CHAPTER – II

REVIEW OF LITERATURE

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REVIEW OF LITERATURE

2.1 INTRODUCTION

In this chapter studies related the variables included in the present study were reviewed, namely, parenting stress, coping and psychological well-being for parents of children with autism, mental retardation and normal children.

2.2 STRESS

Parenting a normal child can be stressful experience due to the demands and hassles of daily living. The stress of caring for children can make parents feel angry, anxious, or stressed out. Although, these tensions are a normal and inevitable part of family life, parents has to learn ways to cope with stress. Particularly, being a parent of child with an intellectual or developmental disability causes stress and depression to family members (Baxter, Cummins, & Yiolitis, 2000; Hayden, & Goldman, 1996). According to the researchers, early parental reactions following the diagnosis of a handicap of child include ambivalence, anger, confusion, denial, self-pity and blame, feelings of helplessness, depression, disappointment, grief, guilt, mourning, rejection, shock, impulses to kill the child and suicidal impulses (Mary, 1990; McConachie, 1986; Ntombela, 1991). Similar reactions of shock, surprise, anxiety, disbelief and disappointment were found by Kromberg and Zwane (1993) in their study of parents of children with developmental disabilities.

A state of shock is characterized by feeling of not being able to register or understand the news of child’s diagnosis and thus withdrawing. This is followed by a reaction stage, during which emotions of denial, sadness, anger, etc., may be felt in a
rush. However, according to Mary (1990) these negative feelings lessened over time and gradually parents enter in an adaptation stage start thinking about what can be done. Finally, parents enter in a reorganization stage are start seeking help and begin to plan ahead (Mary, 1990; McConachie, 1986; Ntombela, 1991).

Three decades of research on this subject has suggested varying outcomes. For example, couples of comparative studies have noted greater stress in parents of children with disabilities than parents of children without disabilities (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Dyson, 1997). Further, Sloper and Turner, (1993) found that up to 70% of mothers and 40% of fathers of severely disabled children reported high level of distress.

Holroyd and McArthur (1976) were among the first researchers to compare levels of stress among mothers of young children with autism, Down syndrome, and a clinical group. In their study of 22 mothers of children with autism, 22 mothers of children with Down syndrome and 32 mothers of children evaluated in a clinic setting, some of whom had mental retardation, they found that mothers of children with autism scored significantly higher than the other two groups on a variety of indices of parenting stress. Specifically, mothers of children with autism reported higher levels of stress than mothers of children with Down syndrome, with respect to being more upset and disappointed with their child, more concerned about the child's dependency and behavior management needs, more concerned about the effect of the child on the rest of the family, and more anxious about obtaining appropriate services.

In particular, Beckman (1991) studied the parents of children with disabilities such as autism, cerebral palsy, multiple disabilities, etc. and non-disabled children on measures of parenting stress. Beckman found that the parents of children with
disabilities reported greater stress as compared to the parents of normally developing children across all domains of the Parent Stress Index. Beckman further added that the parents of children with disabilities did not differ with respect to child related contributors to parenting stress and general life stress scores from parents of normally developing children. In contrast, when stress in mothers of developmentally delayed compared with non-delayed preschool children, Cameron, Dobson, and Day (1991) found statistically significant differences between the two groups of mothers' scores on the Child Domain of the Parent Stress Index. In particular, the level of demandingness and distractibility of developmentally delayed children was reported by mothers to be significantly greater compared to the no delayed children.

Few other earlier studies have reported that parents of children with autism displayed significantly higher levels of stress than parents of children with Down syndrome, and developmentally typical children (Fisman, Wolf, & Noh, 1989; Wolf, et al. 1989). Similarly, Dumas, Wolf, Fisman, and Culligan, (1991) studied 150 families having children with autism, Down syndrome, or typical development and found that the parenting stress was higher in the parents of children with autism than the parents of Down syndrome and children with typical development. Further, Sanders and Morgan (1997) also found that the mothers of children with autism were more prone to be distressed than those of children with Down’s syndrome. Furthermore, Bouma and Schweitzer (1990) and Piven et al. (1991) found that mothers of children with autism had higher stress as compared to mothers of children with cystic fibrosis and typically developing children.

Even more recent studies on parents of children with disabilities reported that the parents of children with autism are at high risk for psychological disorders
(Bromley, Hare, Davison, & Emerson, 2004; Duarte, Bordin, Yazigi, & Mooney, 2005). They experience greater stress than the parents of children with other disabilities and the parents of children without a disability (Honey, Hastings, & McConachie, 2005). Due to increased parenting stress the parents of children with autism are at the risk of relationship breakdown (Higgins, Bailey, & Pearce, 2005). The findings of the study conducted by Brobst, Clopton, and Hendrick (2009), on 25 parents of children with Autism Spectrum Disorder and 20 parents of children without developmental disorders, supported the results reported by earlier researchers. They also found that both mothers and fathers of children with Autism Spectrum Disorder had more stress, less satisfaction in their relationship with their partner, and less availability of social support than other parents.

Herring et al. (2006), in their cross sectional study, found that fathers of children with pervasive developmental disorder reported more stress than other fathers. Similarly, a recent study found that the parents of children with Autism Spectrum Disorder aged 4 to 17 reported more stress than children with health care needs without developmental disabilities, and children without any special needs (Schieve, Blumberg, Rice, Visser, & Boyle, 2007). In contrast, Rodrigue, Morgan, and Geffken (1990, 1992) have not found any significant differences among the stress of father’s children with autism, mental retardation and developmentally typical children.

Researchers found that the parents of children with a disability vary in the levels of stress they experience and that their levels of stress are associated with a wide range of variables (Elder, 2001; Frey et al., 1989; Hastings et al., 2005; Noh et al., 1989). Eisenhower, Baker, & Blacher (2005) found that certain aspects of raising
a child with autism negatively impact maternal stress even after controlling for maternal education level, children's behavior problems, and cognitive level.

