ORIGINAL ARTICLE

Knowledge and identification of pediatric palliative care needs at a specialized institute in Peru

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This study is part of the research conducted by Angela Debora Argume Huaylinos entitled *Correlación entre el conocimiento y la identificación de necesidades en cuidados paliativos en médicos especialistas del Instituto Nacional de Salud del Niño-Breña, 2023* (Correlation between knowledge and identification of palliative care needs among medical specialists at Instituto Nacional de Salud del Niño-Breña, 2023) [Graduate thesis]. Lima: Graduate School, Universidad Nacional Mayor de San Marcos; 2023.

ABSTRACT

Objective: To determine the correlation between knowledge and identification of palliative care (PC) needs among medical specialists at Instituto Nacional de Salud del Niño-Breña (INSN-Breña – National Institute of Child Health-Breña) in Lima, Peru, in July 2023.
Materials and methods: A cross-sectional, analytical and observational study was conducted.
Results: The study included 180 medical specialists, with 34.40 % aged between 30 and 39 years and 51.11 % being women. The majority had a medical specialty (pediatrics), with intensive care medicine being the most frequent subspecialty. Only 12.22 % of the participants had received prior PC training. The average global pediatric palliative care (PPC) knowledge score was 11.65 ± 2.83. Qualitatively, most participants rated their knowledge as intermediate and demonstrated an adequate level of identification of PPC needs. The average score in the questionnaire for identifying patients with PPC needs was 3.53 ± 0.93. All participants with prior PPC training showed adequate identification of PPC needs. The global knowledge score was higher among those who adequately identified PPC needs compared to those who did not (median 12 [IQR: 10-14] vs. median 11 [IQR: 8-2]; *p:* 0.0068). Likewise, the theoretical and legal domain scores were higher in those with adequate identification of PPC needs.
Conclusions: Most participants rated their knowledge at an intermediate level, with the ethical domain receiving the lowest score. The majority demonstrated an adequate ability to identify PPC needs. A significant but weak correlation was found between the global PPC knowledge score and the identification of PPC needs, as well as between the legal domain and the identification of PPC needs. These findings support the implementation of PPC training programs for medical specialists focusing on both theoretical knowledge and practical skills.

Keywords: Palliative Care; Pediatrics; Knowledge; Identification (Source: MeSH NLM).

INTRODUCTION

The World Health Organization (WHO) states that palliative care (PC) "prevents and relieves suffering through the early detection, correct assessment and treatment of pain and other problems, whether physical, psychological or spiritual" [1,2]. The concept of PC is relatively new in medical practice [2]. In our region, Sociedad Peruana de Cuidados Paliativos (SPCP – Peruvian Society of Palliative Care) was founded in 2003, followed by the establishment of Asociación Latinoamericana de Cuidados Paliativos (ALCP – Latin American Association of Palliative Care) in 2011 [3,4]. The latest ALCP report indicates that PC remains insufficiently addressed and implemented across Latin America, with pediatric palliative care (PPC) services accounting for only 7.90 % of the total PC services [3].

According to the Pan American Health Organization (PAHO), PPC is defined as "all care provided to prevent and alleviate the suffering of children and adolescents and their families when faced with problems associated with life-threatening illnesses. These problems include the physical, psychological, social and spiritual suffering of patients, as well as the psychological, social and spiritual suffering of their family members" [5]. Among Latin American countries, Peru has the lowest rate of PPC teams relative to its population, with 0.58 teams per million inhabitants and 0.20 pediatric teams per million inhabitants under 15 years of age. Specifically for the pediatric population, only two PC teams have been reported [3]. Since 2014, Instituto Nacional de Salud del Niño-Breña (INSN-Breña – National Institute of Child Health-Breña) in Peru has operated a PPC unit (PPCU) since 2014. It provides hospital-based support for children with complex medical conditions. This unit manages an average of 60 consultations per month across various medical specialties within the institution [6,7].

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A common misconception is that PC is only for terminal illnesses; however, WHO states that PC can be initiated at any stage of the disease and provided concomitantly with standard medical treatments [2,5]. In general, PC is recommended for patients with life-threatening or life-limiting conditions, including complex heart problems, cystic fibrosis, cancer, cerebral palsy, among others [5,8].

