Parental perception on home therapy and its associated factors for children with cerebral palsy: A qualitative study in Malaysia

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ABSTRACT

Introduction: Children with cerebral palsy (CP) benefit from consistent rehabilitation intervention. Home therapy (HT) consists of therapeutic exercises and activities targeting physical and functional improvement. HT is vital to ensure the rehabilitation provided in the clinical setting is further continued by the client. However, the success of HT mostly depends on compliance and support from caregivers, especially the parents. The objective of this study was to explore parents' perceptions of home therapy and to identify facilitating factors and barriers to it.

Materials and Methods: An interview-based qualitative study was conducted in a public university hospital in Malaysia, utilizing in-depth interviews. Audio recordings of the interviews were transcribed verbatim. The transcript data were coded, and the codes were then organized into themes using a thematic analysis approach.

Results: Data from twelve mothers and three fathers among a total of fifteen children with CP were acquired. Nine themes were derived from transcript data namely : HT is a simple home prescription,HT empowers and enhances experiences of care, Negative experience, goal-directed positive attitude, External Support System, physical health as a barrier, psychological health as barrier, limited time and limited external support system.

Conclusion: Real-life experiences of parents with CP children regarding HT was explored and valuable outcomes were derived from this study to help clinicians to manage children with CP more efficiently and understand their family dynamics better in the local context. Overall, parents perceived HT as doable and it provided physical, functional, and psychological benefits for them as well as improved their confidence and skills to perform exercises on their children and empowered them to monitor their children's progression.

KEYWORDS:
Perception of Home Therapy, Cerebral Palsy, Qualitative Study

INTRODUCTION

Cerebral palsy (CP) is a group of disorders of movement and posture, causing activity limitation that is attributed to non-progressive disturbances occurring in the developing fetal or infant brain.[1] The prevalence of CP in developed countries is 1.5-2.0 per 1000 live births.[2-5] In Malaysia, the data on the prevalence of CP is limited, however, it is estimated to be slightly higher. In 2012, the Ministry of Health registered 215 cerebral palsy children under disability registry .CP is a chronic childhood condition comprised of various motor and non-motor symptoms.[6-8]

Most interventions for cerebral palsy involve comprehensive approaches which are medical optimization, spasticity management, physiotherapy, occupational therapy, speech therapy, orthotics, aids and equipment prescription, and corrective surgery.[9] Besides these approaches, HT ensures the continuity of the rehabilitation program where the clients (i.e., caregivers/parents) were prescribed and educated on the rehabilitation training by the therapists for the caregiver to conduct at home–which is tailored to be feasible and doable using the existing resources at home.[10] HT is a useful strategy for increasing the frequency of therapy when added to regular hospital-based exercises.[11] Goal-directed HT has evidence to provide an increased dose of therapy to improve hand function and ambulation.[10-12]

There are very limited data published on HT for children with CP in Malaysia. It is still unknown to many practitioners or healthcare workers who actively manage CP patients, regarding the prescription of HT and its associated factors in Malaysia. Sadly, during most of the clinic settings, noted parents were found to be not compliant with HT. Novak, in his paper on parents' experience in implementing HT, found that parents generally perceived positive experiences and expressed that HT has multiple benefits for both parents and children.[13] Parents in this study perceive HT as a form of guidance and advice that can be practiced at home to maximize their children's potential as well as increase their confidence to help their children. Hinojosa J, explored the perception of mothers about HT and found that mothers are the main carer, and most of them were stressed about the care for their children including performing HT.[14]

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In a recent study by Demeke ZD, parents perceived HT as important to increase the frequency of training.[15] However, the same study found that there are barriers to implementing HT such as lack of awareness of the importance, lack of support from other family members, and mothers who are the main carers were drained out with other chores and unable to perform HT. Common factors that influence compliance to exercise in hospital settings are parental readiness, the time factor, cooperation and motivation of children, characteristics of the exercise, therapist communication and guidance, and availability of equipment.[16] Although this information has been already studied and published, however, there is a limited understanding of such factors that were also experienced by Malaysian parents with cerebral palsy children in practicing HT.

