© 2019 EDIZIONI MINERVA MEDICA
Online version at http://www.minervamedica.it

European Journal of Physical and Rehabilitation Medicine 2019 August;55(4):494-504
DOI: 10.23736/S1973-9087.19.05474-1

ORIGINAL ARTICLE

The impact of home-based physical rehabilitation program on parents' experience with children in palliative care: a qualitative study

Patricia RICO-MENA [1], Domingo PALACIOS-CEÑA [2, 3] *, Ricardo MARTINO-ALBA [4],
Lourdes CHOCARRO-GONZALEZ [4], Javier GÜEITA-RODRÍGUEZ [2, 3]

[1]Department of Physiotherapy, Podology and Dance, European University of Madrid, Madrid, Spain; [2]Department of Physiotherapy, Occupational Therapy, Rehabilitation, and Physical Medicine, Rey Juan Carlos University, Madrid, Spain; [3]Group of Humanities and Qualitative Research in Health Science of Univesidad Rey Juan Carlos (Hum&QRinHS), Madrid, Spain; [4]Unit of Pediatric Palliative Care, Niño Jesús Pediatric University Hospital, Madrid, Spain

*Corresponding author: Domingo Palacios-Ceña, Department of Physiotherapy, Occupational Therapy, Rehabilitation, and Physical Medicine, Rey Juan Carlos University, Avenida de Atenas, s/n, 28922 Alcorcon, Madrid, Spain. E-mail: domingo.palacios@urjc.es

ABSTRACT

BACKGROUND: Pediatric palliative care programs aim to improve the quality of life of children with severe life-threatening illnesses, and that of their families. Although rehabilitation and physical therapy provides a valuable tool for the control of symptoms, it has been poorly researched to date. Since the family represents such a fundamental support in these cases, it is important to deepen our understanding regarding the value of implementing rehabilitation programs from the parents' perspective.
AIM: The aim of this paper was to explore parents' experiences regarding the implementation of a physical rehabilitation program in pediatric palliative care.
DESIGN: A qualitative methodology was chosen.
SETTING: The unit of pediatric palliative care at the Hospital Niño Jesús (Madrid, Spain).
POPULATION: The inclusion criteria were: 1) parents of children, irrespective of their diagnosis; 2) integrated within the program of palliative care at the time of study; 3) aged between 0-18 years; 4) must be receiving Home-Based Rehabilitation Program by the Pediatric Palliative Care team. Fourteen parents were included.
METHODS: Purposeful sampling method was implemented. Data collection consisted of unstructured and semi-structured interviews. A thematic analysis was performed to interpret transcripts. Guidelines for conducting qualitative studies established by the Consolidated Criteria for Reporting Qualitative Research were followed.
RESULTS: Three main themes were identified: 1) the meaning of physical rehabilitation to parents; 2) physical rehabilitation as an opportunity for patients to stay in their home environment; and 3) home-based physical rehabilitation as part of the families' social environment.
CONCLUSIONS: The main needs of a home physical rehabilitation program are to decrease pain and suffering, together with improving family education and training.
CLINICAL REHABILITATION IMPACT: The experience of rehabilitation programs at home is essential in order to improve both the quality of life and the quality of care of affected children and parents.

(*Cite this article as:* Rico-Mena P, Palacios-Ceña D, Martino-Alba R, Chocarro-Gonzalez L, Güeita-Rodríguez J. The impact of home-based physical rehabilitation program on parents' experience with children in palliative care: a qualitative study. Eur J Phys Rehabil Med 2019;55:494-504. DOI: 10.23736/S1973-9087.19.05474-1)

KEY WORDS: Rehabilitation; Palliative Care; Child; Qualitative research; Home Care Services.

Pediatric palliative care (PPC) is the active, comprehensive care of the child's body, mind and spirit; which includes providing support to the family.[1, 2] Increasingly, PPC is recognized as an essential part of any healthcare system.[3, 4] Up to 50% of deaths in infancy take place during the first year of life, mainly due to perinatal causes such as premature births, congenital syndromes and neurological anomalies. In older children, the causes of death are related to acquired lesions (accidents or traumas) and complex chronic conditions (CCC).[3, 5, 6] Lindley *et al.*

found that the neuromuscular conditions, such as brain/spinal cord malformation, CNS disease, cerebral palsy, muscular dystrophy, were highly prevalent among children with CCC.[7] Also, cancer is responsible for one third of all deaths in children.[8]

Historically, cancer has been associated with palliative care. However, in industrialized countries, many of the children cared for in PPC programs have non-malignant diseases other than cancer.[1, 3, 6] This includes a broad range of conditions affecting the heart, the lungs, the brain and the muscles. The UK charity Together for Short Lives and the Royal College of Pediatrics and Child Health,[9] developed a guide where the neuromuscular conditions were considered "life limiting" conditions, as subgroup 4; *i.e.* "conditions with severe disability, often neurological, which, although they are not progressive, cause extreme vulnerability to health complications and where premature death is anticipated, *e.g.* severe cerebral palsy, and chromosomal disorders." The focus of PPC has long been to improve symptoms, maintain quality of life, and provide support to families when a child has a condition that is highly likely to end in premature death at any time prior to adulthood.[6] On a positive note, affected children who have been derived to PPC experience fewer symptoms and less suffering than those that have not, therefore the need for including interdisciplinary teams that support and collaborate in the decision-making process and in the clinical interventions with the children and their families has been largely emphasized in recent research.[1, 3, 10]

The European Association for Palliative Care (EAPC)[11, 12] highlights the importance of symptom control and providing access to continued physical rehabilitation (PR). According to the European Physical and Rehabilitation Medicine Bodies Alliance,[13, 14] PR Medicine is defined as: "*the primary medical specialty responsible for the prevention, medical diagnosis, treatment and rehabilitation management of persons of all ages with disabling health conditions and their comorbidities, specifically addressing their impairments and activity limitations in order to facilitate their physical and cognitive functioning (including behavior), participation (including quality of life) and modifying personal and environmental factors*."[13]

Several studies have researched the application of PR within palliative care,[15-18] highlighting the need for further studies in order to research the role of PR in life-threatening disease.[19] In this sense, Cheville *et al.*[16] have reported how palliative rehabilitation is function-directed care delivered in collaboration with other clinical disciplines. Furthermore, palliative rehabilitation is aligned with the values of patients who have serious and incurable illnesses. Patients may present intense and dynamic symptoms, psychological stress, and medical morbidity, all of which greatly impact upon autonomy and quality of life.

