

Maternal Stress and Health Quality of Life in Mothers with Special Needs Children: Four-Track Social Policy Recommendations Led by Social Work

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ABSTRACT

Objective: Mothers of special needs children in Pakistan, and across the world, are marginalized populations facing combined challenges of social shame and policy neglect. This study aims to (i) investigate the prevalence of and relationship between maternal stress, social support, and health quality of life in mothers with special needs children and (ii) identify the moderating effects of social support on maternal stress and health quality of life.

Methods: A total of 103 mothers of special needs children attending government special needs schools in Pakistan have been sampled from the cities of Gujranwala and Lahore, the fifth and second largest cities of the country. A cross-sectional survey has been used for data collection, compiled from three standardized international tools: The World Health Organization Quality of Life; The Family Crisis Oriented Personal Evaluation Scales; and the Parental Stress Scale. Special needs children have been used to perform hierarchical multiple regression.

Results: Mothers of special needs children in the country face high levels of stress, receive low levels of social support, and perceive unsatisfactory health quality of life. Social support predicted health quality of life ($\beta = 0.286, p < .01$) and was a moderator for the relationship between maternal stress and health quality of life ($\Delta R^2 = 0.003, \Delta F = 1.463, p < .05$).

Conclusion: Policy development and interventions are needed through a four-track approach including reformation in cultural values to improve social support; state provision for financial relief; opportunities for education and employment for special needs children; and improvement in healthcare service quality.

Keywords: Health quality of life, maternal stress, mothers, social support, special needs children

Introduction

Mothers, as care providers and nurturers, provide the most important support system for special needs children (SNC) (Ren et al., 2020). Multiple and simultaneous tasks that a mother is required to perform include learning about disability; seeking and maintaining treatment (Kwok & Kwok Lai Yuk Ching, 2022); monitoring and advocating for schooling and employability (Satherley & Norwich, 2022); caring for the SNC physically and emotionally (Findling et al., 2022); managing family and social relations (Yamaoka et al., 2022); and maintaining employment and generating finances for treatment (Banda et al., 2022). Needless to say, women face tremendous challenges due to the daily tasks and having to cope with life circumstances of being a mother to an SNC. It is because of all these challenges, that when mothers of SNC receive social support, they become more resilient and show better motivation (Park & Lee, 2022).

Estimates for Pakistan suggest that the disability rate is anywhere between 3% and 17% (Mitra & Sambamoorthi, 2014; Shaukat, 2022), which would mean approximately 35.7 million special needs people in the country (Pakistan Bureau of Statistics, 2020). There are limited health and integrative services for SNC in Pakistan, with grave shortfalls or complete neglect for rural and impoverished communities (Chauhdry, 2022). Lack of opportunities for proper detection, treatment, schooling, and employability contribute to great stress and worry in mothers of SNC, with local research highlighting that mothers face greater stress compared to fathers (Sajjad et al., 2022). Sadly, Pakistani society is still very punitive regarding SNC and mothers face the brunt of shaming and exclusion (Hussain et al., 2022). There is a greater concern when one considers that special needs mothers, who face social

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blame and stigma, are unable to perform their maternal responsibilities optimally (Finardi et al., 2022). To add to the complexity, Pakistani society is also neglectful of mental health problems, and services for mental health are lacking overall let alone for mothers (Neoh et al., 2022). Mothers in the country suffering from postpartum depression receive very little social or health service support, and mothers with SNC receive almost no support (Insan et al., 2022).

Aim of Study

There are no studies to the best of author's knowledge from Pakistan investigating the relationship between maternal stress, social support, and health quality of life (HQOL) in mothers with SNC. The conceptual model for this study is presented in Figure 1 and suggests that the relationship between maternal stress and HQOL is mediated by social support. The study hypotheses are H1. Mothers with SNC in Pakistan face high stress in Pakistan, H2. Mothers with SNC in Pakistan face low social support and H3. Mothers with SNC in Pakistan have unfavorable HQOL. Based on these hypotheses, we aim to investigate the following: (i) the relationship between maternal stress, social support, and HQOL in mothers with SNC, and (ii) the mediating and moderating effects of social support on maternal stress and HQOL in mothers with SNC. It is hoped that this study will provide impetus for improving policy development for special needs families.

