


Challenges Facing Family Caregivers of Children With Disabilities During COVID-19 Pandemic in Palestine

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Abstract

Background: COVID-19 has caused great changes in all aspects of life which affected all people especially vulnerable groups such as children with disabilities (CWD) and their families. **Objective:** This study aimed to examine the challenges facing caregivers of CWD during the pandemic, and to explore these challenges from various physical, social, psychological, and financial aspects. **Methods:** A cross-sectional design was conducted in Palestine, a total of 130 caregivers of CWD completed a survey consisting of demographic and clinical characteristics questionnaire and the short version of the burden scale for family caregivers (BSFC-s) between March and May 2021. **Results:** Most of the caregivers were mothers (76.9%), the mean age of the children was (6.09 ± 3.43 years). The majority (88.5%) of the caregivers felt physically exhausted, about (75.4%) had decreased living standards, and (86.2%) indicated that caregiving is taking their strength. A high burden score was recorded, the mean BSFC-s score was 20.17 ± 5.57. Significant differences in BSFC-s scores were recorded based on the type of disability, and child's ability to take care of oneself, $P < .05$. The total scores of the BSFC-s were positively correlated with the physical, social, psychological, and financial challenges facing the caregivers ($P < .001$). **Conclusions:** COVID-19 has caused increased burdens on the caregivers of CWD and a negative impact on the child's mobility accompanying a lack of access to health and rehabilitation services. Vital factors are to be considered in developing strategic health and rehabilitative plans for promoting better care for caregivers and their CWD during lockdown restrictions time.

Keywords

caregivers, COVID-19, burden scale, children with disabilities

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Introduction

COVID-19 has caused heavy losses around the world, according to the World Health Organization,¹ this virus is a causative agent of a disease that affects humans and may lead to mild and different symptoms from one person to another. Symptoms may appear and may not appear, so everyone is advised to take precautions and preventive measures such as physical and social distancing and wearing a mask.² The pandemic led to great changes in all aspects of life which affected all people especially vulnerable groups such as the elderly, patients with chronic diseases, and persons with disabilities and their families.^{3,4}

Disability is a large and complex challenge as it greatly limits the performance of daily life activities and the ability to integrate with individuals. Disability is defined as a

burden facing the person represented in her/his inability to perform one or more of the functions that are essential in daily life.⁵ Persons with disabilities who often face daily challenges such as reduced resources and limited access to healthcare services are at higher risk of encountering further challenges in the pandemic outbreak.⁶

In Palestine, about 20% of persons with disabilities including physical, mental, and psychological are children

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under the age of 18 years.⁷ There are various reasons for which the disability occurs, it may be the result of an injury, congenital, or acquired that happen suddenly or with age. Children with disabilities (CWD) are mainly taking care by their parents and families, where the caregivers are usually unpaid family members who take care of individuals with disabilities to facilitate performing their daily activities.⁸

Children with disabilities need health, education, and rehabilitation services to improve the individual's functional performance at some stage of their lives, and some of them need this throughout their lives, depending on their physical, psychological, or otherwise health status. These services are usually provided by complementary efforts of a rehabilitation team, schools, patients, and caregivers to prevent complications, improve functional performance, and promote the child's independence level as well as possible.⁹

COVID-19 pandemic led to a great change in different aspects of CWD and their caregivers' lives. This influence was at a large extent due to institutions' outages whether educational or treatment.^{3,10} Most of the caregivers faced some difficulties in dealing with their children and managing their needs solely at homes, as a result of the system change including quarantine and preventive measures that been taken to limit the outbreak spread.^{3,10,11} Some studies have indicated that the caregivers of CWD were negatively affected during the pandemic, and they faced many challenges including physical, social, psychological, and financial burdens.^{4,10,12}

Physically, caregivers of children with disabilities may experience negative physical health¹³ due to increasing physical load that causes musculoskeletal disorders, exhaustion, and fatigue.¹⁴ During the pandemic, the level of care for their children has increased which was accompanied by other responsibilities and limited access to health and rehabilitation services.¹⁰ All are contributing factors to physical health consequences and aggregating physical burdens among the caregivers.⁴

