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# **Engagement of specialized palliative care services with the general public: a population-level survey in three European countries**

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## Abstract

### Background:

There is growing recognition of a need for community capacity development around serious illness, dying and loss, complementary to strategies focusing on health services. Hitherto, little is known about how and to what extent palliative care services in different countries are adopting these ideas in their practices.

**Aim:** To examine views towards and actual involvement in community engagement activities as reported by specialized palliative care services in Belgium, Sweden and the UK.

**Design, setting, participants:** Cross-sectional survey among all eligible specialized palliative care services in Flanders (Belgium) (n=50), Sweden (n=129) and the UK (n=245). Representatives of these services were invited to complete an online questionnaire about their actual activities with the general public and their attitudes regarding such activities.

**Results:** Response rates were 90% (Belgium), 71% (Sweden) and 49% (UK). UK services more often reported engaging with the general public to develop knowledge and skills through a range of activities (80-90%) compared to Belgian (31-71%) and Swedish services (19-38%). Based on a combination of engagement activities 74% of UK services could be labeled as extending their focus beyond the clinical mandate compared to 16% in Belgium and 7% in Sweden. Services' dependency on charitable donations was strongly associated with increased engagement with the general public.

**Conclusion:** An expansion of the mandate of specialized palliative care services beyond a traditional clinically-oriented focus towards one inclusive of community capacity building around serious illness, dying and loss is occurring in different countries, albeit to different degrees and with different intensities.

**Key words:** palliative care, hospices, Belgium, United Kingdom, Sweden, survey, community participation, social participation

## Key statements

### **What is already known about the topic?**

- *There is an increasing interest internationally in public health approaches to palliative care that aim to develop community capacity around serious illness, dying and loss*
- *Community engagement activities by palliative care services have been demonstrated in the UK and New Zealand*
- *It is not known to what extent palliative care services in different countries are adopting these ideas in their practices*

### **What this paper adds**

- *Palliative care services in Belgium, UK and Sweden report community engagement activities indicating an expansion of their traditional clinically-oriented focus*
- *The degree of community engagement seems to be considerably larger in the UK compared to in Belgium and even more so to Sweden*
- *Services' orientation towards community engagement is found to be associated with their dependency on charitable donations for their functioning*

### **Implications for practice, theory or policy**

- *Palliative care services' priorities and activities regarding community engagement seem to be shaped by different traditions, health care systems and cultural norms in different countries*
- *Normative ideas about the role of palliative care services in the development of community capacity, therefore, need to be avoided and a variety of ways to achieve this need to be considered*
- *The fact that at least some palliative care services are expanding their mandate may need to be more fully recognized and supported by health policy makers*

## Introduction

Specialized palliative care services developed in many countries in response to complex needs and problems associated with serious illness, dying, death and grief<sup>1</sup>. These services traditionally focus on assessing and relieving biopsychosocial problems of individual patients and their family members, and in supporting care providers in doing so<sup>2-4</sup>. However, there is growing realization of the limitations of traditional service-led models, with increasing interest on broader impacts of palliative care services, beyond clinical service provision<sup>1-6</sup>. This involves expanding the reach and effectiveness of palliative care services by collaborating with the public to: increase awareness about death, dying and loss and thereby death literacy; empower communities in caring for their own at the end-of-life (here used to include bereavement); and address social, existential and psychological issues that are better dealt with within existing social networks than by health services<sup>1,7</sup>.

This expanding mandate is articulated in a paradigm first referred to over 20 years ago by Kellehear as health-promoting palliative care<sup>8,9</sup> and more recently as public health palliative care<sup>4,10</sup>, derived from the Ottawa Charter for Health Promotion<sup>11</sup>. Such models are based on the premise that while end-of-life care can require professional and medical support, it is predominately a universal experience entailing social responses<sup>4,10,12</sup>. They aim to resituate community and family responses by empowering them alongside, and in partnership with, professional services through community engagement<sup>13</sup>.

A research base about public health palliative care is gradually developing<sup>14-17</sup>, although little prior research has explored specialized palliative care services' community engagement initiatives. A 2013 survey of >200 specialized palliative care services in the United Kingdom (UK), found that 60% prioritized community engagement initiatives to support those facing end-of-life issues, with professionals working closely with communities to support this<sup>18</sup>. A 2016 study found similar results for 15 hospices in New Zealand<sup>19</sup>. These studies indicate that some specialized palliative care services had begun to rethink how they could work with broader communities to improve end-of-life experiences. Such approaches are dependent on norms and cultural influences in local contexts as well as the history and structure of health and social care systems.