Methods

Ethics committee approval was received for this study from the ethics committee of Institutional Review Board, Forman Christian College University (Date: May 31, 2019, Number: IRB/157/05/2019).

This article is part of a wider mixed methods study investigating the HQOL and socio-structural support available for special needs families in Pakistan. Ethics approval for this study has been taken from the Institutional Review Board [Masked for Peer Review].

Sample

The inclusion criterion was Pakistani mothers with SNC in primary and secondary schools. Participant mothers were recruited from two government special needs schools of Pakistan in Gujranwala and Lahore, the names of which have been kept confidential due to lack of permission. Gujranwala and Lahore are both large metropolitan cities in the Punjab province of Pakistan. They are the fifth and second largest cities in the country, respectively (World Population Review, 2020), with some investment from the government for special needs education, unlike in the rural regions. The schools for sampling were selected randomly from a list of government institutes available on the Internet and the final selection of schools for sampling was dependent on permission of school authorities and convenience of authors to collect data.

Survey

A cross-sectional survey was used to collect the data. The survey included 69 questions from standardized tools including (i) the World Health Organization Quality of Life (WHOQOL-BREF), (ii) the Family Crisis Oriented Personal Evaluation Scales, and (iii) the Parental Stress Scale. The survey was translated into the local language of Urdu by the second author who is fluent in both languages, English and Urdu, using forward and backward translation.

Demographic Questions

Participants were asked demographic questions about their age, literacy, and marital status. In addition, they were asked about their employment, family income, and disability of the child.

Maternal Stress

Thirteen questions from the Parental Stress Scale (PSS) (Berry et al., 1995) were used to assess the maternal stress of mothers. The survey asks mothers about their perceived stress and worries with regard to (i) balancing care, (ii) time and energy, (iii) doing enough for SNC, (iv) major stress in life being SNC, (v) inability to manage relations with husband, (vi) financial burdens, (vii) abuse and neglect by healthcare practitioners, (viii) abuse and neglect by society/relatives, (ix) having few choices and too little control over life, (x) future employability of SNC, (xi) inability of SNC to marry and have children of their own, (xii) no one will care for the child after I am gone, and (xiii) lack of sex education and risk of sexual abuse. A 5-point Likert scale was used (1 = strongly agree, 2 = agree, 3 = neutral, 4 = disagree, 5 = strongly disagree), with lower scores indicating lower stress.

Health Quality of Life

Twelve questions from the brief version of the WHOQOL-BREF survey (World Health Organization, 1998) were used to assess the HQOL of mothers. The survey asked respondents about their self-perceived satisfaction regarding their (i) quality of life, (ii) health overall, (iii) physical pain, (iv) medical treatment, (v) leisure activities, (vi) mobility, (vii) sleep pattern, (viii) ability to perform daily activities, (ix) personal relationships, (x) conditions of living place, (xi) access to health services, and (xii) feelings of despair, anxiety, and depression. A 5-point Likert scale was used (5 = very satisfied, 4 = satisfied, 3 = neutral, 2 = dissatisfied, 1 = very dissatisfied), with lower scores indicating lower satisfaction.

Social Support

Thirteen questions from the Family Crisis oriented Personal Evaluation Scale (FC-PES) (McCubbin et al., 1985) were used to assess social support gained by mothers. The survey asked respondents to indicate satisfaction with regard to support from (i) husband, (ii) parents and/or siblings, (iii) in-laws, (iv) friends, (v) community agencies and programs, (vi) neighbors, (vii) information from health practitioners, (viii) care from health practitioners, (ix) professional counselors, (x) other families with SNC, (xi) religious programs and activities, (xii) religious leaders, and (xiii) faith in god. A 5-point Likert scale was used (5 = strongly agree, 4 = agree, 3 = neutral, 2 = disagree, 1 = strongly disagree), with lower scores indicating lower social support from family.

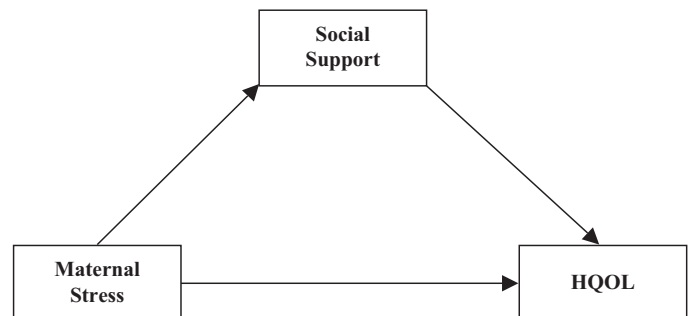


Figure 1. Conceptual Model for this Study, Showing the Hypothesized Mediating Effect of Social Support on the Relationship between Maternal Stress and HQOL. HQOL = health quality of life.