It is important to highlight that PPC differs significantly from adult PC, leading to unique implementation challenges [9,10]. These challenges include a lower number of cases, which results in greater geographical spread (differences in children's cognitive and developmental stages influence their needs), limited therapeutic options, lack of cultural awareness regarding death in this age group, and insufficient professional PPC training [10,11]. To address the need for early identification of children requiring PPC, a research group developed the Paediatric Palliative Screening (PaPaS) Scale to facilitate timely and appropriate referral to specialized services. This scale has five domains: 1. estimated life expectancy, 2. expected outcome of treatment directed at the disease, 3. performance status, 4. symptom and problem burden, and 5. preferences of patient, family or healthcare professional. A score greater than 15 indicates the need for PPC [12]. Identifying when a pediatric patient needs PPC is the first critical step for healthcare professionals involved in their care [13,14].

Despite the well-documented benefits of early PPC referral, studies show that physicians frequently delay referrals, often due to a lack of formal PPC training [10,15]. The low level of PPC knowledge is reflected in physicians' limited capacity to identify the essential aspects for PPC implementation within pediatric hospital settings. Although the management of pediatric patients requiring PC is referred to a specialized unit [16], it is crucial for medical specialists across all pediatric specialties to have a solid understanding of PPC, as this knowledge significantly impacts clinical decision-making [17,18].

The study aimed to determine the correlation between PPC knowledge and identification of PPC needs among medical specialists at INSN-Breña in Lima, Peru.

MATERIALS AND METHODS

Study design and population

A cross-sectional, analytical and observational study was conducted. The study included medical specialists working at INSN-Breña who had completed at least six months of employment and voluntarily agreed to participate. Interviews were carried out between July 12 and 26, 2023. A non-probability convenience sampling method was used, inviting the institute's medical specialists to participate until the required sample size was reached.

Variables and measurements

To assess the variable *PPC knowledge*, a 24-item questionnaire was developed, divided into three domains: theoretical, ethical and legal. Each domain consisted of eight items, scored as one point for correct answers (response options: true [T] and false [F]). For a qualitative assessment of the results, the following rating scale was applied: high knowledge, 17 to 24 points (67.00 %-100.00 %); intermediate knowledge, 9 to 16 points (34.00 %-66.00 %); and low knowledge, 0 to 8 points (0 %-33.00 %). The questionnaire was validated by four experts using the content validity coefficient (CVC) proposed by Hernández-Nieto et al [19]. Globally, the 24 items achieved a CVC greater than 0.90 across the following aspects: clarity (CVC: 0.9896), coherence (CVC: 0.9922), relevance (CVC: 0.9922) and sufficiency (CVC: 0.9922). Some items required wording modifications as suggested by expert assessment, which were implemented before administering the questionnaire.

To assess the variable *level of identification of PPC needs*, the method reported by Rendón-Macias et al. was used by the medical specialists. Five clinical cases of pediatric patients were developed based on the criteria of the PaPaS Scale [12]. Three of the cases met the threshold score (> 15), indicating PPC needs (the participants responded with either "true" or "false" for each case). Qualitatively, the classification was as follows: adequate identification (3 to 5 points) and inadequate identification (0 to 2 points). The clinical cases were validated through expert assessment, achieving a CVC greater than 0.90 across clarity (CVC: 0.9922), coherence (CVC: 0.9922), relevance (CVC: 0.9922) and sufficiency (CVC: 0.9922).

The estimated time to complete both questionnaires was 15 minutes. Data collection was conducted by the study's lead researcher.

Statistical analysis

Normality was assessed using the Shapiro-Wilk test for quantitative variables, which were then summarized using measures of central tendency and dispersion. Qualitative variables were expressed as percentages. Knowledge scores were compared between participants who adequately identified PPC needs and those who did not. Depending on data distribution, either Student's *t*-test for independent samples (for normally distributed data) or the Mann-Whitney *U* test (for non-normally distributed data) was used. The correlation between PPC knowledge and identification of PPC needs was analyzed using Spearman's correlation coefficient, based on the scores obtained in both questionnaires.

