Original Article

Perspectives on Volunteer-Professional Collaboration in Palliative Care: A Qualitative Study Among Volunteers, Patients, Family Carers, and Health Care Professionals

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Abstract

Context. Governments intend to meet resource constraints in professional palliative care by stimulating informal care, including volunteerism. However, little is known about current volunteer-professional collaboration. Such insights are relevant for future policy development regarding volunteer efficiency, quality of care, and the capacity of volunteer care to support health care services and professionals.

Objectives. To explore what constitutes volunteer-professional collaboration around palliative care.

Methods. A qualitative study was conducted using semistructured focus groups with volunteers, nurses, psychologists, and family physicians and semistructured interviews with people with serious illnesses and with family carers. Participants were recruited from hospital, home-care, day-care, and live-in services in Flanders, Belgium. Interviews and focus groups were audio-recorded, transcribed verbatim, and analyzed by using a phenomenological approach. Two researchers coded independently in NVIVO 11 and reached a definitive coding scheme by comparing their resulting conceptual schemes.

Results. Seventy-nine people participated in the study. Volunteers collaborate mostly with nurses, less with psychologists but not with physicians. Volunteer-professional collaboration entails mutual information-sharing regarding patient conditions and coordination of care provision, whereas nurses and psychologists provide emotional and functional support for volunteers. Lack of access to nurses, of leadership, and of patient-information-sharing guidelines were the most prominent barriers to collaboration.

Conclusion. Volunteers are at the front line of palliative care provision and therefore collaborate intensely with nurses, particularly in dedicated palliative care services. However, collaboration with other professionals is limited. The presence and availability of nurses was found to be crucial for volunteers, both for support and to achieve integration through collaboration. J Pain Symptom Manage 2019;58:198–207. © *2019 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Volunteers, palliative care, cooperative behavior, hospice and palliative care nursing, interdisciplinary communication, qualitative research

Introduction

Professional health care currently faces increasing resource constraints,[1] and recent projections predict a continued increase in palliative care (PC) needs.[2] Health care professionals struggle with burnout,[3] and there is a growing realization that merely increasing health professionals and improving professional services are insufficient to ensure continued and better health for all.[4,5] PC is therefore shifting

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toward public health approaches to increase civic engagement and thereby strengthen the social fabric of local communities and increase their care capacity.[6] Volunteering has been linked to greater investment in public care[7] and community involvement,[8] and studies have argued that volunteers contribute to "bridging"[9] and creating social capital.[10] Volunteers have played a major role since the early days of the PC movement and continue to be involved in its provision, both in the community and in institutional settings.[11–13] Governments are therefore turning to informal care, including volunteers, to provide a greater proportion of PC.[14–17] Research has widely documented volunteer presence, turnover rates, task performance, and the training they receive.[12,18–20] Studies have shown that volunteers provide palliative, direct patient care both within and outside dedicated PC services[21] and have the potential to support health care professionals by being involved in the organization of care.[22] They can positively influence the quality of care for patients and their relatives by reducing stress and offering practical and emotional support and providing a link to the community.[12,23–25]

However, it is unclear how these volunteers should be integrated within professional PC provision. An important aspect of integration is collaboration—different parties assuming complementary roles and working cooperatively together, sharing responsibility for problem-solving, and making decisions to formulate and carry out plans.[26] Although much is known about nurse-physician collaboration in patient care,[26–29] hitherto studies on volunteer-professional collaboration have been limited to pediatric PC[30] or hospice team meetings.[31] Literature has shown volunteer care to be complementary to professional care[21,22,32] but not how this actually and potentially translates to volunteer-professional collaboration in practice.

Insights into volunteer-professional collaboration can inform future policy development about efficient use of volunteer, quality of patient care, and the feasibility of the integration of increased numbers of volunteers into professional health care. To address these knowledge gaps, this study aims to explore current volunteer-professional collaboration in PC and its barriers and facilitators, through the diverse experiences of the different people closely involved in the treatment of people with serious illnesses in different care settings.

Method

Design

To explore volunteer-professional collaboration in PC, we applied a qualitative research design, opting for a qualitative descriptive design with grounded theory and phenomenological overtones.[33] We conducted focus groups with volunteers and professional caregivers and individual semistructured interviews with patients and family caregivers in Flanders, Belgium. Focus groups stimulate the exchange of views through discussion, allow mutual differences or similarities to drive the conversation, and enable salient themes to emerge. However, considering the fragile health of patients and the sensitive nature of the subject, individual semistructured interviews were conducted with them and with family carers, allowing every case to be treated as discrete and all participants to speak freely. This article follows the COnsolidated criteria for REporting Qualitative research guidelines for reporting qualitative research.[34]

Context

PC in Belgium consists of dedicated and generalist PC services. Dedicated PC services provide support for primary care (e.g., palliative home-care teams), day care for people with specific PC needs, or PC units; generalist PC refers to certain hospital departments (such as medical oncology departments) and primary care. This coincides with the organization of care in most countries. For a comprehensive overview of the organization of PC in Belgium, see the Belgian Health Care Knowledge Centre report.[35] PC volunteers in Belgium provide direct patient care for patients and their relatives. Their contribution comprises a wide range of tasks, including practical and nursing tasks. Their main contribution is psychosocial, existential, and signposting care tasks.[21]

