Original Article

Palliative Care Awareness Among Advanced Cancer Patients and Their Family Caregivers in Singapore

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Abstract

Introduction: We investigated the awareness of palliative care (PC) services in advanced cancer patients and their family caregivers and whether negative perceptions was a possible barrier to PC utilisation in Singapore. Materials and Methods: Patients with stage 4 solid cancer and their caregivers were interviewed between July 2016 and March 2018 at outpatient clinics located in the medical oncology departments of 2 major public hospitals in Singapore. Patients and caregivers were asked whether they were aware of PC services, how they first learned about them, who first recommended PC to the patient, whether the patient had received PC, and reasons for not receiving PC. Results: Awareness of PC was lower in patients compared to caregivers (43% vs 53%; P <0.01). The odds of being aware in patients was higher if they had higher education (odds ratio [OR] = 2.927; P <0.001) and higher income (OR = 1.798; P = 0.005). Compared to patients, more caregivers reported that a healthcare provider recommended PC to the patient (10% vs 20%; P <0.012). Furthermore, 7% of patients and 15% of caregivers reported that the patient received PC (P = 0.031). The most common reasons for not receiving PC reported by patients and caregivers (respectively) were that the patient was still receiving treatment (68% and 78%), it is not time for PC (76% and 59%) and PC would not be of help (18% and 19%). Conclusion: Less than half of patients indicated an awareness of PC. Our findings suggest that efforts should be made to increase awareness of PC and promote its acceptance in cancer patients and their family caregivers in Singapore.

Ann Acad Med Singapore 2019;48:241-6

Key words: Decision-makers, End-of-life, Perceptions

Introduction

Cancer is the primary cause of death in Singapore and accounts for 30% of all deaths.[1] Patients with advanced cancer suffer from many problems including pain, side-effects from treatment and psychological distress.[2,3] To respond to the needs of these patients, international and local organisations recommend that palliative care (PC) be provided early in the course of illness and integrated with standard oncology care.[4,5] The goal of PC is to improve the quality of life of patients with any life-limiting illness and of their family caregivers by addressing physical, psychosocial and spiritual needs.[4] Several studies have shown that patients with advanced cancer who receive early integration of PC have better quality of life and less depression compared to patients who receive standard oncology care.[6-8]

Despite guidelines, the literature shows that patients lack awareness of PC and have negative perceptions about PC which, in turn, are associated with late or low utilisation of PC services.[9-11] This has been shown to be especially the case for patients with lower education or income.[12,13] Patients also perceive PC as being an alternative to life-extending treatments—that it is only for those nearing end-of-life[14] and associate it with losing hope.[9,15] Therefore, one of the goals of the National Strategy for Palliative Care (NSPC

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2011) in Singapore is to promote public awareness and acceptance of PC services.[16]

The NSPC also recommends promoting open communication on PC between healthcare professionals, patients and caregivers.[16] However, in Singapore, family caregivers often assume the role of being the primary decision-makers for patients and of communicating with the treating physician on the patient's behalf, especially when the patient is an elderly parent.[17-19] These caregivers—with the intention to protect the patient—may not discuss PC with their loved one and may ask physicians not to discuss it with the patient fearing that the patient may lose hope.[20,21] For the same reason, physicians may also not feel comfortable discussing PC with their patients or they may just conform to the wishes of the family.[22] The main aim of this study was to investigate the awareness of PC services in patients with advanced cancer and in their family caregivers in Singapore. We hypothesised that patients are less likely than their caregivers to be aware of PC services and that physicians are more likely to discuss PC with caregivers than patients. The secondary aim was to investigate the relationship between patient demographic characteristics and being aware of PC services. We hypothesised that patient education and income levels are significant predictors of PC awareness. Lastly, we also aimed to investigate whether negative perceptions were possible barriers to PC utilisation (and we were expecting this). The findings from this study can be used to develop strategies and interventions to increase awareness and acceptance of PC in patients with advanced cancer and in their family caregivers.

