

Effect of Expressed Emotion Instructional Guidelines on Family Caregiver's Burdens of Patients with Alzheimer

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Abstract

Background: The stress of providing care for a loved one who has Alzheimer's disease not only impacts their health and raises their mortality risk, but also reduces the care quality. Family carers of Alzheimer's patients deal with several challenges linked to caregiving, including stress, anxiety, and a high degree of expressed emotion. Therefore, **the present study aimed to** determine the effect of expressed emotion instructional guidelines on family caregiver's burdens of patients with Alzheimer's. **Design:** This study was carried out using a quasi-experimental design. **Setting:** This study was applied in neurologic outpatient clinics of a psychiatric hospital in Sohag City. **Subject:** There was a purposive sample of 100 family caregivers of Alzheimer's patients were enrolled. **Data collection tools:** 1) Socio-demographic questionnaire for patients with Alzheimer's and their family caregivers. 2) Expressed emotions scale. 3) Zarit burden scale. **Results:** The results of the current study showed that, following the application of expressed emotion instructional guidelines, scores for family carers' expressed emotion and burdens significantly improved statistically. Additionally, under the studies pre-, post-, and follow-up adoption of expressed emotion instructional guidelines, there were highly statistically significant positive connections between the caregiver's overall expressed emotion and the total burdens score. **Conclusion:** Implementing instructional guidelines for expressed emotion has a statistically significant reduction of caregiver burdens associated with caring for Alzheimer's patients. **Recommendations:** Creating family intervention programs in mental institutions that are systematically ongoing to offer the family caregivers the necessary knowledge and emotional support to assist them in managing challenging thoughts and feelings, lessen the negative expression of emotion, and feel less burdened.

Keywords: Burdens, Expressed emotion, Family caregivers, Instructional Guidelines, Patients with Alzheimer

Introduction

Described in the literature as the "burden of care," these issues might include physical, emotional, social, and financial difficulties for family carers. The stress of caregivers for Alzheimer's patients not only compromises the health of family carers and raises their mortality risk, but it also degrades the standard of treatment (Martínez et al., 2018).

The most prevalent type of dementia, Alzheimer's disease (AD), is the name given to the condition that causes a mental decline in several cognitive domains, including

memory, speech, executive functioning, and visuospatial ability. The severity of this loss causes the person's daily, professional, and social activities to be impaired. Around 26.6 million people worldwide suffer from AD. By 2050, this figure is anticipated to triple to more than 100 million (WHO, 2019). Alzheimer's disease accounts for 50% of dementia cases, and it is a difficult problem (Alzheimer's Disease International (ADI) 2018). It is now acknowledged that Alzheimer's dementia type poses a serious public health threat. Chronic conditions

associated with aging are becoming more common as life expectancy rises globally (Wimo, 2018).

In this situation, family caregivers—referred to as "caregivers"—have a larger responsibility to play (Drummond et al., 2019). Carers can develop social networks, find emotional support, and receive knowledge by receiving educational and social support treatments (Khalil et al., 2020). The Alzheimer's Association predicts that by 2050, 68% of people worldwide may have Alzheimer's disease may reach 130 thousand individuals (Alzheimer's Association, 2022)

Giving care to a patient with a chronic, degenerative condition like AD is an extremely demanding undertaking. The gradual loss of decision-making, orientation, and ultimately communication necessitates higher degrees of monitoring and personal care, even though recent memory loss is one of the disease's early signs. Patients may be reliant on their carers in the later stages of the illness, even for simple everyday tasks like eating and bathing (Babarro et al., 2019).

That caregiver's role is an expression of love and devotion. As a result, the family structure emphasizes the need to help one another. Diagnoses and assessments for Alzheimer's disease (AD) can be mentally, physically, and financially taxing for the carer. Additionally, most family members would want not to learn about the illness in case it interferes with their ability to lead regular lives. Families and carers must comprehend what causes Alzheimer's patients' behaviors to assist them in managing the condition (. It is challenging to give patients treatment because of a lack of medical expertise, social skills, and emotional skills. Additionally, it may result in tension and load (Monteiro et al., 2018).

One way to guarantee this standard of care is to deliver it in a structured setting, such as a nursing home, by using "formal" carers like nurses and doctors. However, care is typically given by family members in an "informal" and unpaid manner (mostly spouses and adult children). Without professional training, these carers can get emotionally and physically drained from their constant interaction with

the patient. They are frequently referred to as "the hidden victims" of AD because of this (Smith and Graves, 2021).

The term "caregiver's burden" was created to describe the buildup of issues that could eventually harm a caregiver's own professional and social life, physical and mental health, and financial prosperity. These issues can range from the stress involved in caring for AD patients to social isolation and financial issues. It can be difficult to care for a loved one who has Alzheimer's, but too much stress can be unhealthy for both and can result in carer burnout. Carers of persons with Alzheimer's report a higher burden than carers of people with other chronic conditions. Additionally, it has been discovered that many caregiver's health, employment, income, and financial security are negatively impacted by providing care for someone with Alzheimer's disease (Monteiro et al., 2018). It has not been determined how AD is seen or how difficult it is for family caregivers. The attitude a carer adopts towards Alzheimer's disease might influence how much money is invested in providing care, perhaps raising mental anguish and hardship (Zwingmann et al., 2018).

