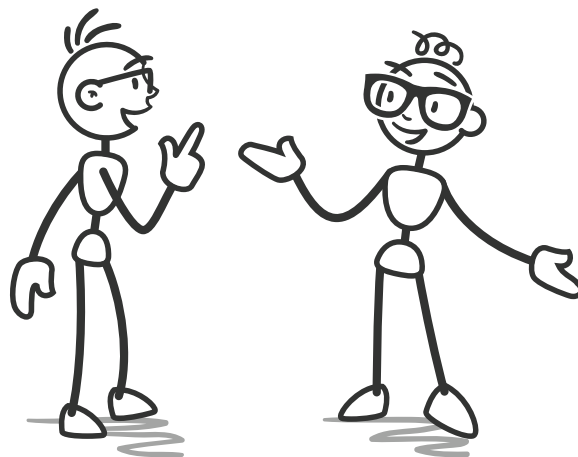




Management Practices for Hospice Palliative Care Volunteers

Patrick Durivage, Isabelle Van Pevenage
and Carole Couturier



ISBN:

Print: 978-2-922582-43-7

Web: 978-2-922582-44-4

March 2015

*Agence de la santé
et des services sociaux
de Montréal*
Québec 

Québec 

Acknowledgements

A project of this scope requires the support of many individuals. The Leading Service in Community Palliative Care for Seniors at CSSS Cavendish – University-Affiliated Centre – CREGÉS would like to thank the Ministère de la Santé et des Services sociaux for providing funding for the completion of this guide.

Advisory committee

- Patrick Durivage, Social Worker, Coordinator of the Leading Service in Community Palliative Care for Seniors, CSSS Cavendish-CAU
- Isabelle Van Pevenage, Sociologist and Researcher, CSSS Cavendish-CAU
- Cindy Starnino, Director of Quality and the University Mission, CSSS Cavendish-CAU
- Claire-Joane Chrysostome, Assistant, Development of the University Mission, Partnership and Outreach, Quality and the University Mission, CSSS Cavendish-CAU
- Joanne Bélanger, Planning, Programming and Research Officer, Department of General Services and Chronic Diseases, Agence de la Santé et des Services sociaux de Montréal

Operational committee

- Carole Couturier, Adult Educator and Project Leader
- Cristina Nitu, Project Officer

Interviews with researchers

- Robin Cohen, Ph.D., M.Sc., B.Sc., Professor, Department of Oncology in the Faculty of Medicine, McGill University, Jewish General Hospital, Staff Investigator, Lady Davis Institute for Research
- Andrée Sévigny, Ph.D., Social Worker, Associate Professor, Department of Family Medicine and Emergency Medicine, Université Laval; Researcher at the Centre d'excellence sur le vieillissement de Québec, and Deputy Director of the Institut sur le vieillissement et la participation sociale des aînés (IVPSA)

Interviews with volunteer coordinators

- Anna Feindel, Hope & Cope, Jewish General Hospital, Montreal
- Louise Lambert, Albatros Est-de-L'Île-de-Montréal
- Anna Maria Malorni, CSSS Cavendish-CAU
- Florinda Martin, Palliative Home-Care Society of Greater Montreal
- Carole Singher, Lumi-Vie
- Chantal Yan, Nova Montréal

Interviews with volunteers

- Joyce Jarand, volunteer
- Pierre Meurice, volunteer
- Odette Michaud Lacroix, volunteer

Review committee

- Joyce Jarand
- Anna Maria Malorni
- Florinda Martin
- Andrée Sévigny
- Carole Singher

Other acknowledgements

- Muriel Guériton, Librarian, Documentation Centre, CSSS Cavendish
- Geneviève Lamy, Coordinator, Knowledge Sharing, CREGÉS, CSSS Cavendish
- Virginie Tuboeuf, Administrative Assistant, University Mission, CSSS Cavendish

Table of contents

Introduction	7
Presentation	8
Methodology	9
Definition of palliative care	9

Section 1: Profile of palliative care volunteers

1. The role of palliative care volunteers	11
1.1 Role category: instrumental support	
1.2 Role category: emotional support	
1.3 A place in the team	
1.4 The can make a difference—a key component	
1.5 Volunteers' mission in terms of their social role	
1.6 Distinctive features of home-based care	
1.7 Home care in rural communities	
1.8 Evolution of the role of palliative care volunteers	
2. Expected competencies for palliative care volunteers	16

Section 2: Five activities related to the management of palliative care volunteers

Activity 1 – Recruitment and selection

1. Important information about recruitment and selection	21
1.1 Motivations for becoming a palliative care volunteer	
1.2 Recruitment sources	
1.3 Male volunteers	
1.4 Review of the palliative care volunteer profile	
1.5 Selection criteria	
2. Potential recruitment and selection pitfalls	30
2.1 Lack of interest in palliative home care	
2.2 Refusal to have volunteers in the home	
3. Ideas on how to improve recruitment and selection	32
3.1 Content	
3.2 Sources	
3.3 The message	
3.4 Volunteer coordinators	
4. Further reading on recruitment and selection	34

Activity 2 – La formation

1. Important information about training	35
1.1 Content of training programs	
1.2 Limits of the volunteer role	
1.3 Training on people skills	
1.4 Training on know-how / 1.4.1 Communication / 1.4.2 Managing stress	
1.5 Approaches and techniques / 1.5.1 Approaches / 1.5.2 Techniques	
2. Potential training pitfalls	44
2.1 Lack of time	
2.2 Lack of training	
3. Ideas on how to improve training	45
4. Further reading on training	46

Activity 3 – Supervision

1. Important information about supervision	47
2. Potential supervision pitfalls	50
2.1 Stressful situations	
2.2 Challenges	
3. Ideas on how to improve supervision	51

Activity 4 – Evaluation

1. Important information about evaluation	55
2. Potential evaluation pitfalls	58
3. Ideas on how to improve evaluation	58
4. Further reading on evaluation	58

Activity 5 – Retention

1. Important information about retention	59
1.1 Motivations	
2. Potential retention pitfalls	62
3. Ideas on how to improve retention	63
4. Further reading on retention	65

Conclusion	66
Bibliography	67
Resources	69
Reference documents	70

Introduction

Volunteers are important allies in palliative care, regardless of the setting (in the home, at a long-term care facility or in a hospital). This document is based on a review of the scientific literature published in North America over the past ten years, as well as interviews with individuals involved in the field. It is aimed at enhancing knowledge and building volunteer resources in the palliative home care sector. This guide proposes avenues for reflection about the practices used to manage palliative care volunteers in general, often with a specific focus on home-based care. The project was funded by the Ministère de la Santé et des Services sociaux following a call for tenders, to which the Centre for Research and Expertise in Social Gerontology (CREGÉS) responded in the summer of 2013.

It worth noting that there is a lack of scientific literature on palliative home care. This area requires further study to better understand its associated practices.

A note on terminology: “hospice palliative care” may be offered in several settings: hospices, hospitals, long-term care facilities and the patient’s home.

Presentation

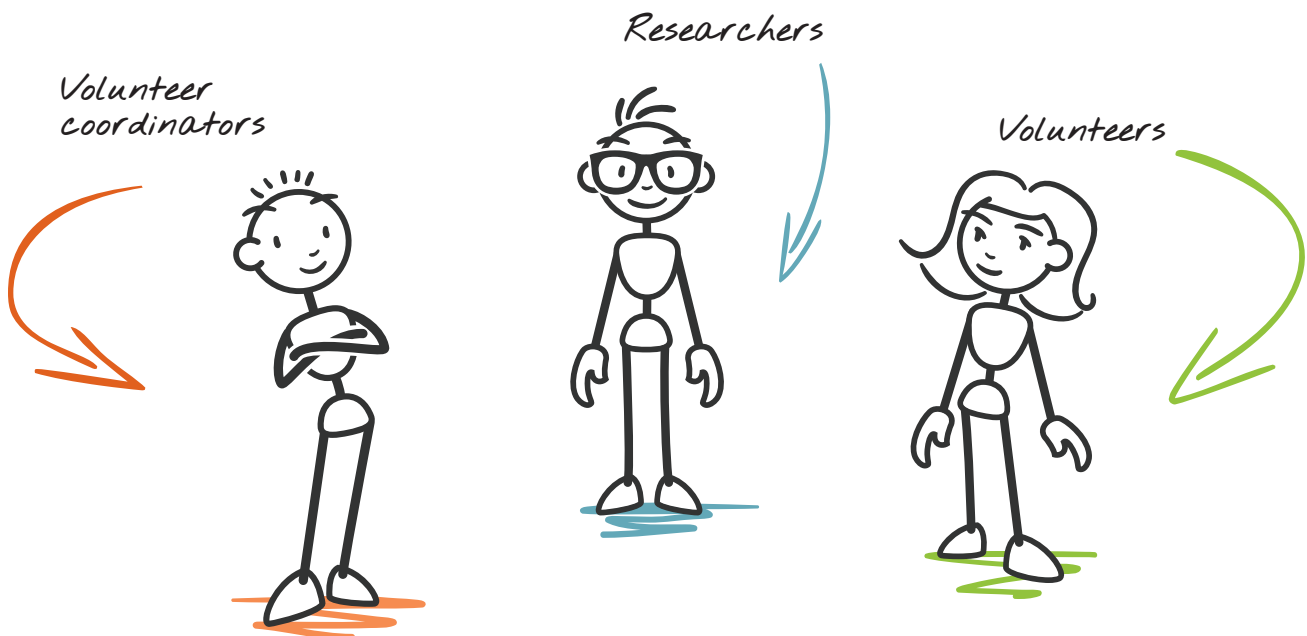
This *Management Practices* guide is a reference tool for coordinators of hospice palliative care volunteers, as well as anyone involved in volunteer supervision.

It is divided into two sections: the first looks at the profile of palliative care volunteers, including their role and the skills they are expected to have. Given the scant scientific literature on the involvement of volunteers in home-based care, this is a general profile for palliative care volunteers.

The second section is focused on five activities related to managing palliative care volunteers, notably: recruitment and selection, training, supervision, evaluation and retention. Each activity has the following headings:

- Important information: what we have noted about the activity;
- Potential pitfalls: problems we have identified in relation to the activity;
- Ideas for improvement: the ideas presented do not necessarily address the problems identified in the previous section—they are general ideas that can help coordinators improve the situation;
- Further reading: a list of resources and references that might be useful.

Excerpts from interviews with volunteers, volunteer coordinators and researchers are included in the guide and are colour-coded according to the type of interviewee. The literature review provides a framework and appears in black in the text.



Methodology

A scientific literature review was conducted using the most relevant databases.¹ There are few studies specifically focused on palliative home care. We had to broaden our research scope to include palliative care practices in hospitals, hospices and homes. Among the 34 selected articles published in North America over the past ten years, only five were on palliative home care. We completed the literature review using the book *Le bénévolat en soins palliatifs ou l'art d'accompagner*, edited by Andrée Sévigny, Manon Champagne and Manal Guirguis-Younger.

To complement, qualify and confirm best practices in palliative home care, interviews were conducted in December 2014 and January 2015 with volunteers, volunteer coordinators and researchers. Three volunteers from the Montreal and Quebec City areas, five coordinators—involved with organizations in Montreal, Laval and at CSSS Cavendish-CAU—and two researchers agreed to answer our questions (see their profiles in the “Acknowledgements” section).

Definition of palliative care

The following definition of palliative care is based on definitions by the World Health Organization and the Canadian Palliative Care Association:

Palliative care is the active, total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Palliative care is planned and delivered through the collaborative efforts of an interdisciplinary team including the individual, family, caregivers and service providers. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with active treatment.

Palliative care affirms life and regards dying as a normal process, neither hastens nor postpones death, provides relief from pain and other distressing symptoms, integrates the psychological and spiritual aspects of patient care, and offers a support system to help patients live as actively as possible until death.²

¹ The review was conducted by Muriel Guériton, librarian at CREGÉS, using the following databases: Embase, CINAHL, Medline, PsycInfo, Social Work Abstract

² World Health Organization and Canadian Palliative Care Association

Section /

Profile of palliative care volunteers

This section looks at the profile of palliative care volunteers and describes their role and the skills they are expected to have. This is a general profile of palliative care volunteers, regardless of the setting (hospital, hospice, home).

1. The role of palliative care volunteers

It is an ambitious task to define the role of palliative care volunteers. In fact, these volunteers have several roles, which may be grouped into two categories:

1. The “instrumental” category includes tasks related to daily domestic activities and practical support: running errands, reading, doing the dishes, paperwork, etc.
2. The “social” category includes roles such as providing emotional and social support to the patient and his/her family.

Volunteers offer **all types of care and support**—emotional, practical, social, spiritual and informational—to patients, families and health care and social services professionals. Sometimes they can even help patients express their needs (or dissatisfaction with the quality of care received) to medical personnel. In these instances, they act as a **“bridge” between the family and medical staff.**³

Although they are asked to help evaluate the needs of patients and their family, volunteers note that they sometimes prefer responding to needs as they spontaneously arise, rather than completing a list of prescribed tasks.

Volunteers complete a number of tasks that **require specific competencies and skills** as well as adequate training or, at the very least, ongoing supervision.

Although the volunteer role is often described as providing support by listening, **some organizations train volunteers to provide certain types of physical care** as well. Volunteers may also be expected to prepare light meals or to give medication prepared by a family member.

³ Sévigny, A. et al. (2010)

1.1. Role category: instrumental support

This role category includes **practical tasks** that provide support to palliative care patients and their loved ones, such as writing letters, sharing hobbies, running errands, doing the dishes, completing paperwork and going on walks.

Some volunteers also offer **respite to the family** and provide information. Finally, volunteers in hospitals are part of the team that seeks to minimize the suffering of patients as they go through the end-of-life stages.

1.2. Role category: emotional support

Studies⁴ show that volunteers provide **emotional, social and sometimes religious and spiritual support** to patients and their family. They can also offer bereavement support to families after the patient's death. Volunteers spend time with patients and their family: they are present, they offer a comforting hand, they listen and build relationships of trust and friendship, accompanying patients in their last moments, making sure they do not feel alone and providing updates to their friends, neighbours and so on. **Volunteers pay particular attention to patients, making them feel special.**

This support helps to relieve the pain and discomfort of patients and their family during this time of their life. **Families appreciate volunteers' support**, which can improve patients' quality of life.⁵

Volunteers can also play a **more proactive role**,⁶ for example, by helping caregivers become more aware of how they perceive pain and encouraging them to talk about it with their health care professionals when possible.