Participants

In addition to people with serious illnesses, we included volunteers, family or informal carers, nurses, psychologists, and family physicians (FPs) as those most relevant to and most closely involved in their treatment and PC. Participants were recruited via health care services. Patients were included via Flemish health care services if they had one or more chronic and/or life-threatening condition and spoke Dutch. Family carers were also included via Flemish health care services if their relative had one or more chronic and/or life-threatening condition and were not required to be connected to patients included in the study. Volunteers were community volunteers providing direct patient care, registered in a health care service, but not professionals working unpaid (see Appendix I for full definition.). FPs were chosen instead of specialists as they play a central role in every care trajectory and because recruiting specialists for every terminal illness was outside the scope of this study. In addition, Belgium does not have clinical specialization in PC, but rather it is offered throughout the basic curriculum of physicians. Care settings were considered based on findings from a

1. Hospital settings
   a. **Medical oncology departments** are hospital departments with a fully established oncology care programme, a hospitalisation programme and a multidisciplinary team focused on oncology.
   b. **Palliative care units** are separate units in (or associated with) hospitals that exclusively provide palliative care.
2. Home care settings
   a. **Facilities for sitting services** organise sitting by volunteers by day or at night. They send a volunteer to people's homes to keep them company, to give basic care and a sense of security. They offer respite care and function similarly to those offered by befriending services.‡
   b. **Palliative home-care teams** are part of the palliative networks i.e. cooperative ventures between different providers and care facilities in a particular region; these are palliative care teams supporting other carers in home or replacement home situations, supported by the network's volunteers.
   c. **Volunteer community home care organisations** are organised by the Christian Sickness fund locally and run by volunteers.
3. Live-in and day care facilities±
   a. **Palliative day care centres** provide care and nursing during the day and have a respite care function for carers.
   b. **Nursing homes** offer permanent care and nursing to elderly people.

Fig. 1. Settings from which participants of focus groups and interviews were selected. Descriptions fully or partially taken from the Agency of Health and Care website (Agentschap Zorg en Gezondheid, 2017). ‡See Walshe et al. (2016a). ±Nursing homes and palliative day-care centers were grouped together mainly because of the low number of palliative day-care centers ($n = 5$) in Belgium and their functional link with nursing homes.

previous study,[21,22] which identified services in Flanders where volunteers provide palliative and direct patient care. These services were selected from existing listings available from the Flemish Agency for Health and Care[36] and divided into three settings: 1) *hospital*, 2) *home-care*, and 3) *live-in and day-care facilities* (see Fig. 1).

Participants were sampled by contacting the service coordinators within each setting. FPs were recruited via local FP networks listed on regional FP association websites. Services and FP networks were contacted by phone or e-mail. Participants' contact details were either forwarded to us by the health services with the participants' approval or they contacted us directly using our contact details mentioned in the health service call. Participants were contacted by phone or e-mail to schedule the interviews and focus groups. Three volunteers dropped out because of lack of time.

Data Collection

Semistructured interviews were individually conducted with patients and with family carers in Dutch. Focus groups were separately conducted for 1) volunteers, 2) nurses and psychologists, and 3) FPs. All took place between March and November 2017. Interviews were conducted by S. V.; focus groups were moderated and observed by S. V., K. C., and other junior and senior researchers making field notes (see Appendix II for interviewer characteristics). Focus groups and interviews were audio-recorded and transcribed verbatim, resulting in a total of 26 transcripts. Participants were given the option to review their transcripts afterward, but there were no requests to do this. Topic guides were developed and reviewed by a team of sociologists (S. V., K. C., J. C., and L. D.) and a psychologist (Y. V. W.) (see Appendix III.) and included the following key topics: volunteer-professional contact, volunteer-professional collaboration, evaluation of collaboration, and barriers to and facilitators of volunteer-professional collaboration. Demographics data were gleaned from participant introductions in the interviews and focus groups.

Data Analysis

Focus group and interview transcripts were analyzed by S. V. and K. C. following the QUAGOL method[37]—an inductive approach and iterative process of constant comparison. Data collection and analysis were conducted quasi-simultaneously. S. V. and K. C. independently read and coded transcripts. Starting with open coding, a conceptual scheme was drawn from each transcript. From the comparison of these schemes, a final conceptual scheme was created, from which a coding tree was constructed (see Appendix II). This coding tree was then discussed in the research team and modified where necessary. Final coding was done in the NVIVO 11 qualitative data analysis software package. The themes that emerged from the data formed the foundation of the final thematic framework. Data saturation was assumed when no new

