Satisfaction and Barriers Regarding Community-Based Rehabilitation Services among Caregivers of Children with Cerebral Palsy in Minia Governorate.

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Abstract

Background: Community-based rehabilitation (CBR) service is a community development strategy designed for persons with disabilities and their families. Measuring caregivers' satisfaction is a recommended approach to assess the overall quality of rehabilitation services and decrease the barriers that hinder reaching them. **Aim:** To assess satisfaction and barriers regarding CBR- services among rural and urban caregivers of children with cerebral palsy in Minia Governorate. **Study design:** A descriptive cross-sectional study was utilized. **Sample:** A purposive sample of one hundred caregivers. **Setting**: The current study was conducted at three governmental rehabilitation centers which provide services for Minia Governorate .**Tools of data collection**: Three tools were utilized to collect data; 1st one: A structured interview questionnaire covered two parts (Socio-demographic data of caregivers, demographic and medical data for child, the 2nd tool: Caregivers' satisfaction regarding CBR- services questionnaire, and 3rd tool: Barriers to Caregivers' Satisfaction with CBR Services. **Results:** It was revealed that 78.0% of rural caregivers and 62.0% of urban caregivers were dissatisfied with CBR services. Significant predictors of dissatisfaction among rural caregivers included financial and transport constraints, long wait times, lack of communication, and family/community support. Meanwhile, urban caregivers cited financial constraints, lack of support, long wait times, and communication issues. **Conclusion:** There are high levels of dissatisfaction with CBR services, and many reported barriers hinder caregivers of children with cerebral palsy in both urban and rural areas from accessing these services. **Recommendations:** Offering training programs for nursing staff to improve their communication skills with disabled children and their families, raising community awareness about available CBR services, and increasing the number of rehabilitation centers at the governorate level while providing equipped transportation for patients.

Keywords: Barriers, Caregivers, Cerebral Palsy, Community-Based Rehabilitation Services, Satisfaction.

Introduction

Cerebral palsy (CP) refers to "a group of disorders that permanently affect a person's ability to move and maintain balance and posture". CP is caused by abnormal brain development or damage to the developing brain that affect a person's ability to control their muscles. It is the most common motor disability in childhood **(Centers for Disease Control and Prevention (CDC), 2024).**

CP classified according to the type of movement disorder to: Spastic (stiff muscles), athetoid (writhing movements), or ataxic (poor balance and coordination), in addition to any additional symptoms, such as weakness (paresis) or paralysis (plegia), **(National Institutes of Neurological disorders and stroke NINDS, 2024).**

A child with CP experiences several disabilities, extending from spastic paralysis, cognitive, speech and visual impairment, chronic pain and, gastrointestinal problems. Accordingly, the child will suffer from several limitations in life and may need to be cared for either by the parent or caregivers **(Sankombo, M., 2023).**

Globally, about 17 million people live with CP **(Guimarães et al., 2023)** and its prevalence is around 2.11 per 1000 live births (**Fafolahan, Davis, Sodipo, & Tiamiyu, 2024 & Potcovaru et al., 2022)**. In Europe, 1.5 to 2.5 children per 1000 live births were diagnosed with CP **(Guimarães et al., 2023)** while in the United States, 3 per 1,000 8-year-old children live with CP **(Centers for Disease Control and Prevention (CDC), 2022).** In **Egypt**, the prevalence of CP is 2.9 per 1000 children, **(Abd Elmagid & Magdy, 2021).**

CP is a type of disabilities that requires comprehensive and continuous community-based services **(Sankombo, M., 2023).** Community-Based Rehabilitation (CBR) is "a community development strategy established by the World Health Organization (WHO) to improve lives of disabled persons and their caregivers within their community." Globally, CBR services are present in more than 90 countries to reduce different burdens on caregivers of disabled children **(Fentanew, Yitayal, Chala & Kassa, 2021).**

CBR- service designed for rehabilitation, equalization of opportunities, and social integration of all Persons With Disabilities (PWDs). It is executed by the combining efforts of PWDs, their caregivers and communities **(World Physiotherapy, 2023).** The CBR-service includes five components which are healthcare, education, social, financial support and assistive devices **(Fentanew et al., 2021)**.

Assessing caregivers' satisfaction is a recommended approach for knowing the overall satisfaction of CBR- services **(Fentanew et al., 2021)** and it is important for effective health services for children **(Beshir et al., 2022).** Satisfaction is "the emotional reaction or psychological state of a person regarding the services he/she received". It varies from person to person owing to several factors such as age, socio-economic status, educational level, occupation, and types of CBR- service **(Fentanew et al., 2021)**.

Satisfaction/dissatisfaction with services accessibility, availability, appropriateness, physical facilities, skills, respectful and supportive care are the basic elements that guide caregivers to be satisfied/dissatisfied about rehabilitation services for children **(Reyad, Mamdouh & Abd-Elmonem, 2024)**.

