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„Being there”— hospice and palliative care volunteering in Austria

Abstract

Volunteer hospice teams are part of the nationwide Austrian concept of a 'Graded Hospice and Palliative Care System'. This three-level system was commissioned by the Ministry of Health and developed by GÖG/ÖBIG, a national research and planning institute for health care, in joint cooperation with Hospice Austria in 2004.

By the end of 2016, there were 3528 Hospice and Palliative Care volunteers in Austria. 2929 volunteers belonged to one of the 162 hospice teams and were involved in direct patient care, 599 volunteers were performing other tasks in their hospice teams or were working within coordinating organizations in their federal state (e.g. as board members, helping with fundraising, etc.). 86% of the volunteers were female. Volunteers contributed in total 405,204 hours. 256,325 (63%) of these were spent in direct patient care in all kinds of settings at home, in palliative care units, in day hospices, inpatient hospices and also in nursing homes.

Volunteers in direct patient care are required to undergo a training based on a standard curriculum developed by Hospice Austria and are organized in teams with a (paid) coordinator.

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From first initiatives until today

Like in most European countries, the Austrian Hospice and Palliative Care Movement and first initiatives to improve end-of-life care in the late 1970's were based on volunteers with different professional backgrounds, many of them medical doctors, nurses or spiritual careers. Among these pioneers was Hildegard Teuschl CS of the congregation of Caritas Socialis Sisters. Sr. Hildegard's approach to hospice work was to start with adequate training with a first course for volunteers in Vienna dating back to 1979. Many participants went back to their federal state or profession and started the first hospice activities, other pioneers organized similar courses with the same curriculum in other parts of Austria. In the 1980's the very first hospice and palliative care services started with profes-

sionals as (paid) carers and volunteers from all walks of life as part of the care.

In 1993 Hildegard Teuschl CS and a group of devoted people founded Hospice Austria, the independent nonprofit national umbrella organization for hospice and palliative care institutions. This was an important step and a prerequisite that a nationwide concept of hospice and palliative care volunteering could evolve and finally was accepted all over Austria.

Hospice Teams as part of the graded hospice and palliative care system in Austria

There is no specific law for hospice and palliative care volunteering in Austria, but there are recommendations made by the Ministry of Health and Hospice

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Austria. The most important is the nationwide Austrian concept 'Graded Hospice and Palliative Care System' [1]. This three-level system was commissioned by the Ministry of Health and developed by GÖG/ÖBIG, a national research and planning institute for health care, in joint cooperation with Hospice Austria in 2004 and revised in 2014. Volunteer Hospice Teams are an integral part of this system.

The first level of this system is the primary health care setting with hospitals, nursing homes, and home care. The second level is support care provided by specialists and involves hospital palliative care support teams and home palliative care support teams. At the third level, specialized hospice and palliative care are provided in palliative care units, inpatient hospices and day hospices.

Hospice volunteers work as teams in all these contexts. Although the graded system has been integrated into the Austrian Health Care Structure Plan as a recommendation, only the standards for palliative care units are compulsory. These standards as defined in the graded system cover the range of professions, the number and qualifications of staff, and the range and quality of services and infrastructure and exist for all specialized hospice and palliative care organizations. Volunteer Hospice Teams are a very important part of this system and they also cooperate with other services. This graded system has also become an EAPC recommendation [2]. A separate graded system for children and young adults [3] exists as well.

As indicated above, the "structural quality" for volunteer hospice teams is defined in the graded hospice and palliative care system. A Quality Manual [4] for all hospice and palliative care institutions issued by GÖG/ÖBIG in 2012 defines their "process quality" by describing the steps of three processes: 1) from the first contact to start of care 2) care 3) bereavement support.

The revised concept of the graded hospice and palliative care system suggests at least 1 hospice team for 30,000–40,000 inhabitants. According to this plan, Austria would need around 210 hospice teams à 10 volunteers. In reality, the size of the hospice teams varies considerably, between 5 to 80 volunteers make one team.

Alongside this concept and before in the late 1990's and 2000's Hospice Austria also developed Austrian standards for volunteers and volunteer managers [5] and curricula [6] for the volunteers' training and this has influenced the development to the stage as it is today. The nationwide data survey [7] — conducted annually since 2005 — provides an excellent insight into hospice and palliative care in Austria, including volunteering.

"Being there" for patients

Hospice and Palliative Care volunteers in Austria were involved in direct patient care from the very beginning, even without a background in health care. "Being there", being with seriously ill and dying patients and their family members, is the great gift volunteers have to offer. Volunteers are sitting at the bedside, talking or reading to him/her, listening to a patient's memories, doing little errands, etc. They never replace professional services but complement them in a unique way. Therefore all volunteers working in direct patient care have to qualify for the challenges that they face in hospice work and must undertake training before they are allowed to work.

Training

Hospice Austria has three nationwide curricula for hospice and palliative care volunteers which are implemented in all nine federal states:

- Basic training (80 hours + 40 hours of practice) [8];
- Hospice and palliative care for children and young people (an additional 40 hours and 40 hours of practice) [9];
- Bereavement support (additional 80 hours or 110 hours) [10].

