

POSITIVE PERCEPTIONS IN PARENTS OF CHILDREN WITH DISABILITIES

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ABSTRACT

A lot has been written about the stressors in the lives of parents of children with disabilities. Studies have been done to understand the types, causes and the effects of these stresses. Most often, only the negative aspects of this situation are highlighted. The work is primarily addressed towards understanding and measuring the negative attitude and adverse consequences of having a child with disabilities. This article examines the existing research done on this aspect. However, the article takes a step forward and focuses on the cognitive processes as a result of experiencing a traumatic event. The authors move away from the negative outcomes and highlight the process of developing positive perceptions in these parents. The focus is on the process of coping that generates positive perceptions and the ways that these positive perceptions are used as an effective coping strategy.

INTRODUCTION

It has been well documented that the parents of children with disabilities experience chronic stress. The recent research evidence has evaluated the types, degree and determinants of the stress faced by the families in caring for their disabled members (1, 2, 3). The literature is uniform in reporting that families do experience high levels of stress. It is also noted that having a child with disabilities affects not only the parents, but also siblings and the relationships among the family members (4).

The nature of stress has been shown to span over several aspects of family life such as daily care demands, emotional distress (e.g., maternal depression), interpersonal difficulties (e.g., parental discord), financial problems and adverse social consequences (e.g., social isolation). Stress experienced by the families is influenced by child specific variables like age, sex and severity of the problem; socio-demographic variables such as social class, family income and domicile; and family coping resources and strategies like acceptance of the child's diagnosis and perception of stigma associated with the disorder (5). Additional stress is also created due to marital conflicts associated with rearing the handicapped child, extra financial burdens to obtain the necessary services, and fatigue and loss of leisure time due to care-taking responsibilities (6).

Added to these is the extent of behaviour problems exhibited by children and adults with disabilities. Not only do child characteristics influence parental stress levels, but negative reactions from others can also serve as a source of stress for the families (7). Parenting a child with a disability increases stress in the areas of everyday management of disruptive behaviours, heavy caregiving responsibilities, and concerns about the future of the child when the parents are no longer able to care for him or her.

PARENTAL ATTITUDE TOWARDS THEIR CHILD WITH DISABILITIES

An enormous amount of research has been done to explore the stressors associated with caring for a disabled child and the deleterious effects these stressors have on parents' well-being. There is research evidence that the family attitude contributes to the prognosis. Family stresses associated with limited financial resources, lack of appropriate services, and insufficient support systems are examples of family system risk factors that can contribute to poor prognosis (8). Environmental risk factors such as lack of services and negative attitudes can also have an adverse influence on the prognosis of the child with disability.

Existing studies reveal that very often the parents have a negative attitude towards their child with disabilities. The parents are plagued with feelings of pessimism, hostility, and shame (9). Denial, projection of blame, guilt, grief, withdrawal, rejection, and acceptance are the usual parental reactions (10). Some parents also experience helplessness, feelings of inadequacy, anger, shock and guilt whereas others go through periods of disbelief, depression, and self-blame. The siblings also experience feelings of guilt, shame, and embarrassment (11).

In India, disability is still viewed in terms of a "tragedy" with a "better dead than disabled" approach, the idea being that it is not possible for disabled people to be happy or enjoy a good quality of life. Cultural beliefs about disability play an important role in determining the way in which the family perceives disability and the kind of measures it takes for prevention, treatment and rehabilitation (12). Studies report that parental expectations from their disabled child were mostly negative and unrealistic. Dalal and Pande (13) investigated cultural beliefs and attitudes of a rural Indian community towards physical disability. The results revealed fatalistic attitudes and external dependence in families with disabled children. In India, there is a very strong belief in the metaphysical causation. Also, most of the respondents felt that the disabled member in their family could not do anything and just needed help and sympathy.

One such instance is the belief in the theory of karma, which is often invoked to explain major life events, including the occurrence of disability. It has also been shown that people tend to accept their own disability as something which has resulted from their past karma or due to God's will and thus often show low motivation to overcome the limitations (14). A

belief that prevails very strongly is the perception of disability as a punishment for past karmas. Any form of disability is looked upon as a curse that has been bestowed upon the family to atone for the sins committed by the person or the family members in their previous lifetimes. In stark contrast, it is the duty of the “non-disabled” to give away food, money, and clothes in charity to the disabled, as a religious responsibility to attain moksha, the ultimate liberation (15).

