PSYCHOSOCIAL EXPERIENCES OF PARENTS WITH MENTALLY RETARDED CHILDREN

(The Case of Six Families in Addis Ababa)

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ABSTRACT

This study explores the social and emotional experiences of parents with mentally retarded children. Six mentally retarded children and their respective parents were the main subjects of the study. Interview guide was used for data collection. The data was presented in a descriptive form and analyzed qualitatively. Two parents quarrelled with their neighbors and other two parents also quarrel with their spouses because of their mentally retarded children. Siblings of the mentally retarded children complain for being disfavored by their parents. Mentally retarded children deprive 3 of the parents of attending social activities outside home, and the parents are penalized as a result. The news that their children are mentally retarded makes parents experience such feelings as: shock, grief, anger, fear, worry, hopelessness, helplessness and acceptance of the fact. Four of the six parents accepted the reality immediately. The parents vary in their coping. Parents' social and emotional experiences are partly interdependent. However, they are not seen as functions of severity of the disability and sex of the children except that mothers of 2 of the 3 female children are anxious that their children may be raped. The children's improvement, counseling and supports that the parents get help the parents in the coping. Therefore, the children should get education so that they would improve. The society at large and family members also should be enlightened as to what mental retardation is and have positive attitude towards mentally retarded children and their parents and be supportive.

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CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Parents are the ones who shoulder the responsibility of caring for their children. The burden is heavier when it comes to those parents of a child with disability, a mentally retarded child in this case, as the child is with many special needs and requires close attendance.

The news or the discovery of the fact that their child is mentally retarded is devastating for parents who naturally dream of bringing up a healthy and competent child (Drew, Logan, and Hardman, 1992). Such families will have hard, tough, and trying times to adjust themselves to such devastating truths. They go through different emotionally traumatic steps before they accept the reality (Smith, Patton, and Ittenback, 1994).

In Ethiopia, many people do think that mental retardation comes as a result of curse from God (Cherinet, 1999), presumably, as a result of some sin that the parents might have committed. It is also considered that the mentally retarded child is possessed by evil spirit(s). As parents realize what other people think of them, they do not freely associate with their neighbors and acquaintances.

Many parents in this country are also reported to hide their mentally retarded child behind doors to avoid the ridicule because of the child and attacks made against the child (Tirussew, 2000).

The rejection of the mentally retarded child, in many cases, is a function of severity of the disability (Tirussew, 2000) – if the child significantly misbehaves and hence that makes him/her attack/insult other people and/or is not able to control his/her saliva, the likelihood of being accepted by other people is less.

Besides the child's demand for close attention, the society's negative attitude towards the mentally retarded child and the parents, threaten parents' emotional life and also the social life considerably.

The society needs to have the proper perception of what mental retardation is and treat the mentally retarded children and their parents accordingly, so that the parents' psychosocial problems be alleviated.

1.2 Statement of the Problem

Parents of a child with disability (mentally retarded in this case), as primary care givers of the child and being the ones the child is identified with, come across

many emotional and social problems and bear a lot of burden. Hence, they too should be given a primary emphasis as the mentally retarded children should.

This research was designed with an intention of finding answers to the following questions:

i- What are the social experiences of parents of mentally retarded children?

ii- What are the emotional experiences of parents of mentally retarded children?

iii- What intervention strategies should be used to alleviate the social and emotional problems that parents of mentally retarded children face?

1.3 Objective and Significance of the Study

As to the knowledge of the researcher, in Ethiopia the experience of parents with mentally retarded children is not researched for with a primary intention of addressing the problems parents face and finding solutions for a better psychosocial adjustment. It has been dealt with in a casual way.

Accordingly, the objective of this study was to find out the emotional and social experiences of parents with mentally retarded children from the families selected in Addis Ababa.

More specifically, the objectives were to find out:

1. How parents interact with neighbors, spouse and siblings; and
2. What parents feel about having a mentally retarded child.
3. What should be done to help parents of MR children.

The researcher believes that, this study will contribute to the existing little knowledge about this issue and is also expected to initiate other interested researchers for further studies. Furthermore, it will give insights, for interested social workers and other concerned bodies, as to how to design their strategies to help parents of mentally retarded children - with the purpose of alleviating the parents' psychosocial problems and consequently for a better life of the children themselves.

1.4 Delimitations of the study

This research deals only with the social and emotional experiences of parents with mentally retarded children. This does not mean that parents do not come across other experiences; rather, the study was designed in such a way that a special emphasis would be given to those particular issues.

To that end, the study was conducted mainly with parents of six mentally retarded children and the children themselves in Addis Ababa. However, mothers alone

were used as source of information about parental experience for they play the major role in parenting and are the main care-givers of their children (Hodapp, 1998; Shaffer, 1988).

1.5 Operational Definition of Terms

Mental retardation – refers to, as defined by American Association on Mental Retardation, substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following adaptive skill areas: communication, self care, home-living, social skills, community use, self-direction, health and safety, functional academics, leisure and work (Smith et al., 1994, p. 75).

Parent – stands for both father and mother or a person who has a parental responsibility for the care and upbringing of the mentally retarded child.

Emotional experience – refers to the feelings parents have in having mentally retarded child and following other people's reaction towards the child and the parents.

Home experience - refers to parents' interaction with spouse, siblings and other persons at home.

Social experience – refers to parents' interaction with and the reaction of neighbors, acquaintances, and significant others towards the mentally retarded child and the parents.

Psychosocial adjustment - refers to social and emotional functioning: the way a person relates to and interacts with other people in his/her environment (Reynolds and Mann, 1987, p. 1276) and the parents' coping with their mentally retarded children.

Educable mentally retarded (EMR; IQ = 50 to 75) - typically describes students who are capable of benefiting from instruction in basic academic areas such as reading and mathematics. Post school adjustment is generally good; EMR students will probably be self-sufficient enough to live independently and to hold jobs (Taylor, Sternberg, and Richards, 1995, p. 85).

Trainable mentally retarded (TMR; IQ = 25 to 50) - applies to students who are capable of learning basic survival skills, but only very basic academic concepts. Post school adjustment for TMR students usually has to be closely monitored and supervised in both employment and living situations (Taylor et al., 1995, p. 85).

Severely and profoundly mentally retarded (SMR/PMR; IQ < 25) - are those who will benefit from instructions in very basic self-help skills (e.g., toileting, dressing, personal hygiene). Post school adjustment requires continuous monitoring and supervision. Such students can only be expected to achieve semi-independence in home living skills as well as more limited vocational-skill development and restricted (sheltered) employment (Taylor et al., 1995, p. 85).

CHAPTER TWO

LITERATURE REVIEW

2.1 Nature and Definition of Mental Retardation

Mental retardation is a term used to refer to a person who has certain limitations in mental functioning and in skills such as communication, self-help, and other social skills. These limitations will cause a child to learn and develop more slowly than a typical child. Children with mental retardation may take longer to learn to speak, walk, and take care of their personal needs such as dressing or eating. They are likely to have trouble learning in school. They will learn, but it will take them longer. There may be some things they cannot learn.

There have been many definitions of mental retardation, all reflecting the different perspectives (Kirk and Gallagher, 1986) and perception of retardation at different times (Smith et al., 1994). As a result of the conflicting views and definitions of mental retardation, a growing number of labels are used to refer to individuals with mental retardation (Smith et al., 1994). For example, feeblemindedness and mental deficiency were used as labels during the later part of the last century and in the early part of this century.

The most common of all the definitions was devised by the American Association on Mental Retardation (AAMR):

> Mental retardation refers to substantial limitations in present functioning. It is characterized by significantly sub-average intellectual functioning, existing concurrently with related limitations in two or more of the following adaptive skill areas: communication, self care, home-living, social skills, community use, self-direction, health and safety, functional academics, leisure and work. Mental retardation manifests before age 18 (Smith & Luckasson, 1994, p. 136).

Grossman (1983) cited in Smith and Luckasson (1994) defined adaptive behavior as "the effectiveness or degree with which individuals meet the standards of personal independence and social responsibility expected for their age and cultural group" (p. 117).

2.2 Classification of Mental Retardation

Different types of classifications of mental retardation have been made so far. The classifications are made based on general cause, specific etiology, educational categories, and severity or degree. Among them, the most familiar classification systems are classification by educational categories and classification by severity or degree (Taylor et al., 1995).

Classification by Educational Categories

This classification system is based on an individual's educational prognosis (expectations) or supposed educational needs (Taylor et al., 1995). The label *educable mentally retarded* (EMR; IQ = 50 to 75) - typically defines students who are capable of benefiting from instruction in basic academic areas such as reading and mathematics. Post school adjustment is generally good; EMR students will probably be self-sufficient enough to live independently and to hold jobs.

The label *trainable mentally retarded* (TMR; IQ = 25 to 50) - applies to students who are capable of learning basic survival skills, but only very basic academic concepts. Post school adjustment for TMR students usually has to be closely monitored and supervised in both employment and living situations (Taylor et al., 1995).

Students labeled *severely and profoundly mentally retarded* (SMR/PMR; IQ < 25) - are those who will benefit from instructions in very basic self-help skills (e.g., toileting, dressing, personal hygiene). Post school adjustment requires continuous monitoring and supervision. Such students can only be expected to achieve semi-independence in home living skills as well as more limited vocational-skill development and restricted (sheltered) employment (Taylor et al., 1995).

Classification by Severity or Degree

The other familiar classification system is classification by severity or degree. This classification system establishes four levels of mental retardation (Smith & Luckasson, 1994; Smith et al., 1994) as follows: mild (IQ range of 50-55 to approximately 70), moderate (IQ range 35-40 to 50-55), severe (IQ range from 20-25 to 35-40), and profound (IQ below 20/25). It should be noted, however, that the 1992 AAMR definition eliminated the levels of severity.

The 1992 AAMR definition and classification manual, as Taylor et al. (1995) report, provides some clarifications on the use and role of classification. First, it must be determined through an assessment process that an individual has mental retardation. Next, three dimensions are recommended for classification: the psychological/emotional strengths and weaknesses of the individual, the health and physical strengths and weaknesses of the individual, and the best environment and types of supports that will help the individual grow, develop and become an integrated member of the society. The supports are categorized into four different levels: *intermittent* with support provided only when the individual demonstrates a need; *limited*, with more consistent support provided over time, but still some what time-limited; *extensive*, with extensive support in long period of time in selected environments; and *pervasive*, where there is constant, high-intensity support provided across all environments.

2.3 Causes of Mental Retardation

Several groups are used to organize the causes of mental retardation. Smith and Luckasson (1994); and Shea and Bauer (1994) divide the causes into four groups: socioeconomic and environmental factors, injury, infections and toxins, and biological causes.

Kirck and Gallagher (1986) make nine major groupings as identified by the American Association on Mental Deficiency (AAMD): infection and intoxication, trauma and physical agent, metabolism and nutrition, gross brain disease, unknown prenatal influence, chromosomal abnormality, gestational disorder, psychiatric disorder, and environmental influences.

Taylor et al. (1995) classify the causes of mental retardation into two major categories - biomedical causes and sociological causes. A few comments will be made about some of the causes.

