DOI: 10.4274/*tftr*.84429

Family-Centered Approach in the Management of Children With Cerebral Palsy

Serebral Palsili Çocukların Tedavisinde Aile Odaklı Yaklaşım

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Summary

There has been a growing understanding that the family has an important role in the life of children with disabilities. Family-centered care was developed to facilitate the process of care of children with special needs and their families. Since then, it has been widely used in child health and afterward implemented to the pediatric rehabilitation. The acceptance of family-centered care and the emergence of new theories on motor development have influenced the management of children with cerebral palsy. The interventions have become more family- and function-focused, rather than child-focused. The purpose of this review is to provide an overview of the theoretical background of the approaches to cerebral palsy, family-centered care as a conceptual framework and its implications for therapy approaches that are used in the management of children with cerebral palsy. *Turk J Phys Med Rehab 2012;58:229-35.*

Key Words: Family-centered approach; cerebral palsy; pediatric rehabilitation

Özet

Engelli çocukların yaşantısında ailenin önemli bir rolü olduğu gittikçe önem kazanan bir görüştür. Aile odaklı bakım, özel ihtiyaçları olan çocukların bakım sürecini kolaylaştırmak ve ailelerine yardımcı olmak için geliştirilmiştir. Aile odaklı bakım çocuk sağlığı alanında yaygın olarak kullanılmakta olup sonrasında pediatrik rehabilitasyon alanında da uygulanmaya başlanmıştır. Aile odaklı bakım anlayışının kabulü ve motor gelişim konusunda yeni teorilerin ortaya çıkması, serebral palsili çocuklara tedavi yaklaşımını etkilemiş, yapılan uygulamalar çocuk yerine daha çok aile ve fonksiyon merkezli hale gelmiştir. Bu derlemenin amacı serebral palside uygulanan tedavi yaklaşımlarının teorik zeminlerini, bir kavramsal yapı olarak aile odaklı bakım anlayışını ve serebral palsili çocukların tedavisinde kullanılan terapi yaklaşımlarına etkilerini anlamak için genel bir bakış sağlamaktır. *Türk Fiz Tıp Rehab Derg 2012;58:229-35.*

Anahtar Kelimeler: Aile odaklı yaklaşım; serebral palsi; pediatrik rehabilitasyon

Introduction

Cerebral Palsy (CP) is the most common disability in childhood. The prevalence of CP is about 2 - 2.5 per 1000 school-age children (1). CP is not a single condition with a clear etiology; it is an umbrella term that defines a series of symptoms related to a wide variety of non-progressive lesions or anomalies that affect the immature brain (2). Some of these symptoms are abnormalities of muscle tone, gait, and posture. Other aspects of functioning are also affected such as perception, vision, learning and language. Epilepsy and behavioral problems can also be observed. There are also secondary symptoms due to the primary deficits such as muscle hypoextensibility, joint contracture, skeletal malalignment, impaired force production, and impaired endurance (3).

Children with CP and other neurodevelopmental disabilities have long-term needs. The physical and emotional health of parents of these children is also worse than the parents of healthy developing children (4). Parental needs and burden of caregiving on families of children with CP has been widely

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examined (5,6). Studies involving families of children with disabilities have identified several types of family needs (7). There are many problems that the family members face such as family functioning, psychological stress, and social isolation (8). Because the child with CP is an important member of a larger family system, there has been a growing understanding of the role of the family in the child's life and the importance of the insights of parents into their child's abilities and needs. Assessment of family functioning can be helpful in guiding interventions and planning according to family concerns and children needs (9). During the past decades, family-centered care has been developed to facilitate care for children with special needs and their families and influence therapy approaches in pediatric interventions. The aim of this review is to outline the theoretical background of the approaches to CP, what family-centered care is and its impact in the management of children with CP.

