VOLUNTEERING IN PALLIATIVE CARE

A STUDY OF VOLUNTEER TASKS, SUPPORT, ROLES, INVOLVEMENT AND COLLABORATION WITH PROFESSIONALS IN THE FLEMISH HEALTHCARE SYSTEM

STEVEN VANDERSTICHELEN

VUBPRESS

Doctoral dissertation submitted in the fulfilment
of the requirements for the Joint PhD degree of
Doctor (PhD) in Social Health Sciences (VUB)
and Doctor (PhD) in Health Sciences (UGent)

Steven Vanderstichelen
Academic year 2018-2019

Volunteering in palliative care

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Promotors: Prof. Dr. Kenneth Chambaere (Vrije Universiteit Brussel)
Prof. Dr. Luc Deliens (Ghent University)

Co-promotor: Prof. Dr. Joachim Cohen (Vrije Universiteit Brussel)

Vrije Universiteit Brussel
Department of Family Medicine & Chronic Care
Faculty of Medicine & Pharmacy

Ghent University
Department of Public Health & Primary Care
Faculty of Medicine & Health Sciences

END-OF-LIFE CARE
RESEARCH GROUP

2019 Uitgeverij VUBPRESS Brussels University Press
VUBPRESS is an imprint of ASP nv (Academic & Scientific Publishers nv)
Keizerslaan 34
B-1000 Brussels
Tel. +32 (0)2 289 26 50
Fax +32 (0)2 289 26 59
E-mail: info@aspeditions.be
www.aspeditions.be

ISBN 978 90 5718 081 1
NUR 882
Legal deposit D/2019/11.161/090

VUBPRESS

FUNDING

This study is part of the ‘Integration of palliative care into home, nursing home and hospital care and into the community in Flanders’ (INTEGRATE) project, a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic University Leuven, Belgium. This study is supported by a grant from the Flemish government agency for Innovation by Science and Technology (Agentschap voor Innovatie door Wetenschap en Technologie) (SBO IWT nr. 140009). The agency had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report, nor in the decision to submit the article for publication.

PROMOTORS AND EXAMINATION COMMITTEE

Promotors: Prof. dr. Kenneth Chambaere (Vrije Universiteit Brussel)
Prof. dr. Luc Deliens (Ghent University)

Co-promotor: Prof. dr. Joachim Cohen (Vrije Universiteit Brussel)

Examination Committee:
Chair: Prof. dr. Lieve Van den Block (Vrije Universiteit Brussel)

Other members: Prof. dr. Sarah Dury (Vrije Universiteit Brussel)
Prof. dr. Peter Pype (Ghent University)
Prof. dr. Leslie Hustinx (Ghent University)
Prof. dr. Anne Goossensen (Universiteit Voor Humanistiek, Utrecht, The Netherlands)
Dr. Libby Sallnow (University College London & CNWL NHS Foundation Trust, London, UK)

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Chapter 3

Vanderstichelen S, Cohen J, Van Wesemael Y, Deliens L, Chambaere K. The contribution of and support for volunteers in palliative care: A healthcare system-wide cross-sectional survey of volunteers. International Journal of Nursing Studies. [Under review]

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ACKNOWLEDGEMENTS

When I started this journey a little more than four years ago, I was a newly graduated sociologist who didn't really want to leave university. I had decided that I was going to challenge myself and prove to myself that I had it in me to do a PhD. It has been a long ride and along the way I have been many things, but never bored. Nor have I been lonely, as I had many people around me that made sure I made it to the end safe and sound. Now, I would like to take a moment to acknowledge and thank those people. They have, directly or indirectly, made this dissertation a reality and have been crucial in shaping me as a researcher and into the person I am today.

First of all, I'd like to thank the chair, **prof. Lieve Van den Block**, and the members of the jury, **dr. Libby Sallnow**, **prof. Anne Goossensen**, **prof. Lesley Hustinx**, **prof. Sarah Dury**, and **prof. Peter Pype**, for reading my thesis critically and challenging me. Your comments and questions were highly insightful, made me reflect critically on my own work and I will take them to heart going forward.

I also want to thank the members of my project group, who have guided me through these four years. **Kenneth**, my promotor and daily supervisor, for supporting me, making me grow as an academic and for teaching me that there is always a way – even if it is not readily apparent. At times, when I thought I would not make it through and the finish line seemed unattainable, you calmed me down and you gave me perspective. Basically, at precisely the right times, you told me exactly what I needed to hear: 'dude, chill. It's fine.' **Luc**, my second promotor, for giving me this opportunity, for putting your faith in me to successfully execute this study, for teaching me to see the bigger picture, for your advice and the for many lively discussions in our project group meetings. Thank you for calling me out when my 'bombastic' writing kept me from getting to the point. And thank you for lending your likeness to our very own ZRL award! **Joachim**, for your critical insights and uncompromising attitude when it comes to research quality and scientific rigour. Your feedback was always extensive and thorough, perhaps overwhelming at times. However, my work was always greatly improved by it. You also introduced me to your network in the public health field, broadening my horizons and helping me build my own network. **Yanna**, for your professional insights as experienced volunteer coordinator and clinical psychologist and for making sure that our research was never out of touch with the reality of daily practice. **Dirk**, my (ex-)promotor and (ex-)supervisor, for helping me take my first steps into academia, you taught me to slow down and be thorough.

I also want to thank the **End-of-Life Care Research Group** in general, for providing a warm, welcoming, encouraging, and challenging environment for me to grow as a researcher, academic, professional, but also as a person. I am grateful for having by so many wonderful colleagues at the research group, both in Brussels and in Ghent. Being surrounded by so many passionate and ambitious people has in turn fueled my own passion and has inspired me to always try and do better. There are few other places where you can really geek out about some of the most niche, specific subjects, particularly when it comes to death, dying and palliative care, without being stared at like you're some kind of weirdo. Every day I am surrounded by a bunch of total nerds, and I love it.

While I cannot hope to name everyone, I do want to thank a few colleagues in particular. First and foremost, my homies, **Lenzo**, **Naomi** and **Isabel**. You guys are the best. Thank you for the support, the input, the laughs, and the cookies when I get hangry. You've seen me in bad and good days alike and have supported me throughout them. **Lenzo, Sigrid, Robrecht,** and **Joni,** for showing me and the other INTEGRATErs around when we first started, including us in the group and making us feel at home. My office colleagues in Brussels in the old IWT office, **Robrecht, Arno, Melanie** and **Maarten**, for the interesting discussions, the much-needed breaks. (**Robrecht**, I really miss playing Magic: The Gathering over lunch, sharing death metal bands and planning for a zombie apocalypse.) My office colleagues in Ghent, **Naomi, Veerle, Isabel, Lenzo** and **Laure**, for making sure we don't work too much and helping me strike an important balance between doing serious research and playing baseball with poster tubes and oranges. **Monica**, for shared frustrations but also a shared love for the Sun Wah supermarket. **Geertje**, **Nadine** and **Kim E**, the research group's collective anchor. How would we ever function without you? (We wouldn't, in case anyone was wondering.)

I am also immensely grateful to my family and friends. My parents, **Jan** and **Caroline**, for bumping uglies and creating me. I have always had your unconditional love and support. Thank you. I owe my sense of justice and fairness to you both, which admittedly, comes with the occasional outburst of righteous indignation and anger at the world. You have made me value sincerity and taught me to be sincere in everything I do. **Peter**, my stepfather, for giving me perspective during times I could find none. You helped me find value in doing things for myself and helped me become a student. My mother-in-law, **孙威**, 谢谢你的爱和支持，谢谢你欢迎我，把我当作你自己的儿子。你总是帮我练习中文，教我不要害怕说话。My father-in-law, **黄国栋**, 谢谢你相信我，对我有耐心，跟我说话。 你教我记住：慢慢来。My grandparents, **Meter** and **Opa, Oma** and **Parrain**, for always believing in me and being my number one fans. My little sister **Ellen** and little brother **David**, whom I am so damn proud of and who have been a source of joy and mental and emotional support. My best friends, some of whom I have not seen in a long time but who disprove the old ‘out of sight, out of mind’ adage. **Olivier**, **Koen**, **Tim**, **Eline**, **Lita**, **Barbara, Darco, Jan, Fritz,** and **Kristof** you guys are some of the most supportive, interesting, passionate and loving people I have the privilege of knowing. I could not ask for better friends. My bandmembers in OLAF: **Kwinten**, **Sam**, and **Dankwart**. Thank you for providing an outlet for me, a way to channel my energy, frustrations and emotions.

Lastly, and most importantly, **Xin**. Your love and support have meant more to me than words can express. You were there, jumping up and down with me, celebrating when I got the job, you were there when I published my first paper, you were there when I got my first rejection. You saw me at my best and you saw me at my absolute worst. You were there when I crashed to pick me up again, each and every time. You have never stopped believing in me and you have supported me every single step of the way. You always see the best in me, even when I sometimes cannot. You were there. And I could not have done any of this without you. For that, and so much more, I love you. 亲爱的我爱你。

PART I – INTRODUCTION

1 CHAPTER 1: INTRODUCTION

1.1 Volunteering as civic engagement

Volunteering at its core refers to work done without direct reciprocal remuneration.
It has been considered as (1) productive work that requires human capital, (2) collective behaviour that requires social capital, and (3) ethically guided work that requires cultural capital[1]. The work or voluntary act may be altruistic, or it may have a defined end goal that does not require direct reciprocity. Belgian law defines it as activities which are *unpaid, non-obligatory, to the benefit of others, done in an organisational framework other than existing familial or social ties, and not performed by the same person or for the same organisation under an employment contract or statutory appointment*[2,3].

According to an extensive report on volunteering ordered by the King Baudouin Foundation (KBS) from 2015, over 1.800.000 people in Belgium are involved in some type of voluntary engagement within or without an organisational framework, which equalled 19.4% of the population of Belgium (aged 15 or older)[4]. 1.166.000 of these individuals (12.5% of the population) performed this voluntary engagement within an organisational framework. According to the report, this latter group of volunteers performed on average 4 hours of voluntary work per week, resulting in 190 hours per year, and a total of 221.2 million hours of voluntary work. This equals roughly 4.1% of the total volume of paid labour in the country and means voluntary work in volume outperforms the farming sector (33.2 million hours) and financial sector (176.3 million hours)[4].

What these numbers show above all is that volunteering work makes up a sizeable portion of the time spent by Belgian citizens and represents a significant aspect of public life that warrants consideration as an important source of societal productivity. It has been linked to increased political involvement[5,6], greater investment in public care[7], and community involvement[8]. It is distinct from philanthropy as it does not per definition depend on personal resources other than time[9]. Rather, research suggests that volunteering is strongly tied to community integration[9], such that overlapping community ties within a physical place pull people into public life and increase the importance of civic engagement. Sociologists have long argued the influence of strong networks on investment in public life and voluntary engagement in public affairs[10–12] and have shown that community involvement is a function of greater solidarity within a community[13]. Not only has social interaction been found to be an important predictor of volunteering[14], other studies have argued that volunteers contribute to 'bonding', 'bridging'[15] and creating social capital[16].

Volunteering is therefore first and foremost a form of civic engagement and firmly embedded in civic life[9]. It pervades all areas of society and has a particularly strong history in the health care sector, dating back as early as the 18th century when many of Britain's hospitals were voluntary in nature[17]. Volunteering was particularly important to healthcare at the end of life as well, as hospices depended on local communities as sources of unpaid voluntary workers to raising funds through charity[18]. Their contributions and importance to healthcare at the end-of-life range farther than fundraising alone and are tied closely together to the history of and changes in the field of end-of-life care.

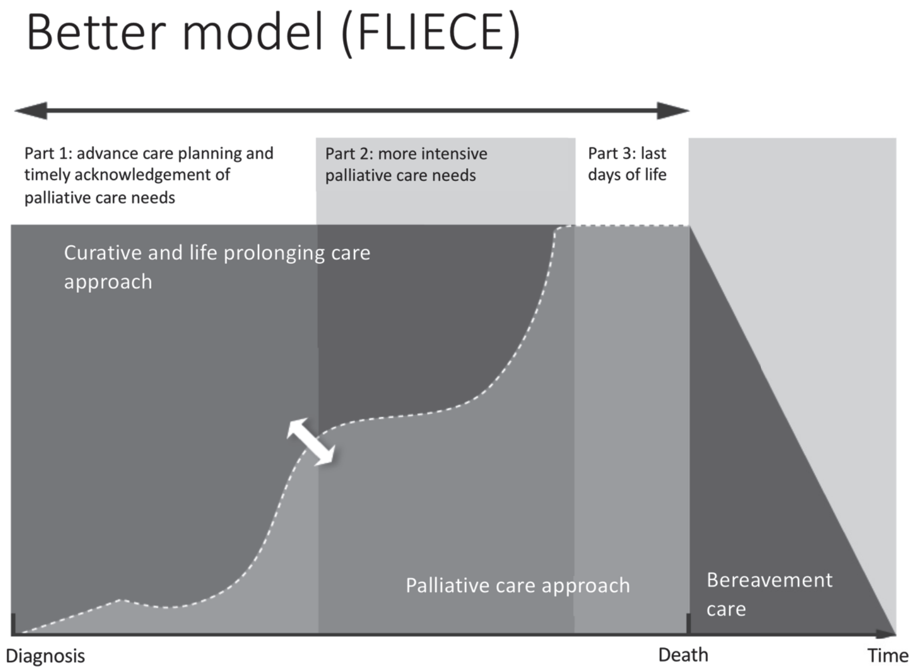
1.2 Societal shifts and changes in end-of-life care

As life expectancy grows and populations age[19], it becomes increasingly likely that each of us will in some way be confronted with chronic and life-threatening conditions, either as patients ourselves, as family caregivers or as friends or acquaintances of someone who faces serious illness. Whereas, in the past, chronic and life-threatening illnesses were rarely diagnosed, life-expectancy was shorter, and people were often assumed to have died from natural causes, we are now, through scientific and medical progress, increasingly better equipped to diagnose these conditions. As life expectancy has grown, death is often no longer an abrupt and quick end stage. Today, people are living longer with illnesses with varying rates of progression and diverse care needs. Chronic and life-threatening illnesses have become increasingly part of our lifeworld and our relationship with death and dying is changing as we are, collectively and individually, faced with caring for a growing population of elderly.

This changing relationship with death and dying was an important impetus for the hospice movement, which was started in the 1950s. The founder of this movement, the English nurse and physician Dame Cicely Saunders (1918 – 2005), was pivotal in shaping a new approach to death and the care for dying people. She introduced the concept of "*total pain*", which included physical, emotional, social and spiritual distress[20–22], and argued that in order to relieve the *total pain* of a dying person, an interdisciplinary approach to care was required[23]. A crucial achievement of the hospice approach was that care for the terminally ill was put into the mainstream medical discussion and was now open to evaluation by health professions similar to other aspects of healthcare[24]. The opening of the first hospice, St. Christopher's, in London (1967), provided the first institution where people in the terminal stage of their illness, after curative treatment was halted, could receive multidisciplinary care specific to their needs.

The hospice approach provided the groundwork for and further evolved into palliative care, a holistic, family-centred model of care based on individual needs that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness[25]. It identifies and treats symptoms which may be physical, emotional, spiritual or social and has contributed to our changing relationship with death by normalising it[26]. The innovation of palliative care was that it could begin at the time of diagnosis and be offered alongside curative treatment. Recent studies, such as the FLIECE-project (see **Figure 1.1**) and the INTEGRATE-project[27,28] in Flanders, have furthermore shown the benefits of early palliative care and suggested a new model for palliative care[29].

Figure 1.1: FLIECE model of palliative care



Today, palliative care is provided in a wide range of settings. In Belgium, palliative care consists of dedicated and generalist palliative care services. Dedicated palliative care services focus solely and specifically on palliative care for people at the end of life. These are palliative care units in hospitals, palliative home-care teams who provide support for primary care, and palliative day-care centres for people with specific needs. Unlike its neighbouring country, The Netherlands, which has a strong hospice tradition, Belgium currently has only one palliative care unit recognised as hospice, which is not located within hospital grounds. Dedicated palliative care services in Belgium are coordinated by regional palliative care networks, 15 of which are located in Flanders, 1 in Brussels and another 9 in Wallonia. The legal framework for these networks was developed in 1997 to ensure palliative care coverage across all regions of the country, regardless of whether the patient was receiving care at home, in a hospital, nursing home, etc.[30,31] Each network is government-funded and covers a region with a population of ca. 300.000 people and includes at least one palliative home-care team, 12 residential beds for palliative care (or a palliative care unit), a palliative support team in every hospital, a palliative function within each nursing home and an optional palliative day-care centre (of which Belgium has 5)[30]. The purpose of the networks is to support the expansion of palliative care within their respective region. Additionally, they have the legal tasks of (1) informing the broader public of the possibilities and offer of palliative care in their region, (2) cooperating and improving the cooperation with different primary care partners in the region, (3) training care providers, (4) help organise and support volunteering in palliative care, and (5) collect quantitative data regarding the provided palliative care in the region[32]. Other health services and care providers that do not focus mainly on palliative care, can and do provide palliative care when necessary. We refer to these services as generalist palliative care and it may be provided by hospital specialists, general practitioners, home-care nurses and nursing home staff. The medical curriculum in Belgium does not have a palliative care specialisation; rather, palliative care is included[a] – albeit to a very limited extent – in the basic curriculum for all physicians, facilitating the integration of palliative care into a diverse range of health services. This thereby prevents palliative care being limited to terminal care but facilitates its provision in chronic care as well.

1.3 The place of volunteering in palliative care

Volunteers have been present in end-of-life care since the early days of the hospice movement and continue to be involved in palliative care today in many shapes and forms. This is reflected and acknowledged in the fact that one of the legal tasks of the palliative care networks in Belgium is to support volunteering in palliative care. Within the palliative care framework, it is defined as an act in which "*time is freely given by individuals, with no expectation of financial gain within some form of organised structure other than the already existing social relations or familial ties, with a palliative approach – i.e. the intention of improving the quality of life of adults and children with life-limiting conditions and those close to them (family and others)."* (Adapted from Goossensen et al.[33].) This encompasses both grass-roots, bottom-up structures (e.g. community initiatives) and top-down formal structures (e.g. coordinated within a healthcare service), but differentiates

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[a] The Royal Academy of Medicine of Belgium produced an advice in 2016 detailing the desired learning outcomes to be implemented by the medical faculties in Belgium and to be achieved by medical students across a period of 6 years. https://www.academiegeneeskunde.be/sites/default/files/atoms/files/Advies20161022.pdf

volunteers from family caregivers, friends and acquaintances such as neighbours – in Belgium and the Netherlands these are collectively referred to as '*mantelzorgers*' or, literally, *mantle caregivers*. It furthermore defines volunteering as a choice, rather than something that happens to you. International studies show that volunteers are present in a plethora of functions and settings, and their task description may vary according to the needs of their environment[34]. They may function as managers, provide support for patients and their relatives, for paid staff, and support the daily workings of an organisation in general[35]. A further distinction can therefore be made between (1) 'D-volunteers' – professionals working within their discipline without being paid – (2) 'B-volunteers' – unpaid board members of hospice and palliative care services – and (3) 'C-volunteers' – members of the local community who offer their time in either care-focused roles or indirect facilitative roles[33,36]. It is these 'C-volunteers' in care-focused roles, for the remainder of this dissertation referred to simply as volunteers, that are the most vital to palliative care provision as they contribute crucially to addressing Dame Cicely Saunders' concept of *total pain*[20–22]. They not only provide care for patients but for the people close to them as well. It is therefore this type of volunteers that will be the main subject of this thesis.

Previous research has shown that volunteers take up several roles[37,38] e.g. assisting with recreational and social programmes, visiting patients, taking them out, providing companionship and support[34,39–41]. Volunteers can positively influence the quality of care for both the person who is dying and those close to them by reducing stress, offering practical[41,42] emotional[41–50], informational[41,42,51], spiritual[42], and bereavement support[40], and providing a link between the healthcare service and the community[41,48,52–61]. Other studies have argued that volunteers contribute to 'bonding', 'bridging'[15] and creating social capital[16]. They thereby contribute to social cohesion by increasing access to end-of-life care[38], home-care support and the ability to die at home, and health services' responsiveness to local needs[57,61]. Finally, there is widespread consensus that volunteer visits raise the general wellbeing and satisfaction of patients[62]. Additionally, it is expected that volunteers will only become more vital to palliative care provision as professional healthcare faces increasing constraints and shifts within palliative care are taking place to meet these challenges.

1.4 Constraints in professional healthcare and the move toward a Public Health approach

The introduction of palliative care to healthcare signalled a broader societal change that reflects our changing demographics and changing relationship with death and with healthcare, of which volunteering has been an important component. Palliative care itself, however, is currently also changing. Traditional divisions between residential care, offered in a care institution, and home-care are fading[63]. The healthcare sector has in recent decades been marked by strong increases in workload[64]. The sector is furthermore plagued by burnout[65] and shortages in staff[66]. It has become clear that, despite recent investments[67] (e.g. €31.7 million in nursing home staff, family caregiver subsidies, etc.), the healthcare system in its current form cannot continue to cope with increasing demand as palliative care needs are expected to rise over the next few decades. In 2014, a study of English and Welsh mortality statistics estimated that 25% of its population had palliative care needs[68]. By 2040, this total is expected to increase by 42%.

Increasingly, healthcare professionals, researchers and health services are therefore adopting a public health approach, in which palliative care is no longer purely a professional service limited to a handful of people in the terminal stage of their life-threatening illness, but something that affects the entire population. Rather than adjusting care provision on a case by case basis, public health approaches strive to improve care by tackling the underlying structural factors that influence access to care, quality of care and the health and wellbeing of the population. Palliative care is evolving from a service-centred model to a differentiated model of palliative care throughout the community. Inspired by the Public Health framework, there is therefore a widespread move to complement the amount of care provided by professionals in favour of care provided by the community itself. In several countries, volunteers are already expected to play a substantial role in future palliative care[69–72]. Recent reports have shown volunteers increase the capacity and resources within individual healthcare services[73], increasing the quality of care – through increased patient interaction, improvements in hospital environment and support for hospital staff – and the care system[74,75]. Other reports suggest volunteers are economically beneficial to health services[61,71,74–76]. In 2006, Help the Hospices calculated "Volunteer Value" by calculating the costs a hospice would have if it paid staff to do the work volunteers do. The general "Volunteer Value" of all independent hospices in the UK was estimated at £112 million (i.e. €128 million[b]), which equalled 23% of the total costs of these hospices combined[71]. In a Johns Hopkins University study ordered by the United Nations, volunteering was shown to increase the gross domestic product (GDP) by an average of 0.9% across 15 countries, contributing 0.7% to Belgium's GDP in 2013[77].

It is within this framework and due to the increasing pressures on professional healthcare that for years the Flemish government has been emphasising a "*socialisation of care*" in its vision texts[78,79]. This socialisation of care represents a stronger and more far reaching integration of care within the community and strives for a greater autonomy of the care recipient[78]. It emphasises participation of and connectedness between people and it looks toward volunteers in particular to play a larger role in achieving this integration and increasing quality of life for people with care needs. The vision texts argue that governments should provide increased support and recognition for volunteering in care as they are considered a cornerstone of society. The motivation for investing in volunteer palliative care is therefore two-fold: (1) the socialisation of care, which is the strengthening and increasing of the collective capacity of local communities, building a bridge between professional and informal care provision and between the sectors of medical healthcare and wellbeing; (2) austerity, aiming to decrease financial constraints and meet current staff shortages in healthcare. However, exactly how volunteers are expected to contribute to this shift is not made clear. Evidence is lacking with regard to what palliative care volunteers in Belgium do, how well they are supported, to what extent they are involved in palliative care and above all, to what extent this further integration of volunteers into palliative care is feasible[80,81].

1.5 Knowledge gaps in literature and in practice

The knowledge report of the Flemish Department of Wellbeing, Public Health and Family indicates several knowledge needs and gaps with regard to health care volunteering in Belgium[80,81]. There is currently scarce scientific knowledge available on care volunteers in Flanders. While large reports on volunteering in

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[b] According to the mid-2006 exchange rate of €1.48 per British Pound Sterling.

general exist[4], it cannot be assumed that their findings are valid for care volunteers in particular. Specific insights are lacking into the capacity of palliative care volunteers to support professional care provision, even internationally. Supportive capacity is shaped among other things by the presence of volunteers, the type of care they provide, their involvement, the support they receive for their work and the extent to which organisations can support and coordinate a volunteering force. These different aspects all represent current blind spots in knowledge of current practices in palliative care volunteering. See **Box 1.1** for a brief oversight of the current knowledge gaps this dissertation will address.

For instance, it is currently unknown what the prevalence is of volunteering in palliative care in both dedicated and generalist palliative care settings. Previous studies have focused mainly on dedicated palliative care services rather than looking at a broader approach to improving wellbeing near the end of life[38,53,59,75,82]. It is also unknown to what extent they provide direct patient care and what tasks they perform. Volunteers' capacity to support care provision is additionally shaped by the extent to which volunteers are sufficiently supported in their current practices. Knowledge with regard to how much training they have, which type of training they have, and which training healthcare services offer to their volunteers is also scarce. It is furthermore unknown whether volunteers feel they are sufficiently trained for the work they do. It is also unknown what type of supervision palliative care volunteers receive and whether volunteers consider it sufficient. Additionally, the supportive capacity of volunteers is shaped strongly by the roles they fulfil in palliative care. Literature has reported a variety of roles ranging in scope from specific (e.g., administration, fundraising) to broader (e.g., companionship and support) tasks[37–39,45]. Roles can be defined as behaviours, rights, obligations, beliefs, norms or a combination; the role is therefore a complex concept encompassing more than a set of tasks. Studying these roles provides a more comprehensive grasp of what volunteers actually do, what they mean to the person who is dying and those around them.

Box 1.1: Knowledge gaps in the current literature on palliative care volunteering that this dissertation will aim to address

Knowledge gaps

- Where in dedicated and generalist palliative care are volunteers **present**?
- To what extent do volunteers provide **direct patient care**?
- What **tasks** do volunteers in palliative care perform?
- What is the **role and position** of volunteers in palliative care?
    - What do volunteers mean to patients, family caregivers, nurses, psychologists and family physicians?
    - What roles do volunteers fulfil in the care for people at the end of life?
- What **training** do volunteers in palliative care have?
    - What training do palliative care services offer volunteers?
    - To what extent do volunteers feel sufficiently trained?
- What type of **supervision** do volunteers in palliative care receive?
    - How do volunteers evaluate the supervision they receive?
- To what extent are volunteers currently **involved** in the organisation of palliative care provision?
    - How do health services and volunteers evaluate their involvement?
- With whom do volunteers in palliative care **collaborate** in care provision?
    - How do volunteers and professional caregivers collaborate in care provision?
    - How do volunteers evaluate their collaboration with professional caregivers?

While many of these aspects treat volunteers as rather passive subjects receiving support and training, it is important to consider volunteers as engaged individuals with active agency in care provision and within the healthcare service too. As engaged members of their community, they may fulfil an important role in filling the support spaces between episodes of professional care[83,84]. The organisational framework of health services may furthermore be an important medium by which communities can be engaged through volunteer involvement in the organisation of care and through collaboration in care provision. In order to anticipate how a stronger volunteering force in palliative care may affect healthcare provision, it is necessary to know to what extent volunteers are currently involved, to what extent healthcare organisations are open to volunteer involvement and how both volunteers and healthcare services evaluate this involvement. Finally, few insights hitherto exist regarding volunteer-professional collaboration in palliative care. While much is known about nurse-physician collaboration in patient care[85–88], hitherto studies on volunteer-professional collaboration have been limited to paediatric palliative care[89] or hospice team meetings[90]. The extent to which volunteers and professional carers work together cooperatively, share responsibility for problem-solving and make decisions to formulate and carry out plans[88] and how volunteers evaluate their collaboration with professionals can provide policy makers and healthcare services with a crucial insights in how to stimulate volunteers' further integration into palliative care and how to alleviate pressures on professional end-of-life care.

1.6 Objectives

The general objective of this dissertation is to understand palliative care volunteering in Flanders and Dutch-speaking Brussels, in terms of who they are, what they do, what their role is and how they support the provision of and may be supported in providing palliative care.

The specific research questions are:

1. What are the characteristics of organised volunteer palliative care in the Flemish healthcare system, in terms of
    a. task performance, role and position of volunteers;
    b. training, and support of volunteers; and
    c. obstacles to maintaining a volunteer force?
2. To what extent are volunteers embedded in palliative care, in terms of involvement in the organisation of palliative care and collaboration with other professional and non-professional carers.

1.7 Methods

1.7.1 RESEARCH APPROACH

This dissertation wanted to achieve both a broad view of the characteristics and practices regarding palliative care volunteering across an entire healthcare system from multiple perspectives, and an in-depth understanding of what volunteers mean to individual patients and care providers and how they work together with other care providers. This required a multifaceted approach in which one data collection would not suffice, nor would one singular research methodology. We therefore opted for three data collections and two main research methodologies – quantitative and qualitative – and three data collection methods – surveys, focus groups and interviews. Quantitative large-scale cross-sectional surveys are well suited for broad, but superficial data collections. They are appropriate to gain insight into the bigger picture and differences between different settings. Qualitative methods are well suited to explore individual and group perspectives and experiences. Each method is described in the following sections.

1.7.2 QUANTITATIVE METHODOLOGY: CROSS-SECTIONAL SURVEYS

1.7.2.1 Survey 1: Healthcare services providing palliative care in Flanders and Dutch-speaking Brussels

We conducted a cross-sectional postal survey between June and October 2016 among healthcare organisations providing care for people with terminal illnesses towards the end of life – though not necessarily in the terminal stage – in the Flemish healthcare system. The Belgian regions (Flanders, Wallonia, and Brussels) have autonomy over various aspects of healthcare in the different language communities (Dutch, French, and German speaking), including home-care, hospital care and long-term care. The Flemish government is therefore responsible for these aspects in Flanders and for the Dutch speaking community in Brussels. We therefore included Flanders and Dutch speaking Brussels in this study and excluded Wallonia as it falls under a different regional authority and the organisation of palliative care differs greatly on the regional level. Other reasons for exclusion include the added analytical complexity resulting from strong differences in context and language differences. We identified organisations and services through the up-to-date listings of recognised healthcare organisations by the Flemish ministry for Welfare, Public Health and Family [91]. We surveyed a full population sample of palliative care units, palliative day-care centres, palliative home-care teams, medical oncology departments, volunteer community home-care organisations and a random sample of 200 out of a total of 783 nursing homes (25.5%). **(See Box 1.2.)** Our total N for this survey was 342.

The questionnaire, newly developed by the project group, consisted of 26 questions, including on *volunteer tasks*, *training*, *current volunteer involvement*, *desired volunteer involvement*, and *organisational characteristics*. The questionnaire was developed based on the literature on volunteerism in palliative care and input from representatives of each organisation type in our sampling framework. It was tested cognitively in two rounds, each with different representatives. The questionnaire can be found in **Appendix 2.2**.

The questionnaire was sent to health services with the explicit request to be completed by the person best informed about the volunteering force of the health service, such as the volunteer coordinator. The request was phrased as such, as we did not know if each health services had a volunteer coordinator, and the function may in some health services fall under the responsibility of another staff member who does not consider it his or her primary function. See **Appendix 2.3** for the questionnaire cover letter. The volunteer coordinator or closest equivalent within the organisation was considered the person most intimately involved with the volunteers from the organisational side and was therefore assumed to be representative to a reasonable degree of the organisational view of its volunteers and their involvement in the organisation of palliative care provision. It is possible that differences in views still exist within the health services' leadership, however it was considered that the person responsible for the volunteers has a mandate from the health service to manage them and thereby represent the health service policy and views on them. The questionnaire asked questions regarding volunteers internal and external to the health service as it is possible that not all volunteers active in the health service belong to the health service. However, it was considered that volunteer work within the health service was still coordinated by the health service according to its own policy. Therefore, data was collected on volunteer practices and the health service practices regarding the volunteers in general. The findings of this data collection are presented and discussed in *Chapters 2 and 5*.

1.7.2.2 Ethical considerations

Contact details of selected health services were acquired through public listings, available on the Flemish ministry for Welfare, Public Health and Family's Agency for Health and Care website[91]. Participants were informed of the study's topic and goals, the voluntary nature of participation, and the study's funding through a cover letter that accompanied the questionnaire. Anonymity in the reporting of the results was guaranteed. Participants were given the contact details of the executive researcher and offered the option to be notified of the study findings. Consent was assumed upon the completion and returning of the questionnaire to the researchers. Response was followed by linking the questionnaires to their organisations in an excel document with a unique numerical four-digit code, of which the first two digits identified the health service type. These codes were then used to follow response and follow-up letters and non-response surveys were sent to health services who had not yet returned their questionnaire. The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Brussels (ref. B.U.N. 143201627927). Approval was granted on March 23rd, 2016.

Box 1.2: Sample framework of healthcare organisations providing palliative care and working with volunteers in the Flemish healthcare system, Belgium, 2015-2019[†]

1. **Dedicated palliative care services (N=44)** are services that specialize in palliative care treatment for people with chronic, life-threatening conditions towards the end of life. This stratum therefore consists of (1) palliative care units (PCU) in (or associated with) hospitals (N=28)), (2) palliative daycare centres (PDC) (N=5), and (3) palliative home-care support teams (PHT) (N=15), which are part of the regional palliative networks and provide support for other caregivers in home or replacement home situations.
2. **Medical oncology departments (MOD) (N=42)** are hospitals departments with a fully established oncology care program, a hospitalization program and a multidisciplinary team focused on oncology. Care provision may both be curative as well as palliative.
3. **Facilities for sitting services (N=40)** organize sitting services by volunteers during the day or at night. The facility sends a volunteer to people's homes to keep them company, give them a sense of security and basic care. They offer respite care and function similar to befriending services.[‡]
4. **Volunteer community home-care organisations (CHC) (N=12)** are organized by the Christian Sickness fund (*Christelijke Mutualiteit*). Their services are locally organized and run by volunteers who pay home visits to the elderly and patients with heavy care needs in their neighborhoods. Not all people who receive visits suffer from chronic, life-threatening conditions, but many of them may.
5. **Nursing homes (NH) (N=783)** offer permanent care and nursing to elderly people. A resident of a residential care centre has his or her own room or living space there. Nursing homes may house residents with chronic, life-threatening conditions.

[†] Descriptions fully or partially taken from the Agency for Health and Care website.[91] [‡] See Walshe et al.[92]

1.7.2.3 Survey 2: Volunteers providing palliative care in the Flemish healthcare system

We conducted a cross-sectional postal survey between June and November 2018 among volunteers from healthcare organisations providing care for people with terminal illnesses towards the end of life. The population for this study consists of all registered volunteers in a selection of healthcare organisations in Flanders and Dutch-speaking Brussels, as determined in the results of **survey 1**, which deploy volunteers in direct patient care for people with serious illness. Listings of these organisations were provided by the Flemish ministry for Welfare, Public Health and Family [92]. Because of the resulting multitude of healthcare organisations, types and large numbers of volunteers, and given the lack of a central register of volunteers, a two-step disproportionately stratified cluster random sample procedure was used. The strata were the organisational settings outlined in **Box 1.2**. The clusters were the individual organisations within those strata, from which, when selected, all volunteers were included. See **Appendix 3.1** for details on the sample method. After sampling, 2273 (total N) volunteers were sent a questionnaire.

The questionnaire, developed specifically for this study, consisted of 23 questions, including on *volunteer tasks*, *volunteer training*, *volunteer supervision, frequency and intensity of volunteer work*, *contact with patients with chronic and life-threatening illnesses*, and *demographic information*. The questionnaire was developed based on the literature on volunteering in palliative care and the questionnaire used in **survey 1**. The questionnaire was cognitively tested in two rounds with volunteers in palliative care. The questionnaire can be found in **Appendix 3.2**.

A particular challenge in this data collection was to find a way to obtain consistency in how volunteers reported task performance. While we were interested in palliative care volunteering, many volunteers do not solely care for people with chronic and/or life-threatening conditions. In order to obtain data only regarding their visits for patients with chronic and/or life-threatening conditions, and therefore potential palliative care needs, we decided to ask volunteers specifically about their last session with a person with a chronic and/or life-threatening condition. We furthermore only collected task performance data if that visit took place within the last 12 months, as it was considered any reported practices outside this window may no longer be accurate. In this manner we built in a routing procedure in the questionnaire such that volunteers were answering explicitly and solely about their last visit with a person with chronic and/or life-threatening conditions. Taken together, the aggregated data on task performance was furthermore considered to adequately describe what volunteers do in such a session. The findings of this data collection are presented and discussed in *Chapters 3 and 6*.

1.7.2.4 Ethical considerations

Contact details of selected clusters (i.e. individual health services) were acquired through public listings, available on the Flemish ministry for Welfare, Public Health and Family's Agency for Health and Care website[91]. Health services were contacted by a data collector via telephone or e-mail and participation was discussed with them. Health services were informed of the study's topic and goals through an information folder. Consent of the health services was given explicitly by agreeing to participate in our study. The mail-out of the questionnaire bundles was coordinated by the data collector in collaboration with the individual health services. No direct contact details of volunteers were collected in this study. The data collector registered the number of volunteers in each participating health service, a corresponding list of codes were drawn up by the executive researcher. The code format consisted of two letters and three numbers (e.g. AA001). Each health service was given a two-letter code, of which the first letter indicated the stratum (i.e. health service type) and the second letter served to distinguish different clusters. A number was added for each two-letter code for each volunteer in that particular health service. The listings of volunteers were kept by the health service, to which the data collector added the codes. Each questionnaire was also coded in this manner. The data collector and health service coordinator ensured that each volunteer received a questionnaire with their corresponding code. This allowed the executive researcher to follow-up response without identifying individual volunteers. Any remaining links between codes and health services was removed upon destroying the file that linked health services to their letter code. Participants were informed of the study's topic and goals, the voluntary nature of participation, and the study's funding through a cover letter that accompanied the questionnaire. Anonymity in the reporting of the results was guaranteed.

Participants were given the contact details of the executive researcher and offered the option to be notified of the study findings. Consent was assumed upon the completion and returning of the questionnaire to the researchers. Health service coordinators sent around a message to their volunteers to encourage participation in the survey but did not collect the data themselves. Surveys were sent back to the researchers via an enclosed, postage-paid envelope that accompanied the questionnaire. This same method was used for follow-up letters and the non-response survey. The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Brussels. (ref. B.U.N. 143201835145) Approval was granted on April 4th, 2018.

1.7.3 QUALITATIVE METHODOLOGY: FOCUS GROUPS AND SEMI-STRUCTURED INTERVIEWS

Applying a qualitative descriptive design with phenomenological and Grounded Theory overtones, we conducted focus groups with volunteers and healthcare professionals and individual semi-structured interviews with patients and family caregivers in Flanders, Belgium, between March and November 2017. An advantage of focus groups is that they stimulate the exchange of views through discussion, allow mutual differences or similarities to drive the conversation and enable salient themes to emerge. A moderator facilitates the discussion by introducing topics and issues for the participants to discuss amongst themselves. He or she occasionally probes the participants to further explore interesting emerging topics or statements expressed by participants. Knowledge is generated in interaction – whether agreement or conflict – between participants. A disadvantage of focus groups is that it does not allow to explore in-depth an individual’s unique experience, but rather focuses on the collective experience and its different facets. Another disadvantage is that, depending on the topic, not all participants may feel comfortable sharing or discussing in group and may be at risk of staying silent. Considering the fragile health of patients and the sensitive, personal nature of the topic for patients and family carers, individual semi-structured interviews were conducted with patients and with family carers. Individual interviews miss the interactive nature of knowledge generation. An advantage of individual interviews is, however, that they allow every case to be treated as discrete and all participants to speak freely. Considering the personal nature of the topic, this was judged a more suitable method of information gathering for patients and family caregivers, as it respects their highly individual experiences. Individual interviews, however, run the risk of getting lost in the highly individual and personal stories of the participant, which may not always be relevant to the research. The role of the interviewer is then to strike a balance, keep the interview on track and guide the participant through it. Semi-structured individual interviews were therefore considered as a suitable method, as they provide the interview with a minimal structure in the form of topics and probes, leaving participants free to talk about these predefined points. As well as people with serious illnesses we included volunteers, family or informal carers, nurses, psychologists and family physicians (FP) as those most relevant to and most closely involved in their treatment and palliative care. Volunteers were community volunteers providing direct patient care, registered in a healthcare service, but not professionals working unpaid. 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. Care settings were considered based on findings **survey 1**. Participants were purposefully sampled according to the following inclusion criteria:

- **Patients**:
    - Patients were at the time of the study being treated at one of the settings mentioned above.
    - Patients were being treated for a chronic, life-threatening condition.
    - Treating physicians would not be surprised if the patient would decease within the next 12 months.
    - Patients were receiving or had at one point received help from a volunteer in their care for their current condition.
    - Patients were mentally competent.
    - Patients spoke Dutch.
    - Patients were be able to communicate.
- **Family caregivers**:
    - Family caregivers were equated with the concept of '*mantelzorgers*', which encompasses more than strictly blood-related relations. They may include friends, neighbours, or other existing social acquaintances.
    - Family caregivers were at the time of the study caring for a family member of whom the treating physicians would not be surprised were they to decease within the next 12 months, or had in the past cared for a since deceased family member with one or more chronic, life-threatening conditions in the last three years.
    - Family caregivers were at the time of the study or had at one point in the past received help from a volunteer in the care for a family member with one or more chronic, life-threatening conditions.

  - Family caregivers were or had been the main informal caregivers for their patient.
  - Family caregivers' patients were blood relatives, friends, or other social acquaintances.
  - Family caregivers spoke Dutch.
- **Volunteers**:
  - Volunteers provided direct patient care to patients in one of the institutional settings mentioned above. (This refers to the immediate, regular, non-sporadic care given by any caregiver – professional or volunteer – and which is part of a curative or palliative approach.)
  - Volunteers were involved in or had had experience with palliative approaches.
  - Volunteers, at the time of recruitment, had been active in the current or one of the other institutional settings mentioned above for at least 12 months.
  - Volunteers were at the time of the study formally organized as volunteers, which requires an official registration with one of the organisation types mentioned above.
  - Volunteers spoke Dutch.
- **Professional caregivers**:
  - Professional caregivers were either GP's, psychologists, or nurses.
  - Professional caregivers were actively involved in the disease process of at least three patients with chronic, life-threatening conditions in the past 12 months who have since deceased or of whom they would not be surprised should they decease within the next 12 months.
  - Psychologists and nurses were working at one of the settings mentioned above.
  - Professional caregivers either had more than three patients receiving care from a volunteer *or* actively worked together with volunteers themselves on a weekly basis.
  - Professional caregivers spoke Dutch.

Topic guides were developed and reviewed by the project group (including sociologists and a clinical psychologist) and included the following key topics: volunteer tasks, task boundaries, the role of volunteers in palliative care, the barriers and facilitators of volunteer care, volunteer-professional contact, volunteer-professional collaboration, evaluation of collaboration and barriers to and facilitators of volunteer-professional collaboration. The topic guides can be found in **Appendix 4.3**. The findings of this data collection are presented and discussed in *Chapters 4 and 7*.

1.7.3.1 Ethical considerations

Participants were purposefully sampled from hospital settings (palliative care units and medical oncology departments), home-care settings (palliative home-care teams, sitting services and community home-care services) and live-in or day-care settings (palliative day-care centres and nursing homes) based on the public listings available on the Flemish ministry for Welfare, Public Health and Family's Agency for Health and Care website[91]. Health services with which a working relationship existed with the research group or executive researcher were consulted first for recruitment. Volunteer coordinators and department heads were contacted by telephone to explain the study aims and design and to request their participation in recruiting participants for the study. The telephone call was followed up with an informational e-mail detailing the study and the types of participants we were looking to include. Cooperating health services were asked to refer participants to us or to send out a call internally with the study aims and contact details of the executive researchers. No contact details of participants were collected, unless potential participants contacted us directly. Participants were personally informed by the researcher on the topic and aims of the study and on what was expected of them should they wish to participate. They were given ample time to consider and ask any and all questions that might arise. This information was also handed to them in the form of an informational letter. After being fully informed they were asked to sign an informed consent form before starting the focus groups or interviews. **(See Appendix 1.1.)** For focus groups, a location was discussed with all participants and chosen to minimize the commute for all participants. Focus group participants were offered a flat-rate reimbursement for their commute and a €25 gift card from a book shop for their time. The interviews took place at a location of the participants' choosing. Often this was in the care setting where they resided or at home. Interview participants were also offered a €25 gift card from a book shop for their time. Data was coded anonymously, and results were reported anonymously in accordance with the provisions of the law on personal data protection. Pseudonyms were used when quoting participants in the reporting of the findings. Due to the sensitive nature of the topics discussed in the interviews, there was a risk that patients and family caregivers may become distressed. In those cases, the interviewer would allow the participant time to process their emotions and offer their support empathically. If necessary, the interviewer would stop the recording and suggest to the interviewer to take a short break or to continue the interview at another time. Participants were also given the interviewers' contact details should they wish to talk or ask any questions after the interview. 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 30th, 2017.

1.7.3.2 Role of the researcher

I would like to switch briefly from the first person plural account that I have given up until this point and that I will take up again for the remainder of this dissertation – as indeed I must, because much of this work was the result of a collaborative team effort – to focus attention on my own role as executive researcher and as author of this dissertation. As the author, executive researcher and as the main interviewer and moderator of the focus groups in the qualitative data collection, it is important to consider my own role, position, attitudes and therefore biases. My education as a Sociologist has provided me with training in both quantitative and qualitative data collection and analysis methods. As a researcher, I felt well prepared for the interviews and focus groups that were conducted in this study.

However, as a human being, interacting with other human beings in this study, I am not an impersonal observer. I am a person with my own opinions, attitudes, and behaviourisms, all of which have inevitably influenced and played a role in the questions I asked, and the assumptions and interpretations I made throughout this study. My interests in volunteering stem from my own experience as a volunteer and my interests in active citizenship. I have been a volunteer myself, albeit in the cultural sector, and therefore have great affinity with volunteering, and have an inherently positive view on the practice and on the empowerment of volunteers.

There was a risk throughout this work that some of my interpretations and conclusions may lean towards normative statements, whereas more critical views of volunteering and critical interpretations of the findings would be less likely to emerge. However, some measures were taken to limit this risk. During data collection, I made field notes during and shortly after the interviews and focus groups which detailed my personal impressions and thoughts that occurred during or afterwards. I took an active effort to challenge myself on my assumptions and took efforts to play the devil's advocate whenever I found myself positively or negatively appreciating certain findings. I paid close attention to challenge participants particularly when I found myself agreeing or interpreting what the participant was trying to say, to counter the risk of assuming meaning by inserting my own. Additionally, I was surrounded by a project group consisting of my two promotors, co-promotor and a clinical psychologist/volunteer coordinator from palliative care practice. Transcripts, findings, assumptions, interpretations and conclusions were all evaluated critically by the other members during project group meetings as a safeguard against my personal biases and I was often challenged on them.

By paying attention to my own personal views on and attitudes towards volunteering, I do not claim I have removed them. However, I hope to have reduced their impact on my work.

1.8 Thesis outline

This dissertation is further divided into four different parts, each encompassing different chapters and treating different aspects of volunteering in palliative care.

Part II: chapters 2-4 will explore the presence and characteristics of palliative care volunteers across the Flemish healthcare system in terms of tasks, training and support for volunteers both at the organisational and individual level. They will also explore the role and position of volunteers in palliative care from the perspectives of those closely involved in the care for people at the end of life, including volunteers, patients, family caregivers, nurses, psychologists and family physicians.

Part III: chapters 5-7 will explore volunteer involvement in the organisation of palliative care and the collaboration between volunteers and professional carers. This part will encompass both quantitative findings at the organisational and individual level, as well as qualitative findings from the perspectives of volunteers, patients, family caregivers, nurses, psychologists and family physicians.

Part IV: chapter 8 encompasses the general discussion of this dissertation, in which I summarise the main findings for each research question, reflect on the strengths and limitations of the studies in terms of methodology and scope, and discuss the importance and relevance of the findings in light of the current state of affairs within palliative care research and their implications for practice, policy and future research.

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PART II – TASKS, TRAINING, SUPPORT, POSITION AND ROLES OF VOLUNTEERS IN PALLIATIVE CARE

2 CHAPTER 2 : PALLIATIVE CARE VOLUNTEERISM ACROSS THE HEALTHCARE SYSTEM : A SURVEY STUDY

Steven Vanderstichelen, Dirk Houttekier, Joachim Cohen, Yanna Van Wesemael, Luc Deliens, Kenneth Chambaere

Published in *Palliative Medicine* 2018, 32(7): 1233-1245

Abstract

Background – Volunteers fulfil several roles in supporting terminally ill people and their relatives and can positively influence quality of care. Healthcare in many countries faces resource constraints and some governments now expect communities to provide an increasing proportion of palliative care. However, systematic insights into volunteer presence, tasks and training and organisational challenges for volunteerism are lacking.

Aim – Describe organised volunteerism in palliative direct patient care across the Flemish healthcare system (Belgium).

Design – Across-sectional postal survey using a self-developed questionnaire was conducted with 342 healthcare organisations.

Setting/participants – The study included full population samples of palliative care units, palliative day-care centres, palliative home-care teams, medical oncology departments, sitting services, community home-care services and a random sample of nursing homes.

Results – Responses were obtained for 254 (79%) organisations; 80% have volunteers providing direct patient care. Psychosocial, signalling and existential care tasks were the most prevalent volunteer tasks. The most cited organisational barriers were finding suitable (84%) and new (80%) volunteers; 33% of organisations offered obligatory training (75% dedicated palliative care, 12% nursing homes). Differences in volunteer use were associated with training needs and prevalence of organisational barriers.

Conclusion – Results suggest potential for larger volunteer contingents. The necessity of volunteer support and training and organisational coordination of recruitment efforts is emphasised. Organisations are encouraged to invest in adequate volunteer support and training. The potential of shared frameworks for recruitment and training of volunteers is discussed. Future research should study volunteerism at the volunteer level to contrast with organisational data.

Keywords:

Volunteers; palliative care; surveys and questionnaires; nursing homes; home-care services; medical oncology

Key statements:

What is already known about the topic?

- Palliative care volunteers may reduce stress, offer practical and emotional support and provide a link to the community for people who are dying and those close to them.
- Citing increasing resource constraints in professional healthcare, some governments, including that of Belgium, are proposing that a larger proportion of care at the end of life should be provided by informal caregivers.
- While literature has widely reported on volunteer tasks, no specific data regarding volunteer numbers, training and recruitment in palliative care are available on which to base this intended policy shift.

What this paper adds

- Psychosocial and existential care and fulfilling signalling functions are the most prevalent tasks undertaken by volunteers but come with increased volunteer training provision.
- Organisations employing volunteers in practical care for people who can no longer function independently more often cite legal and financial barriers.
- The recruitment of suitable and new volunteers are the most cited organisational barriers to maintaining and increasing the numbers of volunteers.

Implications for practice, theory or policy

- Non-specialist palliative care organisations (not including community care) are advised to invest more strongly in volunteer support and training.
- Governments turning to volunteering to combat pressures on professional healthcare are advised to provide shared frameworks that expedite recruitment coordination and standard, context-sensitive volunteer training.
- Tailored recruitment strategies that offer flexible, low-threshold volunteering roles should be devised to engage both younger and older volunteers.

2.1 Introduction

Volunteers played a major role in the early days of the palliative care movement. They continue to be involved in the provision of palliative care, both in the community and in institutional settings[1–3]. Although family and professional caregivers provide the majority of end-of-life care, volunteers take up several roles[4,5], for example, assisting with recreational and social programmes, visiting patients, taking them out and providing companionship and support[6–9]. These tasks are considered as core to providing quality palliative care. Previous studies show that volunteers can positively influence the quality of care for both the person who is dying and those close to them by reducing stress, offering practical and emotional support and providing a link to the community[2,10–12].

There is a widespread move to complement the amount of care provided by professionals, given the limitation in resources allocated to healthcare and the growing needs of ageing populations, and volunteers are expected to play an even more substantial role in future palliative care in several countries[13–16]. Some governments are now pushing for a partial shift from formal healthcare services towards community care (e.g. through volunteerism)[13,14].

The feasibility of such a shift requires an understanding of current volunteer practices; however, data on the total volunteer workforce deployed in palliative care, whether they provide direct patient care and what tasks they perform, are scarce. The extent of relevant training and the barriers to maintaining a volunteer workforce are also unknown. In several countries, including Belgium, palliative care provision is divided into dedicated and generalist (i.e. palliative care provided by care providers other than those of dedicated palliative care services)[17]; previous quantitative studies have focused mainly on dedicated palliative care services rather than looking at a broader approach to improving wellbeing near the end of life[5,18–21].

To address these knowledge gaps, this study provides an extensive description of the current state of organized volunteerism in palliative direct patient care across the entire healthcare system in Flanders, Belgium. It thereby adds to the literature, following the lead of the European Association for Palliative Care (EAPC) Taskforce on Volunteering[22]. The research questions are as follows:

1. To what extent do various healthcare organisations that provide palliative care embed volunteers in patient care?
2. What types of palliative care activities do these organisations have their volunteers perform in patient care?
3. What organisational barriers to maintaining and expanding a volunteer force do these organisations encounter?
4. Which recruitment strategies do these organisations employ?
5. To what extent do these organisations offer training to their volunteers and which subjects are offered?

2.2 Method

We conducted a cross-sectional postal survey between June and October 2016 among healthcare organisations providing care for people with terminal illnesses – who are not necessarily in the terminal stage – in the Flemish healthcare system. The Belgian regions (Flanders, Wallonia and Brussels) have autonomy over various aspects of healthcare in the different language communities (Flemish, French and German speaking), including home-care, hospital care and long-term care. The Flanders government is responsible for these aspects in Flanders and for the Flemish-speaking community in Brussels. We therefore included Flanders and Flemish-speaking Brussels for this study, and excluded Wallonia.

2.2.1 DEFINITION OF VOLUNTEERISM

We define volunteerism in palliative care as

> *the time freely given by individuals, with no expectation of financial gain, within some form of organised structure other than the already existing social relations or familial ties, with a palliative approach, i.e. the intention of improving the quality of life of adults and children with terminal illnesses and those close to them (family and others). (Adapted from Goossensen et al.*[22]*)*

Volunteers do not have an employment contract or statutory appointment within the organisation in which they perform these tasks. This definition is in accordance with that provided by the Belgian federal law[23,24]. We focus on community volunteers in direct patient care, that is, members of the local community that work in care-focused roles and are regularly involved with patients and those close to them, provided they are not merely performing their medical profession unpaid[22]. 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.

2.2.2 SAMPLE

Our unit of analysis is the individual organisation. We identified organisations and services through the up-to-date listings of healthcare organisations recognised by the Flemish ministry for Welfare, Public Health and Family. We considered hospital departments as organisations, as volunteerism is more directly coordinated at this level. Our inclusion criteria were that organisations:

- Provide care for people with terminal illnesses;
- Potentially work with volunteers;
- Are active in Flanders or Brussels;
- Are on the list of healthcare organisations of the Flemish ministry for Welfare, Public Health and Family.

We consulted 12 experts from different types of healthcare organisation where people may come to die and where people with terminal illnesses may be treated to find out where volunteers may regularly be active in patient care (see **Appendix 2.1**). **Box 2.1** provides a list and descriptions of all organisation types included in our sample framework based on this expert consultation.

Box 2.1: Sample framework of Flemish and Brussels healthcare services potentially involving volunteers in direct patient care, Belgium, 2016[a]

1. **Medical oncology departments (MODs; N = 42/42)** are hospital departments with a fully established oncology care programme, a hospitalisation programme and a multidisciplinary team focused on oncology.
2. **Facilities for sitting services (N = 40/40)** organise sitting services 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 similar to befriending services.[b]
3. **Palliative care units (PCUs; N = 28/28)** are separate units in (or associated with) hospitals that exclusively provide palliative care.
4. **Palliative day-care centres (PDCs; N = 5/5)** provide care and nursing during the day and have a respite care function for carers.
5. **Palliative home-care teams (PHTs; N = 15/15)** are part of the palliative networks, that is, cooperative ventures between different providers and care facilities in a particular region – these are palliative care teams supporting other caregivers in home or replacement home situations, supported by the network's volunteers.
6. **Volunteer community home-care organisations (CHCs; N = 12/12)** are organised by the Christian Sickness Fund locally and run by volunteers.
7. **Nursing homes (NHs; N = 200/783)** offer permanent care and nursing to elderly people.

[a]Descriptions fully or partially taken from the Agency for Health and Care website[25]. [b]See Walshe et al.[26]

2.2.3 ETHICAL APPROVAL

The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Brussels (ref. B.U.N. 143201627927). Approval was granted on 23 March 2016.

2.2.4 SAMPLES AND PROCEDURE

We surveyed a full population sample of all organisation types except for NHs where a random sample of 200 from a total of 783 was taken (25.5%). Our total N for this survey was 342. All questionnaires were sent out simultaneously by post, pre-numbered to track response. A thank-you note and reminder were sent out 1 week later; 3 weeks post mail-out a replacement questionnaire and new cover letter were sent to all non-respondents. Five weeks post mail-out the remaining non-respondents were contacted by telephone. New questionnaires were supplied by email when necessary. Seven weeks post mail-out a non-response survey consisting of four questions was sent by post to gauge whether respondents had received the questionnaire, had sent it back and if not why. Questionnaires were addressed to representatives of the organisation. Informed consent was assumed upon participation. Data input did not include the questionnaire numbering, thereby ensuring anonymity of the data set.

2.2.5 QUESTIONNAIRE

The self-developed questionnaire consisted of 26 questions covering (a) volunteer presence, (b) volunteer tasks, (c) organisational barriers to volunteerism, (d) volunteer recruitment, selection and evaluation, (e) volunteer training, (f) volunteer involvement, (g) the respondent's evaluation of volunteer involvement, (h) the organisation's volunteerism policy, (i) the organisation's care capacity and (j) the respondent's demographic information. The questionnaire was developed based on the literature on volunteerism in palliative care and input from representatives of each organisation type in our sample framework. The questionnaire was tested cognitively in two rounds, each with different representatives. Representatives were asked to complete the questionnaire in the presence of the executive researcher in order to identify conceptual clarity or difficulties of the questions. These questions were then reworked between rounds. The questionnaire used items from two validated measures, activities of daily living (ADL)[27], commonly used to measure people's ability to function independently, and instrumental ADL (iADL)[28], commonly used to measure people's ability to live at home independently. All other measures were self-constructed. For details including the specific items used for ADL, iADL and psychosocial, signalling and existential (PSE) care tasks, see the questionnaire in **Appendix 2.2**.

2.2.6 STATISTICAL ANALYSIS

We performed univariate and bivariate analysis using IBM SPSS 24. Cross-tabs were run to calculate proportions for each variable for each organisation type. Percentages were rounded. Chi-square tests were performed to check for statistical differences in proportions across types (significance at $p = 0.05$ or lower was indicated with a (*)). Agreement was calculated for the item batteries regarding ADL-tasks (six items), iADL-tasks (eight items) and PSE tasks (five items) using Cronbach’s alpha to evaluate how closely related these sets of items were as a group. Analysis of variances (ANOVAs) were conducted to test for associations between mean scores of different variables. All categorical variables for volunteer tasks, training and training subjects, recruitment strategies and organisational barriers were recoded into dummy variables for all analyses.

2.3 Results

Out of 342 organisations, a response was received from 258. Out of 84 non-response surveys sent, 27 were returned (25%). Seven organisations (28%) indicated that they had not received a questionnaire. Of those that had received one, 7 (27%) had replied but the reply had not reached us; 37% of those that received a questionnaire but did not return it cited lack of time. Six returned non-response surveys were considered as partial responses, because they either indicated having no volunteers or provided limited data. These were added to the total response, bringing the N up to 264. Non-eligible respondents (e.g. the organisation no longer exists) were subtracted from the sample denominator, bringing it down to 334. In accordance with American Association for Public Opinion Research (AAPOR) guidelines[29], we reached a valid response rate of 79% (264/334; **Table 1**).

Table 1: Survey response

Organisation types	Sample total	Response	Response rate
Medical oncology depts.	39	25	64%
Sitting services	39	33	85%
Dedicated palliative care services	47	45	96%
Paliative care units	27	25	93%
Palliative day-care services	5	5	100%
Palliative Home-care Teams	15	15	100%
Volunteer community home-care	12	10	83%
Nursing homes	197	145	74%
Total	**334**	**264**	**79%**[a]

[a] Calculated with the AAPOR non-response calculator tool[25].

Table 2: Healthcare organisations with palliative care volunteers, Flanders, 2016[a]

Organisation[b]	**Total**	**Dedicated palliative care services**				**Generalist palliative care services**				p-value[c]
		Total	PCU	PDC	PHT	Med onc	Nursing homes	Community care		
								CHC	Sitting services	
N (number of organisations surveyed)[d]	**258**	**45**	25	5	15	25	145	10	33	
Organisations with volunteers	**94%**	**98%**	100%	100%	93%	84%	93%	100%	100%	.144
Organisations with direct patient care volunteers	**80%**	**98%**	100%	100%	93%	64%	73%	80%	97%	.001*
Direct patient care volunteers per organisation (mean (SD))	***76 (28.8)***	***22.39 (2.1)***	*20.3 (2.7)*	*28.2 (10.3)*	*24.1 (3.2)*	*6.3 (1.8)*	*18.9 (1.9)*	*1388.9 (430.6)*	*85.9 (12.6)*	<.001 *
Organisations with internal volunteers	**90%**	**87%**	84%	100%	87%	58%	92%	100%	100%	<.001 *
Organisations with external volunteers	**25%**	**16%**	24%	0%	7%	68%	27%	10%	0%	<.001 *

[a] Organisations were asked to indicate the presence of volunteers in general, as well as the presence of volunteers registered with their organisation (internal) or registered with external organisations (external) and the presence of volunteers involved in direct patient care. Respondents were also asked to report the total of volunteers present for each kind (any, direct patient care, internal and external). Averages of direct patient care volunteers per organisation type were calculated based on the reported totals of direct patient care volunteers via the aggregate command.