Researchers reported that the stress experienced by the parents of children with autism was long-term distress and it was caused by ambiguous nature of the disability and the severity of the disability (Tunall, & Power, 1993). Following a diagnosis, the ambiguity and uncertainty of the child’s prognosis provides another source of stress for parents. For example, in a study examining the impact of uncertainty on caregivers, researchers found that perceived uncertainty regarding the course of the illness became a significant predictor of the caretaker’s future distress (Sanders-Dewey, Mullins, & Chaney, 2001).

Researchers noted that parental distress among parents of children with autism results from factors such as the intensity, magnitude, duration, and unpredictability of autism (Noh, Dumas, Wolf, & Fisman, 1989). Similarly, Lecavalier, Aman, Seahill, McDougle, McCracken, and Vitiello, (2006) in their study of children and adolescents with Autism Spectrum Disorder, found that severity of the core features of autism may additionally contribute to caregiver stress (Lecavalier, Leone, & Wiltz, 2006). Whereas, other existing studies of families of children with autism suggest that behavioral, social, and cognitive dimensions of the disorder are associated with stress in parents. For example, Turner and Sloper, (1996) found that developmental delay among children with autism can cause parental stress.

Further, Kasari and Sigman (1997) found that the parents of children with autism were more likely to perceive their child as having difficult temperament than the parents of children with mental retardation and the parents of developmentally typical children. Problematic sleep in children with autism is associated with higher
levels of parental stress (Doo, & Wing, 2006; Patzold, Richdale, & Tonge, 1998). Moes (1995) found that common characteristics of children with autism such as scattered intellectual abilities or isolated skills and pervasive problem behavior such as self-stimulatory behaviors also contribute to parenting stress.

Studies have showed that the challenging behaviors of children with Autism Spectrum Disorder have been repeatedly associated with high levels of stress in mothers (Bromley, Hare, Davison, & Emerson, 2004; Hastings, Kovshoff, Ward, et al., 2005; Gray, 2003; Lecavalier, Leone, & Wiltz, 2006; Moes, 1995). For example, a recent study by Hastings, Kovshoff, Ward, et al. (2005) demonstrated that behavior problems of preschool children with autism were associated with maternal stress but not adaptive behavior or severity of autism symptoms. Higgins, Bailey, and Pearce, (2005) have pointed out that among parents of children with autism parental stress is often related to the antisocial behaviors such as self-injurious, ritualistic, and obsessive displayed by their children. Similarly, Gray, (2003) also found that the parents experienced high levels of stress due to aggressive or violent children. Parental stress results from their inability to control their child (Martinez-Pedraza, & Carter, 2009, pp. 649).

Further, it was found that the factors like limited social relations and eye contact in autistic children can increase the parental stress. This increased stress among the parents of children with autism may be because of the difficulties in making reasonable predictions regarding the potential and capability of the children. Similarly, the deficit in emotional expressiveness of autistic children may lower empathy between mother and child, and can induce greater parental stress. Hastings
and Johnson (2001) found that the parental stress increases with the severity of the child’s symptoms.

Poorer health in children with autism can increase parental stress by increasing frequency of doctor visits, medication management and financial problems (Johnston, Goldberg, Morris, & Livenson 2001; Lounds, Seltzer, Greenberg, & Shattuck, 2007; Murphy, Bruno, Abbeduto, Giles, Richmond, & Ormond, 2004; Ormond, Seltzer, Greenberg, & Krauss, 2006). Furthermore, Gray (1993) found that almost all the parents of younger and/or more severe autism feel stigmatized in public situations due to the negative characteristics a child which increase the stress among them. Many studies have found that worries about the future of their child can be a significant source of current stress among the parents of children with autism (Bouma, & Schweitzer, 1990; Donovan, 1988; Koegel, Schreibman, Loos, Dirlich-Wilhelm, Dunlap, Robbins, & Plienis, 1992).

Few other studies found that characteristics of parents of children with autism, such as aloofness, hypersensitivity, anxiousness, tense, rigid and, limited friendship also contribute to their increased psychological stress (Murphy et al., 2000; Piven, Chase, Landa, Wrozek, Gayle, Cloud & Folstein, 1991; Piven, Palmer, Jacob, Childress, & Arndt, 1997).

Other important factors associated with parental stress in families of children with autism, includes, the availability of support (Honey et al., 2005) both informal and professional support and feelings of loss of personal control. Woodgate, Ateah, and Secco (2008), in their qualitative study of the experience of parents with children diagnosed with autism, found that parents experiences isolation due to external sources e.g., society’s lack of understanding which increase stress among them. This
research challenged the results of previous studies suggesting that parents tended to isolate themselves from social contact to avoid awkward encounters with outsiders (Gray, 1997). Adjustments to the reality of the child’s condition, housing and finance are some of the other factors that influence parental stress (Gray, 2003).

Recent research suggests that the parental stress may not be determined only by the presence or absence of a disability, rather adaptive behavior deficits (McCarthy, Cuskelley, Kraayenoord, & Cohen, 2006; Saloviita, Italina, & Leinonen, 2003), personal care needs (Neely-Barnes, & Marcenko, 2004; Plant, & Sanders, 2007; Warfield, 2001), and medical needs (Neely-Barnes, & Marcenko, 2004) have been associated with parental stress.

Whereas, the reasons for increased stress among the parents of children with autism than the parents of children with mental retardation includes parents perception of limited feelings of attachment and closeness with their child (Hoppes, & Harris, 1990), less parenting competence, less marital satisfaction, and less family adaptability (Rodrigue, Morgan, and Geflken, 1990, 1992) and more involvement in the treatment of a child for which they may need to staying away from home or from the child.

