Perception towards palliative care among patients with pulmonary hypertension in malaysia: a correlation with disease status

Sue Kiat Tye[1], Norazlina Susila Razali[2], Shakila Amira Ahmad Shauqi[2], Nor Athirah Azeman[3], Nurul Fazira Basran[3], Janet Huey Jing Liew[4] and Ming Chern Leong[4] (ORCID)

[1]Counselling and Chaplaincy Department, Institut Jantung Negara, Kuala Lumpur, Malaysia; [2]Pulmonary Hypertension Unit, Patient Education Centre, Institut Jantung Negara, Kuala Lumpur, Malaysia; [3]Research Department, Institut Jantung Negara, Kuala Lumpur, Malaysia and [4]Paediatric & Congenital Heart Centre, Institut Jantung Negara, Kuala Lumpur, Malaysia

Abstract

Objectives: This study aimed to describe the perception of Malaysian patients with pulmonary hypertension towards palliative care and their receptivity towards palliative care. *Methods:* This was a cross-sectional, single-centre study conducted via questionnaire. Patients aged 18 years old and above, who were diagnosed with non-curable pulmonary hypertension were recruited and given the assessment tool – perceptions of palliative care instrument electronically. The severity of pulmonary hypertension was measured using WHO class, N-terminal pro B-type natriuretic peptide and the 6-minute walking test distance. *Results:* A total of 84 patients [mean age: 35 ±11 years, female: 83.3%, median N-terminal pro B-type natriuretic peptide: 491 pg/ml (interquartile range: 155,1317.8), median 6-minute walking test distance: 420m (interquartile range: 368.5, 480m)] completed the questionnaires. Patients with a higher WHO functional class and negative feelings ($r = 0.333$, $p = 0.004$), and cognitive reaction to palliative care: hopeless ($r = 0.340$, $p = 0.003$), supported ($r = 0.258$, $p = 0.028$), disrupted ($r = 0.262$, $p = 0.025$), and perception of burden ($r = 0.239$, $p = 0.041$) are more receptive to palliative care. WHO class, N-terminal pro B-type natriuretic peptide, and 6-minute walking test distance were not associated with higher readiness for palliative care. In logistic regression analyses, patients with positive feelings ($\beta = 2.240$, $p = < 0.05$), and practical needs ($\beta = 1.346$, $p = < 0.05$), were more receptive to palliative care. *Conclusions:* Disease severity did not directly influence patients' readiness for palliative care. Patients with a positive outlook were more receptive to palliative care.

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Pulmonary hypertension is a progressive disease with poor long-term outcomes.[1,2] The emergence of novel pulmonary hypertension targeted therapies has improved the life expectancy of patients, but the therapy is not curative. Notably, despite therapy, the disease continues to progress with varying degrees of its debilitating symptoms from pulmonary hypertension and its associated complications such as impaired effort tolerance, heart failure, and cyanosis-related complications. These morbidities profoundly affect the quality of life and increase the burden on the healthcare system.[2,3]

Palliative care is a form of care that focuses on providing relief from symptoms caused by chronic illnesses. Symptomatic patients with pulmonary arterial hypertension and CHD who are not amenable to curative treatment benefit from palliative care. Palliative care improves the health-related quality of life for patients and their families. Also, it improves the patients' and their carers' social and mental health. However, there is a paucity of literature to guide the introduction of palliative care in disease management, even though there is an increasing recognition of the importance of doing so.[4,5] While the introduction of palliative care is not new in the field of oncology medicine, its use in the care of pulmonary hypertension is still very limited, especially in Asian countries. In Asia, it is unclear how patients will respond to palliative care and how it is viewed – whether it will be welcomed or viewed negatively as a sign of imminent death or that the carers are giving up on them. It is, therefore, impossible to extrapolate these views from studies of the West given the difference in the cultures, beliefs, and social stigma.

The objective of the study was to describe the perception of Malaysian patients with pulmonary hypertension towards palliative care concerning the severity of the disease, particularly their readiness to receive early palliative care.

