

How Volunteer Services Can Improve and Advance Palliative Care Programs

Abstract and Introduction

Abstract

The critical need for palliative care continues to grow as our population in the United States ages. Palliative care volunteers have been used in various palliative care programs around the country, enabling those programs to meet the critical needs of patients and families. Volunteers receive specialized training on how to interact with patients, families, and other interdisciplinary team members. Volunteers may serve as hosts and greeters; provide patient/family companionship; act as desk clerks; perform data entry; assist staff with direct patient care, legacy and memory making, and journaling; act as patient ambassadors for filling out paper work; speak as part of the speakers' bureau on palliative care; assist with bereavement follow-up; plan special celebrations; and assist in grant writing and fund-raising events. A program established at The Virginia Commonwealth University/Massey Cancer Center Palliative Care Program has successfully used palliative care volunteers for more than 15 years as a means to improve and advance the program to the benefit of the patients and families in their care.

Introduction

As the demand for palliative care (PC) rapidly grows throughout the United States and the clinician workforce tries to keep pace, PC clinicians are challenged to meet the needs of patients and families.^[1,2] This article provides a brief overview of how volunteers can be used as a workforce multiplier and how a PC volunteer coordinator and the volunteers can help ensure that PC program's needs and the needs of patients and families are met.^[3]

Background

The Virginia Commonwealth University/Massey Cancer Center Palliative Care Program was established more than 15 years ago as a part of the Virginia Commonwealth University Health System. The PC program has a dedicated unit with 11 beds, a consult service, and an outpatient clinic, and together, these 3 services see 2000 patients annually. Early in the development of this program, program creators envisioned various roles, value, and potential cost savings for what volunteers might accomplish. A full-time volunteer coordinator was hired specifically for the PC program to address the needs of patients, families, and staff. The volunteer coordinator recruits and selects volunteers, provides orientation and trainings, supports and assigns, and evaluates volunteers. This role is critical to a successful and dynamic PC service. Recent studies have concluded that few PC programs could offer quality care without such volunteer services.^[4,5]

Studies have shown that volunteers in end-of-life care programs are motivated by a variety of factors, including wanting to help ease the pain of others, civic responsibility, deeply felt personal experiences and desires, past experiences with death, and wanting to support the philosophy of hospice care.^[6,7] In the Virginia Commonwealth program, program volunteers are 14 to 75 years of age, from a variety of professions and life experiences. They include high school students, executive board members, and individuals with a wide range of professional and personal backgrounds. Volunteers provide more than 2500 hours of service annually, more than 200 hours a month, to the PC program. These individuals seek out this specialized program, are trained, and are given guidelines to follow during their service. In this institution, there is 1 volunteer office for the entire hospital. An individual wishing to volunteer must complete the hospital application and orientation process. All new volunteers are screened; they undergo a background check, Tuberculosis skin test, and an intensive orientation, including instruction on the Health Information Protection Act, confidentiality, hospital rules, joint commission regulations and guidelines, and safety and hazard competencies. Once the individual has cleared these requirements, they are given an identity document volunteer badge with clearance to certain areas of the hospital, receiving a red volunteer apron, red volunteer vest, or a red volunteer shirt that identifies them as a hospital volunteer to all facility

staff and incoming patients and visitors. Volunteers then undergo a second orientation to the PC program and a specialized competency training, depending on their volunteer status as a junior volunteer (age, 14-18 years), college volunteer (age, 16–24 years), or adult volunteer (18–75 years and older).

Once volunteers complete the basic volunteer training, they may apply for specialty training on the PC unit, after completing approximately 100 hours of volunteering. Generally, adult volunteers receive the more advanced trainings, because they are more likely to remain a volunteer longer than a semester. Volunteers may receive additional individual trainings by being placed with members of the interdisciplinary team. Studies show that training programs directly enhance volunteers' ability to effectively interact with patients, in part because once trained, volunteers perceive that they are better prepared to assist the very ill and to handle the duties involved.^[6] Team members including the chaplain, social worker, psychologist, speech therapist, nutritionist, nurses, physicians, and physical and occupational therapists have organized advanced competency trainings. After these trainings are completed, the volunteer works directly with the volunteer coordinator for the next 3 to 6 visits before going "solo," to ensure that they are comfortable with their functions as a PC program volunteer. Volunteers are regarded as team members and are invited to team functions, including education, interdisciplinary rounds, individual patient celebrations, and legacy and memory making, and may even participate in the interview process of staff for PC positions. Volunteers serve in all parts of the healthcare system, such as the intensive care units, prison unit, emergency department, and outpatient clinics. Flexibility on behalf of staff and volunteers is critical to the mission of the program.