Socially, caregivers of children with disabilities may feel isolated and they communicate less with those around them due to a lack of understanding of their needs.¹⁵ Recent studies recorded a declined social support³ and quality of life for caregivers during the pandemic, issues that increase their social burden.¹⁶

The better the mental health of the caregiver, the better the care will be provided.⁸ During the outbreak of COVID-19, a significant increase in depression and anxiety symptoms was recorded,¹⁷ with a high prevalence of depressive symptoms among caregivers of CWD.¹² Families of children with disabilities suffered mental and parenting stress which influenced their state of anxiety, this might be related to that parents need to spend more time and efforts to take care of their children.³

Caring for any child requires substantial resources, the demands for these resources are often increased when having a child with a disability.¹⁸ The pandemic caused that some of the caregivers lost their jobs or reduced their working hours, which led to the accumulation of necessary expenses for their children, thus increasing the financial burden on caregivers. As they no longer can meet the basic needs of their children in terms of education, treatment, and health care.^{10,15}

Caregivers in Palestine face challenges with their children with disabilities, we expect through our study that various social, psychological, financial, and physical challenges may have increased during the pandemic. To our knowledge, this is the first study addressing the challenges facing the caregivers of children with disabilities. Thus, the aim of this study was to shed light on the challenges facing caregivers of children with disabilities in Palestine during the COVID-19 pandemic, and to explore these challenges from various aspects including physical, social, psychological, and financial.

Methods

In this cross-sectional study, a convenient sample was used, all caregivers providing care and were available for their children with disabilities were invited to participate in this study. The inclusion criteria consisted of caregivers of their children with disabilities (less or equal 18 years old), and who agreed to participate in this study. A total of 130 participants of caregivers were recruited from different cities in the West Bank and Jerusalem. The recruitment procedure was arranged through coordination with different pediatric rehabilitation centers in the West Bank and Jerusalem.

The study received ethical approval from the research ethics committee of Al-Quds University, Palestine (Ref No: 186/REC/2021), which complies with the Declaration of Helsinki. All participants (parents of children) provided written informed consent prior to participation in the study. Also, informed consent was received from the involved pediatric rehabilitation centers. The participant had the right to participate or reject or withdraw from the study at any time without restrictions.

Measures

Demographic and Clinical Characteristics Questionnaire

The questionnaire consists of 4 sections: the first section is designed for gathering demographic data for caregivers including age, primary caregiver, education, and employment status. The second section is about demographic

characteristics of children with disabilities in terms of age, sex, diagnosis, and the child's ability to take care of oneself.

The third section is about assessing child mobility during the pandemic, the section consists of 9 questions focusing on mobility challenges in terms of moving indoors and outdoors, and follow-up during the quarantine period. The questions were as following: did the quarantine period during the pandemic has affected the child's mobility? A categorical response with "yes" or "no" was recorded. A change in the child's mobility and motor activity during the quarantine period was described as "for better," "for worse," or "no change." Also, this section included 2 questions about the child's ability to move indoors and outdoors with responses rating "very good" "good" "fair" and "poor." In addition, 2 questions about the child's need for mobility aids to move indoors and outdoors with a categorical response with "yes" or "no" or "sometimes."

For assessing follow-up of the children during the quarantine period, 2 questions were included: has the child completed the physiotherapy and rehabilitation sessions during the quarantine period? Do parents follow a home treatment program with the child? And a categorical response with "yes" or "no" or "sometimes" was recorded.

The fourth section is about the challenges facing the child and the caregiver in terms of communication, 3 questions were included addressing the child's communication with the caregiver, with peers, and about how well the caregiver understands the child's needs, with responses rating "very good," "good," "fair," and "poor."

Short Version of the Burden Scale for Family Caregivers (BSFC-s)

The BSFC-s is a valid and reliable tool that is used to assess existing burdens on the caregivers,^{19,20} including physical, psychological, financial and, social burdens.

