

Parental views from rural Cambodia on disability causation and change

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Abstract

Purpose: This study explored the beliefs of Cambodian parents of children with cerebral palsy regarding disability causation and their perceptions of the effectiveness of interventions in bringing about change in their child.

Methods: Semi-structured individual and small group interviews were held with 24 parents or carers of children with cerebral palsy between 3-12 years of age who had accessed the rehabilitation services of Cambodia Trust. Convenience sampling was used to draw participants from three rural provinces.

Results: Beliefs around disability causation were mixed, with equal numbers of participants attributing their child's disability to biomedical causes as to traditional causes incorporating elements of Theravada Buddhism, animism and Brahmanism. While many participants had initially sought traditional interventions for their child, few found them to be effective and most had subsequently utilised medical and rehabilitation services. Parents whose children were moderately or severely impaired perceived both traditional interventions and rehabilitation

to be less effective than parents of children with mild impairments. Participants generally judged the effectiveness of interventions based on functional changes in their child.

Conclusions: The complexity of Khmer belief systems was reflected in the range of participants' perceptions of the cause of their child's disability, yet beliefs around disability causation did not appear to have determined their care-seeking behaviour or their perceptions of effectiveness of interventions.

Keywords: Cerebral palsy, disability, Cambodia, paediatric, rehabilitation, belief

Introduction

Cambodia is thought to have one of the highest per capita rates of disability in the world [1]. The destruction of the country's infrastructure as well as the targeted killing of educated professionals during the genocide necessitated both a re-building of medical and health services and a complete restructuring of medical, rehabilitation and healthcare provider educational systems [2]. Physical rehabilitation centres were established throughout the country and staffed with physiotherapists and prosthetist-orthotists to provide services to an estimated 44,000 landmine amputees [3]. Today, however, Cambodia has one of the world's youngest populations [4] with cerebral palsy the most frequently seen disability amongst children presenting at physical rehabilitation centres [5].

Very little is known about the perceptions and beliefs of Cambodian families of children with disabilities [6]. Research undertaken with a range of ethnically and religiously diverse communities in the UK has highlighted the importance of health professionals understanding the beliefs of people with disabilities and their families [7,8]. It has been found that parental perceptions of disability may be a key determinant in influencing their care-seeking behaviour for their child with disabilities [9]. A recent study of mothers of children with disabilities in Bangladesh found that perceptions around disability causation often included both biomedical and traditional factors, such as possession by ghosts and evil spirits. Yet a major determinant of care seeking behaviour was the beliefs of older family members [10]. In Turkey, mothers who believed their child's disability was a result of traditional causes were more likely to seek traditional interventions, while mothers who believed the cause to be biomedical were more likely to access formal medical services [11].

There is a paucity of information on how Cambodian parents of children with cerebral palsy understand the causes of the disability or perceive the effectiveness of traditional or biomedical interventions. While Theravada Buddhism is the official religion of Cambodia, this is overlaid with Brahmanism and an animist belief system

involving spirits and ghosts. Traditionally, beliefs around the cause of childhood disabilities including cerebral palsy have been shaped by both animism and Buddhism. A range of childhood illnesses and disabilities including cerebral palsy have traditionally been described as 'skan'. If in a previous life a child's mother was separated from the child through violence, starvation or war, it was thought that the mother in her anguish may bring illness or 'skan' upon the child following its rebirth into a new life [12]. Yet it has not been known whether this is the dominant understanding of childhood disability in Cambodia today. Cambodia's unique history is said to have impacted Khmer religious belief and worldview, with some arguing that the horrors of the Khmer Rouge genocide led to a widespread questioning of the efficacy of both Buddhism and the spirit world [13]. Furthermore, a dependence upon multilateral and bilateral donor agencies and international non-government organisations in re-building medical services and promoting a biomedical approach to health in Cambodia has led to the undermining of traditional health beliefs and practices, particularly in urban areas [14].

This study had two aims: firstly, to examine the perceptions of parents of children with cerebral palsy living in rural Cambodia regarding family-centred rehabilitation practices [6] and secondly, to explore the beliefs of parents regarding disability causation and discover how parents perceived the effectiveness of various interventions in bringing about change in their child. This paper reports on the results of the second aim of the study.

