

Pediatric Palliative Care: A Survey of Knowledge and Attitudes of Health care Professionals

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Abstract

Introduction: Due to improvements in medical care, children with complex chronic diseases are living longer. Pediatric palliative care should be offered to these children and their families. The aim of the study was to evaluate the knowledge and attitudes of health care professionals of a pediatric department toward pediatric palliative care and identify the possible barriers to the referral of patients.

Methods: A cross-sectional survey of health care professionals working in a pediatric hospital in Lisbon was conducted using a questionnaire that includes 18 multiple-choice questions and one open-ended question.

Results: There were 140 health care professionals who completed the questionnaire. In the multiple-choice questions, 55% (n = 76) believe that pediatric palliative care should start at diagnosis, 91% (n =127) consider it to be as important as curative treatment, and 73% (n = 101) disagrees with the idea of pediatric palliative care being primarily about end-of-life care. The most common reason not to refer a child to pediatric palliative care was an uncertain prognosis (29%, n = 40). In the open-ended question, the most frequent expressions associated with the concept of palliative care were comfort/symptom management (54%, n = 44), quality of life (35%, n = 28), and end of life (32%, n = 26).

Discussion: In our study, multiple-choice questions revealed health care professionals to be well informed regarding pediatric palliative care. Most health care professionals identified the moment of complex chronic diseases diagnosis as the ideal time to start pediatric palliative care. In open-ended questions, end-of life care was still associated with pediatric palliative care suggesting an unrecognized association of pediatric palliative care and death in the attitudes of health care professionals and a potential barrier to timely referral.

Keywords: Attitude of Health Personnel; Child; Palliative Care/trends; Palliative Care/psychology; Palliative Care/statistics & numerical data; Pediatrics; Portugal; Surveys & Questionnaires

Introduction

Due to the improvements seen in medical care, therapeutics, and technology in the last decades, many children with complex chronic diseases are now living into adolescence and young adulthood.¹ These children require interdisciplinary care as well as specialized and expensive interventions. This increase in complex chronic diseases frequency in pediatric departments needs to be accompanied by reform in diagnosis and family support.

In 1998, the World Health Organization defined for the first time pediatric palliative care as active, total, and integral care of the body, mind, and spirit of the child, including family support.²

International guidelines in this area state that all children with chronic and/or life-threatening diseases should have access to palliative care and this type of care should be offered at diagnosis as well as throughout the course of illness, regardless of whether the child is receiving disease-directed treatment or not, and whether the outcome ends in a cure or death.^{1,3,4}

According to the American Academy of Pediatrics, pediatric palliative care should be based on the following principles¹:

- Respect for the dignity of patients and families;
 - Access to competent and compassionate palliative care;
 - Support for the caregivers;
 - Improved professional and social support;
 - Continued improvement through research and education.
- Fewer symptoms and less suffering are found in children that have been referred to palliative care

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services,^{5,6} although rather few of those are referred in a timely manner.⁷ Previous studies have reported important barriers to providing pediatric palliative care, most commonly being uncertainties in prognosis, discrepancies in the treatment goals between the staff and family members,⁸ limited knowledge about pediatric palliative care,^{9,10} discomfort when talking about death, cultural barriers,⁹ and the perception of the health care professionals that families may refuse or have discomfort with the forgoing life-sustaining treatments.¹¹

It is estimated that, in Portugal, about 6.000 children and adolescents are in need of palliative care.¹² Since 2013, pediatric palliative care in Portugal went from level 1 (no known provision or capacity building activities for palliative care of children) to level 4 (evidence of broad palliative care provision for children with training available and focused plans for development of services and integration into health care services).¹³

In a national meeting that was held in Lisbon in June 2013, where recommendations were issued concerning the implementation of pediatric palliative care in Portugal, one of the main barriers identified was the awareness and basic training of health care professionals.¹²

Given the evolution on this field, and the urgent need for the implementation of such recommendations on a national level, it is of utmost importance to evaluate the attitudes and perspectives of health care pediatric teams. The purpose of this survey was to evaluate the knowledge and attitudes of health care professionals toward pediatric palliative care, and consequently to identify the possible barriers to the timely referral of patients to pediatric palliative care. In addition, we hope to use our data to guide future educational strategies for health care professionals in our department.

To the best of our knowledge, this is the first study exploring the barriers to pediatric palliative care implementation in Portugal.

