

ORIGINAL ARTICLE

Problems faced and coping strategies adopted by parents of the children with special needs in Pondicherry: A mixed method study

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developing child.(1) But on the negative aspect, such parents reported to have higher stress levels, anxiety, depression and strained marital relationships.(1) As the child ages, the parenting stress also changes linearly.(4)

As quoted by Moawad, children with special needs include chronic illness, congenital disability, developmental delay, developmental disability, disability, handicap, impairment, and technology-dependent child, as there is no single definition or classification system that is used.(3)

The facilitators to coping include encouragement, assistance and help from extended members of the family like grandparents.(5) The five "Life management skills" that assists parents to cope with their child who needs special assistance are the following: "Reframing-Changing how you are thinking, Passive appraisal-Setting aside your worries, Spiritual support-Finding comfort and guidance from spiritual beliefs, Social support-Receiving social and emotional support from friends and family, Professional support-Receiving assistance from professionals and agencies."(1)

Aims & Objectives

1. To explore the various problems faced by them.
2. To study the coping strategies used by them

Material & Methods

Study type: A cross-sectional study among the selected schools with both quantitative and qualitative technique (Focus Group Discussion).

Study area: The present cross-sectional study was conducted in the schools which are being run by Satya Special School, the Head Quarters of which is located at Karuvadikuppam, Pondicherry. This school has (4) urban (viz at Karuvadikuppam, Sarukupalam, Kuilpalayam and Rainbow Nagar) and 3 rural (Seliamedu, Villianur and Mutrampattu) branches in Pondicherry. The village Seliamedu, coincidentally comes under the rural service area of Department of Community Medicine of our college. We made series of visits to these schools and met the parents of the special children after prior permission and intimation.

Study population: The parents of the special children were enrolled for the study only when they willed and gave consent.

Study duration: The current study was conducted between May - June 2017 (2 months).

Study instrument: A pre-tested semi structured, and self-reported questionnaire was used to get

information from the parents of the special children only after obtaining informed consent.

Sample size calculation: The minimum sample size was calculated to be 187 using nMaster software, assuming proportion with adoption of coping strategies to be 50%, relative precision of 20%, design effect of 1.5 (for choosing special schools as clusters), non-response rate of 20% and 95% confidence limit. To meet this sample size, 3 schools (approx. 60 students in each school) were included in the study. Thus, one school out of three in urban area and two schools out of four in rural area were randomly selected for this study.

Inclusion criteria: The parents (Mother or father) of the special child who gave consent for the study.

Exclusion criteria:

1. Those parents who did not come to school (reasons being absentees, out of station etc.,) on given date and time.
2. The parents who did not give consent for study were excluded.

Strategy for collection: The study investigator met with administration of special school. The quantitative data was collected by the study investigator by administrating self-reported questionnaire among the parents of special child. Information from the parents regarding socio-demographic characteristics, number of children to the parents, sex, birth order of the child, monthly family income, type of disability, problems faced by them etc. and the different coping strategies they are practicing was collected.

Qualitative data regarding problems faced by parents and different coping strategies they are practicing was collected in the form focus group discussions (FGDs) [Hudelson 1994]. For this purpose 2 FGDs till point of saturation (40-45 minutes each) were conducted by the study investigator and facilitated by study guide trained in qualitative research. Each FGD included 8-10 parents of the special children who were willing to participate and talk freely. [\[Figure 1\]](#)

Data analysis - software: The quantitative data entry was done in Epi_data 3.1 while analysis was done by using Epi_data 2.2.2.182. The data is presented in the form of numbers, distribution and percentages, median and IQR (Inter quartile range) in tables and figures. The content analysis of FGDs was done manually.

Ethical approval: Indian Council of Medical Research (ICMR), New Delhi, approved the project and the

study was permitted by Institutional Human Ethical Committee of our college. Individual confidentiality was maintained by the researcher and the study guide

Results

The above table represents socio-demographic profile of the study participants. Out of the total 187 participants, 70.6% were mothers. Majority of them belonged to Hindu religion 174 (93.0%) and most backward class 78(41.7%). One third mothers 61(32.6%) were illiterate, while 149(79.7%) were home-makers. [Table 1]

The parents revealed the management skills that assist them to cope with their child who needs special assistance. The 5 subscales of the coping strategies are: "Reframing, Passive appraisal, Spiritual support, Social support and Professional support." Median of the subscales for reframing was 34 (IQR 29-38), followed by acquiring social support was 27 (IQR 22-31), mobilizing family to acquire & accept help was 15 (IQR 12-17), seeking spiritual support was 14 (IQR 10-16) and for passive appraisal was 13 (IQR 12-16). [Table 2]