Methods

Patient selection

This was a cross-sectional, single-center study conducted via questionnaire. Patients aged 18 years old and older, who were diagnosed with pulmonary hypertension and deemed unsuitable for curative treatment, were recruited into the study. Patients were defined as having non-curative pulmonary hypertension and had previous cardiac catheterisation demonstrating: (a) pulmonary vascular resistance indexed of > 8 Woods unit x m2, (b) pulmonary: systemic vascular resistance index > 50%, and (c) baseline oxygen saturation of < 95% at rest. Patients who were planned for treatment, had concomitant terminal diseases and those under 18 years of age, were excluded from the study. Patients with CHD who were previously treated but had progressive pulmonary arterial hypertension disease were also included in the study. In Malaysia, heart and lung transplants are far and few in between and hence are not a prospective treatment option.

The clinical condition of the patients was measured using WHO functional class, N-terminal pro B-type natriuretic peptide and the 6-minute walking test distance. These parameters were performed 6–12 months from the date of the survey. The cut-off values were derived from the REVEAL risk stratification of patients with pulmonary hypertension.[6] When the survey was conceptualised, the updated version of the REVEAL risk stratification was yet to be available. Therefore the cut-off values were those of the older REVEAL risk stratification. REVEAL risk stratification was not used as the patients in the cohort did not undergo a routine cardiac catheterisation. In addition, many of these patients had CHD with volume loading to either one of the ventricles and hence were not suitable for the REVEAL risk stratification. Cardiac catheterisation-derived hemodynamics were not used as cardiac catheterisation was not routinely performed during follow ups.

Data collection

The study population was identified from the in-house pulmonary hypertension database. Baseline demography and clinical data, e.g., the severity of pulmonary hypertension, were collected from the database. Contact details of the patients were identified and used to contact them.

Perceptions of palliative care instrument was used to evaluate the patients' perceptions of palliative care (Supplementary Material). It consisted of 37 items with seven-point Likert-type scales, assessing (a) feelings about palliative care, (b) thoughts about palliative care, (c) the needs of palliative care, and (d) perceptions of burden. The description of the perceptions of palliative care instrument subscale is tabulated in Table 1.

The perceptions of palliative care instrument was scored on a Likert scale of 1–7, with the higher scores representing strong levels of agreement with the statements of attitudes and beliefs about palliative care. It has good reliability and validity and has been used in patients with pulmonary arterial hypertension.[6,7] To ease the understanding of the respondents, the perceptions of palliative care instrument was translated and back-translated into the local language, Bahasa Malaysia, and reviewed by local language experts before its use in this study. As for the readiness for palliative care, it was first assessed by the scaling question. "How receptive are you towards palliative care now?" The question scale ranged from 0 to 10, with higher scores indicating a more receptive attitude towards palliative care services. The question was further directed to a

Table 1. Description of perceptions of palliative care instrument.

Subscales	Description
Feelings about palliative care	Refers to the patients' emotions toward palliative care
Negative feelings	Feeling anxiety and fear toward palliative care
Positive feelings	Feeling reassurance and hope toward palliative care
Cognitive Thoughts	Patients' reaction toward palliative care
Hopelessness	Patients' perception that their illness was terminal and out of control.
Being supported	Explore whether the aptients received adequate support from the family and healthcare professionals.
Disrupted	Explore the patients' perception as to whether the illness disrupted their daily routin.
Needs	Palliative care needs of the patients, which includes their emotional, practical, and total needs
Perceptions of Burden	Explores the patients' perceptions of being a burden to others around them.

dichotomous question with a score of 0–4 denoted as "No" while a score of 5–10 as "Yes," which was analysed in logistic regression. Its permission for use was granted by its creator.

The assessment tool was electronically administered to patients via Google Forms from March until August 2021. All questions were formulated in a bilingual format, containing the original English version and a translated Bahasa Malaysia version. A phone number was provided to allow participants to clarify doubts concerning the question to prevent misinterpretation of the questions. The patients were followed up two weeks after the assessment tool was distributed. If the assessment tools were not filled out, another reminder would be issued. Patients who did not respond after the issuance of two reminders were deemed not keen to participate in this study. As this study involved an online survey, a response from the participants was a sign of consent and no further written consent was required. Patients were informed prior to the start of the survey that their participation in the study would not affect their future care of patients and that their participation was entirely voluntary. Scale scores were computed as the sum of the items divided by the number of items answered. If more than 50% of the items on the scale were missing, the scale score would not be computed.