There are also challenges with work, family, finances, social life, and some intrapsychic problems including self-esteem and control. The family caregivers for AD were informed that they were not receiving any medical support and community resources. In addition, you can get legal, financial, emotional, and medical support. When families have a thorough awareness of what causes may lead their elderly loved one's behavior to alter, it will be easier for them to support them (Ministry of Health, 2020). The illness may also lead to greater subjective burdens. The patients aren't getting the required physical and mental care because of this issue. A study by Khalil et al. (2020) found that although respondents had a moderate level of knowledge, they had a negative attitude and felt burdened by caring for Alzheimer's patients.

In addition, during the past three decades, the scientific literature has increasingly emphasized the importance that families play in the care of those who have dementia and in

alleviating the burden on carers. Both the perceived load and family caregivers' attitudes toward patients are likely greatly influenced by cultural factors (Cheng, 2017). The caregiving responsibilities of family members of Alzheimer's patients are impacted by how much emotion is expressed. According to **Wang et al. (2017)**, negatively expressed emotions are linked to high levels of load. Psychiatric nurses may provide knowledge on the process of negatively expressed emotion, which is frequently linked to Alzheimer's. As a result, psychiatric nurses also play a crucial role in arming the family carers with fundamental knowledge that will enable them to interact with the patient more effectively and lessen their negative feelings (**Hunter & Miller, 2016**).

The concept of expressed emotion (EE) has gained widespread acceptance as a crucial indicator of the home environment. Developed by Brown, Birley, and Wing in England in the 1960s and 1970s, EE is best viewed as a measurement of the patient-relative connection. The five aspects or patterns of the EE idea are antagonism, warmth, emotional over-involvement, criticism, and favorable remarks. The first three were the only ones linked to a high level of expressed emotion. **Boyd (2015)**, **Hooley and Parker (2006)**, and **Pratibha et al (2012)** are other examples. Family caregivers' expectations for the patient's functioning varied, with low expressed emotion (EE) caregivers allowing for low functioning brought on by a medical episode and high EE carers expecting higher functioning.

Expressed emotion (EE) is regarded as a measure of the family environment that takes into account the standard of the interpersonal interactions and dynamics between family members and schizophrenia patients. A fundamental feature of the home environment that reflects important facets of interpersonal relationships is expressed emotion (**Safavi et al., 2017**).

Finally, low EE caregivers were more adaptable and had calmer emotional reactions to the patient's symptoms than high EE carers. The level of intrusiveness, emotional reaction, pessimism towards the sickness, and tolerance/expectations that carers towards

their patients transmit are all considered to be expressed emotion (EE). Understanding the connection between family relationships and unwell relatives has been made easier with the help of the EE construct (**Garcia-Ribas, 2021**).

The primary aim of nurses throughout the healthcare system is to support the family caregivers. The load on the caregivers is lessened since more care is being given to the sick and aged in their homes and communities by mental health nurses and community health nurses. They teach family carers how to offer expert care so that their loved ones can live longer in their homes and avoid costly long-term care facilities, as well as how to maintain their health and well-being. Additionally, community health nurses are assuming larger roles in care coordination, care transitions, and health and wellness education and promotion, all of which support family carers and lead to an improvement in the care and quality of life for Alzheimer's patients (**Drummond et al., 2019**).

Significance of the Study:

According to the World Health Organisation (WHO), there will be 46.8 million AD sufferers globally in 2020, and this number will nearly double every 20 years, reaching 74.7 million in 2030. According to a systematic review, the prevalence of AD in Egyptians under the age of 50 ranged from 2.01% to 5.07%. Because they are ignorant of the issue, this hurts the carers of the patients. Nationally or internationally, carers for Alzheimer's patients feel overburdened. There are currently 47 million dementia sufferers worldwide, and by 2030 and 2050, those numbers are expected to increase to 75 million and 132 million, respectively (**Wimo, 2018**).

Additionally, there aren't enough institutions and specialists to help caregivers of Alzheimer's patients deal with these challenges. As far as we are aware, the family carers did not participate in the nonexistent awareness program. Carers deal with a variety of psychological issues, such as stress, despair, and worry. Additionally, there aren't many studies in this field of study. Due to the

considerable effects AD has on people, their families, the healthcare system, and the economy, it is one of the main causes of sickness and disability. Thus, future studies will focus on minimizing AD's effects on carers in nursing homes and other facilities for the elderly. So it's crucial to evaluate the burden and quality of life of those who provide care for people with Alzheimer's disease (WHO, 2019).

Aim of the study:

This study aimed to determine the effect of expressed emotion instructional guidelines on family caregivers' burdens of patients with Alzheimer.

Research hypothesis:

Expressed emotion instructional guidelines are expected to have a positive effect on family caregivers' burdens of patients with Alzheimer

Subjects and Methods:

Research design:

This study was carried out using a quasi-experimental design.

Setting:

This study was applied in at neurologic outpatient clinics of a psychiatric hospital in Sohag City. This setting, which is on the first floor, was chosen because it serves the largest portion of the population and has a high case flow rate.

Subjects:

There was a purposive sample of 100 family caregivers of Alzheimer's patients were enrolled.

Sample size calculation:

The power analysis level of significance of 0.95(=1-0.95=0.5) at alpha was used to calculate the sample size. The one-sided significance was set at 0.05, the large effect size at 0.5, and the high significance at 0.001.