Table 1
Characteristics of Participants in Focus Groups

Characteristics	Total Number
N	50
Focus groups	8
Mean duration of focus groups (in minutes)	72 (36–89)
Sex	
Male	7 (14%)
Female	43 (86%)
Age[a], yrs	
<50	0 (0%)
50–59	3 (6%)
60–69	9 (18%)
70+	1 (2%)
Unknown	37 (74%)
Employment status[a]	
Retired	21 (42%)
Employed	22 (44%)
Unknown	7 (14%)
Discipline	
Volunteer (four focus groups)	28 (56%)
Palliative care nurse (two focus groups)	4 (8%)
Palliative care psychologist (two focus groups)	6 (12%)
Family physician (two focus groups)	12 (24%)
Years of working experience[a]	
≤1	0 (0%)
1–2	5 (10%)
3–5	6 (12%)
6–10	13 (26%)
10–15	6 (12%)
>15	3 (6%)
Unclear	17 (34%)
Setting[b]	
Hospital	12 (24%)
Palliative home-care team	11 (22%)
Nursing home	8 (16%)
Palliative day-care center	7 (14%)
Family physicians	12 (24%)

[a]These demographic characteristics were gleaned from the participant introductions during the focus groups.
[b]Hospital settings include palliative care units and medical oncology departments.

Table 2
Characteristics of Participants in Interviews

Characteristics	Total Number of Patients	Total Number of Family Caregivers
N	10[a]	9
Interviews	10	8
Mean duration of interviews (in minutes)	34 (21–58)	55 (30–98)[b]
Sex		
Male	6	1
Female	4	8
Age[c], yrs		
≤29	0	1
30–39	0	0
40–49	1	0
50–59	2	1
60–69	2	2
70–79	1	1
80–89	2	1
90+	1	0
Unknown	1	2
Illness of patient or family caregiver's close one[d]		
Cancer	9	6
Chronic heart failure	1	0
Dementia (including Alzheimer's)	1	1
Parkinson's	0	1
Heart thrombosis	0	1
Cerebral infarction	1	0
Setting[e]		
Hospital	6	1
Palliative home-care team	1	5
Nursing home	1	2
Palliative day-care center	2	0

[a]One interview was conducted with two participants (husband and wife).
[b]One interview was not recorded. This interview was short, and the exact duration is unknown. The calculation of the mean duration of interviews excluded this interview.
[c]Age was gleaned from the participant introductions during the interviews.
[d]One patient had more than one chronic and/or life-threatening condition and one family caregiver or had more than one family member with a chronic and/or life-threatening condition that they had cared for.
[e]Hospital settings include palliative care units and medical oncology departments.

information emerged from interviews and focus groups. The data are re-presented following the Rashomon effect approach,[33] describing the same concepts from the perspectives of different groups of participants. After analysis, quotes were selected and translated by S. V. The translations were checked for consistency in meaning and approved by the entire research team. All participants were given pseudonyms.

Ethical Considerations

The proposal for this study was submitted for approval to the Commissions of Medical Ethics of the University Hospital of Brussels (leading) and the University Hospital of Ghent (local) (Ref. B.U.N. 143201630093). Approval from both commissions was granted on January 30, 2017.

Results

We conducted eight focus groups and 18 semistructured individual interviews. Seventy-nine participants were involved in the study. See Tables 1 and 2 for focus group, interview, and participant characteristics. One family carer who did not speak Dutch well refused audio recording; the interview was short and served to highlight relevant themes in the form of researcher notes. Although initial recruitment targets were not reached for professionals in nursing homes, the research team concluded that data saturation was reached and ended data collection at this point. Four themes emerged from the analysis: 1) contact, 2) support, 3) information sharing, and 4) coordination. Several barriers to and facilitators of volunteer-professional collaboration also emerged. Figure 2 represents the current volunteer-professional collaboration relationships. Thicker lines indicate closer and more frequent collaboration.

Contact With Professional Caregivers

All participants emphasized that volunteers collaborate mainly with nurses and sometimes with psychologists and that contact between volunteers