Financial problems and social constrains, awareness, understanding of rehabilitation choices, the setting of rehabilitation, poor or inconsistent communication with healthcare providers and clients support are factors that act as enablers or barriers for rehabilitation services. Also, limited available service choices personalized to clients' needs can act as a barrier for satisfaction **(Hodyl, Mason, Ribbons & Bailey, 2024).**

People living in rural residences might be less satisfied with their health care as a consequence of poor accessibility to services that, may be due to low socioeconomic status, geographic remoteness, lack of transportation and restricted insurance coverage **(Alhozgi et al., 2021)**. They experience a variety of social and economic inequalities as access to education, employment, health care, and community services **(Ipsen, Hall & Lui, 2022).** They face additional barriers related to transportation and limited services, which means using extra time, energy, and resources than urban people **(Sage, Standley & Mashinchi, 2022).**

Healthcare professionals have a vital role in aiding accessibility to rehabilitation services and seeking the best outcomes for their clients (**Rossi et al., 2023).** CBR- services must be provided by multidisciplinary teams in which rehabilitation nurses play an essential role in facilitating accessibility to health care and coordinating and managing the rehabilitation process. Also, they collaborate with physical therapists and provide interventions based on assessments **(Lorenz et al., 2024).**

Community Health professionals are first line community-based health care workers. their roles can include building relationships between health services and communities, conducting health promotion activities, providing clinical services, and supporting access to specialized care. They can play a key role in screening for CP as a disability. In addition, they can provide basic disability related community health education and counselling **(Iqbal M., 2023).**

Significance of study

Caregivers' satisfaction is a basic indicator for high quality health care. It replicates their awarenesses about service quality, **(Reyad et al., 2024)**. Satisfied caregivers are more likely to return for further care and usually are compliant with the medical provider advice and the recommended treatment plan. Compliance will eventually lead to better health outcomes **(D. Al Deen & Fadhil, 2021).**

Egypt is one of world countries that implemented CBR where CBR- services appeared Throughout the eighties and CBR programs were adopted by international Non-Governmental Organization (NGOs), with the support of national NGOs, (**Kassab, Orfy, Al-Helewa & Alsawahli, 2018).** There is very little Egyptian study that examines client's satisfaction about CBR- services and none of these studies assess rural–urban difference in satisfaction with CBR- services.

Aim of the study

This research aims to assess satisfaction and barriers regarding rehabilitation services among rural and urban caregivers of children with cerebral palsy in Minia governorate.

Research questions

1. What are the satisfaction levels regarding CBR-services among rural and urban caregivers of children with cerebral palsy?
2. Is there a statistically significant difference between rural and urban caregivers'

satisfaction levels regarding to CBR-services for children with cerebral palsy?

3. What are the barriers to CBR-services facing rural and urban caregivers of children with cerebral palsy?
4. What are factors that predict/ associated with satisfaction regarding CBR-services among rural and urban caregivers of children with cerebral palsy?

Subjects and method

Research design:

This study used a descriptive cross-sectional study.

Setting:

The current study was conducted at three governmental rehabilitation centers (Minia University Hospital, Health insurance Hospital, and Comprehensive Rehabilitation Center) all of which provide services for Minia governorate.

Population of study sample:

Sample size was calculated using software program Epi Info version 7.2.5 Depending on the 2.9 per 1000 prevalence of cerebral palsy among children, **(Abd Elmagid & Magdy, 2021)** at a statistical power of 0.95 and significance of less than 0.05, the predicted prevalence is 25% with a margin of error of 5%. The minimal estimated sample size was 90. But, to account for the expected 10% non-response, it was increased to 100. There were 100 caregivers who participated in the study.

Technique of sampling

Three rehabilitation centers at Minia district were identified, and a list was made of all individuals who sought medical care for their children with cerebral palsy at these centers. To conduct the study, a sample of 100 caregivers was selected. This sample was divided based on rural and urban residence, with 50 caregivers chosen from rural areas and 50 from urban areas. The sample size for each center was determined in proportion to the total number of children with cerebral palsy registered at each center as shown in the following table:

Rehabilitation centers	Total Number of Caregivers	Percentage (%)	Number of the selected Sample
Minia University Hospital	100	38.5	38
Health Insurance Hospital	85	32.7	33
Comprehensive Rehabilitation Center	75	28.8	29
Total	260	100%	100

The inclusion criteria were all caregivers had children with cerebral palsy from rural and urban areas and had no more than one disabled child, also, who had willingness to participate in the study.

Study Tools

Three tools were used in the present study for data collection:

The first tool: Structured interview questionnaire:

The researchers designed a questionnaire after evaluating relevant literature **(Ngubane & Chetty, 2017)**. It was split into two parts:

Part I: socio-demographic data of caregiver: such as age, sex, residence, education levels, occupation and income.

Part II: Demographic and medical data of child: such as age, sex, duration of disease, number of siblings of child and types of CBR-services received.

The second tool: Caregivers' satisfaction regarding rehabilitation services questionnaire

It is an interviewing questionnaire adapted from **Goldstein, Elliott & Andrew, (2000) & Hasan, Abdul Aziz & Mohamed, (2021)** and modified by the researchers to assess caregivers' satisfaction regarding rehabilitation services. It included 20 questions under five dimensions of Satisfaction (Access, Administrative Technical Management, Clinical Technical Management, Interpersonal Management, and Continuity of Care)

Scoring system: Satisfaction questions for each satisfaction influencing factor, participants can choose from a five-point Likert scale representing various degrees of satisfaction: 1-very dissatisfied, 2-dissatisfied, 3-moderate, 4-satisfied, 5-very satisfied. The total overall satisfaction scores are categorized as: 'dissatisfied' for scores valued below the mean and 'satisfied' for scores from the mean and above (**Fentanew et al., 2021)**

The third tool: Barriers to Caregivers' Satisfaction with Rehabilitation Services: it is an interviewing questionnaire adapted from N**gubane & Chetty, (2017) & Mlenzana, Eide & Frantz, (2018)** and modified by the authors to assess barriers to rural and urban caregivers' satisfaction with rehabilitation services. It includes 5 multiple chose questions. Scoring system: Barriers questions were given scores 1 and zero for yes and no answers, respectively.