Methods

A qualitative study using a multiple case study strategy [15] was undertaken to explore the beliefs of parents regarding the causes of their child's disability and the effectiveness of interventions in bringing about change. The use of multiple case studies provided the opportunity for description and in-depth analysis of specific details about this sub group of parents of children with cerebral palsy in rural Cambodia, which may have been overlooked with other methods [16, 17]. This study had approval from Cambodia Trust and the Human Research Ethics Committee from Curtin University of Technology, Perth, Western Australia.

Participants

Convenience sampling was used to recruit participants for this study. Parents or carers of a child with cerebral palsy were eligible for inclusion if they had accompanied their child to one of three Physical Rehabilitation Centres in 2008. All three Centres were managed by Cambodia Trust for clients in the rural provinces of central lowland Kandal and southern, coastal Kompong Som and Kampot. Participants from urban areas were excluded

due to the significant demographic differences between better resourced urban areas and rural provinces, where eighty percent of Cambodia's population live [18].

Cambodia Trust staff invited potential participants to participate in the study, providing them with a one page summary of the research in the Khmer language. Participants were assured that a decision not to participate, or to withdraw at any time would not affect their services in any way.

Procedure

A question guide 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, then data were collected using semi-structured individual and small group interviews. 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 of between two and four people at the centre. The remaining eight participants were interviewed individually in their homes rather than in small groups, due to the long distances between participants' home villages. Interviews were conducted in the Khmer language by either a Cambodian research assistant who was not employed by Cambodia Trust or by a physiotherapist who was not known to the participants.

The question guide encouraged participants to share their stories, with researchers able to focus discussions on relevant issues that arose and explore unexpected information throughout the interview [19]. Questions explored participants' beliefs around why their child had a disability, their perceptions of changes in their child over time and explanations for these changes. For example:

- 1. If this path is your child's life, starting from birth and going along to today, can you tell us when the difficulties for your child started? What do you think caused the disability? Do you think there were any other possible causes/ reasons that your child developed these problems?*
- 2. Looking back, what do you think was the last most significant change in your child? Can you tell me about the reasons for this change?*

Analysis

Taped interviews were transcribed into written Khmer and checked for accuracy by the principal researcher who was present at all interviews. A team of three experienced Khmer translators then translated the interviews into

English. A lack of resources precluded a back translation of the interviews to Khmer, the gold standard for ensuring rigor in cross cultural research [20].

Data were analysed by the principal researcher using a Framework Approach, an approach to synthesizing and interpreting qualitative data particularly suited to applied research [21]. The framework approach involves five key stages: familiarisation, identifying a thematic framework, indexing, charting and interpretation [21].

Familiarisation involved the principal researcher listening to the thirteen hours of taped interviews as well as multiple readings of transcriptions in both Khmer and English, while listing key ideas and recurrent themes. A thematic framework through which to examine and reference data was then developed, drawing on a priori issues, emergent issues raised by the respondents as well as themes arising from the recurrence of particular experiences or beliefs [21]. For example, parental beliefs around disability causation fell into and often overlapped between three main categories: biomedical explanations, traditional Khmer explanations and those who reported having no explanations as to why their child was disabled. The integration of traditional and biomedical beliefs was a recurrent pattern in the data and was consistent with studies from a range of other contexts [8-10].

Indexing and charting were then undertaken using the qualitative software package NVivo. Following the Framework Approach, indexing involved systematically indexing or coding individual transcripts based on the thematic framework. Charting then aimed to consider the range of beliefs and experiences for each issue. Finally, the data set were mapped and interpreted as a whole. This included a review of charts, comparing and contrasting beliefs and experiences and searching for patterns or connections. For example, individual parental responses were compared and contrasted in an attempt to search for patterns between beliefs around disability causation and care-seeking behaviours.

Throughout the data collection and analysis process informal discussions were held between the principal researcher and the local research team regarding emerging themes and issues. Formal discussions were then held between the principal researcher and local rehabilitation workers to verify conclusions.

