



Burdens and Coping Strategies among Caregivers having Children with Disabilities at Special Needs Schools

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ABSTRACT:

Background: Raising a child with a disability has been recognized as a major source of burden and distress to family and their caregivers. **Aim:** This study aimed to assess the burdens and identify the coping strategies among caregivers of children with disabilities. **Study design:** A descriptive study design was utilized in this study. **Setting:** The study was implemented in three governmental mixed special needs schools in El-Fayoum city that were selected randomly. **Sample:** A multistage stratified sampling techniques was used in recruiting children and their caregivers. The study sample consisted of 360 caregivers of children with disabilities. **Tools:** Three tools for data collections consisted of, First tool: A structured interviewed questionnaire, Second tool: Zarit Burden Interview (ZBI) scale and Third tool: COPE Inventory scale. **Results:** The study findings revealed that 65.3% of caregivers had moderate to severe burden level while 21.9% had severe burden levels. About 53.9% had moderately coping strategies, while 30.6% had low coping strategies. **Conclusion:** This study concluded that the majority of caregivers had moderate to severe burdens level, and a minority of them had highly coping strategies. Regarding the total coping strategies, the studied caregivers' religious coping, active coping, and substance use were statistically significant independent positive predictors. **Recommendations:** The current study recommended that providing support and educational programs for caregivers directly contributes to the needs of caregivers and leads to improving the care provided to children with disabilities, minimizing their parents' burden levels as well as improving their coping responses.

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Introduction

Families with a child who has special needs experience life differently than other families. Caregivers appear to carry the larger burden of care and may feel a need to be with their child all the times and experience stress related to coping with the heavy load of caregiving. Disability is described as any restriction or lack of ability to perform an activity in a manner or within a range considered normal for human beings. Furthermore, a disability is a physical or mental impairment that substantially limits one or more major life activities, such as caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, learning, reading, concentrating, thinking, communicating, and working (Padilha et al., 2017)

There are a large and growing number of persons with physical, mental, or sensory disabilities in the world today. Coping involves psychological resources and coping strategies that help to eliminate, modify, or manage a stressful event or crisis situation. Although most children typically generate periods of tension for mothers and fathers alike, the stress of parenting a child

with disability may present unique challenges for family functioning. Children's disabilities and distresses may burdens their family members, especially their parents, who are their long term caregivers (Keller & Honig, 2014).

Children with disabilities may affect their parents' quality of life (QOL), also parents might need to spend most of their time taking care of their disabled child, especially if the child has severe disabilities and the parent are then unable to engage in other activities, curtailing their social life and negatively affecting their QOL. Both fathers and mothers of children with disability reported significantly greater amounts of parental stress than did parents of school-age children without disability (Dyson, 2017). Families who have children with educational disability typically experience increased burdens, especially in child rearing responsibilities (Hung, Wu, & Yeh, 2014).

More than one billion of people in the world live with some forms of disability, which nearly 200 million experience considerable difficulties in functioning.

Across the world, children with special needs have poorer health outcomes, lower education achievements, less participation in family life than children without special needs. This is partly because children with special needs experience barriers in accessing services than many of us have long taken for granted, including health, education, employment and transport as well as information. These difficulties are exacerbated in less advantaged communities (**Gomez & Gomez, 2013**).

To achieve the long-lasting, vastly better development prospects that lie at the heart of the 2015 Millennium Development Goals and beyond, we must empower people to living with disability and remove the barriers which prevent them from participating in their communities; getting a quality education, finding decent work, and having their voices heard. Although having a child who is born with a disability is stressful for all involved, little research exists regarding the culture and experience of mothers and fathers who have a child with disability (**Ricci & Hodapp, 2013**).

Children with disabilities create special challenges for parents, so we have to study the burdens and coping strategies among caregivers of children with disabilities at special need schools, the researchers involved all caregivers to decrease the psychological burden on mothers and fathers having less sharing and fewer responsibilities about children care. Additionally, investigating the role of stress in the life satisfaction of caregivers with disabled children is essential because of the increasing importance of engaged fathers within families and the unique experiences of raising a child with a disability.

Significance of the study

Children with disabilities (CWD) have always been a crucial part of society; they're estimated to be 20% of population. In Egypt, there are around 9.4 million CWD. Disability is a complex phenomenon of interactions between the body of an individual and also the society in which the individual lives. Unfortunately, disabilities are non-discriminatory; hence CWD tends to be the most important minority group. According to the World Health Organization (WHO) disability is an umbrella term, covering impairments, activity limitations, and participation restrictions (**Farag, 2013**). In the USA, it's reported that 17% of children under the age of 18 have a developmental disability (**Centers for Disease Control and Prevention (CDC), 2009**).

