



COPING TRENDS OF PARENTS HAVING CHILDREN WITH DEVELOPMENTAL DISABILITIES: A LITERATURE REVIEW

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Abstract:

Having to take care of children with developmental disabilities can affect parents not only in their psychological well-being but also affect physical well-being. Taking care of a child with special needs can be a growing experience or it can become stressful depending on how a parent perceives the event. Depending on the cognitive appraisal and the person-environment interaction, parents can either engage in positive behaviours of dealing with the disability or indulge in poor coping behaviour which will have adverse impact physically as well as psychologically. The present article attempts to highlight the various ways of coping used by parents to deal with their children's disabilities. Review of research papers suggests some clear differences between affected parents and non-affected parents on use of different types of coping strategies along with various moderating factors like education, income, social support available, socio-economic conditions, and type of coping used. There were also findings on how mothers differ from the fathers in their coping behaviours when dealing with disabilities.

Keywords: coping, parents, developmental disabilities

Introduction

Parenting is a tough exercise and having a child with disabilities can make things more difficult. Since children with disabilities have impairment in physio-psycho-social

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development, parents can find their roles very stressful when dealing with developmental issues resulting in social, economic/ financial problems (Laskar, Gupta, Kumar & Singh, 2010), physical and psychological problems (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond & Bolt, 2010). The problems associated with developmental needs of children with disabilities create ambiguity which parents find unacceptable many at times. According to Sharief (2014), parents find it quite stressful to accept the disability of their child. And if a child had severe impairment leading to greater dependency on the caregiver, greater was the discomfort felt by the caregiver. Family also tend to perceive the child with special needs as less valuable as compared to the other non-affected children. The present paper thus will make an attempt to highlight the findings of various studies and see how parents of children with disabilities cope.

Developmental disability is a neurodevelopmental disorder caused by prenatal and postnatal events which leads to impairment in physical, cognitive, or socio-emotional areas. These may take forms as Mental Retardation, Autism Spectrum Disorders, Learning Disabilities, Attention Deficit Hyperactivity Disorder, Cerebral Palsy, Language and Speech Impairment, Locomotor Disabilities etc. In the present article, developmental disorders include Autism Spectrum Disorders (ASD), Learning Disabilities (LD) and Mental Retardation (MR) only.

Coping

Coping includes behavioural strategies that individuals use to reduce the effect or demands of stress (Khan & Humtsoe, 2016). This is usually done through increasing one's resources, changing one's beliefs or perceptions, improving one's control over surroundings, taking help, or reducing one's emotional reactions to stress. According to Folkman and Lazarus (1984), coping efforts serves two main functions: management of the person-environment relationship and regulation of associated stressful emotions. Lazarus (1980) defined coping as *"the cognitive and behavioural efforts made to master, tolerate, or reduce external and internal demands appraised as taxing or exceeding the resources of the individual"*. The concept of coping is primarily a function of cognitive appraisal and thus, highlights the stress perceived by an individual and the person-environment transactions.

The three distinct features of coping in the definition of coping given by Lazarus – coping is a process-oriented approach; coping is contextual; and coping can be successful or unsuccessful depending on the many other factors other than the individual's perception of coping efforts. Coping actions can be of the following types:

A. Problem-Focussed vs Emotion-Focused Coping

According to Folkman and Lazarus (1986), if an individual engages in activities that directly change the elements of the stressful situation, then it is considered problem-focused coping style. On the other hand, if an individual engages in behaviours that are aimed at reducing the emotional reactions like soothing oneself, crying, denying about the problem, blaming others or self for the problem etc., then it is emotion-focused coping style.

B. Engaged vs Disengaged Coping

According to Moos & Schaefer (1993), engaged coping involves dealing with stress directly. Such examples of coping include acceptance, support-seeking, and cognitive reappraisal. On the other hand, disengaged coping is one in which an individual uses denial and wishful thinking. Disengaged form of coping is usually maladaptive in nature.

C. Proactive vs Reactive Coping

According to Aspinwall and Taylor (1997), reactive coping occurs after a stressful episode has occurred. Thus the aim of coping is to compensate for loss or decrease the harm that has already happened. On the other hand, proactive coping is a future oriented form of coping which is aimed to reduce the threat or harm in anticipation of a stressful situation.