The child's family often suffers considerably and their needs can change during the entire process. They may experience anxiety, loneliness and isolation, including a change in their social roles.[20] According to Kars *et al.*[21] difficult situations faced by parents of dying children include having to make decisions concerning the child's treatment, and providing explanations to the child regarding the disease and possible treatments. Also, previous studies,[22, 23] have displayed how rehabilitation must be oriented towards covering the needs and preferences of patients while involving carers in the decision-making process.

Physical rehabilitation provides a valuable tool for the control of symptoms, however it has been poorly researched to date in children with severe life-threatening illnesses, and their families. Qualitative research that focuses on the parent perspective regarding the application of PR interventions on children with terminal diseases is therefore necessary. To our knowledge, no study to date has provided an insight into the parents' experience after the implementation of a home-based PR program for children in PPC. The purpose of this qualitative study was to explore parents' experiences and perspective regarding the implementation of a home-based PR program in children who require PPC.

Materials and methods

The study was conducted in accordance with the principles of the Declaration of Helsinki. The Clinical Research Ethics Committee of the Hospital Niño Jesús also approved (January, 28, 2014) this study (protocol number: R-0065/13; Chairperson of the ethics committee: Julia Asensio Anton). Informed consent and permission to record the interviews were sought in advance. Also, participants gave their informed consent to their participation in the current study.

Design

A qualitative phenomenological study was conducted.[24, 25] Qualitative studies are used in order to achieve a deeper understanding of people's behaviors under certain specific circumstances, such as rehabilitation and terminal disease.[24, 26] Qualitative studies may also be used to get to know the perspective of patients and their families regarding the effects of health interventions.[27] The data obtained *via* qualitative research comes from data collection tools such as interviews, focus groups and participant observation, and in the form of narrative transcriptions, images (drawings, photography) and documents (diaries, letters).[24, 25, 28] Phenomenology is an approach to qualitative research which explores the experiences of people immersed in situations or phenomena. It is based on first-person perspectives (interviews and personal letters), in an attempt to understand the essence of a phenomenon.[25]

Research team and reflexivity

In qualitative research, members of the research team often form relationships with participants.[25] Therefore, it is necessary to describe how these relationships and the researchers' perspectives and assumptions influence data collection and interpretation.[29] For these reasons it is necessary to clarify their identity, credentials, occupation, gender, experience and training. This has been found to improve the credibility of findings.[30]

Five researchers (two women, three men) participated in this study, three of whom (JGR, LCG, DPC) had experience in qualitative study designs. Two were registered nurses holding a PhD (DPC, LCG), two were physiotherapists (PRM, JGR), and one was a physician (RMA). Of these, three researchers (PRM, LCG, RMA) had clinical experience in PPC. The remaining authors had no previous contact with any of the participants. Prior to the study, the position of the researchers was established according to their previous experience and their motivation.[24, 25]

Context

Since 2013, a new program of home PR was implemented at the Hospital Niño Jesús, within the unit of PPC. The new program of home PR is considered a full-fledged rehabilitation program, seeing as it includes all interventions aimed at maintaining, improving and promoting physical status and functionality, and is oriented towards providing a greater autonomy and independence to the person and the family. In this program, PR was integrated within palliative home-care interventions and consisted of techniques on a motor and respiratory level, as well as education and training for parents. The PR program was conducted at the child's home by physiotherapists and the care was catered to the needs of both children and parents.[14] Among the interventions performed by physiotherapists, these include: 1) the assessment of posture and movement problems, administering physical treatments including exercise to maintain movement and alleviate pain; 2) the education and training of parents for the application of motor and respiratory techniques; and 3) specific interventions on a motor and respiratory level: neurofacilitation techniques (neurodevelopmental treatments, proprioceptive neuromuscular facilitation and sensory integration therapy); manual therapy techniques aimed at improving joint mobility and delaying the appearance of orthopedic deformities; respiratory physical therapy for respiratory pathway hygiene, inhalation therapies, breathing exercises; lymph drainage therapy; and maneuvers (*e.g.* specific repositioning maneuvers).

Participants

A purposeful sampling method was used to recruit parents who had knowledge and experience of supporting children in home-based palliative care.[24, 25] Also, a snowball sampling procedure was applied, in the case of parents who put the researcher in touch with other parents in similar circumstances and who met the inclusion criteria (participants M8, M9, F10, F11, M11). Sampling continued until ongoing analysis revealed informational redundancy.[24] Finally, 14 participants were included within the sample and none withdrew from the study.

Inclusion criteria: 1) parents of children, irrespective of their diagnosis; 2) integrated within the program of palliative care at the time of study; 3) aged between 0-18 years; 4) must be receiving home PR by the PPC team; and 5) Spanish language.