Inclusion criteria included:

- Family caregivers from both sexes
- Family caregivers and Alzheimer's patients residing in the same home

Family caregivers were the primary caregivers for the Alzheimer's patients.

Family caregivers are willing to engage in the study.

Tools of data collection:

Three tools were used:

Tool (I) Socio-demographic questionnaire for patients with Alzheimer's and their family caregivers.

It was created by the researcher and contains details about Alzheimer's patients, including their age, marital status, level of education, and occupation. Additionally, the sociodemographic questionnaire contains questions on the family caregivers of Alzheimer's patients, such as their age, marital status, level of education, occupation, and relationship to the patient.

Tool (2): Expressed emotions scale (LEE) .

The Level of Expressed Emotion (LEE) scale, which was adapted from **Abdel Aal & Sayed, (2017)**, was used to measure family carers' expressed emotion. It consists of 60 items with true or false responses. After studying the relevant literature, the researcher revised and rephrased tool items to fulfill the study's objectives. It consisted of five sections that were translated into Arabic. The following were its parts: The questionnaire evaluates three areas: over-participation, animosity, and the first two domains. These are for judging high expressed emotion as well as low expressed emotion, as shown by 4-warmth and 5-positive remarks.

Scoring system:

This 60-item questionnaire assesses self-perceived EE in light of five domains: Statements 1, 55, 51,3,39,20,22, and 27 are included in the first criticism. (2) Statements 8,24,25,58,54,45,6,42,36,44,10,19,35 are considered hostile. (3) Over participation comprises the following statements: 1, 5, 7, 9, 41, 37, 34, 33, 13, 17, 21, and 29 (Statements 2, 23, 59, 26, 48, 4, 43, 40, 38, 11, 12, 15, 26 and warmth) and (5) complimentary comments, which include the following: 56,60,52,46,32,14,16,31,18,30,28. with possibilities for true and false responses. In 14 of the questions, selecting "True" is linked to giving incorrect responses to some of the

items from the five domains. Answering "yes" to questions in those groups refers to having a high level of EE. Higher scores indicate higher levels of expressed emotion. Each item is scored two points for a truthful reaction, which is high for EE, and one point for a false response.

Tool (3): Zarit Burden Interview (ZBI)

It was modified from the Zarit load Interview (Zarit et al., 1980), which was used to assess the burden level faced by family caregivers. It is a self-report questionnaire used to assess the financial, social, emotional, and physical burden attributable to providing care.

Scoring system:

The ZBI includes a 22-item checklist to which participants must respond on a 3-point Likert-type scale, ranging from 1 (rare) to 2 (sometimes), and 3 (always); the physical burden items are 21, 20, 1,14, 10, 8, the psychological burden items are 19, 18, 16, 3,11, 9, 7, 5, and the social and financial burden items are 17, 15, 2,13, 12, 4, and 6, respectively.

Data collection procedure:

• Preparatory phase:

It covers reviewing literature and diverse studies connected expressed emotion and burdens among family caregivers of Alzheimer's patients by using books, journals, magazines, and the internet.

• Validity and reliability:

($\alpha=.84-.95$) Research has demonstrated the validity and reliability of the instrument of expressed emotion. It has been shown that the burden instrument is valid and reliable. Cronbach's alpha of .92 is used to measure the caregiver's burden. Three experts in the community health nursing and medical fields, as well as two experts in psychiatric/mental health nursing and psychiatric medicine, served as the jury group that tested and evaluated the tool to determine its relevance, clarity, and completeness to determine whether it met the criteria for trustworthiness in this study.

• Pilot study:

A pilot study was conducted on 10% of family caregivers of Alzheimer patients to evaluate the clarity and viability of the research methodology. There were no modifications done to the tools before they took their final shape. This sample excluded from the current study sample

Procedure

The following phases were used to begin and complete the study:

Phase I: Planning phase

By establishing objectives, developing teaching abilities, and developing methodology and media, this phase attempts to plan for expressed emotion instructional guidelines for family caregivers of Alzheimer patients.

Phase II: Implementation phase

The previously chosen environment served as the location for the data gathering for this investigation. Selective criteria were used to choose family caregivers who met the requirements. Beginning in February 2023 and ending in March 2023, data gathering (pre-test) was initiated and concluded. The instructional criteria for expressing emotions required three days per week, three sessions of around 35 to 45 minutes each. Each of these groups of no more than ten carers participated in these sessions. -In the neuropsychiatric clinic, the lectures took place in a classroom. To carry out the activities for the expressed emotion program, the classroom had appropriate lighting, was well-furnished, peaceful, well-ventilated, and had air conditioning. For all family caregivers participating in the study, the implementation of the expressed emotion instructional guidelines continued for (three) months, from April to June 2023.

An orientation to the expressed emotion instructional guidelines and its goal took place at the start of the first session. To encourage all of the caregivers participating in the study to follow the directions that were given, the significance and advantages of the instructional guidelines were explained to them. Each session began with a warm

welcome to the carers, followed by an assessment of their motivation for learning, a request for feedback on the material covered in the previous session, and a presentation of the new topic's objectives using language that was simple enough to be understood by carers of their educational level.

