

# Original research

# RESILIENCE IN MOTHERS HAVING CHILDREN WITH DISABILITIES AND BEHAVIOR PROBLEMS: A SURVEY-BASED COMMUNITY STUDY

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Abstract: This research aimed to examine the resilience exhibited by families who are raising children with behavioral issues and disabilities. In a developing society and community with limited rehabilitation and care services, there are major challenges for mothers with disabled children, and the responsibility for a child's growth falls solely on the shoulders of the mother or caregivers. Understanding the resilience of mothers (caregivers) is becoming more important as a process in disabilities for quality development and caring of children with disabilities. Purposive sampling was used to choose 30 samples from a descriptive cross-sectional survey design. Participants completed the Family Life Survey. It included questions about family-level results, social-ecological resources, and behavioral issues with children. High levels of social support and little financial difficulty are conducive to the "good" behavior of families with children who have disabilities and behavioral issues. On the other hand, even in cases where the quantity or severity of behavioral issues in children is minimal, families with inadequate social support and significant financial difficulties generally face difficulties. The study's results support the theory that "resilience" is more closely related to the accessibility and availability of culturally relevant resources than inborn traits or familial or individual characteristics. Almost all resilience items received a maximum response rate of almost 60% from mothers who answered "true" almost always. Approximately 40% of mothers scored poorly on all parts of the rating scale regarding resilience. Children with a severe deficit in their developmental behavior, as shown by the overall mean score of 37.57±3.401 on the Developmental Behavior Checklist and the overall mean score of Connor-Davidson. According to the resilience scale, mothers of children with impairments and behavioral issues had moderately high resilience scores. In terms of the effects on families, improving social ties and easing financial stress might be more crucial than changing behavior.

**Keywords:** Children, behavioral, disabilities, pediatrics.

**INTRODUCTION** According to the International Classification of Functioning, Disability and Health (ICF), "children with disabilities" are characterized as having impairments, activity limitations, participation restrictions, or disadvantages (WHO, 2007) [1]. A child's

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impairment impacts the family system and all its components, which could seriously undermine the family's integrity and structure and cause adjustments to roles, behaviors, and adaptability [2]. Numerous studies' findings suggest that families with disabled children experience higher levels of stress than other families because of the parents' limited time, energy, financial situation, emotions, and potential inadequacy in meeting their children's needs, in addition to their poorer physical and mental health [3-5]. These illnesses have an impact on their quality of life [6]. The women experience difficulties



in their social and familial lives when they have a disabled child. These mothers' inner struggles, imbalances, and feelings of despair and anxiety are caused by their psychological and physical burdens [3]. The quality of life may suffer as a result of parents' rising anxiety and depression levels [7]. Taking care of a disabled child can take up much of a parent's time, particularly if the child has serious disabilities. This can limit the parent's social life and prevent them from participating in other activities, which lowers their quality of life [8]. According to the World Health Organization, quality of life is multifaceted and influenced by various factors such as an individual's beliefs, social relationships, physical attributes, goals, standards, and individual perceptions of life [9-10]. Low life quality impacts coping strategies, family dynamics, and individual adaptations, which makes people less able to cope and escalates conflict [11, 12]. Enhanced resilience is one of the psychological interventions that can raise one's quality of life [13]. The ability to bounce back positively and achieve personal mastery, build self-efficacy and hope, and overcome traumatic life events—like raising a child with a chronic disability—is known as resilience [14].

Mothers of children with disabilities sense a significant caregiving load since they are less resilient, and their overall health and quality of life are significantly impacted. To deal with their children's disabilities and to keep their mental and physical health intact, these mothers require emotional support as well as psychological and psychosocial assistance [5]. A rise in resilience lowers stress and mental strain, supports mental health, raises well-being indicators, and enhances quality of life [16–21].

Resilience is an individual process that enhances the survival and defense mechanisms triggered by larger systems, enabling humans to handle adversity effectively [22]. More resilient people can handle life's challenges more effectively, feel less burdened, and exhibit greater adaptability. Their quality of life would, therefore, be improved [23].

Furthermore, data associates official and informal social support with mother and family outcomes [24-36]. For example, Davis and Gavidia-Payne (2009) discovered that in a sample of families receiving early childhood intervention services, parent perceptions of professional support (i.e., perceived family-centeredness) and

satisfaction with informal support from friends and family were significant predictors of family quality of life along with child behavior problems. Similar findings were made by another study, which showed that perceived social support was a better indicator of changes in mothers of young adults with ASD's well-being over 18 months than the influence of behavioral issues [37].