Pilot study

A pilot study was conducted on ten caregivers (10%) for children with cerebral palsy after developing the tool, to check clarity, validity, and time required for completion. Needed modifications were done according to the results of the pilot study, and the results of the caregivers who participated in the pilot study were included in the study.

Ethical consideration

Nursing faculty approval of the Ethics Committee under code REC 2024 (59); Minia University, was obtained for taking the permission to conduct the research after clarifying the aim of research to ensure their help, support, and to permit the study. Participants were told that their contribution will be voluntary and had the right to discontinue at any time, their data would be kept private, and the data collected would be used only for the purpose of the present study.

The tools Validity and Reliability

The content validity of the study tools was revised by a five-member panel of community health nursing experts to evaluate the tools' clearness, feasibility, and applicability. The reliability of the tools was evaluated through an Alpha Cronbach test, and they were found to be highly reliable, with a score of (Cronbach $\alpha = 0.99$) for Caregivers' satisfaction regarding rehabilitation services questionnaire and 0.826 for Barriers to caregivers' satisfaction with rehabilitation services questionnaire

Procedure

The researchers visited the rehabilitation centers two days a week from 9 a.m. to 11 a.m. (according to rehabilitation centers' schedule) until the predetermined sample size achieved. The directors of the three rehabilitation centers gave their official approval before the study could be carried out. Additionally, formal clearance was obtained from the participating caregivers to specify the study's purpose and the start date for data collection. The researchers gathered

data from the beginning of April 2024 to the end of June 2024. Caregivers' information was gathered during waiting periods for their children. Caregivers were given self-administered questionnaires after explanation. They received assistance and supervision while filling out the questionnaire and, for illiterate ones, the researchers filled out the questionnaire. The data collection tools of the study took about 20 to 25 minutes to complete.

Statistical analysis

Descriptive statistics were used to summarize, tabulate, and show the gathered data. The data were statistically analyzed using the Statistical Package for the Social Sciences (SPSS), version 20. The frequency distribution was utilized to display the qualitative data, and the mean and standard deviation were used to convey the quantitative data's degree of dispersion. Regression was utilized to show how the variables related to one another. The correlations within the quantitative variables were found using Chi squire and independent t-test. At a p-value ≤ 0.05, statistical significance was taken into account.

Results

Table 1: illustrates distribution of rural and urban caregivers according to their sociodemographic data, it showed that mean age of both groups was 34.10 ± 7.810 and 36.34 ± 8.927 years respectively, 76.0% and 62.0% of them were females, also 50.0% of rural caregivers were illiterate while 68.0% of urban caregivers were having secondary education. Most of them were mothers in both group (72.0% and 62.0%) respectively. Concerning to their socioeconomic status, 90.0% and 82.0% of them respectively had not enough income.

Table 2: illustrates demographic data of children with cerebral palsy in both rural and urban groups, it showed that the mean age of them was 6.10 ± 3.991 and 6.54 ± 4.161 years respectively, 62.0% and 58.0% respectively of them were males, also, 58.0% and 76.0% of them were had less than 3 siblings. Concerning duration of their disease, 38.0% and 48.0% respectively of them were diagnosed since more than 5 years ago. More than half of both rural and urban children have less than or equal 4 follow up per month (56.0% Vs 52.0%) respectively.

Figure 1: illustrates that the main types of CBR-services received by rural and urban children with cerebral palsy at Mina city was physiotherapy / health services (42.0% and 30.0% respectively) while all types of CBR-services were reported among only 8.0% and 6.0% of both groups respectively.

Figure 2: reveals that 78.0% and 62.0% of rural and urban caregivers respectively were dissatisfied with CBR-services, also there was a statistically significant differences between rural and urban total satisfaction level where p value was 0.010.

Table 3: illustrates that the main barriers for CBR-services among rural caregivers were transport constraint (92.0%), followed by financial constraints (86.0%), lack of accessibility to rehabilitation services (80.0%), untimely referral (78.0%) and lack of communication from rehabilitation team (76.0%).

Additionally, it reveals that the main barriers for CBR-services among urban caregivers were “lack of family/community support” (84.0%), followed by caregivers’ psychosocial stressors (78.0%), and followed by financial constraints (76.0%)

and lack of communication from rehabilitation team (72.0%).

Table 4: illustrates that **t**here was a statistically significant relation between rural caregivers' levels of satisfaction regarding CBR-services and their age, educational level and income where p-value was .005, .006 and .009 respectively. Also, there was a statistically significant relation between urban caregivers' levels of satisfaction regarding CBR-services and their educational level, occupation and income where p-value was .001, .008 and .020 respectively.

Table 5: exemplifies that there was a statistically significant relation between rural caregivers' levels of satisfaction regarding CBR-services and their child's age, child's sex, child's duration of disease and frequency of services follow-up where p-value was .010, .019 and .003 respectively. Also, there was a statistically significant relation between urban caregivers' levels of satisfaction regarding CBR-services and their child's age, child's duration of diseases, number of child's sibling and frequency of services follow-up where p-value was 0.01, 0.03 and 0.05 respectively.

Table 6: reveals that there were six significant predictors of satisfaction regarding CBR-services among rural caregivers included financial constraints, transport constraint, long waiting periods between follow-up sessions, lack of communication from rehabilitation team, lack of accessibility to rehabilitation services and lack of family/community support where P-value <0.05 in each predictor.

