Unidentified paediatric palliative needs: use of the Paediatric Palliative Screening Scale

Catarina Sofia Rodrigues Preto and Luís Miguel Pereira Condeço

Abstract

Background: Paediatric palliative care should be provided to children and adolescents with complex chronic, life-limiting or life-threatening conditions, from the time of diagnosis, throughout the life course and beyond death, ensuring continuity of care. **Aims:** To identify children and adolescents with complex chronic conditions at a Portuguese healthcare unit who may be eligible for referral to paediatric palliative care. **Methods:** An exploratory, descriptive quantitative and cross-sectional study was conducted, using the Portuguese version of the Paediatric Palliative Screening Scale. A total of 397 children and adolescents attending a paediatric developmental consultation were included in the study. Of these, 10 participants met the study's inclusion criteria and were assessed through telephone interviews with their parents. **Findings:** The use of the screening tool enabled the identification of two participants (20%) who would benefit from referral. **Conclusions:** Integrating systematic tools, such as the Paediatric Palliative Screening Scale, into routine consultations may enable earlier referral to palliative care, improving quality of care and support for families. **Implications for practice:** Routine use of referral tools combined with improved palliative care literacy and communication may facilitate earlier identification of children with palliative care needs and more timely referral to specialist services. Future development of more holistic referral tools that incorporate functional, psychosocial and symptom-related needs could support more equitable, person-centred paediatric palliative care.

Key words: adolescent ● child ● chronic disease ● palliative care ● referral and consultation

Paediatric palliative care (PPC) should be provided to children and adolescents with complex chronic conditions (CCCs), whether life-limiting or life-threatening, and to their families (including parents and siblings), from the time of diagnosis, which may occur even before birth, throughout the entire disease trajectory and beyond death, ensuring continuity of care across all stages (Bergstraesser et al, 2013; Sociedade Portuguesa de Pediatria, 2014; Roland et al, 2022; Cardoso and Pires, 2023).

PPC should be delivered by a multidisciplinary team, referred to as the inpatient paediatric palliative care team (IPPCT), which should include a nurse, physician, psychologist, social worker, nutritionist/dietitian, teacher/educator, therapists and a spiritual care leader. This team works in partnership with families and places them at the centre of care, with the aim of promoting the autonomy of children with CCC (Ramos and Barbieri-Figueiredo, 2020).

CCC in paediatrics refers to long-term medical conditions that have a significant impact on the health and quality of life of children. These illnesses typically persist for 12 months or more (except in cases of early death), and are characterised by the involvement of multiple organ systems or, alternatively, by severe impairment of a single organ. The severity of these conditions requires specialised paediatric care and often leads to hospital admissions in tertiary-level healthcare facilities (Feudtner et al, 2000).

Life-limiting conditions are characterised by the absence of a curative possibility, with death being an inevitable outcome. In contrast, life-threatening conditions encompass clinical situations in which curative treatment is possible, but may ultimately fail, thereby posing a significant risk of death (Chambers, 2018; Roland et al, 2022). These definitions are not only important for conceptual clarity, but also

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https://doi.org/10.12968/ijpn.2025.0042

underpin structured referral decisions using tools such as the Paediatric Palliative Screening Scale (PaPaS), which translates them into measurable categories for clinical practice.

According to Benini et al (2022), PPC should be provided whenever a child or adolescent presents with any of the following: diagnosis of a life-limiting or life-threatening condition; severe episodes of hospitalisation, use of invasive medical devices for life support, difficulty in controlling pain or other symptoms, complex psychosocial or spiritual needs of the child/adolescent and family, difficulty in decision making and anticipated need for bereavement support. It is estimated that around 7500 children and young people in Portugal have palliative care needs (Silva et al, 2023), and globally, approximately 90% of children requiring specialist paediatric palliative care do not receive the care they need (Roland et al, 2022).

