Chapter 2

Review of literature
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A literature review is a description of the literature relevant to a particular field or topic. It is an indispensable part of any study because every research or investigation contributes to the understanding of the field. Every investigation is a part of a collective venture and therefore cannot be seen in isolation. Hence, it is essential that previous viewpoints and findings of the earlier researches regarding the phenomenon to be taken in to consideration. The present research was undertaken to explore the impact of parental stress and social support on self-concept of disabled adolescents. A systematic review of previous researches related to this field is presented below.

Self-concept is an important variable and a number of studies have been conducted to look at the self-concept with its ramification for individuals with disabilities. Research has not, however, consistently found that individuals with disabilities have lower levels of self-esteem and self-worth than their typically developing peers. (King et al., 1993; Chapman, 1988; Silverman & Zigmond, 1983).

Appleton et al., (1994) conducted a study to measure the self-concept of people with spina bifida. Seventy nine young people with spina bifida were given a psychological, medical, carer and occupational therapy assessment and 79 matched able-bodied young people received the psychosocial interview. It was found that the disabled group felt themselves to be less competent in academic, athletic and social aspects of self-concepts, less supported by classmates, equally supported by parents and friends and more supported by teachers than the able-bodied group. Disabled subjects did not discount the importance of any area of personal-social functioning, and experienced greater discrepancies between competence and importance in most academic, athletic, social and physical appearance aspects of self-concept. Disabled
girls assigned very high importance to physical appearance. Physical appearance was more strongly associated with general self-esteem than any other area of self-concept.

In another study Minchem, et al., (1995) examined the relationship between medical and functional severity of disability and levels of self-esteem and self-concept in 79 young people with spina bifida. Greater feelings of global self-worth and of self-esteem in physical appearance were found to be associated with greater severity of disability. This was only in part an effect of lower I.Q. among the most disabled young people. Many of the least disabled had marked impairment of self-esteem. Analysis of the impact of individual aspects of disability confirmed the association between increased self-esteem in physical appearance and global self-worth and diminished functional ability. Academic, self-ratings, however, were higher in the less disabled. Hydrocephalus and continue appeared to have minimal effect on self-esteem. The relationship between severity of disability in spina bifida and self-concept is complex and mediated by a range of factors. It was incorrect to assume that the psychological impact was less in the mildly disabled young person.

Sliffer et al., (2003) investigated the relationships between child/parent dissatisfaction with child facial appearance and the self-concept/social competence of 8 to 15 year old children with (N=34) and without (N=34) oral clefts. Children in both groups had normative psychosocial adjustment but also reported moderate dissatisfaction with facial appearance. Cleft group parents were more dissatisfied with child facial appearance; their children reported better quality of life. They found that parents of children with clefts reporting greater dissatisfaction may respond in positive ways that enhance quality of life.

and palates. 18 patients aged 7-13 years old were interviewed and their mothers or fathers were asked to fill in the questionnaire during the interview. Self-esteem of children showed statistically significant relation with four areas of self-concept such as scholastic competence, athletic competence, physical appearance and behavioral conduct. Self-esteem also showed significant relation with cleft lips and/or palates. No statistical relations was found between self-esteem and other factors such as psychological adjustment at school, parents attitude for child rearing and marital status of the mother.

Van and Alison (1979) examined the relationship between school setting and self-concept in 20 handicapped school children and found no significant correlation. The socio-economic status of the child, however, did seem to have some importance to self-concept. (LH) whether the disabled child is attending a normal school or a special school meant for physically disabled have a significant impact on their self-concept.

Harvey and Greenway (1984) in a comparative study of the self-concept of 20 pre-adolescent physically handicapped children attending normal schools and their siblings nearest in age, 13 physically handicapped children attending special schools and their siblings, and 18 non-handicapped children and their siblings found that mean total scores were lower for both groups of physically handicapped children. When compared to mean scores for the non-handicapped controls, with similar results amongst the groups of siblings, the mean scores for siblings of handicapped children being generally lower than those of the controls. The same results were found when the handicapped children’s groups were pooled and analyzed according to diagnosis. It was also found that there were few significant differences between pairs of target children and siblings, irrespective of their groupings.
Studies on gender differences on self-concept of disabled children reveal significant differences between male and female disabled on different dimensions of self-concept, self-esteem and self-worth.