Aim of the study: This study aimed to assess the burdens and identify the coping strategies among caregivers of children with disabilities at special needs schools in El-Fayoum Governorate.

Research questions:

1. What are the burdens experienced by caregivers of children with special needs?
2. What are the coping strategies used by caregivers of children with special needs?
3. Is there a positive association between the caregivers' burden and their coping strategies?

MATERIALS AND METHODS

Research design

A descriptive study was utilized with this study.

I-Materials

1. Setting

The study was carried out at three governmental mixed special needs schools in El-Fayoum city, Egypt. These schools were selected randomly namely as: El-Amal for Deaf and Dumb Special Needs School, Al-Nour School for the Blind and Intellectual Education School. The total children in the three schools were 764 children, distributed as follows: El-Amal for Deaf and Dumb special needs School 230, Al-Nour School for the Blind 126, and Intellectual Education School 408 students from age 6-18 years.

2. Subjects

Sample size: The sample size is calculated to measure a caregivers' coping rate of fifty, with 5% absolute precision, and at 95% confidence level. Applying a design effect 1.25 for multistage stratified sampling and after accounting of a 10% non-response. The sample size estimated for single proportion using the Open-Epi software package, the desired sample size was 360 caregivers of children with special needs.

Sample technique:

A multistage stratified sampling technique will be used in recruiting students and their parents in the study sample. However, due to the small numbers of students in the impaired vision school, a fixed rather than proportionate sampling will be used. Strata: Stages: First stage (schools): One school will be selected from each category. The second stage (phases): The schools will be stratified by primary, preparatory, and secondary. Third stage (Classrooms): 2 classrooms will be selected from each selected school phase: primary: grades 1 and 6; preparatory: grade 1 and 3, and secondary: grades 1 and 3. The total number of classrooms will be 6 in each school. Fourth stage: students: 20 students will be randomly selected from each of the 18 selected classrooms will be included in the study sample.

Tools for data collection

Three tools were employed based on the related literature:

First tool: The interviewed structured questionnaire was developed by the researchers consisted of two parts: **Part I:** Socio-demographic data of caregivers

includes; age, level of education and work, marital status, family income, and also the number of family members and residence; **Part II:** child data as, name, age (years), gender, birth order, number of child sibling and order of the child among his or her brothers, school year, the health status of the child as type, number (multiple or more than one disability) and cause of disability, duration of disability (years), receiving treatment, child's activities of daily life and also the degree of dependency on others and assessed as altogether, partial and not at all.

Second tool: Zarit Burden Interview (ZBI) scale (1980), which has been translated and adapted to Arabic. This tool used to measure physical, social, psychological, and financial burdens for caregivers of children with disabilities. It's composed of twenty-two items and scores starting from 0 to 88. Higher scores indicate high burden. Caregivers' burdens were divided into four grades, namely severe burden (61-88), moderate to severe burden (41-60), mild to moderate burden (21-40), and little or no burden (less than 21). And assessed by butting true mark in an exceedingly suitable place to decide on whether not at all, rarely, sometimes, much or always.

Third tool: COPE Inventory: The COPE Inventory scale was developed by (Carver et al., 2013) to assess a broad range of coping responses or strategies, was translated into Arabic by a researcher. The inventory consists of 60 items divided into 15 subscales, (1) positive reinterpretation and growth, (2) mental disengagement, (3) focus on and venting of emotions, (4) use of instrumental social support, (5) active coping, (6) denial, (7) religious coping, (8) humor, (9) behavioral disengagement, (10) restraint, (11) use of emotional social support, (12) substance use, (13) acceptance, (14) suppression of competing activities, and (15) planning.

The items are rated on a 4-point scale with values identified as 1, "I usually don't do this at all;" 2, "I usually do this a little bit;" 3, "I usually do this a medium amount;" and 4, "I usually do this a lot." Each sub-scale consists of 4 items. The values of every sub-scale are computed by summing all 4 items listed with no reversals of coding. In other words, the possible values for each sub-scale range from 4 to 16.

Validity and reliability of scale:

According to Carver (2013), the internal consistency of the COPE scales was generally high (> 0.62) with

the exception of 1 subscale, mental disengagement. The test-retest reliability reported by Carver (2013) suggests that self-reports of coping styles are relatively stable.