Procedures

Researchers made initial contact with the parents through the Hospital Manager and the PPC Unit Chief. Researchers explained the purpose and design of the study to the participants *via* an initial face-to-face contact. Participants were then allowed a 2-week period to decide whether or not they wished to participate. During the second face-to-face contact, those who wished to participate in the study were given an informed consent form to sign and permission to tape the interviews was sought. Subsequently, data was collected and the interview was completed.

Data collection

The study was performed between September 2015 and April 2016. The first phase of the study consisted of unstructured interviews[26] with all the participants (N.=14), beginning with the following question: "What has your experience been after the application of PR of your child?"

TABLE I.—*Guide of semi-structured questions.*

Research areas	Questions
Meaning of physical rehabilitation and prior experiences	What does physical rehabilitation mean to you?
	How has your experience been with the physical rehabilitation received?
	Prior to the intervention in your home, what type of physical rehabilitation had your child received?
	How has your experience been with the physical rehabilitation received in the past?
Physical rehabilitation in the home	What type of physical rehabilitation has your child received at home?
	How do you think the physical rehabilitation received in your home has influenced your child?
	What does it give you, as the main carer of your child?
	Do you think the intervention received has been sufficient? What do you feel was lacking?
	What do you think has been the benefit of not having to go somewhere (*i.e.* go to the hospital or educational center) to receive physical rehabilitation?
	Have the recommendations provided by the physical rehabilitation been useful for the management of your child at home?
	What have you learnt from the physical rehabilitation intervention in your home?
Influence of physical rehabilitation on the daily care and management of the child	In what aspects of the child have you noticed changes? If these have been negative, what are they?
Factors of the illness for which physical rehabilitation is most useful	How has physical rehabilitation influenced your child?
Future expectations regarding the influence of physical rehabilitation on the child's quality of life	What do you expect from physical rehabilitation?

After the initial data collection, new areas of interest were identified: 1) the meaning of PR; B) PR in the home; C) the influence of PR on the daily care of the child; 4) factors of the illness for which PR is most useful; and 5) the influence of PR on the child's quality of life. Therefore, it was necessary to develop a second study phase in order to deepen our knowledge regarding these new areas of inquiry. During the second phase, a question guide was elaborated (Table I) using the data obtained in the unstructured interviews that took place in the first phase, and which were used as a basis for the format of the semi-structured interviews.[24, 25] The participants involved in this second phase were the same as the first phase, in order to provide a more in-depth portrayal of their experience.[26] In total, in both phases, 28 interviews were performed.

The interviews were tape-recorded and transcribed verbatim.[31] Researcher field notes were collected during both stages. All interviews were performed individually in the participants' homes (Madrid, Spain) and lasted two hours on average. During the respective interviews, the researcher made notes including contextual descriptions, any non-verbal responses to questions made by participants.

Data analysis

A full literal transcription of each interview was produced, as well as researcher field notes.[24] A thematic analysis was performed[32] by three researchers (PRM, JGR, DPC). All the texts obtained after the transcription of the interviews were subsequently coded and analyzed. The codification and identification of themes was performed *via* reading the overall text, as well as paragraph and in-depth analysis conducted line by line. The coding took place according to the following phases: in the first place, significant units were identified, afterwards these were grouped according to common meanings, and finally themes and subthemes were identified.[32] The data obtained was analyzed separately for both the unstructured and semi-structured

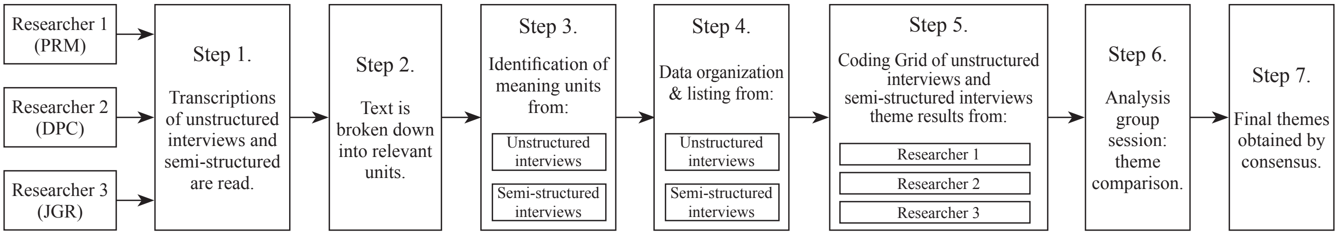

Figure 1.—Description of the data analysis process.

interviews. Subsequently, in both phases, a coding grid was created with the meaning units, their groups and the identified themes.[33] Within this grid, we identified the narratives that justified the results obtained. Thereafter, group sessions were performed among the researchers, during which the themes of both phases demonstrating the parents' experiences were analyzed and compared.[33] Lastly, the final themes were obtained, similarly integrating the narratives from the unstructured and semi-structured interviews. The final themes were decided *via* researcher consensus.[24, 25] No data analysis software was used (Figure 1).

Quality criteria

The Consolidated Criteria for Reporting Qualitative Research (COREQ) were followed.[30] The data reliability method consisted of: 1) cross-triangulation by the researcher (each interview was analyzed by three researchers). Thereafter, team meetings were performed in which the analyses were compared and themes were identified; 2) auditing the material obtained from 10 randomly selected cases by an external researcher. The external researcher assessed the study research protocol, focusing on aspects concerning the methods applied and the study design, following the COREQ guidelines; and c) participants' verification, this consisted of asking the participants to confirm the data obtained during the stages of data collection and analysis.[24] The external researcher is a PhD, and is professor at a different University from the other researchers, with experience in qualitative designs.

