WHAT DOES THE GENERAL PUBLIC KNOW ABOUT PALLIATIVE CARE? A POPULATION-BASED SURVEY

Marjolein Matthys[1,2*], Kenneth Chambaere[1,2,6], Kim Beernaert[1,2], Joachim Cohen[1,3,6], Leen Van Brussel[4], Benedicte Deforche[2,5], Bert Quintiens[1,3,6], Luc Deliens[1,2,3,6], Naomi Dhollander[1,3]

[1]End-of-Life Care Research Group, Vrije Universiteit Brussel & Ghent University, [2]Department of Public Health and Primary Care, Ghent University, [3]Department of Medicine & Chronic Care, Vrije Universiteit Brussel, [4]Flanders Institute for Healthy Living, [5]Movement and Nutrition for Health and Performance Research Group, Department of Movement and Sport Sciences, Faculty of Physical Education and Physical Therapy, Vrije Universiteit Brussel, [6]Compassionate Community Centre of Expertise (COCO), Vrije Universiteit Brussel, Brussels, Belgium

*Correspondence should be addressed to:

Marjolein Matthys
Corneel Heymanslaan 10 - 6K3
9000 Ghent, Belgium.
E-mail address: marjolein.matthys@ugent.be
Telephone number: 0032/473265816

ABSTRACT

Objectives: The need for public education on palliative care has been widely argued for. To develop effective educational strategies, a stronger evidence base is needed on what exactly is known and unknown about palliative care as well as what the differences are between subgroups.

Methods: We conducted a cross-sectional population-based survey. Mail questionnaires were sent to a random sample of 4400 citizens (aged ≥16 years) within 4 municipalities in Flanders, Belgium. The Palliative Care Knowledge Scale (PaCKS) was used to measure knowledge. Associations between knowledge and socio-demographics and various experiential factors were tested, as well as the congruence between actual and self-perceived knowledge scores.

Results: Response was obtained from 2008 (45.6%) citizens. The mean PaCKS score was 7.87 (SD 3.41; range 0-13) with the highest proportion (84.7%) correctly answering that palliative care is not specifically for older adults and the lowest (32.1%) correctly answering that improving the ability to participate in daily life is a palliative care goal. Being aged between 30-59, non-religious, more highly educated, having professional healthcare experience and knowing palliative care through personal experience were significantly associated with higher knowledge, while sex and informal caregiving experience were not. 52.4% self-perceived their knowledge as lower than it actually was.

Conclusions: While the general public seems to be familiar with some basic concepts of palliative care, several key aspects remain unknown. Educational strategies, with suggested potential for community- and experience-based approaches, may need to focus specifically on these aspects and not just on the broader palliative care concept.

Source of funding: This study is supported by a grant from the Research Foundation – Flanders, file number S002219N.

Key words: palliative care, health literacy, information sources, cross-sectional studies, surveys and questionnaires, health promotion

KEY STATEMENTS

i) WHAT IS ALREADY KNOWN ON THIS TOPIC

- Public knowledge on palliative care has been shown to be generally low and this counts as an important barrier to the access and use of palliative care as well as its broader development on a local and global scale.

ii) WHAT THIS STUDY ADDS

- While the general public widely recognizes that palliative care isn't just for older adults or cancer patients, the majority of the population is unaware of several of its key roles, such as enhancing day-to-day activities and managing serious illness-induced stress.

- Knowledge levels differ depending on age, religious beliefs, educational levels, having professional healthcare experience and knowing palliative care through personal experience, while having informal caregiving experience does not affect knowledge.

iii) HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- Rather than focusing on the general concept of palliative care, educational strategies would do better to focus primarily on specific unknown or misunderstood aspects of palliative care, in particular those aspects that actively challenge stigmatized views on palliative care.

- The importance of experience within the personal social context highlights the potential impact of community-based educational initiatives, centered around peer advisors and experience-based knowledge exchange.

INTRODUCTION

Previous studies have often demonstrated low levels of public awareness and knowledge, persistent misperceptions and negative beliefs about palliative care[1–6]. Overall, these observations can be identified as serious obstacles to a timely and equitable use of palliative care[1], potentially leading to unnecessary suffering, inappropriate treatments, suboptimal levels of wellbeing and quality of life and other negative end-of-life outcomes such as dying in non-preferred locations[7]. This lack of public awareness and recognition of palliative care has also been recognized as an important barrier to the further development of palliative care across the Western European region[8] and on a global scale[9]. As argued by Alcalde and Zimmerman, societal awareness is a necessary condition to build enough political pressure to create better palliative care policies and structures[10]. Additionally, public awareness and knowledge on palliative care are needed to stimulate the development and uptake of new public health initiatives in palliative care, aiming to involve the wider community in the care and support for people confronted with serious illness, dying or loss[11]. Educational initiatives can help in this regard[12,13] but for those to be effective, it is important to have an assessment within the local context they are targeting, of what precisely is unknown or misunderstood and what the differences in knowledge are between subgroups. While the international literature on public perceptions of palliative care is slowly emerging, there remains an ongoing need for more research since public perceptions of palliative care are - just like the field itself - constantly evolving and because gaining a broader view on similarities and differences across regions and timespans can help to inform global efforts to improve the access, delivery and uptake of palliative care. Moreover, there is a need for more clarity and a stronger evidence base towards factors associated with palliative care knowledge, since the existing research on this is rather limited and inconclusive[14]. This study therefore set out to investigate the knowledge about palliative care and differences between subgroups among the general public in two urban and two semi-urban cities in Flanders, Belgium. The research question guiding this research is: '*How well does the general public know palliative care and its different aspects?'*. Secondary research questions are:

> 1: Which personal characteristics and experiences are associated with better palliative care knowledge?

