

Facilitators and barriers perceptions to early referral to pediatric palliative care perceived

Percepción de facilitadores y barreras para la derivación a cuidados paliativos pediátricos

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What do we know about the subject matter of this study?

Pediatric palliative care (PPC) is an emerging phenomenon that has been extensively studied in pediatrics. Facilitators and barriers to access by professionals to PPC have been described; however, it is not known how they are perceived by pediatricians and pediatric subspecialists in Latin America.

What does this study contribute to what is already known?

This is a cross-sectional study of the perception of barriers and facilitators of PPC among pediatricians and pediatric subspecialists of three tertiary hospitals in Santiago, who answered an online survey. There is little formal PPC training, and it is perceived as insufficient. An important facilitator is the perceived benefit of PPC, and emotionality is perceived as a barrier to referral for PPC.

Abstract

The perception of facilitators and barriers to referral to pediatric palliative care (PPC) is a widely studied phenomenon, with scarce information in Latin America. **Objective:** to adapt a survey on the perception of facilitators and barriers to PPC referral and evaluation. **Subjects and Method:** electronic survey with cultural adaptation with translation-retrotranslation in pediatricians and pediatric subspecialists of 3 tertiary centers in Santiago. The survey consisted of 4 sections and 51 questions, corresponding to sociodemographic data (including self-perception of spirituality and religiosity), training and clinical practice of the respondent in PPC, and facilitators and barriers to referral to PPC. **Results:** 146 pediatricians were invited and 78 surveys were obtained (response rate: 53.4%). The median age was 42 years and 11.5 years of professional practice. The majority corresponded to pediatricians without subspecialty training (n = 34; 43.6%). Twenty-three (29.5%) of the participants received PPC training, which was perceived as insufficient in 17 (74%) cases; there were also no differences in PPC training when comparing pediatricians with or without subspecialty training. Ninety-five percent of the respondents agreed with the perceived benefit of early referral to PPC for

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patients with life-threatening pathologies, regardless of their diagnosis, although only 47.7% stated that they had made a referral to a PPC team. The emotional relationship with the patients and their families was perceived as a barrier by pediatricians in those subspecialists susceptible to PPC compared with those who were not (20% vs. 50%; $p = 0.03$). **Conclusion:** A significant deficit in PPC training was detected. There were no differences in facilitators and barriers between pediatricians and subspecialties susceptible to PPC. Specialties not accustomed to PPC-susceptible patients may be affected by emotional factors in their decisions.

Introduction

Pediatric Palliative Care (PPC) is the active and total care of a child with life-threatening or life-limiting illnesses, both physical, mental, and spiritual, including family support¹. According to the World Health Organization (WHO), 56.8 million people per year (children and adults) need palliative care, of which at least 7% correspond to the pediatric population. In the case of pediatric patients who require PPC (considered from 0 to 19 years of age), more than 97% come from low- or middle-income countries².

The etiology of patients referred to PPC varies according to the series analyzed, with genetic/congenital as the first cause, followed by neuromuscular pathology, and finally oncologic^{3,4}. This generated a progressive change in the model of care related to PPC from a model focused on pathologies without the possibility of curative treatment to a model of continuous care that integrates interventions from diagnosis to symptomatic support, which was adopted by the WHO in 1998. However, there are facilitators and barriers to effective referral to PPC from pediatric teams. This phenomenon has been widely described, evaluating the perceptions and opinions of health personnel working with children⁶⁻¹¹.

Among the facilitators for referral to PPC perceived by pediatricians are potential benefits in the management of symptoms associated with the disease and/or its treatments, early integration to reduce parental anxiety, and improved interdisciplinary communication, including medical and non-medical personnel^{6,7}. Among the barriers, fear of the family's reaction, the conflict between pediatric and PPC teams, and uncertain prognosis of some pathologies are described, which makes timely referral difficult. However, there are discrepancies between pediatricians' statements and their clinical behavior. Spruit et al. showed that although pediatric oncologists considered the inclusion of PPC to be beneficial, 55% rarely consulted the PPC team¹⁰. On the other hand, Twamley et al. applied an assessment of barriers to referral to PPC in a tertiary center in the United Kingdom that had a specialty team for effective referral; 84% agreed that PPCs should be initiated at the time of diagnosis of a life-threatening

illness compared with 4% who stated that it should be done during the end-of-life process. When asked the open-ended question "*What comes to mind when you think of palliative care?*", there was evidence of an association between symptom management, family support, and PPC service delivery, which is strongly linked to end-of-life management¹¹.