Methods

We conducted a cross-sectional survey of health care professionals working in a pediatric hospital in the Lisbon metropolitan area.

Our pediatric department is a medical surgical unit comprising an emergency service, a pediatric ward, a pediatric and neonatal intensive care unit, an outpatient clinic with several pediatric specialties, and a newly formed palliative care team.

To characterize the knowledge of health care professionals regarding pediatric palliative care, in terms

of basic awareness as well as perceived barriers to referral, a survey design methodology was selected as part of the overall project. The survey instrument used was a questionnaire, previously validated,¹⁴ that contains 18 multiple-choice and Likert scale questions and one open-ended question. The questions covered the demographic background, clinical and palliative care experiences, knowledge of and attitudes toward palliative care and palliative care services, and confidence in the skills related to palliative care provision and referral. The open-ended question was: What comes to mind when you think about palliative care?

For this purpose, we contacted the author of the aforementioned questionnaire and were given permission for its translation and distribution. The distribution to all the clinical staff members was made via a paper questionnaire after obtaining ethics committee approval. The questionnaire was given to all the health care professionals of the department in September 2017. Confidentiality and anonymity were ensured. The translation was performed by two authors of the study. The close-ended questions were analyzed using SPSS® 25. Descriptive and inferential analysis was conducted. A Chi-square test was used for the evaluation independence of the nominal variables, $p < 0.05$. The open-ended questions were analyzed through researching the frequency of the following terms: end of life, comfort/symptom management, family support, service provision, quality of life, and spiritual and social support.

Results

Sample characteristics

Of the 254 questionnaires delivered to the health care staff members, 140 were filled out and returned (response rate of 55%).

From our sample of 140 respondents, 54% (n = 75) were nurses, 36% (n = 51) doctors, 4% (n = 5) physiotherapists, 3% (n = 4) educational professionals, 2% (n = 3) psychologists, one dietitian, and one social worker. About 57% (n = 80) of the respondents had been working in the field of pediatrics for more than nine years. The sample characteristics are shown in Table 1.

Previous experience of health care professionals with palliative care

Twenty-three percent (n = 32) had previous contact with an adult hospital palliative care team, 16% (n = 23) with an adult community palliative care team, and 11% (n = 15) with a long-term inpatient pediatric unit for children with chronic diseases.

Views of health care professionals on why and when to refer patients to pediatric palliative care

When asked about what the adequate situations were for pediatric palliative care to start, over half of the health care staff members (55%, $n = 76$) answered that pediatric palliative care should start once the diagnosis of a complex chronic diseases is made, 26% ($n = 36$) when the disease progresses, 19% ($n = 26$) when the condition deteriorates, 11% ($n = 15$) when the disease has stabilized, 8% ($n = 11$) at the end of life or dying, and 1.4% ($n = 2$) after death (Fig. 1).

The three most common reasons for referring a child to pediatric palliative care would be to develop a pain and symptom management plan (93%, $n = 130$) to provide psychological support (86%, $n = 121$) and to discuss with the parents the option for the child to die at home (86%, $n = 121$). Table 2 shows the most common reasons to refer a child to pediatric palliative care.

The two most common reasons not to refer a child to pediatric palliative care were an uncertain prognosis (29%, $n = 40$) and the perceived reluctance on the part of parents to accept referral (28%, $n = 39$).

Notably, 63% ($n = 47$) of nurses pointed out diagnosis

as an adequate moment to start pediatric palliative care compared to only 40% ($n = 20$) of doctors. This difference was statistically significant ($p = 0.012$).

Knowledge and attitudes of health care professionals toward pediatric palliative care

Half of the health care staff members (50%, $n = 67$) reported the existence of important barriers to the integration of palliative care in the disease-directed care of their patients.

The majority (64%, $n = 87$) answered that pain management and symptomatic control are the main objectives of pediatric palliative care and 12% ($n = 16$) considered an early referral to pediatric palliative care as potentially harmful for parents' hope.

As many as 91% ($n = 127$) believe that pediatric palliative care is as important as curative treatment in the care of the children with complex chronic diseases and 73% ($n = 101$) disagree with the idea of pediatric palliative care being primarily about end-of-life care.

About 52% ($n = 69$) agree that parents are not informed about pediatric palliative care options when a diagnosis with a poor outcome is made and only 54% ($n = 73$) believe that children can play a role in decision making. About 64% ($n = 84$) believe that there are significant opportunities to integrate a pediatric palliative care team into the care and treatment of the children that they work with.

