

# Correlation of Pediatric Palliative Screening Scale and Quality of Life in Pediatric Cancer Patients

Murti Andriastuti, Pricilia Gunawan Halim, Eny Kusriani<sup>1</sup>, Meidiana Bangun<sup>1</sup>

Department of Child Health, Faculty of Medicine Indonesia University, Cipto Mangunkusumo Hospital, <sup>1</sup>Pediatric Nurse, Cipto Mangunkusumo Hospital, Jakarta, Indonesia

## Abstract

**Context:** Palliative care in children is used to be only intended for those in near end-of-life phase. Ideally, palliative intervention should be given since the first time of cancer diagnosis. Palliative care is introduced from the beginning of the treatment by acknowledging that it helps to ensure an ongoing focus on the quality of life (QOL) so that children still can enjoy their life. Several approaches have been used to identify children with the need of palliative care. **Aims:** The aim was to describe the use of Paediatric Palliative Screening Scale (PaPaS Scale) and its depiction to the QOL of children with malignancies. **Settings and Design:** A cross-sectional study was conducted in sixty children age 2–18 years with malignancies, who were consulted to the palliative team. **Subjects and Methods:** Sixty participants were recruited randomly during the study. PaPaS Scale and QOL (using PedsQL™ cancer module 3.0) were assessed at the same time. Cutoff points of 67 for parent-proxy report and 68.9 for self-report were used, those who have scores <67 and <68.9 were grouped as low QOL group. PaPaS scale was divided into three groups: (1) no palliative care needs (score 10–14), (2) considered palliative care (15–24), and (3) need for palliative (≥25). **Statistical Analysis:** Differences between palliative score and QOL were analyzed using Chi-square and Fisher test. **Results:** Children who have lower QOL based on parent-proxy report (<67) included 25 children; they consist of 16 children (64%) with score 10–14, four children (16%) with score 15–24, and five children (20%) with score ≥25. Children with higher QOL (16 children) consist of ten children (62.5%) with score 10–14, four children (25%) scores 15–24, and two children (12.5%) with score ≥25. In the self-report, children with low QOL (eight children) consist of four children (50%) with score 10–14, four children (50%) with score 15–24, and no children with score ≥ 25. Children with higher QOL (11 children) consist of eight children (72.2%) with score 10–14, two children (18.2%) with scores 15–24, and one child (9.1%) with score ≥25. Statistical analysis showed no correlation between PaPaS score and QOL of children with malignancies in parent-proxy report ( $P = 0.89$ ) and self-report ( $P = 0.37$ ). **Conclusions:** This study showed that children with malignancies already had lower QOL despite the low PaPaS scale they had. The results of this study support the provision of early palliative intervention, starting with a small proportion of intervention to improve the QOL of cancer child.

**Keywords:** Palliative, Paediatric Palliative Screening scale, pediatric, quality of life

## INTRODUCTION

Pediatric palliative care (PPC) is an interdisciplinary care that aims to improve the quality of life (QOL) of all children with chronic and life-threatening conditions as well as their families.<sup>[1,2]</sup> In pediatric patients with cancer, ideally, PC should be introduced from the beginning of the treatment and run alongside the disease care.<sup>[3,4]</sup> Late initiation of palliative care is often associated with lower QOL.<sup>[5-7]</sup> Regardless of the disease, physicians identify the need for PC using palliative screening tools. To date, it is still uncertain whether pediatric patients with cancer are suitable to have the general palliative scales applied.<sup>[4]</sup>

Paediatric Palliative Screening Scale (PaPaS Scale) is one of the screening tools designed to identify children with palliative needs. It consists of a series of questions in five domains, which are almost the same domains described in the spectrum of needs framework.<sup>[2]</sup> The goal of palliative care is to improve QOL and it is worth noting that QOL should be considered

**Address for correspondence:** Dr. Pricilia Gunawan Halim, Praha Residence No. 33 Jl. Salemba Tengah, Jakarta Pusat 10440, Jakarta, Indonesia.  
E-mail: pricilia.gh@gmail.com

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in making decision when PC referrals should be made.<sup>[6]</sup> This study is aimed to describe the use of the PaPaS Scale and its depiction to the QOL of children with malignancies. The result of this study is expected to highlight the importance of specific screening tools for pediatric cancer patients and to emphasize the urgency of early PC integration for all pediatric cancer patients, with no further delay due to the unfulfilled scores in the screening tools.