2.3.1 Biomedical Causes

The biomedical causes are further classified into two: genetic causes and environmental causes.

Genetic Factors

There are basically two major types of genetic conditions that can lead to mental retardation: *inherited* and *chromosomal aberration (abnormality)* (Taylor et al., 1995). In the inherited type, the problem can be associated with either *autosomal* or *sex-linked genes*. In the case of chromosomal aberration (abnormality), the aberration can be attributed either to an *abnormal number of chromosome* (Shea & Bauer, 1994) or to *abnormal chromosomal structure*.

Environmental Factors

Smith and Luckasson (1994) grouped the environmental causes according to the time of onset: prenatal, perinatal, and post natal.

Prenatal Factors - Taylor et al. (1995) specify the prenatal factors that can cause mental retardation: poor maternal-diet both before and during pregnancy, fetal alcoholic syndrome that results from the mother's chronic intake of alcoholic beverage or continuous moderate intake of alcohol during pregnancy, mother's infection with rubella or German measles and syphilis(see also Kirk & Gallagher, 1986; Smith & Luckasson, 1994), the mother's exposure to radiation during pregnancy, and blood incompatibility, i.e. Rh incompatibility or A-B-O incompatibility, between the mother and the fetus.

Perinatal Factors - Perinatal conditions occur either at the moment just preceding birth or during the birthing process, itself. These conditions include (Taylor et al. 1995) *premature birth*, or the birth of the child in less than the normal 9 month pregnancy, specific condition during the birthing process itself, for example, if the fetus suffers from *hypoxia* (limited oxygen), *anoxia* (lack of oxygen) (see also Smith & Luckasson, 1994) or *cerebral hemorrhage* and infection of the fetus with *genital herpes* from the mother during the delivery process.

Postnatal Factors - Post natal causes are those that occur after birth (Taylor et al. 1995), such as, severe postnatal nutritional deficit, infant or childhood infections, for example, *encephalitis* and *meningitis* (see also Shea & Bauer, 1994), head injuries, drug abuse, lead poisoning (including automobile exhaust emissions), and mercury poisoning.

Genetic or Environmental Factors - There are a number of conditions associated with mental retardation that can be caused either by genetic or environmental influences. Certain *cranial aberrations* (microcephaly and hydrocephaly, deviations that make the skull much larger or smaller than normal respectively) illustrate this point. Hypothyroidism, a type of disorder that adversely affects the thyroid gland, which is responsible, in part, for normal growth function (Taylor et al. 1995) also can be caused either by genetic or environmental influences.

2.3.2 Sociological Causes

Shea and Bauer (1994); and Smith and Luckasson (1994) refer to a report by Menalascino and Stark (1988) that poverty is a determinant in 75 to 80 percent of people with mental retardation at a higher IQ level where there is no organic basis for the condition.

Taylor et al. (1995) also describe the presence of a higher percentage of children with mental retardation requiring intermittent type of supports who come from lower socioeconomic (SES) environments compared with middle-or-upper SES environments. Some other variables appear to have some relationships to the occurrence of cases of mild mental retardation, for example, *low maternal IQ, insufficient literacy on the part of the parent,* the *number of children in the family* (the greater the number, the higher the probability one of the children will be mentally retarded), and *spacing of children in the family* (the closer the spacing, the higher the chance that one of the children will exhibit mental retardation) (see also Kirk and Gallagher (1986)).

2.4 Parent's Reaction to Mental Retardation

In most of the literature that deal with parents' reaction to the news of their child's being mentally retarded, it is described that parents go through some stages. Drew et al. (1992) put five stages that Rosen (1955) suggested that parents of mentally retarded children go through as follows: "(1) awareness of the general problem in the child's growth and development; (2) recognition that the basic problem is mental retardation; (3) search for a cause for mental retardation; (4) search for a cure; and (5) acceptance of the child."

According to Drew et al. (1992) parents experience such emotions as: *Denial* especially during the initial stage of adjustment; *projection of blame* on other people (like physician, school personnel) they believe are responsible for their suffering; *fear* - associated with having other children with disability, loss of friends, a life time care, and impact on the family unit; *guilt* - when they are unable to blame someone else, they may blame themselves; *mourning and grief* as the birth of a child with mental retardation represents the loss of a dream - hope for a healthy son or daughter; *withdrawal* - they may isolate themselves because of their feelings of shame and guilt; *rejection of the child* - expressed through: i) under expectation of achievement, ii) setting unrealistic (unattainable) goals to justify their negative feelings and attitudes on the basis of negative performance, iii) escape - occupying themselves with various responsibilities that there is little,

if any, time to be at home with the family or place the child at a distance school or institution when comparable facilities are available nearby, and iv) reaction formation - deny negative feelings about the child and publicly present completely opposite images; and the final step in adjustment is *acceptance* of the child's disability, the child, and one self.

Smith et al. (1994) have put the stages that Batshaw, Perret and Trachtenbergs (1992) believe to be fairly representative of the stages families of children with mental retardation go through in their acceptance of the disability as: *Denial* - resist the notion that their loved one is different from others; *depression* - following an awareness that the threat of a disability is real, family members often feel a weakening of their spirit, a sense of loss or even impending doom - that the disability is greater than their resolve to overcome it; *anger and guilt* - once the depression subsides and the family realize that the disability is not likely to overwhelm them, their energy level starts to rise, and there will come a desire to fight back, to challenge the disability and challenge those they may consider to be responsible; *bargaining* - when parents realize that they, too, have a role to play in the course of the disability, they often set out in search of mitigating factors that will allow them to regain some control in their fight to overcome the disability. Finally, the family will come to *accept* the reality of the unwanted and unpleasant situation.

2.5 Factors Affecting Parents' Coping Ability

All the above-mentioned stages are not necessarily to be experienced by all parents. Parents vary in their coping ability Hodapp (1998). For some it may take long time to cope positively with the situation while others may manage to cope positively with their mentally retarded child in a relatively short period of time. Hodapp states, "...not all mothers suffered negative reactions to an equal extent and that certain factors eased the strain of parenting the child with retardation" (p. 73).

Smith et al. (1994) describe such different factors that play the crucial role in the resolution process: the magnitude of the event, the family's general level of vulnerability to outside stress, perception of the seriousness of the event, and the family's regenerative abilities.

Drew et al. (1992) indicate that such factors as religious background of parents, etiology and age of onset affect parents' acceptance of their mentally retarded child.

The presence of mentally retarded child in a family may threaten the welfare of the family as a whole. According to Smith et al. (1994) reaction to the news that a child has a disability, long term impact on family dynamics, and the presence of

internal and external supports are three factors that are important to continued family development.

Hoddap (1998) describes that any family's capacity to cope with a mentally retarded child depends on *external resources* such as money as well as *internal resources* such as the parents' confidence in their ability to teach the child, their problem-solving skills, their attitude toward life, and their religious beliefs. Finally, support from individuals outside the family such as friends, relatives, teachers, schools and social service agencies is stated to be crucial.

How one thinks about parenting a child with mental retardation strongly influences what one feels about the event (Hodapp, 1998). Generally the main distinction here relates to "problem-focused" versus "emotion-focused" coping. Mothers who focus on actively solving problems seem better of than those who focus primarily on their own emotional reactions.

How the child with retardation is perceived by the family is highly related to active and practical coping. Hodapp (1998) states "to many families, such a child is a burden imposed by God; indeed families often feel that they have been chosen to raise the child because of their special strengths and gifts" (p. 81).

The problems of parenting any young child may produce a large amount of parental stress. Later, however, differences generally do emerge between families of children with and without disabilities (Hodapp, 1998).

Two partially competing ideas have been proposed to explain such findings. The first is that certain critical periods may exist during development that cause parental and familial stress. Wikler (1986) cited in Hodapp (1998) found that parents of children entering puberty (11-15) and those entering adulthood (20-21) reported the highest levels of stress.

The second idea is that parents experience a pileup of stressors as the child with retardation gets older, which is called the "wear and tear hypothesis" (Minnes, 1988; Seltzer & Ryff, 1994) cited in Hoddap (1998). This idea is simply that parents become progressively worn by the incessant job of parenting a difficult child. Yet on the contrary, Seltzer and Krauss (1989) cited in Hoddap (1998) found that parents and their adult offspring mutually adapt to each other over the years.

Another age-related difference consists in the way parents use supports as the child gets older. Suezle and Keenan (1981) cited in Hoddap (1998) found that the social supports mothers of mentally retarded children receive become less as their children got older. Hoddap (1998) states:

> Many parents "burn out" on intervention programs, support groups, or parent groups as the child gets older; in addition, fewer such groups exist for older children. Moreover, social service professionals rate the need for supportive services as higher in the early than in the later years, even as parents report a continuing need for support services as the child approaches adulthood. (p. 84)

Parents' reception of a child with retardation can be a function of the family's socioeconomic and intellectual status. Social class (or socioeconomic status) refers to: "one's position within a society that is stratified according to status or power" (Shaffer, 1988, p. 417).

Drew et al. (1992) show the possible relationship that socioeconomic and intellectual statuses have with parents' reception of their mentally retarded child:

> Some families at lower socioeconomic levels place less emphasis on cognitive development and skills and, at times, more emphasis on the development of physical attributes. ... A child with mental retardation born into a family in which education and white-collar jobs are held in high regard may be a great threat and disappointment to the family. (P. 367)

Families with higher incomes experience less stress than those with lower incomes; low income living is more stressful for parents and stress affects the ways parental functions are carried out (Hodapp, 1998; Shaffer, 1988).

Professionals can play significant roles in helping parents to accept their mentally retarded child. "By finding and capitalizing on the positive attributes of the child, the professionals can assist the parents in realizing the child's worth and can guide them towards acceptance" (Drew et al., 1992, p. 381).

Handleman and Harris (1986) write,

> For some parents learning procedures to cope with their difficult child's demands and hearing some sympathetic words of support from a caring teacher may make life considerably easier and thus contribute to a diminution of the sadness, anger, and other negative emotions that have burdened the parent's days. (p. 96)

Often supportive individuals for children, like teachers, serve as supports. for parents as well, conveying information and guidelines on caring for children. Parents' support indirectly affects children when they help parents feel better about themselves and encourage a more positive view of the children (Brooks, 1994).

People who have education, employment, income, and congenial neighborhoods receive more supports (Brooks, 1994). More than any other variable, education determines the number of contacts a person has and the depth and breadth of the social support network. Education appears to increase confidence and skills in social interaction as well as opportunities for meeting new people.

Foremost among the list of natural supports needed by families of mentally retarded children, as to Smith et al. (1994), is a social support system that allows the family to feel that they and their problems are valued by others. Acquaintances, friends, and significant others offer the family a multitude of energy and options that are essential to offsetting the stressors that pervade their lives.

Social supports according to Brooks (1994) are those people (relatives, non relatives, like neighbors, friends), activities (hobbies, recreations), organization (work, churches, government), and environmental resources that provide emotional, instrumental and informational benefits to children and parents. Emotional benefits include feelings of cared for, valued, encouraged, understood, and validated as a person. Instrumental benefits include help with certain tasks like housework, specific aid like money or child care. Informational benefits include advice about child care, referral to resources, and specific guidance about tasks.

