Relationship between Compassion Fatigue and Optimism among Family Caregivers of Children with Autism

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Abstract

Background: Providing care for children with autism may negatively affect psychological, physical, and social aspects and quality of life among their family caregivers. Optimism is important in improving overall well-being by helping them have a positive attitude regarding their child's future health. **Aim of the study**: To assess the relationship between compassion fatigue and optimism among family caregivers of children with autism. **Research design:** A descriptive relational design. **Setting:** The study was applied at the autism unit in the faculty of postgraduate childhood studies affiliated with Ain Shams University. **Subjects:** A purposive sample of 200 family caregivers caring for children with autism. **Data collection tool:** 1) Structured interview questionnaire; 2) Clinical data sheet; 3) Professional Quality of Life Scale; and 4) Life Orientation Test-Revised scale. **Results:** The present study showed that 56.5% of the studied family caregivers of children with autism had an average level of total compassion fatigue and 47.5% of them had a low optimism level/ high pessimism. In addition, there was no statistically significant correlation between total compassion fatigue and optimism among caregivers of children with autism ($P > 0.05$). **Conclusion:** More than half of family caregivers of children with autism had an average level of total compassion fatigue, and slightly less than half of them had low optimism/high pessimism. There was no statistically significant correlation between total compassion fatigue and optimism among family caregivers of children with autism. **Recommendations:** Establishing an educational program for family caregivers of children with autism to raise their coping styles as well as enhance their psychological resilience to deal with burden of caregiving.

Keywords: Autism spectrum disorders (ASD), compassion fatigue, optimism, Family caregivers of children with autism (FCCA)

Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that is considered a long-life disability. It is characterized by persistent problems with social interaction and communication skills in several social settings, special hobbies, and sensory processing of repetitive patterns of behavior. The child requires assistance in daily life **(Adam, et al., 2020).**

Worldwide, the prevalence of ASD is about 1 in 100 children ***(*WHO, 2023).** In Egypt, the overall prevalence of ASD is 3.3% among 41,640 children the age of 1 to 12 years in 8 governorates (***Metwally, et al., 2023).***

Caregivers of children with ASD are predisposed to experience psychological problems because they can regularly meet their children's symptoms profile, in particular, socially unsuitable behavior, aggressiveness, stereotypical gestures, lack of communication interaction, speech, and language impairment. Comparing the parental perspectives of children with ASD with normally developing children, shows that the family caregivers of children with autism (FCCA) have higher parental involvement, fatigue, depression, anxiety,

functional limitations, marital tension, and health issues (**Al-Saadi, 2024).**

Compassion fatigue refers to the cost of care for traumatized individuals and an emotional residue of exposure to suffering. It is the conjunction of secondary traumatic stress and cumulative burnout. Providing long-term care for a child with ASD may result in experiencing compassion fatigue among their family caregivers through posing adverse physical, psychological, emotional, and social well-being. Also, it may threaten the adaptive functioning of the children and their families **(Rafferty, et al., 2020).**

Optimism is a handling device that helps parents to have a positive view of their life leading to higher life satisfaction and quality of life. Parents who use optimism have more flexibility, better communication, and greater family unity while less optimistic parents are more likely to use escaping management, consequently, increasing the liability for depression, anxiety, psychological distress, and maladaptation (**Scheier, et al., 2021).**

Significance of the Study

Parents with ASD are suffering from psychological problems such as stress, anxiety, depression, and burnout as a result of the caring burden and dealing with children`s misbehavior (**Al-Saadi, 2024).** So, it is essential for psychiatric nursing and mental health to address the lived experiences of parents and caregivers of children with ASD, explore their psychological aspect, support them in dealing with their psychological problems as well as focus on the power and the effect of optimism in handling compassion fatigue resulting from caring their children **(Genecov & Seligman, 2023).** So, this study aimed to assess the relationship between compassion fatigue and optimism among FCCA .

Aim of the study:

The study aims to assess the relationship between compassion fatigue and optimism among FCCA.

Research question

Is there an associative correlation between compassion fatigue and optimism among FCCA ?

Subjects and Methods

1. Research design

A descriptive relational design

2. Setting:

The study was carried out at the ASD unit in the faculty of postgraduate studies of childhood affiliated to Ain Shams University. The faculty provides different therapeutic services in 35 units for different child psychiatric disorders such as autism, behavior modification, and family counseling.

