



A Critique of Epidemiological Studies on Psychological Distress in Parents of Children with Mental Retardation and Children with Autism

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ABSTRACT

Having a child with disability in a family is not the same as having a child without a disability. Parents of disabled children after knowing that their children have disability, develop highly ambivalent feelings towards their babies. Parent's social life becomes restricted, and feelings of social rejection and isolation may follow. Parents having a child with mental retardation experience a variety of stressors and stress reactions related to the child's disability and the parents have the feelings of guilt, anxiety, hostility, and insecurity. Having a child with autism also found to be a significant financial burden to the family. Parents of children with autism are more likely to use avoidant coping strategies that may have a negative impact on the marital relationship. Parents may feel self-conscious about taking a child with autism out into the community. An attempt has been made to present a critical analysis of a preliminary review of epidemiological studies on psychological distress in parents of children with mental retardation and autism.

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Introduction

A handicapped child born into a family and grow into adulthood is one of the most stressful experiences a family can endure. Parental reactions of disabled children are shock, denial, depression, guilt, anger, sadness, and anxiety¹. Some parents perceive the handicapped infant as an extension of them and may feel shame, social rejection, ridicule or embarrassment. Many factors influence the reactions of family members: the emotional stability of each individual, religious value and beliefs, socioeconomic status and marital stability. The most immediate reaction is that of depression, often exhibited in the form of grief or mourning. Some parents describe the mourning as being very much like that suffered after the death of a loved one². Recurrent sorrow and frequent feelings of inadequacy are persistent emotions that many parents experience as they gradually adjust to having an atypical child³. Parents have practical problems like financial strain to provide necessary medical expenses, special equipment, and possibly special schools and care takers in the absence of parents. Transportation may become difficult if special equipment must be transported with the child¹. Family relationships may be weakened by the added and unexpected physical, emotional, and financial stress imposed on them⁴.

Parenting a child with mental retardation is not an easy job⁵. Parents having a child with mental retardation experience a variety of stressors and stress reactions related to the child's disability⁶. The parents of retarded children have the feelings of guilt, anxiety, hostility, and insecurity. There is no doubt that many parents respond to having a retarded child with some degree of emotional disorganization, but the intensity and the quality of their reactions vary greatly.

Parents feel sad and depressed at various stages of child's life and experience other emotional reactions. The ultimate impact of the retarded child on the family depends on several factors, such as the degree of the retardation, personality development, and life adjustment of each parent preceding the arrival of the retarded child; the degree of their professional and social success; the adequacy of the marital adjustment; other children in the family & their intellectual progress; and the parental socio economic status. Mothers are more active in their child's care and bear most of the burden associated with it. It also found that the mothers of children with hearing impaired are experiencing significant burden compared to normal children⁷. They may tend to give themselves little time to adjust, as the child with the disability continues to require ongoing care. Many mothers suffer loss of self-esteem when they recognize retardation in their child. They may anticipate social rejection, pity, or ridicule and related loss of prestige. Research has shown that more severe handicapping conditions are associated with poorer psychological well being for mothers; they have only been able to speculate about the reason for such patterns⁸. The feeling of depression is common, particularly when realization of the child's retardation is recent. Some mothers react to the retarded child and manifest the typical grief reaction associated with loss of a loved one.

Parents of children with developmental disabilities face challenges placing them at risk for high levels of stress and other negative psychological outcomes. Parenting a child with autism may pose additional stressors related to the child's challenges in communicating, difficult behaviors, social isolation, difficulties in self-care, and lack of community understanding⁹.

Several studies reported increased psychological distress, including depression, anxiety, and components of stress, such as decreased family cohesion and increased somatic complaints and burnout, among parents of children with autism.

The child with autism typically requires vast amounts of parental time and energy. This drain of resources can affect the marital relationship and the functioning of individual family members¹⁰. Parents of children with autism are more likely to use avoidant coping strategies that may have a negative impact on the marital relationship¹¹. In other hand the mothers of children with autism and mental retardation are more likely to use of active coping, positive reframing, planning and acceptance as the coping strategies to cope with their child's disability¹². Having a child with autism also found to be a significant financial burden to the family¹³. Parents may feel self-conscious about taking a child with autism out into the community. Parents of children with autism experience a sense of isolation from friends, relatives and community. Mothers of autistic children had severe disturbance in their emotional well-being¹⁴. Indeed, many mothers had experienced enough distress to require psychotherapy and/or medication. Mothers of autistic children over 50% screened positive for significant psychological distress and this was associated with low levels of family support and with bringing up a child with challenging behaviour¹⁵ and an even higher level of significantly elevated stress levels being experienced by two-thirds of mothers¹⁶. Mothers of children with mental retardation are experiencing more caregiver's burden in the form of general stain, disappointment, and emotional involvement and seeking more social support than the mothers of normal children¹⁷. Mothers are more stigmatized by their child's disorders¹⁴.

