Attitude toward Parent caring a Child with Disabilities in Khartoum –Sudan

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Abstract

Background: Parents of children with disabilities face significant physical, emotional, and social challenges while managing their caregiving responsibilities. These challenges often require adaptive coping mechanisms to ensure family stability and the well-being of both parents and children.

Objective: To assess the Attitude toward Parent careening a Child with Disabilities in Khartoum –Sudan and to explore the psychosocial challenges they meet .**Methods:** This descriptive cross-sectional study was conducted in two specialized centers for children with disabilities in Khartoum, Sudan. 180 parents were enrolled using a convenience sampling method. Data were collected through a structured questionnaire including demographic information, attitudes toward caregiving, and coping strategies. Data analysis was performed using SPSS, with descriptive statistics and correlation tests applied to find key relationships. **Results:** Most participants were mothers (81.7%), with a mean age of 38.99 years. Key challenges included despair about their child's future (mean: 3.03) and difficulties managing caregiving tasks (mean: 3.04). Adaptation levels were low (mean: 2.29), with inadequate access to social benefits and training programs. Higher education levels correlated positively with improved coping mechanisms ($r = 0.431$, $p < 0.01$). **Conclusion:** Parents of children with disabilities in Khartoum face significant emotional and practical challenges, compounded by limited systemic support. Tailored interventions, enhanced training programs, and robust social support systems are essential to improve their coping ability and overall well-being.

Keywords: *Attitudes, Child, Disabilities, Parents*

Introduction

Caring for a child with a disability presents significant physical, emotional, and social challenges for families. Unlike typical caregiving, it often spans the child's entire life and exceeds the expectations of normal developmental caregiving. Most families are unprepared for the ongoing demands associated with disabilities, leading to increased stress and disruption in family dynamics [(1,2)].

Parents must navigate the emotional impact of the child's diagnosis, while simultaneously coordinating complex medical, educational, and developmental interventions [3]. These responsibilities place a continuous strain on families, requiring additional time, financial resources, and psychological resilience [4,5]. Moreover, the presence of a child with disabilities often affects the entire family system, including siblings and the quality of parental relationships [6].

To cope with these challenges, parents often adopt behavioral and cognitive strategies aimed at reducing stress and improving adjustment. Coping is defined as the process by which individuals manage the demands of stressful circumstances, particularly those that overwhelm normal functioning [7,9]. However, coping strategies do not occur in isolation — they are influenced by a family's environment, resources, and social support systems.

Globally, disability among children is a growing concern. UNICEF estimates that 240 million children worldwide — approximately 1 in 10 — live with a disability, with psychosocial difficulties being the most common [12]. The impact is particularly severe in low- and middle-income countries, where access to support services is limited. In Sudan, according to the 2008 Population and Housing Census, more than 1.8 million individuals aged 5 and above live with some form of disability [13].

Problem Statement:

Despite the increasing prevalence of childhood disabilities, there is limited empirical data in Sudan — particularly in Khartoum — regarding how parents cope with and adjust to the demands of caregiving. Understanding parental attitudes and coping mechanisms is essential to developing targeted interventions that promote resilience and reduce caregiver stress.

Scope of the Study:

This study focuses on assessing the attitudes and coping strategies of parents caring for children with disabilities in Khartoum, Sudan. It aims to explore the psychosocial and practical challenges they face and how various demographic factors influence their ability to adjust. The findings are intended to guide policy and inform the development of supportive services tailored to the needs of these families.

Methods:

Study Design and Setting

This descriptive cross-sectional study was conducted in **Khartoum State, Sudan**, which comprises seven localities and 53 specialized centers serving children with disabilities. It is estimated that around **2,350 children with special needs** attend these centers, with approximately **1,551** aged between 5 and 15 years.

The study was carried out in **two purposefully selected specialized centers** to provide a representative overview of the target population. These centers were chosen based on the volume

and diversity of children served and their accessibility for the research team from different socio-economic backgrounds.

The research was conducted in **two specialized centers for children with disabilities** located in Khartoum State:

- **Al Amal Center for Rehabilitation**: A government-supported facility offering educational and rehabilitation services for children with various disabilities.
- **Babiker Badri Center for Special Education**: A non-governmental organization providing educational support, therapy, and family guidance for children with intellectual and developmental disabilities.

Clarification of Administrative Unit

In the data tables, the term **"administrative unit"** refers to the **local administrative divisions** within Khartoum State (such as Khartoum North, Jebel Aulia, Omdurman), used to categorize participants based on their place of residence for geographic analysis.

