

BRIEF REPORTS

Barriers and Facilitators to Family-centred Paediatric Physiotherapy Practice in the Home setting: A Pilot Study

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ABSTRACT

Purpose: Family-centred paediatric physiotherapy practice is a new and emerging concept in India. This study aimed to understand paediatric physiotherapists' perceptions of the barriers and facilitators to such practice in home settings in Salem city in southern India.

Method: A phenomenological research design was employed in this study. Semi-structured telephone interviews were conducted with a convenience sample of 5 paediatric physiotherapists who offer treatment in the home setting. Open coding analysis revealed themes that were broadly categorised into barriers and facilitators to family-centred paediatric physiotherapy practice in these settings.

Results: Physiotherapists identified several barriers such as educational status, frustrated family members, protective family members, cultural beliefs and external influences. Active participation of family members was perceived as a facilitator to family-centred practice.

Limitations: This pilot study has a number of limitations. As the sample size was small and the participants were selected from a small city, the results may not be generalised to larger areas of India. Also, since the interviews were conducted in English, which was not the physiotherapists' first language, some nuances of their perceptions may not have been reflected.

Implications: The study suggests that paediatric physiotherapists need to have better understanding of parental attitudes, and family culture and beliefs, in order to improve the physiotherapist-family relationship and maximise the outcome for children.

Key words: Family-centred practice, home setting, physiotherapy, paediatrics, qualitative research.

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INTRODUCTION

In the past few decades, healthcare decision-making has changed (Crais et al, 2006). Careful consideration of the client's perspective has become part of the clinical decision-making process (Crais et al, 2006). In the field of paediatrics, the role of the physiotherapist has shifted from client (child) centred practice to family-centred practice (Crais et al, 2006). The core principles of family-centred practice are: respecting each child and his/her family, and supporting and building the strengths of each child and the family (O'Neil et al, 2001; Crais et al, 2006). Family-centred practice mainly focuses upon the parents or the caregivers in decision-making and care giving, as they play a major role in early intervention (Crais et al, 2006).

Family-centred practice is a new and emerging concept in India (Singhi, 2004; Prakash, 2010). Most of the paediatric physiotherapists in India provide their follow-up treatment at the child's home, where parents are encouraged to be involved in the treatment session and are taught specific exercises and the correct methods of handling the child (Cherry, 1989; Broggi & Sabatelli, 2010). Recent evidence suggests that due to the burden of care, parents of children with disabilities are stressed and frustrated (Cherry, 1989; Verma & Kishore, 2009; Pooni et al, 2013). Cultural beliefs about disability and socioeconomic status also affect parental perceptions (Cherry, 1989; Pooni et al, 2013). Educating parents about their child's disability is now becoming an integral part of the treatment plan for the paediatric physiotherapist (Crais et al, 2006). While studies have explored perceptions of parents who have a child with disability, the perceptions of paediatric physiotherapists about their practice and the barriers and facilitators to family-centred care in India have not been examined (Gupta et al, 2012; Pooni et al, 2013). An understanding of the perceptions of paediatric physiotherapists would help to overcome the barriers and strengthen the physiotherapist-family relationship, in order to maximise the child's outcome at home.

The purpose of this study is to address the gaps in literature on the subject, and to better understand paediatric physiotherapists' perceptions of the barriers and facilitators to family-centred practice in the home setting, which often influence their decisions.

METHOD

A phenomenological research design was used to explore the perceptions of paediatric physiotherapists about family-centred practice in the home setting in

India (Mason, 1996). Ethical approval was obtained from the Ethics Committee of the University of East London, United Kingdom.

Participants

Participants were recruited from a private college hospital in Salem, India. Paediatric physiotherapists, who were registered members of the Indian Association of Physiotherapy and who had worked with children for a minimum of 5 years, were eligible to participate. All the 5 paediatric physiotherapists who were working in the college hospital satisfied the inclusion criteria and agreed to participate. Contact letters and consent forms were sent to each participant, explaining the purpose and the process of research.

Data Collection

Data was collected through in-depth qualitative telephone interviews. The open-ended interviews were conducted by the study investigator (SV), using a semi-structured format to ensure the inclusion of concepts related to family-centred practice (e.g., parents, culture, education, and work environment). At the start of the interview, the aim of the study was explained to the participant and verbal consent was obtained. Telephone interviews ranged from 30 - 90 minutes. Participants were asked how they perceived family-centred practice in a home setting (for example: How did they involve parents in the treatment? What affects their decision-making process?). Each interview was audio-taped and transcribed verbatim. The transcriptions were read several times by the study investigator (SV). The data were analysed using an open coding technique in which each line of the transcript is coded (Mason, 1996). The codes were then reviewed and compared, in order to identify recurring patterns and emerging themes related to the facilitators and barriers to family-centred practice in a home setting. Codes and themes were reviewed by the co-investigator (PS), and any discrepancies were discussed and reconciled.