2: How congruent is the actual knowledge score of citizens with their self-estimated knowledge of palliative care?

3: Through what information sources did persons with low levels of palliative care knowledge learn about palliative care and do these sources differ from the sources reported by people with average to high levels of palliative care knowledge?

METHODS

Design

We applied a cross-sectional population-based survey study-design in two urban and two semi-urban cities in Flanders, Belgium.

Population, sampling and data collection procedures

The target population was all citizens aged 16 and older. A random sample was drawn from the population registry by a city official in all four cities. In three of the four cities a simple random sampling procedure was drawn, in one a disproportionally stratified random sample (with an oversampling of registered informal caregivers in the only city which kept such a register; see published protocol for more details[15]). To strive for optimal response rates the Total Design Method[16] was applied and a total of 4400 individuals (1100 in each city; corresponding to an anticipated response rate of 35%, determined by applying a conservative approach[17]) were invited by mail to partake in the survey-study during January – June 2021. Questionnaires were accompanied by a pre-paid return envelope and an information letter indicating among others the goal of the study, reasons to participate and its voluntary and anonymous nature. Individuals were sent a maximum of three reminders at set time intervals in case of continuing non-response. We also provided the opportunity for respondents to complete the questionnaire online.

Survey instrument

The survey questionnaire consisted of several validated scales as well as self-constructed questions measuring in total eight different concepts. We focused on 1) the Palliative Care Knowledge Scale (PaCKS), a validated scale to measure the knowledge and knowledge gaps of palliative care[18], 2) self-constructed questions regarding personal experience with serious advanced illness, the end of life and loss, sources through which information on palliative care was obtained and self-perceived knowledge of palliative care, and 3) socio-demographic information. The PaCKS consists of 13 different statements about palliative care with answer options "correct", "incorrect" and "don't know" and was translated using the forward-backward translation technique. The total score has a range of 0 (no knowledge) to 13 (perfect knowledge) and is calculated by the sum of correctly assessed items (incorrectly assessed items or “don't know” are given a score of 0).

Statistical analysis

For the descriptive analyses, data were weighted to correct for the disproportional stratification (in one city), for sampling error and for differential nonresponse by age. To deal with missing values in the calculation of the total PaCKS score, we chose to only include respondents who completed at least 11 of the 13 items (see Supplementary File - Table 1 and Figures 1 to 3 for sensitivity analysis). To study the relationship between self-perceived and actual knowledge of palliative care, a ‘congruence variable’ was created linking the seven possible values of self-estimation to the fourteen possible values of the total PaCKS score according to a symmetrical scheme (see Supplementary File - Table 2). For the multivariable analysis, missing data of all relevant variables were explored starting from the unweighted dataset. Incomplete data of the total PaCKS score and estimated predictors (sex, professional health care experience, informal caregiver experience, personal experience with palliative care, age, educational level and religion) were multiply imputed using the fully conditional specification method (number of imputations = 15, number of iterations = 20). Missing values for all (categorical) predictors for the multivariable model were imputed using logistic regression. As required, the imputation model was congenial with the analysis model. Potential predictors for the knowledge of palliative care were identified based on literature and, conform recommendations from the ‘table 2 fallacy’ literature[19], directed acyclic graphs were drawn to hypothesize causal relations (see Supplementary File - Figures 4 to 11) so that models would each time be adjusted for possible confounders of the predictor-outcome association, but not for variables identified as mediators. Since the data distribution of the dependent variable, the total PaCKS score, showed an excess of zero's, we applied a hurdle model to investigate associations. For each predictor of interest, the analysis involved two parts: the fitting of a binary logistic model for the zero values and the fitting of a linear regression model for the non-zero values. A sensitivity analysis was performed by running complete case analyses on the original observed data which operates under the stricter assumption of missing completely at random (see Supplementary File – Table 3). All analyses were carried out using SPSS, version 27 and the significance level was set at $p < 0.05$.

RESULTS

Of 4400 questionnaires sent, 2135 were returned. After removing unusable questionnaires 2008 remained, resulting in a response rate of 45.6% (2008/4400)[20]. Characteristics of respondents are found in Table 1.

Table 1. Characteristics of respondents (n=2008).

	Unweighted data		Weighted data[c]	
Sociodemographics[a]	n	%[b]	n	%
Age				
16-29	246	12.4%	306	15.4%
30-44	322	16.2%	362	18.3%
45-59	541	27.3%	536	27.0%
60-74	564	28.5%	505	25.5%
75 and older	309	15.6%	273	13.8%
Sex				
Male	958	48.2%	951	47.9%
Female	1027	51.7%	1034	52.1%
Other	1	0.1%	1	0.1%
Highest level of education				
Lower educational level	525	26.7%	506	25.8%
Medium educational level	655	33.4%	666	33.9%
Higher educational level	741	37.7%	748	38.1%
Other	43	2.2%	43	2.2%
Professional status				
Working	985	49.9%	1038	52.6%
Retired	745	37.7%	658	33.4%
Other (student, unemployed, unfit to work, other)	244	12.4%	277	14.0%
Religion				
Not religious	647	33.1%	675	34.6%
Catholicism	1161	59.4%	1128	57.8%
Islam	89	4.6%	92	4.7%
Other	56	2.9%	58	3.0%
Residence of respondents				

