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Public knowledge and attitudes concerning palliative care

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ABSTRACT

Objective WHO recommends early integration of palliative care alongside usual care to improve quality of life, although misunderstanding of palliative care may impede this. We compared the public's perceived and actual knowledge of palliative care, and examined the relationship of this knowledge to attitudes concerning palliative care.

Methods We analysed data from a survey of a representative sample of the Canadian public, accessed through a survey panel in May–June 2019. We compared high perceived knowledge ('know what palliative care is and could explain it') with actual knowledge of the WHO definition (knew ≥5/8 components, including that palliative care can be provided early in the illness and together with life-prolonging treatments), and examined their associations with attitudes to palliative care.

Results Of 1518 adult participants residing in Canada, 45% had high perceived knowledge, of whom 46% had high actual knowledge. Participants with high (vs low) perceived knowledge were more likely to associate palliative care with end-of-life care (adjusted OR 2.15 (95% CI 1.66 to 2.79), p<0.0001) and less likely to believe it offered hope (0.62 (95% CI 0.47 to 0.81), p=0.0004). Conversely, participants with high (vs low) actual knowledge were less likely to find palliative care fearful (0.67 (95% CI 0.52 to 0.86), p=0.002) or depressing (0.72 (95% CI 0.56 to 0.93), p=0.01) and more likely to believe it offered hope (1.88 (95% CI 1.46 to 2.43), p<0.0001).

Conclusions Stigma regarding palliative care may be perpetuated by those who falsely believe they understand its meaning. Public health education is needed to increase knowledge about palliative care, promote its early integration and counter false assumptions.

Key messages

What was already known?
- Previous surveys have demonstrated low levels of public knowledge about palliative care.

What are the new findings?
- In this national survey of 1518 adults, those with greater perceived knowledge of palliative care had more negative attitudes about palliative care, whereas those with greater actual knowledge viewed it more positively.

What is their significance?
- Clinical
  - Stigma regarding palliative care may be perpetuated by those who falsely believe they understand its meaning.
- Research
  - Public health education is warranted to reduce misperceptions associated with palliative care.

INTRODUCTION

Timely access to palliative care is an urgent public health concern, for which misunderstanding of the meaning of palliative care and its persistent conflation with end-of-life care represent fundamental barriers.[1] Two decades ago, WHO redefined palliative care with an emphasis on improving quality of life for those facing life-threatening illnesses through early identification and proactive treatment of physical, psychosocial and spiritual problems.[2] This definition is supported by recent high-level evidence demonstrating that early involvement of specialised palliative care alongside treatments aimed at prolonging life results in improved quality of life, symptom control and satisfaction with care.[3–6] Clinical practice guidelines now recommend the routine involvement of palliative care teams from the time of diagnosis of advanced disease in patients with cancer and other chronic illnesses.[7 8]

Despite these guidelines, early palliative care integration does not occur

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routinely.[9 10] Referring physicians cite patient and family misconceptions that palliative care is synonymous with end-of-life care as a prominent reason for late referral.[9 11] Although patients receiving early palliative care have lauded the benefits of this model,[12 13] they have also expressed reluctance to disclose receiving this care to their family and friends, for fear of being stigmatised.[14] A paradigm shift to early integration of palliative care would require engagement of the public, who provide informal support for patients, are themselves potential recipients of palliative care services, and directly or indirectly fund health services.

Surveys conducted in North America, Europe, Australia and Asia have demonstrated low levels of awareness and knowledge about palliative care among members of the public and a persistent association of palliative care with end-of-life care.[15 16] However, these surveys did not directly compare perceived knowledge and actual knowledge of palliative care in relation to a formal definition, nor did they assess associations of these levels of knowledge with attitudes towards palliative care. These analyses are important to inform educational public health interventions about palliative care.

We conducted a survey of members of the Canadian public to assess and compare their perceived knowledge of palliative care and their actual knowledge of the WHO definition of palliative care; we examined associations of perceived and actual knowledge with attitudes concerning palliative care.

METHODS

Sampling and data collection

We engaged a Canadian healthcare market research firm, MD Analytics, to distribute the survey through its access to a panel of approximately 500 000 members.[17] Panel members are recruited with the aim of representing the general Canadian public and receive modest point-based incentives to claim prizes such as gift cards. Eligible participants were aged 18 years or older and resided in Canada. The target sample size of 1500 was established to ensure sufficient representation from all Canadian provinces. Strata were created based on region, gender and age, to ensure representation in accordance with Statistics Canada National Census data and to minimise subsequent weighting. Panellists were randomly selected from each province and invited to complete the survey until the target number for each stratum was reached.

Sampling took place by email from 27 May 2019 to 21 June 2019. The survey was accessible only to panellists who received the invitation link; panellists provided informed consent to participate and data were protected by encryption. During sampling, those who exceeded the above-mentioned targets were excluded, as were 'speeders' (survey completion time <50% of median), who were deemed unlikely to have completed the survey thoughtfully.[18] A reminder email was sent 1–2 weeks following the initial invitation; the survey link was active for 4 weeks. Internet protocol address checks were conducted, and respondents were not permitted duplicate survey access.

Survey development

The survey was developed in accordance with the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) statement[19] and was available in English and French. The survey instrument was designed by a multidisciplinary team of experts in palliative care, psychiatry, family medicine, internal medicine, nursing and survey design, and was based on a comprehensive literature review by a health science librarian. To test the content, usability and technical functionality of the survey instrument, it was piloted by our team of multidisciplinary experts, by three MD Analytics associates (including manual checks of links and generation of random data and checking output), and finally by 33 panel members. For questions with several response options, these were randomised to prevent bias.[20 21] Respondents had to answer each question to continue to the next, and were not able to review and change answers.