Leading Roles of Volunteers

Palliative care volunteers visit and work directly with the PC team; they may be consulted by team members, patients, and family member(s). Volunteers serve as hosts and greeters; provide patient/family companionship; act as desk clerks; perform data entry; assist staff with direct patient care, legacy and memory making, and journaling; act as patient ambassadors to assist with paper work; speak as part of the speakers' bureau on PC; assist with bereavement follow-up; plan special celebrations; and assist in grant writing and fund-raising events.

Host and Greeters

One of the most important roles a volunteer can perform in a PC unit is being a greeter and host. When a consult comes in to the PC team, a member or members of the team will meet with the patient and their loved ones. At this time, if the patient is to be transferred to the PC unit, the clinician will contact the volunteer coordinator and request a volunteer to take the family on a tour of the unit. The volunteer may come to the transferring unit, introduce himself/herself to the family, and offer them an orientation to the PC unit. The volunteers are trained to help the family make this difficult transition to the PC unit when their loved one is extremely ill, facing death, on an eventual transfer to an inpatient hospice unit, or returning home with hospice care.

Patient/Family Companionship

The volunteers may assist the family by meeting their various needs by being available in the hospitality house room, assisting with the parking garage and parking tags, identifying food locations inside and outside the facility, supplying phone numbers to the room and unit, and answering other questions the patient and/or family may have. Volunteers help the patients' caregivers on the PC unit or on other units. The volunteer may offer to stay with their loved ones so they may step out to get a cup of coffee, make a phone call, go home briefly, or take other time they may need for themselves. They may also watch over younger family members in the unit's family room.

Desk Clerk and Data Entry

Not all volunteers will want actual direct patient care or contact when they first start to volunteer. First, they must get comfortable with the idea of interacting with patients and family members, so offering alternative tasks until they acclimatize to the program helps. There are many areas in the PC program that need volunteer assistance. An example is sending out patient satisfaction survey mailings; when the surveys are returned, the volunteer inputs all the data into a program that can be accessed and documented later. Other volunteers can act as ward clerks/secretary/receptionists so that someone is always at the front desk to assist patients by answering their call bells, being available to meet the needs of family members, or answering incoming phone calls for staff and patients.

Staff Assistance With Direct Patient Care

Some volunteers will want to participate in direct patient care. They receive specialized training from nursing staff and are always supervised in the assistance of direct patient care. They may also assist by helping transport patients within the hospital to an outside garden area or shopping area if his/her condition allows. Volunteers may also cook snacks for the patients, family, and staff in the unit's kitchen.

Legacy and Memory Making

Legacy making is frequently cited in professional literature, but volunteers can also be involved in this work.^[9]

Specialized training is provided to enable volunteers to assist in legacy and memory making. Such work may involve using narrative practice to "leave a legacy,"^[10] long-term journaling with a patient, other means of legacy work, or memory making for the patients and their loved ones. Volunteers may photograph patients and families together, at their request. The photos may be printed or e-mailed to the patient or family member. Memory making and legacy work can be offered to patients and their loved ones. This may consist of hand photos, handmade blankets, full-painted handprints on blankets and pillows, prints, and thumbprints as a memento of the patient. If a patient has a special bible, the patient's handprints can be placed directly in the front of the bible, or handprints or thumbprints can be placed on pillows and other surfaces.

Journaling

Volunteers can assist patients in writing messages that they would like to say to their loved ones. It may be a letter of forgiveness, a letter of thanks, or even a good-bye letter. Some letters are dated so their children and grandchildren can open them on certain dates or events to hear the advice of their loved one, such as graduation day, 16th birthday (eg, a letter of "things I wish I knew"), a wedding thought, or their own eulogy. This is another way of legacy making, and volunteers can be trained to assist with this task.