Results

Twenty-four parents or primary carers were included in the study: 15 mothers, four fathers, two grandmothers, one aunt and two non-relative carers; a sample representing 60% of the total population meeting the selection

criteria. Participants ranged in age from 18 to 55 years, with a mean age of 37 years. Only three participants were engaged in paid employment, with all 18 female relative-carers describing their principal occupation as caring for their child and family. Fourteen were also engaged in subsistence farming or other informal income generation activities (table 1).

The 22 children whose parents were interviewed were aged between 3-12 years (mean age 6 years; n = 13 males). The type and severity of cerebral palsy varied (table 2) and many had co-existing intellectual or sensory impairments. Four of the 13 school-aged children attended school.

Table 1: A summary of the demographic characteristics of the 24 parents or carers who participated in the study

	Total N= 24	%
Participants		
Age		
18-29 years of age	7	29
30- 44 years of age	10	42
45- 55 years of age	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

Table 2: A profile of the children of study participants

	Total N= 22	Mild [GMFCS I- II] N= 5	Moderate [GMFCS III] N= 7	Severe [GMFCS IV-V] N= 10
Total				
Age				
3- 6 yrs	12	2	3	7
7- 12 yrs	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 rehab				
Less than 1 year	11	4	3	4
1- 3 years	6	0	1	5
4- 8 years	5	1	3	1

Disability causation

This study found that many parents were unsure why their child had a disability. Of the ten participants who reported not having any idea as to why their child had a disability, eight had a child with a severe impairment. Eight of the 24 participants who were interviewed believed that biomedical causes played some part in the disability, while another eight reported on the involvement of some traditional factors (figure 1). Biomedical causes included the impact of vaccinations, injections, maternal health and nutrition during pregnancy and trauma. Traditional factors included karmic destiny and the interference of the spirits (table 3).

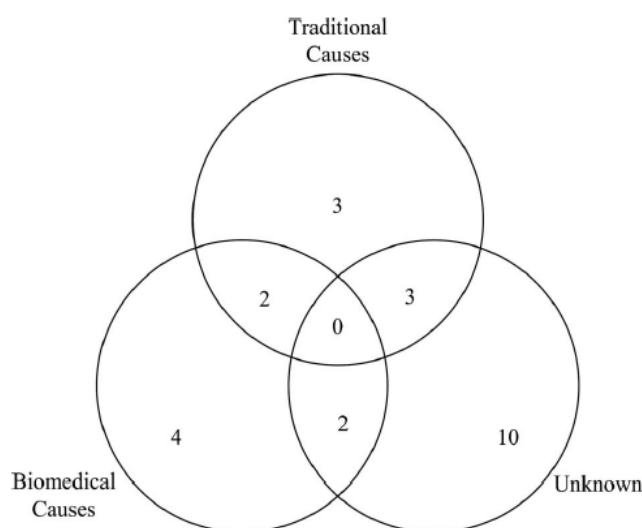


Figure 1. Participants' perceptions of disability causation.

Table 3: Participants' perceptions of the cause of child's disability

Type	Cause	Quotes from participants
Biomedical	Disease or Illness	At first we believed the traditional belief, that the disease was a convulsion caused by evil spirits, and I took him to traditional healer for healing but his condition did not improve. So we took him to the hospital where the brain scan showed he was suffering from meningitis... they said that he had a disability in his head and he would not be like normal children.
	Injury or Trauma	He has had the problem since he was born, when his head hit a metal chamberpot that the nurse had put there, so he got a blood clot on his brain.
	Vaccination or Injection	There was a polio prevention campaign so I took her to get the injection... Two days later she was still crying. My husband blamed me because I had taken her to get the polio injection.
Traditional	Involvement of spirits	Regarding the cause, the elderly people, the doctors, the magicians, no one knows. We said that if there were spirits we could prepare sacrifices and light incense on all the days set aside for observance of Buddhist precepts. After we sacrificed three times he pulled himself up and walked by himself.
	Karma	When I have conferred with others about why my child is like this, they have told me that it is because of karma from a previous life.
Unknown		I don't know. I want to ask whether my child's problem comes from me leaping from a tree when I was two months pregnant. Some people say it's because I had looked at the full moon. Some say it comes from the father's blood being bad. For me, I just wonder about it as when I was pregnant I ate enough. So why how was he born like this?'