At the beginning of the survey, we assessed respondents' level of perceived knowledge about palliative care by asking 'How would you describe your level of knowledge about palliative care?' Respondents selected one of four possible answers: 'I know what palliative care is and could explain it to someone else', 'I know a little bit about palliative care but could not explain it', 'I have only heard the words palliative care, but do not really know what it is', or 'I have never heard of palliative care.'[20 22] Those who had heard of palliative care were classified as having high ('could explain it') or low perceived knowledge ('know a little bit' or 'only heard the words').

Participants who had heard of palliative care were asked to select their level of agreement with statements about common attitudes and opinions about palliative care. These statements were based on a literature search and previous qualitative research by our team[14]; answers were provided on a five-point Likert scale (strongly disagree, somewhat disagree, neither agree nor disagree, somewhat agree, strongly agree).

Midway through the survey, all participants were presented with a lay definition of palliative care based on the WHO definition of palliative care[2] (online supplemental eText 1). The definition was separated into eight salient components; for each component, participants were asked to indicate 'Yes, I knew this' or 'No, I didn't know this'. Participants were classified as having high actual knowledge of the definition of palliative care if they were familiar with at least 5/8 components, including that palliative care can be provided together with life-prolonging treatments and that palliative care can be provided early in the course of illness. The last two components were emphasised

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because they reflect new elements of the 2002 definition, compared with the previous 1990 definition,[23] which relate to early integration of palliative care and are often misunderstood.[14 15 22] The remaining participants were classified as having low knowledge.

Lastly, all participants completed survey items regarding their demographic characteristics and (if they had heard of palliative care) their main source of information about palliative care.

Statistical analysis

To render the sample representative of the total Canadian population, MD Analytics provided survey weights by age, gender and region, in accordance with 2016 Statistics Canada National Census population data. Completed questionnaires were analysed and descriptive statistics were computed for all variables. Statistics are reported as unweighted frequencies and weighted percentages with 95% CIs to provide transparency. In accordance with the CHERRIES statement, the participation rate was calculated as the number of people who filled in the first survey page, divided by those who visited that page, and the completion rate as eligible participants completing the last page, divided by those who completed the first page.[19]

Associations of participants' characteristics with having heard of palliative care (yes/no) and with perceived knowledge of palliative care (high/low) were assessed using the Rao-Scott likelihood ratio χ^2 test for categorical variables and the two-sample weighted t-test for continuous measures. Associations between high/low perceived knowledge of palliative care and items regarding attitudes and opinions about palliative care (agree/strongly agree vs neutral/disagree/strongly disagree) were assessed using weighted multivariable logistic regression analyses; for consistency, both sets of analyses were performed using the sample of patients who had heard of palliative care. All analyses were repeated substituting high/low actual knowledge for high/low perceived knowledge. Both sets of analyses were adjusted for demographic variables associated with high/low perceived or actual knowledge at $p<0.10$. SAS V.9.4 (SAS Institute) was used and two-sided tests with $p<0.05$ were considered significant for all main analyses.

RESULTS

Participant characteristics and perceived knowledge of palliative care

Of 4274 panel members who clicked on the link, 2422 completed the first survey page (participation rate 57%) (online supplemental eFigure). Of the 2422, 809 were excluded (3 lived outside Canada, 8 aged under 18, 646 because targets had been met and 152 speeders). Of the 1613 remaining eligible participants, 1518 completed the survey (completion rate 94%). Compared with the 1518 in the final sample, those excluded due to targets being met were more likely to be female and older, while speeders were more likely to be male and younger; completers were similar to non-completers (online supplemental eTable 1). The median completion time was 10 min (5 min for those who had never heard of palliative care and thus did not complete all items). Of the 1518 participants, 676 stated that they could explain palliative care, 488 knew a bit about it but could not explain it, 198 had only heard the words, and 156 had never heard of palliative care.

Characteristics for participants are listed in table 1, according to whether or not they had heard of palliative care and, among those who had heard of palliative care, according to whether their perceived knowledge of palliative care was high or low. Participants who had heard of palliative care were more likely to be older, retired, married, born in Canada, of European ethnic origin, Christian, have postsecondary education and less likely to be from British Columbia, than those who had never heard of palliative care. They were also more likely to be healthcare professionals and to have, or know someone with, a life-threatening illness. Comparing those with high versus low perceived knowledge, similar relationships were observed (table 1). In addition, those whose main source of information about palliative care was healthcare professionals, rather than friends, family or the media, were more likely to have high perceived knowledge about palliative care.

Attitudes and opinions about palliative care

Attitudes and opinions about palliative care were rated only by participants who had heard of palliative care (n=1362; figure 1). A large majority agreed that palliative care helps with illness-related coping, provides comfort, maintains dignity and relieves pain and other symptoms and most disagreed that palliative care was mainly for older patients and those with cancer. However, 67.2% agreed that palliative care was when 'you can no longer take care of yourself', 63.9% that it meant being close to death, 57.7% that it was a last resort when other treatments failed, and 57.0% that it was the same as end-of-life care. Further, 40.1% found the term 'palliative care' depressing, and only 34.8% agreed/strongly agreed that palliative care offers hope to patients.

Actual knowledge of the definition of palliative care

Demographic characteristics associated with high versus low actual knowledge are shown in online supplemental eTable 2. The strongest associations were with older age, retired employment status, and healthcare providers as a knowledge source.