Hence the primary objective of this research is to explore parents' perception including their understanding and experience with HT, while secondary objectives will be identifying facilitating and limiting factors in performing it. This investigation is important to determine whether we can translate some existing evidence to our local context use, or whether some unique aspects are identified that require for original solution.

MATERIALS AND METHODS

This is a qualitative study utilizing an in-depth interview (IDI) that was conducted based on the guideline by Ryan and colleagues and conceptualized by a hermeneutic phenomenological approach.[18] It is important to collect information that can be produced more consciously from a person's own experience which is fundamental in human-related studies. A qualitative study is a powerful method to explore a richer information gathering and deeper understanding beyond what is presumed by the researcher.[19] Qualitative study also provides insight generation to the participants which creates more information development.[20] In this study, we have adopted the concept of the International Classification of Functioning, Disability, and, Health -Children and Youth version (ICF-CY) model as the study framework. ICF has six domains which are health, body impairment, activity limitation, and restriction in participation which are influenced by contextual factors namely personal and environmental. It is specific to children and commonly used in clinical and research involving CP. In this study, the objectives are based on ICF-CY enabling the covering of all important 6 domains for comprehensive results.[21]

Participantsand recruitment

Participants for this study were recruited via purposive sampling method considering characteristics varieties. Inclusion criteria were the mother or father (being the main carer) of children with a primary diagnosis of cerebral palsy with severity of Gross Motor Functional Classification System (GMFCS) of I-V, aged 3 to 17 years old, undergoing outpatient therapy at Paediatric Rehabilitation Clinic follow-up in University Malaya Medical Centre (UMMC) and the parents must be able to communicate in either English/Malay.

Participants were recruited from those attending therapy at the department. Both primary investigator and co-investigator (AAF) screen potential participants. Agreed participants were arranged for a meeting according to their convenience. Before the agreement, each prospective participant was explained about the study and provided with a consent form. The prospective participants can refuse to participate while their rights are ensured. This study received ethical approval from the University of Malaya Medical Centre – Medical Research Ethics Committee (MREC ID NO: 2018226-6053). The recruitment duration was from 11th June 2018 until 15th January 2019.

Procedure and data collection

All the interview was conducted by primary investigator to avoid any conflict of interest as no previous relationship between the primary investigator and participant. All the interviews were conducted in a dedicated room at the university hospital except one which was conducted at the participant's home. Anonymity and confidentiality were ensured when the room was informed in use during the session and no one was allowed to enter during the session. The session was guided by a set of semi-structured questions but not followed prescriptively. The semi-structured questions were developed based on the objectives of this study, where it became a framework to steer the discussed topic and allow flexibility in which the questions evolved throughout the interview to explore more information until data saturation (Table I). The session begins with establishing rapport and collecting demographic information followed by generic to specific or personal questions. The researcher's role is as an active listener to create a mutual and non-intimidating atmosphere and as a facilitator without providing any comments or instilling judgment. The interviews ranged from 15 to 45 minutes (average thirty minutes) each. The interview was audio recorded with two recorders. Each interview session is followed by a reflection session by the primary investigator and co-investigator to review the responses, interview questions, and interview techniques.