Social-ecological factors have received less academic attention; however, strong evidence links socioeconomic status to maternal outcomes [38-45]. For instance, Emerson et al. (2006) performed a secondary analysis of data from the Families and Children Study of the United Kingdom Department for Work and Pension. They discovered no statistically significant difference in happiness between mothers of children with and without early cognitive delay when socioeconomic position, household composition, and maternal characteristics (e.g., age, marital status) were considered. In a similar vein, the study examined data from the Longitudinal Study of Australian Children and discovered that mothers of children at risk for impairment experienced an enhanced risk of distress and psychiatric disorder that was almost 50% explained by greater exposure to poverty [40].

"The protective variables and processes or systems that lead to a positive outcome despite exposure to stressors that have caused an increase in the risk of psychosis" is the definition of resilience, which is the capacity to adapt favorably or maintain or restore mental health in the face of adversity [46, 47]. Psychologists refer to people who maintain composure in the face of difficulty as resilient. When faced with hardship, tragedy, or a serious threat, resilient people can use their special skills and dynamic capacity to adapt to overcome life's challenges. According to De Terte and Stephens, psychological resilience is the capacity to quickly control one's thoughts, feelings, and behavior to return to one's pre-crisis state [48].

Numerous studies have examined the relationship between resilience and quality of life, focusing on specific disabilities such as cerebral palsy, intellectual disability, behavioral issues, and others [49-53]. However, only a small number of studies have examined the resilience and quality of life of mothers raising disabled children. On the other hand, cultures can impact how parents view difficult circumstances and how outside influences affect



resilience, which can have a differential impact on parents' quality of life [54]. The purpose of this study was to compare the quality of life and resilience of mothers with neurotypically developing children and mothers with disabled children in Farasan. This study hypothesized that mothers with disabled children had different quality of life and resilience than mothers with neurotypically developing children and that the results would support mothers with disabled children and lead to necessary interventions for mothers.

#### **METHODS**

Research Design. The research design selected for this study was a descriptive cross-sectional survey designed to assess the resilience of mothers having children with disabilities and behavior problems. It was a survey-based community study in both the Farasan and Jazan regions of KSA.

Research Approach: Quantitative survey approach.

Research setting: The study was carried out in both Farasan island and Jazan region, KSA.

Research Participants: The population for the present study was the mothers having children with disabilities and behavior problems in both the Farasan and Jazan regions, KSA.

Sample & Sample Size: Mothers having children with disabilities and behavior problems. The sample size was 30.

Sampling Technique: The nonprobability purposive sampling technique, chosen for its thoroughness and precision, was used for this study.

Criteria for sample selection:

### Inclusion Criteria:

- Mothers having children with disabilities and behavior problems.
- Mothers having children with age range from 4-18 yrs
- Mothers can read and write Arabic.
- Willing to participate.

# Exclusion Criteria:

• Mothers having children with disabilities other than behavioral problems.

#### **Data Collection Instruments**

 Semi-structured interview schedule on demographic variables of Mothers such as age, education, number of children, occupation, income, child's age, type of family, total number of family members, type of disability, level of disability, sex of the child, child's place of residence and

of disability, sex of the child, child's place of residence and sources of medical expenses.

- In the short form of the Developmental Behavior Checklist (DBC-24), the Likert scale measures behavior problems in children with disabilities between 4 and 18 years of age. It contained 24 questions with three categories: Not true as far as I know(s) has a 0 score, Somewhat or sometimes true -1 score, and Very true or Often true 2 score.
- The CD-RISC contains 25 items, all of which carry a 5-point range of responses, as follows: not true at all (0), rarely true (1), sometimes true (2), often true (3), and true nearly all of the time (4). The scale is rated based on how the subject has felt over the past month. The total score ranges from 0–100, with higher scores reflecting greater resilience.

Data Collection Procedure:

- Permission was obtained from the dean of the nursing college.
- For mothers selected by inclusion criteria, informed consent was obtained.
- The five categories of the Likert scale on the Quality of Life questionnaire were used to assess the quality of life of mothers having children with disabilities and behavior problems.
- The five-point scale on CD-RISC to assess the level of resilience.
- Education was given to mothers who are having children with disabilities and behavior problems.