Subjects:

A purposive sample of 200 FCCA in the previously mentioned setting.

Inclusion criteria for child:

1-Age from 6 to 12 years old (school age).

2-No neurological or physical disorders or disability.

Family caregivers:

Primary caregivers provide direct care for the children at the same home and don't have other children with special needs or disability.

Sampling size:

After reviewing the annual census of 384 children with ASD who attended the autism units, the sample size was estimated using the following equation according to **Krejcie & Morgan, (1970).**

$$S = \frac{(X2\times N) \times P(1-P)}{(d2(N-1) + (X2\times P(1-P))}$$

- Description:
- S= required sample size.
- X2= the table value of chi-square for 1 degree of freedom at the desired

  confidence level (1.96×1.96= 3.841)
- N= the population size
- p= the population proportion (assumed to be 0.50 since this would provide the maximum sample size).
- d= the degree of accuracy expressed as a proportion (.05).
- Using the previous formula and considering the population size equal 384, the sample size was:
- S= {3.841 × 384 × 0.50 × (1-0.50)} ÷ {(0.05 × 0.05) × (384-1) + 3.841 × 384 ×

  (384-1)} = 368.736 ÷ 1.91775= 200

Data collecting tools:

Data collection tools were:

Tool I: Structured interview questionnaire.

It was translated into the Arabic language to assess the demographic data of children and sociodemographic data of FCCA.

For the child: Age in years, gender, number of siblings, child order, level of education.

For family caregivers: Age, gender, marital status, level of education, degree of contingency, occupation, residence, and income.

Tool II: Clinical data sheet: It assessed clinical data for children with autism. It included enrollment in the behavioral modification program, onset of diagnosis and family history of psychiatric or mental illness.

Tool III: Professional Quality of Life Scale Version 5 (PROQOL)

It was developed by **Stamm, (2009)** to determine compassion fatigue and satisfaction level. It was modified and translated into Arabic by a researcher. 30 items were distributed to two subscales.

-The Compassion fatigue subscale (20 items) assessed secondary traumatic stress and burnout.

-The Secondary traumatic stress(10 items) ex; “I am preoccupied with helping my family in addition to caring for my child”.

- Burnout consists of 10 items ex; “I am not a productive person at work because I devote my life to helping my child”.

-The Compassion satisfaction subscale consists of 10 items ex; “Caring for my child makes me feel satisfied”.

Scoring system

- The score was distributed on a five-Likert scale rated from “1 (never) to 5 (very often)” for all items. Items number 1, 4, 15, 17 and 29. were opposed to rating.

Total scale	Low	Moderate	High
	30-70	70.1-110	110.1-150

Tool V: Life Orientation Test-Revised (LOT-R)

It was adopted from **Scheier, et al., (1994)** and was used to assess optimism versus pessimism among FCCA by identifying family caregivers’ willingness to support their children with ASD. It was translated into Arabic and then back-translated by the researcher. This scale contains 10 items divided into three parts:

1-Optimism (3 items): ex; “In uncertain times, I usually expect the best”.

2-Pessimism (3 items): ex; “If something can go wrong for me, it will”.

3-Filter (4 items): the purpose of these items is to mislead the subjects from the actual measure to ensure the accuracy of answers. The score of these items was omitted from the total score ex; "it's easy for me to relax".

Scoring system:

A 5-point Likert scale was distributed to items 1, 2, 6, and 8 from 0 (strongly disagree) to 4 (strongly agree), while other items were opposite scoring.

Score	Low optimism/ High pessimism	Moderate optimism	High optimism/ Low pessimism
	0-13	13.1-18	18.1-24

Preparatory phase

It was done by obtaining standardized national and international resources (books, articles journals, and internet access) to assess and illustrate the studied variables.

Tool validity

To realize the principle of trustworthiness of the studied tools of this study, the face and content validity were revised by three professors specialized in the field of psychiatric and mental health nursing, at Ain Shams University. Accordingly, the required corrections were applied.