Studies reveal that this negative attitude adversely affects the parents. Family members of children with disabilities are often perceived to experience harmful psychological effects (16). These extreme stress levels heighten negative health outcomes like depression and marital dissatisfaction (17). Parents are found with unstable emotionality, constant grief, psychological ill health, and unsatisfactory social health. Studies have found them to be at a higher risk for marital discord and social isolation. The commonest psychiatric disorder that was found is dysthymia followed by generalized anxiety disorder and moderate depression (18). It is also found that the parents of children with disabilities perceive more problems in themselves and their family.

The majority of literature has highlighted the stresses and the subsequent negative consequences in caring for a child with a disability. The primary focus in this literature seems to be on stress, strain, grieving, and other negative issues. In fact, researchers have even proposed that when a child is diagnosed as having a severe disability, the parents may experience similar cognitive processes to those individuals who have experienced a traumatic event (19). Although many researchers have found that the families of children with disabilities report more stress than do other families, recent research shows that there is no clear evidence that they also report fewer positive feelings or perceptions. In fact, data are suggestive of no differences or even reports of more positive perceptions in families of children with disabilities.

COPING THAT GENERATES POSITIVE PERCEPTIONS

There is evidence in the recent research that has shown that stress need not be an inevitable consequence in a family with a child with a disability. Mullins (20) presented themes arising from a content analysis of 60 books written by parents of children with a variety of disabilities. He identified significant demands and emotional stress, but the majority of the authors also felt that their lives had increased meaning and enrichment as a result of their experience with their children. In a similar analysis of fathers’ published accounts, Hornby (21) noted stressful experiences and negative feelings but also strong positive feelings and claims of personal growth. Furthermore, it has been found that relatives who have been studied less intensively by researchers, such as siblings and grandparents, anecdotally reported positive views about their relative with a disability.

The functional role that positive emotions serve in the context of stressful events was considered by Lazarus, Kanner, and Folkman (22). They hypothesized that under stressful conditions, when negative emotions are predominant, positive emotions may provide a psychological break or respite, support continued coping efforts, and replenish resources that have been depleted by the stress. Positive perceptions could be viewed as a factor ameliorating the impact of a child's disability on family members. Essentially, positive perceptions are different outcomes to stress and other negative experiences but they occur in concert with the negative or stressful experiences. Positive affect might help to bolster psychological and physical resources during stress, act as a buffer against the adverse physiological consequences of stress and help to protect against clinical depression (23).

Existing individual and family focused theories suggest that positive perceptions play a central role in the coping process. It has been proposed that positive perceptions may assist us to cope better with the traumatic and stressful events (24). Cognitive adaptation model of responses to threatening events posits that we attempt to adapt to threatening events by searching for meaning, trying to gain mastery, and enhancing the self. A key mechanism by which this adaptation is achieved is termed as cognitive illusions (24, 25). When these illusions are challenged, different perceptions will be generated in order to maintain meaning, mastery, and/or the self-system. Setting achievable goals and engaging in problem-focused coping in order to achieve them, leads to feeling of control and mastery.

Problem-focused coping refers to efforts directed at solving or managing the problem that is causing distress. It includes strategies for gathering information, making decisions, planning, and resolving conflicts. It also includes efforts directed at acquiring resources (e.g., skills, tools and knowledge) to help deal with the underlying problem, and instrumental, situation-specific, task oriented actions (26). In a stressful situation, it is possible to identify goals and experience efficacy, mastery, and control even in situations that appear uncontrollable and even worsening. However, this often requires relinquishing previous goals that are no longer tenable and turning to new, realistic goals (27).

Under stressful conditions, individuals may bring about, note or remember ordinary events and in fact often infuse ordinary events with positive meaning (28). It may be that when a negative event occurs, the individual creates a positive event or interprets an otherwise ordinary event as positive as a way of offsetting the unpleasant affective consequences of the negative event. Hobfoll (29) commented that people are often keyed to respond to the adverse sequelae of loss by turning their attention to their resources and looking for positive aspects of their lives.

A further coping approach is that of positive reappraisal – cognitive strategies for reframing a situation in order to see it in a more positive light (23). Positive reappraisal enables the

individual to appraise a difficult situation more positively. It often involves deeply held values that are activated by the stressful situation. This kind of coping encourages people to focus on the value of their efforts and is especially important in helping people sustain efforts, such as those associated with caregiving, over long periods of time.

