Volunteering in hospice and palliative care in France and in Poland

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Abstract

This working paper provides an overview on volunteering in hospices and palliative care in the EU member states France and Poland.

In the introduction, the modern hospice movement is described, the concept of palliative care is explained, and a definition of volunteering in hospice and palliative care is given. At the beginning of each country chapter, there is a brief introduction to the beginnings of hospice and palliative care. After this, the following categories will be examined and presented for the two countries: legal regulations, national and regional organisations, practical implementation of assignments and tasks of volunteers, qualification and future recruitment of volunteers.

Overall, the following aspects can be summarised:

- In both France and Poland, the beginnings of the hospice movements can be traced back to the 1970s and 1980s.
- In both countries, volunteers are engaged and involved in hospice and palliative care. Volunteering is codified and regulated by law.
- Also, in both countries, there are national and regional organisations and associations that organise and coordinate the work of volunteers. The volunteers are insured through the organisations and usually have a contract about their workload etc. In France, the SFAP is a large national umbrella organisation. In Poland, the organisations mostly operate on regional level.
- In France, the focus is on being-there and listening. In Poland, in contrast, the volunteers are assigned a larger variety of tasks (e.g. gardening and cleaning work, fundraising).
- The average age of the volunteers is higher in France. The average age is lower in Poland and many younger people are engaged in this field.
- In order to carry out volunteering work, training and further qualification offers are envisioned in both France and Poland. However, there are no unified national guidelines and standards for such qualifications.
- In Poland, children are confronted with the issue from an early age on. Pupils get involved by organising events and collecting donations for hospices and associations, mostly through their schools. For France, no information could be found on innovative approaches or examples to attract and retain volunteers in the future.
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Publishing Information
1 Introduction

The beginnings of the modern hospice movement can be dated back to 1967 when Dr. Cicely Saunders opened the first inpatient hospice in London. From London, the movement spread to many European countries (Hardinghaus 2018: 7). The hospice and palliative care movement can thus look back on a history of more than 50 years - and it is unimaginable without volunteers (Goossensen et al. 2016: 184).

In Germany, the first hospice initiatives developed in the 1980s - thanks to volunteers and without state or financial support. Today, there are about 1500 outpatient facilities, 300 palliative care units and more than 240 inpatient hospices in Germany. This development was accompanied by institutionalisation and professionalisation of hospice and palliative care. In Germany, § 39a (on inpatient and outpatient hospice services) of the Social Security Code V and the Hospice and Palliative Care Act of 2005 established a legal basis for financing and recognising the need for professional care at the end of one’s life (Hardinghaus 2018: 7f).

The concept of palliative care includes accompanying people at the end of their lives and enabling people close to death to improve their quality of life.

The WHO defines palliative care as follows: “Palliative care is an approach to improving the quality of life of patients and their families facing problems associated with a life-threatening disease. This is done by preventing and alleviating suffering through early detection, careful assessment and treatment of pain and other physical, psychosocial and spiritual ailments.” The purpose of palliative care is to ease pain, relieve anxiety and enable a dignified life, following the principle: “Everyone has the right to die in dignity”.

Palliative care is used to ease pain; it can no longer cure symptoms. Palliative care can thus benefit people who are terminally ill but also people suffering from degenerative diseases. Palliative care and palliative medicine are supplemented by hospice work - medical, nursing and hospice cooperation is understood as one single concept. People with a short remaining life expectancy as well as their relatives receive social, psychological and spiritual support. The aim is improvement and continuity of life quality until death. This concept is applied at home, in care facilities, at (inpatient) hospices and at palliative care units in hospitals.

Volunteers are part of the concept and benefit the entire hospice and palliative care system. One definition for volunteering in hospice and palliative care in Europe, which has gained broad international acceptance, is: “The time that citizens voluntarily and without financial motives...”

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1 “The term hospice is derived from the Latin word hospitium and means: Hospitality or lodging. In medieval tradition, hospices were ecclesiastical or monastic hostels along pilgrim paths and served as rest stops for pilgrims. The modern concept of hospices follows on from the idea of the medieval hostel by offering shelter to the dying person who has become displaced.” (Schuchter et al. 2018: 10).

make available within an organised structure which is not an existing social and family relationship, with the aim of improving the quality of life of terminally ill adults, children and adolescents and their families." (Goossensen et al. 2016: 186).

There are different types of deployment of volunteers - they are involved in administration, in the boards of associations, in fundraising, in public relations and in the direct support of ill people. Most of the work of volunteers in Germany is in the psychosocial and spiritual accompaniment and direct support of dying people and their families. Volunteers work in hospitals, hospices, palliative care units, daycare centres, other care facilities and in the patients’ homes. The hospice volunteers are considered to be less in the Hippocratic tradition (separation of medicine and religion) than in the Asklepiian tradition (bio-psycho-social-spiritual medicine). The Asklepiian tradition puts emphasis on “being-there” and is considered to be the core concept of volunteering in hospice and palliative care in the Netherlands and the German-speaking countries (Goossensen et al. 2016: 189).

This unpaid participation in the accompaniment and support of dying people and their relatives shall be the focus of this working paper. Are there differences in France and in Poland (as compared to Germany) with regards to this engagement and the tasks that volunteers perform? In addition, there are current challenges posed by the demographic development of societies in Europe: the number of people to be accompanied and cared for is constantly increasing. And the affected people are changing as well; there will be more and more people with cognitive impairments (e.g. dementia), people with a migration background and thus possibly other conceptions of “good dying”, as well as generally very old and single people. The demand for hospice and palliative care will also grow as a result of changing disease patterns and the disappearance of family structures (Hesse/Pabst 2015: 11). Therefore, the role of volunteers will be all the more important in the future, and it is thus quite understandable that governments are interested in increasing the number of volunteers in this area. In addition, there are several studies showing evidence of a positive effect of volunteers on the satisfaction of the families of those affected (Candy et al. 2015).

