

Life Experiences and Challenges of Mothers of ADHD Children on Parenting at ICH, Chennai

Gayathri Kannadasan¹, Shankar Shanmugam Rajendran²,
Kannan Kasinathan³, Maruthan Anbalagan⁴, Ashalin Raja Brindha⁵,
Shanmugapriya Shanmugasundharam⁶

^{1,5,6}Post Graduate, College of Nursing, Madras Medical College, Chennai – 03. (Affiliated to the Tamil Nadu Dr. MGR Medical University, Chennai).

²Principal, College of Nursing, Madras Medical College, Chennai - 03. (Affiliated to the Tamil Nadu Dr. MGR Medical University, Chennai)

³Associate Professor, College of Nursing, Madras Medical College, Chennai – 03. (Affiliated to the Tamil Nadu Dr. MGR Medical University, Chennai).

⁴Associate Professor, College of Nursing, Madras Medical College, Chennai – 03. (Affiliated to the Tamil Nadu Dr. MGR Medical University, Chennai).

Abstract

Attention-deficit/hyperactivity disorder, or ADHD, is one of the most prevalent neurodevelopmental diseases in children. Mothers of children with ADHD struggle with parenting and frequently use arbitrary approaches. Using a non-probability purposive sampling technique and phenomenological qualitative approach, 6 samples of mothers of ADHD children selected and data collected through semi-structured interview. The study explored and revealed five themes totally: They are family support, knowledge, early symptoms, parenting challenges and mental and emotional wellbeing of the mother. Under each themes the sub themes are derived. The theme of knowledge comprises of the reactions of mother includes informed and references. Initial stages and inattentive sub themes come under early symptoms. Under parenting challenges, the sub themes of education, nurturing and guilt of ineffective parenting derived. This study brought out the profound life experiences and challenges faced by mothers of ADHD children. The insights drawn through the semi structured interviews of 6 mothers through phenomenological design highlights the need of the mother and the challenges they face each day. Hence forth there is a need to develop the tailored interventions, resources and support systems to meet the demands and reduce the burden of the mother.

Keywords: Life experiences, challenges, mothers, ADHD children and parenting.

Introduction:

Children frequently struggle with speeding, making noise all the time, and not waiting their turn. They may occasionally become distracted, as though daydreaming. These behaviours, however, are more of a sporadic issue for certain kids. Attention-deficit/hyperactivity disorder (ADHD) is defined by the fourth Diagnostic and Statistical Manual of Mental Disorders (DSM-4) as a severe and ongoing impairment of psychological development brought on by a high level of impulsive, restless, and inattentive behaviour. In ADHD, hyperactivity is the most obvious symptom group. Youngsters are excessively running and climbing,

frequently in improper settings. They frequently twitch their hands or feet when they ought to be sitting still. The second noticeable symptom of ADHD is inattention. Children frequently overlook nuances and make thoughtless errors in their academics and other activities. When addressed to directly, they don't seem to listen, they frequently don't follow directions, and they don't complete their schoolwork or other assignments. They also struggle to keep their activities and chores organized. They have a tendency to forget things they need to do every day and are quickly sidetracked by irrelevant stimuli. Impulsivity is the third category of symptoms or traits. Children disrupt or encroach on others because they can't wait their time. The condition usually manifests in early childhood, usually before the age of five, and often before that. It frequently lasts throughout adulthood and adolescence. Comorbid conditions affect more than half of kids with ADHD. 30% - 50% have oppositional-defiant disorder, 15% are depressed, 25% conduct disorder, 25% have anxiety disorder, 15-40% have learning disorder and 36% of children with epilepsy. Although the exact aetiology of ADHD is unknown, scientists believe that an increasing number of genetic defects are contributing to the illness. ADHD is treated with a combination of medication and multimodal therapy. An evidence-based therapeutic approach for young children with ADHD is parent-child interaction therapy. The main goal is to improve symptoms and to rectitude to functioning them at homes and schools. Mothers who care for children with ADHD face three major forms of load: psychological and emotional burden, academic track burden, and activities of daily life difficulty.

Background of the study

The most prevalent neuro-behavioural childhood disorder is attention-deficit hyperactivity disorder (ADHD). Compared to other juvenile mental diseases, children with ADHD are challenging to manage because of the significant effects of their symptoms, which include hyperactivity and inattention. Because it affects the entire family, having a child with ADHD is a stressful scenario. However, in low- and middle-income nations like India, little is known about the struggles and experiences of mothers raising children with ADHD.