The objectives of this paper is to present a critique of the epidemiological researchers conducted on the psychological distress in parents of children with mental retardation and children with autism at the national and international levels.

1. Epidemiological data allows better understanding, assessment and therapy and prevention parents mental health problems.
2. Epidemiological data serves as a building block for any kind of plan of action to follow.
3. Epidemiological data also helps in evaluating the factors that affects the development of a problem.

Psychological Distress in Parents of Disabled Children

A large number of studies have been conducting and examine the psychological distress among parents of children with disability.

Parents of 34 handicapped children were compared to a control sample of parents of non-handicapped children on a variety of measures, including marital satisfaction, social support, religiosity, psychological well-being, and a measure of resources and stress and significant differences were found between groups along a number of these dimensions¹⁸. A study on psychological distress in mothers of disabled children and found that, as a group, mothers of handicapped children reported being more depressed than mothers of non handicapped children. The best predictor of maternal distress was the amount of help that the child needed with activities of daily living such as eating, dressing, and grooming¹⁹. Research found that the influence of selected child characteristics on stress in families of handicapped infants and the characteristics considered were rate of development,

social responsiveness, temperament, repetitive, stereotypic behaviors and additional care giving demands. The sample consisted of 31 infants and mothers with the age range of the infants were 6.6 to 36.6 months. The results indicated that four of the child characteristics namely temperament, responsiveness repetitive behavioral patterns and care giving demands, were significantly related to the amount of stress reported by the mothers on Questionnaire on Resources and Stress (QRS), but not significantly related to the amount of stress reported on the schedule of recent experience. No significant difference between child's age and stress was reported²⁰.

The level of perceived stress on several dimensions of parenting was compared in mothers and fathers of conduct disorder, autistic, Down syndrome, and normal children. Results showed that mothers and fathers report very similar levels of stress when parenting exceptional children, although their patterns of stress change as a function of the child's difficulties. Parents of conduct disorder children are most stressed, closely followed by parents of autistic children, while parents of Down syndrome children closely resemble and, in some respects, appear less stressed than parents of normal children²¹. A study conducted on parenting stress and depression in children with mental retardation and developmental disabilities. The subjects for the study were 29 children with developmental disabilities recruited from a population of children receiving services from a university-based outpatient clinic (n = 21) and a school program (n = 8). Results indicated that parent ratings from the CD1 were significantly associated with maternal depression, an index of D&U-III-R depression criteria, and negative self-image, anxiety and conduct problems in children²². Sixty families (56 mothers, 40 fathers) completed measures assessing parenting hassles, nonparenting hassles, and symptoms of psychological distress. The results indicated that child behaviour problems and nonparenting stress were both correlated with parenting stress, and the child behaviour problems played a much stronger, predictive role. In addition, child behaviour problems were positively associated with both maternal and paternal parenting hassles, indicating that parenting stress was associated with hassles pertaining to realistic, as opposed to distorted, perceptions of child behaviour problems. It also showing nonparenting hassles were significantly associated with symptoms of psychological distress in both mothers and fathers; however, parenting hassles also predicted distress in an additive manner²³. A study conducted on Children's delayed development and behaviour problems: Impact on mothers' perceived physical health across early childhood. The study sample comprised 218 families from central Pennsylvania and Southern California, USA. The results indicated that the relation between child behaviour problems and maternal health was moderated by mothers' parenting stress and mediated by depressive symptoms. Early child behaviour problems contributed to later maternal health and beyond early maternal health, suggesting a possible causal association between child behaviour problems and mothers' physical health²⁴.