Results

Fourteen parents were included. The average age of the fathers was 43.25 (SD±8.66) years, and 40.3 (SD±6.33) years in the case of the mothers. The average age of the children was 8.91 (SD±4.83) years. The characteristics of the parents and children are shown in Table II. The parents are presented in the results under the code "F" for father and "M" for mother, followed by the number of participants and the age of children (aoc).

Three major themes representing parents' experiences of home-based PR in PPC were extracted from the inter-

TABLE II.—*Profile of participants.*

Participant code	Age of parents (years)	Number of children	Diagnosis of child	Associated pathologies	Time (in months) within the palliative care program
F1/M1	51 and 49, respectively	1	Severe acquired brain damage	Respiratory and musculoskeletal pathologies	7
M2	41	2	Cerebral palsy	Respiratory and musculoskeletal pathologies	48
F3/M3	41 and 40, respectively	3	Cerebral palsy	Respiratory and musculoskeletal pathologies	17
M4	49	3	Cerebral palsy	Respiratory and musculoskeletal pathologies	16
M5	42	2	Cerebral palsy	Respiratory and musculoskeletal pathologies	13
M6	44	3	Cerebral palsy	Respiratory and musculoskeletal pathologies	12
M7	38	1	Unidentified polymalformative syndrome	Neurological, respiratory, digestive, renal and musculoskeletal pathologies	6
M8	38	2	Patau syndrome	Neurological, respiratory and musculoskeletal pathologies, polydactyly, anophtalmia	1
M9	33	3	Hydranencephaly: congenital malformation of the central nervous system	Neurological, respiratory and musculoskeletal pathologies	5
F10	49	1	Unidentified mitochondrial disease	Neurological, respiratory and renal pathologies	30
F11/M11	32 and 29, respectively	1	Tay-Sachs disease	Neurological, respiratory and musculoskeletal pathologies	24

TABLE III.—*Themes and subthemes.*

Themes	Subthemes
Theme 1: the meaning of physical rehabilitation to parents	Subtheme: personal experience. Subtheme: strategies.
Theme 2: physical rehabilitation as an opportunity for patients to stay in their home	Subtheme: selecting specific intervention. Subtheme: empowering the family Subtheme: professional attitude and training Subtheme: meeting needs and expectations
Theme 3: home-based physical rehabilitation as part of the family social environment.	Subtheme: receiving institutional health support Subtheme: compensating for the influence of environmental conditions

views: 1) the meaning of PR to parents; 2) PR as an opportunity for patients to stay in their home environment; and 3) home-based PR as part of the families' social environment Table III.

The narratives reflect the therapeutic strategies followed in PR at home, adapting to the health conditions and needs of the children. Parents narrated how motor, respiratory, positioning and management techniques were used, as well as education and training for parents.

Theme 1: the meaning of physical rehabilitation to parents

This refers to the experience parents have of the PR received by their children in different settings. The parents formed their own concept regarding what PR meant for them. Parents identified PR as "a technique" that improves the quality of life of the child on a global level, that forms a part of their life and allows the child to be in touch with their surroundings.

Subtheme: personal experience

Participants described how, from the moment they were given the diagnosis of their child, they sought solutions to help their child face the disease. This included problem-solving strategies, and PR became the treatment of choice from very early ages. The parents often spoke of performing a sort of "pilgrimage" in order to find the best method of pediatric PR for their child.

"… it is really important, my son couldn't be without physical therapy, it's part of his life and it is what helps him to connect with the outer world." (M7, aoc 7), "… it's very hard, because we took him to Vojta treatments, we also tried the Fay institutes, and then normal physical therapy. Respiratory physical therapy was the last thing we introduced. We have tried everything that seemed necessary." (F3, aoc10)

Subtheme: strategies

Although most parents spoke of positive experiences with PR, in some cases, parents shared negative experiences related to the therapeutic strategy used on the children. As a result of receiving PR, parents spoke of the many changes they had observed in their children regarding their motor skills, as well as commenting on the progression of the treatment over time. They highlighted the changes relating to the child's body structure and functioning.

"Physical therapy became an obligation, like washing one's face every day, another necessity, just like eating, or giving him his medication."(M3, aoc10), ."... techniques such as Vojta, have not been well suited to the child's exercise tolerance, has caused more fatigue ... we stopped doing it because it was not going well." (M9, aoc5)

PR is experienced as a tool for problem solving, which can improve the daily life of children, although it is necessary to find the appropriate PR for their needs.

Theme 2: physical rehabilitation as an opportunity for patients to stay in their home environment

The parents described how PR applied in the family nucleus was "special", as it adapted to the health conditions and needs of the children at that specific point in time. It gave them the opportunity of staying in much closer contact with their children during whatever time they had left, with trust and confidence.

Subtheme: selecting a specific intervention.

Participants spoke of the fact that beforehand they had not received treatment from a PR within the PPC team. This was accompanied by the feeling that the intervention they had received was unspecific, too little and came late. Albeit, however minimal, it was still perceived as being positive and indispensable.

"It isn't the same, these are the same techniques that are applied at the hospital, but at the same time it feels different, the amount of care, the greater sensitivity... They not only respect our son, but also ourselves and our home. Nothing is imposed; rather, it is shared..." (M7, aoc7), "… he wasn't crooked any more, neither did he deform, he grew straight at least, and in terms of functions such as breathing, these things are essential." (F3, aoc10)

Subtheme: empowering the family

The home-based PR intervention helped the parents feel supported and trust themselves enough to apply some of the techniques, as well as improving their ability to resolve any incidents.

"The fact a physical therapist has come to the home has given me a sense of greater support and trust in myself…" (M1, aoc14)

Subtheme: professional attitude and training

The attitude of the physical therapist within the PPC team had a positive influence on the parents, making them feel more supported.

