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Hospice and Palliative Care volunteering in the Netherlands. Practices of Being There

Abstract

Hospice and Palliative Care (HPC) volunteering is not easily comparable through European countries. Comparison of practices in different countries helps to acknowledge, protect and improve the core of this unique source in palliative care. To this end this contribution describes volunteering practices at the end of life in The Netherlands. It presents quantitative characteristics about numbers of volunteers, type of hospices and hours worked and a qualitative description of the volunteering work guided by the concept of 'Being There'. Some reflections on education of volunteers is added. The satisfaction of relatives with services is discussed and some thoughts on quality assurance of volunteering are shared. All information and data in this publication is retrieved from several 'grey' documents like mission statements, year reports or registration fact sheets. All describe the Dutch situation of HPC volunteering and are written in the Dutch language.

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Volunteering in different Dutch settings

A precise description and comparison of European volunteering practices illuminates the fluent character of HPC volunteering. Volunteering appears to be shaped by different contexts, cultural influences and delivery models [1]. In Europe volunteering roles can be observed varying from gardening, fund raising, doing practical tasks or befriending. Differences between and within countries exist. Roles of HPC volunteers appear not clearly defined and several authors report about confusion of 'role boundaries' [2]. These boundary issues between overlapping roles of volunteers need careful management [3] in order to maximise the flourishing of humane communities around terminally ill patients [4]. By studying characteristics of hospice and palliative

care HPC volunteering in the Netherlands, we will add to a growing body of knowledge that fosters a clearer identity and output of hospice and palliative care HPC volunteering. A need for further clarification of this identity was described in an EAPC White Paper on Hospice and Palliative Care HPC volunteering [5]. In The Netherlands educated volunteers offer where necessary time, attention and assistance — shortly 'Being there' — to terminally ill people and their close ones [6]. In 2017 more than 11.430 volunteers provided 1,43 million hours of care to 12.130 patients in the last months of their lives. Ninety percent of these volunteers are female and 75% are between 50 and 70 years old. The volunteers function within five different organisation types (n=198), ranging from offering volunteers at home to specialized palliative care units within in a hospital or elderly care organisation [6, 7].

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This type of volunteering became available to patients with advanced diseases and their families since the 80s in The Netherlands. Before that time hospices did not exist and it was uncommon for Dutch people to die at home. Leendert Vriel, a terminally ill young man, and his wife changed this tradition with the help of a journalist who wrote columns in a newspaper about their situation. Since then, services that provide volunteers in home situations and hospices have been growing [7]. In 2014 a nationwide survey (n = 1881) showed that in this respect more people could benefit from volunteers and die in a non-medical context. The results indicate that for 32% of the chronically ill people who preferred to die at home this could not be realised [8]. In 2017 The Netherlands scored a crude death rate of 8.9 people, this is the annual number of deaths during a year per 1,000 population at midyear. The Netherlands is number 67 on the Mondial list and Poland was number 33 with a score of 10.4 in 2018 [9].

Two kinds of hospices exist in The Netherlands. Most of these settings are called 'Almost at Home Homes'. These are houses with often 4 to 6 beds managed by a paid coordinator and a large group of volunteers (e.g. 60–120). The physician's and daily help with medication by home care nurses are organized per each individual patient. Volunteers provide direct patient care and run the household in shifts of four hours a week. The second type of Dutch hospices has a professional staff with nurses, a physician and often a chaplain. Here volunteers work in the garden, the kitchen, the reception or help the nurses. Of the total amount of Dutch volunteering hours, 9% is dedicated to tasks other than care, co-ordination or boardwork. Most common other tasks are public relations, handwork, or gardening [7].

The umbrella organisation registers several data from its members by a survey with questions about the organisation, finance, patients and volunteers. The last registration report of the umbrella organisation counted 49 Almost at Home Homes, 10 hospices with professional staff, 84 organisations providing a volunteer at home and 45 combined organisations (both in a hospice and at home). Volunteers were least often involved in palliative care units (n = 10) [7]. At home, one volunteer is matched with a family and stays with the patient so that family members can sleep or do shopping. In specialized palliative care units, they function in the surroundings of a larger care institution.