Table 1.
Reliability Statistics for Scales

	No of Items	Cronbach Alpha
Maternal stress	13	.805
HQOL	12	.833
Social support	13	.799

Note: HQOL= health quality of life.

Reliability Analysis

The Cronbach's alpha results for this study are reported in Table 1. For this study, the Cronbach's alpha coefficients were as follows: (i) for the PSS = 0.805; (ii) for the WHOQOL-BREF = 0.833; and (iii) for the FC-PES = 0.799. All results were above the highly respectable cutoff values of 0.7 and 0.8 (Santos, 1999).

Data Collection

Permission for data collection was sought from the special needs schools and mothers were informed of the research through a notice by the school. The data were collected by the authors between January to June 2019. Two assistants who are MPhil students in education were recruited for data collection and were trained by the authors over a two-day period. Data were collected at the special needs schools in a private room. Mothers were assisted in completing the surveys due to illiteracy or semi-literacy of many participants. A total of 103 mothers agreed to participate in the study. Participation of mothers was voluntary and no monetary compensation was provided.

Data Analysis

Data were entered into Excel and then transferred to Statistical Package for Social Sciences (IBM SPSS Corp., Armonk, NY, USA) version 21.0 for data analysis. Reliability analysis of the standardized scales was completed first. Next, frequencies and percentages of the socio-demographic and study variables were generated. For regression analysis, the constructs of maternal stress, HQOL, and social support were compounded, respectively. Means, standard deviations, and Pearson correlations were calculated to assess the relationship between the dependent and independent variables of the study. Dummy variables were created for social support and maternal stress in order to perform regression analysis (Hardy, 1993). Next, analysis of social support as a mediator was conducted and last, hierarchal multiple regression was performed to assess the moderating effect of social support on maternal stress and HQOL. For hierarchal multiple regression, independent variables were entered in the following steps: step 1-socio-demographic variables; step 2-social support and maternal stress; and step 3-social support x maternal stress. A significance level of .05 was assigned for statistical analysis and constituted two-tailed tests.

Results

Descriptive Statistics

Table 2 reports the descriptive statistics for the sociodemographic characteristics of the sample and also the independent and dependent study variables ($n=103$). Majority of the mothers were between the ages of 36 and 50 years (53.4%) and the rest were between the ages of 26 and 35 years (46.6%). A considerable number of mothers were illiterate (46.6%) and some were single parents (07.8%). Majority of the sampled mothers

Table 2.
Socio-Demographic Characteristics of Special Needs Mothers ($n = 103$)

Variables	f (%)
Mothers age	
26–35 years	48 (46.6%)
36–50 years	55 (53.4%)
Literacy	
Illiterate	48 (46.6%)
Literate	55 (53.4%)
Marital status	
Currently married	95 (92.2%)
Separated/widowed	08 (07.8%)
Employment	
Not working	60 (58.3%)
Working	43 (41.7%)
City	
Gujranwala	72 (69.9%)
Lahore	31 (30.1%)
Monthly family income	
<15 999	35 (34.0%)
16 000–29 999	28 (27.2%)
>30 000	40 (38.8%)
Number of children	
1–2 children	11 (10.7%)
3 or more children	92 (89.3%)
Disability type	
Mental impairment	24 (33.3%)
Physical impairment	22 (66.7%)
Perceived maternal stress	
Never	09 (08.7%)
Sometimes/always	94 (91.3%)
Satisfaction in health quality of life	
Completely	33 (32.0%)
Moderately/not at all	70 (68.0%)
Satisfaction for social support	
Always	35 (34.0%)
Sometimes/never	68 (66.0%)

belonged to Gujranwala city (69.9%) and were not working mothers (58.3%). Majority of mothers indicated that they had a monthly family income of less than PKR 29,999, which comes to PKR 999.96 daily and converts to USD 6.47¹ per day. Thus, majority of the sample belong to the low and middle wealth class of Pakistan. Most of the mothers in the sample have three or more children (89.3%). With regard to the disability type, majority of SNC had a physical impairment (66.7%) versus a mental impairment (33.3%).