The compared countries - France and Poland - have been selected in consultations with the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth (BMFSFJ). France has already initiated a fourth “National Strategy for the Development of Palliative Care and the Accompaniment at the End of Life 2015-2018” (Plan National pour le Développement des Soins Palliatifs et l’Accompagnement en fin de vie 2015-2018). In Poland, voluntary work is a major pillar of support and there is a high proportion of younger people who volunteer in palliative and hospice care. It is particularly interesting to find out how Poland succeeds in motivating young people for such engagement.

3 Moreover, there is a focus on ill adults, not on ill children. In the field of accompanying and supporting children, there are obviously many enthusiastic volunteers and specialised hospices as well.

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Observatory for Sociopolitical Developments in Europe
The following questions and criteria will be addressed in this working paper:

- Is there a legal right to hospice and palliative care in France and Poland? Is volunteering part of any legal regulation(s)?
- Are there national and regional organisations and associations catering for the volunteers and coordinating their engagement?
- What does the structural organisation of volunteering in hospice and palliative care as well as the practical implementation look like?
- What are the tasks and roles of volunteers, how are they involved, and what is the underlying understanding of care and support?
- How are volunteers trained and qualified?
- How can - keeping in mind the foreseeable generational changes - future volunteers be recruited and tied to their volunteering work? Are there innovative approaches and projects?
2 France

The beginnings of palliative care can be traced back to the late 1970s or early 1980s, when the debate about “undignified dying” in hospitals took place in France, too.

In 1984, a team from Paris drafted the Charter for Palliative Care. In 1985, the Association pour le développement des Soins Palliatifs (ASP fondatrice) - the Organisation for the Development of Palliative Medical Care - was founded. In a ministerial circular (Circulaire) in August 1986, palliative care was defined, the care structures described, and the establishment of palliative care units recommended. This document is considered to be the public founding text of the palliative movement (Jaspers/Schindler 2004: 272f).

In 1987, Dr. Maurice Abiven opened the first French palliative care unit at the International University Hospital in Paris. He is thus counted as one of the pioneers in palliative care in France. To support his work, he set up a team of volunteers. In 1989, he was involved in the founding of the Société française d’accompagnement et de soins palliatifs (SFAP), and he chaired the organisation from 1989 to 1993. To this day, the SFAP is an important organisation for all actors involved and an important discussion and negotiation partner for political decision-makers (ibid.: 272ff).

In 1991, a hospital reform law was passed which defines palliative care as the third task of hospitals. In 1994, the UNASP (Union Nationale des Associations pour le Développement des Soins Palliatifs), the National Union of Associations for the Development of Palliative Care, was founded. Ten years on, it already comprised 57 associations with around 1,400 volunteers (ibid.: 272ff).

Overall, four national strategies (1999-2001/2001-2003/2008-2012/2015-2018) were implemented and three laws (see Chapter 2.1) were passed which have influenced the development of hospice and palliative care in France. The national strategies had different targets. The first strategy tried to establish a structure for each Département. The second strategy set a focus on the development of networks and cooperation. The current strategy, the “Plan national 2015-2018 pour le développement des soins palliatifs et l’accompagnement en fin de vie” has four focal points (Ministère des Affaires Sociales, de la Santé et des Droits des Femmes 2015: 10):

- informing patients and put them at the centre of decision-making processes,
- developing outpatient care services, in particular at home,
- improving the qualifications of carers and other relevant actors,
- securing access to palliative care for everyone and thus reducing inequalities in access to palliative care.

The funds allocated for the implementation of this plan amount to 190 million euro. As part of the current 2015-2018 plan, the Centre national des soins palliatifs et de la fin de vie (CNSPFV), a national centre for palliative care and end-of-life care, was opened in January 2016, with the aim of raising public awareness and conducting national awareness campaigns.
2.1 Legal regulations in hospice and palliative care

The first law on palliative care No. 99-477 of June 9th, 1999 established a right of access to hospice and palliative care. Article 10 of this Act regulates the legal recognition of the role of volunteer work in the field of hospice and palliative care. Article 10 furthermore stipulates that volunteers must be selected and trained in associations which are in consultation with health care institutions and comply with a national charter (Moreau, n.d.).

The rights of the first Law of 1999 were updated in Law No. 2005-370 - the so-called Leonetti Law - of April 22nd, 2005. This law reaffirmed these rights with the aim of recognising and strengthening the rights at the end of life, as well as the general strengthening of palliative care. The five basic principles of the law are: benefitting from palliative care, the right not to suffer, the right to refuse treatment, the right to make and apply living wills, and the right to designate a person of trust (Sécurité Soins, n.d.).

The law no. 2016-87 of February 2nd, 2016 changed these provisions on the end of life. It strengthens existing rights and adds new rights for ill people and people at the end of their lives. Every person - healthy or ill - can express his or her own wishes about the end of life by means of living wills, and these are to be respected by the carers (no author, 2016).

The current national plan for 2015-2018 (Plan national 2015-2018 pour le développement des soins palliatifs et d’accompagnement en fin de vie) is in accordance with these new provisions of February 2nd, 2016.