Brugge		561	27.9%	561	27.9%
Sint-Niklaas		515	25.6%	515	25.6%
Herzele		441	22.0%	441	22.0%
Gavere		491	24.5%	491	24.5%
Personal experiences with serious advanced illness, death, dying and loss					
Informal caregiver (currently or in the past)	Yes	739	36.8%	700	34.9%
	No	1269	63.2%	1308	65.1%
Having a chronic illness	Yes	234	11.7%	220	11.0%
	No	1774	88.3%	1787	89.0%
Currently mourning for someone	Yes	447	22.3%	441	22.0%
	No	1561	77.7%	1567	78.0%
Ever work(ed) in health care	Yes	271	13.5%	278	13.8%
	No	1737	86.5%	1730	86.2%
Ever talked with a dying person about his or her death	Yes	602	32.1%	600	31.9%
	No	1274	67.9%	1280	68.1%
Ever kept somebody company who was close to death	Yes	1120	59.6%	1107	58.8%
	No	759	40.4%	774	41.2%

[a]Missing data [unweighted]: n= 26 (1.3%) for age, n=22 (1.1%) for sex, n=44 (2.2%) for educational level, n=34 (1.7%) for professional status, n=55 (2.7%) for religious beliefs, n=132 (6.6%) for 'talked with a dying person about his or her death', n= 129 (6.4%) for 'kept somebody company who was close to death'. No missing values for residence of respondents, having a chronic illness, mourning for someone, work(ed) in health care, and, informal caregiver (currently or in the past).
[b]Valid percentages are given, i.e., not including missing values.
[c]weighing coefficients: 0.58, 0.70, 0.94, 0.98, 1.00, 1.36, 2.26, 2.42

Public knowledge of palliative care

The total PaCKS score was calculated for 1852 respondents (92.2% of total cases). A mean score of 7.87 and median of 8 was obtained (range 0 to 13). 24.1% answered correctly on at least eleven of the thirteen items and 19.8% gave the correct answer on less than six items. The data further showed a zero-inflated pattern with zero-scorers (6.6%) consisting mainly of respondents who filled in "I don't know" (6.1%) on all items (see Figure 1).

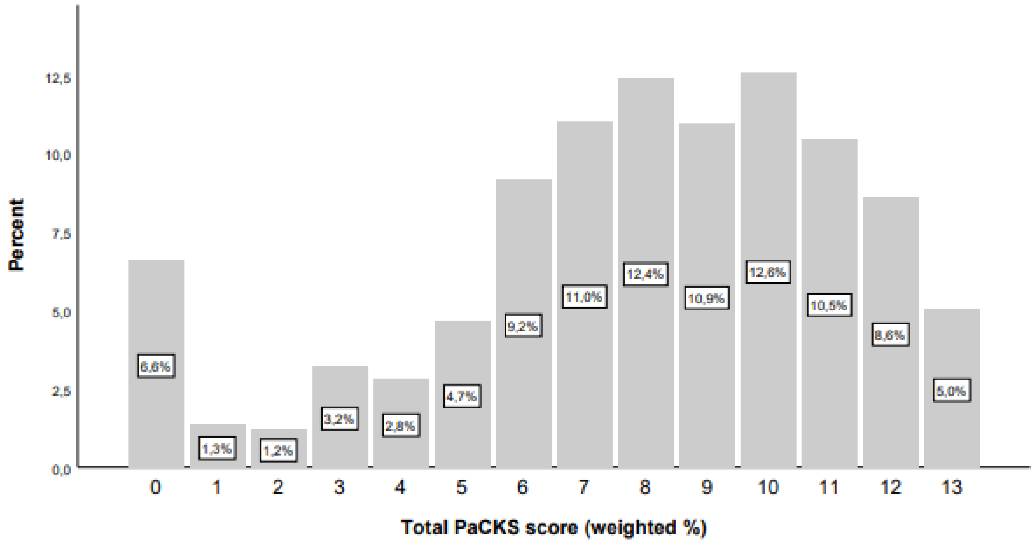

Figure 1 Division of total scores on Palliative Care Knowledge Scale.

Items with strikingly high as well as strikingly low total scores were observed (see Table 2). Less than half of respondents correctly knew that “stress from serious illness can be addressed by palliative care” (35.6%) and that “a goal of palliative care is to improve a person’s ability to participate in daily activities” (32.1%). Likewise, less than half of respondents correctly knew that the statement “palliative care is exclusively for people who are in the last 6 months of life” is incorrect (44.2%). However, the majority of respondents knew that the statements “palliative care is specifically for people with cancer” (82%), “people must be in the hospital to receive palliative care” (78.2%) and “palliative care is designed specifically for older adults” (84.7%) are wrong and that “palliative care helps the whole family cope with a serious illness” (76.1%) is correct. On all but one PaCKS item (item five) the % of people responding ‘I don’t know” exceeded the % of persons giving the incorrect answer.