Only 34.1% of participants in the full sample, 38.2% of those who had heard of palliative care, and 46.1% of those who had a high perceived knowledge of palliative care had high actual knowledge of the WHO definition of palliative care (table 2). More than

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Table 1 Characteristics of respondents, stratified by perceived knowledge of palliative care

Respondent characteristics	Whole population N=1518 No (weighted %) (95%)	Perceived knowledge of palliative care No (weighted %) (95%)					
		Heard of palliative care			Level of knowledge*		
		Yes N=1362	No N=156	P value	High N=676	Low N=686	P value
Age, years				<0.0001			<0.0001
18–24	143 (11.6) (9.8 to 13.4)	97 (8.7) (7.0 to 10.4)	46 (34.3) (26.3 to 42.3)		26 (4.8) (2.9 to 6.6)	71 (12.5) (9.7 to 15.2)	
25–34	268 (17.2) (15.3 to 19.2)	224 (16.0) (14.0 to 18.0)	44 (26.9) (19.9 to 33.9)		104 (15.1) (12.4 to 17.8)	120 (16.9) (14.1 to 19.7)	
35–44	280 (17.0) (15.2 to 18.9)	250 (17.1) (15.1 to 19.0)	30 (16.9) (11.2 to 22.6)		126 (17.3) (14.5 to 20.2)	124 (16.8) (14.0 to 19.6)	
45–54	284 (18.7) (16.7 to 20.8)	259 (19.2) (17.0 to 21.3)	25 (15.3) (9.7 to 21.0)		136 (20.5) (17.3 to 23.6)	123 (17.9) (15.0 to 20.8)	
55–64	278 (18.3) (16.3 to 20.3)	269 (20.0) (17.8 to 22.2)	9 (5.3) (1.8 to 8.8)		139 (21.2) (18.0 to 24.3)	130 (18.9) (15.9 to 21.9)	
≥65	265 (17.1) (15.2 to 19.0)	263 (19.1) (17.0 to 21.2)	2 (1.3) (0 to 3.1)		145 (21.2) (18.0 to 24.3)	118 (17.1) (14.2 to 19.9)	
Gender				0.10			0.08
Female	790 (50.8) (48.2 to 53.4)	720 (51.8) (49.1 to 54.5)	70 (43.1) (35.1 to 51.1)		379 (54.8) (50.9 to 58.7)	341 (48.9) (45.1 to 52.7)	
Male	722 (48.9) (46.3 to 51.5)	638 (48.0) (45.3 to 50.7)	84 (56.3) (48.3 to 64.3)		294 (44.9) (41.0 to 48.8)	344 (51.0) (47.1 to 54.8)	
Non-binary	4 (0.4) (0 to 0.5)	3 (0.2) (0 to 0.5)	1 (0.6) (0 to 1.7)		2 (0.3) (0 to 0.7)	1 (0.1) (0 to 0.4)	
Highest level of education				0.001			<0.0001
High school or less	351 (23.4) (21.1 to 25.6)	299 (21.8) (19.5 to 24.0)	52 (36.2) (28.1 to 44.3)		115 (16.7) (13.9 to 19.6)	184 (26.7) (23.3 to 30.1)	
College/technical degree	608 (40.7) (38.1 to 43.2)	556 (41.6) (38.9 to 44.3)	52 (33.1) (25.4 to 40.8)		273 (41.3) (37.4 to 45.1)	283 (41.9) (38.1 to 45.8)	
University/graduate/professional degree	542 (36.0) (33.5 to 38.5)	496 (36.6) (34.0 to 39.3)	46 (30.7) (23.1 to 38.3)		285 (42.0) (38.2 to 45.8)	211 (31.4) (27.8 to 35.0)	
Marital status				0.01			0.01
Married/common law	800 (52.0) (49.4 to 54.6)	732 (53.2) (50.4 to 55.9)	68 (42.5) (34.5 to 50.6)		386 (56.6) (52.8 to 60.5)	346 (49.8) (45.9 to 53.7)	
Other†	709 (48.0) (45.4 to 50.6)	624 (46.8) (44.1 to 49.6)	85 (57.5) (49.4 to 65.5)		289 (43.4) (39.5 to 47.2)	335 (50.2) (46.3 to 54.1)	
Household income, CAD$				<0.0001			<0.0001
<25 000	233 (16.9) (14.8 to 18.9)	188 (14.7) (12.7 to 16.7)	45 (36.7) (28.0 to 45.5)		69 (10.2) (7.9 to 12.6)	119 (19.1) (15.9 to 22.3)	
25 000–49 999	356 (25.5) (23.2 to 27.9)	319 (25.2) (22.7 to 27.7)	37 (28.5) (20.3 to 36.7)		147 (23.2) (19.8 to 26.6)	172 (27.2) (23.6 to 30.8)	
50 000–74 999	278 (20.4) (18.3 to 22.6)	263 (21.3) (19.0 to 23.6)	15 (12.4) (6.2 to 18.5)		131 (21.1) (17.8 to 24.3)	132 (21.5) (18.2 to 24.9)	
75 000–99 999	203 (14.9) (12.9 to 16.8)	193 (15.6) (13.5 to 17.6)	10 (8.3) (3.2 to 13.4)		101 (16.3) (13.4 to 19.3)	92 (14.8) (11.9 to 17.6)	
100 000–149 999	211 (14.9) (13.0 to 16.8)	198 (15.5) (13.4 to 17.5)	13 (9.8) (4.6 to 14.9)		122 (18.8) (15.6 to 21.9)	76 (12.2) (9.6 to 14.8)	
≥150 000	99 (7.4) (6.0 to 8.8)	94 (7.8) (6.2 to 9.3)	5 (4.3) (0.5 to 8.1)		61 (10.4) (7.9 to 12.9)	33 (5.1) (3.4 to 6.9)	
Employment				<0.0001			0.0003
Employed/self-employed	847 (56.1) (53.5 to 58.7)	757 (55.5) (52.8 to 58.3)	90 (61.0) (52.8 to 69.3)		392 (57.9) (54.1 to 61.8)	365 (53.2) (49.3 to 57.0)	
Retired/semi-retired	343 (22.7) (20.6 to 24.9)	340 (25.2) (22.8 to 27.6)	3 (2.1) (0 to 4.5)		186 (27.7) (24.2 to 31.2)	154 (22.8) (19.5 to 26.0)	
Homemaker/on disability/unemployed	239 (15.8) (13.9 to 17.7)	201 (14.6) (12.7 to 16.5)	38 (25.4) (18.2 to 32.6)		76 (11.2) (8.7 to 13.6)	125 (17.9) (15.0 to 20.9)	
Student	65 (5.4) (4.1 to 6.7)	51 (4.7) (3.4 to 5.9)	14 (11.4) (5.7 to 17.2)		17 (3.2) (1.7 to 4.7)	34 (6.1) (4.1 to 8.1)	
Ethnic background				<0.0001			0.0001
European origins	960 (66.2) (63.7 to 68.7)	922 (70.4) (67.8 to 72.9)	38 (29.0) (20.9 to 37.0)		493 (75.4) (72.0 to 78.8)	429 (65.4) (61.7 to 69.2)	

