
The volunteer in palliative care – a clearly defined role

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First, I want to state that I am giving this lecture on volunteers as a qualified professional person, employed full-time, working within a clearly structured and financially rewarding field. The fact that someone outside the field under discussion has been invited to give this talk is already part of the problem. In the literature and at congresses, the role of volunteers is mainly discussed by members of staff. It is not the volunteers themselves who define their own role. This is done by others who are not members of the same club, so to speak.

Second, I would like to suggest that the story of the good Samaritan from the Bible could have been a story about a non-professional carer. You may remember how a man walks the road from Jerusalem to Jericho and falls among thieves. Passers-by like a priest and a Levite – professional carers, if you like – do not stop and come to the man's assistance. Then a socially less-privileged person enters the scene, he shows empathy and helps the badly injured man lying on the ground. Strangely enough, those who should have felt it their professional obligation to stop and help continued on their path regardless, but the person at the bottom of the social ladder took on the job in their stead. Is charity and empathy (only) the role of the volunteer?

Contribution of volunteers to palliative care

Theoretically, the involvement of volunteers is an indispensable part of the palliative care concept. In the catalogue of values of both hospice work and palliative medicine, voluntary aid and support are regarded as a constituent part of paramount importance. This is not to be understood as a cost-cutting measure to meet the challenges of caring for the dying in terms of healthcare and the changing social and political situation. Volunteers are also not intended as substitutes for professionals, where the latter can no longer be afforded. The contribution of volunteers in hospice work is seen as an independent but nonetheless complementary contribution which 'ensures, that in the public opinion aid for the dying cannot be delegated entirely to the professionals'.

There is hardly a leaflet in the field of palliative care in which volunteers are not mentioned. Textbooks and congresses discuss volunteers as one of their subjects, and sometimes it is even possible to find articles written by volunteers – in which they will not define their role, unfortunately, but describe the problems and challenges of their work from a more emotional point of view. Hospice and palliative care services rely on the contribution of volunteers and could not achieve their social and political aims without them.

Problems of voluntary work

The German hospice movement proudly announces that it relies on the contribution of about 50,000 volunteers! Due to recent legislative initiatives in Germany, resources for the promotion, recognition and social coverage of voluntary workers have been made available. Why then do we need to talk about the problems of voluntary work?

Perhaps we need to talk about it, because the practice of voluntary work in palliative care shows a less than ideal picture.

- Institutional and outpatient services increasingly decline to co-operate with volunteers (they may mention the existence of voluntary services in the daily team meetings but the contribution of voluntary workers is hardly ever seen as one of the cornerstones of their delivery of palliative care).
- Volunteers may become surrogate family members.
- Often enough, volunteers have a negative attitude towards administrative measures, such as documentation, and regard qualifications as incompatible with their general status as informal and empathic carers.
- One of the German translations of 'voluntary work' is 'ehrenamt', meaning 'honorary post'. But in our country it is now not uncommon that such a post carries expectations of some kind of employment security.
- We know that a significant number of people refuse to work as volunteers because their efforts have been frustrated in the past.
- Volunteers may suffer from helper's disease.
- Volunteers are being misused as substitutes for professional staff.
- Some voluntary organisations decline to work alongside professionals, because they believe that only those who have experienced the same kind of suffering, such as bereaved parents in the organisation 'Compassionate Friends', are able to show real understanding.

What are the reasons for the difference between lip service, vision and reality? What are the duties, roles, obligations and rights of voluntary workers? Is a concept of care that relies on volunteers 'old hat'?

Personalities in the volunteer field

And, furthermore, exactly who is this mysterious stereotypical volunteer whom the professionals in the palliative care field seem to know so well? I think, we probably take too simplistic a view of voluntary workers. As there is no such thing as 'a stereotypical dying person', why should there be 'a stereotypical volunteer'? Let us take a closer look.

- Take, for example, a 48-year-old woman. Her children have left home and she is looking for another meaningful

occupation. Having been a housewife, she would like to take up 'some kind of social work' and care for others in a different way. Furthermore, she longs for social contact and interaction.