In Chile, Palliative Care and Pain Relief for oncology patients have been included in the Explicit Health Guarantees (GES) since 2005¹². The GES is a set of benefits guaranteed by Law 19,966 to users of the Chilean healthcare system, whether public or private, to provide timely access, quality care, and financial protection for pathologies or health problems established in Law 12. However, as of March 2022, Law 21,375 came into force, which established palliative care and the rights of people suffering from terminal or serious illnesses, including patients with non-oncological diagnoses^{13,14}. Considering the importance of pediatric palliative care both internationally and locally, this study aimed to describe the barriers and facilitators for referral to PPC in pediatric patients.

Subjects and Method

Adaptation and application of the evaluation survey

An authorized adaptation of the survey published by Dalberg et al⁶ was carried out through cultural adaptation using the method of translation and back-translation into Spanish. Subsequently, a semantic evaluation and adaptation were carried out by an expert committee that included two palliative physicians, one pediatric hematologist-oncologist, one pediatric psycho-oncologist, and one nurse specialist in pediatric palliative care. After collecting the committee's comments and modifications, a second evaluation was conducted by a group of at least 10 potential respondents (not included in the final sample). After integrating the final corrections, a back-translation into the original language was made to compare the similarity of both surveys and request approval from the original author to proceed with the application of the instrument.

The adapted instrument corresponds to a survey with four sections: sociodemographic data (includ-

ing self-perception of spirituality and religiosity), information regarding PPC in the training and clinical practice of the respondent, facilitators and barriers to referral to PPC, and comments. It consists of a total of 51 questions: 13 questions of 51 questions, 13 with multi-choice or short answers, and 38 statements evaluated using a Likert scale. A space for comments is available at the end of the survey (Appendix 1).

Study Group

Pediatricians, child family physicians, and pediatric subspecialists from three tertiary centers (two public and one private) of high complexity in Santiago were invited to participate. The inclusion criteria were pediatricians, child's family physicians, or pediatric subspecialists with predominant clinical activity (50% of the contracted hours) in hospital or outpatient settings. Residents of pediatric training programs or subspecialties, surgical specialties, or professionals with more than 50% of their working days dedicated to nonclinical activities (research, teaching, management, etc.) were excluded. The invitation was sent by e-mail with weekly reminders for six weeks and an invitation to participate in clinical conferences of the different working groups. The survey was hosted on the Google Forms® platform, and only the main authors had access to the results. The responses were collected anonymously. This study was approved by the Scientific Ethical Committee of the Faculty of Medicine of the *Pontificia Universidad Católica de Chile* (ID:200406008) and was performed by the principles of the Declaration of Helsinki.

Statistical analysis

Frequency and percentage were used for categorical variables and numerical variables were described as medians and ranges. A comparison was made between the group of specialties accustomed to PPC Susceptible patients given the pathologies and complexity of the patients they received (Intensive Care, Hemato-Oncology, Neonatology, and Cardiology) and pediatricians and subspecialists. Two-tailed Fisher's exact test was used for statistical tests with Microsoft Excel 2020 (California, US) and Open-Source Epidemiologic Statistics for Public Health (Georgia, US) software. Statistical significance was set at $p < 0.05$.

Results

Demographic characterization

A total of 146 pediatricians and subspecialists were invited from two public and one private hospital center in Santiago. A total of 78 surveys were conducted (response rate: 53.4 %). None of the participants were excluded based on the exclusion criteria. The median age was 42 years (range 28-69 years), and female sex was

predominant ($n = 54$; 69.2%). The most frequent specialties were general pediatric ($n = 34$; 43.6%), neonatology ($n = 7$; 9%), and pediatric intensive care ($n = 6$; 7.7%). The time since graduation from the last training program was 11.5 years (range 1-36 years) (table 1).