2.2 Organisations and interest groups

There are large associations active in the field of palliative care in France. Almost all institutions or organisations in this field also work with volunteers, coordinating or training them. Here is a short overview of the most important organisations and interest groups:

The organisation Jusqu’à la mort accompagner la vie (JALMALV) was founded in 1983 already. JALMALV brings together 80 associations, is present in over 120 French cities and has almost 3,000 active volunteers.

The Union Nationale des Associations pour le développement de Soins Palliatifs (UNASP) has its origins in the Association pour le développement des Soins Palliatifs (ASP) which was founded in Paris in 1984. When the ASP Charter was adopted by other associations and the first nine decided to deepen their contacts, President Jean Faveris proposed to them the creation of a new federation, the UDASP. In 1992 it became the UNASP, meaning the “National Federation of Associations for the Development of Palliative Medicine”. In 1995, the former

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4 The law bears the name of Jean Leonetti, a Member of Parliament who, with the express consent of the government, proposed the law to Parliament for voting.

5 The information on the organisations mostly stems from the organisations’ and interest groups’ websites.

6 The translation of the organisation’s name is: Accompanying life until death.
ASP was renamed to ASP-Fondatrice (ASP-F). At the beginning of 2012, UNASP had 71 associations and 1,850 volunteers supporting patients and their families.

JALMALV and UNASP are thus the largest organisations in France representing volunteers and their interests in hospice and palliative care.

The organisation Société française d'accompagnement et de soins palliatifs (SFAP) was founded in 1989. The SFAP was founded by existing organisations, including UNASP and JALMALV, as a large national umbrella organisation and is still an important organisation for all actors in the field today. Among other things, the SFAP has published guidelines on key areas of palliative care. The SFAP brings together close to 200 volunteer associations with around 7,000 volunteers. The Collège des Associations de Bénévoles d'Accompagnement (CABA) is based at the SFAP. CABA is a network and alliance of volunteer associations and SFAP-members. The CABA steering committee, consisting of nine bodies, meets regularly and proposes opinions, recommendations and communication tools to the board. The main goal is to share knowledge and experiences by volunteers about their deployment as well as learning from each other.

About two thirds of all associations are part of UNASP and JALMALV. Other associations which are not affiliated to any association or are members of the SFAP organise their work and their trainings themselves.

This means that there are around 450 associations and organisations in France, some of which deal quite differently with their volunteers and some of which train them with varying training methods.

### 2.3 Structures and framework conditions for volunteering

The single associations are responsible for recruiting, choosing, training and supporting volunteers. The volunteers commit themselves to regularly accompany one or more patients for a certain number of hours per week. The associations organising the deployment of volunteers have a charter\(^7\) in which the guiding principles, which the volunteers have to obey, are laid down. These principles include respect for the philosophical and religious views of those cared for, respect for their dignity and privacy, discretion, confidentiality and non-interference in care/medical treatment (Centre national des soins palliatifs et de la fin de vie 2018a).

In some cases, the law even stipulates that institutions such as palliative care units must offer voluntary assistance services (Jaspers/Schindler 2004: 284). Structurally, the palliative care units are similar to those in Germany - they often have a multi-disciplinary team also including volunteers and being headed by medical supervisors (Spielberg 2007).

\(^7\) According to article L. 1110-11 of the general health code (Code de la santé publique), organisations working with volunteers are required by law to adopt such a charter.
The organisation JALMALV distinguishes between three forms of volunteering (Fédération JALMALV 2017):

1. The **voluntary accompanying** of people at the end of their lives, in particular by active listening and being-there; this is usually done for half a day per week.

2. Volunteering in the field of **public relations**, consisting of cultural actions aimed at removing the taboo from the topic of dying (e.g. events, discussions, actions in schools, etc.).

3. **Structural volunteering** performed within the associations’ structure, in particular activities aiming at ensuring the stability and visibility of the associations.

At the request of an institution seeking support from volunteers, a support contract (in accordance with Regulation No. 1004 of October 16th, 2000) is to be concluded between the institution and the organisation organising and regulating the cooperation. Volunteers and care personnel cooperate on a partnership-basis. Volunteering is always performed within the framework of an organisation. The actual work is organised jointly as a team. It is supposed to offer additional support for the care staff, thus benefitting the patient. Volunteers must not be seen as additional care staff: Their deployment is an addition to professional care workers. Volunteers are coordinated and trained by a coordinator (Fédération JALMALV 2017).

Decree 2000-1004 of October 16th, 2000 obliges volunteers to report to nursing staff before and after their deployment in institutions, and to keep each other informed. Article 7 defines the information to be disclosed for the performance of the respective tasks. These include, for instance: medical information, the medical history but also personal information like marital status etc. This obligation to exchange information is to improve the quality of care and support for the accompanied patient. The volunteers are subject to confidentiality and non-disclosure obligations.

### 2.4 Participation and responsibilities of volunteers

In 2013, there were 5,076 volunteers working in hospice and palliative care. These figures are based on data obtained in a survey by the CABA of the SFAP. According to the same survey, 35 percent of volunteers work with patients in palliative structures, 36 percent in health facilities, 18 percent in medical-social facilities, 9 percent at home and 2 percent in other places (e.g. prison or other grief counselling) (see Fig. 1) (Observatoire National de la Fin de Vie 2014: 149).

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8 According to statements by French experts, there are currently massive problems to staff these positions and forms of volunteering. This even leads to the dying of some of the associations.

