The role of the family in intervention of infants at high risk of cerebral palsy: a systematic analysis

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ABBREVIATIONS

COPCA	Coping with and Caring for infants with special needs
IBAIP	Infant Behaviour Assessment and Intervention Program
IHDP	Infant Health and Development Program
FCS	Family-centred services
NDT	Neurodevelopmental treatment

During the past two decades, awareness of the role of the family in the child's life has increased and the term 'family-centred services' (FCS) has been introduced to facilitate care for children with special needs and their families. It is, however, unclear how various early intervention programmes incorporate family involvement in service delivery. The present study systematically analyses the nature of family involvement in six frequently used early intervention programmes for infants at high risk of developmental disorders: neurodevelopmental treatment, treatment according to Vojta, Conductive Education, Infant Health and Development Program, Infant Behaviour Assessment and Intervention Program, and Coping with and Caring for infants with special needs – a family-centred programme (COPCA). The analysis shows that the role of the family is diverse: it varies from parent training to be a therapist without attention to family function (in Vojta) to the autonomous family that receives coaching (COPCA). The data suggest two trends over time: (1) from child-focused to family-focused orientation; and (2) from professionally directed guidance to coaching based on equal partnership.

During the past two decades, awareness of the role of family care in the process of habilitation of infants with special needs has increased. Early intervention always has involved both infant and family, but the way in which the family participated changed over time. These changes are reflected, for instance, in the emergence of the concept of family-centred services (FCS) and in the ways in which FCS has been defined and applied.[1–4] In this review we use the CanChild definition of FCS: 'FCS is made up of a set of values, attitudes and approaches to services for children with special needs and their families. It recognizes that each family is unique; that the family is the constant in the child's life; and that family members are the experts on the child's abilities and needs. The family works together with the service providers to make informed decisions about the services and supports the child and family receive. In family centred services the strengths and needs of all family members are considered'.[1,3]

Many professionals support FCS, and parents are generally willing to collaborate as they want the best for their child. Nevertheless, it has been noted that the therapist's attitude to family-centred care is not always automatically translated into family-centred behaviours.[5,6] In addition, the study of Iverson indicated that service providers have a diversity of opinions on the role they believe parents should play in early intervention service. This varies from observer to therapist, active participant, expert of child development, or member of the rehab-team.[7]

The aim of the present study is to review systematically the nature of family involvement in the most frequently applied early intervention programmes for infants aged 0 to 2 years at high risk of cerebral palsy (CP). To get insight into current developments we also included two recently developed programmes in the analyses.

METHOD

Selection procedure

We selected the most frequently applied early intervention programmes available for infants (0–2y) at high risk of CP on the basis of three recent systematic reviews[8–10] and Mayston's update on treatment approaches.[11] Programmes were included when they fulfilled the following criteria: (1) the onset of intervention started after discharge from the hospital; (2) the frequency of occurrence in the reviews; and (3) often applied in clinical practice in the management of early phases of CP. This resulted in the selection of four programmes: Bobath/NeuroDevelopmental Treatment (NDT), treatment according to Vojta, Conductive Education, and the Infant Health and Development Program (IHDP). We regarded NDT, treatment according to Vojta, and Conductive Education as traditional treatment programmes, whereas the IHDP was considered representative of general developmental programmes. We also added two more recently developed programmes: the Infant Behaviour Assessment and Intervention Program (IBAIP) and Coping with and Caring for infants with special needs – a family-centred programme (COPCA).

Next, we searched the literature for descriptions of the five core themes of FCS according to Rosenbaum:[3] (1) the role of the family; (2) role of the therapist; (3) role of parents; (4)

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education of the infant; and (5) communication/partnership in the six selected treatment approaches. In addition we investigated (6) the primary focus of guidance. The databases Pubmed, PsychINFO, Google scholar, and dedicated websites were used to search for original publications of the founders of the programmes, and papers of people who developed the methods further, from 1960 to May 2010. In addition, books in which details of the various methods had been described were used. We used the following search terms: 'family', 'family-centred', 'parents', 'caregivers', 'mother', 'partnership', 'communication professional and parents', 'education', 'team', 'therapist', 'professional', 'individual', 'client centred' or 'child centred', and 'environment'.

Evaluation procedure

The six early intervention programmes were systematically analysed with the help of the five core themes. We summarized the text that explicitly described the role of the family and that of the physiotherapist in relation to the family including parents, siblings, and child (Table I). A family function model was developed to illustrate the roles and relationships between infant, parents, family, the physiotherapist, and the environment (Fig. 1a).[12–15] The model is based on the fundamental idea that the family is regarded as a dynamic system of bidirectional dyads and that the family itself is nested in a larger ecological system including the service providers,[16] in our study paediatric physiotherapists.