Materials and Methods

Participants and Study Setting

The data used in this study came from the baseline survey of a cohort study called Cost of Medical Care of Patients with Advanced Serious Illness in Singapore (COMPASS). The COMPASS protocol paper provides detailed information on the study design.[23] In brief, the baseline questionnaire was administered between July 2016 and March 2018 at outpatient clinics located in medical oncology departments of 2 major public hospitals in Singapore. Patients who were Singapore citizens or permanent residents, aged at least 21 years and diagnosed with stage 4 solid cancer were identified from their medical records and were approached by trained interviewers. Patients were further screened for adequate functional status for participation by: 1) having an Eastern Cooperative Oncology Group (ECOG) performance status ≤2, and 2) being cognitively intact (determined via medical record documentation or tested via the Abbreviated Mental test for those aged ≥60). The inclusion criteria for caregivers included being aged ≥21 and being one of the main persons providing care to the patient or ensuring provision of care or involved in making treatment decisions on behalf of the patient. The study was approved by the SingHealth Centralised Institutional Review Board.

Survey Development

The survey was administered in the preferred language of the participants—English, Mandarin or Malay—which covers 99.5% of language literacy in Singapore. The survey was administered via in-person interviews to the patients while caregivers could opt for completing it on their own. The patient and caregiver questionnaires were developed in consultation with oncologists—first in English and then translated into Mandarin and Malay by professional translators. The questionnaires were finalised after cognitive interviews with 10 participants for each language.

Participants were asked whether they were aware of PC services. Those who were aware about PC were further asked how they first learned about PC services, whether a physician or a healthcare provider had recommended PC to the patient and whether the patient had received PC. Reasons for not receiving PC were documented and this information provided insights on participants' perceptions about PC. The questionnaire also included questions on demographic characteristics.

Analysis

We first present the descriptive statistics on the demographic characteristics of the full sample of patients and caregivers. We then present statistics on PC awareness and if aware, how participants first learned about PC services, whether a healthcare provider recommended PC and whether the patient had received PC. Binomial logistic regression was performed to investigate the relationship between demographic characteristics and patient PC awareness (aware of PC = 1; otherwise, 0). The independent variables of interest were education level (higher than secondary education = 1; otherwise, 0) and income level (higher than median income = 1; otherwise, 0). We controlled for other demographic characteristics, such as gender, age, ethnicity and marital status.

We compared patient statistics with those of caregivers for dyads where both patients and caregivers were recruited using McNemar's test, which is the appropriate version of the chi-square test in the presence of matched pairs. Patients and caregivers who reported not receiving PC at the time of the survey were asked the main reasons for not receiving PC and were allowed to choose from multiple options. Statistical significance was measured at the 5% level. All analyses were conducted in Stata 14 (StataCorp 2015. Stata Statistical Software: Release 14. College Station, TX: StataCorp LP).

Results

The survey was administered to 600 patients and 290 caregivers of these patients. The number of caregivers recruited was lower either because patients did not have a companion caregiver at the time of recruitment or caregivers did not agree to be involved in the study. Table 1 presents the demographic information of the participants.

Table 1. Patient and Caregiver Demographic Characteristics

	Patient (n = 600)	Caregiver (n = 290)
Age, mean (SD)	61 (11)	51 (14)
Female (%)	54	65
Education (%)		
No formal	10	2
Primary and secondary	59	42
Above secondary	31	56
Ethnicity (%)		
Chinese	79	76
Malay/Indian/Others	21	24
Marital status (%)		
Married	73	78
Others	27	22
Employment (%)		
Full-time, part-time	36	60
Others (homemaker, retired, unemployed)	64	40
Median household income ($)*	3500	3500
Religion (%)		
Buddhist	35	30
Christian	22	23
Muslim	16	18
Others	12	11
No religion/free thinker	15	18
Relationship to patient (%)		
Spouse	NA	47
Child	NA	37
Others	NA	16
Primary cancer site, n (%)		
Respiratory	169 (28)	NA
Gastrointestinal	156 (26)	NA
Breast	96 (16)	NA
Genitourinary	78 (13)	NA
Gynaecological	53 (9)	NA
Others†	48 (8)	NA

NA: Not applicable; SD: Standard deviation

*n = 523 for patients; 72 patients reported not knowing their household income and 5 patients did not answer the question. n =189 for caregivers; the income question was only asked to those who worked full- or part-time (n = 195). Among these caregivers, 6 reported not knowing their household income and 2 did not answer the question.

†Including head and neck, musculoskeletal, neurological and skin.

The mean age for the patient and caregiver samples was 61 and 51 years, respectively. The majority of the patients and caregivers were female (54% and 65%), Chinese (79% and 76%) and married (73% and 78%). Most patients had only primary or secondary education (59%) and were not in the workforce (64%) while the majority of caregivers had above secondary education (56%) and were full- or part-time employed (60%). The most prevalent religion was Buddhism among patients (35%) and caregivers (30%). Almost half of the caregivers (47%) were spouses of patients. The most common site of the primary cancer was lung (28%), followed by gastrointestinal (26%) and breast (16%).

