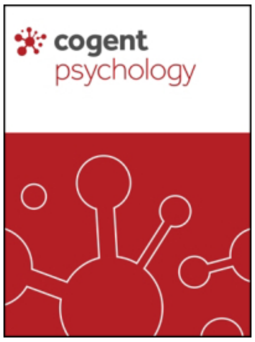

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ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/oaps20

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To cite this article: Dalia Bedewy | (2021) Examining and measuring sources of stress in a sample of caregivers of children with special needs in Egypt: The Perception of Caregivers Stress Scale, Cogent Psychology, 8:1, 1911094, DOI: 10.1080/23311908.2021.1911094

To link to this article: https://doi.org/10.1080/23311908.2021.1911094

Bedewy, *Cogent Psychology* (2021), 8: 1911094
https://doi.org/10.1080/23311908.2021.1911094

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EDUCATIONAL PSYCHOLOGY | RESEARCH ARTICLE

Examining and measuring sources of stress in a sample of caregivers of children with special needs in Egypt: The Perception of Caregivers Stress Scale

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Received: 23 August 2020
Accepted: 26 March 2021

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Reviewing editor:
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Abstract: This study aims to examine stress among caregivers of multiple disabled children and to develop and psychometrically assess an instrument to measure the sources of psychological stress among caregivers. The author developed a 24-item scale to measure the sources of stress among caregivers with (6–18) years old intellectually and physically disabled children. Experts (n = 12) provided a content validity of the instrument before it was administered to (n = 209) both male and female caregivers who are directly involved in the daily care of their disabled children. The experts' agreement about the relevance of the instruments' items to measure caregivers' perceptions of sources of stress related to the care of their children was 89%. Internal consistency reliability for the instrument was .86 (Cronbach's alpha). Factor analysis resulted in four cohesive and theoretically meaningful factors, and there is evidence for convergent validity. The developed instrument is a reliable, valid and empirical measure to assess the severity of stress.

Subjects: Health Psychology; Cognitive Psychology; Educational Psychology

Dalia Bedewy

ABOUT THE AUTHOR

Dalia Bedewy is an assistant professor of psychology at Ajman University (UAE) and Tanta University (Egypt). The author had been involved in many projects for the university such as: Participating in a research about the effect of certain characteristics of the stimuli on selective attention in a sample of university students, 2007. She has participated in a psychological research about the self-regulated learning, 2004, participating in a research about learning disabilities, 2003, participating in a research about Program of Cognitive-Behavioral therapy and Assertiveness for epileptic Patients, 2002. She has also published researches that tackled topics such as school violence, test anxiety, aggressive behavior, and phonological encoding. She has reviewed articles in many SCOPUS-indexed journals such as the *Journal of Health Psychology*. She is a member of the scientific committee of 7th International Conference on Education 2021–(ICEDU 2021 and a member of the Research Ethics Committee of Ajman University.

PUBLIC INTEREST STATEMENT

Children with special needs can be defined as children having difficulties in any area of an individual's functionings, such as impairments, activity limitations, and/or participation restriction in any area of life, which result from interactions between an individual with health conditions and contextual factors such as their environment or personal factors; their caregivers are required to provide services beyond that needed by regular children in order for them to be individually planned or coordinated. This study developed an assessment tool to measure sources of psychological stress among caregivers of children with special needs. The results revealed four factors related to caregivers' experiences of stress (physical strain, emotional strain, socioeconomic strain, child behavior). The study calls for more consideration of policies and procedures should be in place while communicating with individuals with special needs and their caregivers, and it also suggests that intervention strategies for the caregivers should receive more attention.

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Keywords: Stress; children with special needs; measurement scale; caregivers

1. Introduction

The Egyptian Central Agency for Public Mobilization and Statistics in shows that there are more than 10 million children with special needs in Egypt. Parents constantly require information concerning the child's condition, and methods to deal with his/her needs and attitudes (Boyd, 2002). Many studies have revealed that stress among caregivers of children with special needs is multi-factorial including financial, social and emotional attributes (Bailey et al., 1994; Bobbitt et al., 2016; Brinter et al., 2005; Duchovic et al., 2009). Stress modes and emotional instability of the caregiver usually occur with shocking response, denial and anguish attitude to the initial diagnosis of the child's needs (Chou, 2000; Cronin, 2004). Kandel and Merrick (2005) have reported the findings of various studies regarding families having a child with a disability. There are five emotional stages following the birth of such a child: *denial, anger, bargaining, depression and acceptance* (Ferguson, 2002). Caregivers tend to show signs of distress, a feeling of being misfortunate and embarrassment.