Coping Trends of Parents – International Review

Research has shown that caring for children with disabilities can create anxiety and stress for parents. Parenting children with special needs (CWSN) may affect well-being (Feizi, Najma, Salesi, Chorami, & Hoveidafar, 2014); putting parents at risk for stress, anxiety and depression (Mitchell & Hauser-Cram, 2006; Boyd, 2002); difficulties in marriage, and in extreme cases leading to separation (Hartley, Barker, Seltzer, Floyd, Greenberg, Orsmond & Bolt, 2010); and adverse impact on physical health (Miodrag & Hodapp, 2010; Raina et. al, 2005). In addition, if the disability of child is severe, the family tend to feel more socially isolated. And greater stigma. Such families are likely to experience greater stigma, loss of control, absence of support from spouse and also professional help.

Parents, more often than not, are engaged full time in taking care of their children with special needs which affects their social life (Seltzer, Greenberg, Floyd, Pettee & Hong, 2001). Phelps, McCammon, Wuensch & Golden (2009) also found decreased family interactions and activities of recreation in families having children with developmental disabilities.

Parents are more likely to turn towards religion (Kamaruddin & Mamat, 2015), engaging in prayer for reassurance and increased religious activities to feel less stress. Younger parents (20-29) have been seen to be more inclined to seek the Almighty's guidance as compared to the older parents (40-49 age group), for whom inner strength and maturity mattered more (Durban, Rodriguez - Pabayos, Alontaga, Dolorfino-Arreza & Salazar, 2012). Smith (2003) identified different strategies parents employed when they learned that their child has developmental delay. These included components of seeking social support, positive reappraisal, planful problem solving and emotional regulation.

Lyons & Leon (2010) tried to assess the relationship between severity of autism and coping styles of parents of children with autism spectrum disorder and found that emotional – oriented coping strategies were related to parent and family problems and task – oriented coping was related with low scores on physical. Avoidance coping strategy was high among parents having children with severe Autism Spectrum Disorders while distraction likely served as protection for parents having child has more severe symptoms of Autism Spectrum Disorders. It has been seen that parents of children with Autistic Disorder who use avoidance coping strategies tend to be more stressed and experience poorer quality of life (Siah & Tan, 2016; Pisula & Kossakowska, 2010).

Families having children with developmental disabilities in China most frequently employed strategies for coping which included like acceptance of the disability, active dealing with the disability, positively reinterpreting and growing with the experience, suppressing competing activities which could be stressful, and planning to deal with the related stress (Wang, Michaels & Day, 2010).

Most parents have to make changes in their social life because of the demands of a child with developmental disorder which could lead to high levels of frustration and dissatisfaction. Such a negative impact has been seen to be moderated by majority of parents by expressing belief in the child; having an optimistic attitude about their child's life (Jones & Passey, 2005); and by realistically appraising and accepting the disability of the child (Heiman, 2002).

Mothers usually take the larger burden of care for the disabled child and consciously make an effort to be with the child most of the times, leading to experiencing of more stress as compared to the fathers. Such behaviour may influence the use of reframing and passive appraisal to help cope with stressful situations (Moawad, 2012). Most of the mothers of children with Learning Disabilities also have negative attitudes towards the child's disability, characterized by feelings of low self-esteem, guilt, self-blame, sadness, denying the existence of the disability, excess worry and disappointed with the child. Feelings of disappointment can increase when a comparison amongst the child's peers on their achievements (Alias & Dahlan, 2015). However, such negative affect

states are tackled by use of acceptance and active coping strategy and so they tend to feel less distressed as compared to parents of children with other severe forms of disabilities. Mothers attempt to get closer to the family for support while the fathers' difficulty on handling the stressful situation at home may feel the need to put the blame on their wife slowly created distance between them and the family (Durban, Rodriguez - Pabayos, Alontaga, Dolorfino-Arreza & Salazar, 2012). Mothers of young children with an ASD have been reported to use seeking social support coping; they also seek emotional support from family members or close friends to reduce stress (Sajjad, 2011; Montes and Halterman, 2007).