"At home it is different, they not only apply the technique, but they teach it to you and train you, and so they involve you in the treatment and with your son. They make you closer to him" (F10, aoc3), "Respiratory physical therapy is important. We know this is the weakness that our son will have, the more this is cleansed and the more it is worked upon, the more time we will have with him." (M4, aoc15)

Subtheme: meeting needs and expectations

For most parents, the main benefit of home therapy was keeping their son in their own environment and thus avoiding unnecessary trips to the hospital.

"The fact that they can come to the house is a great help, we feel that it is vital that everything be done at home, with his friends, his toys. Staying at home is a part of the therapy." (M7, aoc7), "The fact of not having to move in order to receive physical therapy has meant everything to us. For her, getting out of the house implies suffering, due to the pain. We try to move her around as little as possible. Just leaving the house was like moving home…"(M6, aoc17).

Parents view PR as an opportunity for applying care directed at the needs of the children, within their family environment, facilitating the integration of the family in care and supported by the open attitude of the professionals involved.

Theme 3: home-based physical rehabilitation as part of the family social environment

This refers to how PR is integrated within the social context of the family and their surrounding environment. It is considered as another source of support for the family.

Subtheme: receiving institutional health support

The institutional support that the families received in order to face their children's illness, conditioned their experience. The majority of children had been treated in early intervention centers, in hospitals and in special education centers, but when the health status of their children had worsened, the families were forced to stay at home with their child. Furthermore, the assistance granted by the PPC unit was perceived by all parents as an essential and necessary source of support.

"I had to accept help from neighbors, friends and the PPC unit, I had to realize that I wasn't alone." (M9, aoc5), "I feel very accompanied, because I have the tools to face things. When I can't take it any longer, I go to them" (M6, aoc17), "It hasn't been possible to go back to school and because of the continuous food pump... he hasn't been able to adapt to the pace of a class." (F5, aoc10)

Subtheme: compensating for the influence of environmental conditions

On the other hand, the setting where people lived or the way they lived their life were perceived as factors that influenced the child's wellbeing. Among the needs voiced by families, parents spoke of the economic burden associated with accessing private home PR treatments for their children. This was an expense that they were not able to withstand.

The parents' expectations regarding PR treatments were mainly focused on increasing quality of life. They knew that there was no chance of a recovery, but hoped that the pain and suffering could be decreased, in order to maintain the child's capacity level until the end and avoid any fatal respiratory difficulties that could put the child's life at further risk.

"Changes in temperature really affect him, changes in weather, changes in setting. Because he is immunosuppressed, we have to consider this. At home, maintaining an appropriate temperature has become a priority, cool in the summer and warm in the winter."(M3, aoc10) "There comes a time when the hospital no longer provides rehabilitation, and the rehabilitation that you can provide for your child, at least once a week, is really expensive." (M7, aoc7).

Parents perceive that PR is oriented towards the home, integrating health care into the child's environment, helping to maintain their ties with the family, decreasing the economic costs and maintaining the child's capacity in their own environment until the last moment.

Discussion

This study explored parents' experiences of home-based PR in PPC. The results revealed the importance of PR from the parent's point of view, as a key strategy used to face the illness in children who are terminally ill. Parents perceived it as a valuable service in helping to increase the quality of life and the motor skills of their children at home. These needs are consistent with previous research that has shown that families of children with complex illnesses consider the maintenance of their children's independence as the main objective of PPC.[34]

No prior studies were found to describe the use of different PR techniques in children receiving PPC at home. According to our results, we have observed that parents tend to "complete" the medical treatment provided by applying a number of PR techniques, perceiving the search from one technique to another as a sort of “pilgrimage.” This particular struggle could cause an adverse interaction between different expected effects or even influence the efficacy of the treatment.

In our study, home-based PR was perceived positively based on the personal experiences of participants, considering the weaknesses of the children involved and the limitations of their motor skills. Likewise, Savio *et al.*[35] described favorable experiences regarding the home interventions of physical therapists in children suffering from cancer, which was useful for ensuring the continuity of the same.

The importance of PR as a strategy is reflected in the directives gathered within the clinical guide of the Rainbows Children’s Hospice for children with life-limiting conditions in the UK.[36] Without appropriate treatment, the consequence is a further increase in pain, together with the inability to leave the house, and an increased risk of respiratory infections. These authors recommend PR for cough management and drainage of secretions, as noted by the parents in our study. A study by Vollenbroich *et al.*[37] on pediatric palliative home care revealed that dyspnea (61%) and pain (58%) were the dominant symptoms with an overall high symptom load (83%). The EAPC[11, 12] established that for the control of pain and other physical symptoms, all children should have access to a professional PR treatment 24 hours a day, 365 days a year. Cheville *et al.*[16] propose the definition of “palliative rehabilitation,” on the basis that many patients could benefit from palliative rehabilitation within palliative care, which may lead to improvements of mobility and functionality, therefore delaying disability. Likewise, these authors describe the need to overcome obstacles such as the limited familiarity with manual interventions and rehabilitation services that many palliative clinicians have, as well as misunderstandings regarding the processes of disability and the lack of rehabilitation service delivery models in the advanced cancer population.

Our results show that the application of certain techniques on children can condition the experience of the parents regarding these therapies. The opportunity for providing families with education and training was one of the outcomes which gave parents the most satisfaction. The family-centered approach promotes the development of competencies on a family level, enabling parents to act more effectively within their daily context. Previous studies have demonstrated the effectiveness and the positive influence of the family-centered model in disabled children and their families.[1, 38-40] This is primarily aimed at enriching families by providing these with resources that grant them the possibility of taking decisions during the illness at the level of treatment or even prevention, identifying strategies to be followed or aspects to be tested and modified.[1] To accomplish this, service delivery must be organized in a way that allows health professionals to provide higher levels of input in the early stages while parents come to terms with their role in this process. Peplow *et al.*[41] defend the need for integrating the family of children with cerebral palsy within a holistic model, based on the fact that the perspectives of parents must be included in the decision-making. Furthermore, they conclude that therapy provided at home is characterized by the prescription based on the child’s damage, even though the child may not be in a terminal situation. Our study also highlights the influence of the interaction with the rehabilitation team prescribing the exercise program, recognizing the importance of the professional’s attitude when working with parents in the home.