Caregiver stress can be defined as the extent to which caregivers perceive that their financial status, health, physical health, and social life have dramatically suffered as a result of providing care to the care recipient (Dempsey & Dunst, 2004). The most common stressors reported by these caregivers include financial stress (Heller et al., 1999), social isolation (Kimura & Yamazaki, 2013), increased child behavioral problems (Neece et al., 2012), and disrupted family cohesion (Faramarzi & Bavali, 2017; Mitchell et al., 2016).

There are empirical evidences that caregivers of children with special needs usually experience higher levels of stress than do parents of normal children (Blacher et al., 2009; Hayes & Watson, 2013). It is not clear why some caregivers manage to adjust well to the child's special needs, while others show less success. (Rentinck et al., 2007) reported factors related to the various child-related factors and parent-related factors in the adaptation process.

Measurements and instruments are important tools for caregiver assessment to gather information in order to specify the responsibilities, needs and different resources of the caregiver as well as the ability of the caregiver to fulfill the needs of the child with special needs (Terwee et al., 2012). Health professionals ought to focus on caregivers because caregivers may fail to function effectively if their needs have not been met, even their role supporters to the care recipients might be negatively affected. Over the last two decades, developed instruments of caregivers' assessment have addressed three areas of research: caregiver burden, needs, and quality of life (Farnik et al., 2010).

1.1. Factors related to child and parents

The first reaction of the caregivers to the birth of a child with special needs is usually a complex reaction consisting of denial, shame, resentment and grief. Such emotional state of the caregivers can hinder their capacity to cope with the situation (Van & Selder, 1989; Weiss, 2002). Some families manage to create a closer relationship and successfully take care of the member with the special need using a variety of resources, whereas other families fail to achieve the same level of acceptance, hence, experience more tensions, conflicts, and frustrations between members (An, 2006). Families who cannot cope with the responsibilities of a child with special needs experience sorrow, anger, desperation, and lower self-esteem.

Caregivers of a child with special needs usually feel they lack control over their daily routine, which causes them an unpleasant experience of social, physical, and emotional stress, which eventually affects their psychological well-being (Hassall et al., 2005). Limited social networks due to the responsibilities of taking care of a child with special needs is likely to increase parental stress (Dunn et al., 2001; Murphy et al., 2006; White & Hastings, 2004).

One way to explain caregivers' stress is by depicting it as a counter psychological and physical response to the detected imbalance between responsibilities in family life and the ability to meet those demands (Deater-Deckard, 1998). With all the responsibilities and demands of the parenting life style, parents of children with special needs report high level of stress than do parents of regular children (Silverman et al., 2009). Caretaking for children with special needs magnifies stress that can easily disturb the cognitive and emotional status of all household members (Ross et al., 2011; Seligman & Darling, 1997). Children with special needs experience behavioral problems, such as self-injury and aggressive behavior, which add further demands to the caregivers to resolve (Nachshen et al., 2005).

The reaction of the society may also add another source of stress on caregivers (Dyson, 1991). Khamis (2007) reported that the combined predictors of child characteristics, parent socio-demographics, and family environment accounted for 36.3% of parental stress and 22.5% of parental psychiatric symptoms. Comparison between parents who take care of children with special needs and parents who have regular children shows that the former had a smaller social network (Sharpley et al., 1997). The reason for that limited social network would be the feeling of guilt and shame experienced by the parents (Saloviita et al., 2003), and socialization capacity of the caregivers' life would be negatively affected by such isolation (Upadhyaya & Havalappanavar, 2008). On the other hand, support received by family and friends has been associated with low-stress symptoms (Rosenzweig et al., 2002).

Families of children with special needs often experience decreased financial resources (Curran et al., 2001; Thyen et al., 1999). Caregiving will dispose of certain financial issues that include healthcare expenses, losing a job or career development opportunities and cutting back work hours (Baker et al., 2002; Esdaile & Greenwood, 2003; Newacheck et al., 2004).