Because of the type of relationship that develops, volunteers **often become friends and confidants**.⁷ It is often easier for patients to talk about their fears and uncertainties with a "nonprofessional."

1.3. A place in the team

It is sometimes difficult to **strike a balance between integrating volunteers into interdisciplinary palliative care teams and respecting their role and need for freedom**.⁸ Coordinators must be careful to ensure that practitioners do not overstep the bounds by assigning too many unpleasant tasks to volunteers.

⁴ Planalp, S. et al. (2011); Claxton-Oldfield, S. et al. (2011)

⁵ Pesut, B. et al. (2014)

⁶ Wittenberg-Lyles, E. et al. (2012)

⁷ Savery, C.A. & Egbert N. (2010)

⁸ Pesut, B. et al. (2014)

1.4. They can make a difference—a key component

Some studies⁹ show that volunteers are a **“key component of hospice,”** because they meet a number of patients’ needs. It is recognized that they play an important role in the community and can make a difference in the lives of patients and their family. More specifically, one study¹⁰ reveals that nurses have a very positive perception of volunteers and their role. They believe they make a difference, are willing to help and are important members of the palliative care team. The nurses in this study also noted that volunteers make their job easier.

1.5. Volunteers’ mission in terms of their social role

Some volunteers seek to **improve patients’ quality of life** and help them overcome feelings of loneliness and isolation by **promoting their autonomy**. They aim to help patients **maintain control** over their life for as long as possible. Other volunteers have noted that their main role is simply **“to be there.”**¹¹

Volunteers believe it is important to contribute to society. They see themselves as **“companions”** rather than professionals. They also believe that their approach should allow for a better understanding of **life and death as part of the human condition.**¹²

Finally, some see their role of offering support to a dying person as spiritually and personally enriching.¹³

1.6. Distinctive features of home-based care

The home is considered to be a more intimate space where conversations are more likely to occur. In this setting, it is sometimes difficult to define volunteers’ roles and tasks. In contrast, in health care establishments, these tasks are clearly defined.

The greater intimacy of a home care setting can help volunteers to detect changes in patients and to facilitate their access to care. Volunteers also provide respite, but should not act as a substitute for family members. It is important to develop a close relationship while maintaining a professional distance.

⁹ Block, E.M. et al. (2010); Claxton-Oldfield, S. et al. (2011)

¹⁰ Pesut, B. et al. (2014)

¹¹ McKee, M. et al (2010)

¹² Guirguis-Younger, M., Grafanaki, S. (2008)

¹³ Ibid

1.7. Home care in a rural communities

There is a unique culture of care in rural communities—one that is both formal and informal. The patient belongs to a community that will be affected by his or her death. Some authors define the volunteer’s role in terms of time and community ties. Volunteers have time to listen, to be there, to accompany and to build an authentic relationship. Once again, they are seen as the “bridge” between the patient and, in this case, the community. They give news, keep contact with friends and neighbours, and “**bring the community to the home.**”¹⁴

It is worth noting that health care professionals in rural settings do not make extensive use of volunteers, especially for home-based care.

1.8. Evolution of the role of palliative care volunteers

The role of palliative care volunteers has not significantly evolved, although one study notes¹⁵ that the latter could **facilitate communication** with the family on specific topics. Volunteers should therefore develop communication skills to liaise between health practitioners and the family.

Volunteers could also play **a role as patient advocates**. Their role could be expanded, allowing them to occupy **a much more formal position in the multidisciplinary team**. In such cases, it would be necessary to recognize volunteers’ role, formalize their practices, and offer them an opportunity to move from a peripheral position in the patient’s circle of care to a far more integrated role as a member of the team. This evolution goes beyond compassionate care, allowing volunteers to play a far more active role in advocating on behalf of patients.

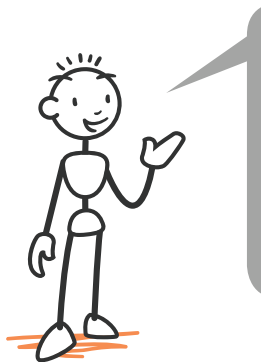
It implies a certain professionalization of the volunteer role and could create expectations on the part of families who would like to be guided and supported in their choices. Volunteers could be asked their opinion on delicate issues, which they would normally refer to health care professionals.¹⁶

¹⁴ Mckee, M. et al. (2010)

¹⁵ Wittenberg-Lyles, E. et al. (2012)

¹⁶ Savery, C.A. & Egbert, N. (2010)

What volunteer coordinators have to say...



It is not a volunteer’s role to change the patient’s life or convince him or her of anything. Volunteers must show respect and must not judge what they see. They have a dual role—that of offering support and comfort to patients and their families. They must be able to work independently, but also as part of a team. Finally, the coordinators we interviewed noted that volunteers must develop good interpersonal relationships with all practitioners.

Highlights

Roles of palliative care volunteers

- Palliative care volunteers play a number of roles that can be classified as either **instrumental** or **emotional**. Instrumental support includes practical tasks while emotional support comprises social, emotional and sometimes spiritual dimensions.
- In many ways, volunteers become a **bridge between the family and health care and social services professionals**, and sometimes help patients to express their needs or dissatisfaction with care received.
- Volunteers describe their **need for freedom** in fulfilling their role.
- Some volunteers prefer to **respond to needs spontaneously expressed** by patients, rather than following a list of set tasks.
- Volunteers need to be **integrated into interdisciplinary palliative care teams**; at the same time, they need to have freedom and flexibility in carrying out their tasks.
- Volunteers meet a number of patients' needs and are therefore a **key component of palliative care**. They can make a difference in the lives of patients and their family. They also provide valuable assistance to health care professionals by making their job easier.
- The role of volunteers in institutional settings is more clearly defined than in home-care settings. The greater intimacy of the home can help volunteers identify changes in the patient's condition and facilitate access to care. **It is important to develop a close relationship while maintaining a professional distance.**
- Volunteers could be called on to become patient advocates, thus playing a far more proactive role in the patient's circle of care. With the professionalization of volunteer's role, there is a risk of increased expectations on the part of families around delicate issues that are currently referred to health care professionals.

2. Expected competencies for palliative care volunteers

Our literature review shows that volunteers should have certain competencies to be able to offer adequate support. These competencies fall into three categories:

1. **Knowledge:** understanding acquired by an individual through study and experience*
2. **People skills:** expected attitudes and behaviours in a given situation
3. **Know-how:** ability to carry out an artistic, intellectual, physical or social activity; dexterity in completing a task; ability to solve practical problems*

(*based on definitions in the *Dictionnaire actuel de l'éducation*, Legendre, 1993)

Table A presents types of knowledge identified in the literature.

TABLE A Volunteer Profile – Types of Knowledge Identified in the Literature

Knowledge ¹⁷	People skills	Know-how
<ul style="list-style-type: none"> • Familiarity with the organization • Familiarity with the palliative care network • Understanding of the role and responsibilities of a volunteer • Understanding of the role and responsibilities of other practitioners with whom volunteers collaborate • Understanding of the experience of patients and their family • Understanding of the bereavement process • General knowledge about diseases and their treatment 	<p>Personal skills:</p> <ul style="list-style-type: none"> • Be attentive • Be calm in stressful situations; be comfortable with death and the patient • Offer a comforting presence • Remain objective and do not get too emotionally involved • Continually adapt as the disease progresses and according to different types of patients (adaptability) • Palliative care volunteers are generally outgoing, open, friendly, independent, optimistic, empathetic, compassionate, understanding and emotionally stable 	<p>Communication skills:</p> <ul style="list-style-type: none"> • Establish open communication with patients and their family; promote social interaction • Listen and communicate/facilitate communication with caregivers on the topic of pain • Be able to communicate effectively in order to provide patient-directed care

¹⁷ Réseau des soins palliatifs du Québec, Volunteer selection (<http://www.aqsp.org/>)

TABLE A Volunteer Profile (Cont'd)

People skills	Know-how
<p>Attitudes toward others:</p> <ul style="list-style-type: none"> • Desire to help ease the suffering of patients and their family and to improve their quality of life • Promote the patient's autonomy and respect his/her desires and wishes • Able to consider other people's perspectives, enjoy helping others • Open to spirituality • Able to meet the patient's emotional needs and support the family • Volunteers believe in the philosophy of palliative care (focused on the person, quality of life, controlling symptoms, relieving distress and dying peacefully) • Volunteers focus on patients' life and do what they can to make them comfortable 	<ul style="list-style-type: none"> • Able to complete small tasks: cooking, making conversation, holding the person's hand, doing dishes, running errands, playing cards, reading out loud, writing letters, sharing hobbies, going on walks, etc.
<p>Being open to others and to new experiences means:</p> <ul style="list-style-type: none"> • Having an active imagination, enjoying variety and being open-minded, accepting patients and their family, regardless of how they live (without making moral judgments), being flexible, showing cultural sensitivity, respecting other people's beliefs 	<ul style="list-style-type: none"> • Able to work with other stakeholders in interdisciplinary palliative care teams
<p>Friendliness:</p> <ul style="list-style-type: none"> • Volunteers are altruistic, trustworthy, sympathetic towards others and eager to help 	<ul style="list-style-type: none"> • Able to offer comfort and respite
<ul style="list-style-type: none"> • Volunteers see resilience and their personal energy as important aspects of their work 	
<ul style="list-style-type: none"> • Palliative care volunteers develop skills and strategies that help them give meaning to death (religious, spiritual, personal development) based on various experiences 	
<p>The qualities expected of volunteers may sometimes be contradictory. Volunteers are expected to be:</p> <ul style="list-style-type: none"> • Autonomous, yet willing to follow instructions • Independent and team players • Focused on solutions when satisfactory solutions do not exist • Aware of their beliefs, values and areas of conflict, but open to the beliefs, values and lifestyles of others • Able to respond to an often depressing reality with creativity, love and hope, while recognizing their limits and knowing when to ask for help 	
<p>Volunteering in rural communities:</p> <ul style="list-style-type: none"> • Desire to give one's time according to the needs of the patient and family (the role is more flexible in a rural setting) • Connection with the community (keeping the patient in the community) 	

References

People skills:

Claxton-Oldfield, S., & Banzen, Y. (2010). "Personality Characteristics of Hospice Palliative Care Volunteers: The "Big Five" and Empathy". *American Journal of Hospice & Palliative Care* 27(6), 407-412.

Guirguis-Younger, M., Grafanaki, S. (2008). "Narrative Accounts of Volunteers in Palliative Care Settings". *American Journal of Hospice & Palliative Medicine* vol. 25, 16-23.

Jovanovic, M. (2012). "Cultural Competency and Diversity Among Hospice Palliative Care Volunteers". *American Journal of Hospice & Palliative Medicine* 29(3), 165-170.

McKee, M., Keley M. L., Guirguis-Younger, M., MacLean M., & Nadin S. (2010). "It Takes a Whole Community; The contribution of rural hospice volunteers to whole-person palliative care". *Journal of Palliative Care* 26(2), 103-111.

Mount, M. B. (1992). "Volunteer support Services, a Key Component of Palliative Care". *Journal of Palliative Care* 8(1), 59-64.

Pesut, B., Hooper B., Lehbauer, S., & Dalhuisen, M. (2014) "Promoting Volunteer Capacity in Hospice Palliative Care: A Narrative Review". *American Journal of Hospice & Palliative Medicine* 31(11), 69-78.

Sévigny, A., et al. (2010). "Making sense of health and illness in palliative care: volunteers' perspectives". *Palliative & Supportive Care* 8(3), 325-334.

Know-how:

Claxton-Oldfield, S., Jefferies, J., Fawcett, C., & Wasylkiw, L. (2004). "Palliative care volunteers: why do they do it"? *Palliative Care Volunteers* 20(2), 78-84.

Mackay, M. M., & Bluck, S. (2010). "Meaning-Making in Memories: A Comparison of Memories of Death-Related and Low Point Life Experiences". *Death Studies* 34, 715-737.

Planalp, S., Trost, M. R., & Berry, P. H. (2011). "Spiritual Feasts: Meaningful Conversations between Hospice Volunteers and Patients". *American Journal of Hospice & Palliative Medicine* 28(7), 483-486.

Savery, C. A. and N. Egbert (2010). "Hospice volunteer as patient advocate: a trait approach". *Palliative & Supportive Care* 8(2): 159-167.

Sévigny, A., et al. (2010). "Making sense of health and illness in palliative care: volunteers' perspectives". *Palliative & Supportive Care* 8(3), 325-334.

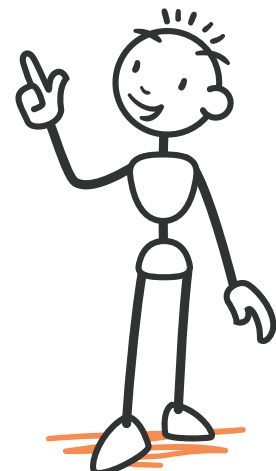
Wittenberg-Lyles, E., Demiris, G, Ferrell, B., & Shaunfield, S. (2012). "Volunteers as Facilitators of Communication About Pain: A Feasibility Study". *Research on Aging* 34(2), 246-253.

What volunteer coordinators have to say...

Table B below shows the main types of knowledge that coordinators spontaneously identified in interviews as being what they look for in candidates. Clearly a broad range of knowledge and skills are desired.

