

Psychological factors in children with cerebral palsy and their families

Svetlana Logar

University Rehabilitation Institute, Ljubljana, Slovenia

Abstract. The aim of this article is to recognise psychological problems in children with cerebral palsy and their families as well as the necessities to provide psychological help without disturbing them. It addresses all areas of functioning of such children and their families, coping mechanisms and the process of adjustment. It highlights the importance of acknowledging disability as a manifestation of a person's ongoing adaptation to respective special needs, i.e. diverse consequences of disability that are affecting every individual child regarding education, self-dependent life, establishing social roles and adaptation to the characteristics of the environment in which affected people are living.

Key words: Child, cerebral palsy, family, coping, adjustment

1. Introduction

Cerebral palsy (CP) is the third most common type of disorders (1) from which disabled children suffers. It can serve as a prototype of childhood disability. In early childhood, CP is manifested as a set of functional limitations that stem from disorders of the developing central nervous system which are interfering with normal developmental progress. Although the impaired motor function is a hallmark of the CP, many children also experience health, sensory and perceptual difficulties, and may have complex limitations in self-care functions such as feeding, dressing, bathing, and mobility (2). They have risks for seizures, difficulties in cognitive functions and primary or secondary difficulties in the areas of behaviour, learning and emotion (3). As a consequence, we must not forget language difficulties and communication problems. The fact that a child with CP may be seriously limited his/her experiences and thus his/her opportunities for learning (1). In addition, children are facing ongoing challenges in establishing their social roles and self-dependent life. For many parents

the child rearing demands can be overwhelming, especially because they are aware that their children may lag behind their peers in motor, emotional, social and cognitive development.

2. Adjustment in children with CP

For psychologists working in a rehabilitation team, it is important to focus on the process of adaptation in children with CP. It is important that they address the child's strengths, as well as disorder specific issues and are aware about the changes which can occur as a child progresses through developmental stages. Affected children pass through the same development stages as typically developing children and must simultaneously solve typical developmental tasks as well as challenges presented by the condition. The developmental crisis may be more intense and chronologically delayed. Chronic disability may interfere with normal developmental tasks and skill acquisitions in early childhood because of reduced physical activity. School entry is often a crisis point because it may highlight differences with peers. Adolescence is the next difficult period challenging their ability to resolve issues of independence from parents, form strong connections with the peer group, deal with the changing body, as well as master romantic and sexual issues. Most adaptation issues are not disease specific but rather involve individual and ecological factors. Adaptation to disability is influenced by the degree of disability, interpretation of disability depending on the age

*Correspondence: Svetlana Logar
University Rehabilitation Institute of the Republic of Slovenia,
Linhartova 511000, Ljubljana, Slovenia.
E-mail: svetlana.logar@ir-rs.si

of a child, visibility of the condition, gender, the level of cognitive, perceptual and communicative functioning of the child, the external trauma (pain, restricted motion, surgery), child's emotional status, self-image, family and social support, attitudes toward the child, as well as the ability to form positive relationship with peers (3).

A brain injury is like a fingerprint. The way which it is expressed is unique to the child and consequently many of its effects upon that child are unique. Estimates of intellectual functioning and the prevalence of intellectual disability in individuals with CP vary widely, but researchers estimate that about a half of children with CP also have intellectual disabilities. On the other hand, the range of intellect includes not only normal but also superior functioning. The issue is both sensitive and important because an individual with CP may be unjustifiably stereotyped as retarded based on unusual appearance, gait or speech (3). The effects of brain injury can be assessed through different cognitive functions. The specific cognitive functions that are influencing learning processes are perceptual abilities (visual-perceptual, auditory-perceptual and perceptual-motor skills influencing perceptual organisation and processing of visual and hearing information as well as visual-spatial processing), numerical reasoning, concrete and abstract thinking, deficits in attention (focused, sustained, selected, divided) as well as associated executive functions deficits and memory deficits, information processing rate and problems in the field of communication (language, understanding speech, reading and understanding, writing). It takes longer to learn new material for children with learning disabilities and, once they have learned something new, they usually forget it more easily. We can observe fluctuations in their performance. For a child with physical disability, learning tasks can take more effort, concentration and energy. Consequently they need more help in the acquisition of skills. The help has to be more systematic, structured and provided by parents, teachers and others.