Data analysis

Each recorded conversation was transcribed verbatim by the researcher(TCB). Participants were given pseudonyms in the transcript to maintain anonymity.[22] Participants were provided with the transcripts for a member-checking procedure to maintain the accuracy of data.[23] Thereafter, the data were analyzed using the thematic analysis technique. Thematic analysis (TA) is a tool to form a framework by finding a pattern in the research that answers the objective of the study.[24] First part of the thematic analysis is to find codes which are smaller units of building blocks that can be categorised together to form themes.[24] In this study TA conducted based on the reference by Naeem et al.[25] The transcripts were read and re-read by two researchers (TCB, AAF) independently. Coding started by identifying sentences that meet the objective and labeled with descriptive words which were then listed down manually in soft copies. The investigators met several times to compare the codes and revised them to ensure the codes matched the objectives, and then together mapped all codes again manually on paper. Codes with similar meanings were grouped into the same category. Subsequently, the data were read again a few times independently and several categories were formed from all

available codes. Finally, themes were formed from similar categories to answer the study objectives. Themes and their categories were mapped manually on a paper by each researcher and compared among until reach more than 90 percent of inter-rater agreement.[25] Final themes were agreed upon and confirmed with the third investigator(JAP), who has experience in qualitative study analysis but was not involved in the data collection and who did know the research participants.

RESULTS

A total of 15 participants agreed to interview among 18 that were selected. This sample size is based on data saturation, in which no further new information was obtained from parents.[25] Among these parents, three were fathers, and one of them quit his job for full-time care. Otherwise, caregivers were mothers, of whom six were housewives and six were still working. Four of the working mothers were professionals, working as a teacher, accountant, nurse, and doctors. The CP children in this study varied from GMFCS level I to V. There were a total of eight children with severe GMFCS 21 levels of IV to V, and among them, four children were enrolled in a special government school. On the other hand, seven children were GMFCS level I to III, and all were attending school. Table II shows the description of participants and children. After TA, nine themes were derived from the data.

SECTION 1: Perception of parents

Theme 1: HT is a simple home prescription

HT is a continuation of the rehabilitation learned

Parents perceive HT as an assignment to be completed at home after their therapy session in the hospital. HT provides the frequency to maintain the treatment effect. It can be done at any time convenient to parents. It is prescribed according to the targeted aim.

"…my understanding of this home exercise program is a series of exercises to be carried out at home so that we can do it for our children every day or at our extra time because the time that we spend in the hospital probably once a week or twice a week …all these exercises has been prescribed by the physiotherapist after they have assessed his condition." (mother 3)

"For me, I understand that this is in addition from doing it in the hospital. When he's in the hospital, he doesn't have a lot of slots, sometimes full. So, at least we make it at home daily, so can improve his muscle tone. Not depending on the hospital only. So, I have that understanding." (mother 8)

Nature of prescribed therapy

Parents further describe HT as a set of feasible exercises and meaningful activities that require no special equipment. It can be performed with items or toys that are available at home.

"Sometimes I would exercise him, I would throw a ball near him and he will try to catch it, and he would throw again." (father 2)

"Ha stretching her hand and leg. Then the hand she always keeps in fits, I'll open, ha stretching. Then I would sit her in the car seat for an hour, and then we hold her. My husband holds her feet, I hold her body, and we raise her." (mother 12)

Theme 2: HT empowers and enhances experiences of care

Optimize the care level

In this study, parents reported that by practicing regular HT, their skill in monitoring the progress and performance of the children improved.

"We are the mother doing for the child; so, we also can know his/her progress. We can keep monitoring." (mother 3)

They felt empowered and could understand their child's condition better even when their children could not express themselves clearly.

"I know he has a way, so I can help him, I know. When you are close to him, you will know it." (mother 8)

"I knew how to care for him and able to know when he wants something." (mother 5)

Parents also become confident in helping their children to perform exercises to improve their impairment and achieve targeted goals.

"I'm confident. I have more confidence in me which lead me to take more effort to improve my son." (father 2)

Optimization of resources

The above results refer to saving time and cost for traveling. It also refers to saving money spent on the severity of the disease as the impairment improves after persistent HT. In this study, two mothers who regularly perform HT, and whose child has a severe type of CP, reported that HT reduces the time spent traveling to the hospital. It also saves the costs incurred for their journey.