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Table 1 Continued

Respondent characteristics	Whole population N=1518 No (weighted %) (95%)	Perceived knowledge of palliative care No (weighted %) (95%)					
		Heard of palliative care			Level of knowledge*		
		Yes N=1362	No N=156	P value	High N=676	Low N=686	P value
Other‡	470 (33.8) (31.3 to 36.3)	377 (29.6) (27.1 to 32.2)	93 (71.0) (63.0 to 79.1)		158 (24.6) (21.2 to 28.0)	219 (34.6) (30.8 to 38.3)	
Religion				<0.0001			0.22
Christianity	775 (53.5) (50.9 to 56.2)	726 (55.7) (52.9 to 58.4)	49 (35.8) (27.5 to 44.1)		375 (58.1) (54.2 to 62.0)	351 (53.3) (49.3 to 57.2)	
Other religions§	139 (10.1) (8.5 to 11.7)	111 (8.9) (7.3 to 10.5)	28 (20.4) (13.4 to 27.3)		56 (8.7) (6.5 to 10.9)	55 (9.1) (6.7 to 11.4)	
No religion	527 (36.4) (33.8 to 38.9)	463 (35.5) (32.8 to 38.1)	64 (43.8) (35.4 to 52.3)		221 (33.2) (29.5 to 36.9)	242 (37.7) (33.8 to 41.5)	
Region				0.003			0.03
British Columbia	182 (12.7) (11.0 to 14.4)	149 (11.6) (9.9 to 13.4)	33 (21.1) (14.5 to 27.7)		62 (9.7) (7.4 to 12.0)	87 (13.5) (10.8 to 16.1)	
Ontario	512 (38.2) (35.7 to 40.8)	453 (38.0) (35.3 to 40.7)	59 (39.7) (31.7 to 47.6)		240 (40.9) (37.0 to 44.7)	213 (35.2) (31.5 to 39.0)	
Quebec	348 (23.4) (21.3 to 25.6)	321 (24.3) (21.9 to 26.6)	27 (17.0) (11.0 to 23.1)		161 (24.7) (21.3 to 28.0)	160 (23.8) (20.6 to 27.1)	
West (except British Columbia)¶	271 (18.7) (16.6 to 20.7)	243 (18.7) (16.5 to 20.8)	28 (18.6) (12.2 to 25.1)		109 (16.8) (13.9 to 19.7)	134 (20.5) (17.4 to 23.6)	
Atlantic**	205 (7.0) (6.0 to 8.0)	196 (7.4) (6.4 to 8.5)	9 (3.5) (1.1 to 6.0)		104 (7.9) (6.4 to 9.5)	92 (6.9) (5.5 to 8.4)	
Born in Canada				<0.0001			0.16
Yes	1235 (80.8) (78.8 to 82.9)	1149 (83.9) (81.9 to 86.0)	86 (56.3) (48.3 to 64.4)		579 (85.4) (82.6 to 88.2)	570 (82.5) (79.5 to 85.5)	
No	275 (19.2) (17.1 to 21.2)	206 (16.1) (14.0 to 18.1)	69 (43.7) (35.6 to 51.7)		95 (14.6) (11.8 to 17.4)	111 (17.5) (14.5 to 20.5)	
Years living in Canada (N=275)				<0.0001			0.01
0–10	76 (28.3) (22.8 to 33.9)	47 (23.2) (17.2 to 29.2)	29 (44.0) (31.5 to 56.6)		14 (13.5) (6.6 to 20.5)	33 (31.0) (21.9 to 40.1)	
11–20	46 (17.9) (13.2 to 22.7)	30 (15.1) (10.1 to 20.2)	16 (26.6) (15.1 to 38.1)		12 (13.4) (6.2 to 20.5)	18 (16.5) (9.4 to 23.7)	
21–30	46 (17.0) (12.5 to 21.6)	32 (15.9) (10.8 to 21.1)	14 (20.3) (10.4 to 30.3)		20 (22.0) (13.3 to 30.7)	12 (11.0) (5.0 to 16.9)	
31–40	30 (10.8) (7.0 to 14.5)	27 (12.8) (8.2 to 17.5)	3 (4.5) (0 to 9.6)		16 (16.9) (9.0 to 24.7)	11 (9.6) (4.0 to 15.1)	
>40	71 (25.9) (20.6 to 31.3)	68 (32.9) (26.4 to 39.5)	3 (4.6) (0 to 9.7)		32 (34.2) (24.3 to 44.2)	36 (31.9) (23.0 to 40.8)	
Healthcare professional				<0.0001			<0.0001
Yes	129 (8.3) (6.9 to 9.7)	127 (9.2) (7.7 to 10.8)	2 (1.2) (0 to 2.9)		100 (14.5) (11.8 to 17.2)	27 (4.1) (2.6 to 5.6)	
No	1389 (91.7) (90.3 to 93.1)	1235 (90.8) (89.2 to 92.3)	154 (98.8) (97.1 to 100)		576 (85.5) (82.8 to 88.2)	659 (95.9) (94.4 to 97.4)	
Live with a healthcare professional				0.23			0.87
Yes	105 (7.3) (5.9 to 8.6)	97 (7.5) (6.1 to 9.0)	8 (5.0) (1.6 to 8.5)		51 (7.7) (5.6 to 9.7)	46 (7.5) (5.3 to 9.6)	
No	1413 (92.7) (91.4 to 94.1)	1265 (92.5) (91.0 to 93.9)	148 (95.0) (91.5 to 98.4)		625 (92.3) (90.3 to 94.4)	640 (92.6) (90.4 to 94.7)	
Participant or loved one diagnosed with a serious or life-threatening illness				<0.0001			<0.0001
Yes	827 (56.2) (53.6 to 58.8)	775 (58.5) (55.8 to 61.2)	52 (37.0) (28.8 to 45.3)		447 (67.6) (63.9 to 71.2)	328 (49.5) (45.6 to 53.4)	
No	646 (43.8) (41.2 to 46.4)	555 (41.5) (38.8 to 44.2)	91 (63.0) (54.7 to 71.2)		221 (32.4) (28.8 to 36.1)	334 (50.5) (46.6 to 54.4)	
Main source of information about palliative care (N=1362)				–			<0.0001
Friends, family, colleagues	514 (41.9) (39.0 to 44.7)	–	–		250 (37.9) (34.0 to 41.7)	264 (46.5) (42.2 to 50.8)	
Healthcare professional/MD	359 (30.3) (27.6 to 33.0)	–	–		247 (38.7) (34.8 to 42.5)	112 (20.6) (17.1 to 24.1)	