However, existing data about specialized palliative care services' community engagement derives nearly exclusively from English-speaking countries, although community engagement in palliative care is gaining momentum internationally. Ongoing discussions among the authors pointed to a need to update extant knowledge by exploring differing settings, needs and potentials, beginning with their own contexts in Belgium, Sweden and the UK. These three countries vary in terms of types of health care systems, organization of palliative care within the countries, and the differences in the extent and role of volunteering activities within palliative care, with Belgium and the UK having a longer tradition of volunteerism in palliative care compared to Sweden<sup>20-24</sup>. Belgium, Sweden and the UK are generally also mapped as having different shared values<sup>25</sup> (see Table A1 in Appendix for a more detailed description). Cross-national comparisons can help to understand similarities and differences across countries at the intercept of community engagement and specialized palliative care provision, and support mutual learning. In this article, we therefore aim to examine views towards and actual involvement in community engagement activities as reported by specialized palliative care services in Belgium, Sweden and the UK.

## Methods

We conducted an online cross-sectional survey among specialized palliative care services in Flanders (Belgium), Sweden and the UK ~~that might feasibly engage with the surrounding community~~. Presentation follows STROBE guidelines<sup>26</sup>.

### Participants

Survey respondents were representatives of specialized palliative care services. A specialized palliative care service was defined as a service dedicated to providing palliative care by professionals either trained in or working predominately within palliative care. In Flanders (Belgium), services were identified through up-to-date listings of services from the Flemish Federation of Palliative Care for Flanders in 2018 (n=50). In Sweden, all adult services voluntarily registered with the 2018 national Palliative Guide were included (n=129). In the UK, services were identified through 2018 listings of services on the Hospice UK online database (n=245). Given the aims of this study, we wanted to include services that might feasibly engage with the surrounding community and therefore excluded services acting only as consultants for other professionals, e.g. hospital-based palliative support teams who mainly have an intramural support function, as these would not be expected to engage directly with the community. For each included service, one person identified as well-placed to know the activities of the service (e.g. coordinators, directors or chairs of the service) received an email invitation, with instructions to forward it if another person within the service was better suited to respond to the survey.

### Questionnaire

Existing questionnaires and instruments were initially perused but deemed inappropriate for our aims. The questionnaire for this survey was in part inspired by Paul & Sallnow's 2013 UK questionnaire<sup>18</sup> but further developed collaboratively within the research team to ensure appropriate operationalization of community activities across countries. 'Community engagement activities' were defined as *"activities that your service does with the general public"*. The community engagement activities surveyed were structured according to Sallnow & Paul's model of power sharing in palliative care (2004) that presents a spectrum of engagement activities with communities, ranging from informing through consulting, to involving, collaborating, and empowering<sup>13</sup>. This spectrum aims to represent increasing engagement, capable of more penetrating health and social outcomes.

A first version of the questionnaire was developed in English and subsequently translated to Swedish and Dutch. In order to reach equivalence across countries we followed previously published guidance on translation and cultural adaptation<sup>27, 28</sup> and performed cognitive interviews, using a 'think aloud approach'<sup>29</sup> with palliative care team members in Flanders, Belgium (n= 6), Sweden (n= 3) and the UK (n= 4) to explore the interpretation of items and concepts. During these interviews, respondents were asked to complete a printed copy of the questionnaire in the presence of a researcher, while voicing their thought process out-loud and remarking on questions, terms or concepts that were unclear or difficult to answer. Based on the results of the cognitive interviews, the questionnaire was further adapted through several meetings with the research team. From the interviews, it became clear that certain key terms in the questionnaire such as 'general public' needed to be defined more explicitly (see Appendix 2 for the English questionnaire). We also specified what was meant with 'full-time equivalent professional care providers employed by the service' and 'volunteers', and used the Swedish expression commonly used for bereavement care, literally translated as "support for survivors" since there is no established phrase in Sweden for "bereavement care". Lastly, space for additional comments and reflections of respondents was included, and an explanatory cover letter to respondents defining the purpose and key terms of this study was added.

The final questionnaire consisted of 11 questions in three modules: 1) characteristics of the services; 2) community engagement activities with the general public - following Sallnow & Paul's conceptual model<sup>13</sup> this was further differentiated as: information provision about the service; public education about palliative care-related aspects; collaborating with other organizations to develop end-of-life skills and knowledge among the general public; and developing new networks together with communities); and 3) attitudes regarding specialized palliative care services' role in engaging with the general public (see Appendix 2 for the English questionnaire).