The researcher emphasized the significance of adhering to each of the expressed emotion teaching criteria, and the benefits of engaging in each new behavior were explained. The caregivers were urged to indicate whether or not they were willing to change their behavior by the researcher. To increase all carers' active participation in the instructional guidelines plan, motivational, problem-solving, and reinforcement strategies were implemented. Each caregiver received a copy of the booklet.

The instruction sessions were held in a classroom on the psychiatric hospital's first floor. According to the caregiver's comprehension and attention span, the researcher constructed the instructional guidelines' content and objectives in the form of eight sessions, each lasting between 30 and 90 minutes. The content of the second session was the objectives of the expressed emotion instructional guidelines are introduced along with the expected results and the schedule for the guidelines. The third session included: theoretical information about Alzheimer's disease and theoretical and practical information about side effects of medications and how to handle them, fourth session : theoretical and practical aspects of their training in patient care, fifth session: theoretical regarding the stated emotion, six session : practical regarding time management to handle caring responsibilities, practical regarding the deep breathing method, and practical regarding the positive meditations, seventh session : practical about using the progressive muscle relaxation technique, eight session : summary of the instructional guidelines sessions and the post-assessment test, and social relation skills with others that strengthen the spiritual side.

Phase III: Evaluation phase

Through the use of the same tools again following the implementation of the

instructional guidelines, the assessment phase was conducted to ascertain the impact of the expressed emotion instructional guidelines on the caregiver's burdens of patients with Alzheimer's. Following the implementation of the expressed emotion teaching guidelines, data was collected over a month. Following the execution of the instructional guidelines for a month, a follow-up was conducted using the same methods.

III. Administrative design

Official approval was obtained from the Dean of the Faculty of Nursing, at Sohag University. A letter containing the title and the aim of the study was directed to the director of the previously selected setting to obtain his approval for data collection to conduct the study.

Statistical analysis

The gathered information was organized and subjected to statistical significance tests as needed. The Computer Statistical Package for Social Science (SPSS), version 20, was used for data collection, coding, and statistical analysis. In the form of frequencies and percentages, data were presented using descriptive statistics. The frequencies and correlations between the study variables were compared using chi-square tests.

The following levels of findings significance were taken into consideration:

P-value < **0.05** Significant (S)

P-value > 0.05 Not Significant (NS),

Highly Significant (HS) p-value <**0.01**

Results:

Table 1, illustrates that, 80% of the patients who were studied were older than 60 years old, and 65% of them were female. 32% of the patients had some level of education, including the ability to read and write. 80% of the patients that were studied were retired from their jobs.

Table 2 shows that, less than three-quarters (70%) of the family carers analyzed were the patients' daughters, with the mean age of the carers being 45 + 74.4. Three-fifths of the carers studied (70%) had ages between 30 and 40. The proportion of married carers was also 70%. Regarding education, it shows that

(34%) of family carers had completed elementary school. Nearly half (46%) of the family carers in the study worked as employees.

Table 3: The comparison of the stated mood of family carers before and after the execution of the instructional guidelines reveals statistically significant differences and improvements ($P < 0.05$).

Figure 1 reveals that, 75% of the family carers in the study exhibited high emotional expression before the adoption of the post-instructional recommendations, but this number increased to 31% after the follow-up period.

According to Figure 2, 77% of family carers had high burden levels before the adoption of the guidelines, but this number fell to 31% afterward and then slightly increased to 35% during the follow-up phase.

According to Table (4), there was a highly statistically significant correlation between the family carers' total expressed emotion score and their demographic data, including

age, the extent of their relationship with the patient, their occupation, and their marital status ($P \leq 0.001$). However, there was no statistically significant association between family carers' education and their total expressed emotion score ($\geq p 0.05$).

Table (5), illustrates that, there were a highly statistically significant correlation between the family carers' overall burden score and their demographic characteristics ($P \leq 0.001$). While there was a statistically significant relationship ($p 0.05$) between the total burden score for family carers and their age and education. Additionally, there was no statistically significant correlation ($P \geq 0.05$) between the total burden score for family carers and their level of relationship or career.

Table (6) denotes that, there was a highly statistically significant correlation between studied family caregivers' total burden score and their patterns of expressed emotion during pre-, post, and follow-up phases of guidelines implementation ($P \leq 0.001$).

Table (1): Socio-demographic characteristics of Alzheimer's patients (n=100).

Items	N	%
Age:		
45-60 years	20	20.0
Over 60 years	80	80.0
Mean + SD :57+7.6		
Sex:		
Male	35	35.0
Female	65	65.0
Level of education:		
Illiterate	24	24.0
Read and write	32	32.0
Primary Secondary University& above	24	24.0
	22	20.0
Occupation:		
Unemployed	8	8.0
Workers Retirement	12	12.0
	80	80.0

Table (2): Socio-demographic characteristics among the studied family caregivers (n=100).