Table 1. Sociodemographic, educational, and clinical environment features of participants^a

Characteristics	n (%)
Age, years. Median (Range)	42 (28-69)
Sexo	n (%)
Female	54 (69.2)
Male	22 (28.2)
No response	1 (1.3)
Religiosity. Median (Range)	7 (0-10)
Spirituality. Median (Range)	8 (0-10)
Time since completion of the last training program, years. Median (Range)	11.5 (1-36)
Primary Specialties/Fellowships	n (%)
General Pediatrics	34 (43.6)
Neonatology	7 (9.0)
Pediatric Intensive Care	6 (7.7)
Endocrinology	4 (5.1)
Pulmonology	4 (5.1)
Hematology-Oncology	4 (5.1)
Cardiology	3 (3.8)
Nutrition	3 (3.8)
Neurology	3 (3.8)
Gastroenterology	3 (3.8)
Nephrology	2 (2.6)
Family Medicine/Pediatric Community	2 (2.6)
Infectious Diseases	2 (2.6)
Palliative Care	1 (1.3)
CPP Training	23 (29.5)
Quality perception of PPC (n=23)	
Very Insufficient	8 (34.8)
Insufficient	9 (39.1)
Sufficient	6 (26.1)
Clinical activities related place.	
Hospital-based	48 (61.5)
Outpatient-based	30 (38.5)
Have you ever provided treatment to pediatric patients with indications of PPC?	
Yes	49 (63.6)
No	26 (33.8)
Unknown	2 (2.6)
Is there a PPC available in your hospital?	
Yes	48 (61.5)
No	14 (17.9)
Unknown	16 (20.5)
Have you ever referred a patient to a PPC consultant?	
Yes	33 (42.3)
No	37 (47.4)
To an Adult palliative care team	5 (6.4)
unavailability of PPC team	3 (3.8)

^aValues indicated as frequency and percentage. PPC: Pediatric palliative care.

Table 2. Perception of statements associated with facilitators for referral to PPC in the group of interviewed pediatricians (n = 78)

Statements associated with facilitators for referral to PPC	n (%)		
	Agree	Disagree	UK
Patients with life-threatening diseases, regardless of their diagnosis or prognosis, can benefit from PPC	75 (96.2)	3 (3.8)	0 (0)
It is necessary to produce clinical trials regarding early referral to PPC.	66 (84.6)	4 (5.1)	8 (10.3)
If PPC are included during the first month after the diagnosis of any life-threatening disease, the potential benefits could surpass the potential risks.	59 (75.6)	6 (7.7)	13 (16.7)
Early integration of PPC would improve interdisciplinary communication	66 (84.6)	4 (5.1)	8 (10.3)
Early integration of PPC would improve the patient's and their family's understanding about their disease.	63 (80.8)	11 (14.1)	4 (5.1)
If the name of PPC was modified (for example, to Continuum Care) the patient's and family's perception would change.	66 (84.6)	7 (9)	5 (6.4)
Addressing potential misunderstanding from parents regarding the goals of PPC by education by the paediatrician in charge would result in higher CCP acceptance levels	71 (91)	3 (3.8)	4 (5.1)
In order to avoid misunderstandings by parents and their families and to improve referral acceptance, it would be beneficial if the PPC team educated healthcare professionals about the objectives of palliative care.	71 (91)	3 (3.8)	4 (5.1)
Better education of health professionals about PPC is a big step towards improving access to PPC.	71 (91)	3 (3.8)	4 (5.1)
Early referral to PPC of all patients with life-threatening diseases as a standard of care would reduce the anxiety related to referral during the illness' course	56 (71.8)	8 (10.3)	14 (17.9)
Early integration of PPC would generate less anxiety, in comparison to referral during illness' relapse or progression	66 (84.6)	4 (5.1)	8 (10.3)
Early referral to PPC would mean more detailed management of patient's symptoms	62 (79.5)	7 (9)	9 (11.5)
Early referral to PPC of patients with potential life-threatening diseases would reduce suffering of patients and their families.	64 (82.1)	5 (6.4)	9 (11.5)

PPC: Pediatric palliative care, UK: unknown.

