

Rehabilitation for children with cerebral palsy in rural Cambodia: parental perceptions of family-centred practices

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Abstract

Background Rehabilitation service providers in Cambodia are increasingly adopting family-centred practices when working with children with cerebral palsy and their families. This study examined the perceptions of parents living in rural Cambodia regarding family-centred rehabilitation practices.

Methods This qualitative study used in-depth semi-structured individual and small group interviews with a convenience sample of 24 parents of children with cerebral palsy from three rural provinces. Participants were drawn from Cambodia Trust's client database and had been involved in a rehabilitation planning process which incorporated family-centred practices.

Results Twenty-four parents and carers of children with cerebral palsy aged 3–12 years were interviewed. Almost all parents valued family-centred practices in rehabilitation, with many of the needs and preferences of parents living in rural Cambodia similar to those of parents in Western contexts.

Conclusions Family-centred approaches to paediatric rehabilitation were found to be valued in and appropriate for a rural Cambodian context. Social and cultural mechanisms to be considered when adapting a Western, family-centred model of rehabilitation planning to the rural Cambodian context include the hierarchical nature of Cambodian culture, the emphasis on group relational patterns rather than individual needs and the context of chronic poverty.

Keywords

Cambodia, cerebral palsy, disability, family-centred services, paediatric, rehabilitation

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Introduction

Cambodia is thought to have one of the highest per capita rates of disability in the world (Mackinlay 2004) with cerebral palsy the most frequently seen disability among children presenting at physical rehabilitation centres (Cambodia Trust, unpublished). Biomedical explanations of childhood disability and the use of physical rehabilitation as a response are not part of traditional Cambodian culture. Yet Cambodia's recent history has seen the dismantling of much that is traditional. Decades of conflict,

genocide and the death of almost the entire educated class permanently changed Cambodia and led to the loss of traditional knowledge and skills in areas including health care (O'Leary 2006).

The wide-ranging nature of cerebral palsy and the varying impacts on each child and their family necessitates an individualized and often multifaceted rehabilitation plan, which can be a challenge in resource-poor contexts. Some service providers in Cambodia have recently sought to address this challenge through incorporating a collaborative goal-setting process into

their rehabilitation planning procedures; a keystone of the family-centred services approach.

A growing body of research exists on the positive outcomes of the family-centred approach to rehabilitation, which is based on the understanding that a child's primary source of support and strength is their family and that the perspectives of the child and their family are important in clinical decision making (American Academy of Pediatrics 2003; Moore *et al.* 2009). Yet there is a dearth of literature into its theoretical or practical applicability to non-Western contexts and developing countries, and it has not been known how family-centred practices have been experienced by Cambodian parents.

Effective collaboration between parents and health care professionals is fundamental to the concept of family-centredness, with parents recognized as being experts on the abilities and needs of their own children (Hanna & Rodger 2002). It was not known whether this recognition of parents as 'experts' would hold meaning in Cambodia's deeply hierarchical culture, where those who are lower in the hierarchy are discouraged from questioning those in authority (O'Leary & Nee 2001; Gartrell 2004). It was also not known whether collaborative goal setting for one individual would be seen as appropriate in a culture where the family is the most important unit and individual rights are understood to be less important than the welfare of the family as a whole (Gartrell 2004; Zucker 2006).

While the challenges of using a family-centred approach with families living in poverty in Western contexts have been outlined by Humphrey (1995), it was not known how the context of chronic and extreme poverty experienced by many rural Cambodian families would impact upon the appropriateness of this approach. Furthermore, much of the anthropological literature on Cambodia describes the culture as being highly fatalistic, where individuals may be reluctant to seek treatment for some illnesses because of a passive acceptance of 'karma' (Kelley 1996; Ngo & Lee 2007).