The responsibilities, challenges and difficulties caregivers of special needs children face might be described as resilient. However, it is controversial the amount of adversity caregivers ought to go through before adaptation takes place can be regarded as a demonstration of resilience (Patterson, 2002). Patterson (Patterson, 2002) shows that families demonstrate resilience when they are competent in performing economic support, nurturance, education and socialization.

2. The purpose of the study

The objective of this study is to develop and psychometrically assess an instrument with demonstrated evidence of validity, to measure sources of psychological stress among caregivers of children with special needs, the Perception of Caregiver Stress Scale (PCS).

3. Methodology

3.1. Participants

Participants were recruited from a facility in Cairo that serves children with special needs all over Egypt. Also, flyers about the study were distributed through contacts at the Ragdeya Association facility in Tanta and special needs support groups. Individuals receiving the flyers were encouraged to distribute them to other people they knew who might be interested in participating. Once the ethical research approval has been received, the author contacted the participant either by E-mail or face to face. The study participants were caregivers of children with special needs, both men (53) and women (156), ranging from 27 to 65. There were three categories of caregivers: caregivers of intellectual disabled children (78), caregivers of hearing disorders children (71), and caregivers of visually impaired children (60). All the participants' caregivers were living in Tanta, Egypt. Completing the scale took 7–10 minutes. Informed consent was obtained from all individual participants included in the study.

3.2. Subjects, protocol, and data analysis

Psychology experts—female (n = 3), males (n = 9)—participated in the validation process of the current study. They are reported to be of more than 16 years of experience as a faculty member of psychology and psychiatry. The participating experts' mean age = 54 years, standard deviation (SD) = 8.7. An E-mail was sent to invite each expert to participate in the validation process. The experts were (n = 8) at the rank of professor, (n = 2) at the associate professor, and (n = 2) PhD lecturers. Initially, experts provided opinion about the overall content of the instrument. The experts' responses were received via E-mail with commenting on the relevance of the scale to be developed before testing the instruments with participants.

3.3. Procedures

Following a deep literature review, regarding developing the scale to measure perceived sources of stress among caregivers of children with special needs, the authors created a table of specification with the initial items to guide item construction. The researcher managed to identify a list of specification with four main components to depict sources of stress among caregivers of special needs children: (1) physical strain subscale (four items), (2) emotional strain subscale (eight items), and (3) socioeconomic strain subscale (seven items), (4) child behavior load (five items). The result was a 24-item following 5-point Likert questionnaire.

Table 2 reveals the PCS four main subscales: (1) physical strain subscale (four items), (2) emotional strain subscale (eight items), socioeconomic strain subscale (seven items), (4) child behavior load (five items).

Experts were invited to rate each item formally for its relevance in measuring stresses, on a 5-point Likert-type scale (0 = never, 1 = rarely, 2 = sometimes, 3 = a lot, and 4 = always). The objective of the consultation with experts was to provide both face and content validity by providing their agreement about the relevance of each item separately as a measure of caregivers' stress. To develop the PCS, it was agreed to include only items receiving a mean score of 3.5 or above rating from experts, as relevant to develop the scale. This process resulted in selecting the PCS (24 items).

Pilot test was used with 20 caregivers of children with special needs. The below aspects of the scale reflect the caregivers' comments and feedback.

(1) Items clarity.
(2) Language difficulty, or language offending .
(3) Items format and layout.
(4) Determining suitable time for the survey administration.

Receiving the experts' feedback, the author modified the scale, the Perception of Caregivers Stress Scale (PCS = 24 items), and emailed/handed it to the participating caregivers of special needs children (n = 260). A total number of valid questionnaire (209/260, 80%) was received. On a 5-point Likert-type scale (from 0 = never to 4 = always) the participants rated their perceptions about each item in measuring sources of stress which result in the final version of the administered scale (see **Appendix** 1).

The participants were told that the information they provided would be confidential and their participation was voluntary, and their consents to participate were collected accordingly.