[b] PCU = Palliative Care Units; PDC = Palliative Daycare Centres; PHT = Palliative Home Care Teams; CHC = volunteer Community Home Care organisations.

[c] Chi-Square analysis was performed to check for significant differences between the individual organisation types. Totals not included.

[d] Missings ranged from 0.4% to 13.6% on total N and were excluded from the analysis. The missings were lowest for PCUs and PDCs (0.0%) and highest for MODS (up to 40.0%) and NHs (up to 15.9%).

Table 3: Tasks performed by direct patient care volunteers in healthcare organisations providing palliative care, Flanders, 2016[a]

Organisation[b]	Total	Dedicated palliative care services				Generalist palliative care services				p-value[c]
								Community care		
		Total	PCU	PDC	PHT	Med onc	Nursing homes	CHC	Sitting services	
N (number of organisations with direct patient care volunteers)[d]	**206**	**44**	25	5	14	16	106	8	32	
ADL (Cronbach's Alpha = 0.812)[e]										
- Helping the patient with eating	**86%**	**82%**	88%	100%	64%	53%	90%	50%	100%	<.001*
- Helping the patient with lifting and moving	**78%**	**89%**	88%	100%	86%	27%	77%	50%	100%	<.001*
- Helping with bathroom visits	**35%**	**49%**	38%	40%	71%	19%	8%	50%	100%	<.001*
- Cleaning the patient	**24%**	**26%**	25%	40%	21%	13%	2%	38%	91%	<.001*
- Dressing the patient	**23%**	**28%**	28%	60%	15%	13%	3%	38%	78%	<.001*
- Washing the patient	**8%**	**21%**	24%	40%	8%	6%	2%	38%	0%	<.001*
Mean of the sum of scores for ADL items (1-6)	***2.51***	***2.88***	*2.82*	*3.8*	*2.62*	*1.33*	*1.8*	*2.63*	*4.69*	<.001*
Standard deviation	***0.12***	***0.28***	*0.4*	*0.92*	*0.45*	*0.49*	*0.09*	*1.05*	*0.1*	
iADL (Cronbach's Alpha = 0.672)[e,f]										
- Transporting the patient	**69%**	**57%**	68%	60%	36%	25%	83%	50%	69%	<.001*
- Helping the patient with phone usage	**55%**	**77%**	100%	60%	43%	40%	41%	25%	84%	<.001*
- Doing groceries for the patient	**54%**	**46%**	68%	40%	7%	31%	57%	50%	69%	.002*
- Helping the patient with food preparation	**45%**	**64%**	96%	20%	21%	31%	41%	13%	47%	<.001*
- Helping the patient with chores	**26%**	**30%**	46%	20%	7%	6%	27%	13%	28%	.066
- Helping the patient with taking medication	**19%**	**21%**	21%	20%	21%	13%	3%	13%	72%	<.001*
- Doing the laundry for the patient	**6%**	**18%**	32%	0%	0%	0%	2%	0%	0%	<.001*
- Manage finances for the patient	**0%**	**0%**	0%	0%	0%	0%	0%	0%	0%	/
Mean of the sum of scores for iADL items (1-8)	***2.7***	***3.05***	*4.26*	*2.2*	*1.36*	*1.4*	*2.5*	*1.63*	*3.69*	<.001*
Standard deviation	***0.13***	***0.33***	*0.31*	*0.97*	*0.46*	*0.38*	*0.15*	*0.63*	*0.32*	
Psychosocial, Signalling and Existential care (Cronbach's Alpha = 0.671)										
- Psychosocial care for the patient	**99.5%**	**98%**	100%	100%	93%	100%	100%	100%	100%	.037*
- Signalling tasks (patient – professional)	**81%**	**93%**	92%	80%	100%	69%	74%	75%	91%	.069
- Psychosocial care for the patient's relatives	**76%**	**98%**	100%	80%	100%	87%	62%	100%	78%	<.001*
- Spiritual/existential care tasks	**75%**	**93%**	92%	80%	100%	69%	68%	88%	72%	.050*
- Signalling tasks (relatives – professional)	**68%**	**93%**	96%	60%	100%	87%	52%	75%	72%	<.001*
Mean of the sum of scores for PSE items (1-5)	***3.98***	***4.75***	*4.8*	*4*	*4.93*	*4.07*	*3.55*	*4.38*	*4.13*	<.001*
Standard deviation	***0.09***	***0.1***	*0.1*	*0.63*	*0.07*	*0.34*	*0.14*	*0.38*	*0.21*	
Medical and nursing tasks	**5%**	**7%**	4%	20%	7%	6%	2%	13%	9%	.346

[a] Items in this table were recoded from 3 categories ('core task', 'secondary task', 'no task') to 2 categories ('task', 'no-task') to reflect whether volunteers performed the task or not. [b] PCU = Palliative Care Units; PDC = Palliative Daycare Centres; PHT = Palliative Home care Teams; CHC = volunteer Community Home Care organisations. [c]Chi-Square analyses were performed to check for significant differences between the individual organisation types. Totals not included. [d]Missings ranged from 1.9% to 8.3% on total N and were excluded from the analysis. Missings were lowest for sitting services, PDCs and CHCs (0.0%) and highest for NHs (2.8%-13.2%). [e]The item batteries for Activities of Daily Living (ADL) and instrumental Activities of Daily Living (iADL) have been validated in healthcare practices.[26,27] [f]The item 'managing finances for the patient" was excluded due to no variance.

Table 4: Organisational barriers to volunteerism and volunteer recruitment strategies for healthcare organisations providing palliative care, Flanders, 2016[a]

Organisations[b]	Total	Dedicated palliative care services				Generalist palliative care services				p-value[c]
						Med onc	Nursing homes	Community care		
		Total	PCU	PDC	PHT			CHC	Sitting services	
N (number of organisations with direct patient care volunteers)[d]	**206**	**44**	25	5	14	16	106	8	32	
Barriers to maintaining and expanding a volunteering force										
Finding suitable volunteers	**84%**	**66%**	72%	40%	64%	80%	87%	100%	97%	.003*
Finding new volunteers	**80%**	**59%**	64%	40%	57%	57%	84%	100%	100%	<.001*
Time investment required	**51%**	**36%**	28%	40%	50%	53%	48%	57%	77%	.022*
Legal prescriptions regarding volunteer tasks	**42%**	**39%**	36%	20%	50%	13%	36%	13%	84%	<.001*
Financial costs for the organization	**32%**	**30%**	16%	20%	57%	19%	26%	25%	65%	<.001*
Integration of volunteers into the organisation	**29%**	**23%**	28%	0%	21%	27%	34%	25%	27%	.722
Recruitment strategies										
Digital media (website, social media…)	**70%**	**74%**	63%	100%	86%	53%	60%	100%	100%	<.001*
Recruitment via current volunteers	**68%**	**42%**	33%	60%	50%	40%	71%	100%	100%	<.001*
Loose print media (posters, flyers, pamphlets…)	**67%**	**49%**	42%	60%	57%	27%	69%	100%	97%	<.001*
Internal printed media (own magazine, newspaper…)	**67%**	**35%**	25%	60%	43%	27%	75%	100%	94%	<.001*
External printed media (magazines, newspapers, radio/tv…)	**41%**	**44%**	38%	60%	50%	20%	31%	75%	69%	.001*
Open day	**40%**	**30%**	25%	80%	21%	13%	45%	38%	50%	.024*

[a] Items in this table were recoded from 3 categories ('large barrier', 'small barrier', 'no barrier') to 2 categories ('barrier', 'no barrier') to reflect whether the potential barriers were experiences as actual barriers or not by healthcare organisations.

[b] PCU = Palliative Care Units; PDC = Palliative Day-care Centres; PHT = Palliative Home care Teams; CHC = volunteer Community Home Care organisations.

[c] Chi-Square analysis was performed to check for significant differences between the individual organisation types. Totals not included.

[d] Missings ranged from 1.5% to 7.8% on total N and were excluded from the analysis. The missings were lowest for PDCs and PHTs (0.0%) and highest for NHs (1.9% - 13.2%).

Table 5: Healthcare organisations offering training to their direct patient care volunteers in palliative care, Flanders, 2016[a]

		Dedicated PC services				Generalist palliative care services				
								Community care		
Organisations[b]	**Total**	**Total**	PCU	PDC	PHT	Medical onc	Nursing homes	CHC	Sitting services	p-value[c]
N (number of organisations with direct patient care volunteers)[d]	**206**	**44**	25	5	14	16	106	8	32	
No training offered	**9%**	**0%**	0%	0%	0%	8%	19%	0%	0%	.008*
Training offered	**91%**	**100%**	100%	100%	100%	92%	81%	100%	100%	.008*
Training subjects offered:										
Themes regarding specific patient groups (e.g. dementia, cancer, etc.)	**71%**	**59%**	56%	20%	79%	29%	74%	88%	97%	<.001*
Organisation's vision and values	**61%**	**80%**	76%	80%	86%	36%	47%	88%	78%	.001*
Volunteer position and roles within care	**56%**	**91%**	96%	80%	86%	64%	29%	63%	81%	<.001*
Ethics (discretion)	**54%**	**77%**	72%	80%	86%	43%	29%	100%	88%	<.001*
Lifting techniques	**48%**	**50%**	56%	40%	43%	14%	33%	88%	91%	<.001*
Guarding personal and professional boundaries	**47%**	**77%**	76%	60%	86%	36%	18%	88%	84%	<.001*
(Hand)hygiene	**46%**	**57%**	84%	40%	14%	64%	47%	25%	25%	<.001*
Ethical aspects of volunteering	**44%**	**68%**	60%	80%	79%	57%	24%	63%	59%	<.001*
Volunteer needs	**44%**	**75%**	76%	60%	79%	14%	20%	88%	72%	<.001*
Organisation's care provision	**43%**	**73%**	72%	80%	71%	29%	19%	50%	75%	<.001*
Basic knowledge and skills in palliative care	**43%**	**93%**	88%	100%	100%	36%	12%	50%	63%	<.001*
Advance Care Planning (ACP)	**16%**	**52%**	32%	60%	86%	7%	3%	13%	6%	<.001*
Number of training subjects offered (median) (Nominal 1-13 scale)	***6.0***	***9.0***	*9.0*	*9.0*	*10.0*	*5.0*	*3.0*	*8.5*	*10.0*	<.001*
Obligatory training offered	**33%**	**75%**	64%	60%	100%	57%	12%	25%	28%	<.001*

[a] Respondents were asked to indicate whether their organisation provided any training to their volunteers and whether obligatory training was provided or not. They were also asked to check any and all training subjects that were offered to their volunteers from a list of 13 subjects. A median was calculated for the total of organisations and each organisation type by calculating the sum of scores for all training subjects (1/0) and calculating the median across organizations via the aggregate command.

[b] PCU = Palliative Care Units; PDC = Palliative Daycare Centres; PHT = Palliative Home care Teams; CHC = volunteer Community Home Care organisations.

[c] Chi-Square analysis was performed to check for significant differences between the individual organisation types. Totals not included.

[d] Missings ranged from 7.8% to 8.3% on total N and were excluded from the analysis. The missings were lowest for Sitting services, PCUs, PDCs, PHTs and CHCs (0.0%) and highest for NHs (14.2%) and MODs (12.5%).

Table 6: Association of volunteer use with volunteer training, organizational barriers and organization types

Variables	ADL^a task performance			iADL^a task performance			PSE^a task performance		
	Below mean (0-2)	Above mean (3-6)	P-value^b	Below mean (0-2)	Above mean (3-8)	P-value	Below mean (0-3)	Above mean (4-5)	p-value
N (%)^c	126 (66%)	66 (34%)		89 (47%)	100 (53%)		62 (31%)	136 (69%)	
- Total training subjects (0-12) (mean)	4.73	8.52	<.001*	5.45	6.71	.021*	4.37	6.68	<.001*
Training subjects (column percentages)^d									
- Themes regarding specific patient groups	61%	77%	.071	64%	70%	.674	53%	72%	.001*
- Organisation's vision and values	47%	76%	<.001*	55%	58%	.850	44%	63%	.001*
- Volunteer position and roles within care	41%	77%	<.001*	48%	60%	.273	32%	62%	<.001*
- Ethics (discretion)	40%	74%	<.001*	52%	55%	.835	34%	57%	<.001*
- Lifting techniques	30%	71%	<.001*	31%	58%	.001*	34%	51%	.001*
- Guarding personal and professional boundaries	32%	68%	<.001*	40%	50%	.413	26%	52%	<.001*
- (Hand)hygiene	46%	36%	.315	38%	48%	.391	34%	47%	.002*
- Ethical aspects of volunteering	32%	58%	.002*	38%	45%	.612	19%	51%	<.001*
- Volunteer needs	29%	64%	<.001*	38%	47%	.463	24%	50%	<.001*
- Organisation's care provision	25%	67%	<.001*	35%	46%	.293	27%	46%	.001*
- Basic knowledge and skills in palliative care	25%	67%	<.001*	28%	51.%	.006*	19%	49%	<.001*
- Advance Care Planning (ACP)	10%	24%	.037*	16%	15%	.863	3%	20%	<.001*
Organisational barriers (column percentages)^d									
- Finding suitable volunteers	82%	88%	.291	83%	84%	.898	85%	82%	.615
- Finding new volunteers	75%	89%	.022*	80%	80%	.966	82%	78%	.555
- Time investment required	44%	63%	.016*	51%	51%	.987	43%	53%	.233
- Legal prescriptions regarding volunteer tasks	31%	59%	<.001*	33%	50%	.018*	38%	43%	.489
- Financial costs (organisational)	22%	49%	<.001*	27%	36%	.184	20%	37%	.020*
- Integration of volunteers into the organisation	32%	23%	.208	30%	27%	.612	32%	28%	.548
Volunteer task performance									
- Mean ADL tasks performed by volunteers (0-6)				2.04	2.95	<.001*	2.29	2.64	.198
- Mean iADL tasks performed by volunteers (0-8)	2.47	3.11	.022*				2.05	3.02	.001*
- Mean PSE tasks performed by volunteers (0-5)	3.86	4.26	.040*	3.7	4.28	.001*			

^{a} ADL = Activities of Daily Living; iADL = instrumental Activities of Daily Living; PSE = Psychosocial, Signalling and Existential care tasks. ^{b} ANOVA F-tests were run for means comparisons, Chi square tests were run for proportional differences between groups. ^{c} Missings ranged from 3.4% to 7.8%. ^{d} Percentages rounded up from 0.5%.

2.3.1 VOLUNTEER PRESENCE

A total of 94% of organisations had volunteers and 80% had volunteers in direct patient care (**Table 2**). Dedicated palliative care services were most likely to have direct patient care volunteers (98%) and MODs least likely (64%). In most cases, volunteers were registered with the organisation surveyed (90%). Those with direct patient volunteers had 57 volunteers (standard deviation (SD) = 7) per 100 patients on average, PCUs had the highest average (256 per 100 patients (SD = 28)) and NHs had the lowest (33 per 100 patients (SD = 3; data not shown in tables).

2.3.2 VOLUNTEER TASKS

ADL and iADL tasks: 86% of organisations had volunteers helping with eating and 78% with lifting and moving (**Table 3**). Significant differences were found between organisation types for all ADL tasks, with sitting services on average having their volunteers perform the most ADL tasks (4.69) and NHs (1.80) ($p < 0.001$) and MODs (1.33) ($p < 0.001$) the least. Transporting patients was the most prevalent iADL task across organisations (69%), particularly in NHs (83%). Sitting services often have volunteers helping patients take medication (72%); this was rare in other organisation types. PCUs (4.26) and sitting services (3.69) on average had volunteers performing the most iADL tasks; MODs (1.40) and PHTs; (1.36) the least. (PCUs-MODs ($p < 0.001$); PCUs-PHTs ($p < 0.001$); sitting services-MODs ($p < 0.001$); sitting services-PHTs ($p < 0.001$).) PHTs had volunteers perform significantly less iADL tasks than PCUs ($p < 0.001$).

PSE: Almost all organisations had volunteers providing psychosocial care for the person who was dying (99.5%), 76% for their relatives. In 81% of organisations volunteers fulfilled a signalling function as a go-between for patients and professional caregivers and in 68% for relatives. Volunteers undertook spiritual and existential care tasks in 75% of cases; whether volunteers provide psychosocial care and signalling tasks for relatives differed significantly across organisation types, dedicated palliative care services on average undertaking the most PSE tasks (3.98) and NHs the fewest (3.55; $p < 0.001$). In 5% of organisations, volunteers performed medical and nursing tasks.

2.3.3 BARRIERS

The most cited barriers to maintaining and expanding a volunteering force were finding suitable (84%) and new (80%) volunteers, and the time investment a volunteering force requires (51%; **Table 4**). For sitting services, legal proscriptions regarding volunteer tasks (84%) were often cited. Financial costs were rarely cited except by sitting services (65%) and PHTs (57%). None of the PDCs cited financial costs as a barrier. Finally, the integration of volunteers into the organisation was identified as a barrier in 29% of organisations.

2.3.4 RECRUITMENT

Digital media (70%), current volunteers (68%) and internal printed media (e.g. monthly magazine) (67%) were the most prevalent recruitment strategies (Table 4). PDCs were the only organisation type of which the majority (80%) uses open days to recruit volunteers.

2.3.5 VOLUNTEER TRAINING

Of all organisations, 91% indicated that training in some form was offered in direct patient care; 33% provided obligatory training (**Table 5**), dedicated palliative care services most often (75%) and NHs least often (12%) ($p < 0.001$). PHTs all provided obligatory training (100%). Overall, the most frequent training subjects were ‘themes regarding specific patient groups (e.g. dementia, cancer)’ (71%), ‘the organisation’s visions and values’ (61%), ‘volunteers’ positions and roles within care’ (56%) and ‘ethics (discretion)’ (54%). ‘Basic knowledge and skills in palliative care’ were only offered by 43%, mainly PDCs and PHTs (100%). ‘Advance care planning’ was only taught in 16%, mainly PHTs (86%).

2.3.6 ASSOCIATIONS WITH VOLUNTEER USE

Organisations that had their volunteers help with more ADL ($p < 0.001$), iADL ($p < 0.05$) and PSE ($p < 0.001$) tasks than the average organisation provided significantly more training subjects to volunteers (**Table 6**). They also more often provided training regarding basic knowledge and skills in palliative care and lifting techniques. Higher-than-average volunteer deployment in ADL and PSE care were both associated with higher provision of most, and in the case of PSE care all training subjects surveyed. Higher-than-average volunteer use in ADL care was associated with higher indication of organisational barriers such as finding new volunteers ($p < 0.05$), time investment required ($p < 0.05$), legal prescriptions regarding volunteer tasks ($p < 0.001$) and financial costs ($p < 0.001$).

2.4 Discussion

2.4.1 MAIN RESULTS

Direct patient care volunteers were present in both dedicated and generalist palliative care, most often in dedicated palliative care (97%–100%) and community care services (80%–97%) but also in a majority of NHs (73%) and MODs (64%). Volunteers across all organisation types perform various palliative care tasks including practical ADL and iADL tasks, the most prominent being PSE care tasks. Dedicated palliative care and community care services stood out regarding volunteer training and training subjects provided; NHs and MODs rarely provided palliative care skills or advance care planning training. Results showed that the most important barriers to having a volunteering force were acquiring new and suitable volunteers. Organisational emphasis on volunteer PSE care was related to higher volunteer training provision, while emphasis on volunteer ADL care was related to both higher volunteer training provision and higher indication of financial and legal barriers.

2.4.2 STRENGTHS AND LIMITATIONS

This study is, to our knowledge, the first to map registered direct patient palliative care volunteering across a whole healthcare system in both dedicated and generalist palliative care. Its scope and sample frame allow observations to be generalised to the Flemish and Dutch-speaking Brussels context. While non-response was low, some bias is possible; some non-respondents may not have volunteers. In some cases, respondents may be remote from their volunteers, affecting the reliability of their responses. Although we followed a robust expert-consultation-based method to determine the sample of organisations potentially providing palliative care volunteers, there may be others with direct patient care volunteers. By focusing on registered volunteers, we potentially missed less frequent, unregistered forms of volunteering. Finally, because of our focus on the Flemish healthcare system, we did not include Wallonia and the French-speaking community in Brussels. As healthcare is differently organised in the French speaking part of Belgium, our results do not apply for palliative care volunteerism in these communities.

2.4.3 INTERPRETATION

This study yields useful insights into the current state of affairs as well as challenges and opportunities for expanding volunteerism in view of the move towards greater informal care provision. However, direct patient care volunteerism imposes challenges and requirements that should be met. Our results indicate that direct patient care volunteers are an important part of palliative care provision, existing in each organisation type surveyed. In line with the existing literature, volunteers help with daily activities and provide PSE care[30], making them complementary to professional care provision, particularly in generalist palliative care services.

Dedicated palliative care services differ internally in a few notable ways. Because palliative home-care service volunteers visit patients living at home (with help from family, friends and home nursing services) they perform fewer of the iADL tasks than full live-in facilities such as PCUs, where staff and volunteers are required to perform them. These volunteers, furthermore, often visit patients alone. This may explain the higher provision of obligatory volunteer training compared with PCUs and day-care centres, as direct supervision is less frequent than in live-in facilities where paid staff and volunteers are in close contact. PDCs were the only group from which not a single organisation indicated financial costs as a barrier. This may be because it is a semi-live-in facility where many patients still spend much time at home and where volunteers only work in the facility. Finally, PHTs provided more training in advance care planning than PCUs. This difference may be explained by the rapid turnover in units and that patients may have already gone through the advance care planning steps prior to admittance to the unit. Regardless, the high percentage of home-care teams that provides this training to volunteers is striking.

Financial costs and legal prescriptions regarding volunteer tasks were overall rarely perceived as organisational barriers for volunteer care provision in Flanders and Brussels. However, indication of these barriers was higher for organisations deploying volunteers in ADL care. Furthermore, organisations report difficulties recruiting, suggesting a key challenge is developing tailored strategies to engage potential volunteers. Given that palliative care volunteers[31,32] and volunteers in general[33] tend to be older, digital media may not be ideal for them but younger generations may be more time-constrained. It is therefore worthwhile offering flexible, well-defined volunteering roles to suit all age groups.

Aside from recruitment, appropriate support and training are crucial. Stronger emphasis on volunteer ADL care and stronger emphasis on volunteer PSE care were both associated with higher training provision. In addition to the higher indication of barriers mentioned above, this suggests that some forms of volunteer use are more resource-heavy than others. Despite increased training requirements, NHs and MODs consistently scored the lowest on 9 of the 12 surveyed training subjects, including 'basic knowledge and skills in palliative care', 'volunteer needs' and 'advance care planning', while their volunteers still perform many of the same care tasks as dedicated palliative care services.

Despite the historical dependence of NHs on informal caregivers in Belgium and problems of understaffing[34,35], NH volunteers receive little training and perform relatively fewer ADL and PSE tasks. NHs may therefore not provide their volunteers with the required support for their tasks and may not employ volunteers efficiently with regard to quality of care. Investing in proper support frameworks in coordination with palliative professionals to train and support volunteers in their provision of direct patient care is therefore recommended. Employing volunteers does not remedy underlying problems of understaffing and lack of funding; however, their presence, when appropriately supported, may relieve stress on staff and increase quality of care and well-being for patients. The development of tension between professional caregivers and volunteers is not yet fully understood, however, and warrants further research into this subject.

To address recruitment and training issues, policy makers may consider a shared framework – a network connecting organisations providing palliative care, coordinated by a regional, national or perhaps even European[36] umbrella organisation – through which volunteers may be recruited and introduced to different healthcare organisations according to individual profiles. The palliative networks in Belgium function regionally and recruitment efforts between organisations are not well coordinated. Frameworks should therefore be designed to expedite coordination and could incorporate standard, context-sensitive training in palliative direct patient care. This could also stimulate locally led community development programmes organised around local NHs, PDCs or regional palliative network[37]. The Compassionate Neighbours project in London, UK, is an example of such a programme[38].

However, the underlying causes for the problems with volunteer recruitment may differ according to the care setting. Future research should investigate these causes within different organisational settings. It should also study the characteristics of palliative care volunteerism at the volunteer level as a contrast with organisational data. International comparative data could indicate whether findings can be generalised to different countries and provide benchmarking opportunities for countries and communities with regard to their palliative care volunteer potential and challenges.

2.5 Conclusion

Volunteers provide palliative direct patient care in both dedicated and generalist palliative care services. They are extensively used in dedicated palliative care and community care settings, providing PSE care as well as more supportive tasks, and are provided with a wide range of training. A narrower approach, with fewer tasks, less training and less focus on interactions with residents, health professionals and relatives, is taken in other settings, such as NHs and MODs. Differences in volunteer use may explain reported organisational barriers and training provision. Given the partial shift from professional to community care provision at the end of life in some countries, policy makers may draw on the insights in this paper in developing policy for healthcare organisations providing palliative care.

2.6 Declarations

2.6.1 ACKNOWLEDGEMENTS

The authors thank **Thijs Reyniers**, who provided the Excel template to track questionnaire mail-out and response, **Jane Ruthven**, who performed language editing of the manuscript, **all volunteer coordinators and organisational representatives** of Flemish and Brussels healthcare organisations, who provided data on their organisation or coordinated data gathering in the organisations under their jurisdiction, and **all experts** from different healthcare organisations in Flanders and Brussels, who participated in our expert consultation.

2.6.2 DATA MANAGEMENT AND SHARING

The data of this study are with the first author and are available upon request.

2.6.3 DECLARATION OF CONFLICTING INTERESTS

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

2.6.4 FUNDING

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the Agency for Innovation by Science and Technology (IWT) as part of the INTEGRATE-project (SBO-IWT 140009).

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3 CHAPTER 3: THE CONTRIBUTION OF AND SUPPORT FOR VOLUNTEER PALLIATIVE CARE: A HEALTHCARE SYSTEM-WIDE SURVEY OF VOLUNTEERS

Steven Vanderstichelen, Joachim Cohen, Yanna Van Wesemael, Luc Deliens, Kenneth Chambaere

Submitted to *International Journal of Nursing Studies* 2019 (in review)

Abstract

Partly due to increasing resource constraints in professional healthcare, some governments are turning to informal caregivers such as volunteers to relieve professional healthcare by providing increased shares of palliative care (PC). Volunteers are an important resource for communities to bridge PC services and the community. However, to date, no studies have systematically mapped volunteers' actual contributions to PC provision and how well they are supported by and within different healthcare services at the individual volunteer level. Such insights are important in order to shape and optimize supportive environments for volunteering in PC. This study provides a description of current organised volunteering practices in PC across dedicated PC services and healthcare services providing generalist PC, in terms of tasks, training, supervision and how volunteers evaluate these. A cross-sectional postal survey of 2273 volunteers from healthcare organisations providing care for people with serious illnesses in the Flemish healthcare system (Belgium) was conducted between June and November 2018. A two-step cluster randomised sample was used, in which volunteers were recruited through their respective volunteering organisations. Response was obtained for 801 (35.2%) volunteers. Volunteers were predominantly women (76.5%), retired (70.8%), aged 60-69 (43.2%) and had a secondary degree (46.7%). Volunteer activities took two approaches: 'multidimensional' or 'practical' support. 'Multidimensional' support represented broad task performance, but emphasised psychosocial, existential and signposting tasks. 'Practical' support represented narrow task performance, emphasising nursing tasks. Structured ($p=.001$) and group ($p<.05$) supervision and volunteer role training ($p<.001$) were positively related to multidimensional support. Multidimensional support was most prevalent among dedicated PC volunteers, while practical support was most prevalent among sitting service volunteers. Results indicate that volunteers can offer complementary support for patients with serious illnesses, although this will require training and consistent supervision. This is currently suboptimal for volunteers in nursing homes and community home-care.

Key words
Volunteering; palliative care; Surveys and questionnaires; training; tasks; public health

3.1 Introduction

Partly due to increasing resource constraints in professional healthcare, some governments are turning to informal caregivers such as volunteers to relieve professional healthcare by providing increased shares of palliative care[1–5]. Palliative care is a family-centred model based on individual needs that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness[6]. It identifies and treats symptoms which may be physical, emotional, spiritual or social. Volunteers have a long history of supporting palliative care and have played an important role since the early days of the palliative care movement. They continue to be involved in palliative care provision, both in the community and in institutional settings[7–10].

Research has widely documented the organisational perspective on volunteering, describing the presence of volunteers, turnover rates, task performance and training they receive[9,11–14], as well as involvement in the organisation of care[15] and the roles and position of volunteers in palliative care[16–20]. Volunteers have also been shown to positively influence the quality of care for terminally ill people and those close to them by reducing stress and offering practical and emotional support and providing a link to the community[9,21–23]. Previous studies have considered palliative care volunteering from the organisational and professional perspective; however, no study has hitherto reported on volunteers' actual contribution to palliative care provision and the support they receive from their organisations at the individual volunteer level reported by volunteers themselves. Furthermore, to our knowledge, no studies have hitherto surveyed volunteers' evaluations of their tasks, training, and supervision.

If governments wish to offset the current resource constraints in professional healthcare by increasing informal care provision, including volunteer care, insights into the supportive capacity of volunteers to be involved in palliative care and the type of palliative care tasks volunteers are confronted with, are necessary. Organisations' and professionals' reports on volunteer contributions to care and the support they provide volunteers for these contributions provide only a partial picture. The full extent of this capacity is also shaped by the extent to which volunteers are sufficiently supported in their current practices. To evaluate this capacity, an extensive description of volunteers' reports and evaluations of their tasks, training and supervision is required.

3.2 Objective

To address these knowledge gaps, this study provides a description of current organised volunteering practices in terms of tasks, training and supervision and how volunteers evaluate these in palliative direct patient care across dedicated and generalist palliative care services. The research questions are:

1. What are the demographic characteristics of palliative care volunteers?
2. What is the contribution in terms of task performance by volunteers in palliative care and their evaluation in terms of time spent?
3. To what extent are volunteers supported, in terms of training and supervision in performing these tasks?

3.3 Method

We conducted a cross-sectional postal survey between June and November 2018 among volunteers from healthcare organisations providing care for people with terminal illnesses towards the end of life – though not necessarily in the terminal stage – in the Flemish healthcare system. The Belgian regions (Flanders, Wallonia, and Brussels) have autonomy over various aspects of healthcare in the different language communities (Dutch, French, and German speaking), including home-care, hospital care and long-term care. The Flemish government is therefore responsible for these aspects in Flanders and for the Dutch speaking community in Brussels. We therefore included (volunteers in) healthcare organisations in Flanders and Dutch speaking Brussels in this study and excluded Wallonia as it falls under a different regional authority and the organisation of palliative care differs on the regional level. Other reasons for exclusion include the added analytical complexity resulting from strong differences in context and language differences. In 2018 the Flemish region and the Brussels region had respective populations of 6,552,967 and 1,198,726 – 46.850 of which are estimated to speak Dutch[24] – inhabitants, accounting for 68% of the total Belgian population[25].

3.3.1 DEFINITIONS

We define volunteerism in palliative care as

> *the time freely given by individuals, with no expectation of financial gain, within some form of organised structure other than the already existing social relations or familial ties, with a palliative approach, i.e. the intention of improving the quality of life of adults and children with terminal illnesses and those close to them (family and others). (Adapted from Goossensen et al.*[26]*)*

Volunteers do not have an employment contract or statutory appointment within the organisation in which they perform these tasks; they are, however, officially registered with the organisation. This definition is in accordance with that provided by the Belgian federal law[27,28]. We focus on *community volunteers* in *direct patient care*, i.e. members of the local community who work in care-focused roles and are regularly involved with patients and those close to them, provided they are not merely performing their medical profession unpaid[26]. Lastly, we focus on volunteers who fit this definition and provide care for people with terminal illnesses and their relatives. This definition was incorporated into our questionnaire.

3.3.2 POPULATION AND SAMPLE

The population for this study consists of all registered volunteers in a selection of healthcare organisations in Flanders and Dutch-speaking Brussels (Belgium), as determined by a previous study[14,15], which deploy volunteers in direct patient care for people with serious illness. Because palliative care is not only provided in dedicated palliative care services but also in certain generalist care services, we included volunteers from the latter setting. Listings of these organisations were provided by the Flemish ministry for Welfare, Public Health and Family[29]. Because of the resulting multitude of healthcare organisations, types and large numbers of volunteers, and given the lack of a central register of volunteers, determining a representative sampling framework was complicated considerably. This necessitated a two-step sample procedure, resulting in a disproportionately stratified cluster random sample of volunteers. See **Box 3.1** for the list of strata and descriptions, and total clusters (i.e. individual organisations) per strata. Based on estimates of average total volunteers per stratum and per cluster, obtained from a previous study[14,15], a required sample size was calculated for each stratum, assuming a 5% margin of error and ∝= 0.05 (for a finite population). Assuming a response rate of 70% a required total of clusters per stratum was estimated. This meant a total of 44 clusters across all strata for an estimated total of 2115 volunteers. See **Appendix 3.1** for details on the sampling procedure.

Box 3.1: Strata from which clusters were sampled[a]

1. **Dedicated palliative care services (N=44)** are services that specialize in palliative care treatment for people with chronic, life-threatening conditions towards the end of life. This stratum therefore consists of (1) palliative care units (PCU) in (or associated with) hospitals (N=25)), (2) palliative daycare centres (PDC) (N=5), and (3) palliative home-care support teams (PHT) (N=14), which are part of the regional palliative networks and provide support for other caregivers in home or replacement home situations.
2. **Medical oncology departments (MOD) (N=16)** are hospitals departments with a fully established oncology care program, a hospitalization program and a multidisciplinary team focused on oncology. Care provision may both be curative as well as palliative.
3. **Facilities for sitting services (N=32)** organize sitting services by volunteers during the day or at night. The facility sends a volunteer to people's homes to keep them company, give them a sense of security and basic care. They offer respite care and function similar to befriending services.‡
4. **Volunteer community home-care organisations (CHC) (N=8)** are organized by the Christian Sickness fund (*Christelijke Mutualiteit*). Their services are locally organized and run by volunteers who pay home visits to the elderly and patients with heavy care needs in their neighborhoods. Not all people who receive visits suffer from chronic, life-threatening conditions, but many of them may.
5. **Nursing homes (NH) (N=105)** offer permanent care and nursing to elderly people. A resident of a residential care centre has his or her own room or living space there. Nursing homes may house residents with chronic, life-threatening conditions.

[a]Descriptions fully or partially taken from the Agency for Health and Care website[29]. [b]See Walshe et al.[30]

3.3.3 ETHICAL APPROVAL

The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Brussels. (ref. B.U.N. 143201835145) Approval was granted on April 04, 2018.

3.3.4 DATA COLLECTION

Data was collected using a written questionnaire, developed by the researchers for this study and addressed to the volunteers in each cluster. Questionnaires were sent to the volunteers by the organisations upon agreeing to participate in the study and volunteers and their corresponding questionnaires were codified so the researchers could track response without collecting individual names and addresses. Clusters were resampled upon refusal, following the same sampling method as before, and efforts were made to document reasons for refusal to assess bias. One sitting service was resampled because their volunteers did not speak Dutch; one community home-care service was resampled due to refusal after prior agreement to participate (no reason given). Upon acceptance to participate, the exact number of volunteers in the organisation was registered and all present volunteers were included for the survey – with the exception of community home-care services which had too many volunteers and where we drew a random sample of volunteers. A data collector (FS) coordinated the recruitment of clusters via phone or e-mail and facilitated data collection by visiting each cluster to facilitate the survey mail-out in collaboration with volunteer coordinators. Our total N for this survey was 2420. Questionnaires were mailed out throughout June 2018. In September a reminder was sent to volunteers who had not yet responded and in October a non-response survey was sent to those who had still not responded. The non-response survey consisted of three questions to gauge the reasons for non-response. Data collection was concluded in November 2018. No personal information was collected, ensuring anonymity.

3.3.5 QUESTIONNAIRE

The questionnaire, developed specifically for this study, consisted of 23 questions, including on *volunteer tasks*, *volunteer training*, *volunteer supervision, frequency and intensity of volunteer work*, *contact with patients with chronic and life-threatening illnesses*, and *demographic information*. The questionnaire was developed based on the literature on volunteering in palliative care and the questionnaire used in a previous organisational survey on volunteering[14,15]. The questionnaire was cognitively tested in two rounds with volunteers in palliative care in order to identify conceptual difficulties in the questions. Volunteers were asked to report the tasks they performed during their most recent session of volunteering for a person with a chronic and/or life-threatening condition, if that session had taken place in the last 12 months. A session was defined as one shift of volunteering or, in the case of home-care, one visit. All other questions referred to their volunteering within their current organisation (i.e. the organisation through which they had received their questionnaire) in general. See **Appendix 3.2** for more details on the questionnaire.

3.3.6 ANALYSIS

We performed uni-, bi- and multivariable analysis using IBM SPSS 25. Cross-tabs were run to calculate proportions for each variable for volunteers from different organisation types. Percentages were rounded. Chi-square tests were performed to check for statistical differences in proportions between volunteers from different organisation types. Significance at p=0.05 or lower was indicated with an asterisk (*). Analysis of variances (ANOVAs) were conducted to test for associations between mean scores of different variables. Categorical Principal Components Analysis (CATPCA) was conducted on the variables for task performance to identify types of volunteer sessions by reducing the original set of variables into a smaller set of uncorrelated components. CATPCA was also conducted on the variables for volunteer training, to identify types of training volunteers have. (**See Appendix 3.3 tables 3-4 for details.**) Questions measuring task performance were divided into six item batteries, each representing a different group of tasks. When one or more, but not all, modules had missing responses, it was assumed respondents had missed or failed to check off the 'none of the above' item for that item battery. Responses were then recoded during data cleaning to check off the latter option as they were not considered real missings. Remaining missings were removed from analyses (listwise).

3.4 Results

Out of a total of 2420 surveyed volunteers, a response was received from **801.** Non-eligible (e.g. in case of overestimation of volunteers per cluster) were subtracted from the sample denominator, bringing the N down to 2273. Two clusters were resampled. In accordance with the guidelines set by the AAPOR[31], we came to a valid response rate of 35.2% (801/2273). (**Table 1**). Response was highest from volunteers from medical oncology departments and dedicated palliative care services. The total response rate was offset by the low response from volunteers from community home-care services, sitting services and nursing homes. Out of 1488 non-response surveys sent, 31 were returned (2.08%). 10.3% indicated no longer or not being a volunteer, 24.1% indicated not providing care for people with chronic and life-threatening conditions as a volunteer, 31.0% indicated never having received the questionnaire and 10.3% indicated they returned it, but it never reached us. 17.2% indicated time constraints for not participating.

Table 1: Survey response

Recruitment settings	Cluster total	Sample total (volunteers)	Response	Response rate[a,b]
Total	**42[c]**	**2273**	**801**	**35.2%**
Dedicated palliative care services	17	502	280	55.8%
Palliative care units	12	329	184	55.9%
Palliative daycare services	1	59	27	45.8%
Palliative Home-care Teams	4	114	69	60.5%
Medical oncology depts.	10	101	61	60.4%
Sitting services	4	676	233	34.5%
Community home-care	1	530	81	15.3%
Nursing homes	10[3]	483	144	29.8%

[a] Calculated with the AAPOR non-response calculator tool (AAPOR, 2017).

[b] The questionnaire consisted of 161 individual items to be completed (optional items excluded). The completion rate for 0 missings was 29.0%; the completion rate for <10% missings – corresponding to <17 individual item missings – was 82.3 %.

[c] 10 of the 12 contacted clusters in the nursing home strata provided a response. For all other clusters we have at least one volunteer response.

Table 2: Volunteer demographics, Flanders and Dutch-speaking Brussels, Belgium, 2018

Total N[a,b]	**801**
Volunteers in direct patient care (%)[c]	83.3
Gender (%)	
Male	24.5
Female	75.5
Age (%)	
<49	6.9
50 – 59	15.4
60 – 69	43.4
70+	34.2
Employment status (%)	
Student or unemployed	9.9
Employed (part- or fulltime)	12.2
Retired	70.8
Sick-leave	5.8
Other	1.4
Highest attained diploma (%)	
None or primary (lower or higher)	6.6
Secondary education (lower or higher)	46.7
Professional bachelors’	29.4
Academic bachelors’, masters' or PhD degree	17.3
Volunteering activity	
Years active in current organisation (%)	
<1 year	7.6
1 - 2 years	12.5
3 - 5 years	23.0
6 - 10 years	21.0
> 10 years	36.0
Volunteer sessions per week (mean)	1.70
Hours per volunteer session (mean)	4.63
Hours per week (sessions x hours)	7.87

[a] Missings ranged from 1.0% to 5.0%.
[b] See Appendix 3.3 Table 1 for demographics per organisation type.
[c] Total number of volunteers that indicate coming into personal contact with at least one person with chronic and/or life-threatening conditions during their volunteer work in the past 12 months.

Table 3: Tasks performed by volunteers in different organisations during their last session with a patient with chronic and/or life-threatening conditions, Flanders and Dutch-speaking Brussels, Belgium, 2018

	Total[c]	Dedicated PC	Medical oncology	Sitting services	Community home care	Nursing homes	p-value[d]
Number of volunteers[a,b]	**n=584**	n=268	n=59	n=156	n=47	n=52	
Practical care tasks, any[e]	**80.2**	88.7	27.1	87.0	73.2	85.7	<.001*
Help with shifting and movement	**60.4**	69.8	8.5	74.0	41.5	49.0	<.001*
Feed patients	**46.2**	61.9	23.7	39.7	26.8	24.5	<.001*
Wash, clean, clothe, help with bathroom visits	**28.5**	32.8	0.0	40.4	26.8	6.1	<.001*
Prepare food, do groceries or chores	**28.3**	46.0	5.1	18.5	9.8	6.1	<.001*
Help patients take prepared medication	**24.1**	22.6	3.4	41.1	22.0	8.2	<.001*
Transport patients	**22.1**	22.3	6.8	15.1	36.6	49.0	<.001*
Help with phone use or managing finances	**4.5**	3.8	1.7	7.5	4.9	2.0	0.377
Psychosocial tasks for patients, any[e]	**96.3**	97.4	98.3	95.9	92.7	91.8	0.328
Being there (being present, active listening, having conversations)	**90.4**	94.0	96.6	89.0	85.4	71.4	<.001*
Provide leisure/relaxation	**56.3**	56.2	37.3	66.4	46.3	57.1	0.004*
Actively gauge the needs and wishes of the person	**41.0**	45.3	32.2	49.3	29.3	14.3	<.001*
Be with the patients in the last days of life	**29.1**	44.5	13.6	19.2	14.6	4.1	<.001*
Psychosocial tasks for patient relatives, any[e]	**74.5**	81.9	81.4	74.0	56.1	44.9	<.001*
Being there for the relatives (being present, active listening, having conversations)	**67.4**	75.5	79.7	62.3	53.7	36.7	<.001*
Provide leisure/relaxation	**35.8**	41.5	23.7	42.5	19.5	14.3	<.001*
Actively gauge the needs and wishes of the relatives	**26.7**	32.1	23.7	27.4	22.0	4.1	0.003*
Be with the relatives during their time of grieving	**23.7**	37.0	8.5	14.4	14.6	6.1	<.001*
Spiritual / existential tasks, any[e]	**58.8**	72.5	61.0	49.3	41.5	24.5	<.001*
Talk about fear of death and dying	**37.1**	49.8	47.5	24.7	19.5	6.1	<.001*
Talk about meaningful relationships	**34.2**	38.9	39.0	32.2	26.8	14.3	0.010*
Talk about accepting death and dying	**33.0**	40.8	37.3	26.7	19.5	14.3	<.001*
Help with farewell rituals	**7.7**	12.1	3.4	3.4	7.3	2.0	0.011*
Prepare the funeral	**2.7**	2.6	1.7	2.7	4.9	2.0	0.955
Signposting tasks, any[e]	**81.3**	89.8	84.7	72.6	82.9	57.1	<.001*
Signal the needs and wishes of the patient to other caregivers	**63.5**	82.6	52.5	48.6	43.9	34.7	<.001*
Be a confidant of the patient	**35.1**	26.0	49.2	42.5	63.4	22.4	<.001*
Signal the needs and wishes of the relatives to other caregivers	**33.9**	49.8	20.3	24.7	14.6	8.2	<.001*
Be a confidant of the relatives	**22.5**	19.6	28.8	29.5	29.3	4.1	0.004*
Refer patients to other caregivers or care services	**20.1**	23.0	30.5	13.7	22.0	10.2	0.029*
Refer patient relatives to other caregivers or care services	**17.1**	19.6	22.0	15.8	9.8	8.2	0.227

Table 3: Continued

Nursing tasks, any^{e}	**43.9**	45.7	1.7	63.7	43.9	26.5	<.001*
Moving and lifting operations	**30.1**	35.8	0.0	36.3	29.3	18.4	<.001*
Helping a patient go to the toilet (while not in the presence of a professional caregiver)	**28.9**	23.8	1.7	56.2	24.4	12.2	<.001*
Give other medication	**11.8**	8.3	0.0	26.0	12.2	2.0	<.001*
Non-pharmacological pain and symptom control (e.g. mindfulness, massages)	**10.2**	15.8	0.0	7.5	9.8	0.0	<.001*
Give analgesic medication	**7.8**	3.8	0.0	20.5	9.8	0.0	<.001*
Other (treating light wounds, placing infusions or probes, first aid/resuscitation, patient ventilation)	**3.6**	1.9	0.0	8.9	4.9	0.0	0.002*

[a] Total number of volunteers that indicate coming into personal contact with at least one person with chronic and/or life-threatening conditions during their volunteer work in the past 12 months.[b] Missings were 3.9% and were excluded (listwise) from the analysis. [c]For two questionnaires it was not possible to determine which organisation type the volunteer was working in. [d]Two-tailed Chi-Square analysis was done to check for significant differences between volunteers from different organisation types. [e]Percentage of volunteers that performed at least one task from this category. *Significance at $p = 0.05$ or lower.

Table 4: Differences in training and supervision received between volunteers from different organisations, Flanders and Dutch-speaking Brussels, Belgium, 2018

	Total[c]	Dedicated PC	Medical oncology	Sitting services	Community home care	Nursing homes	**p-value**[d]
Number of volunteers[a,b]	n=**550**	n=257	n=57	n=154	n=46	n=34	
Obligatory training required by volunteers organisation (%)	**61.5**	89.7	76.7	39.9	20.8	14.3	<.001*
Themes volunteers report being trained in, any (%)	**91.5**	97.8	94.9	92.7	81.1	61.5	<.001*
The position and roles of volunteers in care	**68.4**	81.5	83.1	62.0	45.3	28.8	<.001*
Ethics (discretion, privacy)	**55.6**	70.7	76.3	40.2	43.4	19.2	<.001*
Palliative care	**53.7**	90.0	37.3	27.4	20.8	7.7	<.001*
Vision and values of the organization	**52.9**	63.0	66.1	43.0	47.2	25.0	<.001*
Guarding personal and professional boundaries	**50.4**	61.5	74.6	42.5	37.7	5.8	<.001*
Moving and shifting techniques	**46.3**	45.6	13.6	66.5	43.4	21.2	<.001*
Communication skills	**45.7**	54.8	71.2	31.3	45.3	19.2	<.001*
Communicating patient information to other caregivers	**45.7**	54.8	71.2	31.3	45.3	19.2	<.001*
(Hand)hygiene	**42.2**	50.4	62.7	34.3	18.9	26.9	<.001*
The care offered by the organization	**40.3**	38.9	47.5	50.3	39.6	5.8	<.001*
Themes regarding specific patient groups	**33.8**	22.2	40.7	58.7	22.6	11.5	<.001*
Advance Care Planning	**11.9**	14.8	6.8	12.3	9.4	3.8	0.125
Training patients and their relatives in self-care	**6.2**	7.4	6.8	5.6	5.7	1.9	0.647
Mean training received (0-13)	***5.57***	*6.37*	*6.61*	*5.04*	*4.49*	*2.39*	<.001*[e,f]
Mean training evaluation score (1-5)	***3.97***	*3.98*	*4.25*	*3.94*	*3.93*	*3.71*	0.008*[e]
Supervision received from organisation (%)	**83.7**	89.5	89.3	80.1	64.7	78.6	0.001*
Lack of supervision was problematic (%)	**1.8**	1.5	1.8	2.3	2.0	1.8	
Characteristics of supervision							
At fixed times	**84.2**	89.9	84.0	80.3	93.8	59.1	<.001*
Ad hoc	**83.8**	87.8	74.0	82.4	71.9	86.4	0.040*
Individual supervision	**74.4**	81.1	66.0	74.8	52.9	63.6	0.001*
Group supervision	**94.1**	96.2	92.5	92.3	100.0	86.4	0.041*
Mean supervision evaluation score (1-5)	***3.87***	*3.94*	*3.97*	*3.87*	*3.65*	*3.66*	0.025*[6]

[a] Total number of volunteers that indicate coming into personal contact with at least one person with chronic and/or life-threatening conditions during their volunteer work.[b] Missings ranged from 2.1% to 7.0% and were excluded (listwise) from the analysis. [c] For two questionnaires it was not possible to determine which organisation type the volunteer was working in. [d] Two-tailed Chi-Square analysis was done to check for significant differences between volunteers from different organisation types. [e] ANOVA F-tests were done to test for changes in means. [f] Homogeneity of variances test failed. Differences in means between volunteers from different organisations were significant for Games-Howell post-hoc test, with exception of the mean differences between volunteers from dedicated PC and Medical Oncology and between Sitting services and community home care. See Appendix III table 5 for multiple comparisons. *Significance at $p = 0.05$ or lower.

Table 5: Associations of organisation type, supervision types and received training types with types of volunteering sessions, Flanders and Dutch-speaking Brussels, Belgium, 2018

			Type of volunteer session[d]			
			Multidimensional support (Cronbach's Alpha = 0.870)		**Practical support (Cronbach's Alpha = 0.642)**	
			Mean factor scores[e]	**p-value[f]**	**Mean factor scores[e]**	**p-value[f]**
Total (N[a,b])		580[c]	0.0000	/	0.0000	/
Organisational setting[g]		**%**				
Dedicated PC (N=268)		46.4	0.2619	<.001*	-0.1712	<.001*
Medical oncology (N=59)		10.2	-0.4623		-0.8651	
Sitting services (N=152)		26.3	0.0856		0.5560	
CHC (N=47)		8.1	-0.2873		0.1146	
NH (N=52)		9.0	-0.8044		0.1509	
Supervision						
Fixed (N=467)[h]	Yes	84.6	0.1153	0.001*	-0.0312	0.931
	no	15.4	-0.3065		-0.0199	
Ad hoc (N=467) [h]	Yes	83.1	0.0652	0.471	-0.0468	0.415
	No	16.9	-0.0229		0.0559	
Individual (N=471) [h]	yes	75.4	0.0845	0.192	-0.0332	0.996
	no	24.6	-0.0535		-0.0327	
Group (N=471)[h]	Yes	94.7	0.0731	0.036*	-0.0401	0.523
	No	5.3	-0.3515		0.0931	
Training types			Kendall's tau[i]		Kendall's tau[i]	
Volunteer role training **(Cronbach's Alpha = 0.811)**			0.244	<.001*	-0.118	<.001*
Instrumental nursing training **(Cronbach's Alpha = 0.268)**			0.212	<.001*	0.217	<.001*

[a] Number of volunteers that indicate coming into personal contact with at least one person with chronic and/or life-threatening conditions during their volunteer work.

[b] Missings ranged from 0.8% to 1.4% and were excluded (listwise) from the analysis.

[c] For two respondents it was not possible to determine which organisation type the volunteer was working in.

[d] Mean scores indicate how strongly on average volunteers score on the corresponding type of volunteer session. Positive mean scores indicate positive association with this type of volunteer session, negative scores indicate that volunteers are on average less associated with this type of volunteer session.

[e] CATPCA conducted on volunteer task variables resulted in two dimensions, the object loadings of which were saved as variables. Object scores can be negative or positive and their absolute value indicates how strongly volunteers score on each dimension.

[f] ANOVA F-tests were done to test for changes in means.

[g] The assumption of homogeneity of variances was violated. See Appendix 3.3 Table 6 for Games-Howell Post-hoc tests.

[h] Subset of total N of volunteers that also indicated receiving supervision. Total N for this subset was 504.

[i] Two-tailed Kendall's tau tests were calculated to test for correlations between dimensions, their direction and intensity. *Significance at *p* = 0.05 or lower.

3.4.1 VOLUNTEER CHARACTERISTICS

Volunteers were predominantly women (75.5%), between the age of 60 and 69 (43.4%), retired (70.8%) and 46.7% had a secondary school degree. **(See Table 2.)** The majority of volunteers had been volunteers in their current care organisation for at least 6 years (57%), with 36.0% having been active for more than 10 years. Volunteers had on average 1.70 volunteering sessions per week, in which an average of 4.63 hours of volunteering were performed, resulting in a mean total of 7.87 hours of volunteering per week. 83.3% of volunteers provided direct patient care to at least one person with serious illness in the last 12 months.

3.4.2 VOLUNTEER CONTRIBUTIONS – TASK PERFORMANCE

During their last session with a patient with serious and/or life-threatening conditions, the majority of volunteers (80.2%) performed at least one practical care task during their last session, with the exception of medical oncology volunteers (27.1%). **(See Table 3.)** Most volunteers performed psychosocial tasks for patients (96.3%) and many performed these for patient relatives too (74.5%). 29.1% of volunteers indicated being with patients in the last days of life, including volunteers in sitting services (19.2%), medical oncology (13.6%) and community home-care (14.6%). Existential care tasks were performed most by volunteers in dedicated palliative care services (72.5%), but also by many medical oncology (51.0%), sitting service (49.3%), and community home-care (41.5%) volunteers. 43.9% of volunteers indicated performing at least one nursing task during their last session with a patient with chronic and/or life-threatening conditions. 30.1% of volunteers had performed moving and lifting operations, 28.9% of volunteers had helped a patient go to the toilet without a nurse present, and some volunteers administered analgesic (7.8%) or other medication (11.8%). Nursing tasks were rarely performed by medical oncology volunteers (1.7%). While most volunteers considered their time spent on each of these types of tasks sufficient, 26.1% of nursing home volunteers and 14.3% of community home-care volunteers indicated not enough time was spent on signposting tasks (p<.05). **(See Appendix 3.3, table 2.)**

3.4.3 VOLUNTEER SUPPORT: TRAINING

Of those volunteers who came into personal contact with people with serious illness during their volunteer work, 91.5% indicated having some type of training related to their volunteering work, with volunteers from dedicated palliative care services indicating this most often (97.8%) and nursing home volunteers the least (61.5%). **(See table 4.)**

Hospital settings – i.e. palliative care services (89.7%) and medical oncology (76.7%) – required obligatory training from volunteers significantly more often than other care organisations. Nearly all dedicated palliative care volunteers (90.0%) indicated being trained in palliative care, however, less than half of volunteers in generalist palliative care services indicated having had this training, with nursing homes having the least volunteers with palliative care training (7.7%). While a majority of volunteers in dedicated palliative care services (54.8%) and medical oncology (71.2%) were also trained in communicating patient information to other caregivers, volunteers from other health service types reported this type of training proportionately less often. Dedicated palliative care (70.7%) and medical oncology (76.3%) volunteers had significantly more training in ethics than volunteers of other care organisations. (p<.001) Volunteer training regarding specific patient groups was generally low (33.8%), with the exception of volunteers in sitting services (58.7%) and medical oncology (40.7%). Nursing home volunteers on average reported having the least training (2.39), dedicated palliative care (6.37) and medical oncology volunteers (6.61) the most. Medical oncology volunteers evaluated their training better than other volunteers (4.25/5), nursing home evaluated theirs lowest (3.71/5).

3.4.4 VOLUNTEER SUPPORT: SUPERVISION

Community home-care volunteers received the least supervision from their organisation (64.7%), volunteers in dedicated palliative care services the most (89.5%). **(See table 4.)** Supervision was provided both at fixed times (84.2%) and ad hoc (83.8%) for most volunteers, however nursing home volunteers reported bigger differences between both types of supervision at the aggregate level and more often reported ad hoc supervision (86.4%) than at fixed times (59.1%). Similarly, community home-care organisations reported more fixed supervision moments (93.8%) than ad hoc (71.9%). Volunteers reported group supervision (94.4%) more often than individual supervision (74.4%) across organisation types. Medical oncology volunteers rated the supervision from their organisation highest (3.97/5), community home-care volunteers lowest (3.65/5).

3.4.5 ASSOCIATION BETWEEN TASK PERFORMANCE, TRAINING AND SUPPORT

CATPCA analysis conducted on volunteer tasks revealed two volunteer session types (**See Appendix 3.3 tables 3-4.**) The first type of session was called 'multidimensional support' (Chronbach's Alpha = 0.870) because it included all types of tasks, emphasising psychosocial, existential and signposting tasks. The second type of session was called 'practical support' (Cronbach's Alpha = 0.642) because it emphasised practical and nursing tasks. CATPCA analysis conducted on training variables revealed two volunteer training types. (**See Appendix 3.3.**) The first type was called 'volunteer role training' (Cronbach's Alpha = 0.810), because it focused on the position and roles of volunteers in care, ethics, palliative care, communication, guarding personal and professional boundaries, the vision and values of the organisation and the care provided by the organisation. The second type was called 'instrumental nursing training' (Cronbach's Alpha = 0.216), because it focused mainly on moving and lifting techniques and educating patients and their relatives in selfcare. Sessions from dedicated palliative care volunteers were more pronounced multidimensional (i.e. higher average scores on this dimension), sessions from sitting service volunteers tended to emphasise practical support. **(See Table 5.)** Volunteers that received supervision at fixed times (p=.001) and in group (p<.05) or that had received volunteer role training (p<.001) or instrumental nursing training (p<.001) were more likely to provide multidimensional support in their sessions. Volunteers that had received instrumental nursing training were also more likely to have provided practical support in their last session (p<.001) and volunteers that had received volunteer role training (p<.001) are less likely to have provided multidimensional support in their last session.

3.5 Discussion

3.5.1 MAIN RESULTS

Nearly all volunteers across a variation of healthcare organisations occasionally provide care for people with chronic and life-threatening conditions. Two types of volunteer sessions could be distinguished: (1) 'multidimensional support' representing broad task performance, emphasising psychosocial, existential and signposting tasks; and (2) 'practical support', emphasising nursing tasks.

Dedicated palliative care volunteers were more likely to perform multidimensional support and sitting service volunteers were more likely to perform practical support. Nursing home volunteers had the least training compared to other volunteers and rated it lowest. Community home-care volunteers receive the least supervision and also rated their supervision the lowest, but almost no volunteers perceived the lack of supervision as problematic.

3.5.2 STRENGTHS AND LIMITATIONS

This study is, to our knowledge, the first to examine organised, direct patient palliative care volunteering across the healthcare system in both dedicated and generalist palliative care at the individual volunteer level. This study complements the existing literature reporting on palliative care volunteering at the organisational level by offering an extensive description at the individual volunteer level. It also complements earlier studies limited to dedicated palliative care volunteering[17,32–34] by focusing on both dedicated and generalist settings. Response for dedicated PC services and medical oncology departments were fairly high. Lower response rates from certain types of volunteers, such as those in nursing homes and community home-care, imply possible issues of statistical generalisation and, hence, that results for these particular organisational types should be interpreted with caution. Strongly involved volunteers may be overrepresented in these strata. However, our results confirm the findings from a previous organisational study of palliative care volunteering[14,15] and are contextualised by previous qualitative studies of volunteering in these settings[20], indicating validity of our current conclusions. Data were collected via the healthcare organisations with the health service coordinators functioning as intermediates in the data collection. This was a necessary step as there is currently no central register of volunteers in Belgium, but it complicated the control over the follow-up process.

3.5.3 INTERPRETATION

Our results indicate that a majority of direct patient care volunteers in generalist care settings with patients with serious illnesses also provide palliative care. The types of volunteering sessions identified in this paper indicate two approaches to volunteering in palliative, direct, patient care. The first approach represents a *complementary* approach. It is characterised by multidimensional support, which emphasises all-round care according to patient needs, structured and group supervision, and is related to comprehensive training. The approach offers a "broad" interpretation of the volunteer role, appearing to address an unmet need in palliative care and mainly present among volunteers in dedicated palliative care services. The second approach represents a *substitutive* approach characterised by an emphasis on practical and nursing tasks specifically and is related to instrumental nursing support training. The approach offers a "narrow" interpretation of the volunteer role and could be addressing a need that healthcare organisations may not be able to meet entirely due to a lack of nursing staff and resources. This approach is mainly present in volunteers in generalist care settings, and particularly in sitting services.