The need for PPC and the number of hospital admissions due to CCC have increased over the years in Portugal. However, negative perceptions persist when palliative care (PC) is proposed, as it is often associated with end-of-life situations and withdrawal from the care process (Friebert, 2012; Lacerda and Gomes, 2017; Chambers, 2018). Within the healthcare unit included in the present paper, no specialised PPC team is available. Children and adolescents identified as needing PPC are usually referred externally to the IPPCT at a central hospital, which reflects the importance of structured tools to support referral decisions.

The average age at death among children and adolescents with CCC has increased, due to scientific advances and improvements in healthcare. This has led to the emergence of PPC services and the training of professionals equipped to care for these patients who will eventually transition to adult care services (Lacerda and Gomes, 2017). Referral to PPC has been shown to be valuable in improving quality of life and can reduce the number of subsequent hospital admissions, representing an advantage at economic, clinical and social levels (Fraser et al, 2013; Harrop and Edwards, 2013; Ramos and Barbieri-Figueiredo, 2020).

There are several barriers to early referral, such as healthcare professionals' lack of knowledge about PPC, difficulty accepting the possibility of the child's death by the family, unavailability of PPC and the association of PC with the abandonment of curative treatment. Personal beliefs and characteristics of patients can also influence the timing of referral (Lacerda, 2016; Cuviello et al, 2021; Couto et al, 2023). This highlights the need to train healthcare professionals in PPC and in the field of child and paediatric health, as well as to develop human and relational competencies in areas such as ethics, communication and bereavement (Mendes and Silva, 2013).

Bergstraesser et al (2013) developed a screening tool for palliative care needs adapted for the paediatric population. This tool has proven to be valuable in identifying, assessing and monitoring children and adolescents with palliative needs at an early stage, helping to improve the quality of services provided and reduce the suffering of both patients and their families (Bergstraesser et al, 2013; Cuviello et al, 2021). To properly identify children with life-limiting or life-threatening CCC who could be referred to PPC in a timely manner in Portugal, Palaré et al (2023) translated and adapted the PaPaS. This instrument, consisting of 11 questions across five domains, directly categorises referral decisions into four levels: no referral needed, referral for PPC information and goal setting, preparation for initiation of PPC services and provision of PPC.

With regards to the present paper, PPC is provided in collaboration with another hospital. Currently, the PaPaS is not used in this healthcare unit and referral for PPC is sometimes late. Accordingly, this study was conducted with the aim of identifying children and adolescents with CCC being followed at a Portuguese healthcare unit, who may be eligible for referral to PPC.

Methods

An exploratory descriptive and cross-sectional study with a quantitative approach was conducted, aiming to answer the following research question: can children and adolescents with life-limiting chronic conditions who are followed in a developmental clinic be referred to PPC? The study population (397) consisted of children and adolescents followed in a paediatric developmental consultation at a medium-sized healthcare unit located in inland Portugal, between January and November 2024.

Inclusion criteria

The inclusion criteria for the study were defined as follows:

- Children and adolescents with a diagnosis of a complex chronic life-limiting or life-threatening condition
- With functional limitations and/or dependence in activities of daily living
- Level of mobility or self-care

- Requiring invasive medical devices
- Not followed by a paediatric palliative care team
- Aged between 0 and 17 years old
- Informed consent provided by parents or legal guardians.

After applying the inclusion criteria, the parents of 387 children were excluded for not meeting the inclusion criteria. This left the parents of 10 eligible children/adolescents.

Data were collected between November 2024 and January 2025 through structured telephone interviews with the parents of children and adolescents followed in the developmental clinic. During the interviews, the PaPaS was administered verbally and completed by the research team, in accordance with ethical and legal requirements.Confidentiality was ensured by anonymising participant data and securely storing responses. Informed consent was obtained before the interview. Parents received an explanation of the study and were asked to sign the informed consent form and return it to the research team by email. Participation was voluntary, and refusal to participate did not affect their child's clinical follow-up.

Ethical approval

Ethical approval was granted for this study by the hospital ethics committee. The data collection process was divided into two stages: first, administration of a sociodemographic questionnaire and second, application of the PaPaS scale.