Data analyses

Categorical data were described as a number with frequency and percentage while continuous data as median with interquartile range or mean with standard deviation, as appropriate. Pearson Correlation/Spearman rank correlation analyses were conducted to study the relationship between health-related quality of life, perception of palliative care, and demography and clinical variables. A p-value of < 0.05 in the context of a 2-sided test was considered significant. Logistic regressions were performed to examine the demographic, clinical variables and perceptions of palliative care instrument to assess for significant predictors towards the readiness of palliative care for risk factors with significant p values. The statistical analyses were carried out using IBM SPSS Statistics version 28.0.0.0 (SPSS Inc., Chicago, IL). This

study was approved by the institutional review board (IJNREC/504/2021).

Results

Participants characteristics

A total of 84 patients completed the questionnaires. Table 2 summarises the demography and clinical characteristics of the study population. The mean age during the survey was 35 ± 11 years, with the overwhelming majority being female (83.3 %).

Most respondents were in moderate severity of pulmonary hypertension as defined by the Compera 3-strata risk stratification.[8] Fifty-five (65.5%) respondents had WHO I and II. The median N-terminal pro B-type natriuretic peptide was 491pg/ml (interquartile range: 155,1317.8). Only a third (n = 29) of the respondents had a normal N-terminal pro B-type natriuretic peptide. The median 6-minute walking test distance was 420 m (interquartile range: 368.5, 480m), with the majority (54.8%) of the respondents in the moderate range (165m–440m).

In the questionnaire, we asked our respondents what would ease their acceptance of palliative care. Fifty-three (63.1%) of respondents felt that if the term palliative care could be changed to supportive care, they would feel more receptive towards it.

Correlation of perception of palliative care, demographics and clinical variables, and receptivity towards palliative care

Table 3 depicts the relationships between the respondents' demographic and clinical characteristics and their perceptions of palliative care instrument scores. In bivariate analyses, significant positive correlations between higher WHO functional class and negative feelings (r = 0.333, p = 0.004), as well as higher WHO functional class and cognitive reaction to palliative care: hopeless (r = 0.340, p = 0.003), supported (r = 0.258, p = 0.028), disrupted (r = 0.262, p = 0.025), and perception of burden (r = 0.239, p = 0.041). Similarly, significant positive correlations were found between higher N-terminal pro B-type natriuretic peptide and perceptions of palliative care instrument scales of cognitive reaction to palliative care: hopeless (r = 0.261, p = 0.023) and a negative correlation between higher N-terminal pro B-type natriuretic peptide and feeling of being supported (r = –0.303, p = 0.008). A significant correlation was also noted between 6-minute walking test distance and feeling supported (r = 0.286, p = 0.021).

Table 4 describes the relationship between perceptions of palliative care instrument scores and respondents' readiness for palliative care. Respondents with positive emotion (r = 0.428, p < 0.001) and who felt supported (r = 0.374, p = < 0.001) were noted to be positively correlated with readiness for palliative care, suggesting patients with greater positive emotions and with perceived greater social support were correlated with higher readiness for palliative care. Meanwhile, disrupted cognitive thoughts (r = -0.270, p = 0.013) were negatively correlated with the readiness for palliative care, implying that the more the illness affected the patients' live routines, the lower the receptivity of patients towards palliative care.

Logistic regressions on the effects of demography, clinical variables, and perceptions of palliative care instrument scores to predict patients' readiness for palliative care are tabulated in Table 5. The logistic regression model was statistically significant, $\chi 2 (16) = 29.761$, p < .05. The model explained 61.9% (Nagelkerke R^2) of the variance in readiness for palliative care, proving the sample data fit an expected set of data from a population with a

normal distribution. On top of that, the finding also showed the model correctly classified 89.1% of cases, indicating a high accuracy in classification.