Global: From a systemic review and metanalysis conducted by Nader Salari, Hooman Ghasemi et al., 7.6% of children are diagnose with ADHD of age 3 -12 yrs and 5.6% of teenagers of age between 12 – 18 yrs in the year 2020 have been reported world - wide. Higher prevalence seen among boys than girls. Under ADHD categorization children with inactivity is 33.2%, hyperactivity and impulsive is 30.3%, and combined ADHD is 31.4% . Age increases in both gender the prevalence of ADHD decreases. Prevalence of ADHD children in Africa is 8.5%, South America is 11.8%, North America is 6.2%, and Europe is 4.6%. Japanese and Finnish children score lower prevalence., Jamaican and Thai children score higher, whereas American children score about average. A systemic review and metanalysis (1980- 2023) Jeyapalan Ranjan estimated that in South Asia 6.26% of Chinese children have ADHD, and highest prevalence is among Pakistani children whereas the lowest is among Bangladeshi children.

National: India accounts 5.18% of adults and 25.7% children under 12yrs have ADHD. the highest prevalence state is Maharashtra 6.2% which is revealed through a systemic review done by Sumit Mishra et al., in the year 2024 State: A systemic study done by DR. Jaizal and DR. Suguna from Royapettah hospital Chennai revealed that 9.27% of primary school children under the age of 12yrs have ADHD and were having 18.75% of poor academic performance, 17.7% have poor social behaviour and most of them were from lower middle class family background. Male have higher prevalence a than female.

Chennai: In Chennai, Institute of Child Health and Hospital , Egmore has daily average OPD cases of ADHD is about 3% . children who are under treatment and follow up accounts in the year 2023 is about 100 – 150 cases approximately .

Need for the study

One of the neurodevelopmental illnesses is attention deficit hyperactivity disorder, or ADHD. According to the findings, the incidence of children of age under 12yrs with ADHD is 7.6%. ADHD has deleterious impact on children normal life and mothers who is taking care. The burden of parenting is higher than taking care of a normal child which results in harming the family relationship. The poor understanding, lack of knowledge in parenting the children leads the mother to get into depression and anxiety often.

The cause of ADHD is unknown but in few studies the involvement of genetic abnormality and differences in the brain structure and activity have found out. The condition of children might lead to long – term complications without treatment. Children with ADHD are more impulsive, hyperactive, and inattentive than is typical for their age. Children with ADHD have a difficult time learning how to regulate their behaviour, emotions, activities, and attention. They consequently frequently behave in ways that are challenging for parents to control. Raising children has different obstacles for every parent. The way children are cared for can alter some of the symptoms of ADHD. Identifying areas for growth and creating focused solutions can be facilitated by understanding how ADHD affects parenting. Additionally, signs of ADHD can increase everyday stress and make it more difficult for parents to be emotionally available to their kids. Studies proved that ineffective parenting style and parents' poor psychological wellbeing are the major factors concerning the emergence and progression of conduct issues of ADHD.

Parents worry about the future of the children and their engagement in the antisocial activities, sexual abuse and drug misuse. Involvement of family in the multifaceted treatment of ADHD children is important for good prognosis. Training the parents about effective parenting of ADHD children improve the condition of the children and reduces the stress of parents. The outcome of the study of Firmin et al. exposes that parents of ADHD children experience more stress.

Mothers considered to be foundation of the family. Hence forth the struggles and experience of mothers should be explored to find out the better solution. These studies give greater insight to the researchers and the mental health professionals. Since mothers have deeper relationship with the children, understanding their lived experiences and challenges on parenting the children helps to determine the factors associated with the disorder, needs of the mothers, formulation of policies, resources development and so on which could be useful for both the welfare of the mothers and as well as the children.

Statement of the problem

“Life experiences and challenges of mothers of ADHD children on parenting”

Objectives:

Explore the life experiences and challenges of mothers of ADHD children on parenting in Institute of Child Health, Egmore, Chennai.

OPERATIONAL DEFINITIONS

Life experiences: It is a representation of a person's choices and experiences, along with the insights gleaned from them.

Challenges: It is something new and difficult which requires great effort and determination.