Results

Following the administration of the sociodemographic questionnaire, it was found that 50% of the sample had already heard of PPC, while the remaining 50% were unaware of its existence. However, only 10% were aware of the connection with the IPPCT at a central hospital (*Table 1*).

After completion of the PaPaS, it was concluded that all children/adolescents included in the study were clinically stable and had not experienced any recent hospital admissions (*Table 2*). Regarding the expected outcomes of disease treatment and associated side effects (Table 2), 50% of the participants were not receiving any treatment (medication). Among the remaining 50%, treatment was effective in controlling the disease and prolonging life while maintaining a good quality of life. Across the entire sample, 100% reported no treatment-related side effects.

In this study, 70% of the children/adolescents were asymptomatic and, consequently, experienced no associated stress, either for themselves or for their parents or family. However, 30% of the children/adolescents presented with moderate and manageable signs/symptoms, causing mild stress in 10% and moderate stress in 20% of the children/adolescents. In comparison, these signs/symptoms resulted in moderate stress for 30% of the parents (*Table 2*).

When parents were asked whether they wish to receive palliative care or express needs similar to those addressed by palliative care, seven responded affirmatively (70%), while three (30%) responded negatively. However, based on the researchers' assessment, the entire sample would benefit from PPC (*Table 2*). Finally, it is estimated that all children/adolescents included in the study had a life expectancy of several years (*Table 2*). Through the results of PaPaS, it was possible to determine the level of care that should be provided to the children and adolescents included in the study and 20% of the total sample were eligible for PPC information and goal setting (*Table 3*).

Discussion

The results obtained revealed a significant discrepancy between clinical eligibility for PPC and actual referral. Although the literature recommends that PPC should begin at the time of diagnosis of a life-limiting or life-threatening CCC (Sociedade Portuguesa de Pediatria, 2014; Roland et al, 2022), this principle was not reflected in the present study. Among the 397 children and adolescents followed in the developmental consultation, only 10 presented with diagnoses compatible with the eligibility criteria defined by Benini et al (2022), such as cerebral palsy, rare genetic syndromes (e.g. Pierpont), encephalopathies and other highly complex conditions. However, none of these children/adolescents were enrolled in a PPC programme.

These findings reflected not only a possible underuse of PPC resources, but also pointed to persistent barriers to access. Particularly,

Table 1. Sociodemographic questionnaire

Knowledge about PPC	*n*	%
Yes	5	50
No	5	50
Knowledge of the link between the institution and a central hospital	N	%
Yes	1	10
No	9	90

the cultural and social association of PPC with end-of-life care or therapeutic abandonment, as highlighted by several authors (Lacerda, 2016; Cuviello et al, 2021; Vieira et al, 2021; Couto et al, 2023). Qualitative analysis of the collected data supports this view: although 50% of participants reported awareness of PPC, 30% expressed resistance to potential referral during