Table 2. Demographic and clinical variables of the respondents.

Demographic	Total respondents (n = 84), n (%)
Gender	
Female	70 (83.3%)
Male	12 (14.3%)
Missing data	2 (2.4%)
Age (years)	35 ± 11
Religion	
Islam	58 (69.0%)
Buddhism	11 (13.1%)
Hinduism	4 (4.8%)
Christianity	3 (3.6%)
Sikhism	1 (1.2%)
No data	7 (8.3%)
Marital status	
Single	30 (35.7%)
Married	44 (52.4%)
Divorced	2 (2.4%)
No data	8 (9.5%)
WHO Class	
I	13 (15.5%)
II	43 (51.2%)
III	13 (15.5%)
IV	4 (4.8%)
Missing data	11 (13.1%)
NT-proBNP (pg/ml)	
Normal (<400)	28 (33.3%)
Moderate (400 – 1400)	30 (35.7%)
Abnormal (>1400)	18 (21.5%)
No data	8 (9.5%)
6MWT (distance, m)	
Poor (<165m)	1 (1.2%)
Moderate (165m – 440m)	46 (54.8%)
Normal (>440m)	18 (21.4%)
No data	19 (22.6%)
Pulmonary hypertension group	
Group 1	63 (75.0%)
Group 2	7 (8.3%)
Group 3	3 (3.6%)
Group 4	3 (3.6%)
Group 5	8 (9.5%)

6MWT=6-minute walking test; NT-proBNP=N-terminal pro B-type natriuretic peptide; WHO= world health organisation.

Table 3. Relationship between the severity of the respondents' pulmonary hypertension and perceptions of palliative care instrument scores.

PPCI Scale	6MWT Distance		WHO Class		NT-proBNP	
	r	p value	r	p value	r	p value
How ready are you to hear about palliative care now?	0.175	0.371	0.125	0.767	0.172	0.326
Negative emotion	0.035	0.779	0.333	0.004*	0.205	0.076
Positive emotion	0.014	0.913	0.009	0.940	−0.201	0.082
Hopeless	0.087	0.491	0.340	0.003*	0.261	0.023*
Supported	0.286	0.021*	0.258	0.028*	−0.303	0.008*
Disrupted	0.014	0.914	0.262	0.025*	0.094	0.421
Emotional needs	0.042	0.74	0.217	0.066	0.038	0.743
Practical needs	0.162	0.198	0.129	0.277	−0.105	0.365
Perception of burden	0.148	0.241	0.239	0.041	0.052	0.658

6MWT=6-minute walking test; NT-proBNP=N-terminal pro B-type natriuretic peptide; PPCI=perception of palliative care instrument; WHO=world health organisation.
*depicts statistical significance.

Table 4. The correlation between perceptions of palliative care instrument scores and respondents' readiness for palliative care.

PPCI Scale	How receptive are you to palliative care now?	
	r	p value
Negative emotion	−0.084	0.446
Positive emotion	0.391	<0.001*
Hopeless	−0.136	0.218
Supported	0.422	<0.001*
Disrupted	−0.149	0.175
Emotional needs	0.168	0.126
Practical needs	0.204	0.062
Perception of burden	−0.019	0.866
Physical functioning	−0.099	0.395

PPCI=perception of palliative care instrument.
*depicts statistical significance.

The results showed that positive emotion was a significant predictor of readiness for palliative care (β = 2.240, p = < 0.05), with patients having greater positive emotion, suggesting a higher receptivity among patients towards palliative care. The finding also showed that practical needs were a significant predictor of readiness for palliative care (β = 1.346, p = < 0.05), with higher practical needs suggesting the patients were more receptive to palliative care.

Discussion

With the advent of pulmonary hypertension targeted therapy, most patients experience a prolonged disease trajectory. During follow-up, it may be challenging to determine the optimal timing to introduce the concept of palliative care. When introduced too early, it may cause unnecessary apprehension and anxiety among patients. Conversely, when introduced late, the patients may miss out on the benefits of palliative care. These patients may be relatively stable in heart failure, punctuated by sporadic episodes of acute decompensation. The unpredictability of the development of heart failure and the rapid deterioration of these patients during acute decompensation is a signal for an earlier introduction of palliative care.