Also, it reveals that there were four significant predictors of satisfaction regarding CBR-services among urban caregivers included financial constraints, lack of family/community support, long waiting periods between follow-up sessions and lack of communication from rehabilitation team where P-value <0.001 in each predictor.

Table 1: Socio-demographic characteristics of rural and urban caregivers of children with cerebral palsy in Minia Governorate, 2024:

Socio-demographic variables	Rural (n=50)		Urban (n=50)		Sig. test	p-value
	No.	%	No.	%		
Relationship of caregiver						
Father	12	24.0	19	38.0	X2=.245	.885 NS
Mother	36	72.0	31	62.0		
Grandparent	2	4.0	0	0.0		
Age (years)						
20 ≤ 30	12	24.0	7	14.0	X2= 10.350	.089 NS
31 ≤ 40	29	58.0	25	50.0		
41 ≤ 50	7	14.0	10	20.0		
51 ≤ 60	2	4.0	8	16.0		
Mean ± SD	**34.10 ± 7.810 years**		**36.34 ± 8.927 years**		t= 3.512	.602NS
Sex						
Male	12	24.0	19	38.0	X2= .146	.702NS
Female	38	76.0	31	62.0		
Educational level						
Illiterate	25	50.0	4	8.0	X2=20.166	.003**
Primary	18	36.0	6	12.0		
Secondary	7	14.0	34	68.0		
University	0	0.0	6	12.0		
Occupation						
Employed	7	14.0	27	54.0	X2=10.067	.093 NS
Unemployed	43	86.0	23	46.0		
Income						
Enough	5	10.0	9	18.0	X2=7.178	.078 NS
Not- enough	45	90.0	41	82.0		

NS: Not Statistically Significant.

Table 2: Demographic and medical data of rural and urban children with cerebral palsy in Minia Governorate, 2024:

Variables	Rural (n=50)		Urban (n=50)		Sig. test	p-value
	No.	%	No.	%		
Child's age (years)						
≤ 5 years	31	62.0	26	52.0	X2= 4.233	.895^{NS}
6-9 years	9	18.0	10	20.0		
10-13 years	6	12.0	9	18.0		
14-18 years	4	8.0	5	10.0		
Mean ± SD	**6.10 ± 3.991 years**		**6.54 ± 4.161 years**		t= 2.887	.747^{NS}
Child's sex						
Male	31	62.0	29	58.0	X2= .363	.547^{NS}
Female	19	38.0	21	42.0		
Number of child's sibling						
					X2= 7.904	.095^{NS}
< 3	29	58.0	38	76.0		
3≤5	13	26.0	10	20.0		
> 5	8	16.0	2	4.0		
Duration of disease						
< one year	3	6.0	5	10.0	X2=9.823	.365^{NS}
1-3 years	13	26.0	15	30.0		
4-5	15	30.0	6	12.0		
> 5 years	19	38.0	24	48.0		
Frequency of services follow-up per month						
≤ 2	28	56.0%	26	52.0%	X2=5.812	.759^{NS}
> 2	22	44.0%	24	48.0%		

NS: Not Statistically Significant.

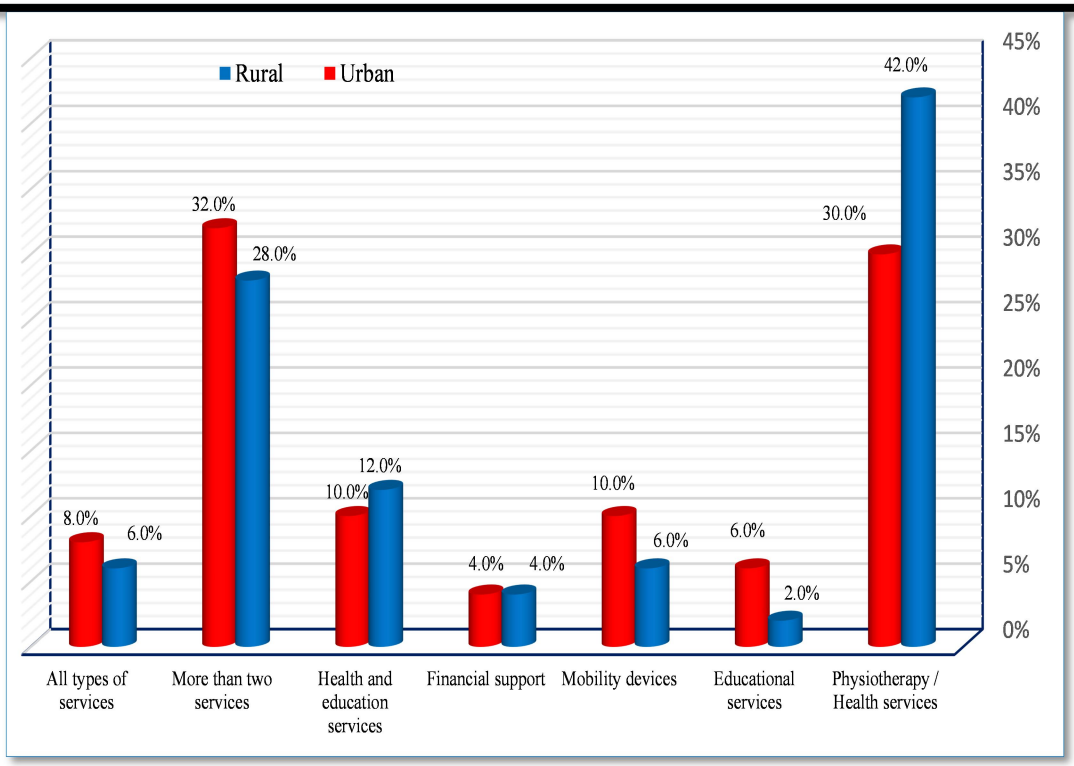

Figure (1): Types of CBR-services received among rural and urban caregivers of children with cerebral palsy in Minia Governorate, 2024.