A sense of concern was reported on behalf of the parents who participated in this study, in relation to their children’s pain, functionality and respiratory health, as their main needs. This reflects the picture described in previous research, which is in line with the main symptoms described.[37] This also fits with recommendations for the application of PR in children with spasticity and for the management of respiratory secretions.[40, 42]

Parents felt that the existence of a specialized home-based resource for covering the needs of their children and helping them was essential. This is in line with previous research that described how the intervention of a specialized pediatric palliative home care team improved the symptoms and quality of life of the affected children.[43-45] The parents noted that the intervention of a specialized team was a quality factor when considering the end-of-life care of children, as well as a main determinant of families’ satisfaction. The similarities regarding the perception of symptoms between parents and therapists appears to be a predictive factor for palliative care.[37]

Researchers have consistently shown that social factors, such as support from the community, together with economic income have a substantial impact on the children’s family. Altay *et al.*[46] proved that the mothers of children suffering from cancer require greater social support, in the form of emotional support and information. Also, Giesbrecht *et al.*[47] described how education on the process, access to social support networks, and being in employment, are factors that influence the ability for caregivers to face problems. The need for financial support was addressed by most parents in our study due to the high costs required in order to care for their children, which is a concept that is mentioned by Weidner *et al.*[48] within the access to care and resources as part of the 7 dimensions that are important for the parents of children receiving end-of-life care.

Pediatric palliative care is considered to be framed within the family centered model, as this approach acts upon the child and the family as inseparable units, aimed at improving the quality of life of both parties.[49] The rehabilitation programs within PPC comprise programs in which the main objective is the reduction of mobility dependence and the inclusion of self-care activities in association with the provision of comfort and emotional support.[50, 51] The main difference between rehabilitation in palliative care compared to *mainstream* rehabilitation programs is marked by the concept "rehabilitation in reverse."[52] This is defined as: *"... another model with which we can fully utilize our therapeutic skills to maximize safe functional mobility and independence. Instead of the progressive improvement possible with a stable disease condition, in palliative medicine there is likely to be a progressive decline. Along the way, a physical therapist can provide training at many levels."*[52] Thus, rehabilitation-in-reverse is where and when the patient is rehabilitated through every step of their physical decline towards death. Regarding the flux of children with CP from one type of rehabilitation approach to the other (from mainstream rehabilitation to rehabilitation within palliative care), several signs may mark the need for this change. These include: reaching a turning point in the child's evolution, reaching a state of irreversibility and growing frailty, and failure to respond – or a decreased response – to conventional therapeutic measures applied in mainstream programs.[53] Due to the difficulty distinguishing such a turning point, several authors have developed screening tools targeted at health professionals, in order to help identify children who may benefit from a palliative care program. This is the case of a tool developed by the multidisciplinary team at Helen & Douglas House Hospices,[53] designed to identify children belonging to four of the disease classifications (*e.g.* cerebral palsy) who may be eligible for receiving pediatric palliative care services.[9]

Our results can be applied in clinical practice, to stimulate the involvement of parents in care, to facilitate their learning process and promote the development of strategies for problem solving in the everyday care of their children. Furthermore, the impact of the implementation of PPC rehabilitation programs on the organization of healthcare services should be studied.[54]

Strengths and limitations of the study

The strengths of our study include the use of triangulation (by researchers to participants, methods, and collected data) and participant validation of the data obtained to ensure confidence in the truth of the findings. Additionally, including children with different illnesses has allowed us to have a much broader perspective of the experience of home-based PR. The limitations are that the children of the parents interviewed varied considerably in age; therefore, the age of the child may influence the parent's experience. Also, the present study has included 14 participants, and 28 interviews have been performed. Previous qualitative studies,[24, 25, 55] describe how the total number of participants included does not depend on a previous calculation of the sample size, rather it is based on the saturation or redundancy of the information obtained in the interviews. Turner-Bowker *et al.*[56] reported that 92-97% of the saturation can be analyzed after interview number 15 and 20. Finally, both partners could not be included in all cases (*i.e.* both the father and the mother), this was because in some cases one of the partners declined participating in the study.

Conclusions

From the parents' perspective, home-based PR is a useful tool in responding to the needs of children who require palliative care. Family training on behalf of the PR is an essential part of this process. The experience of including a PR within a PPC team was positively perceived by the parents. These results describe the need for incorporating PR within PPC services, providing holistic healthcare and support for the children with life-threatening illnesses and their families. This study highlights the need for integrating PR care as a continuum within different care contexts (*i.e.* the hospital, the community, the home). Furthermore, these findings may help improve our understanding of the role of the child and family environment for developing care that is adapted to the needs of children, using their homes as a therapeutic environment for rehabilitation.

References

1. Brock KE, Wolfe J, Ullrich C. From the Child's Word to Clinical Intervention: Novel, New, and Innovative Approaches to Symptoms in Pediatric Palliative Care. Children (Basel) 2018;5:E45.

2. Nelson KE, Feinstein JA, Gerhardt CA, Rosenberg AR, Widger K, Faerber JA, *et al.* Emerging Methodologies in Pediatric Palliative Care Research: Six Case Studies. Children (Basel) 2018;5:E32.

