



Maternal Stress and family resilience with regard to congenital heart disease in children

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ABSTRACT: Parenting is one of the challenging jobs an individual will ever face. Childhood illnesses rudely shatter the sensibilities. Congenital malformations and in particular congenital heart diseases are likely to become important contributors to infant mortality. The objective of the study is to assess the stress levels among mothers of children with congenital heart disease and to study the resilience among families of children with congenital heart disease. Mothers of children who have congenital heart disease and those who come to the hospital for follow up visit in the outpatient department and who fulfill the criteria of inclusion. 50 mothers (n=50) were randomly chosen for the study. The Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1995) is a 36 item scale used to measure maternal stress. Family resilience was assessed using the Family Resilience Assessment Scale (FRAS) developed by Tucker Sixbey (2005). A significant negative correlation was found between the family resilience (FRAS) and parental stress. This relationship suggests that as the family resilience increases, parental stress in mother decreases. The family resilience seems to have a good effect in reducing the parental stress.

Keywords: Maternal stress, Congenital heart disease, Family, Resilience, Children, Parents, Parenting distress, Social work.

1. INTRODUCTION

Children are jewels in the lives of Parents. The birth of a baby is a major life cycle event and is a source of great expectation and hope for parents. A new born baby is the beginning of wonders, hopes and dreams and becoming a parent is one of life's greatest blessings. Parents and immediate family members dream of giving birth to the perfect healthy child, but the birth of a child with congenital heart disease challenges and shatters their dreams. When a child is born with a disability, the unexpected and permanent nature of such an event generally increases a parent's vulnerability to stressors. Parenting is one of the challenging jobs an individual will ever face. Childhood illnesses rudely shatter the sensibilities. Families who have children with chronic illness such as heart disease often experience helplessness, uncertainty and unwellness of being because of difficulties in adaptation to chronic illness (Brazil & Krueger 2000). Critical periods in the life of the chronically ill children, when they become ill or when the illness presents problems are especially difficult on the children and their families. Congenital heart disease (CHD) is one of the most commonly found congenital anomalies. Congenital Heart disease, in a definition proposed by

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Mitchell et al is "a gross structural abnormality of the heart or intra-thoracic great vessels that is actually or potentially of functional significance".

2. How grave is the problem

Congenital heart disease (CHD) is a major health problem facing families in the world today. It is estimated that in at least eight of every 1,000 live births, or about 25,000 to 35,000 babies are born with CHD each year that's almost one percent of all live-born infants, and it accounts for approximately 30% of all congenital abnormalities (American Heart Association, 2006). Children with congenital heart disease often require surgical or interventional treatments and continued medical care throughout their life. Even though the medical and surgical advancements have made the management of CHD simple, yet it has become more expensive. The experience of caring for a child with CHD shatters the dreams of the parents of a healthy child. Parents are distressed with the psychological aspects of anxiety about the child's future and fear about the longevity of the child coupled with the alertness of a medical emergency of the child's condition. A child with CHD is creating not only psychological distress in parents, but also triggers an economic burden in the family. This problem is affecting the rich and the poor alike. This is a matter of grave concern for several families in the state of Kerala. The parents of those children undergone surgical procedures on account of CHD is experiencing and encountering social, economic and psychological problems. This is precisely on account of the future health of the child, longevity of the child and meeting the finance of treatment. Increasing number of children is diagnosed with congenital heart disease each year. Little is known about the parents of children who managed with the psychosocial dimensions of their lives. Some parents are finding themselves proving all the care to these children. The experience of parents caring for a child with chronic heart condition is examined in this study.

3. Objectives

Researcher undertook this study with two objectives. Firstly to assess the stress levels among mothers of children with congenital heart disease and secondly to study the resilience among families of children with congenital heart disease.