Ethical considerations

The study was approved by the INSN-Breña Research Ethics Committee. All participants voluntarily consented

to answer both questionnaires and provided a written informed consent.

RESULTS

The study included 180 medical specialists, with 51.11 % being women and the median age being 45 years (range: 30–74). All participants were over 30, with the majority in the 30–39 age group. The median experience as specialist was five years (range: 0.50–40) and, in most cases (69.44 %), it exceeded that period. Only 12.22 % had received prior PC training and 65.00 % had a clinical specialty. Pediatrics had the highest representation (45.00 %), followed by traumatology (8.33 %). Additionally, 34.44 % of the participants had a subspecialty, the most frequent being pediatric intensive care medicine (19.35 %), followed by neonatology (12.90 %) (Table 1).

Table 1. Characteristics of the participants

Characteristics	*n* (%)
Age (years)	45 (37-56)*
Age range	
30-39	62 (34.44)
40-49	52 (28.89)
50-59	36 (20.00)
60-69	20 (11.11)
≥ 70	10 (5.56)
Sex	
Female	92 (51.11)
Type of specialty	
Clinical	117 (65.00)
Surgical	63 (35.00)
Specialty	
Pediatrics	81 (45.00)
Traumatology	15 (8.33)
Pediatric surgery	9 (5.00)
Plastic surgery	7 (3.89)
Gynecology	6 (3.33)
Others	62 (34.45)
Subspecialty	62 (34.44)
Type of subspecialty	
Pediatric intensive care medicine	12 (19.35)
Neonatology	8 (12.90)
Pediatric nephrology	4 (6.45)
Others	38 (61.29)
Years of experience as specialist	5 (10.00-20.00)*
≤ 5	55 (30.56)
Prior PC training	22 (12.22)

* Median (interquartile range).

The average score on the questionnaire assessing PPC knowledge was 11.65 ± 2.83, with a minimum of 1 and a maximum of 19. The median scores for the theoretical and ethical domains were 4 (RIC: 4–5) and 3 (RIC: 3–4), respectively, while the average score for the legal domain was 3.83 ± 1.70. Considering the classification of the level of PPC knowledge as high, intermediate or low, the majority of the participants (147 [81.67 %]) fell into the intermediate category (Table 2). The mean score of the questionnaire assessing the identification of PPC needs was 3.53 ± 0.93, with scores ranging from 1 to 5. In terms of qualitative assessment, most participants (156 [86.67 %]) adequately identified patients requiring PPC (Table 2).

Qualitatively, when comparing the level of PPC knowledge with the level of identification of PPC needs, 28.00 % of the participants with a low level of PPC knowledge failed to adequately identify cases, while 100.00 % of the participants with high level of PPC knowledge did so adequately (Table 2).

Table 2. Level of PPC knowledge and level of identification of PPC needs

PPC knowledge	Identification of PPC needs		Total
	Adequate *n* (%)	Inadequate *n* (%)	
Low	18 (72.00)	7 (28.00)	25
Intermediate	130 (88.44)	17 (11.56)	147
High	8 (100.00)	-	8
Total	156	24	180

All the participants who adequately identified PPC needs had received prior PC training. Likewise, no differences were observed in years of experience as specialist among physicians who adequately identified PPC needs and those who did not (Table 3).

Table 3. Years of experience as specialist and training based on the level of identification of PPC needs

Characteristics	Identification		
	Adequate	Inadequate	*p*
Years of experience as specialist	13.35 ± 10.52	11.73 ± 10.15	0.48
≤ 5	46 (29.49)	9 (37.50)	0.42
Prior PC training	22 (14.10)	-	-

When comparing global and domain-specific scores for PPC knowledge and level of identification of PPC needs, participants with an adequate level of identification had significantly higher scores in all areas than those with an inadequate level, except for the ethical domain of PPC knowledge (Table 4).