These two approaches may represent two possible ways of volunteer integration into care for people with serious illnesses. The "broader" complementary approach may imply more extensive volunteer knowledge and skills and entails a more extensive contribution to patient care, making these volunteers a valuable resource in light of socialisation of care. This complementary approach has been suggested in international literature to contribute to social capital[35,36] and to bridging the gap between health services and communities[37]. However, the existing needs of a particular care setting may influence the choice in approach to volunteering and whether there is a need for a broad or narrow palliative care volunteer role. For instance, people who volunteer in dedicated palliative care systems receive an intake meeting where their disposition towards death, their experiences and the impact it has had on them are explored. These volunteers care for patients who are dying exclusively, whereas people who volunteer in generalist care settings and services interact with a broader patient population and do not engage solely with patients near the end of life. Our results also suggest that medical oncology departments, for instance, may attribute an entirely different role to volunteers, which seems to be characterised neither by multidimensional support, nor practical support sessions.

In the shift to the socialisation of palliative care in particular, it may be desirable for policy makers and health services to invest in the complementary approach to volunteer activities as it encompasses the broad approach that palliative care requires in its emphasis of practical, nursing as well as psychosocial and existential care and signposting tasks. These types of volunteer care have been shown to be central to the position of volunteers in palliative care[20]. However, investment into complementary volunteer roles requires increased attention to volunteer training and supervision. Moreover, it requires acknowledgement that palliative care is an important focus for volunteers from a wide range of care organisations and settings. The narrow, substitutive approach, which encompasses mainly instrumental practical and nursing tasks, may be more relevant in settings with lower emphasis on palliative care.

However, it should be noted that even in these generalist care settings, there are still volunteers providing palliative care. In those cases, adequate training and supervision are required. Particularly, nursing home and community home-care volunteers appear to lack training and support. These results are striking, considering many people spend their last days of life in nursing homes. Community home-care volunteers signal a relative lack of supervision from their organisation. While community home-care is entirely volunteer-run at the local level, the lack of supervision or guidance from the organisation may signal a need for structural support interventions. These findings confirm previous studies that point out the lack of volunteer support in nursing homes and community home-care[14,15]. Results, however, indicate that training and organisational support are associated with the type of care volunteers provide. This indicates that health services and policy makers may, with minimal investment into volunteer training and support, be able to stimulate complementary volunteering approaches and thereby meet existing needs in professional healthcare. Future research may build on these findings to develop a more comprehensive model of palliative care volunteering across different care settings and services. It may also wish to focus on the requirements for volunteering support specific to nursing homes and community home-care services and to develop interventions that may strengthen palliative care volunteering in these settings.

3.6 Conclusion

A majority of volunteers in both dedicated palliative care services and healthcare services providing generalist palliative care provide care to persons with serious illness. Volunteers in generalist palliative care are, however, trained less and more often perform substitutive care activities such as practical and nursing care tasks that address needs that healthcare organisations may not be able to meet entirely due to a lack of nursing staff and resources. It may be desirable for policy makers and health services to invest in more complementary, multidimensional volunteer care activities. This broad, complementary approach will, however, require more attention to volunteer training and supervision and requires a broad acknowledgement that palliative care is a core focus for volunteers across various healthcare organisations.

3.7 Declarations

3.7.1 ACKNOWLEDGEMENTS

Filip Schriers aided in recruitment, data collection and follow-up.
All **volunteers** who helped in testing the questionnaire throughout development and all **volunteers** who participated in the survey.
All **healthcare organisations** who aided in the mail-out of the survey, the follow-up letters and non-response survey.

3.7.2 DATA MANAGEMENT AND SHARING

The data of this study is kept by the first author and is available upon request.

3.7.3 DECLARATION OF CONFLICTING INTERESTS

The Authors declare that there is no conflict of interest.

3.7.4 FUNDING

This study is part of the ‘Integration of palliative care into home, nursing home and hospital care and into the community in Flanders’ (INTEGRATE-project), a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic University Leuven, Belgium. This study is supported by a grant from the Flemish government agency for Innovation by Science and Technology (agentschap voor Innovatie door Wetenschap en Technologie) (SBO IWT nr. 140009). The agency had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report, nor in the decision to submit the article for publication.

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4 CHAPTER 4: THE LIMINAL SPACE PALLIATIVE CARE VOLUNTEERS OCCUPY AND THEIR ROLES WITHIN IT: A QUALITATIVE STUDY

Steven Vanderstichelen, Joachim Cohen, Yanna Van Wesemael, Luc Deliens, Kenneth Chambaere

Published in *BMJ Supportive and Palliative Care* 2018; 0:1-11 (Epub ahead of print)

Abstract

Objectives Volunteers have an important place in palliative care, positively influencing quality of care for seriously ill people and those close to them and providing a link to the community. However, it is not well understood where volunteers fit into palliative care provision, nor how to support them adequately. We therefore chose to describe volunteer roles across care settings through the perspective of those closely involved in the care of terminally ill people.

Methods A qualitative study was conducted using both focus groups with volunteers, nurses, psychologists and family physicians and individual semi-structured interviews with patients and family caregivers. Participants were recruited from hospital, home, day care and live-in services.

Results 79 people participated in the study. Two volunteer roles were identified. The first was 'being there' for the dying person. Volunteers represent a more approachable face of care, focused on psychological, social and existential care and building relationships. The second was the 'liaison' role. Volunteers occupy a liminal space between the professional and the family domain, through which they notice and communicate patient needs missed by other caregivers. Patient-volunteer matching was a facilitator for role performance; barriers were lack of communication opportunities with professional caregivers and lack of volunteer coordination.

Conclusion Volunteers complement professional caregivers by 1) occupying a unique space between professionals, family and patients and fulfilling a liaison function, and 2) being a unique face of care for patients. Healthcare services and policy can support volunteer role performance by ensuring frequent communication opportunities and volunteer coordination.

Key words

Volunteering; palliative care; role; qualitative research; focus groups; interviews

4.1 Introduction

Partly inspired by increasing resource constraints in professional healthcare, some governments, including the Belgian government, are turning to informal care to make up a greater proportion of palliative care (PC) provision e.g. through volunteerism[1–4]. Volunteers played a major part in the early days of the PC movement and continue to be involved both in the community and in institutional settings[5–7]. They have been shown to influence positively the quality of care for both terminally ill people and those close to them by reducing stress and offering practical and emotional support and providing a link to the community[6,8–10]. Research has widely documented the organisational perspective on volunteering, describing the presence of volunteers, turnover rates, task performance and the training they receive[6,11–13]. Studies have also shown volunteers provide palliative, direct patient care in both dedicated and generalist PC (i.e. PC provided by regular caregivers such as hospital specialists, family physicians [FPs], home-care nurses, nursing home staff), offering psychosocial, signposting and existential care[14] while suggesting a potential for supporting professional healthcare by being involved in its organisation[15].

However, alongside this organisational and economic potential[1,3,16,17], the capacity of volunteers to support professional healthcare is shaped by the roles they fulfil in PC. Literature has reported a variety of roles ranging in scope from specific (e.g. administration, fundraising) to broader (e.g. companionship and support) tasks[18–21]. Roles can be defined as behaviours, rights, obligations, beliefs, norms or a combination; the role is therefore a complex concept encompassing more than a set of tasks. Studying these roles as perceived by all those involved provides a more comprehensive grasp of what volunteers actually do, what they mean to the person who is dying, to family carers and to health care professionals, and their specific contributions to PC provision. Identifying barriers and facilitators in the performance of these roles allows the development of targeted support frameworks for volunteers and the fine-tuning of recruitment strategies.

Previous research on volunteering roles in PC has often included only the perspectives of volunteers[22,23] and patients[21]. Others such as family caregivers, FPs, nurses and psychologists also play a crucial role in the care of people with serious illnesses; roles are not fixed or prescribed, but rather negotiated between individuals and their contexts[24].

This study therefore aims to explore volunteer roles in the following ways:

a) from the perspectives of all those involved in the treatment of people with serious illnesses, and
b) in how they are negotiated (i.e. descriptions of volunteer tasks, boundaries and barriers to and facilitators of role performance).

4.2 Method

4.2.1 DESIGN

In order to explore the tasks and roles of PC volunteers, we applied a qualitative research design, opting for a qualitative descriptive design with grounded theory and phenomenological overtones. We conducted focus groups with volunteers and professional caregivers and individual semi-structured interviews with patients and family caregivers in Flanders, Belgium. Focus groups were chosen because this method stimulates the exchange of views and opinions through discussion and allows mutual differences or similarities to drive the conversation and salient themes to emerge. However, due to the fragile health of people who are dying and the sensitive nature of the subject, individual semi-structured interviews were chosen for them and for family caregivers which allowed every case to be treated as discrete and all participants to speak freely. This article follows the COREQ guidelines for reporting qualitative research[25]. **(See Appendix 4.1 for COREQ checklist.)**

Box 4.1: Settings from which participants of focus groups and interviews were selected[a,b]

1. Hospital settings
    a. **Medical oncology departments (MOD)** are hospital departments with a fully established oncology care programme, a hospitalisation programme and a multidisciplinary team focused on oncology.
    b. **Palliative care units (PCU)** are separate units in (or associated with) hospitals that exclusively provide palliative care.
2. Home-care settings
    a. **Facilities for sitting services** organise sitting services 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 similar to befriending services.[c]
    b. **Palliative home-care teams (PHT)** 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 caregivers in home or replacement home situations, supported by the network's volunteers.
    c. **Volunteer community home-care organisations (CHC)** are organised by the Christian Sickness fund locally and run by volunteers.
3. Live-in and day care facilities[d]
    a. **Palliative day care centres (PDC)** provide care and nursing during the day and have a respite care function for carers.
    b. **Nursing homes (NH)** offer permanent care and nursing to elderly people.

[a] Descriptions fully or partially taken from the Agency of Health and Care website[26]. [b] For a comprehensive overview of the organisation of palliative care in Belgium see the KCE report[27]. [c] See Walshe et al. (2016)[28]
[d] Nursing homes and palliative day care centres were grouped mainly due to the low number of palliative day care centres (n=5) in Belgium and their functional link with nursing homes.

4.2.2 DEFINITIONS

We define tasks as actions or pieces of work to be performed by one or more people that may be grouped by types (e.g. practical, nursing, psychological…). We define roles as collections or combinations of tasks and boundaries which together represent more than the sum of their parts, with a common overarching function or approach. For the definition of *volunteering* see **Appendix 4.2**.

4.2.3 CONTEXT

Palliative care 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 palliative care needs, or palliative care units; generalist PC refers to certain hospital departments (such as medical oncology departments), and primary care. This coincides with the organisation of care in most countries.

4.2.4 PARTICIPANTS

As well as the dying person we included volunteers, family caregivers, nurses, psychologists and FPs as those most important and most closely involved in their treatment and care. 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. Care settings were considered based on findings from our previous study[14,15] which identified services in Flanders (Belgium) where volunteers provide palliative and direct patient care. These services were divided into three settings: 1) *hospital*, 2) *home-care* and 3) *live-in and day care facilities*. **(See Box 4.1.)** Services in Flanders were chosen, because the different Belgian regions (Flanders, Wallonia, and Brussels) each have autonomy over various aspects of healthcare in the different language communities (Dutch, French, and German speaking), including home-care, hospital care and long-term care. The organisation of palliative care therefore differs on the regional level. Other reasons for exclusion of Wallonia and Brussels include the language difference and the long commutes that would be major barriers for the organisation of and participation in focus groups. Services were selected from existing listings available from the Flemish Agency for Health and Care[26].

Participants were sampled by contacting the coordinators or administrators of services 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. Upon agreeing to participate, potential participants were contacted by phone or e-mail to schedule the interviews and focus groups. Three volunteers dropped out as they no longer had time to participate.

4.2.5 DATA COLLECTION

Semi-structured interviews were individually conducted with the dying person and with family caregivers. Focus groups were separately conducted for a) volunteers, b) nurses and psychologists and c) FPs. Both took place between March and November 2017. Interviews were conducted by SV; focus groups were moderated by SV, KC and other senior researchers and observed by SV, KC and other junior and senior researchers making field notes. (**See Appendix 4.3 for interviewer characteristics.**) Participants were given the option to review their transcripts afterwards, but there were no requests to do this. Topic guides for both interviews and focus groups, consisting of open questions and a set of prompts for each question, were developed and reviewed by a team of sociologists (SV, KC, JC, LD) and a psychologist (YVW). (**See Appendix 4.4.**) Both topic guides focused on some of the following key topics: volunteer tasks, task boundaries, the role of volunteers in PC and the barriers to and facilitators of volunteer care.

4.2.6 ETHICAL CONSIDERATION

The study proposal 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 30th, 2017.

4.2.7 DATA ANALYSIS

All focus groups and interviews were audio-recorded (with the exception of one interview where recording was refused), transcribed verbatim and analysed by a junior and a senior researcher (SV and KC) resulting in a total of 26 transcripts. Analysis followed the QUAGOL method[29] – an inductive approach and iterative process of constant comparison. Data collection and analysis were conducted quasi-simultaneously. Two researchers (SV and KC) independently read the transcripts, once without coding and then while openly coding the data. From the open coding of each transcript a corresponding conceptual scheme was drawn. These schemes were compared with each other, resulting in a final conceptual scheme from which a coding tree was constructed (see **Appendix 4.3**). This coding tree was then discussed in the research team and modified where necessary. Coding was done by SV and KC in the NVIVO 11 qualitative data analysis software package. The salient and overarching themes that emerged from the data were the foundation for the final thematic framework. Data saturation was assumed when no new information emerged. After the thematic framework was agreed on, quotes were selected, translated and approved by the research team. All participants were given pseudonyms.

4.3 Results

We conducted eight focus groups and 18 semi-structured individual interviews. Twenty-eight volunteers attended one of four focus groups and twenty-two care professionals attended one of four focus groups. Ten patients and nine family caregivers took part in semi-structured individual interviews. One family caregiver who did not speak Dutch well refused audio recording; the interview was short and only served to highlight relevant themes in the form of researcher notes. Though 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; 79 participants were involved in the study. See **Tables 1 and 2** for participant characteristics.

Table 1: Characteristics of participants in focus groups

N	50
Focus groups	8
Mean duration of focus groups (in minutes)	72 (36-89)
Sex	
Male	7 (14%)
Female	43 (86%)
Age	
<50	0 (0%)
50-59	3 (6%)
60-69	9 (18%)
70+	1 (2%)
Unknown	37 (74%)
Employment status	
Retired	21 (42%)
employed	22 (44%)
Unknown	7 (14%)
Discipline	
Volunteer (4 focus groups)	28 (56%)
PC nurse (2 focus groups)	4 (8%)
PC psychologist (2 focus groups)	6 (12%)
FP (2 focus groups)	12 (24%)
Years of working experience	
≤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[a]	
Hospital	12 (24%)
PHT	11 (22%)
NH	8 (16%)
PDC	7 (14%)
FPs	12 (24%)

[a] Hospital settings include palliative care units and medical oncology departments; PHT = palliative home-care teams; NH = nursing home; PDC = palliative day care centre; FPs = family physicians.

Table 2: Characteristics of participants in interviews

N	19[a]
Interviews	18
Mean duration of interviews (in minutes)	42 (21-98)[b]
Sex	
Male	7
Female	12
Age	
≤29	1
30-39	0
40-49	1
50-59	3
60-69	5
70-79	2
80-89	3
90+	1
Unknown	3
Participant	
Patient	10
Family caregiver	9
Illness	
Cancer	15
CHF[c]	1
Dementia[d]	2
Parkinson's	1
Heart thrombosis	1
Cerebral infarction	1
Setting[e]	
Hospital	7
PHT	6
NH	3
PDC	2

[a]One interview was conducted with 2 participants (husband and wife). [b]One interview was not recorded. This interview was short, but the exact duration is unknown. The calculation of the mean duration of interviews excluded this interview. [c]Chronic Heart Failure. [d]Including Alzheimer's. [e]Hospital settings include palliative care units and medical oncology departments; PHT = palliative home-care teams; NH = nursing home; PDC = palliative day care centre; MOD = Medical Oncology Department; PCU = Palliative Care Unit.

Two themes emerged in analysis: 1) the volunteer as the other face of care and 2) the liminal space that volunteers occupy. The first gives insight into the tasks and boundaries of volunteers and both into the roles they perform.

4.3.1 THEME 1: VOLUNTEERS AS THE OTHER FACE OF CARE

Volunteers were described in the focus groups and interviews as representing a different approach, the 'other face' of care, which made them approachable and easier to confide in. They focused on building a relationship with the dying person and providing psychological, social and existential care for them and those close to them.

4.3.1.1 Focus on psychological, social and existential care

Four types of care were ascribed to volunteers: (a) practical, (b) psychological, (c) social and (d) existential. *Practical care* ranged from serving meals and drinks to transport, sometimes even assistant nursing tasks (e.g. lifting, washing, bathroom visits). Most volunteers performed several of these tasks; some specialised in one. *Psychological care* focused on providing comfort, moral support, being an open and neutral conversation partner who listens to their concerns, and providing respite to family caregivers. *Social care* included dropping by for a chat, keeping the person company and actively listening. Participants from all groups described a volunteer as someone the dying person can talk to while patients and family caregivers indicated that they helped normalise their situation and combat social isolation. *Existential care* aims to maintain the existential and spiritual wellbeing of the person who is dying and includes talking about life and death, existential anxiety (i.e. concerns relating to identity, purpose and being) and religious beliefs. Neither patients nor their family caregivers mentioned existential care; however, volunteers and professional caregivers emphasised its importance.

> **L:** Our [volunteers] presence, er, broadens their capabilities somewhat, because, I think it's often the case that nurses are only content when they have succeeded in the medical. 'The patient feels no pain, has these complaints and I have been able to, er, tend to them etcetera.' And due to the fact that we're also there, they are obligated to also pay attention to the other side of their job.
>
> **Interviewer:** Can you give an example of this other side of their job?
>
> **L:** Yes, I consider it the attention to spiritual care. If we- I wouldn't say if we did not introduce it, but that attention comes, is provided more by the volunteers. And because of that, they also consider it more often. […] I notice that, er, many volunteers, because of that attention that they have and are allowed to give and are able to give to patients, they actually introduce a sort of culture, into which the nurses then also follow.
>
> **- FG 1:** Volunteers (hospital); **L** (man, retired, volunteer in palliative care unit (PCU) for 8 years)

Volunteers, patients, family and professional caregivers identified strict *professional* and *legal boundaries* around practical care tasks. Legal boundaries relate to problems of liability and prohibit volunteers from performing nursing care and household tasks; however, exceptions occurred. FPs and volunteers both indicated that volunteers should not be part of multidisciplinary care team meetings, which should have strict legal and professional boundaries placing volunteers entirely outside the medical and nursing domain, something valued by both volunteers and family caregivers.

> **Marie:** In all other clinics care is provided, healing is done. And volunteers are not allowed into that domain. While, here, they just- medication is only for nurses, right?
>
> **Interviewer:** Right.
>
> Marie: You receive medication, painkillers, that little device that- volunteers don't touch it.
>
> **Interviewer:** No, no, no.
>
> **Marie:** They don't even look at it. She's there for- 'do you want anything? Are you hungry? Some of this? Let's go for a walk, the weather's good. What do you say?' If you'd like to have a chat, etcetera.
>
> - **I7: Marie** (patient in PCU, woman, 83 y/o, stomach tumour, housewife, ex-volunteer)

> [discussing the involvement of nurses in intervision meetings]
>
> **M:** It became too medical I found, and in the end, we [volunteers] have a different function.
>
> **D:** Ah okay, yeah, yeah.
>
> **E:** The point is that we don't meddle in the medical. And the point is that they [nurses] focus exclusively on the practical, well, at least focus a lot on the medical.
>
> - **FG 2:** volunteers (PHTs); **M** (woman, 64 y/o, volunteer in PHT for 12 years); **D** (man, 65 y/o, volunteer in PHT for 6 years); **E** (woman, 69 y/o, volunteer in PHT for 6 years)

Psychological, social and existential care tasks were subject to *ethical* and *professional boundaries*. References to discretion emphasised respecting the trust and privacy of the dying person and not being confrontational. Balancing intimacy and distance was cited as a crucial exercise. Professional caregivers indicated that volunteers should not cross the line when providing psychological guidance. However, these boundaries were never strictly defined.

Because volunteers were 'other' and excluded from medical and professional tasks, they could engage the dying person through practical tasks in ways that created opportunities for psychological, social and existential care provision. They consistently emphasised that the immediate psychological needs of the person took priority over any practical task they may be involved in and were valued by all participants for the psychological and social care they provided.

> **MI:** And also that the direct care for patients is priority. Er, so you're, you're busy in the kitchen with who knows what, but you hear from the nurse that, er, someone is anxious, er, wishes for someone to be near, wishes- you drop everything. There's always two of us, so you can discuss with your colleague- can you take over for a minute-
>
> **Interviewer:** Uhuh.
>
> **MI:** to be there, er, to try to alleviate that immediate need of that moment for that patient.
>
> **MA:** because that's very important.
>
> **MI:** I think that's very important.
>
> - **FG 1:** volunteers (hospital); **MI** (woman, retired, volunteer in PCU); **MA** (woman, retired, volunteer in PCU for 25 years)

4.3.1.2 *Building relationships*

This approach, combined with frequent close contact with patients, allowed volunteers to form a different sort of personal relationship with them from that of the professionals. This affinity for forming relationships was described as a key strength of volunteers throughout discussions with all participant groups and was at the centre of the first volunteering role that emerged from the data: '*being there'*.

Practical tasks such as serving meals or drinks were indicated by volunteers as a way to check in with the dying person and as an opening to be with them, sit down and have a conversation. Patients described volunteers doing little things for them that made a difference e.g. going for walks, granting specific meal requests or making pancakes.

> **Anneke:** There's even a volunteer who, on Valentine, bakes pancakes for everyone.
>
> **Interviewer:** Really?
>
> **Anneke:** Yes.
>
> **Interviewer:** Cool.
>
> **Anneke**: And she had baked cupcakes at home as well.
>
> **Interviewer:** Right.
>
> **Anneke:** A cupcake with a little heart and your name on it for everyone, brought it here for everyone. She made the pancakes here on the spot.
>
> **Interviewer:** Oh, that's cool.
>
> **Anneke:** Yes, absolutely.

- **I6: Anneke** (patient in PCU, woman, 77 y/o, lung cancer, retired secretary)

'Being there' also helped combat the social isolation associated with being ill. Both volunteers and professional caregivers described deep personal conversations between volunteers and the person who is dying but also mentioned the value of light day-to-day conversations. Family caregivers emphasised the value of having a volunteer to listen to them vent frustrations and talk about things unrelated to the patient and their illness.

> **Fien:** Also, yes, those people [volunteers] are made for that, actually. You can listen to them and you can talk to them and you loosen up when- Because, with other people I immediately think, 'well, I might be complaining'. And because you- my world is set in that apartment – […]

> These people are sort of neutral, you understand? I can talk to her a lot, but she doesn't talk to me a lot. She does about things aside from (husband). If I want to talk to her about a trip or something, that's different. A different thing from- right?
>
> **Interviewer:** Right, right, right.
>
> **Fien:** But when it concerns (husband) and the illness, she listens to me. Or she'll come in and say 'how's your week?' Then she listens.

- **I14: Fien** (family caregiver for husband with Parkinson's, woman, 64 y/o)

4.3.2 THEME 2: THE LIMINAL SPACE OF VOLUNTEERS

Whereas the first theme tells us what volunteers represent and what they mean to the dying person, the second explains the emergence of this other face and helps us locate volunteers and the roles they fulfil in a discrete space between professional and family caregivers and the dying person. They are not professional caregivers and do not consider themselves as such - strict professional and legal boundaries exclude them from this domain; neither are they family or social acquaintances. They traverse and act within both the professional and family domains, but do not belong to either of them; they occupy a *liminal space* – a term borrowed from anthropological literature, traditionally used to denote the middle stage of rites, periods in time, or physical locations between thresholds, where one is neither in the previous nor in the following stage or place but rather in a fluid, malleable place that enables new practices to emerge[29].

Volunteers are distant enough for the person who is dying not to feel for them the emotional responsibility that they might feel towards those closer to them, but close enough for them to speak to frankly about their condition and concerns. This lower threshold for engagement creates opportunities for volunteers to be the voice of the dying person and provides the basis for continuity of communication which would be impossible if they were fully part of either the professional or the family domain.

> **Sabine:** And if there's anything, you'll more readily, with a volunteer, they have time to talk to you. And you'll say something and they'll- 'oh I'll talk to a nurse about that.'
>
> **Interviewer:** Uhuh.
>
> **Sabine:** You notice that.
>
> **Interviewer:** Right, right, right, right.

> **Sabine:** See, you'll say something and they, but they'll tell you
>
> **Interviewer:** Yeah.
>
> **Sabine:** We'll discuss it with the nursing staff, yes.
>
> **Interviewer:** So they often signal.
>
> **Sabine:** Yes, yes, yes, they do that.
>
> **Interviewer:** oh, yes, okay.
>
> **Sabine:** If there's anything, they'll, er, they'll pass it on.
>
> **Interviewer:** Yeah.
>
> **Sabine:** And that's what's nice about it.
>
> - **I8: Sabine** (patient in PCU, woman, 69 y/o, throat tumor, retired nurse)

The second role that emerges from our data we are therefore calling the '*liaison role*.' Volunteers appeared to serve a signposting function, in which they picked up on and communicated to nursing staff the needs and wishes of the dying person, ranging from simple preferences and concerns to anxiety, pain, discomfort and even problems in their households. Nurses and psychologists indicated that they depended on volunteers for this, particularly in home-care, where volunteers visit alone. To avoid embarrassment or being a nuisance to nurses, the dying person could be more comfortable opening up to a volunteer, who represented a 'different face' of care, was located outside the medical domain and took an open, neutral approach. Volunteers therefore sometimes functioned as an advocate for the person who is dying and the close relationship that sometimes emerged between them emphasises the importance of this liaison role.

> **AM:** Sometimes you feel, no, sometimes you feel the opposite I think. Like, 'why don't you pass this on'
>
> **Interviewer:** So, in fact, they sometimes see you as a link between-
>
> **AM:** Yes.
>
> **Interviewer:** the care- the other caregivers
>
> **AM:** Things they're afraid to say, yes, yes.
>
> **MA:** But also because many patients are also worried about nurses' time. They don't want to burden the nurses for too long. […]
>
> **AM:** I think it's rather something else. Like, 'if I tell the nurse this', sorry to put it in this way-
>
> **MA:** Uhuh.

> **AM:** But 'she might be angry at me and she still has to care for me.' I've already noticed that a few times, like, 'if I whine and complain too much, well then I'll be the difficult patient here.'
>
> **MA:** Ah yes, uhuh.
>
> **AM:** I've noticed that a few times. And for those things, they come to us.
>
> - **FG 1:** volunteers (hospital); **AM** (woman, volunteer for 20 years, 3 years in PCU); **MA** (woman, retired, volunteer in PCU for 25 years)

The possibilities inherent in this relationship contribute to the concept of customised care, a notion emphasised by specialist PC professionals as encompassing their approach to PC and defined as care provided according to the needs and wishes of the person who is dying and those close to them.

> **RI:** Well. I think you need to know the volunteer a little bit to know who fits in which family or who would mean the most there.[…] yeah, it's necessary to know each other a bit.
>
> **IN:** This situation is so complex, we'll put an experienced volunteer here, haha, right?
>
> **RI:** yes, yes, yes, yes.
>
> **IN:** Or in this case, well here I can put anyone, we'll put that new volunteer here, this is a nice start, a good first situation.
>
> **AM:** uhuh.
>
> **KA:** Yes.
>
> **IN:** So that is customised care. […]
>
> **AM:** Well, also to insert that quality of, of not putting yourself as a volunteer in the foreground.
>
> **Interviewer:** Uhuh.
>
> **AM:** And I think that's when nice customized care can result from it, when, when, yeah, when volunteers can sense that- in this situation, this patient needs this at this moment.
>
> **Interviewer:** Yes.
>
> **KA:** Yes.
>
> **DE:** Yes, it's also customized to the patient-
>
> **AM:** Yes.
>
> **IN:** Yes.
>
> **DE:** and the family
>
> **KA:** Yes
>
> **AM:** and their surroundings.

- **FG 6:** nurses and psychologists (PHT); **RI** (woman, palliative care nurse in PHT); **IN** (woman, nurse and coordinator of PHT); **KA** (woman, psychologist and volunteer coordinator of PHT); **DE** (woman, psychologist and volunteer coordinator of PHT); **AM** (woman, palliative care nurse in PHT)

4.3.3 BARRIERS TO AND FACILITATORS OF VOLUNTEER ROLE PERFORMANCE

Communication, support, coordination and the extent to which the dying person and the volunteer matched each other were important factors influencing volunteer role performance.

Lack of communication opportunities between volunteers and nurses to pass on the concerns of the dying person was indicated as a barrier to the liaison role of volunteers. Lack of regular volunteer briefings and lack of communication opportunities among volunteers were also indicated to disrupt the flow of communication between and among volunteers and nurses, leading to confusion and misunderstandings. Conversely, where these things were present, participants indicated that they facilitated the volunteer liaison role.

> **LI:** I still think more communication.
>
> **RO:** Yes.
>
> **LI:** But I, I think the problem for us is also, with us the nurses work- two nurses work, er, two days in the week, one works three days. Er, the occupational therapist, er, er, Monday, Wednesday and the week after on Wednesday, Friday. So, it's a constant change of people. A lot has to be done and settled in between. And then I think that the communication, I feel, falls short. With daily affairs-
>
> **E:** Yes.
>
> **LI:** that you're not aware of-
>
> **RO:** Yes.
>
> **LI:** and that's, er, sometimes very annoying.
>
> **E:** Yes.
>
> **LI:** And no one is to blame, it's also due to organisation but I often encounter that.
>
> **E:** Yes.
>
> **LI:** And I think it's a shame because it results in a bunch of-
>
> **E:** Yes.
>
> **LI:** yeah, confusion and, and-
>
> **E:** Emotion.

> **LI:** and sometimes misunderstandings.
>
> - **FG 4:** volunteers (PDC); **LI** (woman, 52 y/o, volunteer in PDC for 7 years); **RO** (woman, 74 y/o, volunteer in PDC for 7 years); **E** (man, 61 y/o, volunteer in PDC for 16 years)

Lack of support and coordination for the volunteers impeded their role of 'being there' and the development of the relationship with the dying person. Volunteers often experience direct and indirect bereavement themselves and lack of supervision can complicate their processing of such challenging experiences. Lack of a volunteer coordinator or clear division of responsibilities within the organisation were indicated to increase uncertainty and to impact negatively on the day-to-day functioning of volunteers. However, when support and coordination were present, participants indicated they facilitated volunteer role performance.

> **RI:** And when they have difficult things there, then they do have to be able to talk about it with the nurse: 'I've come across this and there's this, and that's ok but I have difficulties with it'
>
> **AM:** Yes.
>
> **RI:** They need a sounding board like 'I understand that you- but they- I shouldn't say have a more difficult relationship, but these people have lived together like this for forty years. They are not going to change that now near the end of life'-
>
> **Interviewer**: Yeah.
>
> **RI:** That you can help put that into context and that they can find strength in that, like, okay, that's just how it is there. […]
>
> **RI:** But that they receive support of that nurse through reporting, communicating, yes.
>
> **Interviewer:** Yeah, yeah, yeah.
>
> **KA:** Yes, that's very important.
>
> **- FG 6:** nurses and psychologists (PHT); **RI** (woman, palliative care nurse in PHT); **AM** (woman, palliative care nurse in PHT); **KA** (woman, psychologist and volunteer coordinator of PHT)

Patient-matching based on personal compatibility and the needs and wishes of the patient facilitated role performance by volunteers and lowered the threshold to opening up. In palliative home-care, this is facilitated by exploratory home visits by a PC nurse and the opportunity for volunteers to refuse patients and vice versa and in nursing homes and day care settings by scheduling which allows patient and volunteer to become familiar with each other.

> **M:** Yes, so when starting here you fill in a volunteer form. Sorry for talking so much haha. And we can indicate there, for example, 'I don't want dementia patients, I don't want children.' Right, we will construct our own profile a bit and then when there's a request for a volunteer somewhere, the nurse there will check if they can match it. That is done with care. […]
>
> **E:** I have the impression that the nurse, aside from choosing with care who ends up with a family, that they also look at the personalities, also that of the volunteer. And those of the patient or family.
>
> **M:** Yes, I think so-

- **FG 2:** volunteers (PHT); **M** (woman, 64 y/o, volunteer in PHT for 12 years); **E** (woman, 69 y/o, volunteer in PHT for 6 years)

4.4 Discussion

4.4.1 MAIN RESULTS

Volunteers were found to represent an 'other', more approachable 'face of care' and to occupy a liminal space between and overlapping the professional and the family domains. They were found to perform two roles: 'being there' and 'liaison'. The main barriers to performing these roles were a lack of communication opportunities with nursing staff, a lack of support in dealing with difficult situations and a lack of coordination in the care setting. Volunteer-patient matching was an important facilitator.

4.4.2 STRENGTHS AND LIMITATIONS

To our knowledge, this study is the first to conceptualise the volunteer space and to offer distinct and detailed volunteer role descriptions that maintain an internal flexibility. Roles are defined by a multifaceted approach and goal, but not *a priori* defined by how that goal should be reached. Furthermore, we believe this to be the first study to approach the subject from such a broad multi-disciplinary and multi-contextual perspective which includes volunteers, the person who is dying, family caregivers, FPs, psychologists and nurses from three distinct types of care settings. The potential for social desirability in responses, inherent in qualitative research, is off-set by the wide range of participants included. Because interviews were conducted almost exclusively in cancer cases, it is possible that experiences specific to other illness trajectories were missed.

4.4.3 INTERPRETATION

The themes of volunteers as the *other face of care* and the *liminal space* they occupy between the professional and family domains define the role of volunteer as distinct from and complementary to that of professionals. We believe that this *liminal space* - which only volunteers appear to traverse - is precisely what makes volunteers and the care they provide valuable. The concept of *liminality,* indicating a fluid, malleable space between and connecting two conceptually rigid and mutually exclusive domains[30], lends itself well to understanding the volunteer position in palliative care because it allows for non-discrete categories. In anthropology, liminality has been used to indicate moments (e.g. coming of age rites), periods (e.g. periods between history-shaping events or transformations) or physical spaces (e.g. airports) in which identities, institutions, cultures, or locations are in flux, but from which new ones may emerge[31]. Such a space, conceptually, fits the volunteer position, from which they provide complementary care according to continuously changing needs of the patient, relatives, professionals and situations.

The role of *being there* corroborates the finding of other studies that *presence* is a central aspect of volunteer support in PC[8,32–34], through which meaningful encounters with patients emerge[33,35–37]. The analytical categories reported in this paper resonate with a previous study's findings of volunteers 'being with' and 'doing for' patients[38], describing a relational dynamic between volunteers and patients similar to our findings indicating volunteers used practical tasks ('doing for') as a means to perform their role of being present with patients ('being with'). Literature also reports several themes connected to *being there*[32] which we also found important: neutrality and openness, customised care and patient-centredness, developing a close bond with the person who is dying, facilitating intimate conversations and active listening. The findings that volunteers considered themselves and their role as separate from nursing and medical professionals and that volunteer roles are entirely complementary to professional care provision may assuage existing concerns among professionals regarding volunteers in palliative care taking on professional roles and performing nursing tasks[39,40]. While volunteers did occasionally perform assistant nursing tasks – a finding also published elsewhere[14] – it appears that the legal boundaries, and presence of leadership and coordination for volunteers functioned as checks on boundary crossing and facilitated volunteers to perform their own roles.

Aside from the fundamental scientific usefulness of this framework of *liminal space, being there* and *liaison* as a theoretical lens through which to understand PC volunteering across and within care services, our results also point to practical measures to improve PC volunteering. Firstly, a clear conceptualisation of the volunteer's position as relational provides a basis to assess whether a service is providing specific support and infrastructure to optimise the volunteer's performance and some pointers as to how to provide it. It is furthermore a basis for the development of volunteer screening frameworks – potentially alleviating recruitment problems identified in previous research[14] – and training modules regarding specific skill requirements for the role of being there and of liaison. Secondly, the barriers and facilitators identified in this study suggest several practical things that can be done to optimise volunteer role performance such as (1) appointing volunteering coordinators responsible for managing and leading volunteers; funding for an appointed volunteer coordinator could be included in government subsidies (nurses may be considered for this position as our results indicate that they work most closely with volunteers), (2) increasing the access of volunteers to nurses and psychologists to facilitate signposting, continuity of information, processing of difficult situations and to reduce volunteer uncertainty, (3) implementing patient-matching methods suitable to the setting that are sensitive to the preferences of both the person who is dying and the volunteer and (4) avoiding broadening task performance to include the tasks of professional staff. Results indicate that volunteers are able to perform their roles precisely because they are not professionals, are not considered professionals and are not utilised as professionals. Trends towards substitution of paid staff may therefore compromise quality of care provision, waste resources and increase volunteer turnover. While healthcare systems may differ in the organisation of palliative care, the inclusion of multiple perspectives from diverse care settings and the corroboration of our findings by international literature suggests that these recommendations are relevant for palliative care volunteering across regional or national borders.

While this study has highlighted volunteer task boundaries and barriers for volunteer role performance, the limitations of volunteer roles are still unclear, e.g. what the boundaries of volunteer confidentiality are, and whether volunteer presence is desirable or effective in sensitive and distressed end-of-life scenarios. Case studies of difficult end-of-life situations involving volunteers may provide important insights into such issues. Finally, this study has focused on direct patient care volunteering. However, indirect and non-care related volunteering may also fulfil important roles within the context of palliative care. Future research may therefore also consider exploring these aspects of volunteering.

4.5 Conclusion

Palliative care volunteers occupy a unique space between professionals, the person who is dying and those close to them and offer care that is distinct from but complementary to that provided by professionals. Their roles of *being there* and *liaison* help fill the gaps that exist between professionals and family and their position makes them crucial contributors to customised care. Tailored support and infrastructure, for which we make several practical recommendations, are necessary to support this position. We also offer a conceptual lens that may be useful to policy makers and healthcare services to shape the volunteer workforce and to researchers to study volunteers within a wide range of palliative care service settings. The volunteer position and roles outlined in this article are a first step in shaping focused recruitment and support efforts for healthcare services.

4.6 Declarations

4.6.1 FUNDING

This work was supported by the Agency for Innovation by Science and Technology (IWT) as part of the INTEGRATE-project. [SBO-IWT 140009]

4.6.2 COMPETING INTERESTS

None declared.

4.6.3 LICENSE FOR PUBLICATION

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4.6.4 RESEARCH ETHICS AND PATIENT CONSENT

The proposal for this study was submitted for approval to the commissions of medical ethcs 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 30th 2017.

4.6.5 DATA MANAGEMENT AND SHARING

The data of this study is kept by the first author and is available upon request.

4.6.6 ACKNOWLEDGEMENTS

Lenzo Robijn, **Else-Gien Statema**, **Ellen Vanderstichelen**, **Kim Beernaert** and **Aline De Vleminck** helped with the conducting some of the focus groups either as observers or as moderators.

Jane Ruthven provided language editing of the manuscript.

All volunteers, nurses, oncological coaches, psychologists, family physicians and coordinators who agreed to participate in one of the 8 focus groups.

All family physicians from the family physicians' department at Ghent university who agreed to participate in a discussion to reflect on the difficulties with recruiting FPs.

All patients and family caregivers who agreed to participate in interviews for this study.

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PART III – VOLUNTEER INVOLVEMENT AND COLLABORATION WITH HEALTHCARE PROFESSIONALS

5 CHAPTER 5 :

VOLUNTEER INVOLVEMENT IN THE ORGANISATION OF PALLIATIVE CARE: A SURVEY STUDY OF THE HEALTHCARE SYSTEM IN FLANDERS AND DUTCH-SPEAKING BRUSSELS, BELGIUM

Steven Vanderstichelen, Joachim Cohen, Yanna Van Wesemael, Luc Deliens, Kenneth Chambaere

Published in *Health and Social Care in the Community* 2019, 27(2):459-471

Abstract

Ageing populations increasingly face chronic and terminal illnesses, emphasising the importance of palliative care and quality of life for terminally ill people. Facing resource constraints in professional healthcare, some governments expect informal caregivers like volunteers to assume a greater share of care provision. We know volunteers are present in palliative care and perform many roles, ranging from administration to providing companionship. However, we do not know how involved they are in the organisation of care and how healthcare organisations appraise their involvement. To address this, we provide an extensive description of the involvement of volunteers who provide direct patient palliative care across the Flemish healthcare system in Belgium. We conducted a cross-sectional postal survey of 342 healthcare organisations in Flanders and Brussels in 2016, including full-population samples of palliative care units, palliative day care centres, palliative home-care teams, medical oncology departments, sitting services, community home-care services, and a random sample of nursing homes. Volunteer involvement was measured using Sallnow and Paul's power-sharing model, which describes five hierarchical levels of engagement, ranging from being informed about the organisation of care to autonomy over certain aspects of care provision. Response was obtained for 254 (79%) organisations. Volunteers were often informed about and consulted regarding the organisation of care, but healthcare organisations did not wish for more autonomous forms of volunteer involvement. Three clusters of volunteer involvement were found: “strong involvement” (31.5%), “restricted involvement” (44%), and “uninvolved” (24.5%). Degree of involvement was found to be positively associated with volunteer training ($p < 0.001$) and performance of practical ($p < 0.001$) and psychosocial care tasks ($p < 0.001$). Dedicated palliative care services displayed a strong degree of volunteer involvement, contrary to generalist palliative care services, suggesting volunteers have a more important position in dedicated palliative care services. A link is found between volunteer involvement, training, and task performance.

Key words

Belgium, involvement, palliative care, surveys and questionnaires, volunteers

Key statements

What is known about this topic:

- Volunteers are present in dedicated and generalist palliative care services and may perform a wide range of tasks.
- Volunteers can have a positive effect on quality of care of terminally ill patients.
- Governments cite resource constraints in professional healthcare to justify a partial shift from professional care provision to care by the community.

What this paper adds:

- Volunteers are often informed about and consulted regarding the organisation of care provision, but rarely receive any decision-making rights.
- This paper links degree of volunteer involvement in the organisation of care to the training volunteers receive and the tasks they perform.
- Volunteer involvement in the organisation of care may be particularly beneficial to dedicated palliative care services.

5.1 Introduction

As populations age, societies more frequently face chronic and terminal illnesses that may require palliative care. Palliative care is the active, total care of people whose disease is not responsive to curative treatment and focuses on pain and symptom control and social, psychological and existential/spiritual care[1]. It represents an interdisciplinary approach in various settings and from various care professionals and encompasses in its scope the person who is dying, those close to them and the community they live in. Volunteers played a major role in the early days of palliative care and continue to be involved in its provision, both in the community and in institutional settings[2–5]. They may take up several roles ranging from administrative and fundraising to providing companionship and support[6–8], and can positively influence the quality of care for both terminally ill people and those close to them by reducing stress and offering practical and emotional support and providing a link to the community[3,9–12]. Faced with increasing resource constraints in professional healthcare, some governments are turning to informal care to make up a greater proportion of care provision (e.g. through volunteerism)[13–19]. Volunteers can provide palliative, direct patient care in both dedicated palliative care and in generalist palliative care (i.e. palliative care provided by regular professional caregivers such as the hospital specialist, general practitioner, home-care nurses, nursing home staff) providing psychosocial, signalling (e.g. being an intermediary, communicating needs to professional caregivers, etc.) and existential care for people at the end of life and for those close to them[20].

If governments intend to meet the resource challenge facing professional healthcare by expanding the use of volunteers, it is necessary to know the full extent of what support volunteers can offer within palliative care. While we know volunteers provide care, little is known regarding their involvement in the organisation of care, i.e. to what extent they have input or even decision-making rights at the organisational level when it comes to the organisation of care provision. The New Public Health movement has in recent years emphasised the importance of promoting community development and engagement to fill the support spaces between episodes of professional care[21,22]. The organisational framework of health services may be an important medium by which communities can be engaged through volunteer involvement. In order to anticipate how the expansion of informal care may affect healthcare provision, it is necessary to know to what extent volunteers are currently involved and to what extent healthcare organisations are open to volunteer involvement. Furthermore, in order to understand the capacity of volunteers to alleviate pressures on professional end-of-life care and whether policy should play a role in supporting it, it is necessary to explore whether and in what manner volunteer involvement in the organisation of care is connected to the amount and types of training provided to volunteers and the number and types of tasks volunteers perform.

To address these knowledge gaps, this study provides an extensive description of the involvement in the organisation of patient care provision of registered volunteers in palliative, direct patient care across the whole Flemish healthcare system in Belgium. The research questions are:

a) To what extent do different healthcare organisations providing palliative care involve their volunteers in the organisation of patient care provision?
b) How do different healthcare organisations providing palliative care evaluate the degree of involvement of their volunteers in the organisation of patient care provision?
c) Is this degree of volunteer involvement associated with differences in volunteer tasks, volunteer training and the organisation’s evaluation of volunteer involvement?

5.2 Method

We conducted a cross-sectional postal survey between June and October 2016 among healthcare organisations providing care for people with terminal illnesses towards the end of life – though not necessarily in the terminal stage – in the Flemish healthcare system. The Belgian regions (Flanders, Wallonia, and Brussels) have autonomy over various aspects of healthcare in the different language communities (Dutch, French, and German speaking), including home-care, hospital care and long-term care. The Flemish government is therefore responsible for these aspects in Flanders and for the Dutch speaking community in Brussels. We therefore included Flanders and Dutch speaking Brussels in this study and excluded Wallonia as it falls under a different regional authority and the organisation of palliative care differs greatly on the regional level. Other reasons for exclusion include the added analytical complexity resulting from strong differences in context and language differences. In 2017 the Flemish region and the Brussels region had respective populations of 6,516,011 and 1,191,604 inhabitants, accounting for 68% of the total Belgian population[23].

5.2.1 DEFINITIONS

We define volunteerism in palliative care as *the time freely given by individuals, with no expectation of financial gain, within some form of organised structure other than the already existing social relations or familial ties, with a palliative approach – i.e. the intention of improving the quality of life of adults and children with life-limiting conditions and those close to them (family and others).* (Adapted from Goossensen et al.[24]) Volunteers do not have an employment contract or statutory appointment within the organisation in which they perform these tasks; they are, however, officially registered with the organisation. This definition is in accordance with that provided by the Belgian federal law[25,26]. We focus on *community volunteers* in *direct patient care*, i.e. members of the local community who work in care-focused roles and are regularly involved with patients and those close to them, provided they are not merely performing their medical profession unpaid[24]. Lastly, we focus on volunteers who fit this definition and provide care for people with terminal illnesses and their relatives. This definition was incorporated into our questionnaire.

We define volunteer involvement in the organisation of care by the extent to which volunteers have a voice in the organisation and the degree to which it carries weight with regard to how decisions are made about the organisation of patient care provision. As we will discuss below, involvement may vary on a hierarchical continuum[27], ranging from being informed to varying degrees of using this information to have voice[28], culminating in having autonomy over certain aspects of the organisation of care provision. Involvement therefore relates to the organisational aspect of care provision at the micro level and not direct patient care provision itself.

5.2.2 SAMPLE

Our unit of analysis is the individual organisation. We identified organisations and services through the up-to-date listings of recognised healthcare organisations by the Flemish ministry for Welfare, Public Health and Family[29]. We considered hospital departments as organisations, as volunteerism is more directly coordinated at this level. Our inclusion criteria were that organisations:

- provide care for people with terminal illnesses
- potentially work with volunteers
- are active in Flanders or Brussels
- are on the list of healthcare organisations of the Flemish ministry for Welfare, Public Health and Family.

We consulted 12 experts from different types of health care organisation where people may come to die and where people with terminal illnesses may be treated to find out where volunteers may be active in the care of patients. (**See Appendix 1.1.**) **Box 5.1** provides a list and descriptions of all organisation types included in our sampling framework based on this expert consultation.

5.2.3 ETHICAL APPROVAL

The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Brussels. (ref. B.U.N. 143201627927) Approval was granted on March 23, 2016.

5.2.4 SAMPLES AND PROCEDURE

We surveyed a full population sample of all organisation types mentioned in **Box 5.1**, except for nursing homes where, due to practical constraints, a random sample of 200 out of a total of 783 nursing homes was taken (25.5%). This sample of nursing homes was sufficient for a 95% CL with a range of -3/+3 percentage points around a 50% estimate. Our total N for this survey was 342. All questionnaires were sent out simultaneously by post, pre-numbered to track response. A thank-you note and reminder were sent out one week later; three weeks post mail-out a replacement questionnaire and new cover letter were sent to all non-respondents. Five weeks post mail-out the remaining non-respondents were contacted by telephone. New questionnaires were supplied by email when necessary. Seven weeks post mail-out a non-response survey consisting of four questions was sent by post to gauge whether respondents had received the questionnaire, had sent it back and if not why. Questionnaires were addressed to the volunteer coordinator – or closest equivalent – of the organisation as they are closest to the volunteers and therefore are assumed to provide accurate information on volunteering within the organisation. The cover letter stated clearly that participation was entirely voluntary. Informed consent was assumed upon participation. Data input did not include the questionnaire numbering, thereby ensuring anonymity of the data set.

Box 5.1: Sample framework of Flemish and Brussels healthcare services potentially involving volunteers in direct patient care, Belgium, 2016[a]

1. **Medical oncology departments (MODs; N = 42/42)** are hospital departments with a fully established oncology care programme, a hospitalisation programme and a multidisciplinary team focused on oncology.
2. **Facilities for sitting services (N = 40/40)** organise sitting services 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 similar to befriending services.[b]
3. **Palliative care units (PCUs; N = 28/28)** are separate units in (or associated with) hospitals that exclusively provide palliative care.
4. **Palliative day-care centres (PDCs; N = 5/5)** provide care and nursing during the day and have a respite care function for carers.
5. **Palliative home-care teams (PHTs; N = 15/15)** are part of the palliative networks, that is, cooperative ventures between different providers and care facilities in a particular region – these are palliative care teams supporting other caregivers in home or replacement home situations, supported by the network's volunteers.
6. **Volunteer community home-care organisations (CHCs; N = 12/12)** are organised by the Christian Sickness Fund locally and run by volunteers.
7. **Nursing homes (NHs; N = 200/783)** offer permanent care and nursing to elderly people.

[a]Descriptions fully or partially taken from the Agency for Health and Care website[29]. [b]See Walshe et al.[30]

5.2.5 QUESTIONNAIRE

The questionnaire, developed specifically for this study, consisted of 26 questions, including on *volunteer tasks*, *training*, *current volunteer involvement*, *desired volunteer involvement*, and *organisational characteristics*. The questionnaire was developed based on the literature on volunteerism in palliative care and input from representatives of each organisation type in our sampling framework. It was tested cognitively in two rounds, each with different representatives. For more details regarding the questions used to gather data on these characteristics, we refer to our questionnaire supplemented in **Appendix 1.2**.

5.2.6 MEASURES

Questions on volunteer involvement were based on a model of power sharing in palliative care suggested by Sallnow & Paul[27], which was itself developed based on earlier existing community engagement models, and made specifically applicable to care organisations in end-of-life care provision. The model consists of five types of engagement work represented as a spectrum: **inform – consult – coproduce – collaborate – empower**. Each next type of engagement work represents more meaningful forms of engagement, capable of more penetrating health and social outcomes[27]. (**See Box 5.2.)** For each of these levels of involvement the organisations' representatives were asked to what extent they applied them within their organisation (never – rarely – often – always) and to indicate whether they wanted that type of involvement to be less or more or felt it was adequate.

Volunteer task performance was measured using items from validated scales for Activities of Daily Living (ADL)[31] and instrumental Activities of Daily Living (iADL)[32], as well as an item battery for Psychosocial, Signalling and Existential care tasks (PSE) constructed by the researchers. Variables representing the sum of all item scores were constructed for the scales (ADL, iADL) and index (PSE). A binary variable (0-1) was constructed to measure whether obligatory training was provided and an index variable was constructed, based on a list of training subjects constructed by the researchers, to indicate how many different training subjects each organisation offers.

Box 5.2: Conceptual model of power-sharing: five types of engagement works [27].

The five types of engagement work of the power-sharing model adapted to apply to registered volunteerism in palliative, direct patient care in Belgium (Flanders and Brussels):

1. **Inform**
   This type represents the organisation informing its volunteers on how care provision is organised within the organisation. (E.g. what care is provided, how is it provided, by whom and to whom?) This can be done in many ways, such as informational booklets, leaflets, an introduction day, a training course, etc.
2. **Consult**
   This type requires the organisation to consult their volunteers to gauge their opinions and views on the organisation of care. The communication in this type of engagement work is one-way. No feedback is given to the volunteers during or after this consultation. This can be done in the form of a survey or meeting.
3. **Co-production**
   'Co-production' is a step up from consult. In this type of engagement work, communication does flow both ways. It allows the volunteers to determine how well the information they have provided to the organisation has been incorporated or acted upon. The organisation takes into account the volunteers' opinions and views when making decisions regarding the organisation of care.
4. **Collaborate**
   This type of engagement work refers to the organisation and its volunteers working together when developing and organising care provision. In our study, it means volunteers have certain decision-making rights in the organisation of care, though the organisation still holds final authority and overall control.
5. **Empower**
   The final type of engagement work represents the volunteers taking full control of an aspect of care and developing their own responses. This means volunteers have autonomy over certain aspects of care in the organisation. Empower, as the extreme end of the power-sharing model, functions as an ideal type. It is unlikely that organisations would transfer full autonomy and responsibility to their volunteers for any aspect of care, however the extent of autonomy of volunteers may surely vary between organisations.

The questions used to operationalise each level can be found in the questionnaire supplemented in Appendix 2.2. (Questions 14 and 19.)

5.2.7 STATISTICAL ANALYSIS

We performed univariate and bivariate analysis using IBM SPSS 24. Cross-tabs were run to calculate proportions for each variable for each organisation type. Percentages were rounded. Chi-square tests were performed to check for statistical differences in proportions across types. (Significance at p=0.05 or lower was indicated with a (*)). The power-sharing model was not treated as a scale. To our knowledge no previously validated attitudinal instruments exist for this conceptual model; however, face validity of our operationalisation was gauged by presenting it to the original authors of the model for feedback in preparatory stages of the study. Current volunteer involvement and desired volunteer involvement were analysed in relation to the mean number of training topics provided to volunteers and the mean number of ADL, IADL and PSE tasks volunteers performed within an organisation type. Organisations were classified as having 'supportive' or 'less supportive' approaches to each individual type of involvement by linking each organisation's reported current level of that involvement type and their desired volunteer involvement. (**See Box 5.3.**) T-tests were run to test for equality of means. A PRINCALs analysis was performed on the items of current volunteer involvement to identify clear dimensions of involvement and a Two-Step Cluster analysis was performed to identify clusters of volunteer involvement types across the different organisations. (**See Appendix 5.1 for details.**) Cluster membership was then used as a grouping variable for further analyses. Analysis of variance (ANOVA) was used to test associations between degree of involvement and organisation type, training indicators, task performance scales and index, and organisational inclinations towards involvement through an F-test. All statistical tests are two-tailed.

Box 5.3: Classifying organisations into being supportive or less supportive towards increasing each of the different levels of volunteer involvement.

For each level of involvement in the power sharing model (inform – consult – coproduce – collaborate – empower) the reported current involvement (rows) was linked to desired volunteer involvement (columns) and resulted in a supportive or less supportive inclination towards increasing that level of involvement.

E.g.: If an organisation indicated they rarely informed their volunteers on the organisation of care but indicated that they would like to inform them more, this was coded as a 'supportive' inclination towards increased involvement.

	Desired involvement within organisation: For each level organisations indicated whether they would like it to be less, more or think it is adequate		
Actual involvement within organisation: for each level organisations indicated to what extent this applies within their organisation	Less	Adequate	More
Never	Less supportive	Less supportive	Supportive
Rarely	Less supportive	Less supportive	Supportive
Often	Less supportive	Supportive	Supportive
Always	Less supportive	Supportive	Supportive

5.3 Results

Out of a total of 342 organisations, a response was received from 264. Non-eligible respondents (e.g. organisation no longer existing) were subtracted from the sample denominator, bringing it down to 334. In accordance with the guidelines set by the AAPOR[33], we came to a valid response rate of 79% (264/334) (**Table 1**). Out of 84 non-response surveys sent, 27 were returned (25%). Seven organisations (28%) indicated that they had not received a questionnaire. Of those that had received one, 7 (27%) had replied but the reply had not reached us. 37% of those that received a questionnaire but did not return it cited lack of time. Six returned non-response surveys were considered as partial responses;

because they either indicated having no volunteers or provided limited data. The questionnaire consisted of 117 individual items to be completed (optional items excluded). The completion rate for 0 missings was 29%; the completion rate for <10% missings – corresponding to <12 individual item missings – was 83%.

5.3.1 VOLUNTEER INVOLVEMENT

Of all organisations, 75% often or always **informed** their volunteers about the organisation of care; 35% often or always **consulted** their volunteers on how care should be organised; 47% often or always had their volunteers **'co-produce'** the organisation of care; 15% often or always gave volunteers some decision rights **(collaboration)** and 8% often or always gave autonomy **(empowerment)** to volunteers over how aspects of care are organised (**Table 2**). Dedicated palliative care services and sitting services more frequently informed and consulted with their volunteers than did other organisations. Sitting services and Community Home-care services more frequently co-produced, collaborated with and empowered volunteers.

Table 1: Survey response and completion rate

Organisation types	Sample total	Response	Response rate	Completion rate (0% missings)[a]	Completion rate (<10% missings)[b]
Medical oncology	39	25	64%	40%	84%
Sitting services	39	33	85%	3%	82%
Dedicated palliative care services	47	45	96%	20%	96%
Paliative care units	27	25	93%	28%	92%
Palliative day-care services	5	5	100%	0%	100%
Palliative Home-care Teams	15	15	100%	13%	100%
Volunteer community home-care	12	10	83%	10%	80%
Nursing homes	197	145	74%	38%	83%
Total	**334**	**264**	**79%[c]**	**29%**	**83%**

[a] The questionnaire consisted of 117 items which respondents were asked to answer (optional items excluded). The completion rate was calculated by dividing the number of completed questionnaires (0 missings and <10% missings respectively) by the total number of received questionnaires.

[b] 10% missings corresponded to <12 missings on a total of 117 potential missings.

[c] Calculated with the AAPOR non-response calculator tool [33]

Table 2: Reported volunteer involvement in organisations providing palliative care, Belgium (2016)

Organisation		Totals	Medical Oncology	Sitting Services	Dedicated palliative care services[a]	CHC[b]	Nursing Homes	p-value[c]
Number of organisations with direct patient care volunteers[d,e]		**206**	16	32	44	8	106	
The volunteers are informed on how (professional and voluntary) care for the patients is organised. (INFORM)	**Never**	**4%**	6%	0%	0%	0%	7%	<.001*
	Rarely	**21%**	25%	6%	0%	50%	32%	
	Often	**44.5%**	38%	59%	32%	50%	46%	
	Always	**30.5%**	31%	34%	68%	0%	15%	
The organisation requests the opinion of the volunteers on how (professional and voluntary) care for the patients is organised. (CONSULT)	**Never**	**22%**	19%	0%	16%	43%	30%	<.001*
	Rarely	**43%**	69%	28%	41%	29%	46%	
	Often	**32%**	12%	72%	36%	29%	20%	
	Always	**3%**	0%	0%	7%	0%	4%	
The organisation takes into account the opinion of the volunteers when making decisions on how (professional and voluntary) care for the patients is organised. (CO-PRODUCTION)	**Never**	**10.5%**	20%	0%	5%	0%	16%	<.001*
	Rarely	**43%**	53%	22%	41%	29%	50%	
	Often	**39.5%**	27%	56%	45%	71%	31%	
	Always	**7%**	0%	22%	9%	0%	3%	
The volunteers have decision rights regarding how (professional and voluntary) care for the patients is organised. (COLLABORATE)	**Never**	**42%**	75%	28%	41%	0%	45%	.001*
	Rarely	**43%**	12.5%	50%	39%	43%	48%	
	Often	**11%**	12.5%	19%	16%	29%	6%	
	Always	**4%**	0%	3%	4%	29%	2%	
The volunteers are able to make autonomous decisions regarding how certain aspects of the (professional and voluntary) care for the patients are organised. (EMPOWER)	**Never**	**67%**	81%	56%	68%	43%	70%	<.001*
	Rarely	**25%**	13%	28%	23%	14%	28%	
	Often	**6%**	6%	16%	7%	14%	2%	
	Always	**2%**	0%	0%	2%	29%	0%	

[a] Dedicated palliative care services include palliative care units, palliative day care centers and multidisciplinary palliative support teams (home care).

[b] CHC = Community Home Care organisations. [c] Chi-Square analysis was done to check for significant differences across organisation types. [d] Missings ranged from 1.9% to 2.9% and were excluded (listwise) from the analysis. [e] 264 organisations participated in our study, however only organisations with volunteers that provide direct patient care were included for these analyses (=206).