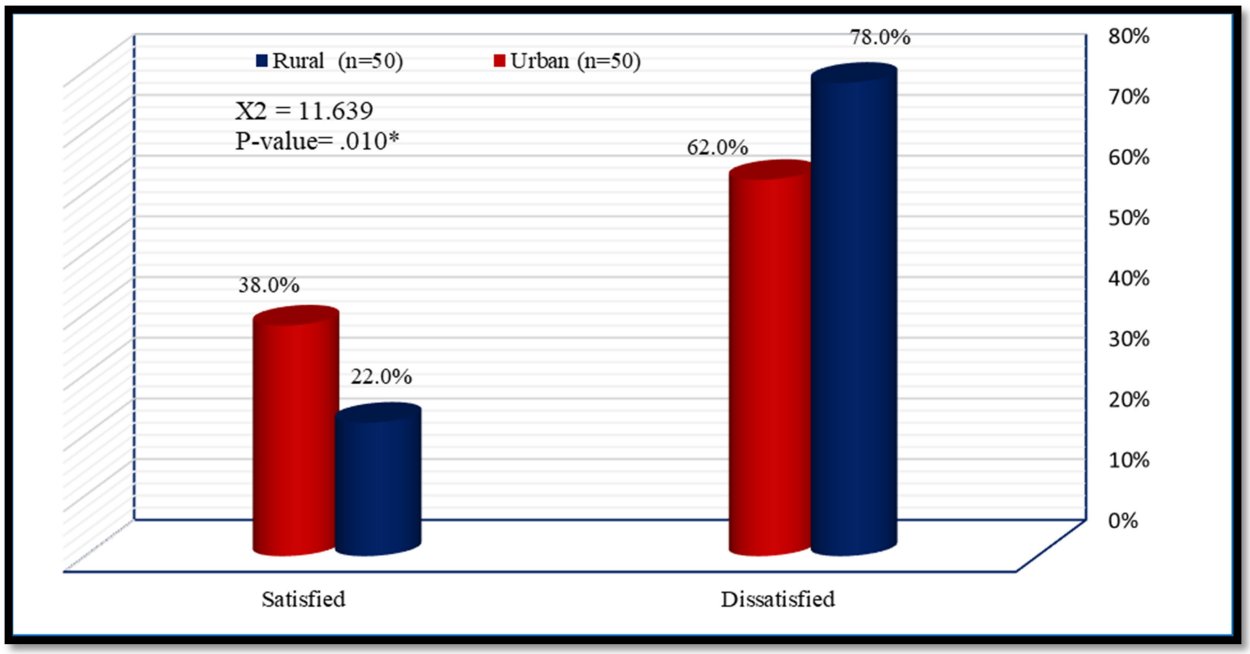

Figure (2): Satisfaction level among Rural and Urban Caregivers of Children with Cerebral Palsy in Minia Governorate, 2024.

Table 3; Barriers of CBR-services among rural and urban caregivers of children with cerebral palsy in Minia Governorate, 2024.

Barriers	Rural (n=50)		Urban (n=50)	
	No.	%	No.	%
1.Poor caregiver and health care professionals' relationship[#]:				
Scarcity of information from healthcare staff	32	64.0	31	62.0
Poor consultation with healthcare team	29	58.0	28	56.0
Lack of communication from rehabilitation team	38	76.0	36	72.0
Untimely referral	39	78.0	29	58.0
2.Facility administrative barriers[#]:				
Lack of accessibility to rehabilitation services	40	80.0	10	20.0
Lack of advice for rehabilitation	33	66.0	12	24.0
Long waiting periods between follow-up sessions	35	70.0	15	30.0
3.Intrinsic inhibitors of caregivers[#]:				
Lack of understanding/awareness about disease	38	76.0	35	70.0
Physical stressors	27	54.0	26	52.0
Psychosocial stressors	36	72.0	39	78.0
4.Extrinsic barriers[#]:				
Lack of family/community support	33	66.0	42	84.0
Financial constraints	43	86.0	38	76.0
Transport constraint	46	92.0	8	16.0
5.Myths and beliefs about cerebral palsy[#]:				
Stigma	29	58.0	31	62.0
Deterioration in the Child's condition	17	34.0	21	42.0
Female children	14	28.0	8	16.0

#: more than one answer was told by each participant.

Table 4: Relationship between rural and urban caregivers' satisfaction regarding CBR-services and their socio-demographic characteristics.