The short version of the burden scale for family caregivers (BSFC-s) is a 10-item scale that developed for measuring subjective burden for family caregivers, items 1, 3, 4, and 9 focus on psychological status, items 2, 6, and 7 (physical status), item 5 (financial status), and items 8 and 10 about the social status. Each item is rated on a 4-point Likert scale with the values "strongly disagree" (0), "disagree" (1), "agree" (2), and "strongly agree" (3). The BSFC-s total score ranges from 0 to 30, a low burden (0-4), a moderate burden (5-14), and a high burden (15-30). A higher degree of agreement indicates a higher subjective burden for the caregiver.

Study Procedures

Data were collected by creating a special form for this study on Google Form, in addition, hard copies (paper form

questionnaires) were used in some institutions where using google form was unfeasible.

The demographic and clinical characteristics questionnaire was designed in the Arabic language which is the mother language of the participants. And the BSFC-s was translated into Arabic from the English version by 2 native Arabic language speakers who worked independently. These translators are health professionals and proficient English language speakers. A primary local version of the BSFC-s Arabic was produced via consensus between the translators. Consequently, a back-translation²¹ was conducted by a proficient Arabic and English languages speaker, who is an expert in the field of cross-cultural translation and validation of questionnaires into the Arabic language, and the back translation version was unanimously confirmed by all translators.

To verify whether the questionnaires are understandable and valid for measuring and achieving the objectives of this study; the used questionnaires were validated before conducting the study, a pilot study was used prior to the commencement of data collection with 12 caregivers of children with disabilities during February to March 2021. The pilot study results have indicated that all the questions were clear, and no further modifications were needed. The recruitment procedure was assembled through coordination with different pediatric rehabilitation centers in the West Bank and Jerusalem. Data collection was conducted at the centers and via google form; enrollment took place between March and May 2021.

Statistical Analysis

Descriptive statistics including mean, frequency and percentages were used to characterize the sample of the children with disabilities in terms of age, sex, diagnosis. . . etc. And, to describe the caregivers' characteristics regarding relationship to the child, age, education, and employment status . . . etc. Also, descriptive statistics were used to illustrate results regarding mobility and follow-up during the quarantine period, the nature of challenges facing the caregiver, as well as demonstrating the distributing values of the burden scale for family caregivers (BSFC-s).

The Mann-Whitney *U* test and Kruskal-Wallis test were used to determine differences in BSFC-s total mean scores. Spearman's correlation was used to measure the association between physical, social, financial, and psychological aspects of the caregivers with the total scores of the BSFC-s. A *P*-value of $< .05$ was set to be significant. Data were analyzed using the Statistical Package for the Social Sciences (SPSS), version 25 (SPSS, Chicago, IL, USA).

Results

A total of 130 caregivers completed the survey, about 80% of the responses were received from the West Bank and

Table 1. Demographic Characteristics of the Caregivers (n = 130).

Variable	N (%)
Primary caregiver	
Mother	100 (76.9)
Father	6 (4.6)
Brother/sister	8 (6.2)
All family members	16 (12.3)
Caregiver age (years)	
≤ 25	23 (17.7)
26-35	64 (49.2)
36-45	37 (28.5)
46-55	6 (4.6)
The number of other children the caregiver is caring for	
1	27 (20.8)
2	28 (21.5)
≥ 3	63 (48.5)
None	12 (9.2)
Caregiver education level	
Elementary school	7 (5.4)
High school	51 (39.2)
University	69 (53.1)
No education	3 (2.3)
Employment of the caregiver	
Public sector	20 (15.4)
Private sector	14 (10.7)
Does not have a job	11 (8.5)
Housekeeper	85 (65.4)
Job changes for a caregiver during the Coronavirus pandemic	
Reducing the number of working hours	36 (27.7)
Increasing the number of working hours	18 (13.8)
Work from home	66 (50.8)
Job loss	10 (7.2)

20% from Jerusalem. About the caregivers' characteristics, the child's mother was usually the primary caregiver (76.9%), the father (4.6%), and all family members (18.5%). Most caregivers were between the ages of 26 to 35 years old (49.2%), a percentage of (53.1%) had a university level, and all caregivers can read. A high percentage of the caregivers were housekeepers (65.4%), and (48.5%) had 3 children or more whom they are caring for as well, and 64% of the participants stated that other responsibilities had a large to moderate effect on them and their ability to care for the child (Table 1).