Table 2. Paediatric palliative screening scale

Disease trajectory and impact on the child/young person's daily life activities		**N (%)**
Dimension 1. Disease trajectory and influence on the child/young person's daily activities (comparison with the child/young person's age group over the last 4 weeks)	Stable	10 (100%)
	Slow deterioration with no impact on daily activities	0
	Unstable and with an impact on daily activities and restriction	0
	Significant deterioration with severe restriction of daily activities	0
Dimension 1.2. Increase in the number of hospital admissions (>50% in 3 months)	No	10 (100%)
	Yes	0
Dimension 2. Expected outcome of disease treatment and associated side effects		N (%)
Dimension 2.1. Treatment directed at the disease (does not concern the treatment of complications related to the disease, e.g. pain, dyspnoea or fatigue)	Curative	5 (50%)
	Controls the disease and prolongs life with good quality of life (QoL)	5 (50%)
	It doesn't cure or control disease, but it does have a positive effect on QoL	0
	Does not control the disease and has no effect on QoL	0
Dimension 2.2. Side effects of treatment (including impact on family and patient, e.g. hospitalisations from the perspective of the patient or family)	None or light	10 (100%)
	Light	0
	Moderate	0
	Severe	0
Dimension 3. Signs/symptoms and problems		N (%)
Dimension 3.1. Intensity of signs/ symptoms and/or difficulty controlling them (in the last 4 weeks)	Asymptomatic	7 (70%)
	Sign(s)/symptom(s) are mild and easy to control	0
	Any signs/symptoms are moderate and manageable	3 (30%)
	Any sign/symptom is severe or difficult to control	0
Dimension 3.2. Psychological disorders (stress) of the patient related to the signs/symptoms	Missing	7 (70%)
	Light	1 (10%)
	Moderate	2 (20%)
	Significant (severe)	0
Dimension 3.3. Psychological disorders (stress) of the parents or family related to the child's signs/ symptoms and suffering	Missing	7 (70%)
	Light≥	0
	Moderate	3 (30%)
	Significant (severe)	0
Dimension 4. Patient or parent and healthcare professional preferences/needs		N (%)
Dimension 4.1. The patient/parents wish(s) to receive palliative care or express(es) needs similar to palliative care	No	3 (30%)
	Yes	7 (70%)
Dimension 4.2. The professional or their team feel(s) that this patient would benefit from palliative care	No	0
	Yes	10 (100%)
Dimension 5. Life expectancy		N (%)
Dimension 5.1. Estimated life expectancy	Several years	10 (100%)
	Between months and 1 and 2 years	0
	From weeks to months	0
	Between days and weeks	0
Dimension 5.2. 'Would it surprise you if this child died suddenly within 6 months?'	Yes	10 (100%)
	No	0

the interview, stating that their children were not dying. This confirmed the presence of prejudices and limited interpretations regarding the nature and aims of palliative care in paediatric settings, known as barriers, as the association of PC with the abandonment of curative treatment, delaying the referral process. The researchers considered that 100% of the sample would benefit from PPC since, as previously mentioned, they had a diagnosis of a life-limiting or life-threatening CCC.

Additionally, the results revealed significant levels of stress in both the children/adolescents and their caregivers, with 30% of the sample showing signs of emotional distress. This finding was particularly relevant, as PPC specifically aims to promote comfort, relieve suffering and provide ongoing psychosocial support (Dantas et al, 2010; Ramos and Barbieri-Figueiredo, 2020). The absence of referral, therefore, may compromise not only the child's quality of life, but also the resilience and wellbeing of the caregiving family.

Another critical point that emerged from the analysis of the results concerns the evolving clinical and demographic profile of children with CCC. Studies have shown that advances in medical and therapeutic technologies had extended the life expectancy of these children, a trend also observed in the present study's sample (Lacerda and Gomes, 2017). This new reality calls for sustained investment in the training of professionals capable of supporting children with complex needs, many of whom will transition to adult care services, requiring an integrated and continuous approach.

The application of the PaPaS, validated for the Portuguese population by Palaré et al (2023), revealed that 20% of participants met explicit eligibility criteria for PPC. However, it is important to note that even among those not deemed eligible according to this scale (80%), several children presented with conditions involving significant functional impairment and poor prognosis, based on the clinical criteria proposed by Benini et al (2022). This discrepancy between the results obtained through the PaPaS and clinical assessment highlighted the importance of using this tool as a complement to, rather than a substitute for, clinical judgement.

The integration of PaPaS scale into routine paediatric consultations may represent a valuable strategy to ensure earlier recognition of needs and to structure referral pathways. However, as shown in the study, its implementation requires parallel efforts to raise awareness among families and professionals, demystifying PPC and clarifying that its scope extends beyond end-of-life care. When used alongside clinical judgement, PaPaS can reduce delays in referral and help bridge the gap between eligibility and access.