## SUBJECTS AND METHODS

A cross-sectional study conducted in sixty children age 2–18 years with malignancies who were referred to the palliative team in Cipto Mangunkusumo Hospital, Jakarta. Patients were recruited through consecutive sampling during the study period from January 2019 to June 2019. PaPaS Scale and QOL (using PedsQL™ cancer module 3.0) were assessed at the same time. PaPaS scale was done by the doctor and palliative team. The assessment of QOL was done by parents/patients.

### Measurement of quality of life

Quality of life was measured using PedsQL™ cancer module 3.0 that consisted of eight dimensions. Each dimension consisted of several items to be answered. Item scaling was answered in a 5-point Likert scale from 0 (Never) to 4 (Almost always). Scores are transformed to a 0–100 scale. Items are reversed scored and linearly transformed to a 0–100 scale as follows: 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0. If more than 50% of the items in the scale are missing, the scale scores should not be computed. The mean score is the sum of the items over the number of items answered. A total score is acquired by summing of all the items over the number of items answered on all the scales. Higher scores indicate lower problems. Cutoff points of 67 for parent–proxy report and 68.9 for self-report were used, those who have scores <67 and <68.9 were grouped as low QOL group (Varni, 2005).<sup>[8]</sup> The module is divided into parent–proxy report and self-report based on the age group (2–4 years, 5–7 years, 8–12 years, and 13–18 years).

### Measurement of Paediatric Palliative Screening scale

PaPaS was measured using the PaPaS scale that consisted of five domains: estimated life expectancy, expected outcome of treatment directed at the disease, performance status, symptom and problem burden, preferences of the patient, family, or health-care professional. Each domain was further divided into two to five questions (items) for a total of 13 items. Each item provided at least two choices (scored 0–4). Higher individual or total scores indicate a greater need for PPC. Palliative score was divided into three groups: (1) no palliative care needs (score 10–14), (2) considered palliative care (15–24), and (3) need for palliative ( $\geq 25$ ).

### Statistical analysis

Differences between palliative score and QOL were analyzed using Chi-square and Fisher tests. Data are presented using charts and divided based on QOL questionnaires: parent–proxy report and child report.

## RESULTS

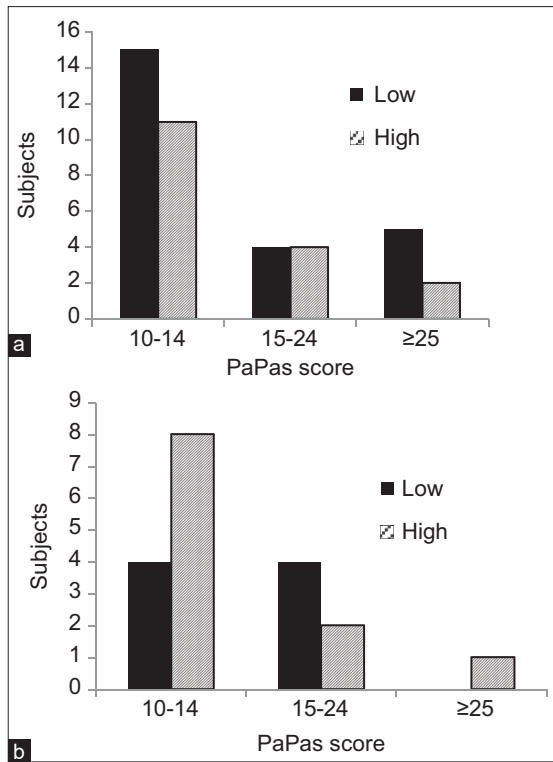
Sixty children were recruited during the study period. They were referred to palliative team due to certain condition during treatment and or hospitalization which considered to need PC. All of them were then assessed by physicians and palliative team, including scoring with PaPaS scale. Participants' characteristics are provided in Table 1.