Health care professionals reported not feeling confident when discussing several pediatric palliative care issues with parents, such as the option of withdrawing or not initiating mechanical ventilation (42%, $n = 59$), the option

Table 1. Sample characterization (n = 140)

| Features | % (n) |
|--|-------------|
| Sex | |
| Female | 87 (122) |
| Male | 13 (18) |
| Clinical service | |
| Pediatric ward | 39 (55) |
| Neonatal intensive care unit | 35 (49) |
| Emergency service | 31 (70) |
| Pediatric intensive care unit | 27 (38) |
| Outpatient | 22 (31) |
| Operating room | 1.4 (2) |
| Years working in the pediatric department | |
| < 1 year | 9 (12) |
| 1-3 years | 13 (18) |
| 4-6 years | 14 (19) |
| 7-9 years | 15 (21) |
| > 9 years | 50 (70) |
| Response rate per profession | |
| Nurses | 75 (116-75) |
| Doctors | 85 (62-51) |
| Physiotherapists | 100 (5) |
| Educational professionals | 100 (4) |
| Psychologists | 100 (3) |
| Dietitian | 100 (1) |
| Social worker | 100 (1) |

Table 2. Common reasons for referral to pediatric palliative care

| Reasons for referring to pediatric palliative care | % (n) |
|--|------------|
| Develop a pain and symptom management plan | 92.9 (130) |
| Provide psychological and social support to parents | 86.4 (121) |
| Discuss with the parents the option of the child/ young person dying at home | 86.4 (121) |
| Discuss issues of illness and dying with parents | 81.8 (112) |
| Pain management | 78.6 (110) |
| Discuss issues of illness and dying with the child/ young person | 78.6 (110) |
| Organize grief counseling | 76.4 (107) |
| Management of other symptoms of concern | 70.7 (99) |
| Discuss do not attempt resuscitation with the parents | 60.7 (85) |
| Resolution of the differences between the wishes of the team and the parents | 58.6 (82) |
| Exploring spiritual issues with the child/young person | 58.6 (82) |
| Exploring spiritual issues with parents | 54.3 (76) |
| Make an emergency care plan with the parents | 47.9 (67) |
| Manage mechanical ventilation withdrawal | 47.1 (66) |

of withdrawing or not initiating hydration and nutrition interventions (39%, n = 55), the option of withdrawing or not initiating intravenous antibiotics (37%, n = 52), the option of withdrawing or not initiating blood products (38%, n = 53), the option of stopping or not initiating active resuscitation (43%, n = 60), and the option of the child dying at home or in a hospital (43%, n = 60). When discussing with the child questions about death and the place of dying, more than 50% do not feel confident. Table 3. shows what our health care team considered to be the value of a pediatric palliative care team in our department.

Most health care professionals (66%, n = 91) reported a high motivation to receive formal training in discussing a poor prognosis with parents, 58% (n = 80) showed interest in learning how to discuss the options of care

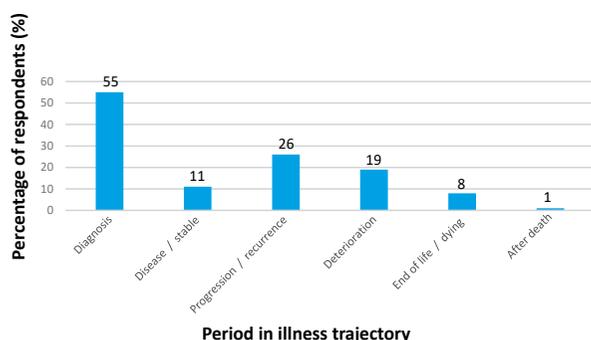


Figure 1. Answers of the health care professionals regarding the adequate timing for pediatric palliative care referral.

with parents, 57% (n = 78) in managing the symptoms of a child/young person with complex chronic diseases (57%, n = 78), and 55% (n = 75) in learning how to refer a child to a pediatric palliative care team.

Associations of health care professionals with palliative care

The open-ended question was answered by 81 health care professionals (57%). The most frequent expression reported was comfort/symptom management (*e.g.* to provide comfort and pain management) (54%, n = 44), followed by quality of life (*e.g.* to ensure quality of life in the face of a chronic condition) (35%, n = 28), and end of life (*e.g.* death and end of life come to mind) (32%, n = 26). Family support was only referred to by 15% (n = 12) of the respondents (*e.g.* to support and empower the family).