"That's why when I go for an appointment, let's say that appointment is for one hour; but it can be only up to thirty minutes because my son becomes tired and moody easily due to the long journey. So, it was like a waste of my time and expenses. So, I feel like I have to do it at home." (mother 8)

Caring for a CP child involves costs related to their care and equipment. The more severe the disability, the more expenses were expected. However, with HT, when the impairment was managed well, it led to an improvement in function. This has reduced the cost of certain items in their care.

"These couple of years her sports shoes last for one year which is longer compared to previous years. So, I know that she is improving and not worsening. At least the one I'm very concerned about is her sports shoes. How long do I have to buy a new one." (mother 1)

Optimization of physical and psychological function

Parents describe that after practicing HT, they could notice improved body structure, activity, participation, and independence. Parents in this study know that HT should be done consistently for a positive outcome.

"Now he can walk longer duration. He can follow me for shopping. Not using his wheelchair, also can stand long." (mother 5)

Table I: Demographic characteristics of the participants

No.	Name of child	CP Type	Child age (in years)	GMFCS level	Child gender	Parent Interviewed	Schooling Status	Venue
1	GSS	Right Hemiplegic	14	I	Female	Mother 1	Yes	Hospital Lobby
2	IM	Triplegic	9	II	Male	Mother 2	Yes	Hospital Gym
3	WK	Diplegic	9	III	Male	Mother 3	Yes	Patient's Home
4	TD	Diplegic	4	II	Male	Mother 4	Yes	Rehabilitation Clinic
5	XY	Diplegic	15	III	Male	Mother 5	Yes	Hospital Gym
6	SF	Diplegic	8	II	Female	Father 1	Yes	Hospital Gym
7	LH	Diplegic	6	II	Male	Father 2	Yes	Hospital gym
8	FR	Diplegic	7	IV	Male	Father 3	Yes	Hospital gym
9	AM	Diplegic	7	IV	Male	Mother 6	Yes	Hospital gym
10	NA	Quadriplegic	3	V	Female	Mother 7	No	Postnatal Ward
11	MH	Quadriplegic	5	IV	Male	Mother 8	No	Rehabilitation Ward
12	HD	Quadriplegic	5	V	Male	Mother 9	Yes	Rehabilitation Clinic
13	WZB	Quadriplegic	7	IV	Male	Mother 10	Yes	Rehabilitation Ward
14	NQ	Quadriplegic	7	IV	Female	Mother 11	No	Rehabilitation Clinic
15	WNA	Quadriplegic	4	IV	Female	Mother 12	No	Hospital Gym

Table II: Semi-Structured Interview Questions For In-Depth-Interview

NO	SEMI-STRUCTURED INTERVIEW QUESTION FOR IDI
1	What is your understanding of a HEP that is prescribed by a physiotherapist and occupational therapist to your child?
2	Can you tell me if there are any changes to your child after performing HEP?
3	Can you describe what are the benefits/impacts of a HEP on you, your child, and your family?
4	What is the barrier for you to engage your child to do or perform a HEP?
5	What are the motivating factors for you to engage your child to do or perform a HEP?
6	What is the barrier for your child to do or perform a HEP?
7	What are the motivating factors for your child to do or participate in a HEP?
8	Do you have any suggestions on how to improve the HEP?

