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Amrita Yadava, Deepti Hooda
and NovRattan Sharma

Parenting Children with Mental Retardation: Determinants of Positive Coping and Functioning

*M. Thomas Kishore**

Mental retardation is a condition, which affects both general intelligence and adaptive behaviour of an individual, and it often presents with various kinds of sensory-motor impairments with increased levels of retardation. Since it is a permanent condition, which grossly impacts the intelligence and general development, it is also known as intellectual and developmental disability. The nature of mental retardation is such that it interferes with many day-to-day functioning of an individual such as self-help skill, social and communication behaviours, academic skills, leisure and recreational skills. It not only affects the individual but also creates many unique situations and needs for the families from the care giving perspective. The demands are obviously more on parents but a differential impact could also be seen on the siblings and grand parents (Peshawaria et al., 1995). Since there is no medical cure for mental retardation as of now, parents and families have to learn to live with a member who has a condition that is chronic and disabling (Blacher et al., 2005). Then certain questions will come up in this regard- how does it impact the family, particularly the parents? How do parents cope with the situation? What is the scope of positive psychology in facilitating positive coping and functioning of parents and families? Literature has answered these questions by exploring the needs encountered by parents and families, and the related impact and the resultant stress and coping. This paper attempts to discuss these issues from parents' perspective.

Nature and Impact of Special Needs

Families of children with intellectual disabilities face diverse needs on the account of the disability in their children. Some of the prominent needs reported by the parents are related to personal care needs (Plant & Sanders, 2007), management of adaptive behaviors (McCarthy et al., 2006), medical (Neely-Barnes & Marcenko, 2004), technical, financial and social needs (Peshawaria et al., 1995; Verma & Kishore, 2009). While these needs are common in the context of other disabilities and non-disabilities, the intensity of the above is usually very high and unique in mental retardation (Dyson, 1996; Peshawaria, 1995; Verma & Kishore, 2009). Then, a question might arise in this context. That

* Reader in Health Psychology, Centre for Health Psychology, University of Hyderabad-46.

is, “are the needs same for all the family members?” The answer comes from a pioneering study done by Peshawaria and colleagues (1995) in India, which indicates that certain needs could be common for all but otherwise the needs of the family members will vary from each other because of the differences in the familial roles. While parents could experience all of the needs discussed above, they are largely defined by the traditional roles. For example mothers are reported to be primarily concerned with emotional succor and physical care needs to the child whereas the fathers are concerned with financial and specific long-term decisions. Nonetheless, mothers are known to experience greater needs and hence greater perceived stress (Bailey et al., 1992; Goldbart & Mukherjee, 1999; Gupta & Kaur, 2010; Mehta et al., 2008; Sethi et al. 2007; Singh et al., 2002; Upadhyaya & Havalappanavar, 2008a; Verma & Kishore, 2009). In contrast, the needs of grandparents centre mostly on information needs about management, services available, future security in order to play a facilitator and decision maker role for parents. Conversely, the siblings will have needs related to management of the child’s behaviour, dealing with future including the possibility of guardianship role. Nevertheless, the needs of siblings will also vary with their own age and resources. For example, in childhood siblings will be confronted with situations in which they do not have a normal playmate or they have to be contended with little attention they get from their parents. But as they grow up, their needs would be about acquiring proper information of the course of the condition; supporting their parents on financial resources and fulfilling their aspirations for self as well as the disabled sibling.

If the parents and families are not supported in meeting their needs, it may further interfere with the development of a child, which in turn will create stressful situations for the parents and family (Azar & Badr, 2006). In this context, the next question that comes up is, “whose needs are important for family functioning?” Ideally, the needs of all the family members are important since each individual member can potentially affect the other to the extent that whole family is affected (Marshak & Seligman, 1993). But from a care giving point of view the needs experienced by parents are more important. And, if, parents happen to be from traditional or joint family systems, the needs of grandparents are given precedence as they would influence the decisions of the parents and family (Peshawaria et al., 1995). Therefore, identifying and supporting the parents in their efforts to meet the needs is one of the most efficient ways forms of intervention, which in turn will facilitate optimum functioning of the family. In this context it must be understood that parents’ needs do not mean the personal needs of the parents but the needs they experience for the child as is evident from several studies (Azar & Badr, 2010; Goldbart & Mukherjee, 1999; Kermanshahi et al., 2008; Verma and Kishore, 2009).