Variables	Rural (n= 50)				Urban (n= 50)			
	Dissatisfied (n = 39)		Satisfied (n= 11)		Dissatisfied (n = 31)		Satisfied (n= 19)	
	N	%	N	%	N	%	N	%
Age (years)								
20 ≤ 30	9	23.1	3	27.3	5	16.1	2	10.5
31 ≤ 40	24	61.5	5	45.5	13	41.9	12	63.2
41 ≤ 50	4	10.3	3	27.3	8	25.8	2	10.5
51 ≤ 60	2	5.1	0	0.0	5	16.1	3	15.8
Fisher's exact test (P – value)	**12.784 (.005)** **				2.701 (.440) NS			
Sex								
Male	10	25.6	2	18.2	10	32.3	9	47.4
Female	29	74.4	9	81.8	21	67.7	10	52.6
Fisher's exact test (P – value)	.262 (.609) NS				1.142 (.285) NS			
Educational level								
Illiterate	22	56.4	3	27.3	2	6.5	2	10.5
Primary	11	28.2	7	63.6	3	9.7	3	15.8
Secondary	6	15.4	1	9.1	23	74.2	11	57.9
University	0	0.0	0	0.0	3	9.7	3	15.8
Fisher's exact test (P – value)	**14.692 (.006) ** **				**14.438 (.001) ** **			
Occupation								
Employed	6	15.4	1	9.1	15	48.4	12	63.2
Unemployed	33	84.6	10	90.9	16	51.6	7	36.8
Fisher's exact test (P – value)	.289 (.865) NS				**11.295 (.008) ***			
Income								
Enough	3	7.7	2	18.2	7	22.6	2	10.5
Not- enough	36	92.3	9	81.8	24	77.4	17	89.5
Fisher's exact test (P – value)	**11.049 (.009) ***				**8.160 (.020) ***			

NS= Not statistically significance * Statistically significant at P – value ≤ .05

** Statistically significant at P – value ≤ .01

Table 5: Relationship between satisfaction regarding CBR-services among rural and urban caregivers of children with cerebral palsy and their child's demographic data.

Variables	Rural (n=50)				Urban (n=50)			
	Dissatisfied (n = 39)		Satisfied (n= 11)		Dissatisfied (n = 31)		Satisfied (n= 19)	
	No.	%	No.	%	No.	%	No.	%
Child′s age (years)								
≤ 5 years	24	61.5	7	63.6	14	45.2	12	63.2
6-9 years	6	15.4	3	27.3	7	22.6	3	15.8
10-13 years	5	12.8	1	9.1	5	16.1	4	21.1
14-18 years	4	10.3	0	0.0	5	16.1	0	0.0
X 2 (P – value)	**11.907(.010) ***				**11.481(.011) ***			
Child′s sex								
Male	24	61.5	7	63.6	16	51.6	13	68.4
Female	15	38.5	4	36.4	15	48.4	6	31.6
X 2 (P – value)	**9.342(.019) ***				1.509(.872) NS			
Duration of disease								
< one year	3	7.7	0.0	0.0	3	9.7	2	10.5
1-3 years	11	28.2	2	18.2	8	25.8	7	36.8
4-5	10	25.6	5	45.5	3	9.7	3	15.8
> 5 years	15	38.5	4	36.4	17	54.8	7	36.8
X 2 (P – value)	**13.310(.003) ****				**11.278(.03) ***			
Number of child's sibling								
< 3	23	59.0	6	54.5	23	74.2	15	78.9
3≤5	11	28.2	2	18.2	6	19.4	4	21.1
> 5	5	12.8	3	27.3	2	6.5	0	0.0
X 2 (P – value)	1.985(.881) NS				**8.318(.050) ***			
Frequency of services follow-up per month								
≤ 2	23	46.0 %	5	10.0	22		4	
> 2	16		6	90.0	9		15	
X 2 (P – value)	**10.753 (.004)****				**10.118(.004) ****			

NS= Not statistically significance * Statistically significant at P – value ≤ .05 ** Statistically significant at P – value ≤ .01

Table 6: Binary logistic regression analysis of predictors/ factors associated with satisfaction regarding CBR-services among rural and urban caregivers of children with cerebral palsy in Minia Governorate, 2024.

Factors#	Rural (n=50)	Urban (n=50)
	Odds ratio (OR with 95% CI limits)	Odds ratio (OR with 95% CI limits)
Lack of communication from rehabilitation team	**1.500 (.066 -3.810)***	.558 (.059- 5.250)
Untimely referral	.449 (.069-2.923)	.128 (.022- .757)
Lack of accessibility to rehabilitation services	**6.285 (1.619-4.915)***	**2.665 (.119- 3.726)****
Lack of advice for rehabilitation	.778 (.070- 8.680)	.794 (.137- 4.595)
Long waiting periods between follow-up sessions	**3.995(1.008-2.932)***	**2.072 (.947- 8.321)****
Lack of understanding/ awareness about disease.	.744 (.119- 4.675)	3.924 (.332- 46.425)
Physical stressors.	.906 (.103- 7.978)	.618 (.049- 7.793)
Psychosocial stressors.	1.667 (.285 - 9.742)	.859 (.019 - 38.280)
Lack of family/community support	**1.547 (.285- 2.542)***	**1.141(.701-2.791)****
Financial constraints.	**7.694(1.117-12.845)****	**2.646 (.443-5.786)****
Transport constraint.	**9.778 (3.413-18.847)****	.578(.237-.199)
Stigma.	1.110 (1.978-3.475)	2.431 (.048-.556)
Female child.	2.035 (.020-. 203)	1.254 (.221-1.249)

#: most frequently answered by participants. CI: Confidence interval *p-value <0.05, **p-value <0.001 indicate statistically significant, and bold= statistically significant factors at a p-value <0.05

Discussion

Cerebral palsy (CP) is among the most common causes of childhood-onset disability, ranging in prevalence across geographical regions and economic conditions (**McIntyre et al. 2022)**. The 2019 Global Burden of Disease study placed CP among health conditions with the highest years of lived disability because of its severity and lifelong duration (**Cieza et al., 2020)**. CBR encompasses a variety of services, including healthcare, therapy, education, and social inclusion. The World Health Organization (WHO) has emphasized the importance of community involvement in delivering these services effectively **(WHO, 2021). Hasan et al., (2021**) emphasized that parents' and caregivers' satisfaction studies are significantly important in providing relevant information on the quality of the service offered and for sustainability of the service.