Journaling can play a significant role in a patient's difficult journey of being very ill and documenting their daily/weekly progress or decline. Many patients work in multiple journals at a time. Some patients have children and a spouse and want to create multiple journals for each child and for his/her spouse.

Volunteers can assist the patient in creating a personal note that can be given to loved ones after the patient's death.

Patient Ambassadors for Assisting With Advance Directives

Volunteers can be trained in assisting patients with advance directive documentation, including advance directive forms, a living will, the "5 wishes" document, and a conversation brochure. The hospital offers hospital wide training through the pastoral care department for their chaplains and others. On April 16th every year, Healthcare Decision Day, the hospital gathers a collaboration of chaplains, social workers,

doctors, nurses, volunteers, and the volunteer coordinator and creates display tables in the main hospital lobby so that all medical professionals, patients, family members, and visitors can get free information and documents about advance directives. Staff and volunteers are available to answer questions.

In addition, treating physicians or chaplains can present to patients and families the do-not-resuscitate form. The volunteer coordinator or volunteer has a wonderful opportunity to work with the staff, patient, and their loved ones to make sure that the patient's wishes will be honored. This fosters open discussions, while the patient is present and sharing his or her wishes with family.

Special Celebrations, Events, and Fundraising

The hospital holds an annual PC memorial service for the families and friends of patients who have passed on during the past 2 years (many families come back every year; some, for many years). The volunteers plan this service, and this is an opportunity for the entire family and friends to be in a safe environment to share their grief and to memorialize their loved one. Other special events coordinated by our volunteers have included patient/family weddings, graduations, renewal of vows, baptisms, golf tournaments, yard and bake sales, and many other projects. Volunteers actively raise funds to support the needs of the program.

Bereavement Follow-up Cards

The bereavement services for our PC program are a very large part of our volunteer program. When a patient dies on the unit, on the PC service but on another unit, at home with hospice, or in the inpatient hospice program, they are all added to our bereavement listing to initiate the card mailings. Within 2 weeks of their death, a card that is signed by our staff and volunteers with a poem insert is mailed to their family and friends. A different card and poem insert will be mailed 3 months later and at 6 months. At the 1 year anniversary, their loved ones will receive another card and poem. The palliative program will also mail out an invitation to the annual memorial service and a holiday letter with suggestions on how to cope with the death of a loved one during the holiday season. Within a few days of the mailings, the volunteer service often receives a phone call, a visit in person, or another card of thanks from the family describing how important these mailings have been for the family during their healing process.

Bereavement Follow-up Calls by Volunteers

An important part of our bereavement program is specially trained volunteers making follow-up bereavement calls to family members within 3 months of the patient's death. A bereavement call may be done sooner to check on family members, if needed. If there is the potential for a complicated grief call, the chaplain for the PC program will be notified, and he will make a call to the family member as well to follow-up.

Palliative Care Speakers Unit

This group of volunteers speaks regionally on a variety of topics including a description of PC, the role of advance directives, or PC program volunteer opportunities. These are valuable opportunities to promote the PC program and recruit volunteers, and also as a means of raising community awareness about PC or advance directives.

Grant Writing Assistance Volunteer

Volunteers work specifically to seek grant opportunities to support the PC program and to meet the needs of the patients and families who are being served and to seek funding for ongoing staff education.

Summary

Faced with an aging population with multiple chronic health problems, PC has become a major consideration on how to provide high-quality care to the many people who will need it. It is all too clear that the numbers of specialist providers will not be able to meet the needs of our rapidly aging population, so it is incumbent upon us that we anticipate and prepare for this need by building a network of volunteers. With today's demands, we recognize that a volunteer program for a PC service is a requirement for an excellent PC program. A PC program's success is directly related to the time, energy, and support of its volunteers. As the demands of PC programs increase and the workforce is further stretched to meet needs, the opportunities and benefits of PC volunteer programs will increase. Nurses are centrally involved in training volunteers and working collaboratively with them to provide the best support possible for patients and families.

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