Items	N	%
Age:		
20 - < 30	20	20.0
30 - < 40	60	60.0
More than 40	20	20.0
Mean \pm SD:	45 \pm 74.4	
Degree of relation:		
Daughter	70	70.0
Son	30	30.0
Occupation		
Employees	48	48.0
Not employees	52	52.0
Education level		
Illiterate	22	22.0
Read and write	22	22.0
Primary Secondary	34	34.0
University& above	24	24.0
Marital status:		
Married	70	70.0
Divorced	26	26.0
Widowed	4	4.0

Table (3): Total expressed emotion among the studied family caregivers of Alzheimer's patients at pre- and post-instructional guidelines. (N=100)

Family caregivers 'expressed emotional Levels		Pre- instructional guidelines	Post- instructional guidelines	X ²	P-value
		%	%		
Criticism	High	70.0	25.0	14.77	< 0.001**
	Low	30.0	75.0		
Hostility	High	60.0	22.5	15.23	< 0.001**
	Low	40.0	77.5		
Over involvement	High	65.0	25.0	17.33	< 0.001**
	Low	35.0	75.0		
Warmth	High	73.0	30.0	19.43	< 0.001**
	Low	27.0	70.0		
Positive remarks	High	75.0	22.5	27.03	< 0.001**
	Low	25.0	77.5		
Total expressed emotion score	High	67.0	20.0	18.66	< 0.001**
	Low	33.0	80.0		

**; Highly significant at p-value < 0.001

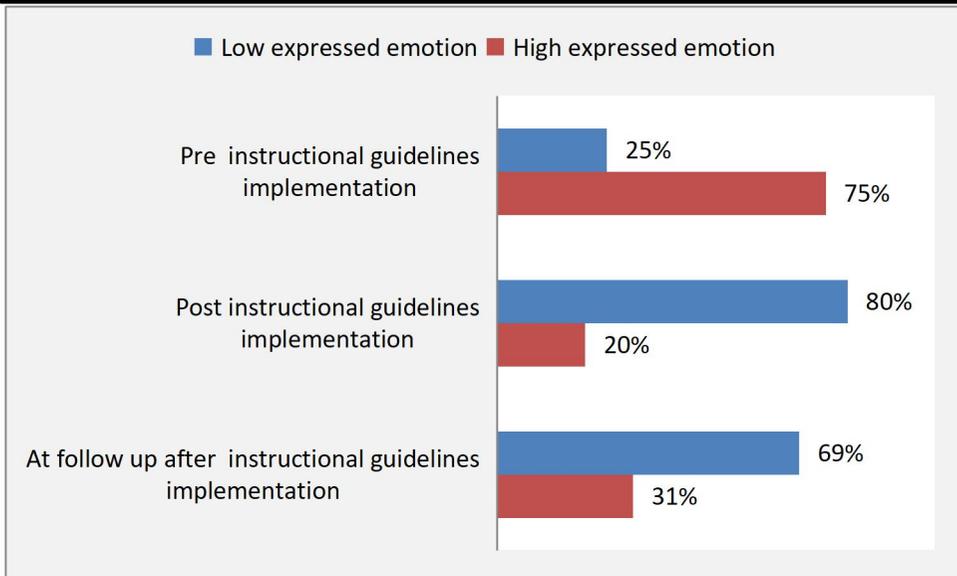


Figure (1): Family caregivers distribution concerning total expressed emotion score pre/post instructional guidelines and follow-up (n=100)

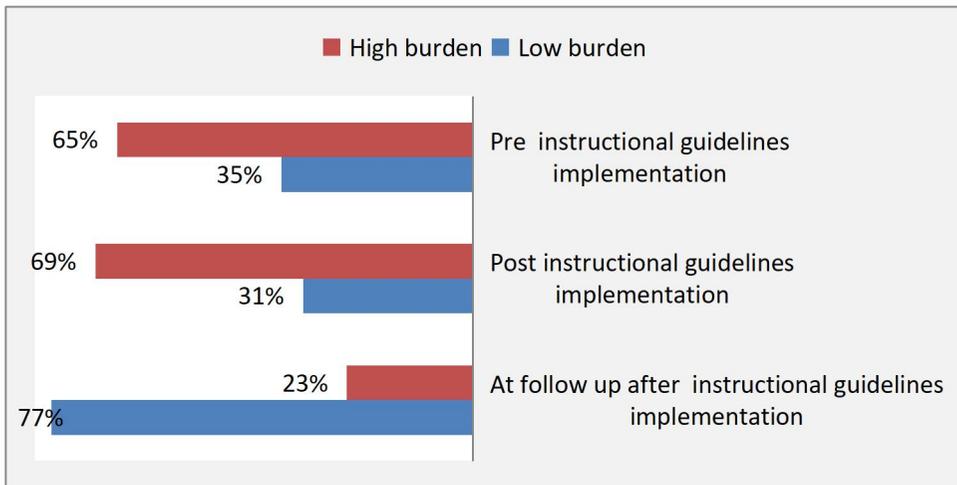


Figure (2): Family caregiver's burden score pre /post guidelines implementation and follow-up (n=100)

Table (4): Association between expressed emotion score of the family caregivers and their demographic data(n=100).

Total score of expressed emotion				X2	P value
Demographic items		High	Low		
		%	%		
Age	20 – < 30	6.0	48.0	23.22	< 0.001
	30 – 40	80.0	22.0		
	More than 40	14.0	30.0		
Degree of relation	Daughter	93.0	35.0	25.45	< 0.001
	Son	7.0	65.0		
Education	Illiterate	15.0	20.0	4.3	.9
	Read and write	10.0	14.0		
	Primary Secondary	60.0	50.0		
	University & above	15.0	16.0		
Occupation	Workers	25.0	69.0	15.34	< 0.001
	Not workers	75.0	11.0		
Marital status	Single	80.0	25.0	26.23	< 0.001
	Married	9.0	71.0		
	Divorced	11.0	4.0		

**; Highly significant at p-value < 0.001

Table (5): Association between burden score of the family caregivers and their demographic data (n=100).

