

The role of volunteers in Palliative care

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Abstract

Background: Volunteers are recognized as the third resource for palliative patients alongside with professional care and family care. They do not replace them. Volunteers have their own special place and their specific role in that care. Besides the volunteers who will be directly with the patient and the family, volunteers who are involved in organizing, fundraising, promotion and various other roles are also important. In order to help volunteers to play their role and to make this assistance sustainable, it is important to have volunteer organizer (manager) that links all three care resources (family, professionals and volunteers).

Keywords: Multidisciplinary team, Palliative care, Palliative patients, Volunteers

INTRODUCTION

The needs of a palliative patient and his or her family (or carer) are manifold and very complex. For this reason, volunteers also play a significant role in the care of such a patient. Volunteers are recognized as the third resource for palliative patients alongside with professional care and family care. They do not replace them. Volunteers have their own special place and their specific role in that care. What can volunteers do for the patient and his/her family? Volunteers can be there for the patient and the family, helping them in a way they need. By putting the patient and his/her family at the centre and providing concrete help, volunteers create an atmosphere of love and attention, contributing at the same time to preserving the true dignity of the human person and the sanctity of life.

“Being there” for the patient

What can volunteers do for the patient? While all other members of the multidisciplinary team have specific tasks and problems that they need to address in relation to the patient and his or her illness (the doctor is focused on managing pain and other symptoms, the nurse on patient care, the social worker on solving social problems, etc.), only the non-health volunteer has no particular task or situation that must be addressed; s/he only has to be present. Therefore, s/he can focus completely on the patient and the family. This does not mean that s/he will not do what is necessary at that moment. It just means that s/he can be completely guided by the situation and do exactly what is needed. Sometimes it will be conversation, other times silence; sometimes it will be some household chores, or doing the paperwork, walking with the patient, and many other such tasks.

The importance of “being there” must be stressed. Terminal patients in the last moments of life do not feel only the pain caused by the approaching physical death, but also the pain of “social death”. This feeling that in the last moments of life they have been abandoned by everyone, that they are no longer of interest to anyone and that people around them can’t wait for their last breath can mean that only one’s social death is worse than physical death. The dying place high expectations of their social network. They constantly express the need for closeness to other people, seeking social support (Callahan, 2005: 104). Mother Theresa also said that there was no gravest illnesses in human life than being “unwanted, unhappy, isolated and left out”.

Volunteers create peace and prepare patients for a peaceful death.

“Being there” for the family

Humans are by nature social beings. They are born into families, live in families for at least a part of their life, and also want to die in a family. Moreover, as Callahan (2005) argues, the quality of dying and death cannot be fully achieved outside the social environment and relationships with other people, especially without family support. However, the family is often weakened by suffering in times of uncertainty and changes resulting from the imminent death of its member. This can make it disorganized and dysfunctional, in need of help and support.

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Volunteers create a feeling that the family is not alone in this difficult situation, that they can always call someone to get advice or extra help. They inform the family about their rights and opportunities for getting other types of assistance (from institutions or organizations), and help them exercise their rights. By spending time with the patient, volunteers provide family members with time for rest or for other activities, which contributes to the feeling of security and stability and helps to prevent excessive fatigue. After the patient's death, the volunteer can offer support in bereavement, as someone who has accompanied the family through the last days of their loved one and who they can trust.

Other positions and roles volunteers have

In addition to the volunteers who are in direct contact with the patient and the family, volunteers who are involved in organizing, fundraising, awareness raising and various other roles are also important.

The other important roles include the following:

- Informing and educating the community about palliative care
- Sharing the experience
- Creating a network of trained volunteers
- Raising awareness about the importance and benefits of volunteering
- Building a better world, by personal growth of volunteers themselves, but also by helping others.

METHODOLOGY

Volunteers management

In order to help volunteers play their role and to make this assistance sustainable, it is important to have a volunteer organizer (manager), who links all three care resources (family, professionals and volunteers). Coordination is necessary to maintain the continuity and quality of care, and to ensure care is complete.