Summary

Research indicated that parents of handicapped children are experiencing more stress than parents of non-handicapped children and the determinants of this stress in psychological aspects are marital satisfaction, social support, religiosity,

psychological well-being. The parents both mothers and fathers of exceptional children; report very similar levels of stress, although their patterns of stress change as a function of the child's difficulties and child's characteristics such as temperament, responsiveness, repetitive behavioral pattern and care giving demands. Parents of conduct disorder children are most stressed, closely followed by parents of autistic children, while parents of Down syndrome children closely resemble and, in some respects, appear less stressed than parents of normal children. In mothers of psychotic children, mothers experiencing more anxiety and depression. In some studies with mothers of children with developmental disabilities; the parental stress and depression were correlated with marital status and family income levels where as few studies revealed that child's sleep and behavior problems were associated with disturbed sleep, increased depression, anxiety and stress levels in mothers.

Psychological Distress in Parents of Children With Mental Retardation

Survey of literature revealed a significant number of studies regarding parental distress of children with mental retardation.

A study compared the mothers of mentally retarded and mothers of those chronically ill. Greater psychological stress was observed in the mothers of mentally retarded children than in the mothers of chronically ill children. Further, they also experienced the burden of anxiety depression, reduced self-esteem and conflict in modulating their hostile and ambivalent feelings²⁵. The adverse effect on marital stability has been studied in 142 families and found that divorce rate among families with a surviving retarded child was 9 times higher than in the general population and 3 times higher than families with a spina bifida child. The findings suggest that the retarded child to the strain on marriage especially, if the relationship between partners was seek before the birth of the retarded child²⁶. 72% of the families had marital disharmony as a result of birth of handicapped child and about 56% of parents had a negative attitude, 88% of the mentally retarded children were neglected by their parents²⁷. An investigation was done to understand the quantum of stress on the parents of mentally retarded children. The results show that parents feel depressed most of the time, and their marital harmony and relations with their family members are disturbed. The parents could not achieve some of their goals and when the child was female it created more social and emotional problems²⁸. Thirty families with a mentally handicapped child were studied, and the attitudes of parents, grandparents and siblings towards the handicapped child were examined and the results showed that the birth of a mentally handicapped child interrupts the normal life-cycle of the family, leading to a crisis. The first reaction in the parents was most often found to be denial, but ultimately adaptation was demonstrated in nearly 80% of the parents. Many of the siblings' and grandparents' reactions differed significantly from those of the parents, being more positive than those of the latter²⁹.

A study conducted on family resources and stress associated with having a mentally retarded child. Internal and external family resources and characteristics of the children were examined. Mothers (n = 60) were asked to complete four relevant questionnaires. Results of multiple regression analyses indicated that characteristics of the child and the family's crisis-meeting resources were significant predictors of various forms of stress³⁰. Research found that parents of

mentally retarded children had significantly higher scores only on the neuroticism scale, indicating that they were more emotionally unstable than the parents of non disabled children. On the other hand, no differences in extraversion between parents of mentally retarded and non disabled children were found³¹. Parental stress was examined in socioeconomically matched samples of mothers and fathers of children with Down syndrome and typically developing children. Parents of children Mothers who reported more responsibility for childcare perceived more difficulties with health, role restriction, and spousal support. Fathers who reported more responsibility for childcare perceived fewer difficulties with attachment and parental competence. Partner stress was associated both with mothers' and with fathers' stress³². A study showed depressive symptoms in mothers of mentally retarded children were significantly higher than in mothers of non disabled children, and higher than in both fathers of mentally retarded children and fathers in the non disabled children. Parents of disabled children had significantly higher levels of negative emotions and lower levels of positive emotions than did parents of non disabled children³³. Parental depression was assessed using the Beck Depression Inventory (BDI) in 216 families with children with autism and/or intellectual disability (ID), and in 214 control families Mothers with children with autism had higher depression scores (mean = 11.8) than mothers of children with ID without autism (mean = 9.2) Forty-five per cent of mothers with children with ID without autism and 50% of mothers with children with autism had elevated depression scores (BDI > 9), compared to 15-21% in the other groups. Single mothers of children with disabilities were found to be more vulnerable to severe depression than mothers living with a partner³⁴.