In 2006, Cambodia Trust introduced a family-centred approach to rehabilitation planning for children with cerebral palsy. The rehabilitation team, commonly comprising a physiotherapist, orthotist and community or social worker, meet with each child and their family following assessment to collaboratively develop an Individual Rehabilitation Plan based on the family's stated goals and needs. Many children initially attend a Physical Rehabilitation Centre for a therapy session once a month. However, clients living in remote areas may stay at the centre for several days of therapy and equipment review once or twice a year, while clients living relatively close may attend weekly for a 30–60 min block of therapy. The Individual Rehabilitation Plans are reviewed every 6 months. This study was

conducted 3 years after the introduction of this approach, to examine the perceptions of parents living in rural Cambodia regarding family-centred rehabilitation practices.

Methods

Approach

A qualitative study using a multiple case-study strategy was undertaken in order to elicit rich data related to the perceptions of parents of children with cerebral palsy and the meaning they give to the rehabilitation process (Ritchie 2001; Punch 2005). Pawson and Tilley's (1997) realist evaluation paradigm, which aims to understand why a programme works, for whom and in what circumstances, was used to assess how a Western model of family-centred practice was perceived in the rural Cambodian context.

Participants

Participants for this study were drawn from a convenience sample of parents or carers living in one of three rural provinces; central lowland Kandal province and the two southern, coastal provinces of Kompong Som and Kampot. These provinces were selected as all three are target areas for Cambodia Trust's physical rehabilitation services. Participants based in urban areas were excluded because of the significant demographic differences between better resourced urban areas and rural provinces, where 80% of Cambodia's population live (Fitzgerald & Sovannarith 2007). Parents or carers were eligible for inclusion if they had accompanied a child with cerebral palsy to a Physical Rehabilitation Centre in 2008 and had been present during the rehabilitation planning process.

This study had approval from Cambodia Trust and the Human Research Ethics Committee from Curtin University of Technology, Perth, Western Australia. Potential participants were invited to participate in the study by Cambodia Trust staff. A one page summary of the research in the Khmer language was read and given to all potential participants and they were assured that a decision not to participate, or to withdraw at any time would not affect their services in any way. A signed or thumb-printed informed consent was sought before the start of the interview.

Procedure

Data were collected through semi-structured individual and small group interviews using a question guide developed and

piloted by the research team. Families who lived close to a rehabilitation centre or were scheduled to attend therapy during the period of data collection were invited to be interviewed in small groups at the centre. The remaining participants were interviewed individually in their homes. To encourage participants to speak candidly about their experiences, interviews were conducted in the local Khmer language by either a Cambodian research assistant who was not employed by Cambodia Trust or by a physiotherapist who had not had any prior contact with the participants. Interviews were taped, transcribed into written Khmer then translated into English.

Development of research tool

An interview guide for use in both individual and small group interviews was developed by the principal researcher (F. M.) with input from the local research team: two Cambodian physiotherapists and one Cambodian research assistant. Revisions were made following piloting with four individuals and one group of three parents, based upon the work of Minichiello and colleagues (1995).

The interview guide was designed specifically for the rural Cambodian context, where activity-based questions encouraging participants to share their stories were thought more likely to generate rich data than questions where participants could perceive there being a correct or preferred answer. The exact wording of questions remained flexible and researchers focused discussions on relevant issues that arose and explored unexpected information throughout the interview (Ritchie 2001). An example of an activity-based question used in this study involved the use of seeds, where the participants were presented with two photos representing therapist-directed versus family-centred rehabilitation planning sessions and were asked to indicate their preference by distributing ten seeds in any way between the two photos; the more seeds indicating their preference. This served as a prompt for further discussions regarding their choice and past experiences of rehabilitation planning.

Analysis

Taped interviews were transcribed into written Khmer, checked for accuracy by the principal researcher who was present at all interviews, then translated into English.

NVivo software was used to organize data into retrievable sections and assist analysis. Following multiple readings of transcriptions in Khmer and English, the principal researcher coded data to 'free nodes' representing the key issues that had been derived deductively from the literature (Neuman 2003). Over

time these were replaced by 'tree nodes' created to store data based on emerging issues, concepts and themes in the data (Lacey & Luff 2007). Data were then displayed using a variety of matrices based upon emerging themes and patterns. For example, as it became apparent that the severity of a child's disabilities was a major variable in parental responses, matrices were developed clustering participants based upon the severity of the child's physical impairment, using the Gross Motor Function Classification System (Palisano *et al.* 1997).