King et al., (1993) in their study of adolescents with physical disabilities found that females were lower in perceived social acceptance, athletic competence and romantic appeal than the normative sample whilst males were lower in perceived scholastic competence, athletic competence and romantic appeal.

Kumar N & Ittyerah M (2007) examined the actual and ideal self-concept of handicapped children, adolescents and adults, with the help of questionnaire to compare their responses to body image, skills/abilities, life experience and social interaction. They found that children had a more positive self-concept than adults and adolescents. Men had a more positive self-concept than females. Further, social interaction and abilities were rated more positively than body image and life experience. Correlations between the actual and ideal selves revealed a positive relation between the actual self and the desired ideal self for all the groups, and there were no gender differences. Narrative analysis of the groups revealed that adults had a more positive view of life as compared to adolescents or children. The positive views of self were a consequence of factors that were largely internal to the respondent, such as the use of mature ways of thinking and maintaining one’s self-respect. The negative views of the self were rooted in external factors over which the individual had little or no control such as poverty and negative attitudes of others. Although the female disabled group had a lower self-concept than males, there was a positive relationship between their actual and ideal selves indicating acceptance of their congenital defects as a challenge to integrate into the mainstream.
Although the process of development of self-concept is the same whether sighted or blind, visual defect influences this process. However there is no clear evidence that the lack of vision has a general effect on visually impaired children.

The findings of earlier studies on differences in self-concept in adolescents suggest that teenagers with visual impairment, including those with low vision, had a lower self-concept in several dimensions than their peers without visual impairment (Beaty 1991, Johnson and Johnson 1991, Obiakor and style 1991, Beaty 1992, Lopez-justicia et al. 2001b). Some of the reasons for the lower self-concept among adolescents with visual impairments are related to the difficulties many of them face when integrating into school and society, probably because adolescents are perceived by peers as less attractive or because they have more obstacles in establishing social relations, perhaps due to their lower autonomy levels (Lopez-Justicia et al. 2001b).

Some studies have been carried out in blind persons to study the differences in self-concept between normally sighted and the blind. In one such study Jevis (1959) found that blind persons showed extreme values, they either had a very low self-concept or over-rated their personal attributes compared to sighted persons. Calek (1980), indicated that blind men had a more positive and realistic self-concept than blind women. In a study to determine the gender differences in self-concept of young men and women, aged 12-17 years with congenital low vision in Spain, Lopez-justicia (2001a) found that young women had a lower self-perception than young men in 3 of the components evaluated (social self-concept, family self-behavior, and moral self-behavior). Young men had higher social self-concept and family and moral self-behavior i.e., they felt more competent in the social field and more valued by their friends than girls of the same age. Young men were more satisfied in terms of family...
relationships, perhaps because they participated more in social activities and these activities presented them with more possibilities.

Amezcua, J. et al., (2001) conducted three studies on Spanish students with low vision, aged 4-7, 8-11, and 12-17 years found that overall, the participants’ scores for some dimensions of self-concept were lower than those of comparison groups of sighted students of the same ages. The participants with low vision were found to have difficulty coping with a number of situations in their school and social lives.

Griffin- Shirley et al., (2006) conducted a study on self-esteem and empathy among 71 students with visual impairments and 88 sighted students. No significant difference was found between the two groups of students in their levels of self-esteem, empathy toward others and bonding with pets.

Lopez et al., (2005) in a further study examined differences in self-concept between children with congenital low vision and their sighted peers and found that the children with low vision scored lower than those with normal vision in aspects of their relationships with classmates but higher in their relationships with parents. But no difference was found on other general or specific facets of the self-concept such as physical ability, physical appearance, verbal ability, mathematics or general subjects.

Parenting a disabled child is highly stressful for almost all the parents. Most of the studies on parenting stress have tried to explore the level of stress experienced by such parents, coping strategies they use to meet the challenges of bringing up a disabled child and predicting the factors of stress in these parents. Results of most of the studies show that a high level of stress is related to parenting a disabled child.

Dyson, L. & Fewell, R. R. (1986) conducted a study in which three questions were asked; (1) Do parents of handicapped children experience more stress than parents of non handicapped children? (2) What are the sources of stress for parents of
handicapped children? And (3) is stress in the parents of handicapped children mediated by an external factor of social support? Findings indicated significantly greater stress in the families with handicapped children, and four factors were identified as significantly related to stress in these families. Perceived family support was significantly greater for families with handicapped children, and although non-significant (p < .057), findings suggest that families without handicapped children who had more support reported less stress.