3. The importance of assessment

An appropriate, comprehensive, and accurate assessment of a child with a disability clearly presents a significant challenge. Assessments involving more than one discipline are recommended. Options include multi-disciplinary, inter-disciplinary, and trans-disciplinary assessments. With a transdisciplinary team, representatives of all disciplines that are

necessary for a child should be present, and the child is observed and discussed by all of them at the same time in order to provide child evaluation totally. Psychological assessment of individual children serves the following purposes: to determine progress on significant developmental achievements; to diagnose cognitive deficits; to determine factors that are facilitating and interfering with the child's learning, to contribute to the decision-making that accompanies the provision of special education and related services, advising teachers, special education teachers and other school staff; to serve as a basis for reporting to parents; and to assist a child with assessing his or her own progress. Based on the assessment of the rehabilitation team and the school team from Hospital School, and after discussion of our findings with parents, it is possible to elaborate accommodations that will enable the child with CP to be included successfully in an educational programme in spite of its specific learning difficulties associated with its perceptual, motor and other abilities.

4. Handicap accommodating assessment

The assessment must thoroughly investigate all areas related to a child's suspected disability by using a variety of valid assessment instruments and observational data. All testing must be done individually. Children with CP present more issues for the assessor than children with other forms of motor impairment. Poor coordination and abnormal muscle tone or complete loss of motor function in the upper extremities impact fine motor control, dexterity and responding to times tests in a meaningful way as well as interfere with their ability to manually manipulate with materials (picking up objects; pointing; holding a pencil; writing, copying, or drawing). Prior to the assessment, the evaluator must ascertain how the child's mobility, manipulative skills, oral-motor functioning, and trunk and head control are affected as well as plan the assessment to compensate for or adapt to these needs (3). The ability to identify the child's cognitive abilities and also behaviour, emotional and social skills despite substantial physical impairment is one of the most challenging and important functions of the psychologist.

5. Test selection and adaptation

When an individual presents physical or sensory disability that impacts test-taking it is necessary for the clinician to ensure fairness and accuracy in test administration and interpretation. Clinical psychologists and neuropsychologists are

confronted with challenges in selecting tests, modifying test administration to accommodate disability, and interpreting results from non-standard test administration. Physical disabilities can impact the extent to which an individual can perform standardized (neuro) psychological tests and batteries. If the purpose of testing is to determine extent to which the physical disability impacts performance of tasks, or when the physical disability is being evaluated, test modification is not appropriate. However, when the physical disability is not the focus of the evaluation, but the standard test administration requires motor skills that are impacted by the physical disability, then alternate means of assessing cognitive functions are necessary (4).

Clinical judgement and experience have led to several common practices for test accommodation and modification in test administration. Adjustment of time limits and avoidance of test speeds, administration of portion of test that does not require skills, is affected by disability, oral administration and responding rather than self-administration, substitution with tests that do not require motor response, use of adaptive equipment to facilitate motor responding when there is residual motor function (e.g. pen and pencil grips, paper holders), use of adaptive equipment to compensate for absent motor response (switches, computers) or communication problems (augmentative communication). Awareness of associated problems such as pain, fatigue and endurance issues, in standardized test conditions presents the necessity to schedule the assessment during optimal time of day with regard to physical discomfort and to plan shorter sessions spaced over several days. Test accommodations are test setting and environment, which may require modification for accessibility and physical comfort. Appropriate positioning can permit better fine motor function, facilitating attention, reducing fatigue, promotion of improved social interaction, and helping structuring the child, thereby optimizing performance. Because of the elevated incidence of attention and concentration problems in children with CP, a testing environment with minimal auditory and visual distractions is especially important.