Table 3: Organisations' inclinations towards their volunteers' involvement, Belgium (2016)

Organisation		Total	Medical oncology	Sitting services	Dedicated palliative care services[a]	CHC[b]	Nursing homes	p-value[c]
Number of organisations with direct patient care volunteers[d,e]		**206**	15	32	44	7	100	
The volunteers are informed on how (professional and voluntary) care for the patients is organised. (INFORM)	**Supportive**	**83%**	80%	97%	100%	57%	72%	<.001*
	Less supportive	**17%**	20%	3%	0%	43%	28%	
The organisation requests the opinion of the volunteers on how (professional and voluntary) care for the patients is organised. (CONSULT)	**Supportive**	**47%**	27%	78%	43%	33%	41%	.002*
	Less supportive	**53%**	73%	22%	57%	67%	59%	
The organisation takes into account the opinion of the volunteers when making decisions on how (professional and voluntary) care for the patients is organised. (CO-PRODUCE)	**Supportive**	**56%**	43%	84%	52%	67%	49%	.008*
	Less supportive	**44%**	57%	16%	48%	33%	51%	
The volunteers have decision rights regarding how (professional and voluntary) care for the patients is organised. (COLLABORATE)	**Supportive**	**18%**	20%	19%	20%	50%	15%	.319
	Less supportive	**82%**	80%	81%	80%	50%	85%	
The volunteers are able to make autonomous decisions regarding how certain aspects of the (professional and voluntary) care for the patients are organised. (EMPOWER)	**Supportive**	**8%**	0%	13%	10%	33%	6%	.098
	Less supportive	**92%**	100%	87%	90%	67%	94%	

[a] Dedicated palliative care services include palliative care units, palliative day care centres and multidisciplinary palliative support teams (home care).

[b] CHC = Community Home Care organisations. [c] Chi-Square analysis was done to check for significant differences across organisation types. [d] Missings ranged from 4.37% to 7.48% and were excluded (listwise) from the analysis. [e] 264 organisations participated in our study, however only organisations with volunteers that provide direct patient care were included for these analyses (=206).

Table 4: Factors associated with organisational inclinations towards volunteer involvement

		INCLINATIONS TOWARDS INVOLVEMENT									
	Total	Inform[a]		Consult		Coproduce		Collaborate		Empower	
		+	-	+	-	+	-	+	-	+	-
Number of organisations with direct patient care volunteers[b,c]	206	162	34	93	104	109	87	35	157	16	175
% of organisations		83	17	47	53	56	44	18	82	8	92
Obligatory training offered %	33	95	5	42	58	52	48	18	82	5	95
p-value[d]		.001*		.174		.261		.980		.192	
Number of training subjects offered (0-13) (mean)	5.99	6.45	3.96	6.41	5.66	6.34	5.68	6.32	5.92	6.53	5.93
p-value[e]		<.001*		.161		.214		.508		.538	
ADL scale[f] (0-6) (mean)	2.51	2.71	1.77	2.91	2.21	2.80	2.22	3.21	2.36	2.81	2.47
p-value		.003*		.005*		.019*		.028*		.446	
iADL scale[g] (0-8) (mean)	2.70	2.77	2.38	3.11	2.36	2.89	2.48	3.16	2.61	2.88	2.69
p-value		.276		.004*		.124		.121		.761	
PSE index[h] (0-5) (mean)	3.98	4.12	3.28	4.17	3.8	4.08	3.84	4.00	3.99	4.00	3.98
p-value		.012*		.042*		.219		.957		.958	

[a] Supportive inclinations indicated as '+', less-supportive inclinations indicated as '-'. [b] Missings ranged from 4.3% to 14.08% and were excluded (listwise) from the analysis. [c] 264 organisations participated in our study, however only organisations with volunteers that provide direct patient care were included for these analyses (=206). [d] Chi-square test. [e] Two-tailed t-test for equality of means. [f] Cronbach's Alpha = 0.812. [g] Cronbach's Alpha = 0.672. [h] Cronbach's Alpha = 0.671

Table 5: Associations with involvement clusters

Variables		Involvement clusters				
CROSSTABS		Strong	Restricted	Uninvolved	Total	p-value[b]
N[a]		63	88	49	200	
Obligatory training offered	Yes (vs. No)	**51%**	**29%**	**15%**	**66.5%**	<.001*
ANOVA						
		Mean	Mean	Mean	Mean	p-value[c]
Range of training subjects offered		**7.51**	**5.92**	**4.15**	**5.99**	**<.001***
Strong vs Restricted[d]		7.51	5.92	/		.016*
Strong vs Uninvolved[d]		7.51	/	4.15		<.001*
Restricted vs Uninvolved[d]		/	5.92	4.15		.020*
ADL scores		**3.12**	**2.52**	**1.76**	**2.51**	**<.001***
Strong vs Restricted[e]		3.12	2.52	/		.127
Strong vs Uninvolved[e]		3.12	/	1.76		<.001*
Restricted vs Uninvolved[e]		/	2.52	1.76		.014*
iADL scores		**3.12**	**2.57**	**2.28**	**2.68**	**.049***
Strong vs Restricted[d]		3.12	2.52	/		.167
Strong vs Uninvolved[d]		3.12	/	1.76		.050*
Restricted vs Uninvolved[d]		/	2.52	1.76		.654
PSE scores		**4.56**	**3.80**	**3.53**	**3.98**	**<.001***
Strong vs Restricted[e]		4.56	3.80	/		<.001*
Strong vs Uninvolved[e]		4.56	/	3.53		<.001*
Restricted vs Uninvolved[e]		/	3.80	3.53		.566

[a] Missings were 22.5% and were excluded (analysis by analysis) from the analysis. [b] Two-tailed Chi-square test. [c] Two-tailed F-test. [d] Tukey HSD post-hoc test. [e] Games-Howell post-hoc test.

5.3.2 ORGANISATIONS’ DESIRED VOLUNTEER INVOLVEMENT

The majority of organisations felt that they adequately inform (82%), consult with (74%), co-produce with (75%), collaborate with (75%) and empower (74%) their volunteers. (Not shown in table.)

5.3.3 ORGANISATIONAL INCLINATIONS TO VOLUNTEER INVOLVEMENT

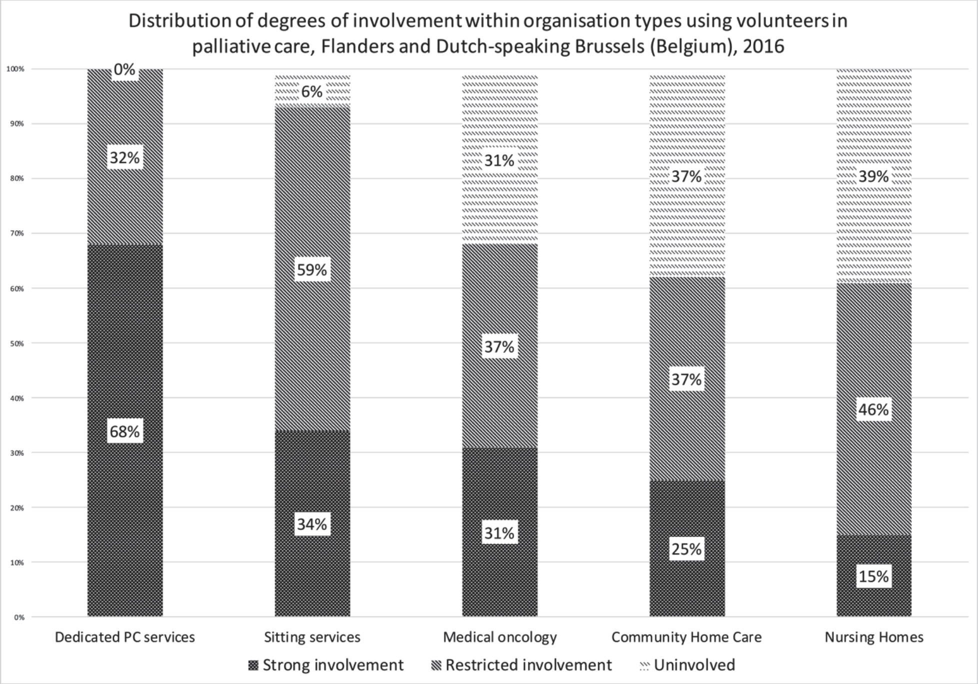
Organisations’ inclinations to each level of volunteer involvement, measured in *supportive* versus *less supportive inclinations* towards increasing each level of volunteer involvement in the organisation of care differed significantly between organisation types. (**Table 3.**) Supportive inclinations towards informing volunteers were found in from 57% of community home-care organisations to 100% of dedicated palliative care services. Sitting services (78%) were the most supportive of consulting volunteers and sitting services (84%) and Community Home-care services (67%) were most supportive of coproducing the organisation of care with volunteers; 82% of organisations were less supportive of collaborating with volunteers and 92% were less supportive of empowering them, with no significant differences between organisation types.

Being supportive towards informing or consulting volunteers was associated with a higher average total of training topics provided to volunteers per organisation, and a higher average total of ADL, iADL and PSE tasks performed by volunteers (**Table 4**).

5.3.4 FACTORS ASSOCIATED WITH VOLUNTEER INVOLVEMENT

A Two-Step Cluster analysis revealed three clusters of organisations in terms of volunteer involvement: ‘strong’ involvement (N=63; 31.5%), ‘restricted’ involvement (N=88; 44%), and ‘uninvolved’ (N=49; 24.5%). **(See Appendix 5.1.)**

Figure 5.1: Distribution of degrees of involvement within organisation types using volunteers in palliative care, Flanders and Dutch-speaking Brussels (Belgium), 2016



Degree of involvement of volunteers in the organisation of care differed significantly between organisation types. (p<.001) **(Figure 5.1.)** The majority of dedicated palliative care services were located in the 'strong' involvement cluster (68%); the majority of sitting services were in the 'restricted' involvement cluster (59%). Medical oncology departments were evenly distributed across all three clusters. A large portion of Community Home-care services (37.5%) and Nursing homes (39%) were in the 'uninvolved' cluster. Nursing homes had the smallest proportional presence in the 'strong' involvement cluster (15%). When testing associations between degree of involvement and mean total of training subjects offered, mean total ADL, iADL and PSE tasks performed, the assumption of homogeneity of variances was violated for the variables measuring ADL and PSE task performance. A Games-Howell test was therefore run for these specific associations. Higher degrees of involvement were associated with higher proportions of organisations offering obligatory training (p<.001), higher means of total training subjects offered (p<.001), and higher scores on the ADL scale (p<.001) and PSE index (p<.001). **(See Table 5.)**

5.4 Discussion

5.4.1 MAIN RESULTS

While a majority of Flemish health care organisations often or always inform their volunteers in the framework of the power sharing model, a minority co-produce the organisation of care with their volunteers and only a small fraction use a model of empowered decision-making by volunteers. Dedicated PC services and sitting services tend to have the highest volunteer involvement, nursing homes the lowest. Having a higher degree of actual volunteer involvement was associated with more volunteer training and more ADL and PSE task performance by volunteers.

5.4.2 INTERPRETATION

The existing literature on palliative care volunteerism contains few studies regarding volunteer involvement, all of which look at involvement in palliative care as the presence of volunteers in care provision[34]**.** To study the full extent to which volunteers may contribute to patient care or health services in palliative care, we drew from community engagement models[35–38] applied to end-of-life care[27]. As such, this study is the first, to our knowledge, to report on different levels of actual volunteer involvement across a healthcare system and not limited to dedicated palliative care services. Whereas literature has extensively covered what volunteers do[3,7,12,20], this study offers new insights regarding the involvement of volunteers in the organisation of care provision. It is furthermore the first study to apply in practice the power sharing model suggested by Sallnow and Paul[27], further bridging the community engagement literature and the end-of-life care literature.

The study's results inform the feasibility of a shift towards greater care provision by the informal sector. Volunteers may support palliative care in two distinct but complementary ways. The first is care provision, i.e. the performance of care and care related tasks for patients, their relatives and other caregivers. Volunteers perform a range of care and care-related tasks[6,7,12] and receive a range of training for this[39–41]. The second is involvement in the organisation of care, i.e. having a voice and decision-rights in the organisation. Volunteer care provision is an important part of palliative care and requires close coordination and supervision by paid staff which means increasing their work load and responsibilities and costing the organisation time and resources. Volunteer involvement on the other hand may complement care provision by putting some of this responsibility and work load into the hands of the volunteers themselves. Increased volunteer autonomy in the organisation of care could potentially translate into a larger capacity for volunteers to support the care organisation.

However, our results indicate that involvement by direct patient care volunteers in palliative care is currently largely restricted to information and feedback. They are well informed and sometimes have the opportunity to give their own feedback on the organisation of care. Sometimes this feedback is taken into account by the organisation. Healthcare organisations indicate being open to volunteer involvement, provided it is limited to these feedback processes. Volunteers are rarely given tangible responsibilities, such as decision-rights or autonomy over any aspects of the organisation of care. However, organisations with more involved volunteers also provide more training, rely more heavily on their volunteers in task performance and are more supportive of this involvement.

Results also suggest that generalist palliative care settings, in particular nursing homes, use a volunteer model with low involvement levels. Dedicated palliative care services and sitting services indicate the highest degrees of actual volunteer involvement. A previous study also indicated that nursing homes provide little training to their volunteers and had them perform fewer tasks relative to other health care organisations[20]. These differences in involvement may therefore also be due to the lower emphasis on palliative care in these generalist care organisations, further emphasising the importance of volunteers to palliative care provision. The associations found between degree of involvement, training provision and task performance may suggest an underlying model of reinforcement in which investment in volunteers can lead to positive experiences and a willingness among organisations to invest further in their involvement. As with specialisation among professional caregivers, training requirements for volunteers may differ according to care settings and the level of involvement of the volunteer may require appropriate skills. Organisations with higher levels of involvement should therefore not necessarily be assumed to be doing better than those with lower levels, but it may depend on the needs and nature of the care setting. For example, the main focus of medical oncology departments is curative care and patients have less intensive care needs. However, the low level of volunteer involvement, training and task performance in nursing homes remains surprising. These results may be due to a lack of recognition of palliative care needs in nursing homes, a lack of coordination resulting from understaffing[42,43], or a mix between care culture, regulations and staff training that may determine what volunteers are allowed to do. Nursing homes may therefore have room to grow towards stronger volunteer involvement and broader volunteer roles than medical oncology departments.

Future research should therefore explore the direction of causality between involvement, task performance and training. Such insights will inform organisations and policy makers on how to improve the provision and organisation of palliative care. Furthermore, to fully understand the capacity of volunteerism in palliative care, the question of whether volunteers feel that they are being listened to and whether they desire or require increased involvement in the organisation of care should be explored. Finally, single-item questions are limited in their capacity to capture complex phenomena such as the higher levels of engagement in the power sharing model. The shape these specific levels of involvement take in practice should be explored.

5.4.3 STRENGTHS AND LIMITATIONS

The data for this article were gathered in a study that mapped registered, palliative, direct patient care volunteering across an entire healthcare system and across generalist and dedicated palliative care services. Its scope and sample frame allow our observations to be reliably generalised to the Flemish and Brussels context. The study uses a conceptual model from the community engagement literature to measure volunteer involvement and the organisation's desired volunteer involvement in palliative care settings. The results indicate a link between task performance, training provision and involvement that may be generalisable across national settings regardless of organisational structure. While non-response was low, some bias is possible. Firstly, in some cases, respondents may have been remote from their volunteers, affecting the reliability of their responses. Moreover, their perspectives may differ from other members of their organisation. However, due to our focus on the organisational perspective, some distance was expected and addressing volunteer coordinators increased the accuracy of our data. The organisational perspective does not necessarily coincide with the experience of their volunteers; however, it does represent the volunteer policy of the organisation. Secondly, although we followed a robust expert-consultation-based method to determine the sample of organisations potentially providing palliative care volunteers, there may still be other settings where palliative care volunteers operate. By focusing on registered volunteers, we potentially missed less frequent, unregistered forms of volunteering. Thirdly, while we lacked sufficient data to test for causality or perform any multivariate analysis reliably, this study offers interesting associations to be further explored in future research. Finally, the items in the questionnaire developed to measure (1) psychosocial, existential and signalling care tasks and (2) training subjects were constructed by the researchers and are likely not to be exhaustive, therefore providing an exploratory description rather than a definitive one. However, an ‘other, please specify’ option was provided for training subjects.

5.5 Conclusion

Organisational involvement of volunteers in palliative, direct patient care is mostly limited to their being kept informed, giving feedback and having this feedback heard by the organisation. Organisational inclinations towards the involvement of volunteers indicate that more autonomous forms of involvement are generally not sought out by the organisation. Dedicated palliative care services, however, display a strong degree of volunteer involvement, in contrast to generalist palliative care services, in particular nursing homes and medical oncology departments. Organisational involvement of volunteers may positively influence volunteer training and task performance which may benefit healthcare organisations by increasing the quality of care provision by volunteers. Given the apparent intentions of governments to meet the resource challenges facing professional healthcare through more care provision by informal caregivers, these results indicate that volunteers may be able to play a valuable supporting role in the organisation of care as well. Increased volunteer involvement may benefit dedicated palliative care services more than generalist care services where emphasis on palliative care is lower. Policy makers, healthcare organisations and researchers should further explore the reinforcement processes between volunteer involvement, training and task performance.

5.6 Declarations

5.6.1 ACKNOWLEDGEMENTS

Dirk Houttekier helped with the design of the study protocol and the data collection.

Thijs Reyniers provided the excel template to track questionnaire mail-out and response.

Jane Ruthven provided language editing of the manuscript.

All **volunteer coordinators and organisational representatives** of Flemish and Brussels healthcare organisations who provided data on their organisation or coordinated data gathering in the organisations under their jurisdiction.

All **experts** from different healthcare organisations in Flanders and Brussels who participated in our expert consultation.

5.6.2 SOURCE OF FUNDING

This work was supported by the Agency for Innovation by Science and Technology (IWT) as part of the INTEGRATE-project. [SBO-IWT 140009].

5.6.3 CONFLICT OF INTEREST

The Authors declare that there is no conflict of interest.

5.6.4 RESEARCH ETHICS AND PATIENT CONSENT

The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Brussels. (ref. B.U.N. 143201627927) Approval was granted on March 23, 2016.

5.6.5 DATA MANAGEMENT AND SHARING

The data of this study is kept by the first author and is available upon request.

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6 CHAPTER 6 : THE INVOLVEMENT OF VOLUNTEERS IN PALLIATIVE CARE AND THEIR COLLABORATION WITH HEALTHCARE PROFESSIONALS: A CROSS-SECTIONAL SURVEY OF VOLUNTEERS ACROSS THE HEALTHCARE SYSTEM

Steven Vanderstichelen, Joachim Cohen, Yanna Van Wesemael, Luc Deliens, Kenneth Chambaere

Submitted to *Health and Social Care in the Community* 2019 (in review)

Abstract

Background Volunteers occupy a specific space in the delivery of palliative care (PC), addressing specific aspects of care and providing a link between professional health care providers and informal care. Engaging and empowering these volunteers can be an important strategy to deliver more integrated and comprehensive PC. Insights into current actual volunteer involvement and collaboration across different health care services providing generalist and specialist PC is lacking.

Objective Describe volunteers' involvement in the organisation of PC and collaboration with professionals, and how they evaluate this.

Design A cross-sectional postal survey of volunteers was conducted between June and November 2018.

Settings Dedicated PC services, medical oncology departments, sitting services, community home-care services and nursing homes in the Flemish healthcare system (Belgium).

Participants A two-step disproportionately stratified cluster randomised sample of 2273 registered volunteers was taken from healthcare organisations providing care for people with serious illnesses.

Methods Data was collected using a written questionnaire addressed to all volunteers in each selected cluster. Data was collected on volunteer involvement in the organisation of PC, volunteer-professional collaboration, and evaluations of these. Uni-, bi- and multivariable analysis was used to describe volunteer involvement, collaboration and barriers. ANOVA was conducted to test for associations between variables. Categorical PCA and Two-Step Cluster analysis were conducted to identify dimensions of involvement and clusters of volunteer involvement.

Results Overall response was 35%, ranging between 15 % and 60% for individual strata. 67% of volunteers were often to always informed about the organisation of patient care and 48% felt the organisation often to always takes their opinion into account, while a minority report having decision rights (18%) or autonomy

(24%). For some, their organisation failed to inform (17%), consult (27%), take into account their opinion (21%), give them decision rights (20%) or autonomy (16%) over certain aspects of patient care provision often enough. Overall, volunteer-professional collaboration was low, and mostly limited to information-sharing. Dedicated PC volunteers collaborated extensively with nurses, often involving task coordination (46%). Ambiguity regarding tasks, agreements and/or rules (15%) and lack of information exchange (14%) were the most cited barriers to volunteer-professional collaboration.

Conclusion A sizeable group of volunteers is open to a higher degree of involvement in the organisation of care in PC services. Collaboration with professionals seems lacking both in width and in depth. Particularly nursing home volunteers indicated a desire and large potential for a more involved and collaborative role in PC provision.

Key words

Volunteering; palliative care; Surveys and questionnaires; involvement; collaboration; nurses

Contribution of the paper

What is already known about the topic?

- Volunteers provide direct patient palliative care in both dedicated and generalist care services, performing a wide range of tasks, including psychosocial, existential and signposting tasks.
- Volunteers positively influence the quality of care for terminally ill people and those close to them by reducing stress and offering practical and emotional support and providing a link to the community.
- Previous research indicates volunteer involvement in the organisation of care may be beneficial to palliative care services

What this paper adds

- Inpatient service volunteers are found to be more limited in their involvement in the organisation of palliative care than extra-mural care service volunteers, who show more autonomous involvement.
- The largest potential for growth and further development of the palliative care volunteer role is found among nursing home volunteers, who were least involved but signalled a desire for increased involvement and collaboration.
- The main barriers to volunteer-professional collaboration were ambiguity regarding tasks, agreements and/or rules and a lack of information exchange.

6.1 Introduction

Partly due to increasing resource constraints in professional healthcare, some governments are turning to informal caregivers such as volunteers to supplement professional healthcare by providing increased shares of palliative care[1–8]. Volunteers have a long history of supporting palliative care and have played an important role since the early days of the palliative care movement. They continue to be involved in palliative care provision, both in the community and in institutional settings[9–12], taking up several roles ranging from administration and fundraising to providing companionship and support[13–15]. As such they can positively influence the quality of care for both terminally ill people and those close to them by reducing stress, offering practical and emotional support and providing a link to the community[11,16–19]. Volunteers can provide palliative, direct patient care in both dedicated palliative care and in generalist palliative care (i.e. palliative care provided by regular professional caregivers such as the hospital specialist, general practitioner, home care nurses, nursing home staff) providing psychosocial, signposting (e.g. being an intermediary, communicating needs to professional caregivers, etc.) and existential care for people at the end of life and for those close to them[20].

Several studies have explored volunteer task performance, training, motivation, economic value and turnover rates[11,19–22]. However, with exception of a few studies that consider volunteer involvement – conceptualised mainly as volunteer presence – in palliative care[23,24] and volunteer-professional collaboration in palliative care[25–27], the literature hitherto lacks insights into the wide variation of volunteers active in palliative care and into how volunteers are integrated into health services and care provision. Most studies limit their focus to volunteers in dedicated palliative care services[14,23,28–30], while research has, for instance, suggested that home-care services, sitting services and – to a lesser extent – oncology wards and nursing homes have volunteers who perform several palliative care-related tasks[20,24,31]. With the exception of qualitative studies, most studies report findings at the level of the health service. Finally, no data is available on volunteer reported involvement and collaboration and how they evaluate these in the organisation of care.

The New Public Health movement has in recent years emphasised the importance of promoting community development and engagement to fill the support spaces between episodes of professional care[32,33]. The organisational framework of health services may be an important medium by which communities can be engaged through volunteering. In order to anticipate how the expansion of informal care may affect healthcare provision and to evaluate the supportive capacity of volunteers within the health service framework, it is necessary to know to what extent volunteers are currently involved in the organisation of palliative care provision, to what extent they are currently collaborating with professionals and to what extent they find their involvement and collaboration lacking or unnecessary.

The research questions of this study are:

1. To what extent are volunteers currently involved in the organisation of palliative care?
2. How do volunteers evaluate their involvement in the organisation of palliative care?
3. How do volunteers currently collaborate with other carers?
4. With whom do volunteers feel collaboration could be improved and what barriers to collaboration do they experience?

6.2 Method

We conducted a cross-sectional postal survey between June and November 2018 among volunteers from healthcare organisations providing care for people with terminal illnesses towards the end of life – though not necessarily in the terminal stage – in the Flemish healthcare system. The Belgian regions (Flanders, Wallonia, and Brussels) have autonomy over various aspects of healthcare in the different language communities (Dutch, French, and German speaking), including home care, hospital care and long-term care. The Flemish government is therefore responsible for these aspects in Flanders and for the Dutch speaking community in Brussels. We therefore included (volunteers in) healthcare organisations in Flanders and Dutch speaking Brussels in this study and excluded Wallonia as it falls under a different regional authority and the organisation of palliative care differs on the regional level. Other reasons for exclusion include the added analytical complexity resulting from strong differences in context and language differences. In 2018 the Flemish region and the Brussels region had respective populations of 6,552,967 and 1,198,726 inhabitants, accounting for 68% of the total Belgian population[34].

6.2.1 DEFINITIONS

We define volunteerism in palliative care as *the time freely given by individuals, with no expectation of financial gain, within some form of organised structure other than the already existing social relations or familial ties, with a palliative approach – i.e. the intention of improving the quality of life of adults and children with life-limiting conditions and those close to them (family and others).* (Adapted from Goossensen et al.[35]) This definition is in accordance with that provided by the Belgian federal law[36,37].

We define *Volunteer involvement* in the organisation of care as the extent to which volunteers have a voice[38] in the organisation and the degree to which it carries weight with regard to how decisions are made about the organisation of patient care provision.

Volunteer collaboration with other carers was defined using Ushiro's[39] operational definition of collaborative practice as "actions related to sharing information about patients, participating in decision-making concerning patient care, and providing comprehensive care to patients from a patient-centred perspective."

6.2.2 ETHICS APPROVAL

The proposal for this study was submitted for approval to the commission of medical ethics of the university hospital of Brussels. (ref. B.U.N. 143201835145) Approval was granted on April 04, 2018.

6.2.3 POPULATION AND SAMPLE

The population for this study consists of all registered volunteers in a selection of healthcare organisations in Flanders and Dutch-speaking Brussels, as determined by a previous study[20,24], which deploy volunteers in direct patient care for people with serious illness. Because palliative care is not only provided in dedicated palliative care services but also in certain generalist care services, we included volunteers from the latter setting. Listings of these organisations were provided by the Flemish Ministry for Welfare, Public Health and Family[40]. Because of the resulting multitude of healthcare organisations, types and large numbers of volunteers, and given the lack of a central register of volunteers, determining a representative sampling framework was complex. It necessitated a two-step sample procedure, resulting in a disproportionately stratified cluster random sample of volunteers. See **Box 6.1** for the list of strata and descriptions, and total clusters (i.e. individual organisations) per stratum. Based on estimates of average total volunteers per stratum and per cluster, obtained from a previous study[20,24], a required sample size was calculated for each stratum, assuming a 5% margin of error and $\propto = 0.05$ (for a finite population). Lacking other empirical studies of similar scope, a response rate of 70% was assumed based on one previous study of palliative care volunteering at the organisational level, which used the same sample population[20,24]. A required total of clusters per stratum was estimated based on this. This meant a total of 44 clusters across all strata for an estimated total of 2115 volunteers. See **Appendix 3.1** for details on the sampling procedure.

Box 6.3: Strata from which clusters (i.e. individual organisations) were sampled †

1. **Dedicated palliative care services (N=44)** are services that specialize in palliative care treatment for people with chronic, life-threatening conditions towards the end of life. This stratum therefore consists of (1) palliative care units (PCU) in (or associated with) hospitals (N=25)), (2) palliative daycare centres (PDC) (N=5), and (3) palliative home care support teams (PHT) (N=14), which are part of the regional palliative networks and provide support for other caregivers in home or replacement home situations.
2. **Medical oncology departments (MOD) (N=16)** are hospitals departments with a fully established oncology care program, a hospitalization program and a multidisciplinary team focused on oncology. Care provision may both be curative as well as palliative.
3. **Facilities for sitting services (N=32)** organize sitting services by volunteers during the day or at night. The facility sends a volunteer to people's homes to keep them company, give them a sense of security and basic care. They offer respite care and function similar to befriending services.[‡]
4. **Volunteer community home care organisations (CHC) (N=8)** are organized by the Christian Sickness fund (*Christelijke Mutualiteit*). Their services are locally organized and run by volunteers who pay home visits to the elderly and patients with heavy care needs in their neighborhoods. Not all people who receive visits suffer from chronic, life-threatening conditions, but many of them may.
5. **Nursing homes (NH) (N=105)** offer permanent care and nursing to elderly people. A resident of a residential care centre has his or her own room or living space there. Nursing homes may house residents with chronic, life-threatening conditions.

[†] Descriptions fully or partially taken from Agency for Health and Care website[40].
[‡] See Walshe et al.[41]

6.2.4 DATA COLLECTION

Data was collected using a written questionnaire, developed by the researchers for this study and addressed to the volunteers in each cluster. Questionnaires were sent to the volunteers by the organisations upon agreeing to participate in the study and volunteers and their corresponding questionnaires were codified so the researchers could track response without collecting individual names and addresses. Clusters were resampled upon refusal, following the same sampling method as before, and efforts were made to document reasons for refusal. One sitting service was resampled because their volunteers did not speak Dutch; one community home-care service was resampled due to refusal after prior agreement to participate (no reason given). Upon agreeing to participate, the exact number of volunteers in the organisation was registered and all present volunteers were included for the survey – with the exception of community home-care services which had too many volunteers and where we drew a random sample of volunteers. A data collector (FS) coordinated the recruitment of clusters via phone or e-mail and facilitated data collection by visiting each cluster to facilitate the survey mail-out in collaboration with volunteer coordinators. Our total N for this survey was 2420. Questionnaires were mailed out throughout June 2018. In September a reminder was sent to volunteers who had not yet responded and in October a non-response survey was sent to those who had still not responded. The non-response survey consisted of three questions to gauge the reasons for non-response. Data collection was concluded in November 2018. No personal information was collected, ensuring anonymity.

6.2.5 QUESTIONNAIRE

The questionnaire, developed specifically for this study, consisted of 23 questions, including on *volunteer involvement, volunteer collaboration with professionals, barriers to volunteer collaboration, and contact with patients with chronic and life-threatening illnesses*. The questionnaire was developed based on the literature on volunteering in palliative care and the questionnaire used in a previous organisational survey on volunteering[20,24]. The questionnaire was cognitively tested in two rounds with volunteers in palliative care. *Volunteer involvement* in the organisation of care was operationalised using Sallnow & Paul's model of power sharing in palliative care[42]. The model consists of five types of engagement work represented as a spectrum: **inform – consult – coproduce – collaborate – empower**. (**See Box 6.2.)** For each of these types the volunteers were asked how frequently these applied to them (never – rarely – often – always) and to evaluate this frequency. Volunteer collaboration with other caregivers was operationalised as three types following Ushiro's definition[39] – exchanging information; making decisions together; coordinating tasks. Volunteers were asked to indicate for a number of possible care providers whether they collaborated with any of them in any of these three ways during their most recent session of volunteering in which they cared for a person with chronic and/or life-threatening condition. Potential improvement of collaboration was measured by asking volunteers to check off any of the previously listed carers if they thought collaboration with them could be improved. See **Appendix 3.2** for more details on the questionnaire.

Box 6.2: Conceptual model of power-sharing: five types of engagement works[42]

The five types of engagement work of the power-sharing model adapted to apply to registered volunteering in palliative, direct patient care in Belgium (Flanders and Brussels):

1. **Inform**

   This type represents the organisation informing its volunteers on how care provision is organised within the organisation. (E.g. what care is provided, how is it provided, by whom and to whom?) This can be done in many ways, such as informational booklets, leaflets, an introduction day, a training course, etc.

2. **Consult**

   This type requires the organisation to consult their volunteers to gauge their opinions and views on the organisation of care. The communication in this type of engagement work is one-way. No feedback is given to the volunteers during or after this consultation. This can be done in the form of a survey or meeting.

3. **Co-produce**

   ‘Co-production’ is a step up from consult. In this type of engagement work, communication does flow both ways. It allows the volunteers to determine how well the information they have provided to the organisation has been incorporated or acted upon. The organisation takes into account the volunteers’ opinions and views when making decisions regarding the organisation of care.

4. **Collaborate**

   This type of engagement work refers to the organisation and its volunteers working together when developing and organising care provision. In our study, it means volunteers have certain decision-making rights in the organisation of care, though the organisation still holds final authority and overall control.

5. **Empower**

   The final type of engagement work represents the volunteers taking full control of an aspect of care and developing their own responses. This means volunteers have autonomy over certain aspects of care in the organisation. Empower, as the extreme end of the power-sharing model, functions as an ideal type. It is unlikely that organisations would transfer full autonomy and responsibility to their volunteers for any aspect of care, however the extent of autonomy of volunteers may surely vary between organisations.

The question used to operationalise each level can be found in the questionnaire supplemented in Appendix 3.2. (Question 18.)

6.2.6 ANALYSIS

We performed uni-, bi- and multivariable analysis using IBM SPSS 25. Cross-tabs were run to calculate proportions for each variable for volunteers from different organisation types. Percentages were rounded. Chi-square tests were performed to check for statistical differences in proportions between volunteers from different organisation types. Significance at *p*=0.05 or lower was indicated with an asterisk (*). Categorical Principal Components Analysis (CATPCA) was conducted on the items of volunteer involvement to identify clear dimensions of involvement and a Two-Step Cluster analysis was performed to identify clusters of volunteer involvement types. (**See Appendix 6.1 for details on these analyses.**) Cluster membership was then used as a grouping variable for further analyses. CATPCA and Two-Step Cluster analysis were also used to explore profiles of volunteer-professional collaboration, but no stable or clear components emerged. The question measuring volunteer collaboration consisted of 12 listed carers, for which volunteers were asked to indicate whether one or more of three aspects of collaboration were applicable (or 'none of these / no contact'). When one or more, but not all, listed carers had missing responses, it was assumed respondents had missed or failed to check off the 'none of these / no contact' item for that item battery. Responses were then recoded during data cleaning to check off the latter option as they were not considered real missings. Remaining missings were removed from analyses (listwise).

6.3 Results

Out of a total estimate of 2420 volunteers, 2273 volunteers were registered and consequently surveyed. A response was received from **801**, resulting in a valid response rate of 35.2% in accordance with the guidelines set by the AAPOR[43]. (**See table 1**). Response was highest from volunteers from medical oncology departments and dedicated palliative care services. The total response rate was offset by the low response from volunteers from community home care services, sitting services and nursing homes. Volunteers were predominantly women (75.5%), aged 60-69 (43.4%), retired (70.8%) and had secondary school diploma's (46.7%). **(Demographics reported elsewhere[31].)** Out of 1488 non-response surveys sent, 31 were returned (2.08%). 10.3% indicated no longer or not being a volunteer, 24.1% indicated not providing care for people with chronic and life-threatening conditions as a volunteer, 31.0% indicated never having received the questionnaire and 10.3% indicated they returned it, but it never reached us. 17.2% indicated time constraints for not participating.

Table 1: Survey response

Recruitment settings	Cluster total	Sample total (volunteers)	Response	Response rate[1,2]
Total	**42[3]**	**2273**	**801**	**35.2%**
Dedicated palliative care services	17	502	280	55.8%
Palliative care units	12	329	184	55.9%
Palliative daycare services	1	59	27	45.8%
Palliative Home-care Teams	4	114	69	60.5%
Medical oncology depts.	10	101	61	60.4%
Sitting services	4	676	233	34.5%
Community home-care	1	530	81	15.3%
Nursing homes	10[3]	483	144	29.8%

[1] Calculated with the AAPOR non-response calculator tool (AAPOR, 2017).

[2] The questionnaire consisted of 161 individual items to be completed (optional items excluded). The completion rate for 0 missings was 29.0%; the completion rate for <10% missings – corresponding to <17 individual item missings – was 82.3 %.

[3] 10 of the 12 contacted clusters in the nursing home strata provided a response. For all other clusters we have at least one volunteer response.

Table 2: Volunteer involvement in the organisation of care in palliative care, Flanders, 2018

Organisation type		Total[3]	Dedicated PC	Medical oncology	Sitting services	Community home care	Nursing Homes	p-value[4]
N[1,2]		**645**	**277**	**62**	**185**	**55**	**64**	
How often are you informed on how care for the patients is organised? (INFORM) (%)	**Never – Rarely**	**33.5**	17.5	61.8	33.3	41.9	76.5	<.001*
	Often – Always	**66.5**	82.5	38.2	66.7	58.1	23.5	
How often does the organisation ask your opinion on how the care for patients is organised? (CONSULT) (%)	**Never – Rarely**	**66.4**	70.5	77.2	53.3	62.8	80.4	<.001*
	Often – Always	**33.6**	29.5	22.8	46.7	37.2	19.6	
How often does the organisation take your opinion into account in decisions about the organisation of care for patients? (CO-PRODUCE) (%)	**Never – Rarely**	**52.1**	54.1	69.6	38.9	41.9	75.0	<.001*
	Often – Always	**47.9**	45.9	30.4	61.1	58.1	25.0	
How often do you as a volunteer have decision making rights regarding decisions on how care for patients is provided? (COLLABORATE) (%)	**Never – Rarely**	**82.5**	88.3	89.7	72.4	65.9	90.2	<.001*
	Often – Always	**17.5**	11.7	10.3	27.6	34.1	9.8	
How often can you as a volunteer autonomously decide about how certain aspects of care for patients are provided? (EMPOWER) (%)	**Never – Rarely**	**76.2**	85.2	88.9	58.1	61.9	88.7	<.001*
	Often – Always	**23.8**	14.8	11.1	41.9	38.1	11.3	

[1]Volunteers that indicated coming into contact with people with chronic and/or life-threatening conditions during their volunteering work. [2]Missings ranged from 9.3% to 11.6%.[3]For two respondents it was not possible to determine which organisation type the volunteer was working in. [4]Chi-square analysis was done to check for significant differences across organisational volunteering settings. *Significance at *p* = 0.05 or lower.

Table 3: Volunteer evaluations of their involvement in the organisation of care in palliative care, Flanders and Dutch-speaking Brussels, 2018

Organisation type		**Total[3]**	**Dedicated PC**	**Medical oncology**	**Sitting services**	**Community home care**	**Nursing Homes**	**p-value[4]**
N[1,2]		**645**	**277**	**62**	185	**55**	**64**	
How often are you informed on how care for the patients is organised? (INFORM) (%)	**Not often enough**	**17.2**	11.9	30.2	12.8	15.0	51.4	<.001*
	Often enough[5]	**82.8**	88.1	69.8	87.2	85.0	48.6	
How often does the organisation ask your opinion on how the care for patients is organised? (CONSULT) (%)	**Not often enough**	**26.5**	27.9	27.3	23.7	23.1	31.6	0.827
	Often enough	**73.5**	72.1	72.7	76.3	76.9	68.4	
How often does the organisation take your opinion into account in decisions about the organisation of care for patients? (CO-PRODUCTION) (%)	**Not often enough**	**20.5**	20.7	19.5	16.4	26.3	28.9	0.435
	Often enough	**79.5**	79.3	80.5	83.6	73.7	71.1	
How often do you as a volunteer have decision making rights regarding decisions on how care for patients is provided? (COLLABORATE) (%)	**Not often enough**	**20.3**	19.8	4.9	21.4	31.4	27.0	0.043*
	Often enough	**79.7**	80.2	95.1	78.6	68.6	73.0	
How often can you as a volunteer autonomously decide about how certain aspects of care for patients are provided? (EMPOWER) (%)	**Not often enough**	**15.9**	16.4	4.4	14.7	20.5	25.6	0.083
	Often enough	**84.1**	83.6	95.6	85.3	79.5	74.4	

[1]Volunteers that indicated coming into contact with people with chronic and/or life-threatening conditions during their volunteering work. [2]Missings ranged from 12.1% to 20.0%.[3]For two questionnaires it was not possible to determine which organisation type the volunteer was working in. [4]Chi-square analysis was done to check for significant differences across organisational volunteering settings. [5]Only 0.4% of volunteers reported they were informed "too often" (this was 0.5% of volunteers in dedicated PC services and 0.8% of volunteers in sitting services). This answer category was otherwise not used by any volunteer, nor for the other four involvement types. This category was therefore merged into the "often enough"category. *Significance at $p = 0.05$ or lower.

Table 4: Types of volunteer collaboration with other caregivers in palliative care, Flanders, 2018

Organisational setting		Collaboration	Fellow volunteers	Volunteer coordinators	Family caregivers	Nurses	Family help
Dedicated PC	**N = 268**[a,b]	Information sharing	66.3%	41.7%	18.2%	78.0%	1.9%
		Decision-making	18.9%	10.2%	2.3%	16.7%	0.4%
		Task coordination	53.8%	8.3%	5.7%	46.2%	0.4%
		Mean score (0-3) [c,d]	***1.39***	***0.60***	***0.26***	***1.41***	***0.03***
		Any contact or collaboration	77.3%	44.7%	20.5%	87.9%	2.3%
Medical oncology	**N = 59** [a,b]	Information sharing	74.1%	44.8%	8.6%	63.8%	1.7%
		Decision-making	13.8%	10.3%	1.7%	6.9%	0.0%
		Task coordination	29.3%	3.4%	1.7%	13.8%	0.0%
		Mean score (0-3) [c,d]	***1.17***	***0.59***	***0.12***	***0.84***	***0.02***
		Any contact or collaboration	77.6%	48.3%	8.6%	67.2%	1.7%
Sitting services	**N = 152** [a,b]	Information sharing	47.0%	43.2%	49.2%	39.4%	26.5%
		Decision-making	11.4%	12.9%	22.7%	10.6%	12.9%
		Task coordination	18.9%	6.8%	22.7%	14.4%	11.4%
		Mean score (0-3) [c,d]	***0.77***	***0.63***	***0.95***	***0.64***	***0.51***
		Any contact or collaboration	52.3%	47.7%	56.1%	43.2%	30.3%
Community home care	**N = 47** [a,b]	Information sharing	62.2%	21.6%	30.6%	29.7%	2.7%
		Decision-making	32.4%	10.8%	16.7%	18.9%	0.0%
		Task coordination	45.9%	8.1%	5.6%	13.5%	5.4%
		Mean score (0-3) [c,d]	***1.41***	***0.41***	***0.53***	***0.62***	***0.08***
		Any contact or collaboration	70.3%	27.0%	32.4%	30.6%	8.1%
Nursing homes	**N = 52** [a,b]	Information sharing	60.0%	44.4%	8.9%	48.9%	2.2%
		Decision-making	26.7%	20.0%	0.0%	8.9%	0.0%
		Task coordination	42.2%	31.1%	4.4%	20.0%	2.2%
		Mean score (0-3) [c,d]	***1.29***	***0.96***	***0.13***	***0.78***	***0.04***
		Any contact or collaboration	71.1%	57.8%	11.1%	55.6%	2.2%

[a] Volunteers that indicated coming into contact with people with chronic and/or life-threatening conditions during their volunteering work. [b] Missings ranged from 7.2% to 7.4%. [c] Carers for which the mean collaboration score did not exceed 0.50 in any of the organisational settings were excluded from the table. These were specialist physicians, family physicians, psychologists, social workers, interns, and religious/existential counsellors. [d] Mean score indicates on average how many of the three specified types of collaboration – i.e. information sharing, decision-making, and task coordination – were indicated by volunteers.

Table 5: Carers with whom volunteer collaboration could be improved and barriers for collaboration with professionals, as indicated by volunteers, Flanders and Dutch-speaking Brussels, Belgium 2018

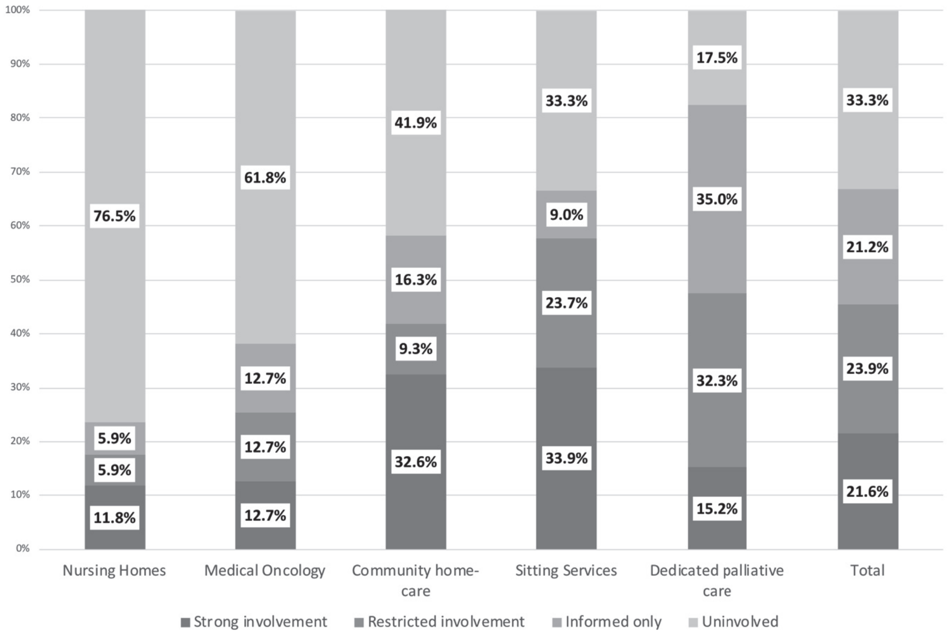
	Total[c]	Dedicated PC	Medical oncology	Sitting services	Community home care	Nursing homes	p-value[d]
N[a,b]	**580**	268	59	152	47	**52**	
Carers with whom collaboration could be improved							
None	**66.3%**	65.0%	75.5%	68.0%	87.1%	41.9%	0.001*
Nurses	**11.0%**	10.3%	5.7%	9.8%	3.2%	30.2%	<.001*
Volunteer coordinators	**8.7%**	9.0%	5.7%	8.2%	0.0%	18.6%	0.062
Fellow volunteers	**8.1%**	5.6%	3.8%	10.7%	3.2%	23.3%	0.001*
Specialist physicians	**7.2%**	11.5%	7.5%	1.6%	6.5%	0.0%	0.004*
Psychologists	**5.8%**	9.4%	9.4%	0.8%	0.0%	0.0%	0.002*
Family physicians	**3.7%**	4.3%	0.0%	3.3%	6.5%	4.7%	0.548
Social workers	**3.1%**	3.0%	3.8%	4.9%	0.0%	0.0%	0.435
Family help	**2.7%**	0.9%	0.0%	8.2%	0.0%	2.3%	0.001*
Spiritual counsellors	**2.5%**	4.3%	1.9%	0.8%	0.0%	0.0%	0.168
Family caregivers	**2.3%**	1.7%	0.0%	4.9%	0.0%	2.3%	0.190
Interns	**2.3%**	3.0%	0.0%	0.8%	0.0%	7.0%	0.094
Barriers for collaboration with healthcare professionals							
None	**60.5**	59.9	70.2	63.7	74.4	29.5	<.001*
Tasks, agreements and/or rules ambiguity	**14.9**	18.3	8.8	12.1	2.6	22.7	0.022*
Lack of information exchange	**13.9**	12.7	10.5	13.7	15.4	25.0	0.246
Lack of consultation moments	**9.3**	6.7	14.0	8.1	7.7	22.7	0.010*
Lack of appreciation	**7.9**	7.5	10.5	8.9	5.1	6.8	0.875
Lack of contact with other caregivers	**7.0**	4.0	7.0	12.1	5.1	11.4	0.040*
No regular caregivers to consult	**5.8**	3.6	3.5	8.1	7.7	13.6	0.057
Professionals' tight work schedules	**4.8**	4.4	1.8	1.6	12.8	13.6	0.002*
Lack of coordination	**4.8**	5.2	3.5	3.2	10.3	4.5	0.483
Lack of support (follow-up)	**3.5**	5.6	1.8	0.8	2.6	2.3	0.156
Professionals are not willing to collaborate	**2.3**	2.0	3.5	2.4	2.6	2.3	0.974
Conflicts with other caregivers	**1.5**	1.6	0.0	2.4	2.6	0.0	0.650

[a] Volunteers that indicated coming into contact with people with chronic and/or life-threatening conditions during their volunteering work in the last 12 months. [b] Missings were 10.9% 16.6%. [c] For two respondents it was not possible to determine which organisation type the volunteer was working in. [d] Chi-square analysis was done to check for significant differences across organisational volunteering settings.

6.3.1 VOLUNTEER INVOLVEMENT

Two thirds of volunteers (66.5%) indicated they are often to always informed about the organisation of patient care, while the majority of medical oncology (61.8%) and nursing home (76.5%) volunteers indicated this happened never or rarely for them. (**See Table 2.)** Across organisational settings, 66.4% of volunteers indicated they were never or rarely consulted about the organisation of care, although just under half (47.9%) of volunteers indicated their opinion was taken into account when decisions on the organisation of care were made. A small group of volunteers reported often or always having decision rights (17.5%) or autonomy (23.5%) regarding aspects of the organisation of care. Preliminary Two-Step cluster analysis based on the variables for 'inform', 'low involvement (consult-coproduce)' and 'high involvement (collaborate-empower)' revealed 4 clusters describing degrees of volunteer involvement. We called these clusters 'Strong involvement' (N=127; 21.5%), 'Restricted involvement' (N=141; 23.9%), 'Informed only' (N=125; 21.2%) and 'Uninvolved' (N=198; 33.5%). **(See Appendix 6.1 for details on the Two-Step Cluster analysis.)** Within sitting service (33.9%), community home-care (32.6%) and dedicated palliative care (15.2%) settings, volunteers reported the strongest involvement in the organisation of care. **(See Figure 6.1.)** Nursing home and medical oncology volunteers displayed the lowest involvement, with 76.5% of nursing home volunteers and 61.8% of medical oncology volunteers being uninvolved.

Figure 6.1: Degree of volunteer involvement in the organisation of palliative care provision by organisational setting



6.3.2 EVALUATION OF VOLUNTEER INVOLVEMENT

Some volunteers indicated their organisation failed to inform (17.2%), consult (26.5%), take into account their opinion (20.5%), give them decision rights (20.3%) or autonomy (15.9%) often enough. **(See Table 3.)** Particularly medical oncology (30.2%) and nursing home (51.4%) volunteers felt they were not often enough informed and community home-care (31.4%) and nursing home (27.0%) volunteers felt they were not given decision rights often enough.

6.3.3 VOLUNTEER COLLABORATION

Volunteers indicate collaborating most of all with fellow volunteers, volunteer coordinators, nurses and family caregivers. **(See Table 4.)** Collaboration with nurses was lowest in home-care (sitting services (43.2%) and community home-care (30.6%)) and nursing homes (55.6%). When present, collaboration primarily involved information sharing. Collaboration with nurses was highest in dedicated palliative care, and most often involved information sharing (78.0%) and task coordination (46.2%). Community home-care volunteers mainly collaborated with other volunteers (70.3%). Community home-care volunteers also indicated exchanging information with family physicians (18.9%) (as did sitting service volunteers (15.2%)) and with specialist physicians (13.5%) more than other volunteers. (Results for collaboration with physicians not presented in table.) Volunteers in sitting services collaborated more frequently with family caregivers (56.1%) and family help services (30.3%) than other volunteers. A few medical oncology volunteers indicated sharing information with social workers (17.2%).

6.3.4 POTENTIAL FOR IMPROVEMENT OF VOLUNTEER COLLABORATION AND BARRIERS TO COLLABORATION

Overall, two thirds (66.3%) of volunteers indicated no carers with whom collaboration could be improved, in their view. **(See Table 5.)** Nursing home volunteers indicated collaboration with nurses (30.2%), fellow volunteers (23.3%) and volunteer coordinators (18.6%) was suboptimal. Some dedicated palliative care volunteers indicated collaboration with specialist physicians (11.5%), nurses (10.3%) and volunteer coordinators (9.0%) could be improved. 60.5% of volunteers indicated there were no particular barriers for collaboration with healthcare professionals. The most often cited barriers for collaboration with healthcare professionals were ambiguity regarding tasks, agreements and/or rules (14.9%), lack of information exchange (13.9%), lack of consultation moments with professionals (9.3%) and lack of appreciation (7.9%). Nursing home volunteers indicated the most barriers, with 70.5% indicating at least one barrier. More than one in five nursing home volunteers indicated ambiguity regarding tasks, agreements and/or rules (22.7%), lack of information exchange (25.0%) and lack of consultation moments with professionals (22.7%) as barriers to collaboration. Community home-care volunteers most often cited lack of coordination as a barrier to collaboration with professionals (10.3%).

6.4 Discussion

6.4.1 MAIN FINDINGS

This study about the involvement of volunteers in direct patient palliative care found that about half of volunteers felt heard regarding decisions on how care for patients with serious illness is provided, but more autonomous involvement such as decision-making rights was low. More than one in four volunteers indicated not being consulted often enough on the organisation of patient care and one in five indicated their opinion was not taken into account by the organisation in decisions regarding the organisation of care. Volunteers appear to be least involved in nursing homes and medical oncology departments. The main barriers to volunteer-professional collaboration were ambiguity regarding tasks, agreements and/or rules and a lack of information exchange.

6.4.2 STRENGTHS AND LIMITATIONS

This study complements the existing literature as the first to add an extensive description of actual individual volunteering practices in direct patient palliative care to the existing descriptions of organisational and professional perspective around palliative care volunteering. This paper also substantially adds to earlier studies that were limited to volunteering in a context of dedicated palliative care services by including generalist palliative care services. Lower response rates from certain types of volunteers, such as those in nursing homes and community home-care, imply possible issues for statistical generalisation and, hence, that results for these particular organisational types should be interpreted with caution. Results nevertheless confirm the findings from a previous organisational study of palliative care volunteering[20,24] and are contextualised by previous qualitative studies of volunteering in these settings[27,44], indicating the validity of our current conclusions. Strongly involved volunteers may be overrepresented in these strata. Low response rates may have resulted from the two-step sampling procedure using first a random sample of health care organisations (clusters) and then a random sample of individual volunteers. Data were collected via the health care organisations with the health service coordinators functioning as intermediates in the data collection. This was a necessary step as there is currently no central register of volunteers in Belgium, but it complicated the control over the follow-up process.

6.4.3 INTERPRETATION

Our study shows the potential for involvement of volunteers in palliative care within a health service framework and their capacity for collaboration with professionals and other caregivers, particularly nurses. However, results also indicate that this potential may currently be underused in many services, particularly nursing homes and medical oncology departments.

The strongest degree of involvement of volunteers in the organisation of care was found among volunteers that worked within patient homes, i.e. extramural care services. Sitting service and community home-care volunteers reported more autonomous forms of involvement within their health service framework than volunteers from other services, indicating they were able to make their own decisions regarding how care for patients was provided. A measure of autonomy may be a requirement for volunteers working alone in the patient's home. The varying degrees of volunteer involvement across different types of health services indicate varying but potential room for volunteers to be further involved in the organisation of palliative care across health services. However, results also suggest that inpatient care services may place a stronger restriction on volunteer involvement, in particular generalist inpatient care services. Furthermore, higher volunteer involvement may not be desirable for every setting, as medical oncology volunteers, for instance, indicated a wish to be more informed and consulted but did not desire more autonomous involvement. Volunteers may operate slightly more in the background of these services.

Across health services, volunteers collaborated mainly with fellow volunteers, volunteer coordinators, nurses and family caregivers. Dedicated palliative care volunteers collaborated most often and extensively with nurses, confirming previous studies that have shown the importance of nurses to palliative care volunteering[27,44]. Inpatient care service volunteers collaborated more with nurses than extramural care volunteers, however the latter collaborated more with family caregivers than other volunteers. The low collaboration with psychologists was surprising, however, as a previous qualitative study suggested the importance of volunteers and psychologists contacts[27]. (See *Chapter 7*.) It may be that psychologists have an important role in support of volunteers, but less frequently interact with them regarding care provision. This suggests there are further avenues of collaboration between volunteers and healthcare professionals outside of direct care provision within the framework of health services that should be explored to fully understand the different shapes volunteering may take in palliative care.

Overall, volunteers appeared satisfied with current levels of collaboration with other care providers. It is possible that volunteers themselves may not see the potential of collaboration with healthcare professionals whom they are not currently collaborating with, and subsequently may not have made any efforts to expand this collaboration. Alternatively, volunteers may have only evaluated in terms of already existing collaborations. However, it is noteworthy that nursing home volunteers were least involved in the organisation of palliative care, indicated a wish to be more involved, indicated potential improvements to collaboration with nurses and indicated the most barriers to collaboration with healthcare professionals. Considering that nursing homes have been shown to invest little into palliative care volunteering in terms of tasks, training, supervision and coordination[20,24,31,44], this may signal an existing potential for nursing home volunteers to expand their role as palliative care volunteers currently not being realised. In light of these findings and the important complementary value of volunteers to palliative care[27,44], we suggest that nursing homes should consider employing volunteers more for palliative care tasks, offer them the required autonomy for this work and invest in the necessary supervision and training and collaboration with professionals to fully integrate them into palliative care provision.

The contrast between nursing home volunteers and volunteers from other care services, shown in the current paper and in previous studies[20,24,31] is striking, particularly considering Belgian nursing homes are historically anchored in their local community and considering many people spend the last days of their life in a nursing home. The reasons behind the poor development of palliative care volunteering in nursing homes may be tied to challenges for palliative care provision itself in nursing homes, e.g. lack of knowledge about the principles and practices of palliative care[45,46], negative care provider attitudes towards death and dying and unnecessary hospital transfers for dying residents[45]. This unfamiliarity with palliative care provision is likely to affect the use of volunteers within nursing homes. Additionally, nursing homes have chronic problems of understaffing[45,47] and time pressure for care staff[45], which likely negatively affect the extent and quality of volunteer coordination within the facility. Finally, it is possible that the healthcare system itself does not sufficiently recognise the nursing home as a setting for palliative care provision[48]. If palliative care is not adequately recognised and supported within nursing homes, it is unlikely that the position of the volunteer in palliative care will be considered. In order to further develop the position of palliative care volunteering in nursing homes, a two-pronged approach may be required by policy makers and health services, in which (1) investments are made in the nursing home as a proper palliative care setting and (2) direct investments are simultaneously made to strengthen the supportive capacity of volunteering by stimulating coordination by and collaboration with nurses in care provision.

6.5 Conclusion

Volunteer involvement in the organisation of and volunteer-professional collaboration in palliative care provision varied across organisational settings but highlighted volunteers' supportive capacity in palliative care. Particularly nursing home volunteers, indicating the least involvement but signalling a desire to be further involved and potential for improvements in collaboration, signalled the largest potential for growth and further development of the palliative care volunteer role within their facility. However, this may require policy makers and health services to invest directly in the nursing home as palliative care setting and in coordination by and collaboration with nurses in care provision.

6.6 Declarations

6.6.1 FUNDING

This study is part of the ‘Integration of palliative care into home, nursing home and hospital care and into the community in Flanders’ (INTEGRATE-project), a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic University Leuven, Belgium. This study is supported by a grant from the Flemish government agency for Innovation by Science and Technology (Agentschap voor Innovatie door Wetenschap en Technologie) (SBO IWT nr. 140009). The agency had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report, nor in the decision to submit the article for publication.

6.6.2 DECLARATION OF CONFLICT OF INTEREST

The Authors declare that there is no conflict of interest.

6.6.3 ACKNOWLEDGEMENTS

Filip Schriers aided in recruitment, data collection and follow-up.

All **volunteers** who helped in testing the questionnaire throughout development and all **volunteers** who participated in the survey.

All **healthcare organisations** who aided in the mail-out of the survey, the follow-up letters and non-response survey.

6.6.4 DECLARATION OF CONFLICT OF INTEREST

The Authors declare that there is no conflict of interest.

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7 CHAPTER 7: PERSPECTIVES ON VOLUNTEER-PROFESSIONAL COLLABORATION IN PALLIATIVE CARE: A QUALITATIVE STUDY AMONG VOLUNTEERS, PATIENTS, FAMILY CARERS AND HEALTHCARE PROFESSIONALS

Steven Vanderstichelen, Joachim Cohen, Yanna Van Wesemael, Luc Deliens, Kenneth Chambaere

Published in *Journal of Pain and Symptom Management* 2019 (accepted)

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 healthcare services and professionals.

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

Methods A qualitative study was conducted using semi-structured focus groups with volunteers, nurses, psychologists and family physicians and semi-structured 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 analysed employing 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, while 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 in 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.

Key words

Volunteers; Palliative Care; Cooperative Behaviour; Hospice and Palliative Care Nursing; Interdisciplinary Communication; Qualitative Research

7.1 Introduction

Professional healthcare currently faces increasing resource constraints[1] and recent projections predict a continued increase in palliative care (PC) needs[2]. Healthcare professionals struggle with burnout[3] and there is a growing realization that merely increasing health professionals and improving professional services is insufficient to ensure continued and better health for all[4,5]. PC is therefore shifting towards 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 healthcare professionals by being involved in the organisation 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] While much is known about nurse-physician collaboration in patient care[26–29], hitherto studies on volunteer-professional collaboration have been limited to paediatric 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 volunteers, quality of patient care and the feasibility of the integration of increased numbers of volunteers into professional healthcare. 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.

7.2 Method

7.2.1 DESIGN

In order 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 semi-structured 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 semi-structured 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 COREQ guidelines for reporting qualitative research[34]. **(See Appendix 7.1 for COREQ checklist.)**

7.2.2 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 organisation of care in most countries. For a comprehensive overview of the organisation of PC in Belgium see the KCE 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].