Anne E. K. (1986) compared mothers and fathers of 125 handicapped/chronically ill children with parents of 127 matched non-disabled children from three separate samples with respect to personal stress, marital satisfaction, and social network size and density. Only mothers of disabled children experienced higher levels of stress than comparison parents. No differences were found in marital satisfaction. Few group differences were found for social network variables, although mothers of handicapped children, had higher-density networks than comparison mothers.

Hussain, A & Juyal, I. (2007) examined the level of stress and coping strategies among parents of physically challenged and normal children. 60 parents (either father or mother) of school going children (30 in each group, namely parents of physically challenged and normal) were taken for the study. Peacock and Wong Stress Appraisal Measure was used to examine their level of stress, whereas Folkman and Lazarus Ways of Coping Questionnaire was used to assess coping strategies adopted by the two groups of parents. It was found that the level of stress among parents of physically challenged children was much higher and significantly differed with their normal counterparts. The two groups also differed significantly in
terms of their coping strategies where parents of normal children were much better than the parents of physically challenged group.

Waisbern et al., (2004) examined predictors of parenting stress in parents whose children were diagnosed with a biochemical genetic disorder. Parents of 263 children with biochemical genetic disorders (139 identified by newborn screening and 124 identified clinically) completed interviews which focused on child health, medical service use, satisfaction with services, parenting stress and family functioning. Multiple regression analyses suggested that child adaptive functioning, parental satisfaction with support, and difficulties parents experienced meeting their child’s health care needs were associated with scores on the Parenting Stress Index.

Warfield, M. E. (2005) tested family resources (i.e. household income and spouse support), parenting challenges (i.e. number of children, difficulty finding reliable child care, and child characteristics), work rewards (i.e. work interest) and work demands (i.e. hours and worked overload) as predictors of parenting role stress among mothers and fathers in two-earner families of five-year-old children with disabilities. The two-level hierarchical model was adopted to assess mothers and fathers as nested within married couples. Both common and unique predictors of maternal and paternal parenting role stress for both parents were studied. Household income and an interaction between child behavior problems and work interest were significant predictors of maternal parenting role stress. In contrast, greater difficulty in finding reliable child care predicted higher levels of parenting role stress for fathers but not for mothers.

Keller and Sterling (2004) examined stress factors in families with a school-aged child with a disability. Path analysis revealed that children’s
demandingness and neediness for care was related more to maternal stress and that child's acceptability was related more to paternal stress.

Cowen, et al., (2002) examined socio demographic, health, and stress characteristics of families parenting a child with developmental disabilities who used respite care interventions, and investigated the degree to which use of a respite care intervention program affects parenting stress, foster care placement, and founded child maltreatment. Results showed that extensive care needs of the children or the families' inability to meet or cope with those needs were major factors contributing to high stress in the parent-child relationship. Comparison of pre- and postest scores indicated significant decreases in total stress, parent domain, and child domain scores.

Deater-Deckard, K. (2005) conceptualized parenting stress and its links to socio-economic resources, family structural characteristics, work and career-related factors, and childcare for mothers and fathers of developmentally disabled children. The most common finding was that although there was great diversity in the challenges faced by parents, the samples of participants resemble each other in terms of the variability in parenting stress that was seen.

Miller, A. C. (1992) investigated 69 mothers of physically disabled children (MOD) and 63 mothers of non disabled children. Testing for differences between groups in responses to stressful parenting events revealed that MOD reported higher levels of depressive symptomatology. Differences in psychological distress and health status approached significance. Testing for mediating influences of coping strategies and cognitive appraisals revealed that emotion-focused coping was related to increased psychological distress in MOD, whereas problem-focused coping was
associated with decreased distress. Both relationships were significant even after controlling for differences in type of parenting stressor.

Pearson, et al., (1993) examined the relationship between parenting stress and social support in 100 mothers (aged 28-56 yrs) of learning disabled children (LDCs) and a control group of 75 mothers with similarly aged non handicapped children. Mothers of LDCs had significantly more stress and significantly less support than those in the control group. The amount of support provided by friends and colleagues was significantly different between the 2 groups. Extended family provided more support to mothers of LDCs than did either work colleagues or friends. No significant correlation was found between total parenting stress and social support.

