

Caregivers of Children with Cerebral Palsy and Resiliency Model of Family Adaptation

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Abstract

The resiliency model of family stress, adjustment and adaptation is a theoretical framework used in this article to understand how families adapt when their child has had a chronic illness. This article describes the resiliency model in relation to the findings of research on families where a child has an unremitting illness. Identifying the factors impacting on the caregivers and the adaptation process they experience provides valuable insight and information to the provision of family centered services.

Keywords: Resiliency model, caregivers, adjustment and adaptation

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INTRODUCTION

The birth of a child with cerebral palsy places the family in a dilemma. Society views parenthood positively, but it views the birth of a disabled child negatively. A child's disability attacks the fabric of marriage in different ways. It excites powerful emotions in both parents. It reshapes the organization of the family. It creates a fertile ground for conflict ^[1]. Statistics related to cerebral palsy, Sharan reported that in developed countries, prevalence of cerebral palsy is 2–2.5 cases per 1000 live births. In the developing world, the prevalence is 1.5–5.6 cases per 1000 live births. About 25 lakh children and people are there in India with CP. About 75% out of approximately 1000 cases of locomotor disabilities were found to be due to CP ^[2]. It is generally accepted that caring for a child who has a developmental disability can involve significant and prolonged periods of time and energy, completion of physically demanding and unpleasant tasks, and frequent disruption to family routines and

activities. Plant and Sanders conducted a study to examine the predictors, mediators and moderators of parent stress in families of preschool-aged children with developmental disability ^[3]. Participants consisted of families with a preschool-aged child (<6 years) with developmental disability from the geographical catchment area of South-east Queensland, Australia. The study results revealed significant inverse relationships between partner/family support and level of parent stress ($r=-0.23$, $n=103$, $P<0.05$) and difficulty of care-giving tasks ($r=-0.27$, $n=101$, $P<0.01$), indicating that lower levels of partner/family support are associated with higher levels of parent stress and more difficulty associated with completing care-giving tasks ^[3]. The resiliency model of family adjustment and adaptation developed by Mc Cubbin and Mc Cubbin is a useful theoretical framework for understanding family adaptation to cerebral palsy and to the related life transitions. The notion of family resilience has evolved from the

family stress and coping and resilience frameworks. The original ABCX framework and then a double ABCX Model are theories that primarily emphasized chronic illness and stress^[4].

The Resiliency Model

Mc Cubbin and Mc Cubbin define family resiliency as “positive behavioural patterns and functional competence individual and the family unit demonstrate under stressful or adverse circumstances, which determine the family’s ability to recover by maintaining its integrity as a unit while insuring and restoring the well-being of family members and the family unit as a whole”. Resilience is the capability of individuals, families, groups and

communities to understand and creatively draw upon their internal and external strengths, resulting in effective coping with challenges and significant adversity in ways that promote health, wellness and an increased ability to respond constructively to future adversity (Hammond) This resiliency perspective explains why in crisis circumstances some families adapt better than others. The resiliency model focuses on family recovery, resiliency and change and highlights family adjustment and adaptation processes. A diagrammatic representation of the model is presented in Figure 1 and each component will now be addressed as it relates to children with cerebral palsy and their care givers^[5].

