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ORIGINAL ARTICLE

The insertion of the Physical Education Professional in Pediatric Palliative Care: a critical review of the literature

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Keywords:
Palliative care, Physical education and training, Hospice care, Pediatrics, Chronic disease, Comprehensive health care.

Abstract

Objectives: Since Pediatric Palliative Care is based on holistic and comprehensive care for pediatric patients and their families, Physical Education is an essential health area for complete interdisciplinary care. Therefore, the objective of this article is to reflect on the insertion of the Physical Education Professional in Pediatric Palliative Care. **Methods:** This is a critical literature review. A theoretical and documentary research was carried out, based on the bibliographic survey in files available in the MEDLINE (via Pubmed) and SciELO databases in the last 5 years. A secondary capture was carried out from the references of the selected articles, in addition to the addition of the authors experience.
Results: Only 4 articles were selected in the main search, with an addition of 1 article in the secondary capture. As much as some studies suggest that increased physical activity can alleviate some symptoms, there is still a lack of robust evidence related to children. The strategies used by Physical Education Professionals must take into account the environment and the patients clinical status. The relevance of plays and games, even in the hospital setting, has been increasingly studied.
Conclusions: Physical Education is an area of ??health that envisions the integrality of care, considering the inseparability of actions, both promotional and preventive, treatment and rehabilitation, which are essential aspects in Pediatric Palliative Care. Important gaps are still found, which must be addressed by education and research.

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INTRODUCTION

Scientific advances in healthcare have been changing the profile of pediatric patients, who now survive with serious chronic conditions. At this moment, Pediatric Palliative Care (PPC) fully and respectfully assists these children and adolescents, bringing life beyond survival to them and their families, who suffer from limiting and life-threatening illnesses.[1]

According to the World Health Organization (WHO), Palliative Care is defined as "the prevention and relief of suffering of adult and pediatric patients and their families, who face problems associated with potentially fatal illnesses, including the physical, psychological, social and spiritual aspects the lives of these patients and their families".[1] Thus, it is understood that PPC does not accelerate or postpone death, and may even positively influence the prognosis of pediatric patients.[1]

PPC imply early identification, adequate assessment and treatment, improving quality of life and promoting dignity and comfort.[1] Therefore, in this context, it is also relevant to remember that the International Children's Palliative Care Network (ICPCN), a global entity that fights for rights of children with life limitations, published a letter declaring that children with life limitations or life-threatening conditions should have the opportunity to play, have access to leisure, interact with siblings and friends and participate in normal childhood activities.[2]

Physical Education (PE), as a field of knowledge, encompasses a wide range of concepts, which, when put into practice, require different means and methods. There are different definitions for the object of study of PE and several authors continue to make contributions to this discussion, one of which is Body Culture - a concept that socially, politically and historically contextualizes the manifestations of human movement.[3] From this perspective, PE includes the following contents: Games, Sport, Dance, Martial Arts, Gymnastics and Circus Activity.[3]

Currently, there is still a limited presence of Physical Education in the hospital environment as a whole, and palliative care is no exception: there are few references that mention the Physical Education Professional (PEP) in the care of patients in Palliative Care , whether pediatric or not.[4]

In February 2020, the Brazilian Classification of Occupations (CBO), under code 2241-40, published that the PEP is classified as a healthcare professional, a very important step in the field, which provided these professionals with greater recognition within the Brazilian Public Healthcare System (SUS), being able to carry out their activities with the proper compensation, like other healthcare professions.[5] Another important legal framework is Article 3 of Resolution No. 391, of August 26, 2020, in which the performance of the PEP in a hospital environment, exercising their functions integrated or not within the multidisciplinary team, including in the sphere of PPC.[6]

Since PPC is based on holistic and comprehensive care for pediatric patients and their families, PE is an essential area of health for complete interdisciplinary care, as, as mentioned above, it encompasses a series of cultural manifestations typical of the children's universe. Therefore, the goal of this paper is to reflect on the insertion of PEP in Pediatric Palliative Care.

