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# Parent experience of implementing home programs: Semi-structured interviews

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# Parent experience of implementing home programs: Semi-structured interviews

## **Abstract**

Abstract presented at the 5th Biennial Conference of the Australasian Academy of Cerebral Palsy & Developmental Medicine, 3-6 March 2010, Christchurch, New Zealand

## **Keywords**

home, programs, semi, parent, structured, experience, interviews, implementing

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ing after their children with CP. The content themes of the discussions were analysed with assistance from Leximancer,<sup>2</sup> a concept-mapping computer program.

**Results:** Overall, parent and expert responses to the parenting program were positive and rated highly for acceptability on a scale of 1–10 ( $M=8.87$ ,  $SD=0.91$ ), usability ( $M=8.24$ ,  $SD=1.71$ ), and behavioral intention ( $M=7.82$ ,  $SD=2.18$ ). Parents highlighted key aspects of what they would want in a parenting program, including how to establish equity at home among siblings, balancing quality and therapy time, and socializing their children with the general community. Parenting tasks performed beyond what most other parents do were also identified, such as administering medication and therapy at home, attending medical related appointments, and providing constant assistance and supervision with children's mobility and daily tasks. This information will be used for the development of a parental outcome measure. It was noted that the relevance of a parenting program to families is closely tied with the tailoring of the program by therapists based on child's varied GMFCS level.

**Conclusion:** Findings revealed an overall positive view of the Stepping Stones Triple P program by parents of children with CP and allied health professionals. This study is an important first step towards the validation of a parenting program for this population and it will lead to a subsequent Queensland-wide survey study and a RCT.

#### References:

1. Sanders MR, Mazzucchelli TG, Studman LJ. *Practitioner's manual for standard Stepping Stones Triple P*. Brisbane: Triple P International Pty. Ltd, 2003.
2. Smith AE, Humphreys MS. Evaluation of unsupervised semantic mapping of natural language with Leximancer concept mapping. *Behav Res Methods* 2006; 38: 262–79.

### 3C.5 Parent experience of implementing home programs: semi-structured interviews

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**Objective:** This study aimed to describe parent views about implementing home programs developed using the Novak & Cusick model<sup>1,2</sup> to help inform practice recommendations for parents and professionals about home program intervention design and implementation.

**Design:** This study used a qualitative methodology because little was known about parent experiences. Parents' perceptions of home program implementation were collected via

semi-structured interviews. The analysis approach adopted was grounded theory to the level of open coding of categories, using two independent raters.

**Method:** A convenience sample was generated by inviting parents of children involved in a randomised controlled trial evaluating home program effectiveness.<sup>3</sup> Eight families (two fathers, eight mothers) gave informed consent to participate in interviews. Interviews were conducted in English, audio taped and transcribed verbatim, with names removed to maintain anonymity. Each participant was interviewed once face-to-face, with four follow-up interviews carried out by telephone. Interviews ranged from 20 to 75 minutes (mean 41min, mode 44min).

**Results:** Results were organised into themes around the four key questions asked of participants: (1) Parents believed practice of home program activities was a part of life for children with cerebral palsy. They used home programs to maximize progress, gain parental guidance and for time management reasons; (2) The Novak & Cusick home program model (2006) was perceived to provide benefits to parents including: support; realism; flexibility; motivation; generalizable activities; reminders to practice; progress updates; and role clarification; (3) Parents advised other parents to accept the disability, never refuse help, be honest, develop routines and consider home programs as essential for the child's development. Home programs also were perceived to provide parents with a positive strategy for improving their child's life; (4) Parents advised health professionals that effective home programs should include parental support, inter-disciplinary coordination, and prognostic information, without pressure to do what they are told.

**Conclusion:** This study provided new knowledge about parents' views and recommendations for designing home programs. Parents perceived that the home program model compared to other 'traditional prescribed' home programs were preferable because they offered them many benefits. Provision of ongoing support to parents was vital, confirming earlier research. This finding was important because it is known that the way parents feel about the home program directly influences how much they use home programs.

#### References:

1. Novak, I. & Cusick, A. Home programmes in paediatric occupational therapy for children with cerebral palsy: where to start? *Aust Occup Therap J* 2006; 53: 251–64.
2. Novak, I., Cusick, A., & Lowe, K. A pilot study on the impact of occupational therapy home programming for young children with cerebral palsy. *Am J Occup Ther* (2007); 61: 475–80.

3. Novak, I., Cusick, A., & Lannin N. Occupational therapy home programs for children with cerebral palsy: a double-blind randomized controlled trial. *Pediatrics* 2009; 124 (4): e606–4.

### 3C.6

#### **Rehabilitation for children with cerebral palsy in rural Cambodia: parental perceptions and experiences**

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*Objective:* This study examined the perceptions of parents living in rural Cambodia regarding the effectiveness of rehabilitation for their child with cerebral palsy and explored the appropriateness of using family-centered rehabilitation practices in the Cambodian context.

*Design:* Qualitative, cross-sectional study.

*Method:* In-depth individual or semi-structured small group interviews were conducted with the parents of 22 children with cerebral palsy from three rural provinces of Cambodia. All had accessed rehabilitation services through the Cambodia Trust in 2008, following the introduction of a rehabilitation planning process which incorporated family-centered practices. Children of participants were aged 3–12 years (mean age 6y; 9 female, 13 male) and type and severity of cerebral palsy varied (GMFCS I:  $n=2$ ; II:  $n=1$ ; III:  $n=7$ ; IV:  $n=7$ ; V:  $n=5$ ). All interviews were conducted in the Khmer language, transcribed then translated into English. Data were analysed with NVivo software using a framework approach.

*Results:* A total of 24 parents were interviewed. Preliminary findings suggest that the needs and preferences of parents living in rural Cambodia were similar to those of parents in Western contexts, where information exchange, respectful and supportive care and partnership or enabling aspects of family-centered care are highly valued. While most parents placed a high value on the informational aspects of family-centered care, few reported receiving information on their child's disability, future outlook or reasons for treatment. Parental perceptions regarding the effectiveness of rehabilitation were mixed. Many parents held to traditional beliefs regarding disability causation and had undertaken extensive searches for healing using traditional Khmer practices prior to or whilst accessing physical rehabilitation services. However, the use of functional goal-setting and reviewing as part of the rehabilitation process appeared to positively impact on parents' perceptions of the effectiveness of rehabilitation.

*Conclusion:* There is little evidence of family-centered practices having been adopted by paediatric rehabilitation services in developing countries. This study suggests that family-centered approaches are highly valued in a rural Cambodian context. Challenges to the implementation of the model include resource constraints and the negotiation of effective parent-health professional collaboration in a deeply hierarchical society where parents and health professionals may hold contrasting beliefs around personhood and the possibility of individual development.