9 Available at: https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000767830&dateTexte=.

10 Figures by CNSPFV show that there were 140,571 codified hospice and palliative care stays in hospitals in 2016 (Centre national des soins palliatifs et de la fin de vie 2018b: 41). Data on other forms of palliative care than palliative care stays in hospitals is not collected by CNSPFV.
On average, volunteers work four hours per week. Women are more often active in this field than men. The group of volunteers is between 50 and 70 years of age on average (Jaspers/Schindler 2004: 285).

With the consent of the ill person or his or her relatives, volunteers can offer their presence/company. In this way, they support the patients and can help strengthening the patients’ social surroundings. The focus is on listening and being-there. While doing so, intimacy and dignity of the patients, their families and their relatives must at all times be respected. This also allows the relatives to take a moment of rest. These accompanying volunteers are neither physicians nor psychologists and do not take part in medical treatment. The volunteers do not have access to the patients’ medical records and never join in making any medical decisions (Centre national des soins palliatifs et de la fin de vie 2018a).

The role of volunteers in hospice and palliative care is precisely described and laid down in a circular (Circulaire Nr. DHOS/O2/2008/99) from the Ministry of Labour, Social Relations, Family and Solidarity and the Ministry of Health, Youth, Sport and Society to palliative care organisations dated March 25th, 2008.

2.5 Training and qualification of volunteers

In order to be allowed to volunteer, specific trainings have to be completed. These trainings focus on ethics, psychology, social issues and grief counselling - and little (or not at all) on medical topics (Jaspers/Schindler 2004: 284).

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The SFAP has developed a three-stage training course for volunteers for their members, which consists of a first step of sensitisation, a second step of basic training and a third step of in-depth further training on various topics (SFAP 2012: 21ff):

1. **Sensitisation and first information** for all people interested in the issue and willing to get engaged. This training aims to bring the various concepts, the hospice movement and the work of the organisations closer to those interested, and also to experiment with the existing instruments, the listening and the accompaniment within the training group. Between 10 and 25 hours of training are scheduled, completed either in half-day or full-day sessions.

2. The **basic training** prepares volunteers for the accompanying tasks. Training contents include theoretical basics about the end of life, palliative care, listening, practical training in listening and common situations in volunteer work as well as practical training for future volunteer caregivers. There are also discussions and talks with other volunteers as well as with a psychologist. Successful completion of this training leads to an employment contract. This basic training is scheduled to take between 40 and 60 hours plus additional time for the mentoring.

3. **In-depth further training** on specific topics: for instance, accompanying surviving dependents, discussing death with children and adolescents, or accompanying people who can no longer express themselves verbally or have a degenerative disease. Such advanced training measures can be completed on request over the years and depending on the programme of the respective association or organisation. The volunteer participates in one or two thematic models per year, consisting of at least two days each and having a scope of 15 to 30 hours.

The qualification measures for volunteers are 75% financed by the health insurance funds, which have their own budgets for this purpose (Jaspers/Schindler 2004: 285). In addition, the French state committed in early 2000 to support the basic and further trainings of volunteers via the **CNAMTS** (Caisse Nationale d'Assurance Maladie des travailleurs salariés). The SFAP was tasked with the administration and implementation of this financial support. To do so, a coordination body as well as a steering committee were established. The steering committee is responsible for the checking of grant applications, the allocation of funds and the evaluation of training measures and support for their further development (SFAP 2012: 5).

For the time being, there are no unified national standards or curricula for the training and qualification of volunteers in the field of hospice and palliative care. Nonetheless, many associations and organisations have access to training materials, like for instance the SFAP (as described) which provides its member associations with such materials.

### 2.6 Attracting and retaining volunteers

According to the president of an organisation, there are the following challenges which volunteering in France will face in the future: He names, among other issues, the development of
support services at home, support at care facilities (so-called EHPAD\textsuperscript{12}) which show a growing amount of inhabitants with dementia illnesses, a general problem with recruiting of volunteers for such tasks as well as a development towards younger volunteers who, however, often only have limited amounts of time due to other (career) occupations. However, he also said there were debates and working groups within his organisation on tackling these challenges.

In the private sector, there are several initiatives by organisations that explicitly go to schools and report on volunteering there in order to raise awareness and promote such activities. Moreover, the associations themselves try to raise public awareness through conferences, publications, film screenings with debates and through articles and interviews in the local press. On the other hand, there are no nationwide campaigns, though.

3 Poland

The very beginnings of palliative care in today’s sense date back to the 1970s in Krakow, when the Catholic Church was looking for new ways to engage with society. The impulse for volunteering in palliative care were the visits by Englishwoman\textsuperscript{13} Cicely Saunders in Poland - her husband was a Polish citizen. The foundress of the first modern hospice gave lectures on this topic in Poland. In 1981, the first hospice association in Eastern Europe was founded, which was at the same time also the first independent charity organisation in Poland based on the work of volunteers (Scott/Howlett 2018: 83f).

During the Communist regime, many of the initial initiatives were run by members of Solidarno\large{\textbf{\textsuperscript{o}}}ś\textsuperscript{14}, the Catholic church and early volunteers - which was met with political reluctance and resistance. An attempt was made to combine the basic attitude of palliative care with the basic attitude of solidarity and resistance against inhuman structures (Jaspers/Schindler 2004: 348). With the end of such political restrictions after 1989, several non-governmental organisations (NGOs) and civic grassroots initiatives were founded. This political turnaround had positive and sustained effects on the development of volunteering in Poland (Scott/Howlett 2018: 86).