RESULTS

The results are summarized in Table I and Figure 1. Most information on family involvement in the three traditional programmes was only available in descriptions in books. Information on family involvement in the other three programmes was available in papers and websites.

The Vojta method

We based our results mainly on the original German books of Vojta and coworkers[17,18] and chapters in books,[19,20] as information on the role of the family in the Vojta method in international papers was very limited. Publications written in Czech, Polish, Japanese, or Chinese were excluded from the analysis. The German books devoted little text to the role of parents. Vojta's view of the role of the parents is, 'Parents can be exceedingly effective therapists using this treatment, so it is surprisingly economical and efficient' (p. 84).[19] In Vojta's approach parents are laymen. It is the therapist who determines the treatment plan and teaches the parent in a one-way direction. The treatment is entirely focused on the child. The term 'parents' was mentioned, but the term 'family' was entirely missing in the texts (Table I and Fig. 1b).

Conductive education

Petö, the original founder of Conductive Education[21] died in 1967 and Maria Hari became his successor. Her publication[22] and the article of Reddihough[23] provided the most articulate descriptions of the role of the family. Conductive Education is, as Maria Hari wrote, 'an all-embracing system with its own register of those who 1 day might require care: its own diagnostic services, counselling services for parents, and client-centered services on the premises of the Institute' (p. 21).[19]

Conductive Education implies education organized by 'conductors'. The conductor is a generalist who combines in her function expertise from medicine, education, physio- and speech therapy and psychology. The conductor designs, organizes, and selects the methods she teaches the child. Conductive Education is a system of education to achieve 'orthofunction', which means the ability to participate and function in society despite disability. Parents are welcome to discuss problems with the conductor but education focuses on the achievements of the child. A specific role of the family has not been described (Table I and Fig. 1b).

NDT

Most of the published articles focused on the neurodevelopmental component of the approach.[24–28] Nevertheless, Bobath[29] and Köng[30] stated already in the 1960s that the parents, especially the mothers, were the most important people in early intervention.

Gradually new ideas were incorporated into the open concept of NDT and the role of the family became more important.[31–34] In the words of Bly, 'Address the family needs, support and encourage them. And educate and teach them about their baby's strengths as well as needs. Involve them immediately in planning the baby's treatment programme, carrying over treatment activities, and setting goals for home' (p. 8).[32] Family education, including parent training, is a key element of NDT, as it allows for consistent therapeutic management of the infant. Still, focus of intervention is on the functional development of the child.[11,32,33]

The caregiver is instructed how to modify care-giving activities so that each daily task can be used to reinforce the improvement of motor patterns, which the infant has learned during a therapy session. The therapist teaches within the framework of a didactic confident instructor–learner interaction. This results in guidance and shared control of decision on treatment goals. It is the responsibility of the therapist to discover the best way for the infant to achieve his/her best functional potential. This implies that the therapist is the key person in the intervention process (Table I and Fig. 1c).

IHDP

The original concept of the IHDP has been described by Ramey et al.[35] The IHDP programme is an educational programme which focuses on parent-infant interaction. As Ramey et al.[34] put it, 'Family and environmental stresses and supports may impinge on infant caregiver transactions in ways that enhance or limit the transactions and the child's potential development, but the caregiver –child interaction is the key' (p. 455) (Fig. 1d).

The parents, embedded in the family, are taught on child development by the combination of a home-based programme, instruction sessions at a child development centre, and parent group meetings for exchange of information and experience. In this way parents are taught to use special games