II. Methods:

1. Ethical considerations: An official permission was obtained by submission of an official letter issued from the Dean of the Faculty of Nursing, El-Fayoum University to the Director of El-Amal for Deaf and Dumb Special Needs School, Al-Nour School for the Blind and Intellectual Education School at El-Fayoum City. Oral consent included an easy explanation of the aim and nature of the study. The researchers emphasized that participation during this study was entirely voluntary; that anonymity and confidentiality were ensured by encoding the data and that they were informed of their rights to opt-out or to withdraw at any time.

2. A pilot study was conducted on 10% (36) of caregivers to verify the clarity of the developed tool and to estimate the time required for filling the sheet. According to the results obtained from the pilot study, simple modifications were done. Those that shared within the pilot study were excluded from the study sample.

3. Each caregiver was individually interviewed to assess physical, social, psychological, and financial burdens and their coping strategies for children's disabilities. The time consumed to answer each questionnaire sheet ranged from 20 to 30 minutes.

4. The fieldwork was performed over a period of three months. The data was collected from September 2019 to November 2019. The data were collected during actual visits to the previously mentioned settings two days per week (Sunday - Thursday).

Statistical analysis

Data entry and statistical analysis were done using SPSS 20.0 statistical software package, data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables; means and standard deviations for qualitative variables. In order to identify the independent predictors of the total coping strategies, multiple linear regression analysis was used and analysis of variance for the full regression model was done. Statistical significance was considered at p -value < 0.05 and 0.01 levels.

Results

Table 1: Distributions of studied caregivers according to their socio-demographic characteristics (n=360).

Demographic variables	Frequency	Percent
Mothers' age		
<20 years	38	10.6
20- < 40 years	158	43.8
40 and more	164	45.6
Mean \pmSD	39.95\pm7.64	
Mothers' education		
Illiterate	118	32.8
Read and write	86	23.9
Primary/Preparatory	108	30.0
Secondary	44	12.2
University	4	1.1
Occupation		
Working	147	40.8
Housewife	213	59.2
Fathers' age		
28 - < 39	59	16.4
39 - < 50	170	47.2
\geq 50	131	36.4
Mean \pmSD	41.89\pm7.96	
Fathers' education		
Illiterate	66	18.3
Read and write	141	39.2
Primary/Preparatory	143	39.7
Secondary	1	.3
University	9	2.5
Occupation		
Governmental work	161	44.7
Free work	199	55.3
Marital status		
Married	198	55.0
Divorced	86	23.9
Widow	76	21.1
Residence		
Rural	208	57.8
Urban	152	42.2
Numbers of family members		
< 5 member	201	55.8
5-7 member	62	17.2
>7 members	97	26.9
Family monthly income		
Adequate	168	46.7
Inadequate	192	53.3

Table 1 shows the socio-demographic characteristics of the studied caregivers, it had been clear that, 45.6 % of mothers were aged 40 and more with a mean age of 39.95 \pm 7.64, and slightly less than half of the fathers (47.2 %) were aged 39 - < 50 years with a mean age 41.89 \pm 7.9. Regarding educational level, about one third (32.8%) of mothers were illiterate, while around two-fifth (39.7%) of fathers had primary and preparatory education. As for occupation, more

than half (59.2%) of the mothers were housewives and also, more than half (55.3% 53.3%) of fathers had free work and were inadequate income. 55%, 55.8% & 57.8% of studied caregivers were married, had < 5 numbers of family members, and from a rural area, respectively.

Figure 1: Distributions of studied caregivers according to caring of their children with disabilities (n=360)