Table 2: Knowledge on different aspects of palliative care [weighted data]

Palliative Care Knowledge Scale (PaCKS)				
	True n (%)	False n (%)	“Don’t know” n (%)	Missings n (%)
1. A goal of palliative care is to address any psychological issues brought up by serious illness.	**969 (51.7%)**	367 (19.6%)	538 (28.7%)	133 (6.6%)

2. Stress from serious illness can be addressed by palliative care.	**667 (35.6%)**	554 (29.6%)	652 (34.8%)	135 (6.7%)
3. Palliative care can help people manage the side effects of their medical treatments.	**916 (49.3%)**	432 (23.3%)	509 (27.4%)	151 (7.5%)
4. When people receive palliative care, they must give up their other doctors.	87 (4.6%)	**1357 (72.1%)**	438 (23.3%)	126 (6.3%)
5. Palliative care is exclusively for people who are in the last 6 months of life.	535 (28.7%)	**824 (44.2%)**	507 (27.2%)	141 (7%)
6. Palliative care is specifically for people with cancer.	96 (5.1%)	**1545 (82.0%)**	244 (12.9%)	123 (6.1%)
7. People must be in the hospital to receive palliative care.	108 (5.7%)	**1480 (78.2%)**	305 (16.1%)	115 (5.7%)
8. Palliative care is designed specifically for older adults.	58 (3.1%)	**1594 (84.7%)**	231 (12.3%)	124 (6.2%)
9. Palliative care is a team-based approach to care.	**1274 (68.8%)**	109 (5.9%)	468 (25.3%)	156 (7.8%)
10. A goal of palliative care is to help people better understand their treatment options.	**999 (53.9%)**	293 (15.8%)	561 (30.3%)	155 (7.7%)
11. Palliative care encourages people to stop treatments aimed at curing their illness.	170 (9.1%)	**1251 (66.7%)**	455 (24.3%)	132 (6.6%)
12. A goal of palliative care is to improve a person's ability to participate in daily activities.	**594 (32.1%)**	526 (28.4%)	733 (39.6%)	155 (7.7%)
13. Palliative care helps the whole family cope with a serious illness.	**1442 (76.1%)**	89 (4.7%)	364 (19.2%)	113 (5.6%)
Bold numbers represent the correct answers.				

Congruence with self-perceived knowledge

36.9% rated their knowledge as very low to rather low (score of less than 4 on a scale from 1 "I don't know anything about it" to 7 "I know a lot about it"), 21.4% situated their knowledge at the midpoint of four and 41.6% rated their knowledge as rather high to very high (score of more than 4). Comparison of self-estimation and actual knowledge scores showed that 52.4% of respondents underestimated their knowledge compared to 22.7% who overestimated their knowledge (see Figure 2). One quarter (25%) estimated their knowledge accurately.

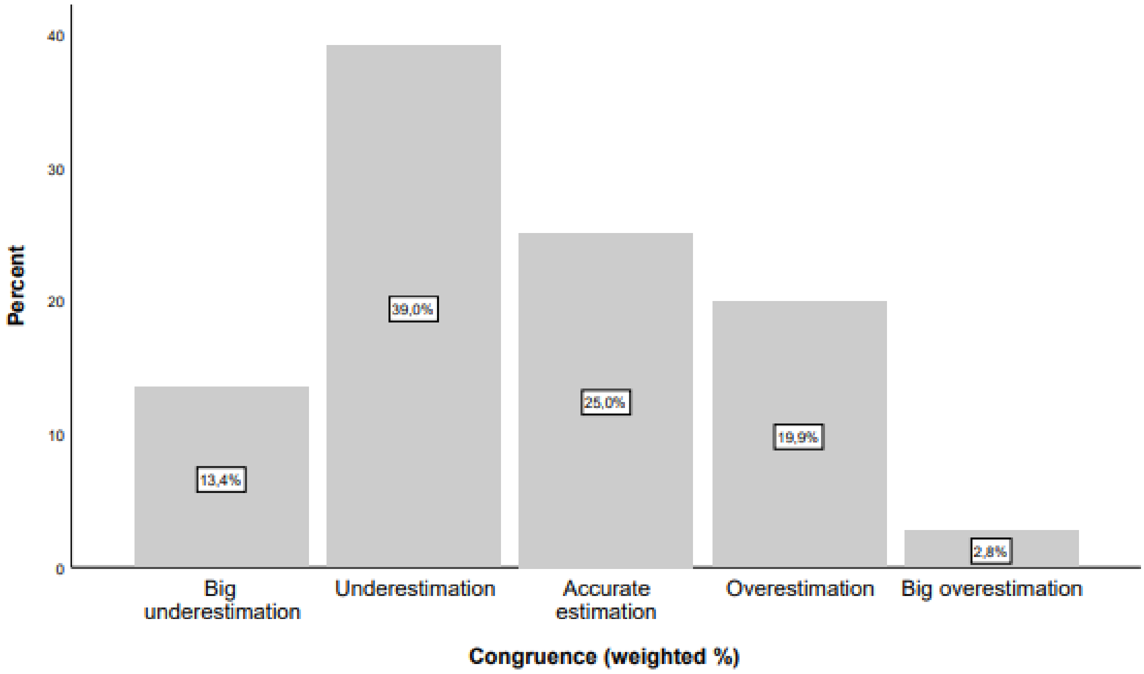

Figure 2 Congruence between self-perceived knowledge and actual knowledge on palliative care.