With regard to the study variables, majority of mothers perceive (i) stress levels sometimes or always (91.3%), (ii) HQOL moderately or not at all (68.0%), and (iii) social support sometimes or never (66.0%).

¹ <https://www.xe.com/currencyconverter/convert/?Amount=999.9&From=PKR&To=USD>

Table 3.
Pearson's Correlations for All Variables of Study

	Mean	SD	Maternal Stress	HQOL	Social Support
Maternal Stress	24.01	5.37	1		
HQOL	20.87	4.93	-0.427**	1	
Social Support	22.31	5.49	-0.285**	0.385**	1

Note: HQOL = health quality of life; SD = standard deviation.

Correlation Analysis

The Pearson correlation test was used to analyze the variables of maternal stress, HQOL, and social support (Table 3). The results showed that HQOL of mothers with SNC was significantly associated with maternal stress ($r = -4.27, p < .01$) and in addition significantly associated with social support ($r = 0.385, p < .01$). Maternal stress was also significantly associated with social support ($r = -0.285, p < .01$).

Mediation Analysis

Table 4 reports the results of the mediation analysis. Maternal stress predicted HQOL of mothers ($\beta = -0.421, p < .001$) and social support ($\beta = -0.285, p < .01$). Maternal stress and social support predicted HQOL ($\beta = -0.346, p < .01; \beta = 0.286, p < .01$). The results show that maternal stress mediates the relationship between social support and HQOL.

Moderation Effect

Table 5 reports the moderating effect of social support on the relationship between maternal stress and HQOL. At step 1,

socio-demographic variables of maternal age, literacy, occupation, family income, number of children, and disability type were entered. At step 2, maternal stress and social support were entered in block 2. At step 3, the interaction of maternal stress and social support was entered in block 3. A significant R^2 change ($\Delta R^2 = 0.003, \Delta F = 1.463, p < .05$), indicated a significant moderating effect of social support on the relationship between maternal stress and HQOL.

Discussion

Findings in this study are the first in Pakistan to identify that there are significant associations between maternal stress, social support, and HQOL and that the effect of maternal stress is mediated and moderated by social support. Our study findings confirm that mothers of SNC face immense stress. International literature suggests that multiple issues can compound stress in mothers of SNC, such as economic stress and lack of financial subsidization (Ren et al., 2020). Inability to manage relations with or gain adequate support from husbands and in-laws can also contribute to stress and depression in mothers of SNC (Lamba et al., 2022). Working mothers of SNC are known to face difficulties in maintaining the work-family balance and sustaining employment and income (Calderwood et al., 2022).

Stress in mothers can also be a consequence of the cultural stigma against special needs families. Many conservative and Muslim societies of the world have cultures that are mostly punitive of both SNC and their mothers (Alabri, 2023; Kilinc, 2022). Mothers of SNC may also experience stress due to the higher risk of abuse and violence facing SNC (Jafree & Burhan, 2020; Seppälä

Table 4.
Mediation Effect of Social Support on Maternal Stress and HQOL

Step	Dependent Variable	Independent Variable	B	SE	B	t
Step 1	HQOL	Maternal stress	-0.388	0.083	-0.421	-4.662***
Step 2	Social support	Maternal stress	-0.279	0.093	-0.285	-2.992**
Step 3	HQOL	Maternal stress	-0.318	0.083	-0.346	-3.848**
		Social support	0.257	0.081	0.286	3.184**

Note: HQOL = health quality of life; SE = standard error.

Table 5.
Multivariate Hierarchical Regression Analysis for HQOL

Step	Dependent Variable	R ²	ΔR ²	ΔF	B	t
Step 1		0.118	0.118	2.148*		
	Mothers' age				0.080	0.833
	Literacy				0.251	2.554*
	Occupation				0.003	0.034
	Family income				0.106	1.035
	Number of Children				0.019	0.188
	Disability type				0.146	1.423
Step 2		0.365	0.247	18.243*		
	Social support				0.360	4.167***
	Parenting stress				-0.266	-3.067***
Step 3		0.368	0.003	1.463*		
	Social support × parenting stress				-.310	-2.997**

Note: HQOL = health quality of life.

et al., 2021). The SNC are almost entirely dependent on their mother's care and supervision, and thus mothers experience immense fear that they may not be able to protect or provide care for their children in the future. Mothers of SNC who face stress can suffer from more complex psychosocial problems, making them ineffective care agents for their dependent children (Yamaoka et al., 2022). Developing nations face immense shortfalls in funding and service development for mental health services (Rathod, 2017). Additionally, mental health services for women and mothers is a severely neglected area in developing regions (Hessami et al., 2022).