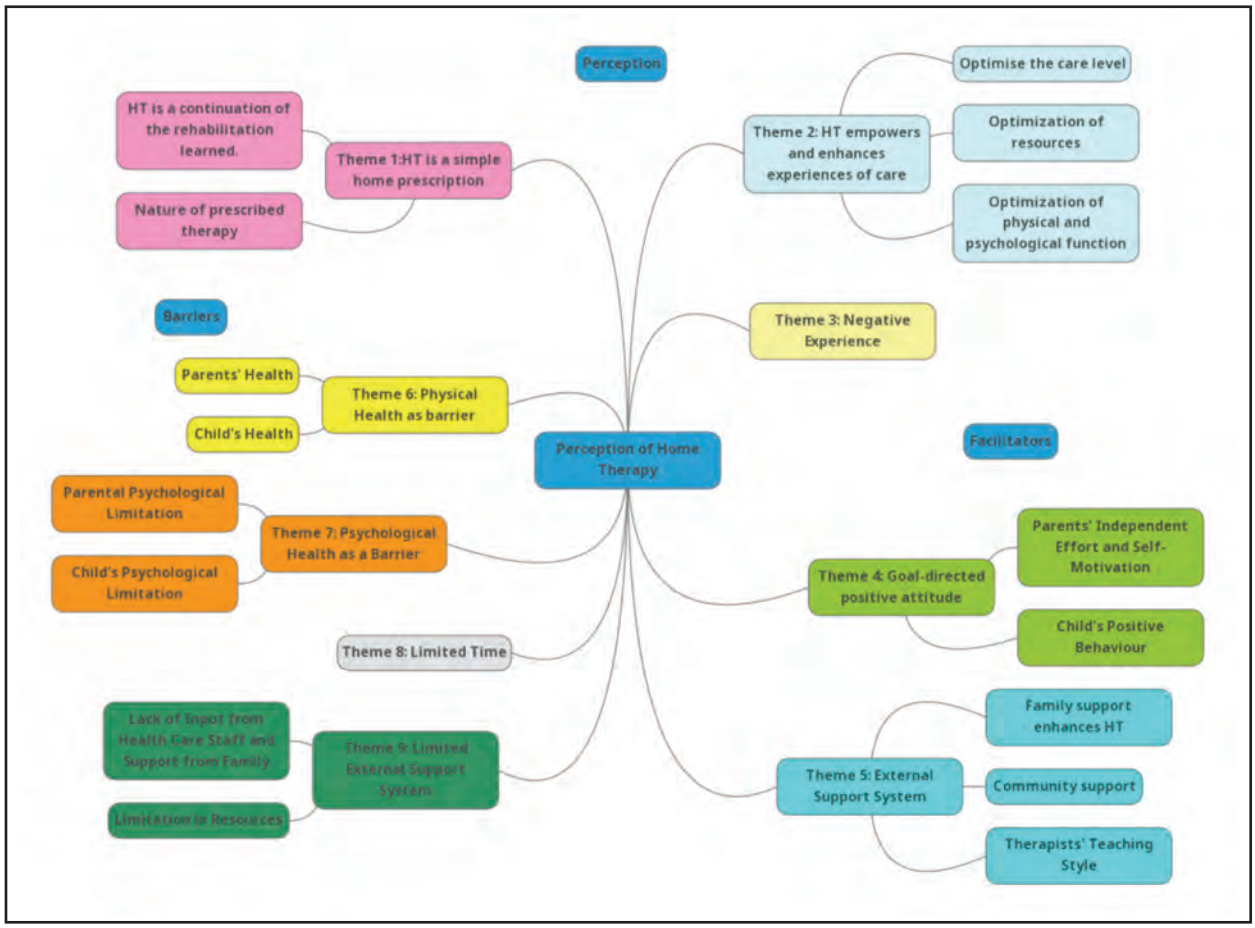

Fig. 1: Thematic Diagram for Factors Associated with Perception of Home Therapy

"I think it will most likely be subtler. I mean, because we are doing it quite regularly, so we don't really realize any like regression. So, not noticing if there is a bit stiffer if we don't do it. Because we kind of do it regularly." (mother 4)

Most parents noted positive psychological changes in their children in which they gained confidence in mobility and participation in functional activity.

"he is brave now, he has confidence in himself, he watches for himself while walking with reverse walker. He even could hold the spoons even though not feeding himself." (father 2)

Theme 3: Negative Experience
Among the fifteen parents, two parents found to have negative experiences during HT. They were namely, non-sustainable positive effects and fear of fall.