RESULTS

Four male physiotherapists and one female physiotherapist participated in the study. The mean age of the participants was 31 years (range 28-35 years). Four of them had post-graduate qualifications in physiotherapy with experience ranging between 6 and 10 years. The analysis revealed 2 overarching themes of barriers and facilitators to family-centred practice in the home setting (Figure 1). Five

sub-themes were related to the barriers and one sub-theme related to a facilitator. Each theme is presented below with illustrative quotes.

Facilitator

Active role of Family

Physiotherapists claimed that active participation of the family members played a major role in paediatric rehabilitation. They also expressed the view that trust and understanding between the family member and the physiotherapist were

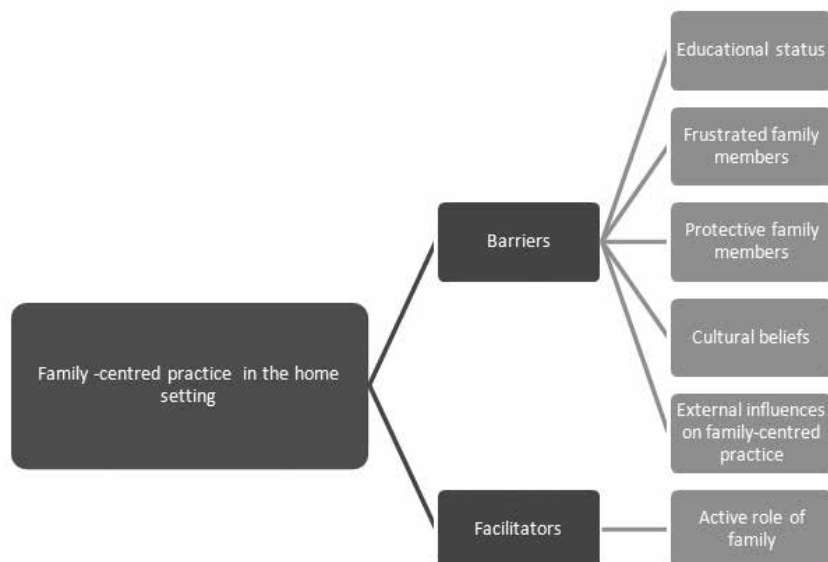


Figure 1: Physiotherapists' perceptions of Barriers and Facilitators to family-centred practice in the home setting

essential to family-centred practice. As parents/caregivers spend the most time with their child with disability, they have a better understanding of their child's needs.

"Family members form a bridge between the child and the therapist."

Physiotherapists felt that the role of the mother, in particular, was essential to the promotion of family-centred practice. The mother's hands-on participation in the treatment session was found to be helpful.

"Mother was helping me a lot (with the treatment)."

Barriers:

a) Educational status

Physiotherapists perceived that the educational status of the parents affected the child's treatment. They felt that parents with little education often had poor knowledge about their child's disability, and found it difficult to understand the role of physiotherapy in improving their child's condition.

"I can say that the patient's parents should have some education or they need to understand at least what their child is, how far the child can become near normal."

Physiotherapists felt that less educated parents were unable to understand their instructions pertaining to ongoing treatment, such as positioning the child appropriately. In consequence, they felt that such parents made their child's condition worse.

"Some illiterate people (parents), they really don't know about what we are doing."

Physiotherapists felt that due to lack of education and knowledge about the disease, most of the parents had unrealistic expectations that their child would improve within a short time. However, one physiotherapist observed that educated parents were also unable to understand the importance of physiotherapy treatment for their child with disability.

"Some of the educated parents do not understand our treatment."

In contrast, one of the physiotherapists claimed that the educational status of the family could not be considered as a barrier, since it is the responsibility of the physiotherapist to explain to the parents about their child's condition and the importance of physiotherapy for their child.

"We cannot expect all parents to be educated, so what I used to do is to get the parents to adjust initially, and then very slowly I will explain the reality to them."

b) Frustrated family members

Physiotherapists stated that parents of children with disability were stressed, often complained about the expense of physiotherapy treatment, and showed little interest in the treatment itself. Therapists perceived that low adherence and discontinuation of treatment were more often encountered in low income families.

