

Role of Parents of Special Needs Children: A Qualitative Study

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2017/2018

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Abstract

The study titled 'Role of Parents of Special Needs Children: A Qualitative Study' aimed at understanding the experiences of parents of special needs children across various domains of life. The sample size comprised of 12 participants (six fathers and six mothers of special needs children) living in Bangalore. Purposive sampling technique was utilized to collect samples. A semi-structured interview method was utilized to collect relevant data from the participants. Thematic analysis was adopted to analyze the data. Results in this study highlighted the challenges faced by the parents of special needs children. Parents displayed positive attitudes in accepting the child despite hardships when compared their situation with the severe case. It was also observed that parents of children with ASD encounter severe challenges due to the ungovernable temper tantrums and dependency issues with the child, compared to the children with LD and MR. Parents of special needs children received major support from family and primary caregivers. Parents reported the dissatisfactory statements due to the lack of social support system existing for the parents of special needs children.

Keywords: Parents of special needs children, challenges, psychological experiences, acceptance

Introduction

‘Special needs’ is a phrase that refers to a vast array of disabilities/ diagnosis. This term includes children dealing with specific medical conditions, developmental delays, congenital and psychiatric condition. Children require accommodation to reach their potentials. Most of the children with difficulties require medications, therapies and other treatments that aid them achieve conventional daily routine. There is an immense need for family support and social support in nurturing the child with difficulty. Assisting a child with disability is team work. Parents, teachers, counselors, therapists will plan and work for the improvement and well-being of the child. Maintaining good rapport with the child helps in clear understanding of the child. Being friendly and playful with the children with special needs help the child overcome the burden of its disorder. This broad term called ‘special needs’ include children facing challenges in medical conditions, behavioral issues, developmental issues, learning issues and mental health issues. However, every child is unique, their requirements are unique. Parents/families concerned with children with special needs have to be adaptable in confronting the difficulties. They should plan and prepare for the frequent changes that accompany with child’s growth. Additionally, parents need to find appropriate medium of information and guidance whilst contacting health professionals. Therefore, the current study aims at understanding the role of parents and exploring their challenges and coping mechanisms through a qualitative methodology

Review of literature

The main focus in this study deals with the parental concerns and challenges dealing with a child with difficulty. Families having child with special need experience life different from other family systems. Parents tend to carry the different set of responsibilities and may feel it as a necessity to be present with the child all the times. It is unique shared experience and an ongoing process of child rearing for the families and can affect all aspects of family either positive or in negative ways. There was significantly lower perceived attachment and gratification in the autistic than the Down syndrome (Hoppes & Harris, 2010). Parents also expressed feelings of being overwhelmed, isolated, unprepared and stigmatized (Lauver, 2010). Parents were able to mobilise resources to help their child in all possible ways. Parents showed positive attitude towards the child’s condition despite the hardships (Altiere & Kluge, 2012). And study also supported the evidence for coaching interventions used within family-centred context. It also encouraged occupational participation in children and adolescents with ASD (Desley, 2014) When a comparison is done between the eastern and western countries, contribution of the western countries has been far greater in terms of research on role of parents of special needs children. There is a lacuna in research studies conducted in Indian context in this regard; therefore, the current study would help in developing better insights about understanding role of parents of special needs children and exploring their challenges in the present-day context.

Research methodology:

The aim of the study was to identify the challenges faced by the parents of special needs children. The study utilized two research questions and objectives:

Research Questions:

1. What are the challenges faced by the mothers of special needs children?
2. What are the challenges faced by the fathers of special needs children?