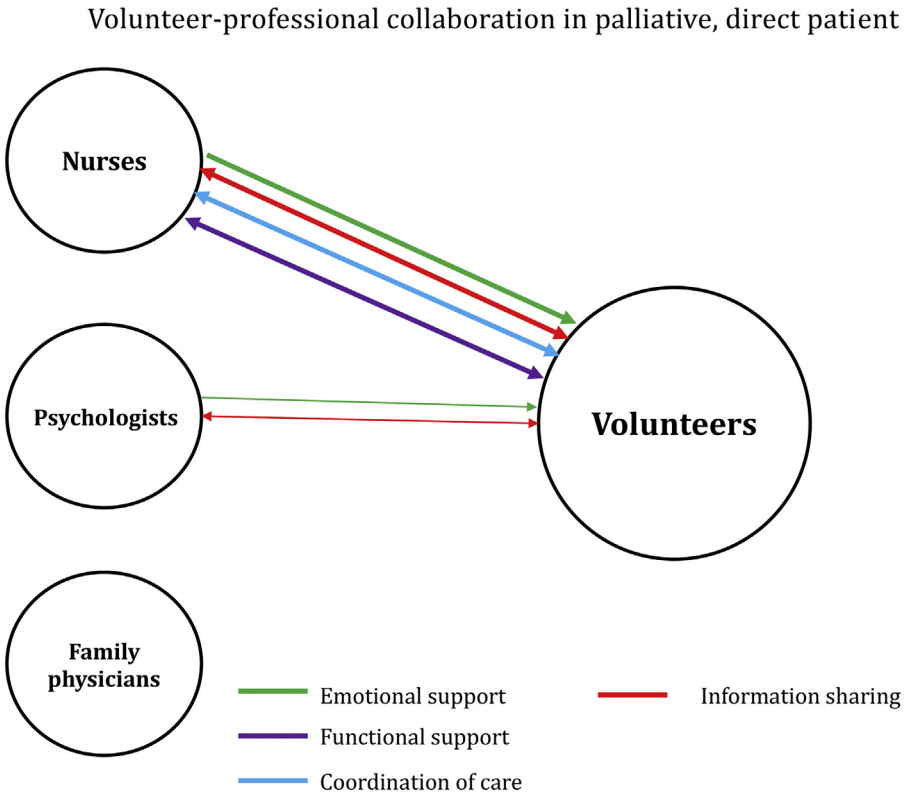

Fig. 2. Volunteer-professional collaboration in palliative, direct patient care.

and physicians was almost nonexistent. Patients across settings generally had little insight into personal and professional volunteer-nurse relationships; however, patients in PC units had the impression that relationships were friendly. Family carers generally felt that volunteers and nurses collaborated well but indicated often not being present during those interactions.

> ***LA:*** *Well, I don't really have a view on that collaboration. I had the feeling that that went well and that she really knew what was going on. So that she was well informed as well and stuff.*
>
> —**Interview 15: LA** *(family caregiver for grandmother with cancer, woman, 26 y/o)*

Patients and family carers described the volunteer-nurse relationships as hierarchical, suggesting that volunteers are there to support nurses and that health care professionals provide directions to volunteers. Medical oncology nurses and psychologists indicated that, although they did not collaborate with volunteers, dedicated oncology nurses may have more frequent contact with them.

Support From Health Care Professionals

Participants described two types of support that health care professionals offered volunteers while working together: *functional* support and *emotional* support.

Functional support entailed feedback and reflection on the functioning of volunteers in the care service, through individual or group meetings in which nurses, psychologists, and volunteers evaluated a recent period or briefed each other before a shift. Volunteers emphasized the importance of these meetings and that coordinators, nurses, and psychologists play a pivotal role in addressing conflicts among volunteers and between volunteers and nurses. Functional support also entailed volunteers drawing on nurses' experience in navigating problematic care situations, such as difficult home situations and ethical boundary issues.

> ***MI:*** *And what does such supervision entail?*
>
> ***AM:*** *Just your functioning in the group, what you think is good, what you think is bad, what they think should be improved. That sounds very, very harsh now, right? But it's brought in a very soft manner and always ends (laughs) on a positive note. (…) But it gives you the chance, I think, to talk openly for once without someone else present, without stepping on toes.*
>
> —***Focus Group 1: Volunteers (hospital)***; ***MI*** *(woman, retired, volunteer in PC unit);* ***AM*** *(woman, volunteer for 20 years, three years in PC unit)*

Emotional support was related to helping volunteers process difficult experiences inherent to PC, such as witnessing suffering and patient decline

and experiencing problematic home situations, bereavement, and grief. Hospital and palliative home-care team nurses and psychologists try to ensure volunteers are debriefed on each individual death or receive a personal follow-up. Palliative day-care volunteers explained that the lack of briefing and debriefing can result in painful misunderstandings between volunteers and day-care guests.

> ***SH:*** *What I do find important for them is that they are also still able to ask; when someone has died and it's someone whom they visited. Then, it's possible to come back to that, like, how was the passing away? And how was the family doing? Because they were involved too, of course.*
>
> *—**Focus Group 5: Nurses and psychologists (hospital)**; **SH** (woman, psychologist in PC unit and palliative support team for one year)*

Information Sharing

Volunteer-nurse communication of developments in the patient's condition and in their home situation was described as a crucial part of volunteer-professional collaboration by participants from every group. Nurses, psychologists, and volunteers from each setting explained that owing to the volunteer's position, availability, and time, they notice patient needs and wishes that health care professionals sometimes miss. Hospital and palliative day-care nurses, psychologists, and volunteers updated each other through daily preshift briefings; those from palliative home-care teams did so through frequent telephone and e-mail contact. Ad hoc informal contact opportunities were also important.

(Talking about patient visits)

> ***IN:*** *So, it's a requirement (…), when there's a (problem), that you then brief the nurse. (…) And then you can contact the nurse—with an e-mail, you can send a text, give a call, but then you're in (contact)—You have a tandem bike. The nurse is at the front and the volunteer is at the back because you're responsible for this together and together you brief each other. (…)*
>
> ***AM:*** *And also report. I think that that's also an important requirement, that when they see things—and that could be related to pain and symptom control or related to care or, you know, right?*
>
> *—**Focus Group 6: Nurses and psychologists (palliative home-care team)**; **IN** (woman, nurse, and coordinator of palliative home-care team); **AM** (woman, PC nurse in palliative home-care team)*

Although all participants agreed that communication of patient information was important for collaboration, the extent to which volunteers were authorized to access a patient's medical information (e.g., diagnosis, prognosis, treatment) was unclear and varied within and across settings. Some PC unit volunteers reported being allowed to edit patient records, whereas others were not allowed access.