Our results indicated that the mean age of the children with disabilities was (6.09 ± 3.43 years), the age ranged between 9 months and 15 years. A percentage of (61.5%) were males. Most of the children had multiple disabilities (45.4%) or autistic disorder (22.3%). They had various levels of ability to take care of themselves, about (65.4%) of the children had poor to fair ability, and most of them

(69.2%) needed help from someone to do their daily tasks (Table 2).

Results of the child's mobility level in terms of moving indoors and outdoors, and follow-up during the quarantine period indicated that the quarantine period has affected the mobility of (77.7%) of the children, about (35.4%) of the answers were that the change in the child's mobility was for the worse. A percentage of (39.2%) answered that the quarantine period affected the child's motor activity, about (30.0%) of the children needed aids to move indoors, and (36.2%) needed aids to move outdoors. About (47.7%) of the parents indicated that the child's ability to move outdoors during the quarantine period was poor, and 13.8% described it as fair, however, the results indicated that the child's ability to move indoors was very good (34.6%) and good (30.8%).

The results showed that a percentage that comprises less than a quarter of the children (22.3%) completed the physical therapy and rehabilitation sessions during the quarantine period. A percentage of (76.2%) of the respondents rated physical therapy and rehabilitation services as being good and very good. Almost half of the parents in this study (54.6%) reported that they were following a home program with their children.

In terms of the communication aspect, we found that most children (74.7%) could communicate well with their caregivers. In addition, almost half of the children (53.8%) could communicate well with other children. Most caregivers (87.7%) indicated that they had a good understanding of their children's needs.

Results of the burden scale for family caregivers (BSFC-s) indicated a high burden level, the mean BSFC-s score was 20.17 ± 5.57 . The mean BSFC-s increased with an increased number of children ranging from 16.0 ± 8.24 for caregivers with no other children to 20.68 ± 5.69 for caregivers with 3 children or more, similar results were recorded if the caregivers had other responsibilities in addition to the child's care. Also, a high burden score was recorded according to the job status ranging from 19.42 ± 6.20 for caregivers who worked at homes to 23.40 ± 4.77 for the caregivers who lost their jobs. No significant differences in the BSFC-s score were recorded according to the age and sex of children, $P > .05$. However, significant differences were recorded based on the type of disability, and the child's ability to take care of oneself, $P < .05$ (Table 2).

Descriptive values of BSFC-s showed that most of the participants (63.8%) had less life satisfaction. A high percentage of (88.5%) felt physically exhausted and about (69.3%) of the respondents had a wish to run away. This study showed that (75.4%) of the participants had decreased standards of living, and (73.1%) of the participants stated that their health was affected by caregiving. Most of the

Table 2. Values of the BSFC-s According to Categorical Variables (n = 130).

Variable	N (%)	BSFC-s score Mean \pm SD	P-value
Child age (years)			
≤ 1	4 (3.0)	19.50 \pm 12.39	.470
1.1-5	63 (48.5)	19.47 \pm 5.35	
6-10	49 (37.7)	21.14 \pm 5.36	
11-15	14 (10.8)	20.04 \pm 4.87	
Sex			
Male	80 (61.5)	21.0 \pm 4.87	.058
Female	50 (38.5)	18.84 \pm 6.35	
Diagnosis			
Cerebral palsy	23 (17.7)	23.30 \pm 4.40	.002
Down's syndrome	19 (14.6)	17.0 \pm 6.16	
Autism spectrum disorder	29 (22.3)	21.51 \pm 5.04	
Multiple disabilities*	59 (45.4)	19.91 \pm 5.24	
The child's ability to take care of oneself			
Poor	46 (35.4)	22.13 \pm 5.13	.024
Fair	39 (30.0)	19.28 \pm 5.94	
Good	45 (34.6)	18.63 \pm 5.36	
Did the quarantine period has affected the child's mobility?			
No	29 (22.3)	17.24 \pm 5.17	<.001
Yes	101 (77.7)	20.86 \pm 5.65	
How other responsibilities affect the caregiver's ability to care for the child			
Large effect	14 (10.8)	22.42 \pm 5.86	.139
Some effect	69 (53.1)	20.20 \pm 5.18	
Small effect	41 (31.5)	19.92 \pm 5.93	
There is no effect	6 (4.6)	16.16 \pm 5.052	