METHOD

This is a critical review of the literature. A theoretical and documentary search was carried out, based on a bibliographic survey in files available in the MEDLINE (via Pubmed) and SciELO databases, with the terms (Child OR child OR "child care" OR "childcare") AND ("Care palliatives" OR "Palliative Care" OR "palliativecare"") AND ("physical education and training" OR "PhysicalEducationand Training" OR "physical activity" OR "physical exercise" OR exercise). The authors did not restrict the types of studies, but limited them to articles published in the last 5 years. Secondary capture was carried out based on the references of the selected papers, adding the authors' experience.

RESULTS

There were 77 publications in MEDLINE and zero in SciELO, with no exclusion due to duplication.

Of these 77 papers, the titles and abstracts of each one were read, then we selected those consistent with the themes of this study. At this stage, we excluded 73 papers, as none of them directly or indirectly dealt with the subjects "Palliative Care" and "Physical Education" simultaneously, nor did they deal with the pediatric age group.

We then chose only four papers[7,8,9,10] in this initial search to be read in full: all of them had a topic pertaining to the proposal of this study. Also, during the complete reading of these publications, a worthy article was found in the references: this article was read in full[11], also includied in the review.

These five publications found were used to construct the text of this study, which also relied on the experience of the authors, as they work on the topics investigated.

The review flowchart can be seen in figure 1.

DISCUSSION

Initially, understanding that the PEP is part of the healthcare team and also of the multidisciplinary Palliative Care team, surprisingly the literature search showed only a few papers on the topics of Pediatric Palliative Care and