Researchers found that socio-economic factors such as education and employment might not serve as a buffer against parental stress. Parents of children with autism experience financial difficulties because they work for fewer hours and have lower earnings than mothers of typically developing children (Olsson, & Hwang, 2006; Parish, Seltzer, Greenberg, & Floyd, 2004) and this financial difficulties can cause stress among parents of children with autism. Work related stress resulting from their absenteeism at work place also increase parenting stress (Warfield, 2001).
Further, Murphy, Bolton, Pickles, Fombonne, Piven, and Rutter, (2000) found that the parents of male child with autism reported more stress than female child with autism.

Mental retardation is one of the most common developmental disorders and the birth of a retarded child shatters the hope and aspirations, and further lead to hopelessness and negative attitude towards the child (Rangaswami, 1995). Mental retardation produces psychological, physical, social, and financial distress to the whole family, particularly parents, as they are virtually the only constant carers (Bristol, 1984). Kromberg and Zwane (1993), in their study of parents of children with mental retardation, found that parents of such children were showed the reactions of shock, surprise, anxiety, disbelief and disappointment. Jani (1967) found that parents of children with mental retardation experienced anxiety about future of their child. Winkler (1981) stated that tremendous amount of stress chronically affects their lives.

One of the earlier studies Jani (1967) also found that the presence of child with mental retardation causes negative effects on parents’ relations with other children without disabilities, increases psychological stress, decreases interaction with neighbors and relatives, increases misunderstandings within family and increases economic loss. This negative effect is a result of the degree of retardation, problem behaviour, burden on the family, etc.

Some studies reported that the parents of children with mental retardation had experienced less stress (Ricci, & Hodapp, 2003), depression (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004), and pessimism (Lewis, Abbeduto, Murphy, Richmond Giles, Bruno, et. al., 2006) than the parents of children with autism. Many other studies found higher levels of parenting stress among the parents
of children with mental retardation than the parents of non-disabled children (Dyson, 1997; Roach, Orsmand & Barrat, 1999; Rodrigue, Morgan, & Geffken, 1990).

Experience of parental stress is depends upon presence of many factors and their interactions with each other (Baxter et al., 2000; Frey et al., 1989; Quine, & Pahl 1991). These factors includes specific child characteristic, such as age, sex, diagnosis, IQ, levels of self-help skills (Perry, Sarlo-McGarvey, & Factor, 1992) and severity of disorder (Kumar, & Akhtar, 2001). Majumdar, Pereira, and Fernandes (2005) found that family’s education and income had an inverse relationship with perceived stress and burden.

Pahl and Quine (1987), in their a large-scale study of the impact of child with a disability on parental stress, found that parents of children with disabilities experienced higher level of stress than control group, due to child characteristics, such as level of disability and family characteristics, such as social isolation (Holmes, & Carr, 1991), adversity in the family, and financial difficulties. Researchers found that parental stress increased with increasing of age their child (Seltzer et al., 2001) because as the child grows older, parents develop a more realistic view of child’s future and outcome. Sharpley, Bitsika, and Efremidis (1997) found that the vast majority of parents reported being stretched beyond their limits because of their child's dependency needs.

Karmanshahi et al. (2008), in their study on parent’s perceptions of lives with children with mental retardation, found six major themes, namely, challenging the process of acceptance, painful emotional reactions, the interrelatedness of mother’s health and child’s well-being, struggles to deal with oneself or the child, inadequate
support from the family and the community, and anxiety related to child’s uncertain future.

However, in contrast earlier observations (Perry, McGarvey, & Pastor, 1992), Hornby (1995) found that parental stress was not affected by child specific characteristic, such as gender and age. Further, Kumar and Akhtar (2001) reported that parents’ education and economic status of the family did not make any difference to the perceived stress and burden.

On the other hand, Mahoney (1958) found that the disabled child can have an integrative effect by focusing the family’s energy in a concerned, loving manner, thereby minimizing some of the other day to day problems.

In general, parents of non-disabled children report less parenting stress, although the specific child and parent characteristics that contribute to parenting stress vary among these studies. As mentioned earlier, Beckman (1991) revealed significant group differences between parents of developmentally disabled and non-disabled children on both the child and parent domains of the Parental Stress Index. Despite the abundance of research focusing on and linking parenting stress to families of children with disabilities, Cameron, Dobson and Day (1991) stated that parenting any child can at times be a stressful experience. Cameron, Dobson and Day (1991) found significant differences between the parents of developmentally delayed and non-delayed children only with respect to child related stress in the areas of acceptability, demandingness, and distractibility.

The parents of normal children reported similar experiences of stress with respect to how reinforcing and acceptable their children were to them, and felt similar
levels of attachment to their children (Beckman, 1991). In contrast to Beckman’s (1991) study, Cameron, Dobson and Day (1991) discovered that the parents of non-delayed children reported similar experiences of stress with regard to all parent characteristics tapped by the Parent Domain, and also in the area of general life stress.

Lavee, Sharlin, and Katz (1996) interviewed 287 families of typically developing school-age children regarding marital stress, economic factors, work, and home roles and number of children and reported that the birth of a child, child entering school, empty nest period, retirement, layoff from work, natural disaster, and disability within the family can be sources of stress for parents of typically developing children. The possibility is that having children increases stress due to the enormous role adjustments.

In sum, the bulk of evidence seems to suggest that parents of normally developing children tend to report lower levels of stress with respect to child characteristics as compared to their cohorts with disabled children. In contrast, these differences become less or non-existent when parent characteristics contributing to parenting stress are compared.

Further, research has shown that many parent experience positive gains as a result of raising a child with autism or other disability, including personal growth, improved relationships with others, and increased patience and empathy (Hastings & Taunt, 2002; Pakenham, Sofronoff & Samios, 2005; Scorgie & Sobsey, 2000). A survey conducted by the organisation Contact-A-Family (2003) showed that a child with a disability can bring the parents to a closer relationship.
Gender Difference

There have been few studies demonstrating both similarities and differences in parenting stress reports between mothers and fathers of children with and without disabilities (Baker, 1994; Beckman, 1991; Krauss, 1993). Many fathers experience initial shock and intense feelings after learning the diagnosis of their children and their adaptation and adjustment was inversely related to the severity of the child’s disability and level of social support (Hornby, 1994). Studies consistently found that fathers reported significantly more problems with attachment (Baker, 1994; Krauss, 1993). Specifically, fathers stress was related to their child’s mood and adaptability than did mother (Krauss, 1993).