In 1993, the National Council for Hospice and Palliative Care Services (NCHPCS\textsuperscript{15}) was founded. It is an advisory body to the health ministry, based in the ministerial structure. It has developed into a body of well-respected experts in the field of hospice and palliative care. The Council aims to support and coordinate the palliative care and hospice movement and to boost further developments in this field. In its first two years of existence, the Council focused on the establishment of norms and guidelines for palliative care, among other issues. Since 1994, the

\textsuperscript{12} EHPAD stands for “Etablissement d’Hébergement pour Personnes âgées dépendantes”. Since 2001, this has included all care facilities specialising in long-term care.

\textsuperscript{13} Generally speaking, there is close international exchange, cooperation and support between the hospice movements of the United Kingdom and Poland.

\textsuperscript{14} Solidarno\large{\textbf{\textsuperscript{o}}}ś: “Solidarity” is a political labour union that has its roots in the strike movement of 1980. It had decisive influence on the political turnaround and the end of Communism in 1989.

\textsuperscript{15} National Council for Hospice and Palliative Care Services.
Ministry of Health nominates a national advisor in the framework of the NCHPCS (Luczak et al. 2002: 218f).

The importance and further development of palliative and hospice care continues to this day. In 2013, there were around 400 different institutions, most of which involved volunteers in their work (Centeno et al. 2013: 235).

3.1 Legal regulations in hospice and palliative care

The Health Care Units Act of August 30th, 1991 includes palliative care units and hospices as medical care service facilities for the first time in Polish law. Also in 1991, the Ministry of Health introduced a preliminary programme to establish palliative care as part of national health policy. According to this, patients have the right to die peacefully and with dignity (Luczak et al. 2012: 218).

In 1998, the "National Programme for the Development of Palliative and Hospice Care in Poland" was adopted jointly by the Ministry of Health and the NCHPCS. The inclusion of hospice and palliative care in Poland’s Health and Social Welfare Act contributed to the integration of the social movement into health and social structures, which at the time was unique in Eastern Europe (Scott/Howlett 2018: 85).

In 2003, volunteering and its basic principles were legally laid down. This law also stipulates how the costs of palliative care in non-governmental institutions are to be borne: The National Health Fund (Narodowy Fundusz Zdrowia) covers 60 percent of the occurring costs. In order to secure their existence, many institutions are thus dependent on fundraising and donations (Jaspers/Schindler 2004: 352).

In 2005, the National Programme for Cancer Care - including the further development of palliative care - was adopted by the Polish Parliament (Centeno et al. 2013: 236).

According to these legal provisions, citizens thus have a right to die with dignity. Health authorities are obliged to implement this right. However, there appears to be a sentiment that this responsibility is not pursued sufficiently. On the one hand, financial public funds for palliative care were reduced in 2002, for instance. On the other hand, the literature suggests that health care concentrates more on the treatment of pain and that differentiated services are more likely to be found in the non-governmental sector - mostly in church-oriented services. Nonetheless, the development of hospice work in Poland is described as being exemplary in Eastern Europe (Jaspers/Schindler 2004: 350).

3.2 Organisations and interest groups

In Poland, there are several national and regional organisations which are active in the field of hospice and palliative care as well; and which are supported by many volunteers and partly run by volunteers exclusively.\(^\text{17}\)

The Polish Association for Palliative Medicine (Polskie Towarzystwo Medycyny Paliatywnej; PTMP) was founded in 2002 as a scientific and medical association and currently has 220 members. The aim of PTMP is to promote and support palliative care, the development of standards in this field as well as interlinking research and practice.

The Polish Association for Palliative Care (Polskie Towarzystwo Opieki Paliatywnej; PAPC) was founded in Poznan in 1989. Initially, the association was active in only two Polish regions. Now, there are branches in 16 regions. For the most part, PAPC is active in spreading the hospice philosophy, organising various training courses and carrying out fundraising activities and campaigns.

The consultative body of the Ministry of Health, the NCHPCS (see Chapter 3), also finances many initiatives by these organisations.

The Association of the Friends of the Sick (Towarzystwo Przyjaciół Chorych), which was founded in 1981, opened Poland's first hospice in Krakow.\(^\text{18}\) The society is considered to be the first non-profit organisation in the field of palliative care in Eastern Europe that built on a particularly strong volunteer commitment. The work was strongly inspired and shaped by Cicely Saunders' concepts and ideas about hospice and there were early contacts and exchanges with the St. Christopher's Hospice in London.

The National Forum of the Hospice Movement (Forum Hospicjów Polskich; OFRH), founded in 1991 (registered as initiative in 1992), represents the interests and coordinates the work of independent hospice services. The Forum also held close contact with the first modern hospice, the St. Christopher's Hospice in London.

The Eastern and Central Europe Palliative Task Force (ECEPT) was founded in 1998 and is an international organisation representing also Eastern European countries. ECEPT aims for national implementation of palliative care and policy measures, public relations, fundraising and implementation of national training and education programmes.

The organisations and associations active in the field of hospice and palliative care in Poland are often rather regionally active and the presence of their work is not particularly visible from afar or online.

\(^\text{17}\) The information on the organisations mostly stems from the organisations’ and interest groups’ websites.

\(^\text{18}\) Poland’s first inpatient hospice in Krakow is also known as the "Krakow model" of inpatient care. In contrast to this, there is also the “Gdansk Model” standing for outpatient care (Wisla 2017: 4).
3.3  Structures and framework conditions for volunteering

The inclusion of palliative care in health systems also led to funding, which has resulted in the employment of paid staff changing the nature of the volunteering sector and reducing the number of volunteers. Volunteering is therefore less involved in medical care today, and rather takes on supporting functions such as being-there for patients (Scott/Howlett 2018: 86).