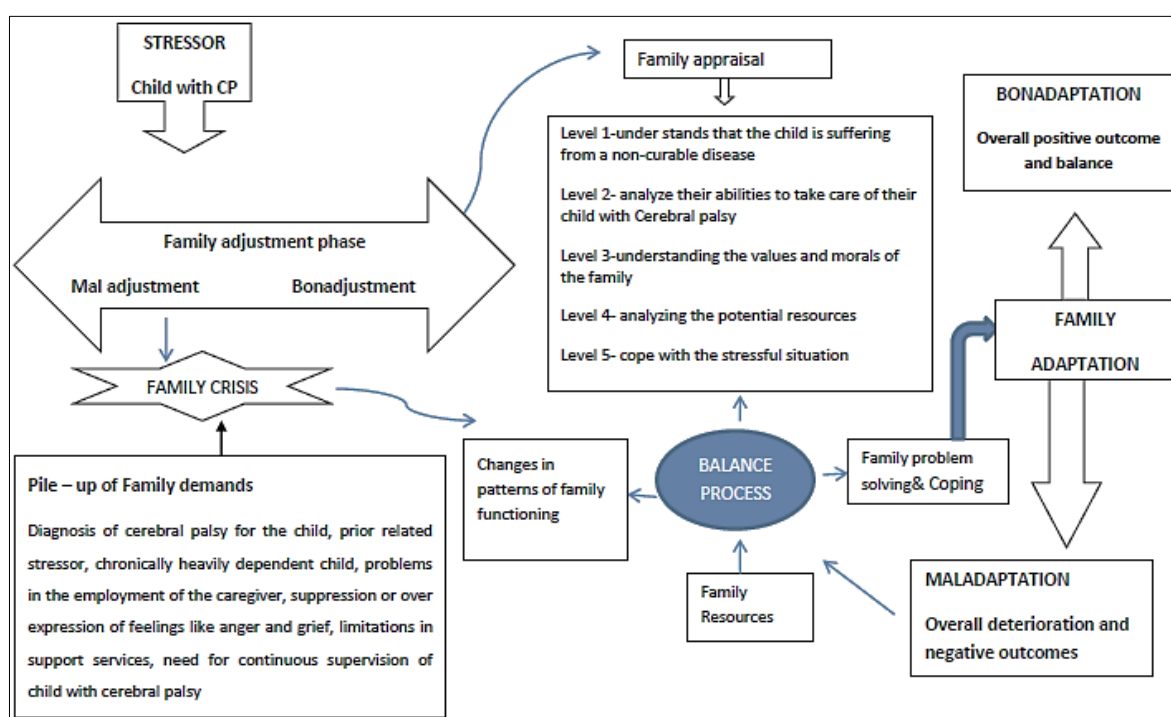


Fig: 1. The Resiliency model of family stress, adjustment and adaptation for children with CP adapted from McCubbin McCubbin(1996).

Family Adjustment Phase

Adjustment outcomes can be conceived as a continuum from bonadjustment (positive and minor adjustments) to maladjustment (poor). The maladjustment extreme indicates the need for actual changes in patterns of family functioning, which inevitably result in family crisis. Crisis

leads family adaptation and change to daily patterns in order to achieve recovery and balance. Where a child suffers from cerebral palsy, families often move through a process of maladjustment i.e. inability to take care of the child with cerebral palsy and family crisis prior to initiating the adaptation phase of recovery.

Family Crisis Phase

Family disorganization, disruptiveness and inability to restore's ability have been used to conceptualize families in a crisis state. Family crisis is identified by the need for families to make changes as a result of ongoing stress or the imbalance between a family's demands and capabilities. Family-instituted changes or adaptations aim to 'restore's ability, order and a sense of coherence. When changes are initiated in families in crisis due to the diagnosis of cerebral palsy for their child, this is an indicative of the commencement of adaptation.

Family Adaptation Phase

Adaptation focuses on the way families manage, change and develop processes and patterns in response to a crisis. Families in this phase are described in terms of resiliency and adaptation. These processes and their components interact to determine the level of family adaptation, as they describe the outcome of family efforts to bring a new level of balance, harmony, coherence and functioning to a family-crisis situation. Considering the importance of resiliency in families of children with cerebral palsy, health professionals need to understand these process components and family factors, in order to provide intervention priorities that assist families' bonadaptation and decrease maladaptation or vulnerability. Bonadaptation and maladaptation are extremes of the continuum of adaptation outcomes and depend on the number and the balance of interactions between components. Bonadaptation in the family is assessed by enhancement of knowledge, skills and reduction in care burden.

Components of Family Adaptation

Family Demands

The level of a family's adaptation is determined by the number of demands experienced by the family caregivers in

taking care of the child with cerebral palsy, balanced with maintaining family functioning. Understanding family demands may assist with the identification of 'higher risk' families and those at risk of maladaptation as well as having information about their needs. McCubbin and McCubbin list the following categories to describe stressors and strains related to the 'pileup' or accumulation of demands, which contribute to family vulnerability.

Initial Stressor and Related Hardships

The families of children with cerebral palsy at risk of experiencing difficulties with adapting to the circumstances associated with the diagnosis of cerebral palsy, their child's residual disabilities and other multiple stressors and strains. To better predict outcomes and target intervention, research must not only evaluate the demands related to the cerebral palsy, but also potential stresses impacting on all facets of family life including assessment of pre-cerebral palsy stressors and strains.

Accumulated Prior Stressors and Strains

Prior stressors and strains from earlier family crises or transitions contribute to the accumulation of family demands and influence how a family will adapt to the new crisis. On presentation at rehabilitation, health professionals would benefit from evaluating pre existing family stressors and strains in order to implement intervention and support strategies that meet the family's unique needs and benefit the child's recovery and progress.

Normative and Unanticipated Transitions

Transitions throughout the lifespan can be a source of stress on individuals and on families. These can best be described as either normative or anticipated, and unanticipated transitions ^[5]. Here the caregivers of child with cerebral palsy may

need to make many adjustments in their personal life to take care of their chronically ill child who depend heavily on them for meeting their activities of daily living. Two main unanticipated transitions can impact on family adaptation and child recovery when a child has had cerebral palsy. First, the family must accommodate the actual crisis event and the direct impact of the injury on the child's functional outcomes. Second, family adaptation must occur in relation to reintegration and transition back into the home, school and community.

Situational Demands and Contextual Difficulties

Societal demands, such as a change in the employment status of a family member or social policies, may affect the functioning of a family. If the caregiver of the child with cerebral palsy is employed he/she may find difficulty to take care of them and need to depend upon somebody else to take care of the child with cerebral palsy. Additional situational demands include financial strain, family burden post cerebral palsy, social class and availability of supports and resources.