- Take the 62-year-old widow. Two years ago, her husband died from cancer after a long period of suffering. During the course of his illness, she had a very hard time. She experienced doctors who were always in a hurry and not very empathic, overstretched and exhausted nurses, endless therapies, and in the end her husband's death became an isolating and segregating experience in a multi-purpose room. At the time she resolved to help work towards a better dying culture.
- Take the man in his mid-fifties, a renowned and extremely respected member of his community with real organisational talent and many connections. He wants to fulfil his communal and social responsibilities, and he also likes being asked for advice and to exert his authority a little. Perfect material for a committee chairperson!
- Take the young mother-of-two, who temporarily neglected her career for the sake of her children, but she left it too long and lost touch with her profession. She hopes that working as a volunteer will give her some additional qualifications, good references and therefore increase her chances to return to her employment as a social worker. She is also interested in personal challenge and development.
- And finally, take the newly qualified physician in his first job. He is disappointed by the reality of work in a hospital and would like to find a place where he can put his ideals into practice, ideals that made him want to become a doctor in the first place.

These five types, chosen at random, may nevertheless be typical examples of personalities working in the voluntary sector.

Common denominators

What is it that these five personalities with five different sets of motivation and five different reasons to take up voluntary palliative care have in common? Is there even the tiniest common denominator? And, furthermore, is the make-up of volunteers completely different from that of professionals? Maybe looking at some of the terms in this field will give us a clue.

Could the status of layperson be the binding factor between these five persons? Not really, because the doctor mentioned above is not a layperson, and the four others bring along life experience and emotional maturity and compassion. This indicates a core competence that is not compatible with the term layperson.

'Honorary post' is a historical term with many promising connotations. But where is the honour? And is there really a post? Outsiders, acquaintances and friends may still have this rather colourful historic meaning in mind when they make comments like, 'This is what you do in your spare time? I couldn't do this kind of job!' A post or a job should have clear descriptions of what it encompasses – this is not true for voluntary work. Whatever needs to be done depends on the varying wishes of those who require support in whichever field is applicable at the time, and, of course, it depends on the co-ordinator, who sets up varying task schedules for volunteers.

The term voluntary work is also ambiguous. You may take up voluntary work, but at the same time you have to make commitments and work according to the schedule you are given – not unlike a professional, who also goes to work every morning according to his/her own will, almost.

Unpaid work – this is what seems to be left at last as the binding factor. But does the term unpaid work, and this means unpaid work done by tens of thousands in each country, somehow belittle the huge commitment of those who do it?

Other terms I found in the literature were charity – a personal obligation to do social good; solidary action; informal care; non-commercial (not-for-profit) work; and acts of social and civil responsibility. They all seem to be rather vague and contrived terms and not very helpful.

If there is no stereotype of a volunteer, then there is also no predefined role that a volunteer should take on. Their roles seem to be as individual as the volunteers themselves. Nevertheless, a volunteer's role is not to be defined by the volunteer him/herself at his/her individual will. We could stop here and answer the title question of this lecture in the negative. 'No, the term volunteer does not imply a clearly defined role.' But this is not a satisfying answer.

The benchmark for contributions of volunteers, their duration and intensity of commitment, can be none other than what a dying person and his/her family need, in addition to pain and other symptom control, palliative nursing care and the social support of professionals.

Therefore, from the viewpoint of a dying person and his/her family, a volunteer is expected to act as a kind of chameleon within the environment of their wishes. What volunteers should not have are aims, ideas or needs of their own. Because the services to be delivered by a volunteer should fit exactly the expectations of those who are in need of support, volunteers can by no means act according to their will/'voluntas', not even according to their wishes. In practice, their commitment is not inclination-oriented, but rather ability-oriented.

This leaves the question as to who would make a good volunteer and who is going to decide this? And furthermore, who places the volunteers according to their abilities and with which families? The co-ordinator has a very important and responsible part in this field. First, she organises information events. Those who are interested in taking up voluntary work will then take part in a qualification course. This early encounter is of paramount importance for further developments; it lays the foundation stone for further commitment and is the key to future success or disappointment. If this early chance to build mutual trust, a feeling of solidarity, co-operation and an openness to honest self-appraisal on both sides is not handled well, the first step to a regressive development is already taken. Therefore, the aims and content of these qualifications need to be well considered. The same applies to the teaching content and the role model aspect presented by the co-ordinator.

