

## The knowledge of physical therapists on palliative care in pediatria em a maternal children´s

### O conhecimento dos fisioterapeutas sobre cuidados paliativos em pediatria em um hospital materno infantil

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**ABSTRACT | INTRODUCTION:** The lack of management in dealing with children in the terminal period of life can become a barrier between the professional and the family. Studies on the understanding of health professionals, especially physiotherapists regarding palliation in pediatrics, are meaningful to establish comfort strategies. **OBJECTIVE:** to describe the knowledge of physiotherapists on palliation in pediatrics. **MATERIALS AND METHODS:** quantitative, descriptive, cross-sectional study, where the adaptation of the pre-structured questionnaire was applied: Bonn Palliative Care Knowledge Test-BPW and a socioprofessional questionnaire, in the physiotherapists of the maternal children's hospital. **RESULTS:** The sample consisted of 44 physiotherapists, of both sexes, with ages varying between 20-50 years, with training time between 1-15 years. The analysis of the percentage of correct answers in the knowledge questionnaire in the BPW, with regard to the item of the philosophy of the CP 27.3% answered correctly, in relation to the priority of the medical treatment in CP 38.7% correct the answer. **CONCLUSION:** The understanding about PC is still superficial, most educational institutions are training professionals in need of knowledge about the premises of PC.

**KEYWORDS:** Palliative care. Pediatrics. Physiotherapists.

**RESUMO | INTRODUÇÃO:** A falta de manejo em lidar com as crianças no período de terminalidade da vida pode tornar-se uma barreira entre o profissional e a família. Estudos sobre o entendimento dos profissionais de saúde, especialmente os fisioterapeutas a respeito da palição na pediatria, são significativos para estabelecer estratégias de para conforto. **OBJETIVO:** descrever o conhecimento dos fisioterapeutas sobre a palição na pediatria. **MATÉRIAS E MÉTODOS:** estudo quantitativo, descritivo, transversal, onde foi aplicado a adaptação do questionário pré-estruturado: *Bonn Palliative Care Knowledge Test-BPW* e um questionário sócio profissional, nos fisioterapeutas do Hospital materno infantil. **RESULTADOS:** A amostra foi constituída de 44 fisioterapeutas, de ambos os sexos, com idade variando entre 20-50 anos, com tempo de formação entre 1-15 anos. A análise do percentual de acertos no questionário de conhecimento no BPW, no que concerne ao item da filosofia dos CP 27,3% responderam corretamente, já em relação a prioridade do tratamento médico em CP 38,7% acertaram a resposta. **CONCLUSÃO:** O entendimento sobre os CP ainda é superficial, a maioria das instituições de ensino está formando profissionais carentes conhecimento sobre as premissas do CP.

**PALAVRAS-CHAVE:** Cuidados paliativos. Pediatria. Fisioterapeutas.

## Introduction

The technological advance has provided survival for children considered to be severely ill; concomitantly, a group of children with chronic diseases and dependent on assistive technology has developed, often with reduced life expectancy and needing repeated hospitalizations.<sup>1</sup>

Dealing with this new patient profile requires a different approach from health professionals, aiming to integrate psychological and spiritual aspects to patient care, thus emerging the Palliative Care (PC).<sup>2,3</sup>

The World Health Organization (WHO), in 2002, defined Palliative Care as "an approach that improves the quality of life of patients (adults and children) and their families facing life-threatening illness—preventing and alleviating suffering through early identification, correct assessment, and treatment of pain and other physical, psychological, social, family, and spiritual problems."<sup>4</sup>

About 98% of children who need palliative care reside in underdeveloped countries like Brazil. Less than 10% of hospitals in Brazil have palliative care teams, but the number of patients who need palliation and manage to obtain it is much lower.<sup>5,6</sup>

One of the basic principles of palliative care for children is care focused on the child, oriented to the entire family, and built with an excellent team-family relationship. For this, the multi-professional team must integrally meet the child's needs, enabling actions that ensure a dignified survival and adequate control of symptoms, understanding the patient and his family in their subjectivity and complexity.<sup>7,8</sup>

The lack of management in caring for children in the terminality of life can become a barrier between the professional and the family. Therefore, the professional must understand how to proceed properly during palliation. As a member of the multidisciplinary team, the physiotherapist must base his intervention on the specificities of the child, understanding in its totality.<sup>5,6</sup>

The discussion about palliative care in pediatrics and the knowledge that healthcare professionals, especially physical therapists, have about it is still

recent in Brazil, and it is believed that the theme is under construction. Studies about the understanding of health professionals, especially physiotherapists, about palliation in pediatrics are significant to establish sensitization strategies, to seek humanized care in a way that the comfort of the child is prioritized.<sup>5-7</sup>

In this context, the present study aimed to describe physical therapists' knowledge about palliation in pediatrics.

