 38/2010, three-year period 2015-2017
 Hospice
 No. of admissions = 42.572
 7.15% of the total cancer patients
 Home
 No. of assisted patients = 40.849

The publications of the Palliative Care Federation: best practices made through heterogeneous working groups

Since 2008, the FCP has published the "Punto e Virgola" - which meaning is semicolon - series, the result of the experience of the members of the confederate organizations and of the most authoritative Italian voices in the field of palliative care. The volumes intend to welcome and guide the ONPs and the aspiring Volunteers, accompanying them in their path: they offer food for thought and relevant information to the citizens, support the work of the professional Hospice team.

CHALLENGES Board of Directors FCP 2018 – 2022

MAPPING
 It is necessary to collect, through an accurate survey, data and information both on the organizations that provide Palliative Care services and pure voluntary organizations, in quantitative and qualitative terms, with the aim of having an overview of the current scenario and conducting an analysis on possible improvement paths;

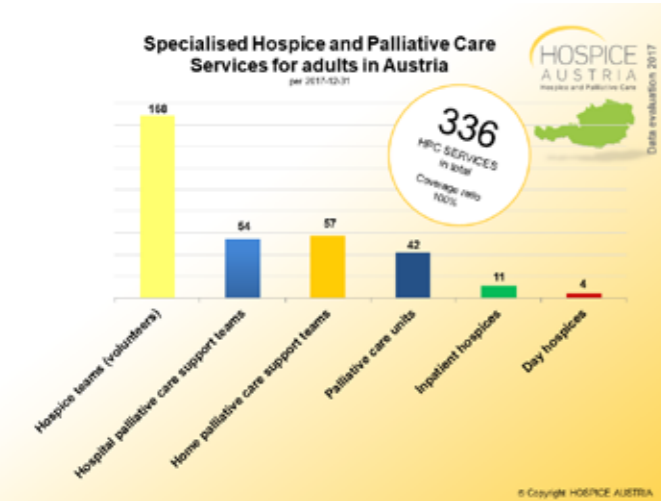
NON - ONCOLOGICAL PATIENTS
 We want to promote access to palliative care for non-cancer patients by implementing care pathways, consistent with the needs, timing and peculiar characteristics that characterize the assistance of the different categories of patients;

SHARED CARE
 We know that end-of-life care is not enough. Timely and early management procedures have to be promoted. These are characterized by interventions with the palliativist together with the branch specialist, aimed at the management and shared planning of care with the patient;

TRAINING/INFORMATION
 Specific training projects, aimed at implementing integrated palliative care pathways, for specialist teams, GPs / PLSS and hospital health workers, nursing homes / Residences for Disabled and Integrated Home Care, have to be developed. The Federation intends to develop, in synergy with voluntary organizations, information and awareness projects aimed at citizens;

INSTITUTIONAL ACCREDITATION
 The relationship of ONP with the National Health System and Regional Health System must be regulated exclusively through "Institutional Accreditation". All conventional forms must therefore be overcome, in particular the allocation of services based on tenders and tenders. The management of the Accredited Structures (Hospice and Domestic UCIP) cannot be outsourced, by the Accredited Body, through "calls for tenders".

Volunteers in Hospice and Palliative Care for Adults in Austria



Patient Care

2 801 volunteers cared for 13 119 patients. Patients' family members are not included in this number.

The main place of care are the patient's home and palliative care units, followed by nursing homes and hospitals.

2 437 people received bereavement support by volunteers.

Levels of Hospice and Palliative Care

	Hospice and Palliative Care		
	1 st level primary health care setting	2 nd level specialists for support	3 rd level specialists for care
acute care	Hospitals departments, wards, ambulatories	Hospital palliative care support teams	Palliative care units
long term care	nursing homes, residencies	Hospice teams (volunteers)	Inpatient hospices
at home	family doctor, specialists, home care, social worker	Home palliative care support teams	Day hospices

Published 2006 by GÖGÜBRO Mag. Leona Peltzer, MSc - Hospice Austria

Roles

2 974 volunteers (86% female, 14% male) are in direct patient care.

387 volunteers work in organisational and supportive roles in administration or fundraising.

180 of them belong to one of the 9 Austrian regional hospice organisations and are volunteering as board

Teams

1 team = 0.5 FTE* coordinator + 10-20 volunteers

Austria had 168 hospice teams in 2017.

Volunteers are offered supervision and training.

Costs like phone calls and transportation are covered by the organisation.



Training

All volunteers are trained according to the curriculum of Hospice Austria (80 hrs + 40 hrs work experience).

Volunteers have to have an ongoing training of 8 hours per year.

Hospice Austria has issued a curriculum for Volunteers in children's hospice teams in 2013.

The National Organisation for Bereavement Support (Hospice Austria is a member) has issued a curriculum for bereavement support.

Challenges and Future Development

- ⇒ Recruiting new volunteers
- ⇒ Retaining volunteers
- ⇒ Nourishing the „spirit“ of hospice volunteering in a highly structured system of volunteering and health/social care.