Clinical interpretation of test results should reflect the psychologist's and neuropsychologist's comprehensive analysis of the extent of disability/level of functioning, comorbid conditions, and how these factors , impact neuropsychological performance independently and in combination. It is important to interpret findings in the context of the test administration

procedures or response formats used. Interpretation should also incorporate any physical discomfort or distress at the time of testing.

6. Entering school

The transition to kindergarten and school is a critical point of time in the life of young children and their families. Resources that may impact the transition include early intervention for the child prior to school entry as well as direct supports for the child, parents and educational teams in schools (5) which are provided by rehabilitation team and educational team. In our rehabilitation setting rehabilitation team is closely collaborating with the Hospital School teacher and the special educational teacher.

Children with physical disabilities are known to be at increased risk for psychosocial and academic problems. Throughout Europe, educational support for children with disabilities has moved towards a model of inclusive education which ensures a child's full participation not only in the classroom but also in all aspects of school life, including excursions and sporting and cultural activities.

The main difficulties for the children were implications of school absence, exclusion from school life, teachers' reactions due to illness or disability, and peer relationships. Parents are frustrated since few teachers appear to be well equipped to deal with the full range of complex needs in their classrooms and they also lack an understanding for constant using appropriate accommodations and adaptations for children with physical disabilities. Rehabilitation professionals can play an important role in supporting children both directly and indirectly, through helping others in school understanding the condition and its impact on school life.

7. Psychological problems

It may be important that chronic psychological problems will have a greater impact than the physical impairments for many children with CP and their families.

Children with CP have higher risk of psychological problems than their non-disabled peers and this may be attributable to problems in adjustment to their adverse circumstances (functional abilities, experience of pain) as well psychosocial factors related to have a brain-based disability. The origins of psychological problems in this group are complex and it is not possible to ignore these factors that also influence adjustment in all children.

7. 1. Behaviour problems

The general pattern of research findings is that many of children with CP have a behavior problem and that parents perceive some behaviour problems which are associated with CP. However, findings also do not develop such problems (6). Although children with CP are at greater risk for developing behaviour problems, they are considerably less likely to develop problems assessed by the antisocial and peer conflict scales (7). Conduct disorder was being more prevalent in mildly affected children, mostly in boys.

7. 2. Social challenges

Parkes et al. (7) described the prevalence, type and severity of behavioral and emotional symptoms in 8–12-year-old children with CP identified from population-based registers of CP in eight European regions. About a quarter of the children had significant psychological symptoms, most commonly associated with peer problems. The same findings were also reported in a study (8) with a representative sample of children with hemiplegia from Western Europe. They are challenged by negative social experiences like feeling excluded and being bullied (7). It is possible that differences in functional ability are more stressful for children with milder forms of CP if they are more similar to their able-bodied peers than the children with severe CP when they have greater of these differences. However, a high proportion of children had normal scores in the prosocial domain indicating a capacity for kindness and consideration to other children. Social competence and adjustment in children with developmental disabilities and chronic health conditions affecting the central nervous system are rated as less socially accepted and less socially competent than their peers (9). Recent models of social competence acknowledge that there are a variety of risk and resilience factors that can hamper or promote social development. Some of those factors are intrinsic to the child (e.g. intellectual functioning which increases the likelihood of deficits in social information processing, atypical social interaction and poor social adjustment), whereas others involve environmental influences (e.g. socio-economic status, parenting behaviours, and parent-child relationships). Parenting beliefs and behaviours as well as the quality of the parent-child relationship and even broader socio-cultural influences, such as the stigmatization (resulting from perceived disability) can influence children's social interactions and psychosocial adjustment.