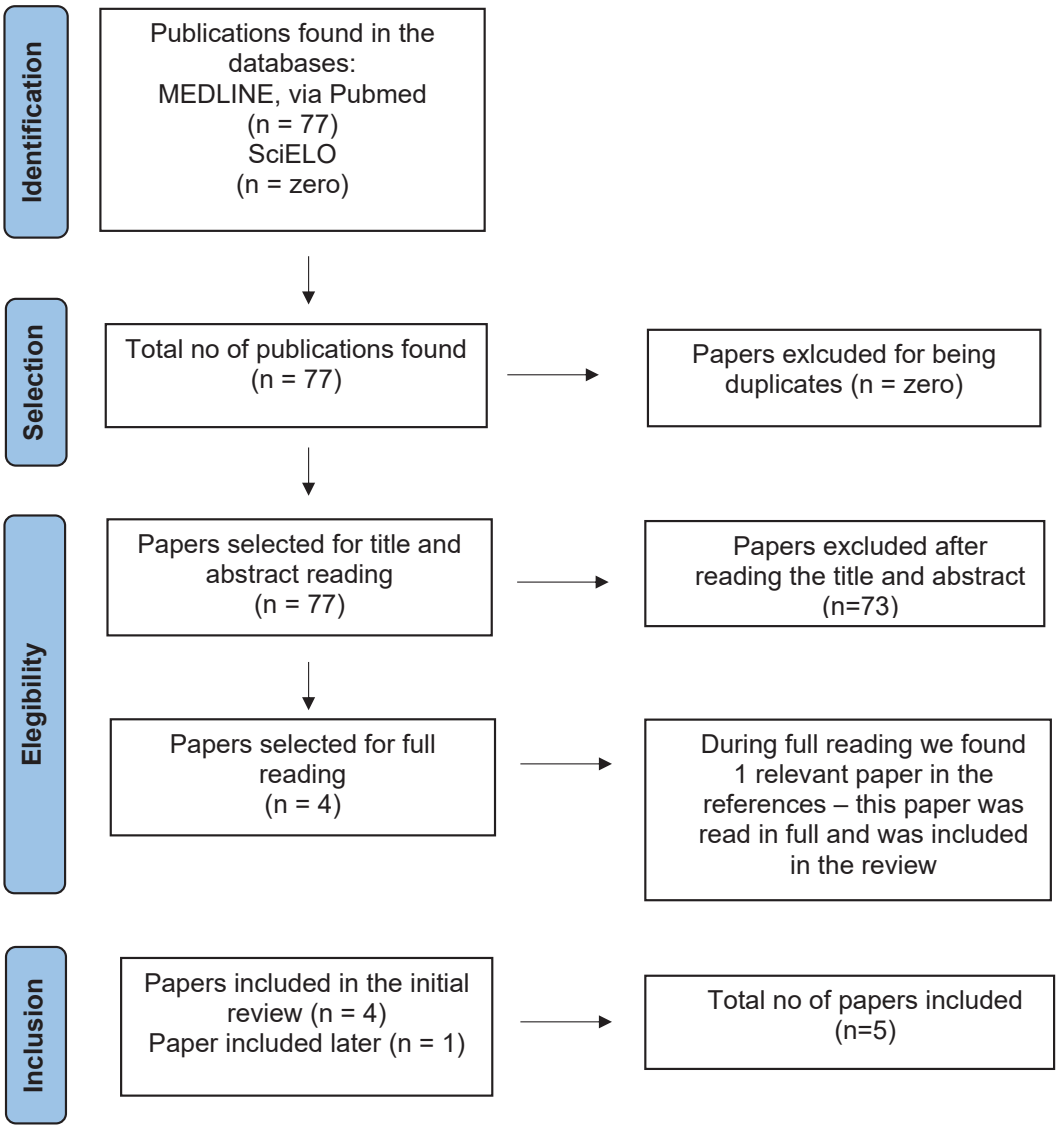

Figure 1. Review flowchart

Physical Education. This can be justified by the recent inclusion of PE professionals in the hospital environment[5] or even by Pediatric Palliative Care being a recent area[1].

The WHO recommends that people of all ages engage in regular and adequate physical activity, and if it is not possible to meet the recommendations due to health conditions, it is advised to be as physically active as possible.[7] Unfortunately, evidence from community-based physical activity interventions indicate that people living with chronic illnesses are often excluded from participating in studies[7]. Based on this, a Cochrane review, published in 2021, evaluated the effects of interventions aimed at promoting physical activity for people with neuromuscular diseases: there were only 13 papers that fit the scope of the study, none of which involved children or adolescents.[7]

The types of research interventions found by the Cochrane review[7] included structured physical activity support, exercise support (as a specific form of physical activity) and behavior change support, which included either physical activity or exercise.[7] Only one study included clearly reported that the goal of the intervention was to increase physical activity, with other studies reporting or planning to analyze the effects of the intervention on physical activity as a secondary or exploratory outcome measure.[7] The review brings research on walking, interactive exercises with and without sensors, such as accelerometers, as well as functional exercises compared to stretching.[7]

What is clearly perceived, even pointed out by the authors of the review[7], is that there is a lack of evidence

related to children and that uncertainty remains about the effectiveness of interventions that promote physical activity and its impact on quality of life, in addition to adverse events, because there is a lack of information, as well as more complete reporting of results.[7] Although there is no single objective measure of physical activity, studies that consider self-reporting can offer a pragmatic approach to capturing important changes at an individual and population level[7], considering the that the patient communicates, whether an adult or a child, is essential, whether he or she is diagnosed with neuromuscular or other diseases.

Robert et al studied patients with endometrial cancer and their well-being, as they would have an increased risk of having a poor quality of life.[8] In addition to analyzing the relationships between changes in physical activity and changes in physical aspects, they also sought to understand mental, social, and other changes that were possible in these patients after receiving a physical activity intervention.[8] Increased physical activity was positively associated with improvements in general health, role limitation due to physical health, and somatic pain and distress.[8] Even though this study does not relate to children, it is interesting to note that the results suggest that increasing physical activity can alleviate some symptoms.[8]

Fatigue is a common symptom in children who are monitored by Pediatric Palliative Care. A study carried out in pediatric oncology explored the effectiveness of non-pharmacological approaches in managing this complex and distressing symptom.[9] Among the interventions found, one of the groups was "Exercise-based interventions".[9] The majority of interventions were carried out during active treatment and in hospital settings, where parents and caregivers were involved to optimize participation.[9] Although fatigue scores were lower between the intervention groups, no study findings were statistically significant.[9] The authors reported, at the end of the study, that fatigue is common among children treated and living with cancer and that the most appropriate setting to carry out non-pharmacological interventions to control this symptom seemed to be the hospital. Unfortunately, however, as there is an absence of any strong evidence, professionals need to be cautious with existing non-pharmacological interventions, suggesting future studies that adopts more rigorous designs, analyzing with validated measures to identify potential benefits.[9]