Volunteers in Hospice and Palliative Care for children and young adults in Austria



Teams

1 team = 0.5 FTE* coordinator + 10 - 20 volunteers.

Austria had 10 children's hospice teams in 2017.

Volunteers are offered supervision and training.

Costs like phone calls and transportation are covered by the organisation.



Training

Hospice Austria has issued a curriculum for Volunteers in children's hospice teams in 2013 as an advanced training (40 hrs + 40 hrs work experience) following a basic training (80 hrs + 40 hrs work experience).

Volunteers have to attend an ongoing training of 8 hrs per year.

Most children's hospice volunteers undergo in a first step the basic training according to the curriculum of Hospice Austria for adults.

Two organisations train their volunteers without prior basic training for adults. Their curricula refer to German children's hospice curricula and are not yet authorized by Hospice Austria.

Challenges and Future Development

- ⇒ Ensuring the service coverage (low number of patients in rural communities)
- ⇒ Recruitment of children's hospice volunteers
- ⇒ Definition of tasks and role (e.g. volunteers vs. nurses)

Patient Care

174 volunteers cared for 187 children, 126 siblings, 212 parents and 19 other persons.

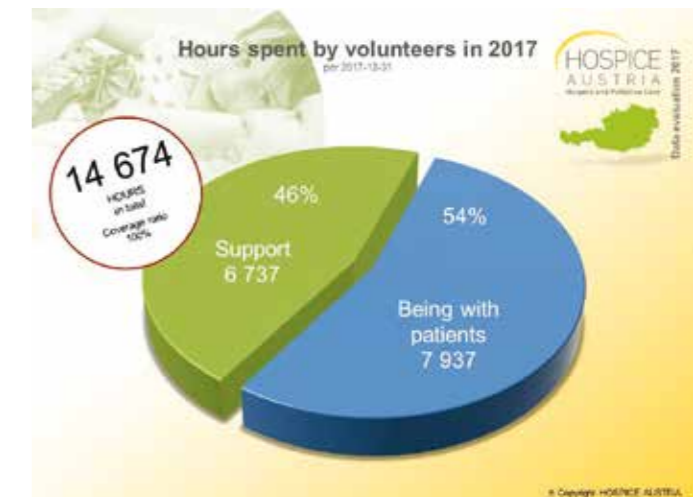
Main place of care is the families' home, followed by hospitals.

Specialised Hospice and Palliative Care for children and young people			
Outpatient services		Inpatient services	
Volunteer Hospice Teams	Home Palliative Care Teams	Children's Inpatient Hospices	Paediatric Palliative Beds
Support		Care	

Roles

174 volunteers (90% female, 10% male) are in direct patient care.

46 volunteers (78% female, 22% male) work in organisational and supportive roles in administration or fundraising.



The 6 737 hours of support include training and supervision for those in direct patient care, furthermore administrative and organisational work, fundraising...



Volunteers in Hungary 2019.



Hungarian Hospice Palliative Association

Agnes Zana – Kinga Farkas – Judit Schaffer – Miklós Lukács – Attila Farkas

Volunteers at the Heart of Hospice and Palliative Care: International Symposium at EAPC 2019, Berlin

Number of trained volunteers: growing tendencies

Year	TV - Country	TV - HHPA
2016	N=169 (81 service from 83)	90
2017	N=144 (70 service from 84)	115
2018	N=305 (34 service from 81)	100



Training

At training centers (HHPA and some bigger services): 40 hrs contained in Regulation volunteer training with self-knowledge and communication parts, including **special training from basic care knowledges**.

At hospice services: service specialized skills, experience with mentors.

Volunteering

Bedside, background, administration – adult and also child care.

Volunteer sources

High school students have to complete 50 hrs community work before graduating – they can be involved.

University students – we can certify their obligatory professional practice.

Benefits

- New communities of volunteers are created.
- Increasing attention and interest from society.
- Increasing general knowledge of the care of serious patients.

Further needs

- Some dedicated, constant and motivated leader volunteers.
- Marketing support for hospice palliative care and volunteering.
- Media/press background for the charity events.
- National database.

Professional volunteers in hospice

Speech therapist, teacher, special educator, Animal Assisted therapist.

Sample story

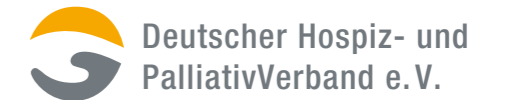
Certified hospice therapy dogs can provide a lot of physical, emotional and social benefits to patients and their families, and often they are the best source of comfort for the hospice patients and their families.

Erika is a hospice volunteer and with her two certified therapy dogs they visit three hospice houses on a weekly basis. The dogs visits: reduce feelings of isolation, anxiety and depression, help take a patient's mind off their aches and pains, encourage communication – including sharing stories and emotions, break the daily routine, help to reduce physical pain, lowers blood pressure, promotes an improved heart rate and general cardiovascular health, increases overall comfort level.