Finally, data were analysed using the realistic evaluation cycle, which considers the social and cultural mechanisms in the environment which may enable or disable intervention outcomes (Pawson & Tilley 1997). Conclusions were gradually drawn and verified in discussion with local rehabilitation workers.

Results

Twenty-four parents or primary carers were interviewed: fifteen mothers, four fathers, two grandmothers, one aunt and two non-relative carers. This sample represented 60% of the total population meeting the selection criteria. The mean age of the participants was 37 years and each had an average of three children under their care. Only three participants were engaged in paid employment. All 18 female relative-carers described their principal occupation as caring for their child and family, with 14 also engaged in subsistence farming or other informal income generation activities (Table 1). None of the participants had access to running water in their home.

The 22 children with cerebral palsy whose carers were interviewed were aged between 3 and 12 years (mean age 6 years; $n = 9$ females, $n = 13$ males). The type and severity of cerebral palsy

Table 1. Participants' characteristics

| Participants | Total $n = 24$ | % |
|----------------------------|-------------------|----|
| Age (years) | | |
| 18–29 | 7 | 29 |
| 30–44 | 10 | 42 |
| 45–55 | 7 | 29 |
| Relationship to child | | |
| Mother | 15 | 63 |
| Father | 4 | 17 |
| Grandmother | 2 | 8 |
| Aunt | 1 | 4 |
| Non-related carer (female) | 2 | 8 |
| Employment | | |
| Paid employment | 3 | 13 |
| Child and home care only | 4 | 17 |
| Multiple informal roles | 17 | 71 |

| | Total | Mild [GMFCS I- II] | Moderate [GMFCS III] | Severe [GMFCS IV-V] |
|------------------------|--------|-----------------------|-------------------------|------------------------|
| Total | n = 22 | n = 5 | n = 7 | n = 10 |
| Age (years) | | | | |
| 3-6 | 12 | 2 | 3 | 7 |
| 7-12 | 10 | 3 | 4 | 3 |
| Gender | | | | |
| Male | 13 | 3 | 6 | 4 |
| Female | 9 | 2 | 1 | 6 |
| Areas affected | | | | |
| Hemiplegia | 2 | 2 | 0 | 0 |
| Diplegia | 3 | 0 | 3 | 0 |
| Quadriplegia | 17 | 3 | 4 | 10 |
| Time in rehabilitation | | | | |
| Less than 1 year | 11 | 4 | 3 | 4 |
| 1-3 years | 6 | 0 | 1 | 5 |
| 4-8 years | 5 | 1 | 3 | 1 |

GMFCS, Gross Motor Function Classification System.

Table 2. Participants children's profile

varied (Table 2). Of the 13 school-aged children with disabilities, 4 attended school. None of the children had epilepsy but many had intellectual or sensory impairments as well as the primary physical impairment.

This study found that most participants valued family-centred practices in rehabilitation. Deductive analysis of data using the principal components of family-centred practice (King *et al.* 2004) revealed that the data were consistent to three of the main tenets of family-centred practice, namely, working in collaborative partnerships with staff, information exchange and the respectful and supportive care shown by the rehabilitation team. The results, according to these main themes, are presented below with quotes from the participants.

Collaborative partnerships

Most parents expressed a preference for working closely with staff, particularly parents of children with mild disabilities, who were most likely to feel that they were 'experts' on their child. Many believed that they should be collaborating with staff in the assessment and evaluation of their child as well as the planning and implementation of rehabilitation, including the choosing of rehabilitation goals. For example, one mother reported:

We are the ones at home with our child every day so we know about our own child and what she can do and what her leg is like. So if they ask us these questions they will soon know the situation better. . . . The staff only see and know of the child outside their home, whereas we live with the child every day. I think the staff will understand only once they ask the mother what the child is like every day at their home

with their family, what they are like and what their needs and problems are. If we only ever see the child in the Centre, we don't know everything. [Mother of a three year old girl with mild cerebral palsy]

Parents of children with severe disabilities were more likely to report feeling ill-equipped to deal with their child's complex needs and rather than valuing collaboration, many preferred the staff to make decisions and implement treatment. Most parents of children with severe disabilities had lost hope in the collaborative goal-setting process and in rehabilitation when their child had failed to reach the goals they had set.