Coping basically involves creating, reinstating, or reinforcing meaning in the midst of stress. This aspect has long been implicated in the appraisal of stress (30) where it helps determine the personal significance of a stressful situation in relation to the individual's beliefs, goals, values, or commitments. This appraised or situational meaning shapes the emotions that the person experiences in the stressful encounter. This is in contrast with the global meaning which refers to a more abstract, generalized meaning related to people's fundamental assumptions, beliefs, and expectations about the world and the self in the world (31).

Because stress by definition is something that an individual cannot contend with through his or her usual means of coping, a traumatic event may actually force an individual to choose a different strategy for resolving a crisis. Dabrowski's (as cited in Hague) (32) psychological model of positive disintegration suggests that once psychological development reaches equilibrium, any further development occurs very gradually. Before rapid development and significant change can occur, disintegration of that equilibrium must take place. Moreover, he suggests that only a life crisis or a major challenge results in that disintegration.

In her study, Janoff-Bulman (33) also maintains that it usually takes an event of traumatic proportions to serve as a catalyst for any positive transformation. Furthermore, she asserts that since this change is largely a result of the interpretation or appraisal of the event rather than the event itself, it can occur simultaneously with the event or even a long time afterward. Palus (34) concurs that such changes are the precipitators of self-growth. This generally happens in two phases: initial disequilibrium and reorganization, i.e., the characteristic way of "doing things" is interrupted, and is substituted by a new and a superior way of acting.

Recent focus has also been on the factors that differentiate families who adapt successfully to the birth of a child with disabilities. It is important to study the impact of a disability on the coping effectiveness of the family unit and extend the concept of positive perceptions as a coping mechanism at the level of the family. The focus here is on family as an interacting system. Meichenbaum and Fitzpatrick (35) affirm that recovery from a traumatic event is predicated on the ability of an individual or a family to adapt in a manner that restores faith in the goodness and inherent value of self and of life. This is accomplished through the construction of narratives, or stories, by the individual or family unit that enables them to interpret the stressful life event in a positive way.

McCubbin and Patterson (36) discovered that some families might adapt well to raising a child with developmental disabilities; a state called “bonadaptation”. Patterson’s family adjustment and adaptation response model (37, 38) is focused on the processes by which families restore the balance between demands and capabilities and minimize their experience of stress. Thus, parents might attend to the positive and emphasize growth and development of the self and the family unit while minimizing limitations of the child and problems caused for the family. A further concept is that of a family schema. A positive outlook may also be a part of such a schema: the shared beliefs, meanings, and values that a family develops in order to coordinate their interaction patterns and consequently, cope or adapt to their situation.

This notion of family schema has also been discussed in the resiliency model of family stress adjustment and adaptation (39). Family schemas within this model are hypothesized to help maintain family stability. They are also the filters through which all experiences, including the appraisal of potential stressors, are evaluated. Having positively focused schemas assists families to maintain a more general positive view of events and, thereby, cope or adapt to challenges. Dunn (40) studied children’s close relationships and suggested that a family’s response to this type of stress influenced the siblings’ perception of the situation. If parents react positively to their child with special need, then the sibling relationship tends to be more positive. If the parents took an optimistic and caring view, then the sibling was more likely to do the same. Thus the parent’s ability to accept their child’s difficulties influences the ways in which a family functions.

There is research evidence that the families benefit when instead of totally depending on external agencies for rehabilitation, parents take charge of the situation and educate and train themselves. Basu and Deb (41) observed significant improvement in the behavior, study habits and prosocial behavior of children with Attention Deficit Hyperactivity Disorder (ADHD) as a result of training parents of children with ADHD. Similarly, in their study Bhan, Mehta and Chhaproo (42) found that irrespective of the economic status of families with a child with cerebral palsy, intervening factors like mother’s personality, optimism, and religious support were found to alleviate the degree of stress. Positive attitude, social support and faith in God helped mothers generate psychic energy to cope with the physical, emotional, and financial aspects of care giving.