Associated factors

Our analysis (see Table 3 for condensed results and Supplementary File - Table 4 for full results) showed that those with lower educational attainment and of younger age (16-29) were less likely to have a knowledge score above 0 and (of those who did score higher than 0) had significantly lower mean PaCKS scores than their counterparts with higher educational attainment and older age (see specific age ranges in table). Non-religious people were significantly more likely to score better than zero compared with those indicating their beliefs as Islamic or ‘other’ and had higher average above-zero knowledge scores than those subscribing to Catholicism or Islam. Having professional experience in health care and knowing palliative care through personal experience were also associated with better knowledge (i.e. nonzero scores and higher average scores). For sex we only found a significantly higher chance of men to score zero but the average scores above zero did not significantly differ between men and women. No significant associations were found with having informal caregiving experience. Our sensitivity (complete case) analysis confirmed all significant associations and achieved similar estimates (see Supplementary File - Table 3).

Table 3: Associated factors with knowledge of palliative care

	PART 1: binary logistic models for zero values		PART 2: linear regression models for non-zero values	
	OR(95% CI)	Sign.	B (95% CI)	Sign.
Model 1 (no confounders)				
Sex*			Sex	
Female	Reference			
Male	0.59 (0.37 – 0.95)	p=0.032	-0.17(-0.44 – 0.11)	p=0.232
Model 2 (no confounders)				
Age*			Age*	
16-29	Reference			
30-44	1.21 (0.66 – 2.22)	p=0.542	0.56 (0.06 – 1.05)	p=0.028
45-59	2.08 (1.14 – 3.78)	p=0.017	0.73 (0.26 – 1.19)	p=0.002
60-74	2.45 (1.11 – 5.37)	p=0.027	0.34 (-0.14 – 0.82)	p=0.166
75+	1.06 (0.56 – 1.99)	p=0.864	0.07 (-0.50 – 0.63)	p=0.815
Model 3 (confounders: sex and age)				
Educational level*			Educational level*	
Low	Reference			
Medium	3.37 (1.99 – 5.71)	p<0.001	0.85 (0.47 – 1,23)	p<0.001
High	10.18 (5.38 – 19.26)	p<0.001	1.69 (1.31 – 2.07)	p<0.001
Other	0.71 (0.30 – 1.70)	p=0.442	0.06 (-0.94 – 1.07)	p=0.900
Model 4 (confounders: sex, age and educational level)				
Religion*			Religion*	
Not religious	Reference			
Catholicism	0.72 (0.42 – 1.22)	p=0.221	-0.36 (-0.65 – -0.08)	p=0.013
Islam	0.10 (0.05 – 0.19)	p<0.001	-2.24 (-3.05 – -1.42)	p<0.001
Other	0.36 (0.13 – 0.97)	p=0.043	-0.46 (-1.24 – 0.33)	p=0.252
Model 5 (confounders: sex, age and educational level)				
Professional experience in health care*			Professional experience in health care*	
No	Reference			
Yes	5.83 (1.35 – 25.19)	p=0.018	1.08 (0.71 – 1.46)	p<0.001
Model 6 (confounders: sex, age and professional experience in health care)				
Informal caregiving experience			Informal caregiving experience	
No	Reference			
Yes	1.35 (0.82 – 2.20)	p=0.233	0.13 (-0.18 – 0.44)	p=0.426
Model 7 (confounders: sex, age, professional experience in health care and informal caregiving experience)				
Knowing palliative care through personal experience*			Knowing palliative care through personal experience*	
No	Reference			
Yes	9.15 (4.00 – 20.95)	p<0.001	0.66 (0.38 – 0.95)	p<0.001

**significant with p<0.05 in all 15 imputed datasets*

Information sources

Informal sources, personal experience and traditional media were the most important sources through which people with low levels of knowledge of palliative care (operationalized as scoring less than the mean PaCKS score) reported having heard of palliative care (see Table 4). Looking only at people with average to high knowledge levels (scoring higher than the mean PaCKS score), the same three information sources were most frequently reported although the relative order differed (personal experience > informal source and traditional media) and the importance of 'formal sources' was relatively higher in this group.

Table 4: Information sources through which people have heard of palliative care [weighted data]

	People with low levels of palliative care knowledge *(n=726)*		People with average to high levels of palliative care knowledge *(n=1110)*	
	n	%	n	%
Informal source[a]	313	**43.2%**	487	**43.9%**
Formal source[b]	66	9.1%	265	23.8%
Traditional media[c]	237	**32.6%**	479	**43.2%**
New media[d]	90	12.4%	183	16.5%
Personal experience[e]	260	**35.8%**	594	**53.5%**
Other source[f]	12	1.7%	43	3.9%
'Never heard from it'	88	12.1%	11	1%
'I don't remember'	49	6.7%	31	2.8%

[a] *through an acquaintance, friend or family member who talked about palliative care and/or works in the field*

[b] *through schooling and/or work as a professional or volunteer*

[c] *newspapers, magazines, television or radio*

[d] *the internet or social media*

[e] *person received, or, a friend, family member or acquaintance receives or received palliative care*

[f] *includes among others: health promotion & health literature, through health care providers/-settings,…*

DISCUSSION

Main findings

Our cross-sectional population-based survey showed that palliative care is generally well known among a substantial portion of the general public but remains an unknown or misunderstood concept for many others. Within a range from 0 (minimum knowledge) to 13 (maximum knowledge), a mean total PaCKS score of 7.87 was found. Some specific aspects of palliative care were very well known such as the facts that palliative care is not only for older adults nor just persons with cancer, yet clear gaps in knowledge were also found with the largest one being that palliative care aims to improve a person's ability to participate in daily activities. Being aged between 30 and 59, non-religious, more highly educated, having professional experience in health care and knowing palliative care through personal experience were significantly associated with higher mean knowledge scores.