In 2017 Dutch volunteers cared for 12.130 patients with advanced diseases and their families. The characteristics of these patients have been stable for the past years: 51% is female, for 75% death is caused by

cancer, for 5% due by heart failure, and for 4% by frailty because of age. The care they receive is at the group level for 60% financed by government and on average for 15% by families themselves. The other 25% comes from diverse sources. Almost all organisations where volunteers provide care have an education plan for their volunteers (93%), many organisations have a plan for coordinators (63%) and 19% have an education plan for board members [7]. The largest part of the courses is provided at a national level, by an academy that is part of the umbrella organisation (VPTZ Nederland).

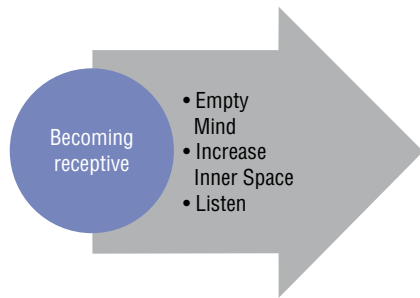
In the Netherlands, volunteering is characterised by the key elements: time freely given, no financial gain, within organisational structure aiming to improve the quality of life of patients. This concept of 'Being There' is considered as the core value of what volunteers do and are. How can this concept be understood?

On Being There

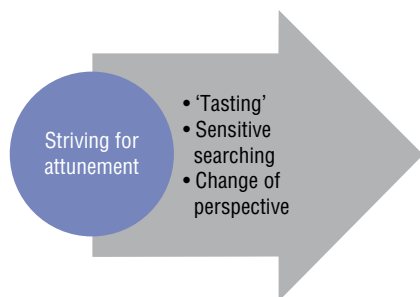
In The Netherlands Being There was chosen a de-cennium ago as the best way to describe what volunteers add to palliative care. From the descriptions by volunteers, it became clear that 'Being There' as a hospice volunteer has a responsive character, meaning that volunteers were extremely keen to 'read' persons, identify concerns, struggles or wishes and shape their contribution as a response to what they had found [9]. A volunteer from a hospice in stead of Hospice in Leiden writes about Being There in a quality improvement session:

Simply, Being There. Simply be with him. Simply?
That simple it is not! Is that the essence of contact, of connection? Attune when I am with the other. Find the balance in what can and what cannot be done. Invite the other, verbally, non-verbally, via touching, eye-contact.
From compassion feel where the other is, not from pity.
What may I do for you? Retaining autonomy of myself and the other. Offering. Being There in the presence of myself. The story of the volunteer that IS with the patient. Distant as well as close.
Time, to let go and to silence. The partner coming in and seeing the scenery. To affect, to touch, physically, mentally, spiritually.
She felt the beauty of the moment. Being There without active doing.
Moving!

This process of seeking relational attunement appeared to be best understood in 5 steps. In the first step, volunteers prepare themselves in several ways. They develop small rituals for themselves in order to leave the business of their daily lives behind. They dress in a certain way, travel to the location in certain ways and enter the patient's room in a certain way. Volunteers describe that they become silent,

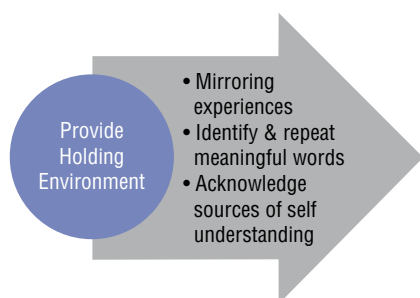


make themselves empty, work their way towards a state of attentiveness and receptiveness. As a next step of Being There, they describe how they put an effort in trying to dedicatedly change perspective with the dying person. They try to delicately pick up tiny signals and use words like 'levelling', 'searching', 'being open to the other's experience'. This creates a searching attentiveness, looking for what is going on. In volunteers this creates feelings of insecurity. Especially in the case of a new patient, volunteers

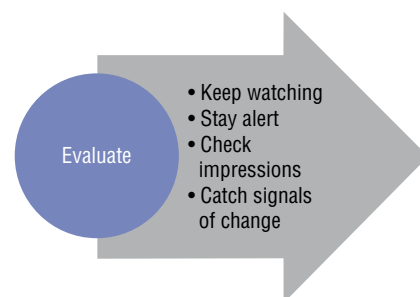


wonder whether they will find a way to connect with the patient's inner world.