Table 4. Level of PPC knowledge vs. level of identification of PPC needs scores

PPC Knowledge	Identification of PPC needs		*p*
	Adequate	Inadequate	
Global	12 (10-14)*	11 (8-12)*	**0.0068**[£]
Theoretical domain	4.40 ± 1.16[†]	3.71 ± 1.27[†]	**0.0085**[¥]
Ethical domain	3 (3-4)*	3 (3-4)*	**0.4050**[£]
Legal domain	3.94 ± 1.70[†]	3.17 ± 1.63[†]	**0.0195**[¥]

* Median (interquartile range).
[†] Mean ± standard deviation.
[£] Mann-Whitney *U* test.
[¥] Student's *t* test for independent samples.

A positive but weak correlation was found between the global PPC knowledge score (Rho: 0.1712; *p*: 0.0216) and the legal domain score (Rho: 0.17; *p*: 0.02) with respect to the identification of PPC needs score. No significant correlation was observed for the theoretical (Rho: 0.11; *p*: 0.15) and ethical (Rho: 0.04; *p*: 0.59) domains.

A correlation subanalysis was conducted based on the following variables: sex, type of specialty, being a non-pediatrician, subspecialty, > 5 years of experience as specialist and prior PC training. As shown in Table 5, the correlation between the global PPC knowledge score and the identification of PPC needs score remained positive but weak in the subgroup of male participants in clinical-surgical and non-pediatric specialties.

Table 5. Subanalysis of Spearman's correlation coefficient for the global PPC knowledge vs. identification of PPC needs scores

Subanalysis variable	Rho	*p*
Male sex	0.2903	**0.0061**
Clinical-surgical specialty	0.2768	**0.0223**
Non-pediatricians	0.2511	**0.0122**
Subspecialty	0.2350	**0.0660**
> 5 years of experience as specialist	0.1217	**0.1763**
Prior PPC training	0.0546	**0.8094**

DISCUSSION

Most participants were between 30 and 39 years old, and 51.11 % were women. These percentages in age group and sex were similar to those reported in the Colombian study by Florez et al. [15]. In contrast, the Mexican study by Sánchez et al. included a higher proportion of female participants, with 80.00 % being between 26 and 32 years old [21].

As for the type of specialty, participants were categorized into two groups: clinical and clinical-surgical. Most specialists were physicians of clinical specialties and, as expected, most participants were pediatricians (45.00 %). This proportion aligns with findings from studies conducted in tertiary pediatric hospitals [15,21] and primary care centers [11,22]. Additionally, 34.00 % of the participants had a subspecialty, with intensive care medicine being the most common. Such percentage closely aligns with the 25.90 % reported in the Colombian study by Florez et al. [15]. This could be due to the complexity of the cases managed at INSN-Breña, as it serves as a referral center for patients from across the country and has a higher capacity for managing pediatric cases, with a strong concentration of intensive care specialists. It should be kept in mind that PC is an essential component of best practices in pediatric intensive care units for patients with life-threatening conditions [23].

In this research, only 12.22 % of the participants had received prior PC training, a finding consistent with the nationwide Colombian study by Florez et al. [15], where only 13.00 % of the surveyed physicians had received such training. In that study, the diverse realities of healthcare institutions influenced the findings, as only 22.00 % of the hospitals in which the participants worked had a PPCU. Likewise, a study conducted with primary care pediatricians in Asturias, Spain, found that only 22.00 % had received some PPC training, yet 100.00 % recognized the need for it [11]. In a tertiary children's hospital, Mota et al. [24] reported that 40.90 % of the participants acknowledged the need for PC training. In contrast, Silva et al. [25] reported that 79.00 % of the nursing staff in a pediatric oncology unit had received PPC training. Despite the presence of a PPCU at INSN-Breña, training rates remained unexpectedly low. This underscores the need for public policies that integrate PPC into institutional health plans and medical education curricula for students and residents [26-28]. Another barrier that should be addressed is the difficulty of communication between specialists, regardless of hierarchy or department [29].