7.2.3 PARTICIPANTS

As well as 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 healthcare services. Patients were included via Flemish healthcare services if they had one or more chronic and/or life-threatening condition and spoke Dutch. Family carers were also included via Flemish healthcare 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 healthcare service, but not professionals working unpaid. (See **Appendix 4.2** 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. Additionally, Belgium does not have clinical specialisation in PC, but rather it is offered throughout the basic curriculum of physicians. Care settings were considered based on findings from a 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 Box 7.2.)**

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 due to lack of time.

Box 7.1: Settings from which participants of focus groups and interviews were selected[a,b]

1. Hospital settings
    a. **Medical oncology departments (MOD)** are hospital departments with a fully established oncology care programme, a hospitalisation programme and a multidisciplinary team focused on oncology.
    b. **Palliative care units (PCU)** are separate units in (or associated with) hospitals that exclusively provide palliative care.
2. Home-care settings
    a. **Facilities for sitting services** organise sitting services 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 similar to befriending services.[c]
    b. **Palliative home-care teams (PHT)** 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 caregivers in home or replacement home situations, supported by the network's volunteers.
    c. **Volunteer community home-care organisations (CHC)** are organised by the Christian Sickness fund locally and run by volunteers.
3. Live-in and day care facilities[d]
    a. **Palliative day care centres (PDC)** provide care and nursing during the day and have a respite care function for carers.
    b. **Nursing homes (NH)** offer permanent care and nursing to elderly people.

†Descriptions fully or partially taken from the Agency of Health and Care website[36]. ‡See Walshe et al.[37] ±Nursing homes and palliative day care centres were grouped together mainly because of the low number of palliative day care centres (n=5) in Belgium and their functional link with nursing homes.

7.2.4 DATA COLLECTION

Semi-structured interviews were individually conducted with patients and with family carers in Dutch. Focus groups were separately conducted for a) volunteers, b) nurses and psychologists and c) FPs. All took place between March and

November 2017. Interviews were conducted by SV; focus groups were moderated and observed by SV, KC and other junior and senior researchers making field notes. (**See Appendix 7.2 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 afterwards, but there were no requests to do this. Topic guides were developed and reviewed by a team of sociologists (SV, KC, JC, LD) and a psychologist (YVW) (**See Appendix 4.4.**) 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.

7.2.5 DATA ANALYSIS

Focus group and interview transcripts were analysed by SV and KC following the QUAGOL method[38] – an inductive approach and iterative process of constant comparison. Data collection and analysis were conducted quasi-simultaneously. SV and KC 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 7.2.**) 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 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 SV. The translations were checked for consistency in meaning and approved by the entire research team. All participants were given pseudonyms.

7.2.6 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 30th, 2017.

7.3 Results

We conducted eight focus groups and 18 semi-structured individual interviews. 79 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. Though 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 7.2** represents the current volunteer-professional collaboration relationships. Thicker lines indicate closer and more frequent collaboration.

Table 3: Characteristics of participants in focus groups

N	50
Focus groups	8
Mean duration of focus groups (in minutes)	72 (36-89)
Sex	
Male	7 (14%)
Female	43 (86%)
Age[1]	
<50	0 (0%)
50-59	3 (6%)
60-69	9 (18%)
70+	1 (2%)
Unknown	37 (74%)
Employment status[1]	
Retired	21 (42%)
employed	22 (44%)
Unknown	7 (14%)
Discipline	
Volunteer (4 focus groups)	28 (56%)
palliative care nurse (2 focus groups)	4 (8%)
palliative care psychologist (2 focus groups)	6 (12%)
family physician (2 focus groups)	12 (24%)
Years of working experience[1]	
≤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[2]	
Hospital	12 (24%)
palliative home-care team	11 (22%)
nursing home	8 (16%)
palliative day-care centre	7 (14%)
family physicians	12 (24%)

[1] These demographic characteristics were gleaned from the participant introductions during the focus groups.

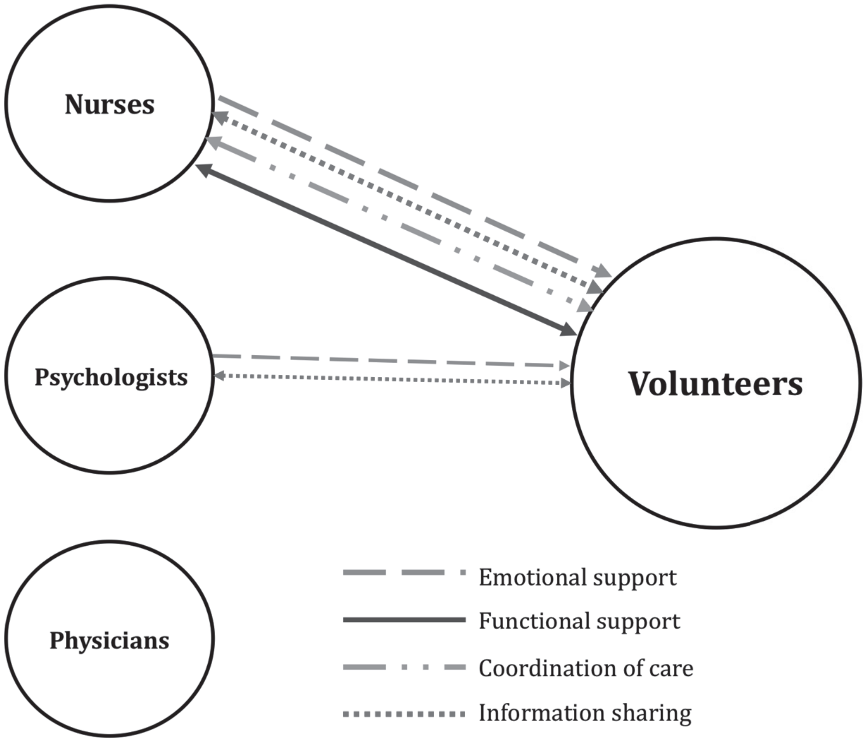
[2] Hospital settings include palliative care units and medical oncology departments.

Table 4: Characteristics of participants in interviews

	Patients	Family caregivers
N	10[1]	9
Interviews	10	8
Mean duration of interviews (in minutes)	34 (21-58)	55 (30-98)[2]
Sex		
Male	6	1
Female	4	8
Age[3]		
≤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[4]		
Cancer	9	6
Chronic Heart Failure	1	0
Dementia (incl. Alzheimer's)	1	1
Parkinson's	0	1
Heart thrombosis	0	1
Cerebral infarction	1	0
Setting[5]		
Hospital	6	1
palliative home-care team	1	5
Nursing home	1	2
Palliative day-care centre	2	0

[1] One interview was conducted with 2 participants (husband and wife).
[2] One interview was not recorded. This interview was short, but the exact duration is unknown. The calculation of the mean duration of interviews excluded this interview.
[3] Age was gleaned from the participant introductions during the interviews.
[4] 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. [5] Hospital settings include palliative care units and medical oncology departments.

Figure 7.1: Model of volunteer-professional collaboration in palliative, direct patient care



7.3.1 CONTACT WITH PROFESSIONAL CAREGIVERS

All participants emphasised that volunteers collaborate mainly with nurses and sometimes with psychologists, and that contact between volunteers and physicians was almost non-existent. 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 healthcare professionals provide directions to volunteers. Medical oncology nurses and psychologists indicated that, while they did not collaborate with volunteers, dedicated oncology nurses may have more frequent contact with them.

7.3.2 SUPPORT FROM HEALTHCARE PROFESSIONALS

Participants described two types of support that healthcare 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 emphasised 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 a 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, 3 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 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 1 year)

7.3.3 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 due to the volunteer's position, availability and time, they notice patient needs and wishes that healthcare professionals sometimes miss. Hospital and palliative day-care nurses, psychologists and volunteers updated each other through daily pre-shift 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 in 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)

While all participants agreed that communication of patient information was important for collaboration, the extent to which volunteers were authorised 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, while others were not allowed access.

7.3.4 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)

7.3.5 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 organisation 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 amongst 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 centre 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)

7.4 Discussion

7.4.1 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 characterised by mutual information-sharing about the patient's condition and its development and by the coordination of care provision together, while 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.

7.4.2 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 wellbeing 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, due to 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 & Rosenstein's definition[26]. This confirms previous studies which report the complementary roles volunteers fulfil in PC by being there, being a liaison and performing signposting tasks[21,32,39–41] 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 organisations may therefore indirectly benefit volunteering too. To address lack of leadership and facilitate collaboration, policy should consider incentivising healthcare 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 organisations with a stronger focus on PC also collaborate more with their volunteers. Previous studies also show that organisations with a stronger emphasis on PC report increased volunteer task performance, training[21] and involvement in the organisation of care[22]. Sharing responsibility was limited in general, potentially due to the legal framework of professional healthcare, 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 organisational framework but through and within the community, responsibilities can be shared[42–44].

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[6,21,45–47] and roles in PC[32,48–51] 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 non-medical professionals in order to inform public debate and policy development. Future research should also further explore the directions volunteers receive from professionals and how they experience these. While healthcare systems may differ in the organisation of PC, the inclusion of multiple perspectives from diverse care settings and the corroboration of our findings by international literature suggests that these recommendations are relevant for PC volunteering across regional or national borders.

7.4.3 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 multi-disciplinary and multi-contextual perspective. While individuals and groups sometimes differed in which aspects of certain topics they emphasised, 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[52] and resulting from the dependent relationship between patients and care providers[53–55] 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. Healthcare 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.

7.5 Conclusion

This study shows that volunteers are at the frontline 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 realisation of volunteer-professional collaboration. Volunteers are therefore complementary to nurses, rather than a replacement for them in the delivery of palliative care.

7.6 Declarations

7.6.1 ACKNOWLEDGEMENTS

Lenzo Robijn, **Else-Gien Statema**, **Ellen Vanderstichelen**, **Kim Beernaert** and **Aline De Vleminck** helped with the conducting some of the focus groups either as observers or as moderators.

Jane Ruthven provided language editing of the manuscript.

All **volunteers, nurses, oncological coaches, psychologists, family physicians and coordinators** who agreed to participate in the focus groups.

All **family physicians from the family physicians' department at Ghent university** who agreed to participate in the member check group discussion.

All **patients and family caregivers** who agreed to participate in interviews for this study.

7.6.2 FUNDING

This study is part of the 'Integration of palliative care into home, nursing home and hospital care and into the community in Flanders' (INTEGRATE-project), a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic University Leuven, Belgium. This study is supported by a grant from the Flemish government agency for Innovation by Science and Technology (agentschap voor Innovatie door Wetenschap en Technologie) (SBO IWT nr. 140009). The agency had no involvement in the study design, in the collection, analysis and interpretation of data, in the writing of the report, nor in the decision to submit the article for publication.

7.6.3 CONFLICT OF INTEREST

Nothing to disclose.

7.7 References for chapter 7

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PART IV – GENERAL DISCUSSION

8 CHAPTER 8: GENERAL DISCUSSION

8.1 Introduction

The general objective of this dissertation was to understand palliative care volunteering in Flanders and Dutch-speaking Brussels, in terms of who these volunteers are, what they do, what their role is and how they support the provision of and may be supported in providing palliative care.

The specific research questions were:

1. What are the characteristics of organised volunteer palliative care in the Flemish healthcare system, in terms of
    a. task performance, role and position of volunteers;
    b. training, and support of volunteers; and
    c. obstacles to maintaining a volunteer force? (*chapters 2-4*)
2. To what extent are volunteers embedded in palliative care, in terms of involvement in the organisation of palliative care and collaboration with other professional and non-professional carers? (*chapters 5-7*)

In this part of the dissertation the main findings of the included studies are discussed. First, the methodological strengths and limitations of the studies presented in this dissertation are considered. Next, the main findings for each research question are summarised. Finally, the importance and relevance of the findings in light of the current state of affairs within palliative care research and their implications for practice, policy and future research are discussed.

8.2 Methodological considerations

Two types of studies were performed over three rounds of data collection to answer our research questions. Firstly, quantitative methodology was used to survey healthcare organisations (survey 1; used for chapters 2 and 5) and volunteers (survey 2; used for chapters 3 and 6) using a written questionnaire. Secondly, qualitative methodology was used to gain in-depth insights into the perspectives of volunteers, patients, family caregivers, nurses, psychologists and family physicians (chapters 4 and 7). Each of the three studies comprised different key strengths as well as different limitations.

8.2.1 QUANTITATIVE METHODOLOGY: CROSS SECTIONAL SURVEYS

8.2.1.1 *Survey 1: Healthcare services providing palliative care in Flanders and Dutch-Speaking Brussels*

8.2.1.1.1 Strengths of the study

This study is the first in Flanders and in the world to map registered direct patient palliative care volunteering across an entire healthcare system in both dedicated and generalist palliative care. It complements earlier studies limited to dedicated palliative care volunteering[1–4]. A robust method, developed with expert consultation, was used to determine the sample of organisations potentially providing palliative care volunteers in the Flemish healthcare system. The study included exhaustive samples of dedicated palliative care services (palliative care units, palliative day-care centres, palliative home-care teams), medical oncology departments, sitting services and community home-care services and a 25% random sample of nursing homes in the Flemish healthcare system (including Flanders and Dutch-speaking Brussels). The Dillman Total Design Method[5] (TDM) was used as a guideline to maximise response by implementing four follow-up rounds. A response rate of 79% (258/342) was reached, thereby allowing observations to be reliably generalized to the Flemish and Dutch-speaking Brussels context. Finally, the study uses a conceptual model from the community engagement literature to measure volunteer involvement in the organisation of care and the organisation's desired volunteer involvement in palliative care contexts. It is the first study to consider volunteer involvement as anything more than presence alone and the first to operationalize the power sharing model developed by Sallnow and Paul [6] and test it quantitatively. Therefore, the study provides the first real and detailed evidence for volunteer involvement in palliative care.

8.2.1.1.2 Limitations of the study

While non-response was low, some bias is possible in the data; some non-respondents may for instance not have volunteers and may not have responded to the non-response survey. In some cases, respondents may not have had frequent contact with their volunteers, affecting the reliability of their responses.

However, due to our focus on the organisational perspective some distance was expected, and volunteer coordinators of the organisations were addressed in order to maximise the accuracy of our data. Nevertheless, it was not always the volunteer coordinator who completed the questionnaire. Additionally, the organisational perspective does not necessarily coincide with the experiences of their volunteers. Moreover, while it does represent the volunteer policy and viewpoint of the organisation, which the survey aimed to explore, it did mean one person represented the policy of an entire health service. Another limitation is therefore that it was impossible to ensure that each health service that responded to our survey was represented by the most suitable person within that organisation. However, it is likely to have been someone with sufficient knowledge of the organisation and its volunteers. Additionally, although we followed a robust expert consultation-based method, there may have been other settings where palliative care volunteers operate. By focusing on registered volunteers, we potentially missed less frequent, unregistered forms of volunteering. Next, the items in the questionnaire, developed to measure (a) psychosocial, existential, and signposting care tasks and (b) training subjects, were constructed by the researchers and are likely not exhaustive, as such providing only an exploratory description rather than an all-encompassing one. However, an "other, please specify" option was provided for training subjects. Given the focus on the Flemish healthcare system, Wallonia and the French-speaking community in Brussels were not described. As healthcare is somewhat differently organised for this community, our results will likely not fully apply to palliative care volunteering in these communities nor in the entirety of Belgium. Additionally, we requested the questionnaire to be completed by the volunteer coordinator of the health service or the closest equivalent, however, only 50.4% of respondents indicated being volunteer coordinators. 15.9% of participants were department heads, 10.9% were directors, 10.5% were head nurses, and 12.4% were classified as other (including animators, physicians, administration workers, care coordinators, etc.). It is not known to what extent the participants who did not indicate being volunteer coordinators were also involved in the coordination of volunteers – albeit not as their main function in the organisation – nor how close they were to the volunteers and volunteering practices in their health service. It is plausible that this varies somewhat. However, this also raises questions regarding the formalisation or presence of volunteer coordinators within palliative care health services in the Flemish healthcare system. As lack of coordination was one of the barriers for role performance (*Chapter 4*) and volunteer-professional collaboration (*Chapter 7*), it appears that not every health services may provide a (dedicated) volunteer coordinator. It is, however, not possible at this time to verify whether this was the case for our respondents. The presence and quality of volunteer coordination may be a future avenue for research into palliative care volunteering. Finally, the results indicate that some health services, particularly medical oncology departments, employ a diversified recruitment model, employing a large share of volunteers that are external to the health service (*Chapter 2*). While this survey attempted to gain an overview of this, it was not within its scope to further explore how this may influence diverse practices and how these volunteers may differ in training or approach. Volunteering practices within a given health service were assumed to be determined and coordinated by the health service policy and management. This assumption was considered plausible due to liability regulations, but due to practical limitations, and because many volunteers are active in more than one health service and in more than one capacity, it was not within the scope of the survey to discern between coordination and management of internal versus external volunteers to test this assumption. It furthermore indicates another complication for palliative care volunteering research that future research may wish to take into account.

8.2.1.2 *Survey 2: Volunteers providing palliative care in the Flemish healthcare system*

8.2.1.2.1 Strengths of the study

This study was the first in Flanders and the first worldwide to examine organised, direct patient palliative care volunteering across the healthcare system, in both dedicated and generalist palliative care, at the volunteer level. It complements the first study's organisational findings with volunteer level data and by extension complements the international literature[1–4] by focusing on both dedicated and generalist settings. Due to the lack of a centralised register of volunteering on the federal or regional levels, a creative solution was found to reach individual volunteers in a systematic way and in large numbers. A two-step disproportionately cluster randomised sample was taken. In this design, strata were defined as the organisation types, individual healthcare organisations in each stratum were regarded as clusters of volunteers, and all volunteers in each selected cluster were included. Health service coordinators in each cluster then facilitated recruitment of their volunteers. The Dillman Total Design Method[5] (TDM) was used as a guideline to maximise response.

8.2.1.2.2 Limitations of the study

While response rates among volunteers from dedicated palliative care services (55.8%) and medical oncology departments (60.4%) were fairly high, the response among volunteers from nursing homes (29.8%), community home-care services (15.3%) were particularly low, resulting in an overall response rate of 35.2% (801/2273). This implies possible issues of statistical generalisation and, hence, that results for nursing home and community home-care volunteers in particular should be interpreted with caution. As data were necessarily collected via the healthcare services with health care service coordinators functioning as intermediates in the data collection, this meant control over the follow-up process was inevitably complicated, and the researchers were dependent on the willingness, time and availability of these coordinators. This may have negatively influenced the response rate and highlights the lack of centralised registers of volunteers as an issue for volunteering research in Belgium in general. It furthermore may highlight why hitherto no other studies in Belgium and worldwide have been able to investigate palliative care volunteering at the individual level at such a scale. This study has arguably succeeded in doing this, but the lack of centralised registers of volunteers has been a noteworthy limitation. Another limitation may have been that data regarding task performance and volunteer-professional collaboration was collected specifically regarding volunteers' last session with a patient suffering from one or more chronic and/or life-threatening illnesses, as opposed to their overall task performance as a volunteer within their service. Individual reports may therefore not be fully representative of their respective work as palliative care volunteer or as volunteer in general, however the sum of all individual reports can still be considered to offer a reliable picture of what volunteers in palliative care do. Within the context of this dissertation, the results of this study are further nuanced, confirmed and contextualised by the findings from the other studies, offsetting the methodological limitations and providing evidence for its main findings.

8.2.1.3 *Qualitative methodology: Focus groups and semi-structured interviews*

8.2.1.3.1 Strengths of the study

A key strength of this focus group and interview study was that it included the perspectives of a diverse range of people who are important actors in the care for people near the end of life, including patients, family caregivers, volunteers, nurses, psychologists and family physicians from three different settings – i.e. hospital, home-care, and live-in and day-care facilities. It is one of the few studies to take such a multi-disciplinary and multi-setting approach to the subject of palliative care volunteering. Because the study focused on the negotiation of meaning regarding volunteers' position and roles in palliative care and their collaboration with professional caregivers, focus groups were used as a method for data collection among all targeted groups – except patients and family caregivers – because they stimulate the exchange of views and opinions through discussion and allow mutual differences or similarities to drive the conversation and allow salient themes to emerge. Due to the fragile health of patients and the sensitive nature of the subject, individual semi-structured interviews were chosen for them and for family caregivers which allowed every case to be treated as discrete and all participants to speak freely. Another key strength is the number of focus groups, interviews and participants in the study. Eight focus groups and 18 semi-structured interviews were conducted, involving a total of 79 participants, ensuring a large number and wide variety of perspectives represented in the data. This study is the first to locate the palliative care volunteer in a conceptual space and to offer detailed volunteer role descriptions that maintain an internal flexibility such that they are practically and conceptually applicable across healthcare services and settings. Roles are defined by a multifaceted approach and goal, but not a priori defined by how that goal should be reached. It is furthermore the first study to offer an in-depth description of volunteer-professional collaboration in palliative care provision.

8.2.1.3.2 Limitations of the study

The limitations of this study include the potential for social desirability bias in responses of participants of the focus groups and interviews. However, the impact of this potential bias is considered limited by the wide range of participants included. Another potential source of bias comes from the fact that the semi-structured interviews with patients were conducted almost exclusively with patients suffering from cancer. It is possible that experiences specific to other illness trajectories were missed and that there is more to be learned from other patient populations. Additionally, while patient data was reliable in its consistency, it was the least rich of the data collected, indicating that perhaps information was missed by not asking the right questions. It is possible that more ethnographic approaches may be appropriate to study patients' experiences with and views on palliative care volunteers. Another limitation may be that participants considered as healthcare professionals were exclusively medical, nursing or psychological, which excludes other professionals such as social workers, physical and occupational therapists and others who may also come into contact or collaborate with volunteers in care provision. The perspectives of other professionals should be given proper consideration in future inquiries. Another potential limitation is that the focus groups were internally homogeneous in terms of disciplines. This was done to represent clear perspectives through each focus group that could be compared in the analysis, and to avoid letting power imbalances influence the conversation. However, it is possible that there exists conflict in views and opinions between the various disciplines that did not emerge due to the homogeneous set-up and were therefore not captured by the researchers. Finally, it is possible that some of the consensus that emerged from the analysis is a consequence of the method and composition of the focus groups, rather than a reflection of concrete practice. The results of this study are essentially based on descriptions, not in-practice observations. It is therefore possible that volunteer-professional collaboration, for instance, happens in other ways and with other carers that were not mentioned because they were not deemed relevant by the participants. More ethnographic approaches may be relevant for the study of volunteer and healthcare professional experiences in palliative care as well.

8.3 Summary of the main findings

8.3.1 WHAT ARE THE CHARACTERISTICS OF ORGANISED VOLUNTEER PALLIATIVE CARE IN THE FLEMISH HEALTHCARE SYSTEM?

Part II of this dissertation focused on (a) the presence and characteristics of palliative care volunteering across the Flemish healthcare system, in terms of volunteer tasks, training and support, and organisational obstacles to maintaining a volunteer force, and (b) the position and roles of volunteers from the perspectives of patients, family caregivers, volunteers, nurses, psychologists, and family physicians.

8.3.1.1 Characteristics in terms of task performance, role and position of volunteers

In *Chapter 2* we studied palliative care volunteering at the organisational level and found that direct patient care volunteers were present in both dedicated and generalist palliative care. They were found to have a higher presence in dedicated palliative care services (97%–100%) and community care services (80%–97%) but also in a majority of nursing homes (73%) and medical oncology departments (64%). Volunteers across all organisation types performed a variety of palliative care tasks including practical help with Activities of Daily Living (ADL) and instrumental Activities of Daily Living (iADL), the most prominent being Psychosocial, Signposting and Existential (PSE) care tasks.

In *Chapter 3* we studied palliative care volunteering at the individual volunteer level and found that nearly all volunteers across all included healthcare service settings occasionally provide care for people with chronic and life-threatening conditions. Two types of volunteer support sessions could be distinguished: (1) 'multidimensional support' representing broad task performance, emphasising PSE tasks; and (2) 'practical support', emphasising nursing tasks. Dedicated palliative care volunteers were more likely to perform multidimensional support and sitting service volunteers were more likely to perform practical support.

In *Chapter 4* we studied the perspectives of volunteers, patients, family caregivers, nurses, psychologists and family physicians from hospital, home-care, and live-in and day-care facilities on the position and roles of volunteers in palliative care. Volunteers were found to represent an 'other', more approachable 'face of care' and to occupy a liminal space between and overlapping the professional and the family domains. They were found to perform two roles: 'being there' and 'liaison'. The main barriers to performing these roles were a lack of communication opportunities with nursing staff, a lack of support in dealing with difficult situations and a lack of coordination in the care setting. Volunteer-patient matching was an important facilitator for the performance of their volunteer roles.

8.3.1.2 Characteristics in terms of volunteer training and support of volunteers

In *Chapter 2* we found that dedicated palliative care and community care services stood out regarding volunteer training and training subjects provided; nursing homes and medical oncology departments rarely provided training in palliative care or advance care planning. Organisational emphasis on volunteer provided PSE tasks and volunteer provided ADL care were both related to higher volunteer training provision.

In *Chapter 3* we found that nursing home volunteers had the least training compared to other volunteers and rated it lowest. Community home-care volunteers receive the least supervision and rated their supervision the lowest, but almost no volunteers perceived the lack of supervision as problematic.

8.3.1.3 Characteristics in terms of obstacles to maintaining a volunteering force.

The results in *Chapter 2* showed that the most important barriers to having a volunteering force were acquiring new and suitable volunteers. Organisational emphasis on volunteer ADL care was related to both higher volunteer training provision and higher indication of financial and legal barriers.

8.3.2 TO WHAT EXTENT ARE VOLUNTEERS EMBEDDED IN PALLIATIVE CARE, IN TERMS OF INVOLVEMENT IN THE ORGANISATION OF PALLIATIVE CARE AND COLLABORATION WITH OTHER PROFESSIONAL AND NON-PROFESSIONAL CARERS?

Part III of this dissertation focused on volunteer embeddedness in the organisation of care based on two indicators: 1) the involvement of volunteers in the organisation of palliative care and 2) the collaboration between volunteers and healthcare professionals. It explored these subjects with quantitative survey data at the organisational and the individual volunteer level and from the perspectives of volunteers, patients, family caregivers, nurses, psychologists and family physicians through focus groups and individual semi-structured interviews.

In *Chapter 5* we studied volunteer involvement in the organisation of care at the organisational level and found that while a majority of healthcare organisations often to always inform their volunteers based on the framework of the power-sharing model, a minority coproduce the organisation of care with their volunteers and only a small fraction use a model of empowered decision-making by volunteers. Dedicated palliative care services and sitting services tend to have the highest volunteer involvement, nursing homes the lowest. Having a higher degree of actual volunteer involvement was associated with more volunteer training and more ADL and PSE task performance by volunteers.

In *Chapter 6* we studied volunteer involvement and collaboration between volunteers and healthcare professionals, as reported by the individual volunteer. It was found that nearly half of volunteers indicated being heard in decisions regarding the organisation of care. However, a third of volunteers indicated a lack of involvement. Across healthcare services, volunteers collaborated with few other carers except fellow volunteers, volunteer coordinators and nurses, and collaboration mainly occurred in the form of information-sharing. The main barriers to volunteer-professional collaboration were ambiguity regarding tasks, agreements and/or rules and a lack of information exchange. Volunteers seem least embedded in nursing homes and community healthcare services.

In *Chapter 7* we studied the perspectives of volunteers, patients, family caregivers, nurses, psychologists and family physicians from hospital, home-care, and live-in and day-care facilities on the collaboration between volunteers and healthcare professionals in the care for people with serious illness. It was found that volunteers in palliative care primarily collaborated with nurses and to a lesser degree with psychologists and have no contact with physicians (family or specialist). Volunteer-nurse collaboration was characterised by mutual information-sharing about the patient’s condition and its development and by the coordination of care provision together, while 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 patient-information sharing and lack of leadership.

8.4 Discussion of the study findings' relevance for current palliative care practice

8.4.1 VOLUNTEERING IN DEDICATED PALLIATIVE CARE

Dedicated palliative care services such as palliative care units, palliative day-care centres and palliative home-care teams were found to provide the most extensive framework for volunteers in palliative care. In terms of the tasks that palliative care volunteers perform, in dedicated palliative care services they perform a broad and multidimensional range of tasks (*Chapters 2 and 3*), including practical care tasks, such as helping patients with ADL[7] and iADL[8] activities, nursing tasks, but particularly performing psychosocial, existential and signposting tasks. Volunteers within dedicated palliative care services also have more extensive training in terms of basic knowledge and skills in palliative care, the position and roles of volunteers in care, ethics (discretion, privacy) and guarding personal and professional boundaries than other volunteers. (*Chapters 2 and 3*) Furthermore, dedicated palliative care services required volunteers to take obligatory training significantly more than other health services providing palliative care (*Chapter 2*). More extensive training was also found to be positively associated with more multidimensional support from volunteers to patients, whereas the lack thereof was associated with more practical support by volunteers, found more often in generalist care services. (*Chapter 3*) Dedicated palliative care volunteers also received supervision more than other volunteers, particularly at fixed times and in group, which were furthermore each associated with more multidimensional patient support.

Dedicated palliative care services appear to involve their volunteers the most in the organisation of care provision (*Chapter 5*), however volunteers from sitting services and community home-care services reported stronger involvement than dedicated palliative care volunteers (*Chapter 6*). Dedicated palliative care volunteers collaborated strongly and extensively with nurses (Chapters 4, 6 and 7), through information-sharing, coordinating tasks and decision-making. Nurses in these services, particularly in palliative home-care teams, relied on volunteers to be kept informed of the patient's condition and situation at home. (*Chapter 7*) The nurse-volunteer partnership in palliative home-care teams was crucial to care provision. Volunteers did not collaborate with psychologists in the provision of care itself, however, psychologists were important in supporting volunteers by offering functional – helping volunteers to act and make decisions in difficult situations such as patient decline, suffering and grieving family members – and emotional support – by helping volunteers process difficult situations such as the death of a patient, experiencing grief, etc.

The complementary, multidimensional approach of palliative care volunteers discussed in *Chapter 3* appears to be nurtured most strongly in dedicated palliative care. This may not be entirely unsurprising as the complementary nature of their contribution lies particularly in their focus on patient wellbeing, offering time, representing an 'other' face of care to patients (*Chapter 4*), taking care of the explicitly non-medical side of care, and signalling to professionals patient needs and wishes that professionals often miss. This emphasis is in line with the very definition of palliative care as a "person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary goal is to optimise the quality of life"[9]. It is "care that helps people live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness."[9] This approach to care not only treats physical care needs, but also emotional, spiritual or social care needs and volunteers appear to specialise particularly in the latter three types of care needs. It is perhaps due to the recognition, by dedicated palliative care services and their staff, of this complementary value of volunteers to healthcare professionals within the framework of palliative care that volunteering is so strongly developed, supported and involved in dedicated palliative care services. Additionally, it is possible that because of the precarious and sensitive nature of the care that is provided and the fragile health of people near the end of life that dedicated palliative care services expect and require a higher degree of engagement from their volunteers. For this same reason, these services employ strict vetting processes, conduct intake interviews, gauge candidates' views, attitudes and experiences regarding death and dying, require minimal training and sometimes require long waiting periods before candidates may start. An engagement in palliative care volunteering is not to be taken lightly, whether in dedicated or generalist palliative care services. The room for and indeed importance of the human approach to patient wellbeing and person-centred care in palliative care may be precisely why volunteers find their place in dedicated palliative care services, why their position within the health service and care provision is more thoroughly developed than elsewhere, and indeed why volunteering has had such a long history in palliative care since the first days of the hospice movement.

The support for palliative care volunteers in dedicated palliative care settings is not perfect, however. Similar to other services, dedicated palliative care services also indicated issues with volunteer recruitment, namely finding new and suitable volunteers. (*Chapter 2*) Recruiting difficulties in dedicated palliative care services may furthermore be compounded by the strict requirements and demands from volunteers in these services. Additionally, some dedicated palliative care volunteers still indicate that collaboration could be improved with nurses and specialist physicians and some experienced problems with ambiguity in the health service regarding tasks, agreements and/or rules and the lack of information exchange. (*Chapter 6)*

8.4.2 VOLUNTEERING IN GENERALIST PALLIATIVE CARE

As the emphasis on palliative care may vary between health services and settings, so too may the approach to volunteering – broad and multidimensional, or narrow and practical approaches (*Chapter 3*) – in terms of the settings' particular needs. Indeed, this may further influence how well developed the palliative care volunteer's position is within any given health service. In contrast to dedicated palliative care services, generalist care service volunteers interact with a broader patient population and do not engage solely with patients near the end of life. However, as this dissertation has shown, volunteers in generalist care settings do care for people with palliative care needs. They perform many palliative care related tasks, including an emphasis on psychosocial, existential and signalling tasks, however, they receive much less training for it than dedicated palliative care services do. (*Chapters 2 and 3*) Sitting services and the volunteer-led local community home-care services, both extramural services who provide care to patients at home, paint a similar picture in terms of task performance, training (*Chapter 2*), and involvement (*Chapter 5*). In fact, sitting service and community home-care service volunteers indicate being much more strongly involved in the organisation of care than dedicated palliative care volunteers (*chapter 6*), indicating they have a measure of decision-making rights and autonomy regarding certain aspects of care provision. Indeed, as these volunteers visit patients by themselves, a certain measure of autonomy could be considered as self-evident and necessary. These volunteers also report a strong emphasis on practical, psychosocial and signposting care tasks (*Chapter 3*). Sitting service volunteers in particular perform several nursing tasks in the patient's home as well. However, volunteers were rarely required to follow obligatory training and the extent to which they receive training in basic knowledge and skills in palliative care, was much lower than their respective health services reported (*Chapters 2 and 3*). The health services found to have the least developed volunteering practices, however, were medical oncology departments and nursing homes. The findings for these settings warrant further discussion.

8.4.2.1 Palliative care volunteering in medical oncology departments

Medical oncology department and nursing homes displayed the least developed volunteering practices. Medical oncology departments and their volunteers appeared to display quite a different profile from all other services and their volunteers. Their volunteers generally did not provide hands-on practical or nursing care, but they did provide some psychosocial, existential and signposting care tasks. (*Chapter 3*) Additionally, their sessions with patients were not characterised by multidimensional, nor practical support sessions. Most medical oncology departments also did not train their volunteers in basic knowledge and skills in palliative care (*Chapter 2*) but volunteers did report receiving training in the position and roles of volunteers in care, ethics, communication skills, and guarding personal and professional boundaries (*Chapter 3*), indicating these services potentially do have a specific role put aside for volunteers that may not coincide with the roles captured by our studies.

Finally, the involvement of medical oncology volunteers was restricted to being consulted and heard, but volunteers neither had nor wanted more autonomous involvement. (*Chapter 6*). Medical oncology services were also least supportive of stronger, more autonomous involvement for volunteers. (*Chapter 5*) Medical oncology nurses and psychologists also indicated that there was very little interaction between themselves and the volunteers in care provision. (*Chapter 7*)

8.4.2.2 Palliative care volunteering in nursing homes

Whereas medical oncology volunteers appeared to have a profile of their own – which may require further study to understand – nursing home volunteers seemed to not have a particular position set aside for them in care provision. ‘Being there’ was still reported as an important task, however there was little to no emphasis on exploring patient needs and wishes or being with them in the last days of life. (*Chapters 2 and 3*) There was also little attention paid to care for patients’ relatives. Aside from ‘being there’, their main tasks appeared to be patient transport, helping with shifting and moving patients and feeding patients, indicating they may currently have a merely substitutive role in the nursing home. This is further suggested by the lack of training for nursing home volunteers. Nearly one in five nursing homes did not offer training, and only 12% required their volunteers take obligatory training. Almost half of nursing home volunteers did not have any training whatsoever. Additionally, volunteer involvement in the organisation of care was extremely low in nursing homes. (*Chapters 5 and 6*) More than three out of four volunteers reported not being informed about the organisation of care by their nursing home. There was however a sizeable demand to be involved more, indicating volunteers feel there is a role for them to be played within the health service. Indicative of this is that a third of nursing home volunteers indicated suboptimal collaboration with nurses and that a large majority of nursing home volunteers reported barriers to collaboration – whereas other volunteers generally reported few.

It is therefore interesting to note that, not only do palliative care needs exist in nursing homes – as many people spend their last days of life there – palliative care volunteers within this setting also express a need for more involvement in the organisation of care and better collaboration with healthcare professionals. Nursing homes may therefore particularly benefit from the broad, multidimensional volunteering approach found in more dedicated palliative care services; however, findings suggest they are currently still far removed from it. The contrast between nursing home volunteers and volunteers from other care services is striking (*Chapters 2, 3 and 5*), particularly considering Belgian nursing homes are historically anchored in their local community. The reasons behind the poor development of palliative care volunteering in nursing homes may be tied to challenges for palliative care provision in nursing homes, e.g. lack of knowledge about the principles and practices of palliative care[10,11], negative care provider attitudes towards death and dying and unnecessary hospital transfers for dying residents[10]. This unfamiliarity with palliative care provision is likely to affect the use of volunteers within nursing homes. Additionally, nursing homes have long-standing problems of understaffing[10,12] and time pressure for care staff[10], which likely negatively affect the extent and quality of volunteer coordination within a health service. Finally, it is possible that the healthcare system itself does not sufficiently recognise the nursing home as a setting for palliative care provision[13]. If palliative care is not adequately recognised and supported within nursing homes, it is likely that the potential contribution of volunteers to palliative care in terms of involvement and collaboration will also not be considered.

8.4.3 IMPLICATIONS FOR PRACTICE

The use of volunteers in terms of task performance was found in *Chapter 2* to be associated with certain barriers to maintaining a volunteering force. Increased emphasis on using volunteers to help patients who can no longer function independently with Activities of Daily Living[7] (ADL) was associated with increased financial costs and legal prescriptions regarding volunteer tasks, and increased training provision for volunteers. This indicates that even a purely practical, substitutive approach to volunteering focused on practical and nursing tasks, such as found in *Chapter 3* is not without its costs and challenges.

Health services across the board reported difficulties in recruiting new volunteers (*Chapter 2*), suggesting a key challenge is developing tailored strategies to engage potential volunteers. Given that palliative care volunteers[14,15] and volunteers in general[16] tend to be older, digital media may not be an ideal tool to reach new people and younger generations may be more time-constrained. It could therefore be more worthwhile to offer flexible, well-defined volunteering roles to suit all age-groups. In *Chapter 4* we suggested role-focused profiles that engage and recruit new volunteers based on their unique position and the importance of ‘being there’ for patients and fulfilling a ‘liaison’ role, from which opportunities for psychosocial, existential and signposting care result. These roles seem to be unique to and at the core of volunteer palliative care as international studies have pointed to similar findings[17–20]. New volunteer profiles should put this ‘goal’ of the volunteer role at the centre of their recruitment focus and efforts, rather than an extensive description of ‘tasks’ that may be the means to achieve this goal. The means to more psychosocial, existential and signposting care may vary according to a patient’s immediate needs and wishes and their personality. The practical tasks leading up to them should therefore be considered secondary to the role of volunteers. Additionally, recruitment issues may require further interregional coordination between the palliative care networks in Flanders and Belgium by extension. The palliative networks in Belgium function regionally and recruitment efforts between organisations may not be optimally coordinated. Frameworks should therefore be designed to expedite coordination and could incorporate standard, context-sensitive training in palliative direct patient care. Health services other than the dedicated palliative care services such as those considered in this dissertation should be properly considered as settings for palliative care provision and therefore receive adequate support from the networks. A previous study has suggested an umbrella organisation or network at the European level may be warranted[21], through which volunteers may be recruited and which support measures may be shared across national borders and equality in coverage across Europe may be stimulated.

Despite the historical dependence of nursing homes on informal caregivers in Belgium and problems of understaffing[10,12], nursing home volunteers receive little training and perform relatively fewer tasks related to Activities of Daily Living, psychosocial and existential care and signposting (*Chapters 2 and 3*). Nursing homes may therefore not be providing their volunteers with the required support for their tasks and may not be employing volunteers efficiently with regard to quality of care. Investing in proper support frameworks in coordination with palliative professionals to train and support volunteers in their provision of direct patient care is therefore recommended. Employing volunteers does not remedy underlying problems of understaffing and lack of funding; however, their presence, when appropriately supported, may relieve stress on staff and increase quality of care and wellbeing for patients. Results indicate that training and organisational support are associated with the type of care volunteers provide. This indicates that health services and policy makers may, with minimal investment into volunteer training and support, be able to stimulate complementary volunteering approaches and thereby meet existing and future needs in professional healthcare. Nursing homes may be one particular setting in which the potential for further development of palliative care volunteering is possible given these investments.

Finally, the contribution of volunteers presented in this dissertation signals an existing but unused potential in community settings, particularly community home-care, to reach people with care needs that currently do not find their way to much needed professional care. Psychological, social and existential care needs – including fear, depression, social isolation, dealing with death and dying – are often not recognized or acknowledged[22]. Despite the extensive evidence for the positive effect of the early initiation of palliative care on the quality of life of people near the end of life[23–28], referrals to palliative care services of patients with palliative care needs still take place too late in the disease process[29], and often only take place in acute crisis situations related to end-of-life decisions and pain and symptom control[30]. The findings in this thesis indicate a significant but unused potential in community home-care where volunteers visit people that are still living at home with considerable (palliative) care needs. These volunteers can and do reach people before health professionals find their way to these patients and, given their important signposting function and role as intermediary (*Chapters 2, 3, 4 and* 7), can therefore play a crucial role in providing care and improving access to care for hard to reach populations. As this dissertation has shown, however, these volunteers currently receive little palliative care related training (*Chapters 2 and 3*), indicating a gap between actual care provision by volunteers and training within volunteer-provided generalist palliative home care and a potential for quality and efficient signposting of palliative care needs.

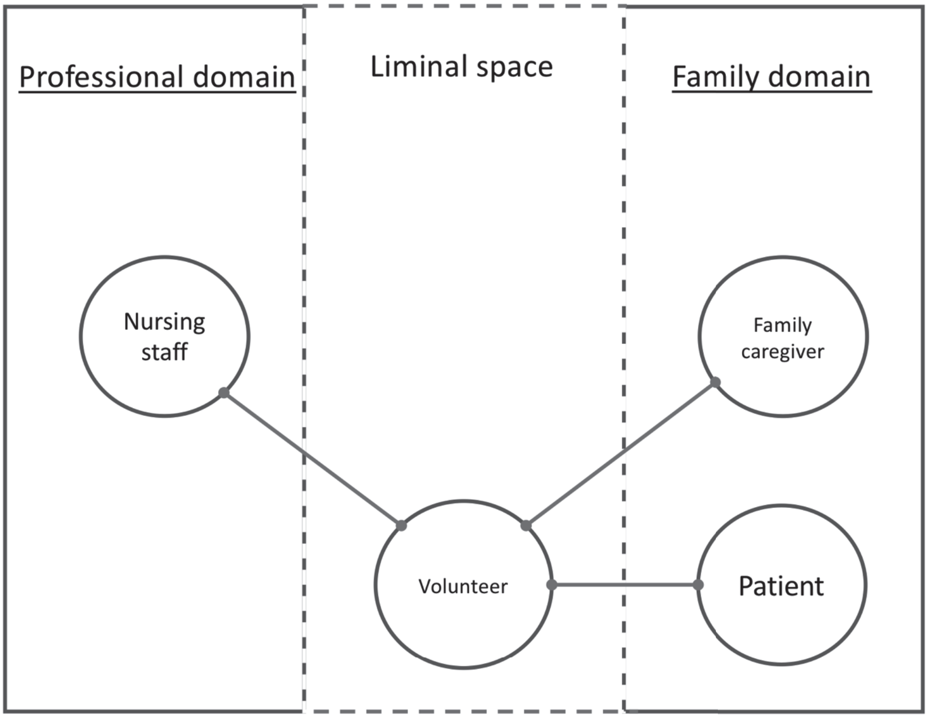
8.5 Discussion of the study findings' relevance for current and future palliative care volunteering research

8.5.1 IMPORTANCE OF THE FINDINGS IN CONCEPTUALISING PALLIATIVE CARE VOLUNTEERS

In *Chapter 1* we discussed briefly a typology of volunteers in palliative care. This typology, first suggested by Ruthmarijke Smeding[31] and adopted by the EAPC Task Force on Volunteering in Hospice and Palliative Care in their White Paper defining palliative care volunteering[19], distinguished between (1) 'D-volunteers' – professionals working within their discipline without being paid – (2) 'B-volunteers' – unpaid board members of hospice and palliative care services – and (3) 'C-volunteers' – members of the local community who offer their time in either care-focused roles or indirect facilitative roles[19,31]. This dissertation has focused on C-volunteers in care-focused roles specifically. The findings of this dissertation suggest that the dichotomous division within the C-category of care-focused roles versus indirect, facilitative roles may be better represented as a spectrum, ranging from non-care focused roles, indirect care roles and practical care roles, to complementary, multidimensional care or support roles. Non-care focused volunteers may focus for instance on administrative work, reception work, public relations of the health service, household work, or charity or fund-raising. Hospice and palliative care in the UK, for example, has a long history of volunteers fundraising[32,33]. Indirect care roles may be volunteers focused on interior decoration of health services, gardeners, transportation of patients, event organisation, etc. Practical supportive care roles may be volunteers who focus on helping volunteers with purely ADL, iADL and even light nursing tasks, supporting nurses within the service. Complementary, multidimensional roles are, then, volunteers who in addition to practical and nursing tasks, focus mainly on 'being there', psychosocial, existential and signposting care tasks. These are the volunteers that may take up advocating, intermediate roles. This is suggested as a spectrum on which volunteers may find themselves in more than one of these categories or even travelling from one to the other and back over time. This spectrum also highlights the broad range of types of support and care volunteers may offer within palliative care.

This may also be the reason why health services and researchers find volunteers in palliative care hard to pin down conceptually. Literature is particularly fuzzy when it comes to describing the role(s) of volunteers and has reported a variety of roles ranging in scope from specific (e.g. administration, fundraising) to broader (e.g. companionship and support) tasks[1,34–36]. Roles can be defined as behaviours, rights, obligations, beliefs, norms or a combination of all of these. A role is therefore a complex concept encompassing more than a set of tasks; roles are not fixed or prescribed, but rather negotiated between individuals and their contexts[37]. In Chapter 4 we attempted to provide an extensive description of palliative care volunteer roles, while maintaining internal flexibility. We discovered that volunteer role performance originates from the unique position volunteers occupied between the domain of medical-professional care and the family domain of the patient and family caregivers. We called this space a *liminal space* because it was defined by the space left entirely between the aforementioned domains and due to its blurred boundaries with these domains. **(See Figure 8.1.)** The concept of *liminality,* indicating a fluid, malleable space between and connecting two conceptually rigid and mutually exclusive domains[38], lends itself well to understanding the volunteer position in palliative care because it allows for non-discrete categories. In anthropology, liminality has been used to indicate moments

Figure 8.1: Model of the volunteer position in palliative care provision



(e.g. coming of age rites), periods (e.g. periods between history-shaping events or transformations) or physical spaces (e.g. airports) in which identities, institutions, cultures, or locations are in flux, but from which new ones may emerge.[39] Such a space, conceptually, fits the volunteer position, from which they provide complementary care according to continuously changing needs of the patient, relatives, professionals and situations. Their position in this liminal space allowed volunteers to perform two roles, which we called 'being there' and 'liaison'.

The role of *being there* corroborated the finding of other studies that *presence* is a central aspect of volunteer support in PC[19,40–42], through which meaningful encounters with patients emerge.[19,43–45] The analytical categories reported in this paper resonate with a previous study's findings of volunteers 'being with' and 'doing for' patients[17], describing a relational dynamic between volunteers and patients similar to our findings indicating volunteers used practical tasks ('doing for') as a means to perform their role of being present with patients ('being with').

Literature also reports several themes connected to *being there*[40] which were also found to be important in *Chapter 4*: neutrality and openness, customised care and patient-centredness, developing a close bond with the person who is dying, facilitating intimate conversations and active listening.

The role of 'liaison' or 'intermediate' emphasises the volunteer's potential as broker[17,46]. Volunteers have elsewhere also been shown to function as confidantes of patients and relatives, as intermediate between patients, medical staff, and relatives, and in some cases as patient advocates[2,47,56–58,48–55]. Within their role as liaison, volunteers often pick up on patient needs and wishes often gone unnoticed by healthcare professionals working under strict time-constrained schedules.

As shown in *Chapter 7*, these volunteer roles lend themselves well to collaboration with healthcare professionals. The time, presence and company they offer are conducive to their second role as liaison, and the liaison role facilitates, and indeed requires at least communication between professionals and volunteers. In fact, this role, as we've seen, makes them a crucial part of the communication chain from patients to healthcare professionals. Communication is therefore at the centre of collaboration between volunteers and professionals and appears to be a core strength of volunteers' contribution to palliative care. The core coordinating and facilitating organ of collaboration is then the daily meeting or briefing in which volunteers and professionals – often volunteer coordinators, nurses and psychologists – share information about patients and their conditions (including health, wellbeing, home situations), and coordinate and plan future steps in care provision. It is the place where reflection happens, where advice is given, and experience shared. This meeting is an important facilitator for volunteer functioning, role performance and quality volunteer care provision.

The conceptual framework suggested in this dissertation, locating volunteers within a *liminal space* from which they perform roles of '*being there*' and as '*liaison*', is fundamentally and scientifically useful as a theoretical lens through which palliative care volunteering across and within care services may be understood. A clear conceptualisation of the volunteer's position as relational furthermore provides a basis on which health services may assess whether they are supporting volunteers in their role and whether they are providing the necessary infrastructure to optimise their performance. The broker's position of volunteers through their liaison role additionally confirms the potential contribution of volunteers to binding, bridging[59] and creating social capital[60]. Moreover, it may, in partnerships between health services and volunteers, allow for the creation of *collective social capital*, a concept recently suggested by dr. Libby Sallnow as a subsequent step beyond linking social capital that fosters independence and reciprocity between communities and organisations[61]. It incorporates the reciprocal and mutual relationships that may develop between community members and healthcare services in end of life care.

8.5.2 RETHINKING THE POWER-SHARING MODEL IN LIGHT OF EMPIRICAL FINDINGS – NEED FOR CONCEPTUAL AND OPERATIONAL CLARITY

To explore the involvement of volunteers in the organisation of palliative care, we borrowed a conceptual model from the community engagement literature. The model of power sharing was developed by Sallnow & Paul[62] based on previous existing models suggested by Arnstein[63], Oliver et al.[64], Popay[65], and Tritter & McCallum[66]. We opted for this model as it was made specifically applicable to end-of-life care contexts. We then operationalised the model to apply specifically to the context of palliative care volunteering within the framework of health services. The power sharing model consists of five types of engagement work represented as a hierarchical spectrum: **inform – consult – co-produce – collaborate – empower**. Each next type on the spectrum represents more meaningful forms of engagement entailing more involvement in the organisation of care.

Interestingly, while the model as hierarchical spectrum initially suggests an unambiguous scale, there appeared to be an empirical inversion between the concepts of ‘consult’ and ‘co-produce’. In *Chapter 5* fewer health services reported that they often to always consulted volunteers than there were health services that reported taking their volunteers’ opinions into account in organisational decision-making regarding the organisation of patient care. This inversion was also found in the volunteer data presented in *Chapter 6*. Perhaps volunteers and health services feel that, despite low consultation, the views and interests of volunteers are still being considered in organisational decision-making. This suggests certain shortcomings in the model or our operationalization of it.

First, there may be lack of **conceptual clarity** with regard to the items 'consult' and 'co-produce'. Does 'consult' capture the frequency with which organisations consult volunteers for their opinion or does it also capture the extent to which volunteers offer their unsolicited opinion? Moreover, it does not capture whether volunteers are able to voice their opinions within their health service effectively. It is, therefore, difficult to speculate exactly how individual participants interpreted the item. Similarly, does the item 'co-produce' capture the extent to which volunteers' opinions and input weigh on decisions that the organisation makes, or does it merely reflect whether participants feel that the organisation has the volunteers' best interest at heart? This, too, is unclear. The conceptual difference between both items may not be unambiguous then and may be differently interpreted by different participants. Generally speaking, these two concepts may consist of different gradations and the current operationalisation does not make explicit which is being measured. Future operationalisation of the model should therefore differentiate between **effective voice and perceived voice**[67], where effective voice represents existing channels and opportunities present in the health service for volunteers to share ideas or input about the organisation of care and perceived voice is the belief of individual volunteers that they are able to share ideas or input and that those ideas will be heard and respected. Individuals may not have the means to use their voice in the organisation but still feel that the organisation has their best interests at heart in its decision-making processes or vice versa. Second, there is a **conceptual difference** between the concept of 'inform' and the other four concepts. Information may be a prerequisite to further empowerment – indeed, empirically the item representing 'inform' was positively correlated with all other items in the model – however, it represents an altogether different concept – one of knowledge as a resource of power but not necessarily an action of power. Finally, the operationalised model contained ambiguity regarding the **agency** it allocates to different parties involved across the different items. The operationalisation of the individual concepts of the model switches agency between items. With regard to 'inform', 'consult' and 'co-produce' the items are phrased with the organisation or health service as the active party and the volunteers as the passive party. However, with regard to 'collaborate' and 'empower' the items are phrased with the volunteers as the active party. The same phrasing was generally kept for both studies (*Chapters 5 and 6)*, which meant volunteers were answering items gauging how much power was shared *with them* *by the organisation* not *between them and the organisation*, indicating that the model assumes an unequal power balance a priori. This is also problematic because the items ‵collaborate’ and ‵empower’ were then the first two items in the question that depart from this assumption, which could mean that volunteers and health services alike answered with different implicit understandings of these items.

It may be worth separating ‵inform’ from the other concepts within the model as it represents an entirely different concept as a source of power but not an action of power. Future empirical enquiry may then test its association with the new model’s outcomes. Future operationalisations should take care that the items have the study population as its subject and items are phrased actively with regard to the subject. All items should be actively phrased, avoiding passive phrasing. Additionally, the model and its operationalisation should make explicit whether they are intended to measure perceived or effective involvement or power sharing. Studies focusing on effective involvement should explore whether structures are in place to include volunteer or community member voices in the organisation of care provision and if and to what extent these are used. Perceived involvement does not necessarily mean effective involvement or vice versa.

Nevertheless, this model remains the current benchmark to measure power sharing in the context of palliative care volunteering. *Chapters 5 and 6* were, to our knowledge, the first studies to operationalise the conceptual model of power sharing. Based on our findings, we therefore suggest future theoretical and empirical efforts should further refine the model in terms of effective voice vs perceived voice, conceptual clarity, and agency.

8.5.3 THE NEED FOR A MINIMAL DATA SET

There are still many challenges facing palliative care research. On the one hand, there are the conceptual, definitional challenges in understanding what, or better, who we are studying that we’ve discussed above. On the other hand, and not entirely unrelated to the conceptual challenge is the challenge of data collection. Hitherto, many countries, including Belgium, still lack centralised registers of volunteers and characteristics of volunteering in palliative care are not systematically collected. Efforts to study volunteering on a large scale, such as at the scale of the health-care system as we’ve done in *Chapters 2, 3, 5 and 6* inevitably run into issues of estimating coverage or reach of the study. In *Chapters 2 and 3* we were forced to work with reported volunteer numbers, which may have been estimates of the respondent. In *Chapters 5 and 6*, we were forced to base our sample frame on these previous estimates as well. We furthermore had to work with health service coordinators as intermediates to facilitate the data collection. This inevitably limited our reach as we were unable to fully control the data collection. Given the recent and vested interest of the Flemish government and health services in (palliative) care volunteering in light of the public health shift towards socialisation of care, we would urge the systematic and periodic collection of a minimal set of data on volunteering in palliative care to facilitate further policy-informing research into this field. This data set could be conducted through the National Institute for Health and Disability Insurance and could include characteristics such as precise volunteer numbers, demographic characteristics of volunteers, place of volunteering (geographically and per type of health service), type of activities (direct patient care, bereavement care, etc.), patient populations reached, etc. The first steps into constructing such a proposed minimal data set and estimating the feasibility of its collection in different European countries are currently being taken by the EAPC Task Force on Volunteering.

8.5.4 FUTURE AVENUES FOR INQUIRY

This dissertation has taken as its task the extensive and in-depth description of a wide range of hitherto under researched aspects of volunteering in palliative care. However, there is still much work to be done. Several avenues remain to be explored and to be studied more in-depth, leaving description behind in favour of effectiveness studies.

First, longitudinal studies of volunteering in hospice and palliative care are still few and far between[68–70]. Minimal data sets collected nationally, and international collaborations can help researchers track evolutions and trends at the European level. Future research should also test the effects of training and coordination on volunteers in different palliative care settings at the regional or local level and explore their influence on the effectiveness of volunteers in increasing quality of care. Researchers may then also consider comparing the effectiveness of volunteers in terms of quality of care between different models of care provision – e.g. top-down versus bottom-up service models.

Second, considering volunteers' unique approach to care, affinity for building relationships with patients and their strong link to the community, researchers should explore the volunteer role in facilitating access to care for vulnerable and hard to reach populations such as isolated elderly, ethnic and cultural minorities, homeless communities, LGBTQ communities, refugees and asylum seekers.

Third, there is a need for evidence-based training programmes to be developed to train volunteers specifically for their intermediary, signposting function between professional healthcare and hard-to-reach patient populations. This requires looking beyond volunteering in health service frameworks. A new model of volunteering may therefore be needed that encompasses and integrates palliative care volunteering within top-down health service structures as well as bottom-up grassroots structures. As this very dissertation exemplifies, the focus is currently still predominantly on volunteering in health service frameworks. Theoretical efforts will be needed to expand this focus, and these will hopefully find the findings presented in this dissertation a useful stepping stone.

Fourth, given the importance of partnerships in the context of public health and compassionate community models, special attention should be given to co-creative methods in all stages of research projects. Recently, there is increasing acknowledgement of the importance of empowerment of patients and informal caregivers, including volunteers. Researchers are able to play an empowering role by designing new models of care, training, collaboration in partnerships with their stakeholders, including patients, volunteers and family caregivers.

Fifth, while the compassionate community model is gaining traction in recent years in the palliative care world, with several initiatives worldwide[71], intervention studies and evaluations focus primarily on outcomes. No thorough process evaluation has been conducted in order to map the fundamental underlying principles for a successful initiative in terms of engaging community members. Community participation and palliative care volunteering researchers may find a fruitful partnership in pursuing a thorough process evaluation.

Sixth, there is more to be learned about the involvement of volunteers in the organisation of palliative care. We have addressed current difficulties with the model and operationalisation that may be amended in future inquiries, however an empirical, psychometric validation of this model is also required. The palliative care volunteering literature currently lacks validated and standardised tools and instruments. It would also be interesting to explore whether our suggestion that perceived involvement and effective involvement may differ and may differently influence other aspects of volunteering holds true when tested. Additionally, the dynamics between knowledge and knowledge attainment, currently conceptualised as 'inform' in the power sharing model, and the other engagement types – consult, co-produce, collaborate and empower – should be further explored. The extent to which healthcare providers create, uphold and enforce knowledge 'enclosures' has also hitherto not been explored and may open up further opportunities to study power dynamics in palliative care.

Finally, hitherto no real benchmarking studies have been conducted regarding palliative care volunteering practices in terms of care provision by volunteers as well as support and development of the volunteer position and role by health services and communities. This dissertation has, by extensively describing current volunteering practices and volunteer involvement at the organisational as well as the individual volunteer level, and by providing a clear conceptualisation of the volunteer's position as relational and encompassing two clearly defined roles, provided a first basis on which such benchmarking may be done. Future inquiry should attempt to use this first framework to construct evaluation methods and tools to explore whether volunteers are being suitably supported in their role within health services and communities alike and whether the necessary infrastructure to optimise their performance is provided.

8.6 Discussion of the study findings' relevance for policy development

8.6.1 HOW DOES VOLUNTEERING FIT IN THE SHIFT TO SOCIALISATION OF CARE

The projected increase in palliative care needs over the coming decades[72] and the current health system's challenges of increases in workload[73], shortages in staff[74], and health professionals plagued by burnout[75] do not bode well for the outspoken ambition to guarantee better health for all[76]. Recent investments in Flanders[77] seem to fall short and there is a growing realisation that merely increasing the number of health professionals and improving professional services will not be sufficient to meet the totality of the challenge in healthcare, including palliative care. Traditional divisions between residential care, offered in care institutions, and home-care are fading[78] and it appears inevitable that healthcare provision will need to be 'socialised' and that communities will once again become an important setting within, through, and by which care will be provided. The World Health Organisation has detailed a framework on Integrated People-Centred Health Services[79], which outlines the engagement and empowerment of people and communities as it's first of five strategies. According to its vision texts, the Flemish government intends the 'socialisation of care' to represent a stronger and more far reaching integration of care within the community and will strive for greater autonomy of the care recipient[80,81]. The socialisation of care intends to build bridges between professional and informal carers and between medical healthcare and the welfare sector. The Flemish department of Welfare, Public Health and Family has issued a decree for local social policy[82] to support this development towards more integrated care and support by local governments. The community is being re-conceptualised as a partner in healthcare provision and together with patients, informal carers are seen as the key proponents of the community through which care provision and capacity should be strengthened. In several countries, volunteers are already expected to play a substantial role in future palliative care [32,83–85]. However, while this dissertation has shown that volunteers do play an important and complementary role in palliative care provision, it has also highlighted current shortcomings in the current framework and development of volunteering in palliative care. Particularly in health services with historically close ties to the community, such as nursing homes and community home-care services, volunteers lack proper embedding in the care continuum, proper support and relevant training for palliative care provision.