Theoretical Background of the Approaches to Cerebral Palsy

Neuro-Maturationist Theory

According to the neuro-maturationist theory, motor development is based on the maturation of the central nervous system and higher centers inhibit and control lower centers. Developmental motor dysfunction is thought to be due to the delay in developmental milestones and the presence of abnormalities in muscle tone and reflexes (10,11). Approaches based on neuro-maturationist theory focus on eliciting normal patterns of movement through sensoriomotor experiences to inhibit abnormal movements and to provide postural adjustments (12). Bobath concept that has evolved in the 1950s is the most popular physiotherapy method and is known as neurodevelopmental therapy (NDT). Based on the neuro-maturationist theory, NDT aims to normalize the muscle tone, inhibit primitive and abnormal reflexes and to facilitate normal movements (13). Other physiotherapy approaches based on neuro-maturationist theory of motor control are Rood, Brunnstrom, proprioceptive neuromuscular facilitation (PNF) and Carr & Shepherd approaches (14). All of these approaches are based on relearning movement in a normal developmental sequence. NDT have evolved over the years with more emphasis on functional independence and active movement by the child but the inhibition of abnormal patterns and, improved quality of movement are still the primary principles (15,16). Although NDT and other approaches based on neuro-maturationist theory are widely used for many years, it has been questioned whether facilitated automatic movement improves voluntary, active movement and there is not a certain evidence supporting the effectiveness of these approaches. There is a lack of high quality studies with objective, valid and reliable outcome measures and the results are doubtful (17,18,19).

Dynamic Systems Theory

It has become increasingly clear that in the domain of motor development, environment has a significant influence. Thelen et al. (20,21) applied the principles of the dynamic systems to the area of motor development of human beings. Applied to physical disabilities, this theory combines reflexive and voluntary motor control. Central nervous system receives and interprets multiple cues from the environment and involves multiple subsystems when planning to reach desired goals and preferred tasks. According to the dynamic systems theory, motor behaviour is organized by the spontaneous self-organization and interaction of many subsystems within the child characteristics, task demands, and environmental influences to achieve a functional goal (22,23). Child characteristics include both the physical impairments like muscle tone, range of motion, balance and the non-physical factors such as cognition, temperament, motivation, and attention. Factors in task demands which affect motor behaviour are the size or shape of a writing instrument, the height of a chair that the child uses to sit down or the size

Table 1. Overview of core themes in the therapeutic approaches using the principles of family-centered care.

	NDT (50,51)	Occupational therapy home programme (52)	Functional therapy (56,57)	Activity-focused therapy (58)	Context therapy (64)
Primary focus of the therapy	Development of normal movement	Achieving identified goals by selected therapeutic activities	Promoting motor skills and achieving functional goals meaningful in the childs environment	Promoting motor learning within the context of the daily routines of the child and the family	Promoting functional goals by changing task or environmental constraints
Role of parents / family	Shared decision making in goal setting, learner and co-therapist	Active involvement in goal setting, decision making, program implementation, evaluation of the goals	Active involvement in goal setting, decision making, implementation in daily life, intervention strategy	Active involment in developing activity- related goals and training	Active involvement in assessment, goal/task identification, intervention strategy
Communication partnership	Bidirectional open information exchange, teacher-learner relation	Bidirectional open information exchange, equal partnership	Bidirectional open information exchange, equal partnership	Bidirectional open information exchange, equal partnership	Bidirectional open information exchange, equal partnership
Education program	Family education and parent training are recommended	Family education, parent training	Interview with parents, group sessions, training program for therapists	Supporting parents to structure opportunities	Interview with parents, training program for therapists

of a spoon in feeding. Environmental influences are physical, social, and attitudinal factors that show facilitation or prevention to achieve an identified goal. Dynamic systems theory also asserts that no subsystem is more important than another and any factor within the subsystems may be a constraint and may prevent achieving a motor goal (24,25). All aspects of child, task, and environment need to be taken into account to help a child for learning a new motor ability. Dynamic system theory also suggests nonlinearity that means a change in one subsystem may change the shape of a motor behaviour, movement is goal oriented, and intervention will be most beneficial in transition periods during which there will be increased variability and new movements are most likely to emerge (23,26).

Ecological Theories

Ecological system theory has stated that the children's development is influenced by several environmental systems within which children live. Interactions between family, school, community, social and political systems, and the individual child will determine developmental outcome (27). According to ecological theory of Gibson, children's development in relation to the environment is through the children's perceptual motor exploration of their surroundings (28). Within these frameworks physical therapy emphasizes the relationship between the individual, task, and environment for motor learning. Children discover solutions to problems for attaining desired objectives (29,30).

The important drawback of the dynamic system and ecological theories when they are applied to CP treatment is that they pay little attention to the substantial effect of the brain's condition on motor development of these children.