7. 3. Emotional problems

It appears that emotional adjustment is associated with the severity of the condition and the degree of functional limitations experienced by the child. More than a quarter of children with CP experienced abnormal scores on the emotion domain.

7. 4. Low self-esteem

Motor impairments are often assumed to have a negative impact on the way of children feelings about themselves. Children with CP did not have a lower global self-worth compared to children with typical development, even though they felt less competent in their athletic skills, schoolwork, and peer relationships (10). Lower scholastic competence is important because it addresses their learning abilities which are compromised by certain aspects of cognition, communication and perception difficulties. Lowered score in Social Acceptance domain is important for a clinician to be aware that children with CP may not be accepted in their environment and may need assistance in developing interpersonal skills that will enhance their confidence in social settings, and place the need for individual assessment. Children with greater intellectual impairment or pain have a higher risk for experiencing psychological problems; those with greater functional impairment have a lower risk. Intellectual impairment was associated with hyperactivity and peer problems in a group of children with hemiplegia. Communication problems are associated with more psychological (behavioral) problems. Around 40% of parents of children with CP perceive their child to have definite or severe difficulties in relation to emotion, behaviour, concentration and getting on with others.

8. Interventions

It is important that psychological aspects of the condition are not overlooked (11). Professionals and parents need to be aware that many of psychological problems require psychological support and interventions. Examining the importance of each domain of child functioning can help us to find important issues in setting goals of therapy and use management strategies which are important for a child and its family. The resilience therapy provides four key principles, i.e. the ways in which we can address the needs of children with disability, their families, educational staff and other important people in broader community working with them: by developing the skills of accepting the precise

starting point for the child, by conserving any good that has happened until now, with commitment to work with them and by enlisting appropriate others to help (12). A range of interventions are designed to increase resilient responses for difficult situations. They constitute five separate, but related arenas. Basics encompass fundamental needs i.e. good-enough housing, financial resources, access to services, play and leisure opportunities, prejudice and discrimination, inequality. Belonging addresses interventions that help a child make good relationships with family, friends and others. Learning arena is compound with interventions that stimulate successful inclusion in educational process to enhance development of a sense of achievement, competence, success, providing for socialization and give a child the opportunity to develop normative peer-to-peer and peer-to-adult experiences and teach and nurture life skills important for self-development throughout individual's life. Coping provides strategies for children to manage better in the moment rather than waiting for some deeper personal transformation to occur i.e. understand boundaries, solve problems, foster their interests, calm down, lean on other. Core-self therapeutic approaches focuses on working at a deep intrapersonal level (building a sense of hope, teaching to understand others people feelings, helping the child to know her/himslef and take responsibility for her/himslef, fostering their talents).

9. Adjustment of a family

Psychologists have to focus on differentiating families along such dimensions as adjustment to a child with special needs, coping with stress and perceiving control in their lives (13). In a therapeutic process we are interested in family culture (psychological characteristics, such as attitudes, values, beliefs, personal traits and adaptation styles of family members and the family as a unit), family interactions (relationship among family members, parents, mother-child, father-child, sibling relationship) and the environment where they live. Adjusting to have a child with a disability is a life-long process. Parent adjustment may also reflect the experiences and responses to ongoing loss. There has been much research into how parents and particularly mothers, adjust to the diagnosis of a chronic illness in their child. The approach adopted in most studies is that parents' reaction to the child's diagnosis is akin to those following bereavement. Parents are producing grief reactions, followed by the stages of shock and