A study conducted to determine the stress among Malaysian mothers of children with mental retardation. Seventy-five mothers of children with mental retardation aged 4–12 years and 75 controls (those without disabilities who attended the walk-in pediatric clinic) participated in the Parenting Stress Index (PSI). In findings mothers of children with mental retardation scored significantly higher than control subjects in both the child-related domain and parent-related domain of the PSI. A large proportion of mothers of children with mental retardation experienced substantial parenting stress, especially Chinese and unemployed mothers³⁵. Research found that parenting stress was explained by parental locus of control, parenting satisfaction and child behavior difficulties. There was also a strong correlation between family supports and parenting stress, this was mediated by parental locus of control³⁶. A study was conducted on maternal distress and expressed emotion: cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. Mothers of children with intellectual disability were assessed at two time points, 2 years apart (n = 75 at Time 1, n = 56 at Time 2). Data were gathered on maternal distress, mental health, expressed emotion, and the child's internalizing and externalizing behavior problems. Consistent with previous research with families of children who have intellectual disability, maternal distress and children's behavior problems entered into a bi-directional relationship over time. This relationship was found to be specific to externalizing problems. Exploratory analyses also suggest that maternal distress and depression had a bi-directional longitudinal relationship. In terms of maternal expressed emotion,

criticism and not emotional over-involvement were cross-sectionals but not longitudinally related to children's externalizing behavior problems and to maternal distress³⁷. In Lebanon a high percentage of mothers of children with intellectual disability had depressive symptoms the factors that determine maternal depression are family strain, parental stress, and family income³⁸.

In 1970, before the introduction of prenatal diagnosis of chromosome anomalies, an unpublished questionnaire study concerning the social and emotional situation of mothers of children with Down syndrome was conducted in southern Germany. To assess the psychosocial impact of the availability of prenatal diagnosis on parents of genetically handicapped children, we re-evaluated and repeated the 1970 study over 30 years later. Although mothers' feelings of guilt for having a child with disabilities remained on a low level, today's mothers have a stronger feeling of being involuntarily segregated in society. On the other hand, they more often experience support and respect from outside, particularly through self-support groups; moreover, tendencies of active withdrawal from social life have decreased³⁹. A study conducted on psychological distress among parents of children with mental retardation in the United Arab Emirates. Participants were parents of 225 mentally retarded children, mothers (N=113) and fathers (N=112) were administered parental stress (QRS-F), psychiatric symptom index (PSI) and family environment scale (FES). The results indicated that child characteristics, parents' socio demographics, and family environment are the predictors accounted for 36.3% and 22.5% of parental stress and parents' psychiatric symptomatology variance, respectively. The age of the child was significantly associated with parents' feelings of distress and psychiatric symptom status, and parental stress was less when the child was older. Parents reported more psychiatric symptomatology when the child showed a high level of dysfunction. Fathers' work appeared to be a significant predictor of parental stress, indicating that for fathers who were not working the level of stress was higher than fathers who were working. Lower socioeconomic level was associated with greater symptom rates of cognitive disturbance, depression, anxiety, and despair among parents⁴⁰. In a cross-cultural study, mothers of children aged 5-18 years with a diagnosis of intellectual disability of such severity that the children attended special schools or centers. Mothers were interviewed individually at home or in the day center attended by their child. Mothers experienced poor mental health, increased levels of child-related stress and poorer family functioning, which the qualitative data further illuminated and their child's behavior problems were a major factor in this⁴¹.

An association between parental stress, parenting competence and family-centred support to young children with an intellectual or developmental disability was conducted with a total of 33 parents who had a child with an intellectual or developmental disability aged 4-7 years participated and one group (n = 12) were parents of children who attended an early intervention program at the Special Education Centre, University of Newcastle. The results suggested that important components of family-centred practice are significantly associated with parent stress. 40% of the variance in stress was explained by two components of family-centred support demonstrates the importance of that support as a potential causal variable for reducing parent stress⁴². A study conducted on psychological well-being in

parents of children with Angelman, Cornelia de Lange and Cri du Chat syndromes. Parents of children with Angelman syndrome (n=15), Cornelia de Lange syndrome (n=16) and Cri du Chat syndrome (n=18), and a matched comparison group of parents of children with autism and intellectual disabilities (n=20) completed questionnaires on both psychological distress and positive psychological functioning. Parents of children with Angelman syndrome consistently reported the highest levels of psychological distress, and parents of children with Cornelia de Lange syndrome the lowest, with parents of children with Cri du Chat syndrome and autism scoring between these two. Positive psychological functioning was similar across the four aetiology groups. The study concluded as parents of children with rare genetic syndromes are at risk for high levels of stress and mental health problems⁴³. Mothers of children with mental retardation experience significant psychological distress than the mother of children with autism in the sub scales of somatization, obsessive – compulsion, paranoid ideations, grand total, and depression. The mothers of children with mental retardation experience more psychological distress than the mothers of children with autism in relation to age and gender of the children, severity of disability and educational back ground of the mother⁴⁴.