Regarding clinical performance, 49 participants (62.8%) reported having assumed the treatment of patients with indications for PPC. Regarding the existence of PPC teams in their hospitals, 14 (17.9%) respondents stated that they did not have any, and 16 (20.5%) stated that they did not know. In addition, when asked whether respondents had made a referral to the existing PPC team, 37 (47.4%) stated that they had never made a referral. 23 of Twenty-three respondents (29.5%) stated that they had received PPC training. Of these, 17 (73.9%) perceived it as insufficient or very insufficient (table 1).

Perception of facilitators and barriers in PPC

When analyzing the statements related to facilitators among the respondents, there was a favorable perception of the benefit of PPC in life-threatening pathologies, generation of evidence, interdisciplinary integration, support in parents' misinterpretations of the PPC team, and reduction of patient and family suffering, reaching over 80% agreement. Another interesting element is the perception of benefits in the change of name to continuous care, which would be beneficial

for the perception of the family. On the other hand, there was a 20% disagreement or lack of knowledge regarding the early integration of PPC, probable over-information, and reduction of anxiety in the family and patient (table 2).

When comparing the barriers associated with PPC, the most agreed upon are the perceived association of PPC with proximity to death by the families, frequency of team visits determined by the treating physicians, prioritization of curative treatment over quality-of-life management, and the difficulty of defining the time of referral to PPC. However, there is a high percentage of "don't know" or no response for statements related to the referral of care, the negativity of overlapping between PPC and treating teams, promoting PPC, the association of end-of-life or death care with PPC, additional burden on parents, guilt about patient death, and parents' fear of letting the treating physician down in the context of symptom management (table 3).

It has been previously described that pediatric subspecialties such as intensive care, pediatric cardiology, neonatology, and pediatric oncology are more associated with the use of PPC tools due to the high

Table 3. Perception of statements associated with barriers to referral to pediatric palliative care (PPC) in the interviewed group of pediatricians (n = 78)

Statements associated with barriers to CPP referral	n (%)		
	Agree	Disagree	UK
The head team – and not the PPC team – should manage symptoms related to treatments.	32 (41)	36 (46.2)	10 (12.8)
The head team – and not the PPC team – should manage symptoms related to the illness	38 (48.7)	28 (35.9)	12 (15.4)
Early exposure to PPC will cause anxiety on parents and families.	23 (29.5)	51 (65.4)	4 (5.1)
PPC is perceived by patients and their families as a sign that the end-of-life is near	66 (84.6)	10 (12.8)	2 (2.6)
The frequency of PPC team follow-up after the first evaluation should be determined by the head team and according to need.	47 (60.3)	26 (33.3)	5 (6.4)
Quality of life is often not prioritized during curative treatment.	50 (64.1)	28 (35.9)	0 (0)
It is hard to find appropriate PPC teams for my patients' needs	45 (57.7)	22 (28.2)	11 (14.1)
There is a lack of funding for referral to PPC programs	47 (60.3)	9 (11.5)	22 (28.2)
It is hard for me as a head physician to transfer the responsibility of care of my patients to another team.	24 (30.8)	53 (67.9)	1 (1.3)
An overlap between the head physician and PPC team could have a negative impact on the care of the patient.	20 (25.6)	58 (74.4)	0 (0)
Early referral to PPC could harm the relationship between the head physician and patient or family	9 (11.5)	66 (84.6)	3 (3.8)
Optimal care of the patient could be limited by the physician's need to take control of every aspect of treatment.	36 (46.2)	38 (48.7)	4 (5.1)
My medical specialty does not promote PPC like other specialties.	19 (24.4)	56 (71.8)	3 (3.8)
PPC is not compatible with the active or curative treatment of my patients.	7 (9)	68 (87.2)	3 (3.8)
I perceive PPC as synonymous of end-of-life care or death	29 (37.2)	49 (62.8)	0 (0)
Early introduction of PPC teams could cause an extra burden to the parents	22 (28.2)	52 (66.7)	4 (5.1)
It is difficult for me to know at which stage during the course of the illness the patients can benefit from a referral to CCP	53 (67.9)	23 (29.5)	2 (2.6)
My emotional relationship with patients and their families influences what treatment options I could offer during relapse or disease progression.	33 (42.3)	42 (53.8)	3 (3.8)
My emotional relationship with patients and their families influences how I communicate treatment options during relapse or disease progression	31 (39.7)	45 (57.7)	2 (2.6)
As head physician, I tend to blame myself for patients' death, which in turn might influence my treatment decisions.	17 (21.8)	58 (74.4)	3 (3.8)
As head physician, I tend to be optimistic in the way I deliver information regarding experimental or 2nd-line treatment options.	22 (28.2)	50 (64.1)	6 (7.7)
As a pediatrician, it is hard for me to talk about death with my patients and their families.	34 (43.6)	44 (56.4)	0 (0)
During my clinical practice, I don't have enough time to discuss end-of-life care with my patients and families	30 (38.5)	45 (57.7)	3 (3.8)
Patients avoid reporting symptoms to their head physicians because they fear letting them down.	14 (17.9)	57 (73.1)	7 (9)
I think that parents fear that if they mention the possibility that their child might die, the clinical team can "give up" on their child.	37 (47.4)	36 (46.2)	5 (6.4)