Consequences of Family Efforts to Cope

Strategies or behaviors a family and its members may use during the adaptation phases include coping behaviours such as the suppression or over expression of feelings like anger and grief, stopping work in order to be with the child during rehabilitation creating financial strain. All these coping responses, and the use of limited coping behaviours can be described as consequences of family efforts to manage the situation which in turn contribute to an increase in family demands and burden.

Intra Family and Social Ambiguity

A family crisis and its demands produce some ambiguity for the family. Caring for a child with cerebral palsy is a long-term undertaking and can create uncertainty in

response to the family changing its structure, roles, rules and responsibilities particularly in families with unclear ideas of the/for the child and family. Limitations in support services can also increase the burden for families.

Newly Instituted Patterns Changing Family Functioning

McCubbin and McCubbin state that although newly instituted patterns of family functioning can potentially restore harmony and balance, these new patterns may also contribute to added strain. The family of the child with cerebral palsy may need to institute new patterns in taking care of them. The parents cannot leave their child alone at home. So always, there need to be someone to take care of the child with cerebral palsy. Home programmes and rehabilitation activities may limit a mother's time with other siblings and may require the father to attend to domestic duties. Similarly, strategies to manage behaviour may alter family relationships, patterns of functioning and family dynamics.

Family Resources: Strengths and Capabilities

All families have some level of resources. Concept of existing resources is the family's use of community and intra familial systems. The existing resources may be adequate or inadequate depending on the nature of the stressor event or family's level of functioning. In this study the existing resources are the personal resources, family system resources and the social support.

Personal Resources

McCubbin and McCubbin list personal resources that may contribute to family adaptation including skills, personality traits, health, self-esteem and ethnic identity. The personal resources include skills in caring the children with cerebral palsy, ability to cope with the stress and the health. Development of these skills

may be depending upon the health care personal that supports the family member in taking care of the child with cerebral palsy and can be enhanced by using the intervention package for the caregivers.

The Family System Resources

Two family system resources are cohesion and adaptability, which have been identified in research investigating family resiliency. Cohesion reflects a family's sense of unity and bonding, trust, support and respect for each other.

Adaptability is a family's ability to address problems and change accordingly. The family system resources include assistance of the family members in caring the child with cerebral palsy.

Social Support

Social support includes all community resources that the family uses to cope with a crisis or life transition. Social support consists of friends, relatives, self-help groups and the health care workers who support the caregiver in taking care of the child with cerebral palsy.

Family Appraisals

Appraisal, or the meanings assigned by the family, is comprised of five levels: stressor, situational, paradigms, coherence and schema appraisal. Except for stressor appraisal, which occurs early during the adjustment phase, these levels are considered fundamental components of the adaptation process.

Level 1: Stressor Appraisal

The first level of appraisal in a crisis is the family's interpretation of the stressor. Health professionals may help reduce long term stress by facilitating the family's acceptance and use of humour to cope. In this level the family members understand that their child is suffering from a non-curable chronic illness.

Level 2: Situational Appraisal

This level refers to the family's appraisal of their capabilities and the balance between the demands, (such as the child's disabilities and related hardships) and family resources. In this level, the family tries to analyze their abilities to take care of their child with cerebral palsy.

Level 3: Family Paradigms

The development of specific domains of family life (such as work, communication and religion) is dependent on a standard, model or paradigm of family rules, beliefs and expectations. Paradigms are a guide for family patterns of functioning, behaviours and daily management, and can be described in the context of culture and ethnicity. Rehabilitation services must be sensitive to the impact family paradigms; culture and ethnicity have on the family's responses to caring for their child with cerebral palsy.

Level 4: Family Coherence

Family coherence, or hardiness, describes the motivational and appraisal bases for transforming the family's potential resources into actual resources, thereby facilitating changes in the family systems, coping and promoting the health of family members and the wellbeing of the family unit.

The caregiver tries to analyze all the personal resources what he/she has and the family and social support system in taking care of the child with cerebral palsy and tries to make balance in his personal and family life.

This can be enhanced by using the specific instruction in caring the child with cerebral palsy. Family education and inclusion in rehabilitation and care planning would directly facilitate family comprehension, management and understanding of the processes and changes occurring.

Level 5: Schema

Family schema attempts to understand and structure a crisis in accordance with the family's shared values, beliefs, goals, priorities, expectations and worldview. It develops family meanings, which creates a family's united understanding of the crisis. In this stage caregiver of the child with cerebral palsy cope with the stressful situation.

Family Problem Solving and Coping

Coping behaviours are strategies undertaken by individuals or the family as a whole to elicit resources and to manage demands. Functions of coping include efforts that: (1) reduce the rate of and effects of demands, stresses and hardships; (2) organize resources; (3) manage the ongoing tensions related to family demands, stressors and strains; (4) facilitate appraisal of the new situation. Coping is the successful management of stress, distress and or improvement of the situation by using problem solving and coping behaviours, which have been associated burden and distress in caregivers of children with cerebral palsy. The coping of the caregivers of cerebral palsy children can be enhanced by support

systems and specific instructions in caring the children with cerebral palsy^[6].

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