Mother: A woman who brings up and nurture a child whom she gave birth or adopted

ADHD: It is defined as one of the developmental disorders where the children have symptoms of persistent inattention and hyperactivity

Children: Plural form of child where it is a stage of human being from birth till puberty or under eighteen years of age

Research tradition: Phenomenological approach used as suggested by Creswell in (2013) to explore the challenges and experiences of mothers of ADHD children.

Assumption: Mothers face very hard in parenting ADHD children as they have impulsivity, low motivation and disorganized behaviour.

Research Question: What are the parenting challenges and experiences do mother have in handling the ADHD children?

Delimitations

- Limited to mothers of ADHD children only
- The study period is limited to 4 weeks
- Limited size sample

METHODOLOGY

Research Approach & design

Qualitative, phenomenological design

Setting of the study: Institute of Child Health and Hospital for children, Egmore, Chennai -08.

Study population

Mothers of ADHD children

Sample size

6 mothers of ADHD children

Sampling technique:

Non- probability, Purposive sampling

SAMPLING CRITERIA

Inclusion Criteria:

- Mothers of children with ADHD children of age 6-12 yrs
- Mothers who are willing to participate
- Mothers who speak and understand Tamil language

Exclusion Criteria:

- Mothers who are not available during the study
- Mothers ADHD children who are sick during the study
- Mothers who are participant in other studies

DATA COLLECTION INSTRUMENT

Demographic variables:

Child's age, mother's age, child's sex, marriage status, mother's educational attainment, work status, place of residence, marital status, family structure, and number of children.

Interview schedule

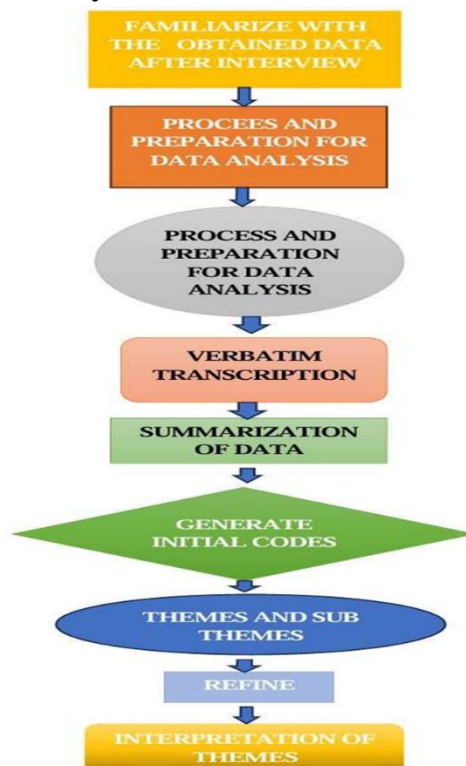
Validity and Reliability:

Experts from nursing and paediatricians determined the validity of the tool. Inter – rater reliability method was used to determine the reliability

Ethical Considerations:

After receiving ethical approval from the Director of the Institute of Child Health and Hospital for Children in Egmore, Chennai, as well as the ethics committee, the study was carried out.

Schematic representation of data analysis



FINDINGS OF THE DEMOGRAPHIC VARIABLES

DEMOGRAPHIC VARIABLES		Number Of Participants	Percentage (%)
Age of the mother	25- 26	1	16.67%
	26-28	1	16.67%
	28-29	2	33.33%
	30 above	2	33.33%
Age of the child	6-9	3	50%
	9-12	3	50%
Sex of the child	Male	3	50%
	Female	3	50%
Educational qualification of the mother	Primary education	2	33.33%
	Secondary education	2	33.33%
	Graduate	2	33.33%
Occupational status of the mother	Home maker	3	50%
	Other work	3	50%
Marital status	Married living with husband	5	83.3%
	Married living apart husband	1	16.67%
Residential place of parents	Urban	4	66.67%
	Rural	2	33.33%
Type of family	Joint	4	66.67%
	Nuclear	2	33.33%
Type marriage	Non consanguineous	4	66.67%
	Consanguineous	2	33.33%
Number of children in the family	One	3	50%
	Two	3	50%

The demographic and diverse background of the 6 participants under score the varied challenges and experiences faced by mothers of ADHD.