The total score of burdens				X2	P value
Demographic items		High	Low		
		%	%		
Age	20 – < 30	25.0	72.0	8.2	.01
	31 – 40	57.0	18.0		
	More than 40	18.0	10		
Degree of relation	Daughter	75.0	65.0	1.3	.27
	Son	25.0	35.0		
Education	Primary	25.0	10.0	11.3	.005
	Secondary	60.0	30.0		
	High education	10.0	60.0		
Occupation	Workers	26.0	55.0	3.2	.10
	Un workers	55.0	35.0		
	Housewife	19.0	10.0		
Marital status	Single	20.0	60.0	17.4	< 0.001
	Married	72.0	33.0		
	Divorced	8.0	7.0		

**; Highly significant at p-value < 0.001

Table (6): Correlation between expressed emotion score and the burden score of the family caregivers (n=100).

The pattern of expressed emotion	Caregiver's total burden score					
	Pre		Post		Follow up	
	R	P-value	R	P-value	R	P-value
Criticism & hostility	0.417	<0.001	0.742	<0.001	0.688	<0.001
Over involvement	0.513	0.001	0.762	<0.001	0.742	<0.001
Warmth & positive remarks	0.402	<0.001	0.762	<0.001	0.732	<0.001
Total	0.476	<0.001	0.768	<0.001	0.832	<0.001

- Highly significant difference $p \leq 0.001$

Discussion

Humans are relational creatures, and the expression of their experiences in the world, encompassing the entirety of this experience as given in the term, "me-the other-the world," is fundamental to their existence. According to his experiences, the person has the power to influence and change the environment in which he lives (Ribeiro et al. 2016).

Less than one-third of them were read and write, according to the study's findings on their educational level. This could be brought on by a disease-related decline in cognitive function or by persistent negative symptoms from the underlying condition. This outcome may be explained by the customary function of most old people in rural areas as farmers, particularly in the past, which resulted in school dropouts for farming.

Less than three-quarters of the carers evaluated were women, according to the present study's findings. According to the study, this outcome might be because women are typically expected to provide the care. After all, they are more responsible for their homes. Thus, they might enjoy greater confidence in their capacity to provide for the Alzheimer's patient. This result can be attributed to the fact that women are more likely than men to be expected to perform caregiving tasks because, unlike men, women see caregiving as an extension of their usual role. They may also feel under pressure to provide more of themselves and guilty if they don't. On the other side, women tend to give more intensive care than men do, for instance, they are more likely to do chores like cooking and cleaning. According to Sharma et al. (2016), nearly half of family caregivers were

female; therefore this is consistent with their findings.

According to the current study's findings on marital status, less than three-quarters of family caregivers were married, Married family members displayed higher degrees of expressed emotion towards their relative sufferers, according to the researcher. The fact that the married family members already had responsibilities for their own families and now have to take on the additional burden of caring for an Alzheimer's patient has probably contributed to their annoyance with the patients. The current study supported Gogoi's (2017) finding that most family caregivers were married.

A majority of family caregivers—more than one-third—had only received their primary education, according to research on the educational level of this group. This may be because family caregivers with higher levels of education are more likely to be believed to be able to comprehend a doctor's instructions on medication schedules.

According to the present study's findings, less than half of family caregivers were unemployed. Similar results were obtained by Goldberg (2020), who stated that roughly one-fourth of homemakers did not have jobs.

It was discovered that less than seventy percent (70%) of caregivers were the patients' daughters. According to the researcher, this outcome could be attributed to the passing of the parents or the Alzheimer's patient having trouble forming relationships with other people as a result of social stigmatization that resulted in fewer opportunities for socialization, marriage, and independent living.

The current finding showed that there were statistically significant differences and improvements between the stated mood of family caregivers before and after the adoption of instructional guidelines. These outcomes may be attributable to the expressed emotion educational guidelines that assisted the family caregivers in reversing negative emotions into positive ones and in learning more about the appropriate communication techniques to interact with their patients in a way that helped them deal with daily stress, burdens, and highly expressed emotions. These findings were in line with a study by **Leszko (2019)**, which established that the psychoeducational intervention led to a decrease in depression and burden levels as well as an improvement in the expression of emotion.

The results of the present study made clear that three-quarters of the carers reported greater levels of expressed emotion before instructional guidelines in connection to the total expressed emotion score of family carers of Alzheimer's patients. These findings were in line with those of **Hamad (2017)**, who noted that family carers of Alzheimer's patients expressed negative emotions at higher levels than other caregivers. The study was titled "Personal constructs in Alzheimer's caregiving: the family caregiving experience of people living with dementia in Egypt." This outcome can be the result of the burdensome expectations that Alzheimer's disease and its symptoms place on family carers, which might cause caregivers to display negative emotions towards their patients.

However, these findings differ from those of the study by **Martnez et al., (2017)** entitled "Expressed emotion, distress, and attributions in Alzheimer's in Mexico." They claimed that family carers of dementia patients seldom exhibited unfavorable feelings towards their patients. This outcome can be the consequence of someone accepting the car that was donated to them without having any ill feelings toward the dementia sufferer.