<https://hospice.hu/legyel-te-is-onkentes>; https://www.facebook.com/HospiceOnkentes/?epa=SEARCH_BOX

Hospizliches Ehrenamt in Deutschland



Morgen

heterogener
jünger
Erweiterung des Engagements
bunt
vielfältig
migrationserfahren

Der Deutsche Hospiz- und Palliativverband e.V. (DHPV) ist seit über 25 Jahren die bundesweite Interessenvertretung der Hospizbewegung sowie zahlreicher Hospiz- und Palliativ-einrichtungen in Deutschland. Unter seinem Dach engagieren sich heute in 1.200 Hospiz- und Palliativdiensten und -einrichtungen mehr als 120.000 Menschen für schwerstkranken und sterbende Menschen, die meisten davon ehrenamtlich.

Bedeutung

Ehrenamtlich in der Hospiz- und Palliativarbeit Engagierte stehen für die gelebte Solidarität mit den schwerstkranken und sterbenden Menschen in unserer Gesellschaft.

Einsatzorte

Der überwiegende Teil der ehrenamtlichen Mitarbeiter*innen ist in ambulanten Hospizeinrichtungen tätig. Weitere mögliche Tätigkeitsfelder sind stationäre Hospize, Krankenhäuser, Alten- und Pflegeheime sowie Einrichtungen für Menschen mit Behinderung.

Tätigkeitsfelder

- Begleitung Schwerstkranker und Sterbender sowie der An- und Zugehörigen
- Trauerbegleitung
- Öffentlichkeitsarbeit
- Vorstandsarbeit
- Verwaltung
- Koordinationsaufgaben

Verbundstudie zur Zukunft des Ehrenamts*

Ehrenamtliche Hospizarbeit ist nach wie vor weiblich und mittelschichtsbasiert und wird – immer noch – überwiegend von Frauen in der späten Erwerbs- bzw. Nacherwerbsphase getragen. Zudem werden bisher überwiegend Menschen der gesellschaftlichen Mitte begleitet, obwohl sich Hospizarbeit als Unterstützungsangebot grundsätzlich an jeden richtet, der Hilfe in der existenziellen Lebenskrise von schwerer Krankheit und Sterben benötigt.

17% der Bevölkerung könnten sich ein Engagement in der Sterbebegleitung grundsätzlich vorstellen; Frauen (23%) weitaus eher als Männer (12%), Westdeutsche (19%) eher als Ostdeutsche (12%). Zieht man die ab, denen hospizliches Engagement wegen Zeitmangel (45%) oder Nicht-Vereinbarkeit mit dem Beruf (29%) im Moment nicht möglich ist, bleiben immer noch 3% der Bevölkerung, die sich ein Ehrenamt in der Sterbebegleitung vorstellen können. Dieses Potential gilt es zu heben.

Fazit

Die ehrenamtliche Praxis sowie die hospizliche Organisationskultur und -struktur müssen offener und heterogener werden. Für eine zukunftsfähige Hospizarbeit muss der Wandel hin zu einem ‚neuen‘, d.h. bunteren, vielfältigeren und flexibleren Ehrenamt vorangebracht werden.

*Quelle: Ehrenamtlichkeit und bürgerschaftliches Engagement in der Hospizarbeit (EhEh) – Merkmale, Entwicklungen und Zukunftsperspektiven, gefördert vom Deutschen Hospiz- und Palliativverband (DHPV), Leitung: Prof. Dr. Werner Schneider (Augsburg), Prof. Dr. Dr. Reimer Gronemeyer (Gießen), Prof. Mag. Dr. Andreas Heller (Wien), Prof. Dr. Thomas Klie (Freiburg)



Am Ende zählt der Mensch. www.dhpv.de

Speakers

Dr. Karl Bitschnau,
Vice President of Hospice Austria,
Head Hospice Vorarlberg.

Mijodrag Bogicevic,
Patient Care Manager, the first hospice
social worker in Serbia and coordinator for
volunteers. He launched a volunteer pro-
gram in hospice and palliative care in Serbia.

Chiara F. R. Caraffa,
Member of the board of the Palliative Care
Federation (FCP, Italy). General Manager of
Presenza Amica, a non-profit organization
that deals with accompaniment at the end
of life and dissemination of the culture of
palliative care internationally.

Prof. Dr. Anne Goossensen,
Professor at University of Humanistic Stu-
dies in The Netherlands on research into
informal care and volunteering in hos-
pice and palliative care. She coordinates
a pre-master course 'Spiritual care at the
end of life' at the university and provides
lectures about care relationships and theory
of presence for care organisations.

Silvia Hartwig,
Head of Unit, Federal Ministry for Family
Affairs, Senior Citizens, Women and Youth,
Germany.

Dr. Birgit Jaspers,
Research coordinator, Department of Palli-
ative Medicine, University Clinic Bonn, and
senior researcher, Department of Palliative
Medicine, University Medicine Göttingen,
Germany

Waltraut Klasnic,
President of Hospice Austria.

Fatia Kiyange, MA,
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*For me, it is far more than a hobby,
it is a part of my life.*

Ewelina Legowska

25th of May 2019, Berlin



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