Almost half of the patients (46%) were aware of PC (Table 2). Among patients who were aware of PC (n = 274), about half (49%) had first heard about it from their family and friends; only 12% had heard from a physician or other healthcare provider. Among those who were aware of PC, only 8% reported that a physician or a healthcare provider had recommended PC and 4% reported receiving PC. As expected, having secondary education or higher (odds ratio [OR] = 2.927; P <0.001) and having higher than median income (OR = 1.798; P = 0.005) were significant predictors of PC awareness among patients (Table 3).

As hypothesised, PC awareness was lower among patients compared to caregivers (43% vs 53%; P <0.01) among patient-caregiver dyads (n = 290) (Table 2). Both groups reported family and friends to be the primary source of information on PC (51% vs 40%). Among dyads who were aware of PC (n = 81), compared to patients (10%), more caregivers (20%) reported that a physician or a healthcare provider had recommended PC to the patient (P = 0.012). This finding is consistent with our hypothesis. When asked if the patient had received PC, 15% of caregivers reported that the patient had received PC while only 7% of patients stated that they did (P = 0.031).

The reason reported for not receiving PC by 68% of patients (n = 263) and 78% of caregivers (n = 69) was that the patient was still receiving treatment (Table 4). The second most cited reason reported by 76% of patients and 59% of caregivers was not believing that it was time for PC. Participants also either reported that PC would not be of help (18% of patients and 19% of caregivers) or that patient's physicians do not think that PC would be of help (7% of patients and 16% of caregivers). A smaller percentage of patients (6%) and caregivers (10%) also reported that getting PC means giving up on life. Study participants also cited other reasons such as PC being expensive (10% for both groups) and not knowing much about PC (8% of patients and 7% of caregivers).

Table 2. Awareness of PC Services

	Full Patient Sample	Dyad		
		Patient	Caregiver	*P* Value
Aware of PC services? (%)	n = 600	n = 290		*P* <0.001
Yes	46	43	53	
No	49	52	34	
Not sure	5	5	10	
(If aware) How first learned about PC services? (%)	n = 274	n = 81		*P* = 0.090
Physician or other healthcare provider	12	19	28	
Family/friends	49	51	40	
Personal research	6	2	5	
Internet/media	29	23	20	
Others	4	5	7	
(If aware) Physician or healthcare provider recommended PC? (%)	n = 274	n = 81		*P* = 0.012
Yes	8	10	20	
No	92	90	78	
Not sure	<1	0	2	
Whether patient received PC? (%)	n = 274	n = 81		*P* = 0.031
Yes	4	7	15	
No	96	93	85	

PC: Palliative care

Table 3. Odds Ratios for Patients Being Aware of PC as a Function of Demographic Characteristics (n = 523)*

	Odds Ratio (SE)	*P* Value
Higher education (higher than secondary education)	2.927 (0.652)	0.000
Male	0.833 (0.164)	0.354
Age	1.005 (0.010)	0.585
Chinese ethnicity	0.729 (0.168)	0.172
Married	0.739 (0.161)	0.165
Higher income (higher than median income)	1.798 (0.372)	0.005
Having comorbidities (other than cancer)	1.017 (0.230)	0.942
Constant	0.656 (0.406)	0.496

PC: Palliative care; SE: Standard error

*n = 523 for patients; 72 patients reported not knowing their household income and 5 patients did not answer the question.

Table 4. Reasons for Patients Not Receiving PC at the Time of the Survey

	Patient, % (n = 263)	Caregiver, % (n = 69)
Patient is still receiving treatment for patient's disease	68	78
Do not believe it's time for hospice palliative care	76	59
Do not think that hospice palliative care would be of help to the patient	18	19
Patient's doctors do not think that hospice palliative care would be of help to the patient	7	16
Getting hospice palliative care will be like giving up on life	6	10
It is expensive	10	10
Do not know much about it	8	7

PC: Palliative care

Discussion

Less than half of patients in our sample reported being aware of PC and the odds of awareness was higher among those with higher income and education levels. Our findings also show that compared to patients, more caregivers reported that they first learned about PC from a healthcare provider. In addition, more caregivers reported that a physician or a healthcare provider recommended PC to the patient and that the patient received PC services. Our study also revealed negative perceptions of PC in cancer patients and their caregivers.