The 2003 law states that volunteers must be insured for their activities through the institution or organisation (Woitha et al. 2014: 5). The principles of volunteer work are also regulated in detail by law, though not the special forms of voluntary work, such as volunteering in hospitals, on help lines, in fundraising, etc. (Scott/Howlett 2018: 87f).

The law stipulates that in order to protect the rights of patients, volunteers in hospices and palliative care must uphold the patients' right to respect for intimacy and dignity, death in peace and dignity, respect for the confidentiality of information about patients, respect for the will of patients and respect for their preferences regarding contact with other people (ibid.: 90f).

According to the law, the cooperation between the volunteers and the palliative centre should be based on an oral or written agreement. This is mandatory for long-term contracts - which means more than 30 days in Poland. In Poland, volunteers can apply for written confirmation of an oral agreement (ibid.: 88f). Volunteers in Poland receive a daily allowance and a travel allowance to cover, among other things, the costs of using public transport (ibid.: 90).

The volunteer coordinators take on a key role within the volunteer teams. Sometimes, these are full- or part-time volunteers themselves. They are responsible for the coordination and communication between the facility’s management, the entire medical team and non-medical professionals. They take care of the volunteers’ training and support and motivate them (Janowicz et al. 2015: 47f).

3.4  Participation and responsibilities of volunteers

Between 2008 and 2013, 45 percent of all palliative care units (about 500) have worked with volunteers. Overall, 2,500 to 3,000 people work as volunteers in the palliative care sector (Woitha et al. 2014: 3). About 85 percent of the volunteers are women. The average age is at 51 years (Jaspers and Schindler 2004). There is no minimum age for volunteering in Poland (Scott/Howlett 2018: 88).

The main tasks of the volunteers are: accompanying patients, serving food, dressing and bathing, cleaning rooms, organising leisure activities, charity work and collecting donations as well as providing information and raising awareness about hospice activities (Scott/Howlett 2018: 86). Woitha et al. describe that there are differences with regard to the tasks that volunteers perform in public and non-public/private hospices: Volunteers work in almost all public hospice services. In non-public hospices, volunteers provide the full range of patient care tasks. The main difference between public and non-public hospices is that a certain part of the hospices has a contract with the Ministry of Health. The rest is supported by the Church and other partners such as Caritas (Woitha et al. 2014: 3).
3.5 Training and qualification of volunteers

There is no unified, standardised training system for volunteers in hospice and palliative care. Training and qualification are not laid down by law either, but a certain level of education or training is usually a prerequisite for volunteering and almost every institution and hospice strives to provide volunteers with the best possible knowledge and skills. Therefore, the various institutions and organisations have developed their own training methods for volunteers. Usually, the trainings are divided into basic and advanced trainings. The existing training programmes have been compiled into a guidebook for volunteer coordinators. This enables institutions to adapt them to their needs and abilities (Janowicz et al. 2015: 49f).

Volunteers who wish to accompany patients usually have to complete theoretical and practical trainings within the associations, under the supervision of experienced doctors and nursing staff. Volunteers must also participate in an interview with a psychologist and a volunteer coordinator. After completion of the training, the trained person joins the care team for a probationary period and becomes its member after positive evaluation of the team and passing an examination. The voluntary service usually starts in a hospice or at a palliative care unit. More experienced and reliable volunteers can then become part of a hospice care team accompanying people at their home (ibid.: 50).

3.6 Attracting and retaining volunteers

In Poland, many young people are made aware of the issue and of volunteering in the area of hospice and palliative care already at school, e.g. through theme weeks and/or fundraising campaigns in cooperation with hospices, where pupils sell cookies and paper narcissuses. Moreover, numerous campaigns, video clips and animated films suitable for children are also broadcast on television in order to raise awareness and remove taboos. In general, there are many campaigns, actions, concerts and sporting events for hospice and palliative care as well as donation collections (Janowicz et al. 2015: 62).

Many educational activities as well as combined fundraising and information campaigns, which are mainly carried out by children and young people, can be traced back to campaign-oriented volunteering. Volunteering services of children and adolescents of school age are thus a form of information about serious illness, disability, death and grief. In order for children and young people to volunteer in hospices and palliative care, the active cooperation of the school is therefore necessary. The teachers play a key role in this. They coordinate the volunteer clubs in the schools and cooperate closely with the hospice coordinators or the responsible persons in the care institutions (ibid.: 54f).

In order to provide teachers with classes and materials in case one parent of a schoolchild dies, “first aid kits” with teaching materials financed by the Ministry of Education were sent to all schools (Radbruch et al. 2015: 48).

In Poland, support for volunteering in hospices starts already in kindergarten. For instance, kindergarten pupils visit hospices before Christmas and sing Christmas songs with the patients (ibid.: 49).
In 2007, the three-year national programme “I like helping” was implemented with the aim of promoting and raising awareness of volunteering and voluntary services. This programme involved 120 hospices. Among other aspects, the programme focused on training volunteer coordinators. A total of 150 people participated in such trainings. Further emphasis was on making volunteering in hospice services known in schools and with people starting from 50 years of age. These three years also saw the development of several publications, educational films and other materials (Krakowiak 2017: 6f).