TABLE 4.3 THEMES, SUBTHEMES, NARRATIONS AND NARRATIVE DESCRIPTIONS

THEME	SUBTHEME	NARRATION	NARRATIVE DESCRIPTION
Family support	Family response	<p><i>No one in our family knows about this, only my husband and I are aware of it. I think we pampered him because he is our only child. - Audio 3</i></p> <p><i>"Yes, ma'am. They are also working, so it depends on them too. He wants the house to be quiet, but he is always in his own world. And a child who hasn't seen his dad all day will be excited and loud when they do. So, both have opposite temperaments". - Audio 6</i></p>	<p>Based on the responses, it seems most families are unaware of the child's condition except for the parents. One parent mentioned only they and their husband know about it, and they pampered their only child. Another parent discussed how their child wants a quiet home environment but gets excited and loud when their working father returns, creating different temperaments to manage.</p> <p>The unawareness of the family and the child often craves for love and affection from his father, the working condition of the father makes him to seldom spend time with the child and on the other hand there is a lack of family support in taking care of the child is seen</p>

	Taboos and cultural background	<p><i>"Our family members always says that the condition of the child is due to the family curse"- Audio – 2</i></p> <p><i>" My husband's family not willing to take care of my child, so left him in my mother's house whom they take care very well" – Audio - 1</i></p>	<p>This theme describes the familial beliefs of reason for ADHD and the negligence in caring the child. Mothers express their inability to inform about their child's condition to the family as they may neglect the child due to the social stigma</p>
--	--------------------------------	--	--

Knowledge	Informed	<p><i>"We came here to find out if he needs medication. Tomorrow morning at 8 a.m., there is a checkup with a heart specialist".- Audio 4</i></p> <p><i>"They asked me many questions. I need guidance on how to handle him. We went to many places, and one doctor said there was no need to send him to OT. I didn't understand anything. Then everyone's advice was difficult to follow; there wasn't a clear approach. They should mention everything in notes as it was a lot of information. It would have been helpful to me, to my family, or to anyone I could share it with. Now, our second visit is delayed because of this. If the information were streamlined and clear, it would have been easier".- Audio 5</i></p>	<p>Under the subtheme of Informed, most parents said they wanted to cure their child's issues as soon as possible. However, one parent felt they did not receive clear information. They described going to multiple places but receiving conflicting advice without a standardized approach.</p>
-----------	----------	--	---

	Reference	<p><i>"I was working, and during that time, one person referred us".- Audio 1</i></p> <p><i>"My cousin, who is studying and working as an intern, told us about it"- Audio 2</i></p>	All parents agreed they came to this centre through some form of referral, whether from a colleague or family member like a cousin studying to work as an intern. This shows the value of informal community referrals that bring families in for support.
Early symptom	Initial stage	<p><i>"For two weeks, it was difficult"-Audio 3</i></p> <p><i>"All children should be healthy and fine. With him being this hyperactive and angry... it was difficult for me".- Audio 5</i></p>	Parents had an understandably difficult time coping at first but later adjusted. One directly mentioned difficulties for two weeks while another found their hyperactive, angry child hard to handle.
	Inattentive	<p><i>"Only with his studies. He doesn't sit to study, and he doesn't listen. There's nothing else".- Audio 3</i></p> <p><i>"If I speak to him with love, he will listen to me. But I can't teach everything with love daily, like brushing his teeth—he won't do it. That depends on our mood. He won't listen to routine tasks".- Audio 5</i></p>	Inattentiveness found that most parents agreed their children were not listening to instructions. This made the children difficult to take care of as the parents would have to repeat themselves multiple times to get their children to listen. Most agreed their children struggled to listen to instructions, especially around studies. One parent specified issues with studying and listening. Another shared their child would only listen if spoken to lovingly but not for routine tasks like brushing teeth depending on mood.

Parenting challenges	Education	<p><i>" My child is having poor academic skills and I am unable to help him to concentrate on his studies" – Audio 6</i></p> <p><i>"I find difficult to teach my child" – Audio 2</i></p>	Some of the parents expressed about their inability of educating the child and mentoring in their studies. One of the mothers felt that due to their financial burden, she was unable to join him in the special classes and will be ideally satisfied when there is special teacher in the school alone
	Nurturing	<p><i>"My child is having disruptive behaviour which causes disturbance to the neighbours and often injures another child" – Audio 3</i></p> <p><i>" Often my child runs away from home and get injured " – Audio 5</i></p>	Based on the responses the mothers as they have intimate contact with the child than any other person in the family, find more difficult in bring up their child with good manners and they puzzled about the future of the children
	Guilt of ineffective parenting	<p><i>"I feel guilty as I am unable to handle him properly and guide him, I feel helpless in caring and directing my child" - Audio 1</i></p> <p><i>" I am exhausted in handling my child and sometimes I feel my child's disorder is because of some curse in our family" – Audio 4</i></p>	Most of the mothers got guilty feeling regarding their child's disorder and failure in parenting their child effectively