The needs of the parents appear to depend on personal resources of the parents, family variables and the characteristics of children, and more importantly the socio-cultural setting to which the families belong. In general, parental age, marital status, and the number of intellectually disabled children in the family affected the outcome (Grant & Whittell, 2000). Among the child’s characteristics, problems behaviours in children (Peshawaria et al., 1995; Upadhyaya and Havalappanavar, 2008a) and girl child with disabilities are universally linked with stress in the parents (Padencheri & Russell, 2004; Rao et al., 2005; Shin et al., 2006; Verma & Kishore, 2009). The reasons could be that problem

behaviours place extra demand on physical care and require specialized knowledge to deal with the same. Whereas, stress associated with girl child may be because of specific cultural beliefs that a girl child is a burden on the family. Another important variable is the age of the child. It is common logic that the needs of the parents will vary with the age of the child. Therefore, the resources available at each stage and the cognitive appraisal of the situation will determine the outcome of the impact on the parents and family. Thus it is understood that there is no set pattern of needs except that they fall in to multiple domains and multiple determinants.

Within the context of parenting, the predominant view is that mental retardation creates stress and burden for the care givers (Wig et al., 1985; Sethi & Sitholey, 1986; Sequeira et al., 1990; Sethi et al., 2007). Sometimes the disability impact of mental retardation is so multifaceted that the parents may not perceive any impact of additional sensory-motor impairments, which are common in mental retardation (Kishore et al., 2004; Datta et al., 2002). For many the impact seems to begin right from the time of receiving the diagnosis triggering range of negative emotions. Sometimes the negative emotions may reach the proportion of disorders in due course (Trute & Heiburt-Murphy, 2002; Majumdar et al., 2005; Kumar and Akhtar, 2001; Webster et al., 2008). Additionally, parents may experience the impact of financial burden, restricted social interactions, mental worries and so on (Peshawaria et al., 2000). There could be some differences between the parents in their needs and perceptions of disability impact but they seem to merge with time (Azar & Badr, 2010; Pelchat et al., 2009; Trute et al., 2007).

We may ponder whether all dysfunctions in the family are due to disability alone? An extensive review done by Neely-Barnes and Dia (2008) indicates that the answer is, 'no'. On the contrary, some will even evince a sense of purpose, psychological growth, tolerance, sensitivity and heightened family functioning by dealing with the crisis (Naseef, 2001; Scorgie & Sobsey, 2000; Stainton & Besser, 1998; Taunt & Hastings, 2002; Trute & Heiburt-Murphy, 2002). For many the child was a source of happiness or fulfillment and a source of strength and family closeness (Felicity et al., 2006). Thus it appears that stress has a negative connotation but the impact of disability on parenting could be both negative and positive (Folkman & Maskowitz, 2000; Neely-Barnes & Dia, 2008; Singh et al., 2008; Kishore et al., 2004). Therefore, understanding positive as well as negative impact of mental retardation is necessary to develop a more balanced view of families and disability (Blacher et al., 2007). Otherwise, if we consider only the negative impact we may tilt towards a charity model for intervention which is not acceptable in a rights based scenario. On the contrary, if we consider only the positive impact, we may ignore extending social support.