Continued

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Table 1 Continued

Respondent characteristics	Whole population N=1518 No (weighted %) (95%)	Perceived knowledge of palliative care No (weighted %) (95%)					
		Heard of palliative care			Level of knowledge*		
		Yes N=1362	No N=156	P value	High N=676	Low N=686	P value
Traditional media	190 (15.9) (13.8 to 18.1)	–	–		69 (10.5) (8.1 to 13.0)	121 (22.2) (18.6 to 25.7)	
Social media	32 (2.9) (1.9 to 4.0)	–	–		11 (2.0) (0.8 to 3.2)	21 (4.0) (2.3 to 5.8)	
Social services/agencies/programmes	59 (5.0) (3.7 to 6.2)	–	–		41 (6.4) (4.5 to 8.4)	18 (3.3) (1.8 to 4.8)	
Other††	48 (4.0) (2.9 to 5.2)	–	–		30 (4.5) (2.9 to 6.2)	18 (3.4) (1.9 to 5.0)	

Number missing or preferred not to answer: gender 2, education 17, marital status 9, household income 138, employment 24, ethnic background 88, religion 77, born in Canada 8, participant or loved one diagnosed with a serious or life-threatening illness 45, main source of information about palliative care 160.

*High level of perceived knowledge: 'I know what palliative care is and could explain it to someone else'; Low level of perceived knowledge: 'I know a little bit about palliative care but could not explain it'; or 'I have only heard the words palliative care, but do not really know what it is.'

†Other marital status includes single, separated, divorced, widowed/widower.

‡Other ethnic backgrounds include African, Asian/Pacific Island, Latin American, Middle Eastern, North American Aboriginal, other not specified.

§Other religions include Buddhism, Hinduism, Judaism, Islam, Sikhism, other not specified.

¶West includes Alberta, Saskatchewan and Manitoba.

**Atlantic region includes New Brunswick, Nova Scotia, Prince Edward Island and Newfoundland and Labrador.

††Other main sources include insurance company, politicians, religious leaders at place of worship, other not specified.

70% of all participants and more than 90% of those with high perceived knowledge knew that palliative care was focused on improving quality of life, and was provided for patients of any age. However, only 53.7% of all participants knew that palliative care could be provided together with other treatments aimed at prolonging life, and only 39.9% knew that it could be provided early in the course of illness; for those with high perceived knowledge of palliative care, these percentages were 67.5% and 51.5%, respectively.

Of the total sample, 88.4% (95% CI 86.8% to 90.1%) agreed/strongly agreed that the definition helped them better understand what palliative care is, while only 1.4% (95% CI 0.7% to 2.0%) disagreed. As well, 90.4% (95% CI 88.8% to 91.9%) agreed/strongly agreed that Canadians should be made aware that palliative care can be included early in the course of the patient's illness (1.0% (95% CI 0.5% to 1.6%) disagreed).

Association of perceived and actual knowledge with attitudes concerning palliative care

Table 3 shows associations of attitudes and opinions concerning palliative care with perceived knowledge of palliative care. Participants with a high perceived knowledge of palliative care were more likely than those with a low perceived knowledge to agree/strongly agree that palliative care is a 'place where people go to die', that palliative care means 'being close to death', that it is a 'last resort', and that it is the 'same as end-of-life care'. Further, those with a high perceived knowledge of palliative care were less likely to agree/strongly agree that 'palliative care offers hope to patients'.