TABLE B Volunteer Profile – Types of Knowledge Identified by Coordinators

People skills	Know-how
<p>Personal skills:</p> <ul style="list-style-type: none"> • Attentive listening skills • Openness to others (different cultures) • Respect (confidentiality) • Neat physical appearance (volunteers should not smell of cigarette smoke or use perfume; they should not wear too much makeup, as this could be offensive to patients) • Not afraid of death • Sensitive • Empathetic • Able to be self-critical • Compassionate • Committed • Honest • Able to adapt to different socioeconomic environments 	<ul style="list-style-type: none"> • Fluency in French • Fluency in English (bilingual) • Ability to speak a second language • Ability to commute frequently • Communication skills



Highlights

Palliative care volunteers: expected competencies

- The competencies volunteers are expected to have fall into three categories: knowledge, people skills and know-how. Given the nature of volunteers' role, **people skills (attitudes and behaviours) take precedence** over the other types of competencies.
- There was a consensus in the literature and among the volunteer coordinators interviewed regarding the main types of people skills volunteers should have. These include **an ability to listen and to be a comforting presence, open-mindedness, ability to communicate in different ways, compassion and commitment.**
- In terms of knowledge, volunteers are expected to **understand their roles and responsibilities** as well as those of the other practitioners with whom they collaborate. Palliative care volunteers are also expected to have **knowledge of the bereavement process and of diseases in general.**
- Volunteers should also want to **help ease the suffering of patients and their family, and to improve their quality of life.**

Section 2

Five activities related to the management of palliative care volunteers

This section looks at five activities related to the management of palliative care volunteers: recruitment and selection, training, supervision, evaluation and retention. Each activity is broken down into four parts:

- Important information
- Potential pitfalls
- Ideas for improvement
- Further reading

Activity 1

Recruitment and selection

1. Important information about recruitment and selection

1.1. Motivations for becoming a palliative care volunteer

To effectively recruit and select future volunteers, it is important to understand their motivations for getting involved in this type of activity. Studies that have developed and validated inventories of motivations can be used to design recruitment and selection tools. The three inventories¹⁸ presented on the next page have been grouped as categories. In all three cases, the main motivations overlap.

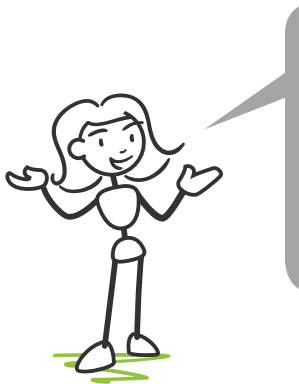
¹⁸ 1) Revised inventory by Claxton-Oldfield, S., Wasylkiw, L., Mark, M., & Claxton-Oldfield, J. (2011);
2) Inventory of motivations for volunteerism, in Fitzpatrick, T., Edgar, L., Remmer, J., & Leimanis, M. (2013);
3) Inventory of motivations for volunteerism, in Planalp, S., & Trost, M. (2009)

TABLE C MOTIVATION INVENTORIES FOR VOLUNTEERISM

1 st Inventory	2 nd Inventory	3 rd Inventory
<ol style="list-style-type: none"> 1. altruism 2. civic responsibility 3. self-promotion 4. free time 5. personal gain 	<ol style="list-style-type: none"> 1. personal values or being concerned about the well-being of others 2. opportunity for new learning experiences 3. enhanced self-esteem and personal development 4. personal experience of receiving a cancer diagnosis 	<ol style="list-style-type: none"> 1. helping others and learning 2. developing relationships 3. feeling of well-being and enhanced self-esteem 4. pursuing career objectives

Age can also be an important factor in volunteers' motivations. For example, students had higher scores for self-promotion and personal gain, while active palliative care volunteers had higher scores for altruism and civic responsibility.¹⁹ Young volunteers are also more motivated by career objectives than older volunteers. Other specific factors can come into play as well. Volunteers who work full-time say they have fewer social motivations than volunteers who are unemployed or retired.²⁰

What volunteers have to say...



Motivations for volunteering

Even if it is not explicitly stated, compassion is the driving motivation for most volunteers. They are keen to help, have perhaps had a personal experience of death, or their professional activities are in a health-related field. When they retire, people often reorganize their daily lives and find they have free time, leading them to seek activities in line with their interests.

¹⁹ Claxton-Oldfield, S. et al. (2011)

²⁰ Planalp, S. & Trost, M. (2009)

1.2. Recruitment sources

The volunteers we interviewed said they had discovered an opportunity to volunteer through people working in health or palliative care, personal contacts, electronic or print sources, or various organizations.²¹

What volunteers have to say...

How were they recruited?

They are proactive people who took steps to find an organization that met their needs. It often takes extended research, several meetings and repeated attempts to find the right place. In one case, the organization initiated contact by inviting the volunteer to present his experience following the death of a loved one. This event sparked the person's interest in becoming a volunteer.

How did they choose the organization?

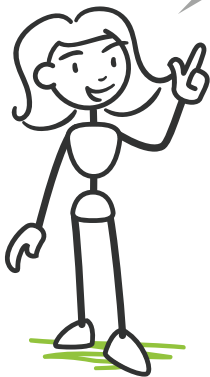
The organization's reputation, the training offered and the organization's health care expertise were factors in volunteers' choices. They also stated that the simple fact of accompanying patients was sufficient motivation to volunteer.

"It was the human side that attracted me."

Volunteers see themselves as those who help end-of-life patients express themselves. They are proud of their ability to listen. On average, they volunteer four hours a week, but the number of hours can increase considerably as the person approaches death. They remain committed until the end. They even accompany the patient from his or her home to the hospital.

*"It was really gratifying for me, at the end, when a doctor said,
"You've done more for him than all of us."*

Volunteers are deeply committed, whether they sign a formal contract or simply give their word, in full confidentiality.



²¹ Planalp, S. & Trost, M. (2009)

What volunteer coordinators have to say...

How are volunteers recruited?

Before starting the recruitment process, there is a needs analysis both for the volunteer and the patient. Coordinators use a form to clearly understand the nature of the request and the skills the patient is seeking.

Word of mouth is a very common and effective form of recruitment. Other options are local newspapers, different types of publications, volunteer centres and ads posted in the community. The coordinator's network and referrals by community organizations are also effective ways to recruit volunteers. Some coordinators recruit at universities or recruitment fairs. Finally, some volunteers recruit other volunteers. Certain coordinators prefer to wait for volunteers to initiate contact with the organization, as this shows their motivation to get involved in this type of work.

The best times to recruit

Almost all coordinators agree that fall is the best time to recruit, since potential candidates are looking for enriching activities to occupy their time. Spring is also an opportune time for recruitment.

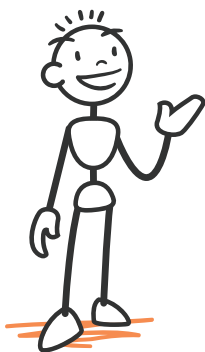
Recruitment strategies

All coordinators agree that volunteers are looking for something and need the organization to respond to this motivation. Coordinators must ensure that potential candidates have long-term objectives, because it takes time to build a relationship of trust with patients. One coordinator said he wanted to find motivated and determined individuals whom he would then match with the right patients.

*"Help your neighbour rather than a stranger.
Someone in the neighbourhood needs you."*

When the prospective volunteer takes the first steps, he or she is more likely to stay the course. While many individuals may show initial interest, several are reluctant to continue when the coordinator contacts them to set up a first meeting. Coordinators say it is important not to put undue pressure on prospective volunteers, preferring to give them enough time to make their decision. They say it is better to ensure that they are truly interested in getting involved. Finally, they note it is very important to find out as much as possible about candidates and their background, to go beyond forms and administrative procedures.

*"We want you because you believe in
helping people die with dignity."*



What researchers have to say...



Volunteer recruitment

The researchers we contacted said that recruitment was a difficult task for volunteer coordinators. Before starting this activity, they need to carefully assess the organization's need for volunteers. Coordinators will determine their priorities according to the situation and context in order to better set objectives and develop an action plan. The usual recruitment methods can then be used (posting available positions on a website, recruitment through other departments or volunteers). While technological tools allow information to be posted continuously, word of mouth is a very effective way to recruit volunteers. It is important to adapt recruitment methods to the target clientele.

“You can use the Internet if you want to reach younger people who are active on social media. Groups looking to recruit younger volunteers might use online recruitment strategies. If you want to recruit volunteers for home-based care, you might be able to reach baby boomers online, but a lot of seniors aren't that familiar with this tool. Word of mouth is still an effective method, although organizations could put certain activities in place to make it more structured.”

1.3. Male volunteers

It is often noted in the literature that it is difficult to find male volunteers. Some researchers have looked more closely at this issue to better understand men's reasons for getting involved.

Men who are interested becoming palliative care volunteers have **offered the following reasons:**²²

- they see the need and enjoy helping others;
- they have already worked in the field;
- they might one day need help for themselves or their family.

Other motivations given by men for becoming palliative care volunteers are: having experienced the death of a loved one and enjoying helping people and having contact with them.²³

²² Claxton-Oldfield, S. et al. (2009)

²³ Weeks, L. E. & MacQuarrie, C. (2011)

We asked men to identify which tasks associated with palliative care volunteer work, from a list of 25, they preferred doing.²⁴

- **Most of the tasks were related to practical support:** running errands, driving patients to medical appointments or to visit friends.
- Some chose tasks related to social support: playing cards, talking to the patient, sharing hobbies, going on a walk, offering company and friendship.
- The men in our sample were less inclined to offer emotional support other than listening to the patient tell his or her life story.
- The men were not as interested in administrative tasks.

Finally, they mentioned that, according to the **social norms** underlying palliative care volunteer work, there were certain expectations regarding the types of support that men could offer. **Men are seen in a more practical role** (e.g., doing repair jobs) and less in a caregiving role with end-of-life patients. While it is acceptable for women to help men, the reverse is less acceptable, especially when the volunteer visits the home. Nonetheless, male patients are increasingly requesting the services of male volunteers. This could encourage men to continue doing volunteer work.²⁵

1.4. Review of the palliative care volunteer profile

In the first section, we examined the profile of palliative care volunteers. The **most sought-after qualities** in palliative care volunteers are: emotional maturity, tolerance, openness, empathy, respect for confidentiality, reliability, attentiveness, ability to work in a team, and being comfortable around death.²⁶

Volunteers commented on the qualities required to do volunteer work. They said it was important to be resilient—in other words to have effectively dealt with past grief. They also noted the importance of seeking personal growth and being community-minded. These volunteers emphasized that they had a very broad understanding of life and death, and that they saw the end of life as part of the human condition. They accepted death and considered life to be precious.²⁷

According to the studies reviewed, there appear to be **new types of volunteers** getting involved in the field. Young adults aged 18 to 35 seeking a practical experience related to their career; baby boomers in their sixties looking for a new life challenge; and newcomers seeking to become integrated in their local community.

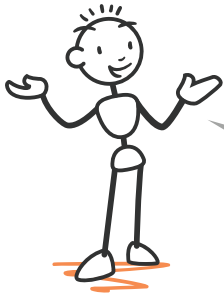
²⁴ Claxton-Oldfield, S. et al. (2009)

²⁵ Weeks, L. E. & MacQuarrie, C. (2011)

²⁶ Pesut, B. et al. (2014); Mount, M. B. (1992)

²⁷ Guirguis-Younger, M., Grafanaki, S. (2008)

What volunteer coordinators have to say...



Ideal palliative care volunteer profile

The types of candidates volunteer coordinators are seeking do not necessarily require experience in palliative care, although this can be useful. The profile is very varied, ranging from part-time students to adults going back to school (nurses, orderlies, etc.) or even immigrants who were professionals in their country of origin and who want to play a role in their community. Although all age groups are represented, most of the people who get involved are retired.

1.5. Selection criteria

A number of organizations offering palliative care services conduct a selection interview and ask for references. Organizations are now more flexible, requiring a six-month commitment instead of a one-year commitment, as was often the case in the past.

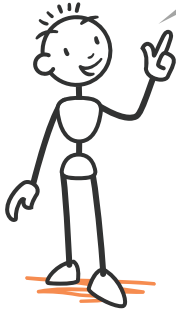
What volunteer coordinators have to say...

How are future volunteers selected?

Interviews are an opportunity to meet and get to know candidates and the reasons they would like to volunteer. It is also very important for coordinators to ensure that candidates are aware that the volunteer work will be carried out in a home setting, if this is the case. In other instances, a first contact is made by phone or email. One coordinator said he tries to convey expectations as realistically and honestly as possible. It is important to clearly assess, beyond a shade of doubt, whether the needs of both parties can be met.

“I try to be as upfront as possible about what we expect from them and what they can expect from us. I don’t want any surprises down the road.”

Candidates are asked for two references and have to agree to a police background check.

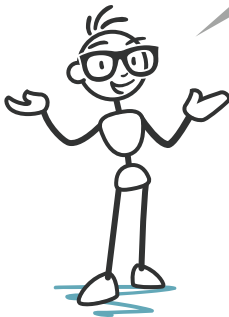


Involvement

Volunteer involvement can take many forms. For some organizations, the candidate must agree to follow a training program before being recruited. Others require candidates to sign a code of ethics or contract.

Some organizations require volunteers to commit for a period ranging from three to six months, while others have no specific commitment period. In general, volunteers are expected to accompany patients three to six hours every week.

What researchers have to say...



Selecting volunteers

Organizations should verify the candidate's skills rather than following a set of rigid selection criteria. To achieve representativeness for the population served, it is important to use intergenerational and intercultural criteria, in order to recruit volunteers of different ages and from different ethnocultural backgrounds. Some candidates have not lost someone close to them or have not yet reached this stage in their life. Age is not a selection criterion, but life experience helps volunteers to develop qualities that are essential for this job. In addition, the coordinator will ask potential volunteers about their interests and ability to accompany patients.

Researchers agree that experienced coordinators are skilled at **matching** patients and volunteers. Beyond the volunteer's personality and availability, coordinators base their decision on their own volunteer experience and skill in finding the right match. This is a crucial step in meeting the needs of the patient and his or her family. A number of factors are taken into account, both related to the patient (personality, interests, family dynamic) and the volunteer (availability, geographical distance, interests, communication skills, openness, etc.).

The interview helps coordinators to understand potential volunteers' motivations and to ensure that they fulfill the organization's mission.

Highlights

Recruitment and selection of palliative care volunteers

- The main motivations for getting involved in palliative care volunteer work are **compassion, free time, professional goals or personal experience of death**. In addition, volunteers show a **strong moral commitment**.
- Although volunteers may be recruited via a variety of sources, **word of mouth** appears to be particularly effective.
- It is **more difficult to recruit men** who are usually seen as playing a practical role.
- Volunteers are often **proactive in looking for** an organization that matches their interests. The **organization's reputation and training** significantly influence volunteers' choice. Organizations must be able to respond to volunteers' motivations in order to attract them.
- Organizations should select volunteers based on **people skills** rather than a set of rigid criteria.
- Recruitment is an important stage that allows both volunteers and coordinators to evaluate motivations and the degree to which the arrangement **meets the organization's needs**.
- It is also important to **coordinate all of the stages following recruitment** (orientation, training and assignment to the appropriate patient) in order to retain the volunteer.
- Some volunteers can be **assigned different tasks** (fundraising, promotion, etc.) if they are not interested in having direct contact with palliative care patients in the home.
- Although it is a constant challenge to find volunteers interested in home-based palliative care, organizations can explore the profiles of volunteers other than those from the health and social services sector or retirees. **New volunteer profiles appear to be emerging:** newcomers, young adults at the start of their career, and baby boomers.