Playing is an activity that can often contribute to different aspects of pain, one of which is pain education, whether for patients themselves or for students in the healthcare field: studies already reveal flaws in education about pain management in medical education, including pediatrics.[10] With cushions constructed to represent the most commonly used opioids and constructed with areas proportional to the strengths of the drugs, MacDonell-Yilmaz states that play can be used as a practical approach in small group sessions, introducing dosages, strengths and rotation of opioids through case-based exercises.[10]MacDonell-Yilmaz has used this teaching method for residents and medical students of the pediatric hematology-oncology service, with a very positive response, being very well received and repeatedly requested by patients.[10] We believe that this can be a strategy to be used also for patients, and here it is also a relevant role for the PEP.

Still on the importance of play and also games, even in the hospital setting, Gjærde LK et al[11] highlighted, in 2021, several gaps in this field of study, mainly with regards to the short and long-term effects of playful activities, and how to systematize the approaches of professionals who implement activities to achieve specific objectives among the children served. Children are at a complex, delicate and decisive moment in their motor development; therefore, in addition to the playful aspect that must be present in the activities offered, it is also important, if possible within the patient's health condition, that the stimuli are directed to the development of the physical capabilities expected for the age covered[11]: maintaining the playful nature of the activities is essential so that the child also has the possibility of dialoging with the world around them, even without using words to do so.[11]

It is important that the PEP has the capacity, together with the interdisciplinary PPC team, to understand the skills of the child it will assist, as well as the limitations resulting from the disease, as well as its progression phases, in order to seek the best care to the pediatric patient[4]. The Care Plan must be drawn up individually, analyzing each case, considering the needs of the child and their family, also paying attention to the patient's autonomy, which may change within the course of the disease.

Within different contexts of Pediatric Palliative Care we find activities in which the PEP can work with pediatric patients. All activities must be part of the care plan and a shared decision with the family, that is, the choice of activities by the PEP must be made with an understanding of the patient as a whole.[4] When planning the action, one must take into account considering what objective is intended to be achieved with the activity, what the patient's preferences are, and what activity can be achieved taking into account the patient's potential and limitations.[3,4,11]

For patients who are at home and without physical limitations, activities that stimulate them, both physically and mentally, should be encouraged as much as possible. Games like hide and seek and hopscotch are great for both cardiovascular stimulation and motor development. Team sports, such as football and volleyball, allow expanding

the capacity for interaction between colleagues. Dances, such as ballet and jazz, in addition to the physical potential they bring, also bring important benefits in socialization and development of self-image. Martial Arts, such as judo, involve the patient in the search for not only physical but also emotional balance, and gymnastics, such as weight training, brings unique bodily benefits, enabling the development of lean mass in patients who possibly have losses in these aspects. Circus activities are great allies to stimulate creativity and communication.[3,4,11]

As for patients who are at home, but who have physical limitations, it is necessary to explore and understand exactly what these limitations and deficiencies the patient has, in order to plan possible goals. Electronic games begin to be a possibility from now on, as they break the barriers of physical limitations, they will always be an option for children and teenagers to feel welcomed. Other games are also welcome, such as dominoes, for example, as the young person will be in the company of another colleague, which will add socialization. Team sports, such as 5-a-side football, for the visually impaired, and 7-a-side football, for athletes with cerebral palsy, are good resources for learning to work as a team, too. Dances, such as ballet, are important ways of expressing emotions and creativity, as are circus activities and artistic gymnastics. The practice of adapted martial arts also carries a foundation of self-knowledge.[3,4,11]

In the ward, attention must be paid to actively listen to the patient and their family, understanding their tastes and customs. The PEP must balance activities based on the cause of hospitalization, which was often necessary to treat a condition or control pain. Considering that these patients are limited to their beds or wards, games are great activity options, such as electronic games and card games, as well as dominoes and Stop, which can be played in pairs, which would be very interesting to maintain socialization in the hospital environment. Activities such as chess and yo-yo stimulate young people intellectually, just as weight training, if done in a way adapted to that teenager, it can be a great option to stimulate movement. There is the possibility of using dance as well, with choreographies in general, done in the patient's own bed, as well as magic, an activity that also encourages creativity; this is especially true all for patients who have long periods of hospitalization or who have sporadic hospitalizations, but who require adaptations to the hospital environment, since certain activities are not possible to be carried out there.[3,4,11]