Once they have an image of the state of the vulnerable person, volunteers try to offer small acts that contribute to a kind of cocoon in which the dying person can feel him- or herself being seen, heard and loved. Some call this a field of attention, built by the volunteer(s) around the dying person. They are there in an attentive way so that the person is not alone. They do not have standardized acts. They are responsive to the specific person, moment and context. They offer responses that might add to relaxation and inner peace of this unique person. What works in one situation, will not have effect in another.

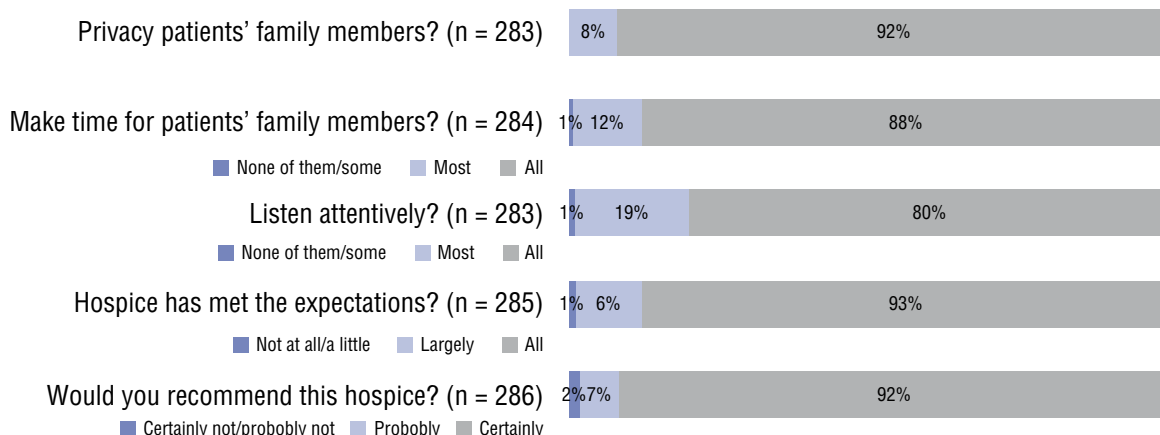


Sometimes that is enough, just to be present and rest together with the patient and with what is there. Sometimes specific questions or concerns arise. Volunteers then offer specific answers. For instance, if they 'read' that the person might be cold, they check this and offer a warmer blanket. Sometimes something to drink or eat is brought. These can be very personalized wishes like drinking a glass of wine at the end of the day together with the volunteer or eating chips with mayonnaise or a herring for one last time. In the latter cases, volunteers go out to arrange this meaningful food for the patient. Responses of volunteers also include answers to questions about the dying process, helping family members to recognize the stages of dying and learning them how to make a patient comfortable. Sometimes volunteers responded to a broader situation, e.g. in a case where family members wanted to send away the four-year-old twins of a dying young mother during the last days or her life. The volunteer advised the family to possibly let the children at home with their mother.



Often volunteers are not sure and enter the space between the patient and themselves, gently proposing an offer, when e.g. laying their hand beside the dying person's pillow, so that he or she can touch it, should it offer relieve. The most prominent aim of volunteers in direct patient care is to create the experience in the patient of mattering, being heard, seen, sometimes loved. Volunteers write about their contribution as a gift from the heart. They hope the patient will share inconveniences, fears and other concerns. And they try to provide typical things that strengthen this person at the existential level, like praying together, having a conversation about cows (with a farmer), or in the

Satisfaction patients' family members (n = 286)



case of insomnia play a game about who can name the most names of apple varieties (with a fruit grower). They add everything to a situation that might help to prevent or reduce feelings of loneliness, fear or despair, relieve tensions of all kind or might add relaxation, joy, peace, or love. Sometimes they gently speak up to family members as an advocate of the patient, for instance, if family members quarrel at the bedside or force a patient to eat. They provide hand or foot massages when helpful, and often hugs are available. They call the physician or nurse if symptoms worsen and may report to a chaplain in the case of spiritual crisis.