Strengths and limitations

One of the strengths of this study lies in the random sampling and the statistical generalizability for the city populations. However, the selection of the four cities might not be enough to argue for theoretical generalizability to the whole of Flanders. Another strength comes from the use of the validated PaCKS scale, facilitating comparisons with other studies and contexts. It can still be argued though that the PaCKS scale's items are too limited and do not capture the broader meaning of palliative care as a vital public health and human rights issue, going beyond being a pure health service.

What this study adds

While the 2015 Quality of Death Index ranked Belgium as the highest scoring country on public awareness and understanding of palliative care services[21], our results paint a more nuanced picture and show - at the very least - that there is much room for improvement. Our obtained mean PaCKS score (7.87) was lower than the mean found in studies among young adults (aged 18-29) in the UK[11] (8.87) and adults in Northern Ireland[2] (8.31) but higher in comparison to three studies done among various samples in the USA (mean scores ranging between 4.38 and 5.25)[22–24]. The differences between these scores may be seen as partly reflecting the diversity in structural conditions and broader socio-cultural settings in which the knowledge on palliative care is embedded (although these differences have to be interpreted cautiously in light of the differences in sample characteristics and potential divergencies in the use of the PaCKS scale between studies). Importantly though, while palliative care is historically anchored the longest in the UK and this might partly explain the higher mean scores, the studies there still report widespread misunderstandings on palliative care, leading to similar conclusions as the studies with much lower mean scores in the USA. Considering the gaps in knowledge found in our sample, many of those seem to reflect a belief that palliative care is synonymous with terminal care or care at the very end of life. Across studies, this persistent view has been reported, often directly linked to the stigma surrounding palliative care[25,26]. Given the prevailing practice of late referrals[27] and the fact that most palliative care services still focus their interventions strongly at the end of life, it is not surprising that a substantial portion of the population sees palliative care as purely terminal care. Understood within this context it also deserves a more nuanced interpretation than merely being a 'misconception' or 'negative belief' as is often done in the literature. However, contrasting to what is often presented as myths or persistent misconceptions of palliative care[28,29] but resonating with findings of two other relatively recent studies[11,30], high proportions of our respondents were familiar with the facts that palliative care is not only for persons who have cancer nor only for older adults, is not given exclusively in hospital settings and has a focus on the whole family. Although minimal improvements over time in public awareness and knowledge of palliative care have been reported[4], other studies have argued differently[11,31]. The results of our study also seem to suggest that the historical developments of palliative care have at least partly seeped through into the public knowledge about palliative care.

With the exception of sex, most of the knowledge associated factors that are frequently brought forward (education, gender/sex, age, personal experience and professional health care experience[4]) were confirmed as relevant to palliative care knowledge in our study. The fact that no significant difference was found between people with or without informal caregiving experience might be explained by the broad range of possible chronic conditions that require or benefit from informal caregiving support, also outside the broad scope of palliative care. Additionally, being religious proved to be a factor related to poorer palliative care knowledge and this differs from earlier studies finding no associations among young adults in the UK[11] or among Asian populations in the USA[23]. Lower knowledge scores among Muslims and Catholics might be influenced by a variety of factors such as individual religious beliefs and practices and access to information and services, but further research (preferably in-depth qualitative research) is needed to fully understand the relation between palliative care knowledge and religion.

Our findings furthermore show the importance of experience within the personal social context on obtaining knowledge of palliative care. This finding emerges consistently across various studies and points to the potential value of community-based educational approaches[32], centered around peer advisors and experience-based knowledge exchange. Efforts to stimulate talking about death, dying and loss, the sharing of personal narratives surrounding these topics, can serve as a vehicle to spread more awareness on the different care options at the end of life. Our results are also in line with previous research showing the unfulfilled potential to promote palliative care through new media such as websites and YouTube channels[33–35] and urges further investigation of the quality of information offered through traditional media channels (which has been shown to be limited in scope and potentially contributing to negative or inaccurate perceptions[36,37]).

In terms of implications for practice and policy, our findings indicate a clear need for educational efforts to improve the public knowledge on palliative care. Previous research has shown that educational initiatives on palliative care are effective in improving knowledge and attitudes towards palliative care[12,24,38]. Importantly though, since many people seem to be already familiar with some of the basic concepts, these educational efforts may need to focus primarily on specific unknown or misunderstood aspects of palliative care rather than (only) on the broad concept of palliative care and its contributions. The implications of the specific understanding of palliative care as terminal care for instance go beyond the conceptualizations of the field itself but also translate into the image it (re)produces of the person with palliative care needs, for example as someone who is “losing the battle”[39] or in a passive, dependent position[33]. Efforts to promote (early) palliative care should therefore pay proper attention to underscore palliative care as care directed at persons who can still have other active treatments and who can still have active roles in life, a life that can last for years. This way not only more knowledge on palliative care can be aimed for but also a reduction in the stigma surrounding it[3]. Public education initiatives are however only part of the puzzle; they will also need to be accompanied by shifts in policy and actual practices that currently perpetuate misconceptions such as late referrals and financial support systems restricted to limited life expectancy.