Stress and Coping

Despite the considerable research on stress in families of persons with mental retardation, there is still little known about the stability and compensatory factors associated with everyday parenting stresses (Gerstein et al., 2009). Though many studies indicate that parenting a child with intellectual disabilities can be a stressful experience (Grant & Whittell, 2000; Gerstein et al., 2009; Lloyd & Hastings, 2008), it is not that every family will buckle under the stress of care giving (Felicity et al., 2006; Gerstein et al., 2009; Neely-Barnes & Dia, 2008) or hide the disabled child from others (Singh

et al., 2002). Rather, some may see it as an opportunity for extraordinary psychological growth (Trute & Heiburt-Murphy, 2002). But it cannot be ascertained that the coping resources necessary for such adjustment are available to all. In this context it is necessary to identify the factors that reduce the parenting stress and facilitate positive coping, which will be of immense help not only in care giving a child with mental retardation but also in dealing with long-term stressors and other life crises.

The facilitating factors and inhibiting factors of positive coping appear to include a set of socio-cultural factors, parental characteristics and child's characteristics. Among the socio-cultural factors, poor socio-economic status (Datta et al., 2002; Gupta & Jain, 2002; Upadhyaya & Havalappanavar, 2008a), ethnicity (Blacher et al., 2007) and rural domicile (Gupta & Jain, 2002) were associated with stress. Though cultural beliefs are important, their effect seems to be related to how one interprets them.

Coping could also be understood as a function of gender roles. For example, fathers coped with the parenting demands effectively when they perceived social support (Kersh et al., 2006; Shin et al., 2006) while mothers coped with the same when they perceived marital quality (Kersh et al., 2006). And, the educational status and economic status of the parents did not reveal a consistent association with stress and coping (Behari & Ruchi, 1995; Datta et al., 2002; Kumar, 2008; Sethi et al., 2007). However, mothers' daily parenting stress significantly increased over time, while fathers' daily parenting stress remained more constant (Gerstein et al., 2009). With regards to the child's characteristics, severity of disability (Sethi et al., 2007), problem behaviors (Kersh et al., 2006; Lloyd & Hastings, 2009; Upadhyaya and Havalappanavar, 2008a), dependency for physical care needs (Cramm & Nieboer, 2011; Felicity et al., 2006) were attributed to greater stress and poor coping in both parents. Sometimes, more than the child's disability parents feel the apathy of the partner affects them in several ways (Gerstein et al., *Journal of Child Health Care*.sagepub.com 2009).

Even in the event of adverse environmental variables, impeding child characteristics and family variables, personal cognitive resources seem to be the most important facilitating factor of coping (Datta et al., 2002; Girimaji et al., 1999; Kumar, 2008; Padencheri & Russell, 2004; Peshawaria et al., 1995). Particularly, cognitive reinterpretation and positive appraisal seem to be very helpful. Further, it was also found that positive appraisal mediates the relationship between stressor and adjustment as well as it helps sustaining positive coping (Folkman & Maskowitz, 2000). It is hypothesized that hope is another important attribute of coping but it did not contribute to positive coping in the long run (Gerstein et al., *Journal of Child Health Care*.sagepub.com

2009). Nevertheless, it is surprising to know that positive and negative appraisal co-occur (Stein et al., 1997) and parents use both positive coping strategies and negative coping strategies for reasons that are yet to be discovered (Girimaji et al., 1999; Upadhyaya & Havalappanavar, 2008b). To some extent answers for this phenomenon comes from a study by Nolan and colleagues (1995), which explains that many parents usually access more than one coping strategy in managing challenging events and circumstances, and these strategies involve behavioural as well as cognitive approaches. These findings may mean that negative perceptions of disability and emotion-focused coping are inevitable however resilient and resolved a person may be.

Model of Positive Coping

There are very few models to explain coping and outcome in parents with mental retardation. Most of the initial models advocated concentrating on the child's variables. With subsequent studies demonstrating the importance of family or environmental features and the parents' cognitive styles (Frey et al., 1989; Hassall & Rose, 2005), it was long felt there is a need to reorient the child-centered programmes to the whole family, particularly the parents (McConkey et al., 2008; Peshawaria et al., 1995). This paradigmatic shift was noted in subsequent models (Perry, 2004; Trute et al., 2010), which pointed that resources, social support, and appraisal will also influence the outcome of coping with a child with mental retardation. Very precisely, family adjustment to childhood disability is associated with elements of strength in mothers' psychological strength. Such strength will include the ability to perceive positive family consequences of childhood disability and to maintain higher proportions of positive emotion in their daily activities. Similarly, parents who felt effective in their parenting role and in control of their child's behaviours have experienced lower levels of stress and higher levels of positive coping (Dukmak, 2009; Hastings & Brown, 2002; Jones & Passey, 2005). These findings have implications for family-centred care, for the educational, health, and social services that support familial structures, and in public education and community programs (Grant & Whittell, 2000).