Tool reliability:

The reliability of the tools was applied to five cases by using the study tools and comparing results after one week. The results were equal in the two measurements. The reliability of the study tools was calculated by Cronbach Alpha Coefficient:

Validity & Reliability Statistics			
Variable	No. of Items	Validity	Reliability
Compassion fatigue	20	0.84	0.720
Compassion satisfaction	10	0.96	0.92
Optimism	10	0.78	0.61

Pilot study

It was conducted on 10% (20 family caregivers) of the total sample size to evaluate and examine the straightforwardness, applicability, and feasibility of the study tools. In addition, it was beneficial in estimating the needed time to complete the data collection process. Based on the results of the pilot study, study tools were not modified and the pilot study was involved in the total study sample.

Fieldwork

The fieldwork took place for five months beginning in the middle of August 2023 and was finished by the middle of January 2024 through the following steps:

First step:

After getting formal approval to collect data, the researcher studied sample in autism units. The researcher presented herself to FCCA and clarified the aim of the study and its process to gain their oral and written approvals. The researcher also clarified that they had the right to discontinue at any time without giving reasons. The researcher assured us that their information would be secret.

There are two autism units in the Faculty of Postgraduate Studies of Childhood. Data collection was done at the waiting area of ASD unite in the Faculty of Postgraduate Studies of Childhood; the waiting area contained about 10 chairs, and this area is wide and well-ventilated.

Second step:

Studied sample were requested to do the questionnaires individually. The researcher read data collection tools to help caregivers who were unable to read or write to fill in the questionnaires. Data were collected in 3 days/week (Monday-Tuesday and Wednesday) from 9.00 am - 1.00 pm. Data collection tools took about 30-45 minutes to fill in. Once the questionnaires had been completed, lots of thanks were given to

family caregivers, children, and faculty authorities for their cooperation.

Administrative design:

A formal approval letter was received from the Dean of the Faculty of Nursing, Ain Shams University to send to the Dean of the Faculty of Postgraduate Studies of Childhood for research conduction.

Ethical considerations:

The research proposal was accepted by the ethical committee in the Faculty of Nursing Ain Shams University with the ethical code 23.12.185. After that, studied FCCA were selected based on their oral and written approval consent to be involved in the study. The researcher emphasized to the subjects on anonymity, and confidentiality of the obtained data as well as the data would be used for scientific research only.

Statistical Design

Study data was estimated by using the computer software Statistical Package for Social Science (SPSS) version 26. Data was the descriptive statistics were calculated by presenting frequencies and percentages, the arithmetic mean (X), and standard deviation (SD) for quantitative data. For studying the associated relationship among study variables, the Pearson correlation test (r-test) was used.

Significance of the results:

- P-value > 0.05 Not significant (NS).
- P-value ≤ 0.05 Significant (S).
- P-value ≤ 0.001 Highly Significant (HS).

Results:

Table (1): displays that the mean age of studied children with autism was 9.19 ±3.32 years and 81.5% of them were between 6 - 9 years old. 78.5% of studied children with ASD were male. Regarding the number of siblings, 31.0% of them had one or two siblings. As regards child order, 68% of studied children were the first child in order among their families and 99.0% of them were in primary school.

Table (2): shows that the mean age of studied FCCA was 31.40 ±9.31years old and 60% of studied caregivers were confined between 26:35 years. 97.5% of primary FCCA were mothers. As regards marital status 95.5% of studied FCCA were married, and 50.5% & 52.5% of them were secondary educated and employed. 81.5% of FCCA lived in urban and 76.0% of them had sufficient income to some extent.

Figure (1): shows that 86.5% of the studied children with ASD were enrolled in the behavior modification program in the autistic unit.

Figure (2): shows that 92% of family history of psychiatric or mental illness of children with ASD didn`t have a history of psychiatric or mental illness.

Figure (3): shows that 67% of the studied subjects had high levels of secondary traumatic stress.

Figure (4): shows that 91.5% of the studied subjects had average levels of burnout.

Figure (5): displays that 56.5% of the studied FCCA had an average level of total compassion fatigue.

Figure (6): shows that 47.5% of the studied subjects had low optimism level/ high pessimism.

Table (3): there was no statistically significant correlation between total compassion fatigue and optimism among studied subjects (p >0.05).

Table (1): Frequency distribution among studied children with ASD regarding to their demographic characteristics (n=200).