Summary

The birth of a mentally handicapped child interrupts the normal life cycle of the family, leading to a crisis. The first reaction in the parents was most often found to be denial, but ultimately adaptation was demonstrated in nearly 80% of the parents. A large proportion of mothers of children with mental retardation experienced substantial parenting stress, especially unemployed mothers, and the characteristics of the child and the family's crisis-meeting resources were significant predictors of various forms of stress. Expressed emotion towards the child with intellectual disability predicted a high level of burden among the caregivers and also the age of child and income of the family significantly associated with burden. Parents of mentally retarded children were more emotionally unstable and negative emotions than non disabled children. Parents of children with mental retardation have experienced parental stress and psychiatric symptomatology and these are associated with age of the child, disability level, socio economic status and father's occupation. Care giver as mother perceived more difficulties with health, role restriction and spousal support whereas care giver as father perceived fewer difficulties with attachment and parental competence. Mothers experienced poor mental health, increased levels of child-related stress and poorer family functioning, family strain, family income; mainly the child's behavior problems were a major factor in this. Some studies revealed that single mothers of children with disabilities were found to be more vulnerable to severe depression than mothers living with a partner. The mothers of children with mental retardation experience more psychological distress than the mothers of children with autism in relation to age and gender of the children, severity of disability and educational back ground of the mother.

Psychological Distress in Parents of Children With Autism

Research studies have been carried out both in Indian and abroad indicating psychological distress among parents of children with autism.

Research found that parental stress associated with characteristics of autism and the autistic child's language and cognitive impairment were judged by all raters as most severe and stressful. Parents of older children judged symptom severity to be lower, but fathers' reported high level of stress⁴⁵. A study compared the different patterns of stress reported by mothers of children with cystic fibrosis, autism, and children without any disorder. Twenty-four mothers from each of these three groups completed the Questionnaire on Resources and Stress Short Form. Autism was found to contribute significantly more to family stress than did cystic fibrosis⁴⁶. Mothers of autistic children reported less parenting competence, less marital satisfaction, more family cohesion, and less family adaptability than mothers of children with Down syndrome and developmentally normal children. Mothers of both autistic and Down syndrome children reported more disrupted planning, caretaker burden, family burden, and frequent use of self-blame as a coping strategy than did mothers of developmentally normal children⁴⁷. Parental stress associated with dependency and management, cognitive impairment, limits on family opportunity, and life-span care⁴⁸. Research also found that parents who reported their autistic children as more difficult in temperamental style had children who were less engaged during a social game with the parent and less responsive in interaction with an experimenter. Parents who reported greater stress had autistic children who were less responsive in social interactions with others⁴⁹.

A study conducted on comparing between parents of children with autistic spectrum disorders and parents with non-autistic children. Thirty-seven families and 66 parents were involved in each case, and four psychological tests were used. It was found that lower levels of coping were associated with higher levels of strain on the family system, that the level of strain on the family system was greater in the families with a child with an ASD, and that the two groups differed in their pattern of coping behavior⁵⁰. To test a model of how mothers cope with the stresses of raising a child with autism, mothers of children with and without autism were interviewed. As predicted, mothers of autistic children: (1) placed less emphasis on career success and were more likely to believe that mothers of young children should not work outside of the home; (2) spent more leisure time with their extended family; (3) placed less emphasis on others' opinions of their child's behavior; (4) placed more emphasis on spousal support and parental roles in their discussions of marriage; (5) had more difficulty understanding their child's behavior; and (6) showed a marginally significant difference in their tolerance of ambiguity. Moreover, mothers of children with autism who showed these characteristics had the greatest life satisfaction overall⁵¹. Eighteen married couples who were the parents of children with autism reported on their stress and their general mental health (i.e. anxiety and depression) and found that mothers and fathers did not differ in their levels of stress and depression, but mothers reported more anxiety than fathers. Partial correlation analysis revealed that child behavior problems and fathers' mental health were associated with mothers' stress. However, neither child behavior problems nor mothers' mental health was associated with fathers' stress⁵². Research also found that parents of children with autism had more psychiatric difficulties than parents of children with Down syndrome⁵³.