*Multiple disabilities included: visual, mobility, hearing or cognitive disabilities.

respondents (86.2%) indicated that caregiving is taking their strength. About (68.4%) of the participants replied that they had conflicting demands. A vast percentage (86.9%) reported that they are worried about the future (Table 3).

The total scores of the BSFC-s were positively correlated with the physical status of the caregivers ($r_s = .737$, $P < .001$), social status ($r_s = .710$, $P < .001$), psychological ($r_s = .681$, $P < .001$) and financial ($r_s = .574$, $P < .001$) indicating that the increasing challenges faced by the participants at all levels were strongly associated with the total scores of the BSFC-s.

Discussion

In this study, the challenges faced by the caregiver of children with disabilities during the COVID-19 pandemic in Palestine were highlighted. Our results showed that the financial, psychological, social, and physical challenges faced by the caregiver have increased and thus led to an increase in burdens on him/her. Usually, the child with a disability needs much more help compared to another child of the same age, and the responsibility for caring for the child is mainly taken by mothers.²²⁻²⁴ Our results showed that (76.9%) of mothers are the ones who take care of their

children with disabilities, a close percentage was recorded in a similar study conducted in India,¹² however, a study conducted in Iran showed that about 50% of the caregivers were fathers.²³ On the other hand, the caregivers have other responsibilities as well, about (48.0%) of them have 3 or more children, and the results indicated that the burden on caregivers increases during the pandemic. The mean BSFC-s score for caregivers who have 3 children or more was (20.68 \pm 5.69) which is greater than the mean BSFC-s score for caregivers who do not have children (16.0 \pm 8.24). This might be attributed that mothers and other family caregivers want to balance the care of their child with the other responsibilities, and this may contribute to an increase in the physical and psychosocial burdens on them, results that are consistent with similar studies findings.^{22,23}

Previous studies indicated that the educated caregiver may bear a lesser burden compared to the uneducated caregiver, as education can positively influence the caregivers' self-confidence in dealing with different life situations, and how they behave in response to health problems faced by their child.²³⁻²⁵ Most caregivers (87.7%) in this study indicated that they had a good understanding of their child's needs, this might be referring to that (53.1%) of the caregivers have completed their university education, and

Table 3. Descriptive Results of the Burden Scale for Family Caregivers (BSFC-s) (n = 130).

Variable N (%)	Strongly disagree	Disagree	Agree	Strongly agree
1. My life satisfaction has suffered because of care	8 (6.2)	39 (30.0)	64 (49.2)	19 (14.6)
2. I often feel physically exhausted	4 (3.1)	11 (8.5)	63 (48.5)	52 (40.0)
3. From time to time, I wish I could “run away” from the situation I am in	9 (6.9)	31 (23.8)	43 (33.1)	47 (36.2)
4. Sometimes I do not really feel like “myself” as I did before	3 (2.3)	13 (10.0)	67 (51.5)	47 (36.2)
5. Since I have been a caregiver, my financial situation has decreased	3 (2.3)	29 (22.3)	51 (39.2)	47 (36.2)
6. My health is affected by the care situation	5 (3.8)	30 (23.1)	61 (46.9)	34 (26.2)
7. The care takes a lot of my own strength	3 (2.3)	15 (11.5)	75 (57.7)	37 (28.5)
8. I feel torn between the demands of my environment (such as family) and the demands of the care	3 (2.3)	38 (29.2)	61 (46.9)	28 (21.5)
9. I am worried about my future because of the care I give	5 (3.8)	12 (9.2)	62 (47.7)	51 (39.2)
10. My relationships with other family members, relatives, friends, and acquaintances are suffering because of the care.	13 (10.0)	39 (30.0)	49 (37.7)	29 (22.3)

most children (74.7%) could communicate well with their caregivers.