This indicates not only challenges at the individual health service level, but also significant societal challenges for the socialisation of care. Society and the job market may need to evolve towards a model in which informal care provision for one's loved ones – e.g. parents, children, siblings, neighbours, friends, community members – is supported within the workplace (e.g. through family caregiver friendly staff policy[86,87]) and valued intrinsically within society for the added value they create in care provision. Currently this care is not adequately valued as such.

People who remove themselves from the job market indefinitely to provide care for family members, friends or community members, thereby relieving stress on an already overburdened healthcare system, do not show up in the national GDP. They earn no income, accumulate no rights and save no pension. The current system is biased towards outsourcing care provision to the professional healthcare system, and therefore offers inadequate support to those who wish to provide care for their loved ones themselves. If the vision behind the ambition to socialise care aspires to stimulate communities to take up care for their own community members – children, parents, siblings, friends, neighbours – then it needs to address this problem inherent in the system at the ground level. As informal caregivers may represent a cost-effective investment for the professional healthcare system[4,32,48,88–90], it may be worthwhile for policy makers to consider expanding the family caregiver and volunteer statutes and to redirect some of its funding towards the support of informal caregivers. Furthermore, there may be avenues to explore for early retirement for people taking up care for people around them. They may currently not be visible in the GDP, however the work of informal caregivers undeniably has economic value. At the healthcare service level, family caregiver friendly staff policy may be implemented such that staff members are familiar with the term 'family caregiver'; family caregiving is made an integral part of the vision of the organisation and its HR policy; family caregiving tasks can be discussed and negotiated with supervisors and colleagues; and the employer provides formal measures or individually customised employment options that make the combination of work and family care feasible for employees[86,87].

Nursing homes and local, volunteer-led community home-care services, together with palliative day-care centres could once again form community anchor points around which community initiatives could be built[91]. One particular public health model in palliative care is promising in this regard. Drawing on the WHO Ottawa Charter for Health promotion (1986)[92], the "Compassionate Community" model has been put forward as a new complementary paradigm, in which palliative care is not limited to formal professional health and social services, but equally encompasses the care provided by informal caregivers in patients' (inner) networks of family and friends as well as in their community[93,94]. The model further opens the door to the shift from a strictly service-delivery model to a community-based model of palliative care for frail older people and people with serious illness. Compassionate communities – to be understood as a collaboration between community-dwelling people, local informal (care) initiatives and professional healthcare services – can be cities, neighbourhoods, universities, etc[95]. The model promotes power-sharing, ownership of care and support by the community as effective vehicles to achieve significant change and needed improvements in palliative care[76,95–97]. It puts increased focus on the role of health care services in promoting health, self-management and empowerment through e.g. training, and in coordination of care[98,99].

This model is gaining traction in recent years, given the emergence of several successful Compassionate Community initiatives in the Anglo-Saxon countries (22 in Australia, 5 in the UK, 3 in Canada, 1 in New Zealand)[71]. In Australia, research has shown that being involved in a caring network at the end of someone's life is transformational at the individual and collective level[71]. In mainland Europe, however, with exception of 2 initiatives in Austria, the model has not yet been implemented. One promising initiative is currently being developed in Flanders within the newly started CAPACITY-project[100]. At the basis of many of these initiatives is a core of community volunteers that work together with researchers and a hospice or palliative care service in partnership to deliver care in their community. One successful example of such a partnership is the *Compassionate Neighbours* project in London, UK[101], in which members of the community come into the hospice to be trained and are then matched with other community members near them to check up on them and provide care where possible. The key distinction between professional services and the *Compassionate Neighbours* project, and what makes this a compassionate community initiative is that the hospice does not take ownership of the volunteers. Rather, the hospice provides training and support and the volunteers provide care in the community in a partnership where power and responsibility are shared between both entities.

While professional health services are promoting the volunteer role in palliative care by providing a framework and a position within their health service, it is also these health services that inevitably limit them in their work. (Chapters 5 and 6)

Those that offer more freedom and autonomy to volunteers, such as the extramural care services like sitting services and community home-care services, do not train their volunteers adequately for the work they do. Those that train and support their volunteers, limit their autonomy for reasons of liability. The current model of volunteering therefore falls short and new hybrid approaches may be required that firmly root the volunteers in their liminal space as partners of the community and partners of health services. The *Compassionate* Neighbours project represents one approach. However, another, broader approach may be to add volunteers to the multidisciplinary care team. Their recognition as an important partner at the table may enhance their role as intermediary. Their presence in the care team – should the patient and volunteer wish it – can contribute to continuity of care, the timely identification of developing palliative care needs, and the holistic palliative care approach. It would furthermore require that the team explores whether a volunteer is present in the patient's network, who may wish to take up the responsibility of joining the care team, or that the team explores the need and desire of the patient to have one appointed one from among the available volunteers in health services or palliative care volunteering associations. Such an approach may improve coordination between health services, healthcare professionals and volunteers. It is important, however, that this happens with respect for the voluntary and informal nature of volunteering and should not formalise the role of the volunteer and risk altering the relationship between volunteers, patients and their loved ones.

The challenge with such partnership models is, then, that this requires health services to relinquish their complete control of their volunteers in favour of more equity in their relationship with volunteers[61]. It is precisely this relinquishing of control that characterises successful compassionate community initiatives such as the *Compassionate Neighbours* project[101]. However, the important role that professional health services, and in particular dedicated palliative care services, play in the promotion of volunteering and the development of volunteer practices should be acknowledged. As this dissertation has hopefully shown, there is certainly a need and place for this type of palliative care volunteering. It is primarily the health services closest to the community, such as community home-care and nursing homes, traditionally dependent on volunteering care provision that appear to be investing least in their volunteers but that will be crucial in achieving a successful socialisation of care.

The unique reach that volunteers have in the community, their approachability as the 'other' face of care (*Chapter 4*), their important location in the chain of communication between patients and family members and professional care (*Chapter 7*) and their broad, multidimensional support in terms of care tasks (*Chapters 2 and 3*) make them extremely well placed to help build the bridge between medical care and welfare and between professional health services and the community. Indeed, they have been building this bridge since the early days of palliative care and as I have argued in this dissertation, they have been meeting needs that healthcare professionals may not be able to meet.

In *Chapter 3* two types of volunteering sessions were identified, indicating two approaches to volunteering in palliative, direct patient care. The first approach represented a *complementary* approach. It was characterised by multidimensional support, which emphasises all-round care according to patient needs, structured and group supervision, and was related to comprehensive training. The approach offered a "broad" interpretation of the volunteer role, appearing to address an unmet need in palliative care and present mainly among volunteers in dedicated palliative care services. This type of approach has elsewhere been shown to meet larger needs of social support[102] and to augment professional care by providing company and information[103]. The second approach represented a *substitutive* approach characterised by an emphasis on practical and nursing tasks specifically and was related to instrumental nursing support training. The approach offered a "narrow" interpretation of the volunteer role and could be addressing a need that healthcare organisations may not be able to meet entirely due to a lack of nursing staff and resources. This approach was mainly present in volunteers in generalist care settings, and particularly in sitting services. This approach has elsewhere been suggested to provide limited, formal support for professionals[104]. The two identified approaches may represent two possible ways of volunteer integration into care for people with serious illnesses. The "broader" complementary approach may imply more extensive volunteer knowledge and skills and entails a more extensive contribution to patient care, making these volunteers a valuable resource in light of socialisation of care. Insights from *Chapter 4* into the roles of volunteers show that it may be the definition of the means and ends of volunteering that appears to separate substitutive approaches to volunteering, which may merely employ volunteers to do another person's job[105], from the complementary approaches to volunteering, which go beyond the bare necessities and requirements of the health service.

What some consider the ends, others consider the means to a more important end. If volunteers serve food to patients, some healthcare services and volunteers may consider this to be the end goal of their task and role as volunteers itself: patients are fed. For many others, however, feeding the patient is only one of the many and varying means to a greater end. In many services, volunteers do the rounds serving food not because that is their task, but because doing that task allows them to check in with patients. In contrast to time-constrained professionals, volunteers possess the valuable resource of time. Therefore, while they are there with the patient, they might as well take a seat and have a chat, talk about day-to-day things, or talk about how the patient is feeling, what has been bothering them. Whereas narrow, substitutive approaches define practical tasks as the ends of volunteer care, complementary and more multidimensional approaches define practical tasks as the means to ends that include psychosocial and existential care. This complementary approach has been suggested in international literature to contribute to social capital[59,60] and to bridging the gap between health services and communities[106]. It is precisely this complementary approach that may therefore be crucial to promote in light of the socialisation of care, particularly in light of Compassionate Community models.

8.6.2 POLICY RECOMMENDATIONS

Volunteering within health services should be encouraged and streamlined.

Firstly, **recruitment** of volunteers and engagement of potential volunteers can be stimulated by **offering more flexible, low-threshold volunteering profiles** centred around role performance, instead of task performance.

Our findings (*Chapter 2*) indicated that many health services experience difficulties recruiting new and suitable volunteers. This may be due to the nature of the current job market and the increasing retirement age in Belgium, which is currently set at the age of 65 and expected to increase to the ages of 66 (by February 2025) and 67 (by February 2030)[107]. It has been suggested that younger volunteers are motivated more by personal gain, show less devotion to their organisation, and often volunteer to enrich their resumé in search for paid work[51,108,109]. Additionally, palliative care health services indicate that younger volunteers often leave once younger volunteers find employment, meaning an investment into younger volunteers in terms of time and training is often wasted. People in the middle of their career often lack time to volunteer and due to the aforementioned increasing retirement age, people who retire are increasingly less capable of actively investing in volunteer work. A second reason is that volunteering is considered too much of a time investment by many people. A possible reason is that the high requirements and the task-focused recruitment may not be appealing to potential volunteers. This means that in the current situation the population of potential volunteers is limited by the job market, the increased retirement age, and the perceived time investment of volunteering. On top of that, as the findings presented in this dissertation have suggested, palliative care volunteering requires particular skills, sensitivities and attitudes towards death, dying and the end of life. Palliative care volunteering is not for everyone and recruitment efforts should acknowledge that in their criteria and intake interviews by assessing motivations, experience and attitudes towards death, dying and the end of life. Dedicated palliative care services already conduct a strict vetting process, however, less is known regarding the recruitment strategies and efforts in generalist palliative care services.

Secondly, volunteers require **multifaceted support** from health services and this ought to be reflected in policy. Support means **training, coordination,** and **supervision**.

Our findings (*Chapter 5*) show a clear positive association between volunteer task performance, volunteer involvement and volunteer training. An investment in training increases volunteers’ capacity; this seems a plausible conclusion. A **training** programme for all volunteers in palliative care – including those in generalist palliative care – should be developed through the Federation for Palliative Care Flanders (FPZV). Particular attention ought to be paid to basic knowledge and skills in palliative care, recognizing and signposting evolutions in palliative care needs and guarding or preserving professional and personal boundaries to protect volunteers in their role. Individual training modules currently exist, however no centralised and systematically disseminated training programmes are currently available.

The presence of leadership and a clear division of responsibilities within the health service facilitates volunteering and volunteer role performance. Considering the close collaboration between volunteers and nurses and the importance for volunteers of emotional support from psychologists and nurses, it is recommended that health services appoint a nurse or psychologist as **volunteer coordinator** per health services or department that works with volunteers.

Our findings (*Chapter 6*) show that **supervision** of volunteers is an important element of collaboration between volunteers and healthcare professionals. This requires the **presence, availability and approachability of nurses and psychologists** and **frequent contact** between them and volunteers. Supervision encompasses two types of support: 1) **functional support**, in which volunteers can reflect on sensitive situations, problematic care situations together with nurses and psychologists and can make decisions and coordinate care together; and 2) **emotional support**, in which volunteers can turn to nurses and psychologists to process sensitive, difficult and stressful situations and experiences such as grieving, family conflicts, patient decline, etc. Volunteers often develop close relationships with patients and their families. It is partly the responsibility of nurses and psychologists to ensure they can continue their volunteering work in a mentally healthy way. Volunteers are furthermore able to support each other in this regard as well, as reports of frequent intervision meetings attest to. However, this requires that health services stimulate contact among volunteers in all settings (e.g. through a dedicated volunteer office or meeting room), and between volunteers and healthcare professionals (e.g. through informal gatherings) to facilitate exchanging experiences. This may be most pressing in health services where volunteers work alone and rarely see their colleagues.

The Flemish government is advised to stimulate cooperation initiatives between professional care provision and local communities to the fullest.

The total number of people that will need long-term palliative care will continue to increase[72], while the availability of healthcare professionals is limited[78]. Merely increasing healthcare professionals is inadequate and not feasible. To meet these challenges, we suggest building local care networks in which volunteering is supported by professional care provision and in which neighbourhood operations are strengthened. Complementary solutions involving informal care providers are necessary, in which informal care providers are optimally deployed and supported. Volunteers and family caregivers both fulfil an important role that is not to be underestimated. Their respective added value to palliative care provision requires its own support and an investment on part of the health services. Both volunteers and family caregivers should be offered a role as partners in care provision, should they wish to play it, as they are key figures in care integration between health services and the community.

Firstly, a volunteer force, while economically advantageous, still **requires financial resources** to fund training, support and coordination. Our findings show that these aspects are crucial to the functioning of volunteer forces. (*Chapters 2, 4, 5 and 7.*)

A well-functioning volunteer force, furthermore, **requires paid staff**, particularly nurses. Our findings show that volunteers work closely together with nurses and both parties often rely on each other to keep each other informed and to complement each other's work in care provision. The presence of nurses is therefore crucial for the integration of volunteers in palliative care. Support of nurses can therefore be indirectly seen as support for volunteers as well. Additionally, collaboration with other care professionals should be explored depending on the care needs of the patients. E.g. collaboration with a social worker may be more relevant in cases of high social care needs. The same may hold true for psychologists and psychological care needs, or family caregivers in home-care settings.

Secondly, the **acknowledgement of the complementary value of volunteers** to professional care implies a recognition that volunteers cannot and are not meant to replace paid staff. It is impossible for volunteering to close structural deficits in professional care. The main reason for this is that they themselves are dependent on the resources and personnel that professional care provision currently lacks.

Finally, **investing in the multidimensional, broad volunteer approach in palliative care** (discussed earlier in the discussion and in Chapter 3) may increase volunteers' capacity to support professional palliative care. More extensive training has been shown to be positively associated with a broad task performance and support approach. Furthermore, training and task performance have in turn been shown to be positively associated with volunteer involvement in the organisation of care. Maximising this supportive capacity may require only small but focused investments in the development of the volunteer position in care but will likely be crucial in achieving the socialisation of care and collaborative initiatives between professional healthcare and local communities.

Voice of Volunteering Charter as advocacy tool.

In 2017 at the EAPC Congress in Madrid, Spain, The European Association for Palliative Care (EAPC) Task Force on Volunteering in Hospice and Palliative Care[110], in collaboration with the EAPC, the Worldwide Hospice and Palliative Care Alliance (WHPCA) and the International Association for Hospice & Palliative Care (IAHPC) launched the **Voice of Volunteering** Charter[19,111,112]. This charter was developed to be used as an advocacy tool for palliative care and policy makers to support volunteering in hospice and palliative care and to outline specific actions policy makers and health services could take to promote volunteering and to ensure support for palliative care volunteers. It entails the following aims:

- Promote the successful development of volunteering for the benefit of patients, families and the wider hospice and palliative care community.
- Recognize volunteering as a third resource alongside professional care and family care, with its own identity, position and value.
- Promote research and best practice models in the recruitment, management, support, integration, training and resourcing of volunteers.

The Charter has been translated by Prof. dr. Kenneth Chambaere and me into Flemish **(see Appendix 8.1)**. The adoption of the Charter by policy makers and health services may contribute to ensuring proper support of volunteers in palliative care in Flanders and Belgium.

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9 NEDERLANDSTALIGE SAMENVATTING

9.1 Inleiding

Dankzij vooruitgangen in de geneeskunde, wetenschap en de modernisering van onze samenleving is onze levensverwachting sterk toegenomen. Dit resulteert in vergrijzende bevolkingen en een stijging van chronische, levensbedreigende aandoeningen. Naar alle waarschijnlijkheid zal ieder van ons op een bepaald punt in ons leven geconfronteerd worden met zulke aandoeningen, zij het als patiënt, als mantelzorger of als vrienden of kennissen van iemand met een chronische, levensbedreigende aandoening. De dood is niet langer een abrupt en kort eindstadium, maar heeft sinds kort een continue aanwezigheid in onze samenleving opgeëist. Mensen leven vandaag langer met ziektes met verschillende ziektetrajecten en zorgnoden. Chronische en levensbedreigende aandoeningen zijn steeds meer een vast onderdeel van onze leefomgeving. Onze relatie met de dood en sterven is hierdoor drastisch veranderd.

Deze veranderingen zetten vandaag heel wat druk op onze professionele gezondheidszorg. Financiële tekorten en een gebrek aan professionele zorgverleners zorgen ervoor dat we als samenleving niet langer tegemoet kunnen komen aan de groeiende vraag naar zorgverlening. Zorgverlening voor een steeds ouder wordende bevolking stelt ons collectief voor een uitdaging en er is een groeiende bewustwording dat enkel en alleen het uitbreiden van het aantal professionele zorgverleners of het verbeteren van zorgdiensten ontoereikend zal zijn. Voorstanders van public health benaderingen verwijzen daarom naar de rol van de samenleving en informele zorgverleners in de palliatieve zorg om deze uitdagingen het hoofd te bieden. Professionele zorgdiensten kunnen bovendien een werkbaar kader bieden waarin de samenleving geëngageerd kan worden door middel van vrijwilligerswerk. In de visieteksten van de Vlaamse overheid verwijst men daarom de laatste jaren steevast naar de ‘vermaatschappelijking’ van de zorg. Hiermee ambieert de overheid een sterkere en uitgebreidere integratie van zorg binnen de samenleving met een grotere autonomie voor de patiënt. De vermaatschappelijking van de zorg benadrukt participatie en verbondenheid tussen mensen en voorziet een grotere rol voor vrijwilligers om dit te bereiken.

Deze verhoogde aandacht voor vrijwilligers lijkt voor de hand liggend, gezien zij reeds sinds het begin van de hospice beweging een aanzienlijke rol spelen binnen de palliatieve zorg. Eerder onderzoek toonde reeds aan dat vrijwilligers een positieve invloed kunnen hebben op de kwaliteit van zorg door het reduceren van stress, het bieden van praktische, emotionele, informationele, spirituele en rouwondersteuning, en door een brug te vormen tussen de zorgdienst en de samenleving. Andere studies argumenteren dat vrijwilligers bijdragen aan het sociale weefsel van een gemeenschap door het bundelen en zelfs creëren van sociaal kapitaal. Tenslotte, is het algemeen erkend dat vrijwilligersbezoeken het algemene welzijn en de tevredenheid van patiënten verhoogd.

Het ontbreekt de literatuur echter nog aan heel wat wetenschappelijke inzichten met betrekking tot vrijwilligerswerk in de palliatieve zorg in het algemeen, en meer bepaald in Vlaanderen. Het ontbreekt specifiek aan inzichten in de capaciteit van vrijwilligers in de palliatieve zorg om de professionele zorg verder te ondersteunen. Deze capaciteit wordt onder meer bepaald door hun aanwezigheid, het type zorg dat ze verlenen, hun betrokkenheid, de ondersteuning die zij ontvangen in hun werk en de mate waarin zorgdiensten een vrijwilligerswerking kunnen ondersteunen en coördineren. Zie **Kader 1** voor een beknopt overzicht van de huidige kennislacunes waar deze dissertatie een antwoord wil op bieden.

Kader 1: Kennislacunes in de huidige literatuur over vrijwilligerswerk in de palliatieve zorg die deze dissertatie wil beantwoorden

Kennislacunes

- Waar zijn vrijwilligers aanwezig binnen de gespecialiseerde en reguliere palliatieve zorg?
- In welke mate verlenen vrijwilligers directe patiëntenzorg?
- Welke taken voeren vrijwilligers uit binnen de palliatieve zorg?
- Wat is de rol en positie van vrijwilligers in de palliatieve zorg?
  - Wat betekenen vrijwilligers voor patiënten, mantelzorgers, verpleegkundigen, psychologen en huisartsen?
  - Welke rollen vervullen vrijwilligers in de zorg voor mensen aan het levenseinde?
- Welke opleiding hebben vrijwilligers in de palliatieve zorg?
  - Welke opleiding bieden palliatieve zorgdiensten aan vrijwilligers?
  - In welke mate voelen vrijwilligers zich voldoende opgeleid?
- Wat voor begeleiding ontvangen vrijwilligers in de palliatieve zorg?
  - Hoe evalueren vrijwilligers deze begeleiding?
- In welke mate zijn vrijwilligers momenteel betrokken in de organisatie van palliatieve zorgverlening?
  - Hoe evalueren zorgdiensten en vrijwilligers deze betrokkenheid?
- Met wie werken vrijwilligers in de palliatieve zorg samen in de zorgverlening?
  - Hoe werken vrijwilligers en professionele zorgverleners samen?
  - Hoe evalueren vrijwilligers deze samenwerking met professionele zorgverleners?

9.2 Doelstelling van deze dissertatie

De algemene doelstelling van deze dissertatie is om het vrijwilligerswerk in de palliatieve zorg in Vlaanderen en Nederlandstalig Brussel beter te begrijpen, in termen van wie zij zijn, wat zij doen, wat hun rol is, hoe zij de palliatieve zorgverlening ondersteunen en op welke wijze zij in hun zorgverlening ondersteund kunnen worden.

De specifieke onderzoeksvragen zijn:

1. Wat zijn de kenmerken van het georganiseerd vrijwilligerswerk in de palliatieve zorg in de Vlaamse gezondheidszorg, in termen van
    a. de taakuitvoering, rol en positie van vrijwilligers;
    b. de opleiding en ondersteuning van vrijwilligers; en
    c. de obstakels voor het onderhouden van een vrijwilligerswerking?
2. In welke mate zijn vrijwilligers in de palliatieve zorg ingebed, in termen van betrokkenheid in de organisatie van palliatieve zorgverlening en de samenwerking met andere professionele en non-professionele zorgverleners?

9.3 Methoden

Kwantitatieve cross-sectionele enquête bij zorgdiensten die palliatieve zorg bieden in Vlaanderen en Nederlandstalig Brussel

Tussen Juni en Oktober 2016 voerden we een cross-sectionele post-enquête uit bij zorgdiensten die zorg bieden voor mensen met chronische en/of levensbedreigende aandoeningen aan het levenseinde in de Vlaamse gezondheidszorg. Zorgdiensten werden geïdentificeerd op basis van een experten consultatie en de beschikbare lijsten van erkende zorgdiensten van het Vlaamse Ministerie van Welzijn, Volksgezondheid en Gezin. We includeerden de volledige populaties van palliatieve zorgeenheden, palliatieve dagcentra, multidisciplinaire begeleidingsequipes, medische oncologie afdelingen, en Samana regio's en een enkelvoudige aselecte steekproef van woonzorgcentra (200/783; 25.5%). De totale N voor deze enquête was 342. Er werd een vragenlijst ontwikkeld, bestaande uit 26 vragen over vrijwilligerstaken, opleiding, huidige betrokkenheid van vrijwilligers, gewenste betrokkenheid, en organisatorische kenmerken. De vragenlijst werd ontwikkeld op basis van de literatuur rond vrijwilligerswerk in de palliatieve zorg en de input van vertegenwoordigers van elk type zorgdienst in ons sample kader. De vragenlijst werd cognitief getest bij deze vertegenwoordigers in twee rondes. De vragenlijst werd verstuurd naar de vrijwilligerscoördinatoren binnen elke zorgdienst.

De resultaten van deze enquête worden behandeld in hoofdstukken 2 en 5.

Kwantitatieve cross-sectionele enquête bij vrijwilligers in de palliatieve zorg in Vlaanderen en Nederlandstalig Brussel

Tussen Juni en November 2018 voerden we een cross-sectionele post-enquête uit bij geregistreerde vrijwilligers uit zorgdiensten die zorg bieden voor mensen met chronische en/of levensbedreigende aandoeningen aan het levenseinde in de Vlaamse gezondheidszorg. De populatie van deze studie bestond uit alle geregistreerde vrijwilligers in een selectie van zorgdiensten in Vlaanderen en Nederlandstalig Brussel, bepaald op basis van de resultaten van de enquête bij zorgdiensten, die aangaven vrijwilligers in te zetten in de directe patiëntenzorg voor mensen met chronische en/of levensbedreigende aandoeningen. Organisaties werden geïdentificeerd op basis van de beschikbare lijsten van het Vlaamse Ministerie van Welzijn, Volksgezondheid en Gezin. Gezien het gebrek aan een gecentraliseerd register van vrijwilligers, werd het sample kader gebaseerd op schattingen van het aantal vrijwilligers verkregen in de enquête bij zorgdiensten en werd er met een twee-staps disproportioneel gestratificeerde aselecte cluster steekproef gewerkt. (**Zie appendix 3.1 voor een overzicht van deze procedure.**) Binnen elk type zorgdienst (=strata) werden individuele zorgdiensten (=clusters) op aselecte wijze geselecteerd. Binnen deze geselecteerde zorgdiensten werden alle aanwezige vrijwilligers geïncludeerd. In totaal werden 2273 vrijwilligers een vragenlijst opgestuurd. De vragenlijst werd ontwikkeld op basis van de literatuur rond vrijwilligers in de palliatieve zorg en de vragenlijst gebruikt in de enquête bij zorgdiensten. De vragenlijst bestond uit 23 vragen over vrijwilligerstaken, opleiding, supervisie, frequentie en intensiteit van het vrijwilligerswerk, contact met patiënten met chronische en/of levensbedreigende aandoeningen, betrokkenheid van vrijwilligers, samenwerking met andere zorgverleners, en demografische informatie. De vragenlijst werd cognitief getest bij vrijwilligers in de palliatieve zorg in twee rondes.

De resultaten van deze enquête worden behandeld in hoofdstukken 3 en 6.

Kwalitatieve focus groep en interview studie

Tussen Maart en November 2018 voerden we focus groepen met professionele zorgverleners en vrijwilligers, en individuele semigestructureerde interviews met patiënten en mantelzorgers in Vlaanderen uit. Focus groepen stimuleren de uitwisseling van ideeën door middel van discussie waarbinnen onderlinge gelijkenissen en verschillen tussen de participanten de conversatie drijven, waardoor onderliggende relevante thema's komen bovendrijven. Gezien de fragiele gezondheid van patiënten en de gevoelige aard van het thema, werd voor patiënten en mantelzorgers echter gekozen voor individuele semigestructureerde interviews. Het voordeel van deze interviews is dan dat het ons toeliet de participanten als discrete, individuele cases te beschouwen en de participanten vrij te laten vertellen. Voor deze studie werden patiënten met chronische en/of levensbedreigende aandoeningen, mantelzorgers van mensen met chronische en/of levensbedreigende aandoeningen, vrijwilligers, verpleegkundigen, psychologen en huisartsen geïncludeerd uit ziekenhuizen, de thuiszorg, dagverblijven en intramurale zorgdiensten. Zij werden beschouwd als de meest nauw betrokken partijen in de zorg voor mensen met palliatieve zorgnoden. Huisartsen werden gekozen in plaats van specialisten, gezien hun centrale rol in elk ziektetraject en omdat het rekruteren van specialisten voor elke mogelijke chronische en/of levensbedreigende aandoening buiten de scope van dit onderzoek viel. Zorgdiensten werden overwogen op basis van de resultaten van de enquête bij zorgdiensten. Topic guides werden ontwikkeld en geëvalueerd door de projectgroep en behandelden de volgende onderwerpen: vrijwilligerstaken, grenzen van vrijwilligerstaken, de rol van vrijwilligers in de palliatieve zorg, de barrières en faciliterende factoren voor vrijwilligerswerk, contact en samenwerking tussen vrijwilligers en professionele zorgverleners, en barrières en faciliterende factoren voor deze samenwerking. De analyse verliep volgens een kwalitatief descriptief design met nadrukken uit de fenomenologie en Grounded Theory. Verschillende perspectieven werden geraadpleegd over dezelfde onderwerpen en analyse volgende constant vergelijkende methode.

De resultaten van deze studie worden behandeld in hoofdstukken 4 en 7.

9.4 Belangrijkste bevindingen

Kenmerken van het vrijwilligerswerk in termen van taakuitvoering, rollen en positie van de vrijwilliger in de palliatieve zorg

In hoofdstuk 2 ontdekten we dat zowel gespecialiseerde als reguliere palliatieve zorgdiensten vrijwilligers inzetten in directe patiëntenzorg. Vrijwilligers hadden de grootste aanwezigheid in gespecialiseerde zorgdiensten (97%-100%) en medische oncologie afdelingen hadden de laagste aanwezigheid (64%). Alle zorgdiensten met vrijwilligers in de directe patiëntenzorg zetten hun vrijwilligers in voor een brede waaier aan palliatieve zorgtaken, inclusief praktische taken gerelateerd aan Algemene Dagelijkse Levensverrichtingen (ADL) en instrumentele Activiteiten in het Dagelijkse Leven (iADL). De meest prominente taken voor vrijwilligers waren echter Psychosociale, Signalerende en Existentiële (PSE) zorgtaken.

Hoofdstuk 3 bevestigt dat vrijwilligers overheen alle zorgdiensten zorg bieden aan mensen met chronische en levensbedreigende aandoeningen. Op basis van vragen over hun taakuitvoering, ontdekten we twee types vrijwilligerssessies: (1) ‘multidimensionale ondersteuning’, bestaande uit brede taakuitvoering met nadruk op PSE taken; en (2) ‘praktische ondersteuning’, met nadruk op verpleegkundige taken. Gespecialiseerde palliatieve zorg vrijwilligers neigen eerder naar multidimensionale ondersteuning voor patiënten, en vrijwilligers uit oppasdiensten neigen eerder naar praktische ondersteuning.

Hoofdstuk 4 verkent de perspectieven van vrijwilligers, patiënten, mantelzorgers, verpleegkundigen, psychologen en huisartsen uit ziekenhuizen, de thuiszorg, dagcentra en woonzorgcentra over de rol en positie van vrijwilligers in de palliatieve zorg. We ontdekten dat vrijwilligers een ‘ander’, meer benaderbaar gezicht van zorgverlening vormen voor patiënten en hun naasten. Ze nemen een positie in binnen een liminale ruimte tussen – en overlappend met – het professioneel-medische domein en het gezinsdomein. Vanuit deze positie vervullen zij twee rollen: ‘er zijn’ en de rol van tussenpersoon. De voornaamste barrières voor de uitvoering van hun rollen zijn een gebrek aan communicatiemogelijkheden met verpleegkundigen, een gebrek aan ondersteuning in het omgaan met moeilijke situaties en een gebrek aan coördinatie in de zorgomgeving. Patiënt matching was een belangrijke faciliterende factor voor hun roluitvoering.

Kenmerken van het vrijwilligerswerk in termen van vrijwilligersopleiding en ondersteuning

Hoofdstuk 2 toont aan dat vooral gespecialiseerde palliatieve zorgdiensten en Samana diensten opleiding aan vrijwilligers aanbieden en ook het grootste aanbod aan opleidingen voorzien. Woonzorgcentra en medische oncologie afdelingen bieden zelden opleiding in palliatieve zorg of voorafgaande zorgplanning aan. Nadruk op ADL en PSE taken voor vrijwilligers was gerelateerd aan een groter aanbod van vrijwilligersopleidingen.

Hoofdstuk 3 toont aan dat vrijwilligers uit woonzorgcentra de minste opleiding hebben in vergelijking met andere vrijwilligers en tevens hun opleiding het slechtst evalueren. Samana vrijwilligers ontvangen de minste begeleiding en evalueren hun begeleiding het slechtst. Slechts weinig vrijwilligers beschouwen hun gebrek aan supervisie echter als problematisch.

Kenmerken in termen van obstakels voor het onderhouden van een vrijwilligerswerking

De bevindingen uit hoofdstuk 2 wijzen erop dat het vinden van nieuwe en geschikte vrijwilligers in het algemeen de meest belangrijke barrières voor zorgdiensten zijn. Een nadruk op ADL taken voor vrijwilligers wordt echter geassocieerd met financiële en wettelijke barrières voor een vrijwilligerswerking.

Inbedding van vrijwilligers in de palliatieve zorg, in termen van betrokkenheid in de organisatie van palliatieve zorgverlening en samenwerking tussen vrijwilligers en andere zorgverleners

Hoofdstuk 5 toont aan dat, hoewel de meerderheid van zorgdiensten hun vrijwilligers vaak tot altijd informeert over de organisatie van de zorgverlening, slechts een minderheid de input van vrijwilligers in rekening brengt bij beslissingen, en slechts een kleine fractie van zorgdiensten een meer empowered model van betrokkenheid hanteert. Zorgdiensten met de hoogste betrokkenheid van vrijwilligers bevinden zich voornamelijk binnen de gespecialiseerde palliatieve zorg en diensten voor oppashulp; de groep van woonzorgcentra had het grootste aantal zorgdiensten met de laagste betrokkenheid van vrijwilligers. Een hogere graad van betrokkenheid wordt geassocieerd met een uitgebreider aanbod aan vrijwilligersopleidingen en een uitgebreidere ADL en PSE taakuitvoering door vrijwilligers.

In hoofdstuk 6 geeft de helft van de vrijwilligers aan dat zij zich gehoord voelen bij beslissingen van de zorgdienst over de organisatie van palliatieve zorgverlening. Een derde van de vrijwilligers signaleert echter een gebrek aan betrokkenheid. Ongeacht het type zorgdiensten, werken vrijwilligers met weinig andere zorgverleners samen, met uitzondering van medevrijwilligers, vrijwilligerscoördinatoren en verpleegkundigen. Deze samenwerking draait voornamelijk rond informatie-uitwisseling. Vrijwilligers lijken het minst ingebed in de palliatieve zorg binnen woonzorgcentra en Samana diensten.

Hoofdstuk 7 verkent opnieuw de perspectieven van vrijwilligers, patiënten, mantelzorgers, verpleegkundigen, psychologen en huisartsen uit ziekenhuizen, de thuiszorg, dagcentra en woonzorgcentra, deze keer over de samenwerking tussen vrijwilligers en professioneel zorgverleners. Samenwerking wordt gekenmerkt door informatie-uitwisseling met betrekking tot ontwikkelingen in de toestand van patiënten, functionele en emotionele ondersteuning voor vrijwilligers, en coördinatie van de zorgverlening door vrijwilligers, verpleegkundigen en psychologen. De voornaamste barrières voor deze samenwerking zijn gebrek aan contact tussen verpleegkundigen en vrijwilligers, gebrek aan duidelijkheid omtrent richtlijnen betreffende het delen van informatie over patiënten, en gebrek aan leiderschap.

9.5 Discussie en aanbevelingen

Praktijkaanbevelingen

De manier waarop vrijwilligers ingezet worden blijkt geassocieerd te zijn met bepaalde barrières voor het onderhouden van een vrijwilligerswerking. Zo is het inzetten van vrijwilligers voor ADL zorgtaken, gericht op patiënten die niet langer onafhankelijk kunnen functioneren, geassocieerd met toegenomen financiële kosten, beperkingen gesteld door wettelijke voorschriften met betrekking tot vrijwilligerstaken en een uitgebreider opleidingsaanbod. Dit geeft aan dat zelfs een puur praktisch en vervangend gebruik van vrijwilligers niet zonder kosten of uitdagingen is.

Een belangrijke uitdaging voor zorgdiensten die vrijwilligers in de palliatieve zorg inzetten is het ontwikkelen van wervingsstrategieën op maat om nieuwe potentiële vrijwilligers te engageren. De bevindingen in deze dissertatie suggereren dat het ontwikkelen van flexibele, maar duidelijk beschreven rolprofielen, ter vervanging van taakprofielen, de drempel tot engagement zouden kunnen verlagen. De vrijwilligersrollen die ontdekt werden in deze dissertatie, namelijk 'er zijn' en de rol als tussenpersoon, vinden hun grondslag in de unieke positie die vrijwilligers innemen tussen de professionele zorg en de privésfeer. Deze rollen lijken de kern te vormen van het vrijwilligerswerk in de palliatieve zorg en zijn prioritair aan specifieke taken die kunnen variëren al naargelang de zorgdienst, context en noden van de patiënt. De huidige wervingsproblemen vergen daarenboven ook betere en interregionale coördinatie tussen de palliatieve netwerken in Vlaanderen. Er is nood aan een kaderwerk dat deze coördinatie vergemakkelijkt en dat tevens gestandaardiseerde, maar context-gevoelige opleidingen centraliseert en aanbiedt aan vrijwilligers in de palliatieve zorg.

Het is tevens aan te raden dat de palliatieve netwerken hun blik verruimen naar reguliere zorgdiensten waarin palliatieve zorg verleend wordt, zoals woonzorgcentra, en hierbinnen ook een leidinggevende en coördinerende rol in opnemen. Hoewel woonzorgcentra historisch een belangrijke rol toekennen aan informele zorgverlening en reeds lang kampen met personeelstekorten, ontvangen vrijwilligers in woonzorgcentra slechts weinig opleiding en hebben zij een relatief beperkte rol in de palliatieve zorgverlening. Het lijkt er dus op dat woonzorgcentra hun vrijwilligers onvoldoende ondersteunen voor het werk dat zij uitvoeren. Een investering in toereikende ondersteuning van vrijwilligers in hun zorgverlening is daarom op zijn plaats. Het inschakelen van vrijwilligers lost structurele onderliggende problemen van personeelstekorten en gebrek aan subsidies niet op, maar hun aanwezigheid – mits toereikende ondersteuning – kan stress reduceren bij personeel en de kwaliteit van zorg en het welzijn verhogen van patiënten.

Onze bevindingen geven aan dat opleiding en organisatorische steun geassocieerd zijn met het type zorg dat vrijwilligers leveren. Dit betekent dat zorgdiensten en beleidsmakers met beperkte, strategische investeringen in opleiding en ondersteuning, een stimulans kunnen geven aan een complementaire vrijwilligersbenadering. Woonzorgcentra zijn op dat vlak mogelijks één setting met een groot onderbenut potentieel.

Tenslotte, wijzen onze resultaten op een bestaand maar weinig gebruikt potentieel van vrijwilligers voor het bereiken van mensen met zorgnoden die de professionele zorgverlening nog niet bereikt hebben. Vrijwilligers binnen Samana, bijvoorbeeld, bereiken mensen met zorgnoden via hun eigen collectief sociaal netwerk. Deze vrijwilligers kunnen een cruciale rol spelen in het verbeteren van de toegang tot zorgverlening, maar ontvangen hier momenteel nog niet de nodige opleiding voor. Dit wijst op een kloof tussen effectieve zorgverlening door vrijwilligers en hun opleiding hiervoor binnen de reguliere palliatieve zorgverlening, maar wijst tevens op een potentieel voor kwaliteitsvol en efficiënt signaleren van palliatieve zorgnoden in de lokale gemeenschap.

Beleidsaanbevelingen

Het aanmoedigen en stroomlijnen van vrijwilligerswerk binnen professionele zorgdiensten

De **werving** en het **engagement** van vrijwilligers kan beter gestimuleerd worden door het aanbieden van **flexibele, laagdrempelige vrijwilligersprofielen** gericht op roluitvoering, eerder dan taakuitvoering.

Vrijwilligers vereisen **veelzijdige ondersteuning** van hun zorgdiensten en dit dient erkend te worden in het beleid. Ondersteuning betekent **opleiding**, **coördinatie** en **supervisie**. Binnen dergelijke opleiding moet specifiek aandacht besteed worden aan basiskennis en vaardigheden palliatieve zorg, het herkennen en signaleren van (evoluties in) palliatieve zorgnoden, en het bewaren van professionele en persoonlijke grenzen ter bescherming van vrijwilligers in hun rol. Momenteel bestaan er individuele opleidingsmodules, maar een gecentraliseerde en systematische disseminatie ontbreekt. Een aanwezigheid van leiding en een duidelijke verdeling van verantwoordelijkheden binnen de zorgdienst faciliteren het vrijwilligerswerk en helpen vrijwilligers bij het uitvoeren van hun rollen. Gezien de nauwe samenwerking tussen vrijwilligers en verpleegkundigen, is het aangeraden dat een verpleegkundige of psycholoog aangesteld wordt als vrijwilligerscoördinator per zorgdienst of afdeling die met vrijwilligers werkt. De supervisie van vrijwilligers is een belangrijk element van samenwerking tussen vrijwilligers en professionele zorgverleners. Dit vereist de aanwezigheid, beschikbaarheid en benaderbaarheid van verpleegkundigen en psychologen, en frequent contact tussen hen en de vrijwilligers. Supervisie omvat twee types ondersteuning: 1) functionele ondersteuning, dat vrijwilligers samen met verpleegkundigen en psychologen helpt te reflecteren over gevoelige of problematische zorgsituaties om vervolgens beslissingen te maken en de zorg gezamenlijk te coördineren; en 2) emotionele ondersteuning, waarbinnen vrijwilligers terecht kunnen bij verpleegkundigen en psychologen om gevoelige, moeilijke en stressvolle situaties en ervaringen te verwerken (bv rouw, familieconflicten, de achteruitgang van patiënten, overlijdens, etc.). Vrijwilligers ontwikkelen vaak hechte relaties met patiënten en hun naasten. Het is binnen zorgdiensten gedeeltelijk de verantwoordelijkheid van verpleegkundigen en psychologen om te verzekeren dat vrijwilligers hun werk kunnen blijven doen op een mentaal gezonde wijze. Bovendien, kunnen vrijwilligers elkaar ook steunen hierin via intervisie vergaderingen. Het is daarom aangeraden dat zorgdiensten onderling contact tussen hun vrijwilligers mogelijk maken en stimuleren door middel van een gedeeld lokaal of informele samenkomsten. De nood hieraan is het hoogst binnen zorgdiensten waarin vrijwilligers vaak alleen werken.

<u>Het stimuleren van samenwerkingsinitiatieven tussen professionele zorgverlening en lokale gemeenschappen</u>

Het aantal mensen dat langdurige palliatieve zorg nodig heeft zal in de toekomst blijven stijgen, terwijl de beschikbaarheid van professionele zorgverleners beperkt is. Enkel het opdrijven van het aantal professionele zorgverleners is ontoereikend en onhaalbaar. Om deze uitdagingen tegemoet te komen, wordt aangeraden om lokale zorgnetwerken te ontwikkelen, waarin vrijwilligerswerk ondersteund wordt door professionele zorgverlening en waarbinnen buurtwerkingen versterkt worden. Complementaire oplossingen zijn vereist, waarin informele zorgverleners betrokken worden, optimaal ingezet en ondersteund worden. Vrijwilligers en mantelzorgers vervullen beiden een belangrijke rol die niet onderschat mag worden. Hun respectievelijke toegevoegde waarde aan palliatieve zorgverlening vereist een eigen ondersteuning en investering door zorgdiensten. Zowel vrijwilligers als mantelzorgers moeten betrokken worden als partners in de zorg indien zij dit wensen, gezien hun sleutelpositie in de integratie van zorg binnen zorgdiensten en de gemeenschap.

Een vrijwilligerswerking, hoewel financieel voordelig, vereist nog steeds financiële middelen ter subsidiëring van opleiding, ondersteuning en coördinatie. Onze resultaten geven aan dat deze aspecten cruciaal zijn voor het functioneren van vrijwilligerswerkingen. (Hoofdstukken 2, 4, 5 en 7.)

Een goed functionerende vrijwilligerswerking vereist bovendien betaald personeel, zoals verpleegkundigen. Vrijwilligers lijken vandaag het nauwst samen te werken met verpleegkundigen. Meer nog, vaak zijn ze afhankelijk van elkaar om goed geïnformeerd te blijven over de patiënt en elkaar aan te vullen in de zorgverlening. De aanwezigheid van verpleegkundigen lijkt dus cruciaal voor de integratie van vrijwilligers in de palliatieve zorg. Ondersteuning voor verpleegkundigen kan in die zin ook gezien worden als indirecte ondersteuning voor vrijwilligers. Maar ook samenwerking met andere zorgprofessionals moet verkend worden, afhankelijk van de zorgnoden van de patiënt. Zo kan samenwerking tussen vrijwilligers en maatschappelijk werkers bijvoorbeeld relevanter zijn in gevallen van prangende sociale zorgnoden. Idem voor psychologen en sterke psychologische zorgnoden, of mantelzorgers in de thuisomgeving.

De erkenning van de complementaire waarde van vrijwilligers voor professionele zorg impliceert een erkenning dat vrijwilligers betaald personeel niet kunnen en niet hoeven te vervangen. Vrijwilligers kunnen onmogelijk de structurele tekortkomingen in de professionele zorg opvullen. Zij zijn namelijk zelf mede afhankelijk van de aanwezigheid van de middelen en het personeel waaraan het vandaag ontbreekt.

Tenslotte, kan investeren in een multidimensionale, brede vrijwilligersbenadering in palliatieve zorg (hoofdstukken 3 en 8) de capaciteit van vrijwilligers om de professionele palliatieve zorg te ondersteuning sterk verhogen. Uitgebreidere opleidingen werden aangetoond positief geassocieerd te zijn met bredere taakuitvoering. Beiden waren tevens geassocieerd met betrokkenheid van vrijwilligers in de organisatie van de palliatieve zorg in de zorgdienst. Het maximaliseren van deze ondersteuningscapaciteit vereist slechts kleine maar gerichte investeringen in de ontwikkeling van de positie van de vrijwilliger in de zorg. Deze zullen echter cruciaal zijn in het bereiken van de vermaatschappelijking van de zorg en van samenwerkingsinitiatieven tussen professionele zorg en lokale gemeenschappen.

Stem van het Vrijwilligerswerk Charter als pleitmiddel

In 2017 werd op het 15e Wereldcongres van de Europese Associatie voor Palliatieve Zorg (EAPC) in Madrid het Stem van het Vrijwilligerswerk Charter gelanceerd. Het Charter is een product van de EAPC Task Force rond Vrijwilligerswerk in de Hospice en Palliatieve Zorg en werd in samenwerking met de Wereldwijde Alliantie voor Hospice en Palliatieve Zorg (WHPCA) en de Internationale Associatie voor Hospice & Palliatieve Zorg (IAHPC) ontwikkeld. Dit Charter werd ontwikkeld als pleitmiddel voor zorgprofessionals in de palliatieve zorg en beleidsmakers om het vrijwilligerswerk in de hospice en palliatieve zorg te ondersteunen. Het detailleert enkele specifieke acties die beleidsmakers en zorgdiensten kunnen doen om het vrijwilligerswerk te bevorderen en om ondersteuning voor palliatieve zorgvrijwilligers te verzekeren. Het heeft de volgende doeleinden:

- Het bevorderen van de succesvolle ontwikkeling van het vrijwilligerswerk ten voordele van patiënten, hun families en de bredere hospice en palliatieve zorg gemeenschap.
- Het herkennen van vrijwilligerswerk als derde hulpmiddel naast professionele zorg en mantelzorg, met een eigen identiteit, positie en waarde.
- Het bevorderen van onderzoek en best practice modellen in het beheer, de werving, ondersteuning, integratie, opleiding en inzet van vrijwilligers.

Het Charter werd vertaald naar het Nederlands door prof. dr. Kenneth Chambaere en mezelf (**zie Appendix 8.1**). De opname van het Charter door beleidsmakers en zorgdiensten kan bijdragen aan het verzekeren van degelijke ondersteuning van vrijwilligers in de palliatieve zorg in Vlaanderen en België.

10 CURRICULUM VITAE

10.1 Author bio

Steven Vanderstichelen, born 20 August 1990, obtained his Master's degree in Sociology (Ghent University) in 2014. In 2015, he joined the End-of-Life Care Research Group at the Vrije Universiteit Brussel (VUB). He has since worked on the INTEGRATE-Project (FWO-SBO) as the executive researcher of the study on Volunteering in Palliative Care. This study was the basis of this dissertation. He is also a Steering Group member of the EAPC Task Force on Volunteering in Hospice and Palliative Care. He has presented his work at numerous national and international palliative care and public health congresses. In 2018, he presented his work as invited speaker in plenary presentations at the second INTEGRATE Congress and at the Flemish Congress for Palliative Care. In 2019, he was awarded a plenary presentation for best abstract at the 16th World Congress of the European Association for Palliative Care in Berlin, Germany.

He is also the badass vocalist of the Ghent-based band OLAF. He will only leave this last part in if no one notices it when proof-reading. The jury members noticed. He still left it in, for he will not be tamed.

10.2 List of publications

Articles in international peer-reviewed journals

Vanderstichelen S, Houttekier D, Cohen J, Van Wesemael Y, Deliens L, Chambaere K. Palliative care volunteerism across the healthcare system: A survey study. May 8, 2018. Palliative Medicine https://doi.org/10.1177/0269216318772263 [2017 SCI impact factor 3.78; Ranking Q1; ranking n° 18/176 in public, environmental & occupational health]

Vanderstichelen S, Cohen J, Van Wesemael Y, Deliens L, Chambaere K. Volunteer Involvement In The Organisation Of Palliative Care: A Survey Study Of The Healthcare System in Flanders and Dutch-Speaking Brussels, Belgium. Health & Social Care In The Community. 2018 Oct 16. https://doi.org/10.1111/hsc.12666 [Epub Ahead of Print] [2017 SCI impact factor 2.782; Ranking Q1; ranking 7/42 in Social Work]

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Vanderstichelen S, Cohen J, Van Wesemael Y, Deliens L, Chambaere K. Perspectives on volunteer-professional collaboration in palliative care: a qualitative study among volunteers, patients, family carers and healthcare professionals. Journal of Pain and Symptom Management. [accepted] [2017 SCI impact factor 3.249; ranking Q1; ranking 2/133 in nursing (miscellaneous)]

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Vanderstichelen S, Gillissen J, Vermorgen M, Vandebogaerde I, Werrebrouck B, Robijn L. Tijd voor een echte vermaatschappelijking van palliatieve zorg?. [Time for a real socialisation of palliative care?] Nederlands-Vlaams Tijdschrift Palliatieve Zorg. 2019 [accepted]

Other publications

Vanderstichelen S, De positie van vrijwilligers in de palliatieve zorg: taken, rollen, en uitdagingen. [The position of volunteers in palliative care: tasks, roles and challenges.] Tijdschrift FPZV, 2019, Trends Wetenschap inzicht. [Published]

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Gilissen, J., De Schreye, R., Maetens, A., Robijn, L., **Vanderstichelen, S.**, Van Rickstal, R., Vermorgen, M. From well-equipped cohort to future research leaders. Preparing the next generation of palliative care researchers. EAPC Blog. 2018.

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– supporting and learning from the EAPC Madrid Charter on Volunteering in Hospice and Palliative Care. EAPC Blog. 2019

Voice of Volunteering Charter – EAPC Task Force on Volunteering (Flemish Translation by **Vanderstichelen S** & Chambaere K)

10.3 Oral presentations

10.3.1 ORAL PRESENTATIONS AT INTERNATIONAL CONFERENCES AND SEMINARS

20-21.01.16, Description of formal, Direct Patient Care Volunteering in Flanders and Brussels: presentation of results. Visit to St. Joseph's Hospice, London, UK. [Invited oral presentation]

09-11.6.16, Meet-The-Expert session: Views and Policies of Representatives of Health Care and Volunteer Organisations on the Roles of Volunteerism in Palliative Care: A Cross-Sectional Study - Research Protocol. 9th World Research Congress of the European Association for Palliative Care (EAPC), Dublin, Ireland [Oral Presentation after abstract submission]

16.02.17, Views of Health Care Organisations Providing Palliative Care on the Position of Volunteers in the Organisation of Care. Visit to St. Christopher's Hospice, London, UK. [Invited oral presentation]

18-20.5.17, Describing the Size and Type of Care Tasks of the Volunteer Workforce in Palliative Care. 15th World Congress of the European Association for Palliative Care (EAPC), Madrid, Spain [Oral presentation after abstract submission].

17-20.9.17, Involvement of Formal, Direct Patient Care Volunteers in Organisations Providing Palliative Care: Results from a Nation-Wide Survey. 5th International Public Health and Palliative Care Conference (IPHPC), Ottawa, Canada [Oral presentation presented by Joachim Cohen after abstract submission].

30.11.17, Het Vrijwilligerswerk in de Palliatieve Zorg in België. Nederlands-Vlaamse Wetenschapsdagen Palliatieve Zorg 2017, Amsterdam, the Netherlands [Oral presentation after abstract submission].

24-26.05.18, Volunteer Involvement in the Organisation of Palliative Care: Results from a Nation-Wide Survey of Healthcare Organisations. 10th World Research Congress of the European Association of Palliative Care (EAPC), Bern, Switzerland

[Poster presentation presented by Kenneth Chambaere after abstract submission].

02-05.10.18, Volunteer Involvement in the Organisation of Palliative Care: Results from a Nation-Wide Survey of Healthcare Organisations. 22nd International Congress on Palliative Care, Montreal, Canada [Oral presentation after abstract submission].

02-05.10.18, Impact of Palliative Home Care Use on Appropriateness of Care and Costs at the End of Life: A Nationwide Quasi-Experimental Retrospective Case-controlled Study. (Presented by Steven Vanderstichelen on behalf of Arno Maetens) 22nd International Congress on Palliative Care, Montreal, Canada [Oral presentation after abstract submission].

25-26.10.18, The Liminal Space Volunteers Occupy and the Roles they Perform within it. 1st International Seminar of EAPC RN and the EAPC Reference Group on Public Health and Palliative Care. Brussels, Belgium [Poster Presentation after abstract submission].

15.11.18-15.12.18, Volunteer Involvement in the Organisation of Palliative Care. International Palliative Care Network Poster Exhibition. [Online Poster after abstract submission]

23-25.05.2019, The Perspectives on Volunteer-professional Collaboration in Palliative Care: A Qualitative Study. 16th World Congress of the European Association for Palliative Care, Berlin, Germany [Poster presentation after abstract submission].

23-25.05.2019, The Liminal Space Palliative Care Volunteers Occupy and the Roles They Perform within it: A Qualitative Study. 16th World Congress of the European Association for Palliative Care, Berlin, Germany [Plenary presentation after abstract submission].

10.3.2 ORAL PRESENTATIONS AT NATIONAL CONFERENCES AND SEMINARS

20.04.17, Involvement of Formal, Direct Patient Care Volunteers in Organisations Providing Palliative Care: Results from a Nation-Wide Survey. Research Day – Student Research Symposium, Ghent University, Gent, Belgium. [Oral Presentation after abstract submission]

08.06.17, Betrokkenheid van Vrijwilligers in de Palliatieve, Directe Patiëntenzorg in België. [Involvement of Volunteers in Palliative, Direct Patient Care in Belgium] Dag Van De Sociologie, Brussels, Belgium. [Oral presentation after abstract submission].

08.06.17, De Omvang en Taken van de Vrijwilligerswerking in de Palliatieve Zorg in België. [The Size and Tasks of Volunteering in Palliative Care in Belgium.] Dag Van De Sociologie, Brussels, Belgium. [Oral presentation after abstract submission].

24.11.17, De Omvang, Taken en Betrokkenheid van de Vrijwilligerswerking in de Palliatieve Zorg in België. [The Size, Tasks and Involvement of Volunteering in Palliative Care in Belgium.] Begeleidingscommissie project INTEGRATE, Brussels, Belgium. [Invited oral presentation]

07.12.17, Workshop vrijwilligers in de palliatieve zorg: uitdagingen en rollen. [workshop volunteers in palliatieve care: challenges and roles], Medical Oncology Department, University Hospital Brussels, Brussels, Belgium. [Invited speaker]

18.06.18, Het andere gezicht van palliatieve zorg – de rol en positie van vrijwilligers. [The other face of palliative care – the role and position of volunteers.] ZRL Seminarie, Ghent, Belgium. [Invited oral presentation]

09.10.18, De positie van vrijwilligers in de palliatieve zorg – taken, rollen en uitdagingen. [The position of volunteers in palliative care – tasks, roles and challenges.] Vlaams Congres Palliatieve Zorg, Turnhout, Belgium. [Invited plenary presentation]

24.10.18, Vrijwilligers in de palliatieve zorg. [Volunteers in palliative care.] INTEGRATE Congress, Brussels, Belgie. [Invited plenary presentation]

15.12.18, Workshop vrijwilligerswerk in de palliatieve zorg. [Workshop volunteering in palliative care.] Werkgroep Equipe-artsen van de Vlaamse MBE's. Federatie Palliatieve Zorg Vlaanderen. Ghent, Belgium. [Invited oral presentation]

APPENDICES

APPENDICES

Appendix 1.1: informed consent forms

Toestemmingsformulier

Voor de participant:

Ik, ……………………………………………………………………………. heb het document "informatie en toestemmingsformulier" pagina 1 tot en met 4 gelezen en er een kopie van gekregen. Ik verklaar hierbij op een begrijpelijke wijze mondeling en schriftelijke te zijn ingelicht over de aard, methode en het doel van deze studie. Ik stem in met de inhoud van het document en stem ook in deel te nemen aan deze studie.

Ik ben er mij van bewust dat dit project ter beoordeling en controle aan het Ethisch Comité van het UZ Brussel en het Ethisch Comité van het UZ Gent werd voorgelegd en ik deze goedkeuring niet moet beschouwen als een motivatie tot deelname aan deze studie.

Ik ben ervan op de hoogte dat deelname aan deze studies geen bijkomende kosten meebrengen en dat er geen financieel voordeel aan verbonden is.

Ik mag me op elk ogenblik uit de studie terugtrekken zonder een reden voor deze beslissing op te geven en zonder dat dit op enigerlei wijze een invloed zal hebben op mijn verdere relatie met de onderzoeker.

Men heeft mij ingelicht dat zowel persoonlijke gegevens als gegevens aangaande mijn gezondheid verwerkt en bewaard gedurende minstens 30 jaar. Ik stem hiermee in en ben op de hoogte dat ik recht heb op toegang en op verbetering van deze gegevens. Aangezien deze gegevens verwerkt worden in het kader van medisch-wetenschappelijke doeleinden, begrijp ik dat de toegang tot mijn gegevens kan uitgesteld worden tot na beëindiging van het onderzoek. Indien ik toegang wil tot mijn gegevens zal ik mij richten tot de toeziende onderzoeker(s) die verantwoordelijk is voor de verwerking.

Ik begrijp dat auditors, vertegenwoordigers van de opdrachtgever, de Commissie Medische Ethiek of bevoegde overheden, mijn gegevens mogelijk willen inspecteren om de verzamelde informatie te controleren. Door dit document te ondertekenen, geef ik toestemming voor deze controle. Bovendien ben ik op de hoogte dat bepaalde gegevens doorgegeven worden aan de opdrachtgever. Ik geef hiervoor mijn toestemming, zelfs indien dit betekent dat mijn gegevens doorgegeven worden aan een land buiten de Europese Unie. Ten alle tijden zal mijn privacy gerespecteerd worden.

Ik ben bereid op vrijwillige basis deel te nemen aan deze studie.

Gelezen en goedgekeurd,

Naam van de vrijwilliger:

Datum:

Handtekening:

Voor de onderzoekers:

Ik bevestig dat ik de aard, het doel en de te voorziene effecten van de studie heb uitgelegd aan de bovenvermelde deelnemer.

De deelnemer stemde toe om deel te nemen door zijn/haar persoonlijk gedateerde handtekening te plaatsen.

Naam van de persoon die voorafgaande uitleg heeft gegeven:

Datum:

Handtekening:

Informed Consent Form [ENGLISH FORWARD-ONLY TRANSLATION]

For the participant:

I, ……………………………………………………………………………, have read the document ‘information and consent form’ page 1 until 4 and have received a copy. I declare that I have been informed in a clear and understandable fashion both orally and in writing about the nature, method and goal of this study. I agree with the contents of the document and agree to participate in this study.

I am aware that this project has been submitted for approval and checking by the Ethical Committee of the University Hospital of Brussels and the Ethical Committee of the University Hospital of Ghent and that I should not consider this approval as motivation to participate in this study.

I am aware that participation in this study does not confer any additional costs nor that there are any financial benefits connected to my participation.

I am allowed to retract myself from this study at any given time without having to offer a reason for this decision and without this decision influencing my future relationship with the researcher in any way.

I have been informed that personal data and data regarding my health will be processed and archived for at least 30 years. I agree to this and am aware that it is within my rights to access and correct this information. Because this information is processed for medical-scientific research purposes, I understand that access to my information may be delayed until after the study has ended. Should I wish to access my information, I will direct myself to the supervising researcher(s) who is responsible for the processing.

I understand that auditors, representatives of the study client, the Medical Ethics Committee or authorised governments, may want to inspect my data to check the collected information. By signing this document, I give permission for this check. I am also aware that certain data will be transferred to the study client. I give my permission for this, even if this means that my data will be transferred to a country outside of the European Union. My privacy will be respected at all times.

I am prepared to voluntarily participate in this study.

Read and approved,

Name of the volunteer:

Date:

Signature:

For the researchers:

I confirm that I have explained the nature, purpose and the foreseeable effects of this study to the above-mentioned participant.

The participant agreed to participate by placing his/her personal, dated signature.