This national approach enables qualified volunteers to work all over Austria. This applies to all volunteers involved in direct patient and family care. If volunteers are working in an office or as board members, this training is not compulsory but is recommended.

Austrian Hospice and Palliative Care Data Survey 2016 and volunteers

By the end of 2016, there were 3528 Hospice and Palliative Care volunteers in Austria. 86% of them were female. Volunteers have various backgrounds, different motivations, different life experiences, their ages vary. 2929 volunteers belonged to one of the 162 hospice teams and were involved in direct patient care, 599 volunteers were performing other tasks in their hospice teams or were working within coordinating organizations in their federal state (e.g. as board members, helping with fundraising...).

Volunteers contributed in total 405,204 hours. In total 256,325 (63%) of these were spent in direct patient care. Volunteers do this in all kinds of settings: at home, in palliative care units, in day hospices, inpatient hospices and gradually also more and more in nursing homes. These numbers do not include the time, care and attention given to the patients' families and others close to them.

In 2016 hospice volunteers cared for 13,170 patients. The place-of-care range was palliative care units 30%, the patients' home 26%, nursing homes 23%, general hospital wards 11%, other places — among them day hospices — 6%, and inpatient hospices 4%. The low number within inpatient hospices — only 4% — is because in 2016 Austria had only 10 inpatient hospices in four out of nine federal states. The reason for this is lack of funding. Palliative care units are specialized hospital wards that are part of the Austrian health care system with clear public funding. A considerable number of these palliative care units, especially in Vienna, have their own hospice team which accounts for the high percentage of palliative care units as a place of care and also the high number of patients the hospice teams care for.

It will still take some time before hospice and palliative care volunteers are broadly working in general hospitals apart from palliative care units.

Volunteer management

Volunteers are organized in Hospice Teams. With the introduction of the graded hospice and palliative care system in 2004 by GÖG/ÖBIG and the Ministry of Health, a Hospice Team was defined as a group of 10–20 volunteers qualified according to the curriculum of Hospice Austria with a (paid) coordinator with at least 0.5 full-time equivalent. Coordinators must have a professional qualification such as a nurse or social work in addition to a multi-professional palliative care course (160 hours with 40 hours of practice). There are also additional requirements, which are defined in the national standards issued by Hospice Austria.

Volunteers, who intend to work in direct patient care, undergo a special training (see above). When starting with their volunteering in hospice and palliative care they become a member of a hospice team.

The national standards issued by Hospice Austria require volunteers to participate in team meetings, receive supervision and undertake ongoing training (at least 8 hours per year). As Hospice Teams also contribute to the annual data survey by Hospice Austria, volunteers are also required to keep good basic records of their work, hours spent in direct patient care and those spent with other activities, how many patients they cared for, where care was given, the age and sex of the patients, how many people received bereavement support, how many volunteers of which sex are members of the team, etc.

Every hospice team is a part of an organization (e.g. Caritas, Red Cross, local Hospice Association, Diakonie, inpatient hospice) which provides accident

insurance, reimbursement of travelling and telephone costs or other expenses that volunteers incur. The organization also provides opportunities for training and further education.

All the standards and regulations mentioned so far evolved from the experience that volunteers work for free, but require attention and support to do their work well. Patients and families have a right to receive qualified volunteer care. This can be achieved by coordinators matching a volunteer and a patient/family and by the fact that volunteers have a basic knowledge and self-reflection about death, dying, hospice and palliative care and their own role in the care system and family system.

The role of volunteers

Volunteers are interacting directly and in their own way with patients and family members. Depending on the place of care there is more or less freedom in doing so, although in general their task is always understood as supporting and being there as a companion. For legal reasons, they should not do any nursing tasks or fill in for the shortage of staff. A well-known challenge in Austria and many other countries is a good cooperation with professionals — being on par with each other.

A European perspective

The EAPC (European Association for Palliative Care) Taskforce on Volunteering in Hospice and Palliative Care in Europe [11], co-chaired by Leena Pelttari, Austria, and Ros Scott, UK, developed a White Paper on Volunteering [12] and issued the Madrid Charta Voice of Volunteering [13] to promote volunteering in the field of hospice and palliative care.

Two international symposia for volunteers and about volunteering also gave insight into similarities, differences, changes and challenges.

Changes and challenges

Austria shares with many European countries the experience that volunteering is changing: generally speaking, people commit for a shorter time, they also want to get something out for themselves, the retention of volunteers is an issue and volunteers' turnover is higher.

Also, the families and situations volunteers meet during their service are getting more complex.

Finances are an issue, as well, as public authorities in only some (federal) states contribute grants to the costs arising.

Conclusions

In Austria volunteering in hospice and palliative care is highly developed and an integral part of hospice and palliative care.

We find it very helpful to have the structures and means to tackle the challenges and at the same time, we strive to keep up the “spirit” of volunteering.

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