Neuronal Group Selection Theory

Neuronal group selection theory (NGST) offers a perfect balance between the aforementioned theories and promotes an effective intervention in children with motor dysfunction (31). Edelman's theory on how the nervous system becomes organized, stores information, and creates new behavioral patterns is identified as the NGST. A key concept of the theory is that the brain operates as a selective system. In addition, the brain is strongly affected by signals from the body and the environment either during fetal development or development after birth. As a result, no two brains are alike, and each person's brain is continually changing (32). Primary movement patterns are necessary to begin movement activity and self-organization process. They are important for the survival of the species and are constrained by genes, epigenetic events of cell division, motion or death. Neurons compete to make synapses. Synaptic connections are weakened or strengthened by experience and repetition. Secondary movement repertoire is selected through experience, repetition and exploration. If the child has the necessary primary repertoire, by experience the synapsis increase and gain strength. Successful adaptive movement patterns are learned through experience and repetition. For example, motor experience such as hand-to-mouth behavior induces a set of neural signaling pathways that activates gene expression within the motor cortex, which precedes synapse formation which in turn precedes motor map reorganization leading to learned sucking behavior (33). Evidence in neuroscience indicates that brain is a highly dynamic organ capable of structural and functional organization and reorganization in response to a variety of internal and external pressures. This neural plasticity is the mechanism by which the brain encodes experience and learns new behaviors (34). Interventions using the principles of NGST aim to reduce sensoriomotor dyscoordination which is a major problem in children with CP. Other motor disorders are additionally treated with different forms of treatment. The treatment should consider the child's environmental conditions including the family (31).

Family-Centered Care

Family-centered care also forms a theoretical framework for the approach to the children with CP. It is a philosophy and an approach of service delivery for children and parents which intends to establish a partnership between the family and the health care providers (35). The notion of family-centered practice derived from Carl Roger's client-centered therapy practice in psychiatry in 1940s. In the mid-1960s, the Association for the Care of Children in Hospitals adopted the Roger's ideas and took client-centered principle to a more holistic approach, especially for psychosocial issues and family involvement. In 1993, the Institute for Family Centered Care was formed to support the practice of family-centered care. Because of the increasing awareness of the providing the physo-social and developmental needs of children and the importance of families in maintaining well-being of their children, the ideas of family-centered care was generally applied in child health. More recently family-centered service has been implemented to the field of pediatric rehabilitation (36).

The definition and principles of family-centered care may change according to the diversity of perception of family and family functioning. Many descriptions of family-centered approach have been developed by authors, researchers or service organizations interested in the field of health care, early intervention and family support. A clear definition guides health care professionals how to approach the delivery of services, behave with families and understand the specific behaviours involved in a family-centered approach.

Institute for Patient and Family-Centered Care defined family-centered care as an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships between health care providers, patients, and families. The vital role of families is recognized in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. Emotional, social, and developmental supports are integral components of health care (37). The CanChild Centre for Childhood Disability Research described the main characteristics of family-centered service as follows: 1) parents know their children best and are experts on their child's needs 2) families are unique and different 3) optimal child functioning occurs within a supportive family and community context 4) each family have the opportunity to decide the level of involvement in decision making of their children and have ultimate responsibility for the care 5) the needs of all family members should be considered (35). Family-centered care, family-centered service or family-centered practice are statements used to refer to an approach of working in collaboration with

families that respects their values and includes provision of support to strengthen family functioning (38). Involvement of parents and other family members in the planning and the evaluation of the intervention is a key factor (39).

Studies investigating the efficacy of family-centered approach in children with neurodevelopmental disabilities and special health care needs reported positive results both for children and parents. Parents of children with neurodevelopmental disabilities, who received more family-centered approach, reported less depression and distress. Services were most beneficial when they were in a family-centered way and address parent-identified issues such as availability of social support, family functioning, and child behaviour problems (40). Parents' sense of control over life events was associated with professionals empowering behaviours and sense of caregiving competency was related to conformity with service providers (41,42). An individualized family-focused model based on collaboration of parents and professionals and parent education resulted in high levels of parenteral satisfaction and accelerated developmental progress in children with moderate or severe disabilities (43). A developmental education program consisted of providing general and specific information, building on parents' skills, and individualizing services for parents of the developmentally delayed infants resulted in developmental gains for infants. Their parents gained also developmental knowledge and participated more in the home treatment program even at a 1 year follow-up (44).