Table I: Overview of core themes in the intervention programmes

	VOJTA	CE	NDT	IHDP	IBIAP	COPCA
Primary focus of guidance	Optimizing child development	'Orthofuncion' Integration of child in society Attainment of independent walking and self-care skills	Optimizing child development	Neurobehavioural communication between infant and parents (especially the mother)	To facilitate and validate parental perceptions of the behavioural cues of their infant	Decision making process of the family: the process of making autonomous decisions in coping and caring for infant with special needs
Role of family	No specific role of family specified	No specific role of family specified	Family is informed and taught about the child's strengths and needs, treatment plan and therapeutic carry-over at home.	Infant is embedded in the family	Infant is embedded in the family	All family members involved Key factor in process of coaching Autonomy of the family Self decision making Responsible for decisions and choices
Role of therapist	Key person in decision making Teacher Parent training	Conductor is key person in decision making Teacher and educator Assists and trains Parent counselling	Key person in guidance/instruction Teacher Parent training Family education	Key person in guidance of caregivers Teacher Support family	Key person in guidance Teacher, in particular of mother Support family	Coach of all family members
Role of parents	Layman Therapist	Parents might discuss child's problems and progress with the conductor	Member of the team Shared decision making in goal-setting Co-therapist (extension of treatment) Learner	To use programmes of games and activities with the child To manage self-identified problems	Mother facilitates interaction with the infant	Parenting according to their own child rearing perspective
Education of infant	Reflex-locomotion, including reflex rolling and creeping.	Structured, individual-oriented development Formal school education principles	Sensori-motor experiences	Programme of games and activities Participation in special child developmental centres	To support the self-regulatory competence of the infant during interaction	Coaching of caregiver Family specific child rearing perspective
Communication/ partnership	One-way communication: Parents laymen, therapist expert	One-way communication, Child is learner, conductor is teacher	Didactic bidirectional open information exchange Teacher–learner relation	Didactic bidirectional open information exchange Teacher–learner relation	Didactic bidirectional open information exchange Teacher–learner relation	Bidirectional, open dialogue in a coaching process Equal partnership

CE, Conductive Education; NDT, neurodevelopmental treatment; IHDP, Infant Health and Development Program; IBIAP, Infant Behaviour Assessment and Intervention Program; COPCA, Coping with and Caring for infants with special needs.

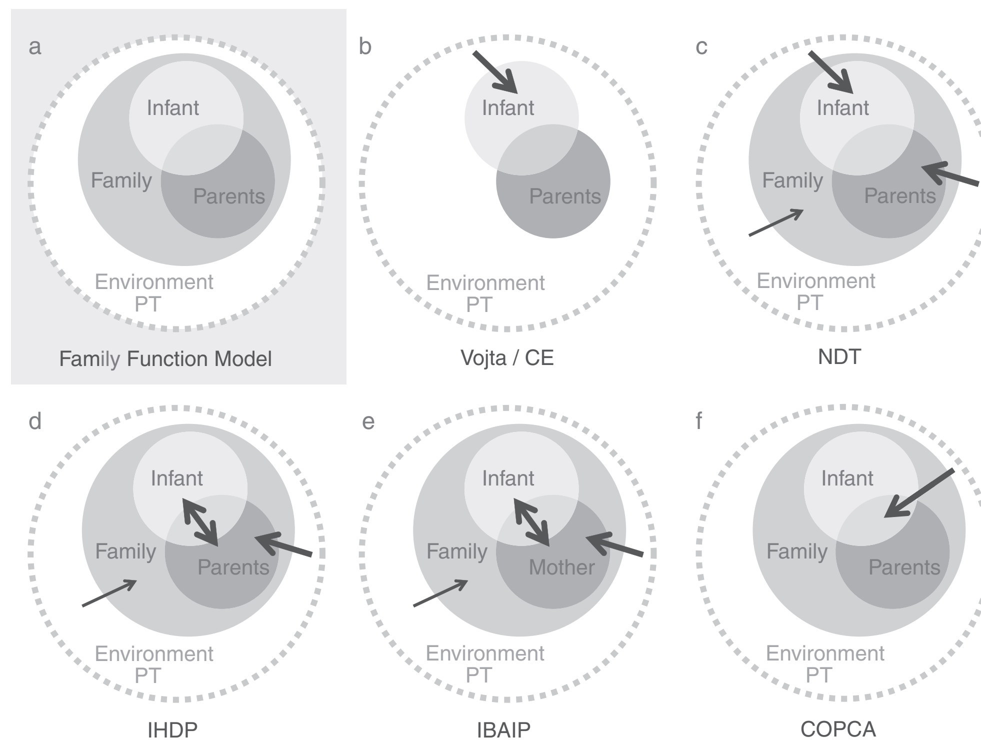

Figure 1: (a) The family function model. The complexity of family function is illustrated by four dynamic elements interacting with each other and changing priorities across a lifetime. The infant–parent dyad is partly embedded in the family circle, which in turn is nested in the ecological environment, which includes the family-centred services (FCS) of the paediatric physical therapist (PT). (b) Representation of family function in treatment according to Vojta and in Conductive Education. The bold arrow indicates that the infant is the primary focus of treatment. No attention is paid to the family component. (c) Representation of family function in neurodevelopmental treatment (NDT). The two bold arrows represent the dual focus of treatment: (1) infant function; and (2) the parent who is instructed to implement the NDT approach at home. NDT recognizes that the parent–infant dyad is partly embedded in the family (standard arrow). (d) Representation of family function in the Infant Health and Development Program (IHDP). The bold bidirectional arrow in the infant–parent dyad symbolizes the importance of the interaction. The parent is taught how to support infant development (bold arrow). It is recognized that the parent–infant dyad is embedded in the family (standard arrow). (e) Representation of family function in the IBAIP. For significance of arrows, see (d). In the Infant Behaviour Assessment and Intervention Program (IBAIP) the mother is the most important person in the infant–parent interaction process. (f) Representation of family function in Coping with and caring for infants with special needs (COPCA). The bold arrow reflects that the dynamic family function process is COPCA's starting point.