Table 1. Demographics of participating caregivers (n = 209)

Non-continuous variables	Frequency	Percentage %
Sex Male/Female	53/156	25.4/74.6
Marital Status Single Married Divorced	23 183 03	11.0 87.6 1.4
Educational degree obtained No degree High school college	73 121 15	34.9 57.9 7.2
working yes no	52 157	24.9 75.1
living village city	137 72	65.6 34.4
Type of special need Visually impaired Hearing disorders Intellectual disabled	60 71 78	28.7 34.0 37.3
Continuous Variables	**Min/max**	**Mean ± SD**
Age	27/65	42.36 ± 8.73
Number of other siblings	2/6	4.36 ± 0.70

* SD: standard deviation

Caregivers were also asked to provide demographics including age, gender, educational degree obtained, and their marital status.

3.4. Collecting and analyzing date

Experts' feedback and comments were used to provide evidence for content validity for the scale; moreover, caregivers' responses were displayed to provide evidence for internal consistency reliability, and convergent validity as adduced in correlation analysis of the caregivers' responses on the subscales of the instrument.

4. Results

Demographics description is displayed in Table 1, where the results of caregivers' responses are reported in Table 2. The internal consistency reliability (Cronbach's alpha) was 0.86 for the 24 items of the PCS. Analyses of variance (ANOVAs) indicated that there were no significant differences in the mean PCS score, between gender and age groups in the severity scores of stress symptoms.

The sample comprised 156 (74.6%) women and 53 (25.4%) men. Participants ranged in age from 27 to 65 years, with an average age of 42.36 (SD = 8.73). Regarding education, 34.9% of the participants had no education, 57.9% had high school education, and 7.2% had university or college education. 24.9% were working where 75.1% were not. As for the place of living, 65.6% were living in villages and 34.4% were living in cities.

4.1. Caregivers' responses

Table 2 shows that the level of sources of stress, caregivers reported low level of sources of stress for most of the scales' items. Moderate-to-severe stress items in the current study were "Do you

Table 2. Psychosocial caregivers’ data

The scale items	* Caregivers’ Responses Min–Max (Mean ± SD)	
Stresses related to physical strain		
Do you feel tired when you are accompanying your child?	0–4	1.6(1.3)
Is taking care of your child has a negative effect on your physical health?	0–4	1.6(1.3)
Do you think you have enough time to sleep?	0–4	2.7(1.3)
Do you feel exhausted even when doing any small task?	0–4	2.0(1.2)
Do you feel headache with no obvious reason?	0–4	1.7(1.3)
Stresses related to emotional strain		
Do you think caring for your child takes much of your time that you do not have time for your own self?	0–4	2.1(1.4)
Do you blame yourself for the slightest matters?	0–4	3.2(1.0)
Do you think your child is dependent on you?	0–4	2.4(1.2)
Do you think you have no privacy anymore because of your child?	0–4	1.6(1.2)
Do you feel you lose your temper for the slightest reason?	0–4	1.9(1.1)
Do you feel you do not do enough towards your child?	0–4	1.4(1.2)
Do you worry for the future of your kid if you are not there for him anymore?	0–4	3.3(1.0)
Do you feel embarrassed by your child behavior?	0–4	1.4(1.3)
Stresses related to socioeconomic strain		
Do you feel tired trying to balance time dedicated to your child and other members of the family?	0–4	1.8(1.2)
Does taking care of your child negatively affect your relationship with your family and friends?	0–4	1.2(1.0)
Do you think caring for your child dramatically affected your social life?	0–4	2.2(1.0)
Do you feel uncomfortable inviting a friend home because of your child?	0–4	1.7(.95)
Do you think other members of your family may get less chances of marriage because of your child condition?	0–4	1.8(1.1)

(*Continued*)

The scale items	* Caregivers' Responses Min–Max (Mean ± SD)	
Do you think your child demands require more money than you can afford?	0–4	2.2(1.3)
Do you feel society deal with your child condition with an appropriate way?	0–4	2.0(1.1)
Stresses related to child behavior load		
Do you think your child ask you for help even for things he/she can do on own self?	0–4	2.1(1.2)
Do you think you are reliable and responsible?	0–4	2.0(1.1)
Do you enjoy your life?	0–4	1.6(1.2)
Do you think your child do not share his feelings?	0–4	1.7(1.3)

worry for the future of your kid if you are not there for him anymore?" and "Do you blame yourself for the slightest matters?"