Many participants noted that their extended family and community had offered advice as to the cause of their child's disability. Family and neighbours most commonly believed the disability to have been caused by spiritual forces or karma and labelled the disability as 'skan'. Yet few participants reported agreeing with information given by others in their village.

'In my heart I wonder what my child did to be like this. When I have conferred with others about why my child is like this, they have told me that it is because of karma from a previous life... They only say that she is skan, and I say that she isn't because I know, I have been there from the start and know that she has never had a fit so she can't be skan'. (Mother of 4 year old girl with severe cerebral palsy)

Beliefs around change

Participants were asked about their past history of care-seeking for their child as well as their current beliefs around what interventions are effective in bringing about change.

Traditional interventions

The majority of participants reported accessing traditional interventions following the initial illness episode or when their child's impairments became apparent, often at the encouragement or insistence of older relatives or villagers. Traditional interventions ranged from having a traditional healer make incantations and spit medicines or betel nut onto the child in a process called *stot*, preparing sacrifices at the Buddhist temple and family members massaging limbs with lemongrass, oils or alcohol.

Only two participants, carers of children with mild and moderate disabilities, believed that traditional interventions had been effective.

'We said that if there were spirits we could prepare sacrifices and light incense on all the days set aside for observance of Buddhist precepts. After we did that three times he pulled himself up and walked by himself'. (Mother of 9 year old boy with mild cerebral palsy)

'With skan, after he was born and they found someone to stot him then he got much better... I don't remember what disease they said he had, I just knew that I had to find someone to stot him'.

(Grandmother of 9 year old boy with moderate cerebral palsy)

Eight participants reported believing that traditional interventions had not been effective, based upon a lack of change in their child's function. Participants who reported having had negative experience with traditional interventions were mainly those whose children were moderately or severely impaired.

'Many traditional healers have come to my house, asking me to give them money, sometimes up to fifty thousand riel. Sometimes they have foretold this or that, and sometimes they have asked me to borrow money from others if I have not had money to pay them. It's so dreadful to hear them speak like that... If a traditional healer could treat my son effectively, my relatives would help me to pay them: I don't want to see my son having such a disability and I would give everything if my son could walk. But I don't want to be cheated'. (Mother of 9 year old boy with moderate cerebral palsy)

'In our village they said that we should massage medicine or oil into her arms and legs each morning. That didn't help so they said to massage lemongrass into her legs but that did nothing either... People told me to look at a chicken thigh then pound it with rice wine and put it on my child's legs and do massage until it is warm, then eventually she will walk. We tried this two or three times but it didn't make her any better. Other people told me to rub to pork oil on her legs but that didn't work either, she still couldn't walk'. (Mother of 3 year old girl with mild cerebral palsy)

'My wife and I massaged him with lemongrass dew every morning for 5 years, never missing a morning. But it has not changed anything... Many years of doing the massage could not help him to walk- he remained the same and we could see no improvement'. (Father of 7 year old boy with moderate cerebral palsy)

Medical interventions and rehabilitation

Having seen no evidence of change in their child following traditional interventions, many participants sought treatment at village health centres, provincial hospitals, national paediatric hospitals, hospitals in neighbouring countries or physical rehabilitation centres. Treatments at hospitals and health centres included the use of

medicines and in four cases, recommendations for parents to stretch the child's limbs at home. Treatments at rehabilitation centres included physiotherapy, provision of information and home programs and provision of orthotics and mobility equipment.

The majority of participants reported believing rehabilitation to be an effective intervention based upon the changes that they had seen in the child. Yet perceptions of effectiveness were largely related to the severity of their child's impairment. Parents of children with mild or moderate impairments were most likely to attribute the changes that they had noticed in their child's development to rehabilitation, citing functional gains as evidence of effectiveness. Few parents of children with severe disabilities felt that rehabilitation was currently effective. Some parents of children with severe disabilities felt that their child had improved in the months following their first visit to the Centre, but most reported having lost hope of change because of a subsequent lack of change. 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.