Family-centered service is associated with parent's satisfaction with services. Respectful and supportive care was found to be related to higher parent satisfaction with children's rehabilitation services (45). Receiving comprehensive information about the child's disability, understanding of parental concerns, and a good communication between parents and service providers have been found to have significant effects on satisfaction in parents of children with developmental disability (46). A sense of partnership between family of children with special health care needs and health provider was associated with less missed school days, greater satisfaction, access to specialty care, and fewer unmet needs for child and the family in a cross-sectional study measuring the family-centered care (47).

Therapy Approaches Using the Principles of Family-Centered Care

Current treatment of children with CP includes a variety of interventions such as physical therapy, pharmacological, biomechanical, and surgical approaches. Physical therapy is the most common intervention. There are 2 main principles of therapeutic approaches based on their emphasis; normalizing the quality of movement and considering the functional activities (48). Vojta and NDT methods are traditional therapy approaches which focus on the first principle. In Vojta method, therapist is the expert who plan and perform the therapy. Parents are laymen and learn from the therapist in a one-way direction. The therapy is child-focused (49). NDT is the most commonly used intervention method for children with CP for many years. In NDT, the therapist is the key person in planning and guiding the treatment, also a teacher for the parents and the family. During the evolution of NDT over years, the role of family became more important. Considering the family needs, supporting and educating the parents, involving them in the treatment program were recommended. However, the therapy remained child-focused (50,51).

The acceptance of family-centered philosophy in pediatric rehabilitation has influenced the management of children with CP. Family-centered practice has been found to be an attractive approach for pediatric occupational therapy (39). Home programs have been designed for implementation of family-centered care in the context of daily life by families (52). Family-centered home programs differ from traditional therapies; therapists do not direct programs instead, they are expert partners of parents working together to support child's development and health through enhancing caregiving competency (53). A model of home program was evaluated in a pilot study (54) including 20 children with spastic hemiplegic CP and in a randomized controlled trial (55) including 86 children. 5 phases of model program was described as follows: establishing a collaborative relationship between the parents and therapist, collaborative goal setting, constructing the home program by selecting therapeutic activities that focus on achieving family goals, supporting the program implementation through parent education, home visiting, progress updates and evaluating the outcomes (52). Home program had positive impact in the pilot study. Eight week occupational therapy home program demonstrated significant differences in function and parent satisfaction with function compared with no program.

During the past few decades, new therapy approaches have been developed also using the principles of the philosophy of family-centered care and the theoretical frameworks of the recent theories on motor development like dynamic system (21,24) or ecological theories (27,28). These approaches assessment and intervention strategies focus on functionality and consider the role of environment and the task in performance of functional activities rather than the impairments of the child. Functional therapy, goal-directed functional therapy, activity-focused therapy, and context therapy are some of the recent approaches sharing similar aspects such as functional task-oriented physiotherapy and involvement of goal setting procedures with the families and parenting programs.

Functional physical therapy emphasizes the learning of motor abilities which are meaningful in the child's environment and achieving functional goals that are established with parents and children according to their priorities. Children have active roles to find solutions for motor problems and practice these problematic motor abilities in functional situations. Parents actively involve in all stages of the program such as goal setting, decision making, and implementation in daily life. Ketelaar and colleagues (56) compared the effects of functional physical therapy and a physical therapy program based on the principle of normalization of quality of movements (NDT or the Vojta method) in 55 children with spastic CP aged between 2 and 7 years. In the functional physical therapy group, the children focused on learning and practicing of motor abilities to perform a task within the natural environment based on identified goals by the child and the parents. After 18 months there were no differences between the groups in basic gross motor abilities measured in a standardized environment, however, the children in functional physical therapy group had improvements in functional skills in daily situations compared to the other

children. Functional training demonstrated benefits also in a pilot study (57) with 14 children with CP. A five-month goal-directed functional therapy was implemented in children's normal settings at home and preschool. Training was performed several times to achieve a goal, for example to stand up from the toilet and walk to the bathroom. Strengthening was an integrated part of the training if needed to carry out a goal. A group session was performed for all children to attend training together with their parents and/or preschool assistants. Over a 5-month period, 77% of targeted goals were fully attained. The therapy influenced significantly children's gross motor capacity and performance in self-care, mobility and social function. Parents' perception of service delivery improved and preschool assistants felt more competent in their care of children.