Items	N	%
Age		
6 ≤ 9 years old	163	81.5
10 ≤ 12 years old	37	18.5
Mean ± S.D 9.19 ±3.32		
Gender		
Male Female	157	78.5
	43	21.5
Number of siblings		
Non	51	25.5
1	62	31.0
2	62	31.0
≤ 3	25	12.5
Child Order		
First	136	68.0
Second	48	24.0
Third	16	8.0
Educational level		
Not read or write	1	0.5
Primary school	199	99.5

Table (2): Frequency Distribution among studied FCCA regarding to their socio-demographic characteristics (n=200).

Items	N	%
Age (year)		
26 ≥ 35 years old	120	60.0
36 ≥ 55 years old	79	39.5 0.5
56≥	1	
Mean ±SD **31.40 ±9.31**		
Gender		
Male	3	1.5
Female	197	98.5
Marital status		
Married	191	95.5
Widow	2	1.0
Divorced	7	3.5
Educational level		
Illiterate	5	2.5
Read and write	9	4.5
Primary education	12	6.0
Secondary education	101	50.5 35.5
High education	71	1.0
Postgraduate education	2	
Degree of contingency		
Father Mother	3	1.5
	195	97.5
Sister	1	0.5
grandmother	1	0.5
Employment		
Employed	105	52.5
Unemployed	95	47.5
Residence		
Urban	163	81.5
Rural	37	18.5
monthly income		
Enough	33	16.5
Not enough	15	7.5
Sufficient to some extent	152	76.0

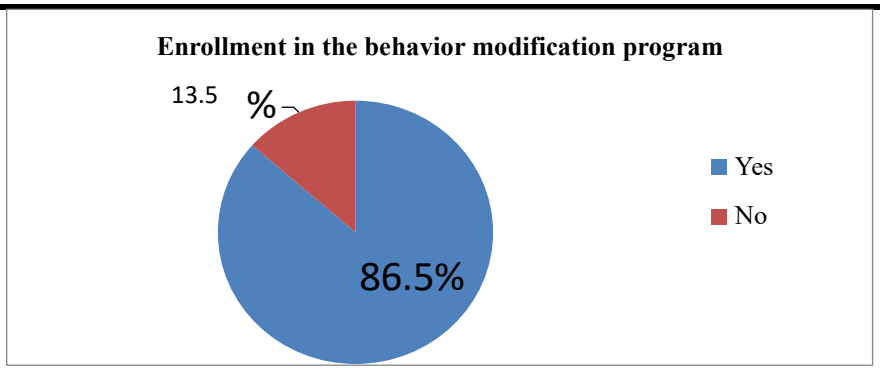

Figure 1: Percentage distribution of enrollment in the behavior modification program in the autistic unite (n=200).

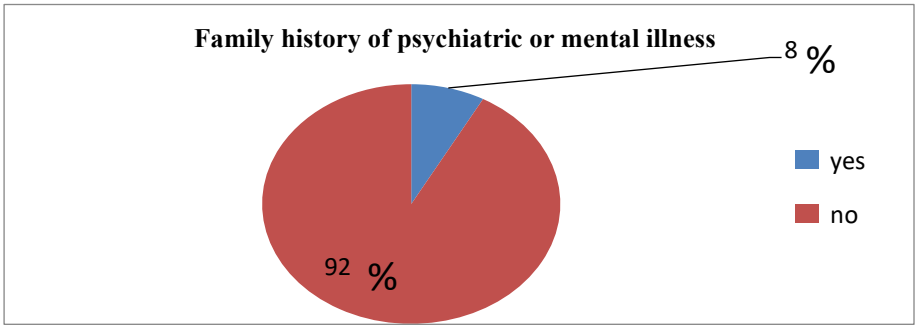

Figure 3: Percentage distribution of family history of psychiatric or mental illness among children with ASD (n= 200).