The assessment of the QOL and PaPaS scale was done in the initial evaluation for all participants. From 60 participants, 38 children (63.3%) have score 10–14, 14 children (23.3%) have score 15–24, and 8 children (13.3%) have score  $\geq 25$ . This showed that when a child is considered to need PC due to certain conditions, the PaPaS score is still low. Further assessment that associate with QOL showed that children who have lower QOL based on parent–proxy report (<67) were 24 children, consist of 15 children (62.5%) with score 10–14, four children (16.7%) with score 15–24, and five children (20.8%) with score  $\geq 25$ . Children with higher QOL (17 children) consist of 11 children (64.7%) with score 10–14, four children (23.5%) scores 15–24, and two children (11.7%) with score  $\geq 25$  [Figure 1a].

In the self-report, children with low QOL (eight children) consist of four children (50%) with score 10–14, four children (50%) with score 15–24, and no children with score  $\geq 25$ . Children with higher QOL (11 children) consist of eight children (72.2%) with score 10–14, two children (18.2%) with scores 15–24, and one child (9.1%) with score  $\geq 25$  [Figure 1b]. Statistical analysis showed no correlation between PaPaS score and QOL of children with malignancies in parent–proxy report ( $P = 0.89$ ) and self-report ( $P = 0.37$ ), respectively.

**Table 1: Characteristics of patients**

Characteristic	n (%)
Gender	
Male	35 (58.3)
Female	25 (41.7)
Age (years)	
2-4	19 (31.7)
5-7	9 (15)
8-12	18 (30)
13-18	14 (23.3)
Diagnosis	
Lymphoma	2 (3.3)
Leukemia	29 (48.3)
Solid tumor	29 (48.3)
Disease duration (years)	
<1	40 (66.7)
$\geq 1$	20 (33.3)
End-of-life period	
Yes	10 (16.7)
No	50 (83.3)
Chemotherapy	
Yes	53 (88.3)
No	7 (11.7)



**Figure 1:** (a) Proxy-reported quality of life and Paediatric Palliative Screening score. (b) Self-reported quality of life and Paediatric Palliative Screening score

Among the variables, we analyzed three variables which possibly affected QOL the most. From parent-proxy report, there was no association between the disease duration, end-of-life period, and chemotherapy treatment with QOL of cancer child [Table 2] as well as in the self-reported module [Table 3]. Children with less duration of the disease do not tend to have higher QOL, likewise, not all children who are not in the end-of-life period tend to have better QOL.

### DISCUSSION

Different from the adult, PPC is generally delivered over a longer time frame and for a wider range of conditions.<sup>[9]</sup> Palliative care is provided to children with life-threatening or life-shortening conditions with a wide range of diagnoses, and there is an overlap with those with severe disabilities and complex needs.<sup>[10]</sup> It was estimated that globally 7 million children and their families required specialized palliative care.<sup>[11]</sup> Based on the mortality data, it was estimated that children aged 0–14 years constitute 6% of the global end-of-life care burden (i.e., nearly 1.2 million individuals).<sup>[12]</sup> Given the prevalence of life-limiting and life-threatening diseases, many of these children and young people will require PC services to manage over 370 International Classification of Diseases-10 diagnostic identified as eligible for the provision of PC.<sup>[13]</sup>

It has been acknowledged that PPC should be integrated into other aspects of pediatrics to make it effective.<sup>[14,15]</sup> However,