Studies have found that the prevalence of stress in mothers of children with autism is higher irrespective of cultures, ages of child and different functioning levels (Koegel, Schreibman, Loos, Dirlich-Wilhelm, et al. 1992). Dumas. Wolf. Fisman and Culligan, (1991) reported that mothers of children with autism are affected more negatively as a result of parenting a child with autism than fathers and they are likely to experience greater stress than fathers (Honey et al. 2005). Beckman (1991) found significant differences on six of the seven subscales comprising the Parent Domain. Specifically, mothers reported more depression, restrictiveness in the parental role, more problems with their sense of competence, more difficulties with their relationship with their spouse, and more negative effects on their health.

Krauss (1993) also demonstrated that mothers reported more parent related stress with respect to their health, role restrictions, and relationships with their spouse. Krauss (1993) also found gender differences between child characteristics contributing to parenting stress. However, Krauss (1993) did not found any
differences between mothers and fathers of young children with disabilities on parent related aspects of parenting stress such as social isolation, depression, and sense of competence.

Davis and Carter (2008) found that mothers of children with autism reported more child related parenting stress than do fathers. Even in more recent study, Dabrowska, and Pisula, (2010) reported that mothers of children with autism scored higher than fathers in parental stress. Mothers have primary responsibility for child care and are more subjected to the challenges associated with their child’s disability because of this they spend more time caring for their child with the disability than fathers (Heller, Hsieh, & Rowitz, 1997). Even with the adults with autism mother continue to provide care to their disable children despite the increased physical size (Holmes, and Carr, 1991; Miller, Gordon, & Daniele, 1998).

Similar results were reported by Smith, Hong, Seltzer, et al. (2010) who found that mothers of an adolescent or adult with an Autism Spectrum Disorder spent more time caring for their grown children and doing household chores, and spent fewer hours engaged in leisure activities than do fathers.

Gray (2003) found that the majority of fathers careers were unaffected by their child’s autism because mothers were most likely to be held responsible for their child's behaviour, both by their husbands and by people outside the family. They were often forced to miss work, perform below their normal level or drop back to part-time status. Further, Gray (2003) added that gender differences in level of stress may be due to gender role socialization of emotions, usually, males are expected to suppress their emotions. Parenting stress was also higher in mothers compared to fathers
because women are more vulnerable than men to stressful events (Rodrigue, Morgan, and Geffken 1992; Venkatesan, 2004).

Keller and Sterling-Honig (2004) found that for fathers, acceptance of the child with the disability and family harmony reduced stress while mothers were also affected by family harmony, lower socioeconomic status and greater care demands predicted stress.

However, smaller studies involving pairs of approximately 30 to 40 mothers or fathers of children with autism did not reported any significant gender differences on the measures of stress (Dyson, 1997; Keller, & Sterling-Honig, 2004; McCarthy, Cuskelley, Kraayenord, & Cohen, 2006). Thus, further research is needed to better understand what contributes to paternal stress for mothers and fathers.

There are very few studies available on the relationship between fathers and their mentally retarded children. This could be related to the fact that previously fathers did not take on an active role in their child’s life. However, presently fathers are also very involved in the care of their children. It is observed that father’s perception of their mentally retarded child is more instrumental while mother’s is more expressive. Fathers concerns centered mainly around the impact of the mentally retarded child on the family budget and the cost of providing help for the child, whether the child will achieve academic success and support him in adult life and whether the child could be able to stand up for himself. Whereas mother’s concerns generally focused on the emotional strain of caring for the retarded child, such as whether the child will be accepted by others and child will be happy regardless of academic achievement or job success, etc.
Earlier studies reported that compared with their spouses mothers experienced higher level of stress (Heller, Hsieh, & Rowitz, 1997; Kumar & Akhtar 2001; Majumdar, Pereira, Fernandes, 2005; Miller, Gordon, & Daniele, 1998; Pruchno and Patrick, 1999; Schilling, & Schinke, 1984). Similarly, Oelofsen and Richardson (2006) also found that mothers of children with developmental disabilities experienced increased stress than their husbands. Most fathers reported that their child’s condition did not have a significant effect on them personally but they are more affected by severe difficulties that their child’s mental retardation presented for their families. This may be due to the gender roles connected to work and child rearing (Gray, 2003). Mothers continue to carry the disproportionate burden in raising a disabled child because they are the primary caregivers for their children (Folkman, & Lazarus, 1988; Schopler & Mesibov, 1992), thereby being more prone to experience stress related to child care (Miller, Gordon, & Daniele, 1998).

The other possible reasons for this gender difference could be that: (a) mothers spent more time in caring for children with mental retardation (Frude, 1992; Heller, Hsieh, & Rowitz, 1997; Pruchno, & Patrick, 1999); (b) fathers' parental roles only infrequently included in rehabilitative or health promoting services, such as visits to the doctor, the drug store, or other special services, relative to the mother (Baxter, Cummings, & Yiolitis, 2000); (c) most mothers are home-makers without additional help and also are restricted to home with no time or provision for leisure activity (Majumdar, Pereira, & Fernandes, 2005); (d) Baxter, Cummings, and Yiolitis (2000) pointed out that father is less confronted with the child's deficiency in his daily living conditions, and they can moderate their stress through sharing experiences with other fathers who are dealing with similar burdens; and (e) fathers have more distant
relationships with their child with intellectual disability than mothers (Beckman, 1991; Bristol et al. 1998; McConachie, 1986; Pruchno, & Patrick, 1999).