## **Data collection**

The online tool LimeSurvey was used to create electronic questionnaires for all three countries. LimeSurvey enables secure, anonymous data collection and ensures confidentiality. After approval from the Ethical Review Board of Brussels University Hospital (ref B.U.N. 143201837115) and in accordance with research ethics regulations in each respective country, respondents were contacted in January 2019 (Belgium and Sweden) and February 2019 (UK) via email with an invitation to participate in the online survey. The questionnaire was accessed through a unique link in the email, which allowed the program to monitor survey response. An information sheet prefaced each survey, stating that survey response was considered as provision of informed consent. Respondents without a recorded response to the questionnaire received an automated reminder email, at timepoints determined by the response rate and praxis in each country: two and four weeks after the first invitation in Belgium, after one, two and four weeks in Sweden, and after one, two, three, five, six and eleven weeks in the UK. In Belgium, a data collector telephoned non-responders one week after the second reminder, to ask if support filling out the questionnaire was desired. Likewise, in the UK a data collector called non-responders in week six. Participants' responses were stored anonymously on the password-protected survey website. After completed data collection (May 2019), individual responses were transferred to SPSS for analysis.

## **Statistical analyses**

Statistical analyses were performed using IBM SPSS Statistics version 26. Descriptive data were aggregated by country and differences in distribution between countries examined with Kruskal Wallance Test. Two-step Cluster Analysis identified clusters of services in relation to community engagement activities. Cluster membership was then used as a grouping variable for further analyses. Chi-square tests were performed to check for statistical differences in service characteristics and cluster membership. Thereafter, multivariable binary logistic regression analyses were performed with cluster membership as the dependent variable and service characteristics as independent variables. Analyses were performed both across and within countries. Models were built hierarchically and multicollinearity between independent variables was avoided. Odds ratios (OR) and 95% confidence intervals (CI) are presented. A Principal Component Analysis (PCA)(Varimax rotation) was performed using data about participants' attitudes towards community engagement to investigate underlying attitudinal structures. Components were selected based on theoretical consistency of items and statistical criteria (e.g. explained variance, eigenvalues, component loadings of the items). Thereafter, one-way ANOVA tests were carried out to explore associations between mean scores for identified attitude-components and relevant service characteristics. Additionally, multivariable analyses were performed to correct for possible confounding factors.

## Results

Response rates were 90% for Belgium, 70.5% for Sweden and 49.4% for the UK. An overview of service characteristics by country is shown in Table 1. Approximately 75% of the UK services offer day hospice care, in contrast to 9% of the Belgian services and 12% of the Swedish services. While <20% of Swedish services involve volunteers, 93% do so in Belgium, with 100% in the UK. Ninety-one percent of Swedish services reported that they could function well without donations, whereas 98% of the UK services indicated that they could not function at all without donations; in Belgium 75% indicated that at least some aspects of their work would not be possible without donations.

### Community engagement activities

In all countries, only a minority of services reported that they planned to initiate activities they were not currently engaged in, in the coming year. However, planned and present engagement in all community activities, with the exception of government collaboration, differed significantly between countries (Table 2). In general, the UK services reported strong community engagement (80-90%) to educate the general public, with moderate activity among Belgian services (31-71%) and least among those in Sweden (19-38%). Approximately 20% of services in Belgium and Sweden reported having built or helped build informal end-of-life support or care networks, whereas in the UK, ~77% of services engaged in building end-of-life networks.

### Factors associated with community engagement

A Two-Step cluster analysis created a typology of services based on their community engagement activities, with three clusters of services we labelled “expanding services” (i.e. extending their focus beyond a clinical mandate; N= 88; 38.4%), “selective engagement services” (i.e. engaging in some community activities but not in general; N= 62; 27.1%), “clinically-oriented services” (i.e. focusing predominantly on direct care provision itself; N= 79; 34.5%). See Appendix 3 for more detail.