disbelief, denial adaptation and adjustment. Parents have reported that when their child was diagnosed with a chronic condition they experienced multiple losses - including the loss of a healthy child as they knew him or her, freedom, spontaneity and confidence in provision of care - as well as the disruption to the family's daily life (14) and the perceived loss of the happier, easier, or more "normal" course of their own lives may have taken and are experienced with higher levels of intrusive thoughts and emotional strain caused by their child's illness (15). Professionals tend to underestimate stressful experiences later while overestimating the initial stress at the time of diagnosis. It has been suggested that more appropriate model recognises the parents suffering from »chronic sorrow«. The accumulated findings from the literature demonstrate that parents of children with intellectual and/or developmental disabilities as well as parents of children in specific illness contexts suffering from long-term periodic sadness. Parents describe prolonged feelings of grief, disappointment and fear in response to continual losses experienced over the trajectory of an illness or disability. Grief is related to either internal or external triggers and reoccurs at times in the child development which remind parents their differences from others - for example, necessity of going special school, living school, overtaking the disabled child developmentally by a younger sibling. It happens when the handicap and its implications for all are thrown most clearly into relief and result in the reawakening of old feelings of loss (16). This sorrow reaction is considered as a normal reaction to a complicated, though difficult situation, and this is distinguished from clinical depression or pathological grief (15). Parents have also described eventually moving on and »doing what you have to do«. Chronic sorrow and increased emotional strength are by no means incompatible. Most of parents, at the same time, also develop increased strength and coping abilities (17).

9. 1. The role of significant others

The variability in the ways of families function may reflect the influence of significant others in formal (private and public agencies, other organisations, the church) and informal (friends, relatives, neighbours) systems which may have significant impact on the family. Family resources such as supportiveness between marital partners and regular contacts with extended family have been found to reduce the risk of stress (17). Open, honest communication, lack of conflict, family cohesion, emotional

expressiveness and family stability help parents to cope (16).

9. 2. Siblings

How siblings adjust to a child with disabilities may influence overall family functioning or that of individual members within the family. Research results show the importance of siblings' relationship especially with parents (18), the closest inside a family, the most fundamental and usually the longest family tie. The nature and quality of the relationship can determine the possibility of emotional support throughout a lifetime and could have positive but also negative impacts on personal and psychological state of siblings. Through their relationships with the special needs of child, the brother or sister can develop patience, understanding, sensitivity and awareness of the special needs of all of the other people within the family. They show gentle and deep feelings for the sibling and develop advocacy skills. They also tend to gravitate toward careers in the helping professions. Unfavourable characteristics of relationships with a special needs of brother or sister on siblings including premature maturity with exposure to excessive demands and expectations, burden of care for the brother or sister, active involvement in domestic chores, early parental expectations of success and independence, need to satisfy parental expectations while the parents are focused on the special needs of child, feelings of guilty, known as the phenomenon of surviving, because they can participate in activities in which the brother or sister is unable to participate in, anger due to excessive parental expectations and demands, shame due to the special needs of brother's or sister's deviations in behaviour. They are over-exposed to pressure and stress and concerned for their own future (leaving their family and create their own family) (19). The relationships of children with special needs are significantly affected by the views, reactions and adaptation skills of the family members. Due to these issues, it is important for psychologist to address the needs of siblings in the family context and provide helping when needed.

Families with children with complex needs go through a progression of stages in adjusting to the child's disability or chronic illness. The timing of this adjustment occurs in the context of horizontal (i.e. predictable events or life cycle transitions, such as the child beginning school and unpredictable events such as diagnosis of a chronic condition) and vertical stressors (i.e. family patterns, myths, secrets and legacies). All of these events occur within the context of

nuclear and extended family, as well as the social, economic and political climate. The adaptation to the initial diagnosis or other changes in the child's functioning will be affected by the interaction between the developmental stage of the family and horizontal and vertical stressors (20).

Factors associated with variation in adjustment have been conceptualized to exist within a risk-resilience framework. Risk factors include parameters of the child's physical disease or disability, the strain of caring for such a child in activities of daily living, and psychosocial stress. The impact of these risk factors is hypothesized to be moderated by socioecological factors (family environment, social support, resources), intrapersonal factors (which reflect an individual's personal beliefs, attitudes and style of behaviour, role restriction), and coping (stress processing abilities, cognitive appraisal and coping strategies). These constitute, a set of resilience factors, proposed to be related to adaptation in both direct and indirect ways (21).