"Travel expenses and fees for the treatment sessions, all these factors are economic oriented and interfere with the treatment."

Physiotherapists also added that even higher income families showed low adherence to treatment, since they changed their physiotherapist often and had a tendency to try alternate therapies other than physiotherapy.

"They think they can try another therapist to see (if the therapist can promote) any change in their child."

c) Protective family members

The excessive care and affection of family members towards their child was perceived as a barrier to effective treatment. Physiotherapists described how family members would become stressed and anxious when their child started crying, and would insist that the treatment be stopped.

"They (family members) think that I am making that child feel pain or stressing the child to do the exercise."

Physiotherapists were often in a very difficult position when the family members asked them to discontinue treatment because they perceived therapy such as stretching exercises to be harmful to their child.

"(I am) not able to explain to the family members, especially parents, old grandma and grandfather."

d) Cultural beliefs

Physiotherapists commented that irrespective of their educational or economic status, every family had a set of traditional/cultural beliefs. From experience they had found that unless parents' cultural/religious beliefs were acknowledged and incorporated into the treatment plan, the parents would hesitate to continue with treatment for their child. One physiotherapist described how an educational strategy could have a detrimental effect.

"If we explain (to) them that these are myths, then they will suddenly lose confidence with us."

Physiotherapists perceived that some of the traditional beliefs could lead to additional problems and increase the complexity of the disabilities.

"They will put some fire (hot iron branding) over the sole of foot, and make the condition worse."

e) External influences

External factors that affected the quality of care and the ability of physiotherapists to promote family-centred practice were identified.

Physiotherapists felt that paediatricians were not referring children at an early stage, thereby affecting the prognosis.

“He referred (the child) to me as CP with mental retardation when she was seven years.”

Physiotherapists mentioned that they had no access to certain treatment equipment in the home setting. In addition, they felt they were unable to spend enough time with their clients as more time was spent on travel.

“Sometimes we are lacking some (treatment) equipment (in a home setting).”

DISCUSSION

This research highlights barriers and facilitators to family-centred practice as encountered by paediatric physiotherapists who work with children in their homes in Salem city in southern India.

Parental perceptions towards family-centred practice and their level of involvement in the treatment programme have a strong influence on whether the practice is family-centred (Broggi & Sabatelli, 2010). This study reinforces the findings of O’Neil et al (2001) that active participation of family members, and the mother in particular, facilitated the implementation of treatment and increased the child’s involvement in the rehabilitation programme.

In India, due to the social stigma associated with disability, parents who have a child with disability are more stressed and anxious, and often use their religion as a coping strategy (Gupta et al, 2012). A recent study suggests that health professionals should understand the family’s culture and beliefs to implement a successful treatment plan (Gupta et al, 2012). However, in contrast to the aforementioned study, physiotherapists in this study perceived that parents/family members’ culture, attitude and emotions towards their child often interfered with the treatment. This clearly demonstrates that in order to develop a successful treatment plan, physiotherapists should understand the impact of the family’s culture on child-rearing practices and their care giving capacity, as the influence of culture, beliefs and attitudes of the family is inevitable (Singhi et al, 1990).

Studies in India have found that families with low socioeconomic status and low literacy rates have less awareness about their child's disability (Verma & Kishore, 2009; Prakash, 2010; Pooni et al, 2013). This study suggests that lack of knowledge about their child's disability is commonly identified among all families, regardless of their socioeconomic status and literacy level. Hence the universal importance of the physiotherapist's role in family education is reinforced.

In Salem city, where the study was conducted, physiotherapists complained about the lack of timely referrals from physicians. This may be due to the power imbalance in the medical decision-making process, and further reinforces the need for shared decision-making among healthcare providers (Fochsen et al, 2006).

CONCLUSION

This study identified potential barriers and facilitators to family-centred practice that are encountered by paediatric physiotherapists in the home setting in India. It is suggested that physiotherapists need to have a better understanding of parental attitudes, and family culture and health beliefs, to best engage the family in the child's care. Educating the parents and explaining the purpose of physiotherapy can help to build a positive physiotherapist-parent relationship.

India is a vast country with diverse cultures and traditions. Physiotherapists work with children and families from different cultures, religions and socioeconomic status. Educating the student physiotherapists about the importance of family-centred practice, and initiating a continuous learning programme after graduation, will be beneficial for their practice. Further research is needed to establish the difference between rural and urban parents and their perceptions about family-centred practice, as well as the perceptions of physiotherapists who work in rural and urban areas.

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