Objectives:

1. To identify the challenges faced by the mothers of special needs children
2. To identify the challenges faced by the fathers of special needs children

Research Design:

The current study utilized qualitative approach to understand and explore challenges and coping mechanisms utilized by the parents of special needs children. The respondents were interviewed using an in depth semi-structured interview

Sample size and Sampling technique:

Semi structured face to face interview was conducted on 6 parents (6 fathers and 6 mothers of special needs children) residing in Bangalore. Purposive sampling technique was utilized to include participants in the study. The participants were selected based on the inclusion and exclusion criteria listed below

Inclusion criteria:

1. Parents of special needs children studying in identified school following inclusive set up
2. Parents of special needs children within the age group of 6-15
3. Parents residing in Bangalore city
4. Parents who volunteered to be the part of this study

Exclusion criteria:

1. Parents of special needs children studying in special school
2. Parents of children who were not clinically diagnosed with special needs
3. Single parent

Tools of Assessment:

Consent form and a demographic data sheet were prepared by the researcher to obtain relevant socio Demographic data of the participant. A set of semi structured questions were predetermined to elicit data connected to the themes .The interview questions were crucial aspect of the study designed by the researcher. The questions were framed to obtain insight about the role of parents of special needs children living in Bangalore. There were set of 30 questions. The questions were broad-based to explore experiences and to understand role of parents of special needs children.

Validation and Piloting phase:

The semi structured interview questions were validated by two psychologists working with special needs children to obtain important insights into the relevance of the questions. Changes were incorporated as per their suggestions. A pilot interview was conducted with one parent to check if the questions were meaningful from their perspective. Based on the feedback relevant changes were made to the interview format.

Procedure of interviewing and data collection:

The selected participants were contacted. Consent was taken for audio recording before the commencement of the interview. Issues concerning confidentiality were discussed and assured by the researcher to the respondent. The participant was seated comfortably and met in place where the respondent was comfortable. Rapport was established to make the participant feel comfortable to answer sensitive questions where there was scope of clarification then and there, if any. Interview was completed in one session

Data analysis:

The obtained data were coded, analyzed and interpreted using thematic analysis.

Results and discussion

The researcher has identified various themes and sub-themes connected with the research objective. The themes and sub-themes are listed in the table below and are discussed further.

Table 1: shows themes and sub-themes derived under the objective 1.Challenges faced by the mothers of special needs children

Objective 1	Themes	Sub-themes
Challenges faced by mothers	<p>a) Sacrificing profession</p> <p>b)Scheduling time for the child</p> <p>c) Over-whelming situations</p> <p>d) Acceptance</p>	<p>a1: Phase of struggle</p> <p>c1: Response from people</p> <p>c2: Future concern</p>

Based on the table this objective focuses on the challenges faced by the parents of special needs children. It analyzes the different aspects of lives of parents during initial stage of diagnosis of the child, supporting the child after diagnosis, challenges while bringing up the child and accepting a child having a disability. The explanations of each sub-category, themes and sub-themes are as follows:

Theme a) Sacrificing profession

Study noticed that mothers of the special needs children sacrificed their professional life to look after the child *“First thing is I left my job...and then everything revolves around him like...after that only I get time...so before he gets up I will get up and finish all my work (ASM) this response explain how mothers of special needs children dedicate their time to support the child in all the areas of life. Mothers have sacrificed their profession as they prioritized children than the profession. Therefore, giving up on the profession was choice made by mothers. Despite the existing challenge mothers of special needs children focused only on the betterment of the child*

Sub-theme a1) Phase of struggle

Mothers of special needs children identified the phase of struggle in making the child independent in the society. They were comparing the progress of their children with other children. This was becoming even more challenging for mothers to make the child survive in this competitive World *“what we were feeling means... he is not learning like other kids of his age... he was not able to understand things appropriately... other activities were fine like eating food, taking bath he was independent but learning wise he was unlike other kids... he was not able to grasp things properly.... we have struggled a lot like...”(PSM), “No...it is not like one person know...they keep referring to n number of doctors...so that was like... (Dragging sentence)..Confusion period for us like...Has something so bad has happened...that’s the biggest question...just because the doctor tells you, you run from one pillar to the other”*(TRM) this

indicates that mothers of special needs children go through stressful situation while bringing up the child with difficulty