Table 4 shows associations of attitudes and opinions about palliative care with actual knowledge of the definition of palliative care. Participants with high actual knowledge were less likely than those with low actual knowledge to agree/strongly agree that palliative care is a 'place where people go to die', that palliative care means 'being close to death', and that it is the 'same as end-of-life care'. Further, those with high actual knowledge were more likely to agree/strongly agree that palliative care offers hope, and less likely to agree/strongly agree that they found the term palliative care depressing, that they would be fearful if referred to palliative care, and to agree referral would mean the 'doctor is giving up'.

DISCUSSION

In this national survey, less than half of participants who had high perceived knowledge of palliative care and believed they could explain palliative care to someone else had high actual knowledge of the WHO palliative care definition. Participants with high perceived knowledge about palliative care were more likely to associate it with care provided as a last resort at the end of life and less likely to believe that palliative care offered patients hope. Conversely, those with high actual knowledge of the WHO definition of palliative care were less likely to associate it with end-of-life care, less likely to find the term palliative care fearful or depressing, and more likely to believe palliative care offered hope. These findings offer important insights for public education efforts about palliative care.

Other studies have similarly reported on the public's misunderstanding that palliative care is associated only with terminal care.[15 16] Our study demonstrated that this misunderstanding was greatest in those with the highest perceived knowledge of palliative care. Further, these participants were not only less likely

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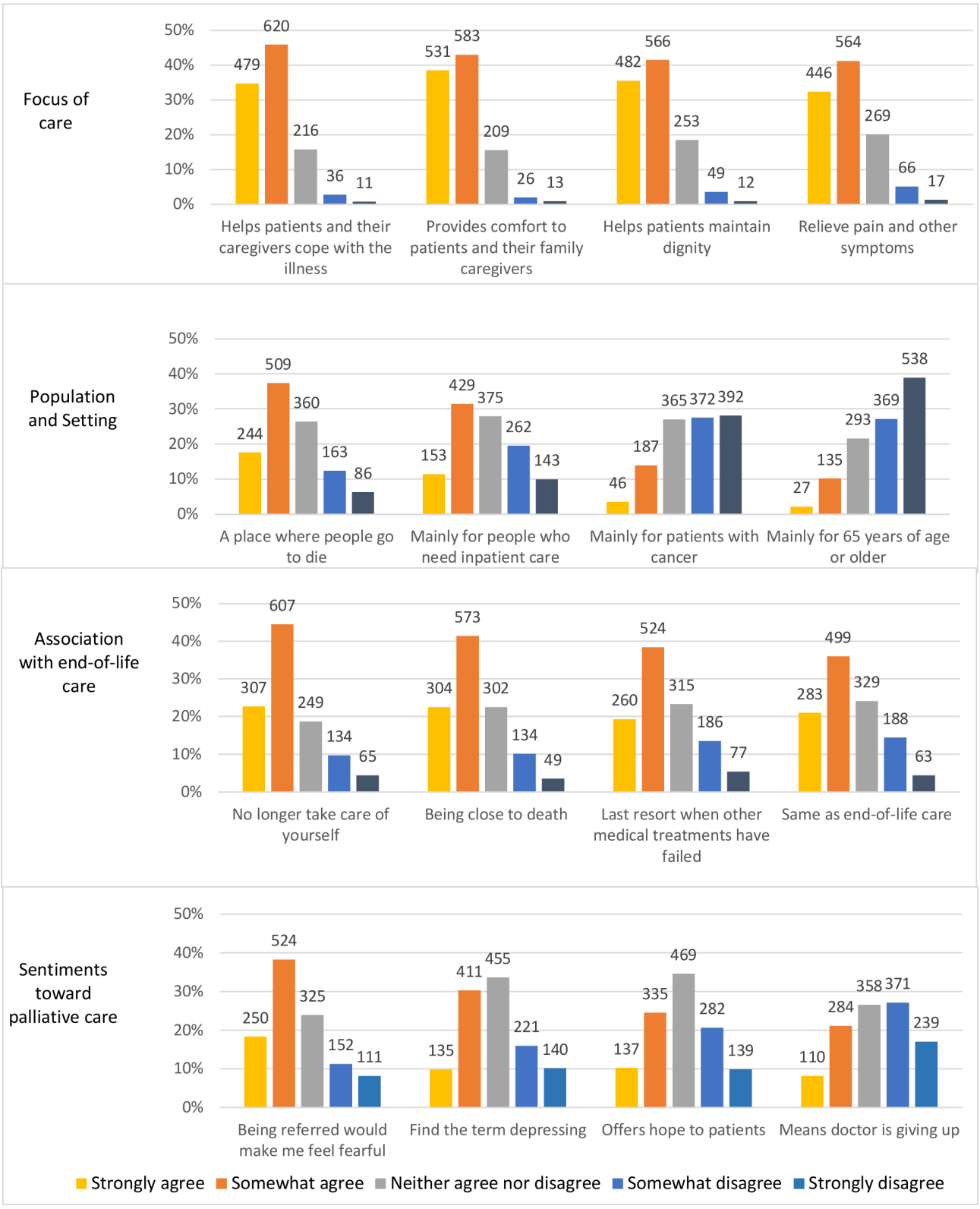

Figure 1 Attitudes and opinions about palliative care, n=1362.