If the biopsychosocial model is applied in the context of mental retardation, it needs to be understood that professionals cannot do much to change the biological condition (*i.e.* the nature mental retardation), which interacts with the psychological and social resources of the parents. However, the latter two attributes (*i.e.* psychological and social variables) are malleable and hence can be the target of intervention. Within this context the review highlights many facilitating factors across cognitive, familial-marital and social domains (table 1), which could be targeted as part of appropriate intervention.

TABLE 1
Showing important factors helpful for parents for coping

Cognitive	Acceptance of child (Lloyd & Hastings, 2008). Control over behaviour problems in children (Blacher et al., 2005; Felicity et al., 2006; Hassall et al., 2005; Lloyd & Hastings, 2009; McConkey et al., 2008). Internal locus of control (Hassall et al., 2005; Hill & Rose, 2009). Optimism, Self-efficacy and satisfaction in caring for their child (Jones & Passey, 2005; Jones & Prinz, 2005). Parenting satisfaction (Hassall et al., 2005). Positive appraisal or reappraisal (Hassall & Rose, 2005; Plant and Sanders, 2007; Trute & Heiburt-Murphy, 2002; Ylven et al., 2006) Self esteem (Trute, 1995; Hassall et al., 2005; Hill & Rose, 2009)
Familial and Marital	Relationship with the spouse (Trute, 1995) Maintenance of family integration (Jones & Passey, 2005). Family cohesion (Trute & Hauch, 1988) Family cooperation (Jones & Passey, 2005).
Social	Informal respite resources (Bailey et al., 1994; Trute, 1995) Social support (Azar & Badr, 2010; Cramm & Nieboer, 2011; Felicity et al., 2006; Park & Turnbull, 2002; Taunt & Hastings, 2002; White & Hastings, 2004).

The facilitating factors indicated in table-1 suggest that parents should be helped to feel that the situations are not beyond their control with reference to the child's physical care and behavioural problems. It will be an advantage if they get support from the spouse and family in this regard. Even informal social support will help parents to manage the situations better. Coping and adaptive function would enhance when the parents feel the child with mental retardation is contributing to family cohesion, cooperation and relationship with spouse. Since most of these factors are subjective and culturally defined, family intervention models must be culturally sensitive. Within the context of parental coping and family functioning, professional support and formal intervention can not fulfill all goals. Further, it must be realized that positive appraisal and positive coping are not mutually exclusive of negative appraisal and negative coping, respectively. Lastly, it must be noted that coping is not entirely liberating and rather, the process itself could prove to be stressful (Folkman, 1997). Therefore, appropriate caution needs to be exercised while encouraging positive coping in parents.

Future Directions

We need to know more about the coping processes which trigger the search for positive psychological states, and the intensity and duration of such states necessary to help sustain individuals in coping with everyday challenges involved in parenting children with mental retardation (Folkman, 1997). Therefore, there is a lot of scope for positive psychology, which is yet to gain credence (Lloyd & Hastings, 2009). However, as a beginning point, the following may be addressed:

1. Why problem-focused coping strategies including positive reappraisal is not sufficient to counter the negative impact of disability?
2. How do perceived positive-impact and positive coping affect the overall perception of disability and related coping.
3. Despite having the capacity to use problem focused strategies and the ability to understand the differential outcome of the same, why parents use roughly equal numbers of positive and negative coping strategies in their adjustment process.
4. What factors facilitate positive reappraisal of the situation
5. The relative scope and limitations of specific professional support with reference to informal social support.

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