Theme b) Scheduling time for the child

Once after the diagnosis of the child mothers identify the difficult areas of the child. And accordingly, mothers schedule their time as per the requirement for the child. These responses help us understand this theme *“morning usually I can’t do anything much other than helping him for his breakfast and lunch so exclusive time for him means after 5 o’clock in the evening once he gets back from school... 5-7 is his study time... I sit with him make him do his home work... teach whatever has been taught in school... then watch TV or play for some time.... eat dinner and sleep..”*(PSM) *“So I wake up morning at 4 o’clock and whatever He needs I prepare first And then later I prepare for other people”*(TAM) *“it is like...before returns from school...I will keep his favorite food ready...so before only I ask what he likes to eat and accordingly I do”* (HM) these responses explain, mothers will dedicate their time to support the child to deal with the difficulty. Mothers help them in academics and also cook their favorite food. Scheduling time help mothers to attend to the child’s concern completely and there by supports the child to grow in a healthy environment. Mothers reported of sacrificing profession and social life for the well-being of the child. However, sustaining the patience throughout and encouraging the kid as and when required seemed to be challenging in the process of bringing up the child with difficulty

Theme c) Over-whelming situations

Mothers of special needs children reported of experiencing situations that were overwhelming

Sub-theme c1: Response from people

“Ya...there are...like whenever you compare with other kids... (pause for 3 seconds) and also when people ask... initially you will be know!”(TRM), *“when people don’t understand these things like special kids they are also humans... so some people forget that... and the kind of looks they give when they are not able to understand or behave properly in group...may be saying something loudly also... the kind of stares we get.... those things like really upset me”*(ASM) the above responses explain the challenges that mothers experience due to the societal pressures. It is difficult to face the society when people around start giving their views about the children with special needs.

Sub-theme c2: Future concern

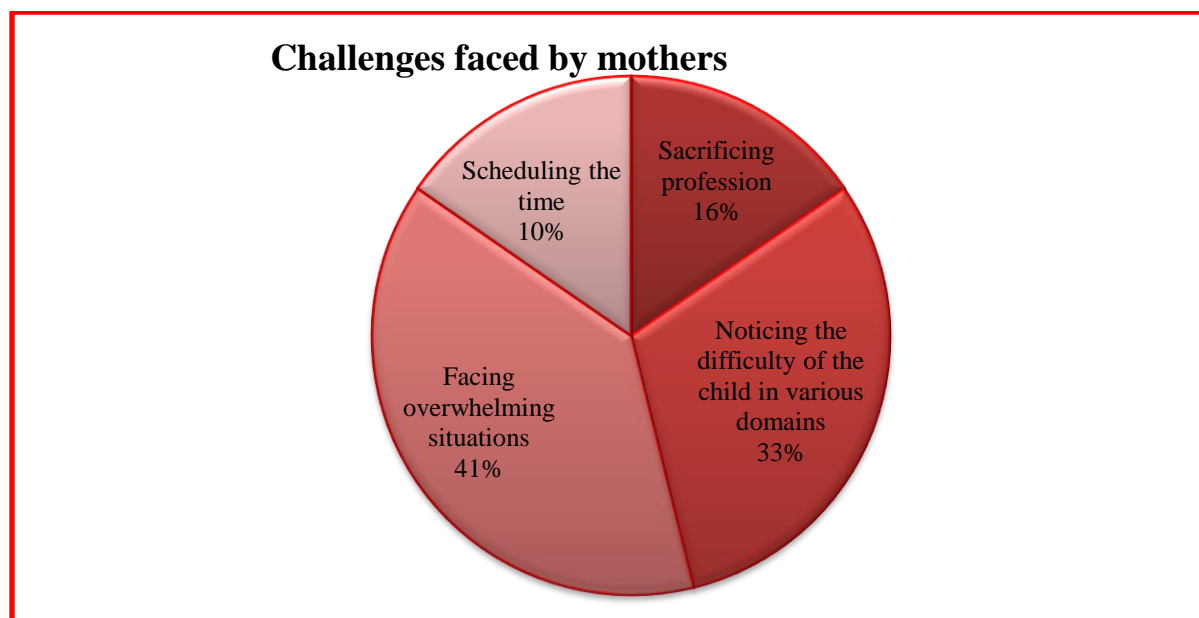
Mothers of special needs children were concerned about their children leading life in this type of environment that portrays low level of understanding towards child’s difficulty and needs *“Like when he is sometimes not able to write...it is little disturbing you know..about his future and(smiles)”*(MTM), *Once what happened you know...he was lost and couldn’t find the route...during that time, we were very tensed and we started searching, going and seeing each*