The present study's findings made clear that family caregivers' levels of expressed emotion improved after the instructional guidelines and follow-up phases about the impact of the guidelines on such expression. This study's findings were in line with those of **Girgis et al.'s (2019)** evaluation of a nursing intervention

program for family caregivers of Alzheimer patients in Egypt, which revealed a highly statistically significant difference between the level of negative expressed emotion in the family towards their Alzheimer patient before and after the program's implementation. This outcome may be attributable to the management program's role in educating the family about dementia, effective communication strategies, and patient-handling techniques. All of that leads to a decrease in the expression of negative emotion toward the patient.

More than three-quarters of family caregivers reported higher levels of loads before the implementation of guidelines, according to the study's findings on the degree of burdens among caregivers. The research by **Hamza, et al. (2018)**, titled "Assessment of level of function of dementia patients has an impact on the caregiver's burden in Egypt," revealed that the majority of participants experience severe hardship. From the researcher's point of view, In addition, behavioral and psychological symptoms of Alzheimer appear to be difficult behaviors for the caregivers, which may become a major source of the caregiver's burden. Caring for a person with dementia is not an easy task and requires a great deal of understanding. Additionally, the stress may result from an imbalance in the demands placed on caregivers 'personal time, social roles, physical and emotional well-being, financial resources, and formal care resources that might be used to support various roles.

The study "Associated factors of caregivers burden among family carers of dementia patients in a geriatric clinic, Siriraj Hospital" by **Siritipakorn & Muangpaisan (2019)**, on the other hand, clarified that carers of patients with Alzheimer reported a low level of burden. This discrepancy might be brought on by differences in cultural norms, economic standing, burden type, and social support from one nation to the next. Additionally, several nations have come to embrace Alzheimer's symptoms as a natural part of aging, which lessens the sense of powerlessness, frustration, and stress.

Regarding the instructional guidelines' impact on carer burden, this study's findings indicated a decrease in carer burden among family carers

following the program and follow-up phase. This finding was corroborated by **Sarhan & Elsayed (2018)**, who examined the impact of instructional guidelines on caregivers' care burden and quality of life for Alzheimer patients in Egypt. They found that the guidelines significantly improved caregivers' knowledge, practices, and ability to handle their workload. This finding may be attributable to the researcher's guidelines session, which included cognitive-behavioral components (such as shifting problematic thinking, assertive communication, and relaxation techniques) that assisted the carers in managing a variety of issues.

However, **Langman (2020)**, in a study titled "Self-care activities for carers of persons with Alzheimer's disease and other dementias," stated that while support groups can offer emotional support, information, and problem-solving skills to caregivers, they do not lessen caregivers' burden. This finding of the current study conflicts with Langman's assertion. This discrepancy may be caused by family caregivers' characteristics that vary from country to country, such as the age of the caregivers, ethnicity, gender, willingness to provide care, education, economic status, coping skills, beliefs, and social support. All of these characteristics are significant in determining how family caregivers will react to intervention.

The current finding showed that there was a highly statistically significant relationship between the family caregivers' total expressed emotion score and their demographic traits, including age, the extent of their relationship with the patient, occupation, and marital status. According to the researcher, these findings may be attributable to the high levels of expressed emotion that are strongly linked to it because of the nature of Egyptian culture, particularly in urban areas, the lack of information about the disease, the stigma experienced by the patient's family, and the psychological and financial burden that forces the caregivers to work extra hours to meet the needs of the family, especially the patient's demands, such as the patient's constant need for attention, and increases the emotional expression of the patient. Regarding education, there is no desire to educate people about mental illness in Egypt. It is common for caregivers to lack the knowledge necessary to

correctly diagnose a condition, manage its symptoms, and apply the recommended treatments, according to the school curriculum.

These results by **Bentsen et al. (2020)** emphasize that there were statistically significant differences regarding the relation between socio-demographics and the expressed emotion of the studied families' pre- and post-protocol interventions related to occupation and carers' occupation and age.

The current study found statistically significant correlations between (family caregivers' level of education) and total levels of expressed emotion at preprogram about the relationship between demographic characteristics of the studied family carers and overall patterns of expressed emotion. However, at the end of the program, there was a statistically significant correlation between the educational level of the family caregivers and all of their emotional expression patterns. According to the researcher, these findings may be the result of the high level of expressed emotion and are strongly correlated with education level due to the absence of information regarding Alzheimer's disease in the educational stages. The current study's findings may also be attributed to the fact that in some developing nations, such as Egypt, personal characteristics may affect the expression of an emotion and amplify or moderate the emotional response to stress from daily life. For instance, when a caregiver is unemployed or working part-time, their income may not be sufficient to meet all of the family's needs, which has a detrimental effect on the family's financial situation.

These findings were in line with a study by Abo **Shereda et al., (2019)**, which found a connection between family members' reported emotions and educational attainment before the psychoeducational nursing intervention.

This finding is consistent with **El-Shinnawy et al., (2018)** study on the emotional burden and involvement of carers for Alzheimer's patients in Egypt. They noted that certain factors, including the carers' occupation, degree of relationship, income, and marital status, can affect the emotions they express. This outcome might be caused by the fact that in some developing nations, like Egypt, personal traits may affect the direction of the expressed

emotion and play a provoking or calming function in carers' emotional responsiveness to daily events.