The coping strategies used by the parent were Reframing: 150(80.2%) knew that they have the strength of solving their problems. 147(78.6%) Accept that the difficulties occur unexpectedly. 141(75.4%) Believe that they can handle their own problems. 140 (74.9%) Accept stressful events as a fact of life. 136(72.2%) try to show that they are strong enough to handle their problems. Spiritual support: 144(77%) have faith in god. Professional support: 135(72.2%) pursued information and guidance from the family doctor. Social support: 118 (63.1%) Share their concerns with close friends. Passive appraisal: 114(61%) watch television to set aside their worries. [Table 3]

When asked about the problems faced by the parents of a special child, it was reported that depression (69%) was most common problem followed by few other problems are mentioned in [Figure 2] Parents also added further to above mentioned list of problems with marital disharmony (3.7%), managing the emotional needs of siblings (0.5%), unable to give the essential care for other child (0.5%) and inconsistency in co-operation leading to lose patience (0.5%).

Discussion

Among 187 parents studied in Pondicherry, the current study has been conducted to study the

various problems faced and the coping strategies adopted by them. The findings of the present study showed that, more than two thirds of the participants (70.6%) were mothers. This could be because of the fact that mothers are involved more in taking care of their special child therefore increases the chances to participate in the current study. The present study revealed that, 67.3% mothers were educated which is almost similar to the study conducted by Gehan EL Nabawy Ahmed Moawad *et al* which showed 71.2% of the mothers were educated.(3) In the present study, around 18.7% of the family had more than two children which is quite less than the a study from Iran where 65.9% of the family had more than two children.(6)

The results of this study showed "reframing" was most common coping strategy followed by "acquiring social support, mobilizing family to acquire & accept help, seeking spiritual support and passive appraisal." This in contrast with a similar study done in Iran, the main coping strategies was "spiritual support" followed by "seeking help, reframing" and others.(6)

When frequencies were computed for the coping strategies used by the caretakers, findings revealed that in majority of parents felt that their family members have strength of solving own problems (80.2%) and have confidence in handling their problems (75.4%). This is indicative of the confidence and readiness to solve their own problems. Whereas the thesis done by Danielle Haaksma showed the frequency of the most used coping strategies was talking to family members (76%), followed by planning (72%), talking to friends outside the family (68%) and acceptance (68%).(7) We feel that counselling sessions by psychologist, motivational speech for the parents can be arranged to boost their moral. This will enable them to carry forward their responsibility effectively throughout life.

Majority of the problems faced by the parents of a special child were depression (69%) followed by economical issues (26.7%) and emotional disturbances (23.5%). We could not find other study quoting the problems faced by the parents of child with special needs. The stress among parents was high and such child demands more care as reported by Sullivan-Bolyai *et al* (8) & Oruche *et al* (9) Such parents are not able to remain active socially.(10,11,12) Parents' attitudes towards their children's level of disabilities probably a main

determinant for social participation.(10,11) Our study revealed that, parents had better attitude towards handling the issue of special child.

This perception of stress may fluctuate with a child's disabilities, monetary aspects and demand of care, apprehension of parenthood, and a sense of social seclusion.(13) But in our study, we found that parents have strength to handle these problems.

We feel that this issue must be studied further to find out ground reality in different part of the country. This will definitely help to planners to provide different set of services including health services to the family members especially to parents and caretakers of child with special need

Conclusion

Depression was one of the major problems faced. Reframing and acquiring social support were the most commonly used coping strategies by parents of special children.

Recommendation

We feel that counselling sessions by psychologist, motivational speech for the parents can be arranged to boost the moral. The additional research might address the coping strategies of other family members, such as siblings and the extended family. The study which will focus on parental coping strategies at different stages of development can also be done. The further research should focus on comparative study between coping strategies used by mothers versus those used by fathers and personal interviews could be conducted.

Limitation of the study

The current study was conducted among parents of selected schools. Thus, the study finding cannot be generalized. We feel that future research should be done on larger populations or in more schools to get more information.

Relevance of the study

The study is unique for Indian settings which help to understand issues related to vulnerable population.

Authors Contribution

All the authors have contributed equally.