Building on the findings from this research and addressing a scarcity of in-depth qualitative research regarding public perceptions of palliative care, our next steps include a reflexive thematic analysis of personal narratives surrounding experiences with serious illness, the end of life and palliative care. This analysis aims to achieve a more profound and contextualized understanding of attitudes towards palliative care. Furthermore, to enhance the effectiveness of forthcoming public campaigns on palliative care, a focus group study will be undertaken to investigate how past (both national and international) educational initiatives on palliative care are received and evaluated by diverse members of the public.

CONCLUSION

Improving public knowledge on palliative care is a crucial part of improving a timely and equitable access to palliative care and stimulating political and community engagement with palliative care. The results of this study highlight this need and show that even though the general public seems to have a relatively good understanding of some of the basic concepts of palliative care, several of its key aspects remain unknown or misunderstood. As long as the general public remains unaware that palliative care is not limited to the last six months of life or that it aims to improve one’s ability to participate in daily activities despite serious illness, a stigmatized perception of palliative care as terminal care can persist, thus obstructing timely initiation of palliative care to fully benefit patients and their families.

Strategies to improve the public knowledge on palliative care will need to be locally grounded, collaborative and adaptable to fully serve the diversity within our societies. This means that to reach all who could benefit from palliative care, now or in the future, educational strategies directed to the general public need to be tailored to the needs and resources of different social groups to ensure existing inequalities in access and use of palliative care are not unintentionally exaggerated. This necessitates actively listening to and involving people from diverse backgrounds in the development of these initiatives. Additionally, global discourses on palliative care, for instance considering compassionate communities, should be effectively translated into the local context. One way to do this is through the existence of durable local partnerships between palliative care practitioners, policy makers, researchers and citizens. By implementing these strategies, we can reduce gaps in knowledge, battle stigmatization, and enhance public receptivity towards palliative care, ultimately leading to improved care and quality of life for individuals facing serious illnesses.

Acknowledgements

The authors would like to thank Dr. Stefanie De Buyser from the Biostatistics Unit at Ghent University for her insights and advice on the multivariable analysis. We further would like to acknowledge that part of this work has been previously presented at the 7th Public Health Palliative Care International Conference “Democratizing caring, dying and grieving: participation, action, understanding and evaluation” and was published as a conference abstract[40].

Competing interests

None declared.

Ethics approval

This study was approved by the Medical Ethics Committee of the University Hospital Brussels with reference B1432020000186 on 16 September 2020. The study was conducted in an ethical manner, adhering to principles of informed consent and confidentiality. Each questionnaire was accompanied by an information letter indicating among others the goal of the study, potential reasons to participate and the voluntary and anonymous nature of it. People’s response to the questionnaire was regarded as informed consent.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study is supported by a grant from the Research Foundation—Flanders (file number S002219N) and part of the project “CAPACITY: Flanders Project to Develop Capacity in Palliative Care Across Society”, a collaboration between the Vrije Universiteit Brussel, Ghent University, and the Catholic University Leuven, Belgium.

Data management and sharing

The data supporting the findings of this study are securely stored on an encrypted server at the Vrije Universiteit Brussel and are available from the corresponding author, M.M., upon reasonable request.

Authors' contribution

B.Q., J.C., K.C, N.D. and M.M. conceived and designed the study. B.Q. and M.M. collected the data. N.D. and M.M. performed the analysis. All authors contributed to the interpretation of the results. M.M. wrote the original draft of the manuscript and all authors critically revised it and approved the final version.

REFERENCES

1. Adjei Boakye E, Mohammed KA, Osazuwa-Peters N, et al. Palliative care knowledge, information sources, and beliefs: Results of a national survey of adults in the USA. *Palliat Support Care* 2019; 18: 285–292.
2. McIlfatrick S, Slater P, Beck E, et al. Examining public knowledge, attitudes and perceptions towards palliative care: a mixed method sequential study. *BMC Palliat Care* 2021; 20: 1–11.
3. Taber JM, Ellis EM, Reblin M, et al. Knowledge of and beliefs about palliative care in a nationally-representative U.S. Sample. *PLoS One* 2019; 14: 1–17.
4. Patel P, Lyons L. Examining the knowledge, awareness, and perceptions of palliative care in the general public over time: a scoping literature review. *Am J Hosp Palliat Med* 2020; 37: 481–487.
5. Grant MS, Back AL, Dettmar NS. Public perceptions of advance care planning, palliative care, and hospice: a scoping review. *J Palliat Med* 2021; 24: 46–52.
6. Huo J, Hong YR, Grewal R, et al. Knowledge of palliative care among American adults: 2018 Health Information National Trends Survey. *J Pain Symptom Manage* 2019; 58: 39-47.e3.
7. Lane T, Ramadurai D, Simonetti J. Public awareness and perceptions of palliative and comfort care. *Am J Med* 2019; 132: 129–131.
8. Lynch T, Clark D, Centeno C, et al. Barriers to the development of palliative care in Western Europe. *Palliat Med* 2010; 24: 812–819.
9. Centeno C, Arias-Casais N. Global palliative care: from need to action. *Lancet Glob Heal* 2019; 7: e815–e816.
10. Alcalde J, Zimmermann C. Stigma about palliative care: origins and solutions. *Ecancer* 2022; 16: 1–7.
11. Mallon A, Slater P, Hasson F, et al. What do young adults know about palliative care? A cross-sectional survey. *Public Health* 2021; 191: 78–84.
12. Akiyama M, Hirai K, Takebayashi T, et al. The effects of community-wide dissemination of information on perceptions of palliative care, knowledge about opioids, and sense of security among cancer patients, their families, and the general public. *Support Care Cancer* 2016; 24: 347–356.
13. Mills J, Rosenberg JP, Bollig G, et al. Last Aid and Public Health Palliative Care: towards the development of personal skills and strengthened community action. *Prog Palliat Care* 2020; 28: 343–345.
14. Lu X, Liu J. Factors influencing public awareness of and attitudes toward palliative care: a cross-sectional analysis of the 2018 HINTS data. *Front Public Heal* 2022; 10: 1–11.
15. Quintiens B, Smets T, Chambaere K, et al. Researching two Compassionate Cities: study protocol for a mixed-methods process and outcome evaluation. *Palliat Care Soc Pract* 2022; 16: 1–13.
16. Hoddinott SN, Bass MJ. The Dillman Total Design survey method: a sure-fire way to get high survey return rates. *Can Fam Physician* 1986; 32: 2366–2368.
17. Baruch Y, Holtom BC. Survey response rate levels and trends in organizational research. *Hum Relations* 2008; 61: 1139–1160.

