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State of psychosocial wellbeing in midlife mothers of children with multiple disabilities: A study with special reference to Kottayam district

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Abstract

Objective: This quantitative study described psycho social wellbeing in the midlife mothers of children with multiple disabilities. **Method:** Data was collected using interview schedules with 60 midlife women. **Results:** There is no difference between the socio demographic characters of respondents and psychosocial wellbeing. **Discussion:** This study concludes that disability throws a devastating impact when the midlife mothers face psychosocial problems, because they are the primary care givers. A problem affecting the mothers can affect the whole family. The mothers have to handle lots of task such as household works, looking after the family, going for job despite their multitasking ability. So, it might become difficult to handle certain situations in their life.

Keywords: *Midlife women, Multiple disability, Psychosocial wellbeing*

Introduction

'Multiple disabilities' means concomitant impairments, such as mental retardation, blindness, mental retardation-orthopaedic impairment, etc. Children with multiple disabilities will have a combination of various disabilities that may include: speech, physical mobility, learning, mental retardation, hearing, visual and brain injury.

A child who is multiple disabled should receive help as early as possible so that he or she can be helped to achieve his/her potential and so that his/her disabilities will not become worse. The child will be slow to make progress and will have difficulty in generalizing. It is important that we are patient and that we set realistic goals that are small and achievable, as the child can learn only in small steps with a lot of practice and repetition. Because children with multiple disabilities have problems with all muscle movement, with understanding and often with seeing and hearing as well, communication is very difficult for them. The birth of a disabled child induces complex feelings in both the parents. There is denial, shock, aggression, unhappiness and even lack of acceptance. In the case of parents, mothers are the most affected section in the family with a multiple disability child.

Many a times, mothers even refuse screening for disabilities in the antenatal period as they would not wish this reality to dawn upon them. Feelings of guilt, depression, anxiety are all part of the adjustment process and

though some of the mothers adjust well, psychopathology remains rampant among the others. Mothers of children with intellectual disabilities have been proven to experience higher levels of stress and depression than their spouses (Riasat, 2012). It has been noted that mothers of autistic children show an increased anxiety with respect to the poor social relatedness, delayed speech development, hyperactivity, behavioural problems and lack of eye contact in their children. Mothers of autistic children are also more introverted and neurotic than other mothers. They have also been proven to be more frustrated, oversensitive and stern than other mothers.

Studies have also presented that 33-53% of mothers with disabled children have depressive symptoms and on comparing mothers of children with Down's syndrome and autism, it is found that the mothers of autistic children were more distressed and also have limited social support (Solomon, 2015). Also, in the legislations the provisions for uplifting the psycho social wellbeing of the mothers of children with disabilities has not been mentioned yet. Most of the studies deal with the family relationships and how disability affects the family. But then the mothers who are the prime support givers of the children with multiple disabilities have not been much focused.

Parents of Disabled Children

The true sufferers are the parents of disabled children. The parent having the female disabled child suffers with more stress, emotional problems and neurotic problems. Likewise, the parents with mentally retarded child also face intensive problem of stress. Sometimes the parents have to take the advice of their physician or counsellor to give some basic training. In Western countries many social issues are advantage to the parents in Government side also. In Indian context the social situations are more pathetic because of the financial problems of the parents and also lack of proper education (Shyam, 2014).

The parents of mentally retorted children usually have to face a range of emotions over a long period of time. They often struggle with guilt. Usually the both parents or one of them blame him that this disability in his child is due to his genetic disorders, alcoholic nature, worries or tensions, or other rational or irrational reasons. Physical tiredness can take an excise on the parents of a mentally retorted child (Solomon, 2015). They need an extra care. All the caring activities likewise nourishing, cleaning, moving and feeding an infant is so easier for a normal child as compared to child having weighs of 80 pounds. These children often required extra care from the physician and other healthcare appointments than a normal child and usually need close medical monitoring. Not only has this but parents also had to face a lot of troubles while educating them.

They have to arrange special private educational facilities or need to consult special education centres for their proper education. These children's usually needs close parental contact with the school system. Their parents have to regularly visit or check the child's interaction with their fellows to make sure they are not being bullied. The disabled children usually required special transportation facilities for their schooling and other activities, the children who have severe disabilities may require to be schooled at home. It is estimated that expenses required to nourish a disabled child as compared to normal child is usually high. These expenses boost up because these children required sophisticated medical equipment and supplies, extra medical care, private education, tutor for home tuitions or specialized transportation facilities. These children required the lifetime care besides of 18 years. Their parents may have to arrange money for a trust whose care their child's when they pass away (Singhi, 2000). A wide range of psycho social problems are experienced by the mothers of children with multiple disabilities (Shyam, 2014). This study can be helpful for the mothers‟ of children with multiple disabilities. This study helps them to

assess and address their psychosocial wellbeing. Unavailability of adequate social worker intervention is a plight of social workers to tackle this issue.