In our study, the timing to introduce palliative care was independent of the severity of the disease, which was measured by the levels of WHO functional class, N-terminal pro B-type natriuretic peptide levels and 6-minute walking test distance. Rather, the major determining factor seemed to be the mental state of the patients. Positive experiences and feelings towards palliative care appeared to reduce barriers to acceptance of palliative care. Consistent with a past study, factors influencing patients' consideration to accept or decline palliative care referral were perceived symptom burden, the perceived need for additional support, and readiness to contemplate a terminal prognosis.[9,10] The early provision of psychosocial and emotional support should be considered a part of care for patients with terminal illnesses, hence the call for earlier referral for palliative care.[5] Once the patients are well-supported emotionally and receive continual compassionate care and empathy from healthcare professionals,[11,12] they are more likely to have positive attitudes and beliefs towards palliative care.

Meanwhile, we noticed a significant positive correlation between the WHO functional class and the "negative emotional" reactions towards palliative care, hopelessness, disturbed, and perception of burden. However, when the patients are surrounded by negative thoughts, resistance towards palliative care starts to surface. Patients with poorer effort tolerance, which was demonstrated by a more advanced WHO functional class, were associated with more negative emotions, such as feeling anxious, depressed, scared, stressed, less hopeful, and more disrupted in their daily routine. They might perceive themselves as a burden to those around them. The finding suggested that palliative care should be instituted before the patient is terminally ill. Meanwhile, there has been a call to recommend that healthcare professionals prepare for negative emotions while introducing palliative care for patients with high symptom burden and disease impact.[6]

Interestingly, patients with more advanced WHO functional classes felt more supported as more attention and resources were channelled to these patients as they drew nearer to the end of the disease trajectory. There was also a significant correlation between the 6-minute walking test distances and the feeling of being supported, underscoring the importance of enhancing the patients' physical capacity through rehabilitation and psychosocial support.

Table 5. Logistic regression analyses of variables affecting the readiness of palliative care.

Variables	B	SE B	95% CI		p	β
			LL	UP		
Demographic						
Age	−0.073	0.066	0.817	1.057	0.264	0.929
Gender	−17.679	13,328.878	0.000	.	0.999	0.000
Clinical variables						
NT-proBNP	0.000	0.001	0.999	1.002	0.488	1.000
6MWT distance	0.002	0.006	0.989	1.014	0.811	1.002
WHO					0.513	
WHO I	−3.020	3.061	0.000	19.682	0.324	0.049
WHO II	−3.097	2.955	0.000	14.791	0.295	0.045
WHO III	−3.512	3.451	0.000	25.874	0.309	0.030
WHO IV	−10.422	5.902	0.000	3.143	0.077	0.000
PPCI						
Negative emotion	−0.087	0.184	0.639	1.316	0.636	0.917
Positive emotion	0.807	0.373	1.078	4.656	0.031*	2.240*
Hopeless	0.077	0.152	0.802	1.454	0.613	1.080
Supported	−0.155	0.219	0.558	1.316	0.480	0.857
Disrupted	−0.195	0.175	0.584	1.161	0.267	0.823
Emotional needs	−0.025	0.065	0.858	1.108	0.699	0.975
Practical needs	0.297	0.138	1.026	1.766	0.032*	1.346*
Perception of burden	−0.022	0.165	0.708	1.352	0.894	0.978

6MWT=6-minute walking test; NT-proBNP=N-terminal pro B-type natriuretic peptide; PPCI=perception of palliative care instrument; WHO=World Health Organisation.
*depicts statistical significance.