**Table 2: Association between variables and pediatric palliative screening score based on parent-proxy report**

Variable	QOL		P
	High, n (%)	Low, n (%)	
Disease duration (years)			
<1	12 (41.4)	17 (58.6)	>0.999
≥1	5 (41.7)	7 (58.3)	
End-of-life period			
Yes	3 (42.9)	4 (57.1)	>0.999
No	14 (41.2)	20 (58.8)	
Chemotherapy			
Yes	15 (42.9)	20 (57.1)	>0.999
No	3 (33.3)	4 (66.7)	

QOL: Quality of life

**Table 3: Association between variables and quality of life based on self-report**

Variable	QOL		P
	High, n (%)	Low, n (%)	
Disease duration (years)			
<1	6 (54.5)	5 (45.5)	>0.999
≥1	5 (62.5)	3 (37.5)	
End-of-life period			
Yes	2 (66.7)	1 (33.3)	>0.999
No	9 (56.2)	7 (43.8)	
Chemotherapy			
Yes	10 (55.6)	8 (44.4)	>0.999
No	1 (100)	0 (0)	

QOL: Quality of life

in fact, the data revealed PC discussion does not occur until late in the illness trajectory, and PC does not begin until close to the time of death. Delays occur both at first PC discussion and PC initiation. Efforts for early PC integration must recognize the complex determinants of PC utilization across the illness timeline.<sup>[3]</sup>

Identifying children who are most likely to benefit from PPC is a great challenge. Referrals typically occur late in the illness trajectory with many children who would benefit not referred at all. Often, the referral was done by a single assessment when physicians believe that the children need PC due to certain conditions, such as chronic pain, end of life, dying, and dyspnea. This understanding of PC only for those in the end-of-life period and dying may be a modifiable factor relevant to late and nonreferral.<sup>[16]</sup> Various approaches have been used to identify appropriate patient populations who will be benefit from PC. Those instruments aim to support health-care professionals in identifying children with PC needs more accurately

PaPaS Scale is a more comprehensive European instrument that currently been used in several countries. It is based on five domains: trajectory of disease and impact on daily activities, expected outcome of disease-directed treatment and burden of

treatment, symptom burden, preferences of patient, parents or health-care professional, and estimated life expectancy. Early validation of this tool has yielded promising results, and it may indeed become a lever to support timely referrals.<sup>[5,17]</sup> Despite this palliative screening tools were intended for a broad spectrum of life-limiting or life-threatening diseases, and especially for children, it consists of chronic disease too. This wide range of diagnosis made those instruments often could not provide a general assessment of PC needs for some illness like oncology. Data showed that despite efforts to spur earlier initiation, many pediatric oncology patients do not receive any PC service, and those who do predominantly receive it near the time of death.<sup>[3]</sup> This condition is opposite to the main purpose of PC, which helps us to ensure a better QOL for children.

In this study, we found that there was no correlation between PaPaS score with the QOL of children with malignancies. This result showed that in pediatric oncology patients, QOL tends to be decreased as the illness goes on. Lower PaPaS score does not depict a better QOL in cancer children. Cancer children will have a disturbance in QOL since the first time of diagnosis, with the peak decrease on the 3<sup>rd</sup> month until the 5<sup>th</sup> month of diagnosis. Impaired QOL can be due to various factors, such as initial shock to the diagnosis and long treatment, followed by overprotective environment that limits the QOL.<sup>[18]</sup> This study supports the integration of PPC in oncology patients along the standard treatment of the disease. Different from other life-limiting diseases, PC should be considered since the beginning of diagnosis in all children with malignancies without exception.

## CONCLUSION

Children with malignancies already had lower QOL despite the low PaPaS scale they had. This study support the provision of early palliative intervention, starting with a small proportion of intervention to improve the QOL of cancer child.

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## Conflicts of interest

There are no conflicts of interest.

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