3. Drake R. Palliative Care for Children in Hospital: essential Roles. Children (Basel) 2018;5:E26.

4. Vissers KC, van den Brand MW, Jacobs J, Groot M, Veldhoven C, Verhagen C, *et al.* Palliative medicine update: a multidisciplinary approach. Pain Pract 2013;13:576–88.

5. Bergstraesser E. Pediatric palliative care-when quality of life becomes the main focus of treatment. Eur J Pediatr 2013;172:139–50.

6. Siden H. Pediatric Palliative Care for Children with Progressive Non-Malignant Diseases. Children (Basel) 2018;5:E28.

7. Lindley LC, Lyon ME. A profile of children with complex chronic conditions at end of life among Medicaid beneficiaries: implications for health care reform. J Palliat Med 2013;16:1388–93.

8. Hain R, Devins M, Hastings R, Noyes J. Paediatric palliative care: development and pilot study of a ‘Directory’ of life-limiting conditions. BMC Palliat Care 2013;12:43.

9. The Association for Children’s Palliative Care (ACT). A Guide to the Development of Children’s Palliative Care Services: Report of the Joint Working Party of the Association for Children with Life-Threatening or Terminal Conditions and Their Families. ACT and the Royal College of Paediatrics and Child Health (RCPCH); Fourth edition. Bristol, UK: ACT; 2018.

10. Komatz K, Carter B. Pain and symptom management in pediatric palliative care. Pediatr Rev 2015;36:527–33, quiz 534.

11. European Association for Palliative Care. IMPaCCT: standards for paediatric palliative care in Europe. Eur J Palliat Care 2007;14:2–7.

12. European Association for Palliative Care. Palliative care for infants, children and young people: The Facts. Rome: The Fondazione Maruzza Lefebvre DÓvidio Onlus; 2009.

13. European Physical and Rehabilitation Medicine Bodies Alliance. White Book on Physical and Rehabilitation Medicine (PRM) in Europe. Chapter 1. Definitions and concepts of PRM. Eur J Phys Rehabil Med 2018;54:156–65.

14. European Physical and Rehabilitation Medicine Bodies Alliance. White Book on Physical and Rehabilitation Medicine (PRM) in Europe. Chapter 7. The clinical field of competence: PRM in practice. Eur J Phys Rehabil Med 2018;54:230–60.

15. Buss T, de Walden-Gałuszko K, Modlińska A, Osowicka M, Lichodziejewska-Niemierko M, Janiszewska J. Kinesitherapy alleviates fatigue in terminal hospice cancer patients-an experimental, controlled study. Support Care Cancer 2010;18:743–9.

16. Cheville AL, Morrow M, Smith SR, Basford JR. Integrating Function-Directed Treatments into Palliative Care. PM R 2017;9(9S2):S335–46.

17. Feldstain A, Lebel S, Chasen MR. The longitudinal course of depression symptomatology following a palliative rehabilitation program. Qual Life Res 2017;26:1809–18.

18. Jensen W, Bialy L, Ketels G, Baumann FT, Bokemeyer C, Oechsle K. Physical exercise and therapy in terminally ill cancer patients: a retrospective feasibility analysis. Support Care Cancer 2014;22:1261–8.

19. Carson K, Mcllfatrick S. More than physical function? Exploring physiotherapists’ experiences in delivering rehabilitation to patients requiring palliative care in the community setting. J Palliat Care 2013;29:36–44.

20. Knapp CA, Madden VL, Curtis CM, Sloyer P, Shenkman EA. Family support in pediatric palliative care: how are families impacted by their children’s illnesses? J Palliat Med 2010;13:421–6.

21. Kars MC, Grypdonck MH, van Delden JJ. Being a parent of a child with cancer throughout the end-of-life course. Oncol Nurs Forum 2011;38:E260–71.

22. Krishnan S, Pappadis MR, Weller SC, Fisher SR, Hay CC, Reistetter TA. Patient-centered mobility outcome preferences according to individuals with stroke and caregivers: a qualitative analysis. Disabil Rehabil 2018;40:1401–9.

23. Krishnan S, Pappadis MR, Weller SC, Stearnes M, Kumar A, Ottenbacher KJ, *et al.* Needs of Stroke Survivors as Perceived by Their Caregivers: A Scoping Review. Am J Phys Med Rehabil 2017;96:487–505.

24. Carpenter C, Suto M. Qualitative Research for Occupational and Physical Therapists. Oxford: Blackwell Publishing; 2008.

25. Creswell JW, Poth CN. Qualitative inquiry and research design. Choosing among five approaches. Fourth edition. Thousand Oaks, CA: Sage; 2018.

26. Kendall M, Murray SA, Carduff E, Worth A, Harris F, Lloyd A, *et al.* Use of multiperspective qualitative interviews to understand patients’ and carers’ beliefs, experiences, and needs. BMJ 2009;339:b4122.

27. Herbert R, Jamtvedt G, Hagen KB, Mead J. Practical Evidence-Based Physiotherapy. Second edition. Oxford, UK: Elsevier Churchill Livingstone; 2011. p. 28-29.

28. Curry LA, Nembhard IM, Bradley EH. Qualitative and mixed methods provide unique contributions to outcomes research. Circulation 2009;119:1442–52.

29. O’Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med 2014;89:1245–51.

30. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19:349–57.

31. Kuper A, Reeves S, Levinson W. An introduction to reading and appraising qualitative research. BMJ 2008;337:a288.

32. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol 2006;3:77–101.

33. Miles MB, Huberman AM, Saldaña J. Qualitative Data Analysis. A Methods Sourcebook. Third edition. Thousand Oaks, CA: Sage; 2014.