## Statistical Analysis:

- Both descriptive and inferential statistics were used for this study. The mean, standard deviation, and mean percentage were used to assess the resilience of mothers with children with disabilities and behavior problems.
- Chi-square was used to assess the association between scores and demographic variables.
- Correlation and coefficient were used to identify the difference between the psychological impact and the resilience in mothers having children with disabilities and behavior problems.

**RESULTS** The highest percentage of respondents were (40%) 20-30 years old, and the lowest percentage (7%) of respondents were in the age group of 18-20 years. The highest percentage of respondents (90%) are married, while the lowest percentage (3%) are widowers. The highest percentage of respondents (63%) have a bachelor's degree, and the lowest percentage (4%) have a master's degree.



S. No	Categories	Not true as far as I know(s)		Somewhat or sometimes true 1		Very true or often true 2	
		Frequ ency	%	Frequ ency	%	Frequ ency	%
1	The child becomes overexcited	8	26.7	9	30	10	33.3
2.	The child chews or mouths objects or body parts	0	0	6	20	24	80
3.	The child confuses the use of pronouns (e.g., uses you instead of I)	0	0	5	16.7	19	63.3
4	The child doesn't show affection	3	10	7	23.3	11	36.7
5	The child grinds their teeth	3	10	19	63.3	7	23.3
6	The child has nightmares, night terrors, or walks in sleep	3	10	9	30	18	60
7	The child is impatient	4	13.3	14	46.7	12	40
8	The child has Inappropriate sexual activity with another	27	90	3	10	0	0
9	The child is jealous	2	6.7	11	36.7	17	56.6
10	The child kicks or hits others	0	0	6	20	24	80
11	The child laughs or giggles for no obvious reason	2	6.7	11	36.7	17	56.6
12	The child is preoccupied with only one or two particular interests	5	16.7	13	43.3	12	40
13	The child refuses to go to school, activity centre, or workplace	0	0	12	40	18	60
14	The child repeats the same word or phrase over and over	2	6.7	9	30	19	63.3
15	The child smells, tastes, or licks objects	0	0	10	33.3	20	66.7
16	The child switches light on and off, pours water over and over, or similar repetitive behaviour	0	0	17	56.7	13	43.3
17	The child is stubborn, disobedient, or uncooperative	7	23.3	14	46.7	9	30
18	The child says he/she can do things that he/she is not capable of	4	13.4	13	43.3	13	43.3
19	The child sees, and hears, something that isn't there, hallucinations	4	13.3	14	46.7	12	40
20	The child tells lies	6	20	21	70	3	10
21	The child is tense, anxious, worried	0	0	17	56.7	13	43.3
22	The child underreacts to pain	0	0	19	63.3	11	36.7
23	The child is upset or distressed over small changes in routine or environment	0	0	14	46.7	16	53.3
24	The child wanders aimlessly	0	0	23	76.7	7	23.3

Table 1. Likert scale on the short form of the Developmental Behaviour Checklist (DBC-24), to measure behaviour problems in children with disabilities between 4–18 years of age