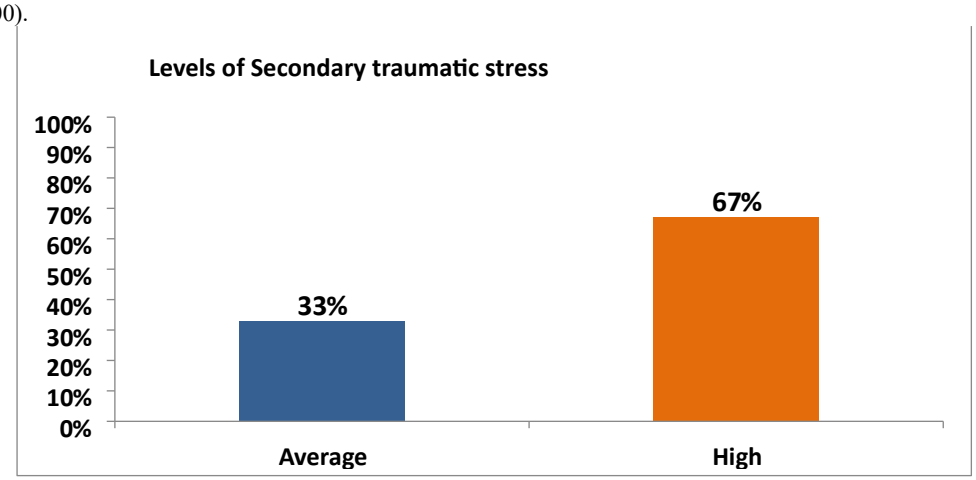

Figure 4: Levels of secondary traumatic stress among studied FCCA (n=200).

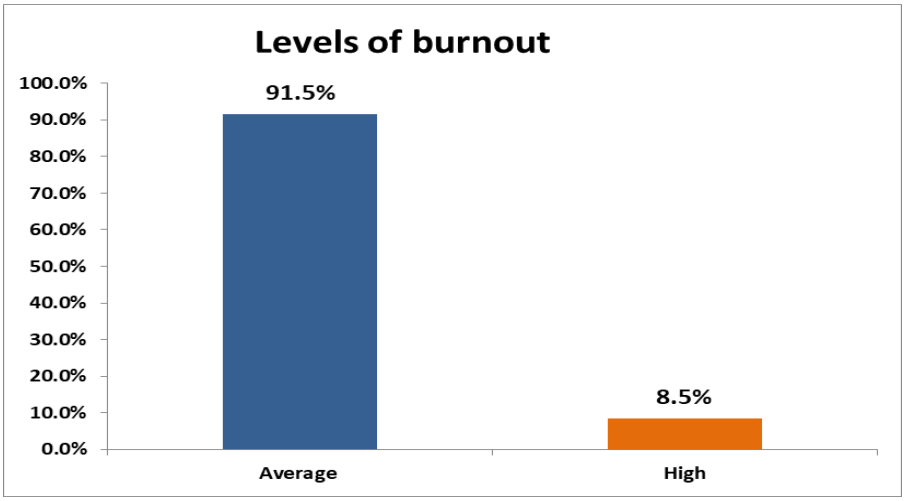

Figure 5: Levels of burnout among studied FCCA (n=200).

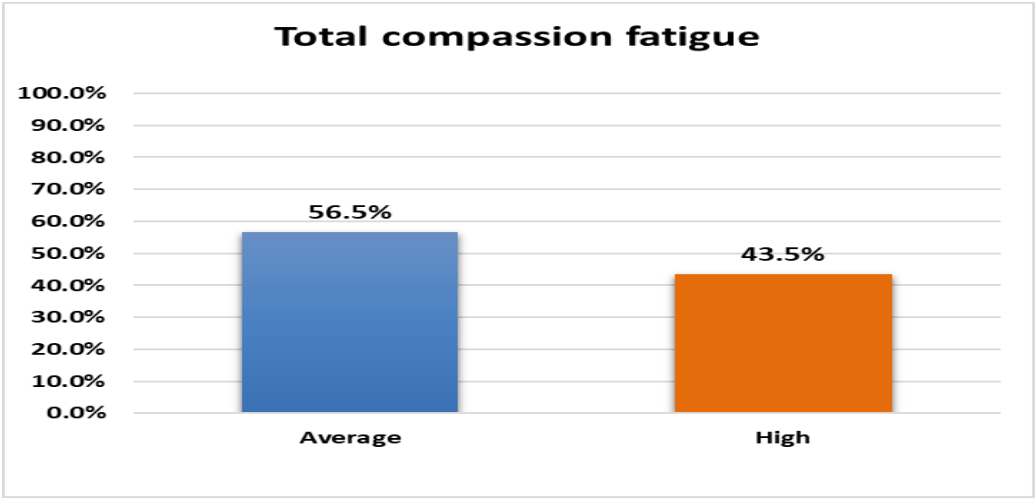

Figure 4: Total compassion fatigue among studied FCCA (n=200).