Background

The families of the children with multiple difficulties face lot of psychosocial problems. Mothers usually experience the most extreme pressures in caring for their disabled children. Because of this situation, such mothers possess a different psychological wellbeing from that of mothers with healthy children. The mothers of children with multiple disabilities suffer from physical and psychological strains. The mothers having occupational responsibilities is another factor affecting the situation. They face lots of stigma especially from the society and even from the other family members. Also, mothers have their responsibility as a housewife including taking care of elderly, taking care of children and taking care of children with special needs. Parents of children with different disorders have higher levels of anxiety and depression, negative parent-child interactions, insecure attachment of the child, physical abuse, and child's behavioural and emotional problems. The mothers of these children experience health problems such as physical problems, psychological problems such as negative emotions which ranged from mild anger to tiredness and frustration.

Any family which has a member, whose social functioning is in adequate or affected, will experience greater depression, anxiety and stress in the family. This indicates the breakdown of reciprocal arrangements that people maintain in their interfamily relationship. The presence of a child with differently able can become a major source for depression, anxiety and stress to the other family members particularly the parents. Beside the degree of disability and associated behaviour problems, the interactive pattern among various families gets disturbed. Communication among them could be based on the feelings of guilt. It thus becomes important to try and understand the problems of these parents in various areas and to assess the level of depression, anxiety and stress in such families. Thus, it helps the parents especially the mothers to achieve an emotional acceptance of all children and the disable.

A review of existing literature reveals evidence suggestive of increased depression, anxiety and stress level in family among the parents. However, the wellbeing of mother and their depression, anxiety and stress has not been comprehensively explored. Thus, a need was felt in the present investigation to examine the level of depression, anxiety and stress which is experienced by parents of children with differently able children.

Main objective

The base objective of the study is to understand the psycho social wellbeing in the mothers of children with multiple disabilities.

Specific objectives

- To know the socio-economic profile of mothers of children with multiple disabilities
- To study the stigma and discrimination experienced by the mothers of children with disabilities
- To evaluate the psycho-social wellbeing of the mothers of children with multiple disabilities

Hypothesis

- As the age of the mother increases, the psychological distress also increases
- The mothers of female children experience more stress when compared to the mothers of male children
- As the age of the mothers increases, the social problems also increase Stigma and discrimination of the respondent is dependent on the gender of the child

Methodology

This quantitative study was conducted in Kottayam, one among the districts of Kerala. The primary data used were obtained from surveys of midlife women respondents. 60 samples were collected from the field. Stratified random sampling was used for the study to collect data from the field. The population in this study is all midlife women between the ages of 40 to 65. As data collection instruments questionnaire was used to collect data on midlife women as the sample. This study has followed all the ethical consideration in the field.

Analysis and discussion

The analysis is done on the basis of the objectives of the study. Statistical package for social science (SPSS) is used for analyzing the data. The analysis includes the socio demographic details of the respondents and their response to the questions framed for the study objectives and hypothesis.

Socio demographic details

The socio economic and demographic profile comprises the basic details of the mothers of the children with multiple disabilities. The characteristics of the population are termed as demography. They cannot be manipulated; hence they are independent variables. It also refers to the characteristics of respondents, which most often includes age, gender, education, socioeconomic status and other information to understand the data.

Sl. No	Subject	Percentages (%)
1	Gender of the child	Male= 61.7% Female= 38.3%
2	Age of the respondent	Pre- midlife (younger than 40) = 30% Midlife (40-50) = 41.7% Post- midlife (above 50) = 28.3%
3	Marital status	Living together with husband= 95.0% Separated= 1.7% Widow= 3.3%
4	Age of child	05-10 =18% 11-14 =55% 15-18 =27%
5	Annual income of the mother	1000-10000 =35% 10001-20000 =15% 20001-30000 =16.7% Above 30000 =33.3%
6	Education of the mother	Primary school=5% Middle school=15%

		High school=31.7% Higher Secondary=15% UG=28.3% PG Above=5%
7	Job type of the mother	Part time=11.7% Full time=28.3% Not Applicable =60%
8	Religion of the respondent	Christian= 58.3% Hindu= 35.0% Muslim= 6.7%
9	Community of the family	OBC= 25.0% SC/ST= 18.3% General= 56.7%
10	Types of family	Joint family= 20.0% Nuclear family= 80.0%
11	Occupation of the family	Daily wage labour= 16.7% Agriculture= 11.7% Engineering= 1.7% House wife= 53.3% Others= 16.7%
12	Cost for health care of the child	Myself= 13.3% Husband= 71.7% Family= 13.3% Others= 1.7%
13	Past incidence of disability in the respondent's family	Yes= 10.0% No= 90.0%
14	Abnormality identified in the Child	0-1= 65.0% 2-3= 21.7% Above 3= 13.3%
15	Lack of oxygen at birth	Yes= 15.0% No= 85.0%
16	Serious illness during childhood	Yes= 3.3% No= 96.7%