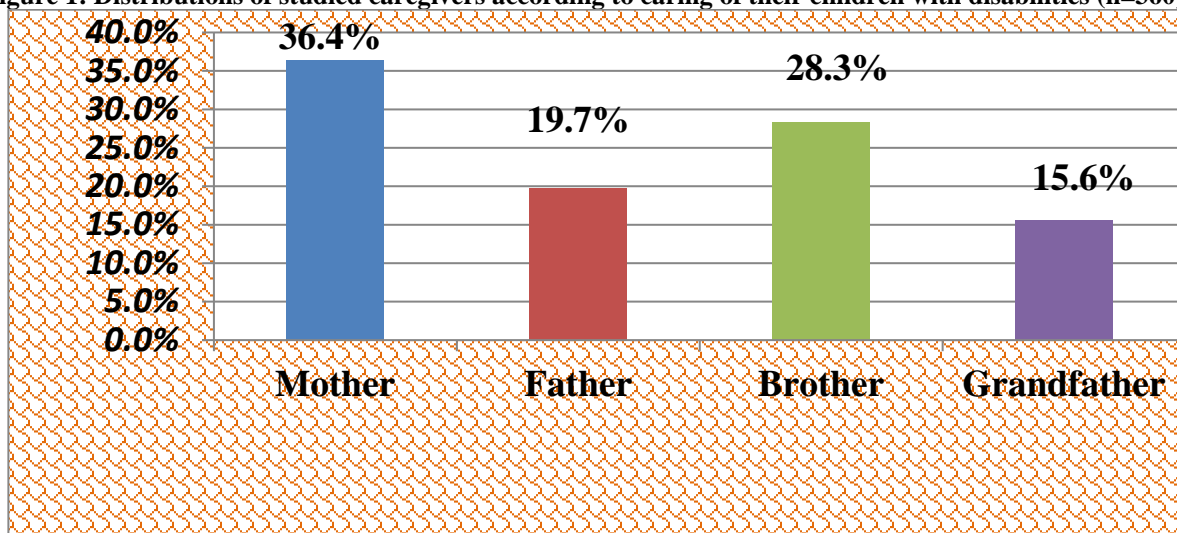


Fig. 1: Illustrated that, more than one third (36.4%) of the studied caregivers were mothers who represent the first caretaker of their children with disabilities, while more than one fourth (28.3%) of fathers represented the second person who caring of their children with disabilities. Only (19.7% & 15.6%) were represented brothers and grandmothers or grandfathers.

Table 2: Distributions of children regarding their socio-demographic characteristics and history of disability (n=360).

Items	No.	%
Child' age		
6-12 years	166	46.1
12- 18 years	194	53.9
Gender		
Male	149	41.4
Female	211	58.6
Type of disability		
Physical	130	36.1
Cognitive	56	15.6
Psychological or emotional	34	9.4
Mixture	98	27.2
Disability related disease	42	11.7
Cause of disability		
Congenital	190	52.8
Acquired	170	47.2
Onset of disability		
1-<5 years	139	38.6
5-10	126	35.0
≥10	95	26.4
Received treatment for disability		
Yes	185	51.4
No	175	48.6
Previous history of congenital disability		
Yes	204	56.7
No	156	43.3

Table 2 showed that, more than half (53.9%) of disabled children were in the age group 12-18 years. And (58.6%) were female. As regards the type of disability, more than one third (36.1%) had physical and more than one fifth (27.2%) had a mixture, Moreover as 15.6% of them, had a cognitive disability. Only (11.7% & 9.4%) had psychological / emotional and disability- related disease. As for causes of disability slightly more than half (52.8%) of them were congenital. Regarding the onset of disability more than one third (38.6%) were 1-<5 years and about half (51.4%) had received treatment. also, more than half (56.7%) had a previous history of congenital disability.

Table 3: Dependency in activities of daily life (ADLs) among children with disabilities as reported by caregivers (n=360).

Daily living activities	Highly dependent		Partially dependent		Slightly dependent	
	No.	%	No.	%	No.	%
Nutrition	160	44.4	141	39.2	59	16.4
Clothing	46	12.8	186	51.7	128	35.6
Bathing	24	6.7	186	51.7	150	41.7
Elimination	26	7.2	97	26.9	237	65.8

Table 3 revealed that the dependency in activities of daily life (ADLs) for disabilities children it found around two thirds (65.8%) of children with disabilities have slightly degree of dependency in elimination and about half (51.7%) have partially dependent concerning clothing and bathing while more than two-fifths (44.4%) have high dependency level in nutrition.

Figure 2: Distributions of studied caregivers according to their total burden level scores for children with disabilities (n=360).