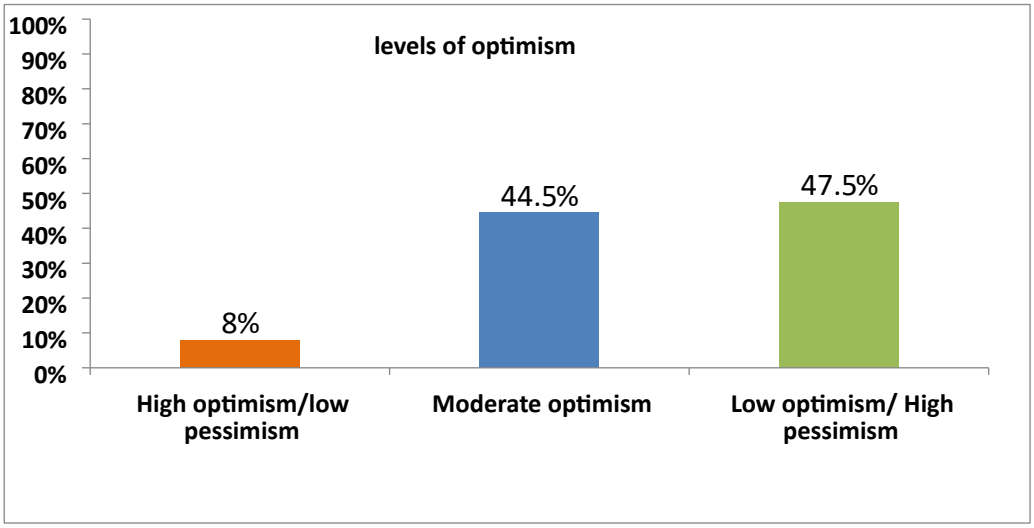

Figure 5: Levels of optimism among studied FCCA (n=200).

Table (3): Correlation between compassion fatigue and optimism among studied FCCA (n=200).

The studied variable		Optimism
Total compassion fatigue	**r test**	-0.008
	P value	0.910

Discussion:

Caring for a child with autism spectrum disorder (ASD) reflected a stressful event for a family because of the burden of long-term care. Optimism enables caregivers to view sufferings as learning experiences or temporary challenges that enable parents of children with ASD to have positive parenting behaviors resulting in positive children's outcomes **Curley, et al., (2023).**

Regarding demographic data of studied children with ASD, the current study displayed

that the mean age of studied children with ASD was 9.19 ±3.32 years and more than three-quarters of the studied children with autism were males. These results may be due to the higher prevalence of ASD among boys than girls **Yan, et al., (2024).**

Regarding the studied children's level of education, almost all of the studied children with ASD were in primary school. This result may be due to the majority of children under the study their age being between 6 - 9 years old (school age) according to the inclusion criteria.

Concerning socio-demographic characteristic data among studied FCCA, the mean age of studied FCCA was 31.40 ±9.31 years old, and almost all of the primary caregivers of children with autism were mothers, this result may be due to that mothers are usually the main person who provide the needed care for their children especially when they are sick.

Regarding employment status, the present study disclosed that slightly more than half of the FCCA were employed. The cause of this result may be due to the need to cover the cost of autism treatment besides the usual financial family responsibilities.

Regarding residence, the study showed that the majority of FCCA resided in urban areas. This result may be because that all Egyptian governments (not only in Cairo) have a specialized unity for autism that provides comprehensive management for children with ASD.

The current study showed that many of the studied children with autism were enrolled in the behavior modification program in the autism unit in the faculty of postgraduate studies of childhood. This result may be due to the availability of a behavior modification program offered by the institute if the child is in need.

This result was supported by **Aftab, et al., (2024)** who conducted a study entitled "Exploring Behavioral Modification Techniques Used by Psychologists for Autistic Children" and showed that the children under study participated in the behavior modification training.

Regarding family history, the current study displayed that almost all of the FCCA didn`t have a history of psychiatric or mental illness. This result may be due to that ASD has unknown causes but has multiple risk factors such as genetic, neurological, and environmental factors **Hirota & King, (2023).** This finding was in correspondence with **Al-Saadi, (2024)** who conducted a study entitled "Predictors of Parenting Stress among Mothers Raising Children with Autism Spectrum Disorder" and showed that the majority of the studied children didn`t have family psychiatric history.