It is very important for volunteers to be continually educated and supported.

This work should be done by a professional volunteer coordinator. Volunteer coordinators are required to have a variety of knowledge and skills such as: management, leadership, deep understanding, empathy, compassion, palliative care knowledge, and the ability to bring a large number of different people together into an effective team. The recommendations from the European Association for Palliative Care say: "The volunteer hospice team consists of at least 10 to 12 hospice volunteers and one dedicated professional coordinator. The coordinator should have an education in the social care and/or the health care sector, with additional specialist training in palliative care."

Palliative care volunteers see a lot of suffering, concern, pain and sadness that inevitably touches them. Just like professionals, volunteers also they need some free time to recover, an opportunity to shed tears and express their feelings. Therefore, they need a sensitive, trained coordinator to monitor and support them. Regular supervision meetings with volunteers are important, at which they can share experiences, speak out about their problems, ask for advice, etc. so that burnout does not occur.

Result

In our 10 years of experience in the NGO La Verna, a typical volunteer is a woman above the age of 50, usually retired. With their maturity and life experience, and the opportunity for a more lasting and continuous commitment to patients and their families (more permanent than in the case of young people whose life circumstances often change), they can be a stronger support and accompaniment.

DISCUSSION

It is not easy to promote palliative care volunteering because it is always associated with death and dying. For this reason it is not easy to attract volunteers. In addressing the broader community it is advisable to send positive messages, share personal stories (both volunteers' and patients'), and emphasize the values of volunteering. To attract volunteers of different ages, a variety of palliative care volunteering programs tailored to different target groups must be developed (kindergartens, schools, students, employees, retirees, etc.). Programs should also be adapted to modern ways of communication.

CONCLUSION

The overarching European Health 2020 Strategy clearly emphasizes the importance of joint efforts, partnerships and involvement of all stakeholders in health and society in achieving the key goals: improving the health and well-being of people, reducing health inequalities and ensuring the health systems that are sustainable and human-oriented.

A multidisciplinary approach, connecting the civil society with the existing system of healthcare, social and spiritual services, contributes to the development of high quality, systematic palliative care in this country. In this way the patient can receive a more holistic kind of care, and families are enabled to take an active part in looking after their loved ones and to preserve their role even in the most grievous moments of their lives. Our experience of working with palliative patients and their families confirms their need for understanding, community support, happiness and the reduction of stress that is inevitable and very pronounced amidst life changes that a terminal

illness brings about.

Palliative care wants to raise awareness about the importance of life even in those moments when we are weak and powerless; it gives warmth and light when life is slowly expiring.

References

1. Arambasic, L. (2005). Gubitak, tugovanje, podrška. Zagreb: Naklada Slap.
2. Buckman, R. (1996). Ne znam sto reci. Zagreb: Skolska knjiga.
3. Callahan, R. (2005). Holistic Home Hospice: Caring for a Dying Father: A Family Hermeneutic Exemplar. *Home Health Care Management & Practice*, 17 (5): 365-369.
4. Cicak, M. (2008) Obitelj u palijativnoj skrbi, *Ljetopis socijalnog rada* 15 (1), pp 113-130.
5. Council of Europe. Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, 2003. [www.coe.int/t/dg3/health/Source/Rec\(2003\)24_en.pdf](http://www.coe.int/t/dg3/health/Source/Rec(2003)24_en.pdf)
6. Havelka, M. (1995). Komunikacija s teskim bolesnikom i njegovom obitelji. In: Jusic, A. et al., *Hospicij i palijativna skrb*. Zagreb: Skolska knjiga i Hrvatska liga protiv raka, 61-63.
7. Radbruch L, Payne S. White Paper on standards and norms for hospice and palliative care in Europe: part 1. Recommendations from the European Association for Palliative Care. *EJPC*. 2009;16(6):
8. Zinic,S. (2019). Volonteri u palijativnoj skrbi, završni rad, Sveuciliste Sjever Varazdin.