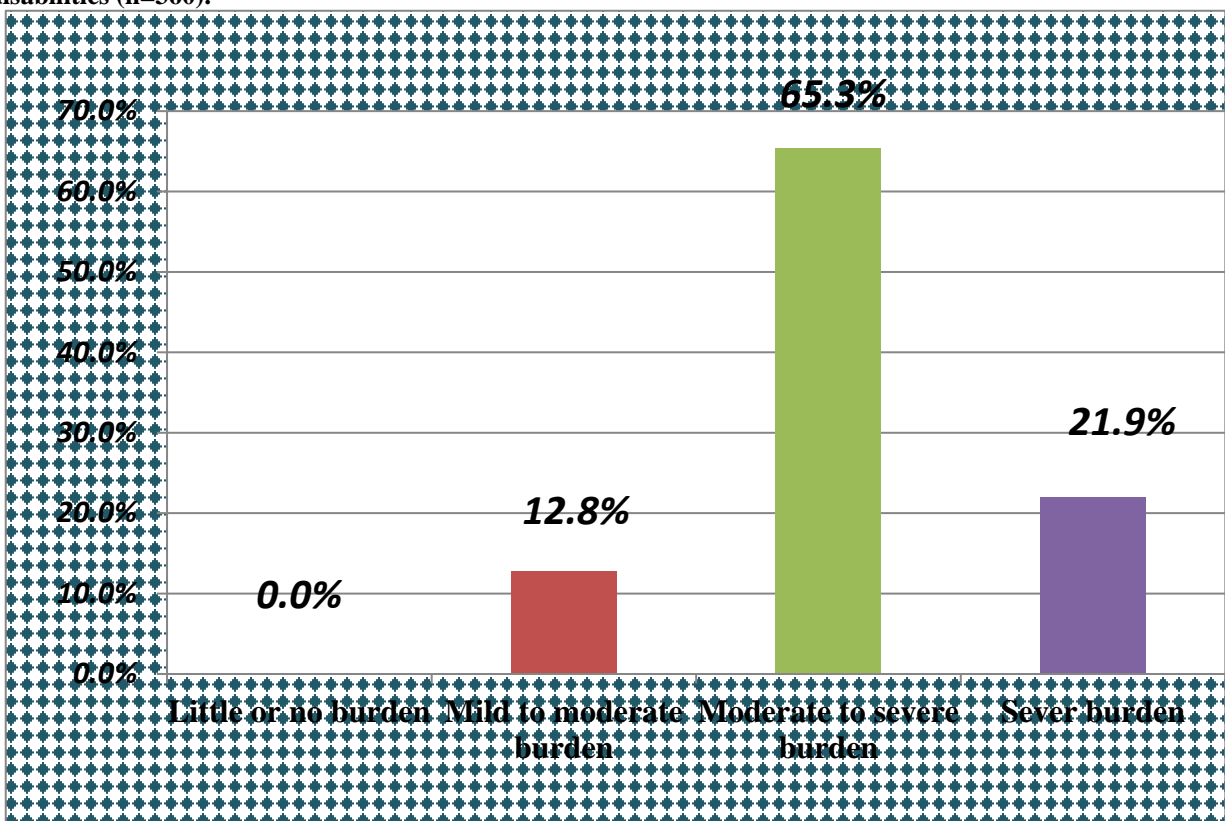


Figure 2 displayed that, the total burden levels scores of studied caregivers regarding children with disabilities. It was found that about two-thirds of caregivers (65.3%) had moderate to severe burden levels while one fifth (21.9%) of them had severe burden level. Only, 12.8% had mild to moderate burden levels.

Table 4: Descriptive statistics of fifty sub-scales of coping strategies among studied caregivers

Fifty Subscales of Coping Strategies	Minimum	Maximum	Mean \pm SD	% of mean score
1. Positive reinterpretation and growth.	4.00	16.00	11.4722 \pm 2.69825	71.70125
2. Mental disengagement	4.00	18.00	10.9833 \pm 2.69938	68.64563
3. Focus on and venting of emotions	4.00	16.00	11.3861 \pm 2.68356	71.16313
4. Use of instrumental social support.	5.00	16.00	11.2556 \pm 2.50153	70.3475
5. Active coping.	4.00	16.00	10.3583 \pm 3.17756	64.73938
6. Denial.	4.00	16.00	10.1361 \pm 3.13144	63.35063
7. Religious coping.	5.00	16.00	11.0611 \pm 2.97841	69.13188
8. Humor.	4.00	16.00	9.8000 \pm 3.58098	61.25
9. Behavioral disengagement.	4.00	16.00	8.8139 \pm 3.57745	55.08688
10. Restraint	4.00	16.00	8.8722 \pm 3.23892	55.45125
11. Use of emotional social support.	4.00	16.00	9.4639 \pm 2.74015	59.14938
12. Substance use.	4.00	16.00	9.3056 \pm 2.44744	58.16
13. Acceptance.	4.00	16.00	10.2833 \pm 3.18033	64.27063
14. Suppression of competing activities.	4.00	16.00	10.4583 \pm 3.02974	65.36438
15. Planning.	5.00	16.00	10.2417 \pm 2.80964	64.01063
Total coping score	90.00	216.00	153.8917 \pm 24.36622	64.12154

It is observed from (Table 4) that, the most sub-scales of coping strategies utilized by caregivers were positive reinterpretation and growth, followed by a focus on and venting emotions, use of instrumental social support as well as religious coping.