Poyadue (43) maintains that there is a stage of adaptation that is beyond acceptance that might be called “appreciation” or the “all right” stage. Parents at this stage may be a resource to families facing difficulties. One effective way of doing this could be through parent support groups. In their study, Singer et al. (44) found that parents involved in a parent-to-parent support group reported an increase in their positive perceptions of their

child with a disability. In effect, one of the key factors of success was a positive outlook on the part of supporting parents. It is imperative that the families adopt a constructive approach of sharing to promote self-confidence and urge for self-reliance to the maximum. In another study, Russell, John and Lakshmanan (45) examined the efficacy of interactive group psycho-education on measures of parental attitude toward intellectual disability. Results indicated a significant clinical improvement in the attitude of parents, their orientation towards child rearing, knowledge of intellectual disability and the attitude towards management of intellectual disability.

POSITIVE PERCEPTIONS: AN ADAPTIVE COPING STRATEGY

It has been shown that positive emotions promote creativity and flexibility in the process of thinking and problem solving (46). Positive affect also facilitates the processing of important, relevant information even if that information is negative and may potentially damage self-esteem (47). Another route through which feeling positive may offset the deleterious physiological effects of stress is through the neuroendocrine system.

The possibility that positive feelings may prevent adverse physiological effects of stress is reinforced by findings that positive and negative affects are associated with different neural structures (48). Studies indicate that the women's positive affect, as a result of meaning-based coping in response to traumatic events, may have made them more physiologically resilient in the face of subsequent stress and may have protected them from the maladaptive neural, endocrine, and immune responses to chronic stress that can lead to diseases (49).

A number of studies have examined positive outcomes of stressful events. Even though the events themselves may not have had favourable resolutions, outcomes include the perception of benefit from the stressful encounters (50), the acquisition of new coping skills and resources (51), the perception of growth related to their stress (52), and the spiritual or religious transformation that results from the stressful experiences (53).

Scorgie et al. (54) did a qualitative analysis of the mechanisms that led parents to achieve positive transformations in their perceptions of their child with a disability. This analysis revealed that parents arrived at a more positive state through three processes: (1) the need to form new identities, (2) attempts to derive meaning from the situation, and (3) the development of a sense of personal control. Many parents find meaning through acquiring new roles like parent – group leaders, conference speakers, or members of advisory councils for schools, hospitals or agencies representing people with disabilities.

Some other parents have focused on acquiring new traits like becoming more compassionate and less self-focused, learning they could achieve rather than remain powerless, developing endurance or greater personal strength in the midst of their feelings of weakness, progressing from depression to being able to view life as worthwhile and of value, and facing life with new boldness rather than capitulating to fear. Though not being able to ‘grin’ and be ‘happy’ overall in life, they were however, able to cultivate a sense of humor and increase the ‘happy times’ in life (55). Some parents have also reported loss of friendships as a result of having a child with disabilities but also cited other parents of children with disabilities, personnel from agencies serving people with disabilities, and caring health professionals as primary members of their new friendship networks. They intimated that they might not have had relationships with such a depth if they had not had a child with a disability.

One of the acquired traits rated highest by the parents was the ability to speak out on behalf of their children. Though for some it is a long and difficult learning process, it stemmed largely from their desire to protect and support their child with disabilities. This was often done to fight against the discrimination and difficulties associated with accessing equal services. Parents have reported the exhilaration of knowing that through advocacy they have “made a difference” in someone else’s life. While there have been reports of disintegration of marriage with the diagnosis of a disability, some parents have also reported that their marriage had emerged stronger as a result of parenting a child with disabilities, citing that the need to find solutions to complex situations and work together as a team required them to improve their communication skills and reinforce their marriage (55).

Research has also been done to understand the themes of positive perceptions. Behr, Murphy, and Summers (56) used exploratory factor analysis to study more than 1200 families and identified nine positive factors: (1) a source of happiness and love, (2) a contribution to family strength, (3) a stimulus for personal growth and development, (4) a source of pride and contribution, (5) a path to learning and contribution, (6) a key to understanding life’s purpose, (8) a guide to understanding future issues, and (9) a stimulus for career growth.

In a review of published research on positive perceptions of families with children with development disabilities, Hastings and Taunt (57) compared themes, items and factors in various research studies and found some key themes about the nature and structure of parents’ positive perceptions and experiences of their child with a disability and the caregiving experience. These can be summarized as: (1) pleasure/satisfaction in providing care for the child, (2) child as a source of joy/happiness, (3) sense of accomplishment in having done one’s best for the child, (4) sharing love with the child, (5) child providing a challenge or opportunity to learn and develop, (6) strengthened family and/or marriage, (7) giving a

new or increased sense of purpose in life, (8) development of new skills, abilities, or new career opportunities, (9) becoming a better person (more compassionate, less selfish, more tolerant), (10) increased personal strength or confidence, (11) expanded social and community networks, (12) increased spirituality, (13) changed perspective on life (e.g., clarified what is important in life, more aware of the future), and (14) making the most of each day and living life at a slower pace.