<p>Mental and emotional wellbeing</p>	<p>Sleeping pattern</p>	<p><i>"Sometime I feel frustrated and remain silent for sometimes when listening to others complaint about my child" - Audio 6</i></p> <p><i>"I often cry, remain sleepless so many nights and express my feeling to my family members about my child's condition" – Audio 3</i></p>	<p>Mothers express that, their deep emotions which they find always bound them during almost every night and makes them sleepless</p> <p>Many of the mothers emotionally moved when expressing about their children, they disclosed that many times they felt to get rid of the family and stay away from the family, some expressed that they spent lot of sleepless night due to the condition of the child.</p>
---------------------------------------	-------------------------	--	--

Discussion:

Current study reveals 5 themes. They are family support, knowledge, early symptoms, parenting challenges and mental and emotional well-being of the mother. Under each themes the sub themes are derived. The theme of knowledge comprises of the reactions of mother includes informed and references. Initial stages and inattentive sub themes come under early symptoms. Under parenting challenges, the sub themes of education, nurturing and guilt of ineffective parenting derived. The challenges of social, emotional and psychological pertaining to the child’s future along with lack of social support reflected in the study done by **Wongelawit Mesfin and Kassahun Habtamu (2024)**. The experiences of mothers concerning the child’s behaviour its impact in the family , guilt of inability and ineffective rearing practices of the ADHD children highlighted by **Mehersa Karimzadeh, Anahita Khodakhshi- koolae (2020)**. **Sophie Leitch, Emma Sciberras, Brittany Post, Bibi Grener, et al (2019)** reveals the maternal stress as result of inability in coping the child’s behaviour

Implications of the study:

The study emphasis the need for nursing involvement in providing knowledge regarding effective parenting in handling the children and addressing social, financial, psychological, emotional and practical challenges of mothers of ADHD children. Nurses need to support the mother , fill the knowledge gaps and coordinate resources and enhance family participation in caring children .

Nursing Practice:

- Provide psychological and emotional support and fill the knowledge gap of mother by educating her about ADHD
- Support mother through the involvement of family members in caring the child and Coordinate the supports outside the family including health care team and other resources
- Steps to reduce the burden by addressing the challenges through comprehensive support and foster measures to reduce the stress and improve overall wellbeing

Nursing Education

- Emphasize the importance of multifaceted comprehensive care and associate emotional, social and psychological support
- Develop strategies to impart effective parenting skills and foster interdisciplinary collaboration and address financial support system
- Teach effective measures in resilience building practices, navigate health resources through course work and Promote update on latest ADHD treatments and therapies

Nursing Administration

- Encompass flexibility in scheduling to accommodate family needs and manage adequate staffing levels on concentrating training programs in educating on ADHD
- Improve patient care quality metrics □ Facilitate health care collaboration and allocate the resources
- Initiate policies to support family-Centred care and establish stress management programs for nursing staff.

Nursing Research

- Explore the needs and burden of mothers in parenting ADHD children
- Asses the effective coping strategies for families, estimate the current support system in managing stress and anxiety
- Explore the impact of society on mothers of ADHD children, Investigate the role of support systems in managing stress and anxiety
- Conduct case studies to improve the strategies of effective parenting, evaluate the effectiveness of current policies and treatments over ADHD children
- Identify the factors that worsen the condition of ADHD children and analyse the importance of family and societal responsibility over the ADHD children
- Investigate the experience of family members and siblings of ADHD children and identify the factors which improve the ADHD children condition, involve diverse demographic groups to get better insight of differences in coping and support mechanisms

Limitations:

- Sample size: only 6 participants so it cannot be a fully representative
- Qualitative Design: statistical data cannot be obtained
- Geographic area: limited generalizability
- Time constraints: long term experiences are limited
- Self- reporting: Based on the memory of the participants
- Focus of mothers: other members of the family views are excluded
- Age of the children: Excluded adolescent children