Our study found that positive emotions towards palliative care and cognitive reactions to palliative care: supported were significantly associated with and predictive of the readiness to receive palliative care. This information underscored the importance of applying these crucial variables to address negative stereotypes in precluding the utilisation of palliative care and to determine the timing and indications of palliative care referral, as currently, there are no studies that identified robust clinical criteria to trigger referral for palliative care in patients with pulmonary hypertension.[5]

Surprisingly, we noticed a significant negative correlation between disrupted cognitive thoughts and the readiness for palliative care, suggesting that the more the illness affected the patients' daily routines, the lower the receptivity of patients towards palliative care. Some patients with CHD have a strong wish to be normal and healthy, leading them to hide their symptoms from healthcare professionals, and sometimes even from themselves.[13] If the patients perceive their illness affects their lifestyles, this could lead to denial of their ill conditions, and an attempt to exceed their physical limitations. Lower receptivity towards palliative care could be a sign of denial of the conditions and a struggle to feel normal.[14]

Palliative care was commonly viewed not only by the patients but also by the health care professionals as giving up on one's illness, thus underutilising the service.[15] About 63.1% of our participants opined that they would be more receptive to palliative care if it were rebranded as supportive care. This nomenclature carries a less depressing connotation, which was concurred by a previous study.[6] This response could be related to its frequent association with end-of-life and hopelessness by stakeholders.[6,16] As high as 17% of physicians voiced their worry that the terms of palliative care might be perceived negatively by patients, while 43% of physicians were concerned that introducing palliative care might be perceived by patients as giving up hope.[17]

The present study helped to clarify the perception of palliative care among adult patients with pulmonary hypertension, and important variables associated with the readiness for palliative care, especially the impact of positive emotions on patients' readiness for palliative care and the feeling of being supported. Such understanding guides future practices and policies in introducing palliative care to patients with pulmonary hypertension. Public awareness campaigns and counselling are helpful in shedding light on patients' misconceptions about palliative care, understanding their plight and struggles, and providing emotional and practical support to them, thus enhancing their positive emotions and perceived support for palliative care. We hope our study will spur future studies to examine the impact of these variables in enhancing evidence-based interventions, which include psychosocial supports, transition, and education programmes.

Limitations

There are some limitations to consider in interpreting the results. Firstly, this study took place at a single-centre with a relatively small sample size, hence obviating generalisation to all patients with pulmonary hypertension, especially those with different cultures and beliefs. Secondly, only participants who are literate and able to access the internet could participate in the research. Other aspects of patients' lives, including quality of life, mental health status and family dynamics, were not captured in this study. These variables may also affect patients' willingness to accept palliative care.

Conclusions

Disease severity did not directly influence patients' with pulmonary hypertension in their receptiveness to palliative care. Patients with a positive outlook were more receptive to palliative care. This study highlighted the importance of public awareness campaigns and patient counselling to reduce negative feelings, e.g., anxiety and stress, enhance positive emotions, e.g., reassurance and hope, towards palliative care, and increase perceived support from family and healthcare providers. The above elements could be incorporated into the transition care and education programme as part of clinical practices.

   Summary box:

1. Disease severity did not influence the patient's receptiveness to palliative care.
2. Patients with a positive outlook were more receptive to palliative care.
3. Careful handling of patients' psycho-emotional health is important to reduce negative feelings and encourage positive feelings to facilitate the early introduction of palliative care.