Cohen, M (1990) investigated how parents of young children in preschool special education programs adjust to their children’s developmental disabilities. The objective of this research was to investigate the cognitive and affective adjustment of parents of special preschool children in comparison to parents of non disabled children, and if emotional well-being affects the judgments that special or comparison parents form about their children. Results showed that parents of special children evaluated their children as demonstrating more internalizing and externalizing behaviors than did parents of non disabled children. In addition, It was found that on a range of affective distress indicators parents of special children had greater rates of depression, anxiety (non-significant), and parenting stress (significant) than parents of non disabled children.

Troster, H. (2001) compared the stress of 47 mothers (aged 25-46 yrs) of children who were visually impaired (aged 8-87 months) with that of mothers of children with no disability to examine which domains were particularly stressful
for them, which factors contributed to their stress and which resources reduced it. The degree of visual impairment, the extent of the child's functional impairments, and the availability of social support were assessed as potential determinants of maternal stress. It was found that mothers of children with visual impairments experienced more stress than did mothers of children with no disability, particularly in areas involving the children's behavior and when the children had multiple disabilities. The major resource for the families was the availability of social support.

The above studies indicate that parenting stress is experienced across all socio demographic groups and many contexts (Crnic & Low, 2002). Parenting stress plays a significant role in children's behavior. It may be directly related to child outcomes (Anthony et al., 2005; Crnic, Gaze, & Hoffman, 2005), or related indirectly through parenting behaviors (Deater-Deckard & Scarr, 1996). Research findings have generally supported the mediating role of parental behavior between parental stress and child adjustment (e.g., Conger et al., 2000; Galambos, Sears, Almeida, & Kolaric, 1995). Furthermore, few studies on stress associated with parenting preschool-aged children lend limited support for the indirect effects of parenting stress on child behavior through parenting (Anthony et al., 2005; Crnic et al., 2005; Deater-Deckard & Scarr, 1996).

An indirect effect of parenting stress on adolescents' self-concept was observed by Seginer, Vermulst, and Gerris (2002) found that childrearing stress was indirectly related to adolescents' positive outlook through parent-adolescent relationships for girls and boys, but childrearing stress was only related to adolescents' emotional stability through parent-adolescent relationships for boys. This study suggests that indirect
effects of parenting stresses on adolescent self-concept are plausible that must be explored.

Diane et al. (2008) they examined longitudinal associations among mothers’ and fathers’ parenting stress at age 10, children’s perceptions of parenting at age 10, and adolescents’ self-concept at age 14 in 120 European American families. Mothers’ and fathers’ parenting stress was related to children’s perceptions of acceptance and psychologically controlling behavior, and psychologically controlling behavior (and lax control for fathers) was related to adolescent self-concept. They further examined which domains of parenting stress and perceived parenting behaviors were associated with adolescents’ scholastic competence, social acceptance, physical appearance, and behavioral conduct. Parenting stress was related to specific parenting behaviors, which were, in turn, related to specific domains of self-concept in adolescence. They concluded that parenting stress appears to exert its effects on early adolescent self-concept indirectly through perceived parenting behavior.

A direct relationship between the parental stress and self-concept was obtained by HH Chiou (2004) in a group of epilepsy children. Forty-nine epilepsy children and their parents were selected for this study. The control consisted of 50 healthy children who were of similar socio-economic status. All epilepsy children were aged 8 to 13 years. The children’s self-concept was assessed by Self-Perception Profile for Children (SPPC). Parental stress was measured by Parental Stress Index (PSI). They also examined the relationship between the children’s gender, age, age of onset of seizure and families’ socio economic status and the epilepsy children’s self-concept and their parental stress. Epilepsy children had higher parental stress and lower self-concept than controls. The epilepsy children’s gender, age, age of onset of seizure and families’ socio economic status were not significantly related to the children’s self-concept and
the parental stress. However, parental stress was significantly related to the epilepsy children's self-concept. This study indicates that education for epilepsy children and their parents is important for children with epilepsy. Appropriate coping strategy of parents with epilepsy children to lower the level of parenting stress may influence the parenting behavior and thus the children's self-concept.

Studies on social support in disabled subjects have mostly been conducted in relation to psychological well being and adjustment.