Brooks (1994) states "...supportive social ties operate generally to improve children's social-emotional functioning and their academic work, and to increase parent's self confidence and well-being and to enhance their perceptions of their children" (p. 295).

The family environment is the most immediate source of support for both children and parents. The younger child gives the older a chance to be a protective caregiver. For mothers who have a close, supportive relationship with their husbands tend to be more patient with their infants and more sensitive to their needs than mothers who receive little support from their spouses and feel that they are raising their children on their own (Shaffer, 1988). Shaffer further states,

> [I]ntimate support from the husband seems to be more important to a mother's life satisfaction than any other kind of social support that she might receive - particularly if her infant is temperamentally difficult....[H]appily married couples seem to function as sources of mutual support and encouragement, so that many child-rearing problems are easier to overcome. (p. 411)

Hodapp (1998) also writes, "[m]others in two-parent families coped more effectively than those in one-parent families as did women in good as opposed to conflicted marriage" (p. 73).

Relatives also are important sources of support for parents with mentally retarded children. Such support from relatives increases parents' positive view of their children and their view of themselves as parents (Brooks, 1994). While relatives are support sources, they can also add stress when their comments to parents are negative and critical. Brooks describes that single mothers appear less likely to have the supports of relatives but can increase such support when they feel more confident and reach out for help.

2.6 Effect of Mentally Retarded Child on the Family

It is reported that the presence of a child with special needs has both negative and positive impact on the relationship between spouses - it can either weaken or strengthen the relationships. Shaffer (1988) states:

> Many parents of infants who require special care have problems with their spouses and believe that rearing a "special" child has made their marriages worse. But for every set of parents who experience marital disharmony as a result of caring for a special child, there is at least one other couple who say that their abnormal infant has brought them closer together! So it appears that the arrival of a baby who requires special attention may disrupt the balance of a vulnerable marriage without shaking the foundation of one that is already on firm ground. (p. 409)

Hodapp (1998) also says that many early studies found that parents of children with disabilities were more likely to be divorced than parents of same-age, typically developing children. However, even in these early studies it was suggested that the birth of a child with mental retardation can also strengthen a marriage.

The presence of mentally retarded child has an impact also on the non-disabled siblings. Hodapp (1998) describes that a role tension is often found in the siblings as they take more responsibilities on housekeeping duties and caring for the mentally retarded child. However, non-disabled siblings of children with mental retardation are only some times more prone than siblings of typically developing children to depression and other emotional problems. Older siblings generally adapted better than younger ones; the younger children suffered more than the older siblings from being deprived of their parents' attention. But older sisters seemed most prone to a variety of emotional problems perhaps because they were forced to perform adult tasks at too young an age. On the other hand, siblings reported that (Hodapp, 1998) their brother or sister with mental retardation had helped them become more empathic and caring, more tolerant of difference among people.

Many families of children with disabilities suffered from what Farber (1970), cited in Hodapp (1998), called "economic immobility." Unlike families of same-age,

typically developing children, families of children with retardation often appeared to stagnate economically, possibly due to parental preoccupation with disabilities and the cost of caring for the child (Hodapp, 1998).

2.7 Parental Reaction to Mental Retardation in Ethiopia

Tirussew (2000) reports what he discovered from a two hours focus group discussion that was held with 13 parents of children with mental retardation at the Mekanisa Center for Children with Mental Retardation. According to the report, most fathers tend to leave all the responsibilities to the mothers and avoid providing the necessary care and attention. These parents are said to have a very insignificant interaction with the people in the neighborhood. This limitation was primarily due to the humiliating reaction of the people in the surrounding. Mothers reported that they are always in a state of worry and anxiety because they are afraid of the fact that their daughters might one day be sexually abused. Parents, especially mothers, also feel that if they die, they will leave their mentally retarded children forever without attendants. The other difficulty mentioned by the parents which needs special thought and attention is the violence brought against their children including such acts as being caught by the police and be beaten. This happens when the police fail to understand that the children are mentally retarded, so whenever they do something wrong they take such measures. Males are more

liable to such problems than females. The other shocking act is the possibility of mentally retarded kids to be stolen and used by adults for begging purpose.

In Ethiopia, many people do think that mental retardation comes as a result of curse from God (Cherinet, 1999), presumably, as a result of some sin that the parents might have committed. It is also considered that the mentally retarded child is possessed by evil spirit(s). As parents realize what other people think of them, they do not freely associate with their neighbors and acquaintances.

Many parents in this country are also reported to hide their mentally retarded child behind doors to avoid the ridicule because of the child and attacks made against the child (Tirussew, 2000).

Most of the literature that deals with these particular issues, psychosocial experiences of parents of mentally retarded children, deals in the Western context-not in the Ethiopian. The present study aims to contribute to the lacuna in the literature on the psychosocial experiences of parents with mentally retarded children in the Ethiopian context.

CHAPTER THREE

METHOD OF THE STUDY

In this study in-depth investigations focusing on a limited number of parents were made. Gall, Borg and Gall (1996) state that, "[o]ne of the main characteristics of qualitative research is its focus on the intensive study of specific instances, that is *cases*, of a phenomenon" (p. 543). Thus, a qualitative research approach is found to be the most appropriate approach for this study.

3.1. Subjects

The main subjects of the study were six mentally retarded children and their parents. The parents were selected after their respective children had been selected based on the following variables: the children's sex and level of retardation. Three of them are females and the remaining three are males. Each group is further classified with respect to the level of retardation as: *educable mentally retarded* (EMR); *trainable mentally retarded* (TMR); and *severely and profoundly mentally retarded* (SMR/PMR) i.e. there are two female and male children in each of the above-mentioned three groups. Thus, purposive sampling was implemented.

All of the MR children, who are subjects of the study, go to a special class for the mentally retarded at Belay Zeleke Primary School. The parents were contacted through the head and teacher of the special class. The reason that I chose to contact the subjects thus was because I believed that the information about the children, with respect to the above-mentioned variables, could be found from their teacher.

The teacher was also asked to give information about the children's class performance and behavior.

3.2. Instrument Used for Data Collection

Interview guide was used for data collection. Interviews with parents were made to gather information about: their background; the emotional experiences they have gone through, and their home and social experiences. The parents have also given information about the situation of their mentally retarded children.

Interview was preferred to other instruments because it helps the researcher to have much more data in a short period of time. Shaffer (1988) writes, "The major advantage of this (interview/questionnaire) approach is that one can collect an enormous amount of information about a parent and his or her children in a short time" (p.400).

3.3. Procedures for Data Collection and Analysis

First, the six children were selected following the information given by their teacher concerning the children's class performance and based on the above mentioned variables. Then, detailed interviews on specific points were made with their respective parents.

In so doing, first, an intensive interview, following the interview guide, was made with each parent. Then, informal interviews were made with each parent on a different day based on the information she had given previously.

The interviewees were free to choose the time of the interviews as it was convenient for them. The first intensive interviews were made in the office of the vice director of the children's school. Each parent was interviewed separately and in private. The remaining informal interviews were privately made in each parent's home.

Each parent was informed in the beginning of the first interview about the purpose of the study and was asked for their willingness to be interviewed and to be tape-recorded. Tape recorder was used during the interviews. The researcher also jotted down some words of the interviewees, but still with undetached attention.

The data was analyzed qualitatively. In so doing, the findings were logically organized or categorized according to the following frameworks: behavioral characteristics of the mentally retarded children; background information about the parents; assistance and counseling given to parents; parents' home and social experiences; and parents' emotional experiences. Based on these categories, the findings concerning each case were independently presented in a description form. Then the findings on the subjects of home and social experiences and emotional experiences of parents were discussed separately. Finally, conclusion and recommendations were made based on the discussion.

CHAPTER FOUR

FINDINGS

4.1 Behavioral Characteristics of the MR Children

Case - one

Case - one is an eleven years old girl who is the first child for her mother with two younger brothers of age eight and two.

She does not differentiate socially unacceptable words and speaks those considered taboo by the society and hence people consider that she is insulting them. They do not understand her because she looks healthy physically and take it as a mockery. She is quarrelsome - all of a sudden kicks, bites, or fights with her brothers and children in the neighborhood. Her mom says that this girl cries obstinately like 'an evil possessed person' if she is insulted or aggressed, unless she kicks back the person who insulted her.

She cannot dress up herself properly, does not keep her personal hygiene by her own, but, if followed up, she can manage to do some activities, like cleaning the floor, making bed, fetching water from the neighborhood, washing clothes, boiling tea and coffee, and cooking. However, there should be some body that attends to her and gives directions all the time.

Her ears give out blood and pus, which has caused partial hearing impairment. When one talks to her she does not respond at all, or bows her head down in silence, or responds after a while. Until she was five she had been too passive that she did not talk, play, laugh, and even was not willing to eat unless forced. All the time her mom and grand parents had the impression that the girl was only being modest. However, now she communicates with others verbally. She started playing with her age mates only after she went to a primary school where she attended grade one and two. It was there that her teachers suspected that she might have mental retardation because she could not cope up with her classmates. She used to laugh for no reason, which her teachers took for mockery.

She was first diagnosed by a physician as mentally retarded at the age of eight. Two years later her mom took her to Belay Zeleke Primary School where she currently attends a special class for the mentally retarded. Her teacher informed the writer that she now manages to read and write alphabets, and do some arithmetic. A 'CBR' (Community Based Rehabilitation) worker from Cheshire Foundation Ethiopia also visits her once in a week and teaches her basic living skills. She is certified by this organization that "she has completed basic activities of daily living (bowel control, feeding, and dressing)". The girl has improved a lot after she started attending the special class and was given instruction by the CBR worker.

If she is around home, she spends most of her time with her mom and siblings. She does not have friends because she is aggressive and her mom would not allow her to join children in the neighborhood being afraid that she would quarrel with them. Her siblings include her in their play activities. The family takes her to relatives when they pay a visit once in a while.

Her mother used to take the child to health center for the problem the child had had with her ears. However, her mom says that the medication had not helped the child at all. She has also been taking her to "tebel" (holy water) but had not got any solution - the ears still discharge pus and blood on and off. Her mother has totally stopped taking the child to physicians advised by her friends that she should have an undivided faith on the tebel.

Her mother has strong faith that the child would improve in her thinking and education as long as she keeps on attending the special class and join the regular class later.

This child is labeled by her teacher as "educable mentally retarded".

Case - two

Case - two is an eleven years old boy who is the first child for his parents and has two younger sisters.

He had not been able to walk by his own until he was ten. There was a birth complication while his mom was giving birth to him. His legs, instead of the head, came first and his legs were dislocated at the knee that the calves were on the front side and the shins on the back. The pediatricians told the parents that the baby had problems with nerves. After a fifteen days stay in Gondor Hospital, where the mother gave the birth, came to Tikur Anbesa Hospital for the problems the baby had with his legs. He stayed for eight years in a special room in the hospital for treatment. At the age of eight he managed to walk with the help of gypsum and crutch. And at ten he managed to walk with out any support. Now he can walk with both his legs opened wide aside below the knee.