The univariable analyses (Table 3) indicate that community engagement differs significantly between services in Belgium, Sweden and the UK. Most UK services (73.5%) are located in the cluster “expanding services” with only one service in the clinically-oriented cluster, while most (69.9%) Swedish services are located in “clinically-oriented services”; only 7.2% are ‘expanders’. For Belgium, 15.9% of services were in the “expanders” cluster and 45.5% in the “clinically-oriented” cluster. Services unable to function at all without voluntary donations are significantly more often in the “expanding services” cluster (n= 52; 75.4%), while services not at all dependent on donations (n= 64; 72%) were generally found in the “clinically-oriented” cluster. Services working with volunteers are also in the “expanding services” cluster (n=83; 52.5%) significantly more than in other clusters.

A cross-country multivariable logistic regression analysis with the cluster ‘Expanding services vs the rest’ as dependent variable, showed that differences between countries remained large, even after controlling for dependency on donations which explained a substantial portion of country differences in cluster membership (see in Appendix 4, Tables A3.1-2).

### Attitudes towards community engagement activities

Table 4 presents attitudes to community engagement by country, highlighting notable differences in perception of knowledge among the general public, reported mandate, available resources, and role of the public in bereavement care. Principal Component Analysis (PCA) was performed on all attitude items to explore their underlying structure, resulting in three components (Table 5; see Appendix 5 for details). The multivariable models showed that respondents from services that function well without donations appear most convinced that the general public is sufficiently informed about end-of-life issues. Swedish respondents supported the statement that specialized palliative care services have a mandate to engage with the general public to a significantly lesser degree than UK respondents ( $p<0.001$ ). Services in the expanding and selective engagement clusters, and those predominately



1 serving rural populations showed more support for this mandate. Respondents from Swedish services  
2 endorsed the importance of informal networks significantly more compared to respondents from the  
3 UK ( $p=0.03$ ), while respondents from services that work with registered nurses were less likely to  
4 endorse this ( $p=0.004$ ).

5

## Discussion

### *Summary of main findings*

This three-country survey indicates considerable country-variation in specialized palliative care services' degree of engagement with the general public, with those in the UK particularly expanding their focus beyond a clinical mandate, compared to those in Belgium and even more so than those in Sweden. The findings suggest that this may partly be due to services' dependency on charitable donations; the majority of specialized palliative care services in the UK indicated they could not function well without donations. It also corresponds with the different attitudes held by services in the three countries about the importance of community engagement for palliative care services and their interpretation of their mandate.

### *Strengths and limitations*

There are some strengths and limitations to consider when interpreting these results. While the results showed high degrees of community activity, the UK response rate was notably lower than that in Paul and Sallnow's previous 2013 survey<sup>18</sup>. The reasons for this are unclear, and may possibly represent a selection bias in favor of those involved in community engagement activities or, alternatively, be due to a satiation effect as community engagement activities are more common in the UK. However, the UK survey findings are in line with expectations based on the 2013 survey that had a high response rate and also showed a high degree of community engagement<sup>18</sup>. Although the response rate in the UK was lower than the high rates obtained in Belgium and Sweden, it is still acceptable and relatively high compared to other surveys among healthcare professionals<sup>30</sup>.

By targeting the entire population of those specialized palliative care services that could feasibly engage with the greater community selection bias was limited. Reliance on one representative of the service as respondent is a potential bias as perspectives may differ within services. Additionally, reported past activities may be subject to recall bias. While we conducted a thorough translation practice to obtain content validity across the three countries, lack of existing culturally appropriate and familiar terminology to cover the areas in focus in both Flemish and Swedish may have affected interpretation of items. Despite written instructions defining key terms, the extent to which terms such as 'community' and 'general public', as well as underlying assumptions in public health palliative care, are understood similarly is unclear<sup>31</sup>.

### *What this study adds*

This study is the first to compare specialized palliative care services' engagement with the general public across countries. The findings indicate that services in all three countries are expanding their traditional clinically-oriented focus to include community engagement to educate the general public or raise awareness about palliative, end-of-life and bereavement care, to some degree. They not only promote their service, but also develop societal capacity by organizing events to reach a broad audience as well as through collaboration with businesses and schools. Such collaborations have various forms of capacity-building potential, for example impacting school curricula, developing new knowledge and skills in different groups, and facilitating networking between different community organizations<sup>32</sup>.

The interest in community engagement from specialized palliative care services' is likely driven both by realization that they reached only a limited group through clinical practice and that working further 'upstream' may be needed to more effectively impact the health and wellbeing of those experiencing serious illness, dying and grief as well as a desire to make a relevant societal contribution to those beyond their formal service clientele<sup>3</sup>. Yet, the findings suggest that the need to expand the reach and mandate of specialist palliative care services is not universally accepted. The striking differences between the three studied countries in the degree to which specialized services engage with communities and hold the view that this is their responsibility is notable. Swedish palliative care services were more restrictive than their Belgian counterparts, who in their turn were more restrictive than services in the UK.