According to Ntombela, (1991), apart from social and emotional problems, mothers also suffer from physical stress because of the higher mobility of the handicapped child, and the obesity and respiratory infections which are common amongst children with mental retardation.

However, in a recent study of parenting stress, Dabrowska, and Pisula (2010) did not found any gender difference among parents of children with mental retardation. Similarly, Dabrowska, and Pisula (2010) did not found any gender difference among parents of typically developing children.

### 2.3 COPING MECHANISM

Birth of a disabled child interrupts the normal life cycle of the family and lead to a crisis. Having an infant with disability is often experienced by parents as the death of the expected normal and healthy child (Moelsae, & Moelsae, 1985). The parents of a child with a disability go through the grieving process such as, denial, bargaining, anger, depression, and acceptance, in order accept their child’s handicapping condition (Seligman, & Darling, 1989). These stages are virtually identical with the five stages of the grieving process associated with death and dying. Grieving is an initial way of coping with a child’s severe disability.

Coping is defined as the process by which individuals respond to threats of stress. Coping strategies have been postulated as one mechanism by which parents adapt to the stresses associated with raising a child with a disability (Beresford, 1994). Coping strategies are divided in two main categories, namely, emotion-focused and
problem-focused. Problem focused coping strategies are used to solve the problem or do something to change the source of stress e.g., planning, and emotion-focused coping strategies are used to reduce or manage the feelings of distress e.g., denial, (Billing, & Moos, 1981; Bright, & Hayward, 1997; Carver, Scheier, & Weintraub, 1989; Folkman, & Lazarus, 1985; Folkman, & Moskowitz, 2000).

Coping with parenting stressors depends on the parents’ attribution to the sources of stress. According to cognitive model of stress and coping, the cognitive appraisal determines whether the person and environment relationship is judged as stressful or not (Lazarus, & Folkman, 1984). The parents’ cognitive appraisals towards their children characteristics determine their stress.

Luecher, Dede, Giten, Fennel, and Maria, (1999) found that the caregiver burden was not related to the severity of the child’s illness, rather it was related to the use of palliative coping skills, namely wishful thinking, self-blame, and avoidance. Frey et al. (1989) found that avoidance coping and wishful thinking was related with high distress among both 48 fathers and 48 mothers of handicapped children.

According to the cognitive theory of coping, problem-focused coping is more commonly used when the situation is seen as more controllable, and emotion centered coping is more frequently used when the situation is appraised as uncontrollable and unchangeable (Folkman, 1984). Thus, because of being more involved with the child’s needs, mothers may be appraising the situation as more uncontrollable, due to their high emotional exhaustion. According to Lazarus’s (1990) theoretical framework, during appraisal process persons first evaluate the harmfulness of the situation and then they evaluate the coping resources. The high education level may
be a resource factor for using problem solving approach more frequently for both mothers and fathers.

In another study, it was found that the problem-focused coping strategies were more used by the parents of handicapped children who were in early intervention programmes than emotion-focused coping styles (Judge, 1998). Park (1998) proposed that personal characteristics directly influence the positive outcomes such as thriving and growth but personal characteristics may be mediated by the appraisal and coping processes.

Autism is one of the most complex and intractable developmental disorders with which families have to cope. Parents of children with autism are often denied of some of the fundamental rewards of parenthood because this disorder has no clear biological marker, the diagnosis and prognosis for autism is fraught with uncertainty, and the social interaction problems, such as forming attachments and showing affection. Thus, the parents experience the birth of disabled child as the death of the expected normal and healthy child (Moelsae, & Moelsae, 1985). Research has shown that autism can create greater parental anxiety and tension than parents of non-disabled children (Sander, & Morgan, 1997); than parents of children with other physical or learning disabilities (Gray, 1993); or parents with children with other developmental disabilities (Hastings, & Johnson, 2001).

However, research has also showed that stress is not an inevitable consequence in these families. A variety of studies have been conducted to identify the factors that mediate or buffer the stress associated with having a child with autism, particularly social support and psychological resources of the parent (Anderson,
Thibadeau, & Christian, 1994). The role of coping for mental health and well-being among mothers of children with Autism Spectrum Disorder is less clear.

Few studies found that coping strategies plays a protective role for parents despite the challenges associated with caring for a child with a developmental disability (Essex, Seltzer, & Krauss, 1999; Seltzer, Greenberg, & Krauss, 1995). For example, Gill and Harris (1991) studied 60 mothers of children with autism, aged 2 to 18, and found that mothers with higher scores on perceived good social support had fewer somatic complaints and fewer depressive symptoms than did those who perceived less social support.

Further evidence of the critical role of social support is provided by a study reported by Sharpley, Bitsika, and Efremidis (1997). They surveyed over 200 parents of children with autism in Australia and found that the vast majority of parents had significantly lower levels of anxiety and depression if other family members felt comfortable with the child's disability and provided care giving assistance. Coping strategies identified by parents of children with autism are spousal support, acceptance of the child, formal services and programs; family oriented training programs and reliance on a social network (Dunn et al., 2001; Fong et al., 1993; Harris, 1994; Hastings, & Johnson, 2001; Robbins et al., 1991; Rodrigue et al., 1990; Skinner et al., 1999).

Fong (1991) reported that mothers of adolescents with autism with high level of stress tend to use ‘threatening’ appraisals, i.e., the tendency to assess situations with worry or concern, whereas mothers low in stress tend to use more ‘benign’ appraisals. It was found that parents often worried about the future of their child (Frith, 2003; Dale, Jahoda and Knott, 2006). Rodrigue, Morgan and Geffken (1992)
compared fathers with children with autism to control group of fathers with typically developing children and found that fathers with children with autism reported more use of wish-fulfilling fantasy and information seeking as coping strategies than did the control group of fathers with typically developing children. They also felt a greater financial impact and disruption of family activities than did the control group.