18. Kozlov E, Carpenter BD, Rodebaugh TL. Development and validation of the Palliative Care Knowledge Scale (PaCKS). *Palliat Support Care* 2017; 15: 524–534.

19. Westreich D, Greenland S. The table 2 fallacy: presenting and interpreting confounder and modifier coefficients. *Am J Epidemiol* 2013; 177: 292–298.

20. The American Association for Public Opinion Research. *Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys*. 2016.

21. The Economist Intelligence Unit. *The 2015 Quality of Death Index: ranking palliative care across the world*. 2015.

22. Kozlov E, McDarby M, Reid MC, et al. Knowledge of palliative care among community-dwelling adults. *Am J Hosp Palliat Med* 2018; 35: 647–651.

23. Shen JJ, Dingley C, Yoo JW, et al. Sociocultural factors associated with awareness of palliative care and advanced care planning among Asian populations. *Ethn Dis* 2020; 30: 459–468.

24. Hoe DF, Johari K, Rahman A, et al. Theory-driven role model stories improve palliative care knowledge among a diverse older population. *Palliat Support Care* 2021; 19: 34–40.

25. Zimmermann C. Stigma Around Palliative Care: Why It Exists and How to Manage It. *J Thorac Oncol* 2019; 14: S1158.

26. Kaasa S, Loge JH, Aapro M, et al. Integration of oncology and palliative care: a Lancet Oncology Commission. *Lancet Oncol* 2018; 19: e588–e653.

27. Jordan RI, Allsop MJ, ElMokhallalati Y, et al. Duration of palliative care before death in international routine practice: a systematic review and meta-analysis. *BMC Med* 2020; 18: 368.

28. Rayment C. Isn't palliative care just for people near the end of their lives? *Marie Curie Blog*, https://www.mariecurie.org.uk/blog/myths-facts-palliative-care/56027 (2016, accessed 24 January 2023).

29. Palliatieve Zorg Vlaanderen. Mythes van palliatieve zorg, https://palliatievezorgvlaanderen.be/patient-mantelzorger/wat-is-palliatieve-zorg/mythes-van-palliatieve-zorg/ (accessed 24 January 2023).

30. Zimmermann C, Wong JL, Swami N, et al. Public knowledge and attitudes concerning palliative care. *BMJ Support Palliat Care* 2021; bmjspcare-2021-003340.

31. McLean S, Lennon P, Glare P. Internet search query analysis can be used to demonstrate the rapidly increasing public awareness of palliative care in the USA. *BMJ Support Palliat Care* 2019; 9: 40–44.

32. Seymour J. The impact of public health awareness campaigns on the awareness and quality of palliative care. *J Palliat Med* 2018; 21: S-30-S-36.

33. Matthys M, Dhollander N, Van Brussel L, et al. The online representation of palliative care by practice, policy, and advocacy organizations: definitional variations and discursive tensions. *Qual Health Res* 2021; 31: 2743–2756.

34. Liu M, Cardenas V, Zhu Y, et al. YouTube videos as a source of palliative care education: a review. *J Palliat Med* 2019; 22: 1568–1573.

35. Claudio CH, Dizon ZB, October TW. Evaluating palliative care resources available to the public using the internet and social media. *Am J Hosp Palliat Med* 2018; 35: 1174–1180.

36. Carrasco JM. Social Representation of Palliative Care in the Media: A Qualitative Analysis of Spanish Newspapers. 2018; 1–12.

37. Kis-rigo A, Collins A, Panozzo S, et al. Negative media portrayal of palliative care : a content analysis of print media prior to the passage of Voluntary Assisted Dying legislation in Victoria. *Intern Med J* 2021; 51: 1336–1339.

38. Li WW, Chhabra J, Singh S. Palliative care education and its effectiveness: a systematic review. *Public Health* 2021; 194: 96–108.

39. Shen MJ, Wellman JD. Evidence of palliative care stigma: the role of negative stereotypes in preventing willingness to utilize palliative care. *Palliat Support Care* 2019; 17: 374–380.

40. 7th Public Health Palliative Care International Conference. Democratizing caring, dying and grieving: participation, action, understanding and evaluation. *Palliat Care Soc Pract*; 16. Epub ahead of print 1 January 2022. DOI: 10.1177/26323524221119941.