CONCLUSIONS AND IMPLICATIONS

The identification of a disability in a child most often comes as a shock. Changes in home routines, vocational life, and relationships with family and professionals are typically required. Basic life assumptions are challenged. The stage may therefore be set for changes to occur. The need of the hour becomes disintegration or abandonment of one's previous life in favor of a new and clearly, a better way of living. These positive indicators do not mean that parents are naïve about, or are blind to the difficulties they face or are in the state of denial. These studies are, but an indication of how the families have been able to successfully weave their lives around the successes in their lives, versus the sorrows in every day living. They have been able to find a meaning in their life by reframing their original appraisal to emphasize on the positive outcomes, such as their abilities to reach out to others in need.

There is ample evidence that parents of children with disabilities do go through prolonged periods of stress than do parents with typically developing children. Like any other child, the family and environmental systems also affect a child with disabilities. A negative attitude towards disability from the family members, relatives, friends and/or the society, not only impacts the child directly, but also adds on to the existing stress levels of the family. Lack of public awareness about the potential of disabled people, often acts as a barrier to their acceptance and participation of the disabled. Awareness raising activities need to be particularly focused upon and formation of self-advocacy groups, which is still at the initial stage, needs to be hastened (58). Mainstreaming disability typically requires a supportive environment and social participation to reduce negative ideas associated with anxiety, insecurity, depression as also education, counseling, and vocational training to develop the capabilities of the individuals.

Though it cannot be disputed that parents of disabled children face a great deal of stress, it is now important to move away from describing these stressors and their adverse effects. Instead, research should now focus on exploring the ways that such families cope with varying degrees of success. Several studies have been done which recognize that many families have been successful in developing positive perceptions regarding raising a child with disabilities. Recent studies have consistently reported that families with a child with disabilities can and in fact do have positive perceptions which leads to better quality of life

for the family, and scope for maximizing the child's potential. Though precipitated by a specific event, formation of positive perceptions is usually a process, which can occur simultaneously or a longtime after the event.

Existing research suggests that positive perceptions play a central role in the coping process and assist us in dealing with the traumatic and stressful events. Not only do they benefit the parents and the siblings in coping with the child, the disability, and the difficulties associated with it; but it also helps the family unit as a whole. The way in which a family functions, is influenced by the parent's perception of their child's difficulties.

This leads to three main implications. Firstly, given this framework, the situation calls out for more extensive exploration. Research on this aspect is virtually missing in the Indian context and thus more studies should be carried out exploring the positive adaptations of parents. It is rather important to understand the conditions that facilitate these positive changes in the perceptions. Also, the focus should move towards collecting longitudinal data. If a research explores only the early reactions to a child with disability, the families could still be recovering from the shock of the diagnosis. Investigators who have examined families at later points in time have frequently concluded that parents are better characterized by commitment rather than sorrow.

This is accompanied with the second implication. It is imperative to look at the tools being used, and whether they provide space and opportunity to give positive responses. If we do not ask positive questions, we would rarely get a positive answer. Chances are that a positively framed question will encourage a positive response from the family. Helff and Glidden (59) analyzed publication trends in research on adjustment in families of children with disabilities from 1970s to 1990s. They suggest that though negativity in published research has decreased over time, however, there has been no increase in positivity over the same period. Criticism has been given regarding structuring of the research, where no space is provided to include positive feelings of parents with a child with disability. They state that investigators still assume primarily negative versus positive assumptions and hypothesis in their research endeavors, which are not likely to yield any positive answers.

Finally, helping families develop a positive outlook might be the serving point of intervention by the clinicians themselves. Although, the research in this area is limited as yet, there is a possibility of developing practical interventions to help families to adapt. Most often the intervention is done at the level of the child and addressing the disability per se. Therapists might want to concentrate on this aspect and facilitate families' coping processes by encouraging and supporting positive outlook on self and life. This can be executed through the course of family therapy, marital therapy, or individual counseling. A very effective way would be moderating self-help or support groups for parents with children with

disabilities. Parents with positive perceptions can help the other parents in the early stages of adjustment develop positive but realistic expectations.

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