In addition to formal and informal social support, parental psychological resources have been found to buffer the effects of stress or to account for the manner in which the stress of parenting a child with autism affects psychological well-being. Use of active coping patterns predicts favorable outcomes in mothers. The type of cognitive appraisals used by mothers of adolescents with autism is another psychological resource that mediates the manifestation of stress.

Research suggests the effectiveness of coping depends on the positive coping strategies used by the parents, the resources available within the family, and the availability of social support from the spouse, family and informal networks (Tarakeshwar, & Pargament, 2001). Most of the studies of interventions for parental stress found that cognitive techniques such as, enhancing problem solving, cognitive restructuring, setting goals, (Hastings & Beck, 2004), case management services and respite care decreases parental stress (Chan, & Sigafoos, 2001).

Another intervention concept closely related to problem-focused coping is the parent's sense of empowerment. Empowerment has been defined as "a person's (i) access to and control over needed resources, (ii) decision-making and problem-solving abilities, and (iii) acquisition of instrumental behavior needed to interact effectively with others to procure resources" (Dunst, Trivette, & Deal, 1988, p. 3).
Interventions that involve empowerment hold promise for helping families deal with the stress of having a child with a disability.

Further, Essex, Seltzer, and Krauss (1999) found that mothers using problem-focused coping to cope with their child's disability experienced less stress than those who employed emotion-focused coping. However, Essex, Seltzer, and Krauss (1999) found that fathers did not get the same benefits from problem-focused coping and only experienced decreases in burden when they refrained from emotion-focused coping.

Moreover, lower level of coping mechanism of parents is related with higher level of stress and tension (Gray, 2006). It was found that active avoidance coping predicted higher levels of stress whereas problem-focused coping was not related to stress among parents of preschool and school-aged children with autism (Hasting, Kovshoff, Brown, et al. 2005). In India, some of the most commonly used coping strategies in times of distress are religious belief, destiny, karma theory, and theory of reincarnation (Dalal, & Pande, 1999).

It is important to discourage parents from using escape and avoidance as a coping style and encouragement of more appropriate coping methods and receipt of social support to reduce the ill effects of stress (Dunn et al., 2001). Emotion-focused coping is only beneficial in situations that are beyond the caregiver's control. Thus, caregiver stress can be decreased by helping the caregiver to focus on aspects of the disability that are under his or her control, such as asking for assistance and advice when needed or advocating for the child’s needs (Ylven et al., 2006). Hardiness and social support are predictors of successful adaptation (Weiss, 2002). There is no direct
relationship between social support and isolation suggesting that some of the parents feel isolated despite receiving social support (Dunn et al., 2001).

In contrast with findings reported by other researchers Abbeduto et al. (2004) found no evidence of a buffering effect of coping with behavioral symptoms for mothers of children with autism, perhaps reflecting the potential ineffectiveness of coping strategies in the face of the uncontrollable stress that may arise from the unpredictable behavior problems associated with autism. Similarly, Higgins, Bailey, and Pearce, (2005) also found that coping style was not related to individual or family adjustment.

Parental coping does not differ with the age of the child with autism. Gray (2006) had found that coping among parents of children with autism changes over time, from problem-focused, to emotion-focused. Aging of parents is associated with less coping through reliance on service providers, family support, social withdrawal, and individualism. They usually cope by their religious beliefs and some other emotion-focused strategies.

**Gender differences**

Gender differences in coping strategies are the ways in which men and women differ in managing psychological distress. Research suggests that mothers and fathers may experience different impacts of childhood disability and have different needs related to coping with the disability. In comparison to fathers, mothers of children with disabilities have been found to exhibit increased symptoms of depression (Hastings et al. 2005; Olsson, & Hwang, 2001), increased caregiver burden (Heller et
al. 1997) and increased stress (Dellve, Samuelsson, Tallborn, Fasth, & Hallberg, 2006; Herring, Gray, Taffe, Tonge, Sweeney, & Einfeld, 2006).

The fathers experience considerable stress due to continual disturbed sleep, the need to take time off work, and to support their partner in managing the child’s behavior. For fathers, the most serious effect of their child’s autism was the stress experienced by their wives. Fathers felt that their sacrifice was in having to work harder to support the extra demands on the family, as a result of the child’s disability.

Mothers and fathers also cope differently with emotional distress; fathers typically suppress their feelings, often at the cost of anger (Gray, 2003). Mothers tend to vent their feelings and had a wider range of emotional expression, feeling grief and sadness in addition to anger and crying. They rely on talking to friends and family as a way of dealing with their emotions, particularly other mothers with a child with autism.

Fathers of children with autism report more frequent use of wish-fulfilling fantasy, and information seeking as coping strategies (Rodrigue et al. 1992). They also reported perceived lack of support (Burke, & Cigno, 1996). Although it was found that fathers were less involved with physical care and domestic tasks, Burke and Cigno (1996) reported that they do provide a high level of support. The fathers are also coping by working away from home. Their child's autism might be encouraging a greater commitment to work. Acquiring social support and reframing the experience to see some positives are most frequently used coping strategies by fathers (Luther, Canham, & Cureton, 2005). The only significant difference between fathers and mothers was in the frequency of using helplessness/self-blaming
approach. Mothers’ scores on frequency of using helplessness/self-blaming approach were significantly higher than the fathers (Luther, Canham, & Cureton, 2005).

Nevertheless, the availability of informal and formal social support and the use of personal psychological resources such as active coping, positive appraisals, and the personality characteristic of hardiness, can ameliorate the stress of parenting a child with autism, at least during the childhood and adolescent stages of family life. Early studies indicated that gender differences in coping were relatively small when the source of stressors were controlled (Billings, & Moos, 1981) and more recent work has similarly revealed small differences between women’s and men’s coping strategies when studying individuals in similar situations (Brannan, & Heflinger, 2001).