Discussion

In this survey, health care professionals from our pediatric department demonstrated having good knowledge regarding the key pediatric palliative care concepts when answering the close-ended questions. Most believed that pediatric palliative care is as important as the curative treatment (91%, n = 127) and that it is not just about end-of-life care (73%, n = 101). The majority believed that pediatric palliative care should

Table 3. Value of having a palliative pediatric care team in the department, as viewed by our health care professionals

| | Not useful, % (n) | Useful, % (n) | Very useful, % (n) |
|---|-------------------|---------------|--------------------|
| Advice on the management of specific symptoms | 4.4 (6) | 52.9 (72) | 35.3 (48) |
| 24 hours and seven days a week advice for family and staff members | 3.0 (4) | 38.5 (52) | 51.1 (69) |
| Joint care and management alongside your team | 1.5 (2) | 49.3 (67) | 40.4 (55) |
| A do not attempt resuscitation/emergency care plan | 2.9 (4) | 48.2 (66) | 38.0 (52) |
| Assistance in the withdrawal of ventilation in the hospital or home setting | 9.6 (13) | 39.0 (53) | 34.6 (47) |
| Coordination of care at home | 0.7 (1) | 37.2 (51) | 56.2 (77) |
| Home visits | 1.5 (2) | 36.5 (50) | 53.3 (73) |
| Coordination of care with other hospitals and the community | 2.2% (3) | 40.1 (55) | 51.1 (70) |
| Support decision making | 0 | 48.1 (65) | 46.7 (63) |
| Psychological support | 0 | 40.9 (56) | 55.5 (76) |
| Make a pain control plan | 0 | 45.3 (62) | 48.9 (67) |
| Social support | 0 | 43.8 (60) | 49.6 (68) |
| At the time of diagnosis, discussions with the parents about future care and treatment | 8.0 (11) | 35.5 (49) | 50.0 (69) |
| At the time of diagnosis, discussions with the child/young person about future care and treatment | 7.2 (10) | 37.0 (51) | 47.1 (65) |
| At the time of progression of the child's condition, discussions with the parents about care and treatment | 1.4 (2) | 36.2 (50) | 55.8 (77) |
| At the time of progression of their condition, discussions with the child/young person about care and treatment | 0.7 (1) | 36.2 (50) | 54.3 (75) |

begin at diagnosis (55%, $n = 76$) and, in general, health care professionals would refer to pediatric palliative care to develop a symptom management plan (93%, $n = 130$), provide psychological and social support (86%, $n = 121$), and discuss issues of illness and dying with parents (86%, $n = 121$). According to international recommendations,^{1,2,15,16} pediatric palliative care is not limited to end-of-life care, but also pertains to the global physical, mental, social, and spiritual care of children and families with complex chronic diseases, from the moment of diagnosis continuing through all the disease trajectory until the period after death. The pediatric palliative care team should be concerned with early symptom control and advanced care planning, offer continued emotional support to help the child cope with psychological issues, give access to resources that promote the child's personality and, where possible, the continuation of daily routines, promote appropriate spiritual care respecting the family cultural and religious background, and promote schooling for as long as possible and social activities for interaction with peer groups. Pediatric palliative care programs should be family-centered, and their needs should not be forgotten, providing thorough knowledge of their child condition and how best to care for them, financial help, and appropriate emotional and bereavement support.¹⁵ Pediatric palliative care programs should offer continuity of care that is available around the clock either at home, in the hospital, or in the community.¹⁵

Although most health care professionals in our department (64%, $n = 84$) agreed that there are significant opportunities to integrate pediatric palliative care in the care for their patients, they also believe that there are possible barriers to the integration of pediatric palliative care, such as the reluctance of parents to accept a referral (28%, $n = 39$) and an uncertain prognosis (29%, $n = 40$).