2. Potential recruitment and selection pitfalls

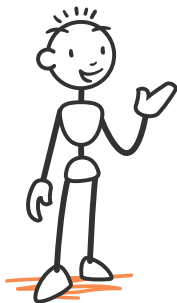
It is sometimes easier to recruit volunteers at hospitals, which are considered safer, than at organizations offering home care. Organizations must also take into account the fact that volunteers must juggle several activities: work, family obligations, leisure and studies. Since volunteers have **fewer hours to offer**, it is sometimes necessary to recruit them in greater numbers.²⁸

It can be difficult to recruit palliative care volunteers who are **culturally competent** and who come from different ethnocultural communities. For example, in a large urban centre, patients who do not speak **the majority language** may find it difficult to access volunteer care.²⁹ Volunteers should also be open to cultural diversity.

People with **certain experiences or views may not be ready to get involved**³⁰ in palliative care volunteer work. These include those who:

- have suffered a recent loss or are in mourning;
- have a lot of stress in their personal and/or professional life;
- have a depressive personality;
- lack social or family support;
- have dogmatic religious views;
- lack humane qualities;
- are experiencing a high level of personal distress;
- have difficulty considering other viewpoints;
- want to proselytize.

What volunteer coordinators have to say...



Coordinators are likewise reluctant to recruit volunteers who:

- are in mourning or have lost someone close in the past 12 months;
- are not punctual;
- have conditions (e.g., in sociodemographic terms, candidates who are unwilling to go to the homes of disadvantaged people or individuals belonging to certain ethnographic groups or living in certain neighbourhoods);
- are not open-minded;
- lack empathy;
- have dogmatic religious beliefs.

²⁸ Pesut, B. et al. (2014);
Claxton-Oldfield, S. et al.
(2009)

²⁹ Jovanovic, M. (2012)

³⁰ Claxton-Oldfield, S. & Banzen,
Y. (2010)

What researchers have to say...



The researchers we interviewed noted that volunteers in institutional settings are not always comfortable with the idea of palliative home care and have different skill sets. It is often difficult to recruit hospice palliative care volunteers.

2.1. Lack of interest in palliative home care

The main reasons volunteers gave for **refusing to work in a palliative setting** were: being too busy, not having enough time, being too old or ill, and the fact that the work is emotionally demanding.³¹

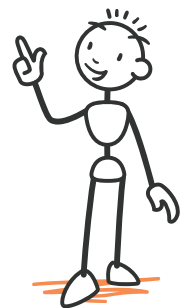
Men are less likely than women to become volunteers, saying they are too busy and prefer to provide practical services such as transportation. Men's lack of interest in palliative care volunteer work could be tied to a lack of time, the fact that it is an emotionally difficult job (fear of becoming attached to the patient), being too old, having a disability, and an inability to cope with death and suffering. There is also a lack of knowledge around palliative care.³²

2.2. Refusal to have volunteers in the home

One study³³ showed that one of the reasons people refuse to welcome volunteers into their home is because they believe the latter do not receive sufficient training. Traditionally, volunteer training is focused on empathy, being a conversation partner, providing support and adapting communications to the situation at hand.

What volunteer coordinators have to say...

Sometimes patients' families find it difficult to accept "strangers" in their home, in addition to all of the other practitioners (doctor, nurse, occupational therapist), as it makes for a lot of coming and going.



³¹ Claxton-Oldfield, S. et al. (2009)

³² Pesut, B. et al. (2014); Claxton-Oldfield, S. et al. (2009)

³³ Savery, C.A. & Egbert N. (2010)

What researchers have to say...



Wide-scale, costly campaigns do not necessarily generate a good return on investment.

3. Ideas on how to improve recruitment and selection

3.1. Content

When recruiting volunteers, **clear information** should be provided in terms of training, the number of hours required and the tasks to be accomplished. Volunteers who are less interested in providing services directly to patients could be involved in peripheral activities such as fundraising, organizing events and other related tasks.³⁴

3.2. Sources

According to some studies, the most effective recruitment methods are: public education programs, talks, presentations to the media, **referrals from community organizations and personal contacts with someone already involved in palliative care**. In addition, volunteer coordinators identified online recruitment and advertising as effective strategies.³⁵

It might be a good idea to **ask male volunteers** to speak at social clubs, churches and other places they frequent about their experience in palliative care to help recruit more men. They could explain what activities they do for end-of-life patients.³⁶

3.3. The message

To recruit volunteers, messages must be **related to tasks** that interest them or their motivations for getting involved, particularly in the case of male volunteers.

Organizations could better target younger volunteers and emphasize how the experience will benefit their career, notably in the helping professions. The organization's reputation can also be a positive factor in recruiting younger volunteers.

³⁴ Claxton-Oldfield, S. et al. (2009)

³⁵ Wittenberg-Lyles, E. et al. (2012)

³⁶ Claxton-Oldfield, S. et al. (2009)

3.4. Volunteer coordinators

Given the **growing demand for volunteers** and the extensive requirements for successful candidates, **volunteer coordinators face higher expectations**. They are now required to have relevant experience, to have studied in the field and to be able to meet set objectives.

Volunteer coordinators must show maturity, leadership, interpersonal skills and autonomy. Research suggests that they should be paid and should have prior volunteer experience.³⁷

What researchers have to say...

To maximize recruitment efforts, existing volunteers could be asked to approach at least one person in their social circle. Organizations could also hold coffee meetings to present their work and attract future candidates. An information booth in a community pharmacy is another possible recruitment strategy. The personal account of one volunteer will reach more people than an organization's promotional efforts alone. To recruit more people, the organization must clearly state its needs, at the same time paying attention to the motivations of prospective volunteers. It is necessary to invest time in translating the interests of prospective candidates into volunteer opportunities. It might be a good idea to avoid focusing solely on recruiting former professionals from the health and social services sector, since other people may be interested in working with people at the end-of-life stage.

“One of the characteristics of volunteers is the fact that they get involved in experiences that are meaningful to them. If the experience isn't meaningful, they won't get involved. I think a lot of young students might be interested in these sorts of questions. That doesn't mean that all volunteers should be people who reflect deeply on the meaning of life, but there is a spiritual quest involved.”



³⁷ Mount, M.B. (1992)

4. Further reading on recruitment and selection

- Selection chart “Recrutement et évaluation des bénévoles en soins palliatifs” (Recruitment and evaluation of palliative care volunteers). Document prepared by the volunteer committee, Réseau de soins palliatifs du Québec, May 2005, page 301, Appendix II. Source: Sévigny, A., Champagne, M., Guirguis-Younger, M. (Eds.) (2013), *Le bénévolat en soins palliatifs ou l'art d'accompagner*, Presses de l'Université Laval, 334 pp.
- (3) Inventory of motivations for volunteerism. Planalp, S., & Trost, M. (2009). “Motivations of Hospice Volunteers”. *AM J PALLIAT CARE* 26, 188-192.
- (2) Inventory of motivations for volunteerism. Source: Fitzpatrick, T., Edgar, L., Remmer, J., & Leimanis, M. (2013). “Job Satisfaction Among Volunteers With Personal Cancer Experience”. *Journal of Social Service Research* 39, 293-305.
- Inventory of motivations for becoming a palliative care volunteer (IMPCV). Source: Claxton-Oldfield, S., Jefferies, J., Fawcett, C., & Wasylkiw, L. (2004). “Palliative care volunteers: why do they do it”? *Palliative Care Volunteers* 20(2), 78-84.
- (1) Revised inventory of motivations for hospice palliative care volunteerism (IMHPCV). Source: Claxton-Oldfield, S., Wasylkiw, L., Mark, M., & Claxton-Oldfield, J. (2011). “The Inventory of Motivations for Hospice Palliative Care Volunteerism: A Tool for Recruitment and Retention”. *AM J HOSP PALLIAT CARE*, 28(1), 35-43.
- Inventory for the effective recruitment of palliative care volunteers: NEO Five Factor Inventory of Costa Jr and McCrae and Interpersonal Reactivity Index (IRI) of Davis. Source: Claxton-Oldfield, S., & Banzen, Y. (2010). “Personality Characteristics of Hospice Palliative Care Volunteers: The ‘Big Five’ and Empathy”. *American Journal of Hospice & Palliative Care* 27(6), 407-412.

Studies³⁸ show that many volunteers receive training before starting their volunteer work and that they consider **this training to be essential and very positive**. Training programs vary in duration from 12 to 24 hours and can go up to 45 hours. Volunteers report being satisfied with the results.³⁹

Also noted in the literature is the importance of assigning palliative care patients to volunteers as soon as possible once their training is completed **in order to keep up motivation levels**.⁴⁰ In some cases, training can help volunteers decide whether they want to continue in this line of activity. **Ongoing training is also considered necessary**.

1. Important information about training

In addition to providing knowledge, training covers the behaviours (people skills) and know-how involved in carrying out various tasks.

Volunteers have expressed an interest in participating in workshops on a variety of topics⁴¹, such as:

- coping with the loss of a patient;
- ethical dilemmas associated with end of life;
- communication strategies;
- spirituality;
- Alzheimer's disease, dementia and delirium;
- suffering.

1.1. Content of training programs

A review of the content of training programs reveals several key elements:⁴²

1. **reactions** to fatal diseases, death, dying and losses experienced by individuals, health care staff and society;
2. **the history and components of palliative care** and end of life, and available resources;
3. developing **listening, communication and facilitating** skills;
4. building **knowledge** around the most common diseases, treatment modalities, medical emergencies and ethical questions;
5. discussions around **the team, members' roles** and volunteers' activities.

³⁸ Weeks, L.E. & MacQuirrie, C. (2011)

³⁹ Lavenburgh, P.H. & Bernt, F.M. (2012)

⁴⁰ Weeks, L.E. & MacQuirrie, C. (2011)

⁴¹ Lavenburgh, P.H. & Bernt, F.M. (2012)

⁴² Mount, M.B. (1992)

Training on roles should also include ongoing training in interdisciplinary palliative care teams in order to maximize the contribution of each team member, including volunteers.⁴³

An important place should be given to **knowledge stemming from the patients' perceptions of their disease, medication, the role of doctors and hospitals, and palliative care**. The basic training should also include a section on discretion and confidentiality, based on the organization's code of ethics.⁴⁴

Content should also look at **cultural diversity** in connection with personal values, family circumstances, lifestyles and cultural traditions.⁴⁵

Volunteers have made a series of recommendations on how to broaden their understanding of cultural diversity: by inviting other volunteers to share their cultural experiences; by inviting patients' family members and leaders of cultural communities to talk about their culture; by creating a calendar with important dates for each culture; by attending cultural competency training sessions; by consulting brochures, books and websites to obtain more information about different cultures.⁴⁶

Hospital training programs must adhere to the requirements of **Accreditation Canada**, which cover all aspects of volunteer management: recruitment and selection, training, supervision and the well-being of palliative care volunteers. Coordinators must also have the competencies required to adequately manage palliative care volunteers.

1.2. Limits of the volunteer role

It is important to recognize the limits of volunteers' role in terms of personal boundaries, familiarity with regulations and who to refer to in cases of doubt. Of course, limits are flexible and may vary considerably from one organization to another. They are part of the culture of the organization in charge of caring for patients at the end-of-life stage. One study has grouped the boundary issues faced by volunteers into three categories: definite boundary issues, potential boundary issues and questionable boundary issues.⁴⁷

⁴³ Wittengerg-Lyles, E. et al. (2010)

⁴⁴ Jovanovic, M. (2012a)

⁴⁵ Savery, C.A. & Egbert N. (2010)

⁴⁶ Jovanovic, M. (2012a); Jovanovic, M. (2012b)

⁴⁷ Claxton-Oldfield, S. et al. (2011b)

Definite boundary issues must be unambiguously presented to future volunteers during their training. These are things volunteers should never do and should be part of the organization's policies:

- accept money from the patient/family;
- lend money to the patient/family;
- lend personal belongings;
- share information with the patient/family on previous professional experiences involving the death of other patients;
- discuss the patient's diagnosis or prognosis with the family;
- agree to be the legal representative of the patient (power of attorney);
- participate in the signing of the patient's will by acting as a witness;
- discuss the situation of the patient and/or family in the community;
- provide medical assistance;
- discuss assisted suicide with the patient (if the topic is raised by the latter);
- gossip about other team members;
- try to "convert" the patient before his or her death.

Potential boundary issues are things volunteers should stop and think twice about before doing:

- accept a gift from the patient and/or family;
- buy a gift for the patient and/or family;
- share personal information with the patient and/or family;
- invite the patient and/or family to an activity or party outside of the volunteering context;
- give a business card to the patient and/or family;
- become emotional in front of the patient and/or family;
- be present at the patient's medical appointment;
- offer advice and opinions to the patient and/or family.

Questionable boundary issues are things volunteers should be aware of doing:

- share personal information with patients and/or their family on previous experiences of losing a loved one;
- give their phone number to the patient and/or family;
- stay with the patient and/or family longer than stipulated;
- accept an invitation from the patient and/or family to join in a family activity/party;
- do work around the house of the patient;
- offer clothing, toys, meals to the patient and/or family;
- stay in touch with (continue to visit) the family after the patient's death.

1.3. Training on people skills

Some training programs⁴⁸ aim to help volunteers develop an awareness around **issues related to loss, bereavement and fear**, particularly the fear of the unknown felt by both the patient and family. Training on how to manage these fears is beneficial to volunteers.

L'importance des savoir-être dans la pratique du bénévolat en soins palliatifs revient régulièrement à travers les nombreux rôles attribués aux bénévoles, le profil recherché et les compétences attendues; tous explicités à la première section du présent document⁴⁹. Aussi il apparaît clair que la formation devrait offrir de nombreuses mises en situation pour "pratiquer" ces savoir-être.