I stopped it (home therapy) and the progression stopped. But when I do that there is a change in it though not much." (mother 2)

"I am worried to help my child to walk at home, while attempting to walk he sways to one side and almost fall." (father 1)

SECTION 2:Facilitating Factors for HT
Theme 4: Goal-directed positive attitude
Parents' Independent Effort and Self-Motivation
Parents are empowered to take over the role of therapist at home. They take the initiative by inventing inexpensive and simple aids and therapy equipment. Parents also said they put in their effort to comply with HT and not depend on outpatient therapy sessions.

"He used to be afraid of loud noises. So,I put some rice in a bottle to shake, to reduce his anxiety towards noise. Then I search online for exercise, I reconfirm the suitability of those exercises with therapist and tried for my son" (mother 8)

Parents reported that they structured an organised schedule for their children to exercise, monitored with a log book, and working parents hired carers to assist their child's in-home therapy. Besides these, parents provide tangible rewards for their children while or after doing exercises.

"we started to have the log book that what are the exercise that he needs to do every day and how many repetitions and how many times. If I cannot do it, the helper do then I would check it from the exercise book where they do the record. I practise giving break forty-five minutes or one hour, where he can play games or watch movie, then rest. Then, after that we continue exercises." (mother 3)

Self-motivation among parents encouraged the incorporation of HT in their daily demands. Most of them expressed their motivation to see improvement in their children.

"Oh, because I have a target that he can walk on his own before he goes to school next year. That's why I'm all out for him." (father 2)

Child's Positive Behaviour
Implementation of HT is easier if the child responds positively. Parents of children above five have noticed that children can accept HT and enjoy it. Older children above nine years showed motivation to perform HT to achieve targeted goals, mainly for physical improvement.

"The factor that motivates me is an effort from my son for exercises. While I do exercise for him I can see he has effort too and he wants to do it too." (father 2)

"He never rejected exercises. When I say whatever he learns in hospital he has to do it at home, he follows. He never gets angry." (mother 5)

"Like my son, he wants to be like his other siblings. He looks at other people and he believe he could do it." (mother 2)

"After doing it for many years, now my daughter do not wait for my instructions. She does exercises by herself as she noticed the improvement. She has the motivation."(mother 1)

Theme 5: External Support System
Family support enhances HT
Several mothers feel fortunate as they have supportive spouses, parents, in-laws, and siblings. While mothers are away, other family members can perform basic exercises for the child. The household chores and therapy responsibilities can be shared. An example of a parent interview goes like this:

"of course, my effort at home and understanding from my eldest son and my husband's understanding doesn't give me all kinds of nonsense work, so I can fully focus on her and I think it's teamwork. It's not just my effort alone." (mother 1)

"his siblings help to monitor his exercises and observe him to avoid any fall or injuries. My older children always support me for his exercises".(mother 2)

Community support
Few parents enrolled in CP support groups. They get motivation and ideas for HT from other parents in the support group. Three mothers also mentioned that encouragement from healthcare professionals regarding the children's achievement during follow-up gives them a boost to continue HT.

"Usually, I am involved with the advocate group for CP children. So, I see these children do achieve improvement in the day to day. So, that's what encouraged me." (mother 6)

"the praises from doctors and nurses, the good words from them, motivate me to continue to do what I do." (mother 1)

Therapists' Teaching Style
Parents in this study give credit to their therapist in the hospital for their goal-orientated intervention. It influences them to perform HT.

"He feels very comfortable with his therapist who has been communicating, talking to him, so he is engaged with her you know. Hence, he is compliant to the homework given by the therapist" (mother 3)

"Each time I bring my son for therapy, she will set the target. So, she will tell me what I should do. Then, when I go to therapy again, she will tell me maybe if we can see improvement or not. If no improvement on that visit, she will add on new therapy and guide me." (mother 10)

SECTION 3: Barriers for HT

Theme 6: Physical health as barrier

Child's Health

Parents are unable to perform HT when their children are not well. Common health issues were infection and seizure, requiring frequent hospital admission. Younger children with severe CP are often tired and sleepy, which also interrupts HT.