He was not able to speak until he joined the special class for mentally retarded children in September 2002 at Belay Zelek Primary School where he is currently attending his class. Presumably, because, according to his mother, while he was in the special room in the hospital, he had not got the chance to speak with people by the age other children develop speech.

According to his teacher, this child does not differentiate alphabets and has very little writing skill but is improving some how. He does what he is told to do. He is showing significant improvement in his speech and behavior. His teacher has labeled the child as educable mentally retarded for the child's relatively good understanding of things.

According to his mother's report he can keep his personal hygiene; dresses himself by his own; makes his bed; tries to practice what he sees other people doing; more than any thing else, he likes to examine things; wants to perform whatever he is told to do at school; is sociable and loves, hugs and kisses people (people also love him); has great interest for music; communicates both verbally and by sign, for he has problem to articulate; understands when rebuked; corrects when his father punishes him physically; and is aggressive and stubborn and will not give away his property unless asked politely. His mom has a strong expectation that he would improve a lot.

He usually likes to spend his time with people older than him, because, according to his mother, he underestimates children and his younger sisters as well. His sisters also do not prefer to play with him because he takes their goods and quarrels. He usually plays alone with his ball in the compound.

Case - Three

Case three is a seventeen years old boy who is the ninth and the last child for his parents with four brothers and four sisters.

As to the description of his mother about his babyhood, he was too slim with a weight significantly much lower than the "normal". However, being given milk powder and 'nutritious' food, he got the normal weight and even became fat.

His parents had already guessed, before they were told by a physician, that the child had been an MR. He was not able to talk by then, when he was about four. The physician told them that he could not be cured. He still cannot speak, but according to his mother he understands what he is told. He also understands gesture. His mother takes him to "tebel" (holy water) for a possible cure. He has no behavioral disorder. As to his mother, he is improving and she believes that he will improve more.

When he is at home, he usually plays in the compound with his friends. As his siblings are older than him, they do not stay at home during the day. But they enjoy his company when they come home in the evening. While he was nine, he was lost for ten days and found on the street. But now he knows his village very well.

According to his teacher, this child does not know the alphabets and does not write and read at all. He cannot do any arithmetic either. His teacher said that the child has not shown significant improvement academically, though he made some behavioral change. He has no patience to sit and do an activity. He cannot speak. He has good behavior. According to his teacher he is "trainable mentally retarded".

Case -four

Case four is a twenty seven years old young woman who is the thirteenth child for her parents with three younger siblings.

According to her mother, she can do nothing by her own - she requires constant follow up; other people dress her up, keep the child's personal hygiene, feed her - if she is given food to eat by her own, she spoils her clothes. She does not accept orders; cries all of a sudden; cannot speak; and is restless at home.

Her mother reported that the child's legs had contracted when she was about one and had been operated in a hospital, and then became normal that the child managed to put on shoes. From then on, according to her mother, she became inactive. This mother thinks that the child's nerve might have been affected during the operation. The child used to say "abbaba, immama" to address her parents before the operation. The parents used to take the child to tebel but when they saw that it did not work they took her to a physician when she was four and were told that the child was an MR. Then the parents wanted to send the child abroad, where her sister was, for medical treatment but they gave up the idea since the physician told them that she could not be cured.

Her mother reported that the child was sent to school at school age but was not able to learn. Currently, she goes to a special class for the mentally retarded at

Belay Zeleke Primary School, where she was admitted to a couple of years back. According to her teacher, she cannot read or write. She can only be trained to do some daily living skills, like washing clothes and rubbing the floor. Hence, her teacher labeled her as 'trainable mental retarded'. Her mother also said that the child does not have hope regarding education; she is sent to school only for her to stay with other children.

When asked how she interacts with the child, her mother responded, "She communicates only with siblings. I do not involve myself with the child than to see what is going on with her except preparing what she needs, like washing her clothes."

When she is at home, the child is restless and wanders with-in the compound. She does not join her siblings than to see them play. According to her mother, she never had the interest to play even while she was a little child.

Her mother said that she did not expect the child to improve any more because the child has grown in age and has not improved so far.

Case - five

Case - five is a sixteen years old girl who is the first and only child for her mother.

As described by her mother, she was not able to speak while she was five. Besides, she was too aggressive and restless. Unless the gate of the compound was closed, she used to run away and hit whoever she met with stone on the head and would be lost. She also used to make herself naked, utter unclear continuous voice, and dribble incessantly. According to her mother, she used to look totally disgusting.

Her mother took the child to a psychiatrist at Amanuel Hospital at the age of eight. The psychiatrist said that the child got maladjusted nerve and could have been healed had she been taken there earlier. He referred her abroad for surgery and gave the child medicine for relief. Her mother says that it is after the medication that the child's behavioral disorders have gone.

Now the child loves people and likes to kiss every body. She does not attack any body. Once she sits somewhere, she rarely moves away and is quiet. However, she some times cries all of a sudden, which her mother attributes to the child's inability to express herself.

Though the psychiatric disorders were managed to be controlled, she was dribbling incessantly, she was not able to control her bowel, feed herself, dress herself up, and keep her personal hygiene.

It was at the age of thirteen that she was first diagnosed as mentally retarded at Cheshire's health center. And then, referred to a special class for the mentally retarded at Belay Zeleke Primary School where the child currently goes to. Her mother says that the child has shown some improvement after she joined the school. Now she can control her bowel, does not sully her cloths, feeds herself, manages to wash her hands and face, identifies objects and brings them when ordered. Nonetheless, it is somebody else that dresses her up, takes her to toilet and bathes her. She cannot speak other than continuously uttering the same meaningless sound but understands what she is told and communicates by sign. Though she does not dribble as much as before, her lips are always wet.

According to her teacher, she cannot be trained to make any thing so far and knows nothing in the academic. Hence, she is in the category of 'severely and profoundly retarded'. Her mother also does not expect the child to improve in the academic task than to hope that she would be trained in some handcraft.

The child had no friend, and children in the neighborhood used to reject her. Because, according to her mother, the child does not speak and play as they like. They used to consider her as a special creature. It is only after the child started to go to school that the children began to approach her. Now, they some times go and play with the child in her compound and also take her to school. There is no little

child in the compound to play with the MR child, which her mother says has contributed for the child's sluggishness to improve.

Her mother hopes that the child would improve, but only if she continues her education in the special class and is given vocational training.

Case - six

Case six is a 21 years old boy. He is the seventh and the last child for his parents.

He was first diagnosed as an MR by a physician at the age of thirteen. According to his mother's description about his childhood, he was not able to stand on his feet until he was three. He was not able to control his bowel until he was 18. He used to tear down his cloths. He never uttered a single word until he was 15. He still cannot dress him self up. He kicks and bites children. He cries hiding himself somewhere. He could not walk properly until he was eighteen. Now, he can understand what he is told but cannot express his idea. His mother said that she does not understand what he says. He communicates by sign. She added that the child does not shut his mouth - he smiles all the time.

According to his mother, he has improved after he joined the special class for the mentally retarded at Belay Zelek Primary School three years ago. Now he can control his bowel. He can feed himself. He can identify objects and brings them

when ordered. He can utter few words. His mother expects that he will improve more and will be able to speak. However, he still needs intensive support.

According to his teacher he cannot be trained so far to make any thing. He is aggressive in the class.

This child always plays inside the compound with little children of four and six. His parents do not allow him to go out, being afraid that he may quarrel with other children in the neighborhood. Other little children in the neighborhood also sometimes come and play with him.

4.2. Back Ground Information about the Parents

Mother of case - one

The mother of case - one is a 27 years old single woman with three children of her own and lives with her parents. She earns her living by collecting rubbish from the surrounding wondering from door to door. Her father is a barber and her mother has passed away nine months back. Her family has six members. She said that the family's SES was lower-class. She is a follower of Ethiopian Orthodox Church. She has received formal education up to grade eight.

When asked about what she thinks was the cause of the child's mental retardation, she said that she did not know. However, she added that people say that she had taken some medicine to abort the baby, which she denies. She also reported that there is no other person with mental retardation in the family.

Mother of case - two

The mother of case - two is a 35 years old married woman. She is educated in a technical school and got a diploma in Secretarial Science. Now she works in a private organization as a typist. By the time she gave birth to the child, she was a secretary at Gondor Medical College, where the hospital in which the child was born is situated. She said that the family's SES was middle-class. They are seven in the family. She is a follower of Ethiopian Orthodox Church.

When asked about what she thinks was the cause of the child's being an MR, she said that it is the birth complication - the baby did not get sufficient oxygen during birth and did not come in the proper direction. She has lost another child also, after the MR child, because of birth complication. Nonetheless, she has reported that there is no other person with disability in general and mental retardation in particular in the family.

Mother of case - three

The mother of case - three is a fifty years old married woman. She is uneducated and is only a housewife. The family lives on the father's pension who used to be low paid employee in the municipality. Hence, the SES of the family is low. The family has eleven members. This mother is a follower of Ethiopian Orthodox Church.

When asked what she thought was the cause of the child's retardation, she responded that she did not know. She added, "I did not say that it was because of this or that. I only said that it was from God, from above." She also reported that there is no other person with disability in the family.

Mother of case - four

The mother of case - four is a fifty-five years old married woman. She is illiterate and is only a house wife. She is a follower of Ethiopian Orthodox Church. Her husband, the bread winner of the family, is a merchant. She said that the family's SES is middle-class. Currently the family has seven members.

When asked what she thinks was the cause of the child's retardation, she responded that she did not know. However, she also said that the child's nerve might have been affected during the operation that the child had on her legs while

Mother of case - six

The mother of case - six is a 50 years old married woman. She has graduated from high school. Currently she is a secretary at a governmental organization. Her husband (the child's father) is a ground technician at Ethiopian Air Lines. They are five in the family. She categorizes the family's SES in the middle-class. She is a follower of Ethiopian Orthodox Church.

When asked what she thought was the child's being an MR, she said that she did not know. However, she added, "Friends and people in the neighborhood relate it to 'ancestral worship'." And hence, she used to take the child to witch-doctors. This mother has reported that there is no other person with disability in the family.

4.3 Assistance and Counseling Required by and Given to Parents

Mother of case - one

As the MR child's parent has been living with her own parents, she has been supported by her parents, especially before the death of her mother. But now, she says that she is incapable of bearing the financial burden incurred by the child's needs for things like health service, food and clothing that the MR child requests for, seeing what other children in the neighborhood have.

This parent used to get financial and material aid from an organization called Christian Children's Fund (CCF), which used to cover 90% of the child's medical expenses. But now she does not get any financial and/or material aid from any body. This parent believes that if she gets sufficient income, she would make the child improve much more by meeting the child's needs.

There is no body who takes care of the MR child when the mother leaves home. She will either lock the door and leave the child outside, because the child may cause some damage if left in the house with out an attendant, or some times entrusts her to the neighbors.

As far as counseling is concerned, this parent said that it is only the CBR worker that she asked what the child's problem was. The CBR worker told her not to force the child to do things beyond her capacity since that might cause an unnecessary stress and frustration on the child and hence the problem would get worse. The same worker also advised her to provide the child with a better diet, which the parent says that she does not afford. When asked about her attitude towards professional counseling the mother responded that it was nice and had helped her.