Another interesting project is the WHAT-project (Hospice Voluntary Service as Tool for Teaching Acceptance and Tolerance) which deploys prisoners as volunteers in hospice work. This is an official form of occupation for prisoners. They assist with the preparation and distribution of meals, for instance. Some prisoners who have completed volunteer training work in a palliative and hospice care team and support the care staff in the daily operation of the hospice. This volunteering service has positive effects on the rehabilitation process. In June 2009, Poland was awarded the prestigious “Crystal Scales of Justice” prize by the European Commission and the Council of Europe for the innovative form of cooperation under WHAT. Even though the project has officially ended, cooperation between palliative/hospice centres and prisons continues, as the programmes have proven to be of long-term benefit to both sides (Janowicz et al. 2015: 59).

There is also cooperation with socially disadvantaged and delinquent minors. Some of them can serve their prison sentences in the hospice as volunteers. This gives them the opportunity to prevent further punishment and take up a socially acceptable activity (ibid.: 57f).

The positive effect of the programmes, media events on television and school activities is that people become familiar with hospice and palliative care and volunteers are proud of their volunteering and talk about it without shame (Radbruch et al. 2015: 45).

Demographic change and the growing number of chronically ill and elderly people living alone at home require concrete action. Given the need to support people in need at home as well as their families, some teams in Poland have started to work with the charity Caritas to explicitly build volunteer services for the chronically ill and the elderly at the end of life (Scott/Howlett 2018: 92).
4 Comparison and Conclusion

Chapter 4 summarises and compares the key results from the various categories in the country chapters on France and Poland. Finally, volunteering in hospice and palliative care will be examined in a broader European context, and future challenges will be presented.

In the two examined countries, hospice and palliative care has been established already in the 1970s/80s. Volunteers have been involved from the very start and are an important part of this (citizens’) movement.

Hospice and palliative care as well as volunteering are legally established and regulated in both France and Poland. In France, four national palliative strategies have so far been implemented and three laws passed that have contributed to the development of palliative care. In both countries, citizens have the right to dying with dignity.

There are national and regional organisations and associations in both countries which organise and coordinate the work of volunteers. In France, there is the SFAP acting as major national organisation and umbrella organisation. In Poland, there are several organisations working predominantly on regional level. The organisations are responsible for recruitment and qualification. The volunteers are insured through the organisations and their work is usually laid down in a contract. The deployment of volunteers is organised and supervised by a coordinator. In France, organisations working with volunteers are obliged to adopt a charter in which they lay down their principles for action.

In France, the focus of the volunteers’ work is set strongly on listening and being-there. They do not take over any medical tasks and do not have access to the patients’ medical records. The role of volunteers is described in detail in a ministerial document. In Poland, the volunteers’ tasks have shifted towards accompanying as well. Today, volunteers are less involved in medical care, but increasingly involved in supporting and accompanying. They are deployed in a variety of ways, though. One reason for this change is the financing of palliative care via the Polish health system and the associated professionalisation. Respect for intimacy and dignity, respect for confidentiality and protection of patients’ rights are codified in both countries and should be respected by volunteers.

In Poland, the average age of the volunteers is at 51 years; in France, the average ranges between 50 and 70 years. These two figures are from a rather not-up-to-date study from 2004. However, the age difference in the two countries also corresponds with the results of a recent scientific study on the age structure of volunteer hospice staff. In Northern and Western Europe, the age structure is between 50 and 80 years, in Eastern Europa between 20 and 40 years. A typical volunteer in Europe is over 50 years old, female and volunteers once a week (Pelttari 2018: 20). In contrast to countries in Western Europe, the persisting cliché in Poland is that voluntary work is rather an occupation for young people (Radbruch et al. 2015: 52). In Poland, the focus is thus on attracting older people as well and winning them over for volunteering. To do so, the 50+ volunteer service was launched, for instance, which is aimed at people aged 50 and over as a target group.
Figure 2 shows an estimate of the number of volunteers working in hospice and palliative care in Germany, France and Poland. In Poland in particular, the number of volunteers per 1,000 inhabitants appears to be very low, at 0.07 (Woitha et al. 2014: 6). Although these figures are based on merely one single survey, they nevertheless show a clear trend with regard to the number of volunteers in hospice and palliative care. Moreover, they are also in line with the general observation that, compared to Northern and Western Europe, there is generally a lower rate of volunteers in post-communist countries, irrespective of the field of deployment (Plagnol/Huppert 2010). The research has also shown that it would be favourable to have better data on the deployment of volunteers in hospice and palliative care in order to be able to better compare and evaluate their significance for hospice work in Europe.

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of inhabitants</th>
<th>Number of volunteers</th>
<th>Volunteers/1,000 inhabitants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Germany</td>
<td>82,046,000</td>
<td>80,000</td>
<td>0.98</td>
</tr>
<tr>
<td>France</td>
<td>65,073,482</td>
<td>29,369</td>
<td>0.45</td>
</tr>
<tr>
<td>Poland</td>
<td>38,153,389</td>
<td>2,500</td>
<td>0.07</td>
</tr>
</tbody>
</table>

The described volunteering is mostly limited to an institutional form within care centres, hospitals and hospices. Care for dying people in their own homes does neither in France nor Poland play a significant role in the publications and in the understanding of volunteering in hospice and palliative care. This is also confirmed by Woitha et al. in their study on forms and settings for volunteers in Europe. They find that volunteering is strongly limited to hospices and palliative care units in Germany, to hospitals in France and to hospices in Poland (Woitha et al. 2014: 7). In a study on volunteering in Europe volunteers and coordinators from 35 countries were surveyed about their roles, motivation, tasks, trainings and challenges. When asked which tasks volunteers perform in their facilities, the following five answers were most frequently cited (over 60 percent each): creative activities (e.g. singing and painting together), emotional contributions (e.g. touching and being-there), conversations and listening, leisure activities (e.g. walking, taking a trip) and offering family members emotional support through conversations and listening.