Several factors may underlie the differences between countries. First, the UK has a longer history of both palliative care and public health palliative care, which is also supported by national end-of-life care policies and strategies<sup>2, 33, 34</sup>. It may thus be that specialized palliative care services in the different studied countries are in different phases of expanding their mandate to engage with communities. Second, the funding of specialized palliative care services can play an important role. In Sweden palliative care is generally funded and run by the state, whereas funding to services is more limited in the UK<sup>35</sup>. The extent to which services in the three countries depend on charitable donations indeed varied strongly in our findings. Dependency on charitable donations from individuals and organizations compared to full reliance on state funding can drive an orientation towards the wider community. Third, the role of volunteerism in palliative care likely plays a role. Belgium<sup>21, 22</sup> and the UK<sup>20</sup> have stronger traditions of volunteerism in palliative care compared to Sweden<sup>23, 24</sup>. Previous research has identified that volunteers occupy a liminal space between the purely medical domain and the community<sup>36</sup>. Therefore, extensive involvement of volunteers both brings the community into the service more explicitly while also enabling services to expand their activities beyond purely clinical work with clients. Fourth, differential organization may also support different views among palliative care services in different countries, not about the usefulness of building capacity across society in dealing with serious illness, dying and grief per se, but rather about the role of palliative care services in achieving this.

## Conclusion

The results from this survey indicate that an expansion of the mandate of specialized palliative care services beyond a traditional clinically-oriented focus, is occurring in Belgium, Sweden and the UK, albeit to different degrees and with different intensities. While services generally appear to view community networks as important partners in end-of-life and bereavement care, the extent to which they view palliative care services as having a role in supporting this engagement relates to healthcare organization and funding, as well as culturally-specific views, traditions and responsibilities related to community engagement. While UK hospices and palliative care services demonstrate a driving role in public health palliative care approaches, this study suggests that normative ideas about how similar results can be achieved in other countries are best avoided. Exploring and developing different contextually-relevant ways to achieve broad coalitions of societal actors to meet community end-of-life care needs appears a constructive alternative.

## **Authorship statement**

All authors made substantial contributions to the concept and design of the study, the drafting and testing of the main questionnaire, and the acquisition of data in their countries. Analyses were led by ADV and JC but all authors contributed to refinements in the analyses and interpretation of data. All authors contributed to the drafting and revising of the article, approved the final version and have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

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## **Declaration of conflicts of interest**

The authors declare that there is no conflict of interest.

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## **Data management and sharing**

Pseudonymized data are stored on a secure server at the Vrije Universiteit Brussel. Access to aggregated data can be provided by the corresponding author upon request after applying measures to minimize risk of reidentification and approval from the responsible data protection officer.

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1 Table 1: Characteristics of the specialized palliative care services surveyed in Belgium, Sweden and  
2 UK, 2019