Study Population

Parents or primary caregivers of children diagnosed with physical, intellectual, or developmental disabilities, who were receiving services at the selected centers and willing to participate during the data collection period.

Sampling Method and Sample Size

A **convenience sampling technique** was used due to logistical considerations and ease of access to the study population. The final sample included **180 parents**, which was deemed sufficient based on accessibility and time constraints. While this method limits generalizability, it was considered appropriate for exploratory analysis within this setting.

Data Collection Tool

1. Data were collected using a **modified structured questionnaire**, developed based on a review of relevant literature and previous validated studies (14,15). The questionnaire consisted of three main sections:
2. **Demographic Information**: Included parent's age, gender, literacy level, employment status, household income (in Sudanese Pounds), and the child's type of disability. Where a parent was unsure of the diagnosis, data were verified using the child's medical records.
3. **Attitude Toward Caregiving**: Adapted from the **Parental Attitude toward Disabled Children (PATDC) scale** developed by V. Karnieli-Miller et al. (original source cited), with minor modifications to suit the Sudanese context. The adapted tool assessed emotional responses, sense of burden, and perceived social support using a 5-point Likert scale.

4. **Coping Strategies**: Based on the **Brief COPE Inventory** by Carver (1997), this section was also slightly modified to reflect local cultural and familial dynamics. The tool measured problem-focused, emotion-focused, and avoidance strategies.

Validity and Reliability

The questionnaire was pilot-tested on **20 parents** (excluded from the final sample) to ensure clarity and cultural relevance. Content validity was confirmed through expert review. The tool showed acceptable internal consistency with a **Cronbach's alpha of 0.71**.

Data Collection Procedure

Participants were given the option to complete the questionnaire **on-site at the centers** or **at home**. For home responses, completed forms were returned to the center, and any missing data were clarified by phone. Each questionnaire took approximately **15–20 minutes** to complete. Confidentiality and anonymity were emphasized to promote honest responses.

Data Analysis

Data were analyzed using **SPSS version 26**. Descriptive statistics (frequencies, percentages, means) were used to summarize demographic characteristics, attitudes, and coping strategies. Inferential analyses included:

- **Pearson's correlation coefficient** to examine relationships between sociodemographic factors and coping mechanisms.
- **t-tests** and **chi-square tests** to determine statistical significance, with a p-value < 0.05 considered significant.

Ethical Considerations

Ethical approval was obtained from the Institutional Review Board and the Ministry of Health, Khartoum State. Participants provided informed verbal consent and were assured of confidentiality and their right to withdraw without consequences. **Informed verbal consent** obtained from all participants due to literacy challenges among some respondents. This approach was approved by the ethics committee and ensured that participation was fully voluntary, with confidentiality maintained.

Study Limitations

The use of convenience sampling may limit the generalizability of the findings. Additionally, reliance on self-reported data may introduce response bias. Future studies should consider using larger and more diverse samples with probability-based sampling techniques.

Results

Table1: Sociodemographic characteristics of the study participants (n=180)

Characteristics	Frequency	Percent
Sex		
Male	33	18.3
Female	147	81.7
Total	**180**	**100.0**
Mother age		
18-28	40	22.2
29-39	58	32.2
40-50	55	30.6
Above 50	27	15
Total	**180**	**100.0**
Level of education		
Basic	31	17.2
Secondary School	48	26.7
Undergraduate	75	41.7
Postgraduate	26	14.4
Total	**180**	**100.0**
Employment status		
Housewife	87	48.3
Employee	70	38.9
Worker	23	12.8
Total	**180**	**100.0**
Source of income		
Governmental Salary	77	42.8
Private	89	49.4
Social Subsidize	14	7.8
Total	**180**	**100.0**
Residences		
Urban of Khartoum	135	75.0
Rural of Khartoum	45	25.0
Total	**180**	**100.0**

Total Number of family members		
1-3	52	28.9
4-6	91	50.6
More than 7	37	20.6
Total	**180**	**100.0**