## Material and methods

This is a quantitative study, descriptive in nature, with a cross-sectional study design, where two questionnaires were applied to physical therapists of the Maternal Child Hospital in the city of Feira de Santana, Bahia-Brazil. The research began after approval by the Research and Ethics Committee of the Hospital Irmã Dulce and the Ethics and Research Committee of the institution where the research was carried out (Opinion no. 4.304.730, September 28, 2020).

Physiotherapists of a maternal and child hospital were invited to participate in the study. They are active in the Pediatric and Neonatal Intensive Care Units and/or in the Emergency, Childbirth, Nursing Unit sectors due to the rotation of professionals in these sectors, and the physiotherapists who are sector leaders because of their active participation in the units. Professionals who work in obstetric care, who were in coordination positions, on leave for health or maternity reasons, on vacation during the collection period, and the researchers of this study were not included.

Initially, a socio-professional questionnaire was applied, consisting of 15 closed questions (mark an x). The questionnaire includes questions regarding gender, age, area of work, time of training and work experience, the existence of complementary training, and issues related to the process of death and dying.

Subsequently, the professionals answered a Portuguese version of the Bonn Palliative Care Knowledge Test (BPW), cross-culturally adapted by the researchers, where the questions inherent to the target population of this study were selected.

The BPW is a self-applicable, anonymous test with an estimated response time of 10 minutes. In this study, the BPW contained 15 questions for the analysis of general knowledge about palliative care and the process of death and dying.

The scale contained in the questionnaire is of the Likert type, in which the respondents marked the validity of the items following the terms "correct," "fairly correct," "not very correct," or "incorrect," as in the rating description below.

Each statement of the knowledge analysis topics has two expected answers: "correct" and "reasonably correct" or "slightly correct" and "incorrect." Thus, questions 1,3,4,5,6,8,10,12,13,14, were considered correctly answered when only one alternative was marked as "slightly correct" or "incorrect", while items 2,7,9,11,15, the expected answers were "correct" or "reasonably correct".<sup>9</sup>

The questionnaire items with the most discrepant frequency of answers will be analyzed individually, where the answers will be divided into correct and wrong ones, according to the referential of the questionnaire, being the same quantified and exposed graphically.

Categorical variables were presented as frequency counts and numerical percentages. The analyses were performed in IBM SPSS Statistics Version 26.

## Results

The sample consisted of 44 physical therapists, of both genders, ranging in age from 20-50 years Table 1.

**Table 1.** Social profile of physical therapists working in neonatology and pediatrics-2020

Sex	n (%)
Female	35 (79,5)
Male	9 (20,5)
Age	
20-30 years old	17 (38,6)
31-40 years old	24 (54,5)
41-50 years old	3 (6,8)

Prepared by the authors, 2021  
Source: Field research, 2020

In the socio-professional questionnaire, the participants answered how long they had been a graduate, how long they have worked in Neonatology/Pediatrics, and answered "yes" or "no" to questions about taking courses on palliative care and whether they believed that the content they learned during college was sufficient to deal with a terminally ill patient.

Regarding professional occupation, 61.4% of the physical therapists have been working for 1 to 5 years Table 2. Regarding the time of work in Neonatology and Pediatrics, 56.8% have from 1 to 5 years Table 2.

When approaching information on terminal patient care during graduation, 93.2% answered that they had not had any information on terminal patient care. Regarding complementary training on palliative care, 65.9% never had such training after graduation Table 2.