	BE	SE	UK
	N (%)	N (%)	N (%)
Survey sent out	50	129	245
Respondents (response rate)	45 (90.0)	91 (70.5)	121 (49.4)
<b>Characteristics of the SPCS*</b>			
<i>Population served</i>			
Mainly rural	7 (15.9)	9 (10.0)	15 (12.8)
Mainly urban	7 (15.9)	23 (25.6)	27 (23.1)
Mixed	30 (68.2)	58 (64.4)	75 (64.1)
<i>Type of service†</i>			
Inpatient beds	27 (60.0)	48 (52.7)	97 (80.2)
Home care	18 (40.0)	56 (61.5)	90 (74.4)
Day hospice	4 (8.9)	11 (12.1)	91 (75.2)
Consultancy (network in Sweden)	/	56 (61.5)	/
Outpatient care	/	/	78 (64.5)
<i>Disciplines connected to the service</i>			
Physicians	43 (95.6)	90 (98.9)	100 (82.6)
Registered nurses	43 (95.6)	91 (100.0)	113 (93.4)
Other nursing staff	8 (17.8)	54 (63.7)	103 (85.1)
Psychologists and/or counsellors	41 (91.1)	4 (4.4)	95 (78.5)
Social workers	23 (51.1)	81 (89.0)	87 (71.9)
Occupational therapists	3 (6.7)	75 (82.4)	91 (75.2)
Physiotherapists	22 (48.9)	75 (82.4)	97 (80.2)
Spiritual workers/chaplain	24 (53.3)	36 (39.6)	95 (78.5)
Dietician	13 (28.9)	62 (68.1)	31 (25.6)
Complementary therapist	/	10 (11.0)	104 (86.0)
<i>Full-time equivalent employed care providers</i>			
<3	3 (6.7)	4 (4.4)	0 (0.0)
3-10	21 (46.7)	10 (11.0)	9 (8.1)
11-20	18 (40.0)	21 (23.1)	1 (0.9)
21-30	2 (4.4)	18 (19.8)	3 (2.7)
31-40	1 (2.2)	10 (11.0)	5 (4.5)
41-50	0 (0.0)	9 (9.9)	9 (8.1)
51-100	0 (0.0)	6 (6.6)	38 (34.2)
101-200	0 (0.0)	12 (13.2)	35 (31.5)
>200	0 (0.0)	1 (1.1)	11 (9.9)
<i>Having volunteers working in the service</i>	42 (93.3)	18 (19.8)	113 (100.0)
<i>Importance of voluntary donations for the functioning of the service</i>			
We can function well without these donations	11 (24.4)	83 (91.2)	2 (1.8)
Some parts of what we do as a service would not be possible without these donations	25 (55.6)	5 (5.5)	8 (7.0)
Substantial parts of what we do as a service would not be possible without these donations	8 (17.8)	1 (1.1)	34 (29.8)
Without these donations we could not function at all	1 (2.2)	2 (2.2)	70 (61.4)

\*Belgian, Swedish, and UK respondents who filled out the questionnaire through question 8 were included in the analysis. Other incomplete returned questionnaires were considered as non response

† Numbers do not add up to total because some services offered more than one type of service. In Belgium the category home care include the palliative care networks.

Percentages are column percentages. Missing values characteristics SPCS: Population served: n=6 (2.3%); Type of service: none, Disciplines connected to the service: none; Full-time equivalent employed care providers: n=10 (3.9%); Having volunteers working in the service: n=8 (3.1%); Importance of voluntary donations for the functioning of the service: n= 7 (2.7%).

1 Table 2: Community engagement activities by specialized palliative care services in Belgium, Sweden  
2 and UK, 2019

	BE (n= 45)			SE (n= 91)			UK (n= 121)			
	To date	No, but in future	No future plans	To date	No, but in future	No future plans	To date	No, but in future	No future plans	
<b>Community engagement activities</b>	%	%	%	%	%	%	%	%	%	p-value*
<b><i>Activities for raising awareness about your service to the general public</i></b>										
Using mainstream printed media	55.6	2.2	42.2	46.2	3.3	50.5	96.5	1.7	1.7	<0.001
Using social media	53.3	6.7	40.0	39.6	3.3	57.1	100.0	0.0	0.0	<0.001
Disseminating printed information	77.8	2.2	20.0	48.4	2.2	49.5	95.7	2.6	1.7	<0.001
Inviting the general public to meet the service	37.8	2.2	60.0	30.8	6.6	62.6	95.7	1.7	2.6	<0.001
Giving talks and lectures	75.6	4.4	20.0	53.8	8.8	37.4	95.7	0.9	3.5	<0.001
<b><i>Activities to educate and raise awareness among the general public about end-of-life care and bereavement issues</i></b>										
Using mainstream printed media	33.3	2.2	64.4	33.7	1.1	65.2	83.6	6.4	10.0	<0.001
Using social media	31.1	4.4	64.4	24.7	5.6	69.7	88.2	6.4	5.5	<0.001
Disseminating printed information	71.1	2.2	26.7	38.2	2.2	59.6	90.0	3.6	6.4	<0.001
Events organized by your service alone	48.9	0.0	51.1	19.1	6.7	74.2	82.7	10.0	7.3	<0.001
Events organized by your service together with other civil society organizations	71.1	0.0	28.9	31.5	5.6	62.9	80.0	12.7	7.3	<0.001
<b><i>Whether the service has been or plans to be engaged with one or more of the following organizations to develop skills and knowledge in the general public</i></b>										
Schools (preschools to secondary school)	68.9	0.0	31.1	25.6	4.7	69.8	79.4	9.3	11.2	<0.001
Colleges or universities	68.9	2.2	28.9	52.3	10.5	37.2	76.6	4.7	18.7	0.003
Businesses	24.4	0.0	75.6	8.1	1.2	90.7	79.4	4.7	15.9	<0.001
Community education programs (adult education)	68.9	0.0	31.1	33.7	4.7	61.6	38.3	8.4	53.3	0.001
Media organizations	33.3	0.0	66.7	15.1	4.7	80.2	72.0	5.6	22.4	<0.001
Religious groups	33.3	0.0	66.7	16.3	3.5	80.2	68.2	4.7	27.1	<0.001
Philosophy groups	28.9	6.7	64.4	3.5	1.2	95.3	29.9	10.3	59.8	<0.001
Patient or informal carer organizations	60.0	0.0	40.0	36.0	16.3	47.4	75.7	10.3	14.0	<0.001
Local regional or national governments	46.7	0.0	53.3	53.5	9.3	37.2	64.5	3.7	31.8	0.069
Other public interest groups or non-profit organizations	68.9	0.0	31.1	22.1	7.0	70.9	83.2	2.8	14.0	<0.001
<b><i>If the service ever built or helped to build informal end-of-life support or care networks, and/or plan to do so</i></b>	18.2	11.4	70.5	21.4	9.5	69.0	76.9	6.7	16.3	<0.001