Recommendations:

- Explore the strategies to magnify and improve the available resources to support the family having ADHD children
- Investigate the methods to improve parenting in handling the ADHD children
- Explore the impact of parenting on the behaviour of ADHD children

- Evaluate the cultural influences, social and environmental impact on the ADHD children management
- Explore the bio – psycho – social impact of parents with ADHD children
- Assess the role of social network in supporting the parents on caring the ADHD children
- Examine the strategies to reduce the burden and empower the family members in the involvement of ADHD children wholesome care
- Evaluate the educational program impact on improving parents' knowledge and management of ADHD children
- Explore the benefits of multifaceted comprehensive care among ADHD children
- Evaluate the effectiveness of communication strategies among nurses towards parents of ADHD children in fostering support and management
- Investigate the medication adherence and family support in the management of ADHD children
- Explore the impact of finance, education and socio- economic status towards ADHD children
- Case studies to identify the long - term outcomes of ADHD children in different ethnic and cultural group in the society

References:

1. Ryan, P., & Sawin, K. J. (2009). The individual and family self-management theory: Background and perspectives on context, process, and outcomes. *Nursing Outlook*, 57(4), 217–225.
2. Rydell, M., Taylor, M., & Larsson, H. (2017). Genetic and environmental contributions to the association between ADHD and affective problems in early childhood—A Swedish population based twin study. *American Journal of Medical Genetics, Part B: Neuropsychiatric Genetics*, 174(5), 538–546.
3. Saini, M., & Shlonsky, A. (2012). *Systematic synthesis of qualitative research*. New York, NY: Oxford university press.
4. Thapar, A., & Cooper, M. (2016). Seminar: Attention deficit hyperactivity disorder. *The Lancet*, 387, 1240–1250.
5. Thapar, A., Cooper, M., Eyre, O., & Langley, K. (2013). Practitioner review: What have we learnt about the causes of ADHD? *Journal of Child Psychology and Psychiatry and Allied Disciplines*, 54(1), 3–16.
6. Theule, J., Wiener, J., Rogers, M. A., & Marton, I. (2011). Predicting parenting stress in families of children with ADHD: Parent and contextual factors. *Journal of Child and Family Studies*, 20(5), 640–647.
7. Veenman, B., Luman, M., Hoeksma, J., Pieterse, K., & Oosterlaan, J. (2016). A randomized effectiveness trial of a behavioral teacher program targeting ADHD symptoms. *Journal of Attention Disorders*, 1–12. [10.1177/1087054716658124](https://doi.org/10.1177/1087054716658124)
8. Wehmeier, P. M., Schacht, A., & Barkley, R. A. (2010). Review article: Social and emotional impairment in children and adolescents with ADHD and the impact on quality of life. *Journal of Adolescent Health*, 46, 209–217.
9. Willcutt, E. G. (2012). The prevalence of DSM-IV attention deficit/hyperactivity disorder: a meta-analytic review. *Neurotherapeutics: The Journal Of The American Society for Experimental Neurotherapeutics*, 9(3), 490–499.
10. Zwi, M., Jones, H., Thorgaard, C., York, A., Dennis, J. A., & Collaboration, C. (2011). Parent training interventions for attention deficit hyperactivity disorder (ADHD) in children aged 5 to 18 years.

Campbell systematic reviews. 12:2. Campbell Collaboration.

11. Mofokeng M, Wath AE Van Der. Challenges experienced by parents living with a child with attention deficit hyperactivity disorder. *J Child Adolesce Ment Heal*. 2017;29(2):137–45. doi: 10.2989/17280583.2017.1364253]
12. Xie Y, Dixon JF, Yee OM, Zhang J, Chen YA, Deangelo S, et al. A study on the effectiveness of videoconferencing on teaching parent training skills to parents of children with ADHD. *Telemed e-Health*. 2013;19(3):192–9.]

Conclusions:

This study brought out the profound life experiences and challenges faced by mothers of ADHD children. The results of the study reveal 5 themes. They are family support, knowledge, early symptoms, parenting challenges and mental and emotional well-being of the mother. Under each themes the sub themes are derived. The theme of knowledge comprises of the reactions of mother includes informed and references. Initial stages and inattentive sub themes come under early symptoms. Under parenting challenges, the sub themes of education, nurturing and guilt of ineffective parenting derived.