Figure 3 Distributions of the studied caregivers according to their total coping strategies score for children with disabilities (n=360).

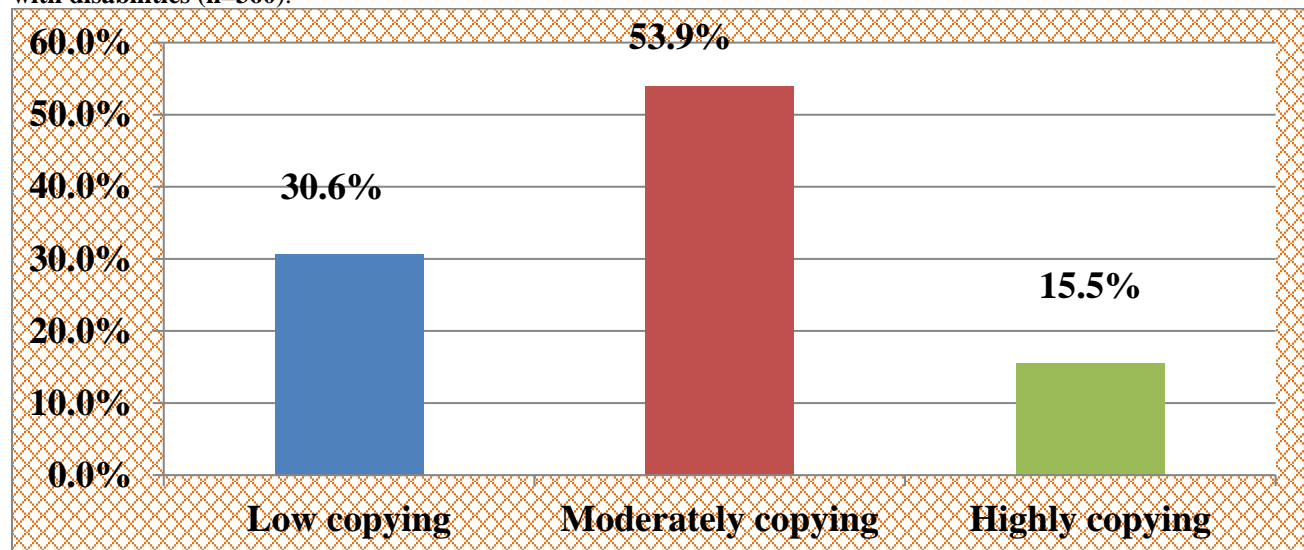


Figure 3: Clarifies the total coping strategies score of the studied caregiver for children with disabilities. It was found that more than half of caregivers (53.9%) had moderately coping strategies while, nearly one third (30.6%) had low coping strategies, and only (15.5%) of them had highly coping scores.

Table 5. Best fitting multiple linear regressions model for the total coping strategies.

Coping Inventory	Unstandardized Coefficients		Standardized Coefficients			95% Confidence Interval for B	
	B	Std. Error	Beta	T	Sig.	Lower Bound	Upper Bound
Constant	31.317	4.310			.000	22.840	39.794
1. Positive reinterpretation and growth.	.212	.393	.050	.538	.591	-.562	.985
2. Mental disengagement	.175	.374	.042	.469	.639	-.560	.910
3. Focus on and venting of emotions	.180	.392	.043	.459	.647	-.591	.951
4. Use of instrumental social support.	.191	.367	.042	.520	.603	-.532	.914
5. Active coping.	.715	.345	.201	2.072	.039	.036	1.394
6. Denial.	-.066	.351	-.018	-.188	.851	-.757	.625
7. Religious coping.	1.298	.420	.342	3.091	.002	.472	2.124
8. Humor.	-.047	.430	-.015	-.110	.913	-.893	.798
9. Behavioral disengagement.	.387	.348	.111	1.115	.266	-.296	1.071
10. Restraint	.608	.387	.147	1.570	.117	-.154	1.369
11. Use of emotional social support.	.665	.367	.144	1.812	.071	-.057	1.386
12. Substance use.	1.146	.307	.322	3.731	.000	.542	1.750
13. Acceptance.	.384	.358	.103	1.074	.283	-.319	1.088
14. Suppression of competing activities.	.616	.351	.153	1.755	.080	-.074	1.306
15. Planning.	-.293	.226	-.631	-1.299	.195	-.737	.151

R-square = .153**Model ANOVA: F = 4.152,****P<0.000***

Table 5: Indicates that the caregiver's active coping, religious' coping, and substance use was statistically significant independent positive predictors. Conversely, positive reinterpretation and growth, mental disengagement, focus on and venting of emotions, use of instrumental social support, denial, humor, behavioral disengagement, restraint, use of emotional social support, acceptance, suppression of competing activities and planning were negative predictors. The model explains 153 % of the variation within the total coping strategies.