9. 3. The influence of rehabilitation professionals on the process of family adjustment

It is the natural role of every family to stimulate the development of their child; they teach the child to explore objects, eat independently, talk, walk and socially interact. For parents of children who are born prematurely or are experienced with complications after their child is born or finding out that their child is not developing as expected, the days afterwards can become a time of uncertainty. Parents' natural competence for nurturing and taking care of a healthy child is replaced with seemingly endless, medical and other interventions. Once the child has been established with the diagnosis of brain injury, the mediation of the subsequent development is, in large measure, transferred to health care professionals, also in rehabilitation settings. The parents are learning new skills how to handle the baby, feed and communicate. While having to cope with their own reactions and emotions, those of their partners, extended family members, friends and community, as well with the demands of establishing a relationship with members of an often large multidisciplinary rehabilitation team, parents have to attend to the baby to establish a secure attachment and upbringing so that there is optimal development of the baby's intellect, emotions and behaviour (22). The most important part of early psychological interventions in rehabilitation setting is exploration of the parents' reactions to diagnosis and treatment, reduction of parental

distress, anxiety and feelings of helplessness, and providing help to find solutions appropriate to them and regain confidence in their parenting abilities. Parents must regain feelings of control and be psychologically ready to make use of support by rehabilitation team and other professionals in their community health services.

With Parents' adjustment and the behavior, they show that the child may be influenced by adequate support from primary health care and rehabilitation professionals. There is a need to increase both awareness and accuracy in identifying psychological issues and addressing them in an appropriate way. A psychologist is sensitive and non-judgemental about episodes of reoccurring sadness. Families help to recognize that the experience of loss is a normal reaction to the diagnosis of a chronic condition and that feeling sad and/or depressed is a common emotional response. They provide support so that they can feel comfortable in expressing these emotions. Psychological help does not shorten the process of adjustment but importantly it moderates emotional oscillations of the family members. Considering the issues of adjustment process issues allows the psychologist to aid the rehabilitation team with better understanding in spite of good intentions, the family has not been able to follow through on treatment recommendations or present barriers to treatment success.

The relation between parent satisfaction with rehabilitation services and subsequent psychological adjustment is an important area (16). The psychologist is addressing to extent which parents receive, understand and recall medical and treatment related information whether they had opportunities to express expectations and concerns or not, and provides emotional support around particularly stress points and chance to talk about their experience with rehabilitation staff. In planning interventions for families, it is particularly important that the rehabilitation team recognises that the roles and values of families as consumers may differ from theirs as providers. Intervention success can be maximized by developing plans that are compatible with the family's goals and realistic for them to implement (20).

The complex responsibilities and activities required for parents on an ongoing basis can result in caregiver burden, social isolation, alteration in employment, uncertainty, as well as personal physical and emotional health problems (2). Parents take on responsibility not only for the care related to their child's disability but also for the quality of their child's life, for creating

friendships and building acceptance in the community. It is important in rehabilitation process to help parents recognize the risk of burnout that can accompany ongoing caregiving and to direct their attention to their personal needs in order to maintain the day-to-day management of the responsibilities, to find ways to positively appraise their role as a caregiver, and identify social supports and resources.

10. Building resilience

Definitions of the concept of resilience usually include the ability to withstand and rebound from crisis and distress. A systemic view of resilience seeks to identify elements that enable families to cope more effectively and emerge harder from crises or persistent stresses. Clinician interventions and research with the families of children with special needs have consistently focused on the problems, stresses and inadequacies of these families. But, from our experiences in rehabilitation setting, we are finding that families may have more successes than failures in dealing with their children. By looking for problems, we may direct attention away from potential positive outcome (17). Parents point many of the positive gains of caring for a child with special needs. They believe that they have been given greater insights, learned acceptance, become more sensitive to others' differences, learned new skills, and gained a sense of fulfilment and becoming stronger and more resilient to life's difficulties (23). The majority expressed the need for a strong belief in the child and in the child's future, an optimistic outlook, and a realistic view and acceptance of the disability (24).