1.4 . Training on know-how

1.4.1. Communication

Communication strategies and the **art of conversation** are vital components of volunteer training. To engage in meaningful conversations with patients, volunteers need to learn about empathetic listening strategies, discovering shared interests, expressing interests and responding without judging.⁵⁰

Other studies⁵¹ point to the need for training on communication skills such as **assertiveness and non-verbal communication**. In a much more proactive approach to volunteerism, these skills should create more competent communicators who will interact more effectively with personnel, professionals, other volunteers, the family and, ultimately, patients.

It is also noted that older patients appreciate the opportunity to talk about their end-of-life experience with people from their community, of the same age and with similar experiences to share.⁵² This desire to share can be an avenue for volunteers seeking to make conversation.

1.4.2. Managing stress

To a lesser extent, studies refer to the need for stress management strategies. The experience of volunteers with end-of-life stage patients is unique in that it **involves working in a context of pain, fear and, ultimately, death**. Volunteers can also experience high levels of stress. It might be necessary to provide them with strategies to reduce the negative effects of stress (talking with the coordinator, seeking emotional support, using relaxation techniques, etc.).

⁴⁸ Brown, M. (2011b)

⁴⁹ Seymour, J. E. et al. (2013)

⁵⁰ Planalp, S. et al. (2011)

⁵¹ Savery, C. A. & Egbert, N. (2010)

⁵² Seymour, J.E. et al. (2013)

What volunteers have to say...

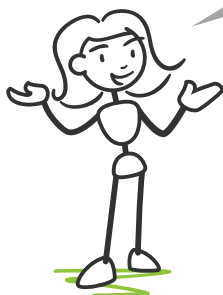
The volunteers we interviewed had not received specific training. Some had worked in health care, but all were aware of the need for training that should be developed by the palliative care team.

“The training should be provided by a health care professional who works with end-of-life patients.”

Identified training needs

The training should look at what it means to be in the terminal phase, the physical changes patients undergo, and how volunteers can respond to this situation. In addition, it would be a good idea to show how to accompany both patients and their family, how to emotionally disengage when the person dies, and how to find the right words and manage negative emotions.

In another vein, volunteers noted the importance of learning to make the distinction between spirituality and religion. Volunteers should not broach the topic of religion unless the patient wishes to talk about it. Volunteers should simply be present and listen.



Volunteers also reported that they should be informed of the care plan and the patient's transfer to the palliative care unit. Some volunteers described situations where they no longer knew what was happening with the end-of-life patient.

What volunteer coordinators have to say...

How should training be provided?

Training topics can be grouped into three main sections, which are presented in various ways, depending on the organization. Some organizations offer a 20-hour training session, while others offer between 36 and 45 hours of training. It is often the coordinator who gives part of the training, with the support of various health care professionals, such as a nurse or physiotherapist and, occasionally, social workers.

Heading #1: How the organization works / defining the volunteer's role

Information is provided on the nature of the organization, its operation and policies, as well as on patients receiving services. The volunteer's role is clearly defined, especially in home care situations where the setting is less structured than in a hospital.

Heading #2: Helping / active listening / communication

Building a helping (or trusting) relationship and active listening are two important topics covered during the training. In addition, exercises, scenarios, role playing, video screenings and discussions are used to cover the various aspects of effective communication (tone of voice, gaze and facial expression, how to express oneself more clearly, etc.).

"Volunteers are there to offer support, to listen."

Heading #3: Death and dying / physical aspects / what to do

The third section covers death and dying, as well as physical, physiological and biological aspects and signs to look out for, so volunteers are not afraid and know what to do if they are alone, especially those offering home-based care. Also covered is the procedure to follow if such a situation arises: what to do and who to contact.

"Volunteers evaluate their own opinions on death and dying."

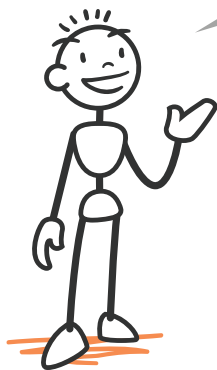
A coordinator noted that their program is approved by the Canadian Hospice Palliative Care Association and that the material is provided free of charge, whereas other organizations might charge \$100. This organization offers training to a large pool of candidates, including health care professionals who wish to expand their knowledge. Content is sometimes complemented with material developed by third-party organizations, such as the Volunteer Bureau of Montreal. Finally, they noted a low dropout rate during the training. The main reasons for quitting were health problems and the advanced age of volunteers themselves.

Ongoing training

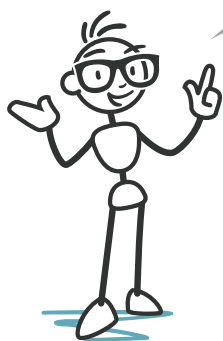
Two types of activities are part of ongoing training: talks/workshops offered by other organizations and discussion sessions combined with the support provided by the coordinator. The topics may stem from requests made by volunteers or may be topics of interest in the palliative care field. These activities are not mandatory, but are highly recommended.

The coordinator's support appears to be very important and allows participants to review specific information. The coordinator looks out for situations that could be difficult for some volunteers.

"We always make time for volunteers to share their feelings and experiences."



What researchers have to say...



Volunteer training

Volunteer training in palliative care can be more focused on people skills. For palliative home care specifically, the topic of privacy is important. The training should ease volunteers' fears (about the patient falling, who to call in case of an emergency or death, etc.) and at the same time clearly define their role. Volunteers need intercultural training to deal with the cosmopolitan reality of large urban centres. They will encounter a diverse range of people in terms of religious beliefs, sexual orientation and so on. It would be difficult to train volunteers to cope with all possible scenarios. However, respect for difference is an essential part of their work. In terms of relationships, they need to develop a comfort level with patients and those around them (caregivers, family and health care practitioners) in order to build trust. Practitioners should be informed of the training provided to volunteers so they can be confident in their ability to manage difficult situations in the home.

Ongoing training

Volunteers are interested in ongoing training activities, but are not always available. Simple lunch-and-learn seminars can be organized, where a volunteer presents a given topic. These activities help to ensure that shared information is retained. An informal discussion allows volunteers to describe the difficulties they encounter, as well as success stories. Volunteers could discuss, for example, their ideas on death and a "good death." However, the coordinator must space out these meetings so as not to make too many demands on volunteers, at the same time ensuring that mandatory training is followed.

1.5. Approaches and techniques

1.5.1. Approaches

Peer training is identified as an adequate approach. It involves an experienced volunteer providing support to a new volunteer. The learning appears to be optimized when two people who have something in common are matched together. This matching can help overcome fear of the unknown in palliative care volunteerism. It also helps to increase new volunteers' knowledge of seniors' health care issues.⁵³

One study⁵⁴ shows that peer training is appreciated by most people, as it creates a stronger sense of belonging and encourages attitude changes through role modeling. The coordinator can also meet training needs, when necessary.

⁵³ Seymour, J.E. et al. (2013)

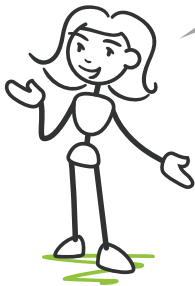
⁵⁴ Ibid

Finally, researchers note it is important **not to impose a strict peer training program**⁵⁵ on volunteers, but rather to help them develop their knowledge around end-of-life care in their own way, while ensuring they have reliable reference tools. It is more important to create a peer training method in collaboration with volunteers, adapted to their specific situation.

1.5.2. Techniques

Several techniques may be used to promote learning and should preferably be varied: case discussions, work groups, self-evaluation, role playing, use of scenarios, patients' accounts, videos showing interviews with patients, conference speakers, practitioners in the field, patients and their family, and other volunteers.⁵⁶

What volunteers have to say...



Suggested training methods

Volunteers find role playing to be an effective training method. They also propose looking at different ways to engage in conversation with patients who do not want to talk about their feelings, but who do want to tell their life story. They suggested developing a toolkit to gather volunteers' ideas regarding the best way to start a conversation with patients.

What researchers have to say...



Proposed methods

One researcher recommended the volunteer training provided by the Canadian Hospice Palliative Care Association. Rather than being given academic material, volunteers prefer training in the form of workshops or discussion, with a focus on interaction. The Canadian Virtual Hospice videos are a popular tool to demonstrate certain techniques. Scenarios and role play make the content more tangible. Volunteers are open to the idea of conference speakers, but not at the expense of discussion. PowerPoint presentations should therefore be used judiciously.

⁵⁵ Seymour, J.E. et al. (2013)

⁵⁶ Lavenberg, P.H. & Bernt, F.M. (2012); Jovanovic, M. (2012)

Highlights

Training for palliative care volunteers

- In terms of knowledge, volunteer training covers **diseases, death, dying, medical care teams, the history of palliative care, available resources, etc.**
- **Much of the training is focused on people skills**, including active listening, communication, cultural awareness, ethics, how to cope with pain and suffering, how to deal with physical changes, and how to disengage emotionally. It is important to define **the limits of the volunteer's role** through training. These limits can vary considerably from one organization to another.
- Volunteering with end-of-life patients can be stressful. It is important to provide volunteers with **relaxation techniques** to reduce the effects of stress.
- In general, training programs are varied and can be spread over 45 hours. The volunteer coordinators consulted said training is provided by a nurse or other qualified personnel at the organization. The main topics covered are: **a) the operation of the organization / the volunteer's role and limits; b) helping / active listening / communication; c) death and dying / physical aspects / what to do?**
- Although the volunteers interviewed did not receive training, they consider **ongoing training activities to be necessary**, along with support from the coordinator. Two types of activities were identified as part of ongoing training: **talks/workshops offered by various organizations and discussion sessions combined with support from the coordinator.**
- **Peer training** is an effective way to create a sense of belonging and to encourage a change in attitude through role modeling. However, it is a difficult approach to implement when volunteers are working in a home setting.
- **A variety of techniques** can help make training sessions more dynamic (role play, patients' accounts, use of scenarios or practitioner accounts).

2. Potential training pitfalls

One study⁵⁷ identified several challenges associated with palliative care volunteering that could be covered during volunteer training sessions:

- stress related to the death of patients;
- difficulty negotiating with family members;
- seeing physical deformities;
- personal stress factors: lack of time, difficulty coping with fears, interpersonal conflicts;
- ethical problems: receiving gifts, providing services that exceed their role, listening to patients talking about suicide, difficulty setting boundaries with patients and their family;
- communication problems: during family conflicts, around denial of death and expression of negative feelings, difficulty communicating with patients.

2.1 Lack of time

Schedule conflicts and lack of time are the main reasons volunteers do not participate in ongoing training activities.⁵⁸

2.2 Lack of training

Studies⁵⁹ show that volunteers do not receive adequate training around cultural competency and communication.

It is also noted that volunteer coordinators have difficulty communicating with volunteers and **assembling them for training/support sessions**. One of the problems is lack of familiarity with communication technologies, as well as **problems scheduling meetings (lack of availability and geographical distance, etc.)**.⁶⁰

Finally, one of the reasons clients appear to refuse the services of volunteers in the home is that the latter do not receive sufficient training.⁶¹

Studies on **volunteer work in rural communities** show that training opportunities in palliative care are limited and volunteer coordinators are rare. Volunteers in rural settings are seldom used, especially in homes.⁶²

⁵⁷ Pesut, B. et al. (2014)

⁵⁸ Lavenburg, P.H. & Bernt, F.M. (2012)

⁵⁹ Pesut, B. et al. (2014)

⁶⁰ Huynh, J-Y et al. (2012)

⁶¹ Savery, C.A & Egbert, N. (2010)

⁶² McKee, M. et al. (2010)

3. Ideas on how to improve training

One study⁶³ showed that volunteers are very interested in participating in training programs and less interested in joining in social activities (evening events, movies, etc.). **It is therefore important to offer volunteers ongoing, adequate training.**

Training activities would help to reduce anxiety and depression among volunteers, and would allow them to develop the competencies they need to work with and better understand end-of-life patients and their family. Training also helps to lessen volunteers' fear of death and maintain their well-being.⁶⁴

Talking to others appears to be an **effective stress management technique**. In a volunteer context, this means talking to a volunteer coordinator to obtain advice and support. In addition to adequate training, researchers propose organizing round table discussions to allow volunteers to share opinions, solve problems and obtain emotional support.⁶⁵

Other stress management strategies include participating in enjoyable activities, taking time off and finding ways to give meaning to life (putting things into perspective, adopting a positive outlook, engaging in spiritual practices, etc.).⁶⁶

Researchers recommend volunteer training that includes communication skills such as assertiveness and non-verbal communication. These skills should help to create more competent communicators who can interact more effectively with professionals, families and patients.

Since it is more difficult to **recruit male volunteers**, it could be advantageous to include content catering to their interests in training programs.

There is not much demand for **volunteers in rural settings**,⁶⁷ especially for home-based care. Developing collaborative relationships among local and provincial organizations offering specific programs would facilitate volunteer training.

Recommendations have been made to organizations offering palliative care services in order to help volunteers acquire **cultural competencies** as part of their training.⁶⁸

One idea⁶⁹ involves **introducing technology into the pre-service training** provided to palliative care volunteers to ensure better use of communication tools. Online training programs are also an avenue to be explored.

⁶³ Lavenburg, P.H. & Bernt, F.M (2012)

⁶⁴ Pesut, B. et al. (2014)

⁶⁵ Brown, M. (2011a)

⁶⁶ Pesut, B. et al. (2014)

⁶⁷ McKee, M. et al. (2010)

⁶⁸ Jovanovic, M. (2012)

⁶⁹ Wittenberg-Lyles, E. et al. (2012)

Volunteers could also play **a role as patient advocates**. Their role could be expanded and they could have **a much more formal place in the multidisciplinary team**. These ideas suggest we go beyond compassionate work to allow volunteers to play a more proactive role as patient advocates.⁷⁰ The training should support the development of this new role.

As already mentioned in the section “The role of palliative care volunteers,” the professionalization of the volunteer role could create expectations on the part of families who might ask volunteers for their opinions on delicate issues that should normally be referred to health care professionals.⁷¹

4. Further reading on training

A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Canadian Hospice Palliative Care Association. Revised and Condensed Edition, 2013, Saint-Vincent Hospital.