Awareness of PC services among patients in our study was 46%. This is lower than other developed countries such as the United States where PC awareness was reported to be as high as 77% in outpatient cancer patients.[10] The odds of PC awareness in patients was higher if they had higher education and income. This is consistent with findings from previous studies which showed that education and income levels are positively correlated with PC awareness.[10,12,13]

We also found that, among the patient-caregiver dyads who were aware of PC, only 10% of patients and 20% of caregivers reported that a physician or a healthcare provider recommended PC. Considering the international guidelines on integrating PC into standard care early in the course of advanced cancer, most patients in our sample should have been recommended PC. The low rates might be due to factors related to healthcare providers and the healthcare system.[24] Referrers may be concerned about limited availability of PC specialist teams and other PC resources or they may be unsure on when it is appropriate to refer a patient to a PC specialist team. In addition, not all physicians are equipped with communication skills to discuss PC referral with patients.[25] It is also possible that primary referring oncologists may have negative perceptions about PC or on the roles of the PC team.[26,27]

Our findings also show that compared to patients, more caregivers reported that they first learned about PC from a healthcare provider, that a physician or a healthcare provider recommended PC to the patient and that the patient had received PC services. These findings suggest that healthcare providers are more likely to talk to caregivers than patients about PC. Although providers may feel more comfortable discussing this topic with caregivers than patients, patients may have different treatment preferences from their caregivers[28] and should be informed of the available care options.

Our study revealed perceptions of cancer patients and their caregivers about PC. The majority of patients and caregivers reported "patient still receiving treatment" as a reason for the patient not receiving PC. This shows that participants perceive that patients have to stop treatment to receive PC. In addition, about 20% of patients and caregivers reported that PC would not be of help. Similar findings were found in a survey of the general public by Lien Foundation. When asked why participants would not consider PC for a life-threatening illness, 26% of respondents reported that they would focus on curing the illness and 35% reported that there is no need or no use for PC.[29] The negative perception of PC in patients and the general population suggests demand-side barriers to PC utilisation in Singapore.

The cost of PC services also seems to be a concern for about 10% of patients and caregivers. Although patients and their families can use their MediSave (a Singapore national medical savings scheme that sets aside part of an individual's income to help pay for certain medical expenses) to pay for PC services (and up to 80% subsidies are provided for PC-related services), some families may not be able to afford PC services or may not be aware of the available subsidies. Consulting patients and caregivers on financial matters and increasing government subsidies for PC may help to alleviate this problem.

Our study is not free of limitations. The rates of PC recommendation and utilisation might be underreported in the survey because some patients and caregivers might not know what PC entails although the patient was referred to and/or received PC services. This might especially be the case if PC services were provided by the oncology team.

PC in Singapore started as charities initiated by volunteers which developed into professional services in less than 10 years.[30] It is now recognised as an essential part of the healthcare system and has been offered in hospitals, hospices and at home for over 30 years.[16] National guidelines recommend making PC as part of standard care for those who are likely to die within the next 12 months.[5] In order to achieve these objectives, efforts should be made to increase awareness of PC services in Singapore in order to be on par with other developed countries,[31] and to understand why patients and their caregivers think PC are not helpful. Future research should be conducted to understand the perceptions of referring physicians about PC, whether there is a need for training programmes to help healthcare providers assess when to refer patients to PC and develop skills and confidence to discuss PC-related issues more comfortably with their patients.[32] Further research can also explore other potential barriers from the healthcare system's perspective.

Conclusion

Our findings suggest that efforts should be made to increase awareness of PC and to promote its acceptance among cancer patients and their family caregivers in Singapore. Based on our findings, awareness campaigns should focus on explaining how PC services can help patients and their families throughout the course of advanced cancer—not just at end-of-life—and that PC can be received with standard care.

Acknowledgement

The authors would like to thank their data collection team at Lien Centre for Palliative Care for their contributions to the study and the participants for giving their time and thoughts in completing their survey. They would also like to thank Ms Audrey Jia Jia Lee for her help with the literature review for the manuscript. The study was funded by Singapore Millennium Foundation (2015-SMF-0003) and Lien Centre for Palliative Care (LCPC-IN14-0003). The trial was prospectively registered on 9 June 2016 (NCT02850640).

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