A survey was conducted among pediatric health care providers to explore barriers to palliative care and found that 55% of the responders reported an uncertain prognosis as a possible barrier for pediatric palliative care referral.⁸ Uncertainty is an inherent dimension in any life-threatening disease, and an uncertain prognosis should act as an indicator that palliative care should be started.⁸

In our study, most health care professionals are not comfortable addressing the child or their family about several pediatric palliative care issues, such as death, prognosis, and end-of-life therapeutics. This communication failure is more evident toward the ill child, possibly because health care professionals are more used to talking with parents in their daily

activities. In line with previous results, health care professionals value the presence of a pediatric palliative care team as especially useful to discuss with parents and children about the treatment care plan at the time of diagnosis (50%, $n = 69$ and 47%, $n = 65$, respectively), disease progression (47%, $n = 65$ and 56%, $n = 77$), and to coordinate home care (56%, $n = 77$). The provision of pediatric palliative care involves a partnership between the child, family, school staff members, and health care professionals, including nurses, chaplains, social workers, primary care physicians, subspecialty physicians, and psychologists.^{15,16} The child should actively and fully participate, pondering their illness experience, developmental capacities, and level of consciousness. Regardless of the prognosis, respect for the child requires they are given a developmentally appropriate description of the condition along with the expected burdens and benefits of the available management options, while asking about and then listening to the child's preferences.¹⁷ The pediatric palliative care team will facilitate the communication between professionals and the family as well as between the hospital and the community. Shared decisions, psychosocial, bereavement support, and control of symptoms will be provided by the team.¹⁸

In one study,¹⁴ most of the survey respondents also demonstrated good knowledge and awareness of the principles of pediatric palliative care in close-ended questions, suggesting that the misunderstanding of the principles should not be a barrier to timely and appropriate referral. In the same study, the most common reason for referral to pediatric palliative care was to discuss with parents the option of dying at home, suggesting a late referral to pediatric palliative care, yet the diagnosis of a life-limiting or threatening disease rarely was the cause for referral.

In our study, the answers to the open-ended question (What comes to your mind when you think of palliative care?) showed that 54% ($n = 44$) of health care professionals associate pediatric palliative care with comfort/symptom management, 36% ($n = 28$) with quality of life, and 32% ($n = 26$) with end of life, which points to a high association of pediatric palliative care with end of life. This type of concept association was also reported by other authors,¹⁹ where most health care providers associated pediatric palliative care with non-curative treatment. According to another study¹⁴ that found similar results in the open-ended question, the divergent results between open and close-ended questions show that health care professionals have not translated into practice what they have learned about pediatric palliative care and a possible barrier to timely

referral may not only be the lack of knowledge but also an unrecognized association of pediatric palliative care and death that was found in the attitudes of health care professionals.

Timely referral to a pediatric palliative care team is of the utmost importance. However, as reported in the literature, a late referral may happen due to several barriers and misconceptions that influence the attitudes and perspectives toward pediatric palliative care. Studies have demonstrated that the acknowledgement of a child's premature death, both by the health care team and the parents, resulted in optimized pediatric palliative care for children with cancer.^{6,8} An early referral to pediatric palliative care is an opportunity to offer the family and child with complex chronic diseases a better quality of life. A rigid distinction between curative and palliative care may hinder the appropriate provision of palliative care to children living with complex chronic diseases. The idea that there is no place for palliative care before the exhaustion of every curative treatment may interfere with the timely introduction of palliative care.¹

In addition to undermining the best care for patients, the misconceptions of health care professionals on pediatric palliative care also influence the negative attitudes of patients and families toward pediatric palliative care.¹⁹ Other barriers to early referral to pediatric palliative care have been identified in the literature and must be addressed when educating health care professionals. In a survey among American pediatricians, some of the reported obstacles included the lack of acknowledgement of an incurable condition by the family, discrepancies in the treatment goals between the staff members and family members, family preferences for more life-sustaining treatment, barriers to communication, limited financial resources, and lack of training and expertise.^{8,20} Family reluctance to accept palliative care and the family view of palliative care as giving up as important barriers to referral to palliative care were identified in another study.²¹ Four main areas that constitute barriers to the planning and development of pediatric palliative care services were identified in Italy¹⁰: sociocultural setting, types of patients and the nature of the diseases requiring pediatric palliative care, training for pediatric palliative care providers, and regulatory and political issues.

Our study had some limitations. The rate of response was only 55%, and although that is higher than similar studies,^{14,22} it probably does not reflect the knowledge and attitudes of all of the health care professionals from our department. The sample was heterogeneous and not everyone that answered the questionnaire will be

involved in treating children with palliative care needs nor will they be a part of a multidisciplinary team. Despite that fact, we included health care professionals such as physical therapists, educational professionals, psychologists, dietitians, and social workers because all of them can potentially identify children with palliative care needs and refer them to the newly formed team. Our study includes data from only one Portuguese center, which limits our ability to generalize our conclusions about the knowledge and attitudes toward pediatric palliative care of health care professionals on a national level.