PPC: Pediatric palliative care, UK: unknown.

prevalence of highly complex pathologies, comorbidities, and complications in their treatment¹⁵. Therefore, we compared the training received by the group of subspecialties accustomed to palliative care with that of the control group of pediatricians and subspecialists.

No significant differences were found in the de-

mographic characteristics or perceptions of PPC facilitators. However, in the perception of barriers, when asked if the emotional relationship between caregiver and patient/family affected the treatment options offered, the subspecialty group accustomed to PPC presented a lower agreement than the control group (20% vs. 50%, respectively; $p = 0.003$) (Appendix 2-3).

Discussion

This work is the first to report on the perceptions of facilitators and barriers of pediatricians from three tertiary hospitals in Chile. A survey was conducted with a response rate of 53.4%, considering the high response rate given the type of instrument (online survey). The high percentage of patients treated with an indication for PPC was associated with nonexistent or insufficient training in the area and low effective access to PPC equipment, reaching up to 40% of respondents who did not have access or were unaware of the existence of the equipment in their center.

There was general agreement regarding the perception of facilitators and barriers to PPC referral. However, there was a high percentage of non-responses, which reflects pediatricians' lack of knowledge regarding the impact of barriers to PPC (tables 2 and 3). Finally, when comparing facilitators and barriers between specialties accustomed to PPC (intensive care, pediatric cardiology, neonatology, and pediatric oncology) and pediatricians from other subspecialties, there were no significant differences.

Palliative care has been extended to multiple areas of pediatrics in a continuum of care paradigm as defined by the WHO in both inpatient and outpatient care^{1,15,16}. Balkin et al. report 30% PPC training in pediatric cardiologists or heart surgeons in 19 centers in the United States and 20% specific training in end-of-life management in children with cardiac disease¹⁷. In addition, the ADAPT study (Assessing Doctors' Attitudes on Palliative Treatment) in Latin America reported training in PPC in 44.4% of its sample¹⁸, and the Latin American Association for Palliative Care reported that only three out of 20 Chilean Medical Schools teach subjects related to palliative care, without specifying special modules for pediatric patients in 2020, which implies that of the 244 care resources reported for palliative care patients in Chile, only eight correspond to PPC teams¹⁹.

This study highlights the gap in the specific training of palliative care tools in the child and adolescent population, which is key in the current national context given the implementation of Law 21,375, which establishes the universal right of access to palliative care for all persons suffering from terminal or serious illnesses. This law came into force in March 2022, stating in Article 7 that "*Universities, technical colleges, and professional institutes that teach health-related study programs should incorporate content on palliative care*"¹³. In this context, it is urgent to incorporate PPC in the training of residents to reduce the knowledge gap. Experiences have been described in the United States that show an increase in the certainty of residents in dealing with cases related to elective classes or reference guides^{20,21}.