Among the specific types of coping styles, Confrontive coping has been seen to be decrease stress and enhanced sense of well-being of parents (Dabrowska & Pisula, 2010; Pottie & Ingram, 2008). However, venting of emotions frequently and constantly ruminating about problems are maladaptive as they do not remove the negative feelings. In fact, doing so only increases the magnanimity of the problem and prolongs feelings of distress (Windle & Windle, 1996). Optimistic parents are also highly likely to use strategies that are help in problem solving, combined with seeking support from significant others (Scheier & Carver, 1992).

Review of Indian Researches

Research indicates that there is gender difference in the perception of stress in which the fathers perceived more positive stress whereas the mothers tended to perceive more negative stress. Mothers also tend to report more use of self-controlling, seeking social support and escape-avoidance coping strategies as compared to the fathers who use more of confrontive coping and planful problem solving to deal with stress (Vinayak & Sekhon, 2012; Khan & Humtsoe, 2016). Vidyasagar & Koshy (2010) compared mothers having children with ASD and mothers of children without ASD and concluded that mothers of children with ASD tend to cope by using available social support; by either escaping or avoiding the problems: or by reappraising the situation in a positive way. Mothers of children with Learning Disabilities are often seen to experience more negative emotions such as denying the existence of a problem, getting easily frustrated, feelings of guilt and stress when a desire to have a 'normal' child doesn't get fulfilled (Chandramuki, Shastry, & Vranda, 2012; Khan & Humtsoe, 2016). Such feelings of failed expectations are further worsened by the accompanying fear about the child's future life and their accomplishments that may not be perceived as very encouraging.

Families of children with MR also use the social support system available most of the time to cope (Farheen, Dixit, Bansal & Yesikar, 2008). On the birth of a disabled child,

parents experience a variety of profound changes to adjust and adapt to the needs of the child. As such, parents who are educated tend to seek help more often, thereby reducing their stress (Kumar, 2008). Hussain & Juyal (2007) compared the stress level and coping behaviour used between parents of physically challenged and parents of normal children and found that parents of normal children had better coping as compared to the parents of physically challenged group. The findings highlight the added stress that parents perceive and experience because of the presence of a child with disabilities and also points towards the maladjusted way in which they attempt to cope with the child's disability. Kalgotra & Warwal (2014) however, concluded that parenting a child with developmental disorders may have positive impact rather than a negative one.

Conclusion

Coping affects parent's psychological functioning through many ways. Sometimes coping can have a direct impact on psychological well-being, or act as a moderator between psychological well-being and the stressor. Studies have shown that use of problem focused coping strategies results in lesser psychological distress and better mother-child interaction while use of negative emotion focused coping increases the possibility of parents experiencing depression and stress-related problems. Quality of life of parents with disabilities can be affected by the degree of disability, associated problems, amount of time spent on care-giving, presence of adequate social support etc. Thus, the disability of a child affects most of the parent/s in a negative way and indulgence in coping strategies like blaming, emotional regulation coping, worrying, withdrawing and feelings of helplessness leads to experiencing of negative moods on a daily basis which increases parental stress and reduces psychological well-being (Pottie & Ingram, 2008).

Results indicate that almost all the parents of children with disabilities tried to have belief in their child's capabilities, remaining optimistic, and being realistic and accepting of the disability to cope with their child's disability (Heiman, 2002). Use of such as coping strategy is effective as it allows an individual to take proactive initiatives to accept or change stressful situations rather than to focus on negative feelings (Carver, Scheier & Weintraub, 1989). The importance of family coping with the stress they experience in having a member with disability often relies on the parents. Hence, how the parents cope with the stressful situation will dictate how the child with disability will be provided services needed for his or her development.

The review highlights some of the positive coping strategies like acceptance, positive reinterpretation and growth, planning, seeking social support etc. which can be used by parents having children with developmental disabilities to cope with heightened

stress. Use of coping strategies like suppression of relationship-focused coping strategies, catastrophizing, and decrease use of positive refocussing and positive evaluation are likely to affect quality of life in a negative way (Predescu & Şipoş, 2013). Gender differences were also reported in almost all studies with fathers being less involved and mothers experiencing more stress and using more negative coping strategies. Mothers also generally looked towards the family or friends for social and emotional support as compared to their male counterparts.

The review thus indicates that intervention plan should include training parents of how to use better coping strategies to handle the perceived stress that comes with taking care of their children with special needs.

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