DISCUSSION

Due to the gap observed in the studies about the burdens that caregivers have during caring of their special needs children, also parents, especially mothers, are considered to have the first responsibility to caring of their children, so this study emphasizes on the requirement for an improved understanding the profile of special needs children, their caregivers' burdens and the way they deal with the burdens. The child with special needs and his or her family are both affected by the child's condition and way of living. Each member of the family experiences effects associated with the child's special needs. Family members' experiences and their responses to the child's illness influence each other directly (Kyle, 2008). Mothers who have children with special needs report higher amounts of stress compared to mothers who do not have children with special needs. A mother's ability to adapt to stressful situations depends upon numbers of variables, including an individual's psychological strengths, individual and family resources, and the form of coping strategies utilized (Ahmann, 2016).

The present study was aimed to assess burdens among caregivers of children with disabilities and identify the coping strategies at special needs schools in Fayoum governorate. According to the socio-demographic characteristics of caregivers, the current study findings revealed that most of the studied mothers and fathers were ranked within the category 40 years and more with mean age 39.95 ± 7.64 and 41.89 ± 7.96 . This finding was in agreement with Moawad (2012), who conducted a study to assess coping strategies of mothers having children with special needs and found that one third (31.5%) of studied mothers their age more than 40 years. On the contrary Khalil (2010), who studied rehabilitation programs for children with Cerebral Palsy (CP) and their caregivers, revealed that there is an equal distribution of the sample within the three age categories between less than 30 and more than 40 years. Age is important in parenting and cares of a child especially; special needs children and understands new experiences with parenting.

According to caregivers' level of education, the current study findings revealed that, about one-third of mothers were illiterate, while around two-fifth of fathers had primary and preparatory education. This finding was in agreement with Ickes et al., 2015 & Liu et al., (2017). The low schooling of caregivers influences the child's general health, low schooling is observed in primary caregivers of children and young adults (PCCYAs) with disabilities because many of those caregivers abandon their studies to dedicate themselves to the role of caregivers, which results in low levels of knowledge and self-care toward their health Gogoi et al., (2016). Low schooling of caregivers impairs them to enter the

labor market; thus, they find your-self dedicating themselves to tasks and caring for the dependent child.

As regards caregivers' occupation this study finding showed that, more than half of mothers were housewives. This finding was in agreement with Farajzadeh et al., (2018) who found that almost all of the studied mothers were unemployed and housewives. While in contrast with Abbasi et al., (2016) who study the QoL of parents of disabled individuals and showed that, just one of the spouses was employed. In my point of view this fact reflects the employment situation of caregivers in this study, suggesting a situation of under employment in which income is less than the Brazilian minimum wage (US\$ 262.66), demonstrating the social condition to which these families are subjected.

The present study showed that, most of the studied caregivers were having inadequate income and were from a rural area. These findings were in agreement with Moawad, (2012) who reported that monthly income (47.3%) weren't sufficient among the studied sample. In support to this, Luckmann (2009) highlighted that when the mother is better educated, this implies a much better job and better income, more health awareness, and therefore the ability to assist their children throughout their child's life.

As regarding marital status, the result of this study revealed that the majority of the caregivers were married; this finding was in accordance with Khayatzaeh et al., (2013) showed that although most mothers of children with CP were married, marital dissatisfaction was significantly higher than mothers of children without disabilities. Also, the result is similar to that found in other studies, conducted by Dardas & Ahmad, (2014) and Chan et al., (2013) representing a potential for strengthening and support when care is divided among spouses.

According to the characteristics of children with disabilities, the present study findings revealed that, most of them were 12-18 years old and were females. This finding is congruent with Darling et.al, (2012) who reported that children with disabilities ranged in age from 5 to 12 years, and 60% were females. Regarding types of disability, the present study findings demonstrated that more than one third had physical and less than one third had a mixture. This finding was matching with Gothwal et al. (2015) who found that, a little over half of the children had either visual or hearing disability.