Parents of 48 children with autism (41 mother-father pairs) reported on child characteristics, and their own stress and mental health. Mothers were found to report both more depression and more positive perceptions than fathers. Regression analyses revealed that parental stress and positive perceptions were predicted by maternal depression; maternal stress was predicted by their children's behavior problems (not adaptive behavior or autism symptoms) and by their partner's depression⁵⁴. A comparative study of stress profiles in mothers of children with autism and those of children with Down's syndrome consists of fifty mothers whose children had autism ($n = 25$) or Down's syndrome ($n = 25$) completed the Questionnaire on Resources and Stress (QRS) and answered some demographic questions. The findings showed that the mothers of children with autism presented higher stress levels on seven of the 15 scales of the QRS⁵⁵. A study found that mothers parenting another child with a disability (in addition to the child with ASD) had higher levels of depressive symptoms and anxiety and lower family adaptability and cohesion compared with mothers whose only child with a disability had ASD⁵⁶. A population-based study was conducted on psychological functioning and coping among mothers of children with autism with Mothers of 61772 children who were 4 to 17 years of age were surveyed by the National Survey of Children's Health, 2003. Autism was measured from an affirmative maternal response to the question, "Has a doctor or health professional ever told you your child has autism?" There were 364 children with autism in the sample. The findings showed that mothers of children with autism were highly stressed and more likely to report poor or fair mental health than mothers in the general population, even after adjustment for the child's social skills and demographic background. However, mothers of children with autism were more likely to report a close relationship and better coping with parenting tasks and less likely to report being angry with their child after adjustment for the child's social skills and demographic background. Having a child with autism was not associated with lower social support for parenting, an altered manner in which serious disagreements were discussed in the household, or increased violence in the household⁵⁷.

The National Survey of Children's Health in 2003 was reported that parents of children with autism were more likely to score in the high aggravation range (55%) than parents of children with developmental problems other than autism (44%), parents of children with special health care needs without developmental problems (12%), and parents of children without special health care needs (11%). However, within the autism group, the proportion of parents with high aggravation was 66% for those whose child recently needed special services and 28% for those whose child did not⁵⁸. A study conducted on behaviour and emotional problems in toddlers with pervasive developmental disorders and developmental delay: associations with parental mental health and family functioning. Participants were 123 parents of children with PDD and without PDD aged 20–51 months. Parents completed a checklist on child behavioural and emotional problems, and individual questionnaires on family functioning, their own mental health, and stress in relation to parenting their child. Child emotional and behavioural problems contributed significantly more to mother stress, parent mental health problems, and perceived family dysfunction than child diagnosis (PDD/non-PDD), delay or gender.

Compared with mothers, all fathers reported significantly less stress in relation to parenting their child⁵⁹. Research also found that the emotional stress of the mothers was correlated with the personality traits of neuroticism and agreeableness, perceived control by the husband, and the children severity of the symptoms⁶⁰. 155 primary caregivers participated in the study to find out the mediating and moderating variables for depression. Results concluded that 42% of participants have scored on severe depression. Perceived personal control, subjective distress, and role disruption mediated the association between internalizing child behaviour problems and depressive symptoms⁶¹.

A multilevel modelling approach was on Daily stress, coping, and well-being in parents of children with autism. The results indicated that higher levels of daily positive mood were predicted by problem focused, social Support, positive reframing, emotional regulation, and compromise coping. It was also found that decreases in daily positive mood were associated with escape, blaming, withdrawal, and helplessness coping. Gender did not moderate the daily coping mood relationship, however coping responses of emotional regulation, social support, and worrying were found to moderate the daily stress mood relationship⁶². The parents of 85 children with Autistic Spectrum Conditions completed measures of their parenting stress, and the children were assessed for autistic severity and behavioural functioning. The results showed that the autistic severity of a child was related directly to parenting stress. However, earlier diagnosis may be detrimental to levels of parenting stress. While parenting stress declined over time from the point at which the parents had first noticed a problem in their child, it failed to change by any significant degree once the diagnosis of ASC had been received⁶³. 162 parents of pre-school children with autism and Down syndrome were participated in the study and the results indicated higher level of stress in parents of children with autism than the counter parts. Mothers of children with autism scored higher than fathers in parental stress; but no difference found in the group of parents of children with Down syndrome and typically developing children. Emotion-oriented coping was the predictor for parental stress in the samples of parents of children with autism and Down syndrome, and task oriented coping was the predictor of parental stress in the sample of parents of typically developing children⁶⁴. The research also found that there is a strong association between mothers' symptoms of stress and depression, and their parenting cognitions about both their children with autism spectrum disorder and a typically developing child⁶⁵.