Content of training courses for volunteers

How to communicate with oneself?

A professional carer must employ a twofold attitude towards the suffering nature of the human existence. On the one hand, the carer needs to detect the reasons for suffering and other people's pain in order to eliminate them. The carer is

expected to give a practical, positive answer to problematic matters of existential and physical suffering. On the other hand, the carer is expected to accept his/her own existential suffering as an indispensable part of the human nature and to live life in harmony with the knowledge of one's own inevitable mortality. In working with a patient facing death, a carer must be able to reflect on his/her own life and attitude towards his/her own mortality. Otherwise, real and true support cannot be given.

Therefore, work on one's own biography is seen as the central element for the delivery of good care. Experiences of loss, death and dying must be considered in terms of one's own concepts of dealing with these experiences. We know that further training programmes that address matters of death and dying are not fruitful unless the participants have previously been given enough room to reflect on their own experiences in this field and make a comparison with the experiences and attitudes of others.

If – for example – a person who still bears a grudge against institutions like hospitals or nursing homes, has not been able to deal with his/her own feelings of guilt or cannot express his/her true hopes and fears, these feelings and unreflected attitudes may surface involuntarily and unexpectedly within inappropriate care contexts and get in the way of delivering good quality care.

Another important aspect of training courses, which include units on autobiographical work and self-assessment, is that participants will learn what impact their previous experience of death and dying has on their expectations of their own death. Every experience has left its mark on one's own concept of what other people's and one's own death should or should not be like. There is a danger of promulgating one's own concept of death, which does not allow others their own individual experience of death.

'As a student, I worked at the university clinics of Bonn during my vacation. One day, all of a sudden I found myself involved in the care for an old patient who, even from his hospital bed, continued to reign over his family members like a despot, so that none of them came to see him. Fearing his death would be a lonesome experience, I undertook measures to make up for his behaviour. The old chap sensed what I was up to and was luckily not too weak to stop me by saying, "Don't even think of dragging my family to my bedside when I'm going to die. This is a moment I will celebrate on my own." I learned a lot from this man.'

Reasons and motivation for caring

The reasons behind the social involvement of voluntary workers, especially in the field of care, must be thoroughly questioned and reflected on. This is quite the opposite of mistrust: it is the first and most important step towards truly autonomous and responsible action. What is it that I am doing? To whose benefit are my actions? What are my intentions?

Some people do what they do because it was the only possible role they were given within their own family, and maybe they were loved and adored only when caring for others. Some people do what they do because they want to rid themselves of the fear of their own mortality, and they may think that dealing with other people's death would cure them of their own fears. Other people do what they do because they feel unimportant, maybe even 'invisible' in

Box 1. PLEASE PROVIDE HEADING

Volunteers contribute:

- Personality
- Openness to self-reflection
- Dependability
- Identification with the care concept and its practical implications
- Willingness to serve and cater for someone else's needs
- Personal strength and life experience that are not limited to the process of helping
- Acceptance of the necessity of training and documentation.

Volunteers need:

- Trust and respect
- Competent, sensitive and (tutelary/protective) co-ordinators
- Continuing training, work assistance and supervision.

Then they can find their roles:

- Voluntarily
- Reliably
- Not oriented to material gains
- In the public arena
- Co-operatively
- Supportively
- Responsibly and autonomously
- Within a framework of limited time and resources.

their ordinary life, and they may like this new position of someone who is in charge. None of these reasons are bad in themselves, but it is very important that volunteers and co-ordinators are aware of them. Otherwise, these reasons may become secretly counterproductive, and they may result in volunteers burdening, rather than supporting, patients; or lead to burnout on the part of the volunteers.

People who work in the care of the dying are often described by others as brave, strong, selfless, empathic, compassionate, kind, warm-hearted, ready to help, altruistic and so on. Before accepting descriptions such as these as self-evident, volunteers should ask themselves whether or not these adjectives describe the true attitudes behind their contribution. They should also ask themselves whether or not some selfish reasons may in fact determine their action, something that would be neither unusual nor 'forbidden'. To be able to do so, volunteers need support from the early stages of their involvement onwards. As already mentioned in my own example of caring for a dying old man, two 'real selves' meet in the process of support. They should see each others as partners, who are responsible for their own actions, and not as 'a help automaton' or 'a mere passive recipient of help'. This means that the helper is truly grounded in his/her own self and able to be open to other people.