and every road and house...then somehow he only figured it out and came back home...so ya...that time we were really tensed..so if we think about future know....very disturbing” (HM) these responses indicate the future concerns of mothers of special needs children

Theme d) Journey of acceptance

Accepting a child with difficulty is a biggest challenge for any parent having a child with special needs. Mothers in this study have shown positive attitude towards accepting the child with difficulty *“We were helping him in all the ways... We haven’t thought anything else about him... like by seeing other kids we didn’t compare and all... so we never compared him to anybody else... however he Was progressing we just supported him.... we have accepted him the way he is...” (TAM)* *“we have to accept we have to support because it’s our kid ultimately... and we can’t say how many years we will stay with him so even in our absence he should be able to survive and lead his life happily... that is the only intension” (PSM)*. These responses convey that despite of hardships in bringing up the child with difficulty, mothers have accepted the children as they are. They did not differentiate or compare with the socially accepted behaviors rather supported the children in their interested areas.

Graph 1: Showing the percentage of the responses about challenges faced by the mothers of special needs children



From the above graph it is identified that 41% of the mothers of special needs children face challenges due to the overwhelming situation that appear in the journey of bringing up the child with difficulty. 33% of the mother’s experience challenges through noticing the difficulty of the child in various domains. 16% of the mothers reported about sacrificing the profession that was identified as another challenge and 10% of the mothers reported that scheduling the time for the child was challenging.

Table 2: shows themes and sub-themes derived under the objective 2.Challenges faced by the fathers of special needs children

Objective 2	Themes	Sub-themes
Challenges faced by fathers	<p>a) Financial constraints</p> <p>b)Scheduling the time for the child</p> <p>c)Over whelming situations</p> <p>d)Journey of acceptance</p>	<p>a1: Shifting jobs</p> <p>b1: Father and son time</p> <p>c1: Comparison with other kids</p> <p>c2: Response from people</p>

The themes and sub-themes mainly focus on the challenges faced by the fathers of special needs children. It also explores the expression of emotions of fathers

Theme a) financial constraints

Sub-theme a1: Shifting jobs

“I shifted jobs so that can help the finances so... though i was in a good position... you need to get hikes every year so changed companies and meeting the finances that was my responsibility” (ASF) this response of a father explains the challenge faced to meet the familial and child’s requirement which is very much needed in the current scenario. And some fathers have also mentioned that to help their child after school hours, they have worked half a day *“See no matter we are busy... Throughout the day... Like from fifth year to tenth year of his age I haven’t gone to office beyond 3 o’clock... I work only half of the day... So, it’s only for my son... So, half the day I never used to work”*(TAF), *“Most of the time one of us will be there with him. Almost 24hours somebody has to be there with him. Only when he goes to school we were doing our work. But even in school know we don’t know when we get a call (laughing) so whenever we get a call we should be ready to go...that’s how it is...”* (TRF) these are the challenges fathers experience in their daily routine.

The current section supports the study conducted by Laufer, (2017) which highlights the challenges faced by parents of special needs children. This result of the study explored that parents experience financial stressors and social isolation along with emotional disturbances taxed when raising a difficult child. Meeting finances becomes very important as the requirement

of the special need's child differs from the general population. Therefore, parents encounter the difficulties in meeting the finances to support their children with the difficulty.