"So, one of the things especially for CP child is that whenever they get sick right, that is the time we really, sometimes we say all the effort we put in for one two weeks may have gone you know, then we have to redo over again." (mother 3)

Parents' Health

Every parent in this study juggles multiple chores and often gets tired and low energy. During this time, they need help from other family members or skip the HT. However, two mothers in this study said they skip most of the HT on weekdays as they are exhausted from other house chores and have limited help from family. One of these mothers works, and the other mother is a housewife.

"I'm tired and not being able to care about him, but so far I try, I try my best." (mother 12)

Theme 7: Psychological Health as a Barrier

Parental Psychological Limitation

Parents reported that their mood is affected, and they are under pressure when incorporating HT into their daily routines and commitments. Some felt anxious when the child fell while exercising. On the other hand, some had confidence issues about progressing in HT.

"So, because I do a lot of things, all these things I become frustrated. So, when I do all these things extra work for my daughter, I become easily hot-tempered". (mother 1)

"It's just that I'm worried, he can't even balance his body. Even though we exercise him, but because he can't balance his body, sometimes he falls by himself, just like that". (father 2)

Child's Psychological Limitation

Children with severe CP of GMFC IV to V are unable to comply with HT. They refuse to exercise and become moody.

"Sometimes she doesn't like it when we want to do it for her, and she's mad about that. Certainly like now, she's smart, if we do some exercises for her, if she doesn't like it, she'll push our hands off or she'll cry and scream." (mother 11)

Theme 8: Limited Time

Parents expressed that limited time is a barrier for parents and children to perform HT. Parents had limited time due to various commitments such as work and house chores duty, and their children also experienced limited time after school to be involved in HT.

"So, my main issue is I don't have enough person to help me. Sometimes, I'm busy with cooking and household jobs; so, I can't assign too much time on him…". (mother 10)

"Yes, lack of time because he needs to spend more time on his academics and really like trying to fight with the times that get more time for him to do. Especially now no exercise for him and sometimes we don't even have half an hour time during weekdays for him. And we really see that he's really deteriorates a lot." (mother 3)

Theme 9: Limited External Support System

Lack of Input from Health Care Staff and Support from Family

Parents experienced limitations in progressing HT when junior therapists are appointed for their child as they are unable to provide goal-directed therapy and guidance for home practise. This causes frustration among some parents in this study. Besides that, low confidence level among family members to perform exercises on the children while parents are working poses limitations for the continuation of HT.

"There's no target set. So, I wouldn't know what my weaknesses are. How far my son has achieved. I don't know what the difference is between the last month and the current month. I don't see because there's nobody assessing." (mother 10)

"like my mother-in-law and siblings are a bit scared to do exercise, because afraid of being wrong, afraid of fall." (mother 10)

Limitation in Resources

Most parents raised concerns about the lack of proper exercise tools or equipment at home to perform HT with their children. Besides that, each time the child progresses to the next level of exercises with therapist at hospital, parents are not equipped with sufficient informative materials for home practise.

"There are no manuals, no videos that we can watch as guidance to progress home therapy." (father 3)

"our equipment is limited. So, we use what we have. If it's here at outpatient therapy, there are many equipment, convenient here. Maybe it's not like this at home." (father 1)

DISCUSSION

This is the first study in Malaysia to examine parents' perceptions of their understanding of HT for children with CP and explore associated factors for implementing HT. In recent years, there were no publications even among countries of ASEAN on this topic or issue. It is important to explore the facts on this topic locally to develop further management protocols to keep young practitioners and stakeholders up to date.

In this study, all parents had a similar understanding that HT is a prescription from a therapist to be done at home to achieve the targeted goal. It offers more frequency and intensity, hence reducing the number of visits to the hospital. A study by Iona Novak, on the experience of parents implementing home exercise, found that the parents perceive HT as guidance and teaching from experts to be conducted at home.[13] This reduces their fear of not having regular exercises by experts in hospitals.