**Table 2.** Professional profile of physical therapists working in neonatology and pediatrics-2020

<b>Training Time</b>	<b>N (%)</b>
<1 year	1 (2,3)
1-5 years	27 (61,4)
6-10 years old	3 (6,8)
11-15 years old	2 (4,5)
16-20 years old	11 (25)
<b>Time of performance in the area</b>	
< 1 year	1 (2,3)
1-5 years	25 (56,8)
6-10 years old	2 (4,5)
11-15 years old	11 (29,5)
<b>Information on terminal patient care during graduation</b>	
Yes	3 (6,8)
No	41 (93,2)
<b>Has taken a course in palliative care</b>	
Yes	15 (34,1)
No	29 (65,9)

Prepared by the authors,2021  
Source: Field research, 2020

The analysis of the overall performance in the BPW considered all the questionnaires where the participants, answered only one option in each answer. All participants answered the questionnaire correctly, totaling 44 questionnaires. The answers obtained are explained in the table below.

The results of the knowledge assessment using the Bonn Palliative Care Knowledge Test are shown in Table 3.

**Table 3.** Analysis of the items of the knowledge section of the adapted BPW-2020 questionnaire (to be continued)

<b>1.The PCs should never be combined with curative treatments</b>	<b>N (%)</b>
Correct	7 (15,9)
Reasonably Correct	11 (25,0)
Correct Slightly	8 (18,2)
Incorrect	18 (40,9)
<b>2.Non-pharmacological asterapies (for example , physiotherapy) are important in pain management</b>	
Correct	40 (90,5)
Reasonably Correct	3 (6,8)
Correct Slightly	1 (2,3)
<b>3.for family members it is always important to remain with the person in the last hours of life until death occurs</b>	
Correct	33 (75,0)
Reasonably Correct	10 (22,7)
Correct Slightly	1 (2,3)
<b>4. PCs require constant emotional closeness</b>	
Correct	32 (72,7)
Reasonably Correct	10 (22,7)
Correct Slightly	1 (2,3)
Incorrect	1 (2,3)
<b>5. With advancing age, people have learned to deal with pain independently, as a result from various experiences</b>	
Correct	5 (11,4)
Reasonably Correct	16 (36,4)
Correct Slightly	10 (22,7)
Incorrect	13 (29,5)

**Table 3.** Analysis of the items of the knowledge section of the adapted BPW-2020 questionnaire (conclusion)

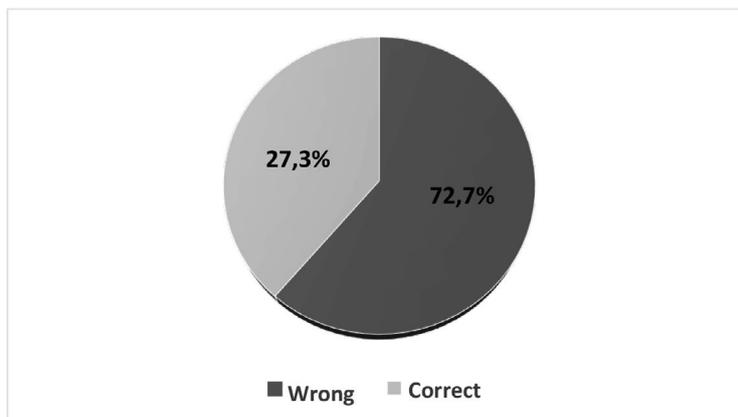
<b>6. The philosophy of the PCs is that they should not be any interventions designed to to prolong life</b>	
Correct	18 (40,9)
Reasonably correct	14 (31,8)
Correct Slightly	3 (6,8)
Incorrect	9 (20,5)
<b>7. Pain threshold is lowered by anxiety or fatigue</b>	
Correct	7 (15,9)
Reasonably Correct	2 (4,5)
Correct Slightly	14 (31,8)
Incorrect	21 (47,8)
<b>8 People with life-threatening diseases should always be informed of the truth, so that they can prepare their dying process</b>	
Correct	34 (77,3)
Reasonably Correct	10 (22,7)
<b>9 Team members do not have to be believers to provide spiritual care to the person at the end of life.</b>	
Correct	26 (59,1)
Reasonably Correct	11 (25)
Correct Slightly	3 (6,8)
Incorrect	4 (9,1)
<b>10. The person who receives PC must accept death</b>	
Correct	2 (4,5)
Reasonably Correct	14 (31,8)
Correct Slightly	15 (34,1)
Incorrect	13 (29,5)
<b>11. Communication skills can be learned</b>	
Correct	35 (79,5)
Reasonably Correct	9 (20,5)
<b>12. Other patients should not be informed about the person's death to avoid disquiet</b>	
Correct	8 (18,2)
Reasonably Correct	20 (45,5)
Correct Slightly	11 (25,0)
Incorrect	5 (11,4)
<b>13. Medical treatment always has priority in CP</b>	
Correct	13 (29,5)
Reasonably Correct	14 (31,8)
Correct Slightly	6 (13,6)
Incorrect	11 (25)
<b>14. When a person dies, the visible rituals and farewell ceremonies should be avoided so as not to cause disquiet</b>	
Correct	3 (6,8)
Reasonably Correct	5 (11,4)
Correct Slightly	7 (15,9)
Incorrect	29 (65,9)
<b>15. The final phase refers to the last 3 days of life</b>	
Correct	4 (9,1)
Reasonably Correct	8 (18,2)
Correct Slightly	11 (25,0)
Incorrect	21 (47,7)