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\*Kruskal Wallis test

Percentages are column percentages (% within country).

Missing values for the different community engagement activities are ranging from 2.3% to 9.7%

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1  
2  
3  
4

Table 3: Types of community engagement by characteristics of specialized palliative care services in Belgium, Sweden and UK, 2019

	Clusters of services in terms of their community engagement			
	Expanding services	Selective engagement services	Clinically-oriented services	
	N (%)*	N (%)*	N (%)*	p-value†
Total	88 (38.4)	62 (27.1)	79 (34.5)	
<b>Country</b>				<b>&lt;0.001</b>
Belgium	7 (15.9)	17 (38.6)	20 (45.5)	
Sweden	6 (7.2)	19 (22.9)	58 (69.9)	
UK	75 (73.5)	26 (25.5)	1 (1.0)	
<b>Population served</b>				0.439
Mainly rural	11 (37.9)	10 (34.5)	8 (27.6)	
Mainly urban	24 (45.3)	15 (28.3)	14 (26.4)	
Mixed	52 (35.9)	37 (25.5)	56 (38.6)	
<b>Type of service</b>				
Inpatient beds	69 (44.5)	38 (24.5)	48 (31)	<b>0.023</b>
Home care	69 (46.9)	41 (27.9)	37 (25.2)	<b>&lt;0.001</b>
Day hospice	62 (65.3)	26 (27.4)	7 (7.4)	<b>&lt;0.001</b>
Consultancy (only for SE)	2 (3.8)	10 (18.9)	41 (77.4)	0.099
Outpatient care (only for UK)	53 (79.1)	14 (20.9)	0 (.00)	0.113
<b>Disciplines connected to the service (yes vs no)</b>				
Physicians	81 (37.9)	55 (25.7)	78 (36.4)	<b>0.046</b>
Registered nurses	87 (38.5)	61 (27)	78 (34.5)	0.968
Other nurses	76 (50)	37 (24.3)	39 (25.7)	<b>&lt;0.001</b>
Psychologists	74 (58.3)	34 (26.8)	19 (15.0)	<b>&lt;0.001</b>
Social workers	67 (38.5)	40 (23)	67 (38.5)	<b>0.020</b>
Occupational therapists	69 (45.1)	38 (24.8)	46 (30.1)	<b>0.012</b>
Physiotherapists	71 (40.3)	42 (23.9)	63 (35.8)	0.136
Spiritual workers	72 (50.7)	28 (19.7)	42 (29.6)	<b>&lt;0.001</b>
Dietician	27 (28.1)	22 (22.9)	47 (49.0)	<b>&lt;0.001</b>
<b>FTE employed care providers</b>				<b>&lt;0.001</b>
<3	1 (14.3)	2 (28.6)	4 (57.1)	
3-10	5 (13.5)	20 (54.1)	12 (32.4)	
11-20	5 (12.8)	7 (17.9)	27 (69.2)	
21-30	3 (14.3)	4 (19)	14 (66.7)	
31-40	5 (31.3)	2 (12.5)	9 (56.3)	
41-50	7 (46.7)	5 (33.3)	3 (20)	
51-100	29 (78.4)	6 (16.2)	2 (5.4)	
101-200	22 (51.2)	13 (30.2)	8 (18.6)	
>200	8 (72.7)	3 (27.3)	0 (0)	
<b>Depending on charity</b>				<b>&lt;0.001</b>
We can function well without these donations	6 (6.7)	19 (21.3)	64 (71.9)	
Some parts of what we do would not be possible without these donations	7 (20.0)	14 (40.0)	14 (40.0)	
Substantial parts of what we do would not be possible without these donations	23 (63.9)	12 (33.3)	1 (2.8)	
Without donations we could not function at all	52 (75.4)	17 (24.6)	0 (0.0)	
<b>Volunteers</b>				<b>&lt;0.001</b>
Yes	83 (52.5)	46 (29.1)	29 (18.4)	