In the Intensive Care Unit there is also a part for the PEP to play, as they needs to have excellent coordination with the intensive care unit team, in addition to the PPC, as actions must be chosen very carefully. A careful physical assessment and the comorbidities involved must be carried out by the entire team, in addition to the PEP, to understand the limitations and act with activities that will be beneficial to the patient. Electronic games are wise choices, considering the limitations that the environment and the gravity of the situation bring. Chess can be an option for children who love competitive games, just as weight training can be something possible, if done in bed. In circus activities, the magic here is what stands out, due to its easy applicability.[3,4,11]

In more complex situations, such as children and adolescents at the end of life, a phase in which Pediatric Palliative Care is often exclusive and death is close, the PEP must have great sensitivity, listening to what the patient has to say, including their tastes and desires, understanding the context in which they finds themselves, whether at home or hospital; in addition to their physical and other limitations, also understanding which ideas are possible to be implemented. Electronic games will always be a way out, as they are easily adaptable to any circumstances. Patients with great physical limitations, but who are cognitively adequate, can practice chess, for example. Magic and dance, whether simple movements or just observed on a device like a cell phone, are also activities that can bring emotional benefits and a sense of belonging. Even if the patient is at an advanced stage of the disease, the PEP's role is still very important, since many children and adolescents are aware of it and there are strategies for this approach.[3,4,11]

A summary of examples of the Physical Education Professional's actions is found in table 1.[3,4,11,12]

FINAL REMARKS

Physical Education is an area of health that envisions comprehensive care, considering the inseparability of actions, both promotional and preventive, treatment and rehabilitation, are all indispensable aspects in PPC. Teamwork for interdisciplinary action, taking into account the individuality of each patient, is also the foundation of the PEP's work. Therefore, it is essential that PPC services have this type of healthcare professional on their team.

There are still important gaps in this perspective: studies focusing on critically ill patients and Physical Education needs to be carried out, in addition to the essential promotion of education in Pediatric Palliative Care.

Table 1. Activities through which Physical Education Professionals can work with children and adolescents in Palliative Care, depending on the location of assistance and phase of the disease

Content	Games	Sport	Dance	Martial Arts	Gymnastics	Circus acitivies
Home environment – examples of activities						
Pacient without physical limitations	Hide and seek; jump over; Roller Carts; Stop; Hopscotch;Pipa	Cycling; Volleyball; Basketball; Tennis; Table tennis; Soccer; Swimming; Long jump;	Circular dances; hip hop; Choreographies in general; Classical Ballet;tap dancing; Jazz	Judo; Kung Fu; Capoeira; Karate; Aikido; Jiu Jitsu (martial arts in general)	Artistic gymnastics; Calisthenics; Bodybuilding; Yoga; Tai Chi Chuan	Walking on a reel; Juggling with balls, clubs; Diabolo; Stilts; Acrobatic trampoline
Patients with physical limitations	Electronic games in general; domino; Stop;	Adapted basketball; table tennis; Adapted football; swimming	Choreographies in general; Adapted ballet	Adapted martial arts in general	Adapted artistic gymnastics; Bodybuilding	Magic; Characters: paintings and acting (clown); balance of objects; Diabolo. Juggling with balls
Hospital environment – examples of activities						
In the hospital ward	Electronic games in general; domino; Stop; Cards (traditional deck)	Chess; Yoyo; basket ball.	Choreographies in general with different musical rhythms.	-	Bodybuilding adapted to the patient	Magic; Juggling; Characters: paintings and acting (clown); balance of objects.
In the ICU	Electronic games in general	Chess	-	-	Bodybuilding adapted to the patient	Magic tricks
Hospital and/or home environment – examples of activities						
Patient at end of life	Electronic games	Chess	Dances in general	-	-	Magic triks

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