Mother of case - two

This mother was expected to pass away because of the birth complication while she was giving birth to this child. She had not seen the new born till five days. By

then the physicians, seeing the baby's physical condition, expressed to her mother (the grand mom of the baby) their intention of killing the baby lest the mother of the baby, their colleague, should not bring up such kind of a child. However, the grand mother disagreed and said, "I will take the responsibility of bringing him up though he may crawl in all his life." Since then the grand mother took all the responsibility of bringing up the child till she passed away when the child was nine. The mother had stayed with the baby only for forty days after the birth and went back to her work place, Gondor, while the baby was admitted to the special room at Tikur Anbessa Hospital. This mother was following the child's progress through telephone and by coming physically to the child taking leaves from her work. But she could not take leave all the time and hence was forced to resign from her work.

There is a girl that takes the child to school and brings him back home. This mother is grateful to the child's teachers for his improvement and the government as well for providing such a special class for mentally retarded children in a regular school. The child's being away from home during the day time by itself satisfies this mother much. Nonetheless, she complains that the government has failed to provide her with a job in the field she was trained for the very reason that she has such kind of a child to bring up.

This mother had counseling from physicians. They told her that the child would improve through time like a "healthy" child would and become normal at the age of fifteen. She believes that this would come true, "Because" she asserted, "the physician had said that the child would walk at the age of ten and he walked." They also advised her to: "teach him; give him love; let him be with people; let him have physiotherapy," and for her not to get tired of him.

Mother of case - three

This family gets medical and material aid from Cheshire Foundation Ethiopia for the MR child. The child is entitled to get free medical service in the organization's clinic. He used to be given milk powder by the organization while he was in the kindergarten of the organization.

This mother reported that people in the neighborhood buy him things they think he lacks, like shoes. His brothers also buy him clothes. This parent reported that there was no special financial burden because of the child.

It is the father who takes the child to school so that he may not be late. But the child manages to get back home by his own.

This mother said that she used to get advice from people in the clinic where she used to take the child when he was a little boy. She was advised to teach, tutor,

and encourage the child to talk. Most of the time it is the father who goes to any place that concerns the child. He attends meetings called by the special needs education section of the school concerning the progress of MR children in their education. He also has attended two meetings called by SOOM and has been given a training on how to treat the MR children. He, along with other parents of MR children, was advised not to reject, annoy and discriminate MR children instead, encourage them. He also was informed that the MR children could do handcrafts (facilitated by the organization) by the time the children manage to do so. This mother said that the counseling was good and helped the parents a lot.

Mother of case - four

This mother reported that the presence of the MR child had no effect on the family unit. Regarding the expense of the medical service, this mother said that it was covered by the child's older sisters. The parents had even planned to take the child abroad. But it is reported that the family had not received neither financial nor material aid from any body else other than the child's sisters.

When asked whether she has got any counseling about the child's condition, this mother responded that there was no body that asked her about the child except SBR workers from Cheshire Foundation who found the child while moving (wandering) from house to house. She said that they told the parents to let the child do 'this and that'. They also tried to teach the child but were not successful

for the child was not willing. When asked what her attitude towards the counseling was, she said, "What would it help if the child is not willing?"

It was reported that the child's father once tried to have the child admitted to a boarding-house just to get rid of her totally, but she was not accepted. Since then there has been no effort made to take the child to any place except the special class where the child currently attends.

Mother of case - five

This mother lives in the same compound where her two married sisters and one married brother live. Her mother (the grand mother of the child) also used to live there before she moved to other place two years back. The mother's family (sisters and a brother) take much care for the MR child. The mother said, "They consider that God gave them the child to test them. And hence, they favor the child so that they may not offend God."

The mother also said that they sympathize with her. She added, "I could not be able to cover all the expense for the sought-for healing of the child if it were not for their financial support. The expense was equivalent to the cost of building a house." The parent used to take the child to different places outside of Addis for tebel and stayed at one place for about 2 to 3 months. But this mother has reported

When asked what she wishes should be done, she suggested that the government should prepare boarding-house for the MR children and take all the responsibilty

of bringing them up so that the mother would be free. She also believes that this will help the children to improve as special classes do and they will be protected. She also suggested that needy parents should get some aid.

Mother of case - six

This mother said that she has taken the child to many witch-doctors and to different tebel. She added, "We have spent all of our money in seeking healing for the child." The family has never got any financial or material support from other sources.

It is the house maid that takes care of the MR child when the mother is away from home. She also takes the child to school and brings him back home. This mother said that every house maid who have worked in the house have been caring to the child. She gives different incentives to the house maids so that they would be more caring to the child.

The older brother of the MR child who is 23 (the only other child who lives with the family) also takes care of the MR child patiently. He closely checks whether the child's needs are met. He takes the child to church and go for a walk with him. He also punishes the MR child. And hence, the MR child is more obedient to this brother than to others in the family.

This mother said to have received no professional counseling concerning the child's condition, except what the physician who diagnosed the child told them that the child would improve through time and they should leave him alone. She also has attended parents' meetings called by SOOM. She was informed as to what mental retardation is and to take care of the child patiently.

4.4 Parents' Home and Social Experience

Mother of case - one

When the MR child speaks socially unacceptable words and those considered taboo by the society, people think that she is insulting and mocking them. This usually creates conflict between the mother and persons who complain to be insulted. This parent has shared one experience to the researcher that she quarreled with one of her villagers for the other person slapped the MR child on her ear, for she wrongly considered that she was insulted, and caused the sickness to aggravate. Because of such conflicts, this parent does not allow the child to go out side. However, people in the neighborhood began to understand her after the CBR worker created awareness on them about the real nature of the MR child. As a result they allow their children to play with the MR child though some times the MR child aggresses against their children.

This parent does not discuss about the child's being an MR with her neighbors. The reason she gave for this is that every body in the neighborhood is busy running to win her/his bread and no one gives attention to such an issue.

When asked about the attitude of the child's father and his relatives towards the MR child, she responded that they had been separated and he had left for abroad when the child was one and before it was discovered that the child was an MR. His relatives also do not know the child's condition. This mother does not get any support from the child's father.

When asked how siblings act/feel towards the MR child, she responded that her immediate younger brother plays, wrestles, and fights with her like other siblings do. He does not consider her as an elder instead as an age mate. This parent helps the sibling cope positively with his MR sister by telling him about her situation so that he would understand her. She also warns him not to call his sister "zegemtegna" (retardate) as do other children in the neighborhood. She treats all of the siblings equally.

Because the MR child makes some damage at home (because of her ignorance) if she is left alone, the parent sometimes misses attending some social gathering like "iddir" and is penalized as a result.

As far as her home experience is concerned, she said that she most of the time quarrels with her husband, the child's father. That is so because he punishes the child physically when the child touches his belongings for the child loves to examine and practice what he sees from other people. She said that she cannot tolerate to see him cry. However, she has reported that this father loves the child and brings him what the child loves. Regarding the siblings she said, "When this child takes his sisters' property, they will quarrel and I will intervene. Then his younger sister begins to cry complaining that I always favor him, and then the house becomes chaotic." When asked whether she does anything to help the siblings cope positively with their brother, she said that she does nothing, thinking that they may consider him as a special creature and reject him. She also said that she treats all of them equally.

When asked about the reaction of her spouse's relatives, she said that they like him, and there is nothing special in relation to the child.

Mother of case - three

When asked about neighbors' attitude and reaction towards the MR child, this mother said, "Neighbors love him; they take care of him even better than I do; they sympathize with me because I had such kind of a child at last, after giving birth to eight normal children before him, and they buy him whatever they think

he lacks. When he quarrels with some body, they stand in favor of him saying, 'He knows nothing; he is helplessly in God's hand.'"

This mother also reported that she discusses with neighbors about the child's situation and they relish his progress and encourage her not to give up. She said, "I have no body except them." When the child watches TV with the neighbors, they inform the mother that he is with them and they bring him back home. The mother will not have a rest unless she knows where the child is. They also allow their children to play with him. They call him on holy days and let him dance. They like him because he amuses them.

This mother has reported that the presence of the child has not created any problem in her marriage. She said, "The child's father is more eager than I to see the child improve. He does not want to see the child in unwanted places." She also said that she has seen nothing negative with the spouse's relatives. And added, "They love him; want him to stay with them over nights; they sympathy with me."

Mother of case - four

When asked about the reaction and attitude of people in the neighborhood towards the MR child, this mother responded that they were living in a secluded compound, and hence do not have any interaction with them. The MR child does not go out side and there is no body that comes to them. This mother also reported

that she did not discuss the child's condition with the neighbors since, she said, "[t]he child's condition is already known and she is once labeled as 'sick person'." And neighbors do not ask this mother about the child's retardation except about the child's gastric case. This mother has reported that there has been no lost friendship or intimacy following the discovery of the child's condition.

When asked about the reaction of the husband towards the child, this mother reported that he calls the child by her name whenever he comes in. And it is he who awakes her every morning and let her go to school. But he does nothing more. It is the siblings who approach the MR child more. This mother also reported that the presence of the MR child has not affected her marriage, and added, "What have we done? It is God who gave us this child."

About the spouse's relatives, she said, "They do not care about us; every body lives his own life."

This mother reported about the feeling and attitude of the siblings saying that they do nothing against the child and are sympathetic about the child's condition. It is the siblings who take care of the child more than the parents. When asked whether the mother did any thing to help the non-disabled siblings cope positively with the MR child, she said, "I have not told them any thing to do," and asked, "What

would they do to her? And what is there to advise once the child is labeled as a sick person?"

Mother of case - five

Before the child's condition improved, people in the neighborhood used to consider that this mother was cursed. They did not use to allow their children to join the MR child, thinking that the child's mental retardation would be 'transmitted' to their children. People also used to discriminate both the MR child and the mother. But now, after the child has shown significant improvement, this mother says that neighbors welcome the child in love and take her to their home to play with them and allow their children to play with the MR child. She also said that people used to condemn her when she took the child out. But now, they encourage her to take the child out. She attributes this to the impact of the media on the society at large.

This mother said that she does not discuss about the child's condition with the neighbors. She added, "Every body cares only when he is faced with the same problem."

This mother has quarreled with many people, especially old ladies, because they advised her to take and entrust the child to witch-doctors, considering that it was a

Mother of case - six

This mother has reported that neighbors do not mistreat the MR child and allow their children to play with her. She discusses about the child's condition with them. They comment that there could be some worship that the family's ancestors might have been practicing to other gods and that this family failed to do, for which the 'gods' might have been upset with her. And hence, neighbors advise this mother to take the child to witch-doctors and to tebel as well.

This mother has taken the child to many witch-doctors. She tried different witch-doctors though she knew that the previous ones did not work, because she was afraid of the gossip that neighbors might consider her as greedy. She has taken the child to different tebel also. She believes that the tebel has helped the child to improve. Now, she says that she has given up taking the child to witch-doctors.