Availability of working was a remarkable factor affecting caregiver burden. Based on our findings a high burden score was recorded according to the job status ranging from (19.42 ± 6.20) for caregivers who worked at homes to (23.40 ± 4.77) for the caregivers who lost their jobs. This indicates that the financial situation of the caregivers has been negatively affected during the epidemic, which has increased the burden on the caregivers, results that are consistent with other studies.^{10,23,26}

Parents of children with disabilities suffer from high levels of anxiety, stress, and depression due to the increase in responsibilities incurred by them, and thus negatively affected the improvement in the condition of their child.^{3,12} In addition, the greater the responsibilities of the caregivers, the greater the psychological pressure on them.¹⁸ Based on our results, the mean BSFC-s score was (22.42 ± 5.86) of the participants who had other responsibilities, which led to an increase in the burden on them. About (69.3%) had a wish to run away from the situation they are in and (87.7%) of them suffered from a stressful situation.

Our results indicated that (61.5%) of the children with disabilities were males, this might be attributed to that in Palestine the rate of disabilities is higher for male children than for females in all age groups.⁷ Different types of diagnosis were recorded in this study including autistic disorder (22.3%), Down syndrome (14.6%), and cerebral palsy (17.7%). The results showed that the mean BSFC-s score on caregivers of children with cerebral palsy was 23.30 ± 4.40 , which is the highest-burden score on caregivers compared to the scores of other disabilities. Similar studies have indicated that physical workload can be an important cause of musculoskeletal disorders in caregivers of children with cerebral palsy (CP),¹⁴ and reduced functioning was associated with lower health-related quality of life among children with cerebral palsy.²⁷

Results indicated that the quarantine period has affected the mobility of (77.7%) of the children, about (35.4%) of the answers were that the change in the child's mobility was for the worse. This might be related to that the pandemic led to the interruption of physical therapy and rehabilitation sessions for (77.7%) of the children. Results that are also evident in a recent study indicated that the lockdown restrictions have negatively influenced levels of physical activity of children with disabilities, and led to a lack of access to specialist facilities.^{28,29} On the other hand, about (54.6%) of the caregivers in this study have followed up the home treatment program with their children, which led to an increase in the time allocated to caring for the child. Considering the other responsibilities of the caregiver, factors that may contribute to negative physical health consequences among the caregivers.⁴ According to previous studies that the greater the physical work provided, the greater the physical and psychological burdens may occur among the caregivers.^{14,18,24}

Socially, caregivers of children with disabilities may feel isolated and they connect less with those around them due to a lack of understanding of their needs.^{15,30,31} Recent studies recorded a declined social support,³ and quality of life for caregivers during the pandemic, issues that increase their social burden.¹⁶ Similar to our results, about 78% of the participants indicated that their relationships with other family members, relatives, friends, and acquaintances were suffering because of the care. In terms of the communication aspect, the current study showed that (74.7%) of children can communicate well with their caregivers during the COVID-19 pandemic. A study by Bentenuto et.al.³² has indicated that during the pandemic and despite the existing difficulties during the lockdown, most of the parents found that spending more time with their children has contributed to strengthening the parent-child relationship. Results that are consistent with our findings that most caregivers (87.7%) indicated that they had a good understanding of their child's needs.

Study Limitations

A possible limitation of this study is that we have used convenience sampling based on the available caregivers of CWD whom we could reach in the pandemic circumstances. Although our sample is not randomized, still the issue of generalizability in terms of external validity remains available. The convenience sample is often considered as the standard within developmental sciences,³³ because probability samples are cost-expensive and it was difficult and impractical to be used during the COVID-19 outbreak.

Conclusion

Overall, this study has demonstrated that physical, financial, social, and psychological challenges facing family caregivers of children with disabilities have increased during the COVID-19 pandemic. The pandemic caused a negative impact on the child's mobility accompanying a lack of access to health and rehabilitation services. Vital factors are to be considered in developing strategic health and rehabilitative plans for promoting better care for caregivers and their children with disabilities during lockdown restrictions time.

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