The current study results demonstrated that the highest percentage of studied caregivers of both rural and urban groups was females, and most of the participants of both rural and urban groups were mothers. Similar results were obtained in previous research carried out by **Alhumaidi et al. (2023)** which assessed

"the quality of life of primary caregivers of children with cerebral palsy from a family perspective", they found that the majority of participants were mothers and the majority of them were married.

The findings of our research demonstrated the distribution of rural and urban caregivers according to their sociodemographic data, it showed that the mean age of caregivers of both groups was 34.10 ± 7.810 and 36.34 ± 8.927 years respectively. The findings in our study were similar to a study conducted in Japan to evaluate "the effects of hippo-therapy on health-related quality of life in caregivers of children with cerebral palsy" where one group receives hippo-therapy and the other group does not, the mean age of caregivers in the two groups was 36.5 ± 6.2 and 35.9 ± 5.9 respectively **(Mutoh, Mutoh, Kurosaki & Taki, 2023)**. **Kassa, Tadese, Eriku, Abich & Fentanew, (2024)** assessed the primary caregivers of children with cerebral palsy in Gondar and Bahir Dar cities were participated in the study. The majority of the primary caregivers were mothers. The mean age of caregivers was 35.4 years.

Our research results demonstrated that half of rural caregivers were illiterate while two thirds of urban caregivers were having secondary education. Concerning to their socioeconomic status, the majority of the participants had not enough income. From researchers' opinion, this finding might be attributed to that Egyptian communities especially rural areas have the culture that doesn't give females the opportunities to complete their education and employment consequently, most of them were illiterates and have no occupation leading to low socioeconomic status. These results are consistent with the Global prevalence of cerebral palsy: a systematic analysis in which **(McIntyre, 2022)** stated that the current birth prevalence of cerebral palsy in low- and middle-income countries (LMICs) is markedly higher than in high-income countries (HICs).

In an Egyptian study at Assiut city it was found that One-third of mothers their ages were ≥ 35 years and two-fifths of them had secondary and intermediate institute education **(Mostafa, Hammad, Sharkawy & Abdalfata, 2024).** In a recent study in the Kingdom of Saudia Arabia to evaluate the quality of life among children with cerebral palsy, it was found that the majority of caregivers have had school education **(Tedla et al., 2024).**

Concerning the demographic data of children with cerebral palsy in both rural and urban groups, our study demonstrated that the mean age of them was 6.10 ± 3.991 and 6.54 ± 4.161 years respectively, and 62.0% and 58.0% respectively of them were males. These results are consistent with the **National Institute of Neurological Disorders and Stroke, (NINDS) (2024)** which reported that most children with cerebral palsy are diagnosed during the first two years of life. But if a child's symptoms are mild, it can be difficult for a doctor to make a reliable diagnosis before the age of 4 or 5.

In an Egyptian study by **Maaty, Mahmoud, Salah & Rashid, (2024)** the majority of the studied children were males. The findings in our study were also similar to a study done at Minia city by **Hussein, El Awady & El Afandy, (2023)**, where half of the children had 3- < 4 years and more than half of them were males. Also, **(Ni, Ding, Wu, Zhang & Liu, 2022)**

found that more than half of the participated children were males. These findings were also in agreement with **Samia et al., (2024)** where one hundred and fourteen child–parent dyads with CP were recruited. The median age of study participants was 8 years, with males being the majority.

Our study results emphasized that the main types of CBR-services received by rural and urban children with cerebral palsy at Mina city was physiotherapy / health services, while all types of CBR-services were reported among vast minority of both groups respectively and more than half of both rural and urban children have less than or equal 4 follow up per month. **Vaidya & Domple, (2024)** clarified that in a developing country like India, availability of services was scarce in the rural areas, and they had to travel to the tertiary care centers for essential medical services. This must be the reason why high quality of life was seen in urban study participants than the ones residing in rural areas.

In a recent study by **Declerck et al. (2024)**, it was found that seventeen percent of participants had never received any rehabilitation services. In urban settings, children with CP may have greater access to healthcare facilities and specialized rehabilitation services.

Our study revealed that more than two thirds of both rural and urban caregivers respectively were dissatisfied with CBR-services, also there was a statistically significant difference between rural and urban total satisfaction level. The results of our research were contrary with **Fentanew et al., 2021,** where more than half of caregivers were satisfied with CBR-service. The possible reasons for the discrepancy might be attributed to variation in socio-cultural characteristics, sample size, study design, amount of service, type, and quality of service.

The current study emphasized that the main barriers for CBR-services among rural caregivers were transport constraints, financial constraints, lack of accessibility to rehabilitation services, untimely referral and lack of communication from rehabilitation team. The same results were obtained by **Adugna, Nabbouh, Shehata, & Ghahari, (2020)**, This scoping review shows that children with disabilities (CwDs) in the selected Sub-Saharan African countries face major barriers including stigma and negative attitudes, poverty and insufficient resources, physical inaccessibility, lack of transportation, lack of privacy, and inadequately trained healthcare professionals to deal with disability. Also, **Tanyanyiwa, 2021** showed the negative experiences that caregivers have had with the therapy program included negative health care worker attitudes, stigma and discrimination, lack of family support, financial challenges, and transport challenges.