She has quarreled with her husband many times since he does not believe that the witch-doctors will help. He believes that the child's mental retardation was caused for the child had not received sufficient breast feeding (the mothers breast fed each of her child only for about forty days after birth). However, the mother defends, "Had it been for the breast feeding that the child became an MR, his siblings also would have been MR's." The parents quarrel over this, too.

These parents also quarrel when the mother deprives the child of some types of food that aggravates the child's gastritis and cause vomiting. The father wants that the child be given whatever he asks for. He over-cares for the child. According to the mother, he is in good terms with the child.

When asked about the reaction of the husband's relatives, this mother said that every body loves the MR child.

The mother some times quarrels also with the older brother of the MR child, when he punishes the child. She said that she favors the MR child to other children of her's. The other children used to complain about this while they were little children. But they understood when she explained.

The mother does not attend to different social gatherings like iddir and does not go even to work when the child's gastritis aggravates, usually once in 3 to 4 months. However, she said that she has never been penalized for her absence from iddir for the people understand the child's condition. She said that there has never been lost friendship or intimacy because of the child's condition.

4.5. Parents Emotional Experience

Mother of case - one

When this mother first learnt that her child is an MR, she was shocked and fainted for a while. She was sick for about a month and spent many sleepless and restless nights. She was pregnant by then (while the MR child was eight). She was afraid that her parents may despise the child. She also grieved and worried thinking that the child will not be educated as her friends do. However, she got relief from this thought after the child joined the special class, where she currently attends, two years later.

This parent had hard time to accept that the child was an MR because she had been attending class in a regular school and was promoted to grade two. It took her about three to four months to accept it. The child's being passive, her refusal of orders and her unreasonable laughter along with her ear problem helped the parent to accept the child's being an MR.

Some children in the neighborhood call the child "zegemtegna" (retardate) or "ibd" (insane) and say to her that she goes to a school for mad children. Then the child cries bitterly and asks back, "am I mad?" The parent reported her reaction to this, "I keep silent as if I have not heard anything while burning inside with rage, and comfort the child telling her that she goes to a nice school."

This parent does not allow the child to go to school if her ears bleed because the parent is worried that it would be worsened. Because of that, it has been more than a month since the child went to school for the last time. The mother also got angry when asked by the personnel in the regular school (where the child used to attend before she came to the special class) for certificate that certifies the child to be admitted to the regular class.

The parent gets sad and worries when the child, watching children in the neighborhood, asks for some thing to eat or dress that the parent cannot afford. The child cries and quarrels with her siblings if she does not get what she asks for. The parent said, "I leave the house than sit there and see all this." However, she does not have any regrets as for not doing any thing, which she could afford and was aware of, and that could help the child to improve.

This parent said that the child's condition has not threatened her self-image. However, she condemns herself saying, "What if I had used contraceptive not to conceive the child". She also says that she could have gone to work abroad (Arab States) and improve her life had not she given a birth to this child.

Her response for the question what worries her most in relation to the child was her financial incapability to meet the child's needs. However, she added that the

child's future life does not worry this parent because she expects that the child would improve.

When asked what she feels about the mere fact that the child is a female, she responded that she does not have any special feeling in this regard.

Mother of case - two

When asked what she felt when she first learnt that the child was an MR, she said, "What the physicians were doing was to save my life since it was in danger because of the birth complication. I did feel nothing regarding the child's condition because I was saved. I myself could have died." She added, "What could I do once God intended it?" Besides, she said that the fact that her mother took the responsibilty of bringing up the child and the care that the physicians were giving the child along with her being away from the child had helped her not to feel bad. She has no low self-mage and attributes it to her being away from the child. The promise that the physicians had given her that the child would be normal also helped her much to accept the child's being an MR. The child's ability to walk has relieved her now. She said that she is glad to take the child any where for the mere reason that she sees him walking.

When asked what she feels when her children quarrel because of the MR child's behavior, she said that she takes it as normal because, according to her, every sibling in every house quarrel among each other.

She said that she feels sorrow to see some people reject the child when he approaches them in love.

When asked what worries her most, her response was what the child's life would be if she dies. She strongly wishes that the child would be self-sufficient so that in case of her death others would not be tired of him.

Mother of case - three

When this mother first learnt that the child was an MR, she grieved and prayed unto God for a healing, believing that it was given from Him. She also said that she has taken the child no where else than church for cure, having faith that God would let the child improve.

When asked how long it took her to accept the fact that the child was an MR, she said that she accepted it immediately and added, "Why shouldn't I accept what God has given me? The child is improving because I am faithful before God." She said that her belief that God gave her the child has helped her to accept the reality.

When asked what she felt about herself after she learnt about the child's condition, she said that she was sorry because she was not educated, thinking that she could have been able to let the child reach a better status.

She said that what worries her most is the child's lack of knowledge as expected of his age and being 'different' from other people.

Mother of case - four

When asked what she felt when she first learnt about the child's being an MR, she responded that she grieved, and added, "I gave up all the effort to cure her knowing that she is useless." This mother has said that she still grieves over the child's condition whenever she sees the child because the child is so 'abnormal' among the other fifteen 'healthy' children of her's. She also said, "I get worried to see the child wandering restlessly in the house while we all sit and have our meal and I could do nothing for her." Nonetheless, she said that she had no other feelings than grief. This mother got relieved relatively only when the child had begun to go to school

This mother said that it did not take her much time to accept the fact that the child is an MR. According to her, the child's being odd with respect to other children helped her to accept the child's being an MR. She also said that she accepts the child as her own daughter and does not discriminate against her as long as she is

able. However, she said that she did not believe that she could do any thing to improve the child's condition.

When asked whether the child's being an MR threatened her self-image, she responded that she felt nothing in that regard except to grieve about the child's condition. She also said that she had nothing to regret about for failing to do any thing that the child needed.

Her response for the question what worried her most when she thought about the child's disability was, "Now I am accustomed to it. But I pray that she would pass away before us (the parents) so that she will not be left without an attendant." She added, "I have no other wish because I do not expect her to grow to 'normal' womanhood."

In relation to the child's being a girl, this mother expressed her worry that the child may be raped.

Mother of case - five

This mother regretted and was angry when she was told by the psychiatrist that the child would have been healed had she taken the child to the psychiatrist earlier. She still regrets it. "However" she said, "I have no other thing to regret about for

failing to do what I knew that would help the child. It was for this very reason that I toiled much."

When this mother first learnt that her child was an MR, she grieved, thinking that all the toil was in vain, and the child would be inferior to her friends. She also was angry, thinking that the child would not be able to do any thing. She wished the child should have died. She added, "You cannot bring anything in mourning and getting upset." She regretted the child's birth and also was fearful until recently that she may give a birth to another MR baby (now she is pregnant).

It did not take much time for the mother to accept the fact that the child was an MR. "Because" she said, "it was there [Cheshire's health center] that the child's case was first given the name MR." Besides, the child's dribbling and behaving much below what is expected of her age, along with the fact that she could not be healed till then also have contributed to the mother's acceptance.

She also was angry at attending the child incessantly. She added, "It was boring to take care of the child all day long. It was not possible to ignore her." But now, the child is doing better and does not need as much intensive care as she used to. However, her mother is still angry to see the child's age mates graduated from high school and to see healthy children of others'. She also said that people's discrimination of both her and the child annoys her.

When asked whether she accepts the child as her own daughter, she said that she takes the child both as a younger sister and a daughter.

When asked whether she believes she can do any thing to improve the child's condition, she said, "Yes, by taking her to different recreation places to please her - the child also loves this, and if she is taught vocational skills."

When asked what worries her most when she thinks about the child's condition, she said, "I wonder what the future holds for the child. What will she be if I die before her?"

When asked whether there is any thing that she feels for the mere fact that the child is a girl, she said she worries that the child may be raped. She added, "I am anxious how the child can express her pain and appetite if she gets pregnant." This mother wishes that the child would get pregnant in the proper way. Because she believes that the child may be healed if she gives birth and have her own baby for she loves babies so much.

Mother of case - six

The mother had already known that the child had a problem while he was a little child, before she was told by a physician, at the child's age of thirteen that the

child was an MR. She was thinking that the child would be deaf. She grieved and was angry about the child's condition. She was also fearful that she may give a birth to a similar baby.

The anger is so strong that she sometimes has headache as a result. She gets angry in cases when the child is not able to communicate what he wants, and when he used to stay at home while other children went to school. Though the grief is still there, she says that she gets comforted when she sees other children with a worse case than her child's. She also has got some relief after the child began to go to school.

She says that she does not feel peace and rest even when she is at her work place. She fears that some thing may happen to him, thinking that he may kick others or be kicked by others.

She had hard time to accept the fact that the child was an MR since she did not know what it meant. However, she had had the impression that the child was not normal. She even has taken him to "Alpha School for the Deaf", thinking that he was a deaf. It is only in the last three years that she was informed about what mental retardation is through the media and meetings called by the child's school and SOOM. She accepted the label after she saw the similarity that her child has

with other children who are labeled 'MR'. She used to call it simply as the work of God.

When asked whether her child's being an MR threatened her self-image, she said, "It has not threatened my self-image because it is what God has given me." She added, "I have to accept what God has given me since I cannot bring anything by mourning and getting upset." She also said that she has nothing to regret about for failing to do something the child needed.

When asked what worries her most in relation to the child's condition, she said that she does not have peace of mind when the child is away from home, i.e. when he goes to school. She is afraid he may get an accident. She added, "I wonder what he would be when he becomes older. I am worried who would take care of him if we, his parents, die."

CHAPTER FIVE

DISCUSSION

5.1 Parents' Social and Home Experience

5.1.1 Social Experience

Some parents of MR children experience quarrel with other people for different reasons. Misbehavior of MR children was seen to be a factor for the quarrel. Two of the cases have reported to have quarreled with people because of their children's misconduct. Mother of case-1 has quarreled with someone who considered the child to insult her. Mother of case-5 also reported to have quarreled with people who avenged her child for the child's aggressiveness.

People's misunderstanding of the MR children's behavior that their misconception of children's conduct as deliberately practiced has contributed much for the quarrel among parents and the other people. The intervention made by the CBR worker to create awareness on the people about the nature of the MR child (case-1) and improvement in her behavior have alleviated the problem.

People's misunderstanding of the cause of mental retardation and their consequent advice for the cure were also seen to cause the quarrel between mother of MR

child and other persons. Mother of case-5 quarreled with other people, especially old ladies, for the advice they have forwarded that the child should be taken and be given to witch-doctors, considering that the child's mental retardation was caused by curse. They were not allowing their children to join the MR child, being afraid that mental retardation would be transmitted to their children.

This misunderstanding of the cause of mental retardation and the advice also created social pressure on mother of case-6. She used to take the child to different witch-doctors though she proved that it had not worked, only for she was afraid of the gossip by neighbors that they might consider her as greedy.

On the other hand, three of the parents have reported that neighbors have positive attitude towards the MR children and allow their non-disabled children to play with the MR children. Neighbors' permission for their children to play with the MR children is a sign of their acceptance of the MR children, which also helps the parents to maintain good social interaction with the neighbors. As to Smith et al. (1994), one of the supports that parents of MR children need is a social support system that allows them to feel that they and their problems are valued by others.