Among the total respondents, 41.7% of the respondents are between the ages 41- 50, 30 % of the respondents are between 31- 40, 28.3% of the respondents are above 50. Among the total children 61.7% of them constitute male and the remaining 38.3 % are females. Among the total respondents, 95% of them are living with their husbands, 3.3% of them are widows and the remaining 1.7% is living separately. Among the total children, 55.5% are between the age 11-14, 27 % of them are between 15-18, and the remaining 18% are between the age 5-10. Among the total respondents, 35% have an annual income 1000-10000, 33.3% of them are above 30000, 16.7% have annual income between 20001- 30000 and the remaining 15% have annual income between 10001-20000.

Among the total respondents, 31.7% have high school education, 28.3% of them are under graduates, 15% each of the respondents have middle school and higher secondary education respectively and 5% each of the respondents have primary and PG level of education. Among the total respondents, 60% do not have a job, 28.3 % of them have full time jobs, and the remaining 11.7% of the respondents have part time jobs.

Among the total respondents, 58.3% are Christian, 35% of them are Hindus, and the remaining 6.7% of the respondents are Muslims. Among the total respondents, 56.7% are generals, 25 % of them are OBC, and the remaining 18.3% of the respondents are SC/ST. Among the total respondents, 80% are having nuclear families, and the remaining 20% of the respondents are living in joint families It is inferred from the table that 53.3% of the respondents are house wife.

Among the total respondents, 53.7% are house wives, 16.7% are Daily wage labourers, 11.7% of them are agriculturalists, 1.7% of them are engineers, and the remaining 16.7% of the respondents are engaged in other occupations. Among the total respondents, 71.7% of the respondent's husband bears the cost for health care of the child, 13.3% of the respondents bear the cost for health care of the child, 13.3% of the cost is borne by the family and 1.7% of the cost is borne by others. Among the total respondents, 90% of them opined that there has not been any past incidence of disability in the respondent's family while the remaining 10% opined that there is past incidence of disability in the respondent's family. Among the total respondents, 85% of them opined that there has not been any past incidence of disability in the respondent's husband's family while the remaining 15% opined that there is past incidence of disability in the respondent's husband's family. Among the total respondents, 65% opined that they identified abnormality in their child at the age of 0-1, 21.7% identified abnormality in their child at 2-3 years old and 13.3% opined that they identified abnormality in their child above 3 years old. Among the total respondents, 91.7% disagree to the statement that malnutrition during pregnancy is the cause for disability of the child while statement 8.3% opined that they agree that malnutrition is the cause for disability.

Among the total respondents, 85% disagree to the statement that lack of oxygen at birth is the cause for disability of the child while 15% opined that lack of oxygen at birth is the cause for disability of the child. Among the total respondents, 96.7% disagree to the statement that serious illness during childhood is the cause for disability of the child, while. 3.3% believe that serious illness during childhood is the cause for disability of the child.

Psychological well-being

The dimensions of psychological well-being according to Ryff are positive evaluations of oneself and of one's past life (Self-Acceptance), the capacity to manage effectively one's life and surrounding world (Environmental Mastery), the possession of quality relations with others (Positive Relations With Others), sense of self-determination (Autonomy), the belief that one's life is purposeful and meaningful (Purpose in Life), and a sense of continued growth and development as a person (Personal Growth) (Ryff, 1993).

Stigma, discrimination and gender of the child

(Independent Samples Test)

Sl. No	Gender	Mean	Sd	Df	T	St
1	Male	1.0541	.22924	58	-.859	.394
2	Female	1.1304	.45770	28.966	-.744	.463

The above table presents the differences between the gender of the respondent's child with the stigma and discriminations experienced by the respondents. The mean score obtained by the female respondents (1.1304) is higher than that of the males. However, the p value is greater than the level of significance at 0.05% level. Hence the table reveals that there is no difference between males and females with regard to their experiences of stigma and discrimination. Since the p value is greater, then the level of significances at 0.05% level, the research hypothesis is rejected and the null hypothesis is accepted. There is no significant difference between the gender of the child and mother's experiences of stigma and discrimination. It means male or female gender of the child does not differ in terms of their stigma and discrimination.