<http://www.chpca.net/media/319547/norms-of-practice-eng-web.pdf>

Accreditation process – Accreditation Canada:

<https://www.accreditation.ca/about-us>

⁷⁰ Savery, C.A. & Egbert, N. (2010)

⁷¹ Ibid

1. Important information about supervision

A number of organizations set up a first meeting between the coordinator, patient and volunteer in order to define the visit objectives. At this meeting, the coordinator also offers his or her availability to answer questions and meet the needs of the patient and family, in addition to the assistance provided by the volunteer.

Volunteers appreciate having a set of rules as well as room to manoeuvre, depending on the situation. Supervision that includes both rules and flexibility, formal and informal communication, discussions around palliative care and more detailed knowledge of tasks, is usually successful. Volunteers say they prefer receiving support from the volunteer coordinator or the palliative care team, rather than from other volunteers.

The limits of the volunteer role were presented in the “Training” section as part of the knowledge to be acquired by volunteers (definite boundary issues, potential boundary issues and questionable boundary issues). Naturally these limits are flexible notions that can vary from one organization to another and are closely tied to the organizational culture. In addition to recognizing the limits of their role, volunteers also need support when situations arise during their activities.

What volunteer coordinators have to say...

What is the best way to supervise volunteers?

The volunteer process starts with the matching of the coordinator, patient and volunteer. This matching does not always occur in a face-to-face meeting; some organizations do it over the phone. Patients are sometimes required to sign a consent form to receive volunteer services. The coordinator may take this opportunity to introduce the volunteer and to explain what the patient can expect in terms of services. The coordinator can also talk about the volunteer's training and explain that s/he is not a health care professional.

One coordinator noted that he did not meet patients to evaluate their needs, since this was done by nurses who make home visits. However, the coordinator did make contact with the family, introduced himself, informed them of the nurse's request, and asked whether the family was willing to have a volunteer come to their home.

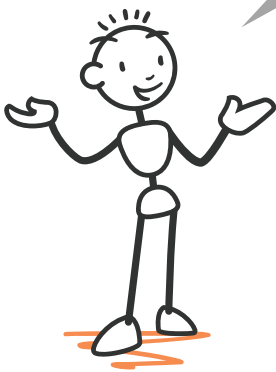
After these initial meetings, there are follow-up meetings which take place in a more or less structured manner. Coordinators check in every 15 days and volunteers send written reports about each visit by email. These follow-up mechanisms aim to show what happens during visits, how the relationship is developing, whether it is a good match, how satisfied the patient is, and whether the number of volunteer hours is sufficient. It is also important to check in with the volunteer to find out whether certain information needs to be conveyed to other parties, such as the nurse.

*"A good match is subjective; that's why we follow up.
We meet and explain how things work.
Then they have to get to know one another."*

The patient's point of view is very important. Patients are informed that they can always contact the coordinator in cases of conflict with the volunteer. Some coordinators encourage volunteers to give patients their personal phone number, while others strictly forbid this.

In this case, it is not the coordinator who supervises the volunteer, but the health care professional who requested his or her services. The coordinator follows up with the professional and facilitates communication among the parties.

Sometimes volunteers are available and waiting to be matched with patients, but there is little demand from the community.



Highlights

Supervision of palliative care volunteers

- Volunteers like to have rules to **guide their actions** as well as room to manoeuvre, according to the situation.
- Successful supervision includes **flexibility and rules, formal and informal communication, discussions around palliative care and a clear understanding of tasks.**
- **Coordinators play a crucial role** in supervising volunteers by helping them to solve problems and providing emotional support.
- Coordinators also have an important responsibility when it comes to matching volunteers with patients. **A good match allows the volunteer to effectively meet the patient's identified needs.**
- Coordinators can refer to the limits of the volunteer's role during their supervision. **Volunteers also need reassurance regarding their role.**
- **Daily recognition** helps to create a stimulating environment, which is important, since many volunteers do not commit for the long term.
- Organizations offer **more or less structured supervision** through follow-up by phone or email.

2. Potential supervision pitfalls

2.1. Stressful situations

Volunteers describe the **most stressful situations related to their work as**: interacting with patients who refuse to let them leave or who don't want them to return; witnessing conflicts in the patient's family; facing death; and not being informed of the patient's death or funeral.⁷²

One study shows that volunteers faced with high emotional demands can feel exhausted, and their health and well-being could be affected.⁷³

2.2. Challenges

Volunteers also describe **personal challenges**: not having time to do volunteer work; not knowing what to expect; not knowing what to do; having to work with a new team that does things differently; lack of communication between the family and organization, or between the coordinator and the volunteer; an imbalance between the patient's needs and the volunteer's availabilities.⁷⁴ Supervision by the coordinator could help volunteers manage these challenging situations.

Formalizing volunteers' role in **rural settings** in terms of number of hours and tasks to be accomplished seems difficult, because volunteers belong to a unique culture of care that is both formal and informal.⁷⁵

Team work can be beneficial, since the work is shared among several people, but can also have its drawbacks. There are situations where the work remains unfinished, since each team member thinks someone else should do it.⁷⁶

Volunteers say they are **very busy and live far** from the organizations offering services to end-of-life patients. This is a major obstacle to holding training/support meetings.⁷⁷

Organizations that do not have a website have a harder time managing and communicating with volunteers.⁷⁸

⁷² Brown, M. (2011b)

⁷³ Huynh, J-Y et al. (2012)

⁷⁴ Brown, M. (2011b)

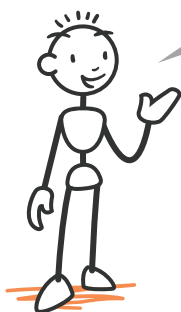
⁷⁵ McKee, M. et al. (2010)

⁷⁶ Azuero, C. B. et al. (2014)

⁷⁷ Wittenberg-Lyles, E. (2012)

⁷⁸ Ibid

What volunteer coordinators have to say...



When volunteers are uncomfortable around the patient, they should consult with the coordinator. If the situation persists, a new match should be found.

It is often difficult for palliative care personnel to stay in touch with volunteers, because of their heavy workload and geographical distances. Volunteer coordinators would like to hold annual meetings with employees to understand the challenges they face on a daily basis. Employees could also get involved in volunteer training.

“It’s a lonely job, but volunteers need to feel supported. Even if they’re at the patient’s home, they need to be listened to.”

3. Ideas on how to improve supervision

Coordinators play a crucial role in supervising volunteers, providing emotional support and helping them to solve problems. Coordinators should be proactive in assessing volunteers’ supervision needs in order to respond in the best way possible. Coordinators’ support is also very important to lighten the load when the tasks exceed the team’s competencies, to offer training and to address areas of imbalance in the team.⁷⁹

Some volunteers appreciate receiving support and feedback from coordinators, preferably on a weekly or monthly basis.⁸⁰ Coordinators must also show openness and flexibility in order to adjust to volunteers’ need for autonomy. By providing support, coordinators can also help to promote a sense of belonging to the organization and allow volunteers to see the positive impact they are having.

Volunteer coordinators must be sure to **match the right volunteer with the right patient**. They should also plan for a rest period between two “assignments” and respect volunteers’ right to refuse.⁸¹

Communication channels must be clearly established between the volunteer, coordinator and medical team to avoid misunderstandings regarding the **type and degree of supervision** to be provided.

Finally, when volunteers decide to leave, coordinators should meet with them to discuss the reasons for their departure. This will help to improve supervision and retention.

⁷⁹ Brown, M. (2011b); Azuero, C.B. et al. (2014)

⁸⁰ Weeks, L.E. et MacQuarrie, C. (2011)

⁸¹ Claxton-Oldfield, S. et Jones, R. (2013)

Activity 3

Other volunteers noted that they **do not like being taken for granted**. Regular support is necessary. This includes organizing lunch-and-learn sessions, and other activities and events that allow volunteers to share opinions, learn and obtain emotional support.⁸²

Volunteers said they wanted to be **informed of the death of patients** and of the funeral date, in order to turn the page and regain a sense of emotional well-being.⁸³

The limits of the volunteer's role should be clearly explained and referred to during supervision.

Coordinators must be on the lookout for **signs of stress** in volunteers and should take action as required.

Technological tools could also help coordinators supervise volunteers. A number of volunteers have **access to computers**, the Internet and email. They regularly use cell-phones and email.⁸⁴ These volunteers are comfortable with technology, but some might need training.

Daily recognition helps to create a stimulating environment. Since many volunteers do not commit for the long term, it is appropriate to focus on their strengths and assign them projects according to their abilities, whenever possible.

⁸² Claxton-Oldfield, S. & Jones, R. (2013)

⁸³ Brown, M. (2011b)

⁸⁴ Wittenberg-Lyles, E. et al. (2012)

What volunteers have to say...

How are they supervised?

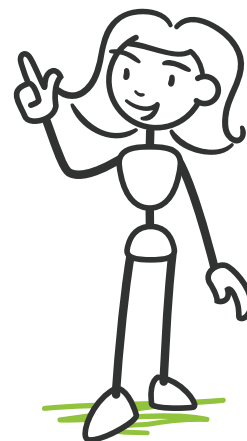
The volunteers we interviewed felt that they were not supervised. They all have extensive experience as volunteers or health care professionals.

Identified supervision needs

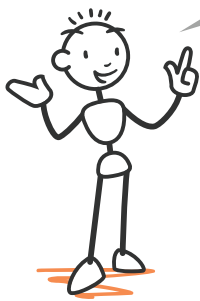
The volunteers felt it would be important that the nurse or social worker communicate regularly with them so they could provide updates on their interactions with the patient. Volunteers could also discuss their concerns or factors making them feel uneasy. After a first visit to the patient, a mechanism should be put in place whereby volunteers have weekly contact with the professional.

“I think I should call the social worker more often to maintain contact.”

Volunteers also noted that the coordinator has an important role to play in matching the patient and volunteer so as to address identified needs.



What volunteer coordinators have to say...



Computers have greatly facilitated coordination and communication with volunteers. Coordinators say they send emails with general information, updates on the patient, and changes or things to look out for. It is a lot faster. In certain cases, the fact that the number of training hours has been increased means volunteers feel more secure and better prepared. Regular follow-up is also reassuring.

Les chercheurs consultés nous disent...



Volunteer supervision

Supervision varies according to the volunteer's experience. New volunteers need to be more closely monitored by coordinators when first meeting with patients. This supervision can help to validate their experiences and reassure them in their role. Hospice volunteers in a home setting need to feel they are not alone, that they are part of a team and that a resource person is available to answer their questions. Practitioners would like to supervise volunteers, but this activity is not recognized as part of their workload. Coordinators cannot respond to all volunteers. Some organizations have over 500 volunteers and only two coordinators. It is up to managers to put in place follow-up mechanisms to facilitate the integration of volunteers in home settings and within interdisciplinary teams.

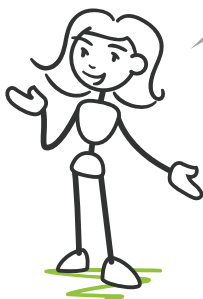
1. Important information about evaluation

In general, little attention is paid to evaluation activities and volunteer departures.

Volunteers are trained and supervised in terms of their role (see “Training” and “Supervision” sections). The limits of this role, which can be grouped into three categories⁸⁵ (definite boundary issues, potential boundary issues and questionable boundary issues), can vary substantially from one organization to another, since they are related to the organization’s culture.

One study⁸⁶ shows how volunteers develop a sense of social identity as they acquire knowledge related to end-of-life care and a better understanding of their role.

What volunteers have to say...



What type of evaluation have they received?

The volunteers we interviewed were not evaluated. Sometimes a health care professional on the care team asks the patient about his or her satisfaction with the service received.

Identified needs

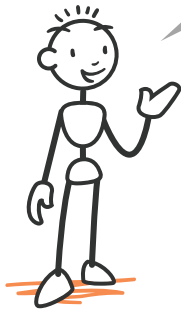
Volunteers agreed it would be difficult to come up with an evaluation method. The only way is to ask patients about their satisfaction and the difficulties they encountered with the volunteer. However, they believe that organizations should make sure that volunteers are doing a good job. They suggested having the nurse (or a social worker) conduct an evaluation using a short questionnaire. The answers could be transmitted to the volunteer coordinator.

“If I haven’t met the client’s needs, I want to know about it.”

⁸⁵ Claxton-Oldfield, S. et al. (2011)

⁸⁶ Seymour, J. E. et al. (2013)

What volunteer coordinators have to say...



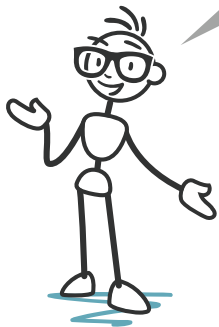
How to conduct a volunteer evaluation?

Currently, there is no formal evaluation procedure, but rather discussions and follow-up by phone or email, and sometimes in person. Volunteers have to communicate their hours, visits and, in some cases, provide an activity log, which helps to maintain contact. Volunteers are invited to contact the coordinator as needed. Since volunteers are often highly experienced, they need less supervision and follow-up. However, coordinators keep a closer eye on first-time volunteers.

One organization has a volunteer assessment that is submitted after the training, along with a survey completed every two years, with a view to improving services offered.

In one case, a performance evaluation is carried out jointly by the volunteer, the patient and the coordinator. The latter sends a self-evaluation form to the volunteer and an evaluation form to the family, which is added to that of the coordinator. A written summary is sent to the volunteer who can meet with the coordinator if he or she wants to.

What researchers have to say...



Evaluation of volunteers

Formal evaluation of volunteers is not yet part of regular management practices. It is done in extreme cases (dismissal) or while the volunteer is still working to ensure quality services are being provided. The activity log (hours worked) is used for occasional follow-ups and sometimes evaluation purposes. Volunteers can make contact or request additional information and training at any time.

Researchers noted that the training is also an opportunity for coordinators to select and evaluate candidates, and for volunteers to evaluate their own competencies. The basic training is a chance for volunteers to reflect on their choice. For coordinators, it provides an opportunity to identify risk factors (ongoing bereavement, conflict of interest) in volunteers seeking to take on the challenge of palliative home care.

According to the researchers consulted, an evaluation could help to support volunteers as they develop their knowledge and skills. Ultimately, an evaluation could ensure that quality services are being provided, and could also help to prevent volunteer burnout. Coordinators must always be attentive to volunteers, because they experience bereavement on a repeated basis.