Rejection of MR children was seen to be a function of, inter alia, behavior and neatness of the children (Tirussew, 2000). If the child significantly misbehaves to the extent of attacking/insulting other people and/or is not neat enough to the

expectations of others, people prefer to get rid of him/her and hence the likelihood of being accepted by other people is less. Children of difficult behavior, case-5, who used to attack people and case-1, who was considered by people to insult were not accepted. Besides her being aggressive, case-5 was described by her mother that she used to look totally disgusting. Her mother also said that people used to discriminate both the mother and the child. It was only after the child showed significant improvement and began to go to school that children in the neighborhood started to approach the MR child.

On the other hand children, who are neat and of agreeable behavior were seen to be welcomed. Mother of case-2 said that her child is loved by neighbors because he also loves them. Similarly, mother of case-3 also said that neighbors like the child for he amuses them by dancing. She also said that neighbors love and take care of the MR child because they sympathize with her for she gave birth to such kind of a child after eight 'normal' children of hers.

Only two of the six mothers of the MR children discuss about the condition of their MR children with neighbors. Mother of case-3 is encouraged by her neighbors on the improvement of the child's development and they also appreciated the mother's faith in God. Neighbors of the other mother, mother of case-6, relate the child's condition to 'ancestral worship' and consequently advise the mother to take the child to witch-doctor and tebel.

The remaining four mothers do not discuss their MR children's situation with their neighbors. Based on this study, the researcher believes that this has got to do with the factors:

1. Neighbors - Neighbors' lifestyle, attitude or willingness to discuss about the MR children, and/or parent's conception of neighbor's attitude towards their MR children and themselves. Mother of case-1 said, "Every body in the neighborhood is busy running to win her/his bread and no one gives attention to such an issue." Similarly, mother of case-5 also said, "Every body cares only when she/he is faced with the same problem." These mothers seem to have an impression that their neighbors do not care about their MR children as such.

2. Physical environment and intimacy - Physical proximity of neighbors' house and/or sharing of a compound and intimacy also have a role to play in the parents' discussion with their neighbors. Mother of case-2 had two experiences in this regard. Neighbors of the previous village, who were living in the same compound with the family of the MR child, were eager to know the child's development and discuss it with the child's grand mother, who was parenting the child by then. However, in the new village, where the child's parents moved to four years back, the child's mother reported that she does not discuss about the child's situation with neighbors for they live in a separate compound and for she did not know the neighbors' character. This is so because she is not intimate with them. Mother of

case-4 also shares this in some sense. She said that they were living in a secluded compound and hence have no interaction with the neighbors.

3. Parents' attitude towards the MR child - Hopelessness of the mother of case-4 for the child's improvement was seen as a factor for the mother's reservation not to discus about the child's mental retardation with neighbors. She said that she did not discuss the child's condition with neighbors since it is already known and once the child is labeled as "sick person". She considers it a futile exercise to do so.

The presence of mentally retarded children was seen to affect the social activities of parents outside home. Three of the parents were deprived of attending social activities outside home because of their MR children. Mother of case-1, sometimes, does not leave the child alone at home lest the child may cause damage because of her ignorance and hence the mother is compelled to miss some social activities and penalized by her iddir as a result. Similarly, mother of case-5 also reported that her social activities used to be affected immensely while the child's behavior was so difficult that she could not be left without an attendant. She used to be penalized many times by her iddir and 'youth association'. Mother of case-6 also fails attending social gatherings and even going to work when the child's gastritis case aggravates. However, she has not been penalized for this for her associates know the child's condition.

5.1.2 Home Experience

The presence of MR child was also seen to affect marriage of some parents. Parents of case-2 quarrel with each other for their different coping strategies with the MR child. The father practices corporal punishment while the mother cannot tolerate to see her MR child cry. Parents of case-6 also quarrel with each other for the different caring style to the MR child, specially when the child's gastritis aggravate. The mother deprives the child of some types of food while the father says that the child should have what ever he wants even if it worsens the child's gastritis. The father's disbelief in witch-doctor for the child's cure was also seen as a cause for the quarrel. They also quarrel because the father blames the mother for the child's being an MR for the insufficient breast feeding the child had. In spite of this, the mothers reported that both of the fathers were caring to their respective MR children.

However, it was seen that the presence of MR child has not affected the marriages of the other parents. Mother of case-3 said that the father is more eager to see their child improve than she does, and it is he who goes wherever that concerns the MR child. Mother of case-5 also said that her husband (the child's step father) is more caring than her (for she is tired of caring for the child).

None of the mothers said that the husbands' relatives have negative attitude towards the MR child and the mother. Husbands' relatives of mothers of case-3

and case-5 were reported to be sympathetic with the mothers. Mother of case-5 attributes their sympathy to their being educated.

The complaint of non-disabled siblings of the MR children for being disfavored by their mother was also seen as an experience that mothers of MR children face at home.

Parents' advice to the non-disabled siblings about their MR brother/sister seems to play a significant role in this regard. Mothers of case-1, case-3 and case-6 advise their non-disabled children as to how they should positively cope with their MR siblings. As a result, the non-MR siblings do not complain for being disfavored. Whereas, sisters of case-2, whose mother said that she did not do anything to help them positively cope with their MR brother, were reported to complain to the extent of putting the house into chaos.

Mother of case-6 also quarrels with the older brother of the MR child when he corporally punishes his MR brother since this mother, too, is sensitive to see her MR child cry. Mothers' being intolerant to see their MR children cry when corporally punished leads the mothers into quarrel with the punisher in the house.

5.2 Parents' Emotional Experience

The news that their child was mentally retarded led all of the parents in this study to such emotional experiences as: shock, grief, anger, fear, worry, hopelessness, helplessness and acceptance of the fact - grief being common to all. Drew et al. (1992) write, "We all grieve when we lose some thing that we cherish or value. The birth of a child with mental retardation represents the loss of a dream - hope for a healthy son or daughter." All of the parents grieved to know that their child is an MR, except mother of case-2. She took her child's disability as the lesser evil, compared to the possibility that she could have died while she gave birth to the MR child because of the birth complication. But she has experienced sorrow later, when people mistreated the child.

In this study, many of the parents did not exhibit the sequential emotional experiences that the literature (Drew et al., 1992; Smith et al., 1994) on the subject says, that parents of MR children go through when they know the fact that their children are mentally retarded. For most cases, the acceptance of their children's being MR's was neither observed as a final step of parents' adjustment to the reality. (The researcher suggests that further studies be made in this regard). According to Hodapp (1998) parents vary in their coping with their mentally retarded children. In addition, they do not suffer the negative reactions to an equal extent.

Four of the mothers accepted the reality immediately. The remaining two also accepted it, but after sometime. There were different factors that helped them accept it immediately or later. The remarkable difference that the MR children exhibit compared to their age mates (case-1, case-4, and case-5) was one of the reasons for their acceptance. The religious nature of the people (mother of case-3) - their belief that their children's mental retardation was given from God also made them helplessly accept the reality. The labeling of the child's problem also plays a role in putting an end to the parents' enquiry or confusion as to what the problem is and hence acceptance. Mother of case-5 expressed one of the reasons why she accepted her child's being an MR, "because it was there [Cheshire's health center] that the child's case was first given the name 'mental retardation'."

On the other hand, there were factors that hinder parents from accepting their children's being MR's. These were: the child's (case-1) being admitted to and being successful at a regular school (she was promoted to grade two), and ignorance of what mental retardation is (mother of case-6). The latter parent did not accept her child's being called an MR only because she did not know what it meant. But she had had the impression that her child was not normal.

Some of the emotions linger in some of the parents in a lesser degree mainly for the following reasons: (1) the reaction of people towards the MR children; (2) the

parents' comparison of their children with other non-disabled children, and (3) parents' inability to do something that could help the children to improve. Mother of case-1 gets angry when other children insult her MR child saying "zegemtegna" (retardate) and/or "ibd" (insane). She also feels sad and worries when she financially fails to meet the child's needs. Mother of case-4 also reported to worry for she is unable to do anything than helplessly see the child being restless while at home. The external demand made on case-1 by authorities of a regular school also made her mother angry. Mother of case-2 grieves when people reject her child. Mother of case-5 also used to get angry when people used to discriminate both her and her MR child. Both mothers of case-2 and case-6 are not comfortable when their MR children draw attention i.e. when people on the street gaze at the children. The mere fact that the children's being different and inferior from their age-mates worries mother of case-3, grieves mother of case-4, and disappoints mothers of case-5 and case-6.

The following experiences were also seen for different reasons. (1) *Fear* of giving birth to another MR child (mothers of case-5 and case-6) (Drew et al., 1992); (2) *uneasiness* when the MR child is away from home (mother of case-1 feels so when her child goes to school while the child's ears bleed, mother of case-6 feels so whenever the child is away from home, and mother of case-3 also said that she does not have peace of mind unless she knows where her MR child is; (3) *anger* - when the MR child fails to communicate what he wants (mother of case-6), and at

incessant care for the MR child and hence total deprivation of social activities and losing the possibility of getting a job (mother of case-5). She also said to be tired of caring for the child and became less caring.

(4) *Helplessness* - mothers of case-2, case-5, and case-6 feel that they cannot change the reality than to accept what they believe God has given them. Mother of case-2 said, "What could I do once God intended it?" And mother of case-6 also said, "I have to accept what God has given me since I cannot bring anything by mourning and getting upset." Mother of case-5 also said, "You cannot bring anything in mourning and grieving." She also blamed God, saying, "I believe that it [the child's being MR] is only because God did not will that she be normal. He could have created her normal as any thing is possible for Him"; (5) *regret* for not using contraceptives not to conceive the MR child (mothers of case-1 and case-5) and losing the chance of going abroad (Arab States) for a job as the result (mother of case-1); (6) *hopelessness* about the child's improvement (mother of case-4). Her being detached from the child could be attributed to this.

The detachment of mother of case-4 from her MR child may be considered as sign of the mother's rejection of the child, which is expressed through, according to Drew et al. (1992), under-expectation of achievement, setting unrealistic (unattainable) goals to justify the negative feelings and attitudes on the basis of negative performance (the child's teacher has reported that the family unrealistically expect the child to perform some activities), and escape (the child's

father once tried to let the child be accepted to a boarding house just to get rid of her. He was not successful, though).

The fact that the mother of case-2 is not intimate with her neighbors (with whom she has lived for four years as a neighbor) could be considered as withdrawal. This is attributable to her possible, yet not expressed, feeling of shame and guilt. Drew et al. (1992) write, "Parents [of MR children] may choose to isolate themselves because of their feelings of shame and guilt" (p. 371).

None of the mothers has said to have low self-image. Mother of case-2 said that her being away from the child, for her mother took the responsibility of bringing up the child, helped her not to have low self-image. The researcher believes that mothers of case-3 and case-4 have no low self-image because they had already given birth to more than eight non-disabled children before their respective MR children. Mothers' belief that the children's mental retardation was given from God can also be considered as a reason for mothers' not feeling low self-image. Mother of case-6 said, "It [her child's being mentally retarded] has not threatened my self-image because it is what God has given me." (The researcher suggests further study be made about it).