A study conducted on the relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. One hundred and forty-nine parents of children with ASD completed a survey of parenting stress, depression, broader autism phenotype (BPA), coping styles, perceived social support, and child symptom severity. Parents reported elevated parenting stress and depression relative to normative samples. A path analysis indicated that both child symptom severity and parent BAP were positively correlated with these outcomes. The relationship between BAP and the outcome measures was partially mediated by maladaptive coping and social support and the relationship between child symptom severity and outcomes was partially mediated by social support⁶⁶. Factors associated with depressive symptoms in parents of children with autism spectrum

disorders found that child sleep quantity was a significant predictor of maternal depressive symptoms, controlling for group and child behaviour. Fathers sleep quality was a significant predictor of paternal depressive symptoms, controlling for child behaviour and child sleep disturbances. It also suggested that along with child behaviour, parent and child sleep variables are associated with parental depressive symptoms⁶⁷. Mothers of children with autism spectrum disorder (N=199) and Down syndrome (N=60) responded to an online questionnaire that assessed their hope and worry. Results reported that hope is a protective factor against psychological distress. Mothers with higher hope reported lower worry as they had more education and older children or children who were higher functioning. Mothers of children with Down syndrome reported lower future-related worry and higher hope⁶⁸. A multivariate model comprises four elements such as parental stress, parental resources, parental adjustment and the child's autism symptoms and found that sense of coherence, internal locus of control, social support and quality of marriage increase the ability to cope with the stress of parenting an autistic child⁶⁹. A pilot study which consists of 265 parents of children with autism from across the United States were administered Impact of Events Scale-Revised (IESR) and the LA Symptom Checklist (LASC). The results indicated that 20% parents are showing PTSS this psychological distress in parents resulting from their child being diagnosed with autism⁷⁰. A study conducted on parental adjustment, marital relationship, and family function in families of children with autism. The participants are 151 families with autistic disorder and 113 families of typically developing children in Taiwan. Both parents completed the self administered questionnaires measuring psychopathology, marital dyadic adjustment, and family function. Both parents of children with autism suffered from more psychopathology and less dyadic consensus than parents of typically developing children; mothers of children with autism, perceived less marital satisfaction, affection expression, family adaptability and cohesion than mothers of typically developing children. They also found that mothers of children with autism displayed more psychopathology and marital maladjustment than did the fathers. This study concluded that parents of children with autism encounter more psychological problems, marital difficulties and family dysfunction, particularly their mothers⁷¹.

The families of children with ASD (N=46), DD (N=25) and TD (N=25) between the age group of 18 months to 30months were compared with parenting-related stress and psychological distress. Parents of toddlers with ASD demonstrated increased parenting-related stress compared with parents of toddlers with DD and typical development but psychological distress did not differ significantly between the groups. Child behaviour problems, but not daily living skills emerged as a significant predictor of parenting-related stress and psychological distress for both mothers of children with ASD and DD⁷². A study examined pain and problem behaviour as predictors of parent stress and also examined how parenting style interacted with pain and problem behaviour to influence parent stress. The total participants are 148 and the mothers (N=132), fathers (N=14), and other two are step parent, adoptive parent. Results showed that problem behaviour was a moderating factor between pain & parent stress and there

was a significant interaction between pain and problem behaviour predicting stress. An overprotective parenting style also moderated the relationship between pain & parent stress and there was an interaction between the two factors predicting stress⁷³. Research also found that regardless of child symptom severity, vicarious futurity strongly predicted stress experienced by parents, hope predicted depressive symptoms, and both predicted life satisfaction. Vicarious futurity and hope were found to be weakly correlated, indicating that both constructs are largely independent when influencing the well-being of parents raising a child with ASD⁷⁴. A study conducted on child atypical symptoms and investigated relations to parental stress and the parenting alliance. The results indicated that parents of highly atypical children reported less stress than parents of children with low levels of these behaviours, an effect that acted through an assessment of the parenting partner as highly involved with the child. However, parents with highly atypical children did not report a similarly better self-focused parenting alliance, indicating that direct emotional support from the partner did not differ between the groups⁷⁵.