Table 2: table of specification, caregivers' ratings of the PCS scale

4.2. Factor analysis

Four exploratory principal component analyses were conducted on the 24-item scale. Based on the Kaiser rule (eigenvalues > 1.0), the percentage of variance accounted for, and the cohesiveness of the factors (i.e. patterns of loadings), a four-factor solution appeared optimum. The four factors accounted for 62% of the variance in responses related to caregivers' experiences of related stresses, and the varimax rotation converged in four iterations. Table 3 contains the factor loadings, the internal consistency reliability analysis, and the proportion of the observed variance for each factor.

Factor 1: physical strain. It consists of five items, has an internal consistency of 0.6, and explains 18% of the observed variance. It refers to the excessive stresses from the physical wearing down of their bodies due to lack of sleep from tending to meet their child's many needs, and the constant traveling to and from many medical appointments. These things can take as much of a toll on the body as lifting can

Factor 2: emotional strain. It consists of eight items, has an internal consistency of 0.6, and explains 10% of the observed variance. The factor refers to stresses relating to constant feel of guilt over trying to balance the needs of the child with special needs with those of any other children or a significant other.

Factor 3: socioeconomic strain. It consists of seven items having an internal consistency of 0.5 and explains 9% of the observed variance. It refers to the way caregivers often feel alone as support groups are not always at convenient times, or there is no childcare to go. They can lose their friends as the friends do not understand this "new" life, and even family can shy away in fear of doing something wrong, or not understanding what the caregiver needs. It also refers to the caregivers' constant worry over insufficient money to meet the child's needs.

Table 3. Rotated component matrix* for the caregivers' stress scores

Rotated Component Matrix[a]

	Factor loading			
	1	**2**	**3**	**4**
Do you feel tired when you are accompanying your child?	.638			
Is taking care of your child has a negative effect on your physical health?	.717			
Do you think you have enough time to sleep?	.635			
Do you feel exhausted even when doing any small task?	.513			
Do you feel headache with no obvious reason?	.694			
Do you think caring for your child takes much of your time that you do not have time for your own self?		.513		
Do you blame yourself for the slightest matters?		.121		
Do you think your child is dependent on you?		.513		
Do you think you have no privacy anymore because of your child?		.439		
Do you feel you lose your temper for the slightest reason?		.705		
Do you feel you do not do enough towards your child?		.439		
Do you worry for the future of your child if you are not there for him anymore?		.596		
Do you feel embarrassed by your child behavior?		.754		

(*Continued*)

Rotated Component Matrix[a]

	Factor loading			
	1	**2**	**3**	**4**
Do you feel tired trying to balance time dedicated to your child and other members of the family?			.542	
Does taking care of your child negatively affect your relationship with your family and friends?			.496	
Do you think caring for your child dramatically affected your social life?			.563	
Do you feel uncomfortable inviting a friend home because of your child?			.599	
Do you think other members of your family may get less chances of marriage because of your child condition?			.452	
Do you think your child demands require more money than you can afford?			.654	
Do you feel society deal with your child condition with an appropriate way?			.577	
Do you think your child ask you for help even for things he/she can do on own self?				.786
Do you think you are reliable and responsible?				.528
Do you enjoy your life?				.779
Do you think your child do not share his feelings?				.420

* Principal components' extraction, Varimax rotation with Kaiser normalization. † Factor loadings <0.40 have been excluded.

Factor 1: physical strain.

Factor 2: emotional strain.
Factor 3: socioeconomic strain.
Factor 4: child behavior load.