In regard to causes of disability this study finding showed that, slightly more than half of the children with disabilities were congenital. In support of this Hegazy and Mekhemier, (2016) who conducted a study about the effect of self-learning package on mothers of children with cerebral palsy found that, the most commonly reported causes of cerebral palsy were

those associated with child labor and pregnancy. Regarding the onset of disability, the majority of them were 1-<5 years and had received treatment. This study was in agreement with **Gothwal et al. (2015)** who found that a mean of time elapsed since the diagnosis of a child's disability 7.5 ± 4.0 (years). While in contrast with **Khalil, (2010)** who found that, the onset age for many children was 2 years.

Regarding the caretaker of studied caregiver for children with disabilities, the present study finding revealed that (**Figure 1**), over one-third (36.4%) of them were mothers who represent the first caretaker who caring for their children with disabilities. The results of this study confirm this reality, because the majority of caregivers within the studied sample were mothers who were the most caregivers for caring of their disabled children while, the second person who providing take care of children with disabilities was fathers. This finding is congruent with **Abbasi et al., (2016)** who reported that the most caregivers were mothers, and most studies exclusively focused on the mothers. In the researchers' opinion, the concentration on mothers on the care of their special needs children is due to the environment and society in which we live is taken into account that the care of children is the main responsibility of mothers.

As regards to dependency in activities of daily life (ADLs), the present study results illustrated that, most children have a small degree of dependency in elimination, and about half have partially dependent in relation to clothing and bathing while more than two-fifths have high dependency level in nutrition. Similar improvements in the independence of disabled children in ADLs were reported by **Stevenson and Megurk, (2013)** and **Peter and Barney, (2016)** after training programs are implemented.

Concerning the total burden levels scores of studied caregivers regarding disabled children, it was found that that the majority of the caregivers' had moderate to severe burden level this is supported by the study done by **Al-Rawashdeh et al., (2016)** about the quality of life and burden of caregivers of children and adolescents with disabilities who found that the prevalence of burden was moderate. Negative impact on QoL was observed with a rise in the level of burden of primary caregivers of children/ young adults with disabilities compared to those without disabilities. In support to this **Marrón et al., (2013)** study the burden of 150 caregivers of children with chronic conditions was evaluated and it was found that mothers of children with physical disabilities were more likely to have a higher burden than those of children without disabilities. Also **Javalkar et al., (2017)** and **Ferreira et al., (2015)** found that, the low percentage of caregivers with severe burden is anticipated since they

undergo a process of psychosocial adaptation over the years and have a less negative perception of matters.

It is observed that, the most subscales of coping strategies used by caregivers was positive reinterpretation and growth, followed by focuses on and venting emotions, uses of instrumental social support as well as religious coping. In researchers opinion this may be due to that in the Eastern Society we have the desire to venting emotions and love speaking with others, and believing on religion and love social relations.

It is observed that, the foremost subscales of coping strategies employed by caregivers were positive reinterpretation and growth, followed by focuses on and venting emotions, uses of instrumental social support moreover as religious coping. From the researchers opinion this may be due to that in the Eastern Society we have the desire to venting emotions and love speaking with others and love social relations, and believing in a religion that helps in overcoming burdens.

Regarding the total coping strategies, the present study indicates that, the studied caregivers' religious coping, active coping, and substance uses were statistically significant independent positive predictors. Incongruent to this, the majority of PCCYAs were religious, as observed in several studies, not only in Brazil, but also in other countries. The study was done by **Chan et al., (2013)**, taking into consideration that fundamental effect of religion is to modify the individual's view of the world, using it as a driving force for better coping and overcoming daily difficulties, minimizing the burden, anguish, and stress of the caring process. **Masuchi and Rocha, (2012)** found in the study pointing to the importance of considering faith, spirituality, and religiosity to offer intending to matters faced.

Conclusion: Depend upon the study findings, we can conclude that, the majority of caregivers had moderate to severe burdens level. Also the minority of them had highly coping strategies. While, the total coping strategies, the studied caregivers' religious coping, active coping, and substance use were statistically significant independent positive predictors.

Recommendations: In light of the current study findings the main recommendations are often stated as follows:

1. The necessity for continuous education and parental training programs for caregivers and families about special needs children to provide them with the needed knowledge, practices & physiotherapy.

2. Provide support programs for people directly contribute to the requirements of caregivers result in improving the care provided to children with disabilities, minimizing their burden levels likewise as improving their coping response.

3. Develop rehabilitation programs by an out-patient clinic at all hospitals, and units, for caregivers and children, through a simple booklet (related to disease, treatment, diet, practices related to rehabilitation) with updated knowledge and instructions about special needs.

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