Coordination

According to hospital patients, volunteers relieved nurses by being first to respond to the nurse call button, by taking over tasks so that nurses can move on to other patients and by discussing with the nurse the appropriate approach to each patient. Volunteers complemented nurses by saving time and providing extra care while nurses continued their rounds.

> ***Sabine:*** *Look, to give you an idea. Last week, right, they showered me, the nursing staff, and the volunteer came over and dried my hair. See, massage to go with it, stuff they don't have to do, actually, but taking her time to do it. And talking to people in the meantime, and it's the whole thing that's taken away from the nurses. (…) That they don't have to put their time into it. See? And they (volunteers) do it and it makes a big difference.*
>
> *—**Interview 8: Sabine** (patient in PC unit, woman, 69 y/o, throat tumor, retired nurse)*

Palliative home-care volunteers, nurses, and psychologists indicated that, through communicating, nurses and volunteers adjusted the care approach together. Volunteers explained that, when they report a problem in the home situation, an interdisciplinary meeting that they may be included in is sometimes set up to address it.

> ***DE:*** *The concerns of the patient, that they've heard, the needs you still see there, the problems you still see there or the problems that, well, that you have difficulties with as a volunteer. (…) So, it's very important that there's a lot of communication regarding that. (…) Either by calling or by sending an e-mail- It's because actually, physically, you're rarely present there (as nurses) and still, you're in this same situation together, so to coordinate that care together, so that you both know what you're doing, or then ask. Then, you can exchange ideas, you know?*
>
> *—**Focus Group 6: Nurses and psychologists (palliative home-care team)**; **DE** (woman, psychologist and volunteer coordinator of palliative home-care team)*

Barriers to and Facilitators of Volunteer-Professional Collaboration

Lack of access to nurses for volunteers was described as a barrier to functional support and coordination of care by volunteers, nurses, and psychologists from palliative home-care teams, hospitals, and nursing homes and as a barrier to information sharing by hospital and palliative day-care volunteers. Lack of time with nurses resulted in information getting lost in between shift changes. Hospital volunteers and palliative home-care nurses and psychologists suggested

collective training sessions for volunteers and nurses may facilitate informal ad hoc contact between them. A physical space for volunteers in the organization was also suggested as a solution.

M: *What we miss, actually, is a space for us. (…) A fixed (space or office) for volunteers. Right, so if we would have a room and there's a training happening, then you already have informal contact opportunities. We often miss that, due to the fact that we don't share a space.*

MA: *We don't have a fixed location. (…) That would make a big difference.*

*—**Focus Group 2: Volunteers (palliative home-care team)**; **M** (woman, 64 y/o, volunteer in palliative home-care team for 12 years); **MA** (woman, 68 y/o, volunteer in palliative home-care team for 7 years)*

Confusion regarding patient-information access guidelines for volunteers was described as a barrier to coordination of care by hospital volunteers and FPs. FPs were unclear about whether volunteers are allowed to take part in illness trajectory discussions with patients and whether they were qualified for this. Hospital volunteers reported widely differing practices regarding their access to and even ability to edit patient records. Nurses and psychologists disagreed among themselves about whether the volunteers' professed need for more patient information was justified; however, volunteers indicated that lacking sufficient patient information impeded the tailoring of their approach to patients. No information-sharing guidelines were described by participants.

LE: *What I have issues with sometimes, but I don't have that much experience with palliative volunteers, but I think that maybe it applies to volunteering in general—regarding professional confidentiality, I have issues with it. I once met a volunteer who really came into my practice: 'Oh and that patient,' you see. And I was like whoah, whoah. I don't have to tell you all of this. (…) No, regarding professional confidentiality, I sometimes think—Because you can be a palliative volunteer and be involved, but if you start spreading that around to everyone, then I think …. I think it's tough. We're so strictly bound to that, but they're not. At least I think not, legally?*

ST: *They are in principle. (…) They don't always take it that seriously, yeah.*

*—**Focus Group 8: Family physicians**; **LE** (woman, family physician); **ST** (man, family physician)*

Lack of leadership was a barrier to coordination of care and information sharing, according to nursing home and palliative day-care center volunteers and hospital nurses and psychologists. Lack of coordinated communication caused loss of information, too much pressure and responsibility on the shoulders of volunteers in nursing homes, and lack of direction for volunteers. Having a volunteer coordinator facilitated coordination of care when contact between volunteers and nurses was lacking, according to nursing home volunteers.

NA: *We want to be led, right? (…) Not so that when you enter: 'well, now what could I do here?' (agreement from others)*

NA: *Well, yeah, that does happen, though. (…) So, you'll have new volunteers—those new volunteers come and then it's just like—(…) 'what should I do here? I have no clue'*

*—**Focus Group 3: Volunteers (nursing home)**; **NA** (woman, retired, volunteer for 12 years)*

Discussion

Main Findings

Volunteers in PC primarily collaborate with nurses and to a lesser degree with psychologists and have no contact with FPs. Volunteer-nurse collaboration was characterized by mutual information-sharing about the patient's condition and its development and by the coordination of care provision together, whereas nurses and psychologists provided emotional and functional support for volunteers. The most prominent barriers for volunteer-professional collaboration were limited volunteer-nurse contact, confusion regarding sharing patient information, and lack of leadership.