Attitude rather than technique

A qualification concept, in which the wishes and needs of dying people and their families are the highest aim, must strive to build up and strengthen certain attitudes rather than techniques. If the aim were to learn a number of techniques, this would imply that those who are cared for, are treated as objects, not subjects. The dying person is not in need of care methods but rather of human care and solidarity. Humanity and solidarity are attitudes, not methods or techniques.

One of the greatest challenges facing the co-ordinator is to act as a role model for volunteers and potential volunteers

in terms of understanding the paramount importance of attitudes in human contacts. She should be able to show clearly the importance of a dialogical approach to others as well as the indispensability of respect for the dignity and integrity of others. She should also be a living example of a well-balanced person in terms of talking about feelings, meaning that she can keep the necessary distance while at the same time still being empathic.

Nevertheless, the wishes and needs of dying patients and their families must be known to the volunteer or – if they are not clear – carefully evaluated. By the same token, patients and families may be under such agonising physical or mental stress that it is difficult for them to define clearly what they want.

Even so, volunteers cannot assume that the wishes and needs of the dying and their families conform to a certain pattern, for each person deals individually with anticipated and real losses. Therefore, the volunteer should be taught to listen carefully to what is being said and to understand non-verbal information.

‘During a supervision session a volunteer once reported about an aphasic patient, to whom she recited a prayer at the end of each of her visits. After the patient’s death she learned from his daughter, when they were preparing the funeral ceremony, that the patient had not been a member of a church for many years. The volunteer felt very insecure about her action in retrospect. When asked why she had believed that the patient would have liked to say a prayer, she answered that she had assumed this were the case. In a role play, where she then took on the role of the patient and reflected on all the observed gestures, it became obvious that the patient must have given enough signs of refusal and ‘inner emigration’ and that the volunteer had been too sure of her assumption to detect those signs.’

This example clarifies how important it is that qualification measures include unprejudiced attention to the patient. Volunteers must understand that perception of a patient should not be based on interpretation and assumptions but on the most attentive listening and observation, without any preconceived conclusions. Therefore, a training unit on ‘how to perceive’ is of the utmost importance.

The neutral point of view that should be taken by the volunteer is not to be misunderstood as being that of a distant observer of the process of dying and the network of family relationships. Neutrality is not indifference, but an independent look at things and processes, unbiased by ideology, prejudices and assumptions.

Let me assume the role of a mature volunteer who might say the following, ‘It is not only us who are in need of training. Those who co-ordinate our services and the institutions and services we are supporting need to be enabled to work along with volunteers. It is not our responsibility to find out what the targets of voluntary

support of these services should encompass. Therefore, these services must clearly define their roles first before they go and develop training aims for us and ask themselves on the basis of these definitions the following questions:

- What is it that the volunteers should do?
- Where should they do it?
- In co-operation with, and complementary to whom, should they do it?

It is the institutions and services and not the volunteers that are responsible for connecting professionals with voluntary workers. The field of care is still largely influenced by the attitudes of professionals. Whenever voluntary informal carers are to be integrated in care, it is also the professionals who have to make certain adjustments. These are necessary, for example, in the field of manifest structures of co-operation and routines. The co-operation with volunteers must be oriented to changing needs and contexts.

Integration

An artificial division of professional and voluntary contributions in the delivery of ‘proper’ treatment and supplementary care, and a reduction of the volunteer to a mere ‘holding of the patient’s hand’, is discriminating and does not comply with the patient’s needs for a holistic approach. In order to deliver a trustful atmosphere of all-encompassing care, volunteers need to be integrated in the early stages of care. They are not some kind of last resort when the professionals are becoming less involved. Rather, they represent an additional and assisting social service of everyday care with certain qualifications of its own. Professionals and volunteers must find the appropriate way to link one with the other most effectively.

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