In our study, parents perceive HT as doable and persistence provides multiple physical, functional, and psychological benefits. HT improves their confidence and skills to perform exercises on their children and empowers them to monitor their children's progression. Besides that HT optimizes resources like time and money. Similar to findings from previous studies , parents are empowered to play the main role in their children's therapy and the progression of physical and functional outcomes.[11,13,15]

Uniquely, parents in this study reported negative experiences from HT, which includes, fear of regression and fear of injuring the child. Further analysis of mother 2 ,showed the reason for the mother to stop HT temporarily is due to time and health factor, same as the barriers that have been experienced by other parents. In a randomized control trial discontinuation of strength training for 6 weeks showed regression in muscle strength among children with CP.[26] Hence, without consistent practice, even small regressions in muscle tone, strength, or flexibility could accumulate, potentially leading to a more pronounced stiffness or decreased mobility. Next, father 1 felt fear about inducing a fall in his child who is also a mild CP, GMFCS II, and an ambulant. He expressed shallow confidence in performing HT during the interview and appeared apprehensive about eliciting injury to the child. Upon exploring further, this father was not compliant with HT until seeing the child improve during outpatient therapy sessions. Following that he was motivated to perform HT. A randomized clinical trial of 6 weeks of a home strengthening program for 21 children with CP aged 8-18 years old did not report any adverse events.[27] Another randomized controlled trial of a sit-to-stand exercise program that was done at the rehabilitation center and at home only reported fatigue as an adverse event.[28] In other available literature, most parents report fear while their CP children are in school and during other recreational activities, but not during HT.[29-31] Limited data was reported about parents having fear while performing HT.

The pronounced facilitator of HT found in this study was the intrinsic motivation of parents and older children for goal achievement. Upon analyzing further, we found these parents have some similar features. They received structured outpatient visits with frequent reassurance from the therapist, they were portrayed as role models to other parents by healthcare workers, most of them were mothers as main carers, and enhanced with improvement of the children. Standard care of rehabilitation should be enhanced with comprehensive psychological intervention to cultivate motivation to facilitate the implementation of HT. This has been not mentioned as a finding in other similar work.

Barriers found from this study were limited resources,time, external support system, and poor physical and mental health of both parents and child. These local findings are generalized to other previous studies as well.[10-11,13-15] However, the unique perspectives found in this study led parents to propose several valuable recommendations based on their perceived ideas and experiences to overcome those barriers. Standard guidance on initiating exercises and to progress the HT should be provided as written documents or videos to parents. Therapists should be aware of individualized goal-setting according to the children's improvement during each visit. Implementing schemes to loan equipment, conduct home visits, or offer telerehabilitation can facilitate HT and minimize barriers. Regular training and guidance for junior therapists will improve the therapist's teaching style. The government or stakeholders should consider involving non-governmental bodies to enhance the support system for HT for CP children. Some of the suggestions here are very specific to this study and not found in previous literature.

Exploring the relationship between parents, families, and therapists would deepen our understanding of this context. Additionally, involving community, governmental, and nongovernmental stakeholders would help to produce a robust impact. Investigating the perceptions of healthcare workers, therapists, and stakeholders in future studies would provide valuable insights.

LIMITATION

In our study, we are lacking sociodemographic data of participants. Hence further analyses of the negative experiences of parents during HT were limited.

CONCLUSION

Motivation to perform HT was high among mothers in this study. These mothers demonstrated adequate family support and encouragement from healthcare workers. They are compliant with HT juggling all other barriers. The pronounced and well-mentioned intervention will be a comprehensive psychological assessment and support for a successful HT. One-stop patient-centered transdisciplinary care of rehabilitation and pediatric psychologists will enhance the care and compliance to HT.

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CONFLICT OF INTEREST DECLARATION

The authors declare that there was no conflict of interest.

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