Interpretation

Volunteer-professional collaboration in PC seems to be mainly restricted to volunteer-nurse collaboration. The importance of the link between volunteers and nurses seems two-fold: 1) contributing to the self-care, emotional well-being, and daily functioning of volunteers and 2) facilitating information-sharing and coordination of care. The close collaboration between nurses and volunteers may be due to their continuous presence in the care setting and their close proximity to each other and to the patients. In palliative home care, their collaboration is further necessitated by the dependency of the nurses on the volunteers because of the volunteer's more frequent presence in the home.

Our study shows that volunteers and nurses assume complementary roles, work together cooperatively, make decisions to formulate and carry out plans, and in some settings share responsibility and problem-solving, in keeping with O'Daniel and Rosenstein's definition.[26] This confirms previous studies that report the complementary roles volunteers fulfill in PC by being there, being a liaison, and performing signposting tasks[21,32,38–40] and provides the first evidence that if volunteers are to be further integrated into PC provision, nurses are crucial in achieving

this; resources to combat nurse understaffing in care organizations may therefore indirectly benefit volunteering too. To address lack of leadership and facilitate collaboration, policy should consider incentivizing health care services to appoint nurses as volunteer coordinators. This added financial investment may diminish the economic benefits of working with volunteers slightly; however, the lack of coordination has been suggested in previous studies to impede the volunteer role and their contribution to care.[32]

Sharing responsibility and problem-solving with volunteers occurred mainly in dedicated PC services, indicating that organizations with a stronger focus on PC also collaborate more with their volunteers. Previous studies also show that organizations with a stronger emphasis on PC report increased volunteer task performance, training,[21] and involvement in the organization of care.[22] Sharing responsibility was limited in general, potentially due to the legal framework of professional health care, liability constraints, and the lack of clear guidelines regarding the information volunteers are privy to and to what extent they are bound by confidentiality. However, compassionate community initiatives have recently shown that when working outside an organizational framework but through and within the community, responsibilities can be shared.[41–43]

In light of governments' current interest in increased PC provision by the community, the lack of debate on what the integration of volunteers into PC should look like is surprising. Previous studies have documented volunteer tasks and training[6,21,44–46] and roles in PC,[32,47–50] but research has hitherto not considered with whom volunteers collaborate and how this impacts care provision. Future research should build on our findings and explore volunteer-professional collaboration quantitatively, including nonmedical professionals to inform public debate and policy development. Future research should also further explore the directions volunteers receive from professionals and how they experience these. Although health care systems may differ in the organization of PC, the inclusion of multiple perspectives from diverse care settings and the corroboration of our findings by international literature suggest that these recommendations are relevant for PC volunteering across regional or national borders.

Strengths and Weaknesses

This study is the first, to our knowledge, to offer an in-depth description of volunteer-professional collaboration in PC provision, from a multidisciplinary and multicontextual perspective. Although individuals and groups sometimes differed in which aspects of certain topics they emphasized, there was little disagreement between perspectives regarding the core topics, indicating reliability of the findings. The potential for social desirability in responses, inherent in qualitative research[51] and resulting from the dependent relationship between patients and care providers,[52–54] was counteracted by including a wide range of participants from different settings separately. Because cancer was the predominant illness among patients, it is possible that experiences specific to other illness trajectories were missed. Health care professionals were exclusively medical, nursing, or psychological, excluding other professionals such as social workers, occupational therapists, and others who may also collaborate with volunteers in care provision. Unfortunately, we were unable to include nursing home nurses and psychologists for a focus group. The study potentially misses interesting and contrasting perspectives in that setting. Finally, the results of this study are based on descriptions, not in-practice observations. Therefore, other forms of volunteer-professional collaboration may happen that were not mentioned because they were not deemed relevant by the participants.

Conclusion

This study shows that volunteers are at the front line of palliative care provision and therefore collaborate intensely with nurses, in particular in dedicated palliative care services. Within this collaborative framework, nurses—and to a lesser degree psychologists—provide emotional and functional support for volunteers and together with volunteers share patient-information and coordinate care provision and complementary initiatives. The presence of nurses was found to be crucial for volunteers, both for their daily functioning and for the realization of volunteer-professional collaboration. Volunteers are therefore complementary to nurses, rather than a replacement for them in the delivery of palliative care.

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Appendix I

Definition of Volunteering

We define volunteerism in palliative care as the time freely given by individuals, with no expectation of financial gain, within some form of organized structure other than already existing social relations or familial ties, with a palliative approach, that is, the intention of improving the quality of life of adults and children with terminal illnesses and those close to them (family and others).[1]Volunteers do not have an employment contract or statutory appointment within the organization in which they perform these tasks. This definition is in accordance with that provided by the Belgian Federal Law.[2] We focus on community volunteers in direct patient care, that is, members of the local community who work in care-focused roles and are regularly involved with people who are dying and those close to them, provided they are not merely performing their medical profession unpaid. Finally, we focus on volunteers who fit this definition and provide care for people with terminal illnesses and their families. This definition was incorporated into our questionnaire.

