Volunteer involvement in the organisation of palliative care

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Volunteer involvement in the organisation of palliative care: a survey study of the healthcare system in Flanders and Dutch-speaking Brussels, Belgium

Abstract

Aging 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 don’t 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<.001) and performance of practical (p<.001) and psychosocial care tasks (p<.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 (6)
Volunteers; palliative care; involvement; Belgium; Surveys and questionnaires

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.

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 (EAPC, 2017). 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 (E. Abel, 1986; Bruera, Higginson, Ripamonti, & von Gunten, 2006; Morris, Payne, Ockenden, & Hill, 2015; Morris, Wilmot, Hill, Ockenden, & Payne, 2012). They may take up several roles ranging from administrative and fundraising to providing companionship and support (Emanuel et al., 1999; Handy & Srinivasan, 2004; Wilson et al., 2005), 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 (Block et al., 2010; Burbeck et al., 2014; Luijkkx & Schols, 2009; McKee, Kelley, Gulrguis-Younger, MacLean, & Nadin, 2010; Morris et al., 2012). 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) (Arno, Levine, & Memmott, 1999; Astrain, 2018; Fast, Keating, Derksen, & Otfinowski, 2004; Help the Hospices, 2006; Janssen, Jongen, & Schröder-Bäck, 2016; Knickman & Snell, 2002; Triantafillou et al., 2010). 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 (Vanderstichelen et al., 2018).

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 (J. Abel & Kellehear, 2016; Sallnow, Tishelman, Lindqvist, Richardson, & Cohen, 2016). 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:

1. To what extent do different healthcare organisations providing palliative care involve their volunteers in the organisation of patient care provision?
2. How do different healthcare organisations providing palliative care evaluate the degree of involvement of their volunteers in the organisation of patient care provision?
3. Is this degree of volunteer involvement associated with differences in volunteer tasks, volunteer training and the organisation's evaluation of volunteer involvement?

**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 (STATBEL, 2017).

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 Goossens et al. (2016)) 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 (Demotte, Vanden Bossche, & Onkelinx, 2005; EU, 2013). 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 (Goossensen et al., 2016). 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 regards to how decisions are made about the organisation of patient care provision. As we will discuss below, involvement may vary on a hierarchical continuum (Sallnow & Paul, 2014), ranging from being informed to varying degrees of using this information to have voice (Allen & Mueller, 2013), 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.

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 (Agentschap Zorg en Gezondheid, 2017). 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 I.) Box 1 provides a list and descriptions of all organisation types included in our sampling framework based on this expert consultation.

**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.

**Samples and procedure**

We surveyed a full population sample of all organisation types mentioned in Box 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.

**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 II.

**Measures**

Questions on volunteer involvement were based on a model of power sharing in palliative care suggested by Sallnow & Paul (2014), 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 (Sallnow & Paul, 2014). (See Box 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) (Katz, 1983) and instrumental Activities of Daily Living (iADL) (Lawton & Brody, 1969), 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.

**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 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 III 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.

**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 (2017), 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%.

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.

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.)

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).

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 III.)

Degree of involvement of volunteers in the organisation of care differed significantly between organisation types. (p<.001) **(Figure 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.)**

**Discussion**

**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.

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 (Candy, France, Low, & Sampson, 2015). 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 (Arnstein, 1969; Oliver et al., 2008; Popay, 2010; Tritter & McCallum, 2006) applied to end-of-life care (Sallnow & Paul, 2014). 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 (Burbeck et al., 2014; Morris et al., 2012; Vanderstichelen et al., 2018; Wilson et al., 2005), 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 (2014), 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 (Burbeck et al., 2014; Emanuel et al., 1999; Wilson et al., 2005) and receive a range of training for this (Horey, Street, O’Connor, Peters, & Lee, 2015; Wittenberg-Lyles, Schneider, & Oliver, 2010; Woitha et al., 2014). 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 (Vanderstichelen et al., 2018). 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 (Hayes et al., 2012; Wowchuk, McClement, & Bond, 2007), 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.

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.

**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.
References


Box 1: Sampling framework of Flemish and Brussels healthcare services potentially involving volunteers in direct patient care, Belgium, 2016†

1. **Medical oncology departments (MOD) (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.‡

3. **Palliative care units (PCU) (N=28/28)** are separate units in (or associated with) hospitals that exclusively provide palliative care.

4. **Palliative day care centres (PDC) (N=5/5)** provide care and nursing during the day and have a respite care function for carers.

5. **Palliative home care teams (PHT) (N=15/15)** are part of the palliative networks i.e. cooperative ventures between different providers and care facilities in a particular region – they 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 (CHC) (N=12/12)** are organised by the Christian Sickness fund locally and run by volunteers.

7. **Nursing homes (NH) (N=200/783)** offer permanent care and nursing to elderly people.

† Descriptions fully or partially taken from the Agency of Health and Care website. (Agentschap Zorg en Gezondheid, 2017) ‡See Walshe et al. (2016)
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 II. (Questions 14 and 19.)
Box 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.

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