than those with low perceived knowledge to believe that palliative care offered hope to patients, but also more likely to have learnt about palliative care from healthcare professionals. In previous surveys and qualitative studies, physicians tended to associate palliative care with terminal care,[9 24–26] and patients and caregivers recalled conversations with healthcare providers who had equated palliative care with end-of-life care.[14] Together, these findings underline the importance of including healthcare professionals as well as patients

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Table 2 Participants' actual knowledge of components of the WHO definition of palliative care

Component of WHO definition of palliative care	Participants indicating they knew this component of the WHO definition* No (weighted %) (95%)		
	Whole population N=1518	Heard of palliative care N=1362	High perceived knowledge of palliative care† (N=676)
Focused on improving patients' quality of life	1172 (76.0) (73.7 to 78.2)	1161 (84.8) (82.8 to 86.8)	630 (92.9) (90.9 to 94.9)
For patients of any age	1157 (74.9) (72.7 to 77.2)	1144 (83.5) (81.4 to 85.5)	634 (93.7) (91.8 to 95.6)
For patients living with any serious illness	1111 (72.6) (70.3 to 74.9)	1100 (81.0) (78.9 to 83.2)	556 (84.3) (81.5 to 87.1)
Includes physical, emotional, spiritual and social support	1008 (65.4) (63.0 to 67.9)	1000 (73.2) (70.8 to 75.6)	579 (85.4) (82.6 to 88.2)
Can include support for family members	969 (62.9) (60.4 to 65.4)	958 (70.1) (67.6 to 72.6)	562 (82.7) (79.8 to 85.7)
Delivered with a team approach	968 (62.7) (60.1 to 65.2)	962 (70.2) (67.7 to 72.7)	578 (85.0) (82.2 to 87.9)
Can be provided together with other medical treatments aimed at prolonging life	829 (53.7) (51.1 to 56.3)	822 (60.0) (57.3 to 62.7)	461 (67.5) (63.8 to 71.1)
Can be involved early in the course of illness	620 (39.9) (37.4 to 42.4)	615 (44.6) (41.9 to 47.3)	357 (51.5) (47.7 to 55.4)
High actual knowledge‡	532 (34.1) (31.7 to 36.5)	529 (38.2) (35.6 to 40.9)	320 (46.1) (42.3 to 50.0)

*For each component, participants indicated 'Yes, I knew this' or 'No, I didn't know this'.

†High perceived knowledge was defined as endorsing 'I know what palliative care is and could explain it to someone else'.

‡High actual knowledge was defined as knowing at least five out of eight components, including that palliative care 'can be provided together with other medical treatments aimed at prolonging life' and that palliative care 'can be involved early in the course of illness'.

and the public in education initiatives about palliative care.

Although participants with high actual knowledge were less likely to find the term palliative care fearful or depressing, and more likely to believe it offered hope, most participants were not aware of important elements of its definition. Palliative care is often not practised as it is defined, with continued late referrals to palliative care services.[10] The distinction between hospice and palliative care is often blurred, with shared organisations such as the Canadian Hospice Palliative Care Association, the American Academy of Hospice and Palliative Medicine, and the Worldwide Hospice Palliative Care Alliance. Efforts to redefine, rename and rebrand palliative care have not been coordinated, and consensus is lacking even among palliative care professionals about what palliative care is and does.[27 28] In order for the public to understand and benefit from the timely provision of palliative care, it needs to be defined consistently and practised as defined.

Table 3 Attitudes and opinions about palliative care and perceived knowledge about palliative care (n=1362)

Attitude or opinion*	Perceived knowledge of palliative care No (weighted %) (95%)					
	High‡ N=676	Low‡ N=686	OR (95%)	P value	AOR (95%)†	P value
Association of palliative care with end of life						
No longer take care of yourself	459 (68.1) (64.5 to 71.8)	455 (66.2) (62.6 to 69.9)	1.09 (0.86 to 1.38)	0.46	1.08 (0.82 to 1.41)	0.59
Place where people go to die	418 (62.0) (58.2 to 65.8)	335 (48.2) (44.4 to 52.0)	1.75 (1.41 to 2.19)	<0.0001	1.64 (1.27 to 2.12)	0.0002
Being close to death	493 (73.2) (69.8 to 76.6)	384 (54.8) (51.0 to 58.7)	2.25 (1.78 to 2.84)	<0.0001	2.20 (1.69 to 2.87)	<0.0001
Last resort	414 (62.5) (58.8 to 66.2)	370 (53.1) (49.2 to 56.9)	1.47 (1.18 to 1.84)	0.0006	1.43 (1.10 to 1.84)	0.007
Same as end-of-life care	451 (66.8) (63.1 to 70.5)	331 (47.5) (43.7 to 51.4)	2.22 (1.77 to 2.78)	<0.0001	2.15 (1.66 to 2.79)	<0.0001
Sentiments about palliative care						
Find term palliative care depressing	261 (38.4) (34.6 to 42.2)	285 (41.8) (38.0 to 45.6)	0.87 (0.70 to 1.09)	0.22	0.86 (0.66 to 1.10)	0.23
Would be fearful of palliative care referral	377 (55.7) (51.8 to 59.5)	397 (57.6) (53.8 to 61.4)	0.92 (0.74 to 1.15)	0.48	0.89 (0.69 to 1.16)	0.39
Referral would mean doctor is giving up on the patient	211 (31.6) (28.0 to 35.2)	183 (27.0) (23.6 to 30.4)	1.25 (0.98 to 1.59)	0.07	1.22 (0.91 to 1.62)	0.18
Palliative care offers hope to patients	194 (28.1) (24.6 to 31.6)	278 (41.3) (37.5 to 45.1)	0.56 (0.44 to 0.70)	<0.0001	0.62 (0.47 to 0.81)	0.0004

*Responses to items regarding attitudes and opinions were dichotomised as agree/strongly agree versus neutral/disagree/strongly disagree.