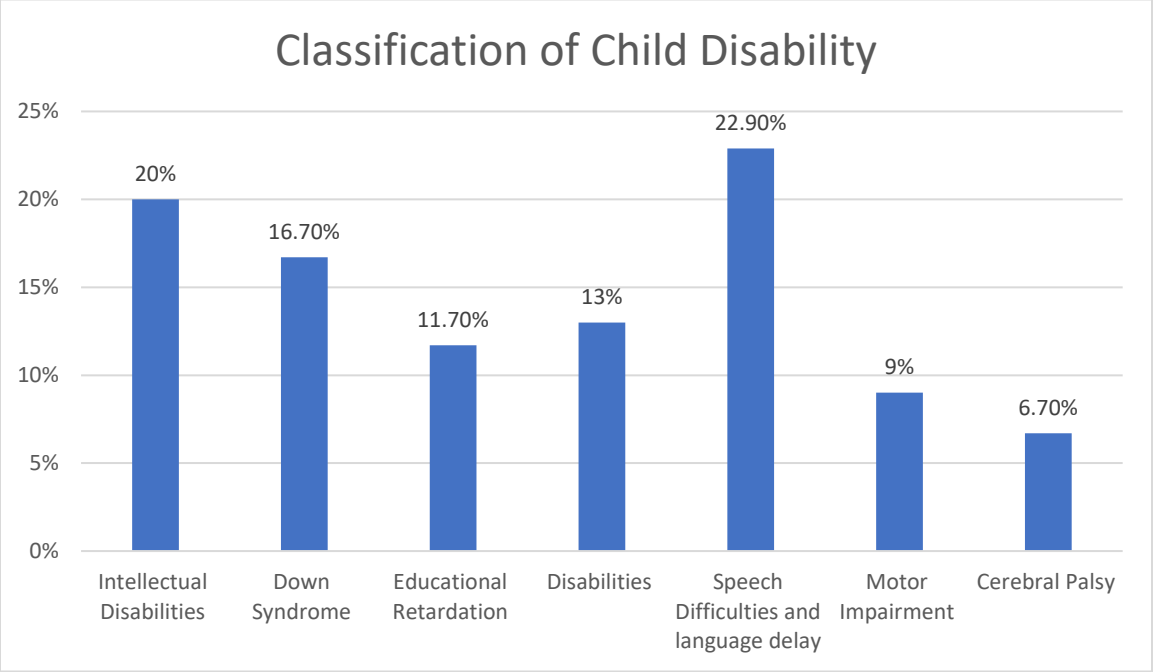


Figure 1 Classification of child disability (n=180)

Table 2: Attitude of parent having a child with disability (n=180)

	Never		Rarely		Sometimes		Most the time		Always		Mean	Result	Std. Deviation
	No	%	No	%	No	%	No	%	No	%			
Feeling difficulties to do or finish housework	46	25.6	1	0.6	83	46.1	42	23.3	8	4.4	2.8056	Sometimes	1.18697
Feeling anxious or anger or displeasure from incompatibility with child	48	26.7	6	3.3	67	37.2	44	24.4	15	8.3	2.8444	Sometimes	1.28950
Feeling despair about child future	46	25.6	4	2.2	63	35.0	31	17.2	36	20.0	3.0389	Sometimes	1.42352
Feeling very sad and nothing made mother happy	61	33.9	8	4.4	76	42.2	29	16.1	6	3.3	2.5056	Rarely	1.20751
Feeling disinterest about daily activities	45	25.0	2	1.1	87	48.3	38	21.1	8	4.4	2.7889	Sometimes	1.16748
obtain adequate sleep	51	28.3	9	5.0	82	45.6	25	13.9	13	7.2	2.6667	Sometimes	1.22816
Feel difficulties to obtain adequate sleep	41	22.8	6	3.3	90	50.0	33	18.3	10	5.6	2.8056	Sometimes	1.14870
Eating healthy and regular meals	35	19.4	1	0.6	82	45.6	41	22.8	21	11.7	3.0667	Sometimes	1.21720
Feeling cannot manage child activities	40	22.2	2	1.1	68	37.8	52	28.9	18	10.0	3.0333	Sometimes	1.26359
Feeling cannot caring of child	58	32.2	3	1.7	57	31.7	34	18.9	28	15.6	3.0444	Sometimes	3.19186
Total	180	100.0	180	100.0	180	100.0	180	100.0	180	100.0	2.86	Sometimes	

The **overall mean score** of 2.86 indicates that, on average, parents "sometimes" experience emotional and physical difficulties related to caregiving.

The **highest emotional burden** was reported in feelings of *despair about the child's future* (mean = 3.04) and *feeling unable to care for the child* (mean = 3.04).

Low mood or depression indicators like *feeling very sad and nothing made them happy* were less frequent (mean = 2.51), falling in the "rarely" range.