Highlights

Evaluation of palliative care volunteers

- In general, **little attention is paid to formal evaluation activities** and volunteer departures. However, follow-up is conducted by phone or email, and sometimes in person.
- **In rare cases, a joint performance evaluation is carried out** by the volunteer, patient and coordinator, and is sent to the family.
- **Volunteers believe it would be difficult to develop an evaluation method** other than asking patients about their satisfaction and whether any problems were encountered. Volunteers also note that it is important to assess patient satisfaction.
- Researchers note that the training period is an opportunity for coordinators to select and evaluate volunteers, and for the latter to evaluate their own competencies. **Ultimately, the evaluation should be geared toward providing quality services.**
- **The activity log submitted by volunteers** allows for follow-up and occasional evaluation. Follow-ups by health care professionals are a form of evaluation.

2. Potential evaluation pitfalls

When volunteers have not received cultural competency training, there can be some confusion, awkwardness or tactlessness that could even affect the health of patients.⁸⁷

End-of-life patients and their family can discontinue the volunteer service following a bad experience, if they feel they have to keep up a conversation, or if they want to spend their last moments with family and loved ones.⁸⁸

3. Ideas on how to improve evaluation

Volunteers like to have regular support and feedback from coordinators. When the volunteer service is discontinued, it is important to obtain feedback from the volunteer and patient to understand the difficulties encountered during their relationship.⁸⁹

Coordinators should ensure that the palliative care philosophy is maintained by regularly communicating with volunteers. It is also important to share impressions of the patient and his or her family with the volunteer, and to ensure that the latter has access to (non-confidential) information on the patient. Finally, it is essential that paid staff recognize the value of volunteers' "work."⁹⁰

What volunteer coordinators have to say...



If a problem occurs, the volunteer service is discontinued. This situation seldom occurs.

4. Further reading on evaluation

- Inventory of instruments used to evaluate palliative care volunteers: Volunteer Function Inventory, Davis' Interpersonal Reactivity Index, Inventory of Motivations for Palliative Care Volunteerism, etc. Source: Pesut, B., Hooper B., Lehbauer, S., & Dalhuisen, M. (2014). "Promoting Volunteer Capacity in Hospice Palliative Care: A Narrative Review". *American Journal of Hospice & Palliative Medicine* 31(11), 69-78.

⁸⁷ Jovanovic, M. (2012)

⁸⁸ Claxton-Oldfield, S. & Claxton-Oldfield, J. (2012)

⁸⁹ Pesut, B. et al. (2014)

⁹⁰ Claxton-Oldfield, S. et Jones, R. (2013)

1. Important information about retention

It is difficult to **develop volunteer loyalty**, especially among young people who are seeking a personal experience as part of their career plan. Nonetheless, they admire the palliative care organization where they work and consider their work to be enriching and socially useful.⁹¹

1.1. Motivations

A number of **motivations** have been identified in the literature and are presented in the “Recruitment and selection” section. To name some of the most common: helping others, learning, building relationships, feeling better and attaining professional goals. It is often noted that **volunteers get involved** in helping others out of altruism.⁹²

Volunteers **continue doing volunteer work**:⁹³

- because of the quality of the organization and its staff;
- because palliative care volunteer work is gratifying;
- to enjoy positive experiences and personal satisfaction;
- because of effective, ongoing communication with the volunteer coordinator;
- because they have free time;
- because they are well matched.

Although it is important to recognize the work of volunteers and to organize social activities, this is not what incites volunteers to continue their involvement. Volunteers report having a high degree of satisfaction because they feel they are **making a difference** and derive fulfilment through their activities. They can learn and take on challenges. The satisfaction they obtain from the relationship with patients and their family is one of the main reasons they continue volunteering. Learning about others and diverse realities is one of the things that makes the volunteer experience gratifying. Volunteers are not necessarily motivated by formal rewards.⁹⁴

The motivations that lead male volunteers to start volunteering in palliative care are: having experienced the death of a loved one, and liking to help people and have contact with them. Most men prefer to offer practical support (shopping, transportation to medical appointments or to visit friends, etc.).⁹⁵ To retain volunteers, it is also very important to match them with the right patients.

⁹¹ Planalp, S. & Trost, M. (2009)

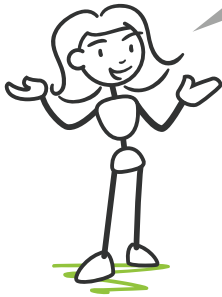
⁹² Claxton-Oldfield, S. et al. (2011)

⁹³ Planalp, S. & Trost, M. (2009); Pesut, B. et al. (2014)

⁹⁴ Fitzpatrick, T. et al. (2013)

⁹⁵ Claxton-Oldfield, S. et al. (2009); Weeks, L.E. & MacQuarrie, C. (2011)

What volunteers have to say...



How to retain volunteers?

Obviously it is essential that volunteers enjoy what they do; the organization has very little influence in this regard. Volunteers note the need to maintain some form of communication—such as the monthly meetings held in hospitals to discuss patient cases. It is important for volunteers not to feel isolated.

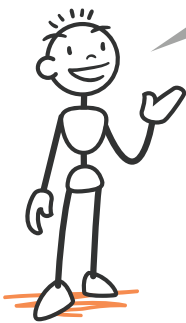
Volunteers also state that the need for supervision is perhaps greater when the patient's condition is deteriorating and it becomes more difficult to accompany him or her.

Small initiatives can have a major impact on retention—for instance, allowing volunteers to participate in events held in the palliative care network.

"I asked the organization for a letter to attend the Réseau des soins palliatifs conference. I was really happy to participate; it really motivated me to keep volunteering."

Finally, interviewees noted that some volunteers prefer short-term assignments, because it allows them more independence and freedom.

What volunteer coordinators have to say...



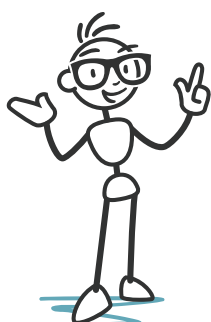
How to retain volunteers?

Daily appreciation helps to retain volunteers and allows for simple interactions such as providing feedback, conveying gratitude and showing empathy.

When volunteers are not matched for a long time, they tend to go elsewhere, because they want to feel useful. Organizations depend on demand to maintain active volunteers.

Holding annual activities is a good way to recognize volunteers' work. Training is another way to keep contact. The professionals who work with volunteers can also show their appreciation.

What researchers have to say...



Volunteer retention

Most researchers agree that a sense of belonging to a team is a major factor in volunteer retention. Team meetings, ongoing training and follow-up by coordinators (by phone or email) help to develop a sense of belonging. There are no formulas in terms of number of contacts, but coordinators must adapt the follow-up mechanisms to the varied needs of volunteers. Coordinators engage in knowledge transfer activities knowing very well that they will not be able to reach all volunteers.

Highlights

Retaining palliative care volunteers

- It is **difficult to develop loyalty among volunteers**, especially younger volunteers who are seeking a professional experience. However, young volunteers highly value the palliative care organization and find their work fulfilling and socially useful.
- There is a general consensus that the nature of volunteer work is itself an important motivational factor. Coordinators can focus on the **altruistic aspect and the quality of the relationship established with the patient** as factors contributing to volunteer retention.
- **Signs of recognition are important** (being appreciated by patients, their family and the palliative care team, and being thanked) although they are not a determining factor in volunteers' decision to continue their involvement.
- Volunteers continue to do volunteer work because it is **gratifying and it gives them personal satisfaction**.
- Researchers agree that a **sense of belonging** to the team is a factor in volunteer retention.

2. Potential retention pitfalls

Evaluation of support needs must take into account a variety of factors, including the fact that an initial volunteering experience is the most stressful period in a volunteer's life.⁹⁶ Volunteers with less than one year of experience are less satisfied and fulfilled than those who have seniority.⁹⁷

One of the biggest challenges for volunteers is helping patients suffering from cognitive impairment and dementia. It is difficult to find ways to interact with them. Volunteers also find it difficult to deal with death. Other challenges include negotiating with the patient's family, experiencing interpersonal conflict, managing fears, experiencing ethical dilemmas and determining the limits of their role.⁹⁸

Feeling exhausted does not necessarily cause volunteers to give up volunteering. There is not a direct link between exhaustion and retention. However, **cynicism** is sometimes described as a factor contributing to volunteer disengagement. The "insensitivity" of the medical system and deterioration of the patient's condition can also be sources of stress for volunteers.⁹⁹

Although a number of volunteers and volunteer coordinators use communication technology tools (email, cellphones, websites, etc.) that facilitate contact, there are still problems with organizing meetings because of **busy schedules and the geographical distance of the palliative care organization.**¹⁰⁰

Certain aspects of volunteer engagement are less satisfying, namely those related to the limits of their role (feeding and lifting the person, when to say "yes" and "no" to requests, etc.). Volunteers do not like it when they have difficulty bonding with patients, or when the latter are suffering or are referred too late to institutions.¹⁰¹

Volunteers tend to **end their volunteering activities** for the following reasons: crises within their own family, exhaustion, old age, health problems or a lack of solicitation on the part of coordinators.¹⁰²

⁹⁶ Brown, M. (2011b)

⁹⁷ Lavenburg, P.H. & Bernt, F.M. (2012)

⁹⁸ Ibid

⁹⁹ Huynh, J-Y. et al. (2012)

¹⁰⁰ Wittenberg-Lyles, E. et al. (2012)

¹⁰¹ Claxton-Oldfield, S. & Claxton-Oldfield, J. (2012)

¹⁰² Ibid

3. Ideas on how to improve retention

The **training activities** described in this document could be a good way to improve volunteer retention. Volunteers say they are interested in learning about topics such as managing the loss of end-of-life patients, ethical dilemmas, communication strategies and various diseases.¹⁰³ If their training is focused on topics of interest to them, they will be more likely to participate and this will have a positive impact on retention as well.

A solid training program and the organization of round table discussions would allow volunteers to share ideas, solve problems and obtain emotional support. Coordinators must inform volunteers of the death of patients and provide them with details about the funeral to help them regain a sense of emotional well-being.¹⁰⁴

When volunteers receive **adequate support** and encouragement from the coordinator and organization, they feel connected to their work, and this strengthens their resolve to stay with the organization.¹⁰⁵

The evaluation of volunteers' support needs must take into account a variety of factors, including the fact that an volunteering experience is the most stressful period in a volunteers' life. Volunteer retention is problematic in the first year of activity. Retention strategies must take this cycle into account. Stress management strategies can help maintain volunteers' sense of well-being.

Overall, it is recommended that palliative care organizations help volunteers acquire skills and knowledge related to patients' cultural practices, that they make internal changes to offer services in several languages, that they promote their services in the community, and that they train volunteers.¹⁰⁶

There appears to be a link between the **degree of altruism** shown by volunteers and the duration of their involvement. The more their decision to volunteer is based on altruism, the longer they will stay. Giving priority to volunteers showing altruism during the selection process could have an impact on long-term retention.¹⁰⁷

The team work model reduces fatigue and ensures that members obtain emotional and hands-on support. The volunteer coordinator plays a very important role in maintaining the team's equilibrium, especially when volunteers encounter situations that exceed their competencies.¹⁰⁸

¹⁰³ Lavenburg, P.H. & Bernt, F.M. (2012)

¹⁰⁴ Brown, M. (2011a)

¹⁰⁵ Huynh, J-Y. et al. (2012)

¹⁰⁶ Jovanovic, M. (2012)

¹⁰⁷ Claxton-Oldfield, S. et al. (2013)

¹⁰⁸ Azuero, C.B. et al. (2014)

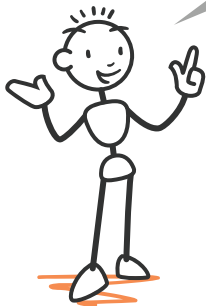
Activity 5

It is also important to assign volunteers to patients **as soon as possible after their training** and to ensure a good match to increase volunteer engagement and retention. The coordinator should give volunteers a break between assignments and should respect volunteers' refusal to get involved with patients again.¹⁰⁹

The organization should support volunteers who end their engagement; this is often considered a difficult stage in their lives. When departures occur, coordinators should interview the volunteer to find out why he or she is leaving. This would help to improve supervision and retention activities.

Coordinators could use volunteer motivation inventories to develop retention strategies. Pleasure, success and recognition are all factors that influence retention. In addition, volunteers greatly appreciate it when paid staff recognize their work. Volunteers want to be seen as partners. Efforts to ensure volunteer satisfaction and well-being have a positive impact on retention rates.¹¹⁰

What volunteer coordinators have to say...



At the outset, it is important to demystify palliative care support in order to correct certain misperceptions. Providing supportive care and attention to clients is not always wonderful; it is important to be honest about the reality of palliative care. Each case is unique. As they gain experience over the years, volunteers feel more comfortable in their role, but they must always remain vigilant for potential pitfalls.

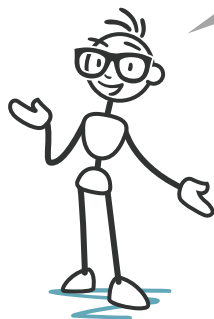
It is important that volunteers feel they are part of a team, even if they do not meet all the practitioners, and to focus on open communication and team work. Volunteers need to talk about their experiences. Team members should create ties with volunteers and get to know them.

*“We have a suggestion box, we talk.
It’s important to give them a degree of freedom.”*

¹⁰⁹ Claxton-Oldfield, S. & Jones, R. (2013)

¹¹⁰ Ibid

What researchers have to say...



Recognition evenings can be a source of motivation for some volunteers. More important for them, however, is listening to patients and feeling that they are useful to the organization. The time they invest should meet a need and their actions should be meaningful.

An organization must invest as much time in developing volunteer loyalty as in recruitment. To retain a volunteer with an attractive profile, the organization must have in place an orientation, training and supervision program to create a sense of belonging. Organizations that have too many strict rules risk losing volunteers. The latter have many commitments and coordinators must respect their availabilities. It is necessary to follow up more often with volunteers to keep them motivated. Reminding them of the limits of their role, as part of the supervision process, can help clarify grey areas. Volunteers need to take their place, at the same time respecting the privacy and needs of the family.

4. Further reading on retention

- Elements from the questionnaire on volunteer retention criteria. Source: Claxton-Oldfield, S. & Jones, R. (2013) "Holding on to What You Have Got: Keeping Hospice Palliative Care Volunteers Volunteering". *AM J HOSP PALLIAT CARE* 30, 467-472.