4. Method

The universe of the study comprises of parents of children who have undergone congenital heart surgery at pediatric cardiology department at Government Medical College, Kottayam. Sample was drawn from the parents of a child, who have undergone congenital heart surgery and those, who comes to the hospital for follow up visit in the outpatient department. 50 mothers (n=50) were randomly chosen for the study. A structured interview schedule was prepared to elicit information regarding parents' socio-demographic profile and child demographics. The Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1995) is a 36 item scale used to measure parental stress. Stress is measured on the PSI-SF on a five-point Likert Scale from (1) strongly agree to (5) strongly disagree. The PSI-SF can yield both a total stress score and scores on three subscales: Parental Distress, Difficult Child, and Parent-Child Dysfunctional Interaction.

To measure family resilience, this study utilized the Family Resilience Assessment Scale (FRAS)

developed by Tucker Sixbey (2005). The measure uses a 4-point Likert scale that ranges from strongly disagrees to strongly agree. The FRAS contains six subscales. The subscales are Family Communication and Problem Solving (FCPS), Utilizing Social and Economic Resources (USER), Maintaining a Positive Outlook (MPO), Family connectedness (FC), Family spirituality (FS), Ability to Make Meaning of Adversity (AMMA). The FRAS consists of sixty six questions and one open ended question. The open ended question was not used in this study. The FRAS uses a Likert scale with strongly disagree = 1 to strongly agree = 4. The quantitative data were analyzed using Statistical Package for Social Sciences (SPSS), version 19. Preliminary analysis included descriptive analysis which was used to examine the accuracy of data by assessing the shape of the distribution (normal, skewness, kurtosis), the missing data, the central tendency (mean, median and mode), the dispersion (range, variance, and standard deviation) of the scores for each variables. In addition, the predominant statistical applications using inferential statistics such as Pearson's- Correlation Coefficient to find out positive or negative correlation. The analysis also performed to examine and test the assumptions for multiple regressions.

5. Results

5.1: Socio Demographic profile of the respondents

Table 1: Age of the respondents

Age	N	%
18-23	4	8.0
24-28	21	42.0
29-32	10	20.0
33-38	15	30.0

It is clear from the table 1 that majority (42%) of the respondent's falls under the age group of 24-28 years.

Table 2: Educational level of the respondents

Education	N	%
Secondary	26	52.0
Graduates	19	38.0
Post graduates	4	8.0
Other	1	2.0

The majority of the mothers have secondary level of education (52.0%) and graduate accounts for 38% followed by 8% of post graduates.

Table 3: Occupation of the respondents

Occupation	N	%
Housewife	26	52.0
Daily wage	12	24.0
Private	11	22.0
Government	1	2.0

The above table explains the occupation of the respondents. Majority of the respondents (52.0%) are housewives as the respondents are females. 24.0% of the respondent's works on daily wages, 22.0% of the respondent's works in private sector and 2.0% of the respondent's works in Government services.

Table 4: Income of the respondents

Income	N	%
Below 10000	12	24.0
10000-20000	29	58.0
20000-30000	8	16.0
30000-50000	1	2.0

The above table depicts the income of the respondents. Most of the respondents (82.0%) belong to the low income group. 16.0% of them belong to middle income group and only 2.0% of the respondents belong to high income group.

5.2 Level of Parenting Stress

Table 5: Level of Parenting Stress among mothers

Levels of Parenting Stress	Percentage
Mild Stress	12.0%
Moderate Stress	40.0%
Severe Stress	48.0%
Total	100%

The level of parenting stress varied from mild to severe stress. 48.0% mothers had severe stress and 40.0% of mothers experienced moderate stress.

5.3 Correlation between Parenting Stress and Family Resilience

Table 6: Pearson Correlation test scores between Parenting Stress and Family Resilience

	Family Resilience	Parenting Stress
Family Resilience		
Pearson Correlation	1	-.617**
Sig. (2 tailed)		.000
N	50	50
Parenting Stress		
Pearson Correlation	-.617**	1
Sig. (2-tailed)	.000	
N	50	50

A significant negative correlation was found between the family resilience (FRAS) and parental stress (the total score on the PSI-SF), with a Pearson correlation of $-.617^{**}$ and a p-value of less than .001. This relationship suggests that as the family resilience increases, parental stress in mothers' decreases.