The results of this study confirm international scholarship and highlight that mothers of SNC need greater support from (i) friends and family (Neris et al., 2023), (ii) community and neighbors (Yamaoka et al., 2022), and (iii) healthcare practitioners and counselors (Oti-Boadi et al., 2022). Ultimately, if social support for mothers with SNC is improved, not only will the HQOL of mothers improve, but it would have a beneficial impact on the development of SNC and also the overall well-being of the special needs family (Dizdarevic et al., 2022). Recent literature suggests that receiving symmetrical assistance and social support is difficult, not just for mothers of SNC, but for women generally across developing nations (Gyan & Mfoafo-M'Carthy, 2022). The results highlight the solitary burden that mothers face in a country like Pakistan where there is policy neglect for special needs families and inadequate protection for the disabled (Rizvi Jafree & Burhan, 2020).

The findings of this study also confirm that specific areas of HQOL in mothers, apart from social relationships and support, must be given attention, such as (i) physical and mental healthcare services and (ii) time and opportunity for leisure. With regard to the first area, access to healthcare services for physical and mental health, Pakistan and many other developing countries of the world face challenges of low health budget allocation (Ashfaq & Bashir, 2021; Taderera, 2017). Additionally, as mentioned above, more conservative and patriarchal societies have low prioritization for women's health, let alone mothers of SNC (Jafree, 2020). With regard to the second area, leisure and physical activity, women in Pakistan and other conservative regions are neither encouraged nor supported for such opportunities and are rather restricted to care duties for the home and family (Laar, 2019). Unless mothers of SNC are supported to seek leisure and gain opportunities for self-care and self-compassion they will be unable to provide quality care to their child and family (Ahmed & Raj, 2022).

Study Limitations

There are some limitations of this study. The sample size is small and there is no representation of rural-based communities. The results are also based on a perception-based survey. However, there are several strengths to this research. The study allows us to conclude empirical evidence related to maternal stress, social support, and HQOL in mothers with SNC, who have been a neglected population for research. Based on the study findings, key recommendations for policy development to improve support for special needs families are proposed.

Conclusion and Recommendations

Based on the findings of this study, we have mapped social policy recommendations for special needs families through a four-track approach. These interventions can be delivered, coordinated, and/or supervised by social protection officers: (i)

Reformation in culture and attitudes-Awareness sessions by community social protection officers about the value and rights of special needs people and their care providers would help to improve cultural beliefs and build a holistic support system. The combined efforts of religious leaders, community notables, and media would be needed in patriarchal and conservative to mobilize collective social support. (ii) Meso-level interventions by the state for financial relief-Financial subsidies, cash transfers, and special allowances for special needs families from low-income backgrounds are critically needed. As financial relief is provided to special needs families, much of the stress of uncertainty, health access, care quality, and opportunities for inclusion would be reduced. (iii) Macro-level interventions for education and employment-The structural inclusion of SNC at schools and universities along with the provision of training for skill development is essential to secure opportunities for employment and autonomy. There would be no better social support for mothers than the security that their SNC would be independent and capable of earning a living in their adult years. (iv) Healthcare services-The development and well-being of SNC require both quality care and continuum of care from trained healthcare practitioners. For mothers of SNC specifically, the provision of hospital-level and community-level support for counseling and health checkups is needed. This is possible through integrating health social protection officers and maternal counseling in maternity wards, gynecology wards, and children's wards at both public and private healthcare setups in Pakistan. Additionally, maternal counseling support can be provided through the primary healthcare services of Pakistan, which can provide help within communities and at the doorstep.

Ethics Committee Approval: Ethics committee approval was received for this study from the ethics committee of Institutional Review Board, Forman Christian College University (Date: May 31, 2019, Number: IRB/157/05/2019).

Informed Consent: Written informed consent was obtained from all participants who participated in this study.

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