All volunteers start with training. There is a national academy and local trainers offer courses in their regions. At the national level, the basic training addresses topics like communication, losses & grief, safety and hygiene, and meaning. Sixteen follow-up courses are offered on these topics, and e.g.: medical knowledge, dementia, collaboration with professionals and complementary care (massage, music). Also, e-learning modules are developed that enable the volunteers to learn at home.

The impact of volunteering in hospice and palliative care is monitored in several ways. Volunteers express their gratitude and the way they learn from their contribution to the care for the dying. Exemplified a citation of a Dutch volunteer letter [10]:

“To be there for the other, to contribute to an atmosphere in which the other is able to say goodbye to his life with dignity. To help him or her, to coach, to support and also to be there for the family provides me with so much satisfaction. Sometimes I think: do I do it for the patients, the families or for myself? We all benefit, that is what I think.” (Female volunteer, age 55)

Evaluation

To learn about results, a pilot with data collection on satisfaction was performed by the Dutch national umbrella organisation [11]. Respondents were recruited by coordinators of 10 hospices in 2015 and 7 hospices in 2016. Questionnaires were sent by email to surviving relatives six weeks after the patients' passing away. The inventory used consisted of 32 questions on 7 axes: information, communication, care around eating and drinking, medical care, spiritual care, aftercare and privacy. In 2015 230 lists were collected from 10 VPTZ member organisations, in the first 6 months of 2016, 66 lists were added from 7 organisations. The results show no significant difference in scores from these two years, therefore the scores were put together. Data show extreme satisfaction with psychosocial and spiritual care, privacy and communication [11]. Table 1 illustrates the high satisfaction of family members about privacy, time, attention, and general impression.

Medical care was rated a little worse. 5% of the respondents said that the medical care provided by the doctor was not good enough. And 7% were not satisfied by the communication with the doctor. Given these results, we looked for an outcome measurement that was more sensitive to a differentiation between experiences.

Quality assurance

Co-ordinators select, supervise and coach volunteers. The former often have part-time jobs. In the Netherlands, many of them spend extra hours on a regular base without payment in order to get the work done. In practice, they appear to have several implicit criteria that define (future) quality of a volun-

teer. For instance: the values of a person, being able to reflect on oneself or unfinished business with own earlier losses. The way Being There is operationalised might seem easy and natural. However, the difficulty is the consciousness that before acting, receptiveness and being able to change perspective are important. This means that from the outside it is difficult to say if a certain act was right or not. The explanation of quality of Being There as offering the best response to a person means that certain routines, rules, habits or customs can be in the way, as well as protocols. A way to illustrate this is the example of a volunteer who was asked to stay in the room while a patient was approaching death. Some family members were in the room as well. The volunteer tried to help the patient and said: 'You can let go. You can go to the Great Light now.'. Was this an example of good volunteering or not? The answer is that we cannot say. It depends on what the dying person believes. If this person told this volunteer the day before that he was hoping to find a Great Light after death, that the idea provided him strength, it was a good action of the volunteer. If the dying person did not believe in a Great Light, it was a misfit and bad care. In reality, the family later explained that they did not believe in a Great Light. This was a relational misfit, a situation to learn from.

In order to clarify quality aspects of volunteering in palliative care, in 2015 a project started aiming to develop a quality framework and instruments for volunteers providing direct patient care. The quality framework is to map volunteering in hospice and palliative care as an act of Being There, clarified in steps [12]. Following this, it is explained that Being There succeeds when the dying person feels he or she is being heard, seen and acknowledged. A successful Being There means offering a response (to the situation of a person) that fits, according to the patient and his or her family. This response can also mean leaving them by themselves, if that is what is best. The quality framework introduces the concept of relational (*mis*) *match* to evaluate the quality of volunteering in direct patient care. The match means that the care offered is experienced as a right response to a patient or situation while mismatch indicates that something went wrong in the five steps of Being There. The consequence of this way of reasoning is that from the outside it is not possible to determine if certain acts of a volunteer are of good (enough) quality. Insider information from the patient or a family is needed to decide on this. An online story bank with more than 128 volunteer stories in palliative care provides

information for reflection sessions in the palliative care organisations where volunteers are involved. In this way, the quality is improved by thinking and discussion together about what is needed to provide the best palliative care.

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