Prepared by the authors, 2021  
Source: Field research, 2020

After the general evaluation, the questionnaire items were analyzed individually, measuring the number of correct and wrong answers.

Questions 6 and 13 represented the items that obtained the greatest discrepancy in the answers, with the most repeated wrong answers (Figure 1 and Figure 2). Of the participants, 72.7% believe that the philosophy of palliative care does not prioritize interventions aimed at prolonging the life of patients in palliative care Figure 1.

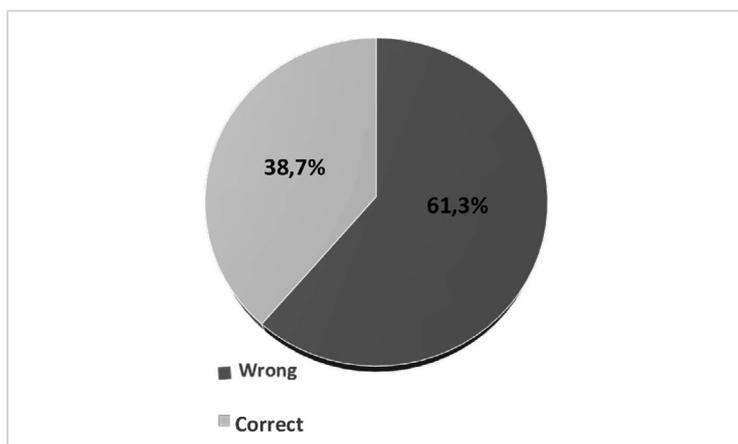
**Figure 1.** Percentage of right and wrong answers to the statement: "The philosophy of PC is that no interventions should be performed to prolong life



Prepared by the authors, 2021  
Source: Field research, 2020

Regarding the item that reports that medical treatment always has priority in palliative care 61.3% answered incorrectly Figure 2.

**Figure 2.** Percentage of right and wrong answers to the statement: Medical treatment always has priority in PC



Prepared by the authors, 2021  
Source: Field research, 2020

## Discussion

The lack of knowledge of professionals is an important factor for patients not to have access to palliative measures; studies and debates on the theme are important for the technical and scientific updating of professionals. Research carried out in other countries exposed a deficit in the formation of health professionals regarding palliative care.<sup>10</sup> About 93.2% of the participants in this study reported that they did not obtain information on terminal patient care during their graduation.

Analogous to the objective of this study, Oliveira, Teixeira, Tavares used the BPW to verify the level of knowledge of professionals within an ICU (Intensive Care Center), exposing at the end of the research that the reflection of the low offer of courses in the area of PC during graduation, reflects within the ICU studied where only 22% of participants had specific training in PC 12, similar to the result of this research where 34.1% of physical therapists reported having some course in PC.