Theme b) Scheduling the time for the child

Sub-theme b1: Father and son time

Fathers have reported of utilizing father and son time. This was one of the stresses relieving activity followed by fathers. *"I usually play with him. Homework and all, he will complete with his mother...so I play Carom with him after dinner...and Saturdays I will take him to the ground to make him play cricket"* (MTF), *"we are going to music class together and we are going to drawing class together so we have dad son time... we go in two wheeler so he enjoys he likes to go"*(ASF), *"During weekends, I will play cricket with him...then he goes to Badminton classes also...and ...sometimes in the evenings... I will... mmmm.... Sit with him for homework..."* (HF), *"Sundays i will be with him the whole day... and we plant together... repair things at home together so only Sundays I get time to spend time with him..."* (PSF), this indicates how fathers were lending their time with their children having difficulty. However dedicating time after work hours was again seemed to be challenging task for the fathers of special needs children.

Theme c) Overwhelming situations

Fathers of special needs children reported of experiencing situations that were overwhelming

Sub-theme c1: Comparison with other kids

"Ya...if I see how the other kids respond and all...you know I feel...aaa...little upset..." (HF) *"Yeah we were feeling.... Like other kids he will not jump around... Run around and doesn't quickly you know do any activity... Won't run easily.... even now... So, somebody told is a problem... Today he is 11... He cannot sit in seven standards... or sixth standard as per the age..."* (TAF) These responses help us understand how fathers compare their children with difficulty, with other children in the society. Disturbance in the emotion is experienced by the fathers of special needs children noticing the difficulty in child

Sub-theme c2: Response from people

societal responses and views is another overwhelming factor for fathers of special needs *"Most of the times... like I feel that you know... people say they have this boy... and nothing much can be done... I feel would have done something better if I had chance... and this could have been better. so that's the only thing"* (ASF) this indicates how dealing with society becomes challenging for fathers of special needs.