Sleep issues and *difficulty managing caregiving tasks* also emerged as common challenges, with both items scoring close to or above the group average

Eating habits and self-care were moderately affected, suggesting that caregiving stress extends into daily routines.

Table 3: Parents adapted with child with disability (n=180)

	Never		Rarely		Sometimes		Most the time		Always		Mean	Result	Std. Deviation
	No	%	No	%	No	%	No	%	No	%			
Get social benefit from agencies	98	54.4	0	00.0	63	35.0	17	9.4	2	1.1	2.0278	Rarely	1.17436
Get training about child pother	92	51.1	2	1.1	51	28.3	32	17.8	3	1.7	2.1778	Rarely	1.27790
Get training about child walk	115	63.9	2	1.1	38	21.1	18	10.0	7	3.9	1.8889	Rarely	1.26354
Get training about child pronunciation and talk	83	46.1	1	0.6	41	22.8	47	26.1	8	4.4	2.4222	Rarely	1.40214
Get training about child eating	106	58.9	0	00.0	45	25.0	27	15.0	2	1.1	1.9944	Rarely	1.24397
Get training about child bathing	117	65.0	1	0.6	41	22.8	16	8.9	5	2.8	1.8389	Rarely	1.21059
Get training about child toileting	109	60.6	2	1.1	40	22.2	23	12.8	6	3.3	1.9722	Rarely	1.28346
Get support from others	54	30.0	1	0.6	89	49.4	30	16.7	6	3.3	2.6278	Sometimes	1.17245
Communicate with social media	56	31.1	4	2.2	65	36.1	42	23.3	13	7.2	2.7333	Sometimes	1.31430
Exercising sport	132	73.3	0	00.0	43	23.9	4	2.2	1	0.6	1.5667	Never	.96358
Participate in social events	21	11.7	0	00.0	98	54.4	50	27.8	11	6.1	3.1667	Sometimes	.98310
Watching cultural didactic programs	47	26.1	1	0.6	70	38.9	50	27.8	12	6.7	2.8833	Sometimes	1.26082
Watching YouTube videos	52	28.9	2	1.1	64	35.6	42	23.3	20	11.1	2.8667	Sometimes	1.35531
Exercising avocation drawing reading	116	64.4	2	1.1	52	28.9	7	3.9	3	1.7	1.7722	Never	1.09254
Total	180	100.0	180	100.0	180	100.0	180	100.0	180	100.0	2.297		

Table 4: Correlation between socio-demographic data and Acclimate of parent with handicapped child

Demographic data	Get social benefit from agencies	Get training about child pother	Get training about child walk	Get training about child pronunciation and	Get training about child eating	Get training about child bathing	Get training about child toileting	Get support from others	Communicate with social media and friends	Exercising sport	Participate in social events	Watching cultural didactic programs	Watching YouTube videos	Exercising avocation drawing reading
	R	R	R	R	R	R	R	R	R	R	R	R	R	R
Sex	-0.013	-0.114	-0.156*	0.071	-0.129	-0.063	-0.134	-0.161*	-0.031	-0.184*	0.051	-0.044	.017	-0.073
Age	-0.023	-0.272**	-0.186	-0.288**	-0.257**	-0.182*	-0.078	0.024	-0.251**	-.246**	-0.072	-0.184*	-.253**	-0.163
Education level	-0.215**	0.116	-0.002	0.222**	0.079	0.095	0.165*	-0.028	0.431**	0.207**	0.097	0.377**	0.384**	0.336**
Vocation	0.060	-0.023	.031	0.046	0.036	0.084	.120	-0.035	-0.037	0.168*	-.003	-0.047	-0.039	0.113
Source of income	0.052	-0.034	0.014	0.055	0.048	0.118	0.114	.171*	-.088	0.165*	-.060	-0.081	-0.096	0.121
Residence	0.074	0.020	-0.010	0.028	0.137	0.151*	0.073	0.120	-0.215**	-0.007	-.085	-0.038	-0.114	-0.127
Members of family	-0.045	0.004	-0.029	-0.021	0.051	0.096	0.060	0.082	-.322**	.195**	-.053	-0.188*	-0.265**	0.128

*Correlation is significant at the 0.05 level (2-tailed).
**Correlation is significant at the 0.01 level (2-tailed).