I am feeling hopeless because I have come for treatment and followed the staff's advice but she is not improving much. The staff told us to help her to move more, but I think her muscles are still the same and I'm not sure whether she will be able to sit or walk. . . . What I want to say is that the staff should be more involved with my child. If they just tell us to do exercises on her muscles it's not enough. If it works by doing that I could do it by myself at home, and wouldn't need to visit this centre, and waste time. . . . No, it is up to the staff's skill and their program. If I knew how to do it I wouldn't need to visit them, I'd do it by myself. [Father of a three year old girl with severe cerebral palsy]

Information exchange

While most parents placed a high value on the informational aspects of family-centred care, few reported receiving information on their child's disability, future outlook or reasons for treatment, as exemplified by this statement:

They haven't told me where the problem comes from or the reasons for treatment. I just heard the staff talking together about 'CP' but I don't know. The staff just help and check my child and talk with the other staff about my child's problems, but I cannot catch what they talking about. I used to hear the word CP but don't know the meaning of it. [Mother of a twelve year old girl with mild cerebral palsy]

Parents of children with moderate and severe disabilities were the least likely to report having received information, suggesting that staff may not want to be bearers of bad news, or may not have the skills or resources to explain concepts around disability in simple and accurate ways. Most parents reported wanting to understand the nature of their child's disability and the reasons for treatment, as well as wanting more information on a range of issues including school inclusion and possibilities for the future care of their child.

It's important that I find staff who can give me information that I can use, like the staff, who strengthen my heart so that I can support my child. Sometimes the parents of children with disabilities really lose their morale. But the staff guide us well, they instruct us and strengthen our morale so we can support our child and don't lose hope in our disabled child. [Father of a four year old girl with moderate cerebral palsy]

Respectful care

The one aspect of family-centred care important to all participants, regardless of severity of disability, was the provision of respectful and supportive care while accessing rehabilitation for their child. All participants reported receiving respectful care, with parents appreciating the staff's polite attitude and their willingness to ask questions of parents.

The reason that I take my child to the Centre is because the staff there pay attention to the patients and they never do anything that upsets us. I have noticed that the staff pay attention to the children and use friendly and funny words with them. The friendliness of the Centre's staff and the attention they show to my child are the reasons I take my child to receive the service there. [Mother of a nine year old boy with severe cerebral palsy]

The hierarchical nature of the Cambodian culture was reflected in the responses of many participants, who reported that it was not appropriate for parents to question or challenge staff about the treatment their child was receiving. While most parents responded positively to the idea of staff questioning

them on the status and needs of their child, parents did not feel it was appropriate that they in turn question staff.

I am afraid to ask questions, because they might think I am interrogating them, but they let us ask any question if we're not clear or don't understand. So I don't ask questions, I'm too afraid to ask questions. [Mother of a three year old girl with severe cerebral palsy]

Discussion

The appropriateness of using family-centred approaches in rehabilitation planning had not been previously examined in a rural, developing country context. This study used a case-study approach with a relatively small sample size to examine the perceptions of parents of children with cerebral palsy in rural Cambodia regarding this commonly used Western approach to rehabilitation planning. The study found that family-centred approaches to paediatric rehabilitation were valued in a rural Cambodian context. Many of the participants' needs and preferences were similar to those of parents in Western contexts, where partnership or enabling aspects of family-centred care, information exchange and respectful and supportive care are highly valued (King *et al.* 2004). Yet interventions rarely work well for all people, in all circumstances, all the time. It was therefore vital to explore the social and cultural mechanisms in the environment which may have enabled or disabled outcome interventions (Pawson & Tilley 1997).