Activity-focused therapy includes structured practice and repetition of functional actions that are directed toward the learning of motor tasks to increase independence and participation of the child in daily routines. As a member of the intervention team, the therapist develops an activity-related goal in collaboration with the child's family (58). A restricted timed before-after study exploring the effects of an intensive, goal-directed and, activity-focused physiotherapy program reported significant improvements in basic motor abilities, self-care in home environments and reduced need for caregivers' assistance in self-care and mobility (59). Goal-directed functional therapy and activity-focused therapy were compared in preschool children with CP in a prospective study (60). Children receiving goal-directed functional therapy showed more gains in everyday activities and gross motor function than those receiving activity-focused therapy where the aims were more general.

Family-centered functional therapy (FCFT) was developed by the CanChild multidisciplinary research team from McMaster University. Family-centered philosophy concepts and dynamic systems theory approach are integrated for the management of children with CP. Focusing treatment directed at functional goals identified by the parents and the child, defining periods of change, identifying and changing the primary constraints in the task, the child or the environment that are preventing the child to achieve functional goals, and providing opportunities for practice in functional contexts are the main principles. Compensatory movement strategies are considered as well as encouraging the children and the families to participate in play and sports activities that will help to maintain flexibility, strength, and coordination (61). In a feasibility study (62) evaluating FCFT, young children with CP demonstrated improvements in individualized motor goals after 3 months. The therapy included both the hands-on intervention and adaptation of the constraint. Using modified FCFT, focused only changing the task and the environment, the alteration in functional performance of three preschool aged children with CP was evaluated in another pilot study (63). Outcome measurements showed an improved performance for at least one of the two tasks for which intervention was obtained. The parents also reported a significant improvement in satisfaction with their children's performance in the tasks addressed.

Context-focused approach evolved from the FCFT. Context therapy shares similar principles with other therapy approaches like functional, task-oriented or activity-focused interventions such as family involvement in assessment and intervention protocols, identification of functionally relevant goals. An important variation of context therapy is; it focuses on changing factors in the task and environment to support child's success at goal and does not try to change the impairments of the child. This approach assumes that changes in the task and environment will facilitate the child to success an activity that can not be performed before (64). In a randomized controlled trial (65), the efficacy of context-focused intervention was compared with a child-focused intervention which included a therapy to remediate the impairments and practice specific movements and tasks. Context-focused intervention included a three-step process: goal identification, assessment and intervention. The family and the therapist set the goals in collaboration, based on the identified problems in order of their importance. In the assessment process, therapists videotaped the child's performance on each identified goal. Facilitating and preventing factors in child's performance within the task and the environment were identified together with the therapists and parents. Factors that could be adopted or changed to help child achieving the goal were determined. Treatment focused on changing the constraints within the task and/or environment. Intervention included practice of tasks in natural environment like home or preschool if feasible. The therapists were encouraged to find solutions to success the goal or the task as quickly as possible even though using the movement patterns such as W-sitting or bunny-hopping which were traditionally thought to be abnormal. After a six-month period and 18 to 24 therapy session both approaches were found to be equally effective and showed benefits in functional skills, caregiver assistance, gross motor function, play intensity, physical activity intensity and diversity.

Conclusion

The emergence of family-centered philosophy in pediatric rehabilitation has influenced the management of children with CP. Family concerns and needs are more considered. Parents are supported and empowered to make decisions and to direct the care for children. The members of the family became equal members to decide about themselves and the intervention strategy. Trends towards interventions for children with CP have changed from child-focused to function- and family-focused. The parenteral involvement and collaboration with the family became an important concept of the intervention. Within this framework, after the family has been empowered with all the necessary information and psycho-social support, goals of the treatment are identified collaboratively with input from the family as well as the child and the rehabilitation team. This transformation in approach brings the identification of the functional goals at the level of activity and participation rather than at the level of impairment.

Studies have shown that children with neurodevelopmental disabilities including CP and their families benefit from family-centered, collaborative care based on shared decision making. On the other hand, most of the studies in the literature on CP and neurodevelopmental disabilities were held in highly developed countries that have widespread and coordinated

services for these children. It is well documented that CP occurs mostly in children who have families with low socioeconomic level. Service delivery systems are quite different in every country, especially in less-developed countries; there are many challenges waiting for the families of children with CP. There is diversity also in perception and functioning of families due to the cultural and political environment. Family-centered care intervention should be tailored according to the countries' unique situation.

Conflict of Interest:

Authors reported no conflicts of interest.

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