5.4 Effect of Family Resilience on Parental Stress

Table 7: Effect of Family Resilience on Parental Stress

Variable	B	Std. Error	Sig.
Family communication and Problem Solving	0.087	0.196	0.660
Maintaining Positive Outlook	-0.663	0.304	0.762
Family Connectedness	-0.140	0.459	0.035
Family Spirituality	-0.816	0.997	0.418
Ability to make meaning of Adverse situations	-1.251	0.395	0.003
Using Social and Economic Resources	0.383	0.286	0.188

R Square = 0.623

The family resilience seems to have a good effect on parental stress. The family resilience subscales such as family connectedness and the ability to make use of adverse situations were found to be significant predictors in lessening the parental stress related with child's heart disease.

6. Discussion

The majority of the respondents fall under the age group of (24-28) the respondents falls under the age group of 18-45. The majority of the mothers has secondary level of education (52.0%) and graduate accounts for 38% followed by 8% of post graduates.

The occupation of the respondents

Majority of the respondents (52.0%) are housewives as the respondents are females. 24.0% of the respondents' works on daily wages, 22.0% of the respondents' works in private sector and 2.0% of the respondents' works in Government services.

The income of the respondents

Most of the respondents (82.0%) belong to the low income group. 16.0% of them belong to middle income group and only 2.0% of the respondents belong to high income group.

The level of parenting stress varied from mild to severe stress. 48.0% mothers had severe stress and 40.0% of mothers experienced moderate stress. A significant negative correlation was found between the family resilience (FRAS) and parental stress (the total score on the PSI-SF), with a Pearson correlation of $-.617^{**}$ and a p-value of less than .001. This relationship suggests that as the family resilience increases, parental stress in mothers' decreases. This finding of this study also suggests that increased parental stress, correlates with less family resilience. The most significant correlations between family resilience and parental distress seem to be with family connectedness, and ability to make use of adverse situations. Family connectedness refers to a family's ability to organize and bond together for support while still recognizing individual differences among members. Family connectedness goes hand in hand to help families normalize and make the difficult situations manageable. This is an important finding as clinical social workers who works with congenital heart surgery team can develop interventions that seek to enhance family resilience. All the targeted interventions making use of resilience should focus on addressing parent's psychosocial wellbeing.

7. Findings

The main findings of the study were as follows:

- The mean age of the respondents is 29 years.
- The majority of the mothers have secondary level of education (52.0%) and graduate accounts for 38% followed by 8% of post graduates.
- Most of the respondents belong to the low income group. As high as 84.0% of them belong to low income group.
- Majority of the respondents (52.0%) are housewives as the respondents are females. 24.0% of the respondents works on daily wages ,22.0% of the respondents works in private sector and 2.0% of the respondents works in Government services.
- The level of parenting stress varied from mild to severe stress. 48.0% mothers had severe stress and 40.0% of mothers experienced moderate stress
- A significant negative correlation was found between the family resilience (FRAS) and parental stress (the total score on the PSI-SF)., with a Pearson correlation of $-.617^{**}$ and a p-value of less than .001. This relationship suggests that as the family resilience increases, parental stress in mothers' decreases.

- The family resilience seems to have a good effect on parental stress. The family resilience subscales such as family connectedness and the ability to make use of adverse situations were found to be significant predictors in lessening the parental stress related with child's heart disease.