Our study illustrated the main barriers for CBR-services detected in our study among urban caregivers were “lack of family/community support”, followed by caregivers’ psychosocial stressors followed by financial constraints and lack of communication from rehabilitation team. These findings were similar to previous study concerning navigating care in urban healthcare systems which identified barriers to managing a child with cerebral palsy, including sociocultural barriers

(values, attitudes and belief systems within society), economic challenges and immediate physical care burdens. Specific barriers included discrimination and isolation, lack of family and societal support, with poor access to health information and formal education **(Mwinbam, Suglo, Agyeman & Kukeba, 2023).**

Parents who are raising children with cerebral palsy encounter challenges, such as financial, social and psychological challenges. The study revealed that, there was lack of support and understanding of the condition from family and friends; this leads to psychological problems such as isolation, worries and stress. Financial constraints were a recurring issue, supported by a previous review **(Smith & Blamires, 2022).**

Statistically significant relation were detected between rural caregivers' levels of satisfaction regarding CBR-services and their age, educational level and income where p-value was .005, .006 and .009 respectively. Also, there was a statistically significant relation between urban caregivers' levels of satisfaction regarding CBR-services and their educational level, occupation and income where p-value was .001, .008 and .020 respectively. The findings in our study were similar to the results of **Vaidya et al. (2024**) which assessed the quality of life (QOL) and its determinants of family caregivers of children suffering from CP, The study found a significant relation of QoL with the age of the caregiver, residence, education, socio-economic class, total number of children, health insurance and accessibility of services.

In the same line **Kassa et al. (2024)** reported that, age, monthly income, educational status, sleeping status, relationship and house composition, number of living children, birth order of child, helpers, and type of CP were all significantly associated with health related quality of life (HRQOL) of primary caregivers of children with CP. Access to educational services for children with CP is generally better in urban areas, where there are more resources and specialized programs available **(Harrison et al., 2019)**.

Statistically significant relation was detected in our study between rural caregivers' levels of satisfaction regarding CBR-services and their child's age, child's sex, child's duration of disease and frequency of services follow-up. Also, there was a statistically significant relation between urban caregivers' levels of satisfaction regarding CBR-services and their child's age, child's duration of diseases, number of child's sibling and frequency of services follow-up.

Fentanew et al., (2021); found that the magnitude of caregivers' satisfaction with community-based rehabilitation services in the study area was more than half. Female gender, older age, being farmer, high monthly income, the high number of services, duration of services started, and frequency of follow-up were factors significantly associated with caregiver's satisfaction. Also. **Mlenzana et al., 2018**, assessed the satisfaction of caregivers regarding rehabilitation services, and found Four key themes emerged, which were financial difficulties, caregiver and therapist relationships, facility

management and caregiver experience with service delivery.

Six significant predictors of satisfaction regarding CBR-services were detected in our study among rural caregivers included financial constraints, transport constraint, long waiting periods between follow-up sessions, lack of communication from rehabilitation team, lack of accessibility to rehabilitation services and lack of family/community support. The findings in our study were similar to a study by **Seroke & Mkhize (2023)**, which found that participants whose children with CP experienced physical, emotional, psychological and social issues, including inaccessible services and buildings and social isolation from family, friends and the community.

Four significant predictors of satisfaction regarding CBR-services were detected in our study among urban caregivers included financial constraints, lack of family/community support, long waiting periods between follow-up sessions and lack of communication from rehabilitation team. These findings are consistent with prior research, which aimed to assess family caregivers' experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana, which also highlighted the importance of family interactions and support for caregivers of children with CP (**Mwinbam et al. 2023).**In an Egyptian study by **Mohamed, Kamal & Gharib, (2022)** which aimed to explore the parents/caregivers of spastic cerebral palsy children satisfaction with the physiotherapy services delivered in the pediatric out-patient clinic of faculty of physical therapy, Cairo university. It was found that the items with high satisfaction are related to the therapist-patient interaction. Similarly, in a systematic review by **Smith & Blamires (2022)**, This review highlighted the need for support networks, collaborate healthcare relationships, clear and accurate information and financial support.

Conclusion

There is a high level of dissatisfaction with community rehabilitation services among caregivers of children with cerebral palsy, both in urban and rural areas. Many reported barriers hinder their access to these services. Significant predictors of satisfaction with CBR services among rural and urban caregivers include financial constraints, transport constraints, long waiting periods between follow-up sessions, lack of communication from the rehabilitation team, lack of accessibility to rehabilitation services, and lack of family/community support.

Recommendations

1. Providing training programs for health care providers especially nursing staff to enhance their communication skills with disabled children and their families.
2. Expanding the number of rehabilitation centers at the governorate level and offering equipped transportation for patients through cooperation with community associations.
3. Decentralizing of rehabilitation services in Egyptian urban areas and urgent Egyptian rural development are needed for establishing rehabilitation services with improving availability, accessibility, and affordability of CBR services within rural areas.

4. Increasing community awareness about available CBR- services through different media channels.
5. Promoting community awareness to reduce the stigma of cerebral palsy through various media channels.
6. Providing an educational program to enhance collaboration among the family and the child's multidisciplinary care team as a united front.
7. Replication of the study with large sample size to further settings.

Limitation of the study

The main constraint in carrying out this study was that there were not accurate and updated disabilities database and very scarce documented prevalence of cerebral palsy in Egypt.

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