'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. We just know to try our best for her. She's our daughter and we feel sorry for her so we try hard to help her'. (Father of three year old girl with severe cerebral palsy)

Participants who believed their child's disability was a result of traditional causes were less likely to have sought traditional interventions than those who reported that their child's disability had a biomedical cause. Five of the eight participants who believed that there were biomedical causes for the disability had tried traditional interventions, yet reported no effect. Three of the eight participants who believed there to be traditional causes for the disability had undertaken traditional interventions, with only two reporting that the intervention had been effective. The group least likely to have accessed traditional interventions were those who reported not having any idea what had caused their child's disability, most of whom were severely disabled.

Discussion

This study aimed to explore the beliefs of parents of children with cerebral palsy in rural Cambodia regarding disability causation and discover how parents perceived the effectiveness of various interventions in bringing about change in their child. The complexity of Khmer belief systems was reflected in the range of participants' perceptions of the cause of their child's disability, yet beliefs around disability causation did not appear to have determined their care-seeking behaviour nor their perceptions of effectiveness of interventions. These findings are a marked contrast with research from other countries, which found that the beliefs of parents and extended family regarding the cause of a child's disability strongly influence the parents' care-seeking behaviour for their child with disabilities [10-11]. While the small sample size in this study precludes generalisation to all parents of children with disabilities in rural Cambodia, it is possible that these findings are a reflection of Cambodia's particularly tumultuous history, the undermining of traditional ideas and the destruction of traditional systems.

Very little research has been undertaken in Cambodia into the current worldviews and beliefs of Khmer communities. Traditional Khmer beliefs include an interplay between Theravada Buddhism, Brahmanism and animism [22]. Yet most of the recent research into Khmer beliefs and the impact they have on daily life has been conducted in the USA with Khmer refugees. This research has tended to stereotype Khmer culture as being highly fatalistic. Examples cited have included individuals reluctance to seek treatment for some illnesses due to a passive acceptance of 'karma' [23, 24] and parents' lack of encouragement for their children's schooling, believing that their achievements or failures are shaped by destiny or fate [25, 26]. It is not known whether the high rates of post-traumatic stress amongst Khmer refugees in the USA [27] may have impacted upon underlying cultural beliefs around 'karma'. Few participants in this study displayed a sense of fatalism. Upon realising 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. While many parents did not have a clear idea of what had caused the disability, most actively searched for interventions, continually assessing results and moving on from treatments which they believed were not producing change in their child.

These findings suggest that rehabilitation service providers need not assume that parents will be less likely to access medical or rehabilitation services if they have traditional beliefs around disability causation. Rather than displaying static beliefs, parents appeared to take into account their perceptions of evidence of effectiveness. For example, participants who had in the past undertaken traditional treatments were those most likely to report currently believing that their child's disability had been caused by biomedical factors. Parents who had more traditional beliefs around disability causation were in fact less likely to have sought traditional treatment. This finding was consistent with studies in a range of contexts which suggest a duality of belief around disability

causation often leads parents to seek both biomedical and traditional treatments for their child with disabilities [9-11]. Following a review of studies of parental beliefs around disability and intervention from various cultures, Danesco concluded that parents and professionals should negotiate around specific practices and beliefs and articulate mutually shared goals for the development of the child with disabilities [9].

The study also highlighted the importance of rehabilitation services motivating parents with evidence of their child developing and attaining functional goals, a finding consistent with studies from a range of contexts [28-29]. Participants in this study cited a lack of change as the key reason for discontinuing traditional treatments. Those parents who reported believing rehabilitation to be an effective intervention did so because they had seen their child attain functional goals. As the vast majority of parents aimed to see their child walk, parents of children with mild to moderate disabilities were most likely to see this goal attained and conclude that rehabilitation was effective.

Most parents of children with severe disabilities reported having lost confidence in the process of rehabilitation when it became clear their child was not going to walk. Only one of the five participants who had been receiving services for four years or more had severe disabilities. The lack of realistic goals amongst these parents highlights the importance of rehabilitation service providers providing parents with basic prognostic information where possible and encouraging parents to be realistic in their in their choice of goals for rehabilitation [30].

This study utilised 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 urbanised settings. Further, limited time and budgets precluded utilising observation as part of the study. It is 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.

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