Coping has been defined as »the effort to master, reduces, or tolerates the demands arising from stressful transaction«. It is preceded by appraisal of the situations (1). Rehabilitation of itself can be viewed as a form of coping in response to a child's disability and the difficulties which arise from this and affect family. For CP as a chronic condition, it is important to acknowledge the characteristic that the course of condition is largely unpredictable and that there is no end for stress. It is very important for the rehabilitation team to provide families with enough reinforcement for exhibiting coping behaviours. Coping provides different strategies to manage better in the moment rather than waiting for some deeper personal transformations to occur (12). Family coping is defined as »a specific effort (covert or overt) by which individual members in the family or the family function as a whole« to decrease or handle a

demand on the family and to acquire resources to manage the situation associated with the demand (25).

Considerable theory and clinical experience suggest that a person's sense of hope (determination to meet goals as well as successful planning of ways to meet them) plays an important role in coping with challenges of living with a child with complex needs (Horton and Wallander, 2001). Attempts to increase personal hope would involve cognitive approaches to bolster the motivation that positive outcomes are possible and the perception that there are ways to achieve this.

11. Social support

It is well established that people who perceive themselves to be supported by others exhibit more positive physical health, mental health and longevity than those who perceive themselves as not having support from others. Being embedded in a social network and having social resources that are responsive to stressful events, have beneficial effects on adjustment in parents of children with disabilities (21). Parents do not tend to blame their physical and emotional stress and fatigue on their children, but rather on not having enough support; the amount of help is available from relatives and friends, social welfare, medical, rehabilitation and educational services (23). Supporting group for parent (led by psychologist and social worker) provides parents in inpatient programme with an opportunity to discuss emotional issues and to learn how to obtain adequate services and to receive information on how children's complex needs affect the child's and families functioning. The group enhances parents' coping skills and helps reducing stress in rehabilitation setting.

12. Conclusion

It is important to acknowledge that psychological assessment and treatment address the needs of children and families, their abilities to participate in the rehabilitation process and their abilities to cope with stress depending on the process of their adjustment to a disability. When providing psychological care, it should not be assumed that a child with disabilities will be a marker for psychopathology. Families with children with special needs may function in unique ways without being pathological (20). The goal of psychological care is to optimize child and family adaptation to physical and psychological problems of everyday living in the context of good psychological health and good

quality, to enhance the capacity of families as well as to build their confidence and resilience. Such care must be available throughout the whole rehabilitation process in the rehabilitation institution as well as in the broader environment.