The study by **Knippenberg et al. (2018)**, titled "Emotional reactivity to daily life stress in spousal carers of people with dementia in Germany," stressed that factors such as age, gender, occupation, income, and care intensity had no bearing on caregivers' emotional reactivity to daily life stress. On the other hand, these findings were in direct conflict with that study. This outcome may be the result of the fact that different countries have different types of elements that have an impact on the conveyed emotion. The caregiver's resources, such as sense of competence, mastery, and coping mechanisms, may be significant in determining the intensity of expressed emotion in various countries.

The current study found no statistically significant correlation between (occupation and relationship between carer and patient) at pre- and post-guidelines about the relationship between sociodemographic characteristics of the family caregivers and overall patterns of expressed emotion. This may be because Egypt is a developing nation, where there is a general awareness of mental illness and diverse viewpoints about it, particularly Alzheimer's disease, its expressed emotion, and how to manage high expressed emotion. As a result, caring for Alzheimer's patients is an extremely strange and nebulous responsibility because a lack of knowledge will increase stress, burden, and expressed emotion.

These findings were in agreement with a study by **Abo Shereda et al., (2019)** demonstrates that, before the psycho-educational nursing intervention, there were no significant relationships between family members' stated mood and their monthly gender, marital status, place of residence, and educational level.

The results of the current study found a statistically significant relationship between family carers' total burden score and their age, education, and sociodemographic characteristics (i.e., sociodemographic characteristics of the studied family carers) and their total burden score. Additionally, there was no statistically significant correlation between the total burden score for family caregivers and their level of

relationship or occupation.

This research was conducted by **Salama et al. (2018)** in rural Lower Egypt and examined the strain on carers caring for elderly people with impairments. They discovered strong relationships between schooling and their level of strain. The demographic characteristics of family caregivers, which are significant in determining the level of burden, maybe the cause of these findings. As the caregivers age, they start to worry about who will eventually look after their sick family member. The caregiver's education level might also help them to have better knowledge about how to handle the stressful situation. Additionally, carers with higher incomes may have greater access to helpful services like adult day health and home health that may help minimize the burdens of caregiving.

The study by **Rosdinom et al. (2019)**, which evaluated the sociodemographic profiles of caregivers and their associations with the burden of care in dementia in Malaysia, disagrees with this finding, finding no statistically significant relationship between the total burden score for family carers and their demographic characteristics. This discrepancy may be caused by the fact that in some regions the sociodemographic characteristics of the carers of dementia patients were not significantly correlated with the level of the burden they experienced, but rather by other factors thought to be related to the burden, such as patient behavioral issues or cognitive impairment.

Regarding the relationship between expressed emotion and burden among family caregivers of Alzheimer's patients, the current study showed that there was a highly statistically significant relationship between the total burden score of the family caregivers under study and their expression patterns during the pre, post, and follow-up phases of guidelines implementation. According to a study by **Abdelmoneium (2016)** on family home carers for elderly people with Alzheimer's in the Arab Region: Perceived Challenges and Policy Implications in Egypt, expressed emotion was found to be a significant contributor to the burden. This outcome may be the result of the relationship between expressed emotion and the burden of care, as well as the fact that both of these variables measure aspects of the

relationship between family members and patients. Families with high levels of worry, tension, negative feelings, and expressed emotions experience cycles of grief and disappointment and perceive their caring situation as being more stressful, all of which can result in higher levels of burden.

On the other hand, this contradicts a study by **Nirmala et al. (2013)** that evaluated caregiver's burden and expressed emotion in Alzheimer's patients in India and discovered that neither the subjective nor the objective burden of the caregivers was related to the intensity of the expressed emotion. This outcome may be the result of differences in how different persons perceive expressed emotion and hardship. Additionally, in some countries, the cycle of expressed emotion during the Alzheimer's disease phases is more closely tied to individual responses to providing care than to the direct and indirect responsibilities of providing care or the degree of hardship.

Conclusion:

It is clear from the results of the current study that the application of expressed emotion instructional guidelines reduces the burden on caregivers of Alzheimer's patients in a statistically significant way. During the pre-and post-implementation phases of the instructional guidelines, there were highly statistically significant relationships between the overall burdens score and the emotional expression patterns of family caregivers.

Recommendations:

Based on the study's findings, the researchers recommended that:

- Creating a consistently ongoing family intervention program in mental institutions to offer the family caregivers the correct information and psychological assistance they need to manage challenging thoughts and feelings, lessen the negative expression of emotion, and lessen their burdens.
- To achieve generalization of the results and wider application of the planned program, it is advised that the current study be

replicated on a bigger subject.

- Preparation of booklets about the types of support systems about how to reach them to help the family caregivers overcome the high EE that they face in caring for patients with Alzheimer.
- A simplified, comprehensive, and illustrated Arabic guided images booklet about expressed emotion and types of burden related to Alzheimer should be distributed to each newly admitted family caregiver of a patient with Alzheimer.
- Create a program in mental hospitals to educate family members of Alzheimer's patients about the significance of expressed emotion and how it may improve or worsen the patient's condition.
- Ongoing education for the staff of psychiatric nurses on how to support the carers and how to deal with their negative thoughts and emotions constructively.

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