and activities to support cognitive, linguistic, and social development and how to use a systematic approach to manage self-identified problems (Table I).

IBAIP

The description of the programme on http://www.ibaip.org was our main source of information for details about it. Essential to the highly structured programme of IBAIP is the notion that parents of very low birthweight preterm infants need help in learning how to cope with the infant's disorganized behaviours and with the lack of clear signals of the infant. According to the programme, 'Parents will benefit through the facilitation and support offered by the training provided by our outreach project, thus assuring of mutually satisfying parent-infant interactions and confidence in their ability to support the neurobehavioral and developmental needs of their infant' (p. 1).[36]

The therapists translate the infant's behavioural communication by a neurobehavioural supportive assessment, the Infant Behaviour Assessment (IBA), into an intervention and caregiving plan. Parents, especially mothers, are taught how to interpret their baby's responses to sensory information to be able to support the infant's self-regulatory efforts and adjustment to the environment. The therapists validate and support parental perceptions and train the parents on how to hold the infant and how to assist it to achieve specified skills. IBAIP recognizes that the parent–infant dyad is partly embedded in the family while the neurobehavioural communication between infant and parents (especially the mother) forms the key of guidance (Table I and Fig. 1e).

COPCA

COPCA has been developed recently in the Netherlands.[37–40] Dirks et al.[37] noted that 'The family is the cornerstone of COPCA. Therefore COPCA's key elements are family autonomy, family responsibility and family specific parenting.' COPCA coaches the family to deal in an autonomous way with the child with special needs and health care. COPCA aims to encourage the family's own capacities for solving the

problems of daily care in naturally occurring parenting situations. The coach does not have an instructional role but supports family members – on the basis of an ongoing equal partnership – to uncover their competencies, goals, desires, hope, and coping strategies.[41,42] This is best reflected by the following parental quote: 'Don't tell me what I can do, have to do or must do, but help me to discover it by myself'. COPCA coaches the family by creating a process in which the family members feel free to explore and discuss alternative strategies. Specific attention is paid to the role and well-being of siblings. The family decides how they would like to be involved in intervention. This includes responsibility for decisions and choices in the care of the infant and in the way to collaborate with health care professionals (Table I and Fig. 1f).

DISCUSSION

Our systematic analysis of FCS emphasized the diversity in the role of the family in the various early intervention programmes. This diversity matches the heterogeneity in parental participation in physical therapy of children with physical disabilities reported in the review of Jansen et al.[43]

The current study suggests the presence of two trends over time. First, programmes seemed to develop from being child focused to family focused. Early intervention services primarily took the form of working directly with the child (Vojta, Conductive Education). Gradually the needs of the family members and the ecological environment circumstances were incorporated in therapeutic guidance, but the approach remained child focused (NDT). Next, infant and family became equally important in the IHDP and IBAIP programmes. Parental involvement is a cornerstone in these programmes. In the most recent programme, COPCA, the family is the centre of the programme – entirely in line with the Canchild definition of FCS.[1]

The second trend over time that might be present is the development of guidance that was professionally directed to coaching based on equal partnership. In most early intervention programmes (Vojta, Conductive Education, NDT, IHDP, and IBAIP) the professional controls the process of treatment with an unbalanced partnership between therapist and parents. The parent is the learner in a dual role, i.e. that of caregiver and 'co-therapist', and the therapist is the teacher. This differs from the approach of the most recently developed programme, COPCA. COPCA encourages family members in an equal partnership, including parents, siblings, and grandparents, to discover their own strategies and to decide for themselves about priorities and intervention.

CONCLUSION

It is generally recognized that FCS is of crucial importance in early intervention of children with or at risk of neurodisability. However, the way in which FCS and family involvement in early intervention in infants at high risk of developmental motor disorders is implemented in daily practice is very diverse. Our review suggests that a major change in attitude and behaviour is needed to implement real FCS. To achieve this we need to investigate what therapists actually do in practice.[44] In addition, studies evaluating the effect of truly family-focused care are required.

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