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Tables**TABLE 1 SOCIO-DEMOGRAPHIC DETAILS OF THE PARENTS OF THE CHILD WITH SPECIAL NEEDS**

S.no:	Characteristics	n (%)
1	Mother's age ≤30 years 31-44 years ≥45 years	27 (14.4) 145 (77.5) 15 (8)
2	Father's age ≤30 years 31-44 years ≥45 years	4 (2.1) 118 (63.1) 65 (34.8)
3	Mother's education Illiterate Primary & Middle Secondary & Higher secondary Graduate & above	61(32.6) 47(25.1) 55(29.4) 24(12.8)
4	Father's education Illiterate Primary & Middle Secondary & Higher secondary Graduate & above	48 (25.7) 45 (24.1) 64 (34.2) 30 (16)
5	Mother's occupation Unemployed/Housewife Employed	149(79.7) 38(20.3)
6	Father's occupation Unemployed/Housewife Employed	12 (6.4) 175 (93.6)
7	Monthly family income <1999 2000-4999 5000-9999 >10,000	4(3.6) 16(8.6) 91(48.7) 76(40.6)

TABLE 2 DESCRIPTIVE STATISTICS OF 5 “SUBSCALES” OF COPING STRATEGIES

Subscales	Median (IQR)
Acquiring social support	27 (22 - 31)
Reframing (viewing conflict or crisis in a positive manner)	34 (29 - 38)
Seeking spiritual support	14 (10 - 16)
Mobilizing the family to get&take help [“social support”]	15 (12 - 17)
Passive appraisal	13 (12 - 16)

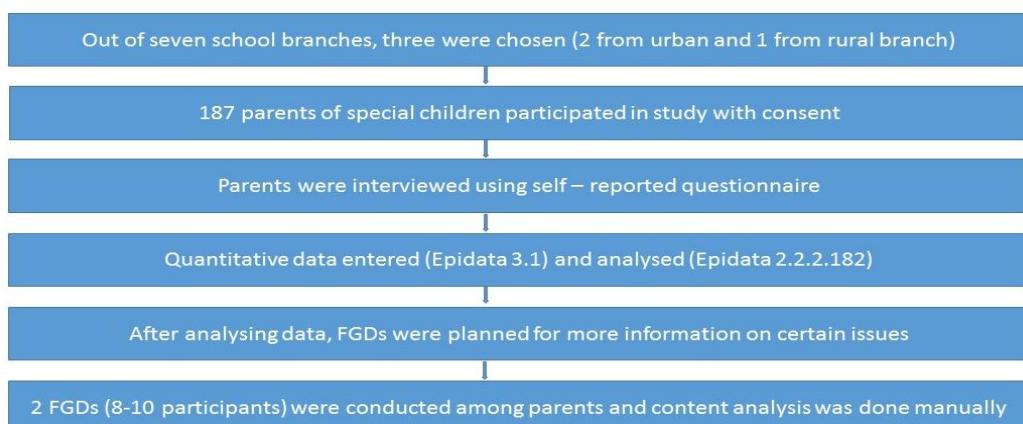
TABLE 3 PERCENTAGE DISTRIBUTION OF COPING METHODS USED BY THE CARETAKERS

S.No:	Coping methods	n (%)
1	Knowing that family has strength of solving own problems	150 (80.2)
2	Accepting that difficulties occur unexpectedly	147 (78.6)
3	Having faith in God	144 (77)
4	Have confidence in handling own problems	141 (75.4)
5	Acceptance to stressful events as a fact	140 (74.9)

TABLE 4 CONTENT ANALYSIS OF THE FOCUS GROUP DISCUSSIONS (FGD)

Category	Codes	Responses of the participants the participants
Difficulties parents face in raising their special child	Problems faced	<p>Feel depressed in coping up and raising the special child (depression all the time)</p> <p>Economic problems and do physiotherapy for the special child (not able to buy medicines)</p> <p>Child faces physical abuse by neighbour kids, social discrimination and treated as untouchable (neighbour kids beats this child and others were not even treat as untouchable)</p> <p>Siblings affected since we (parents) were unable to take care of other children in the family.</p> <p>Lack of attention to other family members (can't able to take care of others)</p> <p>Unable to take the child out due to embarrassment (feeling embarrassed to take the child out)</p> <p>Spiritual misguidance like giving birth to a special child is due to the sins of the mothers and blame is put solely on mothers (because the mother had done sins in the past they've given birth to special child)</p> <p>Tortures by in-laws, marital disharmony, criticisms in the community were also the difficulties faced by the parents of a special child (even we are being tortured by in-laws & have fights in our family)</p>
Coping strategies	Strategies by the parents	<p>"Accepting the fate as it is" was the commonly used strategy by the parents of these special children (accepting it was our fate)</p> <p>Challenging their frustrations, strong will power, ignoring the criticism and unnecessary advice from the society were the other strategies used(taking care of child by ignoring others criticism)</p> <p>Some opted to better live in present; than to think about the past.</p> <p>Some were engaged in recreation works like stitching, doing embroidery works and watching TV as a way of coping strategies</p>

Figures

FIGURE 1 FLOW DIAGRAM OF THE STUDY**FIGURE 2 PROBLEMS FACED BY THE CARETAKERS**