Many of the observational studies of parenting in families of children with mental retardation were primarily study of mothering. One notable exception to this is a longitudinal study of mothers and fathers of school-aged children with mental retardation by Floyd, Costigan, and Phillippe (1997). They found considerable similarity between mothers’ and fathers’ interactions with their children as no significant differences emerged for the proportions of commands and noncompliance, positive and negative behaviors, and for the levels of positive and negative reciprocity between mother-child and father-child interactions at either of the measurement periods. The only major difference was that mothers were much more involved with their children than fathers.

Earlier, Girolametto and Tannock (1994), in a study of 20 married couples, had also reported many similarities between mothers and fathers in interactive behavior with their children with developmental delays. Fathers differed from
mothers, however, along some dimensions of behavioral directiveness in that they used more topic control and response control with their children.

Recently, deFalco, Esposito, Venuti, and Bornstein (2008) studied father–child play interactions with children with mental retardation and found that father play was associated with more child exploration and symbolic play. Further, fathers and children representing high emotional availability were more likely to show more symbolic play and less exploratory play than were those dyads with low emotional availability. Certainly, there seem to be clear similarities with mothers, but father behavior may be different across time and context (Lamb, 2004).

For both men and women, emotion-focused coping is associated with higher levels of psychological distress, whereas problem-focused is associated with lower levels of distress (Kramer, 1997; Lutzky, & Knight, 1994). However, previous researchers have found gender differences in coping. For example, Ptacek, Smith, and Dodge (1994), Thoits (1995), and Vingerhoets, and Van Heck, (1990) found that women less likely to use problem-focused coping and more likely to engage in emotion-focused coping than men. Other researchers found gender differences only in emotion-focused coping (Borden, & Berlin, 1990; Lutzky, & Knight, 1994).

2.4 PSYCHOLOGICAL WELL-BEING

It was assumed that parents of children with developmental disabilities have higher levels of negative affect and lower levels of psychological well-being than parents of non-disabled children. Research has showed that having a child with a disability such as autism presents a unique set of challenges that impacts the health and well-being of parents (Patterson, 2005; Turnbull. Turnbull. Erwin, & Soodak,
Recent studies have found that raising children with autism can have a negative impact on parents' emotional functioning and psychological well-being (Marciano, 2005; Noh et al. 1989).

Gray (2003) found that the parents of children with autism claim that child's autism had severely affected their emotional well-being. Other comparative studies of parents of children with autism and other disabilities such as Down syndrome, fragile X syndrome, undifferentiated developmental disability, and cerebral palsy, also reported that parents of children with autism had more negative impact and poorer well-being during their children's preschool years (Eisenhower, Baker, & Blacher, 2005) and adulthood (Abbeduto et al. 2004; Blacher, & McIntyre, 2006). Further, Ha et al. (2008) had also reported lower mean levels of well-being among parents of children with an autism compared with other parents.

It was found that parents of children with autism had significantly higher depression (measured by Beck Depression Inventory), higher state anxiety (measured by State-trait anxiety inventory) and higher general symptom scores on symptom checklist - 90 than those of mentally retarded children (Sanders, & Morgan, 1997; Olsson, & Hwang, 2001; Ryde & Brandt, 1990). Two recent meta-analyses showed that parents of children with autism were at higher risk for depressive symptoms and clinical depression compared to parents of children with mental retardation and normal children/non-disabled children (Bailey, Golden, Roberts, & Ford, 2007; Singer, 2006). Further, Hodapp, Dykens, and Masino, (1997) found that the mothers of autistic children were more introverted and neurotic than the normal control group.

Factors like difficulties in family adaptability and cohesion can cause these problems among parents of children with autism (Kelly, Garnett, Attwood, &
Peterson, 2008). Lecavalier et al. (2006) pointed out that behaviors specific to autism affects parental well-being. The challenging behaviors of children with autism can lead to poor maternal psychological well-being (Abbeduto et al. 2004; Allik, Larsson, & Smedje, 2006; Herring et al., 2006). Among parents of children with autism, autism symptoms and behavior problems are negatively associated with parental psychological well-being (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006). Further, less severe maladaptive behaviors, less social impairments of the child with autism and lower level of pessimism in the parents’ can leads to more positive parent-child relationship.

Burden of caring a child with autism and stigma caused by child’ disability affect the psychological well-being of parents (Gray, 2003) whereas the greater positive affect and warmth of parent-child relationship can improve psychological well-being (Orsmond, Seltzer, Greenberg, & Krauss, 2006). Likewise, Ha, Hong, Seltzer, and Greenberg (2008) found that psychological well-being improves with longer duration of care among parents of a child with a disability.

Although parents of children with autism are at higher risk for poor emotional and psychological well-being compared with other parents, age group comparisons in cross-sectional studies of parents suggested that upswings may occur over time (Magana, & Smith, 2006). A recent meta-analysis of cross-sectional research (Singer, 2006) had shown that parents of younger children with developmental disability report poor emotional and psychological well-being compared to parents of older children with a developmental disability.

In the study of parents of an adolescent or young adult with autism, aged 13 to 22, Lounds, Seltzer, Greenberg, and Shattuck (2007) showed that although parents
compromise with their emotional and psychological well-being they may adjust to their non-normative parenting roles with experience. Adjustment to care giving challenges among parents of children with autism may reflect normative age-related changes in perspectives that benefit emotional and psychological well-being (Jorm et al. 2005; Kasen, Cohen, Chen, & Castille, 2003). Experiencing more stressful life events was related to more depressive symptoms only for younger mothers, this suggests that older mothers may be better able to cope with general life stressors (Charles, & Piazza, 2009). Social support and experiencing fewer life stressors likely foster well-being and vice versa well-being likely to the maintenance of social support and successful coping (Charles, & Carstensen, 2010).

In contrast to these findings, Olsson and Hwang, (2001) found that there were no differences between parents with children with autism and parents of children with intellectual disability without autism in terms of depression as measured by Beck Depression Inventory.