It has been observed that PPC-susceptible specialties have greater sensitivity to refer and integrate teams in the follow-up of patients than pediatricians from other subspecialties, possibly because pediatricians not used to PPC-susceptible patients could be more influenced by their therapeutic options according to their emotional relationship with them (Appendix 3). Dalberg et al. compared perceptions of facilitators and barriers in pediatric oncology teams and contrasted responses between medical and non-medical staff (nurses and social workers). They found that medical staff slightly agreed with the statement: "*The emotional relationship between caregiver and patient/family influences which treatment options are offered,*" while the non-medical staff was neutral. Therefore, it is important to constantly re-evaluate the countertransference of interpersonal relationships generated between the caregiver and the patient to those generated between the caregiver and the patient to deliver adequate health care without biases that may be detrimental⁶. In addition, it is key to favor potential interventions to raise awareness about the referral and inclusion of PPC teams, regardless of the specialty of the medical group to be intervened. Interventions in groups of pediatric oncology teams have been shown to increase the number of requests for evaluation and change at the time of PPC integration²².

Among the facilitators, the benefit of PPCs in patients with life-threatening pathologies, independent of their diagnosis or prognosis, stands out, with 95% of respondents agreeing with this. However, 47.4% did not make a referral to the PPC team. Twamley et al. reported that 50% of respondents stated that PPCs should be initiated at the time of diagnosis. However, in an open-ended question, the vast majority mentioned end-of-life¹¹. Similarly, McNeil et al. carried out a cultural adaptation of the ADAPT survey and applied it to physicians treating pediatric oncology patients in Latin America. When asked about the role of PPCs in multiple-choice questions, most respondents selected the competencies and functions of PPC teams, including reducing suffering, increasing the quality of life, assessing communication needs, and end-of-life care. However, when asked the free-writing question about the time of starting PPCs, most associated it with the end of life, and the word "terminal" was frequently used¹⁹.

A potential barrier to early referral is the reaction of the patient and family to contacting the PPC teams. In this study, 47.4% of the respondents agreed that parents fear the possibility of their child's death and that PPC admission implies a limitation of curative therapy. A similar report was observed in the ADAPT study, where 36.8% considered that an early referral to the PPC team would cause stress and anxiety in the par-

ents¹⁹. Levine et al. evaluated the perceptions of parents of patients with PPC. Only 8 parents (6.2%) expressed rejection of an early referral (defined as during the diagnostic process) to the PPC team. Negative effects included the impact on the relationship with the treating oncologist, loss of hope for a cure, and interference with the therapy. In the same study, more than 50% of the respondents agreed to include PPC teams from the time of disease diagnosis²³. This differs from the results reported in this study regarding the negative impact on parents and patients of early referral to PPC teams, removing the negative effects based on the opinions of the treating team rather than on the fears and concerns of the patient and caregivers.

The limitations of this research are the bias associated with self-reporting and reflection on daily clinical practice. However, this is one of the first studies to describe pediatricians and associated subspecialties in Chile, which may facilitate the development of multicenter studies to evaluate the phenomenon of facilitators and barriers through a cultural adaptation of a validated survey.

Conclusions

We found a deficit in the perceived quantity and quality of PPC training in Chilean pediatricians. There were no differences in the perception of facilitators and barriers to PPC entry between Chilean pediatricians and subspecialists in Chilean tertiary healthcare centers. Among the facilitators most frequently recognized by the respondents were the benefits of PPC from diagnosis, generation of evidence in the area, interdisciplinary integration, support in parents' misinterpretations of the PPC team, and reduction of patient and family suffering. The most frequently identified barriers were the relationship between PPC and the proximity of death among family members, the frequency of team visits determined by treating physicians, the prioritization of curative treatment over the management of quality of life, and the difficulty of defining the time of referral to PPC. Specialties not accustomed to

PPC-susceptible patients could be affected by the treatment options offered to them during follow-up.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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