References

1. Benza RL, Miller DP, Barst RJ, Badesch DB, Frost AE, McGoon MD. An evaluation of long-term survival from time of diagnosis in pulmonary arterial hypertension from the REVEAL registry. Chest 2012; 142: 448–456. DOI: 10.1378/chest.11-1460.
2. Humbert M, Sitbon O, Chaouat A, et al. Survival in patients with idiopathic, familial, and anorexigen-associated pulmonary arterial hypertension in the modern management era. Circulation 2010; 122: 156–163. DOI: 10.1161/CIRCULATIONAHA.109.911818.
3. Lowe BS, Therrien J, Ionescu-Ittu R, Pilote L, Martucci G, Marelli AJ. Diagnosis of pulmonary hypertension in the congenital heart disease adult population impact on outcomes. J Am Coll Cardiol 2011; 58: 538–546. DOI: 10.1016/j.jacc.2011.03.033.
4. Galiè N, Humbert M, Vachiery JL, ESC Scientific Document Group, et al. 2015 ESC/ERS Guidelines for the diagnosis and treatment of pulmonary hypertension: The Joint Task Force for the Diagnosis and Treatment of Pulmonary Hypertension of the European Society of Cardiology (ESC) and the European Respiratory Society (ERS): Endorsed by: Association for European Paediatric and Congenital Cardiology (AEPC), International Society for Heart and Lung Transplantation (ISHLT). Eur Heart 2016; 37: 67–119. DOI: 10.1093/eurheartj/ehv317.
5. Constantine A, Condliffe R, Clift P, Tulloh R, Dimopoulos K, CHAMPION Steering Committee. Palliative care in pulmonary hypertension associated with congenital heart disease: systematic review and expert opinion. ESC Heart Failure 2021; 8: 1901–1914. DOI: 10.1002/ehf2.13263.
6. Hrustanovic-Kadic M, Ziegler C, El-Kersh K. Palliative care perception in pulmonary arterial hypertension: evaluating the interaction of PPCI, PAH-SYMPACT questionnaire, and the REVEAL 2.0 risk score. Ann Am Thorac Soc 2021; 18: 361–364. DOI: 10.1513/AnnalsATS.202005-552RL.
7. Milne D, Aranda S, Jefford M, Schofield P. Development and validation of a measurement tool to assess perceptions of palliative care. Psych Oncol 2013; 22: 940–946. DOI: 10.1002/pon.3071.
8. Boucly A, Weatherald J, Savale L, et al. Risk assessment, prognosis and guideline implementation in pulmonary arterial hypertension. Eur Respir J 2017; 50: 1700889. DOI: 10.1183/13993003.00889-2017.
9. Schenker Y, Crowley-Matoka M, Dohan D, et al. Oncologist factors that influence referrals to subspecialty palliative care clinics. J Oncol Pract 2014; 10: e37–44. DOI: 10.1200/JOP.2013.001130.
10. Sue-A-Quan R. Patients' experiences and perceptions of the symptom screening with targeted early palliative care (STEP) process. University of Toronto, 2021, https://tspace.library.utoronto.ca/bitstream/1807/108761/1/Sue-A-Quan_Rachel_Ting%20Gee_202111_MSc_thesis.pdf
11. Tye SK, Kandavello G, Gan KL. Types of social supports predicting health-related quality of life among adult patients with CHD in the institut jantung negara (National heart institute), Malaysia. Cardiol Young 2017; 27: 46–54. DOI: 10.1017/S1047951116000068.
12. Tye SK, Kandavello G, Wan Ahmadul Badwi SA, Abdul Majid HS. Challenges for adolescents with congenital heart defects/Chronic rheumatic heart disease and what they need: perspectives from patients, parents and health care providers at the institut jantung negara (National heart institute), Malaysia. Front Psychol 2021; 11: 481176. DOI: 10.3389/fpsyg.2020.481176.
13. Berghammer M, Dellborg M, Ekman I. Young adults experiences of living with congenital heart disease. Int J Cardiol 2006; 110: 340–347. DOI: 10.1016/j.ijcard.2005.08.006.
14. Callus E, Quadri E. Psychosocial aspects of adults with congenital heart disease. In: Alvanrenga M, Byrne D (eds). Handbook of Psychocardiology, Springer, Singapore, 2016.
15. Shen MJ, Wellman JD. Evidence of palliative care stigma: the role of negative stereotypes in preventing willingness to use palliative care. Palliat Support Care 2019; 17: 374–380. DOI: 10.1017/S1478951518000834.
16. Kimeu AK, Swetz KM. Moving beyond stigma–are concurrent palliative care and management of pulmonary arterial hypertension irreconcilable or future best practice? Int J Clin Pract 2012; 66: 2–4. DOI: 10.1111/j.1742-1241.2012.03011.x.
17. Fenstad ER, Shanafelt TD, Sloan JA, et al. Physician attitudes toward palliative care for patients with pulmonary arterial hypertension: results of a cross-sectional survey. Pulm Circ 2014; 4: 504–510. DOI: 10.1086/677365.