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Appendix II

Interviewer Characteristics and Coding Tree Description

Interviewer Characteristics

Below are listed the researchers who functioned as an interviewer or focus group moderator at least once during data collection. All researchers mentioned are members of the End-of-Life Care Research Group (Vrije Universiteit Brussel—Ghent University).

Steven Vanderstichelen (MSc. Sociology), male, referred to as SV, doctoral researcher since 2015, executive researcher of the study, and first author of the manuscript. Steven was involved in all but one focus groups, either as a moderator or an observer, and was one of the researchers who coded the data. Steven's interest in the study subject of palliative care volunteers stems from it being the main subject of his doctoral thesis and on a personal level from having an affinity with volunteering work in general. His interest in volunteering roles stems partly from his education as a sociologist.

Kenneth Chambaere (MSc. Sociology, PhD. Social Health Sciences), male, referred to as KC, postdoctoral researcher, promotor and supervisor of SV, and last author of the manuscript. Kenneth was involved in several focus groups as a moderator or observer and was one of the researchers who coded the data.

Kim Beernaert (MSc. Experimental Psychology, PhD. Social Health Sciences), female, postdoctoral researcher. Kim was a moderator in two of the focus groups with volunteers.

Aline De Vleminck (MSc. Sociology, PhD. Social Health Sciences), female, postdoctoral researcher. Aline was a moderator in one of the focus groups with nurses and psychologists.

Lenzo Robijn (MSc. Sociology), male, doctoral researcher. Lenzo was a moderator for one of the focus groups with family physicians and an observer of one focus group with nurses and psychologists.

Coding Tree Description

Below is an outline of the coding tree used for the analysis in this article.

- Volunteer tasks
  - Practical
  - Psychological

- Spiritual
- Bereavement care
- Respite care
- Signaling tasks
- Responsibilities (non-care related)
- Changes in tasks

- Volunteer roles
  - Type of role
    - Being there
    - Providing the extra
    - Helping people
    - Bringing calm
    - Complementing nursing staff
    - Taking responsibility
    - Providing customized care
    - Combating loneliness
    - Building a bond with the patient
    - Providing care
    - Bringing openness
    - Focusing on the patient
  - Importance of role
- Boundaries
  - Boundaries of volunteering
    - Professional boundaries
    - Boundaries of ability
    - Personal boundaries
    - Ethical boundaries
    - Legal boundaries
    - Exceptions
  - Volunteer autonomy
    - In task fulfilment
    - In initiatives
    - Extramural tasks
  - Boundary work
    - Knowing boundaries
    - Setting and guarding boundaries
  - Information access
    - Type of information
    - Information clearance
    - Information need
- Volunteer support frameworks
  - Financial
  - Legal
  - Training
  - Personal support
- Collaboration with volunteers
  - Interpersonal relationships
  - Communication
    - Contact
      - Availability
      - Contact with care providers
        - Direct
        - Indirect
        - Reasons for contact
    - Meetings and discussions
      - Type
        - Evaluation
        - Supervision
        - Intervision
        - Briefings
        - Introduction
      - Content
        - Patient discussion
        - Discussion of daily functioning
      - Regularity

        - Signposting
            - Content
            - Direction
            - Form
    - Supervision
        - Self-care
        - Timely intervention
        - Integration of new volunteers
- Coordination
    - Responsibility
    - Teamwork
    - Patient-matching
    - Extra initiatives
    - Organization of activities
- Evaluation
    - Evaluation of volunteers
    - Evaluation of professional care
    - Evaluation of collaboration
    - Evaluation of volunteer tasks
- Facilitators
    - Organizational
    - Professional care provision
    - Care
    - Volunteering
- Barriers
    - Organizational
    - Professional care provision
    - Care
    - Volunteering

Appendix III

Scripts for Individual, Semistructured Interviews and Topic Guides for Focus Groups

Appendix Table 1
Script for Patient Interview

Questions (Interviewer)	Probes
Introduction (Five minutes)	
- Thank participants for coming	- Check whether informed consent form was signed
- Introduce self (interviewer)	
- Explain the aim of the study and interview	
- Emphasize confidentiality	
- Explain informed consent	
- Ask to turn off phone for the duration of the interview	
Introductory question (Five minutes)	
- Ask their name	- Short discussion of the difficulties and changes that the illness trajectory has meant for the person
- Can you tell me about your illness trajectory and your current condition?	
○ What has this involved for you?	
Transition question (10 minutes)	
The interviewer checks if the patient currently receives or has received support from one or more volunteers in the past.	
- Can you tell me a little bit more about your experience with volunteers since you've been sick?	- How did you come into contact with volunteers? - Impression of volunteers - Role of the volunteer - Relationship with the volunteer - Expectations
Core questions (30 minutes)	
- Please describe how you are being/were supported by the volunteer	- Value of volunteer - Positive and negative experiences - Influence on patient's care
- In what way do volunteers work together with other caregivers?	- With family physician/specialist/psychologist/nurse? - What do you think about the communication between them? - Do they make plans/agreements among themselves? - What role do the different caregivers play with respect to each other?
- How could this collaboration be improved according to you?	- Probe facilitators and barriers - Opportunities for improvement - Potential influence on patient care
Closing questions (Five minutes)	
Interviewer provides a short summary of the conversation.	
- Is this a good summary of our conversation?	
Final question (Five minutes)	
Alright, we've discussed a lot. Is there anything you would like to add before we finish?	
Thank you very much for your time and contribution to our study. I'd like to give you my contact information, in case you have any additional questions about this interview, the data, or about the research in general.	