References

1. Graham Ph, Turk J, Verhulst FC. *Child Psychiatry. A Developmental Approach* (3rd ed). New York: Oxford University Press 1999.
2. Raina P, O'Donnell M, Schweltnus H, et al. Caregiving process and caregiver burden: conceptual models to guide research and practice. *BMC Pediatr* 2004; 4: 1. <http://www.biomedcentral.com/1471-2431/4/1> 13.11.2009
3. Johnson MR, Wilhelm C, Eisert D, Halperin-Phillips DL. *Assessment of Children with Motor Impairments*. In: Simeonsson JR, Susan L, Rosenthal LS (eds). *Psychological and Developmental Assessment: Children with disabilities and chronic conditions*. New York: The Guilford Press 2001, pp 141-152.
4. Hill-Briggs F, Dial JG, Morere DA, Joyce A. Neuropsychological assessment of persons with physical disability, visual impairment or blindness, and hearing impairment or deafness. *Arch Clin Neuropsychol* 2007; 22: 389-404.
5. Clifford T. *Transition into School: Experiences of Children with Intellectual Disabilities and their Families: a thesis*. Ontario: Queen's University Kingston 2007.
6. McDermott S, Coker AL, Mani S, et al. A population-based analysis of behavior problems in children with cerebral palsy. *J Pediatr Psychol* 1996; 21: 447-463.
7. Parkes J, White-Koning M, Dickinson HO, et al. Psychological problems in children with cerebral palsy: a cross-sectional European study. *J Child Psychol Psychiatry* 2008; 49: 405-413.
8. Parkes J, White-Koning M, McCullough N, Colver A. Psychological problems in children with hemiplegia: a European multicentre survey. *Arch Dis Child* 2009; 94: 429-433.
9. Yeates KO, Bigler ED, Dennis M, et al. Social outcomes in childhood brain disorder: a heuristic integration of social neuroscience and developmental psychology. *Psychol Bull* 2007; 133: 535-556.
10. Shields N, Loy Y, Murdoch A, Taylor NF, Dodd KJ. Self-concept of children with cerebral palsy compared with that of children without impairment. *Dev Med Child Neurol* 2007; 49: 350-354.
11. Parkes J, McCusker C. Common psychological problems in cerebral palsy. *Paediatr Child Health* 2008; 18: 427-431.
12. Hart A, Blincow D, Thomas H. *Resilient Therapy: Working with Children and Families* (1st ed). London: Routledge 2007.
13. Rosenthal SL, Cohen SS, Simeonsson JR. *Assessment of Family Context*. In Simeonsson JR, Rosenthal SL (eds). *Psychological and Developmental Assessment: Children with disabilities and chronic conditions*. New York: The Guilford Press 2001, pp 141-152.
14. Sullivan-Bolyai S, Sadler L, Knafel KA, Gilliss CL. Great expectations: a position description for parents as caregivers: Part I. *Pediatr Nurs* 2003; 29: 457-461.
15. Bonner MJ, Hardy KK, Guill AB, McLaughlin C, Schweitzer H, Carter K. *Development and Validation*

- of the Parent Experience of Child Illness. *J Pediatr Psychol* 2006; 31: 310-321.
16. Bradford R. *Children, Families and Chronic Disease: Psychological Models and Methods of Care*. Taylor and Francis e- Libraries 2002.
 17. Wikler L, Wasow M, Hatfield E. Seeking Strengths in Families: Developmentally Disabled Children. *J Soc Work* 1983; 73-77.
 18. Rumsey N, Harcourt D. Visible difference amongst children and adolescents: issues and interventions. *Dev Neurorehabil* 2007; 10: 113-123.
 19. Wagner Jakab A, Cvitković D, Hojanić R. Neke značajke odnosa sestara/braće i osoba s posebnim potrebama. *Hrvat rev rehabilit istraž* 2006; 42: 77-86 (in Croatian).
 20. Rosenthal SL, Cohen SS, Simeonsson RJ. Assessment of Family Context. In: Simeonsson RJ, Rosenthal SL (eds.), *Psychological and Developmental Assessment: Children with disabilities and chronic conditions*. New York: The Guilford Press 2001, pp 205-224.
 21. Horton TV, Wallander JL. Hope and Social Support as Resilience Factors Against Psychological Distress of Mothers Who Care for Children With Chronic Physical Conditions. *Rehabil Psychol* 2001; 46: 382-399.
 22. Hearst D. Can't they like me as I am? Psychological interventions for children and young people with congenital visible disfigurement. *Dev Neurorehabil* 2007; 10: 105-112.
 23. *Beyond The Limits: Mothers Caring for Children with Disabilities*. Roeher Institute 2000.
 24. Heiman T. Parents of Children With Disabilities: Resilience, Coping, and Future Expectations. *J Dev Phys Disabil* 2002; 14.
 25. Brown O, Howcroft G, Theron T. Resilience in families living with a child diagnosed with hyperactivity/attention deficit disorder: poster. In: *International Conference on Coping and Resilience*, October, 3-6, 2009. Zagreb: Society for Psychological Assistance 2009; 103-104.