Table 4. Reliability statistics for the Perception of Caregivers Stress (PCS) scale

Reliability Statistics		
Cronbach's Alpha Based on	Cronbach's Alpha Based on Standardized Items	N of Items
.869	.867	24

Table 5. Pearson Product Moment Correlations between PCS factors and subscale scores

Subscale Factor 1: physical strain Factor 2:	emotional strain Factor 3: socioeconomic strain Factor 4: child behavior Subscale 1 Subscale 2 Subscale 3 Subscale 4	Factor 1	Factor 2	Factor 3	Factor 4	Subscale 1	Subscale 2	Subscale 3
	Subscale 4							
	1	0.27**	0.42**	0.40*	0.47**	0.70**	0.41**	0.40*
		1	0.20	0.27**	0.46**	0.13	0.64**	0.46**
			1	0.20	0.77**	0.41**	0.34**	0.41**
				1	0.45**	0.56**	0.81**	0.81**
					1	0.29**	0.50**	0.29**
						1	0.46**	0.45**
							1	0.20
							1	

Factor 4: child behavior. It consists of six items having an internal consistency of 0.6 and explains 8% of the observed variance. It refers to stresses caused by the behavior of the child who seems inappropriate and/or demanding. There were significant positive correlations ($p > 0.001$) between factor scores and between the Pearson product moment correlations. Table 4 shows that internal consistency (Cronbach's alpha) is .86 and refers to an acceptable reliability state of the scale. A close inspection of Table 5 reveals the significant correlation between the four factors of the PCS. There were no significant differences between males and females, or across age groups, in the mean scores of the scale's factors.

5. Discussion

There were no differences between male and female caregivers in their perceptions of stress. The results from this study demonstrated that the scale's items, related to caregivers stress clustered into four constructs (i.e. factors), which resulted in four components. The factors are theoretically meaningful and cohesive, as it was demonstrated by the significant correlations between their scores, supporting evidence for convergent validity. The four extracted factors—Factor 1, “physical strain,” Factor 2, “emotional strain,” Factor 3, “socioeconomic,” and Factor 4, “child behavior”—are in concordance with previous research, are theoretically meaningful, and cohesive within the framework of stress among caregivers of children with special needs.

In this study, Factor 1 “physical strain,” which accounts for 18% of the variance, represents the experience of physical load stress, related to the life style many caregivers find themselves have. They are usually giving round-the-clock care, or spending virtually every free moment attending to the needs of their needed children. Others find that their responsibilities are less constant, but never know if they will be needed at one particular moment or the next, so they feel like they need to be constantly available. The feeling of being “always on duty” can take a heavy toll on a caregiver. They show physical strain symptom and that makes them feel more stress. In this study, however, caregivers who completed the PCS reported mild level of stress for most items administered. One of the reasons could be the time of the scale administration. The caregivers reported the scale at the school time not the school break; and during such time, children spend almost 9 hours at school and they get help from their teacher. Perhaps there could be different results if the scale was administered at the school break. In this study, moderate-to-severe stress sources were associated with caregivers’ emotional strain. They embrace a combination of different feelings. They feel worried for the future of their children, they tend to blame themselves harshly, and they are not handling things as well as they should. These findings replicate the findings from other studies, which were conducted among caregivers of mentally retarded children (Bode et al., 2000)

The results of this study suggest that intervention strategies for the caregivers should receive more attention. Offering psychoeducational interventions, psychotherapy, and multicomponent interventions is most effective for improving caregiver well-being in the short term. Pusey and Richards (2001) show that some interventions have broad, nonspecific effects across a range of outcomes (psychotherapy, psychoeducational interventions, and psychosocial interventions), whereas others have more specific effects on targeted outcomes (care-receiver training, supportive interventions)

5.1. Practical implication and future research

If the community aims to develop intervention programs in order to assist caregivers of children with special needs and to minimize their anxiety and decrease their distress, one should develop a reliable tool to measure the sources of their stress and its associated causes.

Implications for this study are clear and self-evident. One apparent implication would be that policies and procedures should be in place while communicating with individuals with special needs. Also, social workers should obtain adequate and updated information about results of studies revealing the level of stress caregivers might feel and sources of it. Practitioners are out to aid caregivers receiving support networks to cope better with stress. Future research in examining the relationship between social networks and caregivers who face stress should be considered. An early intervention program with a focus on parental involvement and providing access to support including counseling, training programs, or regionally located group support associations is needed.

The current study could be a baseline for future research; the scale should be administered to a larger, heterogeneous sample of participants, and in different educational and cultural settings. Future research should as well examine the relationship between sources of stresses and quality of life and self-esteem in family of caregivers of children with special needs, which is lacking in the literature. An early intervention program with a focus on parental involvement and providing access to support including counseling, training programs, or regionally located group support associations is also needed.