Appendix Table 2
Script for Family Caregiver Interviews

Questions (Interviewer)	Probes
Introduction (Five minutes)	
- Thank participants for coming	- Check whether informed consent form was signed.
- Introduce self (interviewer)	
- Explain the aim of the study and interview	
- Emphasize confidentiality	
- Explain informed consent	
- Ask to turn off phone for the duration of the interview	
Introductory question (Five minutes)	
- Ask for their name	- Relationship between patient and family caregiver
- Can you tell me a bit about the person you care/cared for and his/her illness trajectory?	- Short discussion of care background - Short discussion of the difficulties and changes that the illness trajectory meant for the person
○ What has this involved for you?	
Transition question (10 minutes)	
The interviewer checks if the person who is/was dying currently receives or has received support from one or more volunteers in the past.	
- Can you tell me a bit about your experience with volunteers in the care for the person you care for?	- How did you come into contact with volunteers? - Impression of volunteers - Role of the volunteer - Relationship with the volunteer - Expectations
Core questions (30 minutes)	
- Please describe how the person you care/cared for was supported by volunteers	- Value of volunteers - Positive and negative experiences - Influence on patient care
- In what way did/do volunteers work together with the other care providers?	- With the family physician/specialist/psychologist/nurse?
- How could this collaboration be improved, according to you?	- Explore facilitators and barriers - Opportunities for improvement - Potential influence on patient care
Closing questions (Five minutes)	
Interviewer provides a short summary of the conversation.	
- Is this a good summary of the conversation?	
Final question (Five minutes)	
Alright, we've discussed a lot. Is there anything you would like to add before we finish?	
Thank you very much for your time and contribution to our study. I'd like to give you my contact information, in case you have any additional questions about this interview, the data, or about the research in general.	

Appendix Table 3
Topic List for Focus Groups With Volunteers

Questions (Moderator)	Probes	Timing
Reception of participants		10 minutes
• Offer everyone pen and paper to make name cards for themselves and to take notes during the focus groups	Hand out pen and paper Observe and assign places	
• Offer participants coffee/tea/water/juice, and let them talk among themselves		
Introduction		Five minutes
• Thank participants for coming	Gather signed informed consent forms	
• Introduce moderator and observer		
• Explain the aim of the study and focus group		
• Emphasize confidentiality		
• Explain informed consent		
• Explain it is fine to make notes for themselves		
• Request to turn off cellphones		
Introductory question		Five minutes
• Can you all introduce yourselves please?	- How did they become volunteers? - What were their expectations?	
Transitional questions		15 minutes
• How would you describe yourselves as volunteers in care provision?	- Tasks	
• What distinguishes you from other care providers?	- Training—required/received - Responsibilities - Role of the volunteer	
Core questions		45 minutes
• How do you support patients?	- Positive and negative experiences	
• In what way do you work together with professional caregivers?	- Probe problems that are mentioned	
• How does this influence patient care?	- Identify barriers and facilitators	
• How could this collaboration be improved?	- Link back to influence on patient	
Closing questions		15 minutes
• Is this a good summary of the discussion?		
• Are there things that did not come up?		
Final questions		Five minutes
• Ask if they have any other questions		
• Finish discussion		
• Thank participants		

Appendix Table 4

Topic List for Focus Groups With Nurses and Psychologists and With Family Physicians

Questions (Moderator)	Probes	Timing
Reception of participants		10 minutes
• Offer everyone pen and paper to make name cards for themselves and to take notes during the focus groups.	Hand out pen and paper Observe and assign places	
• Offer participants coffee/tea/water/juice, and let them talk among themselves		
Introduction		Five minutes
• Thank participants for coming	Gather signed informed consent forms	
• Introduce moderator and observer		
• Explain the aim of the study and focus group		
• Emphasize confidentiality		
• Explain informed consent		
• Explain it is fine to make notes for themselves		
• Request to turn off cellphones		
Introductory question		Five minutes
• Can you please introduce yourselves?	- What was your first impression of volunteers?	
• How did you first come into contact with volunteers?		
Transitional questions		15 minutes
• What role does the volunteer play in care, according to you?	- Patient support - Responsibilities and tasks	
Core questions		45 minutes
• How do volunteers support patients according to you?	- Benefits and problems	
• In what way do you work together with volunteers?	- Influence on work/influence on care	
• How would you evaluate the current collaboration with volunteers?	- Identify barriers and facilitators	
• How could this collaboration be improved?	- Link back to influence on care	
Closing questions		15 minutes
• Is this a good summary of the discussion?		
• Are there things that did not come up?		
Final questions		Five minutes
• Ask if they have any other questions		
• Finish discussion		
• Thank participants		