S. No	Categories	at	Not true Rarely at all true 0 1		Sometim es true 2		Often true 3		True nearly all the time		
		F	%	F	%	F	%	F	%	F	%
1	Able to adapt to change	2	6.7	5	16.7	9	30	13	43.3	1	3.3
2.	Close and secure relationships	0	0	2	6.7	8	26.7	7	23.3	13	43.3
3.	Sometimes fate or God can help	0	0	0	0	6	20	9	30	15	50
4	Can deal with whatever comes	0	0	4	13.3	10	33.3	8	26.7	8	26.7
5	Past success gives confidence for new challenges	1	3.3	3	10	7	23.4	10	33.3	9	30
6	See the humorous side of things	0	0	4	13.3	6	20	12	40	8	26.7
7	Coping with stress strengthens	0	0	8	26.7	10	33.3	12	40	0	0
8	Tend to bounce back after illness or hardship	4	13.3	9	30	11	36.7	6	20	0	0
9	Things happen for a reason	0	0	6	20	13	43.3	8	26.7	3	10
10	Best effort no matter what	0	0	5	16.7	11	36.7	10	33.3	4	13.3
11	I can achieve my goals	0	0	4	13.3	13	43.4	7	23.3	6	20
12	When things look hopeless, I don't give up	0	0	8	26.7	9	30	13	43.3	0	0
13	Know where to turn for help	0	0	4	13.3	5	16.7	11	36.7	10	33.3
14	Under pressure, focus and think clearly	7	23.3	9	30	11	36.7	3	10	0	0
15	Prefer to take the lead in problem-solving	2	6.7	4	13.3	9	30	12	40	3	10
16	Not easily discouraged by failure	4	13.3	5	16.7	5	16.7	11	36.7	5	16.6
17	Think of yourself as a strong person	3	10	8	26.7	6	20	9	30	4	13.3
18	Make unpopular or difficult decisions	2	6.7	4	13.3	9	30	12	40	3	10
19	Can handle unpleasant feelings	4	13.3	9	30	11	36.7	6	20	0	0
20	I have to act on a hunch	2	6.7	7	23.3	8	26.7	5	16.7	8	26.7
21	Strong sense of purpose	2	6.7	4	13.3	9	30	12	40	3	10
22	In control of your life	4	13.3	9	30	11	36.7	6	20	0	0
23	I like challenges	0	0	4	13.3	7	23.3	11	36.7	8	26.7
24	You work to attain your goals	0	0	6	20	5	16.7	10	33.3	9	30
25	Pride in your achievements	0	0	8	26.7	7	23.3	7	23.3	8	26.7

Table 2. Rating scale on the Connor-Davidson Resilience scale (CD-RISC) to assess the resilience of mothers having children with disabilities and behaviour problems.

The highest percentage of respondents (73%) live in urban, and the lowest percentage (27%) live in Rural. The highest percentage of respondents (57%) have their occupation status as housewives, and the lowest percentage (43%) are working. The highest percentage of respondents (43%) have only 1-2 children, and the lowest percentage (24%) have more than 5 children. The highest percentage of respondents (30%) their children were both 3-5 years and 5-8 years old respectively, and the lowest percentage (13%) were more than 8 years old. The highest percentage of respondents (70%) their family type was Nuclear Families. A nuclear family has two adults with at least one child, and the lowest percentage (4%) were Grandparent Families. The highest percentage of respondents (70%) their family monthly income is 5,000-20,000 SR, and the lowest percentage (10%) is Greater than 20,000 SR. The highest percentage of respondents (53%) their family members of 3-5 members, and the lowest percentage (20%) have 6 or more members. The highest percentage of respondents (90%) their children with Disabilities and Behavior Problems, and the lowest percentage (10%) are without Disabilities and Behavior Problems. The highest percentage of respondents (27%) their children with Disabilities and behavioral problems are Intellectual and physical, and the lowest percentage (3%) is Visual. The highest percentage of respondents (63%) their children's gender is boys, and the lowest percentage (37%) are girls. All the respondents (100%) have their children's place of residence in the family itself. No children were living in rehabilitation centers. The highest percentage of respondents (70%) whose Sources

of medical expenses are Self-paying, and the lowest percentage (30%) is Medicare.

Table 1 - Likert scale on the short form of the Developmental Behavior Checklist (DBC-24), to measure behavior problems in children with disabilities between 4–18 years of age shows that in many aspects of developmental behavior, the child has very true or often true in all the items. Only one item the maximum percentage (90%) of the children has responded not true as far as I know in the item of inappropriate sexual activity with another. Very less percentage around 10 to 20 percent of children responded non-true as far as I know in a few items of DBC-24.

Table 2 - Rating scale on the Connor-Davidson Resilience scale (CD-RISC) to assess the resilience of mothers having children with disabilities and behaviour problems shows that a maximum of around 60 percent of mothers responded true nearly all the time for all the aspects of resilience items. Around 40 percent of mothers had low resilience scores in all aspects rating scale.