Finally, it is plausible to assume that the limited use of the PaPaS scale in clinical settings was due to a lack of awareness regarding its existence and practical applicability, rather than a lack of competence among professionals in the principles of PPC. In this regard, higher education institutions and training organisations play a fundamental role in promoting palliative care literacy, equipping professionals to detect needs early and to ensure timely and appropriate referral.

Limitations

This study has limitations that must be acknowledged. The small sample size (n=10), derived from the limited number of eligible cases in the healthcare unit studied, restricts the generalisability of results. In addition, the single-centre and cross-sectional design prevents longitudinal analysis and wider applicability. Despite these constraints, the findings offer relevant preliminary evidence for the Portuguese context and point to the need for larger-scale, multicentre studies.

Conclusions

PC is essential to ensuring the highest possible quality of life. Therefore, early identification of children and adolescents with palliative care needs is crucial, as is the dissemination and implementation of referral criteria for specialised teams (Silva et al, 2023). Bringing the PaPaS into developmental appointments, primary care, emergency services and paediatric hospitalisation could add real value when it comes to identifying these children. The negative

Table 3. Paediatric palliative care need

No referral needed (score <9)	8 (80%)
Referral for paediatric palliative care information and goal setting (score 10–14)	2 (20%)
Preparation for initiation of paediatric palliative care services (score 15–24)	0
Provision of paediatric palliative care (score ≥25)	0

connotation associated with the concept of PPC must be demystified through health literacy, in order to break down the barriers to the referral of children and adolescents with life-limiting or life-threatening CCC. Honest communication is therefore imperative, so that decisions can be made in a timely manner, rather than as a last resort.

Although the PaPaS scale is a recognised and valid tool for assessing referral needs, it is highly focused on pathology and the acute phase of illness. As such, there is a need for an instrument that better addresses the needs of children and adolescents with life-limiting conditions and dependence in activities of daily living. Future research should focus on the development of a referral tool that does not concentrate solely on pathology or end-of-life scenarios but rather adopts a holistic view of the child or adolescent with a life-limiting condition. Such an instrument should consider individual needs, including dependence in activities of daily living, use of medical devices, symptom control, spirituality, and even educational aspects, representing a step forward in the approach to PPC. In this way, care can become more humanised and personalised, promoting dignity, autonomy and quality of life.

In clinical practice, the PaPaS should be systematically integrated into routine paediatric consultations, supported by training programmes that enhance PPC literacy among healthcare professionals and families.This would allow earlier identification of needs and promote more equitable referral pathways. Future studies should include larger, multi-centre samples to enhance the generalisability of findings and should further investigate clinicians' perceptions and attitudes towards the use of referral tools, such as the PaPaS, to optimise their applicability, feasibility and acceptance across diverse clinical contexts. *IJPN*

CPD reflective questions

- How can healthcare professionals integrate paediatric palliative care referral tools into routine clinical practice while overcoming the misconceptions associated with paediatric palliative care?
- In what ways could a more holistic referral tool improve the early identification and care of children and adolescents with life-limiting conditions?
- What changes in education and training are needed to ensure that children and adolescents with palliative care needs are identified and referred earlier?

Key points

- Timely recognition of paediatric palliative care needs can improve quality of life and facilitate earlier access to specialised care.
- Future referral tools should extend beyond disease severity and end-of-life indicators to include functional dependence, alongside psychosocial, spiritual and educational needs.
- Improving paediatric palliative care literacy among healthcare professionals and families could help dispel misconceptions, encourage honest communication and promote timely referrals.
- Integrating referral tools into routine paediatric practice, alongside professional training and larger multi-centre studies, could strengthen referral pathways and optimise the applicability of paediatric palliative care assessment tools.

Conflict of interest: *None*

Data sharing: *Data are available from the authors on reasonable request.*

Funding: *This research received no external funding.*

Author contributions: *CP: Conceptualisation, data curation, investigation, methodology, resources, validation, visualisation, writing (original draft). LC: Conceptualisation, formal analysis, methodology, project administration, supervision, validation, writing (review and editing)*

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