

## Psychosocial Issues of Parents of Children with Communication Disorders: A Family Perspective

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### Reprint Request

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### Abstract

Intervention of children with disability should be holistic. Rarely, wellbeing of the family is given its due importance. The impact of the disability on the family members is always overlooked. Communication disorders in children pose a significant challenge to the family as a whole and measures should be taken to address this issue. Failure of which, would ultimately have its negative impact on the progress of child with communication disability.

**Keywords:** Psychosocial Issues; Parents; Communication Disorders; Intellectual Disability; Autism Spectrum Disorders (ASD), Family.

### Introduction

Wellbeing of the family and the child is intimately connected. Functions of the family would be affected, when one of its member have chronic illness, which increases exponentially, if the affected one is the child. The process of parenting starts from the conception of child beginning with expectation. Parents invest lot of their energy and resources for the wellbeing of child during the pregnancy. Hence, when they come to know that their child has disability, they show behaviors/emotional reactions ranging from denial to depression. It may lead to multiple consultations, which ultimately would deny the child, the advantage of early intervention. Further, they succumb to a deep distressing situation and may have psychosocial issues, which would require psychosocial interventions.

Communication disability could be an isolated condition or it could be one of the multiple disabilities.

Intellectual disability and autism spectrum disorder form a significant group in children with communication disorders. They are frequently encountered in child psychiatry settings. This article outlines the psychosocial issues of parents of children with communication disorders, with specific reference to intellectual disability and autism spectrum disorders (ASD).

### *Intellectual Disability & Autism*

Intellectual disability is characterized by "significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following adaptive skills areas: communication, self-care, home-living, social skills, community use, self-direction, health and safety, functional academics, leisure and work"[11]. Autism is a neuro - developmental disorder defined by impairments in social and communication development, accompanied by stereotyped patterns

of behaviour and interest [24]. As intellectual disability and autism are in the same spectrum of developmental disorders, parents show similar kind of psychosocial issues.

#### *Psychosocial Impact on Parents & Family*

Chronic illness and disability negatively impacts families and family functioning [26]. In families dealing with a child with chronic illness or disability, parents focus a lot of attention on the child, and risk ignoring their own relationship needs and the needs of their partner [18]. Caregivers of children with ASD require coping with the physical and emotional demands of caring for a child with ASD. Their self-confidence and self-esteem could be eroded in the face of totally unfamiliar child behaviour and unique demands. A person, who is in high conflict marriage, might be more likely to engage in unhealthy behaviours like, smoking and alcohol consumption [6,16].

Parents of the child with ASD often experience helplessness; feelings of inadequacy and failure; anger; shock; guilt; frustration; and resentment [8]. These parents/caregivers have been reported to have less marital happiness. On comparison, parents of children with ASD were reported to have lower marital happiness, family adaptability and family cohesion than parents of children with Down's syndrome, and normally developing children. At the same time the cohesion and adaptability for all three groups fell, within the healthy family functioning range [7]. Here, it should be noted that the high levels of family cohesion could lead to enmeshment, a maladaptive family function [14].

A child diagnosed with ASD may represent a constant source of stress on the family unit. It is not only the caregivers were affected, but also the siblings and relationships among the family members. Hardiness and social support are considered as the predictors of stress in mothers of children with autism, and children with intellectual disability [19]. The three most stressful factors for the parents are, a) permanency of the condition b) Lack of acceptance of autistic behaviour by society and family members; and c) low levels of support provided by health care services and other social services [20]. In other dimension, stress could be a result of the extremely antisocial, disruptive behaviours associated with ASD, such as self-injurious, tantrum and obsessive/compulsive behaviours, which may disrupt a normal family life [19]. Characteristics of children with ASD and behavioural manifestation of these tendencies

make social outings for families difficult. This is likely to place additional stress on families, and create conflict within the family system. If families are not able to engage in joint activities with both the child with ASD and other siblings, they will tend to score low on the measure of family functioning, indicating a risk of the family being disconnected, or not responsive to the needs of all the members' [9].

The psychological distress was significantly higher for mothers, when compared with fathers. Perceived social support from friends were significantly different for fathers and mothers. Coping patterns were more negative distraction for fathers, whereas, for mothers it was more of denial and blaming. Daily care stress and family emotional stress were found more in mothers. Parents whose children were above 10 years were found to have higher level of social stress. Parents of severely autistic children had high levels of daily care, social and financial stress [23]. A study focussed on both the parents, who had children with intellectual disability, it was found that they experience a greater level of stress relating to their children, compared to parents of children without disability. The stress of fathers and mothers was associated with aspects of family functioning as perceived by themselves and their spouses [4].