Conclusion

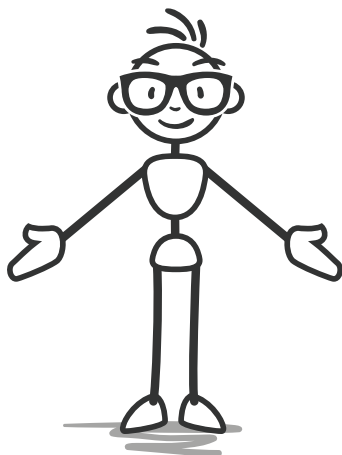
How can we promote and develop home-based palliative care? This was our question at the outset. In this guide, we offer a number of ideas on how to guide and supervise volunteers providing home-based support.

We found it difficult to identify a wide range of best practices specifically tied to the home setting, even though certain organizations have developed a solid expertise in this area. Obviously coordinators require a more specific expertise, given the growing demand for services. Coordinators who welcome and rapidly orient volunteers are better able to retain them for the long term. We have observed that effective matching is key to keeping volunteers committed to end-of-life patients, and coordinators play a very important role in this regard.

Volunteers are neither professionals nor friends, but they are indispensable for organizations seeking to offer a full array of services. Patients trust volunteers and often develop a special relationship with them, which offers respite and comfort to families. Volunteers are a source of tremendous physical, social, emotional and practical support.

In writing this guide, we have confirmed our initial hypothesis; namely that the field of palliative home care is a vast area of study in which further research is required.

We hope that the tools and ideas provided will help organizations to recruit and retain volunteers in teams providing home-based palliative care.



Bibliography

- Azuero, C. B., Harris, G. M., Allen, R. S., Williams, B. R., Kvale, E., & Ritchie C. S. (2014). "Team-Based Volunteerism with the Seriously Ill: A Qualitative Analysis from 10 Volunteers' Perspectives". *Journal of Social Work in End-Of-Life & Palliative Care* 10(3), 282-295.
- Block, E. M., Casarett, D. J., Spence, C., Gozalo, P., Connor S. R., & Teno, J. M. (2010). "Got Volunteers? Association of Hospice Use of Volunteers With Bereaved Family Members' Overall Rating of the Quality of End-of-Life Care". *Journal of Pain and Symptom Management* 39(3), 502-506.
- Brown, M. (2011a) "How they Cope: A Qualitative Study of the Coping Skills of Hospice Volunteers". *American Journal of Hospice & Palliative Medicine* 28(6), 398-402.
- Brown, M. (2011b) "The Stresses of Hospice Volunteer Work". *American Journal of Hospice & Palliative Medicine* 28(3), 188-192.
- Claxton-Oldfield, S., Claxton-Oldfield, J., Paulovic, S., Wasylkiw, L. (2013). "A Study of the Motivations of British Hospice Volunteers". *AM J HOSP PALLIAT CARE* 30(6), 579-586.
- Claxton-Oldfield, S. & Claxton-Oldfield, J. (2012). "Should I Stay or Should I Go: A Study of Hospice Palliative Care Volunteer Satisfaction and Retention". *AM J HOSP PALLIAT CARE* 29(7), 525-530.
- Claxton-Oldfield, S. & Jones, R. (2013) "Holding on to What You Have Got: Keeping Hospice Palliative Care Volunteers Volunteering". *AM J HOSP PALLIAT CARE* 30, 467-472.
- Claxton-Oldfield, S., & Banzen, Y. (2010). "Personality Characteristics of Hospice Palliative Care Volunteers: The "Big Five" and Empathy". *American Journal of Hospice & Palliative Care* 27(6), 407-412.
- Claxton-Oldfield, S., Guigne, S., & Claxton-Oldfield, J. (2009). "How to Attract More Males to Community-Based Hospice Palliative Care Volunteer Programs". *AM J HOSP PALLIAT CARE* 26, 439-447.
- Claxton-Oldfield, S., Jefferies, J., Fawcett, C., & Wasylkiw, L. (2004). "Palliative Care Volunteers: Why Do they Do It". *Palliative Care Volunteers* 20(2), 78-84.
- Claxton-Oldfield, S., Wasylkiw, L., Mark, M., & Claxton-Oldfield, J. (2011a). "The Inventory of Motivations for Hospice Palliative Care Volunteerism: A Tool for Recruitment and Retention". *AM J HOSP PALLIAT CARE* 28(1), 35-43.
- Claxton-Oldfield, S., Gibbon, L., & Schmidt-Chamberlain, K. (2011b) "When to Say "Yes" and When to Say "No": Boundary Issues for Hospice Palliative Care Volunteers". *American Journal of Hospice & Palliative Medicine* 28(6), 429-434.
- Fitzpatrick, T., Edgar, L., Remmer, J., & Leimanis, M. (2013). "Job Satisfaction Among Volunteers With Personal Cancer Experience". *Journal of Social Service Research* 39, 293-305.
- Guirguis-Younger, M., Grafanaki, S. (2008). "Narrative Accounts of Volunteers in Palliative Care Settings". *American Journal of Hospice & Palliative Medicine* 25, 16-23.
- Huynh, J.-Y., Winefield, A. H., Xanthopoulou, D., & Metzger, J. C. (2012). "Burnout and Connectedness in the Job Demands-Resources Model: Studying Palliative Care Volunteers and Their Families". *American Journal of Hospice & Palliative Medicine* 29(6), 462-475.
- Jovanovic, M. (2012a). "Cultural Competency and Diversity Among Hospice Palliative Care Volunteers". *American Journal of Hospice & Palliative Medicine* 29(3), 165-170.
- Jovanovic, M. (2012b). "Improving Cultural Competency Among Hospice and Palliative Care Volunteers: Recommendations for Social Policy". *American Journal of Hospice & Palliative Medicine* 29(4), 268-278.

- Lavenburg, Ph., & Bernt, F. M. (2012). "Training and Supporting Hospice Volunteers: A Regional Survey". *AM J HOSP PALLIAT CARE* 29(5), 355-361.
- Leclerc, B. -S., Lessard, S., Bechenec, C., Le Gal, E., Benoit S., & Bellerose, L. (2014) "Attitudes Toward Death, Dying, End-of Life Palliative Care, and Interdisciplinary Practice in Long Term Care Workers." *JAMDA* 15(207-213).
- Mackay, M. M., & Bluck, S. (2010). "Meaning-Making in Memories: A Comparison of Memories of Death-Related and Low Point Life Experiences". *Death Studies* 34, 715-737.
- McKee, M., Keley M. L., Guirguis-Younger, M., MacLean M., & Nadin S. (2010). "It takes a whole community: The contribution of rural hospice volunteers to whole-person palliative care". *Journal of Palliative Care* 26(2), 103-111.
- Mount, M. B. (1992). "Volunteer support Services, a Key Component of Palliative Care". *Journal of Palliative Care* 8(1), 59-64.
- Pesut, B., Hooper B., Lehbauer, S., & Dalhuisen, M. (2014) "Promoting Volunteer Capacity in Hospice Palliative Care: A Narrative Review". *American Journal of Hospice & Palliative Medicine* 31(11), 69-78.
- Planalp S., & Trost, M. (2009). "Reasons for Starting and Continuing to Volunteer for Hospice". *American Journal of Hospice & Palliative Medicine* 26(4), 288-294.
- Planalp, S., & Trost, M. (2009). "Motivations of Hospice Volunteers". *AM J PALLIAT CARE* 26, 188-192.
- Planalp, S., Trost, M. R., & Berry, P. H. (2011). "Spiritual Feasts: Meaningful Conversations between Hospice Volunteers and Patients". *American Journal of Hospice & Palliative Medicine* 28(7), 483-486.
- Savery, C. A. and N. Egbert (2010). "Hospice volunteer as patient advocate: a trait approach". *Palliative & Supportive Care* 8(2): 159-167.
- Sévigny, A., et al. (2010). "Making sense of health and illness in palliative care: volunteers' perspectives". *Palliative & Supportive Care* 8(3), 325-334.
- Sévigny, A., Champagne, M. et Guirguis-Younger, M. (Eds.) (2013). *Le bénévolat en soins palliatifs ou l'art d'accompagner*. Presses de l'Université de Laval.
- Seymour, J. E., et al. (2013). "Peer education for advance care planning: Volunteers' perspectives on training and community engagement activities". *Health Expectations: An International Journal of Public Participation in Health Care & Health Policy* 16(1): 43-55.
- Spice, R., Read Paul, L., & Biondo, P. (2012). "Development of a Rural Palliative Care Program in the Calgary Zone of Alberta Health Services". *Journal of Pain and Symptom Management* 43(5), 911-924.
- Weeks, L. E & MacQuarrie, C. (2011). "Supporting the Volunteer Career of Male Hospice-Palliative Care Volunteers". *American Journal of Hospice & Palliative Medicine* 28(5), 342-349.
- Wittenberg-Lyles, E., Demiris, G, Ferrell, B., & Shaunfield, S. (2012). "Volunteers as Facilitators of Communication About Pain: A Feasibility Study". *Research on Aging* 34(2), 246-253.
- Wittenberg-Lyles, E., Parker Oliver, D., Demiris, G., & Regehr, K. (2010). "Interdisciplinary Collaboration in Hospice Team Meetings". *J Interprof Care* 24(3), 264-273.
- Wittenberg-Lyles, E., Shaunfield, S., Parker Oliver, D., Demiris, G., & Schneider, G. (2012). "Assessing the Readiness of Hospice Volunteers to Utilize Technology". *American Journal of Hospice & Palliative Medicine* 29(6), 476-482.

Ressources

- **Canadian Hospice Palliative Care Association**
Organization advancing and advocating for quality end-of-life care in Canada
<http://www.chpca.net/>
- **Association des gestionnaires de ressources bénévoles du Québec (AGRBO)**
Association of volunteer resource managers in the health and social services sector
<http://www.agrbq.com/>
- **Volunteer Canada**
Canadian charity organization promoting volunteerism
<http://volunteer.ca/about>
- **CSSS Cavendish**
<http://www.cssscavendish.qc.ca/>
- **Volunteer Bureau of Montreal**
Organization promoting volunteerism in the community
<http://cabm.net/>
- **Council on Palliative Care**
Organization dedicated to increasing public awareness
Volunteer training videos on DVD:
<http://www.mcgill.ca/council-on-palliative-care/events-resources/training-videos-volunteers>
- **Fédération du mouvement Albatros du Québec**
Federation of local volunteer organizations providing palliative care services in homes, hospitals and long-term care facilities
<http://www.fmaq.ca/index.php>
- **Hope & Cope, Jewish General Hospital**
Psychosocial support organization for cancer patients and their family
<http://www.jgh.ca/en/hopeandcope?mid=ctloo>
LeftMenu_ctloo TheMenu-menultemo09
- **Lumi-Vie**
Organization providing moral and spiritual support to people in end of life and in bereavement
<http://www.lumivie.com>
- **NOVA West Island**
Organization providing care and support in the home to cancer and Amyotrophic Lateral Sclerosis (ALS) clients
<http://www.novawi.org/en/>
- **Canadian Virtual Hospice**
Site providing information on palliative and end-of-life care, bereavement and loss
http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home.aspx
- **Réseau des soins palliatifs du Québec**
Group of volunteers and professionals working in palliative care
<http://www.aqsp.org/>
- **The Palliative Home-Care Society Foundation**
Organization providing home-based palliative care services to cancer patients
info@societedesoinspalliatifs.com
- **Palliative Care McGill**
Interdisciplinary network of professionals working across five teaching hospitals
<http://www.mcgill.ca/council-on-palliative-care/about-us/palliative-care-mcgill>

Reference documents

État de situation du bénévolat auprès des personnes à domicile recevant des soins palliatifs et de fin de vie de la région de la Capitale-Nationale,

Final report, Centre d'excellence sur le vieillissement, Centre hospitalier affilié universitaire de Québec, Agence de la santé et des services sociaux de la Capitale-Nationale, June 2011. (in French)

http://www.rrsso3.gouv.qc.ca/pdf/Rap%20ES_Benevolat_Soins_palliatifs_Domicile_Regio3.pdf

Guide pratique (belge) pour collaborer avec des bénévoles dans votre institution de soins.

<http://www.volontariat.be/documents/publications/benevole-milieu-hospitalier.pdf>

Intervenir auprès des personnes âgées en soins palliatifs. Guide de pratique sur le soutien psychosocial à domicile,

Centre for Research and Expertise in Social Gerontology, Centre de santé et de services sociaux Cavendish, 2012. (in French)

<http://www.creges.ca/site/fr/pratiques-de-pointe/soins-palliatifs-communautaires-pour-les-aines/intervenir-aupres-des-personnes-agees-en-soins-palliatifs>

Plan directeur de développement des compétences des intervenants en soins palliatifs, ministère de la Santé et des Services sociaux du Québec.

April 2008. (in French)

<http://publications.msss.gouv.qc.ca/acrobat/f/documentation/2008/08-902-03.pdf>

Rapport soins palliatifs à domicile dans la région de la Capitale-Nationale, au cœur de nos préoccupations, Agence de la santé et des services sociaux de la Capitale-Nationale. April 2009. (in French)

http://www.rrsso3.gouv.qc.ca/pdf/Rapport_soinspalliatifs_internet.pdf

Soins palliatifs et de fin de vie, Volet 1 : recension des écrits, Agence de la santé et des services sociaux de la Montérégie. December 2013. (in French)

http://extranet.santemonteregie.qc.ca/depot/document/3592/Recension_SP_VF.pdf

Soins palliatifs et de fin de vie, Volet 2 : recension des pratiques, Agence de la santé et des services sociaux de la Montérégie. December 2013. (in French)

http://extranet.santemonteregie.qc.ca/depot/document/3593/Pratiques_SP_VF.pdf

The Hospice Palliative Care Volunteers: A Training Program. Ottawa, Ontario: Canadian Hospice Palliative Care Association.

<http://www.chpca.net/volunteers/volunteers-benevoles.aspx>

**Centre intégré
universitaire de santé
et de services sociaux
du Centre-Ouest-
de-l'Île-de-Montréal**

Québec 



**Centre de recherche et d'expertise
en gérontologie sociale**

**University Affiliated Centre of Social Gerontology
of West-Central Montreal Health**

5800 boul. Cavendish suit 600
Côte St-Luc (Québec) H4W 2T5
514-484-7878 extension 1472