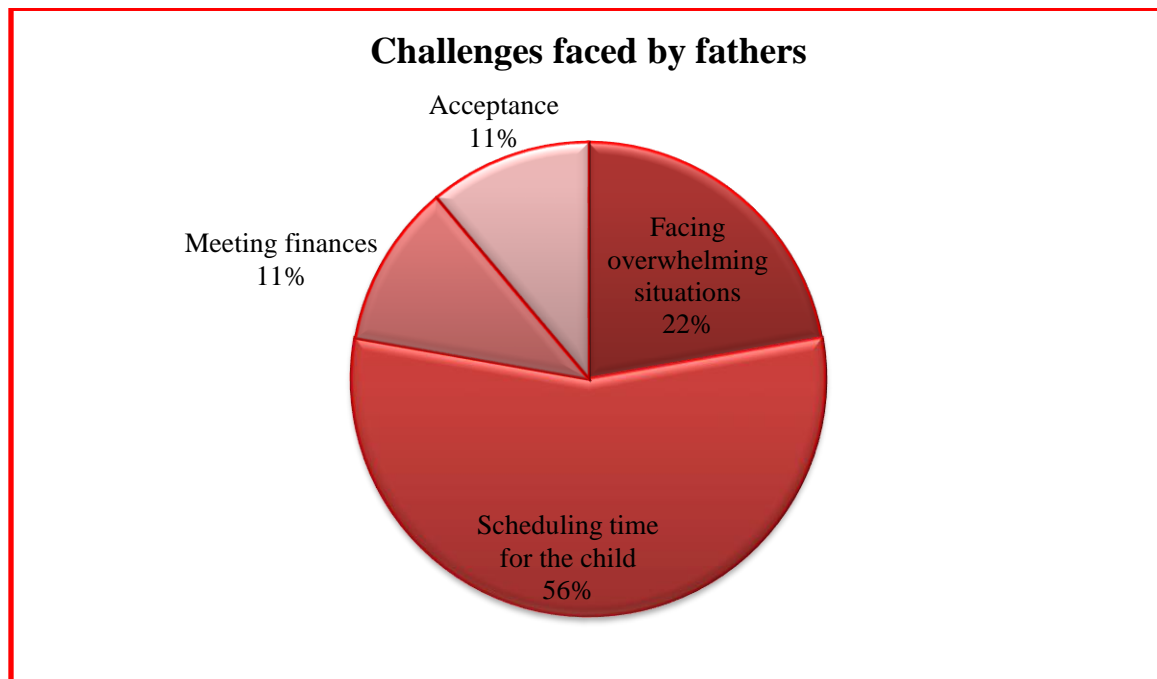
Theme d) Journey of acceptance

Nevertheless, fathers of special needs children have accepted the fact of having a child with difficulty. These are some of the reasons for acceptance of the child for who they are *"Accept in*

the sense...we feel...at least he is like this know.... whenever I see another child.... like some kids they are unable to do their work...so if I compare...I think he is far better...so we are happy with that”(MTF), “we dint accept the fact that this is not there so at one particular time we felt what if he can’t speak... what’s wrong in that... not all people are perfect... we thought on those lines... why should we bother about people.... why should we bother about his school... so all those things came in and then suddenly we felt that... instead of being ignorant let’s take the fact lets accept it and work however it is”(ASF),“Comparatively He is slow... but we should not stop there only we have to go extra step and should work to overcome the difficulties so we have taken the help from the right people and moving”(TAF)these responses indicate that fathers are optimistic towards accepting the child with difficulty

The themes and sub-themes explain the challenges faced by the fathers of special needs children. Fathers of the special need’s children compared their children with other kids in the initial stage of diagnosis which lead to the disturbance in their emotions. It was observed that mothers of special needs children spend and schedule most of their time with the children since fathers were able to spend time with the children only during weekends. Fathers also faced overwhelming situations which made them go through tough times in upbringing the child. However, fathers of these special need’s children have supported and accepted their children, reason being their individual choices

Graph 2: Showing the percentage of the responses about challenges faced by the fathers of special needs children



From the above graph it is identified that 56% of the fathers of special needs children face challenges in scheduling time for the child. 22% of fathers experience challenges due to the

overwhelming situations that appear in the journey of bringing up the child with difficulty. And 11% of the father's experience challenges while meeting the finances and accepting the child with difficulty.

Conclusion

- ❖ Challenges faced by mothers: Facing overwhelming situations was one of the major challenges faced by the mothers of special needs children. They reported of sacrificing their profession and scheduling their time for the well-being of their children. Due to the dependent behavior of the child, mothers expressed concerns regarding the future of the child
- ❖ Challenges faced by fathers: Fathers reported of experiencing overwhelming situations from the social response. Meeting finances and giving quality of time for the child was another challenging factor for the fathers of special needs children
- ❖ It was noticed that mothers spent lot of time with the child compared to fathers since fathers were able to spend time with the child only during weekends. Parents displayed positive attitudes in accepting the child despite hardships when compared their situation with the severe case. However it was also observed that parents of children with ASD faced severe challenges due to the ungovernable temper tantrums and dependency issues with the child, compared to the children with LD and MR.

Limitations

- The current study included 12 respondents (six fathers and six mothers of special needs children) only.
- The geographical region for the current study was restricted to Bangalore city limits.
- Although a number of psychological dimensions were used to understand the themes and sub-themes, use of many other psychological concepts and theories may have helped in better understanding of the analysis of themes that were emerged.

Implications

- This assists psychologists to work effectively with the parents of special needs children in helping them deal with their stress
- The study emphasizes the need for accepting and supporting a special needs child from both family and in societal context
- The process of being identified as a parent of 'special needs' itself is an emotional journey, therefore it is very important to spread awareness regarding the difficulty and need of the child and thereby support the families having special needs children

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