Regarding total compassion fatigue, among FCCA: The present study showed that more than half of studied FCCA had average total compassion fatigue. This result may be due to that more than two-thirds of them had high secondary traumatic stress levels and almost all had average levels of burnout.

This finding was consistent with **Marcinechová, et al., (2023)** who conducted a study entitled "Self-forgiveness, Guilt, Shame, and Parental Stress among Parents of Children with Autism Spectrum Disorder and "**Nik Adib, et al., (2019)** who conducted a study entitled "Perceived Stress among Caregivers of Children with Autism Spectrum Disorder: A State-Wide Study" and mentioned that almost of FCCA had a high level of secondary traumatic stress.

In addition, this study was supported by **Rasoulpoor, et al., (2023)** who conducted a study entitled "Determining the relationship between over-care burden and coping styles, and resilience in mothers of children with autism spectrum disorder" and showed that nearly three-fifths of mothers under the study had high caregiving burnout.

This study was in corresponding with **Halki, et al., (2024)** who conducted a study entitled "Fatigue among Greek Parents of Children with Autistic Spectrum Disorder" and with **Liao, et al., (2022**) who conducted a study entitled "The Levels and Related Factors of Compassion Fatigue and Compassion Satisfaction among FCCA and revealed that almost all of the them had moderate compassion fatigue.

Regarding optimism versus pessimism among studied FCCA, the present study showed that slightly less than half of the them had low optimism levels/high pessimism. This result may be due to that more than two-thirds of studied FCCA had high levels of secondary traumatic stress and almost all of them had an average level of burnout.

This finding was agreed with **Mohammed, (2021)** who conducted a study entitled "The Relationship between Hope, Optimism, and Happiness among Parents of Children with Autism Disorder" and with **Lopez, et al., (2019)** who conducted a study entitled "Associations among Family Burden, Optimism, Services Received and Unmet Need within Families of Children with ASD" and displayed that the almost all of FCCA had a low level of optimism.

While, this finding was mismatched with **Sarwar, et al., (2019)** who conducted a study entitled "Social Support, Optimism, Parental Self-efficacy and Wellbeing in Mothers of Children with Autism Spectrum Disorder " and revealed that most of the mothers of children with ASD had a higher level of optimism. This result may be due to the studied mothers having reported that they have a high level of self-efficacy and have received a high level of social support and health services.

Regarding the correlation between compassion fatigue and optimism among studied FCCA, a recent study shows that there was no statistically significant correlation between total compassion fatigue and optimism among FCCA. Although nearly half of the family caregivers under the study had high pessimism levels, more than two-thirds of them had high secondary traumatic stress and the average level of burnout, there was no statistically significant correlation between the studied variables. This result may be due to more than two-fifths of FCCA having moderate optimism which suggests using a larger sample size to detect the significant relation between the studied variables.

This finding disagreed with **Dallas, et al., (2020)** who studied The Relationship between Selected Factors and Psychological Well-being among Caregivers of Children with Autism in Eastern Thailand and clarified that perceived burden and optimism are the main factors affecting the psychological well-being FCCA

In addition, this result is consistent with **Kozachuk,(2020**) who conducted a study entitled "Family Relationship Hope in Parents of Children with Autism Spectrum Disorder " and reported that hope within the FCCA is a significant negative predictor of depression that means higher levels of family hope is associated with less possibility to have depression.

Conclusion:

The study concluded that:

More than half of FCCA had an average of compassion fatigue and slightly less than half of them had a low optimism level/ high pessimism. In addition, there was no statistically significant correlation between total compassion fatigue and optimism among studied FCCA ($p > 0.05$).

Recommendation:

The study recommended that:

For family:

-Establishing an educational program for FCCA to raise their coping styles as well as enhance their psychological resilience to deal with burden of caregiving.

-Developing counseling programs for FCCA to foster compassion and satisfaction and promote their optimism.

For community:

-Developing awareness programs about ASD including the nature of the disease, the parents' role, dealing with challenges of caregiving, and utilizing community resources.

For research:

-Further research is needed to examine the relationship between compassion fatigue and optimism in large size of FCCA

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