Cambodia's very structured social hierarchy was reflected in the relationships between staff and families, particularly in the reluctance of parents to challenge staff or request information from them. However, the potentially negative impact of this cultural mechanism appeared to have been minimized through the development of supportive, respectful relationships between parents and staff and the focus on information exchange. Where these family-centred practices occurred, collaboration and joint decision making appeared both possible and valued by parents in the rural Cambodian context. This finding highlights the importance of service providers persisting in their efforts to develop supportive relationships with families, even if they perceive a lack of active communication or interest from a family initially.

Central to the family-centred rehabilitation model is the process of parents and therapists looking to the future and identifying which goals are important to the family (Missiuna & Pollock 2000). In writing about the possibility of collaborative goal setting across cultures, Humphrey (1995) outlined the challenges of using this approach with families living in poverty

in Western contexts, suggesting that these parents may have a temporal orientation towards the present. It was also suggested that group relational patterns within communities may lead to disinterest in the individual goals of any one family member. As Cambodian culture emphasizes the welfare of the family as a whole (Gartrell 2004; Zucker 2006) it may have been expected that participants would have shown little interest in goal setting for their child with disabilities, particularly given the context of extreme and chronic poverty.

The study found, however, that the process of goal setting in rehabilitation was valued by parents, particularly those whose children were younger or had mild to moderate disabilities. All parents of children with mild or moderate impairments had seen functional gains made by their child so most believed that it was possible that their child could meet new goals in the future. Parents valued having a space where they were encouraged to articulate their concerns and hopes for the future. Goal setting both ensured that therapy focused on the participation of the child in life situations important to the family and provided parents with vital evidence of their child improving.

While the parents of children with mild to moderate disabilities valued collaborative goal setting, most of the parents of children with more severe disabilities had lost confidence in the process. Of the five participants who had been receiving services for 4 years or more, only one had a child with severe disabilities. The only parents of children with severe disabilities who continued to believe that change was possible were those whose children were younger or who had been accessing rehabilitation services for a relatively short amount of time. Many parents of children with severe disabilities had set unrealistic goals, usually related to walking, then when the child failed to reach the goals the parents had lost hope in the rehabilitation process. This finding highlights the importance of health professionals having the skills and resources to provide basic prognostic information to parents as they guide parents to be realistic in their choice of goals.

While the Cambodian culture has often been stereotyped as being highly fatalistic (Kelley 1996; Ngo & Lee 2007) few participants in this study displayed a sense of fatalism. Upon realizing their infant or child had a physical impairment, most parents did not simply accept traditional explanatory models of childhood illness and disability nor traditional treatments. Many parents actively searched for explanations and treatments, continually assessing results and moving on from treatments which they believed were not producing results. The apparent lack of 'fatalism' within study participants may reflect a bias resulting from the self-select cases in this study. While all

study participants had accessed rehabilitation services, little is known about the perceptions of other parents and caregivers who have never accessed rehabilitation services for their child with disabilities. Despite this, the findings highlight the importance of actively involving families in the design and delivery of their child's rehabilitation: a central tenet of family-centred practice.

This study utilized a case-study approach with a relatively small sample size and only focused on the perceptions of carers of children with cerebral palsy in rural Cambodia. The results may not be generalizable to other causes and types of childhood disabilities and in different socio-economic or urbanized settings. Further, limited time and budgets precluded utilizing observation as part of the study. Further research should include observation of both rehabilitation planning and family life to ensure the collection of more rich data. It is also recommended that further research be carried out in other parts of Cambodia, including urban areas, and the experiences of older children and adults with disabilities other than cerebral palsy also be included.

Key messages

- The needs and preferences of parents living in rural Cambodia were similar to those of parents in Western contexts.
- It is possible for family-centred practices to be used effectively and appropriately within the Cambodian context.
- Collaborative goal setting did not appear to be as effective with parents of children with severe disabilities.

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