Name of the person providing the advance explanation:

Date:

Signature:

APPENDIX 2.1: Experts consulted

Experts consulted in developing our sampling frame:

- Head nurse and palliative care coordinator (Palliative Care Unit)
- Social nurse in radiotherapy (Medical oncology department)
- Head nurse radiotherapy (Medical oncology department)
- Children's psychologist (Children's cancer ward)
- Palliative care coordinator (Hospital)
- National secretary (Community home-care)
- Volunteer coordinator (Community home-care)
- General coordinator (Palliative network)
- Psychologist/volunteer coordinator (Palliative network)
- Volunteer coordinator (Hospital)
- Psychologist and volunteer coordinator (Palliative Day-care Centre)
- Coordinator (Nursing home)

Appendix 2.2

Vrije Universiteit Brussel

UNIVERSITEIT GENT

KU LEUVEN

Vragenlijst over vrijwilligers in de zorg voor patiënten met chronische, levensbedreigende aandoeningen

*Onder **'vrijwilligers'** verstaan we in dit onderzoek elke natuurlijke persoon die een activiteit uitvoert die onbetaald, niet-verplicht, en ten voordele van anderen is, uitgevoerd wordt in een organisatorisch kader anders dan de bestaande familiale of sociale banden, en niet uitgevoerd wordt door dezelfde persoon of voor dezelfde organisatie onder een tewerkstellingscontract of statutaire benoeming.*

Deze vragenlijst is enkel van toepassing op uw organisatie

Kenmerken van de vrijwilligers in uw organisatie

1. Zijn er vrijwilligers werkzaam in uw organisatie?

- ○ Ja
- ○ Nee **-> ga naar vraag 22**

2. Zijn er in uw organisatie vrijwilligers aanwezig, die niet tot de eigen organisatie behoren, maar door externe organisaties ter beschikking worden gesteld van uw organisatie? *(Bv., vrijwilligers van MS-Liga, Stichting Tegen Kanker, patiëntenverenigingen, enz.)*

- ○ Ja
- ○ Nee

3. Zijn er in uw organisatie eigen of externe vrijwilligers aanwezig die betrokken zijn in de directe zorg voor patiënten met chronische, levensbedreigende aandoeningen? *(Bv., kanker, chronisch hartfalen, ziekte van Alzheimer, enz.)*

Met directe patiëntenzorg bedoelen we alle activiteiten waarbij de vrijwilliger direct contact heeft met de patiënt of een naaste van de patiënt, zoals: gezelschap houden, helpen bij het eten of drinken, een naaste bijstaan bij de rouwverwerking, vervoer van de patiënt, enz.

- ○ Ja
- ○ Nee **-> ga naar vraag 22**

4. Gelieve de onderstaande tabel zo nauwkeurig mogelijk in te vullen.

Totaal aantal vrijwilligers in uw organisatie:		
Hoeveel van deze vrijwilligers zijn betrokken in de directe zorg voor patiënten met chronische, levensbedreigende aandoeningen?		
Hoeveel van deze vrijwilligers die betrokken zijn in de directe zorg voor patiënten met chronische, levensbedreigende aandoeningen zijn eigen vrijwilligers en hoeveel behoren er tot externe organisaties?	**Eigen:**	
	Extern:	

Indien geen externe vrijwilligers -> ga naar vraag 6

5. Vermeld de organisaties die externe vrijwilligers ter beschikking stellen voor de directe zorg voor patiënten met chronische, levensbedreigende aandoeningen binnen uw organisatie?
Vrijwilligers afkomstig uit een overkoepelende organisatie, die geen deel uitmaken van de eigen organisatie, gelden ook als extern. Gelieve naam, en zo mogelijk adres, website, en e-mail te vermelden.

	Naam	Adres	Website	E-mail
1.				
2.				
3.				
4.				
5.				

Vrijwilligerstaken

6. Geef aan of de onderstaande taken voor uw vrijwilligers in de directe zorg voor patiënten met chronische, levensbedreigende aandoeningen bij elk contact met de patiënt een kerntaak, secundaire taak, of geen taak vormen.

(Geef een antwoord voor elk van de onderstaande items a.u.b.) **Voor de PATIËNT:**	Kerntaak	Secundaire taak	Geen taak
a. **Algemene Dagelijkse Levensverrichtingen (ADL)**			
De patiënt wassen	○	○	○
De patiënt aankleden	○	○	○
De patiënt helpen bij het toiletbezoek	○	○	○
De patiënt verschonen	○	○	○
De patiënt helpen bij verplaatsing en beweging	○	○	○
De patiënt helpen bij het eten	○	○	○
b. **Instrumentele Algemene Dagelijkse Levensverrichtingen (iADL)**			
De patiënt helpen met etensbereiding	○	○	○
Boodschappen doen voor de patiënt	○	○	○
De patiënt helpen bij telefoongebruik	○	○	○
De patiënt helpen met huishoudelijke taken	○	○	○
De was doen voor de patiënt	○	○	○
De patiënt vervoeren	○	○	○
De patiënt helpen met het innemen van medicatie	○	○	○
Financiën beheren voor de patiënt	○	○	○
c. **Psychosociale zorg voor de patiënt** *(Aanwezig zijn, luisteren, gesprekspartner zijn, langsgaan om te zien hoe de patiënt het stelt, ontspanningsactiviteiten, een band opbouwen met de patiënt, de patiënt bijstaan in de laatste momenten van het leven)*	○	○	○

d. **Tussenpersoon zijn tussen patiënt en zorgprofessionals** *(Een signaalfunctie vervullen, vertrouwenspersoon zijn, professionele zorgverleners attent maken op problemen of zorgen die de patiënt heeft, de patiënt doorverwijzen naar zorgverleners)*	○	○	○
e. **Medische en verpleegkundige taken** *(Pijn- en symptoomcontrole, hef- en til handelingen, verzorging van lichte wonden)*	○	○	○
f. **Spirituele of existentiële zorg** *(Praten over de dood en het leven, praten over religieuze onderwerpen, omgaan met spijt en niet bereikte levensdoelen, omgaan met de betekenis van het leven, omgaan met angst rond het verliezen van zelfstandigheid)*	○	○	○
Voor de NAASTEN van de patiënt *(Bv., gezin, familie, vrienden)***:**			
g. **Psychosociale zorg voor de naasten van de patiënt** *(Aanwezig zijn, luisteren, gesprekspartner zijn, een band opbouwen met de naasten, langsgaan om te zien hoe de naasten het stellen, de naaste bijstaan bij het rouwen)*	○	○	○
h. **Tussenpersoon zijn tussen de naasten van de patiënt en zorgprofessionals** *(Een signaalfunctie vervullen, vertrouwenspersoon zijn, professionele zorgverleners attent maken op problemen of zorgen die de naaste heeft, de naasten doorverwijzen naar zorgverleners)*	○	○	○

Barrières voor vrijwilligerswerk

7. In welke mate zijn de volgende organisatorische barrières een belemmering voor de vrijwilligerswerking in uw organisatie?

(Geef een antwoord voor elk van de onderstaande barrières a.u.b.)	Geen belemmering	Kleine belemmering	Grote belemmering
a. **De financiële kosten van de vrijwilligerswerking voor de organisatie**	○	○	○
b. **De tijdsinvestering die de vrijwilligerswerking vergt**	○	○	○
c. **Het vinden van geschikte vrijwilligers**	○	○	○
d. **Nieuwe vrijwilligers vinden/aantrekken**	○	○	○
e. **De integratie van vrijwilligers in de organisatie**	○	○	○
f. **Wettelijke voorschriften en voorwaarden inzake het takenpakket van vrijwilligers**	○	○	○
g. **Andere, namelijk:** ………………………………………………………………	○	○	○
h. **Andere, namelijk:** ………………………………………………………………	○	○	○

Aanwerving van vrijwilligers

8. Geef aan hoe belangrijk de onderstaande selectiecriteria zijn bij het aanwerven van vrijwilligers voor uw organisatie.

(Geef een antwoord voor elk van de onderstaande items a.u.b.)	Niet belangrijk	Eerder onbelangrijk	Neutraal	Eerder belangrijk	Zeer belangrijk
a. **Motivatie**	○	○	○	○	○

b. **Realistische verwachtingen**	○	○	○	○	○
c. **Mentale en emotionele stabiliteit**	○	○	○	○	○
d. **Verantwoordelijkheidszin**	○	○	○	○	○
e. **Onafhankelijk kunnen functioneren**	○	○	○	○	○
f. **Persoonlijke waarden en normen**	○	○	○	○	○
g. **Relevante werkervaring**	○	○	○	○	○
h. **Communicatieve vaardigheden**	○	○	○	○	○
i. **Beschikbaarheid**	○	○	○	○	○
j. **Oplossingsgericht werken**	○	○	○	○	○
k. **Flexibiliteit**	○	○	○	○	○
l. **Discretie**	○	○	○	○	○
g. **Tactvol zijn**	○	○	○	○	○
h. **Andere, namelijk:** ……………………………………………………… ……	○	○	○	○	○

9. Welke van de onderstaande middelen worden gebruikt om nieuwe vrijwilligers aan te trekken?
(Meerdere antwoorden mogelijk)

☐ a. **Oproep door middel van los drukwerk** (Bv., affiches, folders, flyers)
☐ b. **Oproep in eigen gedrukte media** (Bv., eigen tijdschrift of krantje)
☐ c. **Oproep in externe gedrukte media** (Bv., extern tijdschrift, krant, radio/TV)
☐ d. **Oproep via digitale media** (Bv., website van de organisatie, sociale media, website Steunpunt Vrijwilligerswerk)
☐ e. **Bestaande vrijwilligers worden ingezet om nieuwe vrijwilligers aan te trekken**
☐ f. **De opendeurdag van de organisatie**
☐ g. **Andere, namelijk:**
……
……….................................
……
……….................................

10. Hoe worden vrijwilligers na de aanwerving verder opgevolgd? *Hiermee bedoelen we zowel kritische als positieve feedback voor de vrijwilligers.* *(Meerdere antwoorden mogelijk)*	☐ Er is geen specifieke evaluatie of opvolging van de vrijwilligers ☐ Er is een kijkstage ☐ Er is een proefperiode waarna vrijwilligers worden geëvalueerd ☐ Er is één vast opvolgingsmoment per jaar ☐ Er zijn meerdere vaste opvolgingsmomenten per jaar ☐ Er wordt geëvalueerd wanneer daar een specifieke reden voor is ☐ Er wordt occasioneel feedback gegeven ☐ Andere, namelijk: ………………………………………………………………………
11. Hoe lang blijven vrijwilligers gemiddeld bij uw organisatie werken?	○ Minder dan 6 maanden ○ 6 tot 12 maanden ○ 1 tot 2 jaar ○ 2 tot 5 jaar ○ 5 tot 10 jaar ○ Meer dan 10 jaar

Opleiding vrijwilligers

12. Worden aan uw vrijwilligers opleidingen aangeboden?
Deze opleidingen kunnen zowel door uw organisatie zelf als door externe organisaties gegeven worden.
(Meerdere antwoorden mogelijk)

☐ Neen, er worden geen opleidingen aangeboden.
➔ **Ga naar vraag 14**
☐ Ja, er wordt éénmalig een verplichte opleiding voorzien.
☐ Ja, er wordt éénmalig een niet-verplichte opleiding voorzien.
☐ Ja, er worden regelmatig verplichte opleidingen voorzien. (Bv., één of meerdere keren per jaar)
☐ Ja er worden regelmatig niet-verplichte opleidingen voorzien. (Bv., één of meerdere keren per jaar)
☐ Andere, namelijk: ……………………………………………………………………………………………

13. Geef aan welke van deze onderwerpen aan bod komen in de aangeboden opleidingen. *(Meerdere antwoorden mogelijk)*

☐ De visie en waarden van de organisatie
☐ De zorgverlening van de organisatie (welke zorg er wordt verleend, en door welke zorgverlener)
☐ De positie en rollen van de vrijwilliger binnen de zorg
☐ De eigen noden van de vrijwilligers
☐ Ethische aspecten van het vrijwilligerswerk
☐ Persoonlijke en professionele grenzen bewaren
☐ Thema's m.b.t. specifieke patiëntengroepen (Bv., dementie, bepaalde ziektebeelden, enz.)
☐ Ethische aspecten (discretie)
☐ Basiskennis en –vaardigheden van de palliatieve zorg (Bv., communicatievaardigheden, de vier pijlers, enz.)
☐ Voorafgaande zorgplanning
☐ Hef- en tiltechnieken
☐ (Hand)hygiëne
☐ Andere, namelijk: ……………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………
……………………………………………………………………………………………………

Positie van de vrijwilliger in de organisatie van zorg voor de patiënten

14. Gelieve aan te geven hoe vaak de onderstaande items vandaag in uw organisatie van toepassing zijn in de organisatie van professionele en vrijwillige zorg voor patiënten met chronische, levensbedreigende aandoeningen.

(Geef een antwoord voor elk van de onderstaande items a.u.b.)	Nooit	Zelden	Vaak	Altijd
a. **De vrijwilligers zijn geïnformeerd over hoe zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○	○
b. **De organisatie vraagt de mening van de vrijwilligers over hoe zorg (**professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○	○
c. **De organisatie houdt rekening met de mening van de vrijwilligers bij beslissingen over hoe zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○	○

d. **De vrijwilligers hebben medebeslissingsrecht bij beslissingen over hoe zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○	○
e. **De vrijwilligers kunnen autonoom beslissen over hoe bepaalde aspecten van zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd worden**	○	○	○	○

15. Komen de vrijwilligers als afzonderlijke groep bijeen om de organisatie van zorg (professionele en vrijwillige zorg) **te bespreken?**
(Meerdere antwoorden mogelijk)

☐ Ja, samen met één of meerdere vaste medewerkers
☐ Ja, zonder vaste medewerkers
☐ Neen **-> Ga naar vraag 17**

16. Hoe vaak komen de vrijwilligers als afzonderlijke groep bijeen om de organisatie van zorg (professionele en vrijwillige zorg) **te bespreken?**

Minder dan 1 keer per jaar	Minstens 1 keer per jaar	Minstens 1 keer per 6 maanden	minstens 1 keer per maand	minstens 1 keer per week
○	○	○	○	○

17. Nemen vrijwilligers deel aan overleg waarbij de medische toestand van de patiënten wordt besproken?

○ Ja, systematisch
○ Ja, sporadisch
○ Nee

18. Is er een aparte briefing voor vrijwilligers over de medische toestand van de patiënten?

○ Ja
○ Nee

Persoonlijke visie op de positie van vrijwilligers in de organisatie van zorg voor patiënten

19. Gelieve aan te geven of de onderstaande items in uw organisatie volgens u minder moeten gebeuren, voldoende gebeuren, of meer moeten gebeuren. *Met voldoende wordt bedoeld dat u de huidige situatie goed vindt zoals ze is.*

(Geef een antwoord voor elk van de onderstaande items a.u.b.)	Minder	Voldoende	Meer
a. **De vrijwilligers zijn geïnformeerd over hoe zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○
b. **De organisatie vraagt de mening van de vrijwilligers over hoe zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○
c. **De organisatie houdt rekening met de mening van de vrijwilligers bij beslissingen over hoe zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○
d. **De vrijwilligers hebben medebeslissingsrecht bij beslissingen over hoe zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd wordt**	○	○	○
e. **De vrijwilligers kunnen autonoom beslissen over hoe bepaalde aspecten van zorg** (professionele en vrijwillige zorg) **voor de patiënten georganiseerd worden**	○	○	○

Vrijwilligersbeleid

20. Werd de visie en het beleid inzake vrijwilligers in uw organisatie vastgelegd in een schriftelijk document? *Hieronder verstaan we beleidsdocumenten, afsprakennota's, enz.*	○ Ja, sinds …./…./...... en de laatste versie dateert van …./…./…… ○ Neen, maar een document is in voorbereiding **-> ga naar vraag 22** ○ Neen, maar dat zijn we wel van plan **-> ga naar vraag 22** ○ Neen, en dat zijn we niet van plan **-> ga naar vraag 22**

Indien uw organisatie over een schriftelijk beleidsdocument beschikt omtrent vrijwilligerswerk in uw organisatie, gelieve ons dit document samen met uw ingevulde vragenlijst terug te sturen in de bijgevoegde, gefrankeerde enveloppe.

21. Welke personen of instanties werden geraadpleegd bij het opstellen van dit schriftelijk beleidsdocument? **(***Meerdere antwoorden mogelijk)*	☐ Raad van Bestuur ☐ Directie ☐ Zorgprofessionals (Bv., artsen, verpleegkundigen, enz.) ☐ Patiënten ☐ Naasten ☐ Vrijwilligers ☐ Ethisch Comité ☐ Koepelorganisatie ☐ Juristen ☐ Steunpunt Vrijwilligerswerk ☐ Vrijwilligersverantwoordelijke ☐ Verzekeringsmaatschappij ☐ Andere, namelijk: ………………………………………………………………………

Informatie over uzelf en uw organisatie

22. Wat is uw functie in de organisatie?	○ Directeur ○ Diensthoofd ○ Hoofdverpleegkundige ○ Vrijwilligersverantwoordelijke ○ Andere, namelijk: ....
23. Hoeveel fulltime equivalente professionele zorgverleners telt uw organisatie? *Hiermee bedoelen we enkel de professionele zorgverleners. (Bv., artsen, verpleegkundigen, psychologen, ergotherapeuten, logopedisten, kinesisten, enz.)*	○ 1 – 10 ○ 11– 20 ○ 21 – 30 ○ 31 - 40 ○ 41 – 50 ○ > 50 ○ Niet van toepassing

24. Wat is de zorgcapaciteit van uw organisatie?
(Vul de vraag in die van toepassing is op uw organisatie)

a. **Palliatieve eenheden en woonzorgcentra:**	**Totaal aantal bedden:**	……………
b. **Andere organisaties:**	**Totaal aantal patiënten verzorgd in de afgelopen week:**	……………

25. Hoeveel van uw patiënten hebben één of meerdere chronische, levensbedreigende aandoeningen?
(Bv., kanker, chronisch hartfalen, ziekte van Alzheimer, enz.)

- ○ Geen
- ○ 0% - 25%
- ○ 26% - 50%
- ○ 51% - 75%
- ○ 76% - 100%

26. Indien u nog een toelichting wil geven op bepaalde antwoorden uit de vragenlijst kan u dat hieronder doen. Ook andere op- of aanmerkingen kan u hieronder vermelden.

……
……
……
……
……
……
……
……
……
………

Let op: Herinnering voor het toesturen van schriftelijke beleidsdocumenten

Naast uw antwoorden op deze vragenlijst willen we ook het officiële beleid rond vrijwilligers en vrijwilligerswerk analyseren. Om dit te kunnen doen **verzoeken we u alle aanwezige beleidsdocumenten, afsprakennota's, enz., met betrekking tot vrijwilligers in uw organisatie aan ons op te sturen** in de bijgevoegde antwoordenvelop. Alle antwoorden worden anoniem verwerkt.

Hartelijk bedankt voor uw medewerking.

Vrije Universiteit Brussel

UNIVERSITEIT GENT

KU LEUVEN

Questionnaire on volunteerism in care for patients with terminal conditions

We define 'volunteers' as every natural person performing an activity that is unpaid, non-obligatory, for another person, within an organisational framework other than an existing familial or social relationship, and not performed by the same person or for the same organisation as part of an employment contract or statutory appointment.

This questionnaire only concerns the organisation.

Characteristics of volunteers within your organisation

1. Are any volunteers active within your organisation?

○ Yes
○ No **-> Go to question 22**

2. Are any volunteers active within your organisation, who do not belong to your organisation, but are put at your disposal by external organisations? *(E.g., patient associations, etc.)*

○ Yes
○ No

3. Are any of the volunteers active within your organisation (external or belonging to your organisation) involved in the direct patient care for patients with terminal illnesses? *(E.g., cancer, chronic heart failure, Alzheimer's disease, etc.)*

We define direct patient care as all activities which put the volunteer in direct contact with the patients or patients' relatives, for example: keeping the patients company, helping the patients with eating or drinking, offering the patients' relatives bereavement care, transporting the patients, etc.

○ Yes
○ No **-> Go to question 22**

4. Please fill in the table below as accurately as possible.

Total of volunteers within the organisation:		
How many of these volunteers are involved in the direct patient care for patients with terminal conditions?		
How many of these volunteers involved in the direct patient care for patients with terminal conditions are volunteers belonging to the organisation (internal) and how many belong to external organisations?	**Internal:**	
	External:	

In the case of no external volunteers -> go to question 6

5. Which organisations provide these external volunteers involved in direct patient care for patients with terminal conditions within your organisation?

Volunteers provided by an umbrella organisation that are not part of your own organisation are also considered external. Please provide the name, and if possible the address, website and e-mail of these organisations.

	Name	Address	Website	E-mail
1.				
2.				
3.				
4.				
5.				

Volunteer tasks

6. Please indicate whether the tasks listed below are core tasks, secondary tasks or no tasks at all for your volunteers in direct patient care for patients with terminal conditions.

(Please provide a response for each item below.)	Core task	Secondary task	No task
For the patient:			
a. **Activities of Daily Living (ADL)**			
Washing the patient	○	○	○
Dressing the patient	○	○	○
Helping the patients with toilet visits	○	○	○
Changing the patients (bodily hygiene)	○	○	○
Helping the patients with functional mobility	○	○	○
Feeding the patient	○	○	○
b. **Instrumental Activities of Daily Living (iADL)**			
Helping the patient with food preparation	○	○	○
Doing groceries for the patient	○	○	○
Helping the patient with phone usage	○	○	○
Help the patient with household chores	○	○	○
Doing the laundry for the patient	○	○	○
Transporting the patient	○	○	○
Helping the patient with taking medication	○	○	○
Managing finances for the patient	○	○	○
c. **Psychosocial care for the patient** *(Being there, listening, engage in conversation, stop by to see how the patient is doing, participating in leisure activities, building a bond with the patient, supporting the patient in the last moments of life)*	○	○	○
d. **Being an intermediary between the patient and health care professionals**	○	○	○

(Fulfilling a signalling function, being a confidant, make professional caregivers aware of issues or worries the patient might have, refer the patient to caregivers)			
e. **Medical and nursing tasks** *(Pain and symptom control, lifting and patient handling techniques, care for light wounds)*	○	○	○
f. **Spiritual or existential care** *(Talk about life and death, talk about religious subjects, dealing with regret and unattained life goals, dealing with the meaning of life, dealing with the fear of losing autonomy.)*	○	○	○
For the patients' RELATIVES *(E.g., family, friends…)***:**			
g. **Psychosocial care for the <u>patients' relatives</u>** *(Being there, listening, engage in conversation, building a bond with the patients' relatives, supporting the relatives in their time of grief)*	○	○	○
h. **Being an intermediary between the <u>patients' relatives</u> and health care professionals** *(Fulfilling a signalling function, being a confidant, make professional caregivers aware of issues or worries the relatives might have, refer the relatives to caregivers)*	○	○	○

Barriers to volunteering

7. To what extent are the following organisational barriers a limitation to the volunteerism in your organisation?

(Please provide a response for each of the barriers listed below)	No barrier	Small barrier	Large barrier
a. **The financial costs of having a volunteering force for the organisation**	○	○	○
b. **The time investment a volunteering force requires**	○	○	○
c. **Finding suitable volunteers**	○	○	○
d. **Finding/attracting new volunteers**	○	○	○
e. **The integration of volunteers into the organisation**	○	○	○
f. **Legal prescriptions and conditions governing the responsibilities of volunteers**	○	○	○
g. **Other, please specify:** ………………………………………………………………	○	○	○
h. **Other, please specify:** ………………………………………………………………	○	○	○

Recruiting volunteers

8. Please indicate how important the selection criteria listed below are in recruiting volunteers for your organisation.

(Please provide a response for each of the items below)	Not important	Rather unimportant	Neutral	Rather important	Very important
a. **Motivation**	○	○	○	○	○
b. **Realistic expectations**	○	○	○	○	○
c. **Mental and emotional stability**	○	○	○	○	○
d. **Sense of responsibility**	○	○	○	○	○
e. **Ability to function independently**	○	○	○	○	○
f. **Personal values and norms**	○	○	○	○	○

g. **Relevant work experience**	○	○	○	○	○
h. **Communication skills**	○	○	○	○	○
i. **Availability**	○	○	○	○	○
j. **Problem-solving work ethic**	○	○	○	○	○
k. **Flexibility**	○	○	○	○	○
l. **Discretion**	○	○	○	○	○
m**. Tactfulness**	○	○	○	○	○
n. **Other, please specify:** ………………………………………………………… ……	○	○	○	○	○

9. Which of the resources listed below, if any, does your organisation use to attract new volunteers?
(Please check any and all that applies.)

☐ a. **Loose print** (E.g., posters, pamphlets, flyers)
☐ b. **Internal printed media** (E.g., internal magazine or newspaper)
☐ c. **External printed or non-digital multi-media** (E.g., external magazine, newspaper or radio/TV)
☐ d. **Digital media** (E.g., the organisation's website, social media)
☐ e. **Current volunteers are mobilized to recruit new volunteers**
☐ f. **The organisation's open day**
☐ g. **Other, please specify:**
……
…

10. How are volunteers followed up after recruitment? *Here we mean both critical as well as positive feedback for the volunteers.*
(Please check any and all that applies.)

☐ There is no specific evaluation or follow-up of the volunteers
☐ There is an observational internship
☐ There is a trial period, after which volunteers are evaluated
☐ There is one set follow-up moment per year
☐ There are multiple set follow-up moments per year
☐ There is an evaluation planned when there is specific reason for it
☐ Feedback is occasionally given
☐ Other, please specify:
…………………………………………………………………

11. How long do volunteers stay with the organisation, on average?

○ Less than 6 months
○ 6 to 12 months
○ 1 to 2 years
○ 2 to 5 years
○ 5 to 10 years
○ More than 10 years

Volunteer training

12. Are your volunteers offered training?
This training may be given by your organisation itself, as well as by external organisations.
(Please check any and all that applies.)

☐ No, they are not offered training.
➔ **Go to question 14.**
☐ Yes, a one-time, obligatory training course is offered.
☐ Yes, a one-time, non-obligatory training course is offered.
☐ Yes, multiple, obligatory training courses are offered. (E.g., once or several times per year)
☐ Yes, multiple, non-obligatory training courses are offered. (E.g., once or several times per year)
☐ Other, please specify: ……………………………………………………………………………………………………

13. Please indicate which of these subjects are covered in the offered training courses. *(Please check any and all that applies.)*	☐ The vision and values of the organisation ☐ The care provision of the organisation (which care is provided, and who provides this care) ☐ The position and roles of the volunteers within care ☐ The needs of the volunteers ☐ Ethical aspects of volunteerism ☐ Guarding personal and professional boundaries ☐ Themes regarding specific patient groups (e.g., dementia, cancer, specific diseases) ☐ Ethical aspects (discretion) ☐ Basic knowledge and skills of palliative care (e.g., communication skills, the four pillars of palliative care, etc.) ☐ Advance Care Planning ☐ Lifting techniques ☐ (Hand)hygiene ☐ Other, please specify: ……………………………………………………………………… ………………………………………………………………………

Position of the volunteer in the organisation of care for patients

14. Please indicate how often the items listed below are applicable today in the organisation of professional and voluntary care for patients with terminal conditions in your organisation.

(Please provide a response for each of the items listed below.)	Never	Rarely	Often	Always
a. **The volunteers are <u>informed</u> on how** (professional and voluntary) **care for the patients is organized.**	○	○	○	○
b. **The organisation <u>requests the opinion of the volunteers</u> on how** (professional and voluntary) **care for the patients is organized.**	○	○	○	○
c. **The organisation <u>takes into account the opinion of the volunteers</u> when making decisions on how** (professional and voluntary) **care for the patients is organized.**	○	○	○	○
d. **The volunteers have <u>decision rights</u> regarding how** (professional and voluntary) **care for the patients is organized.**	○	○	○	○
e. **The volunteers are able to <u>make autonomous decisions</u> regarding how certain aspects of the** (professional and voluntary) **care for the patients are organized.**	○	○	○	○

15. Do volunteers come together as a separate group to discuss the organisation of (professional and voluntary) **care?**

(Please check any and all that applies.)

☐ Yes, together with the presence of one or more staff members
☐ Yes, without the presence of staff members
☐ No **-> Go to question 17**

16. How often do the volunteers come together as a separate group to discuss the organisation of (professional and voluntary) **care?**

Less than once per year	At least once per year	At least once every 6 months	At least once per month	At least once per week
○	○	○	○	○

17. Do volunteers take part in meetings in which the medical condition of patients is discussed?

○ Yes, systematically
○ Yes, sporadically
○ No

18. Is there a separate briefing for volunteers on the medical condition of the patients?

○ Yes
○ No

Personal views on the position of volunteers in the organisation of care for patients

19. Please indicate whether, according to you, the items listed below should happen less, happen enough, or should happen more often in your organisation. *By 'happen enough' we mean that you believe the situation is fine as it currently is.*

(Please provide a response for each of the items listed below.)	Less	Enough	More
a. **The volunteers are informed on how** (professional and voluntary) **care for the patients is organized.**	○	○	○
b. **The organisation requests the opinion of the volunteers on how** (professional and voluntary) **care for the patients is organized.**	○	○	○
c. **The organisation takes into account the opinion of the volunteers when making decisions on how** (professional and voluntary) **care for the patients is organized.**	○	○	○
d. **The volunteers have decision rights regarding how** (professional and voluntary) **care for the patients is organized.**	○	○	○
e. **The volunteers are able to make autonomous decisions regarding how certain aspects of the** (professional and voluntary) **care for the patients are organized.**	○	○	○

Volunteer policy

20. Were the vision and policy regarding volunteers within your organisation documented in a written policy? *By this we mean policy documents, official rules, etc.*	○ Yes, since …./…./...... and the last version dates from …./…./…… ○ No, but a document is in preparation **-> Go to question 22** ○ No, but we plan to **-> Go to question 22** ○ No, and we don't plan to **-> Go to question 22**

Should your organisation have a written policy document regarding volunteerism in your organisation, please send us a copy of it together with this questionnaire using the attached post-paid envelope.

21. Who was consulted during the creation of this policy document? **(***Please check any and all that applies.)*	☐ Board of directors ☐ Managing board ☐ Health care professionals (e.g., doctors, nurses, etc.) ☐ Patients ☐ Patients' relatives ☐ Volunteers ☐ Ethics committee ☐ Umbrella organisation ☐ Legal professionals ☐ Associations/institutions that support volunteerism ☐ Volunteer coordinator ☐ Insurance company ☐ Other, please specify: ……………………………………………………………………

Information about yourself and your organisation

22. What is your function in the organisation?

○ Director
○ Department head
○ Head nurse
○ Volunteer coordinator
○ Other, please specify:
....

23. How many full-time equivalent professional caregivers does your organisation have?
By this we mean only the professional caregivers. (E.g., doctors, nurses, psychologists, occupational therapists, speech therapists, physical therapists, etc.)

○ 1 – 10
○ 11– 20
○ 21 – 30
○ 31 - 40
○ 41 – 50
○ > 50
○ Not applicable

24. What is the care capacity of your organisation?
(Please answer the question applicable to your organisation.)

a. **Palliative Care Units and Nursing Homes:**	**Total beds:**	…………….
b. **Other organisations:**	**Total patients provided care for in the last week:**	…………….

25. How many of your patients suffer from one or more terminal conditions?
(E.g., cancer, chronic heart failure, Alzheimer's disease, etc.)

○ None
○ 0% - 25%
○ 26% - 50%
○ 51% - 75%
○ 76% - 100%

26. If you would like to make any additional remarks concerning certain responses on this questionnaire, you can do so below. This space can also be used to make any other remarks concerning this study or questionnaire.

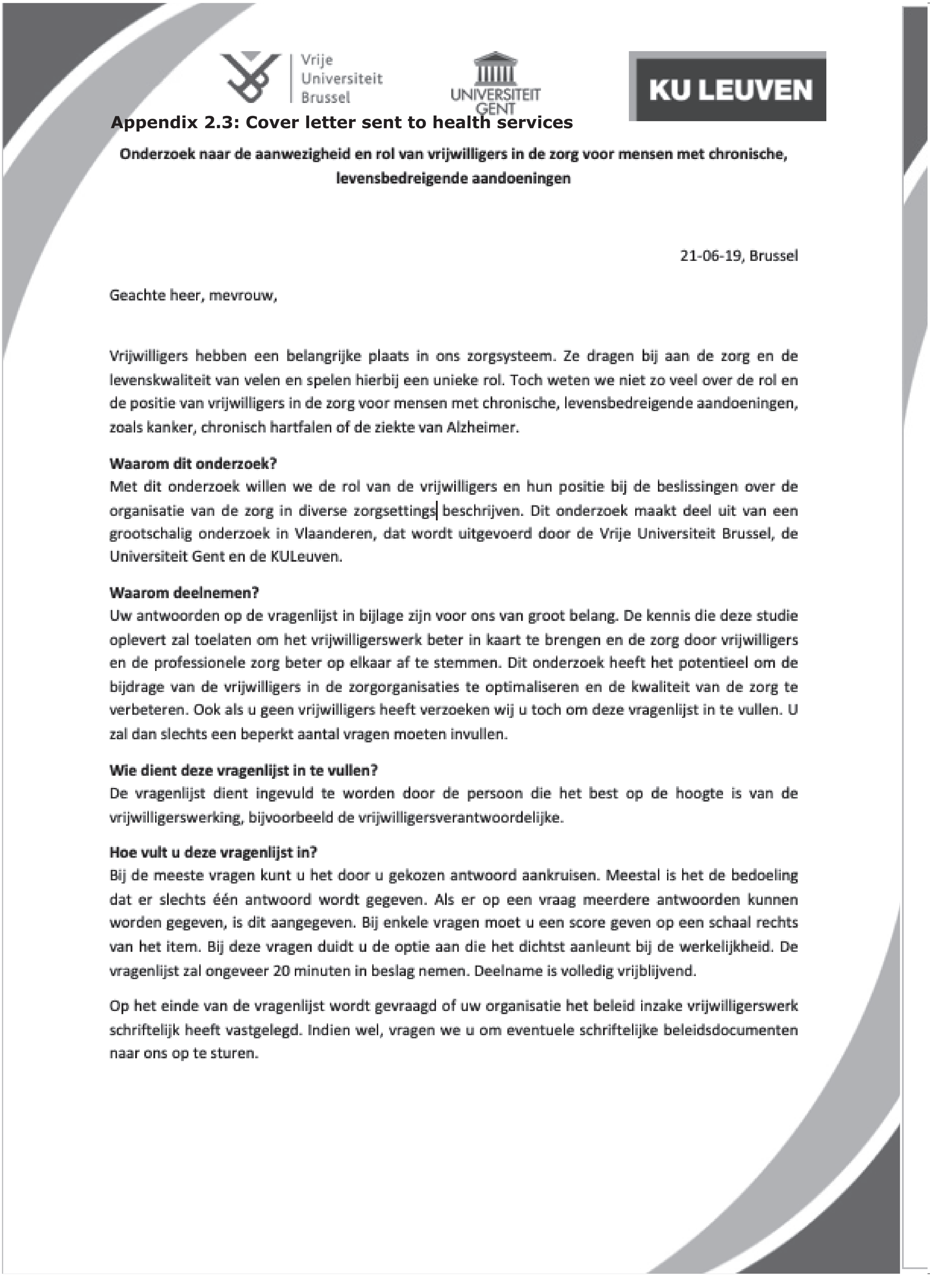
………
………
………
………
…

<u>Reminder:</u> Please send us a copy of your written policy documents

Next to your answers to this questionnaire, we would also like to analyze the existing official policy regarding volunteers and volunteerism. To be able to do this, **we request that you send us any and all types of written policy documents regarding volunteers that are present in your organisation** in the attached post-paid envelope. All responses are processed anonymously.

Thank you very much for your participation.

Appendix 2.3: Cover letter sent to health services



Vrije Universiteit Brussel
UNIVERSITEIT GENT
KU LEUVEN

Onderzoek naar de aanwezigheid en rol van vrijwilligers in de zorg voor mensen met chronische, levensbedreigende aandoeningen

21-06-19, Brussel

Geachte heer, mevrouw,

Vrijwilligers hebben een belangrijke plaats in ons zorgsysteem. Ze dragen bij aan de zorg en de levenskwaliteit van velen en spelen hierbij een unieke rol. Toch weten we niet zo veel over de rol en de positie van vrijwilligers in de zorg voor mensen met chronische, levensbedreigende aandoeningen, zoals kanker, chronisch hartfalen of de ziekte van Alzheimer.

Waarom dit onderzoek?
Met dit onderzoek willen we de rol van de vrijwilligers en hun positie bij de beslissingen over de organisatie van de zorg in diverse zorgsettings beschrijven. Dit onderzoek maakt deel uit van een grootschalig onderzoek in Vlaanderen, dat wordt uitgevoerd door de Vrije Universiteit Brussel, de Universiteit Gent en de KULeuven.

Waarom deelnemen?
Uw antwoorden op de vragenlijst in bijlage zijn voor ons van groot belang. De kennis die deze studie oplevert zal toelaten om het vrijwilligerswerk beter in kaart te brengen en de zorg door vrijwilligers en de professionele zorg beter op elkaar af te stemmen. Dit onderzoek heeft het potentieel om de bijdrage van de vrijwilligers in de zorgorganisaties te optimaliseren en de kwaliteit van de zorg te verbeteren. Ook als u geen vrijwilligers heeft verzoeken wij u toch om deze vragenlijst in te vullen. U zal dan slechts een beperkt aantal vragen moeten invullen.

Wie dient deze vragenlijst in te vullen?
De vragenlijst dient ingevuld te worden door de persoon die het best op de hoogte is van de vrijwilligerswerking, bijvoorbeeld de vrijwilligersverantwoordelijke.

Hoe vult u deze vragenlijst in?
Bij de meeste vragen kunt u het door u gekozen antwoord aankruisen. Meestal is het de bedoeling dat er slechts één antwoord wordt gegeven. Als er op een vraag meerdere antwoorden kunnen worden gegeven, is dit aangegeven. Bij enkele vragen moet u een score geven op een schaal rechts van het item. Bij deze vragen duidt u de optie aan die het dichtst aanleunt bij de werkelijkheid. De vragenlijst zal ongeveer 20 minuten in beslag nemen. Deelname is volledig vrijblijvend.

Op het einde van de vragenlijst wordt gevraagd of uw organisatie het beleid inzake vrijwilligerswerk schriftelijk heeft vastgelegd. Indien wel, vragen we u om eventuele schriftelijke beleidsdocumenten naar ons op te sturen.

Het onderzoek en de vragenlijst werden goedgekeurd door het Comité voor Medische Ethiek van het UZ Brussel en de VUB. De antwoorden worden gecodeerd en bij de rapportering van de resultaten wordt de anonimiteit steeds gegarandeerd. Het onderzoek wordt gesteund door het Instituut voor Wetenschap en Technologie (IWT).

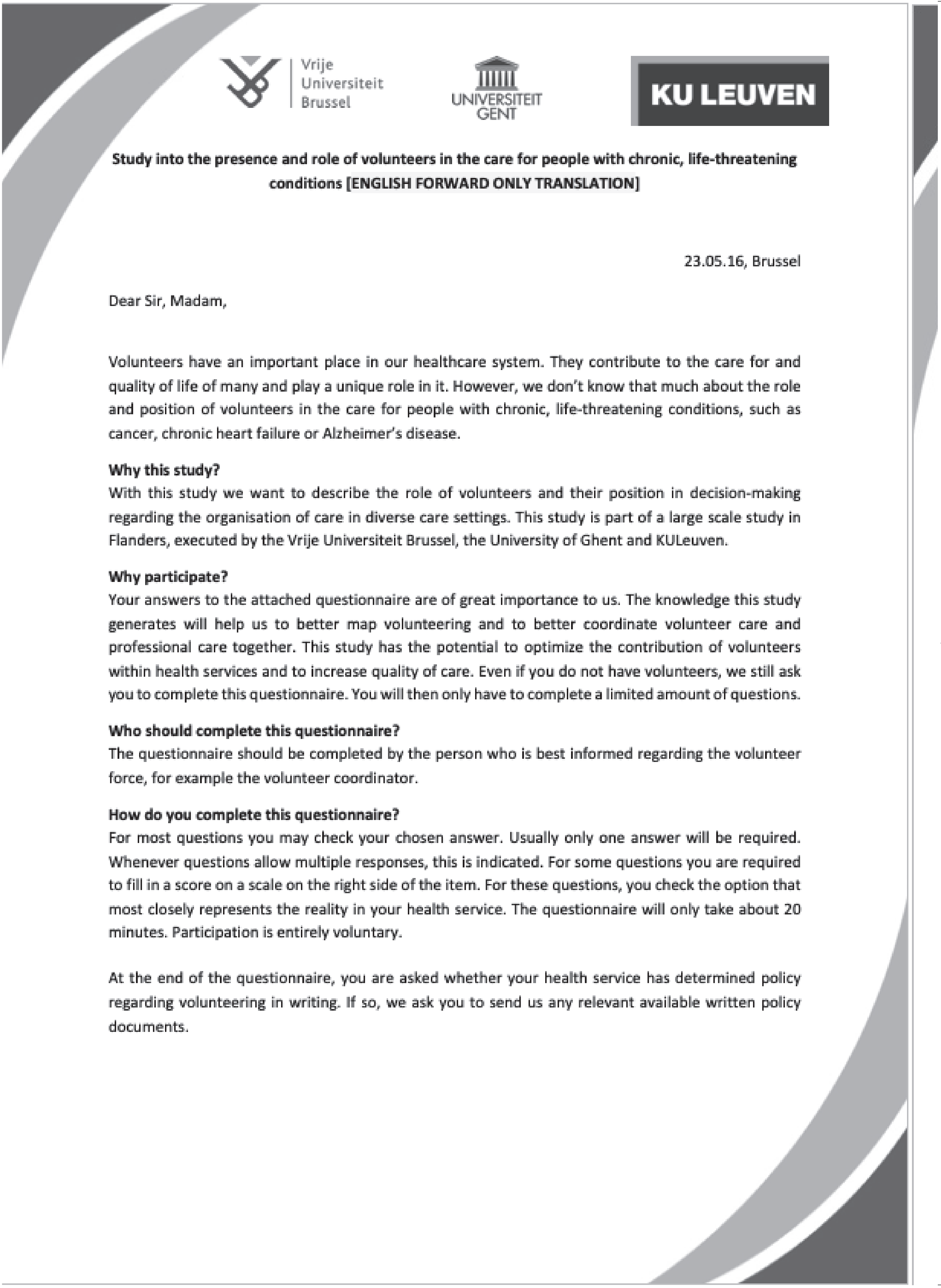
Heeft u nog vragen of opmerkingen naar aanleiding van het onderzoek of deze vragenlijst, of wenst u op de hoogte te blijven van de resultaten van dit onderzoek, dan kunt u contact opnemen met de uitvoerend onderzoeker:

Drs. Steven Vanderstichelen
Vrije Universiteit Brussel, Onderzoeksgroep Zorg rond het Levenseinde VUB & UGent
Laarbeeklaan 103
1090 Brussel
Tel: 02/477. 49. 33.
E-mail: steven.vanderstichelen@vub.ac.be

Namens de onderzoekers danken wij u van harte voor het invullen van deze vragenlijst en uw bijdrage aan deze studie.

Houttekier

Prof. dr. Dirk Houttekier	Prof. dr. Chantal Van Audenhove	Prof. dr. Luc Deliens
VUB	KULeuven	UGent



Vrije Universiteit Brussel
UNIVERSITEIT GENT
KU LEUVEN

Study into the presence and role of volunteers in the care for people with chronic, life-threatening conditions [ENGLISH FORWARD ONLY TRANSLATION]

23.05.16, Brussel

Dear Sir, Madam,

Volunteers have an important place in our healthcare system. They contribute to the care for and quality of life of many and play a unique role in it. However, we don't know that much about the role and position of volunteers in the care for people with chronic, life-threatening conditions, such as cancer, chronic heart failure or Alzheimer's disease.

Why this study?
With this study we want to describe the role of volunteers and their position in decision-making regarding the organisation of care in diverse care settings. This study is part of a large scale study in Flanders, executed by the Vrije Universiteit Brussel, the University of Ghent and KULeuven.

Why participate?
Your answers to the attached questionnaire are of great importance to us. The knowledge this study generates will help us to better map volunteering and to better coordinate volunteer care and professional care together. This study has the potential to optimize the contribution of volunteers within health services and to increase quality of care. Even if you do not have volunteers, we still ask you to complete this questionnaire. You will then only have to complete a limited amount of questions.

Who should complete this questionnaire?
The questionnaire should be completed by the person who is best informed regarding the volunteer force, for example the volunteer coordinator.

How do you complete this questionnaire?
For most questions you may check your chosen answer. Usually only one answer will be required. Whenever questions allow multiple responses, this is indicated. For some questions you are required to fill in a score on a scale on the right side of the item. For these questions, you check the option that most closely represents the reality in your health service. The questionnaire will only take about 20 minutes. Participation is entirely voluntary.

At the end of the questionnaire, you are asked whether your health service has determined policy regarding volunteering in writing. If so, we ask you to send us any relevant available written policy documents.

The study and the questionnaire were approved by the Committee for Medical Ethics of the UZ Brussel and the VUB. The answers will be coded and anonymity will be guaranteed in the reporting of the results. The study is supported by the Agency for Innovation by Science and Technology (IWT).

In case you have any questions or remarks regarding this study or this questionnaire, or you wish to be kept informed of the results of this study, you can contact the executive researcher:

Drs. Steven Vanderstichelen
Vrije Universiteit Brussel, Onderzoeksgroep Zorg rond het Levenseinde VUB & UGent
Laarbeeklaan 103
1090 Brussel
Tel: 02/477. 49. 33.
E-mail: steven.vanderstichelen@vub.ac.be

On behalf of the researchers we sincerely thank you for completing this questionnaire and for your contribution to this study.

Prof. dr. Dirk Houttekier
VUB

Prof. dr. Chantal Van Audenhove
KULeuven

Prof. dr. Luc Deliens
UGent

Appendices

Appendix 3.1: Details on disproportionally stratified cluster random sample

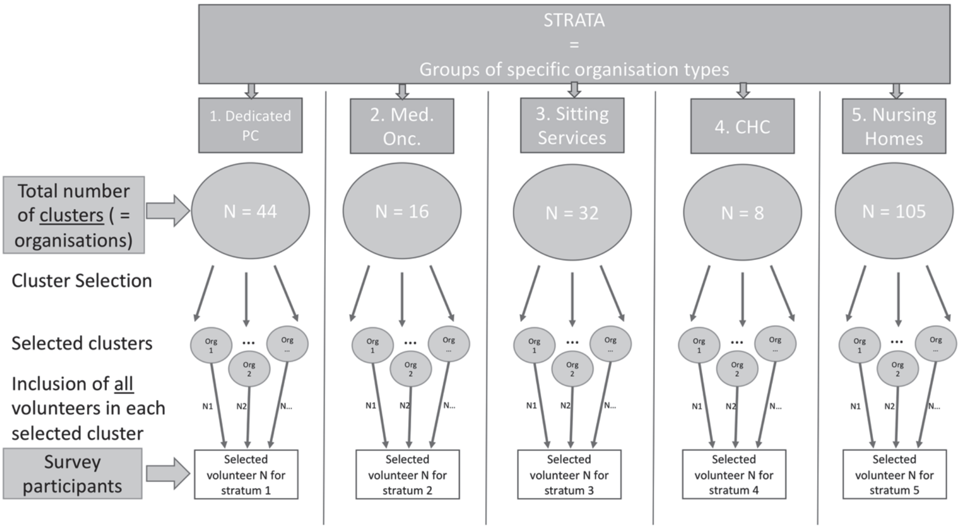
The strata are the types of organisations, the individual organisations within a stratum constitute clusters of volunteers active in direct patient care (within that organisation). Approximates for total number of direct patient care volunteers per stratum and the average total of direct patient care volunteers per cluster were estimated based on data from a previous study. [1,2] Required minimal sample sizes per stratum were calculated based on these estimates for a confidence level of 95% and a 5% margin of error. See **Table 1** for sample sizes per stratum and their respective sample fractions and see **Figure 1** for a model representation of the stratified cluster random sample. Clusters were randomly sampled using IBM SPSS 25 to generate a list of random numbers between set parameters, thereby ensuring the sample of volunteers remains random and statistical generalization towards the population of each stratum remains possible.

Table 5: Stratified Cluster Randomised Sample plan

Strata	Clusters (N)	Est. total volunteers (mean)	Required obtained sample of volunteers[1]	Required sample fraction	Assuming 70% response rate	
					Required sample size	Estimated required clusters.[2] Total/mean
Dedicated PC	44	1018 (24)	280	28%	400	17
Medical oncology	16	279 (17)	116[3]	42%	166	10
Sitting services	32	4377 (146)	354	8%	506	4
CHC	8	17245 (2156)	376	2%	538	1
Nursing homes	103	4336 (44)	353	8%	505	12
Total	**205**	**27255**	**1479**	**5%**	**2115**	**44**

[1] Determined by calculating required sample size for each stratum, assuming a 5% margin of error (i.e. desired precision of 0.05) and alpha = 0.05 (for a finite population). [2] Rounded upwards. [3] Calculated for 7% margin of error (i.e. desired precision of 0.07) due to estimated required clusters exceeding available clusters in stratum of medical oncology departments when calculated for 5% margin of error.

Figure 2: Model representation of stratified cluster randomised sample method



Sample procedure

Clusters – i.e. individual organisations that deploy volunteers in direct patient care – within each stratum were arranged alphabetically in a table column, listing their 'total volunteers' and their 'cumulative total volunteers'. Random numbers between 0 and the total cumulative number of volunteers in the stratum were generated using IBM SPSS 25 to select clusters within the stratum until the required number of clusters was reached to obtain the minimum required sample of volunteers per stratum was reached. A cluster was selected when a randomly generated number fell within the interval of the lower and upper border of its cumulative total of volunteers. See **Table 2** for an example. Larger clusters with more volunteers therefore have more chance to be selected, thereby ensuring the sampling odds is equal for each volunteer in the stratum. Within each selected cluster in each stratum, all registered volunteers were surveyed. An exception was made for the community home care stratum due to the clusters' large numbers of volunteers. Within the single cluster sampled for this stratum, a random sample equal to the initial sample size of 752 was taken. (**See Table 1.**) The random sample was based on the cluster's available list of volunteers.

Table 6: Example of random selection of clusters within a stratum

Stratum	Cluster	Total volunteers	Cumulative total	Selected?
Dedicated palliative care services	PCU A	5	5	
	PCU B	13	18	X
	PHT A	20	38	
	PHT B	50	88	X
	PDC A	34	122	

E.g.: Three numbers are randomly generated: 23, 44 and 78. 23 falls within the 18-38 interval, therefore PCU B is selected. Both 44 and 78 fall within the 38-88 interval, therefore PHT B is selected.

REFERENCES

1. Vanderstichelen S, Cohen J, Van Wesemael Y, et al. Palliative care volunteerism across the healthcare system: A survey study. *Palliat Med* 2018; 32: 1233–1245.
2. Vanderstichelen S, Cohen J, Van Wesemael Y, et al. Volunteer involvement in the organisation of palliative care: A survey study of the healthcare system in Flanders and Dutch-speaking Brussels, Belgium. *Health Soc Care Community* 2019; 27: 459–471.

Appendix 3.2: questionnaire for volunteers

VUB VRIJE UNIVERSITEIT BRUSSEL

UNIVERSITEIT GENT

KU LEUVEN

Vragenlijst over vrijwilligerswerk in de zorg voor mensen met chronische, levensbedreigende aandoeningen

*Deze gehele vragenlijst gaat **enkel** over **uw vrijwilligerswerk** binnen de organisatie die vermeld werd in de begeleidende brief.*

1. Hoe lang bent u al actief als vrijwilliger in deze organisatie?

○ Minder dan1 jaar ○ 1 - 2 jaar ○ 3 – 5 jaar ○ 6 – 10 jaar ○ Meer dan 10 jaar

2. Per week waarin ik actief ben als vrijwilliger heb ik gemiddeld __ sessies.

*Met **een sessie** bedoelen we één shift vrijwilligerswerk of, in geval van thuiszorg, één bezoek.*

3. Ik werk gemiddeld ____ uren per sessie.

4. Komt u tijdens deze sessies ooit in persoonlijk contact met mensen met chronische en/of levensbedreigende aandoeningen? *(Bv., kanker, chronisch hartfalen, ziekte van Alzheimer, enz.)*

○ Ja ○ Nee ➔ **Ga naar vraag 19**

5. Wanneer had u laatst een sessie waarin u in persoonlijk contact kwam met iemand met een chronische en/of levensbedreigende aandoening? *(Bv., kanker, chronisch hartfalen, ziekte van Alzheimer, enz.)*

○ Meer dan een jaar geleden ➔ **Ga naar vraag 11**
○ 7 tot 12 maanden geleden
○ 1 tot 6 maanden geleden
○ 1 tot 4 weken geleden
○ In de laatste week
○ Ik weet het niet ➔ **Ga naar vraag 11**

Vragen 6 tot en met 9** gaan **enkel** over de zorg voor mensen met chronische en/of levensbedreigende aandoeningen in **deze laatste sessie.

6. Welke van de onderstaande taken voerde u uit tijdens deze laatste sessie?
Kruis telkens enkel aan wat van toepassing is, meerdere antwoorden zijn telkens mogelijk. Geef bij het invullen van de tijd een zo goed mogelijke schatting.

a. Welke praktische zorgtaken voerde u uit in deze sessie?

☐ De persoon wassen, aankleden, helpen bij toiletbezoek, of verschonen
☐ Helpen bij verplaatsen en bewegen
☐ De patiënt eten toedienen
☐ De patiënt helpen met het innemen van klaargezette medicatie
☐ Etensbereiding, boodschappen of huishoudelijke taken doen
☐ Helpen bij het telefoongebruik, financiën beheren of bij telefoongebruik
☐ De persoon vervoeren
☐ Geen van bovenstaande taken ➔ **Ga naar vraag 6b**

Hoeveel tijd spendeerde u ongeveer aan deze taken? ______ minuten.

Ik vind dit: ○ Te weinig tijd ○ Voldoende tijd ○ Te veel tijd

b. Welke psychosociale zorgtaken voerde u uit in deze sessie?

- ☐ Er zijn (aanwezig zijn, actief luisteren, gesprekken voeren)
- ☐ Actief de noden en wensen van de persoon nagaan
- ☐ Ervoor zorgen dat de persoon zich ontspant
- ☐ De patiënt bijstaan in de laatste dagen van het leven
- ☐ Geen van bovenstaande taken ➔ **Ga naar vraag 6c**

Hoeveel tijd spendeerde u ongeveer aan deze taken? ______ minuten.

Ik vind dit: ○ Te weinig tijd ○ Voldoende tijd ○ Te veel tijd

c. Welke psychosociale zorgtaken voor de naasten voerde u uit in deze sessie?

- ☐ Er zijn voor de naasten (aanwezig zijn, actief luisteren, gesprekken voeren)
- ☐ Actief de noden en wensen van de naasten nagaan
- ☐ Ervoor zorgen dat de naasten zich ontspannen
- ☐ De naaste bijstaan bij het rouwen
- ☐ Geen van bovenstaande taken ➔ **Ga naar vraag 6d**

Hoeveel tijd spendeerde u ongeveer aan deze taken? ______ minuten.

Ik vind dit: ○ Te weinig tijd ○ Voldoende tijd ○ Te veel tijd

d. Welke spirituele / existentiële zorgtaken voerde u uit in deze sessie?

- ☐ Praten over angst voor dood en sterven
- ☐ Praten over accepteren van dood en sterven
- ☐ Praten over betekenisvolle relaties
- ☐ Helpen bij afscheidsrituelen
- ☐ Voorbereiden van de uitvaart
- ☐ Geen van bovenstaande taken ➔ **Ga naar vraag 6e**

Hoeveel tijd spendeerde u ongeveer aan deze taken? ______ minuten.

Ik vind dit: ○ Te weinig tijd ○ Voldoende tijd ○ Te veel tijd

e. Welke signaaltaken voerde u uit in deze sessie?

- ☐ Noden en wensen van de patiënt signaleren aan andere zorgverleners
- ☐ Noden en wensen van de naasten signaleren aan andere zorgverleners
- ☐ Vertrouwenspersoon zijn van de patiënt
- ☐ Vertrouwenspersoon zijn van de naasten
- ☐ De patiënt doorverwijzen naar andere zorgverleners of zorgdiensten
- ☐ De naasten doorverwijzen naar andere zorgverleners of zorgdiensten
- ☐ Geen van bovenstaande taken ➔ **Ga naar vraag 6f**

Hoeveel tijd spendeerde u ongeveer aan deze taken? ______ minuten.

Ik vind dit: ○ Te weinig tijd ○ Voldoende tijd ○ Te veel tijd

f. Welke verpleegkundige taken voerde u uit in deze sessie?

- ☐ Geven van pijnstillende medicatie
- ☐ Geven van andere medicatie
- ☐ Pijn- en symptoomverlichting zonder medicatie (bv. mindfulness, massage, ...)
- ☐ Verzorgen van lichte wonden (vb. doorligwonden)
- ☐ Plaatsen van sondes en/of infusen
- ☐ EHBO/reanimatie
- ☐ Beademing van patiënten
- ☐ Hef- en til handelingen
- ☐ De persoon helpen bij toiletbezoek (niet in bijzijn van professionele zorgverlener)
- ☐ Geen van bovenstaande taken ➔ **Ga naar vraag 7**

Hoeveel tijd spendeerde u aan deze taken? ______ minuten.

Ik vind dit:	○ Te weinig tijd	○ Voldoende tijd	○ Te veel tijd

7. Zijn er andere taken die u uitvoerde in deze sessie?

○ Ja, namelijk:

………

…………………………………………………………………………………………

○ Neen.

8. Op welke manier werkte u met de volgende zorgverleners samen tijdens of rond deze sessie? *(Kruis aan wat van toepassing is; meerdere antwoorden zijn telkens mogelijk.)*

	Informatie uitwisselen	Samen beslissingen maken	Taken afstemmen op elkaar	Op **geen** van deze manieren / geen contact
a. Collega vrijwilligers	☐	☐	☐	☐
b. Vrijwilligerscoördinator	☐	☐	☐	☐
c. Mantelzorgers	☐	☐	☐	☐
d. Verpleegkundigen	☐	☐	☐	☐
e. Specialisten (artsen)	☐	☐	☐	☐
f. Huisartsen	☐	☐	☐	☐
g. Psychologen	☐	☐	☐	☐
h. Maatschappelijk werkers	☐	☐	☐	☐
i. Stagiaires	☐	☐	☐	☐
j. Religieuze of levensbeschouwelijke consulenten	☐	☐	☐	☐
k. Gezinshulp	☐	☐	☐	☐
l. Andere, namelijk:	☐	☐	☐	☐

……

9. Bij welke van de onderstaande zorgverleners vindt u dat de samenwerking beter kon? *(Kruis aan wat van toepassing is, meerdere antwoorden mogelijk.)*

- ☐ Collega vrijwilligers
- ☐ Vrijwilligerscoördinator
- ☐ Mantelzorgers
- ☐ Verpleegkundigen
- ☐ Specialisten (artsen)
- ☐ Huisartsen
- ☐ Psychologen
- ☐ Maatschappelijk werkers
- ☐ Stagiaires
- ☐ Levensbeschouwelijke consulenten
- ☐ Gezinshulp
- ☐ Geen

Vragen 10 tot en met 18** gaan niet langer enkel over deze laatste sessie, maar over **uw vrijwilligerswerk in deze organisatie in het algemeen.

10. Welke van de volgende items heeft u zelf ooit als belemmerend ervaren in de samenwerking met professionele zorgverleners in deze organisatie?
(Kruis aan wat van toepassing is; meerdere antwoorden mogelijk)

- ☐ Geen
- ☐ Onduidelijkheid over taken, afspraken en/of regels
- ☐ Strikte werkschema's van de professionals
- ☐ Geen vaste zorgverleners waarmee men kan overleggen
- ☐ Geen bereidheid van professionals om samen te werken
- ☐ Gebrek aan informatie-uitwisseling
- ☐ Gebrek aan coördinatie
- ☐ Gebrek aan waardering
- ☐ Gebrek aan ondersteuning (opvolging)
- ☐ Conflicten met andere zorgverleners

12. Rond welke van de volgende thema's heeft u ooit een opleiding gevolgd als deel van uw vrijwilligerswerk?
(Kruis aan wat van toepassing is; meerdere antwoorden mogelijk.)