8. Maternal Stress and family resilience through a social work prism

In social work practice, family and relationship has traditionally given a prime focus of attention from time immemorial. The primary mission of the social work profession is to enhance human well-being and help meet the basic human needs of all people, with particular attention to the needs and empowerment of those who are most vulnerable (Miley, O'Melia, & DuBois, 1998). Parents of children having congenital heart disease are experiencing significant stress and they are more vulnerable to negative psychosocial impact. A defining feature of social work is the profession's focus on individual well-being in a social context and the well-being of society. Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living (NASW, 1996). Mothers of children having congenital heart disease are always in distress and consistently report about the stress arising from child's future health and the draining of financial resources from the family because of the child's expensive treatment. This problem is aggravated by the taxing family burden upon them while confronting with the child's battle to survive.

Social work intervention can help in diminishing the accumulation of stress that the parents are confronting, and encourage them to adopt useful coping strategies. Therefore social workers should work with families to improve family communication and problem solving skills, assist in helping families develop coping mechanisms that help to maintain a positive outlook, while building social connections, and supportive networks. Though this approach seems to be less analytical, it is more aimed towards helping parents of children underwent heart surgical procedures to reduce the parental stress and to seek resilience qualities that can be enhanced. Various psychological and social work interventions can pave the way for increasing parental coping in times of distress and thereby boost the family resilience.

9. The specific social work roles

- Encouraging the mothers and first degree relatives to be optimistic in situation which requires facing an emergency in child's health deterioration and accepting the reality.
- Helping the mothers to use appropriate coping strategies.
- Strengthening the ego of the parents and family members.
- Emphasis has to be given in the area of interaction of children's parents and the treating team.
- Expression of accurate empathy
- Respecting the worth and dignity of the parents and family members
- Counseling to parents for the parental distress and emotional impact of child's condition.
- Facilitate supportive therapy and forming of support group for parents.
- The social worker should give information, provide mobilization of resources, facilitate communication between doctor and the parents; help family make adapt to the altered new parental roles.

- Help the parents of the children and immediate family members to set realistic goals and offer family counseling
- Social work methods like case work and group work can be made use. The methods to reach these tasks include one to one meetings, family work, and group work, focus to their children other than that having congenital heart disease.
- Sharing information and listening
- A multi disciplinary approach reminding the other members of the team to keep the concept of 'person centered approach' as they plan their interventions.
- Developing community network contributing to educational programmes and thereby forms a therapeutic community.
- Psychosocial interventions are aimed at supporting parents not only in times of crisis, but during the entire period of their lifetime. In their clinical role, medical social workers provide a broad range of practical and financial service. Counseling parents and families and helping them with the complex plan and decisions must be made during the times of extra ordinary stress.

10. Implications of social work practice with regard to the study

The dynamics of maternal stress and family resilience must be understood in order to plan effective social work interventions. Intervention studies should be developed based on a solid foundation of knowledge. Exploring family's adjustment during a child's heart disease and hospitalization will provide researchers with a more substantive basis for developing intervention studies for the period immediately following children's surgery. The intervention programmes that promote stress management and stress reduction will benefit the parental well being needs to be undertaken. Furthermore, social workers play a key role in developing interventions that target healthy family functioning. Interventions that are aimed at increasing family resilience as a means to decreasing parental stress need to focus on providing parents with the coping skills needed to directly impact their own well being. Psycho-educational based group interventions focused on learning skills associated with family resilience would also provide the opportunity to develop support groups and parents' networks.

11. Implications of social work practice with regard to the study

This paper examined the maternal stress and family resilience to conceptualize the experience of families of children and to better understand the relationships between family resilience and maternal stress. In addition the study provided more evidence to for the significant stress families are experiencing. In sum, this paper extends the understanding of family resilience and its positive impact on stress. In addition to the emphasis on the importance of assessing different kinds of stressors – and not focusing only on the current stressors families are experiencing – the findings underscore roles of coping and social support in the relationship between stress and resilience. More research identifying the stressors experienced by families of children having disease needs to be done. A comprehensive understanding of how positive family coping strategies influence family resilience is crucial. The results of this study can assist social workers better assess parental stress and to seek resilience qualities that can be enhanced.

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