\*Percentages are row percentages

†Chi² Test

Table 4: Attitudes towards community engagement held by representatives (e.g. coordinators, directors, chairs) of specialized palliative care services in Belgium, Sweden and UK, 2019

	BE (n=45)	SE (n=79)	UK (n=105)	
	Agree/completely agree			
Attitude items*	N (%)	N (%)	N (%)	p-value†
a) For the most part, the general public is sufficiently informed about our service	10 (22.2)	30 (38.0)	21 (20.0)	<b>0.018</b>
b) For the most part, the general public has sufficient knowledge about end-of-life care	3 (6.7)	14 (17.9)	3 (2.9)	<b>0.002</b>
c) For the most part, the general public has sufficient knowledge about bereavement care	5 (11.1)	11 (14.3)	7 (6.7)	0.236
d) As a service, part of our responsibility is to promote the general public to take care of themselves and each other when faced with a life-threatening illness in the future	33 (73.3)	46 (59.7)	88 (83.8)	<b>0.001</b>
e) Our service does not have the time or resources to engage in activities aimed at the general public	19 (42.2)	46 (59.0)	14 (13.3)	<b>&lt;0.001</b>
f) Our service should focus on providing care; working with the general public is not our job	10 (22.2)	37 (47.4)	4 (3.8)	<b>&lt;0.001</b>
g) People's own social networks are at least as important providers of end-of-life care as professionals	32 (71.1)	68 (86.1)	83 (79.0)	0.129
h) People's own social networks are at least as important providers of bereavement care as professionals	34 (75.6)	76 (96.2)	88 (83.8)	<b>0.003</b>
*Percentages are column percentages				
†Kruskall wallace test				
Missing values: item a): n=28 (10.9%); item b) n=30 (11.7%); item c) n=30 (11.7%); item d): n=30 (11.7%); item e): n=29 (11.3%); item f) n=29 (11.3%); item g) n=28 (10.9%); item h): n=28 (10.9%)				

Table 5: Associations between attitudes towards community engagement and specialized palliative care service characteristics in Belgium, Sweden and the UK, 2019

Items	Component 1: Extent to which the public is informed		Component 2: Mandate to engage with communities		Component 3: Importance of informal networks	
Parameter	Coefficient b (95%CI)	p-value	Coefficient b (95%CI)	p-value	Coefficient b (95%CI)	p-value
<b>Intercept</b>	-0.18 (-0.41 to 0.06)	0.15	-0.46 (-0.80 to -0.13)	0.007	-0.04 (-0.22 to 0.15)	0.68
<b>Country</b>						
Belgium			-0.16 (-0.47 to 0.16)	0.33	-0.24 (-0.58 to 0.09)	0.16
Sweden			-0.59 (-0.91 to -0.27)	<b>&lt;.001</b>	0.32 (0.03 to 0.60)	<b>0.03</b>
UK (ref)			ref		ref	
<b>Dependence on donations</b>						
We can function well without	0.39 (0.07 to 0.71)	<b>0.02</b>				
Parts would not be possible	0.09 (-0.24 to 0.42)	0.59				
Without we cannot function (ref)	ref					
<b>Cluster assignment</b>						
Expanding services			1.12 (0.77 to 1.46)	<b>&lt;.001</b>		
Selective services			0.65 (0.36 to 0.93)	<b>&lt;.001</b>		
Clinically-oriented services (ref)			ref			
<b>Population served</b>						
Mainly rural			0.34 (0.04 to 0.63)	<b>0.03</b>		
Mainly urban			0.06 (-0.18 to 0.29)	0.64		
Mixed (ref)			ref			
<b>Disciplines connected</b>						
Registered nurses (No vs Yes)					-1.63 (-2.74 to -0.52)	<b>0.004</b>

Coefficient b values are standardized mean differences