Children with autism are vulnerable to elevated rates of seizures (Billstedt, Gillberg, & Gillberg, 2005; Fombonne, 2003) and gastrointestinal problems (Azfal et al. 2003; Horvath, Papadimitriou, Rabsztyn, Drachtenberg, & Tildon, 1999; Molloy & Manning-Courtney, 2003; Valicenti-McDermott et al. 2006). These health problem in children with autism may play vital role in the well-being of parents because beyond worry about child’s health and health problems can necessitate additional caregiving responsibilities, such as increased frequency of doctor visits and medication management (Lounds, Seltzer, Greenberg, & Shattuck, 2007; Orsmond, Seltzer, Greenberg, & Krauss, 2006).
Researchers found that parents of children with mental retardation have more mental health problems such as depression than parents of typically developing children (Blacher, Shapiro, & Fusco, 1997; Olsson, & Hwang, 2001). Olsson and Hwang (2008) studied parental well-being in Swedish families of children with Intellectual Disability and found that parents of children with intellectual disability reported less well-being than parents of typically developing children. Ha, Hong, Seltzer, and Greenberg (2008) also found that parents of children with Intellectual Disability reported less well-being than parents of typically developing children.

Researchers found that factors such as health problems of child, financial problems of family (Olsson and Hwang, 2008) and parental age (Ha, Hong, Seltzer, and Greenberg, 2008) affects parental well-being among parents of children with mental retardation. Ha, Hong, Seltzer, and Greenberg (2008) found that younger parents reported less well-being that did older parents. In contrast, few other researchers noted decrease in parental psychological well-being with increased age of the child, from childhood through adolescence (Johnston, Hessl, Eliez, Erba, Dyer-Friedman, Glaser, et al. 2003) this is due to increased care demands as well as behavioral problems of the disabled children.

Kersh et al. (2006) reported that high-quality marital relationship is also important for parental well-being. They also found that both mothers and fathers of children with Intellectual Disability reported higher marital quality demonstrated greater well-being. Further, Glidden, Billings, and Jobe (2006), in a study of parents of children with Intellectual Disability, found that parental coping strategies predicted levels of parental well-being. Parents’ use of positive reappraisal strategies was
related to higher well-being whereas the use of escape-avoidant strategies predicted lower well-being.

However, Blacher, Neece, and Paczkowski (2005) found no differences in depression, well-being, and marital adjustment for families with and without children with disabilities.

**Gender Difference**

Mothers of children with autism, compared to fathers, had poor well-being and this difference is caused by gender difference in care taking burden (Gray, 2003). Mothers report both greater depression and greater positive impacts than fathers regardless of race and ethnicity (Blacher, & McIntyre, 2006; Hastings et al. 2005). The burden of caring for the child with autism has fall predominantly upon the mothers because of this they experience low parenting competence, less marital satisfaction, family adaptability and significant levels of chronic stress and fatigue (Sander, & Morgan, 1997). The mothers of children with autism spent more time caring for their children and doing household chores, and spent fewer hours in leisure activities, than fathers. This is also affecting mother’s well-being negatively (Smith et al. 2010).

Similarly, the gender difference in experiencing stigmatization because of child’s autism also cause difference in well-being of fathers and mother (Gray, 1993). Gray (1993) found that mothers or children with autism are more likely to experience stigma than their counter part.

Result of prior research suggests that there are gender differences in psychological well-being and distress. It was found that women reported more
depressive symptoms (Nolen-Hoeksema, 1990; Pruchno & Resch, 1989; Seltzer, 2001; Sharpley, Bitsika and Efremidis, 1997) and have higher levels of subjective burden (Heller, Hsieh, & Rowitz, 1997; Kramer, & Kipnis, 1995; Miller, & Cafasso, 1992) than do men. Similarly, research has revealed that psychiatric morbidity such as depression, anxiety, experiencing high levels of stress are common among mothers of children with mental retardation (Gregory, 1991; Johnson, 1985; and McKinney and Peterson, 1987).

Particularly, Seltzer, et al. (2001) found that mothers exhibit greater depressive symptoms compared to fathers. Similarly, studies of families of young children with mental retardation reported higher score on various measures of global and role specific distress in mother than do fathers (Beckman, 1991; Krauss, 1993).

More recent studies conducted by Pinquart and Sorensen (2006) and Davis and Carter, (2008) found that mothers of children report lower psychological well-being than fathers, although these differences are often small in magnitude (Miller, & Cafasso, 1992). Further, Olsson and Hwang (2008) studied parental well-being in Swedish families of children with Intellectual Disability and found that mothers reported less well-being compared to fathers.

In contrast, Seltzer et al. (2001) found no gender differences in psychological or physical well-being for parents of children with mental retardation. Similarly, Ha, Hong, Seltzer, and Greenberg (2008) found no difference in well-being between mothers and fathers of children with Intellectual Disability in data extracted from a population-based study.
Gender differences in psychological well-being are result of life-long socialization patterns. In the traditional division of family labor, women were expected to take care of family members and household matters, while men were expected to engage in economic activities outside of the home. Today, the boundaries between men’s and women’s roles are becoming less distinct, yet care giving and parenting are still more the responsibility of women than men (Ross, & VanWilligen, 1996). Mothers spend more time caring for their disabled child than men because of which there are prone to experience poor well-being (Müller, & Cafasson, 1992; Pinquart, & Sorensen, 2006).

Greenberg (2002) found that gender differences in parents’ level of stigma and frequency of disruptions also results in gender difference in psychological well-being. Mothers of children with mental retardation are more likely to experience stigma due to the retardation of their child than men which cause poor well-being in them.

2.5 SUMMARY

In this chapter earlier and recent study related to parenting stress, parental coping and psychological well-being were reviewed. Disability and gender wise difference related to parenting stress, parental coping and psychological well-being were stated in this chapter. In next chapter the detailed methodology of this study is covered.