5.2. Evidence for content validity and convergent validity

The literature review inspection and valuable consideration to develop a table of specifications with items for the present scale as well as input from psychology experts enhanced the content and face and content validity of the scale due to their high agreement on the relevance of the items. In addition, there was evidence for concurrent validity (r = .30 with Sheehan Patient-Rated Anxiety Scale (SPRAS).

Table 3. Rotated component matrix* for the Perception of Caregivers Stress (PCS) scale.

Table 3 reveals the following factors:

Factor 1: physical strain.

Factor 2: emotional strain.

Factor 3: socioeconomic strain.

Factor 4: child behavior load.

Table 4 shows that internal consistency (Cronbach's alpha) is .86 and refers to an acceptable reliability state of the scale.

The study aimed to test the convergent validity. Bolarinwa (2015) showed that correlation analysis could be sufficient for convergent validity. Expectation was met and a model of four correlated factors was specified. Based on the correlations between the four factors' scores, there is evidence to support convergent validity for this scale. Convergent validity was demonstrated by the positive significant correlations between the four factors, especially by the significant positive correlation between the scores of Factor 1, "physical strain," and the scores of the other three factors

6. Conclusion

There is acceptable internal consistency reliability, and there is evidence for face, content, and convergent validity of this instrument. Also, prophylactic measures are highly recommended to manage stress among participants, to characterize early recognition of individuals who may be more prone to it, and early intervention might be needed. It is believed that implementing a positive family-centered environment is associated with full awareness of what is expected of them and can discuss perceived skills and weaknesses (Emerson et al., 2010). The current study showed there is an urgent need from all stakeholders to support caregivers of children with special needs. In order to support these parents, the Egyptian government and international community need to take steps to engage supporting systems and awareness of the importance of parental involvement. The government can accomplish this mission by creating additional channels of communication to help educate citizens about children with special needs as well as by better implementing laws and policies to address these children.

7. Limitations of the study

The study is limited to the participant sample (n = 209) from Tanta, Egypt, and the participants' characteristics. The sample is small; furthermore, only one city in Egypt was selected. It is also limited to the data collection and data analysis methods. Future work should include different types of special needs, larger sample and different regions in Egypt. The author stresses that developing a reliable tool to measure the sources of their stress and its associated causes should be the first step to develop intervention programs in order to assist caregivers of children with special needs and to minimize their anxiety and decrease their distress in the future.

Funding
There was no funding for the study

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Declaration of conflicting interests
The author declares no potential conflicts of interest.

Citation information
Cite this article as: Examining and measuring sources of stress in a sample of caregivers of children with special needs in Egypt: The Perception of Caregivers Stress Scale, Dalia Bedewy, *Cogent Psychology* (2021), 8: 1911094.

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Appendix 1. The Final Version of the Perceptions of Caregivers Stress (PCS) Scale

	Never	Rarely	Sometimes	A lot	always
Do you think your child ask you for help even for things he/she can do on own self?					
Do you think caring for your child takes much of your time that you do not have time for your own self?					
Do you feel tired trying to balance time dedicated to your child and other members of the family?					
Do you feel embarrassed by your child behavior?					
Do you feel you lose your temper for the slightest reason?					
Does taking care of your child negatively affect your relationship with your family and friends?					
Do you worry for the future of your child if you are not there for him anymore?					
Do you think your child is dependent on you?					
Is taking care of your child has a negative effect on your physical health?					
Do you think you have no privacy anymore because of your child?					
Do you think caring for your child dramatically affected your social life?					

(*Continued*)

(Continued)

	Never	Rarely	Sometimes	A lot	always
Do you feel uncomfortable inviting a friend home because of your child?					
Do you think you are reliable and responsible?					
Do you think you have enough time to sleep?					
Do you feel exhausted even when doing any small task?					
Do you blame yourself for the slightest matters?			.		
Do you think other members of your family may get less chances of marriage because of your child condition?					
Do you think your child demands require more money than you can afford?					
Do you feel tired when you are accompanying your child?					
Do you feel headache with no obvious reason?					
Do you feel you do not do enough towards your child?					
Do you feel society deal with your child condition with an appropriate way?					
Do you enjoy your life?					
Do you think your child do not share his feelings?					

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