Mellvane, J. M. & Reinhardt, J. P. (2002) examined the relationship of high and low friend and family support for adaptation to chronic vision impairment in 241 men and women. It was found that women with high support from both friends and family had better psychological well-being whereas men with high support from both friends and family or just from family had better psychological well being. Further analysis showed that participants with high qualitative friend support and high quantitative family support had better adaptation to vision loss.

Kef, S. (2002) examined the psychosocial adjustment and the meaning of social support for 316 Dutch adolescents (aged 14-24 years) with visual impairments. It was found that social support, especially the support of peers, was important to adolescents with visual impairments. The differences between visually impaired and sighted adolescents proved to be small but significant.

In another study Kef and Dekovic (2004) found the peer support to be important for the wellbeing of visually impaired adolescents. They examined the importance of parental and peer support for well being of adolescents with and without visual impairment. They included 178 adolescents who were blind or visually impaired and 338 adolescents without visual impairment. Peer and parental support was found to be important for well being of both adolescents with a
visual impairment and sighted adolescents whereas in the group of adolescents with a visual impairment, a positive live relationship existed between peer support and well being. In the group of adolescents without an impairment, well being appeared not be effected by peer support. Parental support was more strongly related to well being of adolescent without impairments than of adolescents who were blind or visually impaired.

Konarska, Joanna (2005) conducted a study to examine the sources of social activity of people with visual and motor impairments of both acquired and congenital types. Individuals with and without disabilities were compared for their self-esteem, level of purpose in life, for system of values and methods of fulfilling their needs. The resulting differences, misfortunes and success were found to be interrelated more with living conditions than with disability itself.

Place, and Hodge (2001) described the behaviors of 8th grade students with and without physical disabilities relative to social inclusion in a general physical education program and found that students with and without disabilities infrequently engaged in social interactions. Two themes emerged for the girls with physical disabilities: Segregated inclusion and social isolation. Students with disabilities interacted with each other to a greater degree than with classmates without disabilities.

Wright (1983) stated that parents of children with disabilities tend to be more overprotective than do parents of children without disabilities because they are usually more concerned with their children’s safety. This may lead them to undermining their abilities.

Holmbeck et al., (2002) tested a mediational model of associations between parental over protectiveness (op), behavioral autonomy, and psychosocial adjustment.
in 68 families with 8 and 9 year old preadolescents with spina bifida and a
demographically matched sample of 68 families with able bodied children. It was
found that mothers and fathers of children with spina bifida were significantly more
over protective than their counterparts in the able-bodied sample, although this group
difference was partially mediated by children's cognitive ability. Both questionnaire
and observational measures of parental over protectiveness were associated with lower
levels of preadolescents decision-making autonomy as well as with parents being less
willing to grant autonomy to their offspring in the future. For the questionnaire
measure of over protectiveness, and only for the spina bifida sample, the mediational
model was supported such that parental op was associated with less behavioral
autonomy, which was, in turn, associated with more externalizing problems.

Deborah et al., (2004) examined both the direct and indirect relations of
parent and peer attachment with self-esteem and also examined the potential
mediating roles of empathy and social behaviour. 246 college students (M age = 18.6
years, SD=1.61) completed self-report measures of parent and peer attachment,
empathy, social behaviour, and self-esteem. The results revealed that parental
attachment had mostly direct effects on self-esteem. Among females, the links
between peer attachment and self-esteem, however, were entirely mediated by
empathy and prosocial behaviour. It was found that although close supportive
relationships with parents and peers are related to adolescent self-esteem, these
relationships are complex.

The above review of researches show that persons with disabilities have lower
self-concept as compared to normals. It is also observed that social support is an
important variable in the context of disability as disabled persons' ability to seek
social support is affected in many different ways. So far, studies have been conducted
on the availability of social support for disabled and its buffering effect on stress. No attempt, as yet, has been made to study social support in relation to self-concept. As social support may give a feeling of belongingness and enhances self-esteem, it may be assumed to have a significant relationship with self-concept. In the present study an attempt will be made to explore the predictive relationship between social support and self-concept.

Research on parental stress show a significantly higher level of stress experienced by parents of disabled children. Researchers speculate a direct or indirect link between parenting stress and self-concept but few studies have been conducted in this field particularly in the context of disability.

The present investigation was undertaken to study social support and parental stress in relation to adolescents’ self-concept. The group of adolescents was chosen for the present research as in adolescence self-concept becomes increasingly differentiated and adolescent’s self-concepts in different domains are conceptually and statistically independent (Harter, 1988).