Parents of children with intellectual disabilities are prone to psychiatric conditions. A comparison between parents of children with intellectual disabilities (n=32) and parents of typically developing children (n=29), revealed that the parents of children with intellectual disabilities had high depression and anxiety scores. Further majority of them met the criteria for possible clinical depression and/or anxiety. The strongest predictor of psychological morbidity was caregiver burden. Another indicator for psychological morbidity was feeling of guilt, indicated for the greatest consequence for depression and anxiety. Poor social support and more problematic child behaviors were associated with increased psychological morbidity in parents caring for a child with an intellectual disability [5].

The degree of psychosocial issues faced by the parents varied as the degree of the disability varied. In a study, conducted among the parents of children with intellectual disability it was found that, a) the levels of psychosocial problems faced by parents of intellectual disability increased with the level of intellectual disability of the child studied b) parents of moderately intellectual disabled children registered more problems in all aspects compared to parents of children mildly intellectual disability. Further, parents of children with mild intellectual

disability were more concerned on focussed preventive and adjustment, whereas, parents of children with moderate intellectual disability were concerned with lifelong adjustment, financial security, that included benefits provided by the Government to the child [22].

Impact of having a child with intellectual disability on the family describes that the indispensable importance of interaction between the child and, family and community. It starts right from the birth and expands throughout the life [10]. Parental attitude towards intellectually challenged children explained that the birth of a child with intellectual disability shattered the hope and aspiration of parents leading hopelessness and negative attitude towards the child [17]. Parents felt that raising a child with disability is time consuming and often emotionally draining. Often they choose not to have another child or spaced their children widely, in order to meet the needs of their child with disability better [12].

#### *Protective Factors*

Patterson (1991) had listed out positive family processes contributing to the good outcomes in children with chronic illness and disability. They are, (a) balancing the illness with other family needs, (b) maintaining clear boundaries, (c) developing communication competence, (d) attributing positive meaning to the situation, (e) maintaining family flexibilities, (f) maintaining family cohesiveness, (g) engaging active coping efforts, (h) maintaining social supports, (i) developing collaborative relationship with the professionals [15]. In a similar manner, though there are psychosocial issues that are obviously affecting the parents and their families, these parents also exhibit protective factors. Protective factors, namely family closeness or connectedness, caregivers coping skills, mutually supportive relationship, clear family organization and direct communication about the illness were observed. The strongest risk factors were conflict or criticism, psychological trauma related to disease, external stressors, family isolation and disruption of developmental tasks by the disease and, rigidity or perfectionism. Hence, family intervention programmes should target these protective and risk factors [25].

#### *Adaptation Process*

Devising an effective intervention program requires knowledge about adaption process and its

stages. The process of adaptation takes a longer time, as it depends upon the particular parents' psychosocial environment. ABC-X model postulates that the bon-adaptation occurs when there is " (a) maintenance or strengthening of family integrity; (b) continued promotion of both member development and family unit development; and (c) maintenance of family independence and its sense of control over environmental influences". Maladaptation, however results when there is, (a) deterioration in family integrity; (b) a curtailment or deterioration in personal health and development of the member or the well - being of the family unit; or (c) a loss or decline in family independence and autonomy . This model must be seen as a dynamic model rather than a static one. This means that stressors, resources, and perception of the families are ever changing and in constant interaction with each other. Thus professionals must keep in mind about the dynamics involved in dealing with such families [13].

It is hypothesized that parents may move through several stages of adjustment adapting to birth of an infant with a handicap. First stage would be shock and denial, second would be involving a period of disorganization bringing out emotions like anger, grief and guilt and the final stage would be acceptance. The rate and the pattern of adjustment process may be varied and dynamic. The emotions that the parents experience appear and disappear and again may reappear unexpectedly or triggered by the medical and behavioural crisis of the child. Hence a prompt and supportive intervention is necessary [2].

#### *Psychosocial Interventions*

Intervention with any family members is in fact intervention given to the whole family [1]. Ignoring family functioning would result in increasing the problems in the family as a whole [3]. Meta-analysis of 'caregiver's (n=78) intervention studies' representing six different types of interventions for different illness revealed significant improvement across six outcomes variables namely, a) caregiver burden b) depression c) subjective well -being d) perceived caregivers satisfaction e) ability/ knowledge and f) patients symptoms. These studies suggest that providing education and support for family caregivers is necessary, but not sufficient to reduce their burden and improve their emotional health. Family caregivers need more intensive interventions that include skill training assistance with problem solving [21].

## Conclusion

Wellbeing of children and the family are interrelated. Communication disorders in children affect the family and a dysfunctional family leads to further deterioration of the child's condition. Appropriate and continuous intervention for the parents should be initiated at the earliest. Health care institutions like hospitals & nursing homes and, the health care professionals are generally patient centric. They work on the dysfunctions of the individual. However, communication disorders in children are known to cause negative psychosocial impact on the family. Parents/caregivers may show symptoms of depression, anxiety, stress and guilt or marital/family issues. Awareness should be created among health professionals to give attention to these issues and make appropriate referrals. Overlooking the psychosocial factors may ultimately affect the child with communication disorders as it erodes the very basis of their support, the family.

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