The children's going to school and getting relative improvement were also seen to have given the parents relative relief.

The financial support that some parents got helped them not to feel a special financial burden because of their MR children. Mothers of case-3 and case-4 said that the presence of MR children did not incur them special financial burden. Mother of case-3 said that the child's brothers buy what the MR child needs. Mother of case-4 (who ranked the family's SES in the middle class) also said that all the child's medical expenses were covered by the child's older sisters. However, mother of case-5 equated the expense that her MR child caused to the cost of building a house. She said, "I could not be able to cover all the expense for the sought-for healing of the child if it were not for their [her sisters and brother] financial support." Their presence now also helped the mother invaluably in that she can leave the child back home with them and go wherever she likes. Hoddap (1998) describes that copping with a mentally retarded child partly depends on external resources such as money.

The support that mothers of case-1 and case-2 used to get from their respective mothers in sharing the responsibilty of parenting their MR children was so significant. Mother of case-1 has now become incapable of meeting the MR child's needs after the death of her own mother and hence become emotionally more stressed. Grand mother of case-2, before her death, also used to take all the responsibilty of bringing up the MR child that the child's mother was relatively free and hence positively coped better by then than now. She said that she did not feel bad to know the child's real condition for the reasons that, inter alia, her

mother took the responsibility of bringing up the MR child and for she was away from him.

The presence of caring housemaid and caring brother of the MR child has given some relief to the mother of case-6 also.

The counseling that parents received from different sources was also seen to have helped them positively cope with their MR children. Drew et al., (1992) also write, "By finding and capitalizing on the positive attributes of the child, the professionals can assist the parents in realizing the child's worth and can guide them towards acceptance" p. 381.

What worries the parents most is what the future holds for their MR children i.e. what would the children be if their respective parents die before them? Tirussew (2000) also reported this. All of the mothers share this point except mother of case-1 (educable mentally retarded), who has strong expectation that the child would be self-sufficient. The old-age life of the MR child also is considered as source of worry for the mother of case-6.

Death wish for the MR child was also seen with some parents. Mother of case-5 used to wish that her child should have died when she was first informed that the child was an MR, thinking that the child could not do any thing. But now she does not have this feeling because she can see the child's behavior is amended and the

child has started to show some improvement in adaptive skills. Here one can see how parent's emotional well being could be a function of the child's significant improvement. Mother of case-4 still wishes that her MR child should die before her. Drew et al. (1992) write, "In some instant parents may react to the birth of such a child [mentally retarded child] with death wishes.

In this study, parents' social and emotional experiences are not seen as functions of severity of the MR children. Instead, the children's behavior was seen to affect them. MR children may have difficult or agreeable overt behavior regardless of their level of retardation. The behavior of case-1 and case-5, who were EMR and SMR/PMR respectively were of the most difficult behavioral problem in the group. That led their respective parents into quarrel with neighbors. When Drew et al. (1992) discuss about the correlation of severity of retardation with parents' adjustment, they state that, "[t]he degree of impact, frustration or disappointment, however, does not necessarily correlate directly with the degree of deficiency" (p. 367).

Regarding the relationship between sexes of the MR children, who are subjects of the study, and the social and emotional experiences of their parents, parents of two of the three female MR children were seen to be anxious that their MR children may be raped. Tirussew (2000) also reported this. Nonetheless, in this study, no other thing was seen in this respect.

CHAPTER SIX

CONCLUSSION AND RECOMMENDATIONS

6.1 Conclusion

The news that their children are mentally retarded naturally leads parents to experience different negative emotions, some of which could be managed in a short time while the other may linger afterwards for various reasons. The parents also go through different negative social experiences as well. In this study, the social and emotional experiences were seen to be partly interdependent. The reaction of the society to the MR child and/or the parents affects the emotion of the parents both positively and negatively. On the other hand, parents' perception of what the people think and react about them and the consequent emotional state of the parent also affect the parents' mode of interaction with the society. If the society treats the MR children and/or their parents in a positive away i.e. if it accepts the MR children and the parents, the parents' feelings will most likely be good, whereas it will be on the contrary if they are treated otherwise. However, the society's reaction was seen to play the main role in this regard.

The society's reaction is dependent mainly on two things i.e. the MR child's behavior and the society's attitude towards mental retardation in general.

The demand of the MR children by itself also affects parents social and emotional experiences. This, again, is dependent on the child's level of retardation and behavior. If the child is highly demanding that incessant attendance is required, the parent will be tired of taking care of the child and also be deprived of the activities outside home. Besides the direct economical need of taking care of the child, the parents' are made unable to generate income, working outside of home (Hodapp, 1998), and compelled to lose their own job. The parents can also be penalized for failing to attend social gatherings.

The home environment, the reaction of the spouse and the siblings, also is one of the main factors for parent's emotional experience. For the parents to have emotional wellbeing, the spouse as well as the siblings should be supportive. In other words, they should be understanding and caring.

6.2 Recommendations

In order to improve the life of parents and their MR children, rehabilitation measures must be taken with respect to:

One- improving the disability level of the MR children. Mental retardation, be it at any level, can be improved. As can be seen in the findings of this study, the MR children have shown significant improvement after they began to attend the special class. And as the result of that, their parents got some relief.

As different studies show (for instance, Tirussew, 2000) many of MR children in this country are kept indoors. It is, therefore, recommendable to find out these hidden children from where they are now and bring them to where they can find education.

The lack of special needs education (Tirussew, 2000) should not be forgotten. The government is highly expected to curb the problem in this respect. Different NGO's and individuals are also expected to extend their hands.

Two – teaching the society, taking the opportunities when the people are gathering in their iddir meetings, to have the right understanding of what mental retardation is and to let the people develop the right attitude towards MR children and their parents. Iddir is chosen because people gather there with a sense of cooperation. Neighbors can also be met when they gather for coffee. CBR workers, therefore, need to be trained for this purpose. The government is expected to work on this too. Mass media can also be used for this purpose. In this study, mothers of case-5 and case-6, respectively, partly attributed the mass media for the changed attitude of people about MR children and her awareness of what mental retardation is.

Developing the society's level of awareness plays a very vital role in helping parents recover their reputation in the society and easily and freely associate with

other people. It also helps parents to be understood when they fail to cope up with the social demands i.e. when they fail to attend to mourning, weddings and the like.

The society is the one who knows where hidden MR children are, therefore, it can be used as the main source of information in finding out the MR children who are kept indoors. The parents of MR children, as members of the society, may also bring forth their MR children.

The society should also be made aware of the need for protection of disabled children from possible sexual abuses.

Parents of MR children also need to be given professional counseling for it has invaluable importance in helping them adjust to the reality that their children are mentally retarded and positively cope with the children's needs (Drew et al., 1992; Harris, 1986; Brooks, 1994). It is essential also to meet the spouse and siblings of the MR children and let them develop their level of awareness about mental retardation that helps them cope positively with the MR children. This helps mothers to be understood and have the burden being shared and get peace at home (Shaffer, 1988). The MR children will also get a better care and love as the result.

Parents also need to be counseled not to ignore their MR children as most of them think that it is given from God and it is beyond what they can do.

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Appendix

Interview Guide

i) General Information about the MR Child

1. Sex
2. Age
3. Where does the child rank in birth order?
4. How do you describe the child's condition?
5. At what age of the child did you know that your child is an MR? Do you think the age of onset is earlier or had you seen the sign earlier?
6. How is the child's medical history? Have you ever taken the child to any where for cure?
7. How is the child's school result?
8. What do you expect in relation to the child's education?
9. Do you order him/her to do some thing for you? If yes what kind of things?
10. How do interact with him/her? Can he/she understand what you tell him/her very well?
11. How much support does he/she require from other people?
12. Does the child have or show any behavioral disorder? If yes, describe.
13. Whom does he/she spend most of his/her time with?

14. Does he/she have non disabled friends? If yes, what age? How long and often does he/she spend with them? If no, why not?
15. Where does he/she usually play?
16. Do siblings include him/her in there games/activities?
17. Do you think that the situation of the child can improve? If yes, how? If no, why not?

ii) Background Information about the Parents

1. Age?
2. Marital status?
3. Level of education?
4. What kind of occupation are you involved in?
5. How is your family's socio-economic status?
6. How many family members do you have?
7. What is your religion?
8. What do you think is the cause of your child's mental retardation?
9. Have you received sufficient information/counseling from professionals? If yes from whom?
10. What have the professionals told you?
11. What kind of attitude do you have for professionals' counseling?
12. Is there any other MR child in your family?

iii) Home and Social Experiences of Parents

1. What is your friends/neighbors attitude and reaction towards your MR child?
2. Do you discus your child's situation with your friends/neighbors? If yes, what do they say? If no, why not?
3. Do your neighbors allow their children to play with your MR child? If no, what do you think is the reason? How do you react then?
4. Do you think that there is a lost friendship/relationship or cooled intimacy following the discovery of your MR child? If yes, what do you think is the reason?
5. Does your spouse show positive attitude towards the child ? If not, how does he/she react? What do you think is his/her reason? What is your reaction for this?
6. How do other family members or siblings feel/act towards the MR child? What is your reaction for this?
7. Do you think that the presence of this MR child in the family has an impact on the family unit? If yes, describe.
8. What have been the reactions of the spouse's relatives?
9. Does the presence of this MR child threaten your marriage? If yes, how?
10. Who takes care of the child when you are not there?
11. Do you do any thing to help the non disabled siblings in coping positively with their MR bother/sister? If yes, how? If no, why not?

12. Do you give time to other members of the family? If no, why? How do they react then?
13. Do you have any other child with disability, who needs your special care? If yes, with what kind of disability?
14. How much has the presence of this MR child affected your social life outside home?
15. How much financial burden has the presence of this child brought on you/the family?
16. Do you get any financial support or support of any kind for this child from other sources? If yes, from where and how much?
17. Did you withdraw from friends, relatives, professionals, or activities that may facilitate the improvement of the child? If yes, why?
18. Do you go out with the child (like shopping, church, recreation centers, etc)? If yes, can you tell your experience? If no, why not?

iv) Emotional Experiences of Parents

1. What did you feel or say when you heard/learnt at the first moment that the child is an MR?
2. What other feelings have followed your knowledge of the child's condition (for example, disbelief, grief, anger, blame, regret, hopelessness, fear, guilt …)? Please put them in the sequence of their occurrence.
3. How strong were the above feelings? How long has each lasted?

4. How long did it take you to accept the truth?
5. What do you think has helped you to accept the reality?
6. Do you accept/treat the child as your son/daughter? If no, why?
7. What feelings do you have about yourselves after you learnt about the child's situation (condition)? Has it threatened your self-image?
8. Do you think/believe that you can do any thing to improve the situation? If yes, what?
9. Do you have any thing to regret about for not having done? If yes, what?
10. What worries you most when you think about your child's disability?
11. Do you have any thing that you would like to tell?

DECLARATION

I, the undersigned, declare that this thesis is my original work and has not been presented for a degree in any other university and that all sources of material used for this thesis have been duly acknowledged.

Name: _____

Signature: _____

Place: _____

Date of Submission: _____