We found some misconceptions of pediatric palliative care. Like previous studies,^{9,19} our survey suggests that there is a need for better training and education in pediatric palliative care in order to meet the educational needs of knowledge, experience, and communication skills of the department health care team. We believe that there are significant opportunities and motivation for training and education in this field. In line with other studies,¹⁴ our work raises the question: what if, despite conceptual changes in palliative care and the demonstration of its worth when initiated before the end of life, the health care professionals will keep associating pediatric palliative care to the concept of death?

Upon the implementation of a pediatric palliative care team in our department, this questionnaire allows for the evaluation of knowledge and attitudes toward pediatric palliative care in order to understand how the process of referral is being made and to develop educational opportunities to enlighten misconceptions. In addition, data from this study can provide guidance to new educational strategies for health care professionals in our department.

WHAT THIS STUDY ADDS

- This is, to the best of our knowledge, the first reported survey on knowledge and the attitudes of health care professionals toward this aspect of palliative care of children in Portugal and thereby begins to fill an evident gap.
- Our work provides a framework for future pediatric palliative care teams, both in training and surveying their health care professionals.
- Our study will enable the new pediatric palliative care team in our department to establish education and training of health care professionals. It is also an instrument of evaluation to be used in the near future to comprehend both the process of referral and the trajectory of knowledge and attitudes of our department in this area.

Conflicts of Interest

The authors declare that there were no conflicts of interest in conducting this work.

Funding Sources

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Protection of human and animal subjects

The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and with those of the Code of Ethics of the World Medical Association (Declaration of Helsinki).

Provenance and peer review

Not commissioned; externally peer reviewed

Confidentiality of data

The authors declare that they have followed the protocols of their work centre on the publication of patient data.

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Cuidados Paliativos Pediátricos: Estudo do Conhecimento e Atitudes de Profissionais de Saúde**Resumo:**

Introdução: A melhoria dos cuidados médicos tem permitido uma vida mais prolongada às crianças com doenças crónicas complexas. Os cuidados paliativos pediátricos devem ser oferecidos a estas crianças e às suas famílias. O objetivo deste estudo foi avaliar o conhecimento e as atitudes dos profissionais de saúde de um serviço de pediatria em relação aos cuidados paliativos pediátricos, bem como identificar as possíveis barreiras ao encaminhamento dos doentes para esses cuidados.

Métodos: Foi realizado um inquérito transversal aos profissionais de saúde de um hospital pediátrico de Lisboa, utilizando um questionário com 18 questões de escolha múltipla e uma questão aberta.

Resultados: Responderam ao questionário 140 profissionais de saúde. Nas questões de escolha múltipla, 55% (n = 76) acreditam que os cuidados paliativos pediátricos devem iniciar-se no diagnóstico, 91% (n = 127) consideram-nos tão importantes quanto o tratamento curativo e 73% (n = 101) discordam dos cuidados paliativos pediátricos serem principalmente sobre cuidados em fim de vida. O motivo mais comum para não encaminhar uma criança

para cuidados paliativos pediátricos foi um prognóstico incerto (29%, n = 40). Na questão aberta, as expressões mais frequentemente associadas ao conceito de cuidados paliativos foram conforto / gestão de sintomas (54%, n = 44), qualidade de vida (35%, n = 28) e fim de vida (32%, n = 26).

Discussão: Neste estudo, as questões de escolha múltipla revelaram que os profissionais estão bem informados sobre os cuidados paliativos pediátricos. A maioria identificou o momento do diagnóstico de doenças crónicas complexas como a ocasião ideal para iniciar os cuidados paliativos pediátricos. Nas questões abertas, verificou-se que os cuidados em fim de vida ainda estão associados aos cuidados paliativos pediátricos, sugerindo uma associação não reconhecida de cuidados paliativos pediátricos e morte nas atitudes dos profissionais de saúde e uma potencial barreira ao encaminhamento atempado.

Palavras-Chave: Atitude do Pessoal de Saúde; Criança; Cuidados Paliativos/estatística & dados numéricos; Cuidados Paliativos/psicologia; Cuidados Paliativos/tendências; Inquéritos e Questionários; Pediatria; Portugal