Summary

Parents of children with autism have more psychiatric difficulties. Parental stress associated with characteristics of autism. All raters judged the autistic child's language and cognitive impairment as most severe and stressful to the parents. Mothers were screened positive for significant psychological distress and that this was associated with low levels of family support and with bringing up a child with higher levels of challenging behavior. Mothers of autistic children have significantly more stress than parents of children with cystic fibrosis. Parents of children with autism experience profound stress. This stress response has specific profile--the most difficult for parents are handicaps related with atypical child behaviors, and the lack of knowledge about real development limitation and child problems. The major factors of the stress are associated with cognitive impairment of the child, dependency and management, limits on family opportunity, and life-span care. The lower levels of coping were associated with higher levels of strain on the family system that the level of strain on the family system was greater in the families with a child with an ASD, and it differed in pattern of coping behavior. Parents of children with autism were more likely to score in the high aggravation range (55%) than parents of children with developmental problems other than autism (44%). When comparing mothers and fathers with autistic children; there is no difference in their levels of stress and depression, but mothers reported more anxiety than fathers. Partial correlation analyses revealed that child behavior problems and fathers' mental health were associated with mothers' stress. However, neither child behavior problems nor mothers' mental health was associated with fathers' stress. In some studies mothers were found to report both more depression and more positive perceptions than fathers.

Critical Analysis for Conclusion

The first reaction of parents of disabled children was most often found to be denial, but later nearly 80% parents have adapted to the disability of their children. Parents of disabled children experienced more stress than parents of non-handicapped children and the determinants of this stress in psychological aspects were marital satisfaction, social

support, religiosity, and psychological well-being of the parents. It was also concluded that the pattern of parental stress was different due to their child's characteristics such as age of the child, disability level, temperament, repetitive behavioural pattern, socio economic status of the family, father's occupation and care giving demands.

Many research studies compared with type of disabilities and found that parents of children with conduct disorder were most stressed than parents of autistic children and parents of children with Down syndrome. A few investigators emphasized that mothers of both autistic and Down syndrome children reported more disrupted planning, caretaker burden, family burden, and frequent use of self-blame as a coping strategy than did mothers of developmentally normal children. One of the aforementioned groups emphasized that mothers of autistic children experienced higher stress levels and more psychiatric difficulties than mothers of mentally-retarded children. Another study concluded that mothers of autistic children reported less parenting competence, less marital satisfaction, more family cohesion, and less family adaptability than mothers of Down syndrome children. In contrast, a study found that the mothers of children with mental retardation experienced more psychological distress than the mothers of children with autism in relation to age and gender of the children, severity of disability and educational background of the mother.

Some researchers concentrated on determinants of the parental stress and concluded that the characteristics of autism such as child's language, cognitive impairment, atypical child's behavior and lack of knowledge about autism were stressful to the parents of children with autism. Among parents of children with developmental disabilities, the parental stress and depression was correlated with marital status, unemployment, family income and family crisis-meeting resources. A few studies emphasized that the major factors of the parental stress were associated with child's dependency, management, limits on family opportunity, and life-span care.

One of the aforementioned groups specified that care giver as mother perceived more difficulties related to health, role restriction and spousal support whereas care giver as father perceived fewer difficulties with attachment and parental competence. On the other hand mothers as well as fathers of children with autism experienced same levels of stress and depression, but mothers reported more anxiety and more positive perceptions than fathers. A number of investigators revealed that child behaviour problems and fathers' mental health were associated with mothers' stress but neither child behavior problems nor mothers' mental health was associated with fathers' stress. Another study showed that child's sleep and behaviour problems were determinants for disturbed sleep, increased depression, anxiety and stress levels in mothers of children with developmental disabilities. Whereas in mother of children with mental retardation, the child's behaviour problems were associated mother's poor mental health, increased levels of child-related stress and poorer family functioning. On the other hand mothers' stress was correlated with low levels of family support and with bringing up a child with higher levels of challenging behaviour. A few studies specified that single mothers of children with disabilities were found to be more vulnerable to severe depression than mothers living with a partner.

Conclusion

A high percentage of mothers of children with autism had more depressive symptoms and more psychiatric difficulties and it correlated with the children severity of the symptoms and age of the child and this source of stress was buffered by coping. Mothers experienced poor mental health, marital difficulties and family dysfunction. Parents considered children with disabilities as burden and it associated with high level of child dependency. The impact of care giving to children with disability is more on the mothers than other family members as mothers are the primary caregiver for the child. Mothers of children with disabilities often experience greater stress and burden which affect their quality of life. Parental training for mothers of children with disability can help the mothers to overcome distress, reduce burden, cope effectively which can improve their quality of life, thus they can handle their children effectively. There are only few Indian studies to show the efficacy of parental training for mothers of children with autism. Hence the author attempted to see the efficacy of parental training to reduce psychological distress and burden and to enhance coping and there by quality of life in mothers of children with autism.

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