†Adjusted for age, gender (excluding other due to small count), education, marital status, household income (<CAD$50 000, ≥CAD$50 000, unknown), employment, European ethnicity, religion, region, new immigrant (≤10 years in Canada), healthcare professional, self or loved one diagnosed with a serious or life-threating illness.

‡High level of perceived knowledge: 'I know what palliative care is and could explain it to someone else'; low level of perceived knowledge: 'I know a little bit about palliative care but could not explain it'; or 'I have only heard the words palliative care, but do not really know what it is.'

AOR, adjusted OR.

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Table 4 Attitudes and opinions about palliative care and actual knowledge of WHO definition of palliative care (n=1362)

	Actual knowledge of WHO palliative care definition					
	No (weighted %) (95%)					
Attitude or opinion*	High‡ N=529	Low‡ N=833	OR (95%)	P value	AOR (95%)†	P value
Association of palliative care with end of life						
No longer take care of yourself	337 (64.8) (60.6 to 69.0)	577 (68.6) (65.4 to 71.9)	0.84 (0.66 to 1.07)	0.16	0.81 (0.62 to 1.05)	0.11
Place where people go to die	259 (49.4) (45.0 to 53.8)	494 (58.5) (55.0 to 61.9)	0.69 (0.55 to 0.87)	0.001	0.60 (0.46 to 0.77)	<0.00001
Being close to death	288 (54.4) (50.0 to 58.8)	589 (69.8) (66.5 to 73.0)	0.52 (0.41 to 0.65)	<0.0001	0.45 (0.34 to 0.58)	<0.0001
Last resort	284 (55.1) (50.8 to 59.5)	500 (59.3) (55.9 to 62.7)	0.84 (0.67 to 1.06)	0.14	0.84 (0.66 to 1.08)	0.18
Same as end-of-life care	272 (51.3) (46.9 to 55.7)	510 (60.6) (57.1 to 64.0)	0.69 (0.55 to 0.86)	0.001	0.59 (0.46 to 0.76)	<0.0001
Sentiments about palliative care						
Find term palliative care depressing	184 (35.2) (31.0 to 39.4)	362 (43.1) (39.7 to 46.6)	0.72 (0.57 to 0.90)	0.005	0.72 (0.56 to 0.93)	0.01
Would be fearful of palliative care referral	265 (50.3) (45.9 to 54.6)	509 (60.6) (57.2 to 64.0)	0.66 (0.52 to 0.82)	0.0003	0.67 (0.52 to 0.86)	0.002
Referral would mean doctor is giving up on the patient	133 (25.8) (22.0 to 29.7)	261 (31.4) (28.1 to 34.6)	0.76 (0.59 to 0.98)	0.03	0.68 (0.52 to 0.90)	0.007
Agree palliative care offers hope to patients	231 (43.4) (39.1 to 47.8)	241 (29.4) (26.2 to 32.6)	1.84 (1.46 to 2.33)	<0.0001	1.88 (1.46 to 2.43)	<0.0001

*Responses to items regarding attitudes and opinions were dichotomised as agree/strongly agree versus neutral/disagree/strongly disagree.

†Adjusted for age, gender, education, marital status, household income (<CAD$50 000, ≥CAD$50 000, unknown), employment, European ethnicity, religion, region, new immigrant (≤10 years in Canada), healthcare professional, self or loved one diagnosed with a serious or life-threating illness.

‡High actual knowledge of WHO palliative care definition: 'Yes, I knew this' to at least 5/8 components, including that palliative care 'can be provided together with other medical treatments aimed at prolonging life' and that palliative care 'can be provided early in the course of illness'; the remainder were classified as having low actual knowledge.

AOR, adjusted OR.

Educational initiatives for the public regarding palliative care are few.[29 30] Existing formal educational initiatives related to palliative care are focused predominantly on end-of-life care and on normalising death and dying.[15 31] These include the international death cafés initiative, which aims to increase death awareness,[32] the Dying Matters campaign in the UK, which aims to 'normalise public openness around death, dying and bereavement,'[33] and the worldwide compassionate communities initiative,[31] which is based on the premise of 'end-of-life care as everyone's responsibility'.[34] While death education is important, similar public education campaigns on the relevance and benefit of early integration of palliative care have been lacking.

This study has limitations. There were differences between participants and non-participants, with the possibility of non-response bias.[21] Although stratification and weighting were used to ensure that population demographics were reflected, it is possible that those who chose to respond differed in their perceptions and attitudes from those who did not. Because the survey was about palliative care, those with some knowledge of palliative care might have been more likely to participate. Indeed, the proportion of participants who had heard of palliative care was larger than in broader health surveys that included questions about palliative care,[15 16] but similar to a Canadian survey on awareness of palliative care.[35] Importantly, the sizeable denominator of participants who had heard of palliative care was advantageous in achieving our aim of comparing attitudes about palliative care among those with varying degrees of perceived knowledge and actual knowledge. The survey was available only in English and French; however, the raw percentage of participants not born in Canada was similar to that of the Canadian population (approximately 20%).

CONCLUSIONS

Members of the public with a high perceived knowledge of palliative care tended to associate it with end-of-life care and were less likely to perceive it as hopeful, whereas those with greater knowledge of its contemporary definition had more positive associations. Enacting a model of integrated palliative care will require a coordinated effort that includes not only those currently providing and receiving care within the healthcare system but also the wider public. Public health education efforts should promote a consistent definition of palliative care that includes its involvement early in the disease course alongside life-prolonging therapies, while also directly addressing misperceptions.

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