Most participants (30.56 %) had ≤ 5 years of experience as specialists, a proportion comparable to that reported by Florez et al. (42.60 %), Sánchez et al. (55.00 %) and Astray et al. Thus, the sample primarily consisted of young specialists [15,21,22]. Conversely, studies by Rendón-Macías et al. and Moya-Dionisio et al. found that most participants had < 10 years of experience as specialists [11,20]. Sánchez et al. also observed that physicians with < 10 years of experience and aged 39 years or older were more proficient in identifying PPC cases, although the statistical analysis showed no significant difference between age groups [21].

The scores obtained in this study varied widely (1 to 19 points out of 24), affecting the variability of the results. The average global PPC knowledge score was 11.65 ± 2.83. Among the three questionnaire domains (theoretical, ethical and legal), the ethical domain had the lowest score. This may be due to the bioethical dilemmas involved in recognizing terminal conditions or determining PC needs, leading to varied perspectives among physicians [18]. Unlike reviewed studies, which primarily reported the percentage of correct responses per item, this study shows global and domain-specific scoring data. For instance, Moya-Dionisio et al. found that 91.00 % of pediatricians correctly identified that PPC should begin at diagnosis, while 97.00 % believed that home was the best place for a pediatric patient to pass away [11].

Most participants (81.67 %) rated their PPC knowledge as intermediate (9 to 16 points). Similarly, the Mexican study by Mota et al. reported that physicians scored a median of 83 points out of 100, with 81.00 % correctly defining PC. However, that study included medical specialists, nurses and administrative staff, making the sample more heterogeneous [24].

The mean score for identifying patients in need of PPC was 3.53 ± 0.93. Most participants (86.67 %) demonstrated an adequate level of identification of PPC needs; that is, they were able to correctly identify at least three cases. These findings are consistent with those of Sánchez et al., where over 60.00 % of the physicians correctly identified a patient requiring PC. However, some responses lacked certainty, likely due to the misconception that certain conditions, such as cancer, are often assumed a priori to have an unfavorable outcome, without considering the variability in disease progression, the different types of cancer and their respective survival rates [15,21].

A total of 28.00 % of participants with low level of PPC knowledge could not adequately identify PPC needs, while 100.00 % of participants with high level of PPC knowledge adequately identified PPC needs. A weak but statistically significant positive correlation was found between the global PPC knowledge score and the legal domain score with respect to the identification of PPC needs score. This finding may be explained by the study conducted by Sanchez et al., which revealed that although most participants were able to adequately identify patients in need of PC, more than half were uncertain about the correct management. In other words, despite having sufficient theoretical knowledge to define PPC, they lacked the practical skills necessary for making therapeutic decisions in such patients [21]. Likewise, Silva et al. [25] reported that, despite most nursing staff received PPC training, very few identified the transition point at which pediatric oncology patients required PC [8]. These findings highlight the need for educational programs that incorporate not only theoretical instruction but also clinical case discussions to enhance practical decision-making skills regarding patients in need of PPC due to different underlying diseases [27].

Previously, in our institution, Garaycochea et al. [30] examined PPC knowledge, attitudes and motivations among health personnel, and also explored the opinion about the functioning of the unit. The study included 153 participants, comprising physicians, nurses and other healthcare staff. They found that 51.00 % of physicians, 46.00 % of nurses and 38.00 % of other professionals had low PPC knowledge. In relation to attitudes, physicians were more inclined toward therapeutic effort limitation, whereas nurses and other professionals showed greater alignment with PC care. However, all groups demonstrated strong motivation to provide PPC for patients with chronic illnesses and those with special needs.

In conclusion, most participants rated the level of PPC knowledge as intermediate, with the lowest scores observed in the ethical domain. Qualitatively, most participants demonstrated an adequate level of identification of PPC needs. A significant but weak correlation was found between the global PPC knowledge score and the identification of PPC needs score. On the other hand, the correlation was significant but weak between the legal domain and the global identification of PPC needs score. Based on these findings, implementing PPC training programs for medical specialists, focusing on both theoretical and practical aspects, is recommended. The questionnaires used in this research could be used as assessment tools before and after training interventions. Future research should replicate this study with participants from different hospitals to enhance the external validity of the results.

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