The distribution of the Mean and standard deviation of the Developmental Behaviour Checklist and Connor-Davidson Resilience scale (CD-RISC) to assess the resilience of mothers having children with disabilities and behaviour problems show that the overall mean score for the Developmental Behaviour Checklist was 37.57±3.401 it reveals that children had a severe level of development behaviour disability and the overall mean score for Connor-Davidson Resilience scale predicts that the

S.No	Description	Max Score	Mean	SD	Correlation &
					Co-efficient
1	Developmental Behavior	48	37.57	3.401	
	Checklist	Mild – 1-16			
		Moderate – 17-32			
		Severe – 33-48			0.243
2	Connor-Davidson	100	42.43	6.611	
	Resilience Scale (CD-RISC)	Low resilience – 1-33			
		Moderate resilience – 34-			
		66			
		High resilience – 67-100			

Table 3. Distribution of Mean and standard deviation of Developmental Behaviour Checklist and Connor-Davidson Resilience scale (CD-RISC) to assess the resilience of mothers having children with disabilities and behaviour problems.



mothers were having moderate level of resilience score of children with disabilities and behaviour problems (Table 3).

There was no significant association was found between the demographic variables and the Resilience score and developmental behaviour score of children with disabilities, except in the level of education significant association was found. There was a positive correlation was found between the Resilience and developmental behaviour score at p>0.05 level.

**DISCUSSION** This study focused on mothers' resilience when raising children with behavioral issues and impairments. Anxiety and disappointment can arise in a family when parents' expectations and wishes for a healthy child are not fulfilled. Having a child with a disability causes one to experience feelings of exclusion, frustration, guilt, and fault. At last, these emotions may manifest as despair or sadness. Iranian academics have undertaken numerous studies on the quality of life of mothers and fathers raising impaired children, but very few have focused on their resilience [55–57]. Test-retest reliability and internal consistency are strong points of the CD-RISC, validated in clinical and general populations. The scale shows validity compared to other stress and hardiness measures. It represents varying degrees of resilience in groups believed to differ, among other things, based on their level of resilience (e.g., general population vs. patients with anxiety disorders).

Mothers of disabled children have significantly lower mean scores, according to the results. Mothers of children with acute lymphoblastic leukemia have significantly lower mean scores than mothers of children with normal conditions, according to research by Baran et al.58. According to Keniş-Coşkun et al. (2020), people become less resilient when faced with challenging life circumstances, such as having a kid with a disability [59]. The resilience of mothers with children who are impaired and mothers with children who are usually developing is similar, according to the findings of this study on resilience. However, as demonstrated by Kenis-Coskun's study, having a child with a handicap or other traumatic life events lowers resilience.60Moms of children with disabilities face diminished resilience and adverse effects on their overall health and quality of life [56].

Based on the explanation of these results, resilience is a personality attribute that can significantly impact an individual's behavior, level of satisfaction, and quality of life. Mothers of disabled children perform poorly and frustratingly; they learn slowly and grow slowly. Additionally, their children's trials and futile efforts may lessen their tolerance; if resilience declines, they may become unable to handle life's challenges and exhibit fragility on even the smallest issues. Consequently, their quality of life declines due to this decline in resilience. However, mothers with strong resilience and personality traits are tolerant rather than accepting failure. Despite encountering numerous challenges, they strive to identify the ideal answer. However, they never give up on attempting to get the intended outcome and are happy with their accomplishment, resulting in a great quality of life.

The current study's findings showed that mothers' quality of life is influenced by their educational attainment; consequently, moms with less education have lower quality of life. The findings of this investigation are consistent with those of Klassen et al.'s studies, Misura et al., and Zareinejad et al. [62-63]. The findings of the studies by Gheysaranpour et al. on parents of thalassemia patients indicated that parents with greater levels of education had a better quality of life [64].

Based on an analysis of the study's findings, we may conclude that a mother's education [Bachelor's degree (63%) & Master's degree (4%)] has several positive effects on her child's health, including increased family income, decision-making ability, better use of already available services, and better child care [65]. Furthermore, higher education associated with is typically socioeconomic status (SES), according to Misura et al., suggesting that the influence of SES may act as a mediating factor between educational attainment and SES [63]. Greater QOL can result from lower mental and physical stress exposure caused by increased income.

**CONCLUSION** Rehabilitation specialists must examine and train women in resilience. Women who have children with disabilities can be empowered by strengthening their resilience through social support, family support, training, hope, etc. Mothers who possess resilience are better able



to handle and manage stressful circumstances. A range of programs could be considered to enhance the social-ecological surroundings for women raising children with disabilities. Resilience is more influenced by the accessibility and availability of culturally meaningful resources than by the intrinsic traits of the individual. Researchers need more information about the interactions between the mother, brother, kids, and family members with impairments. They could achieve this with the aid of longitudinal research.

**Conflicts of interest**: The authors declare no conflicts of interest.

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