Physiotherapy still has its training based on the biomedical model, which predicts the separation between body and mind and the non-existence of the importance of spirituality in the health-disease process. With its rehabilitative focus, the curriculum still centralizes its disciplines in the search for rehabilitation of diseases that restrict human locomotion.<sup>11</sup>

The creation of optional courses is an option to overcome this delay. However, it is still necessary to awaken undergraduates' interest in the subject because it can be taken into their professional lives. About 65.9% of the professionals have never taken a course on palliative care, consolidating the previous information.<sup>11</sup>

In December 2010, the Ministry of Health, through Ordinance No. 4279, established palliative care in its healthcare guidelines. The misinformation about the principles that guide this type of assistance is evident.<sup>13</sup>

However, PC should be initiated from the diagnosis and curative measures and should be used as long as it provides quality of life to patients, according to the WHO principles. In this way, patients receive PC

at different moments in the evolution of the disease, not depriving them of medical treatment associated with an approach that includes spirituality among the dimensions of the human being.<sup>5,6,15,16</sup>

In this study, the BPW items stating that "PC should never be combined with curative treatments" and that "The PC philosophy is that no interventions should be performed to prolong life" were judged correct by 15.9 and 40.9 respectively participants.

One of the principles of PC is the integrality of care, helping the patient and his family to face and relieve physical and psychological symptoms.<sup>6,7</sup> Pain is considered one of the most disabling symptoms in children; item 2 of the BPW refers to non-pharmacological therapies as important in pain management. In the cross-cultural adaptation of the BPW performed by Minosso, Martins, Oliveira<sup>9</sup>, 80% of the professionals and students who participated in the survey answered this item correctly.

The PC manual states that the success of pain management treatment must be elaborated by the interdisciplinary team where physical therapy must act through techniques and exercises seeking the child's comfort.<sup>5,6</sup>

Still, in integral care, the spiritual dimension is of great importance for the patients and their families. When dealing with suffering and pain, the spiritual approach has a positive effect when facing life's challenges, promoting well-being.<sup>17</sup> The ANCP manual states that team members do not have to be believers to approach the patient from the perspective of spirituality, which is invariably confused and overlapping with the religious issue.<sup>5,6</sup>

Spirituality is an aspect of transcendence of the meaning of life allied or not to religion, 59.1% of the participants of this study considered correct the item referring to religiosity and spiritual care provided by team members. For 66.7% of students and 80% of professionals participating in Minosso, Martins, Oliveira's work, the item cited above is considered correct.<sup>9</sup>

Spineli transcribed that for nurses working in PHC (Primary Health Care), spirituality is related to faith and religiosity being an approach to the spiritual dimension and existence.<sup>18</sup>

The construction of the bond between the team and the patient occurs through effective communication. Proper communication enables the exchange and understanding of ideas, thoughts, and purposes.<sup>19</sup>

In order to speak and actively listen to patients and families, interpersonal communication strategies can and should be learned.<sup>20</sup> In this study, item 11, related to learning to communicate, presented 100% correct answers. In the research of Pfister et al., 2013, this item was answered 76.2% by the participants and 100% right by the experts.<sup>22</sup>

Spinelli exposed that the participants of his research stated that in the palliative approach, communication is related mainly to the need for information for patients and families, and the communication of news is considered a critical point. This item showed the highest percentage of correct answers, 96.9%, which shows that according to the professionals, communication in PC can be learned.<sup>18</sup> In this sense, communication is one of the pillars for effective care, allowing the team to direct their care cohesively with care directed to the patient's individuality, family interaction, clear and objective team, which implies better care.

Therefore, there is a need for more publications and debates on the subject. The BPW translated and adapted to Portuguese enables the knowledge of the main deficits, enabling sensitization measures and continued education for the analyzed team.

The results of this study may have limitations related to the application of the questionnaire since it is a self-administered questionnaire and was answered during the participants' working hours, which may limit the attention and time devoted to its completion.

## Conclusion

The present study corroborates the reality that the understanding about palliative care is still superficial, and most educational institutions are training professionals lacking knowledge about the premises of Palliative Care.

## Authors' contributions

Oliveira JLR and Purificação R Rodrigues, and Barreto LA participated in elaborating the study design, data collection, analysis, and interpretation of the results and writing of the manuscript.

## Competing interests

No financial, legal or political competing interests with third parties (government, commercial, private foundation, etc.) were disclosed for any aspect of the submitted work (including but not limited to grants, data monitoring board, study design, manuscript preparation, statistical analysis, etc.).

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