Discussion

The study found that the most common disability types among children were speech and hearing impairments (22.8%) and intellectual disabilities (20%), consistent with global trends highlighting the high prevalence of intellectual and developmental conditions(16). However, Sudan lacks tailored interventions to address the unique challenges associated with each type of disability. In contrast, evidence from higher-income countries demonstrates that specialized programs significantly reduce parental stress and improve caregiving outcomes（17）. In this study, the overall mean Likert score for parental attitudes was 2.86, indicating that parents "sometimes" face caregiving difficulties. Notably, higher stress levels were reported in areas such as concerns for the child's future (mean: 3.03) and managing daily tasks (mean: 3.04). These findings align with previous research emphasizing the emotional burden parents carry when raising children with disabilities, especially in settings lacking systemic support（14）. Bridging this gap in Sudan will require implementing disability-specific caregiver training and expanding psychosocial support services The findings of this study reveal significant insights into the sociodemographic characteristics and coping mechanisms of parents of children with disabilities in Khartoum, Sudan. The majority of participants were female (81.7%), reflecting social norms in which caregiving responsibilities are predominantly assumed by mothers. This trend is consistent with previous studies in low- and middle-income countries, where mothers are typically the primary caregivers for children with special needs due to cultural expectations and gender roles (18).

Education levels varied among participants, with a significant proportion holding undergraduate degrees (41.7%). Employment data showed that nearly half of the respondents were housewives (48.3%), indicating potential financial dependency on spouses or external support systems. Similar findings have been reported in a study conducted in Egypt, which found that mothers of children with disabilities are often unemployed and reliant on family income, adding to the psychosocial burden (19).

The distribution of disabilities—most commonly speech and hearing impairments (22.8%) and intellectual disabilities (20%)—mirrors global patterns that report a high prevalence of intellectual and communication impairments among children with disabilities (16). However, the Sudanese context highlights a significant shortfall in tailored interventions and support systems. Evidence from high-income settings, such as the Netherlands, shows that specialized intervention programs significantly reduce parental burden and enhance family functioning (17). This disparity underlines the need for Sudan to establish structured training programs tailored to specific disability types to alleviate stress and empower caregivers.

The mean Likert score for overall parental attitudes was 2.86, indicating that parents "sometimes" face challenges in caregiving. Feelings of despair about the child's future (mean: 3.03) and difficulties managing caregiving tasks (mean: 3.04) were particularly significant. These findings align with the work of Rayan and Ahmad (2017), who reported elevated emotional stress among parents of children with autism and intellectual disabilities due to uncertainties about their child's long-term development(20)

Conversely, studies in higher-income contexts demonstrate the positive effects of well-established support systems. For example, a study in the Netherlands found that community-based mental

health services and government-funded support programs played a critical role in enhancing parental resilience (21). These findings support the call for investment in accessible mental health services and tailored counseling programs in Sudan to strengthen caregiver support.

Low levels of adaptation were evident in the current study, with a mean adaptation score of 2.29 ("rarely"). Key problem areas included bathing (mean: 1.83) and toileting (mean: 1.97), indicating a lack of practical training for caregiving. This aligns with findings from Chimhenga (2016), who emphasized that inadequate caregiver training is a major barrier to effective care in resource-limited settings(22).

Only 7.2% of participants reported receiving adequate social benefits. This is markedly lower than findings from a U.S.-based study, where over 60% of caregivers of children with disabilities had access to structured social support and welfare programs (23). The stark contrast underscores the urgent need for Sudanese policymakers to develop inclusive welfare strategies, particularly those targeting families affected by childhood disability.

The study also identified important correlations between sociodemographic factors and coping outcomes. Notably, higher education levels positively correlated with better coping mechanisms ($r = 0.431$, $p < 0.01$), echoing similar trends reported in a study from Jordan, which found that educated parents were more likely to adopt adaptive coping strategies (24). In contrast, larger family sizes were associated with lower adaptation scores, likely due to financial and emotional strain. This observation mirrors findings from a Nigerian study that reported a negative relationship between family size and parental coping among caregivers of children with disabilities (25).

Conclusion

Parents of children with disabilities in Khartoum face multifaceted emotional and practical challenges, often in the absence of sufficient systemic support. This study highlights the urgent need for targeted interventions, including **specialized caregiver training**, **accessible mental health resources**, and **strengthened social welfare systems**. Policymakers and practitioners must prioritize these areas to improve the quality of life for caregivers and the developmental outcomes for children with disabilities

Competing Interests:

The authors have declared that no competing interests exist

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