Gender and psychological wellbeing

(Independent Samples Test)

Sl. No	Gender	P value	Mean	Sd	Df	T	St
1 2	Male Female	.086	1.9730 2.0435	.86559 .97600	58 42.556	-.292 -.284	.771 .778

The above table presents the difference between the genders of the respondent's child with the Psychological wellbeing experienced by the respondents. The mean score obtained by the female respondents (2.0435) is higher than that of the male. However, the p value is greater than the level of significance at 0.05% level. Hence the table reveals that there is no difference between male and female with regard to their experiences of Psychological wellbeing. Since the p value is greater, than the level of significance at 0.05% level, the research hypothesis is rejected and the null hypothesis is accepted. There is no significance difference between the gender of the child and mother's experiences of Psychological wellbeing. It means male or female gender of the child does not differ in terms of their Psychological wellbeing.

Difference between Psychological wellbeing and age

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	1.485	2	.742	.910	.408
Within Groups	46.515	57	.816		
Total	48.000	59			

This table presents differences between age of the respondent and their experience of psychological wellbeing. Among the total respondents, 41.7% are between the ages 41-50, 30% of the respondents are between 31-40, 25% of the respondents are above 50 and the remaining 3.3% are between the age 20-30. And the researcher identifies the no difference between the age and psychological wellbeing of the respondents. However, the p value is .408 which is greater than level of significance at 0.05 levels. Hence the table revels that there is no difference between ages of the respondent with regards to the psychological wellbeing.

Ho: There is no difference between psychological wellbeing with others and age of the respondent.

Ha: There is difference between psychological wellbeing and age of the respondent.

Since the p value is greater than the level of significant at 0.05 levels. The research hypothesis is rejected and null hypothesis is accepted. Hence the table revels that there is no significant difference between age of the respondent and psychological wellbeing.

Social Wellbeing and age of mother

	Sum of Squares	Df	Mean Square	F	Sig.
Between Groups	1.912	3	.637	1.154	.336
Within Groups	30.938	56	.552		
Total	32.850	59			

This table present difference between age of the respondent and with their experience of social wellbeing. Among the total respondents, 41.7% of the respondents are between the ages 41- 50, 30% of the respondents are between 31- 40, 28.3% of the respondents are above 50. And the researcher identifies the no difference between the age and social wellbeing of the respondents. However, the p value is .336 which is greater than level of significance at 0.05 levels. Hence the table revels that there is no difference between age of the respondent with regards to the social wellbeing.

Ho: There is no difference between social wellbeing and age of the respondent.
Ha: There is difference between psychological wellbeing and age of the respondent.

Since the p value is greater than the level of significant at 0.05 levels. The research hypothesis is rejected and null hypothesis is accepted. Hence the table revels that there is no significant difference between age of the respondent and psychological wellbeing. So, the total psychological wellbeing can be concluded be like the following.

It is found that male or female gender of the child does not differ in terms of their stigma and discrimination. It is found that male or female gender of the child does not differ in terms of their Psychological wellbeing. There is no significant difference between age of the respondent and psychological wellbeing. There is no significant difference between age of the respondent and social wellbeing.

Suggestions

The public must be given more awareness about disabilities in order to reduce the discrimination faced by the parents as well as the differently able person. The roads and public areas must be made disable friendly such as creating ramps, pavements, buses also must be made disable friendly. Schools must be disabling friendly and the schools must include inclusive education. The parents of the disabled children must be given classes and counselling to effectively handle these children. The government provisions must be made available to every disabled person. Some of the people are illiterate and do not know of the provisions. So, the Government must take initiative in letting all the people know about policies and programmes. The mothers of the children with disabilities can be given trainings related to stress relief through the Panchayaths, Anganwadis and Schools. Exhibitions of the

talents of the differently able children can be conducted so that the stigma of the public can be reduced when they come in contact with the children and their parents.

Family counselling can be made more effective and easily available. Family centre social work can be effective in the families of children with disabilities. A study of certain personality dimensions of mothers of mentally challenged children can be studied. Stress level of mothers and fathers of mentally challenged, autistic and cerebral palsy children can be studied. Life satisfaction, adjustment and psychological well-being of parents of blind and orthopaedic children can be also studied. Comparative study of life satisfaction, adjustment and psychological well-being of parents of normal and disable children can be studied.

Conclusion

This journal mainly deals with the psycho social wellbeing of the mothers of children with multiple disabilities. Mothers of the children with disabilities face many psychological and social problems such as stress, anxiety, discrimination, loneliness, etc. The disability throws a devastating impact when the mothers face psychosocial problems because they are the primary care givers to their children. A problem affecting the mothers can affect the whole family. The mothers have to handle lots of task such as household works, looking after the family, going for job despite their multitasking ability. So, it will be difficult for the mothers to handle those situations in their day to day life. It can obviously lead to worried future of the child. So, this study will be helpful to know and be aware of the situations of the mothers of children with multiple disabilities.

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