34. Tamburro RF, Shaffer ML, Hahnlen NC, Felker P, Ceneviva GD. Care goals and decisions for children referred to a pediatric palliative care program. J Palliat Med 2011;14:607–13.

35. Savio C, Garaventa A, Gremmo M, Camoriano R, Manfredini L, Fieramosca S, *et al.* Feasibility of integrated home/hospital physiotherapeutic support for children with cancer. Support Care Cancer 2007;15:101–4.

36. Jassal SS. Basic symptom control in paediatric palliative care [Internet]. Nineth edition; [Internet]. Available from: http://www.icpcn.org/wp-content/uploads/2013/09/Rainbows-Basic-Symptom-Control-In-Paediatric-Palliative-Care-Ninth-Edition-PDF.pdf [cited 2019, May 6].

37. Vollenbroich R, Borasio GD, Duroux A, Grasser M, Brandstätter M, Führer M. Listening to parents: the role of symptom perception in pediatric palliative home care. Palliat Support Care 2016;14:13–9.

38. Bamm EL, Rosenbaum P. Family-centered theory: origins, development, barriers, and supports to implementation in rehabilitation medicine. Arch Phys Med Rehabil 2008;89:1618–24.

39. King S, Teplicky R, King G, Rosenbaum P. Family-centered service for children with cerebral palsy and their families: a review of the literature. Semin Pediatr Neurol 2004;11:78–86.

40. Resa A, Hakan N. Family-Centered Approach in the Management of Children With Cerebral Palsy. Turk J Phys Med Rehab. 2012;58:229–35.

41. Peplow UC, Carpenter C. Perceptions of parents of children with cerebral palsy about the relevance of, and adherence to, exercise programs: a qualitative study. Phys Occup Ther Pediatr 2013;33:285–99.

42. Fitzgerald DA, Follett J, Van Asperen PP. Assessing and managing lung disease and sleep disordered breathing in children with cerebral palsy. Paediatr Respir Rev 2009;10:18–24.

43. Friedrichsdorf SJ, Postier A, Dreyfus J, Osenga K, Sencer S, Wolfe J. Improved quality of life at end of life related to home-based palliative care in children with cancer. J Palliat Med 2015;18:143–50.

44. Sheetz MJ, Bowman MA. Parents’ perceptions of a pediatric palliative program. Am J Hosp Palliat Care 2013;30:291–6.

45. Vollenbroich R, Duroux A, Grasser M, Brandstätter M, Borasio GD, Führer M. Effectiveness of a pediatric palliative home care team as experienced by parents and health care professionals. J Palliat Med 2012;15:294–300.

46. Altay N, Kilicarslan E, Sarı Ç, Kisecik Z. Determination of social support needs and expectations of mothers of children with cancer. J Pediatr Oncol Nurs 2014;31:147–53.

47. Giesbrecht M, Wolse F, Crooks VA, Stajduhar K. Identifying socio-environmental factors that facilitate resilience among Canadian palliative family caregivers: a qualitative case study. Palliat Support Care 2015;13:555–65.

48. Weidner NJ, Cameron M, Lee RC, McBride J, Mathias EJ, Byczkowski TL. End-of-life care for the dying child: what matters most to parents. J Palliat Care 2011;27:279–86.

49. Gilmer MJ. Pediatric palliative care: a family-centered model for critical care. Crit Care Nurs Clin North Am 2002;14:207–14.

50. Javier NS, Montagnini ML. Rehabilitation of the hospice and palliative care patient. J Palliat Med 2011;14:638–48.

51. Barawid E, Covarrubias N, Tribuzio B, Liao S. The benefits of rehabilitation for palliative care patients. Am J Hosp Palliat Care 2015;32:34–43.

52. Briggs R. Models for physical therapy practice in palliative medicine. Rehabil Oncol 2000;18:18–21.

53. Harrop E, Edwards C. How and when to refer a child for specialist paediatric palliative care. Arch Dis Child Educ Pract Ed 2013;98:202–8.

54. Verberne LM, Kars MC, Schepers SA, Schouten-van Meeteren AY, Grootenhuis MA, van Delden JJ. Barriers and facilitators to the implementation of a paediatric palliative care team. BMC Palliat Care 2018;17:23.

55. Malterud K, Siersma VD, Guassora AD. Sample Size in Qualitative Interview Studies: Guided by Information Power. Qual Health Res 2016;26:1753–60.

56. Turner-Bowker DM, Lamoureux RE, Stokes J, Litcher-Kelly L, Galipeau N, Yaworsky A, *et al.* Informing a priori Sample Size Estimation in Qualitative Concept Elicitation Interview Studies for Clinical Outcome Assessment Instrument Development. Value Health 2018;21:839–42.

Conflicts of interest.— The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript

Authors' contributions.—Patricia Rico-Mena designed and coordinated the study, recruited the participants, performed analyses, interpreted the data, and drafted the manuscript; Lourdes Chocarro-Gonzalez participated in the design of the study, collected data, and contributed to data analysis; Ricardo Martino-Alba contributed to recruitment of the patients, and acquisition of data; Javier Gueita-Rodriguez participated in the design of the study, collected data, and contributed to data analysis and interpretation, and revised the article; Domingo Palacios-Ceña participated in the conception and design of the study, contributed to the interpretation of the results, and drafted the manuscript. All authors read and approved the final manuscript.

Acknowledgements.—The authors thank all parents involved in this study. We also extend a special thanks to Isabel Quintero for her assistance with the write-up and review of this study.

Article first published online: February 15, 2019. - Manuscript accepted: February 14, 2019. - Manuscript revised: January 21, 2019. - Manuscript received: August 3, 2018.