☐ De visie en waarden van de organisatie	☐ Persoonlijke en professionele grenzen bewaren
☐ Het zorgverleningsaanbod van de organisatie	☐ Ziektebeelden van specifieke patiëntengroepen
☐ De positie en rollen van de vrijwilliger binnen de zorg	☐ Voorafgaande zorgplanning
☐ Ethiek (discretie, privacy)	☐ Hef- en tiltechnieken
☐ Palliatieve zorg	☐ (Hand)hygiëne
☐ Communicatievaardigheden	☐ Patiënten en hun naasten opleiden/trainen in zelfzorg
☐ Informatie doorgeven over de patiënt aan andere zorgverleners	☐ Andere, namelijk: …………………………………………
	☐ Geen van bovenstaande
☐ Gebrek aan contact met andere zorgverleners	☐ Andere, namelijk:
☐ Gebrek aan overlegmomenten	……………………………………………

11. Vereiste uw organisatie een verplichte opleiding in het kader van uw vrijwilligerswerk?

○ Ja	○ Nee

13. Hoe zou u uw opleiding in het kader van uw vrijwilligerswerk evalueren?

Zeer slecht	Slecht	Voldoende	Goed	Zeer goed
○	○	○	○	○

Vragen 14 tot en met 17 *gaan over de* ***begeleiding voor vrijwilligers****. Hieronder verstaan we elke vorm van persoonlijke opvolging die vrijwilligers van hun organisatie ontvangen in de uitvoering van hun vrijwilligersrol.*

14. Wordt u op enige wijze begeleid door deze organisatie?

○ Ja
○ Nee, en dit is geen probleem **➔ Ga naar vraag 17**
○ Nee, en dit is wel een probleem **➔ Ga naar vraag 17**

15. Op welk moment gebeurt de begeleiding van vrijwilligers in deze organisatie?

○ Enkel op vaste momenten	○ Zowel op vaste momenten als terloops	○ Enkel terloops

16. Hoe gebeurt de begeleiding van vrijwilligers in deze organisatie?

○ Enkel op individuele basis	○ Zowel op individuele basis als in groep	○ Enkel in groep

17. Hoe zou u de begeleiding van vrijwilligers in deze organisatie evalueren?

Zeer slecht	Slecht	Voldoende	Goed	Zeer goed
○	○	○	○	○

18. Gelieve voor elk van onderstaande items telkens aan te geven hoe vaak dit voor u als vrijwilliger van toepassing is en of u dat voldoende vindt.

a. Hoe vaak wordt u geïnformeerd over hoe de zorg voor de patiënten georganiseerd wordt?	Nooit ○	Zelden ○	Vaak ○	Altijd ○
Ik vind dit: ○ Te weinig ○ Goed zo ○ Te veel				
b. Hoe vaak vraagt de organisatie uw mening over hoe de zorg voor de patiënten georganiseerd wordt?	Nooit ○	Zelden ○	Vaak ○	Altijd ○
Ik vind dit: ○ Te weinig ○ Goed zo ○ Te veel				
c. Hoe vaak houdt de organisatie rekening met uw mening bij beslissingen over de zorg voor de patiënten?	Nooit ○	Zelden ○	Vaak ○	Altijd ○
Ik vind dit: ○ Te weinig ○ Goed zo ○ Te veel				
d. Hoe vaak hebt u als vrijwilliger medebeslissingsrecht bij beslissingen over hoe de zorg voor de patiënten wordt verstrekt?	Nooit ○	Zelden ○	Vaak ○	Altijd ○
Ik vind dit: ○ Te weinig ○ Goed zo ○ Te veel				
e. Hoe vaak kan u als vrijwilliger zelfstandig beslissen over hoe bepaalde aspecten van de zorg voor de patiënten worden verstrekt?	Nooit ○	Zelden ○	Vaak ○	Altijd ○
Ik vind dit: ○ Te weinig ○ Goed zo ○ Te veel				

Demografische gegevens

19. Wat is uw geslacht? ○ Man ○ Vrouw

20. Wat is uw geboortejaar? _____

21. Wat is uw huidige tewerkstellingsstatuut? *(Gelieve 1 antwoord aan te duiden.)*

○ Student
○ Werkzoekend
○ Voltijds werkend
○ Deeltijds werkend
○ (Brug)gepensioneerd
○ Ziekteverlof
○ Andere, namelijk:

22. Wat is uw hoogst behaalde diploma of getuigschrift?

○ Geen
○ Lager onderwijs
○ Lager secundair onderwijs
○ Hoger secundair onderwijs
○ Hoger niet-universitair onderwijs: korte type (professionele bachelor)
○ Hoger niet-universitair onderwijs: lange type (professionele master)
○ Universitair onderwijs – kandidatuur / academische bachelor
○ Universitair onderwijs – licentiaat / academische master
○ Universitair onderwijs – Doctoraat

23. Indien u nog een toelichting wil geven op bepaalde antwoorden uit de vragenlijst kan u dat hieronder doen.

……

……

……

……

……

………

Hartelijk bedankt voor uw medewerking.

VRIJE UNIVERSITEIT BRUSSEL

UNIVERSITEIT GENT

KU LEUVEN

Questionnaire on volunteering in care for people with chronic, life-threatening conditions [ENGLISH FORWARD-ONLY TRANSLATION]

*This entire questionnaire is **only** about **your volunteer work** within the organisation mentioned in the cover letter.*

1. How long have you been active as a volunteer in this organisation?

○ Less than 1 year ○ 1 - 2 years ○ 3 – 5 years ○ 6 – 10 years ○ More than 10 years

2. Per I have, on average, __ sessions per week in which I am active as volunteer.

*By **session** we mean one shift of volunteering work or, in case of home-care, one visit.*

3. I work on average ____ hours per session.

4. During these sessions, do you have come into personal contact with people with chronic and/or life-threatening conditions? *(E.g. cancer, chronic heart failure, Alzheimer's disease, etc.)*

○ Yes ○ No ➔ **Go to question 19**

5. When did you last have a session in which you came into personal contact with someone with a chronic and/or life-threatening condition? *(E.g. cancer, chronic heart failure, Alzheimer's disease, etc.)*

○ More than a year ago ➔ **Go to question 11**
○ 7 to 12 months ago
○ 1 to 6 months ago
○ 1 to 4 weeks ago
○ In the last week
○ I don't know ➔ **Go to question 11**

***Questions 6 to 9** are **only** about the care for people with chronic and/or life-threatening conditions in **this last session**.*

6. Which of the following tasks did you perform during this last session?
Check off only those items that apply, multiple answers are possible. When filling in the time spent, provide as best of an estimate as possible.

a. Which practical care tasks did you perform in this session?

☐ Wash, clean, clothe, help with bathroom visits
☐ Help with shifting and movement
☐ Feed patients
☐ Help patients take prepared medication
☐ Prepare food, do groceries or chores
☐ Help with phone use or managing finances
☐ Transport patients
☐ None of the above ➔ **Go to question 6b**

How much time did you spend on these tasks? ______ minutes.

I think this is: ○ Too little time ○ Enough time ○ Too much time

b. Which psychosocial care tasks did you perform in this session?

☐ Being there (being present, active listening, having conversations)
☐ Actively gauge the needs and wishes of the person
☐ Provide leisure / relaxation
☐ Be with the patient in the last days of life
☐ None of the above ➔ **Go to question 6c**

How much time did you spend on these tasks? ______ minutes.

I think this is: ○ Too little time ○ Enough time ○ Too much time

c. Which psychosocial care tasks did you perform for the patient's relatives in this session?

☐ Being there for the relatives (being present, active listening, having conversations)
☐ Actively gauge the needs and wishes of the relatives
☐ Provide leisure / relaxation
☐ Be with the relatives during their time of grieving
☐ None of the above ➔ **Go to question 6d**

How much time did you spend on these tasks? ______ minutes.

I think this is: ○ Too little time ○ Enough time ○ Too much time

d. Which spiritual / existential care tasks did you perform in this session?

☐ Talk about fear of death and dying
☐ Talk about accepting death and dying
☐ Talk about meaningful relationships
☐ Help with farewell rituals
☐ Prepare the funeral
☐ None of the above ➔ **Go to question 6e**

How much time did you spend on these tasks? ______ minutes.

I think this is: ○ Too little time ○ Enough time ○ Too much time

e. Which signposting tasks did you perform in this last session?

☐ Signpost the needs and wishes of the patient to other caregivers
☐ Signpost the needs and wishes of the patient's relatives to other caregivers
☐ Be a confidant of the patient
☐ Be a confidant of the patient's relatives
☐ Refer patients to other caregivers or care services
☐ Refer patient's relatives to other caregivers or care services
☐ None of the above ➔ **Go to question 6f**

How much time did you spend on these tasks? ______ minutes.

I think this is: ○ Too little time ○ Enough time ○ Too much time

f. Which nursing tasks did you perform in this session?

☐ Administer analgesic medication
☐ Administer other medication
☐ Non-pharmacological pain and symptom control (e.g. mindfulness, massages, …)
☐ Treating light wounds (e.g. bed sores)
☐ Place infusions or probes
☐ First aid / resuscitation
☐ Patient ventilation
☐ Moving and lifting operations
☐ Helping a patient go to the toilet (while not in the presence of a professional carer)
☐ None of the above ➔ **Go to question 7**

How much time did you spend on these tasks? ______ minutes.

I think this is: ○ Too little time ○ Enough time ○ Too much time

7. Are there any other tasks that you performed during this session?

○ Yes, namely:

……

……………………………………………………………………………………………………

○ No.

8. In what way did you collaborate with the following carers during or regarding this session?
(Check all that apply; multiple answers are possible.*)*

	Sharing information	Making decisions together	Task coordination	**None** of these ways/ No contact
a. Fellow volunteers	☐	☐	☐	☐
b. Volunteer coordinator	☐	☐	☐	☐
c. Family caregivers	☐	☐	☐	☐
d. Nurses	☐	☐	☐	☐
e. Specialists (physicians)	☐	☐	☐	☐
f. Family physicians	☐	☐	☐	☐
g. Psychologists	☐	☐	☐	☐
h. Social workers	☐	☐	☐	☐
i. Interns	☐	☐	☐	☐
j. Spiritual counsellors	☐	☐	☐	☐
k. Family help	☐	☐	☐	☐
l. Others, namely:	☐	☐	☐	☐

………

9. With whom of the following care providers would you say collaboration could be improved? *(Check all that apply;* multiple answers are possible.*)*

☐ Fellow volunteers
☐ Volunteer coordinator
☐ Family caregivers
☐ Nurses
☐ Specialists (physicians)
☐ Family physicians
☐ Psychologists
☐ Social workers
☐ Interns
☐ Spiritual counsellors
☐ Family help
☐ None

Questions 10 to 18** are no longer about this last session, but about **your volunteering work in this organisation in general.

10. Which of the following items have you ever experienced as barriers to collaboration with professional caregivers in this organisation?
(Check all that apply; multiple answers are possible.*)*

☐ None
☐ Ambiguity regarding tasks, agreements and/or rules
☐ Professionals' tight work schedules
☐ No regular caregivers to consult
☐ Professionals are not willing to collaborate
☐ Lack of information exchange
☐ Lack of coordination
☐ Lack of appreciation
☐ Lack of support (follow-up)
☐ Conflicts with other caregivers

12. Which of the following themes have you __ever__ received training in as part of your volunteering?
(Check all that apply; multiple answers are possible.*)*

☐ The vision and values of the organisation
☐ The care offered by the organisation
☐ The position and roles of volunteers in care
☐ Ethics (discretion, privacy)
☐ Palliative care
☐ Communication skills
☐ Communicating patient information to other caregivers
☐ Lack of contact with other caregivers
☐ Lack of consultation moments

☐ Guarding personal and professional boundaries
☐ Themes regarding specific patient groups
☐ Advance Care Planning
☐ Moving and shifting techniques
☐ (Hand)hygiene
☐ Training patients and their relatives in self-care
☐ Others, namely: ……………………………………………
☐ None of the above
☐ Others, namely:
……………………………………………………

11. Did your organisation require an __obligatory__ training in light of your volunteer work?

○ Yes ○ No

13. How would you evaluate your training in light of your volunteering work?

Very bad	Bad	Sufficient	Good	Very good
○	○	○	○	○

Questions 14 to *17 are about the* ***supervision of volunteers.*** *By this we mean any form of personal follow-up that volunteers receive from their organisation in the practice of their volunteer role.*

14. Are you in any way supervised by this organisation?

○ Yes
○ No, and this is not a problem ➔ **Go to question 17**
○ No, and this is a problem ➔ **Go to question 17**

15. With which consistency does supervision of volunteers happen in this organisation?

○ Only at fixed times ○ At fixed times as well as ad hoc ○ Only ad hoc

16. How does supervision of volunteers happen in this organisation?

○ Only on an individual basis ○ On an individual basis as well as in group ○ Only in group

17. How would you rate the supervision of volunteers in this organisation?

Very bad	Bad	Sufficient	Good	Very good
○	○	○	○	○

18. Please indicate for each of the following items how often this applies to you as a volunteer and whether you think this is often enough.

	Never	Rarely	Often	Always
a. How often are you informed on how care for the patients is organised?	○	○	○	○
I think this is: ○ Not often enough ○ Often enough ○ Too often				
b. How often does the organisation ask your opinion about how care for the patients is organised?	○	○	○	○
I think this is: ○ Not often enough ○ Often enough ○ Too often				
c. How often does the organisation take your opinion into account in decisions about the organisation of care for patients?	○	○	○	○
I think this is: ○ Not often enough ○ Often enough ○ Too often				
d. How often do you as a volunteer have decision making rights regarding decisions on how care for patients is provided?	○	○	○	○
I think this is: ○ Not often enough ○ Often enough ○ Too often				
e. How often can you as a volunteer autonomously decide about how certain aspects of care for patients are provided?	○	○	○	○
I think this is: ○ Not often enough ○ Often enough ○ Too often				

Demographics

19. What is your sex? ○ Male ○ Female

20. What is your birth year? _____

21. What is your current employment status? *(Please check only one.)*

- ○ Student
- ○ Unemployed
- ○ Fulltime employed
- ○ Part time employed
- ○ Retired
- ○ On sickness leave
- ○ Other, namely:

22. What is your highest attained diploma or educational certificate?

- ○ None
- ○ Primary education
- ○ Lower secondary education
- ○ Higher secondary education
- ○ Higher non-university education: professional bachelor’s
- ○ Higher non-university education: professional master’s
- ○ University education – Academic bachelor’s
- ○ University education – Academic master’s
- ○ University education – Doctorate (PhD)

23. If there is anything you would like to add anything to certain responses in the questionnaire, you may do so below.

……………………………………………………………………………………………………

……………………………………………………………………………………………………

………
……………………………………………

Thank you very much for your participation.

Appendix 3.3

Table 1: Demographic differences between volunteers from different organisation types, Flanders and Dutch-speaking Brussels, Belgium, 2018

	Total	Dedicated Palliative Care	Medical Oncology Departments	Sitting Services	Community Home Care	Nursing Homes
Total N	801	280	62	233	82	142
Number of volunteers in direct patient care (%) [1,2]	645 (83.3)	277 (99.3)	62 (100)	185 (83.3)	55 (71.4)	64 (48.5)
Gender (%)						
Male	24.5	25.0	9.7	18.5	30.5	37.0
Female	75.5	75.0	90.3	81.5	69.5	63.0
Age (%)						
<50	7.3	7.2	3.2	7.0	2.4	12.3
51 – 60	17.2	20.4	22.6	13.9	19.8	11.7
61 – 70	46.2	47.1	50.0	49.6	30.9	46.7
71+	29.3	25.4	24.2	29.6	46.9	29.2
Employment status (%)						
Student or unemployed	9.9	10.0	13.1	9.6	2.5	11.7
Employed (part- or fulltime)	12.2	13.9	13.1	10.4	16.5	8.7
Retired	70.8	67.9	70.5	71.4	79.7	71.5
Sick-leave	5.8	6.8	0.0	6.9	1.3	7.3
Highest attained diploma (%)						
None or primary (lower or higher)	6.6	3.3	0.0	8.3	8.8	12.5
Secondary education (lower or higher)	17.4	12.6	9.8	23.4	18.8	19.9
Professional bachelors' or masters' degree	58.7	59.4	57.4	60.1	56.2	56.6
Academic bachelors', masters' or PhD degree	16.4	23.4	32.8	8.2	15.0	9.5
Volunteering activity						
years active in current organisation (%)						
<1 year	7.6	7.6	4.8	7.8	2.5	11.4
1 - 2 years	12.5	12.6	11.3	14.7	3.8	14.3
3 - 5 years	23.0	21.6	22.6	23.4	15.2	28.6
6 - 10 years	21.0	22.7	25.8	21.2	15.2	18.6
> 10 years	36.0	35.6	35.5	32.9	63.3	27.1
Volunteer sessions per week (mean)	*1.7*	*1.18*	*1.26*	*2.13*	*2.4*	*1.91*
Hours per session volunteer (mean)	*4.63*	*5.26*	*4.17*	*5.25*	*3.53*	*3.04*
Hours per week (sessions x hours) (mean)	*7.87*	*6.21*	*5.25*	*11.18*	*8.47*	*5.81*

[1] Total number of volunteers that indicate coming into personal contact with at least one person with chronic and/or life-threatening conditions during their volunteer work in the past 12 months. [2] Missings ranged from 1.0% to 5.0%. [3] For two questionnaires it was not possible to determine which organisation type the volunteer was working in.

Table 1: Demographic differences between volunteers from different organisation types, Flanders and Dutch-speaking Brussels, Belgium, 2018

	Total	Dedicated Palliative Care	Medical Oncology Departments	Sitting Services	Community Home Care	Nursing Homes
Total N	801	280	62	233	82	142
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Female	75.5	75.0	90.3	81.5	69.5	63.0
Age (%)						
<50	7.3	7.2	3.2	7.0	2.4	12.3
51 – 60	17.2	20.4	22.6	13.9	19.8	11.7
61 – 70	46.2	47.1	50.0	49.6	30.9	46.7
71+	29.3	25.4	24.2	29.6	46.9	29.2
Employment status (%)						
Student or unemployed	9.9	10.0	13.1	9.6	2.5	11.7
Employed (part- or fulltime)	12.2	13.9	13.1	10.4	16.5	8.7
Retired	70.8	67.9	70.5	71.4	79.7	71.5
Sick-leave	5.8	6.8	0.0	6.9	1.3	7.3
Highest attained diploma (%)						
None or primary (lower or higher)	6.6	3.3	0.0	8.3	8.8	12.5
Secondary education (lower or higher)	17.4	12.6	9.8	23.4	18.8	19.9
Professional bachelors' or masters' degree	58.7	59.4	57.4	60.1	56.2	56.6
Academic bachelors', masters' or PhD degree	16.4	23.4	32.8	8.2	15.0	9.5
Volunteering activity						
years active in current organisation (%)						
<1 year	7.6	7.6	4.8	7.8	2.5	11.4
1 - 2 years	12.5	12.6	11.3	14.7	3.8	14.3
3 - 5 years	23.0	21.6	22.6	23.4	15.2	28.6
6 - 10 years	21.0	22.7	25.8	21.2	15.2	18.6
> 10 years	36.0	35.6	35.5	32.9	63.3	27.1
Volunteer sessions per week (mean)	*1.7*	*1.18*	*1.26*	*2.13*	*2.4*	*1.91*
Hours per session volunteer (mean)	*4.63*	*5.26*	*4.17*	*5.25*	*3.53*	*3.04*
Hours per week (sessions x hours) (mean)	*7.87*	*6.21*	*5.25*	*11.18*	*8.47*	*5.81*

[1] Total number of volunteers that indicate coming into personal contact with at least one person with chronic and/or life-threatening conditions during their volunteer work in the past 12 months. [2] Missings ranged from 1.0% to 5.0%. [3] For two questionnaires it was not possible to determine which organisation type the volunteer was working in.

Table 3: CATPCA Component Loadings of volunteer tasks

	Dimension	
Volunteer task variables	Multi-dimensional support	Practical support
Practical care tasks		
Wash, clean, clothe, help with bathroom visits	0.477	0.498
Help with shifting and movement	0.410	0.491
Feed patients	0.477	0.169
Help patients take prepared medication	0.483	0.428
Prepare food, do groceries or chores	0.312	-0.008
Help with phone use or managing finances	0.281	-0.003
Transport patients	-0.044	0.161
Psychosocial care tasks for patients		
Being there (being present, active listening, having conversations)	0.255	-0.106
Actively gauge the needs and wishes of the person	0.575	0.070
Provide leisure/relaxation	0.389	0.054
Be with the patients in the last days of life	0.621	-0.103
Psychosocial care tasks for patient relatives		
Being there (being present, active listening, having conversations)	0.491	-0.239
Actively gauge the needs and wishes of the person	0.594	-0.212
Provide leisure/relaxation	0.530	-0.189
Be with the relatives during their time of grieving	0.629	-0.314
Spiritual / existential care tasks		
Talk about fear of death and dying	0.522	-0.370
Talk about accepting death and dying	0.513	-0.280
Talk about meaningful relationships	0.366	-0.282
Help with farewell rituals	0.401	-0.160
Prepare the funeral	0.189	-0.059
Signposting tasks		
Signal the needs and wishes of the patient to other caregivers	0.510	-0.084
Signal the needs and wishes of the relatives to other caregivers	0.597	-0.271
Be a confidant of the patient	0.264	-0.187
Be a confidant of the relatives	0.427	-0.256
Refer patients to other caregivers or care services	0.428	-0.266
Refer patient relatives to other caregivers or care services	0.488	-0.293
Nursing tasks		
Give analgesic medication	0.403	0.384
Give other medication	0.441	0.463
Non-pharmacological pain and symptom control (e.g. mindfulness, massages)	0.404	0.158
Moving and lifting operations	0.493	0.507
Helping a patient go to the toilet (while not in the presence of a professional caregiver)	0.427	0.543
Other (treating light wounds, placing infusions or probes, first aid/resuscitation, patient ventilation)	0.332	0.259
Cronbach's Alpha (total = 0.919)	0.872	0.644
Total (Eigenvalue) (total = 9.112)	6.451	2.661

Table 4: CATPCA Component Loadings of volunteers' training

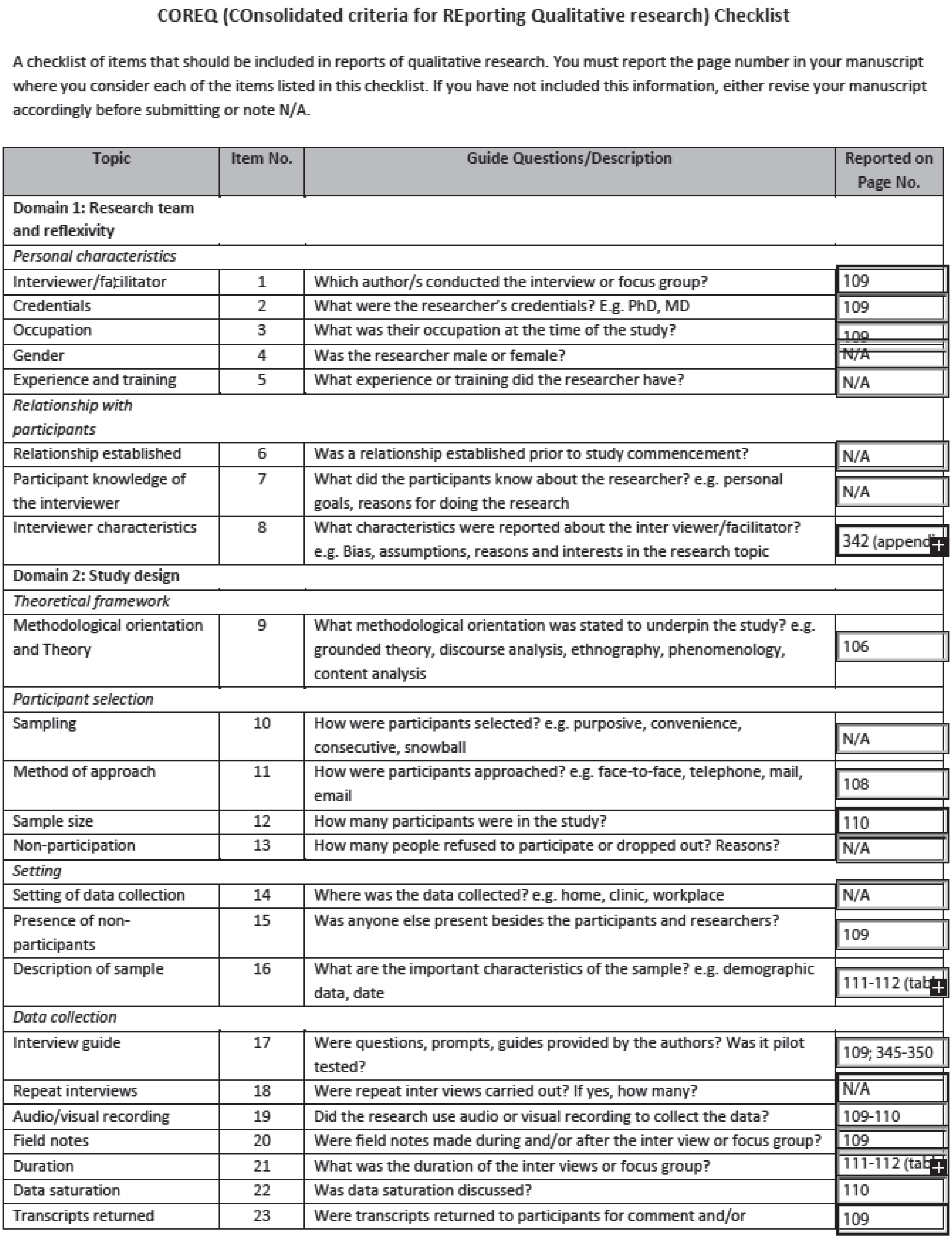
	Dimension	
Training subjects	Volunteer role training	Instrumental nursing training
Vision and values of the organisation	0.661	-0.199
The care offered by the organisation	0.551	0.001
The position and roles of volunteers in care	0.638	-0.33
Ethics (discretion, privacy)	0.715	-0.335
Palliative care	0.523	-0.175
Communication skills	0.664	-0.06
Communicating patient information to other caregivers	0.555	0.158
Guarding personal and professional boundaries	0.698	-0.194
Themes regarding specific patient groups	0.333	0.417
Advance care planning	0.456	0.34
Moving and shifting techniques	0.328	0.585
(Hand)hygiene	0.487	0.22
Training patients and their relatives in self-care	0.362	0.463
Cronbach's Alpha (total = 0.876)	0.810	0.216
Total (Eigenvalue) (Total = 5.214)	3.962	1.252

Table 5: Multiple Comparisons results for Games-Howell post-hoc test on differences in mean total training of volunteers from different organisation types, Flanders and Dutch-speaking Brussels, Belgium, 2018

(I) Organisation	(J) Organisation	Mean Difference (I-J)	Std. Error	Sig.	95% Confidence Interval	
					Lower Bound	Upper Bound
Dedicated PC	Medical oncology	-0.23636	0.36724	0.967	-1.2589	0.7862
	Sitting services	1.33630	0.30133	<.001*	0.5098	2.1628
	Community home care	1.88190	0.47801	0.002*	0.5361	3.2277
	Nursing home	3.98054	0.41670	<.001*	2.8073	5.1537
Medical oncology	Sitting services	1.57266	0.40731	0.002*	0.4451	2.7002
	Community home care	2.11825	0.55099	0.002*	0.5821	3.6544
	Nursing home	4.21690	0.49874	<.001*	2.8273	5.6065
Sitting services	Community home care	0.54559	0.50944	0.821	-0.8792	1.9704
	Nursing home	2.64424	0.45241	<.001*	1.3808	3.9077
Community home care	Nursing home	2.09864	0.58512	0.005*	0.4669	3.7304

* The mean difference is significant at the 0.05 level.

Appendix 4.1: COREQ checklist for chapter 4



COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	109
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	109
Occupation	3	What was their occupation at the time of the study?	109
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	N/A
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	N/A
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	342 (append
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	106
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	N/A
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	108
Sample size	12	How many participants were in the study?	110
Non-participation	13	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	N/A
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	109
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	111-112 (tab
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	109; 345-350
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	109-110
Field notes	20	Were field notes made during and/or after the inter view or focus group?	109
Duration	21	What was the duration of the inter views or focus group?	111-112 (tab
Data saturation	22	Was data saturation discussed?	110
Transcripts returned	23	Were transcripts returned to participants for comment and/or	109

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	109-110
Description of the coding tree	25	Did authors provide a description of the coding tree?	343-344 (app
Derivation of themes	26	Were themes identified in advance or derived from the data?	109
Software	27	What software, if applicable, was used to manage the data?	110
Participant checking	28	Did participants provide feedback on the findings?	109
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	113-122
Data and findings consistent	30	Was there consistency between the data presented and the findings?	yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	113-122
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	113-122

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 4.2: 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 organised structure other than the already existing social relations or familial ties, with a palliative approach, i.e. the intention of improving the quality of life of adults and children with terminal illnesses and those close to them (family and others).* (Adapted from Goossensen et al.[a]) Volunteers do not have an employment contract or statutory appointment within the organisation in which they perform these tasks. This definition is in accordance with that provided by the Belgian federal law.[b,c] We focus on *community volunteers* in *direct patient care*, i.e. 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.[a] Lastly, 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.

[a] Goossensen A, Somsen J, Scott R, et al. Defining volunteering in hospice and palliative care in Europe: An EAPC white paper. Eur J Palliat Care 2016; 23: 184–191.

[b] EU. The Law on Volunteering in Belgium http://europa.eu/%0Dyouth/be/article/45/4528_en (2013, accessed 4 April 2019).

[c] Demotte R, Vanden Bossche F, Onkelinx L. 3 JULI 2005. - Wet betreffende de rechten van vrijwilligers. 2005; 1.

APPENDIX 4.3: Interviewer characteristics and coding tree description

INTERVIEWER CHARACTERISTICS

Below are listed the researchers who functioned as 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 group, either as 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, post-doctoral researcher, promotor and supervisor of SV, and last author of the manuscript. Kenneth was involved in several focus groups as moderator or observer and was one of the researchers who coded the data.

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

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

Lenzo Robijn (MSc. Sociology), male, doctoral researcher. Lenzo was moderator for one of the focus groups with family physicians and 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 paper.

- Experiences of and with volunteering
    - First impressions
    - Expectations
    - Meaning of volunteering
    - Attitudes of volunteers
    - Competency of volunteers
- Volunteer motivations
    - Self-centred
    - Patient-centred
- Influence of volunteers
    - Emotional influence
    - Relationship with volunteer
- Attitudes towards volunteers
    - Value of volunteers
        - For patients
        - For family caregivers
        - For professional caregivers
        - For the organisation
        - In general
        - Person-dependent value
    - Need for volunteers
- Relationship between patients and caregivers
    - Contact with caregivers
    - Distance from caregivers
- 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 customised care
        - Combatting 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
- Volunteer recruitment
    - Responsibility for recruitment
    - Reach
    - Commitment
    - Selection
- Organisational structure
    - Operating structure
    - Organisational scale
        - Geographically
        - Organisational
    - Financial aspects
        - Funding
    - Staff
    - Care facilities
- Evaluation
    - Evaluation of volunteers
    - Evaluation of professional care
    - Evaluation of collaboration
    - Evaluation of volunteer tasks
- Facilitators
    - Organisational
    - Professional care provision
    - Care
    - Volunteering
- Barriers
    - Organisational
    - Professional care provision
    - Care
    - Volunteering

Appendix 4.4: Scripts for individual, semi-structured interviews and topic guides for focus groups

A) Script for patient interviews

Questions (interviewer)	**Probes**
Introduction (5 min)	
- Thank participants for coming - Introduce self (interviewer) - Explain the aim of the study and interview - Emphasise confidentiality - Explain informed consent - Ask to turn off phone for the duration of the interview	- Check whether informed consent form was signed
Introductory question (5 min)	
- Ask their name - Can you tell me about your illness trajectory and your current condition? o What has this involved for you?	- Short discussion of the difficulties and changes the illness trajectory has meant for the person
Transition question (10 min) *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 min)	
- 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 amongst 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 (5 min) *Interviewer provides a short summary of the conversation.*	
- Is this a good summary of our conversation?	
Final question (5 min)	
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.	

B) Script for family caregiver interviews

Questions (interviewer)	Probes
Introduction (5 min)	
- Thank participants for coming - Introduce self (interviewer) - Explain the aim of the study and interview - Emphasise confidentiality - Explain informed consent - Ask to turn off phone for the duration of the interview	- Check whether informed consent form was signed.
Introductory question (5 min)	
- Ask for their name - Can you tell me a bit about the person you	- Relationship between patient and family caregiver - Short discussion of care background

care / cared for and his/her illness trajectory? ○ What has this involved for you?	- Short discussion of the difficulties and changes that the illness trajectory meant for the person
Transition question (10 min) *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 min)	
- 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 (5 min) *Interviewer provides a short summary of the conversation.*	
- Is this a good summary of the conversation?	
Final question (5 min)	
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.	

C) Topic list for focus groups with volunteers

Questions (moderator)	Probes	Timing
Reception of participants		10 min

• Offer everyone pen and paper to make name cards for themselves and to take notes during the focus groups • Offer participants coffee / tea / water / juice and let them talk amongst themselves	Hand out pen and paper Observe and assign places	
Introduction		5 min
• Thank participants for coming • Introduce moderator and observer • Explain the aim of the study and focus group • Emphasise confidentiality • Explain informed consent • Explain it is fine to make notes for themselves • Request to turn off cellphones	Gather signed informed consent forms	
Introductory question		5 min
• Can you all introduce yourselves please?	- How did they become volunteers? - What were their expectations?	
Transitional questions		15 min
• How would you describe yourselves as volunteers in care provision? • What distinguishes you from other care providers?	- Tasks - Training – required / received - Responsibilities - Role of the volunteer	
Core questions		45 min
• How do you support patients? • In what way do you work together with	- Positive and negative experiences - Probe problems that are mentioned	

professional caregivers? • How does this influence patient care? • How could this collaboration be improved?	- Identify barriers and facilitators - Link back to influence on patient care	
Closing questions		15 min
• Is this a good summary of the discussion? • Are there things that did not come up?		
Final questions		5 min
• Ask if they have any other questions • Finish discussion • Thank participants		

D) Topic list for focus groups with nurses and psychologists, and with family physicians

Questions (moderator)	Probes	Timing
Reception of participants		10 min
• Offer everyone pen and paper to make name cards for themselves and to take notes during the focus groups. • Offer participants coffee / tea / water / juice and let them talk amongst themselves	Hand out pen and paper Observe and assign places	
Introduction		5 min
• Thank participants for coming • Introduce moderator and observer • Explain the aim of the study and focus group • Emphasise confidentiality • Explain informed consent	Gather signed informed consent forms	

• Explain it is fine to make notes for themselves • Request to turn off cellphones		
Introductory question		5 min
• Can you please introduce yourselves? • How did you first come into contact with volunteers?	- What was your first impression of volunteers?	
Transitional questions		15 min
• What role does the volunteer play in care, according to you?	- Patient support - Responsibilities and tasks	
Core questions		45 min
• How do volunteers support patients according to you? • In what way do you work together with volunteers? • How would you evaluate the current collaboration with volunteers? • How could this collaboration be improved?	- Benefits and problems - Influence on work / influence on care - Identify barriers and facilitators - Link back to influence on care	
Closing questions		15 min
• Is this a good summary of the discussion? • Are there things that did not come up?		
Final questions		5 min
• Ask if they have any other questions • Finish discussion • Thank participants		

Appendix 5.1: PRINCALS and Two-Step Cluster analyses

Gamma statistics were calculated to look for correlations between our engagement work type variables, which represented volunteer involvement. Based on these analyses, PRINCALS was then used to combine highly correlating variables to create dimensions for volunteer involvement. These dimensions were then entered into Two-Step Cluster analyses.

Appendix Table 1: PRINCALS component loadings and eigenvalues

Component loadings			
Variable	Items	Component loadings[1]	Eigenvalues
Low engagement	Consult	-.919	.8271
	Coproduce	-.900	
High engagement	Collaborate	-.908	.8240
	Empower	-.908	

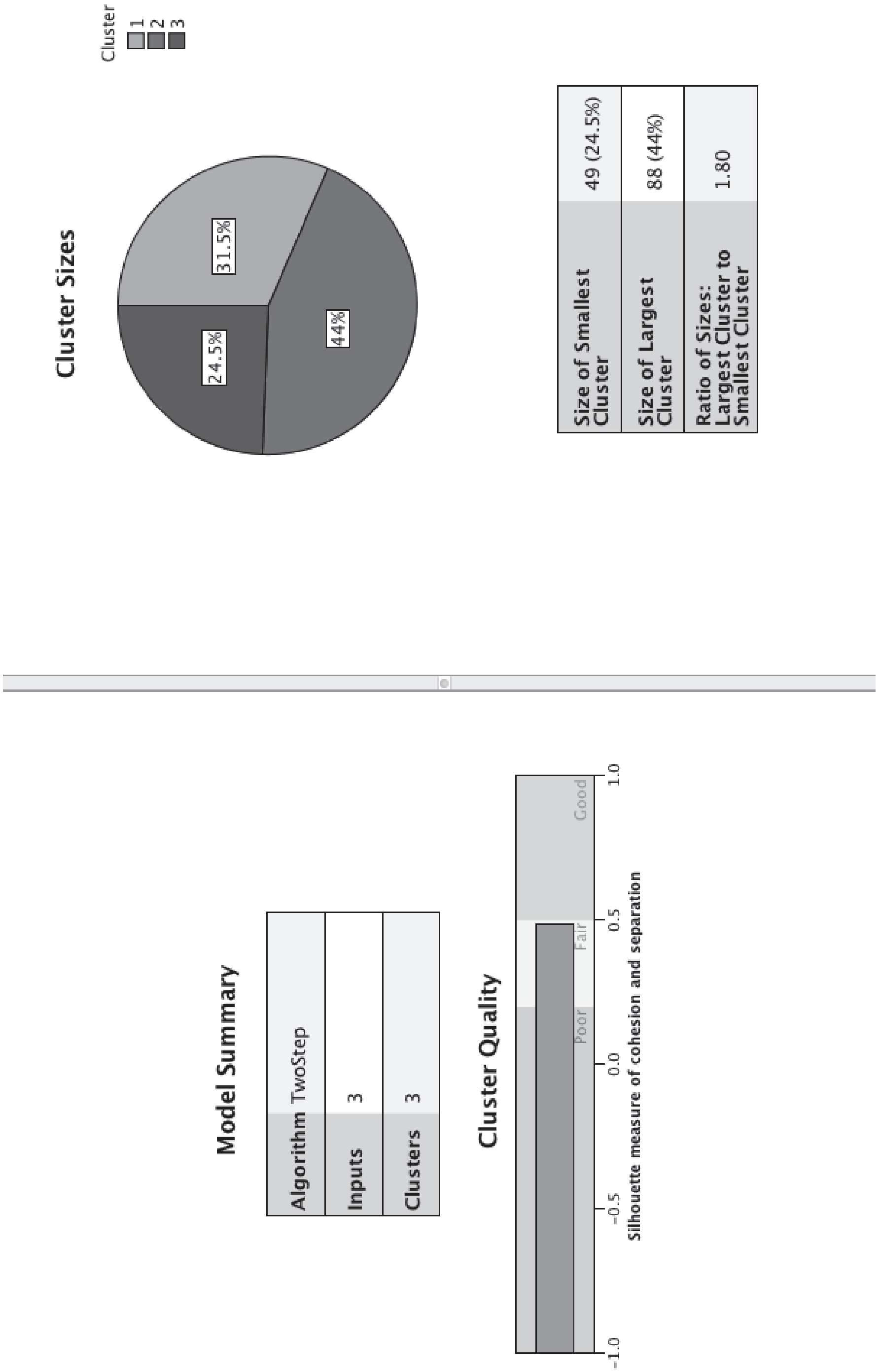
[1] Negative component loadings were transformed to positive.

Volunteer involvement: dimensions and clusters

Calculating Gamma statistics (**not shown in table**) between each possible pair of engagement types revealed that two pairs of types stood out as strong, positive correlations. The first pair was 'consult' and 'co-production' (Gamma value = .812; p<.001), the second pair was 'collaborate' and 'empower' (Gamma value = .747; p<.001). PRINCALS analysis was used to combine each correlated pair into a dimension by saving the component loadings. See **Appendix Table 1** for the component loadings and eigenvalues. We named the dimension based on the 'consult' and 'co-production' engagement work types 'low engagement work' and named the dimension based on the 'collaborate' and 'empower' engagement work types 'high engagement work'. We left out the 'inform' engagement work type, as it stood out conceptually from the other types and it correlated well with all of them, excluding 'empower'.

We then performed a Two-Step Cluster analysis including the original variable for the 'inform' engagement work type and our constructed dimensions for low and high engagement. This resulted in a fair cluster quality with an average silhouette score of 0.5. **(See Appendix Figure 1.)** Three clusters emerged. (**See Appendix Figure 2.**) We named cluster 1 'strong involvement' (N=63; 31.5%) as it consisted largely of organisations that indicated they always informed their volunteers (96.8%) and scored positively on 'low engagement' work (0.63) and 'high engagement' work (0.43). We named cluster 2 'restricted involvement' (N=88; 44%) as it consisted of organisations that often informed their volunteers (100%) and scored neutrally on 'low engagement' work (0.07) and negatively on 'high engagement' work (-0.19). We named cluster 3 'uninvolved' (N=49; 24.5%) as it largely consisted of organisations that indicated they rarely informing their volunteers (83.7%) and scored highly negatively on 'low engagement' work (-0.94) and negatively on 'high engagement' work (-0.20).

Appendix Figure 1: Two-Step Cluster Analysis - Volunteer Involvement

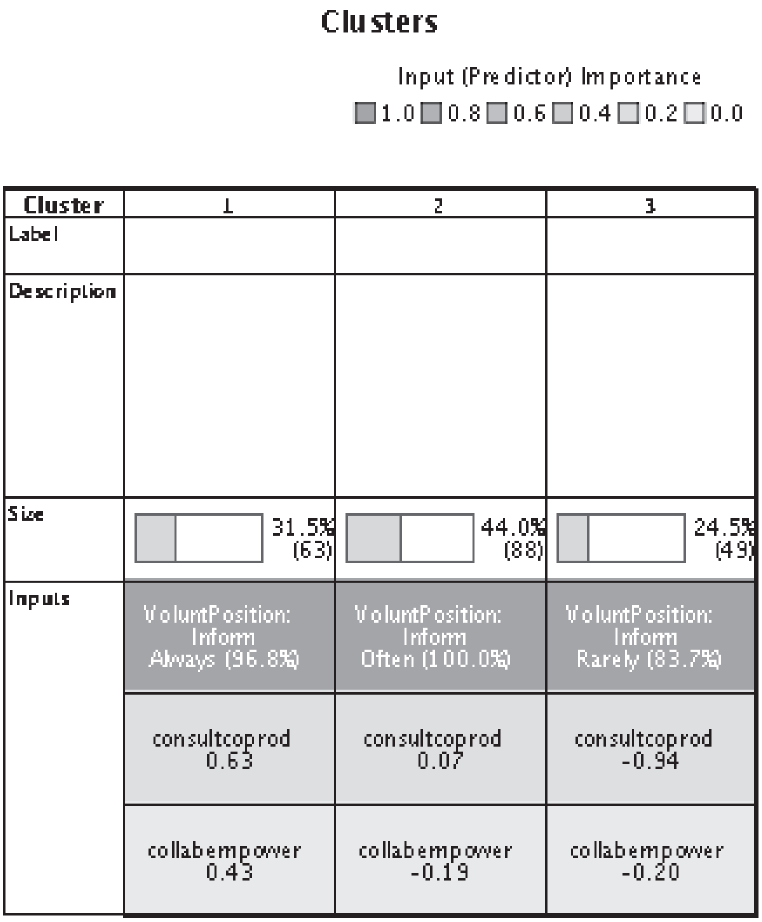


Model Summary

Algorithm	TwoStep
Inputs	3
Clusters	3

Size of Smallest Cluster	49 (24.5%)
Size of Largest Cluster	88 (44%)
Ratio of Sizes: Largest Cluster to Smallest Cluster	1.80

Appendix Figure 2: Volunteer involvement clusters



Clusters

Input (Predictor) Importance

▨ 1.0 ▨ 0.8 ▨ 0.6 ▨ 0.4 ▨ 0.2 ☐ 0.0

Cluster	1	2	3
Label			
Description			
Size	31.5% (63)	44.0% (88)	24.5% (49)
Inputs	VoluntPosition: Inform Always (96.8%)	VoluntPosition: Inform Often (100.0%)	VoluntPosition: Inform Rarely (83.7%)
	consultcoprod 0.63	consultcoprod 0.07	consultcoprod -0.94
	collabempower 0.43	collabempower -0.19	collabempower -0.20

Cluster 1: Strong involvement cluster

Cluster 2: Restricted involvement cluster

Cluster 3: Uninvolved Cluster

APPENDIX 6.1: CATPCA and Two-Step Cluster analysis

Volunteer involvement in the organisation of care

Gamma statistics were calculated to look for correlations between our engagement work type variables, which represented volunteer involvement. **(See Table 1.)** Based on these analyses, Categorical Principal Component Analysis (CATPCA) was then used to combine the highest correlating variables to create dimensions for volunteer involvement. **(See Table 2.)** These dimensions were then entered into Two-Step Cluster analysis.

Table 1: Correlations between volunteer reported types of engagement work, Flanders and Dutch-speaking Brussels, Belgium, 2018

Gamma values	Inform	Consult	Coproduce	Collaborate	Empower
Inform	1.000	0.538	0.526	0.438	0.348
Consult		1.000	0.785	0.691	0.518
Coproduce			1.000	0.701	0.523
Collaborate				1.000	0.707
Empower					1.000

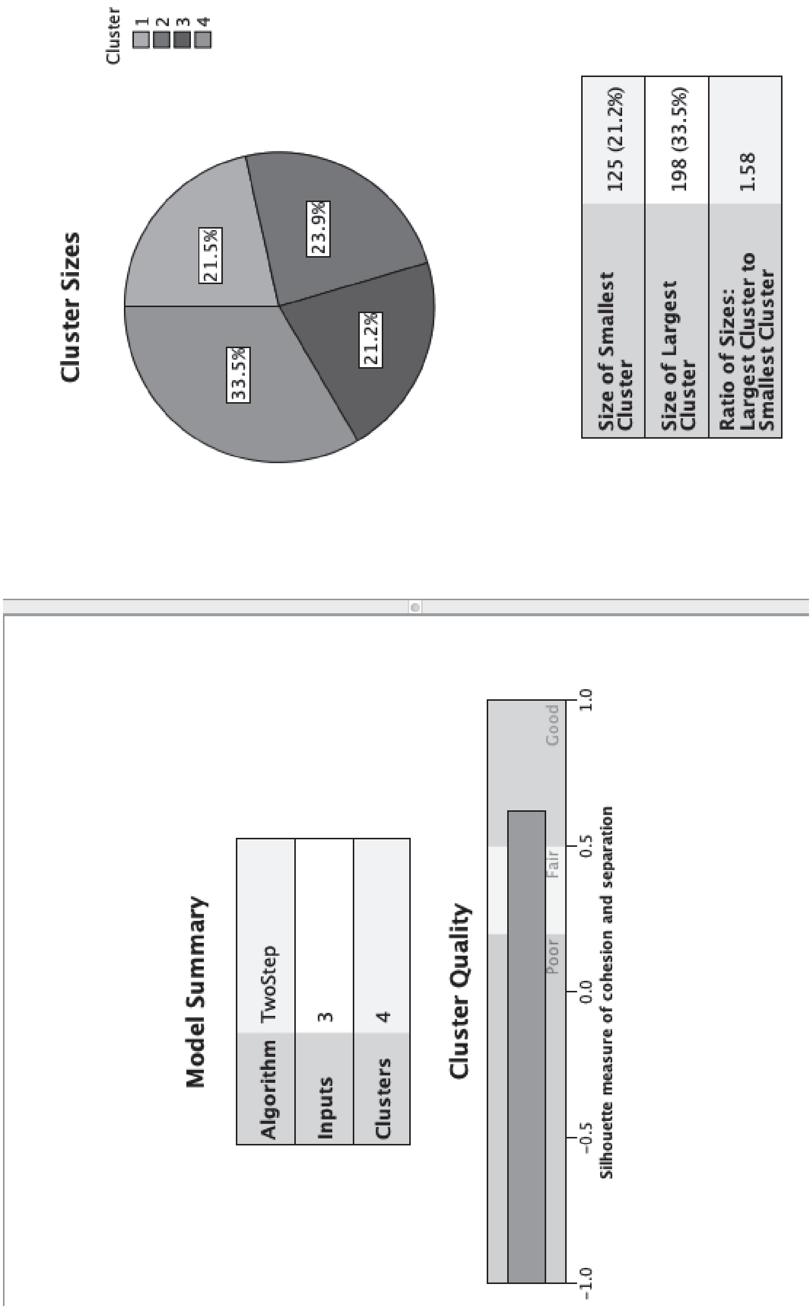
All gamma values significant at p<.001

Calculating Gamma statistics (**Table 1**) between each possible pair of engagement types revealed that two pairs of types stood out as strongest, positive correlations. The first pair was 'consult' and 'co-produce' (Gamma value = .785; p<.001), the second pair was 'collaborate' and 'empower' (Gamma value = .707; p<.001). CATPCA was conducted to combine each pair into a dimension by saving the component loadings. **(See Table 2.)** We named the dimension based on the 'consult' and 'co-production' engagement work types 'low involvement' and named the dimension based on the 'collaborate' and 'empower' engagement work types 'high involvement'. We left out the 'inform' engagement work type, as it stood out conceptually from the other types and it correlated well with all of them. We then performed a Two-Step Cluster analysis including the original variable for the 'inform' engagement work type and our constructed dimensions for low and high involvement. The analysis was instructed to determine clusters automatically and to use Akaike's Information Criterion (AIC) as clustering criterion. Based on the diminishing AIC values from the resulting output, the ideal number of clusters, taking into account face-validity, was determined to be 4. The Two-Step Cluster analysis was conducted again, this time instructed to extract 4 clusters specifically. This resulted in a good cluster quality with an average silhouette score of 0.6. **(See Figure 2.)** Four clusters emerged. **(See Figure 3.)** We named cluster 1 'strong involvement' (N=127; 21.5%) as it consisted of volunteers that indicated often or always being informed by their organisation (100%) and scored highly positive on 'directive involvement' (1.08) and 'reciprocal involvement' (1.64). We named cluster 2 'restricted involvement' (N=141; 23.9%) as it consisted of volunteers who indicated often or always being informed (100%) and scored positively on 'directive involvement' (0.82) but negatively on 'reciprocal involvement' (-0.58). We named cluster 3 'informed only' (N=125; 21.2%) as it consisted of volunteers who indicated often or always being informed (100%) and scored negatively on 'directive involvement' (-0.95) on 'reciprocal involvement' (-0.39). We named cluster 4 'uninvolved' (N=198; 33.5%) as it consisted of volunteers who indicated never or rarely being informed (100%) and scored negatively on both 'directive involvement' (-0.66) and 'reciprocal involvement' (-0.35). Cluster membership was saved as a separate variable for analysis.

Table 2: CATPCA component loadings and eigenvalues of dimensions of involvement

Items	Operationalisation	Dimension 1: directive Involvement	Dimension2: reciprocal involvement
Consult	How often does the organisation ask your opinion on how the care for patients is organised?	.903	
Coproduce	How often does the organisation take your opinion into account in decisions about the organisation of care for patients?	.881	
Collaborate	How often do you as a volunteer have decision making rights regarding decisions on how care for patients is provided?		.870
Empower	How often can you as a volunteer autonomously decide about how certain aspects of care for patients are provided?		.866
Eigenvalues		1.591	1.506
Chronbach's Alpha		0.743	0.672

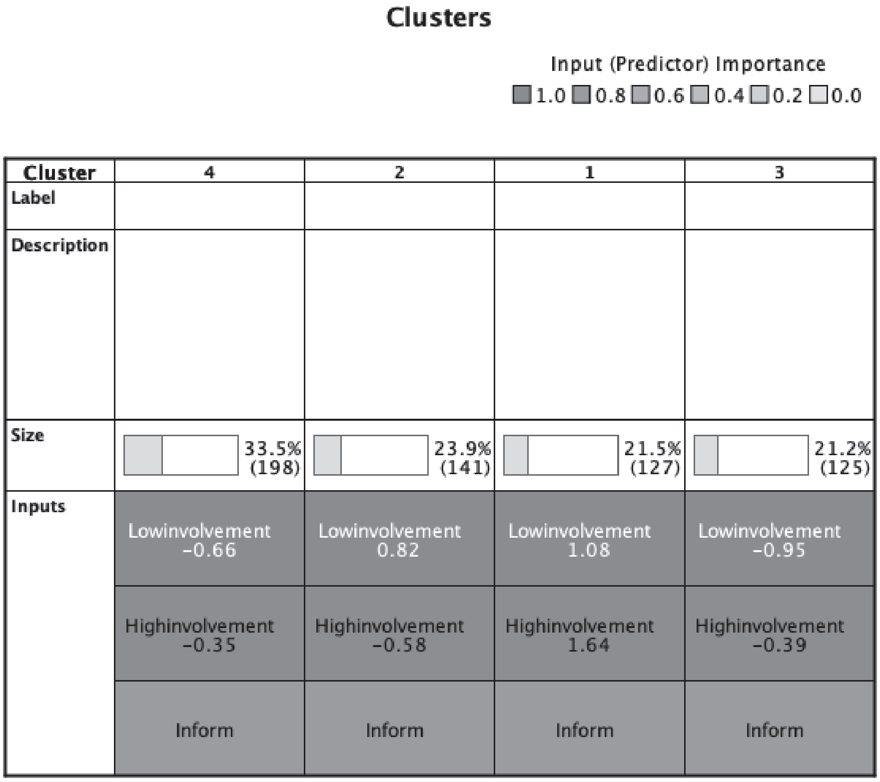
Figure 1: Two-Step Cluster Analysis - Volunteer Involvement



Size of Smallest Cluster	125 (21.2%)
Size of Largest Cluster	198 (33.5%)
Ratio of Sizes: Largest Cluster to Smallest Cluster	1.58

Algorithm	TwoStep
Inputs	3
Clusters	4

Figure 2: Volunteer involvement clusters



Clusters

Input (Predictor) Importance

▨1.0 ▨0.8 ▨0.6 ▨0.4 ▨0.2 ☐0.0

Cluster	4	2	1	3
Label				
Description				
Size	33.5% (198)	23.9% (141)	21.5% (127)	21.2% (125)
Inputs	Lowinvolvement -0.66	Lowinvolvement 0.82	Lowinvolvement 1.08	Lowinvolvement -0.95
	Highinvolvement -0.35	Highinvolvement -0.58	Highinvolvement 1.64	Highinvolvement -0.39
	Inform	Inform	Inform	Inform

Appendices

Appendix 7.1: COREQ checklist for Chapter 7

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	203
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	203
Occupation	3	What was their occupation at the time of the study?	203
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	N/A
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	N/A
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	N/A
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	361 (append
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	200
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	201
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	201
Sample size	12	How many participants were in the study?	204
Non-participation	13	How many people refused to participate or dropped out? Reasons?	201
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	N/A
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	202-203
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	205-206 (tab
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	203; 345-350
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	203
Field notes	20	Were field notes made during and/or after the inter view or focus group?	203
Duration	21	What was the duration of the inter views or focus group?	205-206 (tab
Data saturation	22	Was data saturation discussed?	203
Transcripts returned	23	Were transcripts returned to participants for comment and/or	203

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	203
Description of the coding tree	25	Did authors provide a description of the coding tree?	362-363 (ap
Derivation of themes	26	Were themes identified in advance or derived from the data?	203
Software	27	What software, if applicable, was used to manage the data?	203
Participant checking	28	Did participants provide feedback on the findings?	203
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	208-212
Data and findings consistent	30	Was there consistency between the data presented and the findings?	yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	204-212
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	204-212

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Appendix 7.2: Interviewer characteristics and coding tree description

INTERVIEWER CHARACTERISTICS

Below are listed the researchers who functioned as 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 group, either as 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, post-doctoral researcher, promotor and supervisor of SV, and last author of the manuscript. Kenneth was involved in several focus groups as moderator or observer and was one of the researchers who coded the data.

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

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

Lenzo Robijn (MSc. Sociology), male, doctoral researcher. Lenzo was moderator for one of the focus groups with family physicians and 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 paper.

- 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 customised care
        - Combatting 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
  - Organisation of activities
- Evaluation
  - Evaluation of volunteers
  - Evaluation of professional care
  - Evaluation of collaboration
  - Evaluation of volunteer tasks
- Facilitators
  - Organisational
  - Professional care provision
  - Care
  - Volunteering
- Barriers
  - Organisational
  - Professional care provision
  - Care
  - Volunteering

Appendix 8.1

Stem van het Vrijwilligerswerk
Het EAPC Madrid charter over Vrijwilligerswerk in Hospice en Palliatieve Zorg

Onderteken hier het Stem van het Vrijwilligerswerk – EAPC Vrijwilligerswerk Charter

De *European Association for Palliative Care* (EAPC), de *Worldwide Hospice and Palliative Care Alliance* (WHPCA) en de *International Association for Hospice & Palliative Care* (IAHPC) werken samen om te pleiten voor ondersteuning, erkenning, bevordering en ontwikkeling van het vrijwilligerswerk in hospice en palliatieve zorg door de implementatie van dit Charter met de volgende doelstellingen:

- Bevorderen van een vruchtbare ontwikkeling van het vrijwilligerswerk ten gunste van patiënten, naasten en de bredere hospice en palliatieve zorggemeenschap.
- Erkennen van het vrijwilligerswerk als derde hulpmiddel naast de professionele zorg en mantelzorg, met haar eigen identiteit, positie en waarde.
- Bevorderen van onderzoek en *best practice* modellen in de werving, coördinatie, ondersteuning, integratie, opleiding en inzet van vrijwilligers.

1. Erken de belangrijke rol van vrijwilligers in de totale zorg voor patiënten en hun naasten, en in het bestendigen van hospice en palliatieve zorgdiensten

Acties houden in dat organisaties en individuen:

- Verzekeren dat vrijwilligerswerk een erkende en duidelijk omschreven plaats heeft in hun hospice en palliatieve zorgorganisaties en netwerken. Vrijwilligers vervangen professionele zorgverleners of mantelzorgers niet, maar hebben hun eigen rol.
- Vrijwilligers in staat stellen hun diverse bijdragen te leveren, van patiënten- en naastenzorg tot ondersteuning door fondsenwerving, administratie, bestuur en andere activiteiten die hospice en palliatieve zorg bestendigen.
- Vrijwilligers in staat stellen bij te dragen tot besluitvorming in hospice en palliatieve zorg op individueel, organisatorisch en maatschappelijk niveau en verzekeren dat hun visie en mening gevraagd, overwogen en gerespecteerd worden.

2. Bevorder het vrijwilligerswerk in directe ondersteuning van patiënten en hun

Acties houden in dat:

- Gezondheidsorganisaties erkennen dat ‘er zijn’[1] voor de patiënt en hun naasten de

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[1] ‘Er zijn’ legt de nadruk op de menselijke band, op het ‘aanwezig zijn’ bij de persoon, dat de basis vormt voor het aanvoelen welke soort ondersteuning de vrijwilliger voor deze specfieke persoon op dit specifieke moment kan bieden. Zie de EAPC White Paper over Vrijwilligerswerk for verdere verduidelijking.

kernbijdrage vormt van het vrijwilligerswerk in directe patiëntenzorg.
- Organisaties en individuen actief manieren zoeken om opgeleide vrijwilligers te betrekken in de directe ondersteuning van patiënten en hun naasten, volgens *best practice* modellen uit diverse landen, en patiënten en hun naasten aanmoedigen om gebruik te maken van de beschikbare ondersteuning door vrijwilligers.

3. Verzeker efficiënt beheer van het vrijwilligerswerk, inclusief duidelijk omschreven beleid omtrent rollen, zorgvuldige werving, selectie, opleiding en ontwikkeling

Acties houden in dat:
- Organisaties en individuen efficiënt beheer van vrijwilligers verzekeren met receptieve samenwerking tussen vrijwilligers, naasten en professionelen. Dit is cruciaal voor kwaliteitsvolle en duurzame vrijwilligersdiensten.
- Nationale (of regionale) *best practice* programma’s voor begeleiding, opleiding en kwaliteit ontwikkeld en geïmplementeerd worden in elk Europees land.

4. Verzeker doeltreffende ondersteuning voor vrijwilligerswerk in de hospice en palliatieve zorg op het organisatorisch, lokaal en nationaal niveau

Acties houden in dat organisaties:
- Voorzien in adequate financiering om doeltreffend beheer, opleiding en kwaliteit te verzekeren, inclusief vergoeding van kosten die vrijwilligers maken, zoals verplaatsing, telefoon en verzekering.
- Vrijwilligerswerk als een belangrijk onderzoeksdomein erkennen en subsidiëren en de impact van het vrijwilligerswerk evalueren.
- Nauwkeurige data verzamelen op organisatieniveau voor elk Europees land, inclusief aantal en rollen van vrijwilligers.
- Europese, nationale en regionale wetgeving en beleid dat ijvert voor vrijwilligerswerk in hospice en palliatieve zorg beïnvloeden.

Onderteken hier het Stem van het Vrijwilligerswerk– EAPC Vrijwilligerswerk Charter!
Voor meer informatie, zie het achtergronddocument van het Charter.

Erkenningen
Mensen uit minstens 13 verschillende landen (Australië, België, Duitsland, Hongarije, Ierland, Italië, Kroatië, Nederland, Oostenrijk, Polen, Portugal, Roemenië en het Verenigd Koninkrijk) hebben bijgedragen aan de ontwikkeling van het Charter. We willen graag het werk erkennen van de Stuurgroep van de *EAPC Task Force on Volunteering in Hospice and Palliative Care*, de leden van de Task Force en iedereen die deelgenomen heeft in de consultaties. De Vlaamse vertaling van dit Charter werd voorzien door Steven Vanderstichelen en Kenneth Chambaere van de onderzoeksgroep Zorg Rond Levenseinde (VUB – UGent).