In order to carry out volunteering, training and further education are foreseen in both France and Poland. Volunteering is regulated and organised via the organisations and associations. They are also responsible for trainings and qualifications. Although large associations and interest groups now have training material and concrete training courses which they make available to their members, there are no uniform national standards or curricula for the training and qualification of volunteers in the field of hospice and palliative care in either country. Respond-

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ents to the above-mentioned study on volunteering in Europe stated that 67 percent of volunteers received between eight and 40 hours of training and courses. 21 percent passed more than 49 hours of training. The median is at 20 hours. The WHO sees it as the duty of states to anchor and strengthen palliative care in national health systems and to take additional measures to do so. One such measure is providing trainings for volunteers.20

In France, no information was found on innovative approaches or examples to attract and retain volunteers in the future. It was only found that the associations are dealing in working groups with the topics of future recruitment and the changes in volunteering. Especially the growing share of people with dementia as well as general problems with recruiting are considered to be the main challenges. It remains to be seen which measures will be implemented in the future. In Poland, in contrast, children are confronted with the issue from early age on. Pupils get involved by organising events and collecting donations for hospices and associations, mostly through their schools. Moreover, numerous campaigns, video clips and animated films suitable for children are also broadcast on television in order to raise awareness and remove taboos. The deployment of prisoners as volunteers in hospice services is an innovative approach and appears to bring benefits for both sides. Another challenge - the growing number of chronically ill and elderly people - has led to the explicit development of volunteering services for this target group in Polish communities. It seems that this topic plays a major role in the public discourse in Poland. On the other hand, many initiatives in Poland seem to be heavily dependent on fundraising and donations to carry out their work, partly due to lack of funding.

Drawing a deeper comparison of hospice and palliative care is difficult due to the different cultures, health systems, policies and legal systems, different understanding of volunteering but also of dealing with the topic of dying in terms of spirituality and faith. Rather, the similarities with regard to future challenges, in particular changes in volunteering, the increase in people with chronic illnesses and the growing need for hospice and palliative care in general, are more notable.

Finally, volunteering in hospice and palliative care needs to be put into a broader context.

There is a general change in volunteering: People are increasingly interested in short-term engagements. People work longer, have less time and volunteer work is thus less interesting and appealing to them. In addition, there is a tendency to choose and alternate more between different volunteering offers. This change can be observed in all of Europe (Pelttari 2018: 21). Keeping this in mind, it is necessary to rethink volunteering with regard to deployment and training; people want to get involved quickly and be put to practical use, and stay with their task for shorter periods of time than before (Schneider 2018: 3).

The cooperation with employed, professional staff is named as a major challenge (Pelttari 2018: 20). Volunteering in hospice and palliative care should be seen as an independent task, with an own position, identity and value, and existing alongside family care and professional

care. Volunteers and professionals must not be in competition with each other, but they should meet each other on eye level (Goossensen et al. 2016: 189).

A high priority on training and qualification leads to a significant professionalisation - and this has led to the fact that some volunteers are no longer willing to take over activities in the household or in the garden, as they have learned that the focus of their support lies on psychosocial support. The volunteers have thus become more professional on the one hand, but at the price of less flexibility with regard to their potential tasks, on the other hand. After all, qualification also means specialisation and higher expectations with regard to the tasks. One idea to counter this professionalisation of volunteering - and in particular its disadvantages - might be the introduction of a separation into qualified and unqualified (less formalised) voluntary work.

Eastern European societies are the fastest ageing societies in the European Union. In addition to this, many young people continue to move to the West. These societies thus need training for professionals and volunteers, international cooperation, research and European exchange of good practices. This holds also true for the field of hospice and palliative care (Scott/Howlett 2018: 93).

In countries like Estonia, Poland, Lithuania and Slovakia, membership in the EU has boosted the development of volunteering. EU policies encourage the development of volunteering through many European projects and programmes, and with financial support. There is European exchange and "learning from each other" which can have benefits for all parties involved (ibid.: 87).

The "EAPC Task Force on Volunteering in Hospice and Palliative Care in Europe" was founded and a European Charter was developed in order to support this European exchange and cooperation. The European Charter on Volunteering in Hospice and Palliative Care "Voice of Volunteering" was presented at the EAPC congress in Madrid in 2017. The international Charter calls upon all to recognise the important contribution, activities and role of volunteers, from their being-there for patients to organisational tasks, and to promote and support dying people and their dependants and relatives. Other core aspects of the Charter are the safeguarding of effective management via clearly defined roles, a careful selection procedure as well as the qualification and further training of volunteers. A final demand of the Charter is effective support for volunteering on organisational, regional and national level. The implementation of the Charter depends on the stages of development of the single European countries with regard to volunteering in hospice and palliative care (Pelttari 2018: 22ff). In the Atlas of Palliative Care 2013, Germany, Poland and France are ranked equally with regard to the development status of their hospice and palliative care - namely as countries in which hospice

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EAPC stands for "European Association for Palliative Care". The association includes 55 member associations from 31 countries. The EAPC organises annual European conferences as well as global congresses. More information at: www.eapcnet.eu/home.
and palliative care are at an advanced stage of integration into the regular health care system\textsuperscript{22} (Centeno et al. 2013).

\textsuperscript{22} The original text reads: “Worldwide palliative care alliance level of development: 4B. Countries where hospice-palliative care services are at a stage of advanced integration into mainstream service provision.”
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